



UvA-DARE (Digital Academic Repository)

What is your story?

Exploring narratives of patients with cancer using visual tools, literary texts, and art

Bood, Z.M.

Publication date

2022

Document Version

Final published version

[Link to publication](#)

Citation for published version (APA):

Bood, Z. M. (2022). *What is your story? Exploring narratives of patients with cancer using visual tools, literary texts, and art*. [Thesis, fully internal, Universiteit van Amsterdam].

General rights

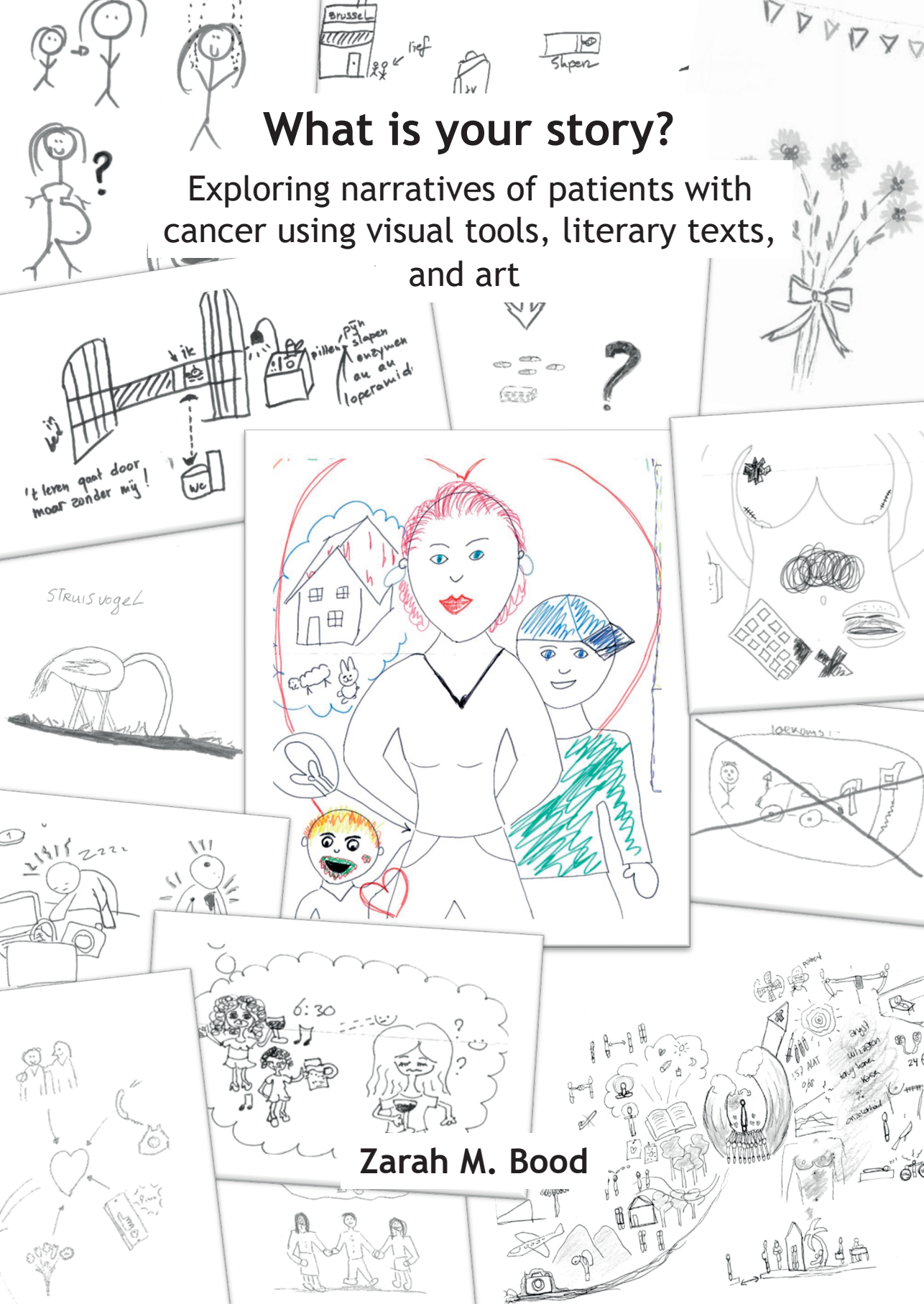
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

What is your story?

Exploring narratives of patients with cancer using visual tools, literary texts, and art



Zarah M. Bood

What is your story?

Exploring narratives of patients with cancer using
visual tools, literary texts, and art

Zarah M. Bood

Colophon

ISBN 978-94-6419-571-2
Cover art Z.M. Bood
Lay-out Z.M. Bood
Printed by Gildeprint, The Netherlands

The research for this doctoral thesis received financial assistance from The Dutch Cancer Society (KWF Kankerbestrijding) and The Young Academy, Royal Dutch Academy of Sciences (De Jonge Akademie, De Koninklijke Nederlandse Akademie van Wetenschappen)

Copyright © 2022, Z.M. Bood, Amsterdam, The Netherlands. No part of this thesis may be reproduced without the permission from the author.

What is your story?

Exploring narratives of patients with cancer using visual tools,
literary texts, and art

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

prof. dr. ir. P.P.C.C. Verbeek

ten overstaan van een door het College voor Promoties ingestelde commissie,

in het openbaar te verdedigen in de Agnietenkapel

op vrijdag 28 oktober 2022, te 13.00 uur

door

Zarah Margartha Bood

geboren te Alkmaar

Promotiecommissie

| | | |
|-----------------------|--|--|
| Promotores: | prof. dr. H.W.M. van Laarhoven prof. dr. M.A.G. Sprangers | AMC-UvA AMC-UvA |
| Copromotores: | dr. M. Scherer-Rath dr. E. Helmich | Radboud Universiteit AMSTA |
| Overige leden: | prof. dr. A.A. Kaptein prof. dr. Y.M.P. Engels dr. J.M. Tromp prof. dr. C. van Zuylen prof. dr. E.M.A. Smets prof. dr. D.L. Willems | Universiteit Leiden Radboud Universiteit AMC-UvA Vrije Universiteit Amsterdam AMC-UvA AMC-UvA |

Faculteit der Geneeskunde

Table of contents

| | | |
|------------|--|-----|
| Chapter 1 | General introduction | 9 |
| Chapter 2 | Living with advanced cancer: rich pictures as a means for health care providers to explore the experiences of advanced cancer patients | 23 |
| Chapter 3 | Repeated use of rich pictures to explore changes in subjective experiences over time of patients with advanced cancer | 47 |
| Chapter 4 | This is what life with cancer looks like: exploring experiences of adolescent and young adults with cancer using two visual approaches | 67 |
| Chapter 5 | The effects of art therapy on anxiety, depression and quality of life in adults with cancer: a systematic literature review | 89 |
| Chapter 6 | Narrative recognition and identification: a qualitative pilot study into reading literary texts with advanced cancer patients | 111 |
| Chapter 7 | “I’ll be your rock” - A case report from a multimodal narrative intervention for patients with advanced cancer | 137 |
| Chapter 8 | General discussion | 153 |
| Chapter 9 | Summary | 165 |
| | Samenvatting | 171 |
| Appendices | Dankwoord (acknowledgements) | 178 |
| | Over de auteur (about the author) | 181 |
| | PhD portfolio | 182 |

CHAPTER 1

GENERAL INTRODUCTION

General introduction

“You are talking about what you have drawn and your feelings about the things you have drawn. Without the drawing it might have been a completely different conversation, more superficial. This goes deeper, this goes deeper into your actual feelings.” - 63 years old female with advanced esophageal cancer

Impact of cancer diagnosis

The diagnosis of cancer is likely to have a profound impact on people. They are suddenly confronted with their own mortality and are forced to make important choices with respect to care and treatment options.(1) Regardless of the treatment, patients with cancer often suffer from physical pain, loss of autonomy, sadness about the loss of their old life, and fear about the future, which significantly decreases their quality of life (QoL).(1, 2)

Patients who choose to receive anticancer treatment, be it surgery, chemotherapy, radiotherapy, and/or hormonal treatment, can face various physical side-effects, including nausea, vomiting, fatigue, hair loss, and neuropathy.(3, 4) These physical side-effects negatively impact daily life and could lead to psychosocial struggles such as a negative self-image, social limitations, and reduced sexual enjoyment.(4)

Having cancer may also be regarded as an experience of contingency.(5, 6) Contingency means that everything could have been different in life, that what happened was not impossible, but also not necessary.(5-8) An experience of contingency arises when a life event, such as having cancer, conflicts with an individual's ultimate life goals. When life goals are jeopardized, an existential crisis may arise.(5-7, 9)

Consequently, feelings of despair, depressive feelings, and anxiety may occur in patients with cancer.(10) To improve well-being, patients need to make meaning of their life with cancer and integrate the diagnosis and prognosis in their life story. In other words, they need to adjust their life story.(6)

To be able to help patients with cancer to adjust their life story as best as possible, we first need to know more about their illness experience. However, talking about the impact of cancer on one's life can be difficult.(11, 12) Therefore, in this dissertation, we will explore ways for patients to express their feelings and

experiences beyond questionnaires and regular in-depth interviews. Specifically, we will describe visual tools to gain insight into the experiences of patients with cancer. Subsequently, we will investigate art-based interventions to stimulate meaning making and thereby possibly improve psychological health and overall QoL.

Using visual tools to gain insight into illness experience

Communication through visual images (visuals) is a fundamental part of human communication and has always been a part of human culture - from prehistoric cave paintings and Egyptian hieroglyphs to contemporary poster and activist street art.(13, 14) As humans we are often better able to communicate using pictures, symbols, and diagrams, than using words. Visuals enable us to overcome barriers of language and culture.(14) Additionally, non-verbal communication can capture unconscious feelings and emotions and can serve as a support when words fall short.(13-15) For instance, when a topic is unpleasant to discuss, people tend to resort to describing only one aspect of the situation or simplifying the situation by only describing the part that is easy to talk about, while leaving the difficult, emotional impact untold. In these circumstances, visuals could be a helpful tool.(16, 17) In addition to expressing feelings and emotions, visuals are also able to aid the thinking process and enable information to be grasped more easily. Simple examples of visual representations that can summarize the information in a concise and clear way, are mind- and roadmaps.(18)

Visual tools in combination with interviews show promising results for gaining an in-depth view of someone's perspective on a difficult situation.(13, 14, 16, 17, 19) Having cancer can be categorized as such a situation.(1-4) Current methods to capture the experiences of patients with cancer, such as questionnaires and in-depth interviews, may not be able to provide a complete picture of the impact of the cancer on the patient.(11-13, 15, 20) If we could invite patients with cancer to tell their story through visual images, in addition to written or spoken language, we might gain a more comprehensive understanding of what they are experiencing.(15, 16, 19, 21, 22)

Among people with cancer, various visual tools have been used to gain insight into their stories, such as drawings(23-26), paintings(27), comics(28, 29), and photovoice(30, 31). Several of these studies have shown that visual tools, especially in combination with verbal techniques, can be helpful in unravelling

experiences of patients.(22, 24-26, 32, 33) Participating patients expressed that they were better able to share their illness experience, that creating the visual gave them more insight into unconscious feelings, and that it helped to access deeper emotions.(26, 29) Furthermore, a recent study by Van Alphen et al.(25), that asked cancer patients to draw the chemotherapy-induced hair loss, argued that part of the described experiences might have remained unexplored without the use of the visual tool. In the present dissertation we will examine the role of visuals to obtain a comprehensive view on the experiences of patients with cancer. We will investigate two visual tools, drawings and photovoice, as these show promising results in gaining insight into the stories of patients.(24, 31)

Drawings

Broadbent et al.(24) provide an overview of studies that explored patients' illness perception using drawings. They describe a variety of drawing instructions being used, including the instruction to draw oneself, the part of the body that is affected by the illness, the illness itself, or how the illness made them feel. The review shows that drawings can aid in understanding the illness experience.(24) However, in most of the studies, the drawing instruction had a narrow focus and did not invite the patient to draw his/her situation as a whole.(24, 26)

A visual tool that could possibly provide a more comprehensive view of the experiences of patients with advanced cancer are **rich pictures (RPs)**. RPs are unstructured visual representations in the form of a drawing, that attempt to capture an individual's perspective of a difficult or a complex situation. The drawing can include different elements, such as, people, objects, processes, conflicts, and feelings.(13, 15, 16, 19, 34, 35) It aims to unravel the maze of all these elements and their interactions into one format.(13, 15, 16) RPs can support dialogue as they allow individuals to tell their story and how they see their place and role in relation to the situation.(15, 16, 19, 35) Discussing positions, sizes, and colors of the different elements in the drawing can aid the conversation between participant and interviewer, and give valuable insights into the participant's perspective.(16, 35) For instance, the actual size or placement of an element or icon could represent the importance of the element to the individual.(14)

RPs originate from systems thinking, where it is an established tool used to gain understanding within a complex situation.(13, 36) Recently RPs have also been introduced into healthcare settings. Cristancho et al.(17) adopted RPs as a means

to gain insight into surgeons' perceptions on complex surgical situations. Molinaro et al.(37) applied RPs to better understand how medical trainers, health care professionals, and parents of newborns experience difficult conversations in the neonatal intensive care setting. Both studies show that RPs can give insight into the unspoken and overlooked features of the experience and, therefore, show promising results for the application of RPs to gain insight into experiences of key actors within the health care sector. However, to the best of our knowledge, RP research that focusses on the experiences of patients has not yet been conducted. Hence, the present dissertation will investigate RPs as a visual tool to gain a more comprehensive view of the experiences of patients with cancer.

Photovoice

During photovoice participants are invited to document meaningful aspects of their experience through photographs.(30, 31, 38-40) Because participants are in charge of the topics they want to capture, photovoice will likely highlight parts of the experience that are most salient to the participants. A collection of photos can provide a glimpse of the realities of the lives of the patients with cancer.(30) For this reason, studies argue that photovoice is a promising method to explore experiences of patients undergoing cancer treatment.(30, 31, 40) On that account, we will examine photovoice as another visual tool to obtain a comprehensive view of the cancer experience of patients.

Art-based interventions to promote meaning making

When trying to make meaning of a contingent life experience, people are forced to explore new possibilities. In other words, meaning making stimulates creativity.(41) Creativity is defined by Csikszentmihalyi(42) as “any act, idea or product that changes an existing domain, or that transforms an existing domain into a new one” (p.28). Being creative is associated with expression of emotions and divergent thinking, it can provide the creator with different perspectives on a situation, and it can aid the development of new ways in dealing with the situation.(43) Various studies have suggested that engaging in creative art activities can promote meaning making and enhance well-being.(43-47)

Engagement in art-based interventions is suggested to improve meaning making and well-being through multiple mechanisms. For example, on the psychological level, creation of art products can provide a safe distance from overwhelming emotions and enable externalization, it can promote expression of negative and

positive emotions, increase autonomy, and promote a positive self-image.(44, 46) Additionally, art-based interventions can help normalize an ‘abnormal’ and overwhelming experience and thereby promote a sense of well-being.(46) On a cognitive level, art-based interventions enable participants to address existential questions and concerns around the loss of life, reinforce positive memories, and provide distraction from fatalistic thoughts.(44) Art-based interventions have been shown to be effective in various populations, such as adults with grief, veterans with post-traumatic syndromes, and children and adults with cancer.(45)

In this dissertation we will investigate two intervention types in which art is used to promote meaning making, help adjust the story of patients with cancer, and thereby intend to improve the QoL: art therapy and co-creative art-making. We will describe art therapy as an intervention in its broadest sense. Co-creative art-making will be discussed as part of an intervention we developed in the context of the In Search Of Stories (ISOS) intervention.

Art therapy

Art therapy can be defined as a therapeutic art-based intervention delivered by an art therapist with the aim of increasing well-being and psychological functioning(48). A review by Dunphy et al.(44) outlines that art therapy generally consists of sessions of one hour to 90 minutes, held once or twice a week, over a period of a month to a year, depending on the chosen art form. An art therapy intervention may include all sorts of disciplines, such as singing, dancing, making music, drawing, painting, coloring, sculpting, writing, or poetizing.(43-46, 49, 50) The participant is encouraged to create the art by oneself or in a group, under the guidance of the art therapist.(44, 48, 50, 51) Several studies have investigated the effect of art therapy on the QoL of cancer patients. Since the findings regarding effectiveness are ambiguous,(48, 50-52) we will conduct a review of the effects of art therapy on psychological symptoms and QoL.

In Search Of Stories (ISOS) intervention

During the ISOS intervention patients engage in a co-creative art-making project with a professional artist, to potentially facilitate the integration of the contingent life event into the patients’ own life stories. Starting point for the co-creative art-making in ISOS is the patient’s narrative which is explored by a spiritual counsellor with the help of a RP. Directly afterwards, patients are provided with exemplary narratives, in the form of literary texts, that enable interaction between the

exemplary narratives and the patient's narrative. In interaction with the text(s) the co-creative art-making is expected to empower patients to create their own, new, narratives of life. Co-creative art-making is different from art therapy in the way that it is guided by an artist, not an art therapist, and is done in collaboration between participant and artist. The main aim is to create an art piece - with increasing well-being of the patient as a secondary aim. (49, 53) In co-creative art-making the participant and artist create art while making use of the participant's narrative. (53)

Context of the research

The present studies were all conducted within the context of the ISOS project. The project aims to improve the QoL of patients with advanced cancer by offering them a narrative, multimodal intervention. The intervention addresses key-concepts of patients' narrative framework of interpretation and meaning making. Figure 1 shows how the ISOS project is designed. The intervention consists of the patient choosing and reading a literary text, followed by a process of co-creative art-making. Effects of the intervention are measured, among others, by letting patients draw RPs. In preparation of the ISOS intervention, multiple pilot tests were performed with RPs and a pilot test was conducted with the exemplary narratives. Additionally, a literature review on art therapy interventions was conducted to gain insight into the potential of art-based interventions. This dissertation will report on the findings of these pilot tests and some preliminary results of the ISOS project.

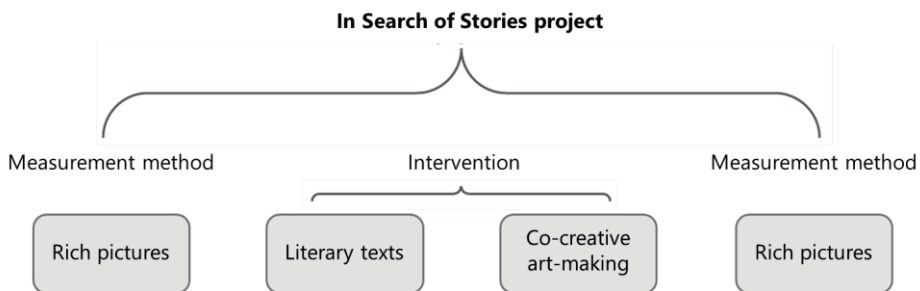


Figure 1. The design of the ISOS project

The ISOS project was developed by researchers from various disciplines and organizations in The Netherlands. It involves a collaboration between the Departments of Medical oncology and Medical Psychology of the Amsterdam University Medical Centers (UMC) in Amsterdam, the Faculty of Philosophy, Theology and Religious Studies of the Radboud University in Nijmegen, and the University of the Arts Utrecht. The research team was advised and supported by ‘Stichting voor Patiënten met Kanker aan het Spijsverteringskanaal (SPKS)’ and ‘Stichting Geneeskunst’. The pilot tests, that this dissertation will report on, were mainly conducted within the context of the Department of Medical Oncology of the Amsterdam UMC. One pilot test was conducted in collaboration with the F|FortFoundation, a Dutch organization that aims to improve the mental well-being of adolescents and young adults (AYAs) with cancer.

Aim and research questions

The aims of this dissertation are twofold. First, we will explore the use of the visual tools RPs and photovoice and their potential to gain insight into the story of patients with cancer. Second, we will examine how patients may adapt their life story using art-based interventions. We will answer the following research questions:

1. How can rich pictures and subsequent interviews be used as a method to gain insight into the experiences of patients with advanced cancer? (chapter two)
2. How can the repeated use of rich pictures make changes in subjective experiences of patients with advanced cancer visible over time and what are the most optimal research conditions to achieve this? (chapter three)
3. What are the experiences of adolescents/young adults (AYAs) living with cancer and how can rich pictures and photovoice help AYAs with expressing these experiences? (chapter four)
4. What is known about the effects of art therapy interventions on anxiety, depression and quality of life in adults with cancer? (chapter five)
5. In which way are patients helped to recognize experiences of contingency, to reflect on one's own life story, and to integrate these experiences into one's life story, by selecting and reading exemplary stories? (chapter six)
6. What is the potential of the In Search of Stories intervention to uncover the story of a patient with advanced cancer and promote meaning making? (chapter seven)

Questions one till three, and questions five and six, will be investigated using a qualitative research design. The fourth research question will be examined by conducting a systematic literature review.

Outline of the thesis

Along the lines of our two aims, this thesis will consist of two main parts. First, in chapters two, three and four, we will focus on visual tools as a method to gain insight into the stories of patients with (advanced) cancer. *Chapter two* explores RPs as a means to explore the experiences of advanced cancer patients. *Chapter three* will report on the repeated use of RPs to explore changes in subjective experiences over time of patients with cancer. Chapter two and three both report on studies that were executed in the context of the Amsterdam UMC. *Chapter four* will describe the use of RPs, as well as photovoice, to gain insight into experiences of AYAs with either curative or palliative cancer. This study was conducted in collaboration with the F|FortFoundation.

Second, we will expand on how art interventions could help patients with cancer to integrate the experience of having cancer into their life story. In *chapter five*, we will present a systematic literature review on the effects of art therapy on anxiety, depression, and QoL in adults with cancer. *Chapter six* reports on a pilot test on the first phase of the ISOS intervention - the reading of literary texts that function as exemplary narratives. Specifically, in chapter six we aim to explore whether reading these literary texts can stimulate recognition and encourage patients with cancer to talk about their life story. Lastly, we will report on preliminary results of the ISOS intervention in *chapter seven*. We will present a case report of one of the patients who participated, aiming to study the potential of the intervention to promote meaning making in a patient with advanced cancer.

The thesis will be concluded by a general discussion and a summary in *chapters eight and nine*.

References

1. Kyota A, Kanda K. How to come to terms with facing death: a qualitative study examining the experiences of patients with terminal Cancer. *BMC Palliat Care*. 2019;18(1):33.
2. Nayak MG, George A, Vidyasagar MS, Mathew S, Nayak S, Nayak BS, et al. Quality of Life among Cancer Patients. *Indian J Palliat Care*. 2017;23(4):445-50.
3. Nies YH, Ali AM, Abdullah N, Islahudin F, Shah NM. A qualitative study among breast cancer patients on chemotherapy: experiences and side-effects. *Patient Prefer Adherence*. 2018;12:1955-64.
4. Choi EK, Kim IR, Chang O, Kang D, Nam SJ, Lee JE, et al. Impact of chemotherapy-induced alopecia distress on body image, psychosocial well-being, and depression in breast cancer patients. *Psycho-Oncol*. 2014;23(10):1103-10.
5. Kruizinga R, Hartog ID, Scherer-Rath M, Schilderman H, Van Laarhoven H. Modes of relating to contingency: An exploration of experiences in advanced cancer patients. *Palliat Support Care*. 2017;15(4):444-53.
6. Hartog I, Scherer-Rath M, Kruizinga R, Netjes J, Henriques J, Nieuwkerk P, et al. Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol*. 2017;25(6):1-17.
7. Kruizinga R, Scherer-Rath M, Schilderman JB, Sprangers MA, Van Laarhoven HW. The life in sight application study (LISA): design of a randomized controlled trial to assess the role of an assisted structured reflection on life events and ultimate life goals to improve quality of life of cancer patients. *BMC cancer*. 2013;13:360.
8. Scherer-Rath M, Van den Brand J, Van Straten C, Modderkolk L, Terlouw C, Hoencamp E. Experience of Contingency and Congruent Interpretation of Life Events in Clinical Psychiatric Settings: A Qualitative Pilot Study. *J Empir Theol*. 2012;25(2):127-52.
9. Kruizinga R, Scherer-Rath M, Schilderman J, Weterman M, Young T, van Laarhoven HWM. Images of God and attitudes towards death in relation to spiritual wellbeing: an exploratory side study of the EORTC QLQ-SWB32 validation study in palliative cancer patients. *BMC Palliat Care*. 2017;16(1):67.
10. Pitman A, Suleman S, Hyde N, Hodgkiss A. Depression and anxiety in patients with cancer. *BMJ*. 2018;361:k1415.
11. Anderson WG, Alexander SC, Rodriguez KL, Jeffreys AS, Olsen MK, Pollak KI, et al. "What concerns me is..." Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer*. 2008;16(7):803-11.
12. Pearce MJ, Coan AD, Herndon JE, 2nd, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer*. 2012;20(10):2269-76.
13. Bell S, Morse S. How people use rich pictures to help them think and act. *SPAR*. 2013;26(4):331-48.
14. Berg T, Pooley R. Rich pictures: Collaborative communication through icons. *SPAR*. 2013;26(4):361-76.

