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A randomized trial evaluating the effects on psychological outcomes

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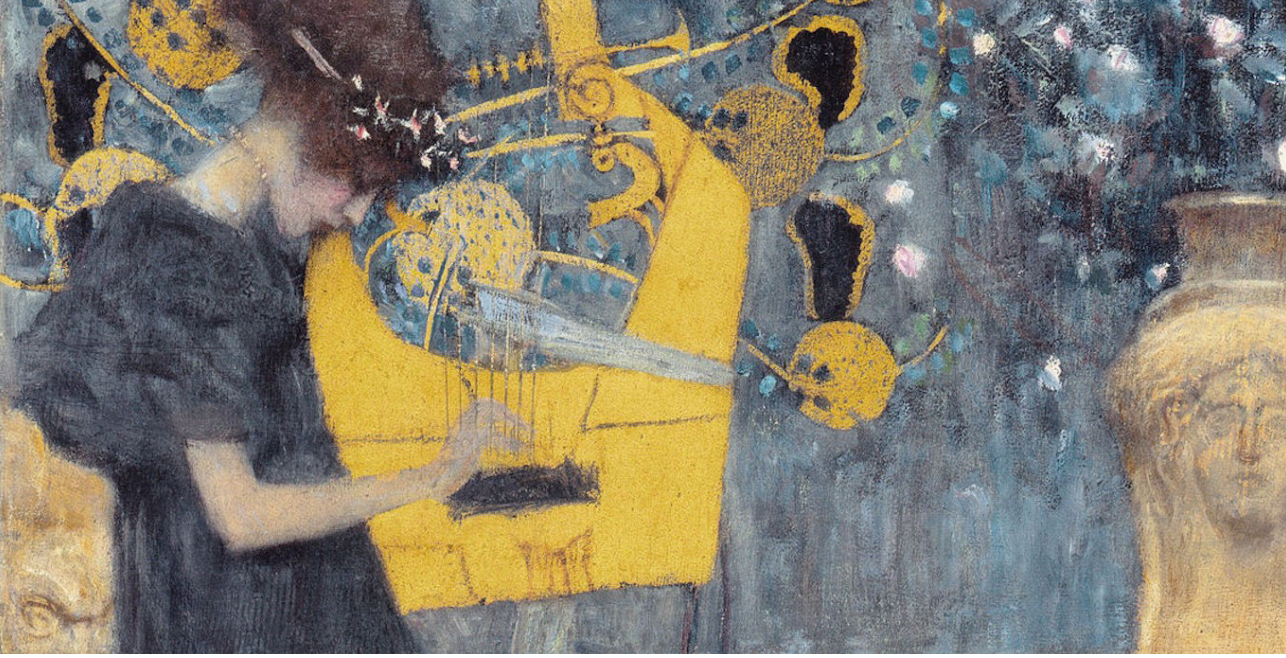

ARTS-BASED PSYCHOTHERAPY FOR WOMEN RECOVERING FROM GYNECOLOGICAL CANCER

A RANDOMIZED TRIAL EVALUATING THE EFFECTS ON PSYCHOLOGICAL DISTRESS

BY
MARGARETA WÄRJA

DISSERTATION SUBMITTED 2018

AALBORG UNIVERSITY
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CV

Margareta Wärja (1956) is a licensed psychotherapist and group psychotherapist working in private practice for the past 30 years, and an educator and supervisor specializing in arts-based approaches. She is a part-owner of Expressive Arts Inc., Stockholm. For over two decades, she has been engaged in the collaborative educations of the Norwegian and the Swedish institutes of expressive arts therapy. Today, Margareta is a trainer in the master's program in psychological health and expressive arts at University College of Southeast Norway.

Margareta received a Bachelor of Arts in Music Pedagogics and Dalcroze Methodology from the Royal College of Music in Stockholm, and another Bachelor's degree in Music Therapy from California University of Long Beach, USA. She was registered as a music therapist in 1983. Specializing in psychiatry, she worked for some years in psychiatric hospitals in Houston, Texas. During this time, she studied Analytical Psychology (C.G. Jung) and psychodrama. Margareta moved back to Sweden in 1986, implemented music therapy in psychiatric facilities in Stockholm, and was involved as a teacher and supervisor at the music therapy program at the Royal College of Music in Stockholm. While still living in USA she started GIM training in the Bonny Method of Guided Imagery and Music (GIM), became a Fellow of the Association for Music and Imagery (FAMI) in 1995, and some years later became one of the first European GIM trainers. Margareta has a certificate degree in expressive arts pedagogy and arts-based research methods from the European Graduate School in Switzerland. In the graduate degree from the Royal Academy of Music in Stockholm in 2010 she formulated tentative theories for a GIM adaptation evaluated in the present study. The same year Margareta was granted a PhD Mobility Fellowship at Aalborg University in Denmark.

ENGLISH SUMMARY

Gynecological cancer survivors are affected in all aspects of their lives. Cancer impacts sexuality, reproduction, embodiment, self-esteem, and general quality of life. The aftermath of illness and its treatment are often long-lasting. A complex intervention study was performed for gynecological cancer survivors (N = 57) involving one two-year qualitative preparatory phase leading up to a randomized trial in which the effects of two arts-based psychotherapy treatments (individual and group) on psychological outcomes were evaluated.

Clinical characteristics at baseline revealed high self-assessed psychological stress. It was hypothesized that when relationally contained in a therapeutic context, participants would explore a wide range of emotional suffering as a result of cancer, such as unresolved grief, unexpressed feelings, fears of dying, and bodily stigmas. This study presents the effects of arts-based psychotherapy on body image, sexuality, fear of cancer recurrence, and existential distress. A method called KMR–Brief Music Journeys was implemented in group and individual formats. This approach is founded on a preconception of body and mind as a connected unity. The theoretical frame for how the intervention may cause change was based on a psychodynamic and existential theories of implicit, unconscious, and affect regulating processes. The arts-based treatment approach applied in this study is founded on theories of phenomenology, psychodynamics, and affect regulation, and the use of the arts as vehicles for nonverbal communication and emotional content.

Our results showed a significant decrease in existential distress, and significantly improved bodily well-being for both approaches. Effect sizes ranged from medium (d = 0.47) to large (d = 0.83). The positive findings were sustained at seven-month follow-up. Bodily well-being, existential distress and quality of life were significantly improved. We found that a supportive and nonjudgmental group therapy approach was particularly helpful in providing a safe space for addressing previously unaccepted feelings such as bodily shame, and low self-esteem. To conclude, arts-based psychotherapy after gynecological cancer can decrease psychological distress and improve overall QoL significantly. Further research and clinical implementation is strongly recommended.

This thesis is built on six papers (presented below) and one linking text. Three papers relate to background literature and clinical methods, and three to results. Of the latter, two present findings from the randomized trial, and one paper shows evaluations of body image paintings using a new assessment tool.

LIST OF PAPERS

This thesis is based on the following papers

Paper I
Hertrampf, R., & Wärja, M. (2017). The effect of creative arts therapy and arts in medicine on psychological outcomes in women with breast or gynecological cancer: A systematic review of arts-based interventions. *The Arts in Psychotherapy,* 56, 93–110.

Paper II
Wärja, M. (2015). KMR (Short Music Journey) with Women Recovering from Gynecological Cancer. In D. Grocke & T. Moe (Eds.), *Guided Imagery and Music (GIM) for individual and group therapy* (pp. 253–266). London, UK: Jessica Kingsley.

Paper III
Wärja, M., & Bonde, L. O. (2014). Music as a co-therapist: Towards a taxonomy of music in therapeutic music and imagery. *Music and Medicine, 6*(2), 16–27.

Paper IV
Wärja, M., Nyberg, T., Forss, G., & Bergmark, K. (2017). Wing-clipped bodies after gynecological cancer: Characteristics and quality of life reported within a complex intervention of arts-based psychotherapy. Manuscript in preparation.

Paper V
Wärja, M., Nyberg, T., Forss, G., & Bergmark, K. (2017). Reclaiming the Body after Gynecological Cancer: A randomized trial of the effects of arts-based psychotherapy on body image, sexuality, and existential distress. Manuscript in preparation.

Paper VI
Gerge, A., Wärja, M., Gattiono, G., & Nygaard-Pedersen. I. (2017). The body in the mind: The appearance of the phenomenological self assessed through pictures before and after arts-based psychotherapy for gynecological cancer survivors. Paper in review.

Paper I can be retrieved at: http://dx.doi.org/10.1016/j.aip.2017.08.001
Papers II and III in Appendices V and W (by permission of the publishers).
Papers IV-VI are not available in print at the date of submission.

SVENSK SAMMANFATTNING

Många kvinnor som genomgått behandling för gynekologisk cancer är negativt påverkade av sina sjukdomserfarenheter, såsom i kroppsuppfattning, självkänsla, sexualitet och reproduktionsförmåga. Psykologiska effekter av sjukdom behandlingar och fysiska seneffekter är ofta långvariga, en del är livslånga. De har uppmärksammats i tidigare studier inom Klinisk Cancer Epidemiologi (KCE, Karolinska Institutet, Stockholm och Sahlgrenska Universitetssjukhuset, Göteborg) och visar på behovet av en psykoterapeutisk behandling för denna specifika grupp av canceröverlevare.

Målet med vår forskning har varit att skapa och utvärdera en korttidsterapi för kvinnor som varit onkologiskt färdigbehandlade för gynekologisk cancer. Studien startade med en förberedande kvalitativ fas, som resulterade i avgränsningen av fyra framträdande problemområden: kroppsbild, sexuell hälsa, rädsla för återfall i cancer samt existentiella svårigheter. Två separata konstnärligt inriktade psykoterapi-interventioner utformades, den ena i form av en individualterapi och den andra en gruppterapi. Populationen för studien var patienter på kontrollbesök på Radiumhemmet vid Karolinska Universitetssjukhuset i Stockholm. Ett urval om 57 personer randomiserades till de två terapiformerna. De psykologiska effekterna av interventionerna efter avslutad terapi har utvärderats genom självskattningar i både kvantitativ och kvalitativ form (text och bild). Data insamlades och kvantifierad information bearbetades och analyserades statistiskt.

En musikterapeutisk metod KMR - Korta Musikresor - integrerad med annan konstnärlig metodik (expressive arts) tillämpades. Ett grundantagande i metodiken är att kropp och psyke är en sammansatt enhet. Den teoretiska ramen är psykodynamisk och existentiell med särskild inriktning på implicita och omedvetna (icke verbala) processer, affekter och affektreglering. Vi avsåg att de psykoterapeutiska interventionerna skulle kunna ge deltagaren möjlighet att känna och bearbeta material inom ett brett område av emotionellt lidande förknippat med cancersjukdomen, såsom sorg, förlust, uppdämda känslor och affekter kring bl.a. rädsla för återfall eller kring stigma knutna till kroppsupplevelse, sexualitet och kroppsbild. I avhandlingen redovisas resultaten av interventionens effekter på variabler inom forskningens problemområden.

Våra resultat visade att genomgången terapi inom tre av problemområdena kunde ge goda förbättringar, såsom en minskning av existentiella svårigheter, förbättrad kroppsligt välbefinnande och kroppsbild samt sammantaget en ökad livskvalitet (QoL; $p = \leq 0.05$). Effektstorlekarna (Cohens *d*) i dessa variabler varierade från medium ($d = 0.47$) till stark ($d = 0.83$). Effekterna kvarstod vid en uppföljning efter sju månader. Inom området sexuell hälsa fann vi dock ingen eller endast en svag förbättring. Vi fann också att en stödjande terapigrupp kunde ge särskilt goda resultat kring möjligheten att föra fram, bearbeta och acceptera tidigare ofta skambelagda

upplevelser, såsom känslan av kroppen som skadad eller främmande förknippat med en låg självkänsla. I samtliga dessa variabler skedde förbättringar.

Deltagarna visade vid utvärdering med få undantag en stor tillfredsställelse (särskilt för individualterapin) över att ha deltagit i terapiarbetet.

Vår slutsats är, att konstnärligt inriktad psykoterapi, enskilt eller i grupp, bör kunna användas i rehabilitering för canceröverlevare inom gynekologisk onkologi för att minska denna patientgrupps psykologiska svårigheter inom definierade problemområden samt härigenom bidra till en ökad livskvalitet i stort. Det är dock en liten studie med begränsningar och bristande möjligheter till långtgående slutsatser och implikationer. Fortsatt forskning och utvärdering är därför starkt rekommenderad.

Avhandlingen är sammansatt av sex artiklar samt denna övergripande ramberättelse. En publikation behandlar tidigare forskning och två den av oss tillämpade psykoterapeutiska metodiken. En artikel redovisar resultaten i baseline och en annan effekterna av de båda interventionerna. En artikel presenterar en utvärdering med ett nytt utvecklat analysverktyg för förståelsen av våra forskningsdeltagares målade bilder kring sina kroppsupplevelser.

Av publicistiska skäl kan tabeller med statistiska data endast presenteras i de båda resultatartiklarna (paper IV och V).

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ACKNOWLEDGEMENTS

This project has been a rite of passage, professionally and personally. I have travelled far into unknown territory, expanded my horizons and returned with valuable knowledge and discoveries. I am changed. The journey also represents the fruits of many years of work prior to this project with music, arts, and psychotherapy together with clients, students, and colleagues. This thesis owes its existence to the many helpers who contributed to the implementation of this comprehensive project.

First, a warm and sincere thank you to the many women, survivors of gynecological cancer, who participated in this study: the women of the initial interview study, the helpers with validation of questionnaires, the participants in the pilot study, and the participants in psychotherapy for the randomized trial. My heart is filled with gratitude for your time commitment, dedication and engagement. Most of all I thank you for your willingness to share your suffering and dread, and teach me about survival, hope, meaning and kindness in the face of severe adversities.

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A warm thank you to all the professors and educators at the Doctoral School of Music Therapy at Aalborg University. I feel honored to have been part of this fine collaboration with such an open and curious attitude towards learning. My sincere appreciation goes to the bright and witty Tony Wigram in memoriam, whose generous mindset made it possible for me to be granted a mobility fellowship. Thank you Hanne Mette Ochsner Ridder for your courage to take the helm after Tony. Your firm

commitment and wisdom is a gift to this community. Special thanks goes to two professors who have been of particular support and guidance related to writing projects; thank you Inge Nygaard Pedersen and Cathy McKinney for your generous feedback and sharing of expertise. My appreciation also goes to all you fellow students and the many inspiring forerunners of my research family at Aalborg. You have cheered me up and given helpful reflections and backing. Special thanks to you Ruth Hertrampf. Our collaboration with one paper of this study has been a heroine's journey in itself. We worked hard and had an immense learning adventure, and the friendship that developed between us sings in my heart.

One day you, Anna Gerge, knocked on my door and kindly inquired if we could play together. This became the beginnings of an inspirational collaboration. You enrolled as fellow student at Aalborg, and we became co-writers. Thank you Anna for sharing your knowing. I have appreciated your clarity of direction, your search for knowledge, and for always keeping the creative fire alive and burning. You are a fighter. Yet, the most precious gift is your warm friendship.

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In the stumbling start of this journey, when the road was yet unclear, I contacted you Birgit Feychting, chair of GCF (patient organization in Stockholm) and was invited to a board meeting the next day. This gathering became the fuel that ignited this project. It was also the occasion when I first met Karin Bergmark. Thank you Birgit, Catherine Dahlström, Kerstin Hultsten Susanne Rehlin, and Wiveka Ramel, and for your warm welcome. The enthusiasm and assistance from you all in GCF has been vital and provided deep meaning for the development of this project, and for me personally. A sincere appreciation goes to you Wiveka, who volunteered your time in the last phase of this study and generously spent many hours entering the collected data into a software program. Thank you for you meticulous work and for your loving ways of communicating.

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We know from research and clinical findings that the therapeutic relationship is what matters most. My sincerest heartfelt gratitude goes to you all therapists – Gudrun Hofsten, Karin Johannesson, Marie Sodell, Gabriella Rudstam, Lena Uggla and Ann Wenkel Harup – who delivered arts-based psychotherapy for the women in the study. Thank you for the excellent professional work of care, and for being flexible with your time. Your engagement, presence and faithfulness has helped me "trust the process." My appreciation goes also to you Katarina Mårtensson Blom for steadfast holding as a consulting supervisor. From me personally, I thank you for your encouragements, friendship, and reminding me to surrender to the moment.

I am fortunate to belong to an extended expressive arts family. You are many who have cheered me on. Thank you all! Some close colleagues and friends stand out. Thank you Paolo Knill and Margo Fuchs your interest and for showing me how to live in vitality with the arts. Thank you Steve Levine for your friendship, and for excellent help with my application years ago; that made a difference. Thank you Markus Alexander for the deep sharing, and for always reminding me to play, laugh, sing, and be a bit wild and crazy. Thank you my close colleagues at Expressive Arts, Stockholm; Anita Båge, Elisabeth Ekman, Karin Gerling, Anne Saari, and Erika Sinander. Your loving attention, contagious laughter, and good cries through the ups and downs (in all our lives) have truly mattered. Also, a note of thanks to you Per Apelmo who always stayed interested. A warm thank you from my heart to all the great and talented colleagues at the Norwegian expressive arts team. I have felt your warm support.

I have the good fortune to have worked with you Melinda Meyer DeMott, my gifted big sister, for almost three decades. Your generosity, friendship, love, and also bright reflections related to this project have been unfailing. You are a pathfinder who knows the hidden ways out of sticky situations.

Per Espen Stoknes, kindred spirit and trusted comrade musician, thank you for your, keen awareness, sensitivity and for always being there in need. You simply used your winged Hermes shoes and arrived to my rescue and solved tricky technical matters.

I am also privileged to be part of a world-wide community of Guided Imagery and Music practitioners. Thank you all who have stayed curious, been engaged and sent loving support! My gratitude goes especially to you Bolette Beck, Marilyn Clark, Ginger Clarkson, Louise Dimicelli-Mitran, Isabelle Frohne-Hagemann, Svein Fuglestad, Lars Rye-Bertelsen, Torben Moe, Solveig Overland, and Ellen Thomasen. Gina Kästele, my gratitude for inviting me to Germany to teach KMR. Leslie Bunt, playmate in the worlds of music and myth, thank you for sharing the depths of human soul and for useful reflections. My sincere appreciation to you Dag Körlin, Lisa Summer, and Björn Wrangsjö for your engagement and valuable sharp methodological and theoretical feedback in the developing stages of the KMR work. Thank you Fran (Frances Smith Goldberg), for your loving friendship, and for always pointing to music as an ever present and never waning source of healing, growth, and profound transformation.

A warm note of gratefulness to the many music therapy colleagues in Sweden who have expressed an interest in this study! A special thank you to Ingrid Hammarlund for faithful support; to Anci Sandell for warmth and caring resonace; to Märtith Bergström-Isacsson for advice and backing; to Katarina Lindblad for cheers and for being an advocate for receptive music therapy as chair of the Swedish association for music therapy, and to Rut Wallius for imperative information. Thank you also my inspiring Norwegian music therapy colleagues, Gro Trondalen and Unni Thanum Johns for your curiosity, helpful advices and for riding the waves with me.

My deep thankfulness to all you eleven enthusiastic women in the Swedish KMR training group that was conducted during this study time. Your earnest questions and honest reflections guided me in gaining more understanding of this method.

Thank you Tim Honig for excellent and prompt language editing, and for providing useful suggestions of the content that improved the overall comprehension and reading experience of this thesis.

Most of all, I am grateful to my family. Thank you Irja Jonina and Klara Regina, gracious daughters, for your patience and humor and for saying the most important words again and again: “you can do it,” “we believe in you,” “we love you,” and “this is not the end of the world”! To Gunder, my beloved husband, your intellectual and loving moral support has been a foundation. You have provided help in so many ways. To mention some: as a psychologist consultant, as being responsible for finances, and as an ardent and persistent fundraiser. Moreover, you have given continuous reflections on my texts, have remained curious, and have become a co-writer. You have shown me what it means to love.

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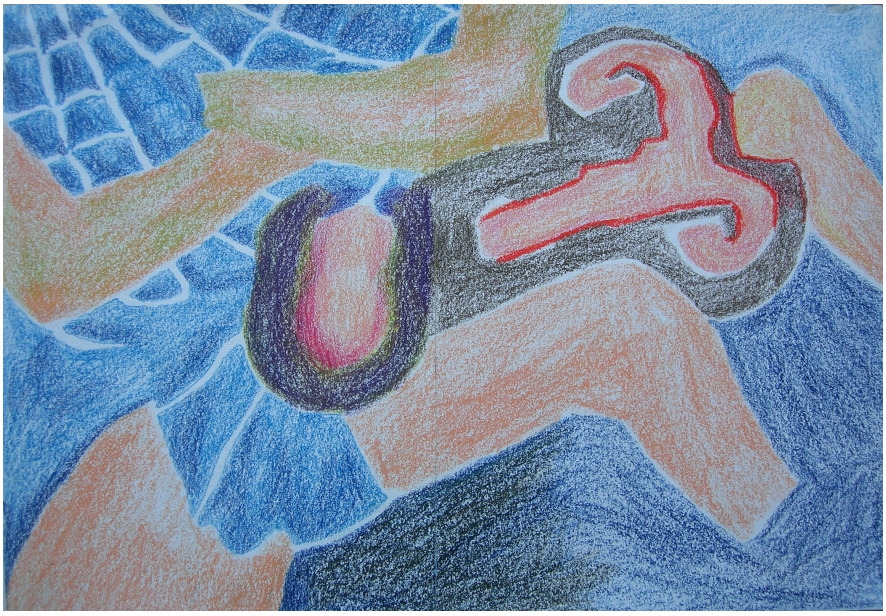
PRELUDE

Paintings with titles by "Anna", from the journey of reclaiming her body after gynecological cancer. Her story is summarized in a case vignette in Paper III (Appendix W, one more painting is found at the end of chapter 7).



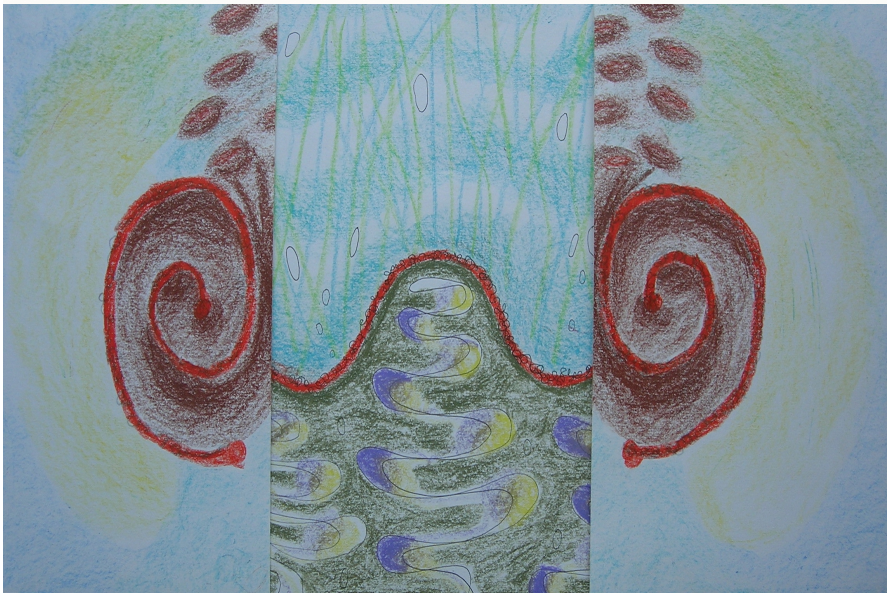
On the operating table - trying to protect myself

Sex... blistering, burning pain

Don´t touch me

Curtain of shame

I show him my shaky world



Spirals of pleasure and love

Female restoration - courage - strength - integration

TABLE OF FIGURES

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TERMINOLOGY AND ABBREVIATIONS

Adjuvant treatment	Additional treatment that usually refers to treatment after surgery such as chemotherapy.
Brachytherapy	Delivering radiation directly to the site of a tumor using an intracavitary device.
CAT	Creative Arts Therapy, refers to the different arts-based disciplines such as music therapy, dance therapy and art therapy.
EXA	Expressive Arts Therapy; involves the integration of all the arts in working with psychological change (referred to as intermodal expressive arts).
FU	Follow-up measurement
EORTC-QlQ-C-30	The European Organisation for Research and Treatment of Cancer, 30 items quality of life questionnaire.
GCF	Gynekologisk cancerförening i Stockholm (Gynecological patient organization in Stockholm).
GIM	Guided Imagery and Music
GrpMI	Group Music and Imagery
GYNONC-QoL-CSBAE	Gynecologic Oncology-Quality of Life-Coping, Sexuality, Body and Art Experiences (study-specific questionnaires).
HADS	Hospital Anxiety and Depression Scale
HADS-A	Hospital Anxiety and Depression Scale, only anxiety subscale.
HCP	Health care practitioners
Herth Hope	Herth Hope Index
KCE	Klinisk Cancer Epidemiologi [Department of

	Clinical Caner Epidemiology, Karolinska Institute, Stockholm and Sahlgrenska Academy, Göteborg]
KMR	Korta musikresor [KMR-Brief Music Journeys]
KMS	Kroppsmedvetande skala [Body Consciousness Scale]
MADRS	Montgomery-Åsberg Depression Rating Scale
MI	Music and Imagery
SATPA	Safety Assessment Tool of Pictorial Artefacts
The Bonny Method	The original format of Guided Imagery and Music, a psychotherapy method developed by Helen Lindquist Bonny (1976, 1978, 1980, 2002). Today referred to as The Bonny Method or the Bonny Method of Guided Imagery and Music.
QoL	Quality of life

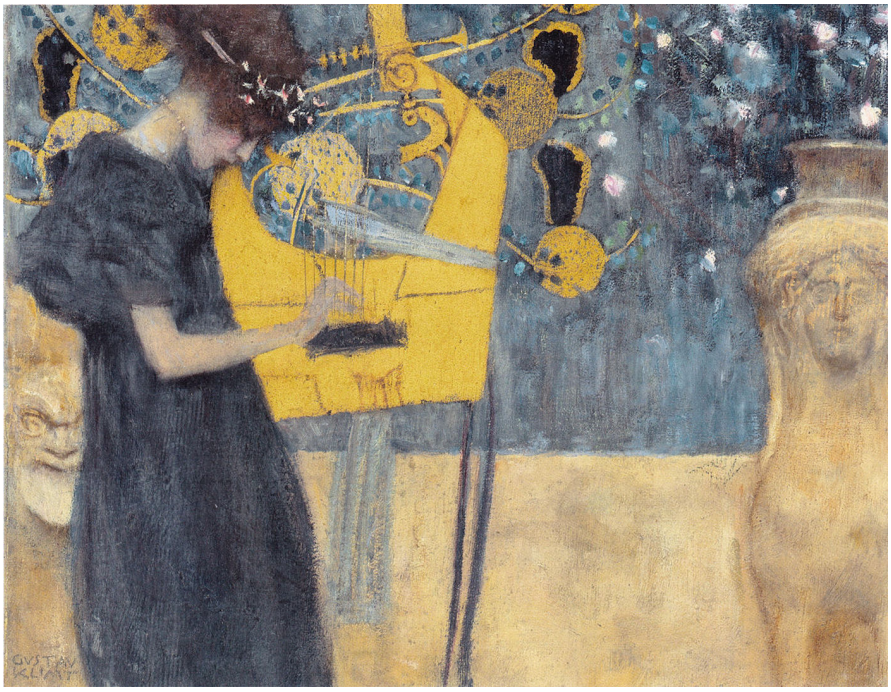
Malignancies in female genitals and reproductive organs are referred to as gynaecological cancer, or gynecological cancer. In this text, I have chosen the latter spelling.

Gynae is ancient Greek for woman (γυναίκα).

Painting by participant of her experience of her body after psychotherapy (Paper VI).

STUDY IMAGE: MUSIC (DIE MUSIK I)

This painting by Gustav Klimt (oil on canvas, 37 x 45 cm, 1895), has served as a signature image of the study and was used on questionnaires and postcards.



AESTHETIC RESPONSE

Dark portals to the not yet formed. She bends her head, draped in soft and weighty velvet. Cradling a golden lyre. Ancient guardians of fate standing numb with unbending faces. She turns inside, sinking into stillness. This is a waiting-room. A timeless dwelling. Yet, this space in between carries dreams of roads ahead. Tentatively she begins plucking the strings, searching, and playing slowly. Releasing tender melodies. Songs resonate deep in the bones and become embodied. She waits. Listening for her stories. A gust of dry wind brings fragrant blossoms of hope. Here she can find fresh water, subtle greenery, and the solace of gentle music.

CHAPTER 1: INTRODUCTION

Women recovering from gynecological cancer are affected in all aspects of their lives. The bodily site of this disease is associated with privacy, silence, and taboo (Bergmark, 2007; Swedish Cancer Society, 2009; Solbrække & Lorem, 2016). Hence, gynecological cancer impacts the core of the woman's body, her identity, sexual life and intimate relationships (Bergmark, Åvall- Lundqvist, Dickman, Henningsohn, & Steineck, 2002; Gilbert, Ussher, & Perz, 2011; Krychmann, Pereira, Carter, & Amsterdam, 2006). A cancer diagnosis usually strikes without warning and in an instant the individual is faced with questions of existence, mortality and meaning-making (Vos, 2015). Diagnosis, illness, and treatments can also be terrifying, invasive and traumatic (Keitel, Lipari, & Wertz, 2017; Wettergren, 2007).

Besides a potential death threat, gynecological cancer survivors may have to deal with the loss of female body-parts that are symbolically charged and associated with sexuality and being a woman (Bergmark, 2007). Late effects of treatments involve varying degrees of bodily changes such as pain, lymphoedema, weight-gain, hair loss, decreased sexual health, and loss of fertility (Bergmark, 2002, Bergmark, Åhvall-Lundqvist, & Steineck, 2000). Thus, these women are at risk of developing psychological distress and long-term complications influencing sexuality and overall quality of life (QoL; Bergmark, 2007, Bergmark & Dunberger, 2013; Reis, Nezihe, Beji, & Coskun, 2010; Wenzel,Vergote, & Cella, 2003).

Withe increase of cancer survivorship, and having to live with a changed body, there is a growing need for treatment approaches addressing cancer-related psychological distress and recovery. The creative arts therapies and arts-based interventions have been found to be effective for people with cancer (Archer, Buxton, & Sheffield, 2015; Boehm, Cramer, Staroszynski, & Osterman, 2014; Bradt, Dileo, Magill, & Teague, 2016; Bradt & Goodill, 2015; Bro et al., 2017; Hertrampf & Wärja, Puetz, Morley, & Henning, 2013; Tsai et al., 2014). Today, psychosocial support and care alternatives after active oncological treatment are lacking in Sweden (Hellbom & Thomé, 2013). The overall purpose of this interdisciplinary study was to contribute to the restoration of psychological health, improvement of QoL and bodily well-being of gynecological cancer survivors. More specifically, the aim was to assess the effectiveness of arts-based psychotherapy for women recovering from gynecological cancer.

OVERVIEW OF CONTENT

This thesis consists of five articles, one book chapter, a linking text, references, appendices, and supplementary material on USB. The book chapter and two articles are published. One article is in review, and two are in manuscript (Figure 1-2). The linking text is divided into seven chapters (Table 1-1).

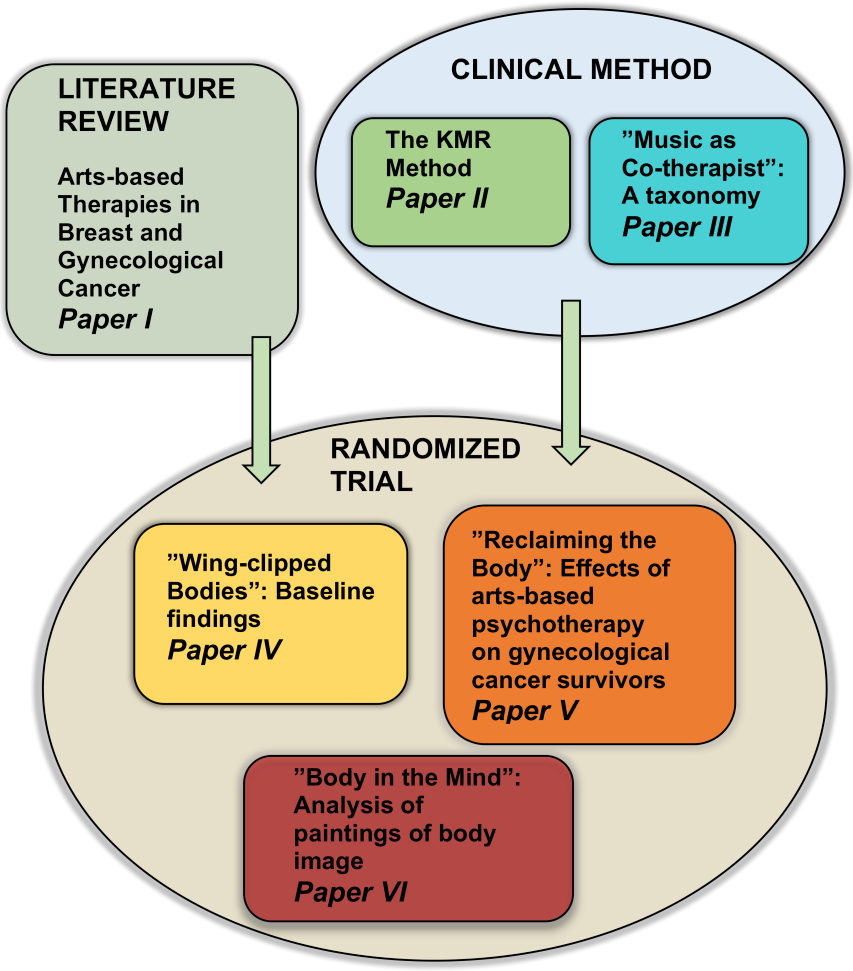


Figure 1-1. Overview of the six papers included in thesis

Chapter	Content	Paper
1 Introduction	The first chapter declares my personal motivation and background governing this thesis. It gives a brief overview of the clinical population, survivors of gynecological cancer. Information about the organizational contexts and settings is provided, and the research team is introduced. Other collaborations, funding, and ethics approval are presented.	
2 Cancer rehabilitation (background)	The second chapter gives an introduction to oncological rehabilitation and the specific needs of the study population. Furthermore, this chapter summarizes **Paper I**, the findings of a systematic literature review on trials with arts-based interventions for women with breast or gynecological cancer.	**I**
3 Arts-based psychotherapy (background)	The third chapter provides an overview of the theoretical background and contexts of the arts-based psychotherapies. Here, two papers, relating to the intervention are summarized: **Paper II** on KMR-Brief Music Journey method that includes a group therapy vigniette, and **Paper III** on theories and procedures regarding music selection for working with music and imagery in therapeutic settings. In addition, this paper contains an individual case vigniette from the pilot study.	**II** **III**
4 Aims	The fourth chapter states the overall aim of the study, the research questions, and the specific aims of the included papers designed to address and answer the inquires of this thesis.	
5 Methods	The fifth chapter is divided in two main sections a) research methods, and b) clinical methods. It first describes the methods we chose to answer the research questions and summarizes sequential steps and findings of the preparatory phase that includes the pilot study. Moreover, it presents outcome instruments and qualitative measures. It also explains the procedures of the randomized trial and sums up the data collection phase. This section includes a description of the clinical methods of two arts-based psychotherapy interventions. In it, the content of both treatment protocols is laid out, and information about the providers, settings and material is provided.	
6 Results	The sixth chapter summarizes results of the randomized trial and reviews three papers: **Paper IV** presents clinical characteristics and findings at baseline; **Paper V** presents major findings and effects of the randomized trial; and **Paper VI** provides results of analysis of body image paintings assessed by a tool for evaluating visual arts products (SATPA).	**IV** **V** **VI**
7 Discussion	The final chapter discusses results and findings as related to the research questions, the two interventions, and relevant literature. Furthermore, the validity of the research methods, and the strengths and limitations of the study are examined. In addition, this section suggests recommendations for future research and concludes with relevance for clinical applications.	
References & Appendices	This thesis is supplemented with several appendices. In addition, extra material related to the data collection is provided on USB.	

Table I-1. Overview of content of thesis

PERSONAL MOTIVATION

The background, motivation and personal resonance leading up to this project were braided together mainly of four strands: the artistic, clinical, training and research, and personal).

RESONANCE WITH THE ARTS

The arts can open gateways for knowledge, inquires, and expressions of both the suffering and liberation of humanity. To me, all the arts are interconnected and offer a basis for living, playing and creating meaning out of the givens of my existence. Music was all around me while growing up and became a reliable attachment figure, a way to relate and communicate with others, and afforded profound joy. Through playing the flute I learned that music has a temporal dynamic direction and movement, a harmonic vertical space, and an imbedded narrative. Studies in Dalcroze music education (Spector, 1991) gave a deepened understanding of the intimate bond between music, movement and embodiment that influenced me to study and embrace all the arts. This notion of time, space, content, and direction in music (and other art forms) can be used as a vehicle in interpersonal interaction and communication in therapy. In telling and retelling our personal stories we are changed. Through arts they become layered and symbolic, holding multiple narratives and perspectives. Professionally, I found a home base in the intermodal approach of expressive arts therapy and in the Bonny Method of Guided Imagery and Music (GIM). In both fields, the aesthetic and the creative process are acknowledged as transformative agents in working with change, i.e. the capacity of the arts to bring about experiences of well-being, meaning and integration.

CLINICAL RESONANCE

My theoretical frame has evolved over many years and is grounded in psychodynamic and existential psychotherapy, theories of attachment and affect regulation, and phenomenology. Early on, my thinking was influenced by analytical psychology (Jung, 1964) and the world of symbols, archetypes, and mythology (Wärja, 1994, 1999). Mythic stories and tales continues to be a source of knowing. As a clinician, educator and researcher working with imaginative processes, the arts have been at the core of my work. In using arts in psychotherapy, attention is on the tacit knowledge of the body. It is the body that feels, sings, paints, dances, listens, and suffers. Through the years, clients with whom I worked have come to face emotional distress, trauma, abuse, and existential concerns. One group of clients has been cancer survivors. Detached feelings and alienation of the body have been prevalent. I became interested in the process of self-generated helping images, evoked through imagination and the arts, as ways to rebuild trust and empowerment in one's own body and emotions.

Women with gynecological cancer are affected in the inner rooms connected to reproduction, femininity, and sexuality. Experiences of anguish, suffering, need avenues for expression, release, and reflection. It is a journey of reintegration, empowerment, and reclaiming the body.

RESONANCE OF TRAINING AND RESEARCH

The beginning steps leading up to this study were taken about twenty years ago working in psychiatry with receptive music therapy with traumatized clients. I found the classical GIM music was too dynamic and emotionally evocative and began to experiment with modified shorter programs and nonclassical pieces of music that were combined with visual arts methods, and body-oriented psychotherapy techniques. This led to the development of KMR–Brief Music Journeys (KMR; Wärja, 2010). In 2008, I conducted a qualitative interview study with five therapists working with KMR that resulted in tentative theoretical tenets; I concluded that the next step was to try out KMR in clinical outcome research (Wärja, 2010). Moreover, the concept and symbol of "mothering" (not gender specific, but rather holding and containing) had been explored in an earlier publication (Wärja, 1999) that also influenced the development of the present study. Here music was conceptualized as a sounding presence that, when relationally held, could convey nonverbal implicit experiences of safety to support clients as they tackle emotional difficulties. Today we know that safety and emotional stabilization are prerequisites to working with trauma and crisis (Gerge, 2017b; Herman, 1992). In essence, my motivation was to explore how existential themes and disruptive cancer-related body experiences could be regulated and addressed in arts-based psychotherapy. Moreover, I was motivated to test the effects of KMR within an oncology setting and study the use of short pieces of music and art-making in attending to emotional distress, fragility and existential loss. My intentions were also to contribute to methodological development and theoretical understanding of the use of arts in psychotherapy in people with cancer.

PERSONAL RESONANCE

With cancer, the basic questions of life and existence are always present. Past and future realities are shattered. My personal resonance and experience with family members, close friends, and colleagues confronting cancer have exposed me to an emotional current caused by the effects of this disease. In setting up this research it was vital to: respect the integrity and individual perspectives of each informant; acknowledge the impact of cancer on intimate relationships and entire family systems; and remember that behind statistical tables and graphs are unique stories of suffering and hope in the face of cancer.

CLINICAL POPULATION: GYNECOLOGICAL CANCER

Gynecological cancer refers to any cancer that starts in a woman's reproductive organs and can arise in the endometrium, fallopian tubes, ovaries, cervix, vulva and vagina. In 2013 the worldwide proportion of gynecological cancer among female cancer diagnoses was 16.3%. Of this, cervical cancers made up 7.0%, endometrial 4.8%, ovarian 3.6%, and other forms 0.9%. (International Agency for Research on Cancer, 2013; World Health Organization, 2013). Cervical cancer was the fourth most prevalent cancer among women worldwide and the most frequent cause of death in women in developing countries (International Agency for Research on Cancer, 2013; World Health Organization, 2013). Today, due to screening programs and successful treatment, survival rates have increased in developed countries. In Sweden, about 2.900 women are diagnosed with gynecological cancer annually, making up 12% of the cancers affecting women, and 1000 women die annually from gynecological malignancies (Swedish Cancer Society, 2009). Approximately 30.000 live with various late effects and complications (Swedish Cancer Society, 2009). After treatment is completed, survivors may need additional professional help for social and psychological consequences and to alleviate possible late effects and physiological complications.

Gynecological oncology is a specialty of combined medical expertise in working with women with gynecological tumor diseases. This expertise comprises a multidisciplinary approach, and treatment is based on the integration of gynecological and oncological methods and skills (Sorbe, Frankendal, & Högberg, 2013). This requires a holistic view that includes knowledge of etiology, epidemiology, tumor biology, prevention, targeted health controls, tumor diagnoses, follow-up and treatment. A specialist in gynecological oncology will evaluate possible late effects of the disease and treatment including aspects of sexuality and fertility. Furthermore, this involves assessing needs for rehabilitative measures, psychosocial support, palliative care, and end of life care (Sorbe et al., 2013). Survival is directly related to the spread of the tumor at the time of diagnosis. A cancer diagnosis is based on clinical examination, imaging, pathological examination, and evaluation. This involves a biopsy and staging of the disease, which is a process to determine the cell type, size of the tumor, and whether malignant cells have spread to nearby lymph nodes or other parts of the body. Treatment includes surgery, chemotherapy, radiotherapy (external and internal, i.e. brachytherapy) and endocrine therapy. See Appendix A for more specific information on the major types of gynecological cancer.

CONTEXT OF THE STUDY

MAIN ORGANIZATIONS

This study was designed as an interdisciplinary project. It has been feasible based on the support and collaboration of professionals from four organizational parties (Figure 1-2).

1. Aalborg University in Denmark where I was enrolled in 2010 as PhD Fellow at the Doctoral Programme of Music Therapy.
2. Karolinska University Hospital in Stockholm. All participants were recruited from the outpatient gynecological oncology department at the Oncology Clinic. The arts-based group psychotherapy intervention was held at the Department of Cancer Rehabilitation.
3. Karolinska Institute in Stockholm and the Department of Oncology and Pathology and the division of Clinical Cancer Epidemiology (KCE) provided the context for the preparatory phase, the randomized trial, and statistical analysis.
4. Expressive Arts Stockholm, Inc. was the setting for the pilot study, participant screening for the trial, all interviews, and the qualitative data collection. This was also the location for most of the individual psychotherapy treatments.

Figure 1-2. Collaborating organizations

THE RESEARCH TEAM

The research team consisted of fourteen individuals. All members were specialized in their respective discipline.

Core team

Margareta Wärja, PhD Fellow, MA, CAGS[1], lic. psychotherapist, teacher and supervisor of psychotherapy, music therapist, expressive arts therapist, GIM therapist and authorized trainer: principal investigator. *Lars Ole Bonde*, Prof. Dr. musicologist, GIM therapist and authorized trainer: thesis advisor. *Karin Bergmark*, M.D., PhD., gynecological oncologist: thesis advisor, and medical consultant. *Gunder Forss*, lic. psychologist, lic. Psychotherapist, CAGS: psychological consultant, budget, and fundraiser.

Individual therapists

Gudrun Hofsten, M.D. psychiatrist, lic. psychotherapist, teacher and supervisor of psychotherapy, GIM therapist. *Karin Johannesson*, social worker, lic. psychotherapist, teacher and supervisor of psychotherapy. *Gabriella Rudstam*, PhD Cand., MA, lic. psychotherapist, music therapist, expressive arts therapist, GIM therapist. *Lena Uggla*, PhD Fellow, music therapist, GIM therapist.

Group therapists

Marie Sodell, RN, oncology nurse, expressive arts therapist, group therapist. *Ann Wenkel Harup*, RN, oncology nurse, expressive arts therapist, group therapist.

Recruitment and additional support

Eva Lindberg, RN, oncology nurse: recruitment. *Katarina Mårtensson-Blom,* PhD, lic. psychologist, lic. psychotherapist, teacher and supervisor of psychotherapy, GIM therapist and consulting clinical supervisor for the therapists. *Tommy Nyberg*, PhD Fellow, MSc: statistician. *Wiveka Ramel*: data management and data entry.

ADDITIONAL COLLABORATION

Anna Gerge, PhD Cand., MSc, lic. psychotherapist, expressive arts therapist, accredited consultant in EMDR, teacher and supervisor of psychotherapy. Anna joined the project in the last phase of data collection and analysis. An arts-based method of inquiry was created in which qualitative data of this study was used (Gerge, Wärja & Nygaard-Pedersen, 2017a, 2017b). Anna developed a tool for analysis of pictorial artifacts: Safety Assessment of Pictorial Artifacts: SATPA (Gerge, 2017a,

[1] Certificate of Advanced Graduate Studies in expressive arts theory and methodology.

2017b; Gerge & Nygaard-Pedersen, 2017) that was applied in assessing body images (Paper VI; Gerge, Wärja, Gattino, & Pedersen, 2017).

Ruth Hertrampf, PhD, music therapist, GIM therapist. We have contributed equally to a systematic review article (Paper I) focused on the literature on arts-based therapies in breast and gynecological oncology (Hertrampf & Wärja, 2017).

The patient association GynekologiskCancerFörening (GCF) Stockholm is an organizational body for women diagnosed with gynecological cancer and related family members. The aims are to provide support to members, to communicate with the medical profession, and address politicians assigned to govern medical care in oncology. Members of the GCF board have welcomed and supported this project from the start. They have participated in interviews, given feedback on various texts in the preparatory phase, and have contributed to data management and data entry of the randomized trial.

FUNDING

The project has been supported by external funding. Most important, a mobility fellowship from Aalborg University granted in 2010 made it possible to conduct this study. The pilot phase was supported by a contribution from Ax:on Jonsson Foundation. Implementation of the main study was feasible due to a grant from Ekhaga Foundation (grant Dnr 2012-27). We received funding from Olu-Birgit Jepsson's Music Therapy Foundation for technical equipment. In addition, support was given for material from the Infinity Foundation.

ETHICS APPROVAL

This study was reviewed by the regional board of ethics located at Karolinska Institute in Stockholm. Ethics approval was granted on January 19, 2012, no: 2011/2131-31/5 (Appendix B).

The trial was registered: ISRCTN50156343: Assigned 03-04-2012 (Wärja, Bonde & Bergmark, 2012).

CHAPTER 2. CANCER REHABILITATION

This chapter introduces psychosocial oncology and the specific rehabilitative needs of the study population[2]. Moreover, it summarizes Paper I, a systematic review of arts-based treatments for women with breast or gynecological cancer.