15. Cristancho S, Bidinosti S, Lingard L, Novick R, Ott M, Forbes T. Seeing in different ways: introducing "rich pictures" in the study of expert judgment. *Qual Health Res.* 2015;25(5):713-25.
16. Cristancho S. Eye opener: exploring complexity using rich pictures. *Perspect Med Educ.* 2015;4(3):138-41.
17. Cristancho SM, Bidinosti SJ, Lingard LA, Novick RJ, Ott MC, Forbes TL. What's behind the scenes? Exploring the unspoken dimensions of complex and challenging surgical situations. *Acad Med.* 2014;89(11):1540-7.
18. Bell S, Morse S. Rich Pictures: Means to Explore the 'Sustainable Mind'? *Sustain Dev.* 2013;21(1):30-47.
19. Helmich E, Diachun L, Joseph R, LaDonna K, Noeverman-Poel N, Lingard L, et al. 'Oh my God, I can't handle this!': trainees' emotional responses to complex situations. *Med Educ.* 2018;52(2):206-15.
20. Kruizinga R, Hartog ID, Jacobs M, Daams JG, Scherer-Rath M, Schilderman JB, et al. The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis. *Psycho-Oncol.* 2016;25(3):253-65.
21. Ellis J, Hetherington R, Lovell M, McConaghy J, Viczko M. Draw me a picture, tell me a story: Evoking memory and supporting analysis through pre-interview drawing activities. *Am J Eng Res.* 2013;58(4):488-508.
22. Williams IC. Graphic medicine: comics as medical narrative. *Med Humanit.* 2012;38(1):21-7.
23. Harding S, Bradford J. Drawing: A novel approach to understanding appearance change in people following treatment for head and neck cancer. *SAGE Open Med.* 2019;7:1-10.
24. Broadbent E, Schoones JW, Tiemensma J, Kaptein AA. A systematic review of patients' drawing of illness: implications for research using the Common Sense Model. *Health Psychol Rev.* 2019;13(4):406-26.
25. van Alphen K, Versluis A, Dercksen W, de Haas H, Lugtenberg R, Tiemensma J, et al. Giving A Face to Chemotherapy-Induced Alopecia: A Feasibility Study on Drawings by Patients. *Asia Pac J Oncol Nurs.* 2020;7(2):218-24.
26. Cheung MM, Saini B, Smith L. Using drawings to explore patients' perceptions of their illness: a scoping review. *J Multidiscip Healthc.* 2016;9:631-46.
27. Gerge A, Pedersen IN, Gattino G, Wärja M. The body in the mind - Assessing the phenomenal self through paintings created by gynaecological cancer survivors. *Arts Psychother.* 2020;71(1).
28. Holmes MS. Cancer comics: Narrating cancer through sequential art. *TSWL.* 2013;33(1):147-62.
29. McMullin J, Rushing S, Sueyoshi M, Salman J. Reanimating the Body: Comics Creation as an Embodiment of Life with Cancer. *Cult Med Psychiatry.* 2021;45(4):775-94.

30. Wong SS, George TJ, Jr., Godfrey M, Le J, Pereira DB. Using photography to explore psychological distress in patients with pancreatic cancer and their caregivers: a qualitative study. *Support Care Cancer*. 2019;27(1):321-8.
31. Niepage M, Georgievski G, Shama W, Lucchetta S. Exploring Adolescents' Cancer Journey Through Photovoice: A Narrative Synthesis. *J Adolesc Young Adult Oncol*. 2018;7(1):15-21.
32. Elkis-Abuhoff D, Gaydos, M., Goldblatt, R., Chen, M., & Rose, S. Mandala drawings as an assessment tool for women with breast cancer. *Arts Psychother*. 2009;36(4):231-8.
33. Nainis N, Paice JA, Ratner J, Wirth JH, Lai J, Shott S. Relieving symptoms in cancer: innovative use of art therapy. *J Pain Symptom Manag*. 2006;31(2):162-9.
34. Armson R. Drawing rich pictures. In: Armson R, editor. *Growing wings on the way: systems thinking for messy situations*. Axminster, UK: Triarchy Press; 2011. p. 57-9.
35. Cristancho SM, Helmich E. Rich pictures: a companion method for qualitative research in medical education. *Med Educ*. 2019;53(9):916-24.
36. Bell S, Berg T, Morse S. Rich Pictures: Sustainable Development and Stakeholders - The Benefits of Content Analysis. *Sustain Dev* 2015;24(2):136-48.
37. Molinaro ML, Cheng A, Cristancho S, LaDonna K. Drawing on experience: exploring the pedagogical possibilities of using rich pictures in health professions education. *Adv Health Sci Educ Theory Pract*. 2021;26(5):1519-35.
38. Polo KM, Ingram G, Mather T, Ragle A, Scholl N, T. W. "It takes a village to get through cancer," A photo-elicitation study exploring lived experiences of community cancer survivors. *Br J Occup Ther*. 2021;84(3):154-63.
39. Capewell C, Ralph S, Symonds M. Listening to Women's Voices: Using an Adapted Photovoice Methodology to Access Their Emotional Responses to Diagnosis and Treatment of Breast Cancer. *J Patient Exp*. 2020;7(6):1316-23.
40. Georgievski G, Shama W, Lucchetta S, Niepage M. Through our eyes: A photovoice intervention for adolescents on active cancer treatment. *J Psychosoc Oncol*. 2018;36(6):700-16.
41. Williams N. The Role of Contingency Adduction in the Creative Act. *Psychol Rec*. 2020;71:543-51.
42. Csikszentmihalyi M. *Creativity: Flow and the psychology of discovery and invention*. New York: Harper Collins; 1996.
43. Irons JY, Garip G, Cross AJ, Sheffield D, Bird J. An integrative systematic review of creative arts interventions for older informal caregivers of people with neurological conditions. *PLoS One*. 2020;15(12):e0243461.
44. Dunphy K, Baker FA, Dumaresq E, Carroll-Haskins K, Eickholt J, Ercole M, et al. Creative Arts Interventions to Address Depression in Older Adults: A Systematic Review of Outcomes, Processes, and Mechanisms. *Front Psychol*. 2018;9.
45. Phillips CS, Becker H. Systematic Review: Expressive arts interventions to address psychosocial stress in healthcare workers. *J Adv Nurs*. 2019;75(11):2285-98.

46. Derman YE, Deatrick JA. Promotion of Well-being During Treatment for Childhood Cancer: A Literature Review of Art Interventions as a Coping Strategy. *Cancer Nurs.* 2016;39(6):E1-E16.
47. Zimmermann N, Mangelsdorf HH. Emotional benefits of brief creative movement and art interventions. *Arts Psychother.* 2020;70.
48. Wood MJ, Molassiotis A, Payne S. What research evidence is there for the use of art therapy in the management of symptoms in adults with cancer? A systematic review. *Psychooncology.* 2011;20(2):135-45.
49. Collie K, Bottorff JL, Long BC. A narrative view of art therapy and art making by women with breast cancer. *J Health Psychol.* 2006;11(5):761-75.
50. Puetz TW, Morley CA, Herring MP. Effects of creative arts therapies on psychological symptoms and quality of life in patients with cancer. *JAMA Intern Med.* 2013;173(11):960-9.
51. Geue K, Goetze H, Buttstaedt M, Kleinert E, Richter D, Singer S. An overview of art therapy interventions for cancer patients and the results of research. *Complement Ther Med.* 2010;18(3-4):160-70.
52. Archer S, Buxton S, Sheffield D. The effect of creative psychological interventions on psychological outcomes for adult cancer patients: a systematic review of randomised controlled trials. *Psycho-Oncol.* 2015;24(1):1-10.
53. Dörr H, Hübner F. If you are not there, where are you? Mapping the Experience of Absence Seizures Through Art: Utrecht HKU Professorship Performative Processes & IT&FB; 2017.

CHAPTER 2

LIVING WITH ADVANCED CANCER: RICH PICTURES AS A MEANS FOR HEALTH CARE PROVIDERS TO EXPLORE THE EXPERIENCES OF ADVANCED CANCER PATIENTS

Zarah M. Bood, Michael Scherer-Rath, Mirjam A.G. Sprangers, Liesbeth Timmermans, Ellen van Wolde, Sayra M. Cristancho, Fenna Heyning, Silvia Russel, Hanneke W.M. van Laarhoven, Esther Helmich

Based on:

Bood ZM, Scherer-Rath M, Sprangers MAG, et al. Living with advanced cancer: Rich Pictures as a means for health care providers to explore the experiences of advanced cancer patients. *Cancer Medicine*. 2019; 8(11):4957-4966.
doi:10.1002/cam4.2342

Abstract

Background

To provide holistic care to patients with advanced cancer, health care professionals need to gain insight in patients' experiences across the different domains of health. However, describing such complex experiences verbally may be difficult for patients. The use of a visual tool, such as rich pictures (RPs) could be helpful. We explore the use of RPs to gain insight in the experiences of patients with advanced cancer.

Methods

Eighteen patients with advanced cancer were asked to draw an RP expressing how they experienced living with cancer, followed by a semi-structured interview. Qualitative content analysis, including the examination of all elements in the drawings and their interrelationships, was used to analyze the RPs.

Results

The RPs clearly showed what was most important to an individual patient and made relations between elements visible at a glance. Themes identified included: medical aspects, the experience of loss, feelings related to loss, support from others and meaningful activities, and the integration of cancer in one's life. The added value of RPs lies in the ability to represent these themes in one single snapshot.

Conclusions

RPs allow for a complementary view on the experiences of advanced cancer patients, as they show and relate different aspects of patients' lives. An RP can provide health care professionals a visual summary of the experiences of a patient. For patients, telling their story to health care professionals could be facilitated when using RPs

Introduction

The diagnosis of advanced, incurable cancer is likely to have a profound impact on people.(1-4) The limited lifetime left may directly conflict with the goals people have in life, and, as such, may entail an experience of contingency.(2, 3) Contingency refers to the randomness of life, that everything could have been different.(2-5) When life goals are jeopardized, questions like “why me” and “why now” may arise.(1, 3, 4, 6) Patients need to make meaning of their life with cancer and incorporate diagnosis and prognosis in their life story.(4) Integrating advanced cancer in one’s narrative of life, however, is challenging, and feelings of hopelessness, depression, and even the desire for a hastened death were found to be common among patients with advanced cancer.(1, 7) Therefore, care for patients with advanced cancer needs to address psychosocial, spiritual and existential health in addition to physical health.(2, 6, 8-10) Despite improvements in cancer care in developed countries, these non-physical domains remain largely unattended.(10-12)

The experience of contingency can be conceptualized as an interpretation crisis, and people may not be able to find words to express what is happening to them, that is, words may be insufficient in capturing intense experiences.(3-5) Thus, the use of questionnaires or in-depth interviews can only uncover part of patients’ experiences.(10, 13) A different approach invites patients to tell their story through visuals, in addition to spoken language.(14-18) Various visual tools have been used among cancer patients in developed countries to evoke these visual narratives, such as drawings, paintings, and comics.(18-20) Furthermore, visual tools have been used in community work in for example Sub-Saharan countries.(21) The combination of verbal and visual tools was found to be helpful in unravelling experiences of patients with cancer.(18-20) However, previously used tools only focussed on one specific experience, such as physical pain or anxiety.(18-20)

A visual tool that could provide a more comprehensive view of the experiences of patients with cancer is the Rich Picture (RP).(14, 16, 17, 22, 23) An RP is a drawing that someone creates about their experience, including all the people, materials, processes, interactions, and feelings that contribute to the experience.(14, 17, 23) RPs originate from systems engineering and were originally used to explore complexity. Recently RPs have also been used in, for example, medical education research with surgical experts and with medical trainees, inviting participants to draw a complex and challenging situation in their work.(14, 16) RPs were found to aid understanding, dialogue and the sharing of experiences.(14, 16, 17, 24)

To the best of our knowledge, RPs have not yet been applied to capture the experiences of patients. Our aim was to explore the use of RPs and subsequent interviews as a method to gain insight in the experiences of patients with advanced cancer in an academic medical centre in the Netherlands.

Methods

Study design and participants

We adopted an interpretive qualitative approach that was largely guided by the principles of constructivist grounded theory, such as purposive sampling and constant comparison.(25, 26) An iterative approach to data collection and data analysis was taken, that is, data analysis started alongside data collection to inform subsequent sampling and data collection.

Patients were recruited from the Department of Medical Oncology of the Amsterdam University Medical Centers, Location AMC, the Netherlands. We asked patients above the age of eighteen with a diagnosis of advanced, incurable cancer, receiving palliative treatment and/or best supportive care, to participate. Patients with all types of solid tumors who were sufficiently fit to participate, were eligible. Patients were approached during appointments at the hospital by their attending oncologist. We aimed to include approximately fifteen patients, a sufficiently large sample size to obtain meaningful findings with a grounded theory research design.(25)

Data collection

The first author (Z.M.B.), a PhD student with a research masters in global (mental) health, conducted all the interviews. Three pilot interviews were carried out to train Z.M.B. in RP interviewing and were discussed with an experienced RP researcher (E.H.). We asked patients to make an RP about their experience of living with advanced cancer, followed by a semi-structured interview. At the start of each RP session, we used a published example of an RP as an example to show patients which icons and symbols could be included and how it might look when completed.(22) This specific example was also used in previous RP research.(14, 16) Patients were provided with an A1 paper sheet, colored pencils and markers, and were given the time they needed to draw the RP, with a maximum of 30 minutes. This maximum was chosen to prevent overburdening patients and for the reason that in clinical practice more than 30 minutes is expected not to be feasible because of time restraints. When the drawing was finished, patient and interviewer engaged in an interview about the RP. The interviewer started with

the open question “Can you explain to me what you have drawn?”, and then asked more specific questions about elements of the RP (e.g. about the colors, shapes, specific elements, and relationships between them). The interviewer aimed to understand each element of the RP, the meaning behind them and the reason they were drawn. In total, the RP session would take around one hour.

Data analysis

Interviews were transcribed verbatim and were used to support the analysis of the RPs. To analyze the combined “Rich Picture/interview” data, two main strategies were used: RP viewing sessions and gallery walks. During RP viewing sessions one single RP was discussed in detail for an hour by six to eight researchers who had experience with RP research. We analyzed the RPs using content analysis. (27, 28) An analytical framework, based on the work of Carney and adopted by Bell, Berg, and Morse was used to guide the analysis. (24, 29) The aim of these sessions was to obtain multiple perspectives on the content of the RP and explore different ways of seeing. Analysis included the examination of all elements of the drawings, such as facial expressions (e.g. smiling or crying) and body language (e.g. holding hands) of figures, use of color, arrows, thought and speech bubbles, placement and interrelatedness of elements, size of elements, and the use of metaphors and symbols.

To gain insight in patterns, differences, and similarities across the whole set of RPs, we organized three gallery walks in which all RPs were hung in a room in random order. All attendees would walk around the room to get a first impression of the RPs, and would then sit down to discuss the RPs together. In order to allow for multiple perspectives to enrich the interpretation, these gallery walks were held with different participants. The first two gallery walks included researchers with experience in RP research and members of the research team respectively, building on backgrounds as diverse as medicine, psychology, theology, arts, systems engineering and qualitative research. To validate our interpretations, we held the third gallery walk with four (former) patients with cancer. These patients, two males and two females, were all treated for stomach or esophageal cancer and were currently free of disease.

Finally, the first researcher combined the interpretations from the RP viewing sessions and gallery walks into a table in Word, to which we applied open coding to the RPs and the corresponding interview text to create initial codes. The first researcher subsequently clustered codes into themes. Evolving interpretations

were discussed and refined in weekly meetings between Z.M.B. and E.H. and presented to the research team three times during the analysis process. To interpret the findings in the context of experiences of contingency, the analysis was further informed by a theoretical model that is based on previous research on contingency of Hartog et al.(4)

Ethical considerations

The Medical Ethics Review Committee of the Academic Medical Centre stated that no ethical approval was needed for the study. Confidentiality of patients was ensured and all collected data was coded and stored in a protected database in the hospital. Prior to participation, all patients were informed about the potential risk of emotional distress and their right to withdraw from the study at any moment. We obtained written informed consent from each patient.

Results

In total, eighteen patients were included in the study, of which eleven were female. Patients' age ranged from 31 to 81 (mean age 62). Patients had esophageal, stomach, pancreas, colon, or ovary cancer. The sample included patients who were diagnosed with advanced cancer just two months before the interviews, while others had lived with advanced cancer for one to four years. Almost all patients had a partner. The characteristics of each patient can be found in appendix A.

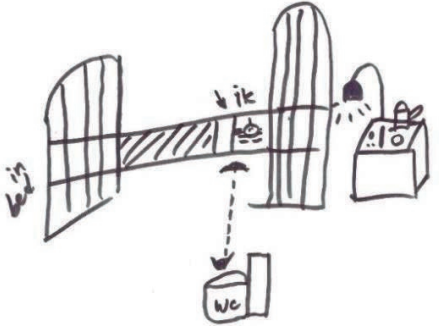
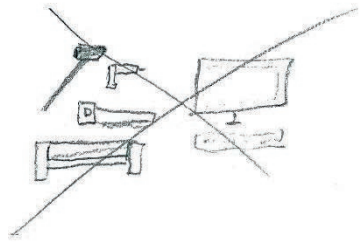
For the recognition of the different elements in the RPs, the input of patients during the gallery walk was vital. Patients participating in the gallery walk recognized many elements of the RPs that were not readily identified by researchers and health professionals, such as specific physical sensations and emotions. The main findings of the gallery walks were that a great loss and many intense emotions were depicted, and that relationships between people appeared as a central theme in the RPs. Additionally, the experience of contingency and the way patients dealt with it, in order to restructure their life story, were represented in the RPs.


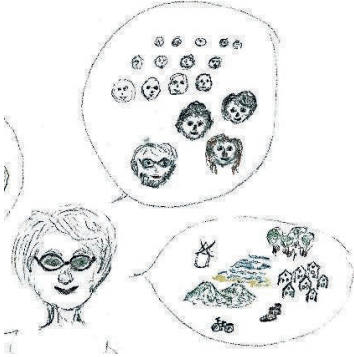
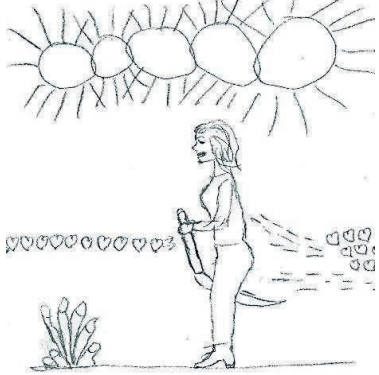
Based on the RPs and interviews, we identified five themes (table 1), which together formed an overarching narrative around contingency and show how patients shape and transform their individual accounts of their experiences. Patients' accounts often started with medical aspects and the physical experience of having cancer, which was followed by the experience of loss, feelings around

the loss, being supported by others and through meaningful activities, and integrating the cancer in a new life story. We will illustrate how those themes interrelate by presenting three individual patient stories, that serve as exemplar cases representative of our main findings. Fictional names are used, but RPs and quotes are numbered according the process of anonymization.

Table 1. The five themes with exemplary pieces of RPs and related quotes

Medical aspects and the physical experience of having cancer were for example drawn by patients lying in bed. The experience of loss was often illustrated by crosses through the lost elements, such as work. Feelings around the loss of these elements included sadness and anger. However, patients were supported by family and friends, and tried to engage in meaningful activities. How patients related to the cancer, and whether they were able to integrate the disease in their life, was made visible, for instance by depicting how patients fought the cancer and tried to stay positive.

| Theme | Part of an RP | Quote |
|--|---|--|
| Medical aspects and the physical experience of having cancer |  | I drew myself, here, that is me. Me in bed. [...] And very close to the toilet (WC), because now that is of course the biggest disaster, that you have to go to the toilet all the time and stomach ache and everything. - P14 |
| The experience of loss |  | Well, that I don't work, I am no longer able to. - P7 |

| Theme | Part of an RP | Quote |
|--|--|---|
| <p>Feelings around the loss</p> |  | <p>And now I feel more like... like from all angles a dagger has been stabbed through my heart [cries]. [...] Now my tears just fill a pool you know. I don't want to do it regularly in front of my family, but when I am alone it feels like the tears won't stop coming. - P5</p> |
| <p>Being supported by others and through meaningful activities</p> |  | <p>Since I have cancer I have received an incredible amount of support from my husband and my sister and her daughters, my cousins. But also from colleagues, from friends, and from family, well incredibly much, I never expected that to be honest. [...] Besides, there are holiday and leisure activities [...] - P3</p> |
| <p>Integrating the cancer in a new life story</p> |  | <p>This is me with a scythe in my hands. This is the cancer, which I am fighting. Suns for positivity. Because I am trying really hard to stay really positive. - P8</p> |

Frank

Frank was a 49 year old male with stomach cancer. Two months before the interview he was diagnosed with advanced cancer and he was now receiving chemotherapy. When asked to make a drawing that represented his experience with living with advanced cancer, he drew a scale with a negative and a positive anchor, symbolizing his life (figure 1A). The anchors were filled up with the most important elements of his life. In the interview, he explained:

“Well as you can see, it’s a big scale for me, which symbolizes life and well, for me it is not in balance. He tipped a bit to... well, I have the positive and the negative side and of course because of the cancer he tipped to the negative side.”
- P6

Around the scale, Frank drew other factors that affected the anchors. In this way he identified the main factors and clarified whether they positively or negatively affected impacted his life. In response to the contingent experience of getting cancer, he considered the factors that might have caused the cancer and the underlying question whether the disease was his own fault, as the most important medical aspects (figure 1B).

These included his demanding work schedule and related stress, unhealthy eating habits, and a possible error in his DNA. The experience of loss was closely related to some of the physical aspects of having cancer, such as fatigue and neuropathy (figure 1C), and resulted in him not being able to work, causing him to feel useless (figure 1C). As a consequence of the experience of loss, he depicted feelings of sadness (figure 1C), worries about his financial status (figure 1D), and thoughts about approaching death (figure 1D). On the positive side of the scale, he depicted his family, doing sports, going on holiday, eating healthy, and in general enjoying life (figure 1B).

Despite the fact that he drew more elements around the positive anchor, a pointer on top of the scale indicated that his experience was more heading towards the negative side of the scale (figure 1B). Frank explained that the cancer limited him in doing the positive things. However, the pointer was now going in the other direction, because he was trying to regain a positive life balance by focusing on the positive factors that he was still able to do, as a means of integrating the cancer in his life story.

“Yeah, you are not able to do much. That is why I indeed like to meet up with people and also to keep playing sports if I am physically able to [...]. So I regularly meet up with people of whom I think, yes I like to see him or her. Yes, I find that important now. Something that you always used to postpone like, well I am busy, I don't have time for this, it will come another time, I now think, no I will just do it right away.” - P6

In response to the tragic of losing his health and ultimately his life, Frank described how he shifted priorities, which can be interpreted as a transformation of his life story.

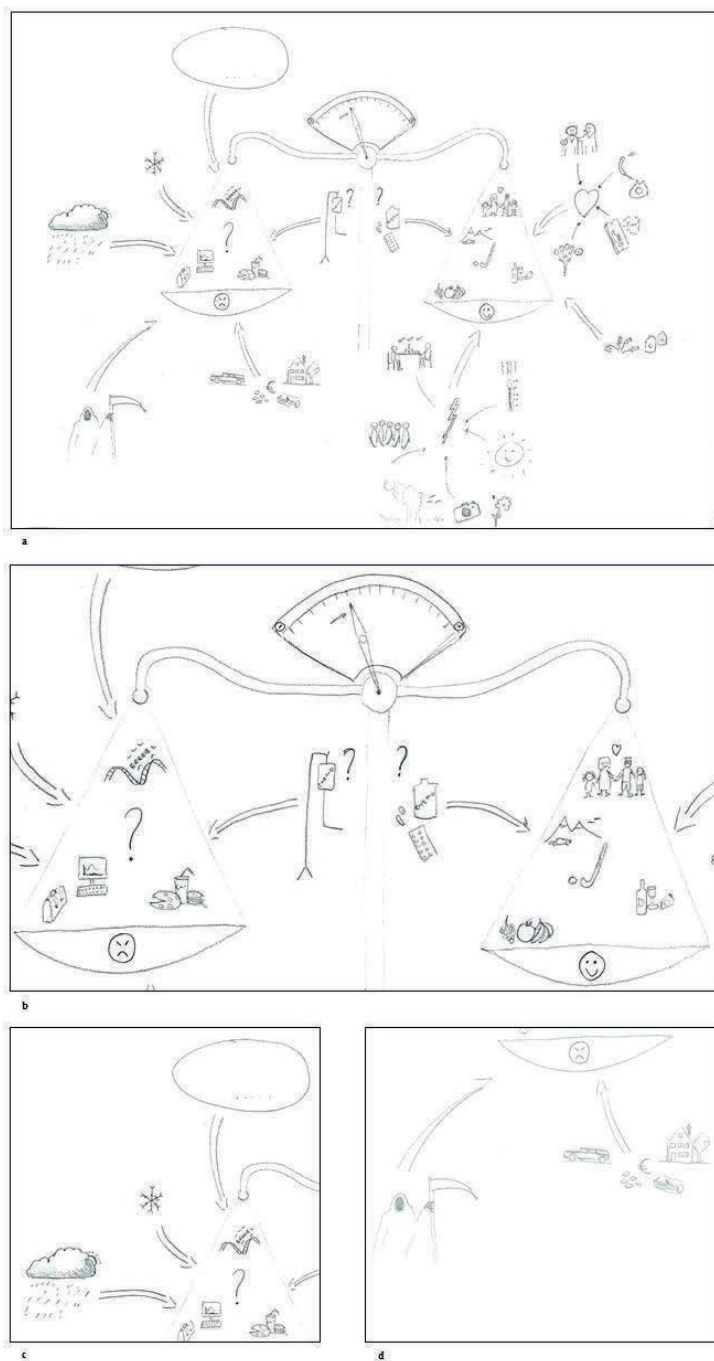


Figure 1: Rich Picture drawn by patient P6

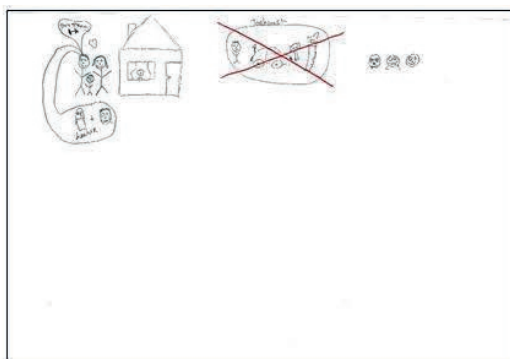
(A) The Rich Picture (B) A scale with a negative anchor on the left and a positive anchor on the right, in which factors of the patient's life are drawn. The negative anchor includes the question about what caused the cancer: work related stress (suitcase and computer), unhealthy eating habits, or an error in DNA. The positive anchor includes family, doing sports, going on holiday, eating healthy, and in general enjoying life. Chemotherapy is drawn in the middle of the scale with question marks, representing the consideration whether the therapy is negative or positive. (C) Factors that affect the negative anchor of the scale: feeling useless (empty balloon), cold weather that increases neuropathy (snowflake), and feeling sad (rain cloud). (D) Thoughts about death and worries about the financial status of the family have a negative effect on the life of the patient.

Leo

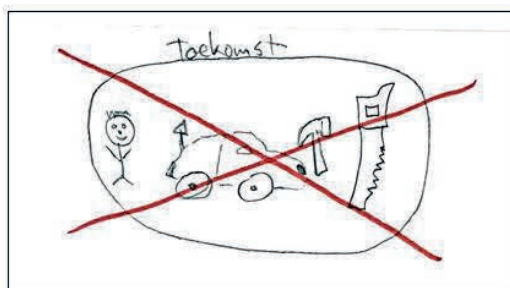
Leo, was a 31 year old male with advanced esophageal cancer. He had lived with the diagnosis for a little more than two years and had recently decided to stop chemotherapy. In his drawing, he did not depict any medical aspects, but focused on the experience and feelings related to loss, indicated by a big red cross through his future (figure 2A,C). The loss of a future not only made him sad, but also angry (figure 2D). He was angry about losing his career prospects, which made him feel useless, and about getting cancer at such a young age. Despite the central experience being one of loss, he could still feel happy when spending time with his family. Leo was clearly struggling with the integration of the cancer and approaching death into his life story, feeling sad, but on the other hand wanting to stay strong for his family (figure 2B).

The experience of loss that is central to this RP was also strongly conveyed by the large empty space that is part of the RP (figure 2A). Only when drawing, Leo realized how small his world had become, as illustrated by the following quote:

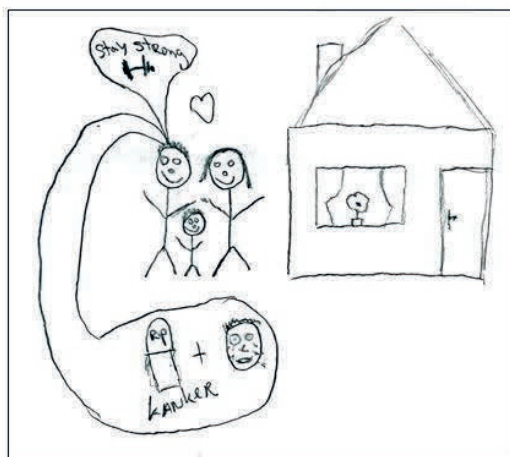
“It’s also abrupt you know, it’s suddenly from everything to nothing. Well, yeah, you can actually see that in my drawing as well. And that shocks me to be honest. [...] When you are telling someone it still seems quite something, but now that I see it on paper, the only thing I actually still have are my family and my house. The rest is just gone. [...] I think that this shows that in reality it is less glamorous than when I would just tell someone.” - P2



a



b*



c**



d

Figure 2: Rich Picture drawn by patient P2

(A) The Rich Picture (B) A red cross is drawn through the future of the patient, which included his son, his dream car, and his career as carpenter. (C) The patient and his family standing next to their house. The patient is thinking about his approaching death because of the cancer, but is trying to stay strong for his family. (D) The patient has mixed emotions, he is often angry and sad, but sometimes he feels happy when spending time with his family.

Translations: *Toekomst = future;
*Kanker = cancer

Rachel

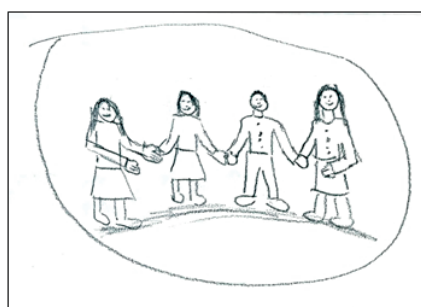
Rachel, a 63 years old female, lived with advanced esophageal cancer for a little more than two years. She drew no medical aspects and the loss she experienced was not directly clear from the RP (figure 3A). Instead, she focused on her family, how they supported each other, and how she hoped to spend as much time with them as possible (figure 3B,D). After the loss of previous life goals, her wish was now that her family would support each other and enjoy their life, even after she has gone (figure 3C): *“I am looking happily at them, at their happy faces, that they may be happy as well, not because I am gone, but because they are together, the three of them, that they can support each other. That is my goal actually.”*

When asked to reflect on the experience of making a drawing in comparison to talking without having to draw first, Rachel said:

“Yes it is clear that this is different, because now you are talking about what you have drawn, about your feelings about what you have drawn. And otherwise this may have been a completely different conversation, well... more superficial, let’s call it that way, this is deeper, this goes deeper into your feelings. That is how I feel it at least, because you are drawing what is going on in your mind.” - P9



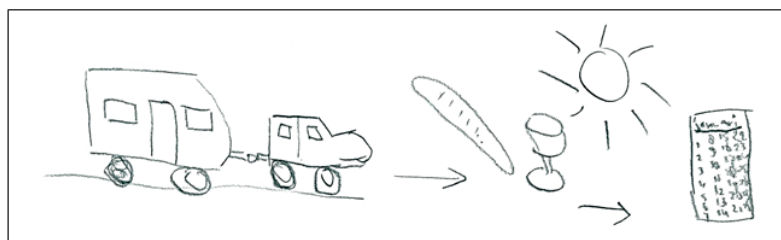
a



b



c



d

Figure 3: Rich Picture drawn by patient P9

(A) The Rich Picture (B) The patient and her family holding hands to show how close and supportive they are. (C) The patient after her death, looking down on her family with a smile. (D) The hope that the patient is still able to go on holiday and enjoy life together with her family. A calendar with January writing on it indicating that the patient hoped to live until at least that month.

Discussion

This is the first study using RPs in advanced cancer patients. RPs helped patients to tell their story and talk about what is most important to them and what other factors, aside from the disease, play a role in their life. The most dominant themes shared through the RPs and interviews were the experience and feelings around loss, and the importance of social relationships. Social relationships provided support and comfort, but also caused sadness, because patients realized they had to leave their loved ones behind. The themes found in our study correspond with findings of previous studies that have used questionnaires and in-depth interviews. (9, 30-33) Rather than providing new themes, the added value of RPs lies in the ability to represent the themes in one single snapshot. It provides a complementary view on the experiences of patients and gives insight into the relevant themes and how these interact. Furthermore, creating an RP can be considered an introductory step in narrative meaning making itself, as drawing one's story might stimulate reflection and meaning making in the interpretation crisis resulting from an incurable cancer diagnosis. (4, 10, 16) While RPs touch upon the aspects of art-based therapy, art-based therapies target the integration of a disease in their life to develop a new life story. (34) Slightly countering this, RPs are about helping patients to construct and tell their *current* life story, not create a new one. (21) RPs can lay the foundation for art-based therapy by gaining insight into the current life story of the patients before developing a new life story.

Some limitations of our study need to be acknowledged. First, engaging in an RP session of approximately an hour may be too burdensome and therefore less feasible for patients who are in a more advanced disease stage. Additionally, not all patients will feel comfortable with expressing themselves visually. Related to the study design, only one interviewer conducted all the interviews. The choice of interviewer may influence the data collection as patients are more likely to open up when they feel comfortable with the interviewer. Hence, data could have been different with another interviewer. Also, the stakeholders participating in data analysis may have shaped the interpretation of the data. We therefore included a diversity of relevant stakeholders.

These limitations are all related to the qualitative approach in the use of RPs. However, despite the disadvantages of such a qualitative measure, in our opinion, the large advantage of RPs, that is, being able to provide a visual summary of patients' experiences, outweighs these disadvantages. Also, we acknowledge that our findings are culturally bound and relate to a Dutch way of sharing experiences.

How comfortable patients are with this method depends on their cultural background. To examine whether RPs can be used in patients with different backgrounds, RP research should be conducted in other cultural groups and countries.

The clinical implications of RP interviews are noteworthy. By using RPs, it is possible to literally *see* what the experiences and feelings of an individual patient are. Thus, RPs may help health professionals to gain insight in the perspective of the patient. For patients, telling their story to health care professionals might be facilitated if they could refer to the visuals used in the RP. Thus, we envision a practice where patients are stimulated to make an RP at home or in a meeting with a palliative care counsellor, and then bring this RP to an appointment with their attending clinician. Alternatively, given the finding that patients attending the gallery walk easily recognized the expressed elements of the RPs, a collection of symbols and metaphors drawn in RPs could be made and used when talking to patients. Health care professionals could ask patients which symbols and metaphors they recognize from their own experiences and which they find most important, creating a low-threshold starting point for patients to talk about their concerns.

Author contribution

Zarah M. Bood: patient recruitment, data collection, data analysis and data interpretation, manuscript writing, manuscript review

Michael Scherer-Rath: data analysis and data interpretation, manuscript review

Mirjam A.G. Sprangers: data analysis and data interpretation, manuscript review

Liesbeth Timmermans: data analysis and data interpretation, manuscript review

Ellen van Wolde: data analysis and data interpretation, manuscript review

Sayra M. Cristancho: data analysis and data interpretation, manuscript review

Fenna Heyning: data analysis and data interpretation, manuscript review

Silvia Russel: data analysis and data interpretation, manuscript review

Hanneke W.M. van Laarhoven: study design, patient recruitment, data analysis and data interpretation, manuscript writing, manuscript review

Esther Helmich: study design, data analysis and data interpretation, manuscript writing, manuscript review

References

1. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet*. 2003;361(9369):1603-7.
2. Kruizinga R, Scherer-Rath M, Schilderman JB, Sprangers MA, Van Laarhoven HW. The life in sight application study (LISA): design of a randomized controlled trial to assess the role of an assisted structured reflection on life events and ultimate life goals to improve quality of life of cancer patients. *BMC cancer*. 2013;13:360.
3. Kruizinga R, Hartog ID, Scherer-Rath M, Schilderman H, Van Laarhoven H. Modes of relating to contingency: An exploration of experiences in advanced cancer patients. *Palliat Support Care*. 2017;15(4):444-53.
4. Hartog I, Scherer-Rath M, Kruizinga R, Netjes J, Henriques J, Nieuwkerk P, et al. Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol*. 2017;25(6):1-17.
5. Scherer-Rath M, Van den Brand J, Van Straten C, Modderkolk L, Terlouw C, Hoencamp E. Experience of Contingency and Congruent Interpretation of Life Events in Clinical Psychiatric Settings: A Qualitative Pilot Study. *J Empir Theol*. 2012;25(2):127-52.
6. Kruizinga R, Scherer-Rath M, Schilderman J, Weterman M, Young T, van Laarhoven HWM. Images of God and attitudes towards death in relation to spiritual wellbeing: an exploratory side study of the EORTC QLQ-SWB32 validation study in palliative cancer patients. *BMC Palliat Care*. 2017;16(1):67.
7. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-11.
8. Puchalski CM. Spirituality and the care of patients at the end-of-life: an essential component of care. *Omega*. 2007;56(1):33-46.
9. Lin HR, Bauer-Wu SM. Psycho-spiritual well-being in patients with advanced cancer: an integrative review of the literature. *J Adv Nurs*. 2003;44(1):69-80.
10. Kruizinga R, Hartog ID, Jacobs M, Daams JG, Scherer-Rath M, Schilderman JB, et al. The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis. *Psycho-Oncol*. 2016;25(3):253-65.
11. Pearce MJ, Coan AD, Herndon JE, 2nd, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer*. 2012;20(10):2269-76.
12. Balboni TA, Vanderwerker LC, Block SD, Paulk ME, Lathan CS, Peteet JR, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol*. 2007;25(5):555-60.
13. Anderson WG, Alexander SC, Rodriguez KL, Jeffrey AS, Olsen MK, Pollak KI, et al. "What concerns me is..." Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer*. 2008;16(7):803-11.

14. Cristancho S, Bidinosti S, Lingard L, Novick R, Ott M, Forbes T. Seeing in different ways: introducing "rich pictures" in the study of expert judgment. *Qual Health Res.* 2015;25(5):713-25.
15. Ellis J, Hetherington R, Lovell M, McConaghy J, Viczko M. Draw me a picture, tell me a story: Evoking memory and supporting analysis through pre-interview drawing activities. *Am J Eng Res.* 2013;58(4):488-508.
16. Helmich E, Diachun L, Joseph R, LaDonna K, Noeverman-Poel N, Lingard L, et al. 'Oh my God, I can't handle this!': trainees' emotional responses to complex situations. *Med Educ.* 2018;52(2):206-15.
17. Cristancho S. Eye opener: exploring complexity using rich pictures. *Perspect Med Educ.* 2015;4(3):138-41.
18. Williams IC. Graphic medicine: comics as medical narrative. *Med Humanit.* 2012;38(1):21-7.
19. Elkis-Abuhoff D, Gaydos, M., Goldblatt, R., Chen, M., & Rose, S. Mandala drawings as an assessment tool for women with breast cancer. *Arts Psychother.* 2009;36(4):231-8.
20. Nainis N, Paice JA, Ratner J, Wirth JH, Lai J, Shott S. Relieving symptoms in cancer: innovative use of art therapy. *J Pain Symptom Manag.* 2006;31(2):162-9.
21. Bell S, Berg T, Morse S. What is a Rich Picture. In: Bell S, Berg T, Morse S, editors. *Rich Pictures: encouraging resilient communities.* Abingdon, Oxfordshire; New York: Routledge; 2016. p. 1-36.
22. Armson R. Drawing rich pictures. In: Armson R, editor. *Growing wings on the way: systems thinking for messy situations.* Axminster, UK: Triarchy Press; 2011. p. 57-9.
23. Bell S, Morse S. How people use rich pictures to help them think and act. *SPAR.* 2013;26(4):331-48.
24. Bell S, Berg T, Morse S. Issues in the analysis of Rich Pictures: Eductive Interpretation. In: Bell S, Berg T, Morse S, editors. *Rich Pictures: encouraging resilient communities.* Abingdon, Oxfordshire; New York: Routledge; 2016. p. 167-214.
25. Charmaz K. *Constructing Grounded Theory.* 2nd edition ed. London: SAGE Publications; 2014.
26. Kahlke RM. Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. *Int J Qual Meth.* 2014;13:37-52.
27. Bell S, Berg T, Morse S. Rich Pictures: Sustainable Development and Stakeholders - The Benefits of Content Analysis. *Sustain Dev* 2015;24(2):136-48.
28. Berg T, Pooley R. Contemporary Iconography for Rich Picture Construction. *Syst Res Behav Sci.* 2012;30(1):31-42.
29. Carney JD. A Historical Theory of Art Criticism. *J Aesthet Educ.* 1994;28(1):13-29.
30. Garcia-Rueda N, Carvajal Valcarcel A, Saracibar-Razquin M, Arantzamendi Solabarrieta M. The experience of living with advanced-stage cancer: a thematic synthesis of the literature. *Eur J Cancer Care.* 2016;25(4):551-69.
31. Benzein E, Norberg A, Saveman BI. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliat Med.* 2001;15(2):117-26.

32. Johansson CM, Axelsson B, Danielson E. Living with incurable cancer at the end of life--patients' perceptions on quality of life. *Cancer Nurs.* 2006;29(5):391-9.
33. Andreassen S, Randers I, Naslund E, Stockeld D, Mattiasson AC. Patients' experiences of living with oesophageal cancer. *J Clin Nurs.* 2006;15(6):685-95.
34. Stuckey HL, Nobel J. The connection between art, healing, and public health: a review of current literature. *Am J Public Health.* 2010;100(2):254-63.

Appendix A. The characteristics of the patients (n=18)

| Participant number | Sex | Age | Type of cancer | Months between diagnosis ¹ and interview | Patient receive palliative treatment? | Patient have other registered diagnoses ? | WHO performance status |
|--------------------|--------|-----|----------------|---|---------------------------------------|---|------------------------|
| P1 | Male | 66 | Esophagus | 46 | Yes | Yes | 0 |
| P2 | Male | 31 | Esophagus | 27 | Not anymore | No | 0 |
| P3 | Female | 64 | Esophagus | 13 | Yes | Yes | 0 |
| P4 | Male | 65 | Esophagus | 37 | Yes | Yes | 0 |
| P5 | Female | 59 | Pancreas | 2 | No | Yes | Unknown |
| P6 | Male | 49 | Stomach | 2 | Yes | No | 1 |
| P7 | Male | 45 | Stomach | 33 | Yes | No | 0 |
| P8 | Female | 68 | Esophagus | 4 | Yes | Yes | 1 |
| P9 | Female | 63 | Esophagus | 27 | Yes | Yes | 2 |
| P10 | Female | 56 | Stomach | 8 | Yes | Yes | 1 |
| P11 | Female | 75 | Ovary | 19 | Yes | Yes | 1 |
| P12 | Female | 46 | Stomach | 14 | Yes | Yes | 1 |
| P13 | Male | 79 | Colon | 33 | Yes | Yes | 2 |
| P14 | Female | 73 | Pancreas | 7 | Yes | No | 1 |
| P15 | Female | 81 | Esophagus | 32 | Yes | Yes | 1 |
| P16 | Male | 71 | Esophagus | 40 | Yes | Yes | 1 |
| P17 | Female | 60 | Pancreas | 4 | Yes | No | 1 |
| P18 | Female | 73 | Pancreas | 21 | Yes | Yes | 0 |

¹ Specifically the diagnosis of *advanced* cancer

CHAPTER 3

REPEATED USE OF RICH PICTURES TO EXPLORE CHANGES IN SUBJECTIVE EXPERIENCES OVER TIME OF PATIENTS WITH ADVANCED CANCER

Zarah M. Bood, Michael Scherer-Rath, Mirjam A.G. Sprangers, Liesbeth Timmermans, Ellen van Wolde, Sayra M. Cristancho, Fenna Heyning, Silvia Russel, Hanneke W.M. van Laarhoven, Esther Helmich

Based on:

Bood ZM, Scherer-Rath M, Sprangers MAG, et al. Repeated use of rich pictures to explore changes in subjective experiences over time of patients with advanced cancer. *Cancer Reports*. 2022; 5(1): e1428. doi: 10.1002/cnr2.1428.

Abstract

Background: The combination of verbal and visual tools may help unravel the experiences of advanced cancer patients. However, most previous studies have focused on a specific symptom, at only one moment in time. We recently found that a specific visual tool, originating from systems thinking, that is, rich pictures (RPs), could provide a more comprehensive view of the experiences of patients with advanced cancer.

Aim: To examine whether the repeated use of RPs can make changes in subjective experiences of patients living with advanced cancer visible over time.

Methods and Results: We performed a prospective study with a generic qualitative approach that was mostly informed by the process of grounded theory. We invited patients to make an RP twice, at the start of the study, and again after two months. Both RP drawing sessions were directly followed by a semi-structured interview. Patients above the age of eighteen with all types of solid tumors and with a diagnosis of advanced, incurable cancer, were eligible. Eighteen patients participated and fifteen patients were able to draw an RP twice. In eight RP-sets, considerable differences between the first and second RP were noticeable. Two patterns were distinguished: 1) a change (decline or improvement) in physical health (five patients), and/or 2) a change in the way patients related to the cancer (three patients).

Conclusion: RPs are a valuable qualitative research method that can be used to explore the experiences of patients with advanced cancer, not only at a single point in time but also over time.

Background

Having advanced incurable cancer has a profound impact on the quality of life of cancer patients.(1-4) Patients may not always be able to find words to express what they feel, particularly in such confusing and distressing circumstances.(5, 6) Hence, current methods to capture subjective experience, such as questionnaires and in-depth interviews, possibly only uncover part of the experiences of patients with advanced cancer.(7-9) This is also important because patients' experiences can change over the course of their illness.(10) For example, a systematic review and meta-analysis by Van Kleef et al. shows that cancer patients experienced an improvement in some physical symptoms and emotional functioning during treatment, but a deterioration in role functioning, fatigue and negative feelings about hair loss.(11) If we could invite these patients to tell their story through visuals, in addition to spoken language, we might gain a more complete understanding of what they are experiencing during the whole course of their illness.(6, 12-15)

In previous studies, the combination of verbal and visual tools was found to be helpful in unravelling the experiences of patients.(15-19) For instance, reviews by Broadbent et al. and Cheung et al. provide an overview of studies that explored patients' illness perceptions using drawings and conclude that drawings can aid in understanding the illness experience.(18, 19) However, it should be noted that in most of the studies reviewed, the drawing instruction had a narrow focus - it asked patients to draw themselves, the illness, the part of their body that is affected by the illness, or how the illness made them feel.(18, 19) Additionally, in all but one of these studies, drawings were made at only one moment in time.(15-19) We recently found that a specific visual tool, originating from systems thinking, that is, rich pictures (RPs), could provide a more comprehensive view of the experiences of patients with advanced cancer.(20) RPs are drawings that research participants create to express their experiences, including different elements, for example, people, materials, processes, interactions, and feelings.(5, 6, 12, 13, 21)

RPs were found to combine different aspects of patients' lives, communicating these in one single snapshot.(20) This promising finding encouraged us to address the subsequent question: How can the repeated use of RPs make changes in subjective experiences of patients with advanced cancer visible over time and what are the most optimal research conditions to achieve this? We explored these

questions in a qualitative study among the same patients with advanced cancer who had drawn an RP previously. (20)

Methods

Study design and patients

Reporting of the study was done according to the consolidated criteria for reporting qualitative research. This study adopted a generic qualitative approach that was mostly informed by the process of grounded theory. (22) We applied purposive sampling and started data analysis alongside data collection to inform subsequent sampling and data collection. We invited patients to make an RP twice, at the start of the study, and again after two months. Both RP drawing sessions were directly followed by a semi-structured interview. The findings of the first round of RP interviews were previously published. (20) The present study will specifically focus on the repeated use of the RPs.

We adopted a constructivist research paradigm acknowledging that knowledge is co-created between researchers and patients. (23) Patients constructed their own reality when making an RP, which was refined during the interaction with the interviewer (Z.M.B.), a female PhD student with a research masters in global (mental) health, who was trained in RP interviewing by E.H., a female elderly care physician, and experienced RP researcher with a PhD in qualitative research. The backgrounds of the other researchers (i.e. medicine, theology, arts, qualitative and RP research) shaped the interpretation of the RPs further.

Patients were recruited from the Department of Medical Oncology of the Amsterdam University Medical Centers, location AMC, the Netherlands. Patients above the age of eighteen with all types of solid tumors and with a diagnosis of advanced, incurable cancer, were eligible. They were consecutively approached during appointments at the hospital by their attending oncologist. If they expressed interest in participating in the study, they were contacted by Z.M.B. for further information on the study, including the goals of the study, and to obtain formal informed consent. Patients did not know Z.M.B. before start of the study.

Data collection

During the first phase of the research we included eighteen patients, as this allowed for some loss-to-follow-up enabling a sufficiently large sample size to obtain meaningful findings. (20, 23) Clinical data, such as performance status, were

obtained from the medical chart. From February until June 2018, we conducted two RP sessions of approximately one hour with each patient, with an interval of two months, in a setting of their preference: at the hospital or their own home, and with or without a family member or friend being present. In both sessions, we asked patients to make an RP that depicted how they experienced living with cancer at the moment in time. Patients were encouraged to include all aspects of their life that they felt were relevant to their experience. When the RP was finished, the interviewer invited the patient to explain the content of the drawing, which was followed by more specific questions about the colors, shapes, and specific elements used. All interviews were audio recorded. During the whole study period Z.M.B. kept a notebook to collect field notes. A detailed description of the procedure of the interviews has been described previously.(20)

Repeated use

To explore different options for instructing patients for drawing the second RP, we divided the patients into three conditions at the time of the second interview. In condition one, patients were asked to make a completely new RP. In condition two, patients were presented with a copy of their RP from the first interview and subsequently asked to make a new RP. We left it to the patient's own discretion whether the new RP would be related to the first, for example, by expanding or deleting elements, or would be unconnected. In condition three, patients were given a copy of their RP from the first interview and invited to make adjustments on the copy itself, rather than making a new RP. For example, patients could adjust elements, erase elements, add new elements, change colors, or even leave the RP as it was when they felt it still represented their current experience.

Patients were assigned to the three conditions alternately, in order of appearance at the second interview, such that the first available patient was assigned to condition one, the second patient to condition two, the third to condition three, the fourth to condition one, etc. However, patients could change conditions during the RP session when they were not able or willing to follow the instructions specific to those conditions. For instance, when patients expressed a wish to make a new RP, they were allowed to switch to condition two, or when patients opposed to making a new RP, they could switch to condition three.

Data analysis

Interviews were transcribed verbatim and used to support the RP analysis. Transcripts were not returned to patients for additional comments. Data analysis of the combined “rich Picture/interview” data included both inductive and deductive approaches. The first set of RPs was analyzed in an inductive way, as described in detail before.(20) During so-called “RP viewing sessions” one single RP was analyzed in detail for an hour by six to eight researchers who had experience with RP research, using content analysis.(24, 25) In gallery walks, all RPs were pinned to a wall in random order. Attendees (researchers with backgrounds in medicine, theology, arts, and qualitative research, and RP research, and also cancer patients) walked along to study the RPs and subsequently discussed the RPs together, looking for patterns, disparities and similarities across the entire data set. The RP viewing sessions and gallery walks resulted in an initial set of open codes, that were further developed and clustered into themes through open and focused coding of the corresponding interview transcripts.(20)

The second set of RPs was again analyzed by Z.M.B. and E.H. and, for each individual patient, compared to the first RP of that particular patient. We explicitly looked for similar or different metaphors, visual motifs, and change of color or size of specific elements between the first and second RP.

To support our analysis of the subjective experiences of patients with advanced cancer, our interpretation of how patients relate to cancer, and whether this changed over time, we adopted a deductive approach, alongside the inductive analysis. Deductive analysis was directed by a theoretical model describing modes of relating to contingent life events developed by Kruizinga et al.(26) Contingent life events are unexpected life events that conflict with the goals people have in life. The model describes four modes: denying, acknowledging, accepting, and receiving. Denying means that people do not engage in the process of interpretation of the life event, and hence have no existential questions and (deliberately) pretend the event does not affect one’s life. In the acknowledging mode people recognize that the life event has an impact on their life and that life goals are affected. Accepting means that people acknowledge the impact of the life event, and also take the first steps to create a new life story. The last mode, receiving, describes the full integration of the life event in one’s life story. We studied the combined “Rich Picture/interview” data to arrive at an interpretation of the mode of relating to contingent life events that might be most applicable for

each patient. Interpretations of the data were initially discussed by Z.M.B. and E.H. and subsequently presented to the full research team to reach final consensus.

Ethical considerations

No formal ethical approval was needed for the study, as confirmed by The Medical Ethics Review Committee of the Academic Medical Centre, since the Medical Research Involving Human Subjects Act is not applicable (ref. no W17_476 # 17.549). We obtained written informed consent from all patients and patients were informed about their right to withdraw from the study at any moment. Patients were informed that their RPs would be used for research purposes and could be displayed to others for data analysis. All patient data was treated confidentially and stored in a protected database in the hospital.

Results

Patients

Eighteen patients participated in the first session of RP drawing and interviews (table 1). (20) Five patients were lost to follow up during the study. Two of them passed away before the second session, one declined further participation, and two could not find time due to busy private schedules.

Findings

Five out of thirteen RP-sets (first and second round of RPs) showed little to no difference between the two RPs, with the patients explaining that their life indeed had not changed noteworthy. These patients preferred to work on a copy of their first RP (condition three), because it still represented their current situation.