REHABILITATION AND QUALITY OF LIFE

Cancer rehabilitation is an ongoing process that involves the whole trajectory of treatment procedures for the person with cancer (Hellbom & Thomé, 2013). Rehabilitative measures should be addressed and tailored to the unique problems of the individual person afflicted by cancer (and may include the family). Rehabilitation is divided into three main phases: assessment and diagnosis, active treatment, and posttreatment. It is also needed in the case of recurrence, chronic phases of the disease, or palliative care. It is essential to continuously assess, support, and strengthen the innate resources of the person with cancer. The development of psychosocial cancer care was initiated in the 1970s along with research in the area (Carlsson et al, 2007). In the Swedish literature, this term refers to psychological and social aspects of one family member being diagnosed with cancer, the effect on the individual, the family or social system, the reactions related to the disease, and the need for support and help to work through the crisis. The term psycho-oncology used in American literature is defined by Holland (1998) as the study of psychological reactions of patients, the family around the patient, and the treating professionals in all phases of the disease. Furthermore, it entails the investigation of psychological, social, and behavioral factors that relate to survival.

Carlsson (2007) argued that the resistance to addressing psychological and social problems connected with cancer have been caused by negative associations with psychiatric problems. For most persons, a cancer diagnosis will create a crisis reaction. How the illness is experienced, appraised and coped with will vary between individuals and across the various phases of treatment. In fact, most persons afflicted with cancer find ways to handle the crisis of diagnosis and subsequent treatments (Carlsson 2007, Hellbom & Thomé, 2013). Patients with comorbidity, such as

[2] This study has evolved over many years. In reviewing the literature and presenting background theories, I have decided to include highly relevant and more recent literature that has been published after we conceived, designed and implemented the study.

psychiatric history or other somatic illnesses, run a higher at risk of not being able to cope with a cancer diagnosis (Kissane et al., 2004).

QUALITY OF LIFE

Quality of life (QoL) refers to the overall satisfaction with life and wellbeing. It is a complex term that includes different aspects of what makes life worth living for the individual person. It is an individual, subjective and dynamic expression, implying that the experience of what this means will change over time and with different life events (Carlsson, 2007). The concept of recovery is related to rehabilitation and ameliorated QoL. According to Altmaier (2017), this refers to an individual non-linear process, unique to each person, of becoming whole after trauma and major life crises. Recovery requires the following resources: a) connectedness, b) storytelling, c) hope, d) building a new identity, e) meaning, and f) empowerment (pp. xii-xiii). Thus, QoL and recovery are evaluated in terms of the ability to create coherence within and meaning of the givens of existence (Antonovsky, 1987/2000). According to the definition of the World Health Organization, QoL is the individual perception of one's life situation within a cultural context and a specific value system that includes aims, expectations, standards and concerns (WHO QoL, 1995). It is estimated that about 30% of all individuals treated for cancer are in need of additional psychosocial rehabilitative help and care in order to return to a meaningful QoL (Carlsson, 2007). In addition, around 20% are in need of specialized professional help such as psychotherapy, psychiatric care, or special diets. Difficulties experienced by individuals with cancer can be expressed in ways such as depressive symptoms, anxiety, sleep disturbances, negative self-image, and absence of pleasures and meaning in life. To maintain optimal QoL, cancer rehabilitation should be individualized (Hellbom & Thomé, 2013).

Psychological distress and rehabilitation

Distress is a term used in the literature referring to uncomfortable and overwhelming feelings and an inability to handle and cope with cancer (Brandberg & Hellbom, 2013). Like any traumatic event, cancer can be experienced as a sudden and major disruption (Vos, 2015). There is no consistent picture in the literature of the impact of crisis reactions and distress related to cancer and earlier comorbidity (Rose & Hellbom, 2013). Coping implies a dynamic process and refers to how a person is able to handle internal and external demands and stressors in a given situation. Lazarus and Folkman (1984) formulated the following definition: "Coping is a constantly changing cognitive behavioral effort to manage specific external or internal demands that are appraised as taxing or exceeding the resources of a person" (p 141). Psychological rehabilitation addresses living and coping with a changed life situation related to an affliction. The severity and duration of psychological symptoms and difficulties will determine the need for specialist help such as psychotherapy or

psychiatric evaluation. According to Brandberg and Hellbom (2013), the psychotherapy approach offered at oncology clinics in Sweden is primarily cognitive and behaviorally based and focuses on handling everyday crises, improve coping, and reducing stress. There is a lack of psychodynamic and existential nonverbal/verbal therapy approaches that focus on emotion expression and affect regulation.

Research on psychological difficulties associated with cancer has mainly addressed anxiety and depression (Carlsson, 2007). Many patients go through periods of depression during and after treatments and may need antidepressive medication (Hellbom, & Thomé, 2013). A later meta-analysis found that the incidence of depression varied between 0–58%, depending on how depression was defined, the kind of measurements that were used, and when in the course of cancer illness that depression was assessed (Massie, 2004). A more recent study found that about 30% of cancer patients suffer from either anxiety or depression (Brintzenhofe-Szoc et al., 2009). Trauma is bodily based (van der Kolk, 2014). Some persons inflicted with cancer develop more severe reactions such as traumatic stress or PTSD (Holt, Jensen, Gilså Hansen, Elklit, & Morgensen, 2016). Coping and living with cancer can develop into an experience of psychological growth or posttraumatic growth, which becomes transformative and may lead to living a more rich and authentic life (Keitel, Lipari, & Wertz, 2017; Tedeschi & Calhoun, 1996).

REHABILITATION NEEDS OF GYNECOLOGICAL CANCER SURVIVORS

Women recovering from gynecological cancer are underrepresented in psychosocial oncology research (Swedish Cancer Society, 2009; Solbrække & Lorem, 2016). Despite the high prevalence of these forms of cancers among women, there is a lack of intervention studies developed specifically to meet the needs of gynecological cancer survivors (Chow, Chan, Choi, & Chan, 2016; Hersch, Juraskova, Prince, & Mullan, 2009; Manne et al., 2007). Although the psychological distress is reported to be high, reviews and studies report generally report good QoL for this population (Bradley, Rose, Lutgendorf, Costanzo, & Andersson, 2006; Dahl et al, 2013; Goncalves, 2010). This may be due to a process of response shift in which internal experiences and subjective measures of life's quality can change in the recovery after a serious illness such as cancer (McClimans, et al., 2013; Schwartz & Spranger, 1999). Nevertheless, a number of studies point out long-term impairment related to sexual health and function, and body image (Bergmark, 2007; Carr, 2013; Ratner, Foran, Schwartz, & Minkin, 2010; Steele & Fitch, 2008; Ter Kuile, Weijenborg, &

Spinhoven, 2010). Survivors may develop treatment-induced side effects and long-term late effects impacting QoL (Bergmark & Dunberger, 2013; Urbaniec, Collins, Denson, & Whitford, 2011; Westin et al., 2016). Late effects generally refer to symptoms that occur at the earliest after three months and persist two years after oncological treatment has ended. It has been estimated that at least between 25–50% of the individuals will experience chronic sexual problems and difficulties after cancer treatment (Schover, 2005). In a population-based survey involving 256 women diagnosed with early cervical cancer, it was found that compared with healthy controls, sexual dysfunction was the major area of difficulty that had the most negative influence on the women after treatment (Bergmark et al., 2002, Bergmark, Åvall-Lundqvist, Dickman, Henningsohn, & Steineck, 1999). Additionally, in this study 18% of the women reported having been victims of sexual abuse (Bergmark, Åvall-Lundqvist, Dickman, Henningsohn, & Steineck, 2005). Women who have removed body-parts through surgery may experience a loss of vital organs, which are associated with being a woman. When ovaries are taken out, women of fertile age will have an immediate onset of menopause. Symptoms may include weight-gain, hot flashes, and feelings of growing old prematurely. The process can be quite traumatizing (Bergmark & Dunberger, 2013; Juraskova et al., 2003). Pelvic radiotherapy and brachytherapy can result in vaginal shortening and stenosis that may cause sexual dysfunction. Another late effect is secondary lymphedema caused by surgery, infection. This occurs when the lymphatic fluid cannot be transported away sufficiently through the body and instead produces abnormal swelling. The result may be a chronically progressive condition that can develop into one of the more disabling late effects (Bergmark et al., 1999; Lindquist, Enblom, & Bergmark, 2015). In one study focused on gastrointestinal side-effects of gynecological malignancy (Dunberger et al., 2010; 2010b), it was found that almost half (49%) of the 616 participants experienced distressing symptoms after radiotherapy that involved defecation urgency with fecal leakage. This will affect sexuality and QoL in general.

ARTS-BASED APPROACHES IN ONCOLOGY

The use of the arts in oncology settings (arts in medicine and creative arts therapy) has generally been well researched and documented (Aldrigde, 1994, 1996; Archer et al., 2015; Bohem et al., 2007; Bonde, 2005; Bradt et al., 2016; Bradt, Shim, & Goodill, 2015; Bro et al., 2017; Bunt & Marstson, 1995; Burns, 2001; Hanser, 2006; Hartley & Payne, 2008; Hertrampf, 2017; Olofsson & Fossum, 2009; Puetz et al., 2013). At the time of beginning this project in 2011, thorough literature searches did not detect any outcome studies specifically focusing on arts-based approaches and gynecological cancer survivors. While a few non-outcome studies were identified, they were qualitative case study reports. To follow up our searches, a systematic review was conducted in 2016 (Hertrampf & Wärja, 2017). In order to collect trials

for a substantial review, studies on women with breast cancer were added to the inclusion criteria. Although these are clearly two different cancer diseases, the rationale for including both was the common ground regarding clinical relevance, which is further discussed in the paper.

PAPER I: SYSTEMATIC REVIEW

Breast and gynecological cancer are two diagnoses affecting women worldwide (breast cancer accounts for 25% of cancer in women, and gynecological cancer for 16.3%; International Agency for Research on Cancer, 2013; World Health Organization, 2013). Nonpharmacological research in oncology has grown considerable in the last decade. The systematic review (Hertrampf & Wärja, 2017) was conducted following the recommendations of the PRISMA guidelines (Liberati, Tezlaff, & Altman, 2015) and summarized the current evidence of arts-based interventions on psychological outcomes for women with breast or gynecological cancer. In evaluating eight previous reviews in oncology it was found that all except one had included studies combining trials of music medicine and music therapy; this muddles the boundaries between practices and complicates interpretation of results. Consequently, the rationale for this review was to assess and present findings from each field separately. One aim was to assess the outcome of creative arts therapy (CAT) and arts medicine (AM) on targeted populations, and the other aim was to evaluate the quality of reported interventions.

Exhaustive searches were conducted between the first of March and the first of September 2016, and included randomized and quasirandomized trials with repeated measures, published in English, and involving adult women only. The following databases were used: CINAHL, Cochrane Library, EBSCOHost, MEDLINE, PsycINFO, PubMed, RILM, Scopus, Web of Science Core Collection, ProQuest Digital Dissertations, and The Center for Music and Health Database on Music Therapy Literature. Searches resulted in 294 items, and 104 were found to be potentially relevant after duplicates were removed. After reading abstracts and articles, 21 papers from 17 trials remained for inclusion in this review[3]. In total 1,703 women had participated (83.1% breast cancer, 16.9 % gynecological cancer). Ten papers described the use of CAT and 11 used AM; 19 papers focused on breast cancer and two AM studies on gynecological cancer. No studies providing CAT for the latter population was identified. Each paper was assessed using the GRADE (Grades of

[3] References of included studies and overview of place in trajectory are found in Appendix U.

Recommendation, Assessment, Development and Evaluation Working Group), and effect sizes were calculated when sufficient statistical information was provided (standard deviation and means for baseline and posttest, and when applicable for follow-up). Effect size is an important outcome to assess clinical relevance, and especially useful in small samples (Gold, 2004).

Interventions were of varying quality and implemented during a variety of periods throughout the entire treatment trajectory, though few studies had been conducted in the follow-up phase after active treatment had ended. Anxiety and depression were most the most prevalent outcomes across studies. Body image and sexuality were hardly evaluated. Results yielded small to large effect for AM and null to large effect for CAT. Reporting on interventions was generally poor and essential information for replication, comprehension, and clinical application was lacking. As a result, a check-list was developed by the authors for reporting on arts-based interventions for future studies. We found that the evidence supports that arts-based interventions may be useful for the both breast and gynecological cancer survivors, but that more research is needed, in particular for gynecological cancer.

CONCLUSIONS OF REVIEW RELATED TO PRESENT STUDY

There is an evident lack in the literature of arts-based psychotherapy interventions with gynecological cancer survivors. Moreover, research on the uses of arts-based interventions during the rehabilitation phase after oncology treatment has ended is scarce. No study in the systematic review by Hertrampf & Wärja (2017) included women exclusively from the phase after oncology treatment had ended. Three studies involved participants in the post-oncology treatment phase together with women in active treatment, or in a palliative care. (Ho et al., 2016; Monti et al., 2013; Sandel, 2005). The two music medicine studies in gynecological cancer were implemented at colposcopy screening and during brachytherapy (Chan et al., 2003; Chi et al., 2015). In the updated Cochrane report of music interventions that included 52 trials (mixed cancer sites; Bradt, et al., 2016), only one study (Burns, 2001) was conducted with participants (N = 8) after oncology treatment had been completed, results showed improvement in mood and QoL compared with control after 10 GIM sessions. In the systematic review of 10 CAT studies (Archer et al., 2015) no trials were performed during this phase. To conclude, our systematic review identified two music medicine studies in gynecological oncology where music had been implemented at screening and active treatment. No study was found applying any of the arts-based therapy approaches with gynecological cancer survivors. In addition, there is a dearth of literature studying the use of the arts with survivors (of any cancer site) in the post-oncology stage of rehabilitation.

CHAPTER 3. THE ARTS IN PSYCHOTHERAPY- BACKGROUND

This section introduces the theoretical contexts of the arts-based intervention, KMR–Brief Music Journeys (Paper II). An essential component of this approach is the therapist-selected music tailored to the individual client or a group of clients. Rationales for selecting music in therapeutic settings is presented (Paper III).

ARTS-BASED PSYCHOTHERAPY

Creative arts therapy (CAT) is a meta-term referring to arts-based professions that use different arts approaches in psychotherapy to address suffering and assist in interpersonal transformation and optimizing psychological change (Nielsen, King, & Baker, 2016). Bradt and Goodill (2013) proved the following definition of (CAT)

> The implementation of an arts intervention by a trained, credentialed creative arts therapist; the presence of a systematic psychotherapeutic process; and the use of individualized treatment interventions. Thus, CAT uses a wide range of arts experiences to address specific therapeutic issues identified individually for patients and always includes patient assessment, treatment, and evaluation. Specialties include art therapy, music therapy, dance/movement therapy, drama therapy, poetry therapy, and expressive arts therapy. (p. 969)

The intervention used in this study, KMR–Brief Music Journeys (KMR; in Swedish, Korta Musikresor; Wärja, 2010, 2014a, Wärja, 2015a), is a psychotherapy approach based on receptive music therapy (Frohne-Hagemann, 2007; Grocke & Wigram, 2007) and grounded in methods and theoretical tenets of expressive arts therapy (EXA; Gerge, Wärja & Pedersen, 2017a, 2017b; Wärja, 2013a, 2013b, 2015b) and the Bonny Method of Guided Imagery and Music (GIM; Wärja, 1999, 2012b, 2017). Moreover, this work adheres to theories of affect regulation and attachment, embodiment, implicit processing, and psychodynamics (Halprin, 2003, Hill, 2015, Schore, 1994; Stern, 1985, 2005).

Psychotherapy is found to be effective for addressing psychological distress, trauma, and suffering (Wampold, 2010). Regardless of theoretical base, it involves an intersubjective relationship rooted in humanistic values (Wampold, 2010; Mårtensson Blom & Wrangsjö, 2013). Today, psychotherapy research is concerned with how different therapies have an effect, what kind of factors – seen across the range of

methods – have positive outcomes, and for what kind of problems (Philips & Holmqvist, 2008; Wampold, 2010, 2015). The so-called common factors have been researched thoroughly and address factors such as: alliance, empathy, expectations, cultural adaptations and therapist differences (Wampold, 2015). One finding is the extensive support for relational factors and alliance to predict a good outcome (Orlinsky & Howard, 1986; Philips & Holmqvist, 2008).

EXISTENTIAL PERSPECTIVES

> The existential position emphasizes a different kind of basic conflict (than the Freudian): neither a conflict with suppressed instinctual strivings nor with internalized significant adults, but instead a conflict that flows from the individual's confrontation with the given experience (Yalom, 1980, p. 8).

EXA is closely related to existential phenomenology and psychotherapy. Playing with imagination and engaging our human capacity to shape our world is central to this practice (Wärja, 2015b, 2017). Image and metaphors can hold both conscious and unconscious affect states and support the person in exploring the inner world (Bonde, 2000; Goldberg, 1992). When we create, we are forming the conditions of our existence (Meyer DeMott, 2017a). The phenomenon that arrives in the creative process is seen as containing multiple narratives; thus, it can hold many different stories and perspectives (Knill, Levine, & Levine, 2005; Levine, 2009; Levine & Levine, 1999, 2011, 2017; Wärja, 2013a, 2013b, 2015b, 2017; Gerge, Wärja, & Pedersen 2017a, 2017b). Existential psychotherapy is a relevant theoretical and methodological basis for working with persons with cancer (Keitel, Lipari, & Wertz, 2017). It concerns meaning-making, developing coherence, and making active life choices (Strang, 2007; Vos, 2015; Vos, Craig, & Cooper, 2015). The use of arts-based psychotherapy provides direct experiences involving all senses which allows for new perspectives to old narratives (Meyer DeMott, 2017; Wärja, 1999a, 1999b, 2015b). Thus, the arts provides ways to live from the source of innate resources and self-compassion.

The development of humanistic psychotherapies started in USA during the 1950s and 1960s and were rooted in existential philosophy (Stiwne, 2008). A concept of "four life worlds" is used which concerns 1) the physicality of our bodies, 2) our relationships and social networks, 3) our identity – who we are and want to become, 4) how we create meaning and coherence of our life. Throughout life we will encounter small and large crises. The way an individual responds and deals with the situation will determine her quality of life and growth. A crisis can bring about change and development or stagnation (Stiwne 2008, 2009; van Deurzen, 1998, 2003; Yalom, 1980). According to Yalom (1980), the given concerns of existence that are

inescapable are: freedom, existential isolation, meaninglessness, and death. Receiving a cancer diagnoses is a major crisis that brings in a life-death perspective (Strang, 2007; Vos, 2015). The arts can help the person with cancer address pain, agony, aging, the changed body, and the fear of dying (Archer et al., 2015; Hartley & Payne, 2008). We are in a constant process of being and becoming, and we are co-creators in regards to how our lives and identity develops (May, 1985, 1994).

ATTACHMENT AND AFFECT REGULATION THEORY

Findings from research on neurobiology, attachment and affect regulation have impacted today's theories and practice of psychotherapy (Cozolinio, 2002; Shore, 1994, 2003a, 2003b, 2012; Siegel, 1999). Evolutionary psychology speaks of how the interpretation of reality is based on information cognition, affect and communication. The ability to attach and create basic trust is the prerequisite for healthy growth and for reciprocal relationships (Bowlby, 1969,1994; Broberg, Granqvist, Ivarsson, & Risholm Motander, 2006; Wennerberg, 2010). Thus, the experience of safety is the basis for sound development. Attachment theories describe how human beings develop and addresses the individual's ability to use and turn to significant others for security, comfort and protection in times of distress or when there is a sense of danger (Stolorow, Atwood, & Brandchaft, 1994). Intersubjectivity grows from shared lived experience and from sharing attention, intention, and affectivity (Stern, 2004). These are regulating processes that are both innate and learned (Malloch & Trevarthen, 2010; Stern, 1985, 2004). The arts-based psychotherapies have been found to be helpful in addressing trauma and assisting in creating experiences of safety and stabilization (Gerge, 2017b, 2018; Körlin, 2005; Meyer DeMott, 2017a, 2017b; Meyer DeMott, Jakobsen, Wentzell-Larsen, & Heir, 2017; Wärja, Nyberg, Forss, & Bergmark, 2017a, 2017b). The arousal system and affects in a person fluctuates within what is referred to as a "window of tolerance" (Siegel, 1999). The ability to self-regulate is lost when the arousal level is such that the person has moved outside that space. The individual can no longer think clearly, and may become upset and impulse-driven (anxious/hyper aroused), or defensive or inhibited (depressed/hypo aroused). Underlying factors for affective fluctuations relate to early attachment experiences and trauma (Schore, 2003a, 2003b). Support for an increased adaptive affect-regulation capacity has been noted with arts-based therapy methods for persons with exposure to traumatic and existential crises (Bonde, 2005; Gerge, 2017b, 2018; Lindvang & Beck, 2017; Meyer DeMott, 2017a; 2017b, Meyer DeMott et al., 2017; Körlin, 2007-2008; Rudstam, 2010; Rudstam et al., 2017; Torres, 2015a, 2015b; Wärja et al., 2017a, 2017b). In this study, we have been attentive to participants' capacity for regulating affect related to cancer and its treatments, and the need for establishing safety (Wärja, 2012b, 2013, 2016b; Wärja, Sodell, & Gerge, 2016).

EXPRESSIVE ARTS THERAPY

In EXA concepts such as spontaneity, creativity, existence, holistic, "here and now," meaning-making, self-actualization, and human potential are emphasized (Knill, Nienhaus Barba & Fuchs, 1995; Knill, Levine & Levine, 2005; May, 1985, 1994; Yalom, 1980). It is an approach rooted in phenomenology, aesthetics and humanistic-existential psychotherapy (Kenny, 1989, 2006; Knill, Nienhaus Barba, 1995; Knill, Levine, & Levine, 2005; Langer, 1942; Levine, 1992; Levine & Levine, 1999, 2011, 2017; McNiff, 1981, 1992, 1998, 2004; Wärja, 1999, 2013a, 2015b, 2017). The work is multimodal combining all the arts defined by Meyer DeMott (2017a) as

> In EXA, a therapist uses various expressive modalities. EXA considers non-verbal forms of expression to be an essential part of the human being´s total communication, including expression through and from the body. EXA involves a combination of movement, visual arts, music, poetry, drama and film. The intermodal approach builds on the understanding that all expressions are body based and connected to the senses. (p. 154)

EXA acknowledges that expression and communication through the arts is an essential and distinctive attribute of being human. "It is where we shape hopes and dreams and stories of suffering" (Wärja, 2015b, p. 246). The arts provide nonverbal relational spaces for human connection and communication in which the aesthetic experience is central to the work. The work by psychoanalyst Donald Winnicott (1971) is central to EXA (Levine, 1995) and provides a theoretical foundation for the uses of play and imagination as a bridge (transitional space) between internal (implicit) and external (explicit) worlds, and for affect regulation (Beck & Lindvang, 2017; Gerge, 2015, Gerge, Ranch, & Rudstam, 2010). Curiosity, spontaneity, intentionality, and free play provide fuel for creative explorations in a therapeutic relationship (Knill, Nienhaus Barba, & Fuchs, 1995; Levine, 1992; Knill, Levine, & Levine, 2005; Levine & Levine, 1999, 2011, 2017; Wärja, 1999). Working with the arts in therapy introduces an expanded range of play (Meyer DeMott, 2017a, 2017b; Wärja, 1999; 2015b). Each mode of expression contributes unique qualities to work with emotional distress, trauma and existential questions. Wärja, (2015b) stated

> Some arts, such as music and dance are embedded in the temporal mode. They emerge, dissolve, pass and transform in each moment. Others, such as the visual arts and sculpting, concern themselves with shaping objects, things and devices in space that hold their stories and can be viewed, explored and revisited time after time (p. 246).

After a traumatic experience the flow between the inner world of imagination and the outer world of expression is often deadlocked. EXA offers ways to start "playing" and unlocking the blockage (Meyer DeMott et al., 2004/2017, 2017a,).

INTERMODAL APPROACH

Understanding the interconnectedness of the senses is a linchpin underlying the work in EXA, which informs how to proceed in a given situation (Wärja, 2013a, 2015b). In the 1970s, Paolo Knill introduced the concept of intermodality (Knill, Nienhaus Barba, & Fuchs, 1995). This refers to the understanding that every artistic discipline is primarily based on a specific bodily modality (e.g. music on audition, visual on sight), but all stems from the body's capacity for sensing. Gendlin (1978) suggested a procedure called "focusing" for the therapeutic process to turn inside the body and pay close attention to what the senses bring and what is emerging in a given moment. When the quite right image arrives that matches what the client experiences, Gendlin calls this a "felt sense." This way of working is generally applied in EXA. In each distinct art form, the modalities of the other arts lie dormant in the background as potential resources. For example, a visual image may hold a sense of rhythm, and maybe a tonal space, and a dramatic act. The client and therapist are engaged in dialogue where the artwork/experience is approached in a noninterpretive, nondirective, and nonreductive manner. In the course of therapy, the therapist pays attention to and follows the process closely, and when the timing seems right, the process moves on to using a different art form. The purpose can be to deepen an image or provide some reflective distance. How and when this so-called intermodal transfer takes place is a matter of context, therapeutic alliance, and issue at hand. In working with psychological change through the arts we need to work directly with feelings. "Verbal reflections and integration can take place only after having had a [feeling-based] experience in the *here and now*, as in intermodal expressive arts" (Wärja, 2015b p. 250).

AESTHETIC RESPONSE

Aesthetic response is another major concept of EXA that provides an artistic way to relate and respond to a client's work (Gerge, Wärja, & Pedersen, 2017a, 2017b: Ødegaard & Meyer DeMott, 2008). This approach has been applied by the psychotherapist assigned to this study. An aesthetic response refers to the response that the psychotherapist/witness gives to an experience in the therapeutic setting. It can be given in any art form, as song, a poem, a dance, a painting, or a story. It is also an avenue to engage in more unconscious and implicit processes involved in psychotherapy, as a mean to better understand oneself and the other person, and to explore the dynamic material that moves in the work. Additionally, the arts provide experiences of beauty, vitality and ineffability (Aigen, 1995; Dissanayake, 2003;

Stern 2010), and holds us in the present moment (Stern 2004). Knill stated, "The response has a bodily origin. When the response is profound and soul-stirring, we describe it as moving, touching or breathtaking" (Knill, Nienhaus Barba & Fuchs, 2005, p. 137). Aesthetic response uses arts to shape the intuitive knowing of a given experience. We agree with Polayani (Gerge, Wärja & Pedersen, 2017b) who affirmed that we can know more than "we can tell even if tacit knowledge is part of everyone's daily life, it is not easily shared, nor easily articulated" (p. 4). Aesthetic response can also be used by the therapist as a way to express and release affective material evoked after a psychotherapy session (Gerge, Wärja, & Pedersen, 2017a, 2017b; Ødegaard & Meyer DeMott, 2008). In some occasions when appropriate, the response might be shared with the client. Most often however, it serves as a helpful tool for process-oriented supervision (Wärja, 2013a, 2013b). Meyer DeMott (2007) states the potential of the aesthetic response giving room to the "third narrative" (p. 33) defined as the narrative emerging between the person telling the story and the one receiving it, thus strengthening intersubjectivity though the arts.

GUIDED IMAGERY AND MUSIC

The Bonny Method of Guided Imagery and Music (GIM) was developed in the 1970s and 80s by Helen Lindquist Bonny (1921-2010), an American music therapist researching the effects of music on imagination, and how music listening in expanded states of consciousness could be used to facilitate self-exploration and personal growth (Bonny, 1976, 1978, 1980, 2002; Bonny & Savary, 2005; Bruscia & Grocke, 2002). This original format is today referred to as The Bonny Method. Music is at the core of this individually-tailored therapeutic work and affords "the language of immediacy" (Bonny, 1987/2002, pp. 103–115). Relaxation techniques and music from pre-selected music programs are used. The individual session format lasts between 90–120 minutes and involves an initial verbal conversation, an induction and preparing to meet the music, the music listening experience, and a reflective processing of the experience related to the initial issue/concern. The therapist chooses classical music sequences to support and stimulate the internal experience. Inherent in the GIM music are the cycles of tension, release, and anticipation inflecting the flow of emotions (Langer, 1942, Meyer, 1956). Guided Imagery and Music (GIM) was defined by Bruscia (2002) as the umbrella term for all music therapy practices that include music and imaging in an altered state of consciousness. Thus, GIM refers to Helen Bonny´s specific form of therapy as well as a spectrum of approaches and variations involving intentional music listening and imagery for therapeutic purposes (Grocke & Moe, 2015). Today, GIM is one of the major music therapy traditions used world-wide, and has been well-researched (Bonde, 2005; Beck, Hansen, & Gold, 2015; Grocke, 2010; Hertrampf, 2017; Maack, 2012; McKinney & Grocke, 2016;

McKinney & Honig, 2017; Torres, 2015a; Wärja, Nyberg, Forss, & Bergmark, 2017a). It is used for psychotherapeutic purposes, healing, self-development, spiritual growth, and in supervision (Bruscia 2002; Mårtensson Blom, 2003-2004, 2011). The capacity of music to evoke emotional responses in clients working in GIM has been theorized as a major function contributing to improved affect regulation and positive psychological change (Goldberg, 1992; Beck & Lindvang, 2017; Maack, 2012; Mårtensson Blom, 2011, 2014). Music as an emotional change agent has been supported by findings in the study of music psychology (Gabrielsson, 2008, 2011; Juslin, 2015; Juslin & Sloboda, 2010; Meyer, 1956). The function of the music in all therapeutic approaches is to provide holding and support and be a container for the experience (Summer, 2009). The undertaking of selecting music for therapeutic use is described in Paper III (Wärja & Bonde, 2014). Music and Imagery (MI) is one adaptation that is used individually and with groups (GrpMI). Here the client listens to shorter classical and non-classical pieces of music with an intention, or a focus, for the listening. KMR is a MI adaptation based on psychodynamic and relational theories (Bruscia & Grocke, 2002; Bonde 2005; Mårtensson Blom, 2014; Trondalen, 2016).

PAPER II: KMR-BRIEF MUSIC JOURNEY WITH WOMEN RECOVERING FROM GYNECOLOGICAL CANCER

This paper[4] introduces the intervention used in this study in closer detail. KMR is a psychotherapy approach developed by the author based on the MI tradition as it was conceived and developed by Goldberg (1994, 2001, 2015) and Summer (2002, 2009, 2015), and in dialogue with Swedish GIM practitioners (Wärja, 2010, 2013a, 2015a, 2015b, 2017). Short and carefully selected pieces of nonclassical music are used in focused listening in a slightly altered state of consciousness to address psychological and existential concerns and distress in individual and group psychotherapy. The theoretical base and methodological approach of KMR is rooted in mainly three traditions: the Bonny Method (Bonny, 2002); expressive arts therapy (Knill, Levine, & Levine, 2005; McNiff, 1981, 1992, 1998, 2004) and existential and psychodynamic psychotherapy (van Deurzen, 2010; Mann, 1973; Stern, 2004; Strasser & Strasser, 1999; Yalom 1980; Figure 3-1). The structure of a KMR session is similar to the original Bonny Method format and consists of six steps: a) preliminary conversation agreeing on a relevant focus for the work, b) using relaxation techniques to expand altered states of consciousness, c) the brief music listening experience, d) a bridge

[4] Wärja, 2015a, paper provided in Appendix V.

back to ordinary consciousness, e) art experience, f) verbal processing, reflection, and finding the essence (Figure 3-2).

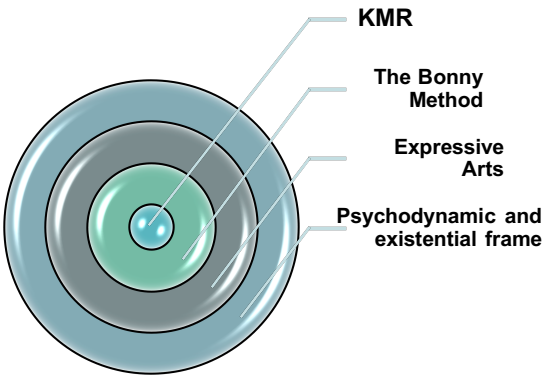


Figure 3-1. Theoretical contexts of KMR

This paper (Wärja, 2015a) describes the similarities and differences between the original Bonny Method and KMR. The central differences are the length of the session (90-120 min in GIM and 60 min in KMR), the kind of music that is used (GIM applies classical musical programs lasting about 20–40 minutes, and in KMR nonclassical music of 2-6 minutes is used, such as film or folk music), and in KMR there is no verbal conversation (guiding) while the music is playing, which is the way of working in the Bonny Method. One additional alteration for working in KMR compared with the Bonny Method is that KMR includes an emphasis on the spontaneous expressive shaping through visual arts (or other EXA methods) in response to the music and the internal imagery experience. A case vignette is provided from one of the group psychotherapy processes of this study where the focus was on working with body image and full-size drawings. Paintings of body image experiences are provided.

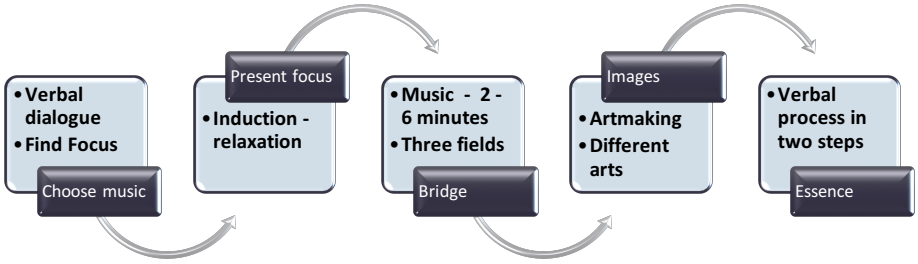


Figure 3-2. Structure of the KMR session (Wärja, 2013a, 2015a, 2015b, 2017)

PAPER III: MUSIC AS A CO-THERAPIST: A TAXONOMY

This article[5] addresses the process and grounds for selecting music for therapeutic purposes, a topic that has been a controversial in the music therapy literature, and provides rationale for facilitators using receptive music for therapeutic purposes. Findings in music in medicine research in particular suggest that client-selected music is most effective. However, in relationally held music therapy and music psychotherapy the use of therapist-selected music has been found to be useful and effective (Bruscia & Grocke, 2002). In this paper, the groundbreaking work of Helen Lindquist Bonny is presented (1978, 1980, 2002). Background information about the method and its development and structure is provided. In essence, coming from the humanistic, human potential, and transpersonal traditions, Bonny was an advocate of psychotherapeutic work using expanded states of consciousness supported by dynamic music and metaphorical imagery work. She trusted the inherent powers of the human mind to provide helpful images while listening to music and talking with an attentive guide (therapist). About 100 music programs have been developed, mostly from the Western classical tradition for specific therapeutic use based on musical dynamics, intensity profiles, and aesthetic qualities.

With the development of the Bonny Method within clinical settings came a need for tailored adaptations and modifications, for example, in working with persons with psychiatric illnesses, PTSD or other traumatic experiences, or severe existential crises. In this tradition music has been regarded as a "co-therapist;" however, no previous classification existed for how to choose music for working with music and imagery. Bonde (2005) and Wärja (2010) had formulated tentative structures for how to select music from a contingency of musical intensity and complexity. In this paper, a matrix of three major categories was proposed: 1. supportive music, 2. mixed supportive and challenging music, and 3. challenging music; each has three sub-categories. This classification system/taxonomy, is based on theoretical and methodological rationales of how to select music for individual clients and groups in therapeutic settings. The music applied in the KMR approach is from the three supportive categories in the taxonomy, which are based on the lighter moods of Hevner's Mood Wheel (1937; categories 3, 4, 5, and 6).

The clinical relevance of using this taxonomy is exemplified by a group music and imagery (GrpMI) vignette from a psychiatric setting and one cases study from the pilot phase of this study focused on sexual and existential distress where music and visual arts was implemented with gynecological cancer survivors.

[5] Wärja & Bonde, 2014, paper provided in Appendix W.

CHAPTER 4. AIMS AND RESEARCH QUESTIONS

AIMS

First, the overall aim of this study was to contribute to the amelioration of emotional and psychological health for gynecological cancer survivors, and to provide evidence-based knowledge in order to improve rehabilitation after oncology treatment. Second, the specific aim was to evaluate the effectiveness of two arts-based psychotherapy interventions on psychological outcomes for this population

RESEARCH QUESTIONS

What is the effect of one initial interview and twelve individual arts-based psychotherapy sessions of KMR–Brief Music Journeys, or one individual interview and eight arts-based group psychotherapy session of GrpMI/KMR on

- Body image?
- Sexual health?
- Fear of cancer recurrence?
- Existential distress?

PAPERS ADDRESSING RESEARCH QUESTIONS

These questions were addressed in several articles. Specific aims of included papers were:

I. To conduct a systematic literature review with the objective of providing current evidence for arts-based interventions on psychological outcomes in randomized trials for women with breast or gynecological cancer.

II. To describe the development of KMR-Brief Music Journeys, the arts-based therapy method implemented and evaluated in the study; to illustrate this treatment approach with a short vignette from one therapy group in the randomized trial; and discuss its relevance for the study population.

III. To provide a matrix/structure for choosing music based on theoretical concepts and clinical experiences in order to facilitate the selection process of recorded music for therapeutic contexts and in working with psychological change through music and imagery.

IV. To describe the preparatory qualitative phase of developing a complex intervention; and provide results of clinical characteristics and psychological distress of gynecological cancer survivors reported at baseline of the trial, before randomization took place.

V. To present major findings related to the four research questions (body image, sexual health, fear of cancer recurrence, existential distress) evaluated in a randomized trial of two arts-based psychotherapy approaches for women recovering from gynecological cancer.

VI. To present results of analyzes of 28 participants paintings of human figure (body image) collected at three timepoints in the trial (baseline, posttest, FU) using a new assessment tool (SATPA); and to report outcome measures for depression, anxiety, and QoL of the whole study sample as covariates.

CHAPTER 5. METHODS AND MATERIALS

This chapter is divided in two main sections: a) research methods and b) clinical methods. The original study design was a multi-strategy, explanatory sequential study, aimed at collecting and triangulating qualitative and quantitative data (Wärja, 2013c). However, due to organizational circumstances at Karolinska University Hospital, it was not possible to keep the planned design within the time frame. A summary of the original plan and changes is found in Appendix C.

RESEARCH METHODS

The methodology of this study was based in the epidemiological tradition (Rothman, 2002), further developed in the hierarchical step model designed to control for causation bias (Steineck, Hunt, & Adolfsson, 2002), as discussed in Chapter 7. Our method is in line with a complex intervention study recommended by the Medical Research Council (2008). This research approach refers to involving many interacting components and identifying a theoretical frame of reference for what creates change in the intervention under investigation. In short, the process starts with a phase of thorough field research to build an evidence base and select relevant measuring instruments. This is followed by a pilot/feasibility study leading up to a randomized trial. The results are assessed for its use in clinical settings (preferably through a RCT; Craig et al., 2008; Medical Research Council, 2008).

THEORETICAL FRAME AND RESEARCH CONTEXT

We used an interdisciplinary framework grounded in theories of medical oncology, psychosocial oncology, psychological vulnerabilities related to cancer, coping abilities (Bergmark & Dunberger, 2013; Hellbom & Thomé, 2013), existential crisis, psychodynamics, affect regulation (Schore, 2003a, 2003b, 2003c, 2014; Stern, 2005; van Deurzen, 1998, 2003), and arts-therapies (Bonny, 1980; 2002; Knill, Nienhaus Barba, & Fuchs 1995; Knill, Levine, & Levine 2005, Levine & Levine, 2011, 2017; McNiff, 1981, 1992, 1998, 2004; Wärja, 1999, 2010, 2015a, 2015b, 2017; Gerge, Wärja, & Pedersen, 2017a, 2017b). Our initial hypotheses were broad and rooted in the literature and clinical knowledge showing that gynecological cancer treatments can have a negative effect on mood and QoL in general, and more specifically on experiences of the overall functions of the body, body image, sexual function, and sexual relations (Bergmark et al. 2002, Bergmark & Dunberger, 2013; Stead, Fallowfield, & Brown, 2007). In the spring of 2011, I was invited to be an associate member of Department of Oncology and Pathology and the division of Clinical Cancer Epidemiology (KCE) at Karolinska Institute in Stockholm. This unit was

developed by prof. Gunnar Steineck at Radiumhemmet at Karolinska University Hospital in 1992. This group has implemented epidemiological studies in oncology and survivorship in Sweden and Iceland and a number of studies on suicide involving related family members (Omerov, 2014). Early on, Prof. Steineck initiated a research method based on interviews to identify the prevalence of psychological and sociological influences of symptoms on survivors (Rådestad et al., 1999). Findings were then used to construct a study-specific questionnaire for the main phase of quantitative data collection (Omerov et al., 2013; Steineck et al., 2002). This research group has produced a substantial body of around 100 publications based on this approach.

PREPARATORY PHASE

The inductive preparatory phase lasted about two years an started with an interview study to gain a comprehensive understanding of the study population aimed at constructing questionnaires and developing treatment protocols. Furthermore, we selected supplemental instruments, chose methods for the qualitative data collection, designed a procedure for documenting essential information about the treatment sessions, and selected music and arts material (Figure 5-1).

STUDY POPULATION

We identified the study population as women who had completed oncological treatment for gynecological cancer at least 3 months before inclusion, and at most 24 months after treatment had ended. Based on clinical observations, we knew that the return to everyday life was a potentially vulnerable time for survivors. We also knew this transition may elicit psychological distress and a new or prolonged crisis reaction. Moreover, within this period late effects and complications after treatment may surface that would affect psychological function and well-being (Bergmark & Dunberger, 2013).

INTERVIEW STUDY

The interview study included 23 participants and consisted of face-to-face, semi-structured, in-depth interviews conducted by me and audio-recorded with permission, following the guidelines of Kvale (2009). The informants were told about the purpose beforehand. Nine women were asked about experiences after cancer and strategies for coping; 14 health care practitioners (HCP) discussed professional perspectives of working with this population. The interviews had no time limitation and lasted generally between 45–90 minutes. Themes were repeated that led to saturation before all scheduled interviews were completed; especially with HCP. We finished all

appointments as they provided networking opportunities in the construction of the randomized trial.

Interviews with gynecological cancer survivors

Interviews with women were conducted in a comfortable psychotherapy office at the institute of expressive arts in Stockholm. Interviewees had different gynecological cancer diagnoses and ages and were at varied time post-treatment: five women had just ended oncological care and had expressed a need for psychosocial support; three members of GCF (a patient association) had completed medical care between five and ten years earlier; and one woman in one of my supervision groups had undergone treatment for cervical cancer 25 years earlier.

Each interview started with space for questions, then I simply said: "Please talk freely about your experiences of being treated for cancer and how your life is now." When needed, I made deepening questions or affirming comments, and requested clarifying information, such as: "how was that for you;" "that sounds like a difficult experience;" "considering the situation it seems that you handled this as well as you could;" and "can you say more about that."

Interviews with health care practitioners in gynecological oncology

HCP informants had worked between 5–25 years in oncology. Most interviews were held at Karolinska University Hospital, and some at the expressive arts institute. The following professionals were interviewed: an oncologist specializing in gynecological oncology, an oncology nurse specializing in gastro-intestinal late effects, nurses specializing in sexual function after cancer, a nurse working with brachytherapy, a psychiatrist, a psychologist, two psychotherapists, a family therapist, a social worker, a physical therapist, two expressive arts therapists, a music therapist, and a dance therapist. The main focus of the interview was the oncology care and rehabilitation such as: oncological treatments, symptoms, late effects, QoL, rehabilitation needs, and psychosocial care. In addition, I inquired about personal reflections on working with this group of women.

Summarized content of interviews

The stories told by nine survivors were unique, subjective and personal accounts. Most women spoke in an open, direct, and poignant manner. They talked about being faced with overwhelming feelings and challenges such as: fearing death, thinking of recurrence and loosing loved ones, feeling extremely tired, mourning the loss of a good sexual life, groping for a new intimacy with partners, becoming isolated and alone, and not being able to trust one's own body. The interviews immersed me in an emotional current of profound distress, pain, and suffering.

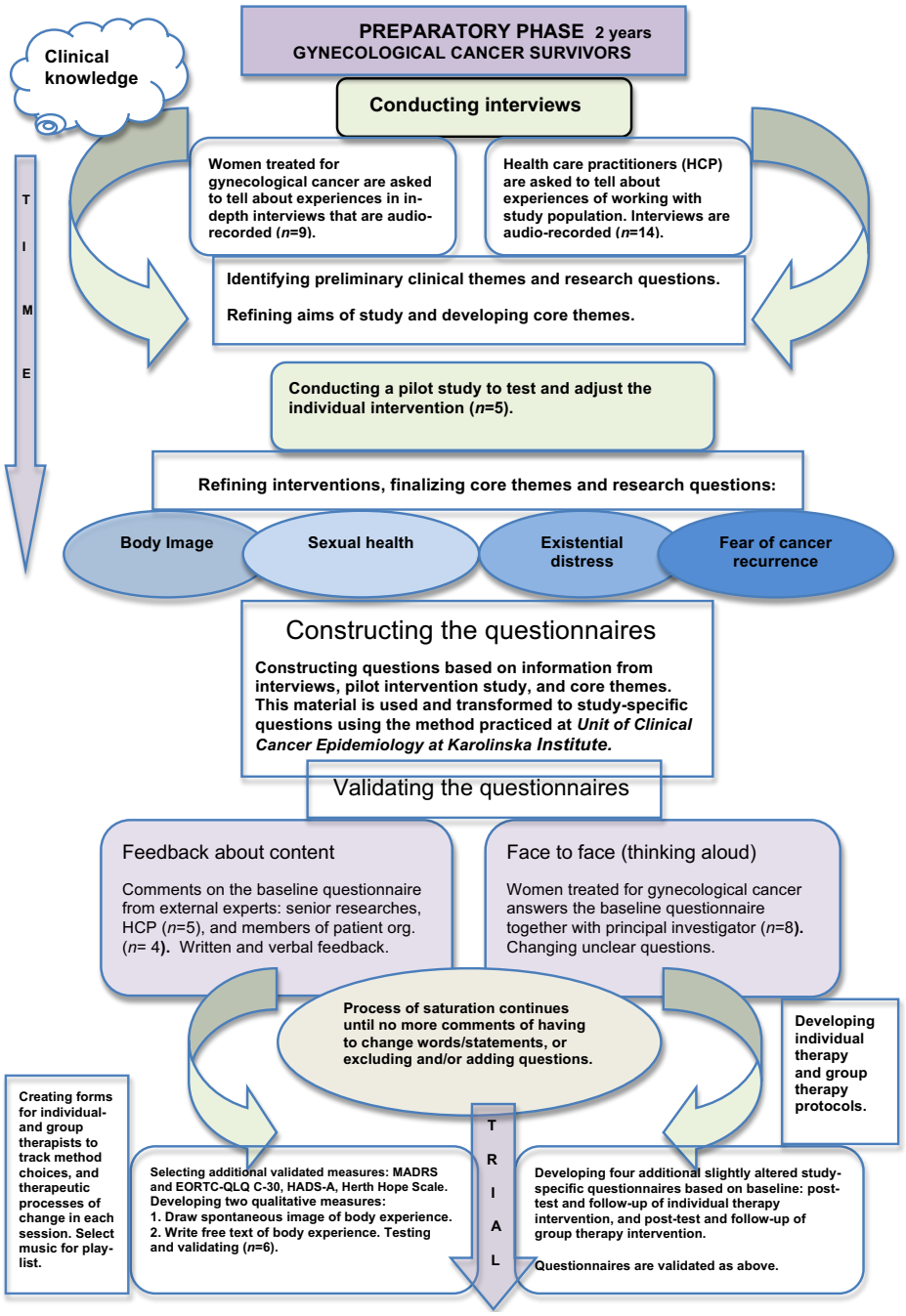


Figure 5-1. Overview of preparatory qualitative phase

Nevertheless, they also conveyed a compelling and humbling will to live, to hold on to hope, invite pleasure, and not to forget humor as a rescuer in the midst of despair. Interviews with 14 HCP were highly informative and painted a rich picture of interdisciplinary specialists providing best possible care for the individual women. They spoke of the specifics related to their specialty, how they coped with taxing demands, and what made the work worthwhile. The need for psychosocial care after oncology treatment was stressed. All HCP stated that work was profoundly meaningful, and that the challenges were mainly organizational. A common thread was that working at the existential edge made this occupation exceptional, and contrary to what one might believe, a very alive place to be.