In the other eight RP-sets, considerable differences between the first and second RP were noticeable. Two patterns could be distinguished: 1) a change (decline or improvement) in physical health (five patients), and/or 2) a change in the way patients related to the cancer (three patients). Although represented across all three interview conditions, patients whose physical and/or mental condition considerably changed more often preferred to make a new RP (condition one or two). Two patients expressing considerable change, however, were assigned to condition three and were able to show changes by building on/changing their previous RP. Below we describe the results of five patients as an example.

Rich pictures illustrating changes in physical health

A decline in physical health was visible when comparing the first and second RP of patient P6 (figure 1A,B). In his first RP, this patient drew a snowflake to represent the neuropathy he experienced when the weather was cold. He also drew an empty balloon symbolizing the emptiness of his days due to his inability to work. Whereas he put a cross through the snowflake in his second RP, as the weather got better, he added a drawing of his hand and feet hurting because of neuropathy (figure 1B). He also added a drawing of himself sleeping on a pillow, having stomach pains, with his ribs showing through his skin, and his hair falling out. In sum, he was more tired and in pain, and suffered from weight loss and alopecia due to chemotherapy. This visualized decline was confirmed by his medical record that indicated an elevated WHO performance status (from one to two), indicating deteriorating physical health.

Table 1. Patients characteristics (n=18)

| Partici- pant number | Date first interview | Date second interview | Gender | Age | Months between diagnosis ¹ and first interview | WHO perfor- mance status (first interview) | WHO perfor- mance status (second interview) | Interview condition second interview: original placemen t | Interview condition second interview: final placemen t |
|----------------------------|-------------------------|-----------------------------|--------|-----|--|---|--|---|--|
| P1 | Feb. 2018 | May 2018 | Male | 66 | 46 | 0 | 0 | 1 | 1 |
| P2 | Mar. 2018 | May 2018 | Male | 31 | 27 | 0 | 0 | 2 | 2 |
| P3 | Mar. 2018 | May 2018 | Female | 64 | 13 | 0 | 0 | 1 | 3 |
| P4 | Mar. 2018 | June 2018 | Male | 65 | 37 | 0 | 0 | 3 | 3 |
| P5 | Mar. 2018 | May 2018 | Female | 59 | 2 | Unknown | Unknown | 3 | 3 |
| P6 | Mar. 2018 | May 2018 | Male | 49 | 2 | 1 | 2 | 3 | 3 |
| P7 | Mar. 2018 | May 2018 | Male | 45 | 33 | 0 | 1 | 2 | 3 |
| P8 | Mar. 2018 | LTFU ² | Female | 68 | 4 | 1 | - | - | - |
| P9 | Mar. 2018 | LTFU ² | Female | 63 | 27 | 2 | - | - | - |
| P10 | Mar. 2018 | May 2018 | Female | 56 | 8 | 1 | 3 | 1 | 1 |
| P11 | Apr. 2018 | LTFU ² | Female | 75 | 19 | 1 | - | - | - |
| P12 | Apr. 2018 | LTFU ² | Female | 46 | 14 | 1 | - | - | - |
| P13 | Apr. 2018 | June 2018 | Male | 79 | 33 | 2 | 1 | 2 | 3 |
| P14 | Apr. 2018 | June 2018 | Female | 73 | 7 | 1 | 0 | 1 | 1 |
| P15 | Apr. 2018 | LTFU ² | Female | 81 | 32 | 1 | - | - | - |
| P16 | Apr. 2018 | June 2018 | Male | 71 | 40 | 1 | 1 | 3 | 3 |
| P17 | Apr. 2018 | June 2018 | Female | 60 | 4 | 1 | 0 | 2 | 2 |
| P18 | May 2018 | June 2018 | Female | 73 | 21 | 0 | 0 | 1 | 1 |

¹Specifically the diagnosis of advanced cancer; ² Lost-to-follow-up

The RPs of patient P14 showed improved physical health. In the first RP, the central element was the patient lying in bed, in close proximity of the toilet and medication, whereas in the second RP only a small bed was drawn (figure 1C,D). Additionally, in the first RP, the patient specifically wrote down that she could not cycle anymore and could not join others in activities. In the second RP, she drew pictures of cycling and hiking. The increasing physical health of the patient was in line with the improvement of her WHO performance status (one to zero).

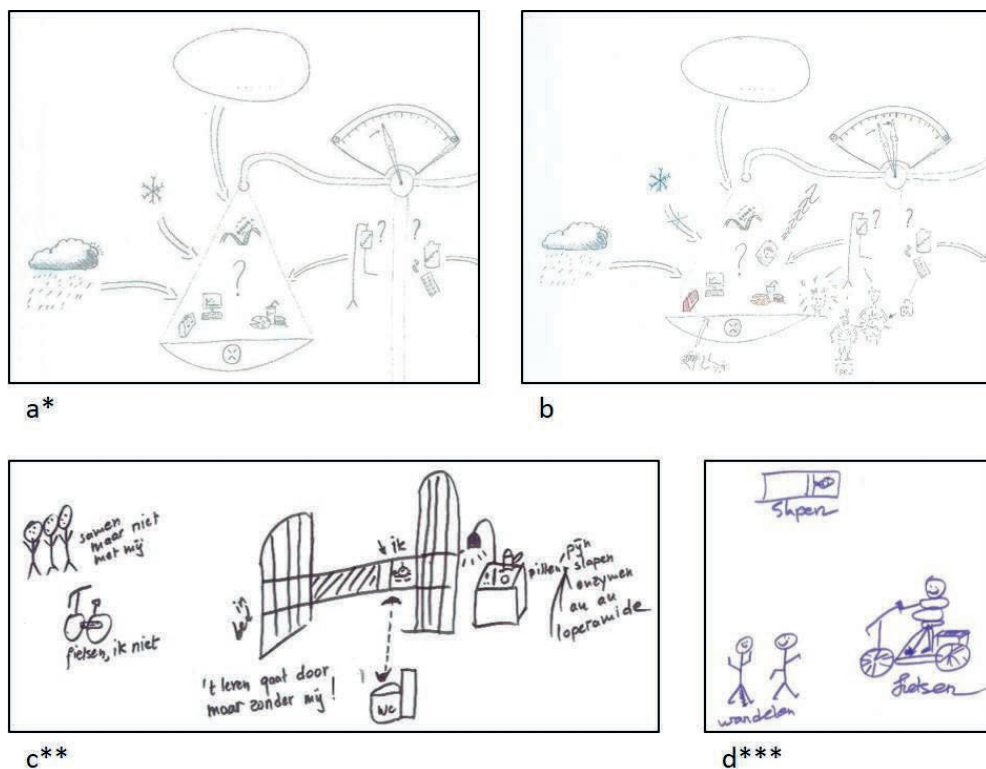


Figure 1. Rich pictures (RPs) that make differences in physical health visible

(A) Part of first RP of patient P6. (B) Part of second RP of patient P6. (C) Part of first RP of patient P14. (D) Part of second RP of patient P14.

**Translations (from left to right): together but not with me; cycling, not me; in bed; life goes on without me!; me ("ik"); toilet ("WC"); pills - pain, sleeping, enzymes, ouch ouch, loperamide

**Translations: slapen = sleeping; wandelen = going for a walk; fietsen = cycling

Rich pictures illustrating differences in the way patients relate to cancer

The repeated use of RPs allowed us to identify distinct ways of relating to cancer over time. Patient P2 drew himself in his first RP thinking about death and the loss of his future, and explicitly depicted the sadness and anger this invoked (figure 2A). He acknowledged he had cancer, but did not accept it. For his second RP, however, he just drew one element: an ostrich sticking its head into the sand (figure 2B). He explained: *“I bury my head in the sand, I just pretend it is not there”*. In other words, after initially acknowledging cancer, he now decided to try to deny the existence of cancer.

A change from acknowledging to acceptance was found in patient P5. In her first RP she depicted great sadness and anger about the loss of her life and drew, among other things, her grave and a peace sign with a question mark over it (figure 2C). She had added the latter sign because the question *“is this supposed to bring me peace?”* kept popping up in her head. Hence, this patient acknowledged her situation, but steps towards acceptance were not yet taken. In her second RP she put a cross through the peace sign and the question mark and colored the grave with orange and green, because her immanent death was less haunting. She also added three elements to the RP: flowers, leaves, and an Ohm-sign (figure 2D). These, respectively, represented the happiness about being able to exercise her hobbies, the inner peace she had now found, and the regained connection with her religion. About finding inner peace she said: *“I think the acceptance is just way bigger. A certain calmness, more inner peace than the first time.”*

Patient P18 showed a transition from acknowledging to receiving. In her first RP she depicted the cancer in her body and the mental struggles she was having (figure 2E). She acknowledged the cancer and the effect it had on her life. In her second RP, she drew herself walking in the sun, on flowers, towards the unknown future (figure 2F). As she explained, the cancer is her shadow, living with her, and death is a little bird sitting on her shoulder. The sun and flowers were drawn because she is enjoying life and because she felt like she had become a happier person. She explained that she actually gained a lot from the cancer: *“I think that what you go through, if you don’t let it get you down, can give you a lot of strength and energy, and also happiness. [...] So I am actually happy with the cancer, as weird as it sounds.”*

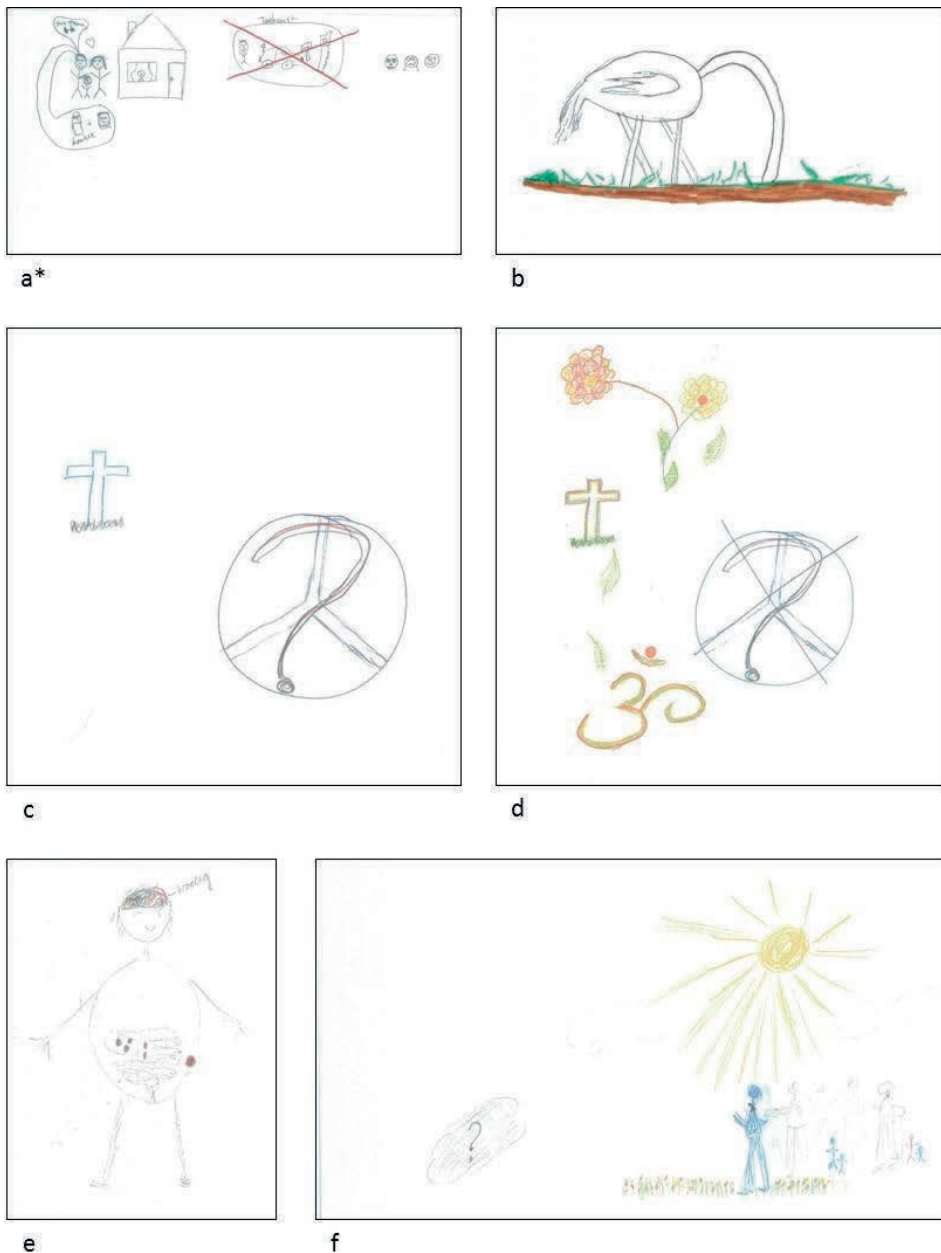


Figure 2. Rich pictures (RPs) that make differences in in the way patients relate to the cancer visible

(A) First RP of patient P2. (B) Second RP of patient P2. (C) Part of first RP of patient P5. (D) Part of second RP of patient P5. (E) First RP of patient P18. (F) Second RP of patient P18.

Discussion

Main findings

Our results suggest that the repeated use of RPs can make changes in the subjective experience of living with cancer visible over time, specifically by giving insight into changes in physical health and the way patients related to living with cancer (denying, acknowledging, accepting, or receiving(26)). Additionally, our study suggests that for repeated use of RPs different interview formats yield similar results, that is, inviting patients to make a new drawing versus providing them with a copy of their previous RP to work on.

What this study adds

To the best of our knowledge, this was the first study that examined the potential of RPs as a method for capturing changes in subjective experience of living with cancer over time. Previous research has applied RPs to gain insight into subjective experiences at one time only.(20) Since we found that the repeated use of RPs revealed meaningful changes over time, we suggest that the repeated use of RPs has potential as a longitudinal follow-up tool or as an outcome measurement before and after an intervention, for example, a mental health intervention for advanced cancer patients.

In comparison to other studies that used drawings to explore patient experience(16, 18, 19), the added value of RPs lies in the ability to represent all important themes of a patient's life in one single snapshot. When making an RP, patients are invited to include everything that they consider relevant to the situation in their drawing, from events, people and objects to feelings and emotions, instead of just focusing on one element such as pain or anxiety(16, 18, 19). Hence, the repeated use of RPs allows for insight in changes in all aspects of a patient's life. Furthermore, previous research such as Van Kleef et al.(11) has shown that even though overall quality of life (QoL) of cancer patients seems to remain stable over time, changes in different health-related QoL domains are often present and not always captured by the QoL score. This suggests that a measurement method, such as an RP, that gives insight in these different domains could be of added value. RPs could not only uncover those specific changes in QoL domains, but also give insight into the relationships between these QoL domains.

A next step in RP research could be to investigate the use of RPs in combination with other measurement methods, such as questionnaires. A relevant question will

be whether RPs in combination with questionnaires would provide a more comprehensive representation of the experiences of cancer patients than either one alone. In this way, the effect of interventions could possibly be measured more comprehensively.

Strengths and limitations

A strength of our study is that it explored the repeated use of RPs in a rigorous way. We built upon previous RP research, examined three different interview conditions, and performed an interim analysis. The interim analysis allowed us to make the best possible use of our thirteen patients, as we did not waste interviews on interview conditions that were not working. It should be noted that we did not intend to make a formal comparison in terms of outcome between the three modes of instruction, but rather aimed to investigate what approach would work in clinical practice. Patients who experienced little to no changes in their illness experience, preferred receiving a copy of their previous RP instead of making a new RP. In turn, some patients had a clear preference for making a new RP, because the first RP did not reflect their current experience. Based on these findings, we argue that when patient preferences for the drawing of RPs is taken into account, repeated use of this interview format is feasible.

Next, researchers from different backgrounds, but also patients, an artist, and doctors, gave us the opportunity to incorporate many backgrounds in the data interpretation, enriching the results. In this study, we aimed for consensus in data interpretation between the different actors, while level of agreement between coders was not of main interest. A final strength of this study is the use of the theoretical model of Kruizinga et al.(26) to support the interpretation of how patients relate to the cancer at the two moments of time.

Generalizability of our findings, however, might be limited due to practical factors. RPs may not be suitable for all patients with advanced cancer, as engaging in an RP session of approximately an hour may be too burdensome. In addition, not all patients may feel comfortable with expressing themselves using visual methods. This may be patient, age, and culture dependent. Finally, as is the case with almost all measurements, drawing of an RP may by itself induce a change in one's experience of living with cancer, because a reflective process is brought into motion. The sensitivity of RPs to pick up changes after an intervention compared to a control group needs further investigation.

Conclusions

RPs were found to provide insight into changes in physical condition as well as how patients relate to living with cancer. RPs are a valuable qualitative research method that can be used to explore the experiences of patients with advanced cancer, not only at a single point in time, but also over time.

Author contribution

Conceptualization, HWML and EH; Methodology, HWML, EH, ZMB; Investigation, ZMB; Formal Analysis, all authors.; Writing - Original Draft, ZMB ; Writing - Review & Editing, all authors; Visualization, ZMB.; Supervision, HWML; Funding Acquisition, HWML.

References

1. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-11.
2. Hartog I, Scherer-Rath M, Kruizinga R, Netjes J, Henriques J, Nieuwkerk P, et al. Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol*. 2017;25(6):1-17.
3. Smith EM, Gomm SA, Dickens CM. Assessing the independent contribution to quality of life from anxiety and depression in patients with advanced cancer. *Palliat Med*. 2003;17(6):509-13.
4. Jordhoy MS, Fayers P, Loge JH, Saltnes T, Ahlner-Elmqvist M, Kaasa S. Quality of life in advanced cancer patients: the impact of sociodemographic and medical characteristics. *Br J Cancer*. 2001;85(10):1478-85.
5. Bell S, Morse S. How people use rich pictures to help them think and act. *SPAR*. 2013;26(4):331-48.
6. Cristancho S, Bidinosti S, Lingard L, Novick R, Ott M, Forbes T. Seeing in different ways: introducing "rich pictures" in the study of expert judgment. *Qual Health Res*. 2015;25(5):713-25.
7. Kruizinga R, Hartog ID, Jacobs M, Daams JG, Scherer-Rath M, Schilderman JB, et al. The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis. *Psycho-Oncol*. 2016;25(3):253-65.
8. Pearce MJ, Coan AD, Herndon JE, 2nd, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer*. 2012;20(10):2269-76.
9. Anderson WG, Alexander SC, Rodriguez KL, Jeffreys AS, Olsen MK, Pollak KI, et al. "What concerns me is..." Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer*. 2008;16(7):803-11.
10. Al-Batran SE, Ajani JA. Impact of chemotherapy on quality of life in patients with metastatic esophagogastric cancer. *Cancer*. 2010;116(11):2511-8.
11. van Kleef JJ, Ter Veer E, van den Boorn HG, Schokker S, Ngai LL, Prins MJ, et al. Quality of Life During Palliative Systemic Therapy for Esophagogastric Cancer: Systematic Review and Meta-Analysis. *J Natl Cancer Inst*. 2020;112(1):12-29.
12. Cristancho S. Eye opener: exploring complexity using rich pictures. *Perspect Med Educ*. 2015;4(3):138-41.
13. Helmich E, Diachun L, Joseph R, LaDonna K, Noeverman-Poel N, Lingard L, et al. 'Oh my God, I can't handle this!': trainees' emotional responses to complex situations. *Med Educ*. 2018;52(2):206-15.
14. Ellis J, Hetherington R, Lovell M, McConaghy J, Viczko M. Draw me a picture, tell me a story: Evoking memory and supporting analysis through pre-interview drawing activities. *Am J Eng Res*. 2013;58(4):488-508.
15. Williams IC. Graphic medicine: comics as medical narrative. *Med Humanit*. 2012;38(1):21-7.
16. Elkis-Abuhoff D, Gaydos M, Goldblatt R, Chen M, & Rose S. Mandala drawings as an assessment tool for women with breast cancer. *Arts Psychother*. 2009;36(4):231-8.
17. Nainis N, Paice JA, Ratner J, Wirth JH, Lai J, Shott S. Relieving symptoms in cancer: innovative use of art therapy. *J Pain Symptom Manag*. 2006;31(2):162-9.
18. Broadbent E, Schoones JW, Tiemensma J, Kaptein AA. A systematic review of patients' drawing of illness: implications for research using the Common Sense Model. *Health Psychol Rev*. 2019;13(4):406-26.

19. Cheung MM, Saini B, Smith L. Using drawings to explore patients' perceptions of their illness: a scoping review. *J Multidiscip Healthc.* 2016;9:631-46.
20. Bood ZM, Scherer-Rath M, Sprangers MAG, Timmermans L, van Wolde E, Cristancho SM, et al. Living with advanced cancer: Rich Pictures as a means for health care providers to explore the experiences of advanced cancer patients. *Cancer Med.* 2019.
21. Armson R. Drawing rich pictures. In: Armson R, editor. *Growing wings on the way: systems thinking for messy situations.* Axminster, UK: Triarchy Press; 2011. p. 57-9.
22. Kahlke RM. Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. *Int J Qual Meth.* 2014;13:37-52.
23. Charmaz K. *Constructing Grounded Theory.* 2nd edition ed. London: SAGE Publications; 2014.
24. Bell S, Berg T, Morse S. Rich Pictures: Sustainable Development and Stakeholders - The Benefits of Content Analysis. *Sustain Dev* 2015;24(2):136-48.
25. Berg T, Pooley R. Contemporary Iconography for Rich Picture Construction. *Syst Res Behav Sci.* 2012;30(1):31-42.
26. Kruizinga R, Hartog ID, Scherer-Rath M, Schilderman H, Van Laarhoven H. Modes of relating to contingency: An exploration of experiences in advanced cancer patients. *Palliat Support Care.* 2017;15(4):444-53.

CHAPTER 4

THIS IS WHAT LIFE WITH CANCER LOOKS LIKE: EXPLORING EXPERIENCES OF ADOLESCENT AND YOUNG ADULTS WITH CANCER USING TWO VISUAL APPROACHES

Zarah M. Bood, Floor van Liemt, Mirjam A.G. Sprangers, Annita Kobes, Yvonne Weeseman, Michael Scherer-Rath, Jacqueline M. Tromp, Hanneke W.M. van Laarhoven, Esther Helmich

Based on:

Bood ZM, van Liemt F, Sprangers MAG, et al. This is what life with cancer looks like: exploring experiences of adolescent and young adults with cancer using two visual approaches. *Supportive Care in Cancer*. 2022; 30(4): 3353-3361.
doi: 10.1007/s00520-021-06775-9.

Abstract

Introduction: Talking about illness experience can be challenging for adolescents and young adults (AYAs) with cancer. Visual tools, in addition to spoken language, might make this easier, such as rich pictures and photovoice. We aimed to obtain a comprehensive view of the cancer experience of AYAs by using rich pictures and photovoice.

Methods: AYAs (18-35 years old) who had any type of cancer, or were in remission from cancer, were eligible. AYAs drew rich pictures about their experience of living with cancer and explained these during subsequent interviews. Some of the AYAs also participated in photovoice and spent two days with a photographer to make photos about their illness experience. Rich pictures and photos were first analyzed separately, using open coding, after which the identified themes were compared.

Results: Twelve AYAs made rich pictures, of whom seven also participated in photovoice. The two most predominant themes emerging from the data were struggles related to the future and defining one's identity. The AYAs expressed concerns for the future related to relationships, education, and employment. Relating to defining one's identity, many AYAs expressed that the cancer had a negative impact on their body- and self-image. The main themes were visible in the rich pictures as well as in the photovoice, however, subtle differences in sub-themes were found.

Conclusions: We found that cancer has an effect on many aspects of AYAs' lives. Further research on how the identified themes play a role in the lives of AYAs with cancer is needed.

Introduction

Receiving a diagnosis of cancer is life altering at any age, but especially for adolescents and young adults (AYAs) it can be very disruptive. The life of AYAs, at the age from 18 to 35, is often marked by developmental milestones, including transitioning into further education or employment, leaving childhood homes, gaining financial independence, and forming intimate emotional and sexual relationships.(1-3) Therefore AYAs represent a unique patient population, with needs and challenges that differ from those of adults and children with cancer.(1-4) Nevertheless, AYAs with cancer have been an understudied population and their experiences have rarely been investigated. Consequently, there is a lack of interventions that meet their needs.(1, 3) If we could obtain a comprehensive view of the impact of a cancer diagnosis at such an age, further research might be able to design interventions to support AYAs and assess their effects.

One of the difficulties that can be encountered when exploring cancer experiences of patients, is that words may be insufficient. Thus, questionnaires or interviews possibly give insight into a limited part of AYAs cancer experiences.(5-9) Alternatively, AYAs may be invited to tell their story through visual methods, in addition to spoken language.(8-12) The combination of visual and verbal methods, such as drawings and comics, was found to be helpful in uncovering experiences of children and adults with cancer.(12-17) Although it has been suggested that AYAs may also benefit from sharing their experiences in a visual way, few studies actually attempted to investigate this.(1, 18)

A visual tool that could possibly provide a comprehensive view of the experiences of AYAs with cancer is rich pictures (RPs).(19) RPs are drawings that one creates to express one's experiences, which may encompass different elements, for example, people, interactions, and feelings.(9-11, 20, 21) We recently conducted a study with a group of adults (mean age 62) with advanced cancer who were asked to draw an RP about their experience of living with cancer.(19, 22) The findings suggest that RPs can help patients to tell their story about how cancer affects their lives. The RPs can provide insight into what is most important to the patient and may shed light on how multiple aspects of well-being, such as physical, emotional, and social well-being, are affected by cancer.(19, 22) Nonetheless, RP research has not yet been performed amongst AYAs with cancer.

Another upcoming visual tool to explore cancer experiences is photovoice. (23, 24) In photovoice, participants are invited to document meaningful aspects of their experience through photographs. (23) The photovoice methodology has not been used widely amongst cancer populations. (24) Some studies, such as Wong et al. (23) and Georgievski et al. (25) have adopted photovoice to explore the experiences of, respectively, older adults or teenagers (under eighteen years) with cancer. These studies have demonstrated that photovoice can create a valuable opportunity for patients with cancer to share their experiences with others. (24) However, when focusing on photovoice research amongst AYAs, there are limited studies and the few available have included cancer survivors only, not AYAs currently living through cancer. (24) There are no studies that have adopted photovoice with AYAs in active cancer treatment, even though experiences between AYAs with active cancer treatment and cancer survivors could differ. (24) For this reason, the F|FortFoundation, a Dutch organization that is committed to improving the mental well-being of AYAs with cancer, organized a photovoice project for AYAs undergoing cancer treatment. They invited a group of Dutch AYAs to express themselves by taking photos of certain themes that are important to them together with a professional photographer.

In the present study we aim to obtain a comprehensive view of the cancer experience of AYAs by using two visual methods: RPs and photovoice. All participants were asked to create an RP, and approximately half of the participants also took part in the photovoice project, in collaboration with the F|FortFoundation.

Methods

Study design

Two qualitative visual research methods were used: RP interviews and photovoice. The original project of the F|FortFoundation comprised the photovoice. We added RP interviews to be able to compare the methods and see if different themes would come up.

The present study adopted a constructivist research approach, acknowledging that knowledge is co-created between researchers and participants. (26) That is, the photos of the photovoice project are shaped by the participant, the photographer, and F.v.L. (an experience expert). Additionally, the interpretation of the RP is the result of the interaction between participant and the interviewer Z.M.B., a female

PhD student with experience in doing RP interviews with oncology patients. To give an example: as Z.M.B. had experience with doing RP interviews with adult patients, she went in with knowledge of existing themes amongst adults, which could help her grasp the meaning of the RP better, but could also lead to her making presumptions. To minimize the latter in data analysis, we employed a second encoder, A.K., who has a master's degree in pedagogy and a PhD in child obesity. Additionally, E.H., a female elderly care physician, with ample experience in RP research, was directly involved in data analysis.

Photovoice project of the F|FortFoundation

Participants

AYAs (18-35 years old) who had cancer, or were in remission from cancer, could apply to the photovoice project by sending an introductory text about themselves to the F|FortFoundation. The project was promoted on social media, and on the website of the F|FortFoundation and partner organizations. There was no restriction in cancer type, demographic area within the Netherlands, or the illness period. In total, 35 AYAs applied to the photovoice project, of which six were male. Ages ranged from 22 to 36 years and the most prevalent type of cancer was breast cancer (14 out of 35). From all 35 submissions, the second author F.v.L. chose eleven participants, aiming for a diverse group, with different ages, cancer types, and cultural backgrounds. In this group of eleven, four were male.

Data collection

To facilitate the photovoice, six relevant domains for AYAs with cancer were identified in a brainstorm session, organized by F|FortFoundation, in which F.v.L. gave the main input. Defining six domains was to facilitate a structure where AYAs were asked to make one photo for each domain. The six domains were: 1) the essence: "This is the pure definition of me"; 2) the wrong gear: "I am pushing the accelerator pedal, but I am not moving. I cannot keep up with my peers"; 3) concerns about the future: "What will happen with me after this treatment?" 4) the remedy: "What I need to be able to handle the toughest moments of my treatment"; 5) forms of interaction: "I have to take control over the interactions between me and others. "; 6) the end: "What does death actually mean and how will dying look like for me?".

All participants worked with a photographer for two days. A week before meeting the photographer, the participant was interviewed by F.v.L. about how the six

domains played a role in his/her life. After the interview, F.v.L., together with the photographer, developed a mood board based on the interview answers as preparation for the photography days. On the first photography day, F.v.L., the photographer, and the participant discussed the mood board and determined composition and location for the photos. The rest of the two days were used to make six photos, one for each domain. Photos could be portraits, still lives, landscapes, or any other composition. Each photo was accompanied by a caption, written by the F|FortFoundation and approved by the participants. F|FortFoundation developed a book with all the photos (ISBN: 978-90-9034928-2).

RP interviews

Participants

F|FortFoundation informed the eleven photovoice participants about the complementary RP interview study and asked them to participate. The first author (Z.M.B.) contacted the seven consenting participants by phone to confirm their involvement. Subsequently, AYAs who indicated interest in the F|FortFoundation project, but were not chosen for the photovoice, were also invited by Z.M.B. to participate in the RP interviews.

Data collection

Z.M.B. conducted two RP interviews with each participant. For participants taking part in the F|FortFoundation project, the first interview was held before they started working with the professional photographer and the second interview was held around two to three months later, after completion of the photovoice project. For participants who were not involved in the F|FortFoundation project we chose similar time intervals.

Participants were asked to make an RP about their experience of living with cancer, followed by a semi-structured interview. An example of an RP was shown to the participants to give them an idea of which icons and symbols they could use and how an RP might look when completed. (19, 22) When the RP was completed, the interviewer asked the participant to explain what she/he had drawn, starting with the open question, and then asked more specific questions about elements of the RP (e.g. about the colors, shapes, and specific elements). All RP interviews were audio recorded.

The first three interviews were held in a setting of participants' preference: at their home or somewhere else, with or without someone else being present.

However, due to the COVID-19 pandemic, we had to perform the remaining interviews online, using Microsoft Teams.(27) After the interviewer gave instructions on how to draw an RP, the participant was given approximately 30 minutes to complete the RP individually (with the video call muted). When the RP was completed, the participant would send a photo of his/her RP to the interviewer, who in turn, would share her screen with the photo so both participant and interviewer could look at the RP while discussing it.

Data analysis

RPs and photos were first analyzed separately. RP interviews were transcribed verbatim and were used to support the RP analysis. The combined RP/interview data was analyzed by Z.M.B. by applying analysis tables, in which the RPs and the corresponding interview text were grouped and analyzed using open coding, in an inductive approach, as described in detail before.(19) A second coder, A.K., checked all codes and made some suggestions to rename and add some codes. After discussing this together, Z.M.B. agreed with these suggestions and no conflicts occurred. Subsequently, Z.M.B. clustered all codes into overarching (sub)themes.

We applied a similar approach to analyze the photos. Each photo was analyzed separately, by looking at what was in the photo and what was written in the caption. The first author, Z.M.B., described what could be seen on the photo and then applied codes to the photo and the caption. After all photos were analyzed, the codes were clustered into subthemes and main themes. Z.M.B. discussed this process and the emerging themes with E.H.. Subsequently, Z.M.B. and E.H. compared the themes that emerged from the RPs to ones in the photos, explicitly looking for similar or different metaphors and visual motifs.

Ethical considerations

No formal ethical approval was needed for the study, as confirmed by The Medical Ethics Review Committee of the Academic Medical Centre. Confidentiality of participants was ensured and written informed consent was obtained from each participant.

Results

Participants

We interviewed twelve AYAs of whom seven participated in the photovoice. Eleven of the twelve AYAs were female and the average age was 31 years (SD of 3.6 years). The AYAs had different types of cancer, including lymphoma, breast, ovarian, brain, or testicular cancer. Half of the AYAs received curative treatment, five received palliative treatment, and one did not answer that question. An overview of the demographics of the participants can be found in appendix A.

Findings

The two most predominant themes emerging from the data were struggles related to a) the future and b) defining one's identity. These main themes were visible in the RPs as well as in the photovoice; however, slight differences in sub-themes were found. For instance, while in both RPs and photos the effect of the cancer and treatment on the body and body-image were mentioned, the uncertainty surrounding being able to become pregnant was only depicted in the RPs. Furthermore, the difficulty of dating was also depicted in both visual tools, but the impact of the cancer on experimenting with one's sexual orientation, was only visualized in the photovoice. We will expand on the two main themes with examples from the RPs and photos.

Concerns for the future

The AYAs expressed concerns for the future related to multiple areas of their life, like relationships, education, work, finances, and housing. Especially relationships, education, and work were often depicted and mentioned as areas in which they experienced significant struggles.

A. Relationships

Participants raised multiple concerns regarding the impact of the cancer on relationships in their life. AYAs who did not have a partner, talked about the difficulty of dating during cancer treatment and were worried about how they would be able to find a love partner even after (complete) remission. For instance, a 28-years-old female with lymphoma drew a big broken heart with a sad face next to it on her RP (figure 1A). She explained that she tried to go on dates during her treatment, but had difficulties with the fact that she did not want to tell everyone that she had cancer. She said: *"I am of course not the same person I was before I got sick. So that also makes it very hard to get to know new people, because, will*

you tell the person this and if so, when will you tell that person?”. Two other AYAs, a 31- and a 32-year-old female depicted their wish to have another child and talked about the insecurity whether becoming pregnant was still possible due to the chemotherapy. Figure 1B shows an example of how this was depicted in an RP.

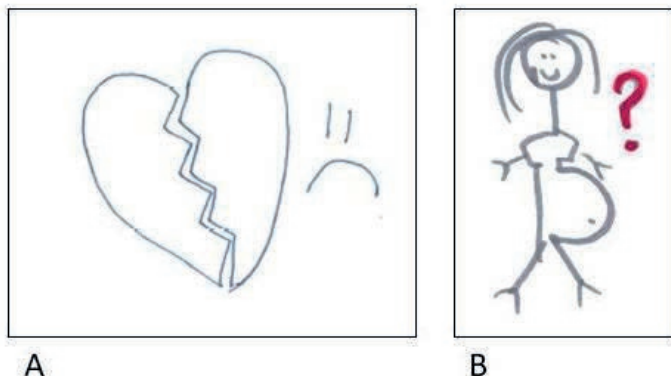


Figure 1. Relationships

A) Part of RP of P7 that shows a broken heart and a sad looking face; B) Part of first RP of P5 that shows herself with a pregnant belly and with red marked question mark, depicted the uncertainty if getting pregnant is still possible.

B. Education and work

A 23-year-old female expressed multiple concerns regarding her future. In her RP she drew herself surrounded by all her concerns for the future (figure 2A). She drew her tumor, her education, work, and herself being pregnant. Her concerns surrounding work was also the topic of one of her photos. On the photograph she sits at a white table with the mask of the radiation therapy on her face (figure 2B). The photo is accompanied by the caption: *“At job interviews they will come up with excuses for not hiring me. I already want to shout it out: Look at me, look at my skills, and do not look for traces of my disease.”*

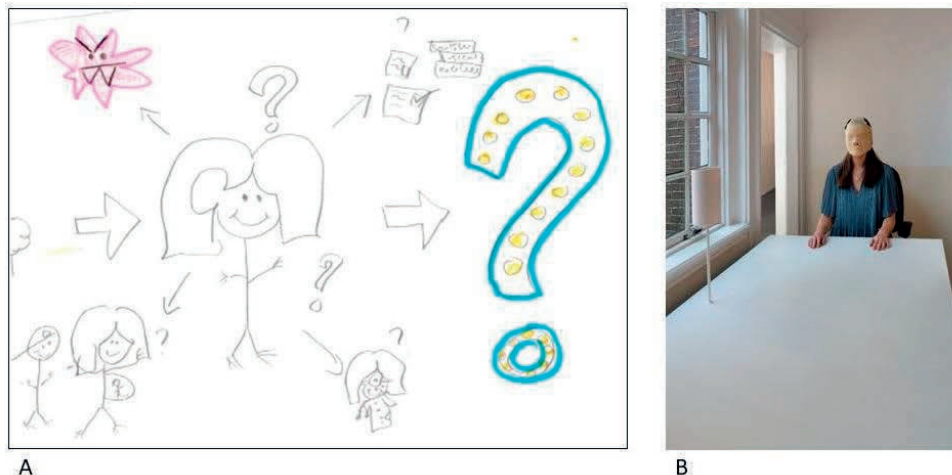


Figure 2. Education and work

A) Part of first RP of P2 in which she drew herself surrounded by elements that are uncertain in the future, including the tumor, education, getting a career, and getting pregnant; B) Photo from photovoice project in which the AYA is wearing her radiation mask to a job interview

Struggles with (re)defining one's identity

The cancer obstructs the identity of AYAs in many ways. For instance, many AYAs expressed that they felt segregated from their peers and being perceived differently. The cancer also exerted an effect on their body- and self-image, and on exploring one's sexual orientation, which may induce a need to redefine their identity.

A. Feeling segregated from peers

A 25-years-old female focused her first RP on feeling segregated from her peers and her life coming to a standstill, while others of her age were developing careers and enjoying life (figure 3A). She literally drew a line separating herself from her peers. Another example is a 32-years-old female who drew two islands in one of her RPs: one with herself on it and the other island inhabiting other people (figure 3B). Other people get pregnant, move in together, go on holidays, and get jobs. From her own island she is looking at them with envy, not being able to have this herself.

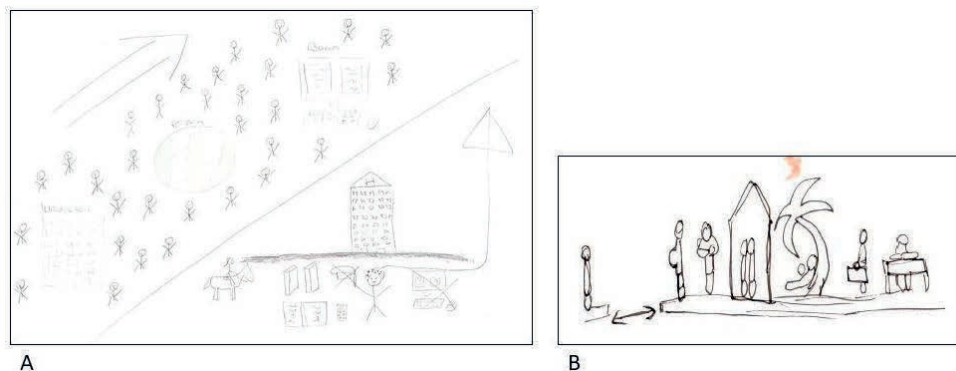


Figure 3. Feeling segregated from peers

A) The first RP of P3 in which the AYA drew a line between her and her peers, depicting how she felt completely segregated from her peers; B) Part of first RP of P9 where she drew herself on the island on the left, and others her age on the island on the right accomplishing things she cannot do because of the cancer

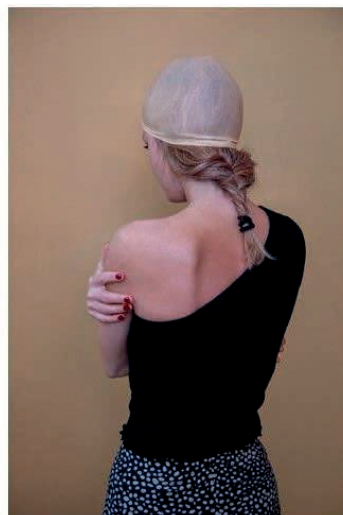
B. Perceptions of others

Many AYAs talked about their concerns of how others were perceiving them. For instance, they suddenly became an ill person, as if that was now their sole identity. One AYA (28-years-old female) said: *“Suddenly you are that sick girl.”*

A 25 years old female was afraid others thought she was lazy. A photo from the photovoice shows a building with scaffolds in opaque covering (figure 4A) - a metaphor for her working on her personal development, but people not being able to see this from the outside. A second photo of this participant pictures herself with a hairnet on, her back to the camera, and holding herself (figure 4B), accompanied by the following text: *“You can’t see anything from the outside. That’s why they often cannot believe it, cannot comprehend it. [...] Sometimes I fantasize about being bald. Would people then realize that this is real? (But thank god I still have my hair).”*



A



B

Figure 4. Perceptions of others

A) Photo from photovoice project of a building with scaffolds in opaque covering, to depict that no one can see the progress that is made inside; B) Photo from photovoice of an AYA with a hairnet on, her back to the camera, and holding herself

C. Changing appearance and self-image

Multiple AYAs talked about their appearance changing. A 28- and a 32-years-old female talked about how chemotherapy made them lose their hair and gain weight. Regarding her weight, the 28-year-old drew a scale in the RPs (figure 5A): *“I drew a scale, because I really gained a lot of weight during the chemotherapy, ten kilos. Well, I was not happy about that. [...] Weight also really is a thing that I of course think about a lot.”*. The other AYA had a photo made in which she is sitting in a chair with just a tank top and big boots on, showing part of her body (figure 5B). The caption of the photo shows that she had a hard time accepting her changed body: *“Hair loss, amputation, weight gain; I am trying to accept myself and I know I can be proud, but it often does not feel like that. I worked hard to love my body, to form it to my image of a hot woman. Now I lost all footing.”*.



Figure 5. Changing appearance, self-image, and sexual orientation

A) Part of RP of P7 that shows a scale, depicting how she gained weight during cancer treatment; B) Photo from photovoice project of an AYA showing off her changed body, that she had trouble accepting; C) Photo from photovoice project of entangled ribbons in the colors of the rainbow, referring to the LGBTQ community

D. Sexual orientation

One of the participants (32-years-old female) had a photo made to express her struggles with experimenting with her sexual orientation during the cancer treatment (figure 5C). The photo shows ribbons in the colors of the rainbow that are tangled, and is accompanied by the caption: *“I was ready for it, creating an account on Tinder, to figure out if I like women or men, maybe something in between. Now it’s way too complicated. Do I use an old photo or a photo with me without hair? The fear of rejection paralyzes me.”*.

Discussion

We aimed to obtain a comprehensive view of the cancer experience of AYAs by using the visual methods RPs and photovoice. It became clear that cancer has an effect on many aspects of an AYA’s life and impacts their development in areas such as relationships, fertility, education, employment, self-image, and sexual orientation.

In previous studies about experiences amongst AYAs with cancer, mainly concerns regarding education and employment were mentioned frequently. Literature reviews from Warner et al.(1) and Fardell et al.(2) reported several studies on the negative impact of cancer on educational trajectories and employment of AYAs. Our data provide further support for these experiences of AYAs. What also becomes apparent from the extant literature, is that most studies on cancer experiences of AYAs are quantitative.(1, 2, 28, 29) Our qualitative study adds to current literature by providing visuals to accompany written and spoken text. RPs and photovoice are able to present the story of an AYA in one image (RPs) or a collection of images (photovoice), instead of providing large amounts of text. Furthermore, the fact that participants have control over the topics they want to depict helps with determining which themes are most important to them.

To the best of our knowledge, RPs, or other drawing methods, have not been used to explore experiences of AYAs with cancer before. Drawing as a method to gain insight into experiences has mostly been used among children and older adults.(13-17, 30, 31) Photovoice has been conducted with AYAs, but only with cancer survivors, not AYAs currently undergoing cancer treatment.(24, 32, 33) Studies from Yi(32, 33) have described late medical and psychosocial effects of surviving (childhood) cancer and retrospect experiences of the treatment period. Our findings focused on present experiences with cancer treatment, which gave us valuable information on which themes play a role during treatment, such as being forced to put a halt to studying and/or working, feeling segregated from peers, experiencing changes in appearance, and struggles surrounding dating during treatment. Besides, our study proves that AYAs under treatment are able to participate in photovoice - although time- and energy-consuming - and all AYAs described their participation as a very valuable experience. Hence, we found that RPs and photovoice have the potential to uncover experiences of AYAs currently undergoing cancer treatment.

Using two visual tools allowed us to compare specific affordances of the two tools. We were able to see substantial overlap in themes, but also found that the methods could complement each other. In some cases, the RP gave a deeper insight into what a theme meant to an AYA, while in other cases the photos provided a stronger view. These disparities could stem from the fact that the photovoice started with predetermined domains, while this was not the case with the RPs. Furthermore,

the photos were made in consensus between photographer, patient, and F.v.L., contrary to the RPs where patient had full control over what they wanted to depict.

Comparing the findings of the present study to the RP study we previously conducted with adults, we see that main themes are similar.(19) However, the AYAs placed more emphasis on the effect of the cancer on defining their identity. For example, topics as (online) dating, pregnancies, and problems with studying or finding a career path, were very important to AYAs, but hardly mentioned by the adults in our previous study.(19) Hence, our findings add to the notion that AYAs represent a unique cancer population.(1-4)

Furthermore, our findings imply having cancer at such a young age can be extremely difficult. Based on our results as well as other(1-4, 28, 29), we argue that AYAs are in need of targeted interventions, especially focusing on improving psychosocial health. For instance, more initiatives such as the AYA care team from the 'National AYA Young and Cancer Care network', a Dutch organization, could be developed. The AYA care team is active in every academic hospital in the Netherlands and assigns every AYA with cancer an AYA nurse, a medical psychologist, a sexologist, an occupational physician, a fertility specialist, and a social worker.

Strengths and limitations

Three strengths of this study are noteworthy. First, all phases of data analysis were executed by at least two authors, which stimulated dialogue between authors in order to prevent tunnel vision.(34) Second, the involvement of F.v.L., an experience expert, as interviewer for the start of the photovoice, allowed participants to feel understood and more comfortable to tell their story. Third, the fact that the interviewer of RP interviews, Z.M.B., was a young adult herself and thus was in the same life phase as the AYAs, could also have increased connection and understanding between AYAs and interviewer.

A limitation of the study is that the photovoice started with a priori themes which were not used in the RPs. The RPs were also not taking into account at the time of deciding on the a priori themes in the photovoice. Photovoice and RPs were treated as two completely separate elements, while integrating them might have been even more beneficial for gaining insight into the experiences of the AYAs. Another limitation is that only one male participated in our study, possibly making our

findings less representative to the general AYA generation. Lastly, the methods could be very demanding for participants and are therefore possibly difficult to use for AYAs with advanced stages of cancer.

Conclusion

Our visual tools show a detailed picture of what it is like to have cancer as an AYA. We found that cancer has an effect on many aspects of an AYA's life, such as relationships, fertility, education, employment, and self-image. Further research on how these themes play a role in the life of AYAs with cancer is needed.

Author contribution

Conceptualization: FVL, ZMB, HWML; Methodology: FLV, ZMB, HWML, EH; Formal Analysis and investigation: ZMB, AK, EH; Writing - Original Draft: ZMB; Writing - Review & Editing: all authors; Supervision: HWML, EH; Funding Acquisition: HWML.

References

1. Warner EL, Kent EE, Trevino KM, Parsons HM, Zebrack BJ, Kirchhoff AC. Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer*. 2016;122(7):1029-37.
2. Fardell JE, Wakefield CE, Patterson P, Lum A, Cohn RJ, Pini SA, et al. Narrative Review of the Educational, Vocational, and Financial Needs of Adolescents and Young Adults with Cancer: Recommendations for Support and Research. *J Adolesc Young Adult Oncol*. 2018;7(2):143-7.
3. Smith AW, Keegan T, Hamilton A, Lynch C, Wu XC, Schwartz SM, et al. Understanding care and outcomes in adolescents and young adult with Cancer: A review of the AYA HOPE study. *Pediatr Blood Cancer*. 2019;66(1):e27486.
4. Barr RD, Ferrari A, Ries L, Whelan J, Bleyer WA. Cancer in Adolescents and Young Adults: A Narrative Review of the Current Status and a View of the Future. *JAMA Pediatr*. 2016;170(5):495-501.
5. Hartog I, Scherer-Rath M, Kruizinga R, Netjes J, Henriques J, Nieuwkerk P, et al. Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol*. 2017;25(6):1-17.
6. Kruizinga R, Hartog ID, Scherer-Rath M, Schilderman H, Van Laarhoven H. Modes of relating to contingency: An exploration of experiences in advanced cancer patients. *Palliat Support Care*. 2017;15(4):444-53.
7. Scherer-Rath M, Van den Brand J, Van Straten C, Modderkolk L, Terlouw C, Hoencamp E. Experience of Contingency and Congruent Interpretation of Life Events in Clinical Psychiatric Settings: A Qualitative Pilot Study. *J Empir Theol*. 2012;25(2):127-52.
8. Ellis J, Hetherington R, Lovell M, McConaghy J, Viczko M. Draw me a picture, tell me a story: Evoking memory and supporting analysis through pre-interview drawing activities. *Am J Eng Res*. 2013;58(4):488-508.
9. Cristancho S, Bidinosti S, Lingard L, Novick R, Ott M, Forbes T. Seeing in different ways: introducing "rich pictures" in the study of expert judgment. *Qual Health Res*. 2015;25(5):713-25.
10. Helmich E, Diachun L, Joseph R, LaDonna K, Noeverman-Poel N, Lingard L, et al. 'Oh my God, I can't handle this!': trainees' emotional responses to complex situations. *Med Educ*. 2018;52(2):206-15.
11. Cristancho S. Eye opener: exploring complexity using rich pictures. *Perspect Med Educ*. 2015;4(3):138-41.
12. Williams IC. Graphic medicine: comics as medical narrative. *Med Humanit*. 2012;38(1):21-7.
13. Elkis-Abuhoff D, Gaydos, M., Goldblatt, R., Chen, M., & Rose, S. Mandala drawings as an assessment tool for women with breast cancer. *Arts Psychother*. 2009;36(4):231-8.
14. Nainis N, Paice JA, Ratner J, Wirth JH, Lai J, Shott S. Relieving symptoms in cancer: innovative use of art therapy. *J Pain Symptom Manag*. 2006;31(2):162-9.

15. Angstrom-Brannstrom C, Norberg A. Children undergoing cancer treatment describe their experiences of comfort in interviews and drawings. *J Pediatr Oncol Nurs*. 2014;31(3):135-46.
16. Boles JC, Winsor DL. "My School Is Where My Friends Are": Interpreting the Drawings of Children With Cancer. *J Res Child Educ*. 2019;33(2):225-41.
17. Linder LA, Bratton H, Nguyen A, Parker K, Wawrzynski SE. Symptoms and Self-Management Strategies Identified by Children With Cancer Using Draw-and-Tell Interviews. *Oncol Nurs Forum*. 2018;45(3):290-300.
18. Baerg S. "Sometimes There Just Aren't Any Words": Using Expressive Therapy With Adolescents Living With Cancer. *Can J Couns*. 2003;37(1).
19. Bood ZM, Scherer-Rath M, Sprangers MAG, Timmermans L, van Wolde E, Cristancho SM, et al. Living with advanced cancer: Rich Pictures as a means for health care providers to explore the experiences of advanced cancer patients. *Cancer Med*. 2019.
20. Bell S, Morse S. How people use rich pictures to help them think and act. *SPAR*. 2013;26(4):331-48.
21. Armson R. Drawing rich pictures. In: Armson R, editor. *Growing wings on the way: systems thinking for messy situations*. Axminster, UK: Triarchy Press; 2011. p. 57-9.
22. Bood ZM, Scherer-Rath M, Sprangers MAG, Timmermans L, van Wolde E, Cristancho SM, et al. Repeated use of rich pictures to explore changes in subjective experiences over time of patients with advanced cancer. *Cancer Rep*. 2021:e1428.
23. Wong SS, George TJ, Jr., Godfrey M, Le J, Pereira DB. Using photography to explore psychological distress in patients with pancreatic cancer and their caregivers: a qualitative study. *Support Care Cancer*. 2019;27(1):321-8.
24. Niepage M, Georgievski G, Shama W, Lucchetta S. Exploring Adolescents' Cancer Journey Through Photovoice: A Narrative Synthesis. *J Adolesc Young Adult Oncol*. 2018;7(1):15-21.
25. Georgievski G, Shama W, Lucchetta S, Niepage M. Through our eyes: A photovoice intervention for adolescents on active cancer treatment. *J Psychosoc Oncol*. 2018;36(6):700-16.
26. Charmaz K. *Constructing Grounded Theory*. 2nd edition ed. London: SAGE Publications; 2014.
27. de Joode K, Dumoulin DW, Engelen V, Bloemendal HJ, Verheij M, van Laarhoven HWM, et al. Impact of the coronavirus disease 2019 pandemic on cancer treatment: the patients' perspective. *Eur J Cancer*. 2020;136:132-9.
28. Zebrack B, Kent EE, Keegan TH, Kato I, Smith AW, Group AHSC. "Cancer sucks," and other ponderings by adolescent and young adult cancer survivors. *J Psychosoc Oncol*. 2014;32(1):1-15.
29. Jones JM, Fitch M, Bongard J, Maganti M, Gupta A, D'Agostino N, et al. The Needs and Experiences of Post-Treatment Adolescent and Young Adult Cancer Survivors. *J Clin Med*. 2020;9(5).