Analyzing data from interviews

The interview material was analyzed by using a simplified version of thematic analysis (Braun & Clarke, 2006). Data was sorted in four major steps: 1. repeated listening; 2. collecting thematic statements; 3. organizing in thematic clusters; and 4. pulling together larger core themes. Repeated listening was used in two main ways: "open listening" when taking a walk or relaxing in a chair, and "focused listening" while taking detailed notes. I replayed parts of the recording for clarity and comprehension. Statements that stood out and that provided fundamental information were discussed on an on-going basis with Dr. Bergmark. Next, these statements were organized into larger thematic clusters. In the last step, the clusters were moved together into themes holding core information for tentative research questions and for the tailored questionnaires (Figure 5-2). Illustrations of statements from survivors and HCP and thematic statements are found in Appendix D.

Core themes after interview study

The four core themes related to psychological distress of gynecological cancer survivors that were identified from the interviews were: body image, sexual health, depression and anxiety, and existential distress.

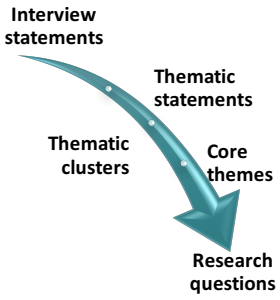


Figure 5-2. Data sorting and analysis of interviews

PILOT STUDY

The tentative protocol for the individual intervention was evaluated in a pilot study involving five women spanning over 18 months (Wärja, 2011, 2012a, 2012b). The setting was the expressive arts institute in comfortable rooms with music equipment and painting material. The participants were recruited from the outpatient gynecological oncology department at Karolinska University Hospital by means of purposive sampling on the basis of a) having expressed emotional distress to their contact nurse or medical doctor; b) diagnosis; c) age; and d) current life situation. Level of psychological distress, motivation for psychotherapy, and willingness to work with arts-based methods were assessed by me in an interview. I worked with four participants, and a colleague with one other participant (clinical characteristics in Appendix E). Qualitative measures of body image drawing and written text of body experience were collected three times (baseline, posttest, and follow-up (FU). The first participant received 16 sessions spread out over six months. The four subsequent treatment cycles contained 12 sessions over three to four months. The change of duration was based on practical and financial reasons, as well as recommendations by Mann (1973). An interview followed termination of treatment that focused on benefits, and any suggestions for the protocol. This was followed-up after six to eight months. We made some adjustments and decided to implement 13 sessions in the individual intervention. The results of the pilot study will not be described here, though one case vignette, "Anna," is presented in paper III (Wärja & Bonde, 2014, Appendix W; selected paintings are found in the prelude, and on p 92 of this thesis).

Adjusting core themes after pilot study

One major consequence of the pilot study was changing the core theme "depression and anxiety" to "fear of cancer recurrence." This theme emerged for all five participants (Wärja, 2012a, 2012b). We also found that this theme was associated with existential threats and fears of dying. This concept was supported in the literature (Horlick-Jones, 2011; Maheu, Lebel, Tomei, Singh, & Esplen, 2015; Maheu et al., 2016).

FINAL CORE THEMES OF STUDY

In summary, the four core themes that we extracted from interviews and the pilot study (Figure 5-3) were used for developing research questions, questionnaires, and treatment protocols. These themes are psychodynamic, existential, overlapping, evolving, and interconnecting. Moreover, they are in line with the literature and previous findings of prevalent psychological distress related to this population.

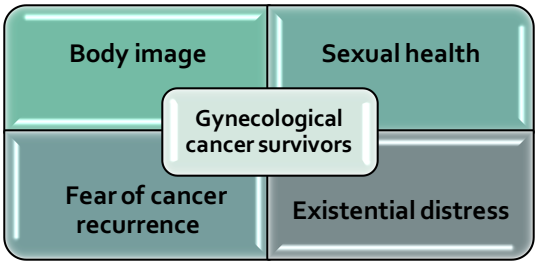


Figure 5-3. Core themes extracted from interviews and pilot study

Body image

Distress related to body image were highly prevalent in the interviews and the pilot study. The construct of body image is complex with multi-layered meanings within psycho-oncology (White, 2000). Body image has been used for the outer picture, its aesthetic value and appearance, and sexual attractiveness (Fingeret, Teo, & Epner, 2014). Body image also entails physical sensations, movements, emotional and sensory experiences, and more unconscious bodily states (Lundgren & Bolund, 2007). Related terms expanding on this phenomenon are: body self as connected to cancer-induced premature aging (Sakson-Obada & Wycisk, 2015); body experience in terms of living with a cancer diagnosis (Lundgren & Bolund, 2007); and body-awareness of how the body is used and perceived, related to the past and present (Roxendal, 1985). In our work, we used the psychoanalytically oriented definition of body image formulated by Schilder (1935/1978). "Body image is the picture we form in our mind that is to say the way in which the body appears to ourselves" (Schilder, 1935/1978, p. 11). This concept is applied in the context of more recent theories of neuroscience (Cozolino, 2002/2010; Damasio 1994, 1999, 2010; Siegel 2003, 2007), and affect regulation in psychotherapy in which the body is viewed as non-conscious, as well as the deep unconscious (Schore, 2014). Furthermore, body image refers to a dynamic relation to the self and involves the experience and evaluation of bodily appearance and bodily sensations and how it is serving the self. It entails an evaluation of one´s physical health, motility, energy and strength. This concept involves the notion of self-states; hence, body image is related to various self-states such as self-image, self-esteem, and self-confidence.

Sexual health

Concern about sexual health is integral to the lives of women recovering from gynecological cancer (Stead, Fallowfield, & Brown, 2007), which was confirmed in the qualitative phase. Gynecological cancer has obvious major impact in sexual function, since the cancer involves sexual and reproductive organs, producing direct physical and existential effects. The nature of oncology treatments requires stepping

over bodily boundaries of integrity and privacy. The woman's most private sexual parts are invaded by treatment procedures and examinations. Shame and guilt may arrive as an aftermath of diagnosis and treatments (Ashing-Giwa et al., 2004; Bergmark, 2007; Bergmark, Åvall-Lundqvist, Dickman, Henningsohn, & Steineck, 1999; Solbræke & Lorem, 2016). For many women feelings of being sexually attractive, or having sexual desire, is lost after cancer treatments (Ashing-Giwa et al., 2004; Carr, 2013). Experiencing pain and discomfort during sex adds to the burden of sexual dysfunction. Sexual health is a state of physical, mental and social well-being in relation to sexuality. It relates to body image and to sexual bodily functions. Moreover, it involves intimacy, having a sexual relation to self and/or partner, an ability to be aroused, and have sexual pleasure (and sexual release). We agree with the definition of sexual heath by WHO (2006) as:

> a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. (Chapter 3, p 6.)

Fear of cancer recurrence

Fear of cancer recurrence is connected to both existential and psychological distress and to overall QoL, and is one of the most alarming states (Simrad et al., 2013). Frequent themes are worrying and being afraid of cancer relapse, fears of leaving loved ones behind, fears of suffering, and ultimately a fear of death. Cancer is an attack on the body, leading a person to become highly aware of bodily states and sensations. Fears have both a realistic side, and more ruminating and even "hypochondriac" features where the individual is preoccupied with bodily signs and symptoms. We suggested that a woman with low self-esteem who has difficulty trusting her body, others, and oncological treatments, may suffer greater distress, lowered QoL, and possibly cancer-induced trauma (Holt, Jensen, Gilså Hansen, Elklit & Morgensen, 2015; Tveit Sekse, Raaheim, Blaaka, & Gjenedahl, 2011).

Existential distress

Existential distress has been associated with death and dying and with palliative phases of cancer treatment (Strang, 2007). Nevertheless, experiences of existential concerns and distress were prevalent for participants in the qualitative phase of the study despite the good prognosis of survivorship in our population. Existential distress refers to suffering that is not relieved by treatment of physiological symptoms. Moreover, it can involve intense levels of worry, generalized anxiety, and

fears that something unknown and terrifying might occur. These feelings are often related to an assumption of having lost control, and that life has little or no meaning. This distress may also entail a spiritual/religious and philosophical crisis (Leung & Esplen, 2008; Strang, 2007). Thus, the person has problems adapting to the conditions of life and of being and of existence (Vos, 2015). The ability to cope with individual conditions and the existential givens are lowered, such as coping with crisis during the life cycle (Strang, 2007). For our study, we assumed this might entail having feelings of mistrust of nature, of one's body, and of other people; and also possibly experiences of cultural differences and alienation.

QUANTITATIVE INSTRUMENTS

The primary instrument was a study-specific questionnaire in five slightly altered versions, developed in line with the KCE method (Steineck, Hunt, & Adolfsson, 2002). In addition, we selected five supplementary validated measurements.

STUDY-SPECIFIC QUESTIONNAIRES

We started by constructing a baseline questionnaire around symptoms and QoL based on interviews, the pilot study, clinical experiences, and relevant literature. Next, we developed four additional questionnaires based on baseline responses: one posttest and one FU questionnaire for each intervention (see Figure 5-3 for an overview of the questionnaire preparation and development).

Baseline: GYNONC-QoL-CSBAE

The study-specific instrument is called Gynecological Oncology-Quality-of-Life-Coping, Sexuality, Body and Art Experiences (GYNONC-QoL-CSBAE; Appendix F provides a summary of sample questions in English related to the research inquiries). We selected a seven-point visual digital scale and tic-boxes, and provided ample space for qualitative comments. Significant validated questions from earlier KCE questionnaires were included, and new were added to reflect the four research questions. One new section focused on cultural experiences and use of the arts.

Specific questions were constructed to address psychological self states related to body image (Kohut, 1997; Stern, 1985; section D), that also pertained to all research questions. We asked about self-image, self-esteem, and self-confidence. The background rationale was the developmental theoretical premise of the emerging self acquiring competencies in self domains, as suggested by Stern (1985): self-agency (sense that one's actions stem from oneself); self-coherence (sense of being whole

and having bodily boundaries); self-affectivity (sense that one's own feelings are connected with other self-states); and finally, the self-narrative (sense of having a time perspective of now, past and future). The self as an appropriated whole is constituted through the crucial process of attachment and regulating relationships with caregivers within the first two years of life (Hill, 2015; Schore, 2009, 2014). Later in adult life, disruption by a major crisis such as cancer can activate fragilities of earlier developmental self domains related to failures in developed trust and attachment.

We included the anxiety items on the Hospital Anxiety and Depression Scale (HADS-A; Zigmond & Snaith, 1983). HADS is a short and widely used measurement to assess psychological distress in cancer patients that is available in many languages. It is found to be a reliable and valid measure of anxiety and depression. Each subscale has 7 items using a four point Likert scale from "not at all" to "very much". Score range from 0–42 and included designations of "Normal" (0– 7); "Mild" (8– 10); "Moderate" (11–14), and "Severe" (15– 21). The clinically relevant cut-off for diagnosis is 7 for each sub-scale (Appendix F).

Moreover, the Herth Hope Index (Herth, 1992) was included (Appendix J). It has been found to be a reliable measure of hope with a high internal consistency (Haugan, Utvaer, & Moksnes, 2013). Also, 10 items from a Swedish scale for body image called Kroppsmedvetande skala (KMS; Body consciousness scale, my translation; Anders Schiöler, 1998) were added (in Appendix F, part D). These questions were related to specific bodily states such as shame and alienation. KMS was developed to assess body awareness, body consciousness, and body image in psychotherapy. It was constructed and validated by means of factor analysis. Permission for use was given by the developer. The final version of the baseline questionnaire has 261 items and is organized into eight sections (an overview of content is provided in Table 5-1).

Posttest and FU: GYNONC-QoL-CSBAE

Questions were removed that were repetitive and not relevant such as oncological treatment, previous history, and interests and experiences in the arts. In the last section of the instrument (H) we asked the participant to evaluate and assess how helpful the intervention had been, which subsequently was followed up seven months later. The main differences between the individual and group therapy forms were questions related to the treatments. In the questionnaires for the individual psychotherapy we asked specific questions about relationship to the psychotherapist and alliance, and in the ones for group therapy we focused more on the experiences of working together in a group setting, and included detailed questions based on the therapeutic factors developed by Yalom (1975; Appendix G). Posttest and FU questionnaires were sent out by postal mail two weeks before the scheduled posttest and FU interviews.

Section	Content baseline questionnaire GYNONC-QoL-CSBAE	Items
A General questions, earlier care and medical history	Demographics, co-morbidity, earlier psychotherapy or psychological help, experiences of crisis/ trauma, use of medications, use of alcohol and/or drugs.	37
B Recent treatments, and self-care	Current cancer diagnosis and treatments, experiences of all steps in cancer trajectory, psycho-social care during treatment phase, self-care, exercise, strategies for coping.	41
C Quality of life and existential concerns	QoL, social functioning, family, spiritual practice, existential concerns, worry, anxiety, (HADS-A), and depression, various other affect states as related to cancer, shame, guilt, fear of cancer recurrence, intrusive thoughts, thinking of death and dying, Herth Hope Index.	54
D Body experiences and self-states	Body image, self-image, self-esteem, self-confidence, body experiences before and after cancer, 10 KMS questions of specific bodily states, side effects and late effects of cancer treatments.	47
E Sexuality	Sexuality before and after cancer, sexual activity, arousal and pleasure, sexual dysfunction, intimate relationships.	27
F Sexual assault	Sexual abuse/incest/assault.	10
G Culture and leisure	Cultural partaking's, leisure activities, arts activities, general strategies for coping with cancer experiences.	36
H The questionnaire	Experiences of filling out the questionnaire.	9
In total		261

Table 5-1. Content of study-specific baseline questionnaire, GYNONC-QoL-CSBAE

Validating the questionnaires

The baseline questionnaire was tested for validity continuously in the developing phase and feedback was integrated into the form along the way. In total, 17 survivors participated in the validation process. The five pilot study participants filled out the questionnaires at three time points. Eight women participated in a process called "face to face" (thinking aloud), which meant that I sat together with a woman as she filled out the questionnaire and made comments on details and relevance as she went along. Four members of the patient organization (GCF) filled out the form and gave written comments. The final step was to invite five HCP to assess the questionnaire and provide comments and reflections. The additional four questionnaires (posttest and FU) were validated in a similar procedure.

SUPPLEMENTAL MEASUREMENTS

In addition to HADS-A and Herth Hope Index, we selected two additional instruments: EORTC-QLQ-C30 and MADRS. These were chosen for their wide use in cancer research and in depression.

EORTC QLQ-C30

The European Organization for Research and Treatment for Cancer Quality of Life Questionnaire (EORTC QLQ-C30, 2001) is a QoL measure for people with cancer (Appendix H). The EORTC QLQ-C30 is one of the most commonly used measures in clinical trials across Europe; it is also widely used across North America and the rest of the world (Fayers et al., 2001). The questionnaire is easy to complete and applicable across a cultural spectrum. It consists of 30 multidimensional cancer-specific items that underpin five multi-item functional subscales: physical, role, emotional, social and cognitive functioning; three multi-item symptom scales: fatigue, pain and emesis; a global health/quality of life subscale; five single items to assess symptoms: dyspnea, loss of appetite, insomnia, constipation, diarrhea; and one single item assessing the financial impact of the disease.

MADRS

The Montgomery-Åsberg Depression Rating Scale (MADRS; 1979) consists of 9 items and the total score can vary from 0–60 (Appendix I). MADRS has high joint reliability, and has been widely used. It has been demonstrated to have predictive validity for major depression, and is sensitive for change (Rush, First, & Blacker, 2008). The cutoffs are “not depressed” (0–11) and “mild depression” (12–20). A score of less than 21 that persists for a minimum of two weeks indicates “major depression,” and a score of greater than 40 indicates a need for further assessment for hospitalization.

QUALITATIVE MEASUREMENTS

For gathering qualitative data, we used three qualitative measurements for the participants and three forms for the therapists briefly introduced below.

EXPERIENCES OF THE BODY AFTER CANCER

From the pilot study, clinical experience, and the literature, we knew that cancer and oncology treatments affect body image causing major psychological distress. Consequently, we decided to focus on experiences of the body and the changed body after cancer in the qualitative data that were collected by me at three time points: baseline (at inclusion), posttest after intervention ended, and at seven months FU (at FU body paintings were only collected for participants in individual therapy).

Painting and writing a text about the body

The woman was invited to sit at a table prepared for painting and provided with drawing paper (size 40 x 58 cm) and various art materials: liquid paint, watercolor, water, oil pastels, charcoal, sponges, and different size brushes. The first task was to paint a picture freely of the experience of your body after illness and cancer treatment. Afterwards I simply asked: is there anything you would like to tell me about this drawing? I took notes and typed into the summary text of the screening interview. Next, the woman was given a form inviting her to write down thoughts about her body after cancer (Appendix O).

QUALITATIVE FORMS FOR THE THERAPISTS

Three additional study-specific forms were developed to be used in documentation by the therapists. They contained tic-boxes, seven-point digital scales, specific questions to be answered in writing, and spaces for free comments.

Initial interview - alliance

This form comes in two versions (individual and group) and is a summary of the initial meeting, experience of alliance, emotional contact and any out-standing information.

Tree drawing form

This was used to describe what emerged after the tree drawing in the initial session and had only two items with space for writing: the client's own world after the tree drawing and the therapist's reflections.

Therapist's experiences

One form was filled out after the interview, and another form was used after each session for documentation (in two versions, individual and group). The individual form consisted of 16 items and the group of 13 items. Both forms addressed the experiences and asked specific information. The purpose was to check treatment

fidelity, summarize the content, track the issues that were addressed, and document the experience of alliance and verbal exchange. Three items were related to the arts: title of selected music, how the music worked in the session, and how helpful the visual arts had been. The final item was to give a spontaneous title for the session (an aesthetic response). Therapists were asked to enter information immediately after the session had ended. The co-therapists conducting the group therapy were instructed to fill out the form separately before talking to each other.

Table 5–2 gives an overview of all the measurements and forms used in the trial.

Quantitative measures	Qualitative measures	Forms filled out by therapists
GYNONC-QoL-CSBAE ▪ 261 items ▪ In five versions: baseline; posttest indiv. and group; ▪ FU posttest indiv. and group ▪ Includes: HADS-A, Herth Hope, and 10 items from KMS EORTC-QOL-C30 MADRS	Spaces to write comments in GYNONC-QoL-CSBAE Paint experience of body Write about experience of body Draw a tree (first and last session)	Initial interview session (two versions: individual and group) Story-of-cancer Paint-yourself-as-a tree Individual therapists' reflections after each session (1-12) Group therapist's reflections after each session (1-8)

Table 5-2. Overview of measurements and forms used during the trial

MAIN STUDY – RANDOMIZED TRIAL

The main study was a randomized trial with two parallel treatment arms (Robson, 2002; trial flowchart is found in Appendix C). Participants were recruited from the outpatient gynecological oncology clinic at Karolinska University Hospital. All women in the larger Stockholm area who were in need of primary oncological treatment or adjuvant oncological treatment after surgery were referred to this clinic.

Inclusion and exclusion criteria

In line with epidemiological practice, we aimed to identify and provide information of the study to an unselected group of gynecological cancer survivors scheduled to attend medical follow-up. Screening was conducted in two steps. Potential participants were first assessed by oncology specialist Dr. Bergmark using weekly appointment lists and medical charts. A second assessment was performed by me in an individual interview.

Eligible for inclusion were women who:

- were between 18–75 years;
- had completed oncological treatment for gynecological cancer between 3–24 months prior to inclusion;
- were evaluated to have a good medical prognosis within the study period;
- were assessed to have psychological distress related to cancer;
- were motivated for psychotherapy in any of the two interventions; or
- were available during the study-time.

Women were excluded who

- had a psychiatric diagnosis/illness,
- had substance abuse,
- had significant co-morbidity, or
- participated in other psychosocial care/counseling/psychotherapy

SCREENING INTERVIEW

Eligible participants were approached by nursing staff in the waiting room area at the time of appointment and given a short written text about the study (Appendix K). When interested, a semi-structured in-depth interview was scheduled in the expressive arts office outside the hospital to evaluate level of psychological distress related to cancer, current life situation, motivation for psychotherapy, and readiness to work with arts-based methods. If the person was not interested or when the nurse was not able to ask, this information was noted down in a form or on the appointment lists (Appendix M). All screening interviews were conducted by me and had no time limitations. Written notes were taken and transcribed. At this time, the woman was given a more extended text about participating in the study (Appendix L). I briefly described the treatments, gave space for questions, and then inquired about whether the person would consent to be randomized to either of the two interventions. (When that was not the case the person was excluded). After inclusion and signing of informed consent (Appendix N), the woman participated in two qualitative tests and filled out two forms (EORTC-QLQ-30, and MADRS). She was then given the

baseline questionnaire to fill out at home together with a self-addressed stamped envelope. I went over the content briefly.

POWER CALCULATION AND SAMPLE SIZE

The sample size for the intervention was determined through calculating statistical power based on documentation of the related approach of GIM that had revealed medium to large effect sizes in previous research (Bonde, 2005). The correlation among repeated administrations of the primary variables was unknown in this population. Thus, we decided to use a medium effect size as the effect of KMR had not been evaluated before (Appendix P). We aimed for a sample of 60 participants where 20 would be randomized to individual therapy and 40 to group therapy. We estimated a larger attrition for the group therapy arm based on clinical experience. To allow for dropouts, we included a larger sample than called for in terms of power calculations. In addition, the calculation is estimated to be $r=.5$ that allows for the possibility that the correlation among repeated measures might be higher than estimated; see flowchart of study design and sample size (Appendix C).

RANDOMIZATION AND ALLOCATION

Randomization was performed in permuted blocks in order to achieve balance between groups (Baily, 2008). We aimed to include five groups of 12 participants each. They were named group: I; II; III; IV; and V. Four participants in each randomization group would receive individual therapy, and eight would be assigned to group therapy. When one group of participants had been included, randomization and allocation was conducted by the statistician by means of a computer-generated program. Results of randomization were communicated by the statistician to Dr. Bergmark in a concealed document, and then given to me. A second randomization procedure was performed in terms of assigning therapist to participants allocated to individual therapy. The therapist received the name and phone number of the woman. In the next step, I informed the participants of the result; for individual therapy clients, I provided name of therapist and notified them to expect a call to set up an appointment; for the participants assigned to group therapy, I gave the exact time for the start of treatment and notified them to first expect a call for an individual meeting.

STATISTICAL METHODS OF ANALYSIS

The outcome results of statistical analysis are present as frequencies (*n*), proportions (%), mean, standard deviation (SD), median, odds ratio (OR/POR), effect sizes (Cohen's *d*; Cohen, 1988), and significances (p-value, alpha was set to 0.05) under each major research theme. We performed a per-protocol-analysis, which is different from an intention-to-treat analysis in the following way(s): instead of using the last score obtained from persons who dropped out, outcome data gathered from the

questionnaires of those participants who completed the measurements was used (Sedgwick, 2011).

We calculated differences in ordered categorical outcomes before to after treatment, as well as between the two treatment groups, using proportional odds ratios (POR). This is a measure of the overall tendency of scoring higher or lower on the outcome scale, e.g. post-intervention compared to pre-intervention, and it allowed us to use the full range of the response options which is more powerful than methods which rely on simplified outcomes. POR were estimated with mixed logistic regression, using interactions between time and treatment group and a random individual effect to account for the repeated measurements in the same individual. We also present odds ratios (OR) using dichotomized outcomes, i.e. proportion reporting above/below a certain cutoff, which were estimated using corresponding mixed logistic regression. We used Cohen's *d* to quantify effect sizes for the treatment interventions, which is a summary measure of the mean difference between the scores at the two time-points. Following Cohen´s (1988) recommendations, the pooled standard deviation of both groups at baseline was calculated and used when the standard deviations between conditions differed at baseline. Results were interpreted as small effect (d = 0.20), medium effect (d = 0.50), and large effect (d = 0.80; Cohen, 1988). For summed scores, we similarly assessed differences in mean of the repeated measurements using mixed linear regression. The significance level was set to 0.05.

We present all outcome measures with 95% confidence intervals (CI). Calculations were performed using SAS software (version 9.3, SAS Institute Inc., Cary, NC, USA).

QUANTITATIVE AND QUALITATIVE DATA COLLECTION

Multiple sources of data were collected during four years of the main study phase consisting of: a) quantitative and b) qualitative instruments, c) interviews, d) various forms filled out by therapists, and e) artwork produced during interventions. Quantitative and qualitative measurements were gathered at three time points: baseline around the time of inclusion, posttest after the intervention, and FU seven months after posttests (see Table 5-2 for kinds of collected measurements, and Table 5-3 for time points in trial).

In-depth interviews with all participants were conducted by me at baseline and posttest, and with the individual participants at FU. The interviews were focused on experiences of therapy related to alleviating psychological distress (posttest), and lasting effects (at FU). Notes were taken during all interviews and transcribed. Baseline forms were given out at screening and submitted through postal services. Posttest questionnaires were sent out after completion of therapy and delivered at the posttest interview appointment for all participants, and were again brought at FU

interview for participants in individual therapy and submitted by post for group therapy participants. In addition, two qualitative measures (paintings and written texts of body) were collected for all participants at posttest interview. Paintings and texts were collected at FU for participants assigned to individual therapy, and written FU texts for group therapy participants were submitted through the post.

TREATMENT FIDELITY DURING TRIAL

Treatment fidelity is assured by attending to methodological details of intervention and monitoring data collection for targeted outcomes (Robb, Burns, Docherty, & Haase, 2010). To safeguard treatment fidelity in our study and provide the best possible care for the participants, a number of precautions were taken: detailed protocols, forms for clear and transparent session reporting, monitoring the process, supervision, and on-call problem solving.

Data collection	Individual therapy	Group therapy
Questionnaires	Baseline, Posttest, FU	Baseline, Posttest, FU
Paint experience of body	Baseline, Posttest, FU	Baseline, Posttest
Write text of body experience	Baseline, Posttest, FU	Baseline, Posttest, FU
Interviews	Baseline, Posttest, FU	Baseline, Posttest
Arts products	In each session	In each session
Forms of interventions (overview in Table 5-4)	After each session	After each session

Table 5-3. Time points of data collection in trial

ETHICAL CONSIDERATIONS OF DATA STORAGE

At inclusion, each participant was assigned a number, such as II-4 or III-9 (group two, person number four; group three, person number nine). Two members of the core team, Dr. Bergmark and myself, had the key to identify the participants. This key was stored in a secure space at the expressive arts institute. The questionnaires were kept in a safe at Karolinska University Hospital during the data collecting phase, and in a secure location in the expressive arts office after all data was collected. The produced paintings (and some texts) were collected and stored in a secure manner by the therapists in their respective offices. At the end of the data collection phase, all art products were handed over to me. They were photographed and stored securely.

CLINICAL METHODS

The theoretical foundation and methodology of this study has been introduced in Chapter 3 and at the beginning of this chapter. More fundamentally, in our clinical methods, we were influenced in our thinking by theories of women's relationships with their bodies, identities, and social roles, and by the feminist works of Jean Baker Miller (1987; Baker Miller & Pierce Stiver, 1998), Jessica Benjamin (1995, 2005) and Marion Woodman (1993).

ARTS-BASED TIME-LIMITED PSYCHOTHERAPY INTERVENTION

We designed two arts-based treatments (individual and group) in the KMR format in which we adapted a psychodynamic short-term psychotherapy format by Mann (1973), and existential time-limited psychotherapy frame described by Strasser and Strasser (1997). This existential approach is based in phenomenology and humanistic psychotherapy in line with this statement by Carl Rogers (1980):

> Individuals have within themselves vast resources for self-understanding, and for altering their self-concepts, basic attitudes, and self-directed behavior; these resources can be tapped if a definable climate of facilitative psychological attitudes can be provided. (p 115)

The concept of time is central and contrasts other psychotherapy models that use an open-ended format (Mann, 1973; Strasser & Strasser, 1999). The essence of a time-limited approach is the emphasis on temporality, that time for the work has a clear beginning and an ending. It uses a structural model in which existential themes are central, and involves an agreed focus or "outcome" for psychotherapy that is explicit between client and therapist. Thus, the construct of existential time is utilized to activate the self-healing capacity, identify resources and face suffering. The concept of authenticity is acknowledged as being able to stand on one's own. "True authenticity of human beings is to face and be aware of the temporality of our existence" (Strasser & Strasser, 1999, p 27).

PROVIDERS, PROTOCOLS AND ADHERENCE

Providers

Four individual and two group therapists were assigned to deliver the interventions in the trial (introduced in chapter 1). All professionals had extensive clinical experience (between 15–35 years) and were trained in psychotherapy, the KMR method, and in trauma work. In addition, the individual therapists were educated in the Bonny Method and were all in private practice. The group therapists came from Karolinska University Hospital.

Protocols

Protocols for the individual and group psychotherapy interventions were developed from previous clinical experiences, discussions in the team, conclusions of the pilot study, and support of the literature (Bergmark, 2002; Goldberg, 1992; Strasser & Strasser, 1999; Summer, 2009, Yalom, 1975; Yalom & Leszcz 2005; Wärja, 1999, 2010). This process lasted about 1.5 years. Two manuals were written with detailed information about each session. In designing the interventions, we aimed for resembling a natural psychotherapy setting. It is essential to keep in mind that the treatments were conducted within a theoretical frame of psychotherapy in which the arts-based methods were held in a therapeutic relationship involving reflections and verbal exchanges (Wärja, 2015b, 2017). During the last phase of protocol development, the therapists were involved. Suggestions for change were discussed in the core team, which resulted in minor alterations.

Adherence

As described earlier, our goal was to assist in adherence to treatment fidelity and to stay within the structure to the best of our abilities (Robb et al., 2010). However, we allowed for some flexibility related to needs of the participants. Music was suggested for some sessions, though the therapist could make changes based on clinical judgment. Before implementation I met four times with all therapists to go over each of the session protocols. We practiced some parts, such as the full-size body painting, and scenarios of past-present-future. In addition, we examined the music, listened to new pieces, and discussed possible applications. Moreover, we went over the forms to be filled out during treatments. Before the trial started, the core research team met with all therapists to review the tasks and clarify any questions. Furthermore, we set up a meeting where Dr. Bergmark gave an informal lecture on diagnoses, oncology treatments, and late effects. During the data collection phase of the main study, we met once a year as a whole team. Consultations were available for individual therapists as a space for examining issues of concerns related to the therapeutic process. Supervision/consultation for the group therapists was provided by me on an ongoing basis for the first two included groups, and then as needed. During the trial, Dr. Bergmark served as medical consultant regarding oncological questions and concerns. We were both available for matters related to implementation and practical questions.

SETTINGS AND MATERIALS

All private offices had central locations and were furnished and equipped for arts-based psychotherapy. Three individual therapists worked at the expressive arts institute, and one had an office in another central part of Stockholm. The group therapists conducted the groups in a large therapy room in the psychosocial unit at Karolinska University Hospital in a separate building from the oncology clinic. A

package with art materials was distributed to each therapist consisting of liquid paint, oil pastels, watercolors, charcoal, brushes of various sizes, sponges, masking tape, a stack of paper size (30 x 50 cm), and a roll of paper for large paintings. In addition, a CD with 20 music pieces was provided; we used Herman Kardon MS 150 CD players. Produced artifacts were later documented using a Canon camera.

INDIVIDUAL ARTS-BASED PSYCHOTHERAPY

The individual intervention followed the recommendation by Mann (1973) of 12 weekly sessions (Figure 5-4). We added one interview for alliance building and information giving, that in reality served as the first session. Each session lasted 60 minutes Mann divides the process in three distinct phases: a) beginning, b) working through, and c) ending/closure. It is becomes a mutual collaborative task between participant and therapist to move through these phases.

Content of the individual therapy protocol

Session 0: The first meeting was an inquiry aimed at building alliance with the assigned therapist and focused on the subjective experience of cancer and its treatments (the personal cancer-story). Additionally, it entailed a task-oriented drawing exercise (paint-yourself-as-a-tree).

Session 1: This session centered on the "life-line," a drawing task where the woman made a timeline from birth to present day with peaks and valleys symbolizing her life story in the way it currently made sense to her. She could, for example, write in texts and draw symbolic images of out-standing experiences. The rationale was to continue to build trust, and assess earlier stressful events and resources before cancer. At the end of the session the woman was asked to think about what to work on in therapy related to experiences of cancer.

***Session 2*:** The focus/aims of psychotherapy was defined by using a process called 'life-mosaic'. Small pieces of paper were provided on which one theme each was written. These so-called mosaic-pieces symbolized current life issues that could be moved around, placed in various combinations, and thus played with.

Session 3: Here the focus was on establishing a safe place. Identifying safety is an essential and foundational piece of work with clients having experiences of crisis or trauma (Gerge, 2017b). In addition, it is a helpful step when introducing working in non-ordinary states of consciousness such as in KMR, GIM or EXA (Wärja, 1999, 2015a, 2015b; Gerge, 2017a, 2017b; Meyer DeMott, 2017b). The woman was asked to describe a place, real or imagined, that she experienced as safe; a place where she

could fully relax, rest and recharge. The safe place was used as entry for the first KMR experience.

Sessions 4 and 5: In these sessions the work centered on the individually defined themes of therapy (life-mosaic).

Sessions 6 and 7: Work on body image (bodily experiences after cancer) was the specific aim here. Full-size drawing was used. The contour of the woman's body was traced on a large piece of paper and hung on the wall. The instruction was to paint experiences of the body after cancer. KMR music from the safe category (Wärja & Bonde, 2014) was played to initiate this exercise and imagine going into the body, and alternatively looking at the body from the outside. In the next session, the task was to face the painting, keeping eyes open as the therapist provided guidance into (or looking at) the painted body image with the help of steady, slowly unfolding music. After the music, the woman was invited to make changes in the drawing, if needed, as a response to the deepened experience with the image.

Session 8*:* Again, this work focused on life-mosaic.

Session 9: Addressing existential themes, time perspectives and the experiences of cancer through use of scenarios and simplified drama techniques (Stoknes, 2008). The woman would imagine stepping back into the past at the time of diagnosis, take a moment and reconnect to that experience, then move into the "now" and reflect on the present time. In the next step, she imagined stepping into the future, visualizing her life two years ahead. Here she listened to a piece of music with the intent to imagine her future life. The aim was to regain a sense of an untraumatized timeline and facilitate reflection upon the life journey as intact, despite the cancer experience.

Session 10*:* The worked centered on any last issues of life's mosaic that needed to be addressed.

Sessions 11 and 12*:* The last two sessions concentrated on closure. In the eleventh the focus was on making an art installation of all the drawings (called panorama installation). Here, KMR music was used to connect and take in the whole process. At the end of this session the therapists invited the woman to bring a piece of music for the last meeting that expressed her therapy process and experiences. In the final session, the goal was to set priorities for the future and to reflect on the journey and the therapeutic relationship, and to listen to music. The therapist had also selected one piece as an aesthetic response (Gerge, Wärja, & Pedersen, 2017a, 2017b). The final part was to talk about the road ahead, and realistic goals for the future.

Figure 5-4. Content of the individual therapy protocol.

ARTS-BASED GROUP PSYCHOTHERAPY

For the group therapy intervention (Figure 5-5), we used the 12 therapeutic factors identified and described by Yalom (1980, Yalom & Leszcs, 2005). In addition, we integrated six of the nine therapeutic factors for arts-based group approaches (Meyer DeMott, 2004/2017, 2017a, 2017b, built on the work by Yalom, 1975) that were slightly adapted to our population as follows (1) The arts can help survivors find an expression for their distress and learn to cope with the symptoms with the help of each other. (2) The group supports members to be in the present – in the here and now. (3) The group functions as witness to each member's cancer-story. (4) Movement creates energy and gives a sense of life and vitality in the body. (5) Through the arts and the group work, one will gain new perspectives on one' life's stories. (6) Art-making provides distancing to distress and gives permission to 'play' in the transitional space to increase the range of coping strategies.

Furthermore, we attended to Herman's recommended three phases for working with traumatic experiences (1992): (1) establishing safety, (2) reconstructing the trauma story, and (3) integration, restoring the connection between survivors and the community. Arts-based therapy has been frequently used in phase-oriented trauma work (Van Lith, 2016). In KMR the music is selected from the three first supportive categories in the taxonomy, while the group process was intended to arch over all three phases of trauma work and hypothesized to move back and forth in the course of therapy.

The group therapy treatment consisted of eight weekly sessions of 2.5 hours (150 minutes) involving between five and eight participants. The structure was related to the format of group music imagery (GrpMI) using a KMR protocol. Relevant here is the description provided by Grocke and Moe (2015) of implementing music and imagery in groups. Usually, an image is introduced as a focus for the music listening; the clients experience the music without verbal interaction with the therapist or other group members. GrpMI in its therapeutic intention focuses on group factors (e.g. socializing, interpersonal focus) and is mostly supportive (Grocke & Moe, 2015). In this study, the group therapy intervention is referred to as KMR/group. All five groups were co-led by the same two group and expressive arts therapists who also were experienced oncology nurses.

Content of the group therapy protocol

Session 0*:* The first meeting was an individual 60 min initial inquiry with one of the therapists that included subjective experiences of cancer (cancer-story and paint-yourself-as-a-tree). Specific questions concerned previous experiences of groups, and possible apprehensions of working in a group setting. At this time, the woman was asked to bring a piece of music to the first session that expressed feeling/experiences of having had cancer.

Session 1: The first group session focused on building cohesion, trust and alliance, and the importance of confidentiality was stressed. In the first session, each member played her self-selected song or short piece of instrumental music. After each music listening experience there was a time for sharing and reflecting among all of how the music was experienced, and of feelings and personal association. The therapists facilitated interaction and emotional exchanges.

Session 2*:* Here the attention was on establishing the safe place. The KMR format was also introduced. Throughout all sessions the pictures and painting were reflected upon in the group applying the phenomenological approach (described in chapter 3 and briefly below). In addition, in this second session members used the life-mosaic procedure to identify the individual focus for the group therapy work as related to experiences of cancer.

Sessions 3 and 4*:* The work centered around body image and creating the full-size paintings. The format was similar to the individual intervention, with the difference that reflections around the large body image painting were first done in dyads or triads, and then in the whole group. KMR was used to deepen the work.

Session 5*:* Here the focus was on sexuality and sexual function after cancer. This session started with a reading of the therapists of the definition of sexuality formulated by the WHO (2006a, see p. 40). This was followed by an open reflection and discussion around sexual themes. The therapists introduced psychoeducative materials and information on sexuality and cancer. Furthermore, active body-oriented methods were applied: African drum music and grounding exercises (Lowen, 1975). This approach in particular aimed at finding a way to stand firmly, feel the support of the grounded body, and sense the bodily center and the pelvic region. This body warm-up was followed by a KMR experience focused on sexual themes.

Session 6*:* This work dealt with future perspectives, scenarios, and drama techniques (Stoknes, 2008) in order to identify and set priorities and realistic goals, and to also reflect on helpful and adaptive coping strategies. In the start of the session participants looked back on the time of cancer diagnosis; next how life was perceived in the present; and then literally stepped into an imagined future two years ahead, reflected upon this with a peer, and followed by a KMR experience. As in the individual approach, the aim was to regain a sense of an untraumatized timeline.

Session 7: Here the participants worked individually to create a collage from clippings in magazines and newspapers to create an image of their future perspectives/dreams/hopes (related to session 6), but also of fears and worries that might surface. These collage products where then reflected upon with the whole group.
Session 8: In the last closing session, all drawings, paintings, and written texts that had been produced were used to create an individual installation about the essence of the work (panorama), and identify what was most important to bring back into life from participating in group therapy.

Figure 5-5. Content of the group therapy protocol

COMMONALITIES BETWEEN TREATMENT INTERVENTIONS

A number of methodological characteristics were held in common for both treatment arms, they are described briefly below.

Working with visual arts in psychotherapy

Drawing and painting were used in both approaches, most often following the music listening. In both interventions, the painted images were reflected upon by using the phenomenological approach applied in expressive arts. In short, this refers to the process of inviting an immediate experience of the art phenomenon and speaking of it by letting the image/paining/drawing "be free and speak as it is" (Knill, Nienhaus Barba, & Fuchs, 1995; Wärja, 2015b). Opening up and freeing the image from the personal context allows for multiple narratives and perspectives. In the individual therapy this was simply practiced and modeled by the therapist. In the group therapy work this approach was explained by the therapists in an easy and relaxed manner in order to engage the members in this way of relating to images; in other words, reframing from analyzing and reducing the image as merely an illustration of a problem, or an issue that could be interpreted directly in the lifeworld of the person who made it. The use of aesthetic response was also explained and encouraged; specifically, how an art-work can create an emotional reaction that can be expressed as a spontaneous response in another art-form (Gerge, Wärja, & Pedersen, 2017a, 2017b).

Grounding

Grounding was used in both interventions. This is a method from the body-oriented psychotherapies and usually refers to the vertical position of standing and the person's capacity to connect with the ground, to stand on one's legs and feet and feel supported (Lowen & Lowen 1978). The theoretical stance is the connection between a stable balanced physical body and a psychological stability with the capacity to tolerate and

regulate affects (Levine, 2010). The person puts her attention to the ground and the experience of gravity, and senses the body as it moves in different position, attempting to release and be aware of tensions. This approach was used in the protocol of the group intervention. In the individual intervention, grounding was more readily applied in sitting comfortable in a chair and sensing the connection to the holding of the chair (and implicitly to the ground).

Altered states of consciousness

The methodology of both interventions involved the use of altered states of consciousness introduced by the therapists to prepare the client for listening to music (Tart, 1990). There are number of ways and methods to work with inductions, for example mindfulness meditation (Kabat-Zinn, 1994), hypnosis (Brown & Fromm, 1986; Erickson, Rossi, & Rossi, 1976), and active music making (Aldridge, 2006; Aldridge & Fachner, 2006). Typically, the therapist assists by suggesting that the client closes her eyes, turns inside, and shifts attention to the breathing experience; allowing sensations, feelings, and images to float by in a stream of consciousness, and if possible begins to release tension in the body. In the next step, right before the music is played, the therapist suggests the focus for the listening, such as imaging a favorite place in nature or of safety.

Selecting music – developing the discography

Each therapist was provided with a CD disc and a list of the KMR music. This discography was developed by applying the three subgroups in the supportive category of the continuum of music and imagery taxonomy, each of which are called (1) the secure and safe field, (2) the secure and opening field, and (3) the secure and exploring field (Figure 5-6). The compositions were selected for their aesthetic qualities, for being reliable, and for belonging to the 'lighter moods'(Hevner, 1937; Wärja & Bonde, 2014). As recommended, we aimed for transparent music reporting (Robb, Burns, & Carpenter, 2011). The therapists used the specific session form to document the selected music, the rationale for that choice, and how well that music seemed to have served the therapeutic process. Table 5-4 displays an overview of the final playlist of KMR music used in the trial. A more detailed discography is found in Appendix Q.

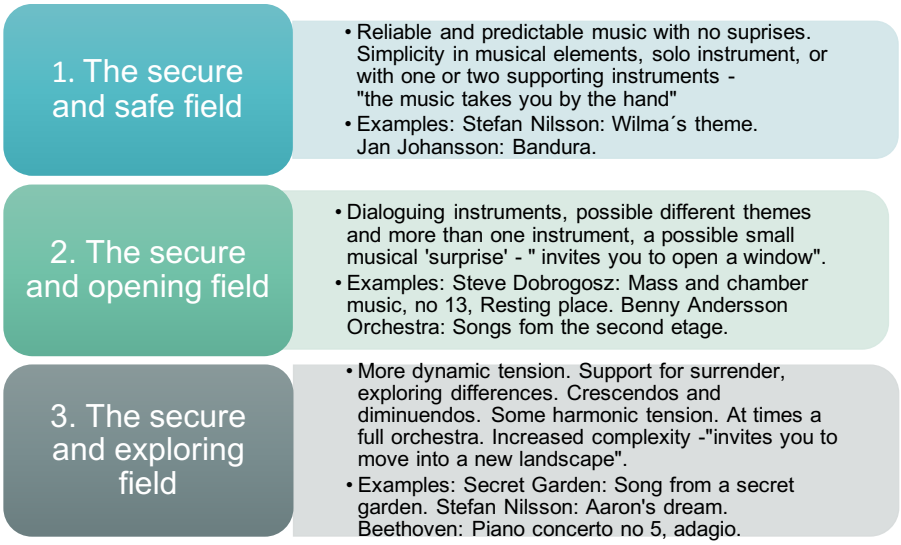


Figure 5-6. Three subcategories of supportive music in the taxonomy of music for therapeutic music and imagery work (Wärja & Bonde, 2014)

Title	***Composer***	***Duration (min+sec)***
Sånger från andra våningen	Benny Andersson	3.52
Piano Concerto no 5:2	Ludwig van Beethoven	6.53
Om Namo Bhagaveta	Deva Primal	7.06
Resting Place	Steve Dobrogosz	3.41
Innocent	Fläskkvartetten	3.33
Balance *	Guem	4.58
Palladio	Karl Jenkins	3.43
Bandura	Jan Johansson	2.27
Sacco e Venzetti-Speranze Di Libertia	Ennico Morrocome	2.29
Aarons Dream	Stefan Nilsson	3.57
Gabriellas piano (As in heaven)	Stefan Nilsson	3.18
Mot den nya världen	Stefan Nilsson	2.42
Wilmas tema	Stefan Nilsson	1.57
Canon in D	Pachelbel	7.43
Evening in the Forrest	Roger Quilter	2.47
Gymnepedie no 1. (flute & harp)	Erik Satie	3.02
Songs of the Secret Garden	Secret Garden	3.43
Song of Union	Joanne Shenadoah	2.57
Kärlek	Magnus Strömberg	3.02
Allt under himmelens fäste	Johan Svendsen	3.17
Wintertraum	Jürgen Volkmar	3.00

*only used in group therapy

Table 5-4. Playlist of KMR music for trial

CHAPTER 6. RESULTS

This chapter starts with information on participation and participant responses, followed by results reported in three papers of the thesis, Papers IV, V and VI. Paper IV presents an overview of inclusion criteria, demographic data for the participants (N = 57), clinical characteristics, and self-assessed psychological conditions at baseline. Paper V provides the results of the arts-based psychotherapy interventions, and finally, Paper VI presents assessments of body image paintings and covariates of treatment effects on depression, anxiety, and QoL measured by MADRS, HADS-A, and EORTC-QLQ-C30. Results tables for Papers IV and V, which include more detailed statistical data, are not provided here due to publication restrictions. A summary of the music chosen by the therapists is provided at the end of this chapter and discussed in relation to clinical findings and the taxonomy as a tool for selecting music based on assessed needs (Wärja & Bonde, 2014).

PARTICIPATION IN TRIAL

The CONSORT statements were applied in order to document participation and attrition (Altman et al., 2001; flowchart is provided in Appendix T). During the time of inclusion, 2881 women were screened for eligibility. All possible participants (n = 594, targeted person-time) had been evaluated for inclusion based on information in the medical charts and on our inclusion/exclusion criteria. In this group we have three categories: the observed participants (N = 57), the non-participant group (n = 255), and the non-informed group of potential participants (n = 282). Among the non-participants declining to participate, we have documented reasons for 130. Reasons for the remaining 78 were not collected.

One hundred and four women expressed an interest in the study and were assessed by me. Of those, 24 were excluded during a telephone screening for reasons related to practical questions, and 80 were assessed in a face-to-face interview that was held in the expressive arts office. Of those 80, we included 60 women; the excluded 20 persons did not need or were not motivated for psychotherapy, or not willing to accept randomization (for instance, were only willing to accept one of the two approaches), or not available during the study time. Three persons dropped out right after inclusion and before filling out the baseline questionnaire; one stated that the questionnaire was too difficult, and two did not provide reasons. Examples of noted reasons for non-participation within the 130 persons who declined were: not needing psychotherapy, distance in commuting, planned travels, physical limitations, and family reasons. For 78 women who were asked but declined to participate, the reasons are unknown. In

addition, three participants who had initially been included dropped out before filling out baseline questionnaires due to family reasons (n = 1) or unknown reasons (n = 2). These three participants were therefore excluded. For those who declined to participate for known reasons (n = 130), those who declined with unspecified reasons (n = 78), and those who were not asked (n = 282), we have a loss of information in the targeted person-time and no way of knowing how this may have influenced our results.