Chapter 4

30. Sadruddin MM, Hameed-Ur-Rehman M. Understanding the perceptions of children battling cancer about self and others through drawing. *South Asian J Cancer*. 2013;2(3):113-8.
31. Rollins JA. Tell me about it: drawing as a communication tool for children with cancer. *J Pediatr Oncol Nurs*. 2005;22(4):203-21.
32. Yi J, Kim MA, An S. The Experiences of Korean Young Adult Survivors of Childhood Cancer: A Photovoice Study. *Qual Health Res*. 2016;26(8):1044-54.
33. Yi J, Zebrack B. Self-portraits of families with young adult cancer survivors: using photovoice. *J Psychosoc Oncol*. 2010;28(3):219-43.
34. O'Connor C, Joffe H. Intercoder Reliability in Qualitative Research: Debates and Practical Guidelines. *Int J Qual Meth*. 2020;19:1-13.

Appendix A: Demographics of the participating AYAs

| Participant number | Gender | Age | Type of cancer | Time between diagnosis and first interview (in months) | Treatment | Participant in F FortFoundation project |
|--------------------|--------|-----|-------------------|--|------------|---|
| P1 | Male | 35 | Testicular cancer | 5 | Curative | Yes |
| P2 | Female | 23 | Brain cancer | 5 | Palliative | Yes |
| P3 | Female | 25 | Ovarian cancer | 16 | Palliative | Yes |
| P4 | Female | 34 | Breast cancer | 16 | Curative | Yes |
| P5 | Female | 32 | Lymphoma | 11 | Curative | Yes |
| P6 | Female | 32 | Breast cancer | 64 | Curative | No |
| P7 | Female | 28 | Lymphoma | 16 | Curative | Yes |
| P8 | Female | 33 | Breast cancer | 45 | Palliative | No |
| P9 | Female | 32 | Breast cancer | 8 | Curative | Yes |
| P10 | Female | 30 | Breast cancer | 22 | Palliative | No |
| P11 | Female | 35 | Breast cancer | 14 | Missing | No |
| P12 | Female | 31 | Lymphoma | 19 | Palliative | No |

CHAPTER 5

THE EFFECTS OF ART THERAPY ON ANXIETY, DEPRESSION AND QUALITY OF LIFE IN ADULTS WITH CANCER: A SYSTEMATIC LITERATURE REVIEW

J.T. Bosman, Zarah M. Bood, Michael Scherer-Rath, Henny Dörr, Nirav
Christophe, Mirjam A.G. Sprangers, Hanneke W.M. van Laarhoven

Based on:

Bosman JT*, Bood ZM*, Scherer-Rath M, Dörr H, Christophe N, Sprangers MAG,
van Laarhoven HWM. The effects of art therapy on anxiety, depression, and
quality of life in adults with cancer: a systematic literature review. *Supportive
Care in Cancer*. 2021; 29(5): 2289-2298. doi: 10.1007/s00520-020-05869-0.

*Authors contributed equally

Abstract

Purpose

While there is increasing evidence for the effectiveness of psychosocial support programs for cancer patients, little attention has been paid to creativity or art as a way of addressing their psychological problems and improving quality of life. This review provides an overview of interventional studies that investigate the effects of art therapy interventions on anxiety, depression and quality of life in adults with cancer.

Methods

We conducted a literature review with a systematic search. The databases PubMed/MEDLINE, PsycINFO, and EMBASE were searched for articles on art therapy among adult (eighteen years and above) cancer patients, published between September 2009 up to September 2019. Search terms were established for each database specifically. A total of 731 publications was assessed for relevance by title and abstract. The remaining 496 articles were examined using three inclusion criteria: interventions were guided by an artist or art therapist, participants were actively involved in the creative process, and, anxiety, depression, and/or quality of life were included as outcome measures. Methodological quality of the included studies was appraised using specific checklists.

Results

Seven papers met the inclusion criteria. Data was extracted from three non-randomized intervention studies and four randomized controlled trials. All studies used a quantitative design with validated outcome measures. Four articles described positive effects of art therapy on anxiety, depression, or quality of life in adults with cancer.

Conclusion

Art therapy could possibly help decrease symptoms of anxiety and depression, and improve quality of life in adult cancer patients. However, because of the heterogeneity of the interventions and limited methodological quality of the studies, further research using stringent methods is needed.

Introduction

Background

Receiving the diagnosis cancer may evoke strong emotions of anger and anxiety and can be considered traumatic.(1) When the emotional burden of being seriously ill stretches beyond patients' ability to cope, it may even result in mental disorders.(2) Indeed, anxiety and depression disorders are common among cancer patients(3, 4), as they affect 10% and 20% of the cancer population respectively, which is two to three times higher compared to the general population.(5) Symptoms that are clinically relevant, but do not meet the DSM-criteria for an anxiety or depressive disorder, such as insomnia or distractibility, are even more frequent among cancer patients.(6, 7) These symptoms of depression and anxiety affect quality of life (QoL) adversely.(8, 9)

The relevance of interventions that address psychological symptoms is increasingly recognized,(10) and several supportive care interventions have been shown to be effective among cancer patients.(11-13) An example of such a supportive intervention is art therapy. Several definitions of art therapy are available, which are partly non-overlapping. The British Association of Art Therapists (BAAT) defined art therapy as “a form of psychotherapy that uses art media as its primary mode of communication”.(14) Similarly, art therapy is seen by Pamela et al. as a form of psychotherapy, practiced by trained art therapists, aiming at therapeutic goals.(15) Rather than an approach to enhance self-expression, others emphasise the creative process in art therapy that has healing effects and enhances patients' well-being.(16, 17)

A forensic psychiatry study showed the beneficial use of art therapy in the treatment of destructive aggression.(18) Haeyen et al.(19) found improvements in self-expression among patients with personality disorders undergoing art therapy. Another study highlighted the value of art therapy programmes on emotion regulation in active duty military service members with post-traumatic stress disorder and traumatic brain injury.(20)

In oncology, however, art therapy as a supportive care intervention is relatively new and previous literature studies in this field contain some limitations. For instance, Geue et al.(21) and Wood et al.(22) use a variety of study designs, making it hard to draw conclusions because of the heterogeneity of the studies included. Furthermore, Ennis et al.(23) focus on the beneficial effects only, thus, not paying

attention to potential negative outcomes. Most importantly, all reviews indicate that more research is needed in this field and since upcoming literature about art therapy in cancer care is increasing rapidly, more reviews may be relevant. Therefore, the present review provides a systematic literature overview of the available effectiveness of this form of therapy in adult cancer patients.

In this review, we will define art therapy as an art intervention, aimed at decreasing symptoms of anxiety, depression, and/or increasing QoL, which is delivered by someone with expertise in arts (an artist or professional art therapist). This ensures that there is professional guidance in the use and making of the art, although this does not necessarily involve professional psychotherapeutic involvement. An art therapy intervention may include all sorts of disciplines, like singing, drawing, painting, coloring, sculpting, writing or poetizing. Our aim is to provide an overview of interventional studies that investigate the effects of art therapy interventions on anxiety, depression, and quality of life in adults with cancer. We focus on the *making* of art and will leave out passive forms, such as listening to music or looking at paintings.

Methods

Systematic literature review

We conducted a literature review with a systematic search to provide a summary of the evidence on the use of art therapy in cancer care.

Search strategy and inclusion criteria

We performed a search in the databases PubMed/MEDLINE, PsycINFO, and EMBASE, because we deemed these to be most relevant to our research topic. We searched for publications from September 2009 up to September 2019 and no restrictions regarding publication type were made at this stage. We only included publications that were available in English. The search contained the following search terms: “art therapy” OR “art-making” AND “cancer” OR “oncology”. Search terms were adjusted for each database specifically and can be found in appendix A. Using this strategy, we obtained a total of 968 articles. Of this entire search, 280 publications were derived from PubMed/MEDLINE; 256 from PsycINFO, and 432 from EMBASE. Subsequently, 237 duplicate articles were removed. Two reviewers (J.T.B. and Z.M.B.) first screened the remaining articles by title and excluded clearly irrelevant articles. The remaining 496 publications were assessed by J.T.B. and Z.M.B. based on their title and abstract, using the following inclusion criteria:

studies including adults above the age of eighteen with cancer who were involved in art-making in the presence of an artist or an art therapist, employing anxiety, depression, and/or QoL as outcomes. To increase the validity of our results, we only included prospective cohort studies with a controlled design.

Critical appraisal

The Critical Appraisal Tools by the Joanna Briggs Institute (JBI) were used to examine the methodological quality of the studies.(24) For the non-randomized intervention studies, we used the JBI Critical Appraisal Checklist for Quasi-Experimental Studies, and for the randomized controlled studies we used the JBI Critical Appraisal Checklist for Randomized Controlled Trials.

Data extraction and analysis

The following information was extracted from each study paper: authors, year, study design, number of patients, female to male ratio, number of patients in the intervention/control group, cancer diagnosis, duration and methods of the art therapy intervention, type of instructor of the art therapy intervention, outcome measures, and main findings. A descriptive analysis was performed to evaluate the results.

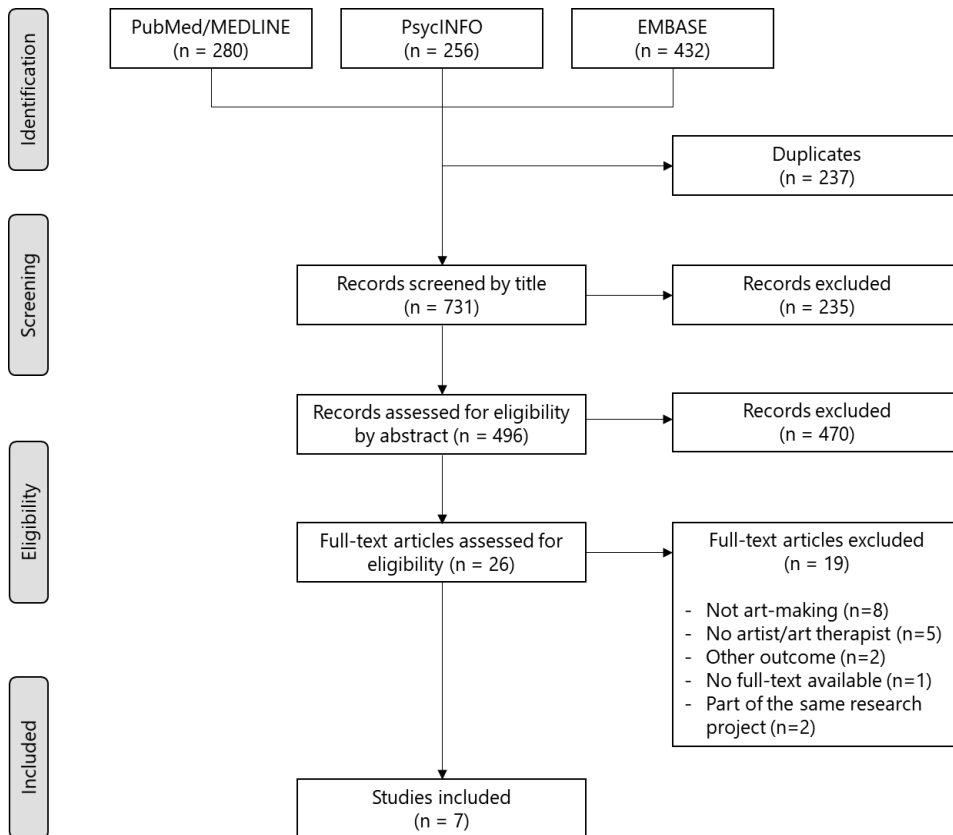
Results

Overview of articles

Twenty-six articles were read in full text of which nineteen articles were excluded, because they did not meet the inclusion criteria, for instance, they did not focus on art-making or did not include an artist or an art therapist. Hence, seven articles were suitable for further analysis. These included three non-randomized intervention studies and four randomized controlled trials. An overview of our selection strategy can be found in figure 1.

The number of participants reported in the articles varied between 24 and 183. Six out of seven papers included more than 50 patients. Three studies focused on female cancer patients only.(25-27) In the remaining articles, patents with a variety of cancer diagnoses were included. In general, more women than men participated in the art therapy trials. A complete overview of the sociodemographic characteristics was given in all studies, except for Radl et al.(27) who only reported age and race of the participants. Four articles described the diagnosis of the patients and their clinical characteristics.(27-30)

Figure 1. Selection strategy



Critical appraisal

The non-randomized controlled trials were assessed based on nine questions about the methodological quality of the studies (table 1). In all articles, the examined causes and effects were clear. The measurements were psychometrically robust and were applied both before and after the interventions. However, the patients in the control group were only similar to the patients in the intervention group in one study.(29) For example, in one study, the control group consisted of patients who declined participation in the art therapy program, which may have caused selection bias.(28) Also, it was often unclear whether the control group and the intervention group received similar cancer treatment apart from the art therapy intervention.(28, 30)

Table 1. JBI Critical Appraisal¹

| Quasi-Experimental Studies | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | | | | |
|------------------------------|-------|--------|--------|--------|-------|--------|-------|-------|-------|-------|-------|-------|-------|
| Bozcuk et al. (2017) | Green | Red | Orange | Green | Green | Orange | Green | Green | Green | | | | |
| De Feudis et al. (2019) | Green | Green | Red | Green | Green | Green | Green | Green | Green | | | | |
| Geue et al. (2013) | Green | Red | Orange | Green | Green | Green | Green | Green | Green | | | | |
| Randomized Controlled Trials | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 |
| Jalabandani et al. (2019) | Green | Orange | Red | Green | Grey | Orange | Green | Red | Green | Green | Green | Green | Green |
| Jang et al. (2016) | Green | Orange | Green | Green | Grey | Orange | Green | Green | Green | Green | Green | Green | Green |
| Porter et al. (2018) | Green | Green | Green | Orange | Green | Green | Green | Green | Red | Green | Green | Grey | Green |
| Radl et al. (2018) | Green | Green | Green | Green | Green | Red | Green | Green | Green | Green | Red | Green | Green |

¹ Green, answer is “Yes”; Orange, answer is “Unclear”; Red, answer is “No”; Grey, not applicable

The checklist regarding randomized controlled trials consisted of twelve questions. In all studies, true randomization was used, however, blinding the treatment was self-evidently not applicable in any of the studies.(25, 26) Porter, McConnell (31) noted that their outcomes assessors were blinded. All seven articles used appropriate statistical analysis. No studies were excluded based on their methodological quality.

Description of the included articles

Bozcuk et al. (2017)

Bozcuk, Ozcan (28) included participants from the outpatient chemotherapy unit Akdeniz University Medical Faculty in Antalya, Turkey. Patients were classified based on their previous exposure to painting art therapy and were divided into two intervention groups. Patients declining participation served as control group. An

art therapist with experience in painting art therapy worked with everyone individually. First, he provided information about the materials and techniques and then he let the patients make as many watercolour paintings as they wanted during a chemotherapy appointment. Afterwards, the art therapist encouraged the patients to elaborate on the meaning and subject of their finished work. The number of finished paintings was registered as a representation of motivation.

De Feudis et al. (2019)

De Feudis, Graziano (29) provided art therapy sessions of 90 minutes in the Medical Oncology Out-Patient unit of San Paolo, serving a population of adult cancer patients from Puglia, Italy. Each patient participated in one group session. The control group was on a waiting list to receive art therapy and meanwhile received usual care. A psychotherapist skilled in art therapy guided the sessions, assisted by a psycho-oncology team. The intervention took place in a room equipped with a large amount of art materials and background music. Groups consisted of a maximum of eight people, varying in age, gender, and diagnosis. The therapy focused on three principles: production of spontaneous artwork, provocation of self-reflection, and sharing experiences with group members. Afterwards, all patients were offered the opportunity of additional psychosocial support.

Geue et al. (2013)

The hemato-oncological patients in the study of Geue, Richter (30) were recruited from the Leipzig University Hospital, Germany. Hemato-oncological patients who lived too far away to participate formed the control group. Twenty-two weekly sessions of 90 minutes were held under the supervision of an art therapist. The groups consisted of patients of different genders and ages. The intervention consisted of three phases: becoming familiar with drawing (assisted by an artist), watercolour painting by oneself, and creating an individual book to express feelings. All decisions regarding the content or design of the book were made by patients themselves.

Jalambadani et al. (2019)

Jalambadani and Borji (25) investigated Neyshabur women with breast cancer visiting the Razavi Hospital of Mashhad City, Iran. They conducted twelve weekly mindfulness-based art therapy (MBAT) sessions, lasting on average 90 minutes. The control group was on a waiting list to receive art therapy and was provided with usual cancer care. The MBAT-program focused on the procedure first used in Monti,

Peterson (32), involving an introduction to art-making, self-picture assessment tasks, exploration of art materials and mind-body relationship, creative problem-solving, meditation, free art-making, and group discussions. The interventions were guided by an artist with psycho-oncological training.

Jang et al. (2016)

Jang, Kang (26) examined the effects of mindfulness-based art therapy (MBAT) in women with breast cancer, who had received surgery and radiation therapy at Wonkwang University Hospital, South-Korea. The patients in the MBAT-group were provided with twelve weekly sessions lasting 45 minutes each. The qualified art therapist encouraged the patients to express their inner feelings. Both the intervention group and the control group continued to have standard post-treatment care.

Porter et al. (2018)

Porter, McConnell (31) developed music therapy sessions for hospice patients in Northern Ireland with an Eastern Cooperative Oncology Group (ECOG) performance of two or lower. The intervention group received a total of six 45-minute individual music therapy sessions, twice a week. The control group underwent usual cancer care. A trained and registered music therapist provided the program using an interactive approach. Patients could participate by singing or listening to known music, but they also got the opportunity to create something of their own, that is, a melody, song, rhythm, or instrumental piece. The music therapist supported the patients in the creative process.

Radl et al. (2018)

Self-Book art therapy was offered by Radl, Vita (27) to female cancer patients undergoing active oncological treatment in a major hospital in Philadelphia, USA. Both the intervention group and the control group had access to all available complementary (psychological) therapies, but only the intervention group created a Self-Book. The participants worked with an art therapist individually in six sessions (“agreements”) of about 50 minutes. The purpose of the art therapy was to create a self-reflective book to express one’s feelings and experiences. During the first five sessions, the patients were instructed to fill the pages of their book with creative artwork related to a given subject (safe place, supports, strength

and virtues, wishes for loved ones, wishes for oneself). In the final session, the patients were encouraged to decorate the cover of the book.

Findings: effect on outcome measures

Anxiety

Out of the four studies measuring anxiety, two found a significant improvement. De Feudis, Graziano (29) reported a significant reduction in anxiety scores in the intervention group, with the score decreasing from 44.3 to 37.1 ($p = 0.002$), while the anxiety scores in the control group did not significantly change. However, the study did not find a significant difference in anxiety scores between the two groups. In the study of Jang, Kang (26) anxiety scores were significantly improved compared to the control group ($P < 0.001$). Geue, Richter (30) did not find any significant differences, neither within the invention group nor between the intervention group and control group. Bozcuk, Ozcan (28) compared anxiety scores amongst two interventions groups and one control group and found that anxiety scores did not differ significantly between the group.

Depression

Three of the seven studies compared depression scores between intervention and control groups. Jang, Kang (26) and Bozcuk, Ozcan (28) found the depression scores in the intervention group to significantly improved compared to the control group ($p < 0.001$ and $p = 0.001$ respectively). Geue, Richter (30) found neither significant improvement in depression scores within the groups nor between the groups.

Quality of life

Six studies reported on QoL or QoL related scales, such as well-being, of which four found an improvement in these outcome variables. Bozcuk, Ozcan (28) reported a significant difference in QoL between the intervention groups and the control group ($p = 0.001$). In addition, as expected through the regression to the mean principle, patients with lower QoL appeared to take greatest advantage from painting art therapy program. All participants declared they enjoyed taking part in painting art therapy program. The intervention was also found to be feasible during chemotherapy sessions. Jang, Kang (26) also reported improvement in quality of life, with the global health status/QoL score increasing from 26.4 to 81.3 ($p < 0.001$). Significant beneficial effects on functional scales, physical symptoms, and financial difficulties were also noted. None of these changes were found in the control group. Additionally, Jalambadani and Borji (25) showed statistically

significant decreases in symptoms of distress in the intervention group compared to the waiting list control group. The scores of physical health, psychological symptoms, social relationships, and environmental factors were improved significantly, as well as QoL scores. Lastly, De Feudis, Graziano (29) reported that 89.3% of the participating patients considered the art therapy program beneficial to their well-being.

Radl, Vita (27) documented no statistically significant differences between the Self-Book therapy intervention group and the control group for the primary outcome (emotional distress) or the secondary outcome (psychological well-being). However, they did find significant improvement in the spiritual well-being of the patients taking part in the Self-Book art therapy program. Also in the study of Porter, McConnell (31) changes in McGill Quality of Life questionnaire (MQoL) scores, as well as in physical symptoms, and psychological and existential well-being, from baseline to the first assessment (week one) were not statistically different between the intervention group and the control group.(31)

Summary of results

In conclusion, of the seven studies, four identified significant results regarding anxiety, depression, or QoL.(25, 26, 28, 29) Of the four studies that studied anxiety, half found significant improvements in anxiety scores, the other half did not.(26, 29) Regarding depression, two studies found significant improvement in depression scores and one did not.(26, 28) Four out of six studies regarding QoL showed significant improvement in QoL after the art therapy intervention.(25, 26, 28) Hence, three studies did not identify any significant results regarding anxiety, depression or QoL.(27, 30, 31) Nevertheless, all participants considered the experience valuable to their well-being, what came up anecdotally as well as through questionnaires after completion of the intervention. An overview of the results of all studies can be found in table 2 and 3.

Table 2. Study results: Quasi-Experimental Studies

| Reference | Bozcuk et al. (2017) | De Feudis et al. (2019) | Geue et al. (2013) |
|--------------------|--|--|--|
| Study design | 3-group comparative study | Non-randomized pre-post study design | Prospective intervention study |
| Diagnosis | | | |
| Participants | Adult cancer patients receiving chemotherapy | Adult cancer patients | Adult cancer patients who had just finished acute treatment |
| N ¹ | 97 | 115 | 183 |
| F:M ² | 54:43 | 88:27 | 94:89 |
| IG:CG ³ | 65:32 | 59:56 | 54:129 |
| Intervention | | | |
| Methods | Painting art therapy program (PATP): introduction about technique and materials, making watercolour paintings, elaborating about the meaning and subject of the paintings | The production of spontaneous artwork; provoking individual self-reflections connected to the art work; shared meaning making within the group | Structuring materials and practising experimental drawing; introducing watercolours; creating an individual book |
| Duration | Six weeks | Four months; each participant took part in one session (90 min) | 22 weekly sessions of 90 minutes |
| Instructor | Professional painting artist | Therapist with expertise in art therapy | Artist with psycho-oncological training |
| Outcome measures | EORTC-QLQ-C30 questionnaire; Hospital Anxiety and Depression Scale (HADS) | State-Trait Anxiety Inventory-Form (STAI-Y); Edmonton Symptom Assessment Scale-Revised (ESAS-R); two open-ended questions about satisfaction with the intervention | Hospital Anxiety and Depression Scale (HADS); Questionnaire on Coping with Illness (FKV); Perceived Adjustment to Chronic Illness Scale (PACIS) |
| Main findings | <ul style="list-style-type: none"> - Significant improved QoL and decreased depression in cancer patients who received PATP - All participants enjoyed the intervention to some extent - PATP may be of more benefit to patients who are relatively in more need of help - PATP is feasible during chemotherapy sessions | <ul style="list-style-type: none"> - Significant reduction in anxiety and psychosomatic distress symptoms (drowsiness and fatigue) were found in the IG compared to the CG - Most participants perceived art therapy as having a positive influence on their well-being - Intervention format was considered appropriate by other staff members | <ul style="list-style-type: none"> - No changes in depression scores were found for the IG - Anxiety scores decreased in a pre-post comparison, but there were no significant differences with the CG - Subjective experiences were positive throughout |

¹N number of patients; ²F:M female to male ratio; ³IG:CG intervention group to control group ratio;

⁴NA not applicable

Table 3. Study results: Randomized Controlled Trials

| Reference | Jalabadani et al. (2019) | Jang et al. (2016) | Porter et al. (2018) | Radl et al. (2018) |
|--------------------|---|--|---|--|
| Study design | Semi-experimental study | Randomized controlled trial | Randomized controlled trial | Randomized controlled trial |
| Diagnosis | | | | |
| Participants | Women with breast cancer, any stage | Women with breast cancer stage 0-III | Oncology hospice inpatients | Female cancer patients |
| N ¹ | 124 | 24 | 51 | 60 |
| F:M ² | 124:0 | 24:0 | 36:15 | 60:0 |
| IG:CG ³ | unclear | 12:12 | 25:26 | 30:30 |
| Intervention | | | | |
| Methods | The 8-week MBAT program of Monti et al. (2006) | Korean mindfulness-based stress reduction's (K-MBSR) psychological intervention combined with the 8-week MBAT program of Monti et al. (2006) | Singing, playing, listening to known music; creating a melody, rhythm, song or instrumental piece | Creation of a journal-style, self-reflective visual book |
| Duration | Twelve weeks; once a week; 90 minutes | Twelve sessions; 45 minutes | Up to six individual sessions over three weeks | Six sessions; 50 minutes |
| Instructor | Artist with psycho-oncological training | Qualified art therapist | Trained and registered music therapist | Art therapist |
| Outcome measures | WHO Quality-of-Life (WHOQOL)-BREF questionnaire | Personality Assessment Inventory (PAI); EORTC-QLQ-C30 questionnaire | McGill Quality of Life questionnaire | Distress Thermometer (DT); FACIT-Sp; Patient-Reported Outcomes Measurement System Brief Psychological Well-being test (PROMIS) |

| Reference | Jalabadani et al. (2019) | Jang et al. (2016) | Porter et al. (2018) | Radl et al. (2018) |
|---------------|---|---|---|--|
| Main findings | <ul style="list-style-type: none"> - Patients in the IG showed significantly decreases in symptoms of distress compared to the CG - Support for the hypothesis that MBAT intervention can help decrease distress levels and improve QoL | <ul style="list-style-type: none"> - Compared to the CG, patients in the IG reported significantly decreased depressive symptoms after treatment - Compared to the CG, patients in the IG reported significantly decreased anxiety after treatment - Global health status in the IG was increased after the treatment period | <ul style="list-style-type: none"> - As expected, the change from baseline 1 was not significantly different between IG and CG - Notable improvement in existential well-being in IG compared to IG - Notable disimprovement in physical well-being in CG compared to IG | <ul style="list-style-type: none"> - No statistically significant differences between Self-Book art therapy in IG and CG for the primary outcome (emotional distress) or the secondary outcome (psychological well-being) - Statistically significant increase in participant's spiritual well-being compared to the CG - Greater effects in younger participants |

¹N number of patients; ²F:M female to male ratio; ³IG:CG intervention group to control group ratio;

⁴NA not applicable

Discussion

Main findings

In this systematic review we found some positive effects of art-making on anxiety, depression, and QoL in adults with cancer. Four out of seven included studies described these beneficial effects. All studies reported that participants considered the experience valuable to their well-being.

Interpretations

These results partially support the findings of previous non-controlled studies on the effectiveness of art therapy on psychological outcomes in cancer care. (21-23, 33) This is somewhat encouraging, because novel, evidence-based interventions to improve psychological outcomes for cancer patients are urgently needed, especially in view of the increased life expectancy of this patient population (34), which prolongs the period of being ill. Whereas QoL is considered of main importance by cancer patients (35), psychological needs are still unrecognized and undertreated. (36)

In our review, we only considered interventions involving active art-making by the patients. Clearly, many other forms of art therapy interventions for cancer patients exist, from purely passive appreciation of art to more interactive forms such as co-creation, in which an artist creates art while making use of the patient's narrative. (37) Active creative work is likely to differ in its mental impact from passive art consumption and is therefore best investigated separately.

Strengths and limitations

Strengths

For this review, we did not only search the commonly used database PubMed/MEDLINE, but also EMBASE and PsycINFO, providing an overview of the literature that is as complete as possible. Next, we used a stringent definition of art therapy, focusing on art-making in the presence of an artist or an art therapist only. In this way, the studies were highly comparable. We excluded all studies that did not use a control group, which increased the validity of our results. Finally, the included studies were from countries across the world, enhancing the generalizability of the results.

Limitations

Despite the strengths of this review, our findings need to be interpreted with caution. The included articles showed several methodological shortcomings. First, three out of seven studies were not randomized, which may have led to selection bias. (28-30) Randomization of the participants was only attempted in the RCTs, because others were afraid that randomization might decrease the willingness of patients to participate. Second, it is not entirely certain that all the effects found in the non-RCTs are due to the art therapy interventions, because the included studies did not address controlling for confounders. For instance, it was often not clear what the cancer characteristics, such as metastasized or non-metastasized, of the patients were. Third, there was a remarkable imbalance in participation between men and women, as three out of seven studies did not include male patients at all. Tavani already addresses the low number of male art therapists,(38) but only few studies have elaborated why men are less likely to participate in art-making programs. This should be investigated further in order to make art therapy suitable for a general population. Finally, the widely varying cultural settings of the included studies is likely to have contributed to the heterogeneity of the studies.

Clinical implications and future research

Our findings are supportive for further development of art-making approaches in cancer care. To improve the clinical evaluation of these approaches, the methodological shortcomings, for example, the lack of randomisation, need to be addressed. Outcomes of this review suggest that more randomized controlled trials with larger sample sizes are needed to establish the evidence of art therapy's effectiveness for adults with cancer. We also recommend developing a protocol to standardize art therapy interventions that are also feasible for clinical practice and for continuation at home.

Conclusion

In conclusion, art therapy involving a professional art therapist or an artist and active art-making of the patients can possibly have positive effect on anxiety, depression, and QoL in of adults with cancer. However, further research with stringent definitions of art therapy as an intervention and appropriate randomized designs are urgently needed.

Author contribution

JTB, ZMB, and HWML designed the study. JTB and ZMB collected and analyzed the data. JTB, ZMB, and HWML wrote the manuscript and all authors participated in manuscript review. All authors approved of the final of the manuscript.

References

1. Cordova MJ, Riba MB, Spiegel D. Post-traumatic stress disorder and cancer. *The Lancet Psychiatry*. 2017;4(4):330-8.
2. Smith HR. Depression in cancer patients: Pathogenesis, implications and treatment (Review). *Oncol Lett*. 2015;9(4):1509-14.
3. Wilson KG, Chochinov HM, Skirko MG, Allard P, Chary S, Gagnon PR, et al. Depression and anxiety disorders in palliative cancer care. *J Pain Symptom Manage*. 2007;33(2):118-29.
4. Watts S, Prescott P, Mason J, McLeod N, Lewith G. Depression and anxiety in ovarian cancer: a systematic review and meta-analysis of prevalence rates. *BMJ Open*. 2015;5(11):e007618.
5. Pitman A, Suleman S, Hyde N, Hodgkiss A. Depression and anxiety in patients with cancer. *Bmj*. 2018;361:k1415.
6. Association AP. Diagnostic and statistical manual of mental disorders. *BMC Med*. 2013;17:133-7.
7. Brintzenhofe-Szoc KM, Levin TT, Li Y, Kissane DW, Zabora JR. Mixed anxiety/depression symptoms in a large cancer cohort: prevalence by cancer type. *Psychosomatics*. 2009;50(4):383-91.
8. Barrera TL, Norton PJ. Quality of life impairment in generalized anxiety disorder, social phobia, and panic disorder. *J Anxiety Disord*. 2009;23(8):1086-90.
9. Kolovos S, Kleiboer A, Cuijpers P. Effect of psychotherapy for depression on quality of life: meta-analysis. *Br J Psychiatry*. 2016;209(6):460-8.
10. Stomski NJ, Petterson A, Kristjanson L, Lobb EA, Phillips M, Williams A, et al. The effect of self-selected complementary therapies on cancer patients' quality of life and symptom distress: A prospective cohort study in an integrative oncology setting. *Complement Ther Med*. 2018;37:1-5.
11. Xiao F, Song X, Chen Q, Dai Y, Xu R, Qiu C, et al. Effectiveness of Psychological Interventions on Depression in Patients After Breast Cancer Surgery: A Meta-analysis of Randomized Controlled Trials. *Clin Breast Cancer*. 2017;17(3):171-9.
12. Kampshoff CS, Chinapaw MJ, Brug J, Twisk JW, Schep G, Nijziel MR, et al. Randomized controlled trial of the effects of high intensity and low-to-moderate intensity exercise on physical fitness and fatigue in cancer survivors: results of the Resistance and Endurance exercise After ChemoTherapy (REACT) study. *BMC Med*. 2015;13:275.
13. Xunlin N, Lau Y, Klainin-Yobas P. The effectiveness of mindfulness-based interventions among cancer patients and survivors: a systematic review and meta-analysis. *Supportive Care in Cancer*. 2018:1-16.
14. BAAT. What is art therapy? British Association of Art Therapists 2014 [Available from: <https://www.baat.org/About-Art-Therapy>].
15. Pamela E. Therapeutic Art-making and Art Therapy: Similarities and Differences and a Resulting Framework. 2015.
16. Nainis N, Paice JA, Ratner J, Wirth JH, Lai J, Shott S. Relieving symptoms in cancer: innovative use of art therapy. *J Pain Symptom Manage*. 2006;31(2):162-9.

17. Derman YE, Deatrick JA. Promotion of Well-being During Treatment for Childhood Cancer: A Literature Review of Art Interventions as a Coping Strategy. *Cancer Nurs.* 2016;39(6):E1-E16.
18. Smeijsters H, Cleven G. The treatment of aggression using arts therapies in forensic psychiatry: Results of a qualitative inquiry. *The arts in psychotherapy.* 2006;33(1):37-58.
19. Haeyen S, van Hooren S, van der Veld W, Hutschemaekers G. Efficacy of Art Therapy in Individuals With Personality Disorders Cluster B/C: A Randomized Controlled Trial. *J Pers Disord.* 2018;32(4):527-42.
20. Jones JP, Walker MS, Drass JM, Kaimal G. Art therapy interventions for active duty military service members with post-traumatic stress disorder and traumatic brain injury. *International Journal of Art Therapy.* 2018;23(2):70-85.
21. Geue K, Goetze H, Buttstaedt M, Kleinert E, Richter D, Singer S. An overview of art therapy interventions for cancer patients and the results of research. *Complement Ther Med.* 2010;18(3-4):160-70.
22. Wood MJ, Molassiotis A, Payne S. What research evidence is there for the use of art therapy in the management of symptoms in adults with cancer? A systematic review. *Psychooncology.* 2011;20(2):135-45.
23. Ennis G, Kirshbaum M, Waheed N. The beneficial attributes of visual art-making in cancer care: An integrative review. *Eur J Cancer Care (Engl).* 2018;27(1).
24. Tufanaru C, Munn Z, Aromataris E, Campbell J, Hopp L. Chapter 3: Systematic reviews of effectiveness. *The Joanna Briggs Institute 2017* [Available from: <https://reviewersmanual.joannabriggs.org/>].
25. Jalambadani Z, Borji A. Effectiveness of Mindfulness-Based Art Therapy on Healthy Quality of Life in Women with Breast Cancer. *Asia Pac J Oncol Nurs.* 2019;6(2):193-7.
26. Jang SH, Kang SY, Lee HJ, Lee SY. Beneficial Effect of Mindfulness-Based Art Therapy in Patients with Breast Cancer-A Randomized Controlled Trial. *Explore (NY).* 2016;12(5):333-40.
27. Radl D, Vita M, Gerber N, Gracely EJ, Bradt J. The effects of Self-Book((c)) art therapy on cancer-related distress in female cancer patients during active treatment: A randomized controlled trial. *Psychooncology.* 2018;27(9):2087-95.
28. Bozcuk H, Ozcan K, Erdogan C, Mutlu H, Demir M, Coskun S. A comparative study of art therapy in cancer patients receiving chemotherapy and improvement in quality of life by watercolor painting. *Complement Ther Med.* 2017;30:67-72.
29. De Feudis RL, Graziano G, Lanciano T, Garofoli M, Lisi A, Marzano N. An art therapy group intervention for cancer patients to counter distress before chemotherapy. *Arts Health.* 2019:1-14.
30. Geue K, Richter R, Buttstadt M, Brahler E, Singer S. An art therapy intervention for cancer patients in the ambulant aftercare - results from a non-randomised controlled study. *Eur J Cancer Care (Engl).* 2013;22(3):345-52.
31. Porter S, McConnell T, Graham-Wisener L, Regan J, McKeown M, Kirkwood J, et al. A randomised controlled pilot and feasibility study of music therapy for improving the quality of life of hospice inpatients. *BMC Palliat Care.* 2018;17(1):125.

32. Monti DA, Peterson C, Kunkel EJ, Hauck WW, Pequignot E, Rhodes L, et al. A randomized, controlled trial of mindfulness-based art therapy (MBAT) for women with cancer. *Psychooncology*. 2006;15(5):363-73.
33. Archer S, Buxton S, Sheffield D. The effect of creative psychological interventions on psychological outcomes for adult cancer patients: a systematic review of randomised controlled trials. *Psycho-Oncol*. 2015;24(1):1-10.
34. Meyer AC, Drefahl S, Ahlbom A, Lambe M, Modig K. Trends in life expectancy: did the gap between the healthy and the ill widen or close? *BMC medicine*. 2020;18(1):1-10.
35. Nayak MG, George A, Vidyasagar M, Mathew S, Nayak S, Nayak BS, et al. Quality of life among cancer patients. *Indian journal of palliative care*. 2017;23(4):445.
36. Pearce MJ, Coan AD, Herndon JE, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Supportive Care in Cancer*. 2012;20(10):2269-76.
37. Dörr H, Hübner F, editors. *If you are not there, where are you? Mapping the Experience of Absence Seizures Through Art*. Utrecht HKU Professorship Performative Processes &IT&FB; 2017.
38. Tavani R. Male mail: A survey of men in the field of art therapy. *Art Therapy*. 2007;24(1):22-8.

Appendix A. Search strategy

PubMed/MEDLINE

(art therapy [MeSH] OR art therap* [tiab] OR art program [tiab] OR art-making [tiab] OR art making [tiab] OR performative arts [tiab] OR artwork [tiab] OR music therapy [MeSH])
AND
(neoplasms [MeSH] OR neoplasm* [tiab] OR neoplasia*[tiab] OR cancer*[tiab] OR oncolog*[tiab] OR tumour* [tiab] OR carcinoma* [tiab] OR malignan*[tiab])

PsycINFO

(art therapy OR art therapist OR art program OR art-making OR performative arts OR music therapy)
AND
(neoplasms OR cancer OR oncology)

EMBASE

(art therapy/ OR (art-therap* OR art-making OR artwork OR music making).ti,ab,kw.)
AND
(neoplasm/ OR (neoplasm* OR cancer* OR oncolog* OR tumour* OR malignan*).ti,ab,kw.)

CHAPTER 6

NARRATIVE RECOGNITION AND IDENTIFICATION: A QUALITATIVE PILOT STUDY INTO READING LITERARY TEXTS WITH ADVANCED CANCER PATIENTS

Albert Kamp, Zarah M. Bood, Michael Scherer-Rath, Yvonne Weeseman, Nirav
Christophe, Henny Dörr, José Sanders, Mirjam Sprangers, Esther Helmich,
Liesbeth Timmermans, Ellen van Wolde, Hanneke van Laarhoven

Based on:

Kamp A, Bood Z, Scherer-Rath M, et al. Narrative recognition and identification:
a qualitative pilot study into reading literary texts with advanced cancer
patients. *Journal of Cancer Survivorship*. 2021; 16(3): 531-541.
doi: 10.1007/s11764-021-01048-0

Abstract

Purpose: Patients with advanced cancer can experience their disease as a contingent life event. The sudden interruption of their life stories can obscure life goals and disrupt meaning making. In the context of the research project “In search of stories,” we aim to investigate the reading and discussion of selected stories which present ways of dealing with a contingent life event. In addition, we examine the use of a newly developed guide for reading these exemplary texts together with advanced cancer patients.

Methods: This qualitative study describes the experiences of five patients with advanced cancer who participated in a guided reading and follow-up discussion of selected literary texts. The intervention consisted of reading a selected story, after which each patient was interviewed, using the reading guide as a conversation template. The interviews were then thematically analyzed for their conceptual content using a template analysis.

Results: All five conversations showed some form of recognition in reaction to the chosen text, which led to personal identification of experiences of contingency, such as loss of life goals, impending death, or feelings of uncertainty. Besides the important role of identification, revealed by the responses to the questions in the reading guide, the discussion of the text helped them articulate their own experience and sources of meaning. Diverse worldviews came to the fore and concepts of meaning such as fate, life goals, quality of life, and death were discussed.

Conclusions: First experiences with our newly developed reading guide, which was designed to support the structured reading of stories containing experiences of contingency, suggest that it may help patients to express their own experiences of contingency and to reflect on these experiences.

Introduction

Falling seriously ill, for example when someone is diagnosed with incurable cancer, has a profound impact on one's personal life and their individual life stories.(1) The illness not only affects a patient's physical health, but his/her psychological and spiritual wellbeing are also at stake.(2) Being diagnosed with a life-threatening disease places pressure on a patient's expectations from life and can be experienced as a contingent life event. Contingency refers to the idea that everything could have been different, and compared to one's plans and expectations could develop otherwise.(3) The occurrence of the life event is a possibility, not a certainty. This experience of contingency can be described as a crisis of meaning and interpretation, something that complicates the progress of the patient's meaningful life story.(4) In cases where the cancer diagnosis leads to an unexpected disruption of a patient's life, the patient has to reinterpret his/her life story.

The process of reinterpretation, to search for and express meaning in life, relates to the concept of spirituality.(5) According to Puchalski et al. (p. 887), "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."(6) Several studies have shown the importance of spiritual care in advanced cancer patients.(7-9) Despite an increasing recognition of the significance of spirituality when dealing with a terminal illness(10), it is still underappreciated in the palliative care of oncological patients, and patients have reported unmet spiritual needs.(11)

In randomized clinical trials, spiritual interventions addressing existential themes using a narrative approach have shown positive effects.(12) However, effect sizes were moderate, which may, among other factors, be due to the common understanding that attribution of meaning to experiences of illness is an individual process that people should experience alone. However, patients can find themselves "empty handed" when it comes to creating meaning or constructing a meaningful life story.(13, 14)

In the research project "In search of stories", we set out to develop a narrative intervention in order to contribute to the process of meaning making of advanced cancer patients. Under the guidance of a spiritual counsellor, patients are provided

with a selection of literary texts in which several ways of dealing with a contingent life event are presented. The exemplary stories are a starting point for the conversation about a patient's own life story. After discussing their life story, patients engage in a co-creative art-making project with a professional artist, empowering them to create their own new life story.(3, 15)

In this study, we focus on the part of the project in which the literary texts are read and discussed. These texts offer patients the possibility to recognize similar lived experiences and introduce them to other views and interpretations. In this way the patients could distance themselves from their own perspective and look at their own situation in new ways. Central to this process is the notion of narrative identification. From a cognitive linguistic point of view, some form of identification is necessary in the process of reading literary texts, such as recognizing words and concepts, in order to create coherent mental representations of these concepts (16) and to comprehend the narrative presented as a meaningful story.(17) A cognitive linguistic approach focuses on the cognitive processes by which our interaction with the world is mediated through informational structures in the mind.

In addition to the recognition of situations and events, it is important to observe how patients identify with characters in the story, whose visions on the events are presented.(18) Readers may find themselves invested in the goals and plans of characters, causing them to experience emotions as the story unfolds.(19)

Alternatively, narrative identification points to the psychological process that individuals form an identity by integrating life experiences into their personal life story.(20-22) The connection of life experiences to concepts of meaning and worldview refers to the spiritual component which, in a way, forms a further elaboration of the psychological process of narrative identification.

Offering patients exemplary narratives could stimulate a process of narrative identification in a cognitive linguistic, psychological, and spiritual respect. This process starts by recognizing words and concepts (linguistic), followed by identifying with subjects and situations (psychological), and connecting these to the patient's own life experiences and worldview (spiritual).(23) The extent to which this connection takes place depends to a considerable degree on the perceived similarities between the main character and the reader.(24)

We report on our first experiences with reading and discussing exemplary literary texts with advanced cancer patients, using a newly developed reading guide to assist the process of narrative identification.

Methods

Selection of literary texts

The literary texts were selected by the following authors who all have a different expertise relevant to the project: clinical oncology and palliative care (H.v.L.), medical psychology (M.S.), qualitative health research (E.H., Z.M.B.), language studies and narrative discourse (J.S.), religious studies and theology (M.S.R., E.v.W.), performative processes in arts (H.D., N.C.), and primary and community care (L.T.). The selection process consisted of three phases: 1) collection of relevant book and story titles suggested by all authors; 2) selection of specific text fragments from the suggested books by Z.M.B., N.C. and H.D.; 3) discussion and final selection of the passages by Z.M.B., N.C., H.D., H.v.L. and M.S.R.

In phases two and three, the following criteria were used: the story is written in a literary style, it contains a contingent life event (i.e., an event that happened, but not necessarily one that had to happen, and one that turned life upside down), the story tells about life goals that come under pressure or presents new life goals, it describes at least two different perspectives on contingency, and it invites readers to reflect on or to question their own situation. In addition, we applied practical selection criteria: the story could be read in ten to fifteen minutes to engage patients less familiar with reading texts, and it presented various perspectives, for example regarding culture, religion, gender, and age of the protagonists. Using this method, we evaluated 42 texts and eventually selected ten texts or fragments.(25)

Three narratives are classically oriented (Greek) and/or play an important role in various religious traditions (Jewish, Christian, Islamic): “Orpheus”, “Job”, and “Yunus”. In the Greek story of Orpheus, the protagonist’s wife dies from a snake bite, after which Orpheus descends into the underworld to try to retrieve her.(26) Job, a righteous character, is successful in life, but in a short time he loses all that is near and dear to him, and then rebels.(27) During a storm at sea, Yunus ends up in the belly of a large fish and fears death.(28)

Four stories have a more contemporary style and are more accessible in a literary sense. In “The Fault in Our Stars” (John Green) (29), two people fall in love and enjoy life despite their incurable illness. The story “Code Catnip” (“Code Kattenkruid” in Dutch, by Jacques Vriens) (30) depicts a grandfather’s struggle to tell his grandchild that he will die. “The After Days” (“De nadagen” in Dutch, by A.N. Ryst) (31) describes the story of a son who witnesses the decline of his parents. “Farewell from Phoebe” (“Afscheid van Phoebe” in Dutch, by Vonne van der Meer) (32) describes the difficult and lonely task of a woman who has to give birth to her dead child.

The three other stories are more fictional, appealing strongly to the reader’s imagination. In “Death of an old man” (Roald Dahl) (33), delusion and reality become intertwined when a pilot fights for his life after his plane is shot down. “The Metamorphosis” (“Die Verwandlung” in German, by Franz Kafka) (34), describes the thoughts of a man who wakes up one morning after being transformed into a huge insect. The story “The Ant’s Departure” (“Het vertrek van de mier” in Dutch, by Toon Tellegen) (35), describes how each animal in the forest personally deals with the sudden absence of the ant.

All ten stories were made available as a paper booklet. To support patients in their decision which story to read, a website was developed which included brief summaries and animated trailers of each story, developed by students at the University of the Arts, Utrecht. The website also contains the full written text of each story together with an audio version, produced by Thinium Audioboekproducties BV.

Reading guide

As part of the intervention developed in the research project “In search of stories”, the patient can choose one of the selected literary texts and reflect on it during a meeting with a spiritual counsellor. To support this process, A.K., expert in the field of religious studies and cognitive narratology, developed a reading guide. The purpose of the reading guide is to enable patients to process the narrative and become acquainted with the diversity of views offered in the chosen story. At the same time, the reading guide also helps patients increase awareness of their own experiences and their identification with the subjects and situations in the narrative, thus stimulating the process of re-interpretation and meaning making.

The reading guide contains three stages of reading and reflecting: close reading, recognizing, and connecting (table 1).

Close reading

The close reading elements of the reading guide are based on the previous experience of A.K. (36) in the context of reading spiritually oriented texts using a cognitive linguistic approach.(37) The focus of this stage is on the textual level of the narrative and the world of the story presented, stimulating patients to read consciously and carefully. In this textually-oriented stage, patients are encouraged to imagine the narrative world and distinguish between the recounted “acts” and the “spoken text” when reading the story (“Who do you hear?”). In this way, their awareness is increased regarding the perspective of who “speaks” and through whose eyes they are looking. In doing so, the diversity of views is revealed as well as the choices made by the narrator and the characters.(38) Secondly, questions that focus on “time” and “space”, “subjects” and “situations”, as presented in the narrative, explicitly bring the narrative world to the fore (“What do you see?”). The narrative world, or story-world, is the cognitive linguistic concept that refers to the complex mental representation readers construct during the process of reading.(39) Stage one concludes by focusing on the readers’ understanding of unfamiliar words and by looking at the various concepts, metaphors, and/or figures of speech (“How is it presented in the text?”).

Recognizing

Stage two focuses on the interaction between readers and texts and on their recognition of various aspects within the story. In this psychologically oriented stage, patients are invited to indicate which characters and situations they identify with, or which elements in the narrative emotionally move them. In order to stimulate patients’ involvement, the questions at this stage were formulated in terms of the first person. Empathizing with subjects (“In whom do I recognize myself?”), knowing similar events (“Which event do I recognize?”), or being touched by striking details (“What moves me?”) play a significant role in the process of meaning making. From a cognitive linguistic point of view, recognition is necessary to conceptualize and thereby to constitute meaning in order to form a coherent mental representation. From a psychological point of view, recognition is needed for the process of narrative identification.

Connecting

Stage three connects the narrative with the patient's personal life story. Although not every narration moves or has a deep meaning for readers, it may evoke emotions and thoughts, support or question existing ideas, or open up new insights. At this spiritually oriented stage, the focus of the reading guide is on reflection and re-interpretation and therefore (as in stage one) is formulated in the second person ("How does the story affect you?"). Sub-questions focus on the elements in the story that touch the patients, emphasizing what this story personally means for their life narrative.

Table 1. Narrative identification and reading guide

| Narrative identification | Research area | Reading guide |
|---------------------------------|--|------------------------------------|
| Cognitive linguistic | Textual level of the narrative | Stage 1: Close reading |
| | Focus on linguistic perspective (narrator-characters) | "Who do you hear?" |
| | Focus on narrative world (time-space-subjects-situations) | "What do you see?" |
| Psychological | Focus on linguistic presentation (words-concepts-metaphors) | "How is it presented in the text?" |
| | Interaction readers and texts | Stage 2: Recognizing |
| | Focus on subject identification | "In whom do I recognize myself?" |
| | Focus on situation identification | "Which event do I recognize?" |
| Spiritual | Focus on detail/concept identification | "What moves me?" |
| | Readers life narrative | Stage 3: Connecting |
| | Focus on reflection ((emotional) response-thoughts-ideas) | "How does the story affect you?" |
| | Focus on (re)interpretation (concepts of meaning-sources of meaning) | |

The reading guide pilot study

In November and December 2019, we tested the reading guide presented above in a pilot study.

Ethical considerations

The pilot study's research protocol was assessed by the Medical Ethics Review Committee of the Amsterdam University Medical Centers which decided that formal approval was not needed. Patients were orally informed about the study and by an information letter, including a warning of the potential risk of emotional stress and their right to withdraw from the study at any time. Patient confidentiality was ensured and all collected data was coded and stored in a protected database. Written informed consent was obtained from each participating patient.