Fifty-seven participants were randomized to individual psychotherapy (n = 18) or group therapy (n = 39). Of those, seven individuals left before treatment begun. In the individual therapy condition, one individual left due to family reasons. For group therapy, two persons moved to other parts of the country, one woman had a cancer recurrence, one did not give a reason for leaving, and two persons were no longer able to attend the group due to a change in working hours. Another five participants dropped out during active treatment. Two had been allocated to individual therapy: one dropped out due to moving to other part of the country, and for one the reasons not known. Three had been allocated to group therapy: for two, the treatment approach did not meet their needs (individual therapy outside the study was subsequently offered), and one person moved to another part of the country. Two participants who had completed group therapy did not fill out posttest measurements (one stated the questionnaire was too repetitive, and one dropped out due to recurrence). Four additional group therapy participants did not fill out measurements sent by postal mail at FU, for whom the reasons are not known. These persons did not respond to repeated attempts to contact them. In order to check for dissatisfaction with treatment for these four individuals lost at FU, we conducted a sub-analysis of self-assessed satisfaction at posttest. For example, the question “How satisfied are you with having participated in the group?” was answered by all four as being highly satisfied. Another question inquired about level of total satisfaction of the whole intervention experience. All four checked five on a seven-point digital scale (0 = very dissatisfied and 6 = very satisfied). The group experience was rated as highly positive, such as feeling very accepted and part of a group and not feeling alone with their problems. We therefore have no reason to believe that dropout at FU was caused by dissatisfaction with therapy.

For individual therapy, the 15 participants who completed therapy attended all 13 sessions and fulfilled all measurements (100% adherence). For the five groups randomized to group therapy each group consisted of 5–8 members. In total, three persons dropped out after starting group therapy. For the 30 participants who completed the group intervention, 95% attended all sessions. We lack information for non-participation for total six persons (11%): one person did not start the allocated

intervention, one dropped out after eight sessions of individual therapy (not reachable despite many contact efforts), and four group therapy participants did not fill out FU and did not respond to repeated contact attempts. Response rate was generally high. For individual therapy at posttest and FU, response rate was 88% (15/17). For group therapy, it was 85% at posttest (30/33) and 72% at FU (24/33).

PAPER IV: WING-CLIPPED BODIES – FINDINGS AT BASELINE

This paper presents characteristics of 57 gynecological cancer survivors having completed oncological treatment 3–24 prior to inclusion. Appendix R provides a flowchart before randomization. Time and frequency of inclusion are presented in Table C-1 in Appendix C. Fifty-seven key variables in the study-specific baseline questionnaire related to the four research questions were selected for this analysis.

In the GYNONC-QoL-CSBAE baseline questionnaire we investigated the degree of suffering by using a category scale or tic-boxes (Appendix F). For seven-point digital questions we applied: low 1–2, moderate 2–4, and high 5–6. For dichotomized questions, we analyzed: not at all/a little, or moderately/much. Psychological problems were ranked according to the distress they caused. Questions involve larger and multilayered concepts such as body image or QoL, and more specific questions focused on one aspect of a phenomenon. For example, “feeling ashamed of my body”, or “avoiding the mirror when I am naked” are two specific aspects of body image. The degree of patience, or ability to concentrate can be related to QoL and meaning-making. Questions concerning self-states were reported in the section of the questionnaire pertaining to body image. For fear of cancer recurrence and existential distress we inquired about the overall existential health and asked more specific questions focused on various affective states, different fear states and intrusive thoughts, and coping strategies. Viewed together as a whole, all variables reported here are interrelated and paint a clinical picture of the level of suffering reported by the participants at baseline.

DEMOGRAPHIC AND CLINICAL CHARACTERISTICS

Demographic information and clinical characteristics are found in Appendix S (showing data for the whole sample at baseline and after randomization). The mean age was 56.5 years. Ten percent were in the age range 27–34, and 62% were between ages 55–75. Most women were married, cohabiting, or had a partner (72%). A minority were in childbearing age (20%) and a majority had children (70%). As the

risk of contracting gynecological cancer increases with age, the sample was representative to the greater study population.

Prevalence of diagnosis was as follows: endometrial cancer 42%, cervical cancer 32%, and ovarian cancer 17%, and other forms 9%. A large majority had received chemotherapy (81%) and been treated with surgery (77%), and 63% had been exposed to brachy therapy and 54% to external radio therapy. A majority of the participants were employed (58%), and 11% were on sick leave. The women were well-educated: a large majority (64%) had obtained a college or university degree, to be compared with 28% of the general population in Sweden, and 44% for an urban area such as Stockholm (SCB, 2017).

Participants reported having physically active lives, and 79% were involved in a weekly exercise regime that for the most part consisted of frequent walks, but also involved other workout activities. This is slightly more than the average female population of Sweden (72%; SCB, 2017). More than half stated having a religious faith, albeit between a little to a strong faith. Noteworthy is that 40% reported previous psychotherapy treatment, and that 39% had received psychiatric and psychological help/consultation at some point in their lives prior to cancer (for example related to depression, exhaustion, insomnia, work related stress). We found a high prevalence of earlier traumatic events; 63% reported having had such incidents prior to cancer diagnosis (such as death of a child, exposure to war, harassments, severe illness of significant others). For sexual assault, we found 14% exposure.

The participants were living in an urban environment with access to a variety of culture offerings. Twenty-seven percent reported that they attended cultural events (concerts/operas/shows) on a monthly or weekly basis. About half (48%) read fiction weekly or daily, which is about the same as for average females in Sweden (45%). For weekly/daily activities during the preceding six months, 53% reported being active music listeners, 4% had used visual arts (painting/drawing), and 18% had been working with crafts (characteristics of the population are discussed below under methodological considerations).

ASSESSED PSYCHOLOGICAL DISTRESS AT BASELINE

Despite stable socioeconomic background and modifiable factors (such as frequent exercise and some leisure activities), this group exhibited high psychological distress on a number of variables at baseline.

Body image and sexuality

For a majority of the women, we found moderate bodily (80%) and psychological well-being (71%). Moderate levels were also reported for self-states: self-image 70%, self-esteem 65%, and self-confidence 75%. In addition, satisfaction of appearance and acceptance of one's body was moderate for 56% and high for 40%. Furthermore, for specifics of moderately/much distress, we found that a fairly high percentage of the participants did not trust their bodies (36%), many were ashamed of their body after cancer (41%), and many experienced the body as damaged (43%). Fatigue as an effect of cancer treatment was present for more than half the women on a monthly/weekly/daily basis (57%). Matters related to sexuality are generally central to this population. Our data show that most women did not feel sexually attractive (73%). Pain during sex had affected 43% of the participants, and a large majority (70%) was not satisfied with their present sexual life (with or without a partner).

Fear of cancer recurrence and existential distress

Results related to existential distress showed that almost half the group experienced frequent fears of cancer recurrence (43%). Fear reached a peak of high intensity for 18% and moderate level of intensity for 55%. Twenty-seven percent had frequent intrusive thoughts related to cancer. The overall experience of life stress (in terms of QoL) was reported to be high for 30%, and moderate for 57%.

Conclusion

This group of cancer survivors had been informed by medical professionals that they had a good cancer prognosis. Nevertheless, they presented substantial psychological distress related to all four research questions. In symbolic words, their bodies were "wing-clipped". Noteworthy characteristics were high education level, previous exposure to trauma, and high prevalence of earlier psychotherapy.

PAPER V: RECLAIMING THE BODY – FINDINGS OF A RANDOMIZED TRIAL

Fifty-seven questions in the study-specific questionnaires were selected to answer the four research inquiries (of which 27 were assessed post-treatments). The results presented here were based on questionnaire answers from 57 participants at baseline, 43 at posttest and 39 at FU. As described in paper IV, questions related to body image and existential distress involved both wider concepts and more specific targeted

problem areas related to experiences of the body and of QoL. All these areas are interrelated and present a change pattern after arts-based psychotherapy.

Body image and sexual health

Bodily well-being was significantly improved from baseline to posttest with medium to large effects for both treatments. The effects were sustained at 7 months for both interventions with a slight increase at FU for group therapy (d = 0.83). A similar pattern was found for psychological well-being. Here a higher effect was noted for individual therapy arm at posttest (d = 0.79) that dropped at FU (d = 0.37), while for the group therapy arm, the effect size increased at seven months FU (from d = 0.59 to 0.75). Related to these variables were questions pertaining to self-states and aspects thereof. Results show substantial and significant improvements for self-image, self-esteem, and self- confidence. Self-image was improved for women in both treatment arms at posttest with medium effect (0.52 and 0.57); effects were slightly improved for both treatments at FU (0.59 and 0.57). For group therapy, we found significant increase for self-esteem with a medium effect (d = 0.63 at posttest and d = 0.65 at FU). No significant improvement was reported for individual therapy; albeit the effect size was d = 0.40 at both posttest and FU. Five specific body image aspects were assessed: feeling ashamed, avoiding the body, feeling it as damaged, feeling it as foreign, and experiencing having 'strong and sturdy legs'. On all the specific bodily aspects, we found significant improvements for group therapy, but not for individual therapy, although here positive tendencies and nonsignificant improvements were found. For sexual health, we evaluated only two variables in this analysis. Experiences of being sexually attractive had increased significantly at FU for the group arm, while the interventions did not have any significant effects on how important sex was in life. For individual therapy, no statistically significant increase was found for the importance of sex, although an increase of 15% between baseline and posttest that was decreased to 8% at FU.

Existential distress and fear of cancer recurrence

Overall quality of life was improved notably for both treatment approaches at posttest that were sustained at FU. We found a medium to high effect (individual 0.66 and group 0.78) that remained at FU (0.60 and 0.81 respectively). A significant increase with medium effect sizes of the extent of meaningfulness in life was noted at posttest for both arms and sustained at FU for group therapy, but not individual therapy. In addition, for the group therapy arm, depression decreased significantly, and the effect was sustained. The more specific inquires of satisfaction of patience, concentration, and initiative (related to self efficacy and ability to handle one's life) yielded positive results. For initiative we noted significant increase for both treatments at posttest and FU. Satisfaction with patience and concentration was greatly improved at posttest for group therapy and was sustained for concentration but not for patience; and for

individual therapy we noted a tendency of improvements for both variables. Questions related to fear of cancer recurrence showed significant improvements for group therapy. The fear frequency decreased at posttest, and the fear intensity decreased significantly at posttest and remained. Our data show that persistent thoughts of death related to cancer were reduced for the group therapy participants at posttest and FU, and for the participants of individual therapy a large significant decrease occurred at FU. Associating bodily symptoms with recurrence yielded some improvements for both arms, though was not statistically significant.

Participation satisfaction and benefit findings

Participants were asked specific questions included in GYNONC-QoL-CSBAE questionnaires about satisfaction and perceived benefits of treatments related to treatments and taking part in the study (Appendix G). Results were dichotomized as not at all/a little and moderately/much/high, and for digital scales as low (0-1); moderate (2-4); high (5-6). The inquiry concerned the total experience of psychotherapy and details related to different parts of the interventions. Twelve questions were constructed and adapted from Yalom's therapeutic factors of group therapy (1980) and consequently answered by persons in the group arm (Appendix G). Findings showed an exceptional high satisfaction (moderately/much) for both approaches in terms of having participated in therapy. For individual therapy there was 100% satisfaction at posttest and at FU for having been in therapy, and for the individuals in group therapy, this inquiry was rated as 96% at posttest and 93% at FU. For persons in individual therapy the greatest satisfaction (rated as high) at posttest was in having space to work on matters related to cancer (100%); having an attentive therapist (94%); facing emotions (93%); and verbalizing these experiences (93%). These responses of benefits and satisfaction increased for persons in individual therapy after seven months to 100% in relation to having an attentive therapist and for facing and feeling emotions. Albeit, satisfaction of having space to work on one's issues decreased from 93% to 67%. For the group participants, the satisfaction with working on personal issues was high (44%) at posttest and increased to 77%; as for facing and feeling emotions (62%) that improved to 70% at FU. For specific questions of different parts of the two interventions (music listening, drawing, talking), the perceived satisfaction was rather equally distributed between moderate and high for music and art. For talking about the experiences elicited through the arts the perceived satisfaction was high at both posttest and FU for both approaches, and the total experience of the whole treatment was scored as highly satisfying, albeit higher for individual therapy: 100% at posttest and 87% at FU; and for group 72% and 70% respectively.

Benefits of the 12 group specific factors were rated as moderately/much/high for a large majority of the participants. For example, for belonging to a group and not being

alone we found 89% (moderately/much) benefit at posttest and 88% at FU. For universality, (not being the only one with these problems), it was 89% posttest that increased slightly to 92% at FU. Talking about one´s experiences of cancer in the group was 96% at posttest and 78% seven months later. For the related question of being helped by others in the group who brought up issues resembling one's own, we noted 93% satisfaction at posttest, that was sustained (92%). Altruism, i.e. giving of oneself to help others, was also experienced as high (89%) at posttest and was sustained (88%). Speaking of life and death together with women in a similar situation was beneficial for 81% at posttest and 83% at FU.

Conclusion

Clinical characteristic and findings at baseline identified a range of psychological symptoms of distress that were significantly improved with mostly medium and some large effect sizes at posttest and FU on a number of variables related to the four research questions: body image, sexual health, fear of cancer recurrence, and existential distress. Overall satisfaction for participation at posttest and FU was similarly high for both individual (100%) and group therapy 96%.

PAPER VI: THE BODY IN THE MIND – FINDINGS OF BODY IMAGE PAINTINGS

A newly developed tool named the Safety Assessment Tool of Pictorial Artefacts (SATPA; Gerge, 2017a, 2017b; Gerge, Gattino, & Pedersen, 2017) was used to evaluate paintings of body image related to experiences of cancer collected in the randomized trial (N = 57) aimed at studying effects of arts-based psychotherapy on gynecological cancer survivors (Wärja, Bonde, & Bergmark, 2012). One purpose of paper VI was to conduct an external validation of this tool using artwork produced by a clinical population (here gynecological cancer survivors). Another purpose was to present and discuss the findings as related to body image of this population. The focus in this thesis is on the latter, thus the tool itself is briefly presented while matters of validity are not presented, nor discussed in this context.

SATPA AND PERCEIVED SAFETY

SATPA is based on the assumption that visual arts material produced in therapeutic settings could be used to detect various levels of safety, or absence thereof (Gerge, in press; Gerge & Pedersen, 2017). The tool was constructed to detect differences in experienced patterns of neuroception, a concept developed by Porges (2001, 2011) that relates to experiences in activations of the central nervous system, and to levels of safety and threat. A state of safety was according to Gerge (in press) defined as a

phenomenological experience (Gendlin, 1978; Merleau-Ponty, 1945/1963) of having access to self-regulating and self-soothing capacities (Krystal, 1988). It was hypothesized that signs visible in paintings correspond to changes in affect and inner states addressed in psychotherapy. SATPA is a proxy measure and uses 11 clearly defined perspectives aimed at detecting patterns of neuroception by using proxy measures. The theoretical frame of reference is based in phenomenology (Merleau-Ponty, 1945/1963, 1962b), psychodynamic theory, and theories of affect-regulation (Schore, 1994). The work is grounded in the inherent human capacity to resonate and activate implicit relational knowing in clinical work and research (Stern, 2004).

BODY IMAGE

Body image was defined based on the work of Schilder (1935/1978) and contemporary neuroscience and psychodynamic psychotherapy. It was conceptualized as an ongoing appraisal of how the body is perceived from phenomenological, existential and physiological perspectives. Schilder discussed the experience of the body as one unity, or as "bodilyness." Body image is related to the appearance of the body and perceptions of various self-states, and can be connected to embodiment. From a psychodynamically oriented neuroscience-affective perspective, the body can be regarded as the deep unconscious (Schore, 2014) that is involved in ongoing regulating processes of the felt sense of the body (Damasio, 1994, 1999; Cozolino, 2002/2010).

PAINTINGS AND MEASUREMENTS

The paintings were part of the larger data set of qualitative and quantitative data collected at three times (baseline, posttest, and FU at seven months; Wärja, Nyberg, Forss, & Bergmark, 2017a). These paintings were spontaneous expressions of participants' subjective life-worlds as related to body image and cancer. The instructions given were *Paint a picture quite freely and spontaneously about the experience of your body today, after illness and after cancer treatments. How do you see your body? How does it feel? How do you experience your body?*

In this assessment, paintings from 28 participants were analyzed out of 57 women who had created paintings at baseline, and 43 who completed them at posttest. Pictures that depicted a human figure, created at either baseline or posttest were included. In total 65 pictures were analyzed by two raters independent of the study who performed the evaluations independently of each other (baseline $n = 28$; posttest $n = 28$; and FU $n = 9$; only participants in individual therapy completed a FU painting (see Appendix Y for examples of paintings). The aim here was to assess differences in pictures between timepoints as related to perceived neuroception. No differentiation was made between paintings in terms of randomization arms. The results were compared with findings of outcomes of the whole study sample as

measured by: EORTC-QOL-C30 for QoL, MADRS for Depression; HADS-A for Anxiety (Appendix X).

RESULTS OF BODY IMAGE ANALYSIS

Results of the assessments show how paintings produced in therapy could potentially be used to identify differences in self-agency, self-efficacy, embodied felt sense, and levels of stress that in turn could be related to the aftermath of cancer and its treatments. Findings of the analysis are presented in Appendix X. Before therapy a number of paintings were assessed as exhibiting feeling unsafe and ambivalence. At posttest after therapy had concluded, 80% of the rated human figure drawings became larger, and a majority became more sheltered, more relaxed, and dressed. Furthermore, images were more contextualized and had more soothing surroundings, for example darkness and heavy clouds disappeared and other symbols, such as suns and (happy) hearts appeared. The affective tone changed from loneliness to joy and calmness.

The findings of analysis of paintings co-variated with findings of statistical measures for the whole sample of decreased depression and anxiety, and increased QoL at posttest that were sustained at FU.

Conclusions

It was hypothesized that a time-limited psychotherapy involving music, art, and verbal exchanges (KMR-Brief-Music Journey) would yield a significant decrease in distress for gynecological cancer survivors that could be related to retaking experiences of safety as depicted in body image paintings before and after psychotherapy. The more embodied and regulated self-states identified in the images covariated with decreased depression and anxiety, and improved QoL.

SUMMARIZED RESULTS – AS ANSWERS TO RESEARCH QUESTIONS

The overall purpose of this thesis was to assess the efficacy of two arts-based psychotherapy approaches on psychological distress of women recovering from gynecological cancer. More specifically, four core themes that grew out of an in-depth interview study became the basis for research questions to be examined: the effects on body image, sexual health, fear of cancer recurrence, and existential distress. We present strong and significant results for both treatments, with medium to large effect sizes for a number of variables at posttest that were sustained at seven months FU.

Our findings measured by 25 questions in GYNONC-QoL-CSBAE, and supplementary instruments, can be summarized as follows: (1) All variables pertaining to experiences of body self were significantly improved with medium to large effect sizes. (2) A large majority did not feel sexually attractive and did not regard sex as important at baseline. However, they also reported not being satisfied with current sexual life (with or without a partner). A significant improvement was found for increased feelings of being sexually attractive at posttest for group therapy, though did not remain at FU. Experiences of sex being more important in one's life yielded no significant changes, although all participants reported an increase from baseline to posttest that was sustained at FU. (3) Fear of cancer recurrence was reduced, when measured as thoughts around death and dying related to cancer for group therapy at posttest and FU, and for individual therapy at FU. Finally, (4) regarding existential distress and QoL, we noted a significant decrease with medium to large effect sizes for distress and significant amelioration for overall life quality that remained at FU. In addition, we found substantial improvement for all participants on the ability to take initiative that were sustained seven months later. Also, significant improvements were reported for group therapy for having increased patience and concentration.

SUPPLEMENTARY INSTRUMENTS

The positive results on decreased psychological distress measured by our study-specific questionnaires were supported by the highly significant reductions for all participants of anxiety and depression, and improvements of QoL assessed by HADS-A, MADRS, and EORTC-QOL-C30 partly reported in paper VI. Herth Hope Index did not yield any significant changes for any of the treatment arms. We suggest that these questions were not quite applicable, or sensitive enough for our sample (post-oncology treatment and good prognosis of survivorship).

CLINICAL SIGNIFICANCE

Self-assessed participation satisfaction, benefit findings, and information on clinical relevance related to the research questions were collected in GYNONC-QoL-CSBAE at posttest and FU. Results indicated that all participants perceived they had benefitted considerably from treatments pointing towards clinical significance and usefulness. These reports were congruent with statistical findings. The positive support for both approaches may also be contributed by the common factors inherent in psychotherapy

ADDITIONAL FINDINGS – MUSIC SELECTED BY THERAPISTS

Providing precise information and transparent documentation of the music applied in trials has been stressed (Burns, 2012). Table 6-3 presents the music we used. These findings are additional and not explicit in the research questions. Nevertheless, the music selected by the therapists is of interest to note in order to understand more about the effects of the KMR approach for our study population related to affect regulation and holding. This overview states how the three supportive categories of the taxonomy (Wärja & Bonde, 2014) were used. To sum up, results showed that Pachelbel's *Canon* (category 2) was most frequently selected, followed by *Bandura* (category 1) and *Sånger från andra våningen* (Songs from the Second Etage; category 2). Two pieces from the list were never used: *Palladio* (category 3) and *Allt under himmelens fäste* (Everything under the Holding of Heaven, category 3).

KMR discography used in trial of arts-based psychotherapy (group and individual) for gynecological cancer survivors				
Title	*Composer*	*Min+se*	*Category Taxonomy*	*Frequency used*
Canon in D	J. Pachelbel	7.43	2	29
Bandura	Jan Johansson	2.27	1	24
Sånger från andra våningen	B. Andersson	3.52	2	22
Innocent	Fläskkvartetten	3.33	3	19
Aarons Dröm	S. Nilsson	3.57	3	17
Wilmas tema	S. Nilsson	1.57	1	15
Om Namo Bhagaveta	Deva Primal	7.06	1	14
Resting Place	S. Dobrogosz	3.41	2	14
Gymnepodie no 1. (flute, harp)	E. Satie	3.02	2	12
Songs of the Secret Garden	Secret Garden	3.43	3	12
Mot den nya världen	S. Nilsson	2.42	3	9
Song of Union	Shenadoah	2.57	2	7
Sacco e Venzetti-Speranze Libertia	E. Morrocome	2.29	2	5
Balance (only used in groups)	Guam	4.58	3	4
Kärlek	M. Strömberg	3.02	3	4
Piano Concerto no 5:2	Beethoven	6.53	3	4
Wintertraum	J. Volkmar	3.00	3	4
Evening in the Forrest	R. Quilter	2.47	3	1
Gabriellas piano (As in heaven)	S. Nilsson	3.18	1	1
Allt under himmelens fäste	J. Svendsen	3.17	3	0
Palladio	K. Jenkins	3.43	3	0

Table 6-3. Music selected by therapists, frequency and category in taxonomy

CHAPTER 7. DISCUSSION

This study was held within a humanistic frame of reference with a treatment approach grounded in psychodynamic and existential psychotherapy and in the use of the arts as it provides avenues for resourceful meaning making. The initial aim was to triangulate quantitative and qualitative data, which was in line with my professional resonance of contributing to an understanding of effects and experiences of the psychotherapeutic use of the arts in oncology, and specifically of music listening in a relaxed state for the purpose of evoking imagery. As this was not possible, this thesis is mainly presented as an outcome study. Nonetheless, in a larger perspective, our data set has the potential to provide a more comprehensive understanding of the benefits and shortcomings of arts-based approaches for our study population.

To the best of our knowledge, this is the first randomized study investigating the effects of arts-based psychotherapy for gynecological cancer survivors. Both initial literature searches (in 2011) and recent findings from a systematic review conducted five years (Hertrampf & Wärja, 2017) later confirmed a present dearth in the literature in this regard. Furthermore, there is a scarcity of outcome studies in the rehabilitative phase after active oncology treatment has ended. This chapter will (a) provide a brief summary of the results and clinical relevance, (b) discuss findings related to the research questions, (c) briefly discuss the selected music related to the taxonomy, (d) compare the results of individual psychotherapy and group therapy, (e) discuss strengths and limitations of our choice of methodology and study design, and finally, (f) present conclusions and implications for clinical significance and relevance, and future study recommendations.

DISCUSSION OF FINDINGS RELATED TO RESEARCH QUESTIONS

INTRODUCTION

In this discussion, each research question will be addressed separately. Still, it is essential to keep in mind that the four questions were closely interrelated within the interventions (Figure 7-1). They constitute complex psychological patterns that affect each person differently depending on demographic and hereditary factors, the persons' subjective life history, and available resources. Such individual contributing factors are: gynecological cancer diagnosis and treatments, socio-economic level,

social networks, earlier trauma, attachment style and capacity to regulate emotions, and coping style. Psychodynamically oriented psychotherapy is based on the premise that when one psychological concern is addressed and worked through, other related problem areas will be impacted. Therefore, in dynamic affective regulating therapy, various aspects of psychological distress and suffering do not have to be focused on explicitly, nor addressed cognitively, for positive changes to occur (Hill, 2015; Schore, 2012: Stern, 2010; The Boston Change, Process Study Group, 2010).

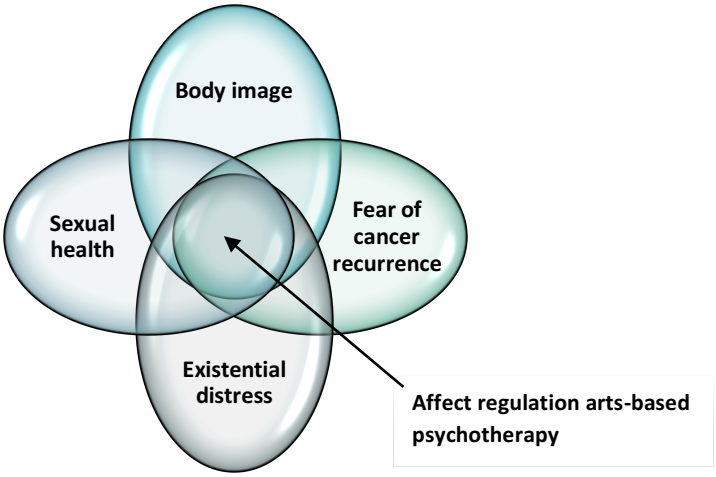


Figure 7-1. Interrelating core themes in treatments

Experiences of the body is central to people dealing with cancer. It is the body that has been impacted by a life-threatening illness. Thus, our research questions all related to the sense of body-self. In this study, the body is regarded as a phenomenological experience of the wholeness of the body-self unit that is constantly evolving (Merleau-Ponty, 1962). The study protocols were developed from this stance. Existential phenomenology (Heidegger, 1996/1953) addresses the inescapable existential condition that life will come to an end. Svenaeus (2000a, 2000b) drew on the writings of Heidegger in discussing the experiences of being afflicted by an illness, such as cancer, that disrupts ordinary life. An illness can be experienced as "unhomelike" and uncontrollable. Hence, a disease may introduce experiences of being detached from one's body that is no longer felt like living in the house of the body. These metaphors capture our baseline findings of bodily shame, not trusting or feeling the body and lowered self-esteem – experiences that can remain for an extended time after treatment and may turn into a life-long distress (Dunberger et al., 2013).

Self-states are bodily based and are complex developmental and psychodynamic concepts that may be more or less unconscious. They refer to both internal and external states and experiences of oneself, which can be attacked and diminished under the influence of severe stress and traumatic events such as a life-threatening illness (Svenaeus, 2000a, 200b; Vos, 2015). Hence, self-state variables are overarching notions that also are associated with emotional distress. In our study, it was evident that most of the evaluated psychological variables of cancer-related psychological distress were greatly improved and sustained by our methods. We have not found other literature using arts-based methods that confirms or contradicts our findings.

BODY IMAGE

Our baseline data showed that a majority of the women reported an overall acceptable level of bodily well-being, despite frequent treatment-related late effects. This is in line with research on QoL for gynecological cancer (Bradley, Rose, Lutgendorf, Costanzo, & Andersson, 2005; Bradley et al., 2008; Dahl et al., 2013; Goncalves, 2010). It is known that patients with cancer in general develop coping strategies that entail making a response shift to the present life after illness and treatments (McClimans et al., 2013). Yet, on another deeper psychological layer, the high prevalence of shame, distrust of the body, and experiencing it as foreign and damaged among the women partaking in our study showed more hidden, repressed and dysregulated aspects of the body self relationship (not living on the house of the body; Sakson-Obada & Wycisk, 2015). Addressing the body and mind split involves working towards bridging inner and outer worlds of bodily experiences and acknowledging conscious and unconscious processes of the body (Schilder 1935/1978). Support for this view is found in modern neuroaffective theory (Hill, 2015; Schore, 2014). This bodily "split" was evident in our participants at baseline, most likely caused by invasive treatments and late effects together with previous comorbidity. Our baseline results were in line with findings in one interview-study of long-term gynecological cancer survivors, 5–6 years posttreatment, who described the body as "unhomelike" with experiences of emptiness, altered sexuality, and increased vulnerability of their lived bodies (Sekse, Gjengdahl, & Råheim, 2011). In our study, we showed that embodiment (inhabiting the house of the body) was substantially improved as an effect of arts-based psychotherapy (Gerge, Wärja, Gattino, & Pedersen,2017; Wärja, Nyberg, Forss, & Bergmark, 2017a).

It is hypothesized that negative body image is connected to lowered self-esteem (Lerner, Karabenic, & Stuart 1973), which is in accordance with our results. Feelings of inferiority and lowered self-esteem may surface in relation to infertility as a consequence of cancer. This may be associated with female identity such as: who am

I now without my uterus/ovaries? One study reports that women who experienced greater body shame reported significantly greater body image disturbances and poorer QoL post-treatment (Boquiren et al., 2013), as in our study. Hence, for these participants, it seemed that the arts-based psychotherapy offered an opportunity for working through of the cancer experience and integration of the post-cancer condition. A person with a better-integrated body self identity is more able to regulate affect and the flow of emotions as shown in the analysis of body image paintings (Gerge, Wärja, Gattino, & Nygaard, 2017). Further analysis of qualitative findings will be undertaken using texts of body image and full-size body image drawings (Wärja & Gerge, 2016a, 2016b).

SEXUAL HEALTH

No studies in the Cochrane reviews on music interventions (Bradt et al., 2016; N = 52) and dance therapy (Bradt, Shim, & Goodill, 2015; N = 3) have investigated effects on sexuality. This lack was also evident for the systematic review on breast and gynecological cancer (Hertrampf & Wärja, 2017; N = 21). Here only one study assessed sexual questions and found a small effect for the use of art therapy with women undergoing chemotherapy for breast cancer (Öster et al., 2006). At baseline for a majority in our sample, sexual matters were reported to be of not much importance. This might have been a partly contra phobic strategy, as pain and discomfort during sex were prevalent. In addition, the bodily appearance was associated with shame, and viewing the body in the mirror while naked was avoided. Not feeling sexually attractive and being comfortable in the changed body after cancer, as reported in our study, will complicate sexuality and intimate relationships and is associated with an erosion of self-esteem (Wenzel et al., 2003). This has not been reported in the literature but is a clinical observation with major impact. Thus, it is possible that the importance of sex was denied, since participants also reported that the present sexual life (with or without a partner) was not satisfying, suggesting dissatisfaction in terms of the future as well as the present situation with a compromised sex life. The improvement in sexual health at posttest supports the benefit of group therapy. While there was no significant change in sexual health for individual therapy, though the results had a tendency towards improvement.

In our questionnaires, we collected detailed questions about sexual health to be analysed further. From earlier research conducted at KCE, we know that the late effects after treatments have an adverse influence on sexual health Bergmark, 2007; Bergmark et al., 1999, 2002). From clinical experiences, we have also found that requesting professional help for sexual concerns usually comes later than 3–24 months after treatments ended, which was our inclusion period. This is In line with findings from a cross-sectional study on the long-term effects for cervical cancer

survivors (Dunberger & Bergmark, 2013) and from interview reports of loss of desire and an active sex life 5–6 years post treatment (Tveit Sekse, Gjengdal, Råheim, 2013). Our study also demonstrated that addressing body image and sexual concerns in psychotherapy is of uttermost importance. Sexuality and body image are interwoven. Hence, sexuality encompasses a wide range of bodily states, individual sensuous experiences, and ways to express sexual intimacy. We suggest that a trusted relationship to the changed body is the basis for making sexual life and function more comfortable, accessible and pleasurable (Wärja, 2011, 2012b, 2017; Wärja, Sodell, & Gerge, 2016).

FEAR OF CANCER RECURRENCE

Fear of cancer recurrence is one of the most distressing and engulfing states after cancer for persons for whom oncological treatment has ended (Christ & Grunfeld, 2012). No previous studies have been found for arts-based intervention research targeting this as a specific outcome (Hertrampf & Wärja, 2017). Symptom severity and perceived stress have been positively correlated with pathways of somatic symptoms and elevated psychosocial stress in cancer survivors (Hall et al., 2017), and cancer-specific distress has been shown to be highly linked to stress and symptoms despite the average of four years since cancer treatments. This is consistent with our findings. For our participants, fear of recurrence was relevant and realistic. For the person with experiences of cancer, it can be like a hovering shadow that will follows along in life in more or less noticeable ways. The goal in psychotherapy in our study was not to take away the fear of cancer, but rather help the women regulate, control, and reduce overwhelming fear states that could otherwise impact QoL and hinder them from making positive life-changes, and realistically evaluating her life situation. Various methods were applied to reduce stress, identify triggers, and confront cancer-related worries. The arts were used to create a reflective distance towards helplessness, stress and excessive body symptoms, and to find resources. Using focused music listening, such as GIM, has been found to be particular helpful in stress-reduction (Beck et al., 2015). In addition, carefully selected music can assist in affect regulation (Beck, 2017). The goal in our study was to help the person begin to regulate, tolerate and handle states, and help the person to stabilize inside her window of emotional tolerance (Siegel, 1999). The arts are particularly helpful for regulating affective states that have moved outside the window of emotional tolerance, such as high arousal and numbing (Beck & Lindvang, 2017; Gerge, Ranch, & Rudstam, 2010). Fear is an affective state that, when highly aroused, immobilizes a person and, when longstanding, inhibits functional life. Using arts in psychotherapy will introduce movements, change, spontaneity, and ultimately joy. This may bring openings for multiple perspectives in dealing with a difficult situation. An art product or a creative act such as music, painting poem, or a dramatic vignette can create a space to contain,

or even symbolize, a feeling, problem, or state of suffering. This reflective space makes it possible to dialogue, to step in and out, and to "play" with adversities (Wärja, 2015b; Meyer, 2017a, 2017b).

Support for our methods were found in one feasibility study assessing fear of recurrence in 56 women with breast or ovarian cancer in which a cognitive-existential group protocol of six sessions was implemented (Lebel et al., 2014; Maheu, Lebel, Tomei, Sing, & Esplen, 2015). The interventions included psychoeducation, guided imagery, relaxation, mindfulness, various skill-building techniques, and encouragements from the providers to confront and express negative feelings. Women reported that not feeling alone, expressing feelings together with others, learning emotional control, and using imagery to face the worst scenario, were particularly helpful to reduce cancer-related distress, support emotional expression, and develop coping skills. Support was reported with medium to large effect sizes for reducing fears that remained at 3 months. These results are in line with our findings that showed less fear intensity and lowered intensity of intrusive thoughts of death as a result of treatment. These findings underline the use of active methods that were inherent in our protocols such as: addressing emotional cancer-related existential stress directly, attending to affect regulation, and applying active techniques such as scenarios, relaxation and music-evoked imagery. We have reason to believe that the qualitative data, to be analysed further, will shed more light on how the arts were used to address fears of recurrence (Gerge, Wärja, Gattino, & Nygaard Pedersen, 2017; Wärja & Gerge, 2016a, 2016b, Wärja, Sodell, & Gerge, 2016).

EXISTENTIAL DISTRESS

As earlier discussed, cancer interrupts habitual life and places existential questions and the fragility of the body in the foreground. The goal of psychotherapy, in our existential arts-based frame, was not to remove anguish and affliction by a cognitive understanding and new actions (though this may also grow naturally from the work; Stiwne, 2008, 2009; van Deurzen, 1998, 2003; Wärja, 2015b, 2016). Instead, the arts were provided as containers and places for profound resonance and release. Held within a therapeutic relationship, the person was invited to an exploratory creative process in which it was possible to discover symbols and images for coping, and to find inner resources for transforming distress and agony into a coherent new meaning in the altered life perspective. A severe crisis may even contribute to major personal growth (Stiwne, 2008, 2009). Jungian analyst Marion Woodman, afflicted with endometrial cancer, stated, "The gift of cancer is the gift of Now, a sense of all time precariously lodged within it. Living with death is a more abundant life" (Woodman, 2000 p. xvi). For the women in our study, life's meaning and quality before psychotherapy was generally good, again in line with earlier research findings, and

possibly post-traumatic growth (Cormio et al., 2017). Nevertheless, for our participants, psychotherapy contributed to significant improvements on variables related to existential distress and QoL that remained stable at FU, suggesting that everyday life had indeed become enriched. We have no other studies to compare with as psychological distress as an effect of arts-based therapy has not been evaluated for this population. The literature related to other cancer populations point out that distress, such as depression, anxiety, and worry hinders the capability to organize life in such a way that it carries meaning and has direction. Support for the positive effects of music interventions and art therapy on depression, anxiety and QoL have been documented in a number of studies (Bradt et al, 2016; Boehm et al, 2014; Hertrampf & Wärja, 2017). For art therapy with women in chemotherapy for breast cancer, depression was lowered significantly (Thyme et al., 2009) and QoL was improved (Svensk et al., 2009). These findings are in line with our group participants for whom the frequency and intensity of depression and worry decreased substantially at posttest, effects which persisted seven months later.

We inquired about satisfaction with initiative, patience and concentration in the present life situation at baseline and then after therapy. Participants made substantial improvements as a result of the psychological interventions. Findings from GYNONC-QoL-CSBAE on depression, anxiety and QoL covariated with results of the whole sample from MADRS, HADS-A, and EORTC QLQ-C30. In our study, the effects of a more positive self-image and higher self-esteem were correlated with higher bodily and psychological well-being, a better ability to take initiative, to be patient, and to concentrate. All together, these results point to the increased capacity for agency and self-efficacy (Bandura, 1997, 1988). There is a lack of studies in gynaecological cancer survivors in this aspect (Hertrampf, Wärja 2017), but our comprehensive clinical experience points to the importance of these aspects.

MUSIC SELECTIONS BASED IN THE TAXONOMY

The capacity to access and symbolize emotional material held in the body, which may be less acceptable or negative to the conscious mind (Hill, 2015; Stern, 2005), is a great strength of the arts-based methods. This is particularly apparent in music as a time-based art (Bonde, 2005, 2017; Bonny, 1976, 1978, 2002; Bruscia & Grocke, 2002). As supported by our findings, intentional music listening with expression through visual arts and verbal exchanges provided our participants a safe base for retaking and living more fully in the house-of-the-body after cancer (Wärja, Nyberg, Forss, & Bergmark, 2017a). There is support in the literature for holding and supportive music in helping clients connect with feelings and inner resources. This music provides an “aesthetic holding presence” that can assist in restoring and regulating emotions, which can be shaped and expressed further in visual arts and

processed and integrated together with the therapist (and/or group members; Dimiceli-Mitran, 2015; Goldberg, 1992, 2002; Hertrampf, 2017; Meadows, 2013; Summer, 2002, 2009; Wärja, 1999, 2010).

We found that music from category one and two in the taxonomy (Wärja & Bonde, 2014) were most used by the therapists, suggesting the need for firm holding and limited musical dynamics. Hence, we suggest that the therapists selected music based on rationales for affect regulation (Beck & Lindvang, 2017). Pachelbel's Canon was played the most often and chosen by all therapists, possibly due to suggestions in the protocols while facing the full-size body image painting (eyes open), and at the time of closure for the "panorama installation" (displaying the produced arts). Thus, the purpose of this canon, played by strings, was to provide a reliable tonal atmosphere and a steady tempo for attending to paintings, and not foremost for an inward imagery experiences. Bandura was the music second-most often used. This piece is played by piano and double-bass and has a slow and gently rocking rhythm suggestive of a lullaby and safety. The two pieces most often chosen in category three were Innocent and Aron's Dream. The former has a suggestive syncopated rhythm and is more challenging. The latter is graciously holding with a slow and steady crescendo, and yet suggestive of dreamy, longing and plaintive moods (Hevner, 1937), having a potential to open up to emotions while being firmly supported. However, in order to know when in the protocols the more explorative music was used, and how it served the therapeutic process, we need to conduct more thorough qualitative analysis.

DISCUSSIONS ON ARTS-BASED INDIVIDUAL AND GROUP PSYCHOTHERAPY

This project was initially designed to compare individual psychotherapy with a waitlist control condition as described in Appendix C. Still, the control intervention was originally designed as a considerable treatment in its own right, involving group therapy after the proposed waiting time. The rationale included ethical considerations (to provide a substantial treatment), and the research consideration to assess the effects of arts-based group psychotherapy (to be analysed post PhD). Due to unforeseen circumstances resulting in unintentional waiting period in all included patients, we investigated the effects of two hypothesized equal psychotherapies. It is self-evident that there were major differences in content, process, and delivery between the two approaches, of which some are addressed here. Both interventions applied the KMR method designed for individual and group psychotherapy. We found medium to high effects for most analysed variables for both approaches, though

generally, group therapy had a larger effect on a number of dependent variables. This may partly be due to the difference in sample size and the more severe psychological distress at baseline for group participants (Tommy Nyberg, internal statistician, personal communication). The difference between the arms, however was not statistically significant.

Central to both approaches was the development of a therapeutic atmosphere and safety in which the person felt secure and supported to express feelings, either verbally or through the arts (Gerge 2018; Herman, 1992; Meyer DeMott, 2017a). As shown in our results, we found that our methods were useful in this regard. Our data show strong support for both approaches in reducing psychological distress and increasing overall QoL. Both interventions attended to work in the three phases used for addressing trauma and severe crisis (namely stabilization, working through trauma, and integration and coming back into the community; Herman, 1992). The qualitative data provided by the therapists' documentation has yet to be analysed in order to more fully understand how the therapeutic process evolved, and how the arts were used and understood.

INDIVIDUAL PSYCHOTHERAPY

The women in individual therapy were each followed by a dedicated therapist, with a structured treatment protocol that allowed for individualized flexibility. This way of working has gained support in a recent review of music interventions in oncology by Bro and colleagues (2017) who recommended using tailored interventions adapted to the needs of participants with cancer. From the questionnaires, we know that the relationship and bond with the therapist was one factor contributing for the exceptionally high satisfaction among women in individual therapy involving the experience of undivided attention and care. Thus, we gathered that a reliable working alliance had been developed for all women who completed individual therapy, and that the therapeutic relationship contributed to feeling helped, as supported by the high satisfaction at posttest that remained seven months later. Our results are supported by a study by Manne and colleagues (2016) in which 225 women newly diagnosed with gynecological cancer were randomized to two different psycho-oncology treatments, the results of which revealed a correlation between good working alliance and reduced depressions. This impact has been underlined in the large body of psychotherapy research reinforcing the effects of sturdy therapeutic alliance as correlated with positive outcomes (Wampold & Imel, 2015).

Working directly and actively in psychotherapy with feelings and emotions has transformative and healing powers affecting change as supported by research in neuroscience and affect regulation (Fosha, 2002; Fosha, Siegel, & Solomon, 2009). We found support for our methods focusing on the usefulness of emotional expression

in a study for women newly diagnosed with gynecological cancers receiving six individual psychotherapy sessions ($N = 173$; Myers Virtue et al., 2015). Researchers underlined the importance of expressing negative feelings about cancer-related topics for therapeutic progress. In line with the perspectives of Fosha (2002), we suggest that providing avenues to ventilate all kinds of emotions is essential throughout the treatment trajectory and post-cancer treatment. In our study, facing and feeling one's emotions was another factor that was highly rated in individual therapy, that even increased to 100% perceived satisfaction at FU. The individual psychotherapists were attentive and skilled in working with affect regulation and attunement initiated through the arts.

Music was selected consciously (using the taxonomy) to help the woman open up to feelings. The visual arts provided ways to shape and express various affective states, memories, and symbolic images evoked in the music that consequently were reflected upon. In sharing the music and imagery experience and the produced art-work, the therapist was focused on deepening and following the ability of the woman to deal with the affective material. This speaks to a different kind of methodology than for group therapy. Inherent in the individual work is the implicit intersubjective web of communication that moves and billows between the two engaged in a kind of 'musical' duet (Mårtensson-Blom & Wrangsjö, 2013; Malloch & Trevarthen, 2010; Trondalen, 2016). It is a certain act of verbal and non-verbal communication that allows for exchanges of conscious, unconscious and nonconscious psychic material. A particular kind of intimacy and 'tuning in' develops in this way of working in individual psychotherapy that makes the person feel seen, mirrored and accepted, which in turn supports the development of more grounded embodied self-states. We argue that this way of working (through the arts and careful affect regulation) had positive effects on the outcomes. Results from our study can be associated with findings of psychodynamic psychotherapy (Schore, 2012).

GROUP PSYCHOTHERAPY

The positive effects for GrpMI for people with cancer are supported by the literature. Hertrampf (2017) found a significant reduction of anxiety and depression, and improved QoL for women with breast or gynecological cancer in six group sessions that were sustained over a period of 4 months after the intervention. Though our study included exclusively gynecological cancer patients in rehabilitation phase with good prognosis with a significantly worse impact on overall quality of life, sexuality, and fertility than breast cancer survivors, we found significant improvements (Wärja, Nyberg, Forss, & Bergmark, 2017a, 2017b). Dimicelli-Mitran (2015) conducted a six session psychoeducative format with mixed cancer diagnosis where participants evaluated the group as highly supportive and useful in reducing stress and increasing

wellness and coping. We found a strong support for group therapy on self-esteem, and for specific aspects of body image such as shame and experiencing the body as damaged. In our study, group treatment also had a greater effect on depression and worry, in line with Hertrampf (2017). In addition, group therapy was more effective for abilities such as increasing concentration, initiative, and patience, which are qualities related to increase self-efficacy and in turn related to QoL. Group therapy was also more effective in decreasing fear of cancer recurrence. Again, these aspects have not been addressed in previous studies. Based on our data and group dynamic theories (Foulkes, 1974; Whitaker, 1985), we suggest that it was more difficult to access and work with sexual problems in individual therapy, and that group therapy could better uncover and address these matters. The psycho-educative information on sexual health provided by the group therapists may have paved the way for speaking more freely. Hence, when peers addressed sexual problems openly and explicitly, this made it possible to relate and begin dealing with previously unexpressed emotions. Sexual issues related to cancer and treatments were addressed by the individual therapists when this theme was brought up.

The expressive arts method (EXA) lends itself well for working in group settings. One difference between the two interventions was a greater emphasis on EXA methodology in the group protocol in comparison with the individual arm. Thus, the group therapists could utilize various techniques aimed at building cohesion, such as sharing and reflecting personal material in dyads, and then expanding communication to all members in order to support trust in the group as a whole. This was found to be effective as participants reported high satisfaction and benefits with the format. Group therapy participants were subjected to a more structured protocol and had to adapt to the rhythm of the group (and also compete) for attention and space. Nevertheless, previous findings in group therapy research have showed that positive effects occur in witnessing other group members expressing emotions and disclosing information that resembles one's own (Whitaker, 1985; Wärja, 2013b). Mirror reactions is one such factor contributing to change (Foulkes, 1964). Thus, the basis for group therapy is that when one person is working, the whole group is at work. The therapeutic factors identified by Yalom (1980) and used in GYNONC-QoL-CSBAE were helpful in tracking what constituted positive changes in group therapy. Sharing information and feelings with others with similar experiences was the factor rated most helpful. In the groups, alliance was directed towards therapists and other group members. Group members appreciated that the group therapists were also experienced oncology nurses. This may speak to the need for psychoeducative information, which was more prevalent in the groups. Support for this view was found by Sekse & Vika, (2016). Other factors highly rated in the group therapy condition were universality (belonging to humanity), group cohesion, hope, and interpersonal mirroring. Our findings are in

line with a study in expressive arts group therapy with people with trauma (n = 70; Meyer DeMott et al., 2017) in which the specific EXA group factors (Meyer DeMott, 2004/2017) were found to be effective. Results showed significant improvements compared with control (n = 73) in coping with symptoms of trauma, strengthening life satisfaction, and developing hopes for the future. We suggest that one contributing factor for the strong effects of group therapy is the empowerment of "sisterhood," which gives support and encouragement to female cancer survivors in a group setting, as found in the literature (Dibbel-Hope, 2000; Hertrampf, 2017; Lebel et al., 2014; Maheu et al, 2015; Kissane et al., 2004). Generally, mirroring, recognition and identification in group psychotherapy has been found to be highly effective in reducing feelings of self-consciousness and shame and increase self-esteem (Foulkes, 1964; Whittaker, 1985). We assume that the bond that was established at the onset of the groups through self-selected music listening, and recognition and sharing of feelings (vulnerabilities) and cancer-related experiences (universality), contributed to group-cohesion and safety among our group participants. To sum up, even though our study results showed stronger outcomes for group therapy, both approaches were effective, useful and clinically sound. Moreover, participants in individual therapy reported higher satisfaction and benefits with all aspects of treatment. We need to study qualitative measures in more depth and triangulate data in order to gain a more comprehensive understanding of similarities and differences between the arms.

METHODOLOGICAL CONSIDERATIONS

In line with epidemiological praxis at KCE we aimed to include an unselected group of participants. In order to optimize validity, we used the hierarchical step model for reducing bias (Steineck, Hunt, & Adolfsson, 2002). A number of careful steps were taken to reduce bias and be aware of potentially confounding factors, such as misrepresentation, misclassification and analytical adjustment (Figure 7-2). Confounders are inevitably introduced as one moves away from the perfect person-time (person-time is an estimate used in epidemiology of incidence of the actual time-at-risk in years, months or days that all participants contribute to a study). In the ideal study, we would have included all gynecological cancer survivors fitting our inclusion criteria and randomized them into arts-based psychotherapy or a control condition. As this was not feasible, we aimed for a sample of 60 participants supported by power calculations of a medium effect size, since the effect of KMR had not been tested previously. As all real-life studies involve a certain degree of challenges, a number of confounding factors must be considered. These are described and discussed here.

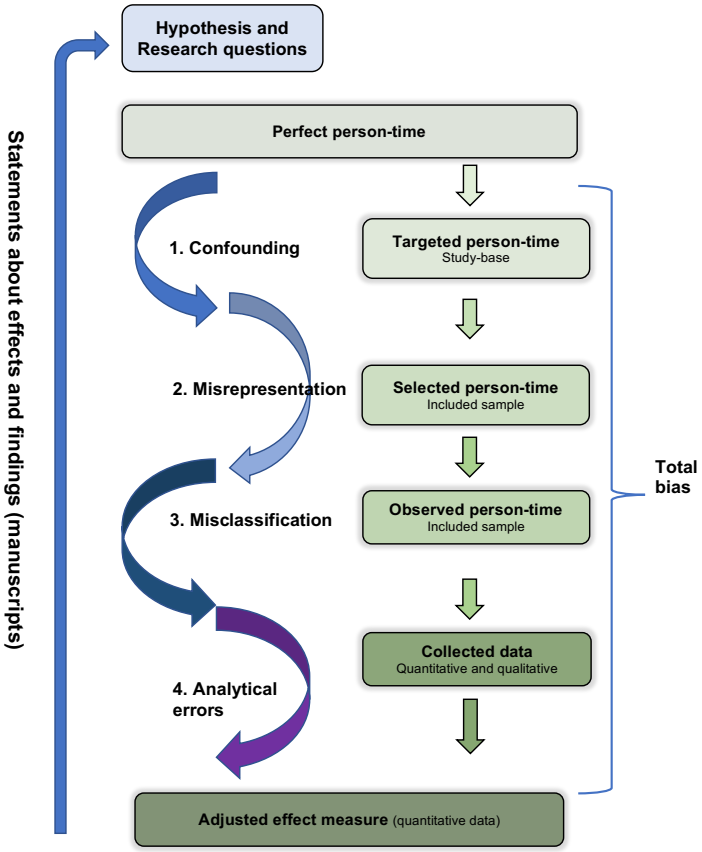


Figure 7-2. Hierarchical step model (Steineck, Hunt & Adlofsson, 2006)

MISREPRESENTATION

In the process of recruiting participants, we were able to access the entire population of gynecological cancer survivors scheduled to attend medical appointments post oncological treatments during the inclusion period at Karolinska University Hospital, a tertiary facility in the greater Stockholm area. From the entire population of 2881 patients, 594 survivors fitting our inclusion criteria were identified. We controlled for bias of the observed person-time introduced by misrepresentation that may occur when participants leave, resulting in a loss of a portion of the person-time. We worked

to minimize dropouts and prepared to collect information about reasons for leaving in order to assess how a loss may relate to the outcome. In addition, we took steps to track non-participation, i.e. women in our target person-time who, for one reason or another, did not participate

In this group, 312 were informed, 208 declined, and 104 were screened by the principal investigator (MW). Of those, we included 60 participants; three dropped out before completing baseline measurements, leaving 57 to be randomized. For the 208 who were asked but not interested, we have documented reasons for 130, but not for 78.

One consequence of the organizational changes at the oncology clinic was the large number of potential participants (n = 282) who were not informed about this study (nurses did not have time or opportunities to ask). Thus, we have a loss of information about those who were not asked, and about those who were asked and declined (for whom the reasons are not known). We know that this shortcoming was mainly due to the pressured work situation for the nurses, particularly during the last year of the inclusion time. We have a rich data set of demographic and clinical information of the included sample but have only access to limited clinical data in medical charts of the target sample of 594 survivors. Therefore, we cannot rule out the possibility that those who did not participate were somehow different from our sample. Still, we have no reason to believe that there was a systematic error in how this information in person-time was lost.

At baseline, the GYNONC-QoL-CSBAE provided detailed socio-demographic information about known possible confounding factors such as age, living situation, marital status, education, previous traumatic events, co-morbidity, varying cancer treatments, religious practices, relationships, and other modifiable factors (exercise, self-care, leisure activities, and partaking in cultural events).

Our study included a sample of women (mean age 55.5, range 27–75), most of whom had a steady partner, a high level of education, were still active in the workforce, had sought prior psychological support, exercised regularly, and reported leisure time. Nevertheless, this self-selected sample presented a high level of emotional distress as an aftermath of cancer, possibly contributed to by prior experiences of trauma and existential fragilities. Another factor to consider is the nature of the offered treatment. It is inevitable that self-selection will occur in recruitment for psychotherapy. In this research, we were interested in studying the effects of therapeutic treatment in which it was possible to address profound cancer-related distress. Persons interested in participating in a psychodynamic psychotherapy study have to be motivated and prepared to work on psychological problems and be ready to face emotional suffering.

The person also needs to be able to find the time and commitment for such an obligation. For younger persons with smaller children, carving out the time might have been difficult. In this sample, 40% had been in verbal psychotherapy before and thus knew what this might entail. It does not suggest however, that participating in arts-based psychotherapy would predict a positive outcome. We assume two main factors contributed to the self-selected sample: (1) the socio-economic level and high level of education, and (2) the high prevalence of cancer-related distress. There was also a large incidence of reported earlier traumatic events and having sought support from social services. One other factor that might have contributed to the characteristics of our sample was that a majority reported being active music listeners. We do not know to what extent previous trauma exposure and modifying factors differ from the larger study population. Psychological well-being is based on a number of factors, such as education, active leisure time and social network.

In reflecting on the recruitment process, we think one major problem was not having access to one research nurse assigned to this study. Even though the nurses (in particular one) were indeed engaged in providing written information to eligible persons, they could not speak about the intervention in more depth.

Participants' response rate and adherence to treatment was generally high. For a majority of participants who left before starting treatment or dropped out during therapy, we have documented their motives and have no reason to believe that this loss of information was a systematic confounding factor.

MISCLASSIFICATION

Regarding misclassification, we encountered a threat to validity involving errors in the instruments (questionnaires). This refers to constructing unclear questions and measuring a non-existent exposure, when in fact this is not correct. Recommended ways to address these problems are randomization and blinding. We applied randomization and some blinding, but for obvious reasons it is almost impossible to obtain blinding in psychotherapy studies (Bradt et al., 2016).

This study was carefully designed and grounded in the initial qualitative phase. The use of study-specific questionnaires has been a hallmark of the KCE research group for over two decades. The rationale is that many validated forms are not specific and sensitive enough to capture nuances of distress and degrees of symptoms for a particular population. A drawback of our methods is that it complicates comparison with findings of other studies that used generic questionnaires, such as EORTC-QLQ-C30, HADS, MADRS. Therefore, we supplemented our data collection with these instruments. We aimed to build a study-specific measurement with high internal

construct validity that was designed for the particular and assessed needs and circumstances of our study population: gynecological cancer survivors, post oncology treatment. Our five questionnaires (GYNOC-QoL-CSBAE) were meticulously constructed from in-depth interviews. The identified themes were subjected to face-to-face validity with women in recovery after gynecological cancer, and then thoroughly peer-reviewed. Nevertheless, we might have missed questions of importance. We strived to formulate questions that were conceptually and intuitively clear, thus easily understood. The three individual versions were tested in a pilot study, resulting in only minor alterations, pointing to the feasibility of GYNONC-QoL-CSBAE. One alteration was the addition of questions specifically related to group dynamics for group therapy at posttest and FU. We did not test these specific questions beforehand, which may have been a shortcoming in the design. Even though our questionnaires were found to be useful and viable, they nonetheless required considerable time, engagement and effort to fill out. We therefore inquired about possible stress due to the testing exposure and were available for support if needed. On the other hand, particularly during the phase of buildings the questionnaires and face validity, a number of survivors stated feeling seen, respected and understood as the cancer-related psychological suffering was taken seriously and addressed in such detail. These clinical observations are supported in a study by Thulin and colleagues (2013) who found that the use of study-specific questionnaires was a positive experience for 95% of the study population of gynecological cancer survivors (n = 789) and urinary bladder cancer survivors (n = 491). Participants reported that the questions provided an opportunity to reflect on their illness, treatment and survivorship. In our study, no reports of discomfort were expressed. In addition, in filling out these forms privately at home, the person has time to reflect, come back to certain questions, and report on matters such as assault, trauma, sexual matters and feelings of shame that could otherwise be difficult to speak about in an interview with an unfamiliar person.

Another step to avoid bias was to plan the two interventions carefully. Development of the arts-based psychotherapy was an interdisciplinary endeavor in our core team and constructed based on clinical experiences and methodological fine-tuning, and on feedback from professionals working with these methods. The individual protocol was tested in a pilot study. The therapists who delivered the interventions in the main study were trained in psychotherapy and the specific approaches used, had extensive clinical experience, and were prepared beforehand. Supervision was provided when needed. Treatment fidelity and adherence were monitored meticulously by using different forms and documentation, such as the forms filled out by therapists of all sessions, and the checklist for reporting on arts-based interventions (Hertrampf & Wärja, 2017).

In terms of blinding, the therapists were blinded to the results of the contents of the self-assessed questionnaires (only cancer diagnosis and age were provided). The purpose was that having information beforehand might influence and limit choice of treatment methods, instead of allowing a focus for therapy to emerge within the therapeutic alliance, as was our intention. No therapist was part of the core research team, whose members in turn were blinded to the progress of therapy. Moreover, persons who received individual therapy were randomized to the therapists. We are aware that randomization is not the natural way to enter into psychotherapeutic relationships. There is support in the literature for better outcomes for psychosocial treatments, especially for individuals with cancer, when the person can make a choice based on personal preferences (Ben-Ayre et al., 2015). Nevertheless, we found exceptionally high participation satisfaction for both treatment approaches.

Due to the previously mentioned structural changes at the hospital, inclusion was affected, which obstructed the inclusion period beyond our control. This posed a limitation for our study and potentially impacted our positive findings, implying that we might not have measured what we intended using our questionnaires. For example, instead of cancer-induced distress we could have collected data caused by other kinds of psychological problems outside experiences of cancer. Then again, for women recovering from gynecological cancer, we emphasize that "time does not heal." From previous research, theoretical understanding and clinical experiences of survivors, we know that treatment-induced late effects and their physical and psychological impact are not reduced by time, and the effects of treatments like radio therapy may even progress over time Persons afflicted with gynecological cancer are exposed to invasive treatments having a profound impact on self-esteem, body image, and sexuality, as shown in our study and previous research (Bergmark et al., 1999; Bergmark & Dunberger, 2013; Dunberger et al, 2010a, 2010b; Mikkelsen, Sørensen, & Dieperink, 2017; Sekse et al., 2010; Sekse, Gjengedal, & Råheim, 2011; Steineck et al., 2017; Urbaniec, Collins, Denson, & Whitford, 2011; Westin et al., 2016). Grounded in our broad clinical experience, we have noted that the psychological suffering of this population as a consequence of illness and treatments will not heal but rather be repressed unless it is addressed. Hence, despite the prolonged waiting, cancer-related distress was still prevalent for our sample. Thus, we hypothesized that waiting for therapy did interfere with not the outcomes. Data supporting this hypothesis are (1) the significant results and clinically sound effect sizes (Cohen's *d*) that were sustained at seven months FU, (2) no one left the study because they declined to wait, (3) participants had been informed at the time of inclusion that therapy would focus specifically on cancer-related problems and was thus worth waiting for therapy, and (4) exceptionally high positive ratings of satisfaction and reported benefits for being able to address cancer-induced stress and for expression

of emotions. These points suggest that our interventions adequately attended to the emotional needs of this group of women. Nonetheless, to fully understand whether or not waiting had an adverse, positive, or any effect on outcomes, an additional larger study would need to be conducted.

The extended time to recruit participants also affected the study design, and instead of a waitlist control condition, we present findings of two interventions (the waitlist group became an intervention). The loss of the control condition adds a limitation to our study. The first two inclusion groups and randomization procedures moved according to plan and the third was slower but acceptable, but inclusion was strongly impacted for the last two groups. This caused variation in waiting time before psychotherapy treatment could begin. The mean time between end of oncological treatment and inclusion in the study was nine months in both arms. The mean time of waiting for individual therapy was six months (range 1.5–10.5 months), and for group therapy the mean waiting time was 10 months (range 1–12 months). From initial analyses of this data set we have no reasons to believe that waiting for therapy impacted our results or caused misrepresentations. When this problem became apparent the participants were contacted through letters informing them about the situation and that inviting them to contact us if needed. In addition, a personal call was made to all (n = 10) who had been waiting more than eight months inquiring if they wanted to continue waiting. For nine persons, the answer was yes. One stated feeling distressed but decided still to stay in the study. This woman started therapy a couple of months after this discussion, and she expressed high satisfaction with psychotherapy in the posttest interview.

ANALYTICAL ADJUSTMENT

When all data had been collected, the last step was to apply relevant statistical methods. In this final part of the step-model, we used our theoretical understanding and clinical knowledge of the study population and the intervention methods in order to assess for errors and analyze and interpret the findings. One major strength of this study was the joined competences of the members of the interdisciplinary research team who contributed to the analysis and manuscript preparation. In this study, we collected both quantitative and qualitative data. The hierarchical step model refers to the former. As a consequence of prolonged recruitment and waiting we were not able to use a control group and instead evaluated the effects of two different arts-based treatment approaches that were both hypothesized to have an effect. The statistical methods were adjusted accordingly and based on our theoretical and clinical knowledge. In this thesis, we used mixed models and performed a per-protocol-analysis (or as-treated) as the strength of this procedure is to restrict the analysis to those participants who adhere to the study protocols, which gives an accurate picture

of the maximum benefits of treatments (Sedgwick, 2011), instead of assuming that previous reports/scores reflect the accurate situation.

The statistical analysis of GYNONC-QoL-CSBAE was limited to mainly 57 variables in our baseline questionnaires that were most relevant for the four research questions. From those we selected 25 that were analyzed for the effects of treatments. There remain additional questions and variables worth analyzing and comparing with our current findings. Using more refined multivariate analysis, such as adjusting for age, diagnosis, education, prior trauma and psychotherapy, would most likely provide additional information and give a richer understanding of predictors and what factors support change for this population. However, sub-analysis needs to be considered with care and caution and might not provide meaningful data due to the small sample size. In one publication (Paper VI) we presented results of the total sample of supplementary instruments HADS-A, EORTC-QLQ-C30, and MADRS together with analysis of qualitative data. In discussing findings and effects of the two treatment arms, one must keep in mind that the sample size in individual therapy was less than half compared with the group intervention, thus making the statistical analysis in the individual arm more tentative as the ratings of one individual could "tip" the statistical calculations in one direction or another. It was therefore vital to use effect sizes, instead of only p-values, to assess clinical relevance, especially in smaller samples (Gold, 2004). For future analysis, we are interested in studying outcomes of the implemented generic instruments with findings in GYNONC-QoL-CSBAE. Another route to take is to make use of the substantial qualitative data set to be analyzed further and triangulated.

GENERALIZABILITY

Our study was conducted in Sweden between 2012 and 2016 with participants from a large urban area (greater Stockholm). We aimed for a non-selected group that would be representative for the whole of Sweden and possibly the Nordic countries. In terms of psychological distress as a consequence of diagnosis and oncology treatments, we have no reason to believe that there are greater differences between the study population of gynecological cancer survivors (n = 594) and our sample. Concerns about sexual health, fertility and body image are long-lasting concerns of women recovering from gynecological cancer (Stead, Fallowfield, & Brown, 2007, Bergmark et al., 2002, 2005). Again, in accordance with previous research and clinical experiences we emphasize that long-term late effects do not diminish over time, contributing to existential distress that needs to be addressed with a combination of tailored medical, psychosexual, and psychosocial interventions (Manne et al., 2008; Urbaniec et al., 2011).

We do not have access to demographic data to be able to compare our sample and the greater study population in other clinical terms (apart from treatment and basic characteristics). We suggest that differences in demographic characteristics, especially the higher education and socio-economic level compared to the population as a whole, may have impacted the self-selection process accepting an invitation and committing to participate in music and arts-based psychotherapy. Most participants were active in the work force and may have had working positions and life conditions that helped them to adapt to the terms of time and space in order to participate. Previous traumatic events or earlier experiences of psychotherapy may also have been influential factors. On the other hand, regardless of what factors may have influenced the selected sample, our firm view is that emotional suffering, dread and distress as a consequence of cancer, constitute shared common ground for a large part of the population of gynecological cancer survivors. In addition, based on our clinical experience and research findings, we hypothesize that the substantial and positive results of this study would have been even stronger with participants with limited resources and diminished protective modifying factors such as lower education, low socioeconomic level, and a single lifestyle. Women with less supportive life circumstances are more likely to repress traumatic experiences and have been found to exhibit more severe psychological distress as a consequence of gynecological cancer (Ashing-Giwa, 2004; Bergmark et al., 1999). We know that the self-selected sample differed in educational and socioeconomic levels; thus, considering these special characteristics of our sample, we cannot generalize our findings to the greater study population. Nevertheless, we trust that our findings are sound and reliable, and can serve as a springboard for a deeper understanding of the specific needs for therapeutic support of a substantial part of the population. From that standpoint, our results may be generalized to similar populations in other geographic areas, and in rehabilitation of women with other cancer diagnoses.

RECOMMENDATIONS AND IMPLICATIONS

Women treated for gynecological cancer are greatly underrepresented in the psycho-oncology literature on the use of psychotherapy for cancer-related psychological problems (Hertrampf & Wärja, 2017). In this study, we have shown that KMR-Brief Music Journeys, an arts-based psychotherapy method, was useful and effective for reducing psychological distress for this group.

CLINICAL SIGNIFICANCE

The treatment protocols in this study were constructed to specifically address the experiences of a changed body and body-image post-cancer, and to focus on regulating negative affect related to cancer (working both non-verbally and verbally). We found that both individual and group therapy had substantial effects and positive outcomes suggesting that our methods could affect dysregulated body-self states and develop a more trusted, vital, and integrated relationship to the body-self. These results were supported by qualitative findings of analysis of spontaneous paintings of body experiences before and after treatment that showed an improvement in terms of embodiment, and increased trust and acceptance of the changed body (Gerge, Wärja, Gattino, & Nygaard Perdersen, 2017). We resonate with Sekse et al., (2013) who suggested that a phenomenological theoretical perspective of embodiment and sexuality is relevant in order to understand and reflect upon the experiences of a changed body for women recovering from gynecological cancer. Our receptive music and expressive arts-based method is in line with "the paradigm shift" from cognitive behavioural psychology to body-based affect regulation theory and modern neuroscience (Damasio, 1999; Hill, 2015; Schore, 2014). This theory integrates developmental and attachment psychology and creates a direct connection with early relational learning and the adult's reactions to crisis later in life. Moreover, this theory and corresponding psychotherapeutic practices have shown that emotional and traumatic problems must be addressed directly and primarily in the therapeutic relational context with accompanying emotions. Thus, there is strong scientific support to open up the therapeutic range of interventions to therapy models like the arts-based psychotherapies.

RECOMMENDATIONS FOR FUTURE RESEARCH

As this is the first study of its kind, our findings need to be investigated further. Hence, it is recommended that future endeavours use this kind of design in order to provide a more nuanced and multifaceted picture of the layers inherent in the results. For this we recommend using control group conditions with comparable sample sizes. Individual and group psychotherapy are two different treatments methods in their own right, and thus need to be evaluated separately in order to provide more precise information about the various parts of the interventions (such as alliance, therapist's role, implicit and explicit process, functions of the arts and length of therapy). For studies assessing arts-based psychotherapy methods, it is vital to also use qualitative measures for adding nuance, understanding, and depth to the statistical data (Bradt et al., 2015). The present study was performed in the post-oncology treatment phase. We further suggest that KMR and other arts-based therapy interventions tailored to other phases in the treatment trajectory are developed and evaluated. On a more general level, we advise that the taxonomy for music selection is researched in more

depth for its use in music medicine and CAT within oncology settings. Moreover, for future studies we must develop strategies to reach women with lower socio-economic background as we know from clinical experience that this is a risk group prone to high psychological cancer-induced distress. In addition, we must provide relevant information and tailored interventions, and also obtain support from the health care system making it feasible for this group of women to participate in psychotherapy.

RECOMMENDATIONS FOR CLINICAL PRACTICE

Foremost, there is a major lack of psychosocial interventions designed for women recovering from gynecological cancer (Chow et al, 2016; Hersch et al., 2009; Hertrampf & Wärja, 2017). Rehabilitation for these cancer survivors must to be assessed and adapted to individual needs, stipulated as one major goal of rehabilitative services in Sweden (Ekwall, 2009; Hellbom & Thomé, 2013). This entails offering different kinds of treatments for various kinds of psychological problems, as one size does not fit all (Wärja, 2016). Thus, we recommend that findings from the self-assessed questionnaires of GYNONC-QoL-CSBAE, supported by results from HADS-A and MADRS, be applied to improve aftercare and rehabilitative services for this group. Additionally, effective interventions need to attend to all four themes of this study: the changed and altered body, sexual function, fears of recurrence, and meaning-making. Moreover, it is advised that sexual concerns be addressed directly and explicitly both in individual and group therapy (Wärja, Nyberg, Forss, & Bergmark, 2017a, 2017b).

We stress the benefit of a therapeutic process and relationship, and that this needs ample time and space. We concluded that a dosage of 12 individual sessions were sufficient, which is in line with recommendations for GIM of a minimum of 10 sessions for clinical populations (McKinney & Grocke, 2004). For group therapy, we found that six group sessions were not sufficient to address psychological distress for survivors post oncology treatment, but that eight sessions of 150 minutes were satisfactory. Moreover, we recommend the use of an initial individual interview to gather pertinent clinical information, build alliance and prepare for the group work. A group therapy approach has many advantages. A supportive and nonjudgmental group therapy setting can provide a safe space for sharing previously unaccepted feelings such as shame, worthlessness, and inferiority. This space can provide opportunities for healing, since shame, low self-esteem, and negative self- and body-image are related to the social self and the inherent human primary need of belonging, feeling accepted, and participating in a community of others. Encountering women with similar experiences of cancer and late effects (sisterhood) is a strong motivator. As we have seen in our study, we also found that the tailored approach in individual therapy was highly appreciated and beneficial. People differ, and for some persons

individual therapy is the preferred treatment for addressing needs that cannot be fully met in a short-term group context (such as prior comorbidity, PTSD or matters related to personality disorders, or simply personal preferences). Further analysis is likewise needed in order to more fully understand the participants' experiences, and how these parameters covariate with the effects of both interventions.

We suggest that structured (group) and semi-structured (individual) protocols are used and developed in order to evaluate treatments. Furthermore, in order to implement this method in oncology in Sweden in the near future, we suggest that a tailored training in the Arts in Medicine tradition (Hertrampf & Wärja, 2017) is developed and tested for interested oncology professionals such as nurses, physical therapists, and counsellors since such methods seem to hold promising supportive and soothing capacities in rehabilitation medicine. This approach can also involve training in how to use the taxonomy for more conscious music selection in various oncology settings.

Overall, supported by the substantial results of this study, we recommend the use of arts-based psychotherapy as a means of working with verbal and non-verbal exchanges and affect regulation. Modern psychodynamic and interdisciplinary methods are not only justified, but as the participants in our study have demonstrated, also needed and requested in oncology. Healing the mind-body gap requires treatments in which the body is "retaken, reclaimed, and regained" after experiences of cancer. This in turn demands the use of methods, such as the arts-based psychotherapies, that apply non-verbal, implicit and relational ways of working with affect regulation combined with secondary verbal processing for comprehending and integrating these experiences.

CONCLUSIONS

The overarching aims of medical treatment and care, and of rehabilitative medicine, are to assist the person to heal, reintegrate, readjust, and reclaim the body after illness. In line with this, we performed an intervention study (Craig et al., 2008; Medical Research Council, 2008) based on interdisciplinary clinical experiences and theory. Our research methods were designed to meet high quality standards. We used findings from previous research in our group (KCE) and applied an underlying theoretical base for how the selected psychotherapy interventions may cause change (Wärja, Nyberg, Forss, & Bergmark, 2017a, 2017b).

Moreover, we used the theoretical construct and methodological structure of a taxonomy of music intensity to select music for the interventions (Wärja Bonde, 2014).

The primary purpose was to help the individuals decrease emotional pain and suffering and ameliorate QoL. More specifically, we hoped to address and regulate emotional reactions related to cancer, find strategies for better coping with an altered life situation, and enhance wellbeing. The overall results presented here show that the time-limited arts-based psychotherapy that we implemented for women in recovery from gynecological cancer had substantial and positive effects and reduced psychological distress significantly.

Source of Life by “Anna”

POSTLUDE

This poem by Göran Sonnevi (1974, no 150, p 309) has followed me for decades - a poetic statement of the complexity, beauty, and ineffability of humankind, just like the gift of music. It is my aesthetic response to this entire study – to be followed by listening to a piece of music: the Double Concerto for Two Violins by J. S. Bach.

Det växer en människa ur
Musiken, bortanför
alla modeller
Underbart fri, redan!

fullständig
människa, vidöppen
för sorgen, smärtorna
glädjen

En människa kan aldrig reduceras
till summan av
sina funktioner

i moment av ständig nyskapelse
finns inget tvång

varje modell
innebär tvång

vi kan inte heller leva
utan dem
men lever egentligen bara
i ögonblicken vi kastar bort dem

En människa är ingen variabel

Inte ens i allts oändliga funktion

A human being grows from
the Music, beyond
all models

Wonderfully free, already!

complete
being, wide open
for grief, pain
joy

A person can never be reduced
to the sum of
her functions

in the moment of ongoing recreation
is no constraint

every model
means constraint

we cannot either live
without them
but can only truly live
in the moments we throw them away

A human being is no variable

Not even in its infinite function

(Translation by Margareta Wärja).

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APPENDICES

Appendix A. Major types of gynecological cancer

Five major types of gynecological cancer impacts women: endometrial, cervical, ovarian, vaginal and vulvar (Figure App. B-1).

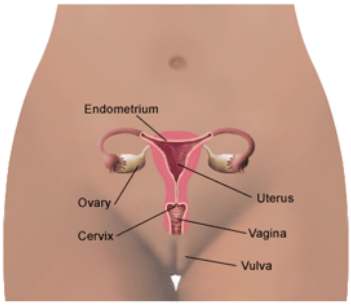


Figure App. B-1. Women's sexual and reproductive organs
http://sylvester.org/cancer/gynecologic/education Retrieved October 30, 2017.

Corpus cancer – Endometrial cancer

Endometrial cancer is the most common tumor of corpus uteri that seldom arises before the age of 40. Most incidents occur in postmenopausal women with a mean age of around 60 (Sorbe et al., 2013). Obesity is a known risk factor, which has been linked to 40 % of the incidence worldwide. In endometrial cancer, malignant cells have formed in the tissues of the endometrium (the lining of the uterus). This lining is hormonally sensitive and shed during the menstrual cycle. Factors that lead to excess estrogen, such as obesity and no ovulation can cause a thickening of the lining, which in some cases develops into cancer. A common symptom is vaginal bleeding. Eighty percent of women with endometrial cancer are diagnosed in an early stage when the tumor is limited to the uterus giving a good prognosis. The most common treatment is to remove the tumor through surgery with a total vaginal or abdominal hysterectomy and salphingo-oophorectomy (removal of fallopian tubes and ovaries). Adjuvant treatment can be prescribed depending on histology and involve chemotherapy, external radiotherapy, and/or brachy therapy (internal radiation).

Cervical cancer

The incidence of cervical cancer has decreased in the last decades due to regular and organized gynecological PAP-smears. The cervix is the lower narrow end of the uterus and connects the uterus with the vagina. Persisting infection with human papillomavirus (HPV), which is sexually transmitted, causes cervical cancer. Possible

contributing factors are smoking, early age of becoming sexually active, many sex partners, use of birth controls pills, and HIV infections (Sorbe et al, 2013). These factors are not independent but may be linked to vulnerability. The disease gives no symptoms in early stages, and vaginal bleedings and discharge develops in later stages. When detected in an early stage the prognosis is good. This kind of gynecological cancer affects primarily younger women, and many women are under the age of 50 at the time of diagnosis. Surgery or radiotherapy are the most common treatments. Cervical cancer has been associated with guilt and shame as this disease is related to sexual activity. Vaginal cancer is a rare disease related to cervical cancer, mostly caused by HPV, with about 30–40 new cases in Sweden annually.

Ovarian cancer

Ovarian cancer develops in women of all ages but more seldom in younger women in their 20s. It often grows slowly over long time, sometimes referred to as "the silent killer," and is the leading cause of death among gynecological cancers. However, five-year survival has gradually increased in Sweden from 28% in 1960s to 43% in women diagnosed 1999-2003. In 2011, five-year survival had increased to 53% in the largest region in Sweden (Åvall-Lundqvist, 2013). Typically, women with ovarian cancer have no specific symptoms until the disease has spread to the upper abdomen; thus 60–70% are diagnosed in a late state. Surgery plays a significant and crucial role in the treatment of ovarian cancer and is used to remove the tumor and for diagnostic purposes. An early diagnosis of ovarian cancer most often occurs in asymptomatic women attending routine check-ups. The causes are not fully understood, but dominating risk factors are related to reproduction and hormones. Ovarian cancer requires a combination of surgery and chemotherapy.

Vulvar cancer

In Sweden, the incidence of vulvar cancer is approximately 150 new diagnoses annually. In younger women (mean age of 55) vulvar cancer has been associated with HPV infections and immunological factors. In older women (mean age of 77) there are no such connections (Lindell & Hellman, 2013), but rather an association with chronic skin inflammation. The preferred treatment for vulvar cancer is surgery. Adjuvant radio(chemo)therapy or primary radio(chemo)therapy may be used.

Appendix B. Ethics approval

PROTOKOLL 2012/5:1
2012-01-19

Sammanträde i Stockholm

Avdelning 5

Ordförande
Birgitta Widebäck

Ledamöter med vetenskaplig kompetens
Claes-Robert Julander *(företagsekonomi)* vetenskaplig sekreterare
Siv Fischbein *(specialpedagogik)*
Karin Helmerson Bergmark *(sociologi)*
Ilona Koupil *(ojämlikhet i hälsa)*
Francisco Lacerda *(lingvistik)*
Ulla Manns *(genusvetenskap och idéhistoria)*, deltar ej i ärende 2011/2004-31/5 och 2011/2084-31/5.
Teresa Simon Almendal *(skatterätt)*
Jerzy Sarnecki *(allmän kriminologi)*
Ann-Charlotte Smedler *(psykologi)*, deltar ej i ärende 2011/2042-31/5.
Sten-Åke Stenberg *(sociologi)*

Ledamöter som företräder allmänna intressen
Maria Modig
Anders Rehn
Annika Sandström
Elisabeth Wennerholm
Anne Wompa

Administrativ sekreterare
Ann-Christin Becker

§ 1 Ordföranden förklarar sammanträdet öppnat.

§ 2 Den administrativa sekreteraren anmäler att den vetenskaplige sekreteraren sedan föregående möte den 15 december 2011 har fattat 4 beslut i ärende som avser ändring av ett godkännande.

§ 3 Ansökningar om etisk granskning av forskningsprojekt, se **Bilaga**.

§ 4 Ordföranden förklarar mötet avslutat och meddelar att nästa sammanträde i avdelning 5 äger rum torsdagen den 16 februari 2012.

Birgitta Widebäck
Ordförande

Claes-Robert Julander
Protokollförare, vetenskaplig sekreterare

Adress	Besöksadress	Telefon	Fax	E-post	Hemsida
FE 289 171 77 Stockholm	Nobels väg 9 171 65 Solna	08-524 800 00	08-524 866 99	kansli@stockholm.epn.se	www.epn.se

Regionala etikprövningsnämnden
i Stockholm

Protokoll 2012/5:1

Utdrag ur protokoll från sammanträde den 19 januari 2012 i avdelningen 5.

Nya ärenden

Diarienummer
2011/2131-31/5
Föredragande
Siv Fischbein

Sökande: Stockholms läns landsting
Behörig företrädare: Roger Henriksson
Projekt: Musikterapi för kvinnor behandlade för gynekologisk cancer.
Forskare som genomför projektet: Karin Bergmark

BESLUT
Nämnden godkänner forskningen.

Beslut expedierat till behörig företrädare.
Kopia för kännedom till ansvarig forskare.
Att utdraget överensstämmer med originalet intygar:

Ann-Christin Becker, administratör/expedierat. 2012-01-25

Appendix C. Original Mixed Method study design

Mixed method study

This project was originally conceptualized as a mixed methods research study aimed at triangulating quantitative and qualitative data within the frame of the PhD study (Creswell, & Plano Clark, 2007). Due to organizational changes at the Oncology Clinic at Karolinska University Hospital, we could not follow through with the original design, which was a multi-strategy, explanatory sequential study (Robson, 2002)[6]. The initial plan was to compare outcome measurements related to the four research questions of the individual intervention with data from pretest provided by the control group (a waitlist control) collected right before the start of the group therapy intervention (see flowchart Figure App C-1).

As described in detail in the linking text, we first conducted a thorough inductive qualitative phase that consisted of an interview study, constructing and selecting measurements, running a pilot study, and designing two study protocols. In the next phase, the main study, we used a permuted block design. When 12 participants had been included based on our criteria, we performed randomization to either individual therapy or a waitlist.

All participants had been informed that they would receive either individual therapy or group therapy, and that randomization would take place when 12 persons had been included. In addition, if the woman was randomized to group therapy she had been informed that therapy would start three to four months later. This did not seem a long wait as the starting time worked well within the rhythms of the seasons, such as after or before a summer holiday (Swedes generally take long summer breaks/holidays).

Prolonged inclusion

The recruitment process worked according to the estimated time frame for the first two groups and within an acceptable time for the third group. However, for group four and five the time needed to recruit participants took far more time than planned (Table App. C-1).

[6] Robson, C. (2002). Real world research: A resource for social scientists and practitioner- researchers. Oxford, UK: Blackwell.

Permuted block	Participants *N* = 57	Inclusion period	Time for inclusion
Group I	12	March 24, 2012 – June 7, 2012	3 months
Group II	11	October 4, 2012 – December 11, 2012	2 months
Group III	12	February 5, 2013 – July 1, 2013	5 months
Group IV	12	July 19, 2013 – February 28, 2014	7 months
Group V	10	March 19, 2014 – March 10, 2015	12 months

Table App C-1. Time periods for inclusion of participants for trial

Due to changes in the work load, the nurses involved in recruitment did not have the sufficient time in their schedules to follow up and inform all potential participants on the weekly appointment-lists who had been screened by Dr. Bergmark. With the organizational changes at the clinic and a growing workload, it was a challenge to find sufficient time. Providing information to a potential participant eligible for inclusion involved a number of steps and difficulties.

Parallel design with two arms

The consequences of the prolonged inclusion and waiting time that fluctuated between persons in both treatment arms influenced the design in such ways that we could not use the data from the pretest of the waitlist control group for comparison with posttest of the individual intervention arm (see discussion of methods in chapter 7). Therefore, instead of a wait-list/control group we decided to use a design of two parallel treatment arms and compare measurements within each arm at three timepoints, and between the treatment arms (see flowchart Figure App C-2). In other words, this study developed into a randomized trial in which we compared two arts-based psychotherapy interventions. Hence, the timeline in this PhD project became stretched out and did not allow sufficient time to triangulate outcome findings with the qualitative measures.

(In paper VI we present some findings where we bridge qualitative and quantitative data: body image drawings, results of HADS-A, EORTC-QOL-C30, and MADRS of the whole study sample).

Change in one study protocol

We made another change in the design based on clinical needs that emerged within the course of the research. he initial study protocol for group therapy had six weekly sessions. When I met with the participants from the first group therapy for an individual interview at posttest after treatment had ended, I found that there was generally a high satisfaction with the therapeutic help that had been received, but that the group time had not been quite sufficient. A number of participants stated that they would have needed a few more sessions to allow for the work and process to settle in and be integrated. This feedback was in accordance with the opinions of the two group therapists. They meant that the allotted time was too short to meet the needs of the participants, and to follow through with the aims of the study protocol. As a consequence, we discussed the situation in the core research team together with the therapists and the head of the oncology clinic.

We decided to favor the assessed clinical and therapeutic needs of the participants over staying with the original design. As a result of this meeting we added two more sessions to the group therapy protocol. Thus, the participants randomized to group therapy in inclusion groups II-V had eight weekly sessions.

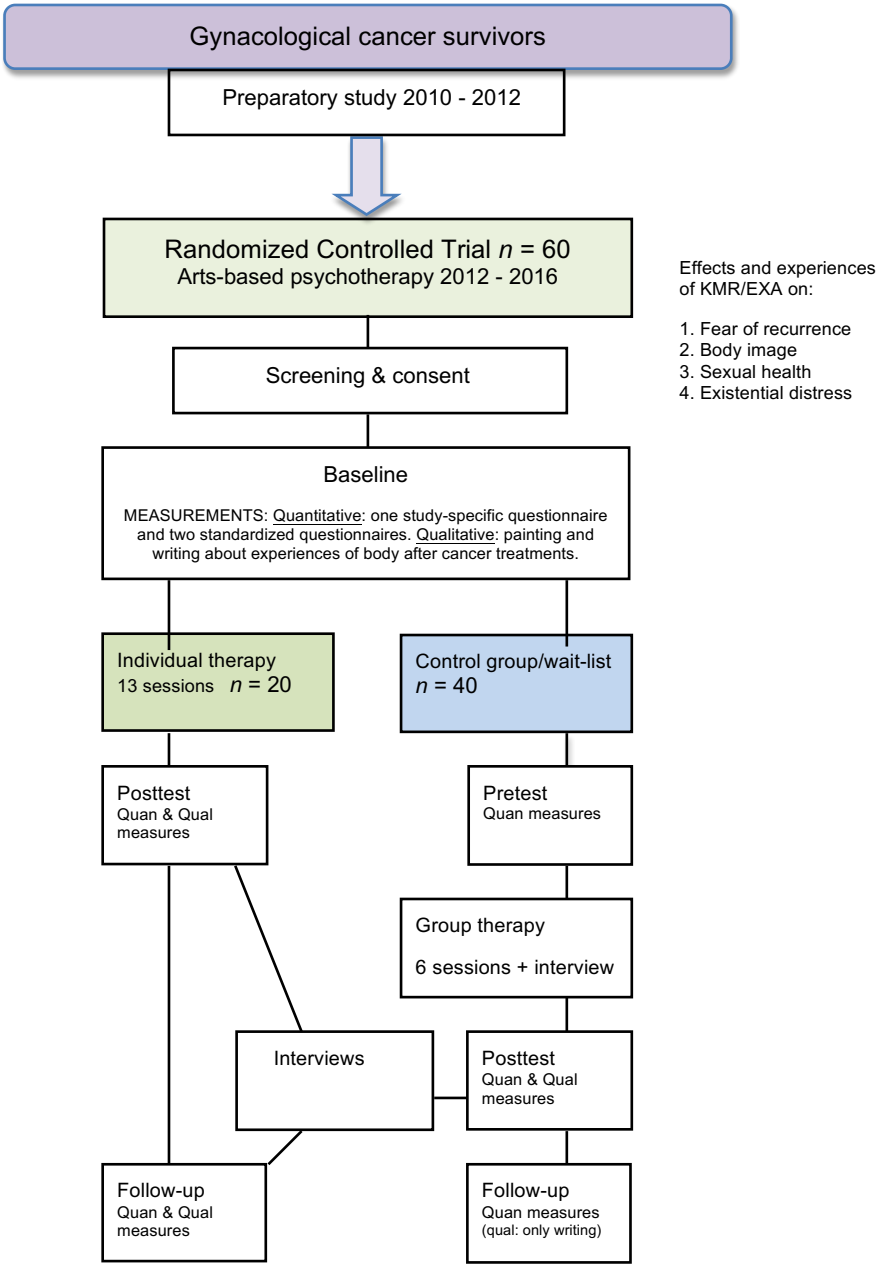


Figure App C-1. Flowchart of original design

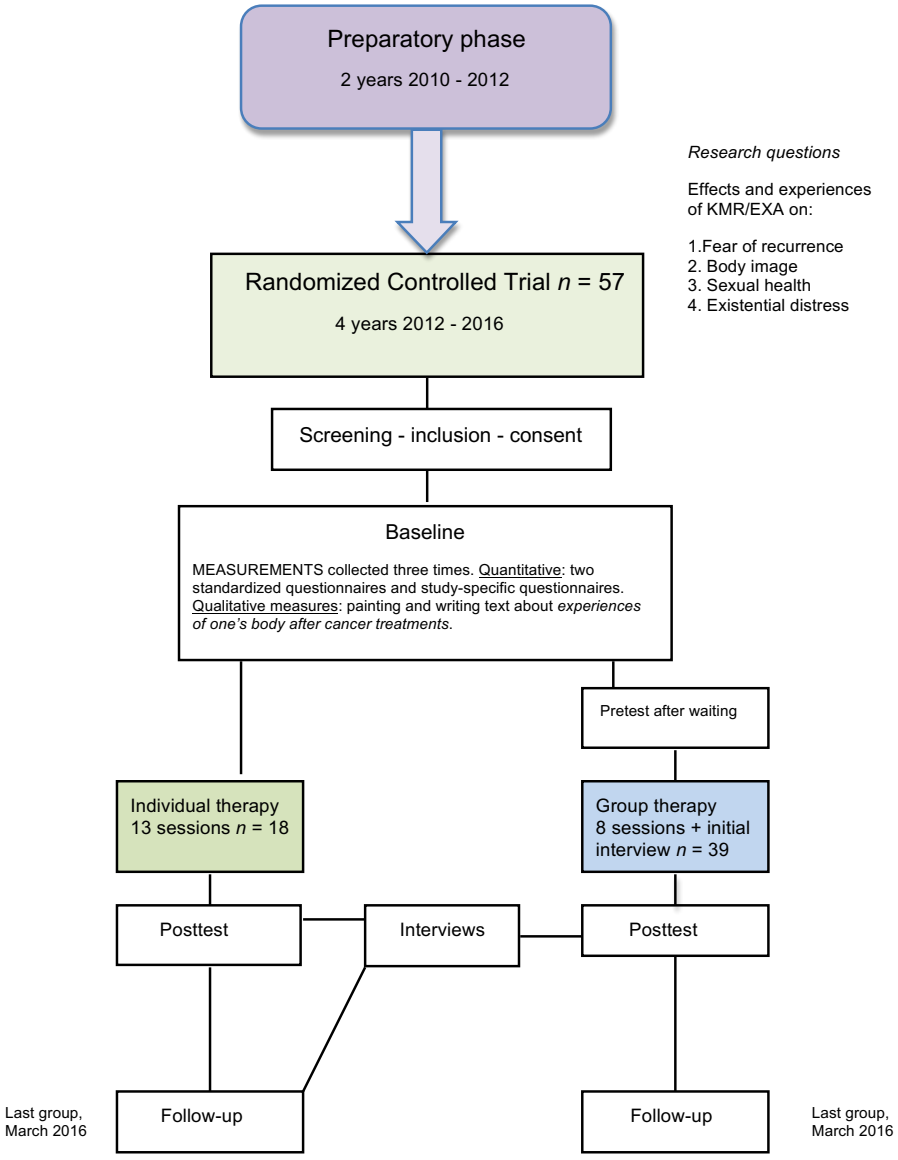


Figure App C-2. Flowchart of revised design with parallel treatment arms

Appendix D. Statements from interviews with gynecological cancer survivors and HCP

Here follows illustrations of interview statements from the preparatory phase in the study, followed by a summarized sentence by me in italics. There is no hierarchical order among statements (Tables App D-1, App D-2.)

SURVIVORS
"Everyone expects me to come back and be like I was before". *Anxieties, worries and fears after treatment; hard to return to a functioning every-day life.*
"I know it is my fault, time to be punished." *Feelings of guilt and shame of having lived a life that brought on and caused the cancer.*
"I was surprised, but it was rather OK during treatments, everyone was so kind and professional. But now I´m in a crisis, where is the help?" *The full emotional impact of cancer comes first after oncological treatment has been completed.*
"I don´t recognize my body anymore." *The body feels detached, fragmented, and foreign.*
"I used to enjoy sex…I have no sex appeal." *Sexual problems, loss of pleasure, and pain during intercourse.*
"We had planned a family. How can I live without having any children?" *Loss of fertility creates an identity crisis, and an existential loss.*
"The body has betrayed me*." Not trusting the body.*
"Every little ache in the body is felt like the cancer is back. I can think – 'probably not,' but it feels that way." *Fears and anxieties that the cancer will return.*
"Who am I as a woman? What is my worth*?" Identity crisis and negative self- image*.
"How can I possibly live with this knowing and the engulfing fears?" *Existential crisis.*

Table App D-1. Interview statements gynecological cancer survivors

HCP
"It is necessary to help the woman speak of fears of death and help find ways to cope with anxiety. And to begin release what is pent up in the body. So many fears held there." *Fears, existential crisis.*
"It is central to listen and take in each story. Hear what this woman says. Most important is to listen, listen, listen…" *Each woman has a unique experience and subjective story.*
"The whole family is affected – a systems approach is helpful where there is room for everyone in the family to deal with the situation." *The family system and the psychosocial context.*
"There is a great deal of unnecessary suffering and misunderstanding here. This can be helped with proper treatment and information. And check-out how she feels in her body." *Sexuality, and the body; important to ask the direct questions about sexuality.*
"Women with cancer are often so very thankful, but help her to also express her negative feelings. There is anger about cancer, and so much fear to get cancer again, even when the risk is rather low." *Negative feelings and fears needs an avenue for expression.*
"Due to high mortality, as many women with gynecological cancer have a relapse, we must be ready and prepared to help her cope with high degree of stressors and fears of dying." *Existential themes, fear of cancer, and coping.*
"Many women are depressed with very low serotonin levels. Some even severely depressed. They can be greatly helped by anti-depressive medicine as a way to return to every-day life. And this we can help with!" *The prevalence of depression as a treatment-induced effect.*
"It is important to also work with other means than talking, for example with physical therapy, music, dance or arts. We must work with the body. This can help the woman find her strength and develop resources. It is a safe way, and creates a positive space for reflection. In fact, working nonverbally makes it easier to then talk." *The need for nonpharmacological treatment*.
"I was the only one in a huge hospital to provide psychotherapy and counseling. This must be changed. We must have these options. Especially after treatment has ended, or when the person has a relapse." *The importance of offering psychotherapy in oncology*.
"Medical staff needs to be informed about sexual distress and dysfunctions that are caused by treatment procedures. And they should discuss this with the patients. It is indeed unfortunate that this is not happening." *HCP's need more knowledge about sexual dysfunctions, and learn how to address sexual concerns with women with gynecological cancer.*

Table App D-2. Interview statements health care professionals

Appendix E. Pilot participants

Clinical characteristics for the five participants in the pilot study. (Table App. E-1).

Age	*Employment*	*Marital status*	*Children*	*Diagnosis*	*Treatment*	*Time post treatment*
45	Self-employed artist	Married	0	Endometrial	Surgery, brachy, chemo	12 months
42	Media/advertising	Single	0	Ovarian	Surgery, chemo	18 months
55	Civil engineer	Married	3	Ovarian	Surgery, chemo	12 months
25	Pre-school teacher	Married	0	Cervical	Surgery, brachy radio-therapy	36 months
29	Copy-writer	Married	1	Cervical	Chemo, brachy	24 months

Table App E-1. Clinical characteristics pilot participants.

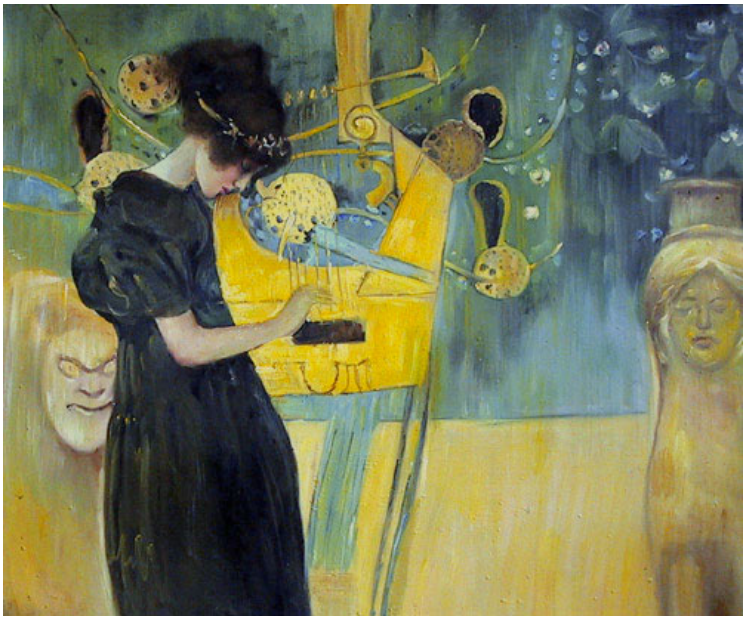
Appendix F. GYNONC-QoL-CSBAE- a sample

This study-specifc questinnaire comes on five versions: baseline, individual posttest and FU, and group posttest and FU. It contains HADS-A and KMS (provided here among the sample questins) and Herth Hope Index which is found in Appendix J. (The Swedish original five versions are found on USB).

SAMPLE QUESTIONS FROM THE BASELINE QUESTIONNAIRE

Music Therapy for Women Treated

For Gynecological Cancer



GYNONC-QoL-CSBAE

Gynecological Oncology - Quality of Life - Coping, Sexuality, Body and Art Experiences

A study of

Music Therapy for Women Treated For Gynecological Cancer

Project address:

Expressive Arts

Fjällgatan 23 b

116 28 STOCKHOLM

Klinisk Cancerepidemiologi

KI, Karolinska Universitetssjukhuset, Z5:U1

171 76 STOCKHOLM

Cover: Gustav Klimt, *Musik,* 1895

Number: _____

The purpose of this study is to evaluate a form of music therapy for women treated for gynecological cancer with the aim to contribute to better care and rehabilitation. This work is conducted within a psychotherapeutic frame where verbal dialogue and the therapeutic relationship is the basis for the work. In this method, we will also use music listening and paintings. You do not need to have any previous experiences with music or artwork to participate in the study.

This questionnaire is developed specifically for this study and contains questions about symptoms, hospital care and treatment, quality of life, existential questions, self-image, self-esteem, body experiences, sexuality, experiences of the arts and cultural events, and self-care. The form starts with questions about life in general and experiences before cancer. All questions have been constructed through input from interviews with gynecological cancer survivors. These women have shared their experiences, thoughts, feelings, difficulties and personal needs.

These questions are constructed in such a way that you will **always** answer by checking the item that best corresponds to your situation. Sometimes we ask many questions in a row on one theme. It is important to us that you **answer each separate question**. We have provided many spaces where you can write additional comments. As you see, this questionnaire contains many questions. It is easy to miss a question. Please look through the form to make sure that you have answered all questions. In the last part, we ask how the experience of filling out the form was for you. At times, it may be hard to answer some questions. We are grateful that your answers are as close as possible to your personal life situation and experiences.

The therapists who are assigned to this project **will not** be given any information about the results of the forms filled out by participants during the study time. You are of course free to share any information you like with your own therapist. There might be thoughts and feelings that can be helpful to share prior to the work in therapy. The work in therapy and the forms that you fill out will be treated with strict confidentiality. The material is handled according to the ethical code of medical research.

You are always welcome to call if you have questions or need some assistance.
You can reach secretary Gerda Bergqvist at 08/640 74 47 and Margareta Wärja on: 070-749 07 56, or email: margareta.warja@expressivearts.se

This project is a collaboration between Aalborg University, Karolinska University Hospital, Karolinska Institute, and Expressive Arts Stockholm Inc.

Thank you for your valuable contribution!

Project Group

Margareta Wärja, PhD Fellow at Aalborg University, lic. psychotherapist, music- and expressive arts therapist, Expressive Arts Stockholm Inc, Sweden.

Karin Bergmark, M.D. PhD., Karolinska Institut, Stockholm, and Sahlgrenska University Hospital, Göteborg, Sweden.

Lars Ole Bonde, Prof. Dr. Aalborg University, Denmark.

Gunder Forss, lic psychologist, lic. psychotherapist, Expressive Arts Stockholm Inc, Sweden.

The baseline questionnaire contains 261 questions. This sample of 76 questions was selected based on the questions and variables most relevant to this thesis. Many questions in this form have sub-categories/items. For example, HADS-A (C16) is counted as one question but has seven separate items. Ample space is provided throughout the questionnaire for writing open comments on the themes of inquiry, such as body image, sexuality, oncological care, self-care.

Part A: total questions *n* = 37, sample *n* = 9

A. General questions and previous care
The questions below are relevant for this study and focus on life in general, previous experiences, your current life situation, and earlier medical care. Answer the item that is most relevant to you.

Date of today: _____

A. 1. When where you born? Year: _____

A. 2. In which country where you born?

- ❑ Sweden
- ❑ Other country, please specify _____

A. 7. Are you today

- ❑ Married or cohabiting
- ❑ Widow
- ❑ Living alone with partner living apart
- ❑ Living alone without steady partner

A. 11. Which is your highest education/degree?

- ❑ Elementary school or equivalent
- ❑ Secondary school or equivalent
- ❑ College or university

A. 12. Are you today

- ❑ A student
- ❑ Seeking employment
- ❑ Self-employed
- ❑ Employed
- ❑ Not employed, household work
- ❑ On sick leave
- ❑ Disability pension
- ❑ Retired

A. 14. Have you given birth to a child (children)?

- ❑ No
- ❑ Yes, (how many children): _____

A. 21. Have you been in psychotherapy before cancer and its treatments?

- ❑ No
- ❑ Yes, namely:
  Check what is most relevant. You may check as many as apply –

  - ❑ Yes, cognitive psychotherapy (CBT)
  - ❑ Yes, psychodynamic therapy
  - ❑ Yes, family therapy
  - ❑ Yes, other, please specify: _____

A. 23. Have you at any time before cancer treatment sought help for psychological problems?

- ❑ No
- ❑ Yes, general practitioner
- ❑ Yes, company health care
- ❑ Yes, out-patient psychiatric clinic
- ❑ Yes, private clinic
- ❑ Yes, other, please specify: _____

A. 31. Have you at any time in your life had a traumatic experience or event (or events) apart from cancer?

You may check as many as apply –

- ❑ No

- ❑ Loss of a child
- ❑ Physical assault
- ❑ Accident, namely: _____
- ❑ Sudden death, namely: _____
- ❑ Robbery/assault
- ❑ Severe illness, namely: _____
- ❑ Rape
- ❑ Other, namely: _____

Illustration of an additional space for comments that reappear throughout the form.

Space for additional comments related to traumatic events in life.

_____
_____
_____
_____
_____
_____
_____
_____
_____

Part B: total questions *n* = 41, sample *n* = 11

B. Recent medical care and treatments, and self-care
You who participate in this study have been treated for gynecological cancer. We ask you to answer the following questions regarding care and oncological treatments. The questions pertain to care at Radiumhemmet and other facilities. If you need to clarify anything in terms of your care there is space provided.
In this section, we also ask about self-care before and after cancer.

B. 1. What kind of gynecological cancer have you been treated for?

- ❑ Uterine cancer (corpus cancer, endometrial cancer)
- ❑ Cervix cancer
- ❑ Ovarian cancer
- ❑ Other form, specify: _____

B. 10. What kind of cancer treatment (treatments) have you received?

Circle the digit that best correspond to you -

Operation	No	Yes
External radiation	No	Yes
Internal (brachy) radiation	No	Yes
Chemo therapy	No	Yes

Other, namely: _____

B. 20. When was oncological care terminated? _____

B. 22. Did you have any kind of psychological support and/or psychotherapy after cancer treatment?

- ❑ No
- ❑ Yes, namely: *You can check more than one alternative –*
  - ❑ Psychologist
  - ❑ Medical doctor
  - ❑ Social worker
  - ❑ Nurse
  - ❑ Other, namely: _____

B. 24. What problems did you need help with? *You may check as many as apply –*

- ❑ Not relevant

- ❑ Depression
- ❑ Family problem
- ❑ Life crisis
- ❑ Fear of cancer recurrence
- ❑ Exhaustion (fatigue)
- ❑ Anxiety
- ❑ Other reason, namely: _____

B. 30. Have you been exercising regularly (every week) during the last six months?
You may check as many as apply –

- ❑ No
- ❑ Yes, dance
- ❑ Yes, gym
- ❑ Yes, group training (such as aerobics, group workouts, body pump)
- ❑ Yes, jogging
- ❑ Yes, walks
- ❑ Yes, horseback riding
- ❑ Yes, swimming
- ❑ Yes, with walking sticks (so-called Nordic walking)
- ❑ Yes, other kind, namely: _____

B. 32. How helpful has it been to exercise for your bodily well-being?

❑ Not relevant

Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6

Not at all helpful Very helpful

B. 32. How helpful has it been to exercise for your psychological well-being?

❑ Not relevant

Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6

Not at all helpful Very helpful

B. 34. Have you used any other kinds of self-care on a regular basis during the last six months?
You can check more than one alternative –

- ❑ No
- ❑ Yes, relaxation exercises
- ❑ Yes, meditation/mindfulness
- ❑ Yes, a special diet, namely: _____
- ❑ Yes, yoga/qigong
- ❑ Yes, other form, namely: _____

B. 35. How helpful has this self-care been for your bodily well-being?

❑ Not relevant *Circle the digit that best correspond to you -*

0----------1----------2----------3----------4----------5----------6

Not at all helpful Very helpful

B. 36. How helpful has this self-care been for your psychological well-being?

❑ Not relevant *Circle the digit that best correspond to you -*

0----------1----------2----------3----------4----------5----------6

Not at all helpful Very helpful

Part C: total questions *n* = 55, sample *n* = 17 (HADS-A is included: C 16)

C. Quality of life
It is common that a person who has received a cancer diagnoses and goes through with treatments, starts thinking of existential questions. These questions can relate to the meaning of life, faith, how to create a meaningful existence. It can also relate to thoughts about "why did I get cancer," feelings and fears of cancer recurrence, and how to continue living a life as rich as possibly. Also, the term quality of life involves issues of personal and intimate relationships to other people.
We ask you to answer the following questions about how you have handled these themes: how you feel about them, and how you think and reflect on these matters.

C. 1. How do you perceive your quality of life during the last six months?

Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6

Lowest possible quality of life Highest possible quality of life

C. 2. How meaningful has your life been the last six months?

Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6

Worst possible meaning Highest possible meaning

C. 3. How well do the following five (three in this sample) questions correspond to you during the last six months? *Check the box that best correspond to you –*

c). What religion is closest to you?

❑ None
❑ Christianity
❑ Islam
❑ Judaism
❑ Buddhism
❑ Hinduism
❑ Other, namely: _____

d). How strong is your religious faith?

❑ I do not have a religious faith
❑ I have a small religious faith
❑ I have a somewhat strong religious faith
❑ I have a strong religious faith

e). Do you have a "personal faith" that gives meaning to your life?

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

C. 16. (HADS-A). How well do these statements correspond to your situation during the last six months?
Check the box that best correspond to you -

a). I feel tense and "wound up":

- ❑ Most of the time
- ❑ A lot of the time
- ❑ From time to time
- ❑ Not at all

b). I get a sort of frightened feeling as if something awful is about to happen:

- ❑ Very definitely and quite bad
- ❑ Yes, but not too badly
- ❑ A little, it doesn't worry me
- ❑ Not at all

c). Worrying thoughts go through my mind:

- ❑ A great deal of the time
- ❑ A lot of the time
- ❑ From time to time, but not too often
- ❑ Only occasionally

d). I can sit at ease and feel relaxed:

- ❑ Definitely
- ❑ Usually
- ❑ Not often
- ❑ Not at all

e). I get a sort of frightened feeling like "butterflies" in the stomach:

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

f). I feel restless:

- ❑ Very much indeed
- ❑ Quite a lot
- ❑ Not very much
- ❑ Not at all

Intrusive thoughts mean that you suddenly, and in places that are not connected with the illness, have disturbing thoughts of cancer and related problems – it can also involve an experience of not being able to control your thoughts. Intrusive thoughts and worry are often connected. We ask about this in different questions, first about experiences of intrusive thoughts, and then about worrying.

C. 36. Have you had intrusive thoughts about cancer during the last six months?

- ❑ No, never
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

C. 37. How disturbing has these intrusive thoughts about cancer been during the last six months?

- ❑ Not relevant

0----------1----------2----------3----------4----------5----------6

Least possible distress Most possible distress

C. 38. Have you been worrying about cancer recurrence during the last six months?

- ❑ No, never
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

C. 39. How much have you worried about cancer recurrence during the last six months?

- ❑ Not relevant

0----------1----------2----------3----------4----------5----------6

Least possible worry Most possible worry

C. 43. Have you noticed that during the last six months you avoid thinking about or have feelings related to experiences of events that remind you of cancer?

- ❑ No
- ❑ Yes

Stress is a concept that we use in everyday language to describe the total experiences - our thoughts, feelings, bodily sensations and bodily reactions - in relation to how we experience the different parts and contents of life, discomfort and fears.

C. 45. How stressed have you been during the last six months related to your total life situation (health, quality of life, relationships, work)?

0----------1----------2----------3----------4----------5----------6

Lowest possible stress Highest possible stress

m) I believe that each day has potential

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

n) I feel my life has value and worth

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

Part D: total questions *n* = 46, sample *n* = 14 (10 sub-items from KMS: D 17).

D. Body experiences and self-image

It is rather common that when treated for gynecological cancer a woman may have a changed body experience and self-image. Bodily functions can be affected by treatments, and the person can become more attentive to signs and signals of the body. ***Self-image*** relates to the way one sees oneself as a whole person with all the different aspects and parts of one's personality. Self-image gives an overall view and experience of oneself.

Self-esteem relates more specifically to self-worth, experiences of eligibility and feelings towards oneself "on the inside." ***Self-confidence*** is a related concept that means how you perceive what you perform and accomplish, which is often also based on how others receive and appreciate what you do.
We ask you to answer the following questions about body-image and self-image.

D. 1. How have you experienced your bodily well-being during the last six months?
Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6
Worst possible well-being Best possible well-being

D. 2. How have you experienced your psychological well-being during the last six months?
Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6
Worst possible well-being Best possible well-being

D. 5. Have you had problems with fatigue during the last six months, in other words felt deeply tired, exhausted, and powerless?

- ❑ No, never
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

D. 6. Have you associated signals and symptoms of the body as possible signs of cancer recurrence?

- ❑ No, never
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

D. 8. How have you experienced your self-image during the last six months?

(The experience of all of who you are). Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6

Worst possible self-image Best possible self-image

D. 10. How have you experienced your self-esteem during the last six months?

(The experience of self-worth). Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6

Worst possible self-esteem Best possible self-esteem

D. 12. How have you experienced your self-confidence during the last six months?

(How you value your performance and how it is received by others). Circle the digit that best correspond to you-

0----------1----------2----------3----------4----------5----------6

Worst possible self-confidence Best possible self-confidence

D. 17. (Body Consciousness Scale; KMS).

How well do the following statements relate to you during the last six months?

a) I enjoy resting and relaxing

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

b) I feel ashamed of my body or parts of it

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

c) I try to avoid checking in with my body and how I feel

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

e) It is hard for me to accept and like my body the way it looks

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

f) My bodily experiences help me understand my feelings

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

g) I avoid looking in the mirror when I am nude

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

h) I can no longer trust my body

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

i) My legs feel strong and steady

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

j) My body feels damaged

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

k) My body feels foreign

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

D. 18. One consequence of treatment for gynecological cancer is that one cannot become pregnant. Has this affected you?

- ❑ Not relevant
- ❑ I could not become pregnant before cancer illness

- ❑ It has not affected me
- ❑ It has affected me a little
- ❑ It has affected me somewhat
- ❑ It has affected me a lot

D. 21. Have you missed the organs taken out in surgery (uterus and ovaries)?

- ❑ Not relevant, I have not been operated upon

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

D. 27. Have you experienced lymphedema as an effect of treatments during the last six months?

Lymphedema is a swelling in the limbs that occurs when lymphatic fluid is collected in the body and not removed.

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

D. 28. Have you had intestinal problem as an effect of treatments during the last six months?

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot Namely: _____

D. 29. Have you had urinary problem as an effect of treatments during the last six months?

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot Namely: _____

D. 47. How well do you accept your body the way it looks today?

0----------1----------2----------3----------4----------5----------6

Not at all accept Fully accept

Part E: total questions *n* = 27, sample *n* = 8

E. Questions about sexuality
Generally, treatments for gynecological cancer affects women's sexuality, sexual experiences, and identity as a sexual being. We ask you to answer the following questions about how you have handled these themes after being treated for cancer.

E. 3. How sexually attractive have you felt during the last six months?

- ❑ Not at all
- ❑ A little
- ❑ Somewhat
- ❑ Very much so

E. 4. How satisfied are you with this situation?

- ❑ Indifferent
- ❑ Not at all satisfied
- ❑ A little satisfied
- ❑ Somewhat satisfied
- ❑ Very satisfied

E. 13. How important has sex been to you during the last six months?

- ❑ Not at all important
- ❑ A little important
- ❑ Somewhat important
- ❑ Very important

E. 15. If your longing for sex should be the same in the future, how does this affect you?

- ❑ Not at all satisfied
- ❑ A little satisfied
- ❑ Somewhat satisfied
- ❑ Very satisfied

Various problems and pain during sex may occur.

E. 21. Have you had problems with superficial pain during sex, (i.e. pain in the mucous membranes and opening of the vagina) during the last six months?

- ❑ Not relevant

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

E. 22. Have you had problems with deep pain during sex, (i.e. pain from deeper inside the vagina and in the pelvis) during the last six months?

- ❑ Not relevant

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

E. 24. Has the pain affected your relationship to your partner so that you have had sex more seldom during the last six months?

- ❑ Not relevant

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

E. 27. How satisfied are you with your total experience of your sexuality and our sex life during the last six months (even if you don´t have a partner).

- ❑ Not relevant

- ❑ Not at all satisfied
- ❑ A little satisfied
- ❑ Somewhat satisfied
- ❑ Very satisfied

Part F: total questions *n* = 10, sample *n* = 3

F. Sexual assault
Girls and women are especially affected by sexual assault. Research has found that about 15 % of all women have been exposed to some kind of sexual assault After such an experience, life in general, and sexual life and well-being may be affected. If a person in addition has been treated for gynecological cancer, such a previous exposure to violation may influence how she goes through with cancer treatments.

F. 1. Have you at any time been exposed to any form of sexual assault? Try to evaluate the level of assault for you, not by legal terms.

- ❑ No, never
- ❑ I may have been sexually assaulted
- ❑ Yes, I have been slightly sexually assaulted
- ❑ Yes, I have been somewhat sexually assaulted
- ❑ Yes, I have been severely sexually assaulted
  Namely by: _____

F. 2. Have you been subjected to repeated violations?

- ❑ Not relevant

- ❑ No
- ❑ Possibly
- ❑ Yes, namely by: _____

F. 7. If you have been exposed to sexual assault, has this had a negative influence on cancer treatments?

- ❑ Not relevant

- ❑ Not at all
- ❑ A little
- ❑ Somewhat
- ❑ A lot

Part G: total questions *n* = 36, sample *n* = 9

G. Cultural experiences, partaking's and interests
As mentioned above, the purpose of this study is to evaluate a form of music therapy for women treated for gynecological cancer. It involves listening to carefully selected pieces of music, possible use of painting, and a discussion about the experiences in relationship to the current life situation. We ask you to answer questions about your previous relationship with music and the arts, and about taking part in cultural events. Choose the alternative that corresponds to you. There are spaces for open comments.

G. 2. Have you participated in any cultural events (dance, theatre, concerts, opera, poetry readings, shows) during the last six months?

- ❑ No
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week

G. 5. Have you visited any art exhibitions during the last six months?

- ❑ No
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week

G. 11. Have you read (or listened to) books during the last six months (such as fiction or poetry)?

- ❑ No
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

G. 15. Have you been listening to music in an active way during the last six months?

- ❑ No
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

G. 17. How important has it been to actively listen to music during the last six months?

- ❑ Not relevant

Circle the digit that best correspond to you -

0----------1----------2----------3----------4----------5----------6

Not at all important Very important

G. 19. Have you played any musical instruments as an adult?

- ❑ No
- ❑ Yes, namely: _____

G. 22. Have you been singing on your own or together with others during the last six months?

- ❑ No
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

G. 27. Have you been painting or drawing during the last six months?

- ❑ No
- ❑ Yes, occasionally
- ❑ Yes, every month
- ❑ Yes, every week
- ❑ Yes, every day

G. 22. Have you been working with crafts during the last six months?

With crafts, we mean activities such as knitting, embroidering, working with clay, ceramics, and other activities such as working with silver, leather, wood, metal.

- ❑ No
- ❑ Yes, occasionally
- ❑ Yes, about every week
- ❑ Yes, about every day

Part H: total questions *n* = 9, sample *n* = 5

H. The questionnaire
We ask you to answer how this experience has been for you about filling out the questionnaire before you start music therapy.

H. 1. Has filling out questionnaire had any negative influence on you?

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

H. 2. Has filling out questionnaire had any positive influence on you?

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

H. 4. Did any questions influence you in such a way that you became worried?

- ❑ No
- ❑ Yes, question (please provide letter and number) _____

H. 7. How long time did it take to fill out this questionnaire?
It took about _____ hours and _____minutes to fill out the form.

H. 8. The purpose of this study is to improve the care and rehabilitation for women treated for gynecological cancer. Do you have any additional comments or reflection to share with us?
_____
_____
_____
_____
_____
_____

Thank you for your valuable contribution!

Appendix G. Participation satisfaction and benefits in GYNONC-QoL-CSBAE

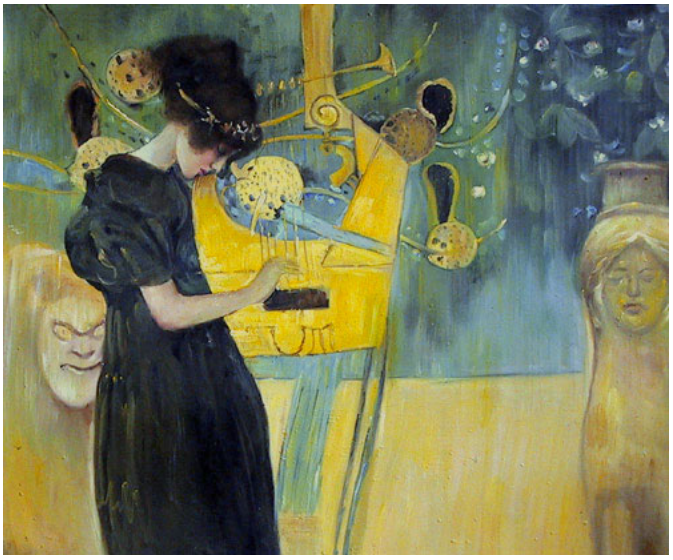
(Swedish version included in study-specific questionnaires, on USB).

QUESTIONS ABOUT PARTICIPATION SATISFACTION AND BENEFITS FROM THE LAST SECTION OF QUESTIONNAIRES IN:

Individual Therapy Posttest and FU

and

Group Therapy Posttest and FU



GYNONC-QoL-CSBAE

Gynecological Oncology - Quality of Life - Coping, Sexuality, Body and Art Experiences

Four questionnaires were developed to be used at posttest after treatment had been completed, and then again about six to seven months after posttest. In the last section of all forms was a section with questions about the level of satisfaction at having participated in therapy. These questions were the same in all four versions, apart from specific questions for group therapy based on Yalom's therapeutic factors, H17 II.

The following text was in individual therapy and group therapy posttest forms

This form is intended for you who participated in individual/group therapy. You recognize the form, many of the questions are the same as you answered before you started the therapy. Some questions have been formulated to address questions after you have completed treatment. At the end, under section H, there are these new questions related to evaluating and reflecting upon your experience of therapy.

The following text was in individual and group therapy FU forms

This form is intended for you who participated in individual therapy. You recognize the form, many of the questions are the same as you answered before you started the therapy. Now a little more than six months have passed since you ended therapy. With this form, we ask you to reflect upon the work today. Maybe you have made has some new discoveries and reflections. Some questions have been formulated to address questions after you have completed treatment. At the end, under section H, there are these new questions related to evaluating and reflecting upon your experience of therapy.

The text below was found in both posttest and FU forms in both treatments

Please note that the questions here have the same numbers as in the previous form, this is to help us when we analyze the answers. This means that some numbers are missing and some are in "wrong" order.

These questions are constructed in such a way that you will **always** answer by checking the item that best corresponds to your situation. Sometimes we ask many questions in a row on one theme. It is important to us that you **answer each separate question**. We have provided many spaces where you can write additional comments. As you see, this questionnaire contains many questions. It is easy to miss a question. Please look through the form to make sure that you have answered all questions. In the last part, we ask how the experience of filling out the form was for you. At times, it may be hard to answer some questions. We are grateful that your answers are as close as possible to your personal life situation and experiences.

The work in therapy and the forms that you fill out will be treated with strict confidentiality. The material is handled according to the ethical code of medical research.

You are always welcome to call if you have questions or need some assistance.
You can reach secretary Gerda Bergqvist at 08/640 74 47 and Margareta Wärja on: 070-749 07 56, or email: margareta.warja@expressivearts.se

This project is a collaboration between Aalborg University, Karolinska University Hospital, Karolinska Institute, and Expressive Arts Stockholm Inc.

Thank you for your valuable contribution!

H. Experiences after you have participated in individual music therapy and arts-making
We ask you to answer and reflect upon your experiences after having participated in music therapy.

Questions at posttest and FU were the same, the only difference was that in some questions, when relevant, we pointed out that this was about looking back to the experience that had occurred and reflect upon it in the present day. For example, in question H17:

Now about six months later we ask you to reflect upon your experiences of therapy and how helpful they have been in different parts of the therapy process. Items 17 i) and l have been slightly altered to fit this population.

ABOUT THERAPY

H. 10. How satisfied are you with having participated in therapy?

- ❑ Not at all satisfied
- ❑ A little satisfied
- ❑ Somewhat satisfied
- ❑ Very satisfied

H. 11. Has therapy helped you with handling your worry about cancer recurrence?

- ❑ I did not have any worry

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, very much

H. 12. Has therapy helped you with handling intrusive thoughts about cancer recurrence?

- ❑ I did not have any intrusive thoughts

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, very much

H. 13. Has therapy been of help in developing more trust in your own body?

- ❑ I did not distrust my body before

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, very much

H. 14. Has therapy been of help in working through questions related to sexuality?

- ❑ Not relevant

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat

- ❑ Yes, very much

H. 15. Has therapy been of help in terms of developing your self-image?

Self-image relates to the way one sees oneself as a whole person with all the different aspects and parts of one's personality. Self-image gives an overall view and experience of oneself.

- ❑ Not relevant. I have not needed to work on my self-image

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, very much

H. 16. Has therapy been of help in terms of handling existential questions that have occurred in relationship to cancer? *(This may relate to creating meaning in life and about handling different life circumstances).*

- ❑ Not relevant

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, very much

H. 17. We ask you to reflect upon your experiences of therapy and how helpful they have been in different parts of the therapy process.

Circle the number that best corresponds to you -

a) To have space to work with my experiences and questions

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

b) To meet and to feel my own feelings

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

c) To be in a relationship with a therapist who listens to my story

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

d) To work with experiences of cancer

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

e) To listen to music

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

f) Relaxation exercises

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

g) To make paintings around my experiences and of my self-image

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

h) Music listening *in combination* with arts-making

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

i) The verbal talk itself about the experiences

0----------1----------2----------3----------4----------5----------6

Minimum help Maximum help

k) Other things, namely: _____
_____
_____
_____

H 17 II. Only for group therapy (posttest and FU).
The following questions relate specifically to experiences of participating in a group therapy process. Please check the items that correspond best to you.

a) To help others and give of myself has been meaningful

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

b) I have experienced that I belong to a group and I am not alone in my situation

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat

- ❑ Yes, a lot

c) I have experienced that I am not the only one with my kind of problem

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

d) I have a greater understanding for how others experience me

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

e) The group has helped me develop a greater trust in other people

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

f) Members of the group have given me helpful advice

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

g) It has been helpful to me to see how other people bring up relevant life questions

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

h) I felt accepted and that I belonged to the group

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

i) The group helped me understand how I feel and think about cancer

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

j) It was helpful to be in a group and share experiences with others

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat

- ❑ Yes, a lot

k) To find out how others have handled problems that were similar to mine has been helpful

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

l) To talk with other women that have been in a similar situation about life questions – life and death – has been helpful

- ❑ No not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

H. 18. How satisfied have you been <u>overall</u> with working with music, arts and talking in therapy?

Circle the number that corresponds to you

0----------1----------2----------3----------4----------5----------6

Very dissatisfied Very satisfied

H. 19. Has there been any special theme in therapy that has influenced you in a positive way?

- ❑ No
- ❑ Yes, namely:

_____
_____
_____
_____
_____
_____

H. 20. Has there been any special theme in therapy that has influenced you in a negative way?

- ❑ No
- ❑ Yes, namely:

_____
_____
_____
_____
_____
_____

H. 21. Has there been any special theme in therapy that has surprised you?

- ❑ No
- ❑ Yes, namely:

_____
_____
_____
_____
_____
_____

H. 22. Has it been helpful to you to participate in a research study where you have been in interviews, have filled out many forms, and painted pictures?

- ❑ No, not at all
- ❑ Yes, a little
- ❑ Yes, somewhat
- ❑ Yes, a lot

Please specify,

_____
_____
_____

H. 23. Has participating in a research study influenced you in a negative way?

- ❑ No
- ❑ Yes, namely:

_____
_____
_____
_____
_____

H 24. What has been the <u>most important</u> experience or discovery related to being in therapy?

_____
_____
_____
_____
_____
_____
_____

Appendix H. EORTC-QLQ-C30

(Swedish version is found on USB).

ENGLISH

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year): 31

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

ENGLISH

During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

Appendix I. MADRS

(Swedish version is found on USB).

Name:_____ Date:_____

Montgomery-Asberg Depression Scale (MADRS)

Instructions: The ratings should be based on a clinical interview moving from broadly phrased questions about symptoms to more detailed ones which allow a precise rating of severity. The rater must decide whether the rating lies on the defined scale steps (0, 2, 4, 6) or between them (1, 3, 5). It is important to remember that it is only rare occasions that a depressed patient is encountered who cannot be rated on the items in the scale. If definite answers cannot be elicited from the patients, all relevant clues as well as information from other sources should be used as a basis for the rating in line with customary clinical practice. This scale may be used for any time interval between ratings, be it weekly or otherwise, but this must be recorded.

1. ***Apparent Sadness***
Representing despondency, gloom and despair, (more than just ordinary transient low spirits) reflected in speech, facial expression, and posture. Rate on depth and inability to brighten up.
0 No sadness
1
2 Looks dispirited but does brighten up without difficulty.
3
4 Appears sad and unhappy most of the time.
5
6 Looks miserable all the time. Extremely despondent.

2. ***Reported Sadness***
Representing reports of depressed mood, regardless of whether it is reflected in appearance or not. Includes low spirits, despondency or feeling of being beyond help without hope. Rate according to intensity, duration and the extent to which the mood is reported to be influenced by events.
0 Occasional sadness in keeping with the circumstances.
1
2 Sad or low but brightens up without difficulty.
3
4 Pervasive feelings of sadness or gloominess. The mood is still influenced by external circumstances.
5
6 Continuous or unvarying sadness, misery or despondency.

3. ***Inner Tension***
Representing feelings of ill-defined discomfort, edginess, inner turmoil mounting to either panic, dread or anguish. Rate according to intensity, frequency, duration and the extent of reassurance called for.
0 Placid. Only reflecting inner tension.
1
2 Occasional feelings of edginess and ill-defined discomfort.
3
4 Continuous feelings of inner tension or intermittent panic which the patient can only master with some difficulty.
5
6 Unrelenting dread or anguish. Overwhelming panic.

4. ***Reduced Sleep***
Representing the experience of reduced duration or depth of sleep compared to the subject's own normal pattern when well.
0 Sleeps as usual.
1
2 Slight difficulty dropping off to sleep or slightly reduced light or fitful sleep.
3
4 Sleep reduced or broken by at least two hours.
5
6 Less than two or three hours sleep.

5. ***Reduced Appetite***
Representing the feeling of loss of appetite compared with when well. Rate by loss of desire for food or the need to force oneself to eat.
0 Normal or increased appetite.
1
2 Slightly reduced appetite.
3
4 No appetite. Food is tasteless.
5
6 Needs persuasion to eat.

6. ***Concentration Difficulties***
Representing difficulties in collecting one's thoughts mounting to incapacitating lack of concentration. Rate according to intensity, frequency, and degree of incapacity produced.
0 No difficulties in concentrating.
1
2 Occasional difficulties in collecting one's thoughts.
3
4 Difficulties in concentrating and sustaining thought which reduces ability to read or hold a conversation.
5
6 Unable to read or converse without great initiative.

7. ***Lassitude***
Representing a difficulty getting started or slowness initiating and performing everyday activities.
0 Hardly no difficulty in getting started. No sluggishness.
1
2 Difficulties in starting activities.
3
4 Difficulties in starting simple routine activities which are carried out with effort.
5
6 Complete lassitude. Unable to do anything without help.

8. ***Inability to Feel***
Representing the subjective experience of reduced interest in the surroundings, or activities that normally give pleasure. The ability to react with adequate emotion to circumstances or people is reduced.
0 Normal interest in the surroundings and in other people.
1
2 Reduced ability to enjoy usual interest.
3
4 Loss of interest in surroundings. Loss of feelings for friends and acquaintances.
5
6 The experience of being emotionally paralyzed, inability to feel anger, grief or pleasure and a complete or even painful failure to feel for close relatives and friends.

9. ***Pessimistic Thoughts***
Representing thoughts of guilt. Inferiority, self-reproach, sinfulness, remorse and ruin.
0 No pessimistic thoughts.
1
2 Fluctuating ideas of failure, self-reproach or self-depreciation.
3
4 Persistent self-accusations, or definite but still rational ideas of guilt or sin. Increasingly pessimistic about the future.
5
6 Delusions of ruin, remorse or unredeemable sin. Self-accusations which are absurd and unshakable.

10. ***Suicidal Thoughts***
Representing the feeling that life is not worth living, that a natural death would be welcome, suicidal thoughts, and the preparations for suicide. Suicidal attempts should not in themselves influence the rating.
0 Enjoys life or takes it as it comes.
1
2 Weary of life. Only fleeting suicidal thoughts.
3
4 Probably better off dead. Suicidal thoughts are common, and suicide is considered as a possible solution, but without specific plans or intention.
5
6 Explicit plans for suicide when there is an opportunity. Active preparations for suicide.

Total Score:_____

Appendix J. Herth Hope Index

Item 2 and 9 were altered and divided in two items each (short range goals; long range goals, and give caring love; receive caring love). Swedish version found in GYNONC-QoL-CSBAE (on USB).

HERTH HOPE INDEX				
Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.				
	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**
1. I have a positive outlook toward life.				
2. I have short and/or long range goals.				
3. I feel all alone.				
4. I can see possibilities in the midst of difficulties.				
5. I have a faith that gives me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
11. I believe that each day has potential.				
12. I feel my life has value and worth.				

Appendix K. Invitation to participate - short

Shorter version handed out by nurse (Swedish version is found on USB).

KAROLINSKA
Universitetssjukhuset

Invitation to participate in a study

MUSIC THERAPY FOR WOMEN TREATED FOR GYNECOLOGICAL CANCER

What is the purpose of the study?

There is a great need for support and specialized rehabilitation for women afflicted with gynecological cancer. When medical treatment is completed the person might need additional professional support to work through experiences and feelings related to treatment that can influence the current life situation.

The purpose of this study is to evaluate one form of music therapy for women who have completed treatment for gynecological cancer. There is a lack of thorough evaluations and research in cancer rehabilitation and that is why we need to carry out more studies. This therapy is done in a psychotherapeutic frame where the verbal dialogue is the base. The person will listen to carefully selected recorded music and then talk about the experience related to the life situation after cancer. You don't need any knowledge about music to participate.

Who can participate?

We invite you who have completed medical treatment, and are between 18 and 75 years of age, and attend check-ups at the Gynecological Oncology Outpatient Clinic at Radiumhemmet. In music therapy the aims are to access personal resources.

All therapist are experienced psychotherapists. Treatment is provided free of charge and will take place in a psychotherapy institute in central Stockholm close to public transportation.

Treatment is conducted individually or in a small group. We estimate it will take four to five months. You are free to leave the study at any time without any explanations. This work is conducted under strict confidentiality and you are assured full anonymity. All material is securely stored.

Responsible for the study

The study will be carried out by Margareta Wärja, PhD Fellow, lic. psychotherapist, music therapist, expressive arts therapist.

The research study is a collaborative project between four parties: Aalborg University, Karolinska University Hospital, Karolinska Institute, and Expressive Arts Institute, Inc.

Interested?

If you are interested to participate, please fill out the contact form below and hand over to the nurse. You will be contacted for an interview. This talk will assess if the therapy offered in this study can be helpful for you. At that time, more information will be given, and there will be plenty of time for questions. If you have any questions before you are welcome to contact Margareta Wärja.

Phone: 070-749 07 56, margareta.warja@expressivearts.se

You can also contact Eva Lindblad nurse at Gynecological Oncology Outpatient Clinic at Radiumhemmet. Phone: 073-978 91 93.

Interest in:
"Music therapy for women treated for gynecological cancer"

I am interested in the possibility to participate in this study and hereby sign up for an interview: Please print, thank you.

Name: _____

Telephone: _____

Other contact information:_____

Appendix L. Invitation to participate - extended

Longer version provided at interview (Swedish version is found on USB).

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Invitation to participate in a study

MUSIC THERAPY FOR WOMEN TREATED FOR GYNECOLOGICAL CANCER

What is the purpose of the study?

There is a great need of support and specialized rehabilitation for women afflicted with gynecological cancer. When medical treatment is completed the person might need additional professional support to work through experiences and feelings related to treatment which might influence the current life situation.

The purpose of this study is to evaluate one form of music therapy for women who have completed treatment for gynecological cancer. This work is conducted within a verbal psychotherapeutic frame. In this method, the person listens to carefully selected pieces of music and talks about the experiences and the current life situation afterwards. In music therapy the aims are to increase quality of life and access personal resources. No special knowledge or skills in music is needed to participate.

There is a lack of high quality evaluations and research of music therapy in cancer rehabilitation and we need more knowledge of the effects in order to develop these treatment methods. We plan to use the findings from this research project in future rehabilitation programs.

Who can participate?

We invite you who have completed medical treatment, and are between 18 and 75 years of age, and go for check-ups at the Gynecological Oncology Outpatient Clinic at Radiumhemmet.

How is the study organized?

A main part of this research is conducted as a so-called randomized study. What this means is that persons who are included in the study will be randomized to either individual music therapy of 12 sessions, or to a so-called wait-list group for whom group therapy will start about six months after inclusion.

It is only chance that determines if the person will be assigned to individual therapy or the waitlist, and later group therapy.

For us in the research project your participation is equally important regardless of which treatment you are involved in.

We will use pre-recorded music and discussions to address the current life situation related to cancer treatments. After music listening we usually work with painting (no previous experience is required). The individual sessions are weekly and each lasts 60 minutes. The whole process will take about four to five months. Persons in group therapy will meet for eight weekly sessions for two and a half hours on Mondays between 16.30-19.30. Group therapy will take about three months.

Before treatment starts we ask you to fill out questionnaires, then again after therapy is completed, and then seven months later. The questions address problems that might develop as a consequence of diagnosis and treatment. These questions relate to different aspects of ”quality of life.” The questionnaire that you fill out after therapy has some questions that focus on your experiences of having participated in therapy. This will be followed up again after about seven months.

Therapists and aims of therapy

All therapists are experienced psychotherapists who have specialized training in the music therapy methods that we will use in the study (both for individual and group sessions).

Therapy is provided free of charge and will take place in a psychotherapy institute in central Stockholm close to public transportation.

The aims of therapy are to increase coping abilities, enhance quality of life, and to be able to live a life as rich as possible.

Findings from previous studies have shown that individuals who participate in therapies like this – in individual or group settings – are helped by working through emotional difficulties related to cancer diagnosis and its treatments. The work may involve addressing emotional experiences that have been put on hold. Thus, the focus of therapy is to face some of these feelings related to cancer through verbal dialogue and music listening together with a supportive and qualified psychotherapist.

The study adheres to ethical praxis and ensures full anonymity

Treatment is conducted under confidentiality. Your name will not be used in any documentation; instead you will be given a code. Only the project leader (MW) and her supervisor at Karolinska Institute (KB) will have access to the key between the code and the person. Information will be stored securely at Karolinska Institute according to ethical praxis in medical research.

The interview material and answers from the questionnaires will be coded and analyzed with statistical methods without any use of personal data.

If you are included, you are free to leave the study at any time without any explanations.

Responsible for the study

Karolinska University Hospital is supporting this project and is responsible for adherence to ethical praxis. Contact nurse at the Gynecological Oncology Outpatient Clinic at Radiumhemmet is Eva Lindblad. Phone: 073-978 91 93.

The study will be carried out by Margareta Wärja, PhD Fellow, lic. psychotherapist, music therapist, expressive arts therapist (contact information below).

Research supervision is provided by Dr. Karin Bergmark at Karolinska Institute, and Prof. Lars Ole Bonde at Aalborg University/Institute of Communication/Music Therapy.

The research study is a collaborative project between four parties: Aalborg University, Karolinska University Hospital, Karolinska Institute, and Expressive Arts Institute, Inc.

The study is financed by a fellowship from Aalborg University, and from grants from different foundations.

How will I get information about the results?

The aim is to publish the results of the study in a doctoral thesis by Margareta Wärja.

Findings and summaries of results will be published in scientific journals, and in other kinds of more accessible publications.

Participants in this study will be invited to an open lecture in which the results will be presented. Space will be given for questions.

Any questions

If you have any further questions you are welcome to call or send an email.

Margareta Wärja

Phone: 070-749 07 56

margareta.warja@expressivearts.se

Appendix M. Documenting non-participation

(Swedish version is found on USB).

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1 (1)

DOCUMENTATION OF REASONS FOR NOT WANTING TO PARTICIPATE IN THE STUDY:

"MUSIC THERAPY FOR WOMEN TREATED FOR CANCER"

Date: _____

Name (of patient): _____

- ❑ No need for psychotherapy
- ❑ Commute was too long
- ❑ Nurse did not find the time to ask and give out invitation
- ❑ Other reason, namely: _____
  _____

Other comments:
_____
_____
_____
_____
_____
_____

Name of nurse: _____

Appendix N. Informed Consent

(Swedish version is found on USB).

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1 (1)

Informed consent

Study: Music therapy for women treated for gynecological cancer

Gynecological Oncology Outpatient Clinic; Karolinska University Hospital, Stockholm; Aalborg University, Denmark; Expressive Arts Stockholm Inc.

- **Participant**

I hereby accept to participate in the study stated above. I have been informed about the study verbally and in writing. I am aware that participation is voluntary and that I at any time can leave without providing any reasons for leaving the study, and that leaving will not in any way influence my continued care at the hospital.

Place and date ……

…… ……..
Signature Name in print

I hereby assure that I have provided verbal and written information about the study stated above.

- **Confidentiality and use of personal information**

All personal information is handled under a code of confidentiality. Documents in this study that handle personal identification numbers are stored securely. The interviews will be coded and analyzed without any involvement of personal information.

Place and date ……

…… ……..
Signature Name in print

JIL

Appendix O. Paint and write text of body image

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1 (1)

MÅLA FRITT

Musikterapi för kvinnor som behandlats gynekologisk cancer

Måla en bild helt fritt om upplevelsen av din kropp efter sjukdom och cancerbehandlingar.

Hur ser du på din kropp? Hur känns din kropp? Hur upplever du kroppen?

Du kan måla föreställande eller mera symboliskt.

Det handlar inte om att ”prestera” en fin bild utan mer om att måla fritt och spontant och låta bilden växa fram.

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1 (1)

FREE PAINTING

Music therapy for women treated for gynecological cancer.

Paint a picture quite freely and spontaneously about the experience of your body today, after illness and after cancer treatments.

How do you see your body? How does it feel? How do you experience your body?

You can make a picture which looks like a person, or it can be a more symbolic image.

This task is not about creating a “nice looking picture”, but rather to allow the picture to grow and develop freely and spontaneously.

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1 (1)

SKRIFTLIG REFLEKTION
Musikterapi för kvinnor behandlade för gynekologisk cancer

Nummer Datum:

Skriv ner några rader helt öppet och fritt om tankar, känslor och upplevelsen av din kropp efter sjukdom och cancerbehandlingar. Hur ser du på din kropp? Hur känns din kropp? Hur upplever du kroppen och hur tycker du att den fungerar? Skriv fritt och spontant. (Du kan använda baksidan om du behöver).

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1 (1)

WRITTEN REFLECTION
Music therapy for women treated for gynecological cancer

Number Date:

Right down a few sentences freely and open about thoughts, feelings and experiences of your body after illness and cancer treatments. How do you see your body? How does it feel? How do you experience your body, and how do you think it functions? Write freely and spontaneously. (If needed you can also use the reverse side).

Appendix P. Power calculations

F tests - ANOVA: Repeated measures, between factors

Analysis:	A priori: Compute required sample size			
Input:	Effect size f		=	0,5
		α err prob	=	0,05
		Power (1-β err prob)	=	0,95
		Number of groups	=	2
		Number of measurements	=	4
		Corr among rep measures	=	0,5
Output:	Noncentrality parameter λ		=	14,4000000
		Critical F	=	4,1300177
		Numerator df	=	1,0000000
		Denominator df	=	34,0000000
		Total sample size	=	36
		Actual power	=	0,9577864

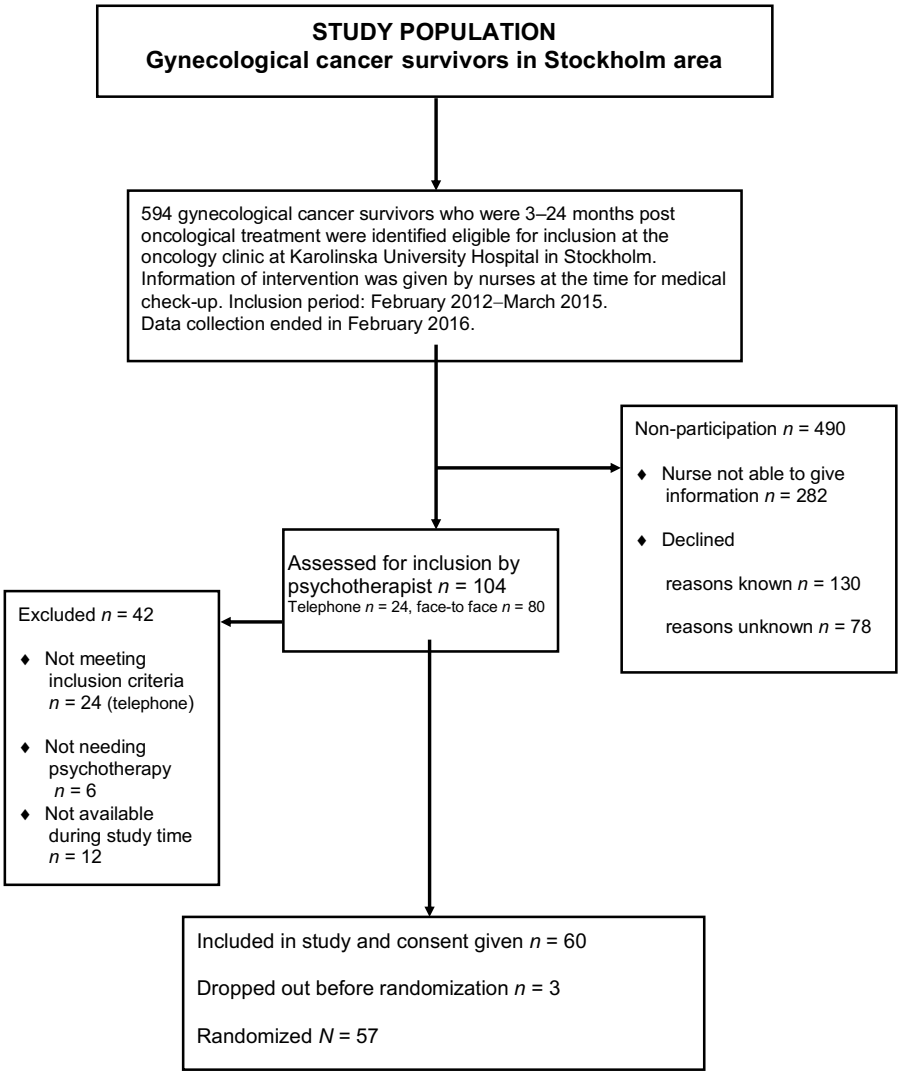
Appendix Q. Detailed discography in trial

Table App P-1. Detailed trial discography

Artist	Track/Title	Composer	Album	Duration sec	Recording
Österbottens Kammarorkester. Dir: Juha Kangas	Op. 27: Allt under himmelens fäste	Johan Svendsen		209	EMI 5 66306 2
Stefan Nilsson	Arons dröm	Stefan Nilsson	Juloratoriet Soundtrack	241	Virgin – 7243 8 46952 2 4
Jan Johannson	Bandura	Jan Johannson	Folkvisor (Jazz på ryska)	151	SEYKU1508001 HEPTAGON HECD-000
Adrian Leaper & Slovak Radio Symphony Orchestra	As you like it, Op. 21: II Evening in The Forrest	Roger Quilter	Where the Rainbow Ends, Country Pieces and other works	171	SERVA0531006 Marco Polo: 8223444
Stefan Nilsson	Gabriellas piano	Stefan Nilsson	Så Som I Himmelen Soundtrack	198	Virgin – 7243 863294 2 4 SEPQA1500508
Mischa Maisky Pavel Gililo	Gavotte	Jean-Baptiste Lully	Meditation (Arr. for Cello and Piano)	170	0289 431 5442 0 DEF058704770
Nora Shulman & Judy Loman	Gymnopedie no. 1, Flute & Harp	Eric Satie		186	Naxos – 8.554166
Fläskkvartetten	Innocent		Pärlor från svin 1995	217	HKI199717607 MVG Records – MVG 124
M. Strömberg U. Claesson M. Larsson A. Jonhäll, A. Nilsson, F. Lidin	Kärlek	Magnus Strömberg	Sallön Soundtrack	186	SELBD9501304 Naxos – 8.557853

Stefan Nilsson	Mot den nya världen	Stefan Nilsson	Pelle erövraren Soundtrack	166	Virgin – 7243 8 46952 2 4
Deva Premal	Om Namo Bhagavate		Embrace	430	Prabhu Music – WS 0044 USWS4030440
Karl Jenkins/Carmine Lauri/David Alberman/London Symphony Orchestra	Jenkins: Palladio, for Strings (Excerpt, Allegretto)	K. Jenkins	Still with the Music - The Album	343	Sony Classical 1996 GBPFW0800554
Steve Dobrogosz	Resting Place	Steve Dobrogosz	Mass and Chamber Music	221	Phono Suecia / PSCD 107 SEPXS9712130
Gastone Chiarini (oboe)	Sacco e Venzetti-Speranze Di Libertà	Ennio Morricone	Love Themes	153	RCA Victor – LSP-4612 ITB007001026
Secret garden Rolf Løvland and Fionnuala Sherry	Song from a secret garden		Moods	213	NOACM9502070
Joanne Shenandoah	Song of union	Joanne Shenandoah	Life Blood	176	Triloka Records – 697-124 137-2-IN02, Worldly Music – 697-124 137-2
Benny Anderssons Orkester	Sång från andra våningen	Benny Andersson	Sånger från andra våningen Soundtrack	236	Mono Music 2001SEAUA0101090
Stefan Nilsson	Wilmas tema	Stefan Nilsson	Skärgårdsdoktorn Soundtrack	121	Virgin – 7243 8 46952 2 4 SEYKU1508104
J. Volkmar	Wintertraum	Unknown	Unknown	180	Unknown

Appendix R. Flowchart baseline before randomization: Paper IV

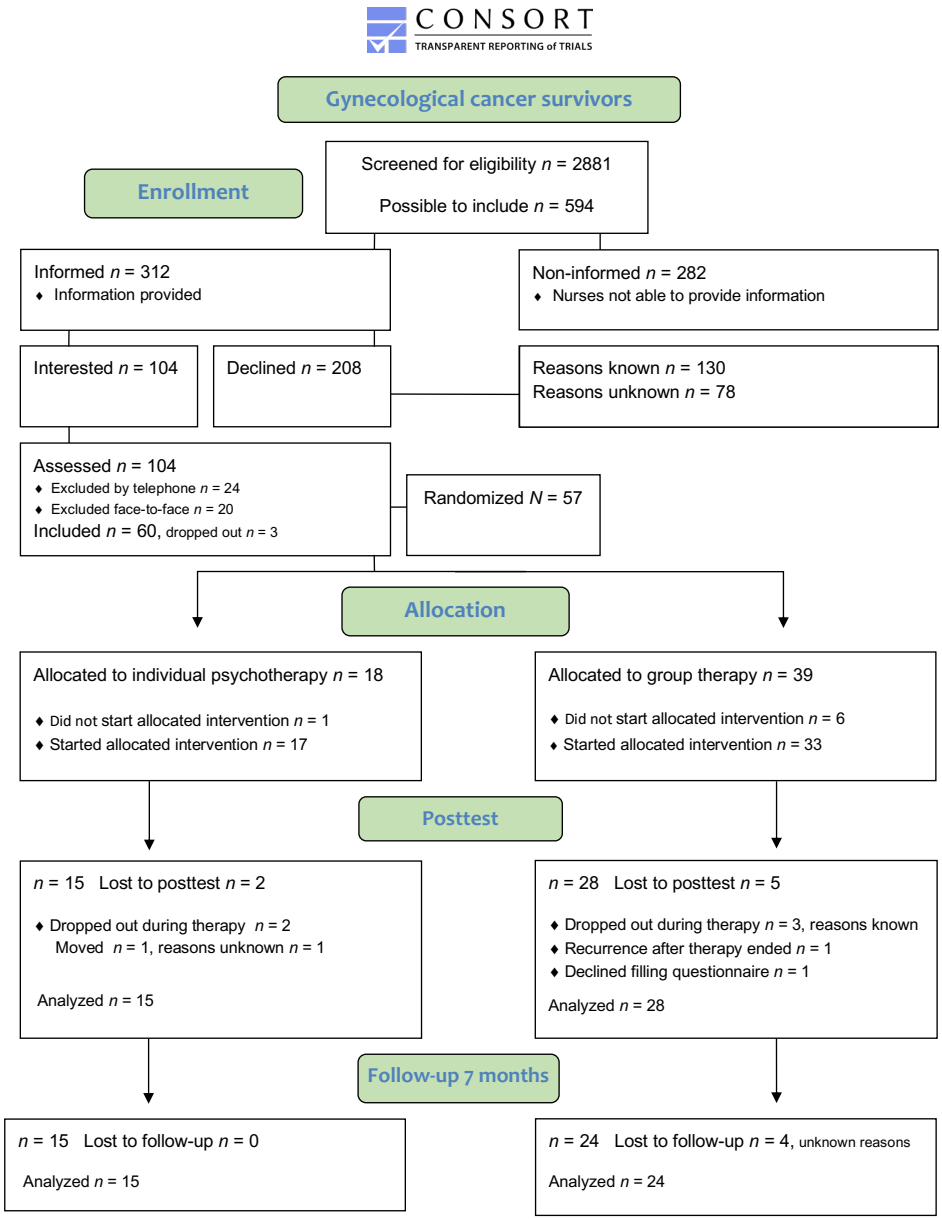


Appendix S. Demographics and clinical characteristics (randomized): Paper V

Characteristics cancer survivors		*Total sample n = 57 n/N (%)*	*Group therapy n = 39 n/N (%)*	*Individual therapy n = 18 n/N (%)*
Age	27-34	6/57 (10)	2/39 (5)	4/18 (22)
Mean age = 56.5	35-44	6/57 (10)	4/39 (10)	2/18 (11)
	45-54	10/57 (18)	7/39 (18)	3/18 (17)
	55-64	15/57 (26)	11/39 (28)	4/18 (22)
	65-75	20/57 (36)	15/39 (39)	5/18 (28)
Gynecological cancers	Cervical cancer	18/57 (32)	13/39 (33)	5/18 (28)
	Endometrial cancer	24/57 (42)	15/39 (39)	9/18 (50)
	Ovarian cancer	10/57 (17)	7/39 (18)	3/18 (17)
	Other form	5/57 (9)	4/39 (10)	1/18 (6)
	Brachytherapy	36/57 (63)	23/39 (59)	13/18 (72)
	Chemotherapy	46/57 (81)	32/39 (82)	14/18 (78)
	Radiotherapy	31/57 (54)	23/39 (59)	8/18 (44)
	Surgery	44/57 (77)	29/39 (74)	15/18 (83)
Marital status	Married/cohabitating	36/57 (63)	24/39 (62)	12/18 (67)
	Has partner, lives alone	5/57 (9)	3/39 (7)	2/18 (11)
	No partner/widow	16/57 (28)	12/39 (31)	4/18 (22)
Higher education	College or University	36/57 (64)	24/39 (62)	12/18 (67)
Employment status *	Employed	33/57 (58)	23/39 (59)	10/18 (56)
	Unemployed	2/57 (4)	2/39 (5)	0
	Retired	20/57 (35)	17/39 (44)	3/18 (17)
	Sick leave/disability	6/57 (11)	5/39 (13)	1/18 (6)
	Student	3/57 (5)	1/39 (3)	2/18 (11)
	Housework	2/57 (4)	2/39 (5)	0
Place of residency **	Stockholm	44/57 (77)	29/39 (74)	15/18 (83)
	Small town/rural area	13/57 (22)	10/39 (26)	3/18 (17)
Country of birth	Sweden	50/57 (88)	36/39 (92)	14/18 (78)
	Other country	7/57 (12)	3/39 (8)	4/18 (22)
Children	Yes	40/57 (70)	26/39 (67)	14/18 (78)
Exercise (last six months)	Yes, once a week	44/56 (79)	28/38 (74)	14/18 (78)
Religious faith (a little - strong)	Yes	30/56 (54)	20/39 (51)	10/17 (59)
Former psychiatric help (prior to cancer)	Yes	22/57 (39)	16/39 (41)	6/18 (33)
Former psychotherapy (prior to cancer)	Yes	23/57 (40)	15/39 (38)	8/18 (44)
Reported traumatic event (prior to cancer)	Yes	36/57 (63)	25/39 (64)	11/18 (61)
Kinds of reported traumatic events *				
Physical assault	Yes	6/57 (11)	4/39 (10)	2/18 (11)
Sexual assault	Yes	8/57 (14)	6/39 (15)	2/18 (11)
Accident	Yes	6/57 (11)	4/39 (10)	2/18 (11)
Severe illness (of significant others)	Yes	12/57 (21)	9/39 (23)	3/18 (17)
Unexpected/unprepared death	Yes	19/57 (34)	13/39 (33)	6/18 (33)
Other ***	Yes	13/57 (22)	7/39 (18)	6/18 (33)
Cultural/leisure activities (last six months)				
Concerts, opera, show	Yes, monthly/weekly	15/56 (27)	10/38 (26)	5/18 (28)
Reading books (fiction)	Yes, weekly/daily	27/56 (48)	18/39 (46)	9/17 (53)
Active music listening	Yes, weekly/daily	30/57 (53)	21/39 (54)	9/18 (50)
Playing a music instrument	Yes	1/57 (2)	0	1/18 (6)
Working with painting/drawing	Yes	2/57 (4)	1/39 (3)	1/18 (6)
Working with crafts (last six months)	Yes	22/56 (39)	14/38 (37)	8/18 (44)

* Multiple answers possible. ** Total number does not equal 100%. ***Such as: death of child, premature birth, infidelity, experience of war, harassments, financial loss, family related stress.

Appendix T. CONSORT flowchart: Paper V



Appendix U. Paper I: Systematic review – included studies and place in trajectory

Hertrampf, R. S., & Wärja, M. (2017). The Effect of Creative Arts Therapy and Arts Medicine on Psychological Outcomes in Women treated for Breast or Gynecological Cancer: A Systematic Review of Arts-Based Interventions. *Arts in Psychotherapy*, 56C, pp.93–110. http://dx.doi.org/10.1016/j.aip.2017.08.001

Binns-Turner, P. G., Wilson, L. L., Pryor, E. R., Boyd, G. L., & Prickett, C. A. (2011). Perioperative music and its effects on anxiety, hemodynamics, and pain in women undergoing mastectomy. *American Association of Nurse Anesthetists Journal, 79*(4), 21–28.

Bulfone, T., Quattrin, R., Zanotti, R., Regattin, L., & Brusaferro, S. (2009). Effectiveness of music therapy for anxiety reduction in women with breast cancer in chemotherapy treatment. *Holistic Nursing Practice*, *23*, 238–242. http://doi.org/10.1097/HNP.0b013e3181aeceee

Chan, Y. M., Lee, P. W. H., Ng, T. Y., Ngan, H. Y. S., & Wong, L. C. (2003). The use of music to reduce anxiety for patients undergoing colposcopy: A randomized trial. *Gynecologic Oncology*, *91*(1), 213–217. http://doi.org/10.1016/S0090-8258(03)00412-8

Chi, G. C.-H.-L., Young, A., McFarlane, J., Watson, M., Coleman, R. L., Eifel, P. J., . . . Grace, C. C.-H.-L. (2015). Effects of music relaxation video on pain and anxiety for women with gynecological cancer receiving intracavitary brachytherapy: A randomised controlled trial. *Journal of Research in Nursing*, *20*(2), 129–144. http://doi.org/10.1177/1744987114529863

Dibbell-Hope, S. (2000). The use of dance/movement therapy in psychological adaptation to breast cancer. *The Arts in Psychotherapy*, *27*, 51–68. *The Arts in Psychotherapy*, *26,* 73–80.

Hanser, S. B., Bauer-Wu, S., Kubicek, L., Healey, M., Manola, J., Hernandez, M., & Bunnell, C. (2006). Effects of a music therapy intervention on quality of life and distress in women with metastatic breast cancer. *Journal of the Society for Integrative Oncology*, *4*(3), 116–124.

Ho, R. T. H., Fong, T. C. T., Cheung, I. K. M., Yip, P. S. F., & Luk, M.-Y. (2016). Effects of a short-term dance movement therapy program on symptoms and stress in patients with breast cancer undergoing radiotherapy: A randomized, controlled, single-blind trial. *Journal of Pain and Symptom Management*. http://doi.org/10.1016/j.jpainsymman.2015.12.332

Li, X.-M., Yan, H., Zhou, K.-N., Dang, S.-N., Wang, D.-L., & Zhang, Y.-P. (2011). Effects of music therapy on pain among female breast cancer patients after radical mastectomy: results from a randomized controlled trial. *Breast Cancer Research and Treatment*, *128*, 411–419. http://doi.org/10.1007/s10549-011-1533-z

Li, X.-M., Yan, H., Zhou, K.-N., Dang, S.-N., Wang, D.-L., Zhang, Y.-P., … Zhang, Y.-P. (2012). Effects of music therapy on anxiety of patients with breast cancer after radical mastectomy: A randomized clinical trial. *Journal of Advanced Nursing*, *68*, 1145–1155. http://doi.org/10.1007/s10549-011-15

Monti, D. A., Kash, K. M., Kunkel, E. J., Moss, A., Mathews, M., Brainard, G., … Newberg, A. B. (2013). Psychosocial benefits of a novel mindfulness intervention versus standard support in distressed women with breast cancer. *Psycho-Oncology*, *22*, 2565–2575.

Moradian, S., Walshe, C., Shahidsales, S., Ghavam Nasiri, M. R., Pilling, M., & Molassiotis, A. (2015). Nevasic audio program for the prevention of chemotherapy induced nausea and vomiting: A feasibility study using a randomized controlled trial design. *European Journal of Oncology Nursing, 19*, 282–291. http://doi.org/10.1016/j.ejon.2014.10.016

Öster, I., Svensk, A. C., Magnusson, E., Thyme, K. E., Sjödin, M., & Åström, S. (2006). Art therapy improves coping resources: a randomized, controlled study among women with breast cancer. *Palliative & Supportive Care*, *4*(1), 57–64. http://doi.org/10.10170S147895150606007X

Palmer, J. B., Lane, D., Mayo, D., Schluchter, M., & Leeming, R. (2015). Effects of music therapy on anesthesia requirements and anxiety in women undergoing ambulatory breast surgery for cancer diagnosis and treatment: A randomized controlled trial. *Journal of Clinical Oncology*, *33*, 3162–3168.

Puig, A., Lee, S. M., Goodwin, L., & Sherrard, P. A. D. (2006). The efficacy of creative arts therapies to enhance emotional expression, spirituality, and psychological well-being of newly diagnosed Stage I and Stage II breast cancer patients: A preliminary study. *The Arts in Psychotherapy*, *33*, 218–228.

Romito, F., Lagattolla, F., Costanzo, C., Giotta, F., & Mattioli, V. (2013). Music therapy and emotional expression during chemotherapy. How do breast cancer patients feel? *European Journal of Integrative Medicine*, *5*, 438–442.

Sandel, S. L. P., Judege, J. O., Landry, N., Faria, L., Ouellette, R., & Majczak, M. (2005). Dance and movement program improves quality of life measures in breast cancer survivors. *Cancer Nursing*, *28*, 301–309. http://doi.org/10.1097/00002820-200507000-00011

Stordahl, J. J. (2009). The influence of music on depression, affect, and benefit finding among women at the completion of treatment for breast cancer. *ProQuest Dissertations and Theses*. Retrieved from http://scholarlyrepository.miami.edu/cgi/viewcontent.cgi?article=1336&context=oa_dissertations

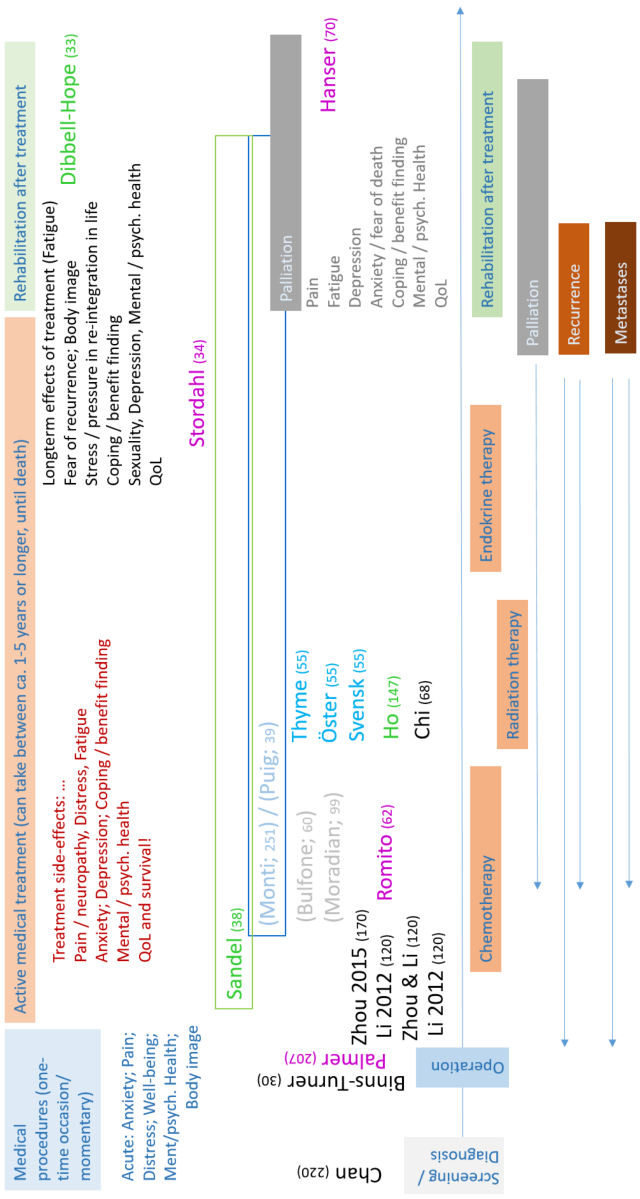
Svensk, A.-C. C., Öster, I., Thyme, K. E., Magnusson, E., Sjödin, M., Eisemann, M., … Lindh, J. (2009). Art therapy improves experienced quality of life among women undergoing treatment for breast cancer: A randomized controlled study. *European Journal of Cancer Care*, *18*(1), 69–77.

Thyme, K. E., Sundin, E. C., Wiberg, B., Öster, I., Astrom, S., & Lindh, J. (2009). Individual brief art therapy can be helpful for women with breast cancer: a randomized controlled clinical study. *Palliative & Supportive Care*, *7*(1), 87–95.

Zhou, K., Li, X., Li, J., Liu, M., Dang, S., Wang, D., & Xin, X. (2015). A clinical randomized controlled trial of music therapy and progressive muscle relaxation training in female breast cancer patients after radical mastectomy: Results on depression, anxiety and length of hospital stay. *European Journal of Oncology Nursing*, *19*, 54–59.

Zhou, K. N., Li, X. M., Yan, H., Dang, S. N., & Wang, D. L. (2011). Effects of music therapy on depression and duration of hospital stay of breast cancer patients after radical mastectomy. *Chinese Medical Journal*, *124*, 2321–2327.

Place in treatment trajectory if studies in systematic review



Appendix V. Paper II: KMR-Short Music Journeys

CHAPTER 22

KMR (Short Music Journeys) with Women Recovering from Gynecological Cancer

Margareta Wärja

Listening to selected pieces of music can provide a safe and creative space for profound therapeutic work. The intent of this chapter is to present a receptive music therapy method called Korta Musikresor (KMR) (Short Music Journeys), based on listening to short pieces of music together with a professional therapist trained in the method, such as a music therapist, psychotherapist or expressive arts therapist. After the music listening, an art experience follows (Kästele and Müller, 2013; Wärja, 2010). The method will be introduced in ways that are applicable to both individual and group therapy. A structure for applying KMR in group therapy in oncology will be presented in more detail. In short, KMR can be essentially defined as

> an enhanced focused attention on the experiences and phenomena in the inner world of clients by listening to a short piece of music selected by a therapist based on the present life situation, current emotional state, ability to regulate affects, and/or issue that is the focus for exploration, and using arts to shape the essence of that experience followed by a verbal process to reflect upon the whole sequence of events in a relational context. (Wärja, 2012; Wärja and Bonde, 2014; Figure 22.1)

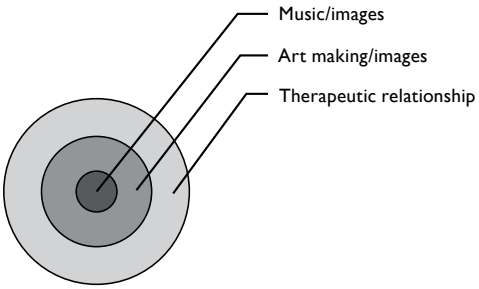


Figure 22.1 The essences of the KMR process

The imagery process is self-generated, meaning that images emerge inside the client in response to music and the intersubjective sharing that takes place in the therapeutic relationship (Mårtensson and Wrangsjö Blom, 2013). The typical session is unguided where the client is supported to open and surrender to the music. There are instances where a so-called talk-over is used: this refers to providing verbal instructions while the music is playing. KMR is used in individual or group psychotherapy, clinical settings such as psychiatry, oncology and palliative care, and in private practice. Pressing life problems, crises and traumatic experiences, and psychosomatic and psychiatric distress can be addressed. It is possible to work with families and couples, and with personal development. In addition the method can be utilized in individual supervision or with teams and groups (Wärja, 2013). In addressing experiences of trauma the initial step is to establish a phase of stabilization to build resources and resilience and assess the client's ability to regulate and tolerate affects (Schore, 2003; Van der Hart, Nijenhuis and Steele 2006).

Theoretical frame

KMR has been developed by this author and is embedded in a theoretical frame consisting of the Bonny Method (GIM) (Bonny, 1978, 1980; Bonny and Summer, 2002), expressive arts therapy (Levine and Levine, 2005) and existential and relational psychotherapy (Stern, 2004; Van Deurzen, 2010). It is the combination of these interrelating parts that makes up the whole, which defines this method (Figure 22.2).

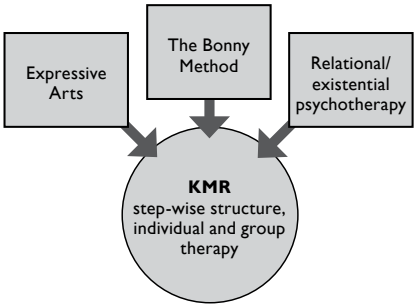


Figure 22.2 The theoretical frame of KMR

KMR applies the basic structure developed by Bonny for the individual session where a client travels to selected music programs in the presence of a qualified therapist and allows that music to elicit images and experiences that are dealt with in the therapeutic relationship, which is the base for the work. Playing with imagination and engaging the capacity to shape it is the base for expressive arts. As we create we are shaping the

conditions of our existence (Levine and Levine, 2005). The focus is on lived embodied experiences in the field of play in which new images are born and discoveries can be made (Kenny, 2006). Paying attention to earlier attachment patterns and building trust to create the therapeutic alliance is fundamental to opening up and receiving the music. Change in psychotherapy is based on lived experience and moments of meeting (Stern, 2004). The process of surrender through music is a core concept and can be described as profound intersubjectivity and moments of meeting that can strengthen trust and the ability to work on therapeutic goals (Mårtensson Blom and Wrangsjö, 2013). Inherent in the KMR structure is finding a theme and defining a focus for the music session. This resonates well with the aims of existential psychotherapy and pertains both to individual therapy and working with groups (Yalom, 1985). In existential psychotherapy there is an awareness of the physicality of our bodies, our relationships, identity and social networks, and how we create meaning and coherence in our life.

The music in KMR

In KMR carefully selected brief pieces of music are used, lasting between two and six minutes. A metaphor used in regards to the music is to 'open up', which applies to both therapist and client. Opening up precedes surrendering. To open up is the whole process of preparing for entering the musical space (including verbal exchange and induction).

Most music selections come from the non-classical repertoire, such as film and folk music; a few supportive pieces from the GIM repertoire are included (see the appendix at the end of the chapter). The intent of the music is to provide holding, support and safety, and give some degree of dynamic vitality to support exploration and evoke images and body sensations. Supportive music is stable, fairly predictable and stays within the mood spectrum of categories 3–4–5–6 in Hevner's (1937) mood wheel (i.e. light moods) – see Chapter 30 of this volume. The music has a clear melody with a reliable rhythm, consonant harmonic structure and few surprises. In choosing a piece of music for KMR, listening for the melody is of particular importance, as it is in the foreground and carries the narrative. The melody needs to be comprehensible and predictable. In developing intersubjectivity Mårtensson Blom and Wrangsjö (2013) have pointed out how the different musical elements can be considered in this regard and speak to the role of the melody:

> Intersubjectivity can develop with help of the music. The different musical elements interact: *melody* consists of notes linked together. These group themselves together like syllables of small meaningful units or strophes. The melody is perhaps the strongest element that can carry and symbolize our need for meaning… The melody can portray/represent a narrative form, a life story and the tones always have a direction 'away' or 'home' depending on their placement in the given scale. We perceive how the notes inform about where the melody 'is going', giving the

> melody both a spatial and temporal character. Here we can see how the melody as an element can be compared with shared intentionality, one of the building blocks of intersubjectivity. (p. 222, translation Margareta Wärja)

When selecting a piece of music for a client the levels of trust, basic attachment patterns and ability to tolerate and regulate affect are carefully assessed and considered. In order to help in the process of selecting appropriate music a metaphor of three different fields is applied: (1) secure and holding field, (2) secure and opening field, and (3) secure and exploratory field (Figure 22.3) (Wärja and Bonde, 2014).

1. Secure and holding field	• Music that is reliable and predictable with no surprises. It will take you by the hand and lead you gently. Simplicity in musical elements; solo instrument carrying the melody with one or two supporting instruments. • Examples: Stefan Nilsson: *Wilma's Theme*. Jan Johansson: *Bandura*.
2. Secure and opening field	• Music that can open up to a 'tiny surprise'. • Music with dialoguing instruments; two different themes and more than one instrument possible. • Examples: Steve Dobrogosz: *Mass and Chamber Music*, No. 13, Resting Place. Benny Andersson's Orchestra: *Songs from Second Floor*.
3. Secure and exploratory field	• Music with some dynamic tension. Gives further support for surrender and a possibility of exploring differences. Crescendos and diminuendos. Some harmonic tension. Different voices. More elements of complexity. • Examples: Secret Garden: *Song from a Secret Garden*. Beethoven: *Piano Concerto No. 5*, Adagio.

Figure 22.3 Three fields of music for KMR

Structure and procedures for individual and group therapy

The individual session is conducted in a 60-minute format, and a group session usually runs between 90 minutes and two and a half hours. During the music the client sits in a comfortable chair and is able to self-regulate the intensity of the experience with eyes open or closed. The format is basically analogous to the Bonny Method (see Figure 22.4).

1. Verbal dialogue; agree on a specific focus
2. Induction; body-relaxation, concentration and presenting a focus
3. Music listening (unguided/talk-over); 2–6 minutes
4. Bridge back to the room
5. Art making
6. Verbal processing; find essence.

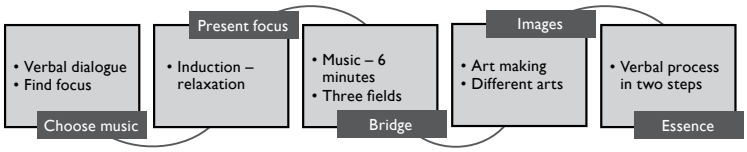


Figure 22.4 The structure and flow of the KMR session

Verbal dialogue

The individual session starts with a verbal dialogue around current life themes and material from earlier sessions. The therapist is attentive to the relational field and alliance. The talk narrows down to find and formulate a precise focus. Art work can be used to further define the focus. In working in group therapy, the first phase concerns checking in verbally, warming up to the group's present and past themes. Here various bodywork techniques are helpful, such as grounding, mindful breathing and free spontaneous movements. The process of finding a focus grows from the dynamic interactions of the group. Previous art can be utilized, warming up through art experiences. The focus is formulated widely enough to encompass all members. Postcards or photos are helpful ways to open to imagination, especially in developmental stages of a group, such as: 'find a safe place where you can relax and just be'; 'let yourself be drawn to an image/card that speaks to you right now'; and 'find an image/card of your experience in this group'.

Induction

The induction/relaxation is tailored to the individual client or the group as a whole. Similar relaxation techniques as in the Bonny Method are applied, such as breath, color, light and progressive relaxation (for instructions see Grocke and Wigram, 2007, Chapter 4). A slightly altered state of consciousness is induced. The therapist uses a warm and resonant voice, speaking in the present tense with short and directive sentences. In a group setting each member is encouraged to find a separate place and the therapist addresses the individual person – for example: 'Take some time and make yourself comfortable… notice that this is a time to be with your own images, feelings and sensations… turn your attention to your breath…' At the end of the physical relaxation comes the focus with support to open to the music. The induction lasts about 3–4 minutes, which is about the same amount of time as the music. Experience has shown that a rather lengthy induction is useful in supporting clients to open more fully and surrender to the music. In working in individual therapy this can be assessed and regulated with each client. When using talk-over the induction starts with physical relaxation without music, and as attention is directed on the task the music is turned on, for example reviewing an art process, or experiencing the body from within (see group case study).

Music

There is generally no guiding while the music lasts (the exception is directions used in a talk-over). During the music the therapist serves as an anchor. Working in groups the attention is on the implicit field of the whole group. Anchoring involves staying present in the music, noticing movements and facial expressions. This intersubjective way of relating and holding the space non-verbally is an essential part of this method and involves being aware of associations and felt sense. If a client in individual therapy is about to cry but holds back, the therapist can say: 'Let go, just allow the tears to come.' In a group session it is possible to say: 'If you feel like crying just allow that to happen and let the music hold you.' When a member in a group expresses feelings it will most likely affect others and can be processed after the music.

Bridge

Shortly after the music has ended the therapist states: 'The music has come to an end, take some time and finish your experience. Notice if there is something that needs to happen or needs to be done…and what you need to remember and bring back from this experience.' Clients are helped to come back into a more normal state of consciousness by stretching and opening their eyes.

Art making

Art making after the music is not mandatory but clearly encouraged. The advantage of visual art is that it can be saved and reviewed. Various art materials are provided (different-size papers, crayons, gouache, coal, acrylic paint, clay) with instructions to draw or create something spontaneously from the experience. There are times when visual arts are not the most appropriate way to proceed. When, for example, there is a need to release tensions and emotions, a better way might be to involve the body through music, movement or drama. Free writing can be used when a story or message needs to be remembered. Art making in groups is an active process where members influence, inspire and encounter each other. There are infinite possibilities to explore image material using the dynamic potential of a group, such as: instrumental and movement improvisation, music composition, dance choreography, group drawings, three-dimensional art installations, vignettes through role play and drama.

Verbal processing

The verbal processing is conducted in two steps, which are presented here separately for individual and group settings.

INDIVIDUAL THERAPY

The first step is an open exploration of images that emerged through music and art. Client and therapist engage in a reflective and associative dialogue such as: 'What stands

out?'; 'Say more about that'; 'Let's stay with this for a moment'; 'What is the essence from this experience?'; and 'What surprised you?' Viewing the visual art product one can say: 'When you look at this drawing what do you notice?'; 'Is there a sound that goes with this image?' This part of the dialogue resembles guiding in the Bonny Method; the therapist stays in present tense and assists in deepening the relationship with images through embodiment and opening to sensations and feelings. In the second step of the verbal processing the therapist inquires and reflects upon how the journey relates to the current life situation. For example: 'Let's return to the question that we started with – how do you sense that these images might relate to that issue?' In most cases the session is part of a therapeutic process that continues over time. Before ending, the therapist supports the client to find the essence and to stay with images that are ambiguous and not fully understood until the next appointment. It is advisable to refrain from immediate interpretation; staying open and being inquiring and non-interpretive is the preferred approach.

GROUP THERAPY

As mentioned above existential group psychotherapy serves as a theoretical foundation (Yalom, 1985). This way of facilitating a group requires skills in dealing with communication, dynamics and group process. When needed the therapist helps to sort out entangled dialogues, probes for information, and clarifies collective themes. The group becomes a holding microcosm of society where all kinds of affects can be mirrored, expressed and contained. Between members there is a potential play space that opens up in which images come alive and in which the *imagination* is put into motion. The therapist facilitates each member to share from the music journey and pays attention to resources which otherwise may be unrecognized. How the verbal exchange around images is conducted is described above for individual therapy. A visual image most likely holds a sense of rhythm and possibly a tone or sound. Maybe there is a story line, a text or drama and directions for movements and dance. Before closing a session clients are helped to formulate what has been most important to bring from the session.

KMR in comparison with the Bonny Method

Supporting a client to open to a short piece of music is essentially the same process as encouraging using the music in the traditional Bonny Method of GIM. There are however some major differences, and the way music is used is the key. As mentioned above the original GIM programs consist of sequenced Western classical music with a wide variety and dynamic intensity. KMR utilizes short, fairly stable single pieces mostly from the non-classical tradition. The intent of KMR music is to provide holding and support and slight dynamic movement without surprises, to be compared with GIM music which moves from supportive to challenging with sudden leaps and surprises and diverse contrasts. Another major difference is the unguided music experience in

KMR, whereas in GIM the verbal dialogue in the music is the hallmark of the method. Another distinction relates to the process of finding a focus for the journey. In GIM the focus/theme can be more wide and open, compared with KMR where the client finds a specific and precise focus. There are various approaches and theoretical frames used in the practice of GIM, and in KMR the theoretical foundation is clearly defined. An overview is presented in Table 22.1.

Table 22.1 The major differences between KMR and the Bonny Method

	KMR	**The Bonny Method of GIM**
Context	**Individual (60 min) and group therapy (90–120 min).**	**Individual therapy (90–120 min).**
Structure of session	Six steps: 1. Verbal dialogue 2. Induction/clearly defined focus 3. Music 4. Bridge 5. Art 6. Verbal processing	Six steps: 1. Verbal dialogue 2. Induction/focus/theme/open travel 3. Music 4. Bridge 5. Art 6. Verbal processing
Music	Single pieces 2–6 minutes, non-classical, from film music, folk music and some supportive classical GIM pieces. Unguided/talk-over	Programs consisting of sequenced pieces from the Western classical tradition, 20–40 minutes. Guided
Art	Expressive arts methods: visual arts, clay, movement/dance, drama, music making, writing	Often mandala drawings
Verbal processing	In two distinct steps	Differs in relationship to the theoretical frame
Theoretical frame	Expressive Arts, Existential/Relational Psychotherapy	Different traditions such as: Humanistic, Gestalt, Psychoanalytic, Jungian, Transpersonal

Case study: KMR group therapy in gynecology

A short-term group therapy format of eight sessions (2.5 hours each time) was implemented within a KMR/expressive arts format after a waiting list period in a RCT-study in oncology with women treated for gynecological cancer with good prognosis (Wärja, Bergmark and Bonde, 2012). Women with gynecological cancer are affected in many areas: identity, self-image, self-esteem, sexuality and relationships (Bergmark *et al*., 2002; Caldwell Sacerdoti, Koopman and Laganá, 2010). The study was a mixed methods design measuring specific outcomes and describing experiences in regards to improving quality of life. Music listening, spontaneous drawing and verbal reflection were applied to address experiences after

cancer treatment, such as existential questions, bodily and sexual dysfunctions, and fear of recurrence. There was some freedom in the protocol (developed in 2013 by Wärja, Sodell and Wenkel) to tailor interventions for the group in order to best explore difficulties, develop coping skills and find resources. Receiving a cancer diagnosis is usually a major crisis that concerns life, death and survival. Participants are supported to face the here and now and work on relevant issues in regards to life after cancer treatment.

This group consisted of seven women aged 27–73 treated for cervix, ovarian or uterine cancer, and was conduced by two nurses and expressive arts therapists trained in KMR. The therapy was divided into three main phases: building trust (Sessions 1–2), working with body image, sexuality and existential questions (Sessions 3–6) and harvesting and goodbye (Sessions 7–8). Table 22.2 gives an overview of the main therapeutic themes and chosen KMR music.

[AQ] Table 22.2 Summary of the group therapy process for women treated for gynecological Cancer

Session	Content	Music/Fields: 1. Holding 2. Opening 3. Exploring	Group themes/comments
0	**Individual interview:** 'The Cancer Story'. Experiences of cancer and of being in groups.		The participant has been randomized to wait/list and group therapy. Each member has an hour's interview with one of the therapists to prepare for the group.
1	**Group building through sharing personal music:** Bring music that speaks to current life situation after cancer.	Music chosen by participants and brought from home.	Sharing stories and music. Sadness and loss, aloneness. The body feels exhausted. Traumatic experience around finding out about having cancer. Building trust and group coherence. The music brings positive energy. Guilt feelings about survival, and others in the group seeming to be worse off. Mourning not feeling well and healthy. Frustrations that family members and friends think that one should be happy that it is now over. Intensity and focus in the room as members stand up and paint the experience of one's own body. Everyone is engaged. 'It feels like the music brings in something healthy.'
2	**Life-themes/tree drawing** a) what to focus on? b) what to leave behind to go on? Paint yourself as a tree.	Talk-over Dema Preval (1)	
3	**Body image – Part I** Whole body painting (outline of actual body size). 'Paint the body today after cancer treatment. What experiences and feelings does your body carry?'	Secret Garden: *Song from a Secret Garden* (3)	

cont.

Session	Content	Music/Fields: 1. Holding 2. Opening 3. Exploring	Group themes/comments
4	**Collage** Use the body drawing as a start. 'Find images that speak to experiences and feelings of your body today and in everyday life.'	Benny Andersson: *Sånger från Ändra Våningen* (2)	Sadness and mourning. Fighting to become whole again. 'Like I am climbing towards the light.'
5	**Sexuality – Body image Part II** WHO's definition – intro. 'Is there a need for some changes?' (Possibility to paint and change drawing.) KMR (talk-over).	African drums (warm up) Jenkins: *Palladio* (3)	Longing for intimacy and to feel attractive. Feeling guilty for not having sex. Discussion about sexual pleasures and dysfunctions: loss of lubrication and elasticity having **[AQ]**. Frustrations around using vaginal dilatator. Laughter and deep sharing. All body paintings were changed into becoming more accepting. **[AQ]**
6	**Collage: My life right now** Existential themes. 'What creates meaning in your life?' Find images from newspapers and magazines.	Fläskkvartetten: *Innocent* (3)	Who am I today? A new kind of identity. How to deal with negative thoughts, worries and anxiety. How to be with family members. Disappointment around friends that leave. Existential themes. Questions of spirituality. Strong emotional experience going back to time before cancer diagnosis. Engagement around stepping into the future. Enjoying the creative process of shaping a possible future. Feelings of hope. Sadness that the group is ending soon.
7	**Future projection timeline: past–now–future** (psychodrama vignettes) 'Write a short letter to yourself dated two years ahead.' Paint yourself as a tree.	Nilsson: *Wilmas Tema* (1) (While standing two years ahead in the future)	
8	**Closure: Art installation of the journey** 'What do you bring with you from the group?' The road ahead… Goodbye.	*Gymnopédie No. 1.* for flute and harp. (talk-over)	Sharing stories of the trees, surprise for the positive changes. Feelings of acceptance and happiness. Gratitude for the closeness in the group. Having learned so much. Sad to leave and also ready to continue with life.

In the very first session each participant played a self-selected piece of music in regards to being treated for cancer. This supported building group cohesion and created an immediate bond in the group. In the next session the symbol of a tree for oneself was the focus for KMR as a way to self-reflect and formulate pertinent issues and themes. In the working phase the group dove right into exploring present painful and ambivalent feelings around

the body, examining sexual difficulties and feelings of shame and guilt, and facing questions of death and how to create meaning of life. Here a life-size drawing and KMR experiences were used (Figure 22.5; also see plates 22.1–22.7). In the final two sessions there was an invitation to create scenarios to express hopes and wishes for the future. The entire process was concluded by reviewing all the images with the support of music (talk-over) and by sharing verbally.

Figure 22.5 **[AQ]**

After therapy all members participated in a semi-structured interview around experiences of being in the group (see box below). Working therapeutically through the arts in a group setting was reported as being helpful, holding and transformative by all seven women.

Essence of comments after group KMR therapy for women treated for gynecological cancer

71 years, uterine cancer
I accept my body more now. Actually think it is fine. I am happy that I was part of this group. I learned so much and felt very secure. Sad it has ended. It feels better with my husband now. We will seek help to help us get back to our sex life.

55 years, cervical cancer
I now have hopes for the future. Before I just lived three months at a time, between the check-ups. I could express myself exactly the way I felt without any one laughing at me. When I got cancer I always thought of those who were worse off. I never stopped and felt my own feelings. Now I feel more open. The group gave me energy. I feel grateful.

28 years, cervical cancer
It was great. Listening to music was good. First a bit strange to paint, but it really worked. Easier than talking. You found new things to say. It was just super! It was difficult to look at my big body painting. Then I really understood what I have been through. Others in the group helped me see it in new ways. I was happy that I could change how I saw it and paint again.

59 years, uterine cancer
Now I feel like a woman with power. Before I was closed in, like in a bubble. Felt indifferent. First I was a bit afraid of the group. The leaders were wonderful, and I felt secure. I have been scared of a relapse. Now I am no longer so worried. I dare to check in with how I feel, and say no when I must. I also feel fragile, like a blossoming cherry tree. I will take better care of myself. Good to speak about everything, including sex and finding a new partner.

73 years, uterine cancer
I liked that we brought our own music. Difficult to see that I have become so old after the cancer, but my feet are still dancing. It was good to speak about sex. I have felt sorry for my husband. We will try to have sex again. I really liked that we painted trees. When I was ill I looked at the trees outside my window. I talked with them every day. It was fantastic to be in this group. I would have liked to continue for a long time.

56 years, ovarian cancer
In the first painting I had no face. Being part of the group has changed things totally. I am friends with myself, and have a happy face. At the same time period as the group I was visiting a good friend who then died of intestinal cancer. The group has been very helpful. At first I was upset when there were complaints in the group, thinking about my friend dying. But then I understood that I had my own journey. The best part was that we could talk so openly about sex.

68 years, ovarian cancer
What a fantastic group. I liked that we had a young woman among us. She had such humor, we laughed a lot. I now feel happy. I had really been at the bottom. Such an open group. After every session I had many things to bring home and think about until next time. I felt secure.

Conclusion

In summary KMR is a versatile adaptation that can be used in individual and group psychotherapy in various clinical settings and for educational purposes to address a wide range of needs, crisis situations and interpersonal problems. In essence it involves a process of surrendering where the aesthetic qualities of short pieces of music mostly from the non-classical tradition become the matrix for change within the holding role of a therapeutic relationship.

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Appendix: Music list

Benny Anderssons Orkester (CD): *Sånger från andra våningen* (*Songs from Second Floor*) 3:52

Beethoven: *Piano Concerto No. 5*, Adagio 6:53

Deva Preval: *Om Namo Bhagavate* 7:06

Dobrogosz: *Mass and Chamber Music*, Resting Place 3:41

Fläskkvartetten: *Innocent* 3:33

Jenkins: *Palladio*, Allegretto 3:43

Johansson: *Bandura* 2:27

Kater: *Song of Union*, Trad. Arr. 2:52

Löfman: *Makh Jchi* 2:02

Löfman: *The Wedding* 4:02

Lully: *Gavotte* 2:50

Morricone: *Sacco e Vanzetti Speranze de Liberta.* 2:29

Myers: *Cavatina* 3:33

Nilsson: *Arons Dröm* (*Aaron's Dream*) 3:57

Nilsson: *Gabriella's Piano* 3:18

Nilsson: *Mot den nya världen* (*Towards the New World*) 2:42

Nilsson: *Wilmas Tema* (*Wilma's Theme*) 1:57

Pachelbel: *Canon in D* (slow version) 7:23

Puccini: *Madame Butterfly*, Humming Chorus 2:46

Quilter: *Evening in the Forest* 2:47

Satie: *Gymnopédie No. 1* for Flute and Harp 3:02

Secret Garden: (CD), *Song from a Secret Garden* 3:43

Strömberg: *Kärlek* (*Love*) 3:02

Svendsen: *Allt under himmelens färste* (*All under the Hold of Heaven*), Trad. Arr. 3:19

Vaughan Williams: *Prelude on Rhosymedre* 3:58

Wolkmar: *Wintertraum* 3:00

Appendix W. Paper III: Music as co-therapist

Music & Medicine | 2014 | Volume 6 | Issue 2 | Pages 16 – 27 Wärja & Bonde | **Music as Co-Therapist: A Taxonomy**

Full Length Article

Music as Co-Therapist: *Towards a Taxonomy of Music in Therapeutic Music and Imagery Work*

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Abstract

In receptive music therapy, music listening is used as a therapeutic medium in many different ways. The Bonny Method of Guided Imagery and Music (GIM) is a specific receptive music therapy model where the client or patient listens to selected classical music in an expanded state of consciousness in an ongoing dialogue with the therapist, facilitating symbolic and metaphorical imagery in many modalities. In this model, music is often considered a "co-therapist", and more than 100 music programs are used to address specific issues and problems. However, no classification of the music used in GIM exists. This article presents a matrix with 3 major categories: 1) Supportive music – 2) Mixed supportive and challenging music – 3) Challenging music, with three subcategories within each category. Based on a review of literature related to music listening in music and medicine the taxonomy is introduced and its relevance for the Bonny Method discussed, with special focus on two adaptations: KMR-Brief Music Journeys and Group Music and Imagery (GrpMI). Vignettes from KMR with one individual cancer patient and from GrpMI sessions with psychiatric patients are presented and related to the taxonomy.

Keywords: ***Guided Imagery; Therapeutic music; Psychotherapy; Music classification***

multilingual abstract | **mmd.iammonline.com**

Introduction

The intent of this article is to address the field of receptive music therapy, and more specifically Guided Imagery and Music (GIM), with the particular focus on criteria for selecting music in sessions. GIM "refers to all forms of music imaging in an expanded state of consciousness, including not only the specific individual and group forms that Helen Bonny developed, but also all variations and modifications in these forms created by her followers" [1]. (See also Grocke's introduction in this volume). In GIM, as in receptive music therapy in general, the selection of music for a client is a significant, but also a difficult, and even controversial issue. What music is appropriate for which clients, and how is the choice of music related to the pathology or physical/psychological/existential problems of the client? The literature contains many examples of playlists, music programs and recommended single pieces (for an overview, see [2]). However, there is no general consensus on how the music can be classified according to the therapeutic needs and stamina of the client/patient. The authors have independently worked with the classification issue as related to the musical repertoire of GIM and to various client groups. A synthesis of this work in the form of a matrix with 3 major categories: 1) Supportive music – 2) Mixed supportive and challenging music – 3) Challenging music, will be presented and developed into a simple taxonomy of two layers. The first part of the article will review literature related to music listening in music and medicine, introduce the Bonny Method, and lay out the structure of the taxonomy formulated by the authors. In the second part of the article two adaptations: KMR-Brief Music Journeys developed by Margareta Wärja [3,4], and Group Music and Imagery (GrpMI) [2] as used by Bonde and Pedersen [5-7] are presented to illustrate the background and clinical uses of the taxonomy. Vignettes from one individual cancer patient and group sessions with psychiatric patients will be provided.

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Margareta Wärja, Hästholmsvägen 17, 116 44 Stockholm, Sweden. Email: margareta.warja@expressivearts.se | COI statement: The authors declared that no financial support was given for the writing of this article. The authors have no conflict of interest to declare.

Background

Literature on therapeutic music listening

In Music Medicine the use of playlists is a growing and promising trend [8,9]. In a pilot study (n= 15) conducted at a noisy emergency department Short and Ahern [8] developed and tested a music tool to provide relaxation in the waiting

room of a large hospital. Using mp3 players, patients could select their preferred music from a series of playlists in 4 different genres. Findings suggest that most patients reported feeling better and that music matching their personal preferences was helpful. Further research is recommended. The research team at Aalborg University has tested a number of playlists (played through a sound pillow) for and with both coronary patients [10] and psychiatric inpatients, including the following genres: Easy listening, Classical, Jazz, MusiCure (specially composed music for hospitals), Nature sounds and Rock/pop [11]. Results are promising, and playlists enable patients to have a choice. Various approaches of music listening have been used in medical care: Depth Relaxation [12], Anthroposophic Music Therapy [13], Regulatory Music Therapy [14]. An early pioneering example of Music Medicine based on playlists in different genres was "Music Rx", developed by Helen Bonny [15,16] and based on her own experiences as a coronary patient. Bonny invented a number of taped music programs (from 25 – 35 minutes in length) to be used at different stages of medical treatment at coronary care units. The selected music was generally described as "sedative" and "not stimulating", and with the intent to evoke a positive mood [17]. Results from a pilot study testing the Music Rx format with 26 patients at two different hospitals suggested "significant findings in direction of decreased heart rate, greater tolerance of pain and suffering, and lessened anxiety and depression in patients listening to music" [18].

The Bonny Method

The Bonny Method of Guided Imagery and Music (GIM) (here referred to as the Bonny Method) is an individual receptive music psychotherapy approach developed by Helen L. Bonny and based on humanistic and transpersonal psychology. Today, the Bonny Method (with adaptations) is one of the major models of music therapy in the world and it is practiced in four continents [19,20]. The individual session lasts 90-120 minutes starting with a verbal dialogue identifying current life themes and finding a pertinent focus. This is followed by an induction/relaxation phase that moves into the music. Already in the induction the client enters a slightly altered state of consciousness (ASC) [1,16,21,22] that will expand during the music. A dialogue about the ongoing experience takes place in the music listening phase. The client's imagery can be clothed in various kinds of bodily felt senses (visual, bodily, auditory, gustatory, olfactory etc.). Dialoguing in this manner requires acquired therapeutic skills and in-depth knowledge about the music in the Bonny Method. The music is acknowledged as a "co-therapist" and as the primary mover and energizer of the both intra- and interpersonal experience where the therapist supports the client in a continuous deepening and surrendering to the musical space [23-25]. After the music journey there is a bridge back into ordinary consciousness. Drawing and/or using other multimodal art is suggested and applied along with the concluding verbal reflection to explore the imagery as well as psychological themes and evolving insights. Sequenced classical music is used to develop and support an unfolding imagery experience. Bonny generated 18 music programs for therapeutic purposes [16,26,27]. Since then, more than 100 music programs have been documented [27]. The term *program* refers to selected pieces of music designed to work in a precise sequence lasting between about 30 – 40 minutes. After experimenting with different music genres Bonny settled on classical Western art music for reasons of variability, complexity, aesthetics, and the necessity to provide some degree of tension and release to support and match internal states in order to facilitate exploration of unconscious material [16]. The concept of the "affective contour" [16,28] was fundamental to Bonny´s programming and was used to graphically depict and represent the dynamic changes and intensity in a given music when selecting music for a program. Bonny considered musical elements such as: pitch, dynamic range, rhythm and tempo, melodic contour, harmonic structure and instrumentation [5,28]. She was meticulous in finding a performance of a selected piece of an aesthetic quality that would fit into the intent and character of the program [26].

The original individual format of the Bonny Method is suited for clients with ego-strength and enough stamina to tolerate the intensity also of challenging music and the duration of about 30 – 40 minutes of music. It became evident that adaptations of the original format were demanded to meet specific needs and problems for clinical areas such as: crises and trauma, oncology, palliative care, cardiac diseases, neurological disabilities, and psychiatry. This has led to the development of discrete methods to be used both individually and with groups such as: Music Breathing [29], Music and Imagery (MI) [30], Supportive Music and Imagery Method (SMI) [31,32], Group music and imagery (GrpMI) [2], KMR-Brief Music Journeys [3,4] (the last 2 are introduced below).

Selecting music for music and imagery

The literature on receptive music therapy contains few examples of clear steps and/or procedures for selecting music for clients/participants. Grocke and Wigram [2] present guidelines for using pre-recorded music and selecting appropriate music based on its potential in specific clinical contexts. Thus, selecting music requires both thorough clinical and musical skills. A common approach is to use the *iso-principle*, referring to attuning and matching music to the mood and general energy level of the client [33,34]. In the Bonny Method the "affective contour" of the entire program is considered and assessed for a particular client. Summer [35] introduced two basic notions to be used in selecting music for a music and imagery session: *music as holding*, and *music as stimulating*. Applying concepts from developmental psychology formulated by Winnicott [36] she also suggested finding music that is "good-enough" to address states of "me-ness" and "not-me-ness" to work on forming an identity (a sense of a true self), which separates the person from others

and makes him/her recognizable and special. The true self relates to an individual's experience of "me-ness". In addition, Summer [37] has applied three concepts based on the work of Wheeler *supportive, re-educative* and *re-constructive* [38]. The therapist assesses current functioning level and needs of the patient and this will determine where on this psychotherapeutic continuum the work can be done. Thus the music (such as musical structure, predictability, complexity, dynamics) is attuned and adjusted accordingly. Summer provides examples of music corresponding to the 3 levels.

The development of the taxonomy

The authors have independently worked on developing procedures for selecting music for clients in therapeutic music and imagery work. Based on an analysis of the relationship between different types of music in GIM and the music-assisted imagery in 6 cancer survivors' individual Bonny Methods sessions Bonde [39] developed (a) 3 music categories Supportive, Mixed and Challenging, and (b) a grounded theory on this music-imagery relationship. This theory is briefly unfolded in *Table 3*. In forming the approach called KMR-Brief Music Journeys [3,4] Wärja outlined a method for selecting a piece of short music based on levels of intensity and musical complexity to be used in individual therapy and in working with groups (therapy and supervision) [40]. Music used in KMR includes only the supportive level of the taxonomy (*Figure 3 and 4a*).

Figure 1. Hevner's Mood Wheel (redesigned graphics by the authors).

Supportive music is used to create a safe framework around the music-listening experience. It is used throughout the therapy, predominantly in the first five sessions. Supportive music is stable, fairly predictable and stays within the mood spectrum of categories 3-4-5-6 (i.e. light moods) in Hevner's mood wheel (Figure 1)[1]. The form types are simple, namely typically strophic (song form or variations), ostinato-based, dual or ternary. The imagery evoked and sustained by supportive music is easy and safe and has a static quality or develops slowly, be it memories, nature imagery or metaphoric fantasies. Emotional imagery is often comforting and reassuring.
Mixed supportive and challenging music is used to assess and facilitate the client's readiness to explore problem areas and new realms. Mixed music has a supportive beginning and ending, however some episodes may present the participant with a challenge, typically by changes in mood (also including categories 2 or 7), tempo and volume, a higher level of tension, which also means an increase in intensity. The form types are often more elaborate ternary forms with contrasting middle sections, or more rhapsodic forms. The images evoked and sustained by mixed music include core images and self-images pointing at problem areas or developmental potentials. Mixed music can be used throughout the session series. All GIM music programs include one or more selections of this type that may lead to more difficult emotional realms.
Challenging music is introduced when the participant is comfortable with the individual Bonny Method session format and has proved resonant to different musical styles and is able to work with therapeutic challenges. Challenging music serves as a musical container for therapeutic work with problem issues and difficult emotions. Challenging music is highly intense. It can be powerful, dramatic, but also sustained in a certain mood, typically categories 7, 8, 1 and 2 of Hevner's mood wheel, inviting the participant to confront problems or explore emotional dilemmas or losses. The forms of music here are often developmental (sonata form, metamorphosis) and include contrasts in many musical parameters. The three types or categories are independent of musical style and client preferences.

Table 1. A grounded theory model of how different categories or types of music influence the imagery *(adapted from Bonde [39]).*

[1] The American psychologist Kate Hevner (1936) was a pioneer in developing instruments to study listeners' perception of mood in music. The 'mood wheel' is still used in GIM research.

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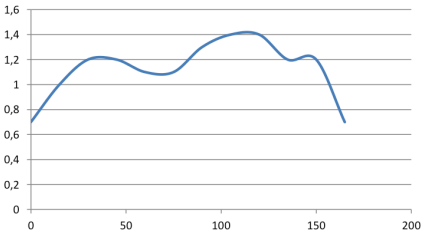
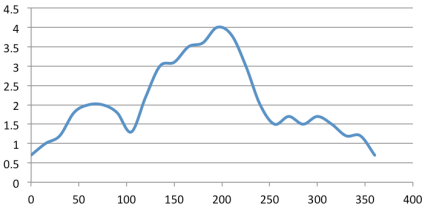
The matrix of 3 prototypes of music is illustrated graphically in *Figure 2*. The x-axis indicates duration. Supportive music last only few minutes, while Mixed and Challenging music can be much longer. The y-axis indicates intensity on a scale from 0-5. Supportive music fluctuates typically around 1-2 in few minutes. Mixed music has a few episodes of high intensity (up to 4+), while challenging music can have many episodes with high intensity (up to maximum).

Intensity – Supportive prototype profile



Intensity – Mixed supportive-challenging prototype profile



Intensity – Challenging prototype profile

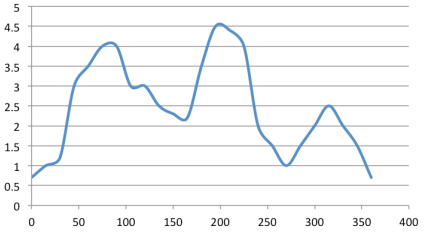


Figure 2. a-b-c. The prototypes of intensity profiles: Supportive – Mixed – Challenging. *The x-axis indicates levels of tension on a scale from 0-5. The y-axis indicates duration in seconds.*

In the taxonomy developed by the authors the 3 prototypes have been separated into three discrete sub-categories each (1-3, 4-6, 7-9). The level of intensity is gradually increasing from left to right (*Figure 3*).We will now unfold the taxonomy by presenting the types (or 'fields') at level 2 with summarized descriptions of the music qualities in each field, and with examples of music classified in the different fields (*Figure 4*).

Fields of supportive music

3 fields of varying musical complexity, all within the secure end of the matrix/taxonomy have been developed:

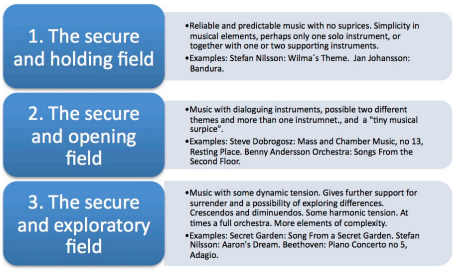


Figure 4a. The 3 fields of supportive music.

In these 3 fields the intent of the music is to provide security and holding. The fields are called: *Secure and holding* (Example: Stefan Nilsson: *Wilmas Tema ((Wilma´s Theme))*, Jan Johansson: *Bandura*), *Secure and opening* (Example: Steve Dobrogosz: *Mass and Chamber Music*, No 13, Benny Anderssons orkester: *Sånger från andra våningen (Songs from the Second Floor)*), and *Secure and exploratory* (Example: Song from a Secret Garden, Benny Andersson's Orchestra). There are no major musical surprises. The rhythm is steady and the melody and harmonic progression is clear and predictable. The pieces are mostly instrumental with some possibilities of using vocal music without words, or a 'foreign language' most likely not understood (lyrics will influence the images). The purpose of the fields is to provide music that allows for surrender and metaphorically speaking; "to give in to the musical embrace". The compositions are selected for their aesthetic quality, and for belonging to the "lighter moods" of the spectrum of Hevners's mood wheel [17].

Fields of mixed supportive-challenging music

In these 3 fields the intent of the music is to invite the listener to explore new vistas and experience emotions that may be somewhat challenging. They are called: *The explorative field with surprises and contrasts* (Bach: *Shepherd Song*, Respighi: *Gianicola*),

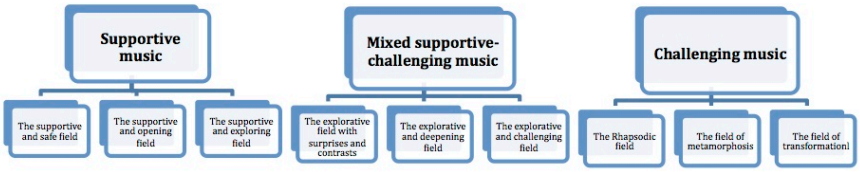


Figure 3. The Taxonomy of Music for Therapeutic Music and Imagery work.

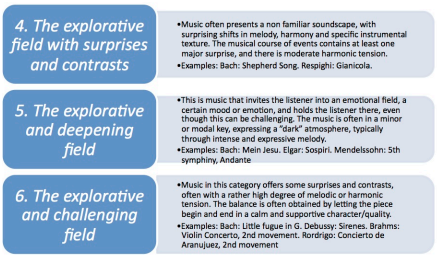


Figure 4b. The 3 fields of mixed supportive-challenging music.

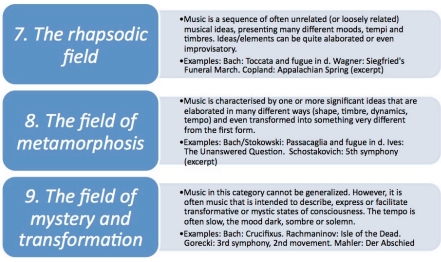


Figure 4c. The 3 fields of challenging music.

The explorative and deepening field (Bach: *Mein Jesu*, Elgar: Sospiri, Mendelssohn: 5th *symphony*, Andante), and *The explorative and challenging field* (Bach: *Little fugue in g*, Debussy: *Sirenes*, Brahms: *Violin Concerto*, 2nd movement, Tveitt: *O be ye most heartly welcome*). The music is no longer predictable, and it can present several types of musical surprises. The rhythm and tempo may change, and the melody and harmonic progression can be elaborate and somewhat surprising. The pieces are mostly instrumental, but voices can also be used (however text will be in 'foreign languages' such as Latin, French or German). Metaphorically speaking, this music introduces "not-me"-states and shorter episodes of high intensity and tension, including the darker categories of Hevners's mood wheel [17].

Fields of challenging music

In these 3 fields, the intent of the music is to invite the listener to explore new, enigmatic-mystic and even frightening areas of consciousness. They are called: *The rhapsodic field* (Bach: *Toccata and fugue in d*, Wagner: *Siegfried's Funeral March*, Copland: *Appalachian Spring*, excerpt), *The field of metamorphosis* (Bach/Stokowski: *Passacaglia and fugue in d*, Ives: *The Unanswered Question*, Shostakovich: 5th *symphony*, excerpt), and *The field of mystery and transformation* (Bach: *Crucifixus*, Rachmaninov: *Isle of the Dead*, Gorecki: 3rd *symphony*, 2nd movement, Mahler: *Das Liede von der Erde*. Der Abscheid, excerpt).The music is unpredictable, and it presents a lot of challenges: changing rhythms and tempos, sudden shifts in timbre or mood, high degrees of harmonic and melodic tension. The pieces are mostly instrumental, but voices can also be used (however text will be in 'foreign languages' (for most Anglo-Americans) such as Latin, French or German). Metaphorically speaking, this music introduces and elaborates "not-me"-states and it includes episodes of high intensity and tension, including the darker and in principle all categories in Hevners's mood wheel [17].

Applying the taxonomy in clinical work

To illustrate how the taxonomy was developed, and how it can be applied in clinical work we will introduce 2 adaptations of the original Bonny Method: KMR-Brief Music Journeys [3,4] and Group Music and Imagery (GrpMI) [2] and give examples of choices of music. The experiences of working extensively with these approaches have contributed to the development of the taxonomy. The work in KMR provides examples of choosing supportive and least challenging music. A condensed case study of selecting supportive music to meet specific clinical needs will be provided. In selecting music

within the mixed supportive-challenging fields illustrations from GrpMI are used. Our experiences of choosing music from the challenging fields of the taxonomy are based on applying the original one-to one format of the Bonny Method. In this approach the verbal dialogue between client and therapist during the listening experience is of uttermost importance in using challenging music for therapeutic purposes. Procedures and rationales for choosing music within the Bonny Method frame have been discussed previously in the literature [16,22,28].

KMR-Brief Music Journeys - the use of supportive music

The music used in KMR-Brief Music Journeys lasts 2-6 minutes. The timeframe of a typical session is 60 minutes. KMR has been developed over time and is embedded in theoretical frames of the Bonny Method [22], the phenomenological approach of expressive arts therapy [41], and existential psychotherapy [42]. A contained focus is established in a verbal dialogue and the client is encouraged to use music as support and, as the work progresses, a step-wise exploration of current life-themes. The session is unguided with the client reclining in a comfortable chair having eyes open or closed. Thus it becomes a shared listening experience between client and therapist. A slightly altered state of consciousness is induced. After the music listening experience follows art-making (or expression through other art modalities) and verbal reflection and integration. The session format is basically analogous to the Bonny Method (*Figure 5*). The intent of music is to maintain *support, holding, and safety*. Metaphorically speaking the purpose of the music is to provide positive "mothering qualities" [43]. The music is quite predictable, with a steady pulse, a clear and noticeable tempo, one or a couple of melodies/themes, a predictable thematic harmonic progression with a beginning and solid ending. Most music selections come from the non-classical repertoire, such as film- and folk music, with a few supportive pieces from the Bonny Method repertoire. The metaphor of 3 different "musical fields" (presented above in the taxonomy) is applied in selecting music for a particular client: *the field of security and holding, the field of security and opening,* and *the field of security and exploration.*

Here follows an example where the individual KMR format is applied as a short-term music and art psychotherapy intervention in an ongoing RCT-study in oncological rehabilitation with women treated for gynecological cancer [44]. The study is a mixed methods design measuring specific outcomes and describing experiences in regards to quality of life. Music listening, spontaneous drawing, and verbal reflection are used together to address experiences after cancer treatment. Brief single pieces of music are applied to focus on existential questions, bodily and sexual dysfunctions, and fear of recurrence, as exemplified below.

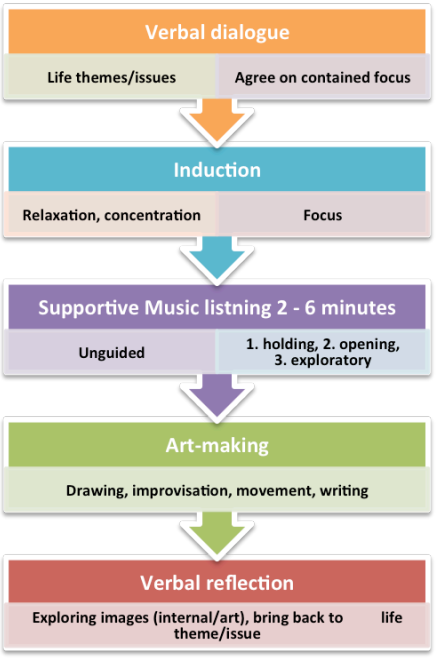


Figure 5. The structure of the KMR-Brief Music Journey session.

The act of choosing a piece of music is the responsibility of the therapist and involves interrelating parts such as: (A) relating the music repertoire to the 3 musical fields in the supportive end of the taxonomy, (B) assessing ego-strength and ability to regulate and tolerate affect, (C) listening for "the music" of the client during the verbal dialogue (i.e. how to match rhythm, tempo, pitch, timbre and dynamics of speech and semantic content), (D) evaluating how well a particular piece of music functions in the therapeutic process as a whole. The therapeutic process involves expressing and exploring difficulties, developing coping skills and finding resources.

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In the preparatory pilot phase of the study a 47 years old women whom we shall call Anna, treated for uterine cancer, participated in a series of 15 sessions. In between sessions she decided to write a diary. The main focus was to address loss of femininity, sexual distress and fear of dying. *Table 2* provides an overview of main themes, imagery and selected music, and shows that all 3 fields of supportive music in the taxonomy were explored. During the first phase Anna worked on facing fears, slowly building trust to her body, and mourning her losses. She asked if it was possible to find meaning again, and if her body ever could be trusted. Sex had been a strong bond between Anna and her husband, which now was broken. She wrote: *Everything was torn out of me. All the femininity that I so painfully had built up... now taken away from me. I was an empty body without the weight of my uterus, this magical body part, although it never gave me any children, it had initiated me into the mysteries of life. It was there, in my most vulnerable body part that the cancer grew. How destructive.*

After medical treatment was completed Anna had experienced how people around meant she now should be grateful and have a positive outlook on the future. She on the other hand felt totally miserable, paralyzed and depressed. She wrote: *"I have disconnected the body and live in my inner world. The feeling is of being separated from my body. That is how it was during treatment. The hospital owned my body. At any time it can be taken away by the illness and by death."* After having established a safe space with the help of *Sånger från andra våningen* (Songs from the Second Floor) the next necessary step was to move into suffering and fears of recurrence. Here the gentle and rich timbre of *Arons dröm*

Session	Title / Themes	Music / Field	Sophia's Images / Essences of Comments
1	**Safe Secure place** Red comforter.	B. Andersson: *Songs from the Second Etage.* ***No 2***	*The world of the dead.* *Cancer, the expected catastrophe.*
2	**Terror, death, aloneness, femininity** Death of grandmother.		*There is nothing positive in being a woman.* *Afraid of men's anger.*
3	**Boundaries**	S. Löfman: *Mack Jchi.* ***No 1***	*Mixed up pain of mother and grandmother.*
4	**Losses:** No children, sexuality My body and creativity	S. Nilsson: *The Dream of Aaron.* ***No 3***	*The cliffs by the sea. Sunny at first. Rain, wind and thunder. There is nowhere to hide. Feeling all the losses.*
5	**Darkness and cancer** Fears of cancer. How to go on and find meaning?	J. Johansson: *Bandura* (twice). ***No 1***	*Piece by piece I fall apart. I wish someone would hold me. All the pain and suffering in the world is around me.*
6	**The sensitive artist** Fate and destiny.	B. Andersson: *Songs from the Second Floor.* ***No 2***	*Can I trust my body again?* *Being caught in a spell of destiny?*
7	**Hope and comfort** Maybe sensitivity is also something good? Being able to tune in. Crying and crying.	Tense release induction. Letting the music hold the body. Fläskkvartetten: *Innocent.* ***No 3***	*The music is sad but brings comfort. There is a landscape of long paths. Walking there I can find hope and safety. It is just to endure this. To walk the paths and search for myself.*
8	**Two opposing forces** One part wants to die the other part wants to live.	S. Dobrogosz: *Resting Place.* ***No 2***	*My therapist asks me about wanting to die.* *No, I don't. I know I want to live.* *I bring the box of crayons with me home. I will paint!*
9	**Abundant art** Sharing art work from drawing at home.	No music.	*Energy and life. Pictures of femininity and sexuality. Death is purple.*
10	**Songs from the second floor** Stories of sexual assault.	J. Svendsen (arr) *Everything under the Holding of the Sky.* ***No 2***	*I am so angry!* *I paint a small child of shame behind a curtain.*
11	**Sexuality and anger** Bottomless loss. Fighting!	K. Jenkins: *Palladio, Allegretto.* ***No 3***	*I liked the fighting. Wanting to laugh. Finally! I found a whole and capable woman in the family who is not a victim: my aunt's grandmother.*
12	**Helpful mothers of the past** Whole body painting.	J. Johansson: *Bandura* and S. Nilsson: *The New World.* ***No 1***	*Yellow and orange of upper body, like burning.* *Blue is being stuck to the ground. Purple is like death.* *I will try to make contact to my mothers of the past.*
13	**Secret Garden: Songs from a Secret Garden** Purple in pelvis changes from death to wisdom. Meeting past mother figures.	Secret Garden: Songs from a Secret Garden. ***No 3***	*I realize that purple is not death. I need the purple. It brings spirituality and wisdom. Connecting me to my female ancestors. I feel strength in my pelvis.*
14	**Waking up** Art installation. "Terror, Femininity, Death, Boundaries". And hope.	Pachelbel *Canon in D.* ***No 2***	*I stay in daily contact with my female ancestors. I tell myself, and others that life will be ok again.*
15	**Harvesting** Ending, closure. Gratitude and separation.	Beethoven *Piano Concerto 5: 2.* ***No 3***	*Tired, feeling a bit numb after ending therapy. Have confronted my mother with clinging to her diagnosis. No more secrets!*

Table 2. Overview of a KMR series of 15 sessions.

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(Aaron's Dream) gave strong support to give in and acknowledge her haunting terror of cancer. She was taken by how the music lifted and comforted her (this piece moves to a soft, yet determined and holding crescendo). She dared to face fears of falling apart and expressed a need to be held. The slow and tender rocking of a folk-tune called *Bandura* (played twice) gave a reliable space for surrender. Giving in to feelings was a turning point. In the seventh session the piece *Innocent* was selected to provide movement and further emotional support. Here a clear and nurturing cello voice floats gently through a rolling and slightly syncopated rhythmic landscape. It brought tears, comfort and rays of hope. After this session Anna began to draw at home. Images gushed out like a cleansing river and gave her renewed energy and direction. In session ten and eleven she worked on releasing anger related to earlier sexual assault that surfaced during cancer treatment. Here the sturdy rhythmic container of *Palladio* provided a space for fighting and empowerment.

The emotional bodily release opened up a to reaching out and explore a new sexual relationship with her husband. The final phase of the process focused on building strength, finding resources, and discovering wisdom. In the thirteenth session *Song from a Secret Garden* was used. Here a graceful melody played by solo violin that is picked up by a sonorous cello and supportive strings, led her to encounter what she experienced as "feminine wisdom". This was a welcomed surprise. In the closing session Beethoven's compassionate *Adagio* from the 5^{th} *Piano Concerto* offered an aesthetic embrace for harvesting the work. In the collaborative interview (a structured dialogue between interviewer, therapist, and client) [45] a few weeks after therapy had ended, one question specifically addressed what had been most helpful during the therapy process. Anna stated:

Most important was to have a space and a time to connect with my feelings. Without that my drawings and writings would have no deeper meaning. The music journeys were very helpful. They supported me to move into a kind of other state where it was easier and safer to begin to feel. But if I had not trusted you, (the therapist) I would never have dared to fully feel my feelings."

Group Music and Imagery (GrpMI) study – the use of music with a mixed profile

In an exploratory study, Bonde and Pedersen [6] documented processes and outcomes of Group Music and Imagery (GrpMI) [6] therapy with relatively well functioning psychiatric outpatients. Functioning was defined as a score of min. 41 (of 100) on the Global Assessment of Functioning (GAF) Scale. The participating patients (n=17) had different diagnoses, but all had social anxiety as an important problem area. GrpMI was offered in small groups (2-4 participants) in sequences of 8-10 weekly 90 minutes sessions (participants could continue participation in a new group, if they wished – and they often did). The format of the session was close to the standard format: 1.) A quite long (45-60 minutes) initial verbal dialogue focusing on participant's needs and concerns here and now led to 2.) A short relaxation induction and the therapist's choice of a piece of classical music (duration 4'-12') with a mixed supportive-challenging intensity profile. 3.) After an unguided music listening participants made 4.) An individual (mandala) drawing in silence. 5.) The session was concluded with a short discussion of the meaning and relevance of the music listening experience and the drawings.

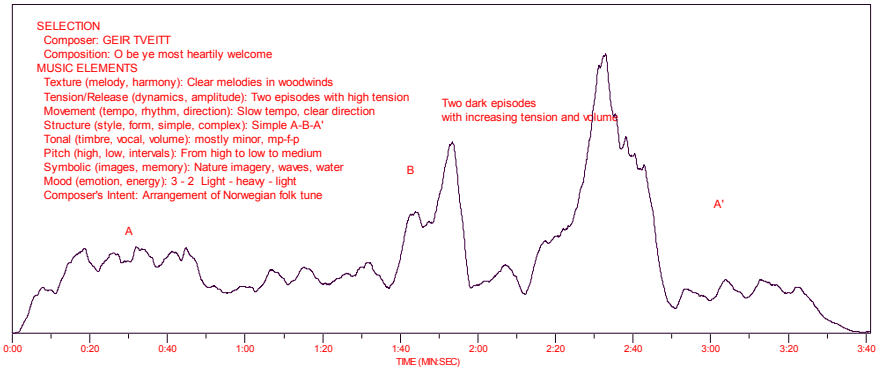

Figure 6. Annotated intensity profile (Mia) of Geir Tveitt: O be ye most heartily welcome. *The x-axis indicates levels of tension on a scale from minimum to maximum. The y-axis indicates duration in minutes and seconds.*

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The processes and outcomes of the study have been reported elsewhere [5-7] so in this context focus will be on the music used in the sessions. The taxonomy presented in this article was not developed, when the study was designed, however, it was an explicit premise that the music should have a mixed intensity profile and the experiences gained from this study have been valuable in developing the taxonomy. This decision was based on the following rationale: The participants in the groups are persons in recovery. They need not only support, but also some grade of challenge in their process of returning to everyday life, with a need to see themselves and their life strategies with fresh eyes. As metaphor and analogy music can offer a non-threatening presentational symbol of emotional states and relational modes of being [46], and it has been documented that clients in GIM very often report their imagery experiences during music listening as metaphors [47]. Music with a mixed profile has the potential to present the listener with a limited and controlled challenge within a supportive framework (musical as well as social). However, supportive and even challenging music could be used at the discretion of the music therapist, if the session prelude indicated such needs, e.g. if the participants were expressively exhausted (-> supportive music) or ready and courageous (-> challenging music)

The mixed profile can be exemplified by the music that was used for the individual assessment of all potential participants: The Norwegian composer Geir Tveitt's *O be ye most heartily welcome*, an elegant contemporary arrangement of a Norwegian folk tune. This piece is the opening of the GIM program *Soundscapes* with Norwegian music only [48]. *Figure 6* shows the intensity profile of the piece, made in the Mia software program [46].

Framed by a beautiful and tranquil beginning and a corresponding ending the short piece has 2 'dark', more or less challenging episodes during which the listener might react. In the assessment the patient was sitting up; there was no relaxation, but an invitation to close the eyes and 'let the music take you wherever you need to go'. A typical example of an experience was this tiny narrative from a 44 years old woman: It was like a fairy tale of a person visiting a forest where there was light and darkness. A 'troll' was hiding in the shadows, but later it came forward and took what it needed before returning to the shadows, as the light returned. The experience was not scary, and she thought it was fine music.

In a group of 3 participants the piece was played again in a late session. None of the participants recognized the music. However, their experience was close to what came up in the assessment. The division of the music in 3 sections was a common, salient feature: A peaceful beginning (nature imagery) – a darker, more dramatic tension building to a climax (a stone quarry with a funeral procession; a ditch; an intentional interruption of the music) – a return to the mood of the beginning (with a touch of sadness). More examples of music used in the GrpMI session can be seen in *Table 3*.

Bach: Adagio in C (Baroque/Romantic) 5.12
Beethoven: Violin Concerto No.2 (Romantic) 10.13
Boccherini: Cello Concerto No. 2 (Classical) 5.53
Brahms: Violin Concerto No. 2 (Romantic) 8.56
Brahms: Piano Concerto No.2, 2nd movement (Romantic) 11.45
Brahms: Double Concerto No.2 (Romantic) 12.19
Britten: Sentimental Saraband (Romantic/20th century) 6.37
Copland: Corral Nocturne (20th century) 3.49
Elgar: Enigma Variations No.8+9 (Romantic) 5.38
Liadov: The Enchanted Lake (Impressionistic) 7.58
Picker: Old and Lost Rivers (20th century) 6.35
Ravel: Piano Concerto No.2 (20th century) 7.00
Ravel: Dahpnis & Chloë (excerpt) (Impressionistic) 7.15
Respighi: Gianicola (Impressionistic) 6.20
Shostakovich: Piano Concerto No.2, 2nd movement (20th century) 6.37
Villa-Lobos: Bachianas Brasileiras #5 (20th century) 6.41

Table 3. Examples of music with a mixed profile used in the sessions. *(All selections from GIM music programs, with durations taken from the 'Music for the Imagination' CD series or program lists).*

The GrpMI study documented that classical music with a mixed supportive-challenging intensity profile was effective in evoking imagery of therapeutic relevance for relatively well-functioning psychiatric outpatients. A specific selected piece of classical music with a mixed intensity profile, Tveitt's *O be ye most heartily welcome*, was an effective and reliable tool in the assessment of potential participants in GrpMI therapy for such patients. There is no reason to believe that music with the mixed intensity profile could not be used in GrpMI therapy with e.g. somatic patients in rehabilitation, however, this demands further research.

A 40 years old man whom we call Ole was referred to GrpMI in relation to individual outpatient psychotherapy. He had a long history of Obsessive-Compulsive Disorder and experienced a fast and significant effect of medical treatment. Like most of the GrpMI participants he had no experience with group therapy, and social anxiety was an important focus. Ole participated in 2 groups over 5 months. His goals were: 1) enhancing self-esteem and sense of identity, 2) experiencing focused attention and serenity, 3) increasing the capacity to accept support and care. Social anxiety was quickly reduced to a minimum in the first group (with 4 participants), and over time he developed a deep insight in his now abandoned compulsive behaviour and how it was related to his life history. He used music therapy to explore new ways of living and relating in a world no longer dominated by anxiety and compulsive rituals. In the group and through music listening he explored his relationship with all sorts of emotions, also complex and difficult feelings. He developed an open and honest communication with the other group

members who appreciated his sharing of experiences and reflections. After the last session of the 2nd group he sent an e-mail:

I have decided to stop participating in music therapy. It has been very good for me to be in the group, and I am grateful for the treatment you have offered me. I will never forget your role in the process of shaping my present, fantastic life. My family and I live a very different life than we did before. I am deeply grateful for the options the psychiatric system has offered me, including music therapy. There is a new freedom and lightness in my everyday life (without anxiety or compulsive drives and acts), something I have never experienced before. I can enjoy life with my family and other loved ones without neglecting disasters and threats in the world around me. "I know the world I sing is the world I live in."

Discussion and conclusion

Selecting the music in MusicMedicine and in receptive music therapy requires expert clinical and musical skills. Playlists and lists of recommended recordings to be used in music interventions in hospitals have been developed together with protocols for specific techniques to be used with specific clinical populations [2]. In the Bonny Method of GIM highly specialized music programs have been developed, and GIM therapists learn to select programs as related to their clients' needs. However, the literature does not include a more systematic classification of the music used in MusicMedicine, receptive music therapy, GIM and its individual and group adaptations.

When working with more severe psychological and interpersonal difficulties, life-crises, traumatic experiences and dissociation it is necessary to have a thorough method for selecting music. We have found that the taxonomy can serve that function. The ability to attach and create trust is the prerequisite for growth and for reciprocal relationships. The field of attachment is essential in understanding the concept of dissociation and its effect on trauma [49]. When trust is established there is also a sense of surrender to the other and a readiness to give and receive the experiences that will come with the mutual connection, such as communication of various affect states. In addressing experiences of crises and trauma the initial step is to establish a phase of stabilization and building of resources. It is essential to evaluate the ability of the client to regulate and tolerate affects [50,51]. Thus in the act of selecting a piece of music, as illustrated by the clinical vignettes (KMR and GrpMI), the levels of trust, basic attachment patterns, and affect regulation are carefully assessed and considered. The taxonomy is based on both many years of clinical experience and on research in the relationship between imagery and music in GIM [39,46]. We think the taxonomy is inclusive of more music genres than the music used in the Bonny Method (e.g. Easy listening, Jazz, Film Music and Folk Music). In developing the taxonomy, Hevner's Mood Wheel and Bonny's concept of affective contours are important frameworks. When making selections for a music program, Bonny considered the specific mood(s) and emotional potential of that particular composition. We propose that the 1st step in selecting a piece of music for clinical purposes is evaluation of the mood(s) characteristic of that piece. The 2nd step is to determine where in the taxonomy the piece will fit in. In addition, the clinical conditions must be assessed and carefully considered. This refers to alliance, ego-strength, level of attachment, needs for stabilization, current affects, therapeutic timing, and not least the therapeutic relationship. The clinical assessment and the matrix of the taxonomy creates the base on which the music selection rests.
In psychotherapy the therapist is attentive on the quality of the connection with the client and aims to create a relationship that can carry and hold a range of affect states and needs. Being able to feel, sort out, and possibly also understand something of the origins of ones problems are fundamental to psychotherapy. Much of the communication in psychotherapy takes place in the implicit domain of relational knowing and is more or less an unconscious process [52]. In a meta-analysis on what factors have effect in psychotherapy there was extensive support for relational factors (alliance) rather than what kind of method or technique that is used [53]. Another finding regarding working alliance was the importance of the client's subjective experience that the therapist cares for the patient in a positive way [54-56]. In receptive music therapy the therapist may choose music of the client. The question of how and in what ways the therapeutic relationship may influence the therapist when selecting a piece of music is of interest here. A related question in turn is how that choice influences alliance. One assumption is that the quality of the alliance presents an "implicit fuel" that is vital for the selection process. In other words, the relational field between the therapist and client provides an intuitive antenna for the therapist in selecting a piece of music. However, the question whether this is actually what is taking place is a point for more research.

Returning to the case vignette above (KMR-Brief Music Journeys) Anna stated that the music had the capacity to move her to a space of safety where she could connect, and begin to express and work with her feelings. This in turn helped her understand some of the roots of her fears, and how the cancer illness had brought back earlier traumatic experiences. She pointed out the importance of feeling safe and held in the therapeutic relationship. In this case vignette of 15 sessions (*Table 2*) the therapist chose music from only the 3 supportive fields to meet, contain, move and gently stimulate the therapeutic process in a direction of release, acceptance and change. Here the concept of "music as a god-enough mother" [43] can be discussed. This refers to the ability attributed to music of providing experiences of being present, holding, and nurturing. It also refers to the encouragement to move forward and explore new terrains in a way that is bearbable. The aim is to help the client tolerate affects and being able to experience different affect states while staying connected to one's body. Choosing music with this in mind means turning to the supportive end of the taxonomy. In an interview study

of 5 psychotherapists' perspective of the function of the music used in KMR-Brief Music Journeys [57] it was stated that the music was experienced as providing supportive and nurturing qualities which in turn strengthened alliance and trust building. The 3 different musical fields (*secure and holding, secure and opening, secure and exploratory*) provided helpful metaphors in selecting a piece for specific therapeutic issues. Another point to consider is to be aware of precisely how the music begins (tempo, instruments, dynamics), and which mood [17] is conveyed in the first half minute. Awareness of how the music ends, and an awareness of the aesthetic qualities of the music is also of importance. Prior to moving into the shared listening experience it is essential to build and develop "good- enough" trust. The therapeutic alliance creates the fundament for the client's ability to fully open up to receive the music. One finding from the study [57] was the importance experienced by the therapists to communicate both verbally and non-verbally their belief in the power of the music to bring about holding and provide a potential space for change to occur. This finding needs to be investigated further.

In conclusion, this article presents a fairly simple taxonomy in 2 levels - a main level of 3 specific 'generic' types of music with therapeutic potential, and a sub-level of 9 subtypes or 'fields'. Application of the taxonomy with greater awareness of the Mood Wheel needs more investigation and discussion. In summary: the mood of the music, its placement in the taxonomy, and clinical evaluations contribute to the therapist's choice of music. We think the taxonomy has the potential to facilitate a focused selection of music to address levels of emotional tolerance and to work with affect tolerance and regulation. So far, our clinical experiences are more or less limited to the fields of oncology and psychiatry. We know that the taxonomy makes sense and can be used in practice within these fields, but it will need further research to establish the taxonomy as a generic classification and clinical tool. More systematic clinical studies focusing on the uses of non-classical music and its relationships with the taxonomy are necessary. Developing a deeper understanding of the uses of more music genres is also of importance. It is especially relevant to study and describe music fitting into the mixed supportive-challenging and challenging subcategories as the music presented here is mainly from the classical Bonny repertoire.

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Appendix X. Paper VI: Existential distress of total sample: EORTC QOL-C30, MADRS, HADS-A and analysis of body image

Self-assessed depression, anxiety and QoL in gynecological cancer survivors (total sample) before and after arts-based psychotherapy
N = 57

Measurements	***Baseline*** Ind. *n* = 18 Gr. *n* = 39 M (SD)	***Posttest*** Ind. *n* = 15 Gr. *n* = 27 M (SD)	***Baseline-Posttest*** *d*	***FU*** Ind. *n* = 15 Gr. *n* = 21 M (SD)	***Baseline-Follow-up*** *d*	***Baseline-posttest*** 95% CI p-value	***Baseline-FU*** 95% CI p-value
MADRS	12.2 (8.10)	6.78 (5.03)	0.64	6.52 (7.12)	0.69	-4.73 (-6.73 to -2.72) **<.0001**	-4.21 (-6.31 to -2.72) **0.0002**
HADS-A	7.73 (3.82)	5.44 (3.48)	0.60	6.14 (3.97)	0.42	-2.12 (-3.02 to -1.22) **<.0001**	-1.52 (-2.46 to -0.58) **0.002**
EORTC-QOL-C30 Global QoL	65.6 (20.4)	74.2 (13.9)	0.42	74.8 (18.2)	0.45	7.47 (1.62 to 13.32) **0.013**	7.27 (0.93 to 13.60) **0.025**
EORTC-QOL-C30 Emotional functioning	64.3 (23.6)	77.6 (20.0)	0.56	79.2 (22.2)	0.63	13.01 (4.29 to 21.74) **0.004**	14.30 (5.06 to 23.53) **0.003**
EORTC-QOL-C30 Social functioning	72.8 (27.8)	84.5 (21.0)	0.42	87.5 (18.4)	0.53	10.27 (2.70 to 17.86) **0.009**	11.86 (3.63 to 20.08) **0.005**

Table X. Aspects of depicted body-representations, present or absent in the human figure-drawings

	Baseline *n* = 28 (%)	Post-treatment *n* = 28 (%)	Odds ratio (CI 95 %)	Fisher's exact test (p-value)
Empty genitals	5 (17.9)	0 (0.0)	0	0.05
Absent/non-existent genitals	7 (25)	2 (7.1)	4.30 (0.81 to 23.09)	0.14
No face	6 (21.4)	1 (3.6)	7.36 (0.82 to 65.83)	0.10
Fragmented human figure	7 (25)	2 (7.1)	4.30 (0.81 to 23.09)	0.14
Pain	17 (60.7)	9 (32.1)	3.26 (1.08 to 9.77)	0.06
Tears/weeping clouds	2 (7,1)	2 (7.1)	1.00 (0.13 to 7.64)	1.00
Encapsulated	3 (10.7)	3 (10.7)	1.00 (0.18 to 5.43)	1.00

Table X. Changes in body size

	Baseline *n* = 20 (%)	Post-treatment *n* = 20 (%)	Odds ratio (CI 95 %)	Fisher's exact test (p-value)
Body size expanded	20 (100)	16 (80)	0	0.10
Body size diminished	20 (100)	0 (0)	0	<.001

Appendix Y. Sample of paintings used in analysis of body image: before and after arts-based psychotherapy

Baseline	Posttest
	
	
	

SUMMARY

This PhD thesis presents a complex intervention studying the effects of arts-based psychotherapy on gynecological cancer survivors. Women recovering from gynecological cancer are affected in all aspects of their lives. The aftermath of illness and its treatment are often long-lasting. The overarching aims of rehabilitative medicine are to assist the person to heal, reintegrate, readjust, and reclaim the body after illness.

A qualitative preparatory phase led up to a randomized trial in which we evaluated the effects of two arts-based interventions on psychological outcomes. An arts-based psychotherapy method called KMR–Brief Music Journeys was implemented in group and individual formats.

This thesis is built on six papers and one linking text. Three papers relate to background literature and clinical methods, and three to the results.

We found that time-limited arts-based psychotherapy implemented for women in recovery from gynecological cancer had substantial and positive effects on quality of life and reduced psychological distress.

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