Procedure

Patients were recruited from the Department of Medical Oncology of the Amsterdam University Medical Centers, Location AMC, the Netherlands. We approached patients who were diagnosed with advanced, incurable cancer, and receiving palliative treatment and/or best supportive care. Based on their willingness, eight patients initially agreed to participate in this study. Due to personal circumstances three patients, of which two female patients, refrained from participation, resulting in a purposive sample of five male patients. The first contact with patients was established by the outpatient unit manager of the Department of Medical Oncology during a visit in the context of their treatment. After gaining initial consent, each patient was contacted by phone by the project researcher (A.K.), who provided further information on the study and made a personal appointment for an interview if patients agreed. All consenting patients were offered the opportunity to be interviewed either at the hospital or at home.

The session consisted of the patient choosing and reading one of the presented stories, discussing the narrative using the reading guide, and concluding with debriefing questions to evaluate the session. All sessions were audio recorded. Since neither the supportive website nor the booklet was yet available, patients were offered a random choice of three stories from the selection of ten: one of the three classically oriented, one of the four contemporary texts, and one of the three more fictional stories. At the request of one patient, all ten stories were shortly introduced at that particular meeting. The interviews were conducted

according to a predetermined protocol in which the reading guide questions functioned as interview questions. The session started with getting acquainted, followed by introducing the study, choosing, and reading one of the three stories by the patient, stage one “close reading”, stage two “recognizing”, stage three “connecting”, with ended with a final evaluation and conclusion.

Data analysis

The audio recording of each session was thematically analyzed regarding its conceptual content by means of a template analysis, as described by, among others, King.(40) This type of thematic analysis is very suitable for qualitative research in the setting of patient-centered medical care, as also shown by studies of, among others, Brooks et al.(41) in the context of qualitative psychology, or De Vries et al.(42) in the context of patients with advanced cancer. We used Atlas.ti-software to encode and analyze the data of the recorded conversations.(43)

Template analysis involves the application of a coding “template” with which qualitative data, such as interview transcripts, are thematically coded and interpreted. The “template” itself consists of a number of themes identified by the researcher. The analysis often starts with some a priori themes, which are expected to be relevant for the analysis. After reading and rereading the data, these (deductive) themes can be revised and refined, and supplemented with inductive themes which emerge in the transcripts. Ordering and specifying themes and sub-themes creates a hierarchically-structured template which is applied to all obtained data (i.e., the interviews).

The first two interviews were coded by AK based on the questions of the reading guide. This initial template was discussed with M.S.R., after which five a priori (deductive) main themes and five sub-themes (of the first two main themes) were established: 1) story choice, 2) narrative identification, 3) experience of contingency, 4) concepts of meaning, and 5) sources of meaning.(44) The sub-themes of story choice were the specific chosen stories, the sub-themes of narrative identification were the identification with subjects and/or situations in the story (table 2).

Based on a detailed reading of all five interviews by A.K., the template was further discussed and refined with help from M.S.R., after which ten inductive sub-themes were added to the final template for three of the main themes (table 2): sub-

themes loss of life goals, impending death, uncertainty (aspects of experience of contingency); sub-themes fate, life goals, quality of life, death (specific concepts of meaning that came to the fore); sub-themes Christian worldview, Buddhist worldview, Secular worldview (specific sources of meaning which were mentioned). The analysis and interpretation of the data by A.K. was discussed with E.v.W., M.S.R. and H.v.L.

The main themes of the template match the research concepts described in the “Introduction” section. The specific choice of one of the selected stories and the interaction with the text can provide insights into the process of narrative identification. The specific content of the experience of contingency and the way in which the experience was discussed can provide insights into the way in which the patient connects the experience of contingency to concepts of meaning, and, in a larger context, to his or her worldview.

Table 2. Template analysis

| Main themes | Sub-themes |
|------------------------------|---|
| 1. Choice of story | 1.1 Job 1.2 The Fault in Our Stars 1.3 Code Catnip 1.4 Death of an old man |
| 2. Narrative identification | 2.1 Subject 2.2 Situation |
| 3. Experience of contingency | 3.1 Loss of life goals 3.2 Impending death 3.3 Uncertainty |
| 4. Concepts of meaning | 4.1 Fate 4.2 Life goals 4.3 Quality of life 4.4 Death |
| 5. Sources of meaning | 5.1 Christian worldview 5.2 Buddhist worldview 5.3 Secular worldview |

Results

Patients

Five patients, all male and aged 54 to 74 years, agreed to take part in the pilot study. Three had a Christian upbringing, but were not religiously active; the other two had no specific religious background. The interviews took place at each patient's home according to their preference, the main reason being that they perceived their home as more suitable for discussing personal and inner life. Each interview lasted 75 to 90 minutes in total, of which 60 minutes were spent reading and discussing the story. Most patients were tired after 60 minutes because of the intensity of the conversation. We note that future meetings of this intervention part will have to be more efficient. Given the availability of the website and the booklet, less time will be needed for the project's introduction, and patients can choose and read a story prior to the meeting.

Choice of story

All five participants chose a story that was close to their personal experiences. For example, the choice for the story of "Job" was prompted by the patient's past religious education, combined with a strong identification with the main character: "Job experiences "It befalls me". Because that is how you experience it with cancer." (P1, aged 65).

Two patients chose "The Fault in Our Stars", a story about an impossible love affair. For one patient (P2, aged 74) the memory of his love for his deceased wife and the impossible love for someone else in the present established a strong association with the chosen story. The other patient (P3, aged 54) was interested in all ten stories. The love for his wife, who he had lost to cancer, appealed directly to the story of "Orpheus". However, the combination of a new love and his own illness made "The Fault in Our Stars" more appropriate for him. The "Code Catnip" story was chosen by another patient (P4, aged 72) based on an experienced dilemma in the present and on his recognition of the main character. Like the acting subject in the narrative, he is a grandfather who finds it difficult to explain to his grandchild that he is terminally ill. The patient who chose the story "Death of an old man" (P5, aged 70) had a strong preference for narratives situated in the Second World War.

During all five interviews, the first stage of the reading guide was of limited value. The questions "Who do you hear?", "What do you see?" and "How is it presented

in the text?” functioned mainly as a means of checking whether the story had been properly understood. Since the narrative had just been introduced and had only just been read, there was hardly any need to explicitly re-activate the story-world. Nevertheless, during the meeting, parts of the story were regularly referred to, thus bringing the mental representation of the narrative world (back) to the forefront of the conversation. In particular the question about subjects, situations, and events (“What do you see?”) acted as a point of reference during the sessions, maintaining the focus on the theme of experiences of contingency, especially at times when the conversation deviated too much.

Narrative identification and experiences of contingency

In response to the second stage questions “In whom do I recognize myself?”, “Which event do I recognize?”, “What moves me?”, almost all participants answered immediately, often intuitively. For example, in the story of “Job”, known passages were quoted almost immediately by the patient, such as “Naked I came from my mother’s womb, and naked shall I return there” (Job 1:21) (27). For this patient, the quotation meant that things are fixed in life and cannot be changed. Highly emotionally charged statements also emerged: “Nobody asks to become ill, it happens to you and Our Lord did not predetermine it.” (P1, aged 65). This patient recognized the life experiences of the character of Job but not Job’s anger or revolt. The patient also recognized the experience of different perspectives (in the story these are articulated by the locations in heaven and on earth), but he did not evaluate his personal situation as being “unfair”. His recognition of himself in the narrative subject Job and his empathy with the situation of the main character quickly led to personal experiences of his illness. For example, the parallel to the friends of Job, who “interrogate” Job about his beliefs, evoked the memory of similar reactions of others in the patient’s personal environment: “That’s how it happens in real life. Opinions [on how to deal with your illness] come from all sides. But what do you do with them [opinions of others]?” (P1, aged 65).

Other salient examples of textual recognition and personal identification occurred after reading “The Fault in Our Stars”; the narrative evoked strong emotions in both patients. For one, the story initially appealed to the concept of love and sexuality. He pointed out that being seriously ill does not mean that people can no longer have sex, a theme also reflected in the story. Moreover, it turned out that he strongly identified with the narrative protagonist Augustus, not so much

because of appearances or specific character traits, but mainly because of Augustus' views on life: "It's about living in the here and now, getting cancer is just bad luck." Although the story initially evoked romantic connotations and was reminiscent of his love in the here and now, during the conversation his memories of his first wife and of his life as a whole predominated: "I no longer have a future, only a past." This patient still thought his life was worth living, although as in the story, the practical limitations of, for example, a stoma did not make it any easier: "I just expect to muddle through until it's over." (P2, aged 74).

For the other patient, the narrative subject itself was not the point of recognition, but a detail in the story: "I got up, dragging my body and the cart across the carpet that was older than Augustus would ever be, and I knelt at the base of the chair and put my head in his lap and hugged him by the waist" (*The Fault in Our Stars*, chapter 13). The recognition of the thought about the carpet, and thereby the finiteness of human existence, caused this patient to think about the duality that illness entails. On the one hand there are feelings of lust for life, cheerfulness, love, and also sexuality: "It also ends nicely in the story, when they say, "Let's try to make love"; "try nothing", I said, "just do it." (P3, aged 54). On the other hand, there is the continued presence of impending death and its consequences for his family and loved ones: "The realization (of death) hurts because I project that realization onto someone else..." The fact that he was now confronted with cancer for the second time in his life, but this time himself, resulted in the prominence of the subject of his own mortality during the conversation: "When my wife passed away I really thought, well this was it. I considered myself almost immortal, this is not going to happen to me. That is of course not based on anything, but we have had our share." (P3, aged 54). In retrospect, the patient's identification with an apparently insignificant detail related to a textual comment about the age of a carpet activated all kinds of affectionate emotions and experiences of contingency in his own life's story.

For the patient who chose the story "Code Catnip", the identification process ran parallel to his reasons for choosing this story. Like the main character, he is a grandfather who has a hard time communicating with his (grand)children about his illness and inevitable death: "Well, of course I see the game playing between an elderly man who is ill and probably also has a chance of dying, who also loses his quality of life, but yet still empathizes with the life of this child, and that is also what you have to do..." Besides communicating about his health and prospects, this

patient found it difficult to deal with the day-to-day consequences of his illness: “But what bothers me the most is my loss of quality of life. I didn't have to work that hard anymore and at the age of 72 I had a pretty good life. In fact, it all went well. I travelled all over the world, everything went fine. That was suddenly taken away. And that bothers me.” His deteriorating quality of life had made him decide to end his life through euthanasia when the time is right, just like the main character in the story: “I'm aware that I have my own choice too ... And if it has to happen, it will happen. And I am confident that I will be helped if necessary.” (P4, aged 72). For this patient, the strength of the textual identification lay in the conceivability of the story as a whole. He understood the protagonist's struggle with himself, with his environment, with his own death, and he recognized his own final choices.

When discussing the story “Death of an old man”, the identification process was mainly through recognizing the actions and situations in which the main character found himself. The chosen story, in which delusion and reality intertwine, details the dire situation of the protagonist who hangs from a parachute after his plane has been shot down. While he fights for his life, he ends up in a kind of mud pool. The patient in question linked the narrative's evoked images metaphorically to his own situation. He had been diagnosed with cancer for the fourth time in his life and, a few years earlier, had also suffered a brain hemorrhage. He associated the shot pilot in the story with the situation that had befallen him; the pilot's hanging from a parachute he associated with his own helplessness, the pool of water and mud in the story with his own struggle: “That you have the strength to escape, and come out of the pool.” When discussing the end of his own life, and a possible afterlife, this patient repeated an image from the story, as a kind of visionary future reality in which he hopes to meet his wife again: “There is always someone waiting for me ... that must be (in the story) a woman waiting for him.” (P5, aged 70).

Concepts of meaning and worldview

In the third stage of the reading guide, patients were asked the question: “What does the story mean to you?” This question is intended to stimulate the connection of the evoked experiences with the reader's own ideas and insights, and also as a first step towards reflection and reinterpretation. As a separate question, it turned out to be difficult for the patients to answer. However, it did evoke reactions about the perception of contingency on the one hand and the patient's view of life

on the other. In a sense, it was striking that no matter how different each person's life was and how distinct each personal situation was regarding the illness, both the contingent nature of the experience and the view of life were formulated in similar terms.

The experience of contingency in relation to incurable cancer was, more or less, called "fatum", the fate that befalls you without anyone being guilty: "it happens to you ... it is my fate and you have to make do with that" (P1, aged 65), "it is bad luck ... just by chance" (P2, aged 74), "coincidence, this just happens, there is no reason for it, just like that ... that will not happen to me" (P3, aged 54), "pure bad luck" (P4, aged 72), "it happens to you" (P5, aged 70).

When talking about these initial reactions, about what being seriously ill does to you in an emotional or spiritual sense, a more differentiated picture emerged than a resigned determination of fate alone. One patient mentioned grief: "Then your world collapses. I couldn't read anymore, I couldn't remember any more books... that moment, from me first hearing the death sentence" (P1, aged 65); panic: "In the beginning it was blind panic. Not really blind panic, but when I was diagnosed and discovered it was not really curable, then I experienced it as something really serious, just because my wife died" (P3, aged 54); incomprehension: "I've always said: what have I done wrong? But yes, so be it" (P5, aged 70); and anger: "Setbacks, with which you have learned to deal with, you can accept. But this is too much. This is too much, this is the straw that broke the camel's back" (P4, aged 72).

The description of the emotion associated with the experience of contingency for patients also provided a brief insight into their worldview. Such as the thought "what have I done wrong", which turned out to be mainly about this patient's struggle with his religious views. Although he had not believed in a god for a long time, his incomprehension turned out to be religiously formulated: "No, I sometimes think, why is he (God) punishing me for the fourth time?" (P5, aged 70). Another patient, who indicated that he was no longer religious, at least not actively, verbalized a clear spiritual attitude to life in the course of the conversation, in which his Christian worldview resonated: "I do not look at life negatively. I don't look at it as finite either. I know, I've never blamed (God) ... I still think there's something more." (P1, aged 65). Although he had a Christian youth, and although the Buddhistic worldview appealed to him, another patient

placed his situation in a secular perspective: “I expect I expect to keep struggling until the end.” (P2, aged 74).

The patients without a religious background referred to their worldview in a secular way, pointing to the existential wellbeing in the here and now and secular views on afterlife: “I don’t believe in an afterlife, and I don’t believe in a god. No, I believe it should happen here and now.” (P3, aged 54); “There is no answer to anything, no, you have to find that yourself ... after this life it is over” (P4, aged 72).

Discussion

We reported our first experiences with reading and discussing exemplary literary texts that contain experiences of contingency with advanced cancer patients, using a newly developed reading guide to assist the process of narrative identification.

All five patients showed some form of recognition in reaction to the chosen text, which ranged from textual recognition of situations in which the characters find themselves, to specific thoughts and ways of thinking, from small details in the narrative world to the story as a whole. Such personal connections of readers with the stories they have read, is studied extensively in the research on literature and narrative discourse, witness the aforementioned studies on literary response by Oatley (19), on audience identification by Cohen (24), or identification with characters by Van Krieken et al.(38) Some authors, like Frank (45), more specifically emphasize how stories invite readers to adopt different perspectives and can be used to enhance human lives and relations. The same author emphasized in his former research the importance of the personal stories told by people afflicted with illness and its therapeutic effect on ill people’s lives.(46) However, the intervention tested in this study above all aimed to activate patients own experiences of contingency, by means of reading and discussing one of the selected stories. For example, the story of “Job” triggered an identification with a similar situation of inexplicable suffering. “The Fault in Our Stars” evoked empathy with the protagonist’s ideas, appealing to the patient’s own thoughts about love and life. The same story touched another patient with a striking detail, which opened up various thoughts on his view of life. “Code Catnip” appealed to a personally-recognizable reality because of the story as a whole, instead of one

single detail. “Death of an old man” stimulated a metaphorical identification with the narrated situation, the patient’s actual life being a struggle.

The combination of narrative recognition and identification with highly emotional reactions, after reading similar stories by patients with an incurable disease, shows great similarities with the observations made by Gerald West during sessions with discussion groups of HIV-infected patients in South Africa.(47) In one of the group meetings, after reading and exploring chapter three of the book of “Job”, a participant said, “We are like Job; we are good people who were not looking for this thing, and yet now we are infected” (West, p. 63) (48). Just as our patient who chose the story of “Job”, this participant strongly identifies with the suffering of the protagonist Job, and at the same time stated that his own life differed. And just like our patient, the participants from the discussion group in South Africa elaborately detailed their experiences of being judged by their families, friends, and churches (West, p. 64) (48). The examples show that the story of Job seems to evoke similar responses of recognition by different readers, detailing experiences of contingency in view of a severe disease.

The results of the pilot study show that narrative identification on a psychological and spiritual level may also occur. The various emotions regarding their illness (such as grief, panic, incomprehension, anger), the diverse concepts of meaning (such as fate, life goals, quality of life, death) and connections to their worldview, as expressed when discussing the text, bear witness to this. The emotions, concepts of meaning, and sources of meaning correspond to the three domains of meaning making, mentioned by La Cour and Hvidt.(49) They distinguish a secular, religious, and a spiritual domain, that partially overlap each other. Calling something “fate” for example, is not exclusive to a religious worldview, nor is the concept “quality of life” exclusively secular. More generally speaking, the words belong to the vocabulary of meaning making. The meaning of these concepts depends on the specific situation of each individual patient and relate to their personal worldview.

In other words, the textual narrative world of each story provided words and images which enabled the patients to individually express their own experience of contingency and to rethink what they had endured. In this way, the interaction between literary texts and the story of patients stimulated the reflection on their

own experiences, enabling them to place these experiences in a larger context of meaning making and worldview.(50)

The reading guide, as a reviewing tool and conversation template, demonstrated its potential to activate the recognition of experiences of contingency. The conceptualization of the narrative reality (stage one of the reading guide) and the direct questioning of recognition and identification (stage two of the reading guide) give focus and direction to the conversation. Especially the strong and emotional responses of patients to the reading guide questions “In whom do I recognize myself?”, “Which event do I recognize?”, “What moves me?”, seem to open up a powerful connection to personal experiences of contingency and view of life. Together with the question about the meaning of the story for the reader (stage three of the reading guide), thoughts about meaning making and the patient’s worldview are activated in a purposeful way.

Although the implementation of stage one, close reading, may at first sight seem limited because the story had just been read by the patient, in a setting where the story is read at an earlier moment, this stage of the reading guide will probably contribute more when reactivating the story. Moreover, it can be argued that starting with the specific details of the story itself- rather than directly with the patient story- facilitates patients when telling their story; one of the participants explicitly mentioned that he was pleased to start the conversation with the written story rather than with his own experiences. Someone else’s (literary) story gave him the opportunity first to distance himself from his own story and perspective, and secondly, to look at his own situation through new eyes.(51)

In stage three, the question "what does this story do to you" turned out to be difficult for patients to answer directly. Patients were unable to easily place their experiences in a larger context of meaning making and worldview. However, during the interviews, when further discussing the story in relation to their own experiences, various concepts of meaning were explicitly mentioned, sometimes directly related to a worldview (e.g. Christian worldview, Buddhist worldview, or Secular worldview). Although our study used a different conversation template, our findings are consistent with the study by La Cour and Schnell (44). Their empirical research show that it is helpful during a semi-structured interview to specifically question participants on their sources of meaning, since it appears to be difficult for participants to express this on their own.

Several limitations of our study should be acknowledged. Our sample consisted of five Dutch men, whereas a larger group of patients, with diverse cultural backgrounds, and a more balanced composition regarding gender could have widened the results of the thematic analysis. It should also be noted that with the exception of the stories “Farewell from Phoebe” and “The Ant’s Departure”, the literary stories were mainly from a male perspective. Patients who are not male might respond differently to the male-voiced texts, and vice versa. In the future, additional texts that reflect perspectives besides the male perspective might also need to be included. Due to the small sample of participants, we did not reach data saturation in the thematic analysis. However, rather than aiming for data saturation, the thematic analysis was employed to explore if and how patients relate to the stories they were presented with. Future research should investigate the full breadth and depth of the themes that are evoked by these stories.

Conclusion

In conclusion, first experiences with our newly developed reading guide designed to support a structured reading of stories containing experiences of contingency suggest that it may help patients to express their own experiences of contingency and to reflect on these experiences. Further research is needed to investigate whether introducing recognizable narratives that represent experiences of contingency and discussing a selected story with a spiritual counsellor contribute to improving the supportive care and quality of life of advanced cancer patients.

Author contribution

Albert Kamp: study design, reading guide, data collection, data analysis, data interpretation, manuscript writing, manuscript review.

Zarah Bood: story selection, manuscript writing, manuscript review.

Michael Scherer-Rath: study design, story selection, manuscript review.

Yvonne Weeseman: manuscript review.

Nirav Christophe: story selection, manuscript review.

Henny Dörr: story selection, manuscript review.

José Sanders: story selection, manuscript review.

Mirjam Sprangers: story selection, manuscript review.

Esther Helmich: story selection, manuscript review.

Liesbeth Timmermans: story selection, manuscript review.

Ellen van Wolde: study design, story selection, manuscript review.

Hanneke van Laarhoven: study design, story selection, manuscript review.

References

1. Yang W, Staps T, Hijmans E. Existential crisis and the awareness of dying: the role of meaning and spirituality. *Omega (Westport)*. 2010;61(1):53-69.
2. Scherer-Rath M. Ervaring van contingentie en spirituele zorg. *Psyche en Geloof*. 2013;24(3):184-95.
3. Kruizinga R, Hartog ID, Scherer-Rath M, Schilderman H, Van Laarhoven H. Modes of relating to contingency: An exploration of experiences in advanced cancer patients. *Palliat Support Care*. 2017;15(4):444-53.
4. Dalferth IU, Stoellger P. Religion als Kontingenzkultur und die Kontingenz Gottes. In: Dalferth IU, Stoellger P, editors. *Vernunft, Kontingenz Und Gott. Konstellationen Eines Offenen Problems*. Tübingen: Mohr Siebeck; 2000. p. 1-44.
5. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: reaching national and international consensus. *J Palliat Med*. 2014;17(6):642-56.
6. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med*. 2009;12(10):885-904.
7. Balboni TA, Vanderwerker LC, Block SD, Paulk ME, Lathan CS, Peteet JR, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol*. 2007;25(5):555-60.
8. Balboni TA, Paulk ME, Balboni MJ, Phelps AC, Loggers ET, Wright AA, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol*. 2010;28(3):445-52.
9. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-11.
10. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet*. 2003;361(9369):1603-7.
11. Pearce MJ, Coan AD, Herndon JE, 2nd, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer*. 2012;20(10):2269-76.
12. Kruizinga R, Hartog ID, Jacobs M, Daams JG, Scherer-Rath M, Schilderman JB, et al. The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis. *Psycho-Oncol*. 2016;25(3):253-65.
13. von Engelhardt M. Biografie und Trauma. In: Liebau E, Zirfas J, editors. *Dramen der Moderne. Kontingenz und Tragik im Zeitalter der Freiheit*. Bielefeld: Transcript Verlag; 2010.
14. Makropoulos M. *Modernität und Kontingenz*. München: Wilhelm Fink Verlag; 1997.

15. Hartog I, Scherer-Rath M, Kruizinga R, Netjes J, Henriques J, Nieuwkerk P, et al. Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol.* 2017;25(6):1-17.
16. Langacker RF. The Contextual Basis of Cognitive Semantics. In: Nuyts J, Pederson E, editors. *Language and Conceptualization, Language Culture & Cognition 01.* . Cambridge: Cambridge University Press; 1997. p. 229-52.
17. Emmott C. *Narrative Comprehension. A Discourse Perspective.* Oxford: Clarendon Press; 1997.
18. de Graaf A, Hoeken H, Sanders J, Beentjes JWJ. Identification as a Mechanism of Narrative Persuasion. *Commun Res.* 2012;39(6):802-23.
19. Oatley K. A taxonomy of the emotions of literary response and a theory of identification in fictional narrative. *Poetics.* 1994;23(1-2):53-74.
20. McAdams DP. *The Stories We Live by.* New York: Guildford Press; 1993.
21. Singer JA. Narrative identity and meaning making across the adult lifespan: an introduction. *J Pers.* 2004;72(3):437-59.
22. McAdams DP, Manczak E. Personality and the life story. In: Mikulincer M, Shaver PR, Cooper ML, al. e, editors. *APA Handbook of Personality and Social Psychology.* 4. Washington DC: American Psychological Association; 2015. p. 425-46.
23. Nuyts J, E. P. Overview: on the relationship between language and conceptualization. In: Nuyts J, Pederson E, editors. *Language and Conceptualization, Language Culture & Cognition 01.* Cambridge: Cambridge University Press; 1997. p. 1-12.
24. Cohen J. Audience identification with media characters. In: Bryant J, Vorderer P, editors. *Psychology of Entertainment.* Mahwah NJ: Lawrence Erlbaum Associates; 2006. p. 183-98.
25. Dörr H, Bood Z, Christophe N, Kamp A. *Wellicht. Een verhalenbundel in het kader van het project Op zoek naar verhalen.* Amsterdam2020.
26. Fry S. *Orfeus. Helden.* Amsterdam: Thomas Rap; 2019.
27. *Job. Nieuwe Bijbelvertaling.* Haarlem: Nederlands Bijbelgenootschap; 2004/2007.
28. Kathir I. Yunus. *Stories of the Prophets.* South Carolina: Createspace Independent Publishing Platform; 2015.
29. Green J. *Een weeffout in onze sterren.* Haarlem: Gottmer; 2014.
30. Vriens J. *Code Kattenkruid.* Amsterdam: Uitgeverij Unieboek | Het Spectrum BV; 2018.
31. Ryst AN. *De nadagen.* Amsterdam: Em. Querido; 2009.
32. Van der Meer V. *Afscheid van Phoebe. Het limonadegevoel en andere verhalen.* Amsterdam: De Bezige Bij; 1985.
33. Dahl R. *Death of an old man. Over to You: Ten Stories of Flyers and Flying.* New York: Reynal and Hitchcock; 1946.
34. Kafka F. *De gedaanteverwisseling.* Benthuisen: Astoria Uitgeverij; 2017.
35. Tellegen T. *Het vertrek van de mier.* Amsterdam: Em. Querido; 2009.
36. Kamp AH. *7evensprong. Handreiking bij het lezen van bijbelteksten.* Zeist: Uitgave Pastorale Dienstverlening van het Aartsbisdom Utrecht; 2001.

37. Kamp AH. *Inner Worlds. A Cognitive Linguistic Approach to the Book of Jonah* (Biblical Interpretation Series 68). Leiden: Brill; 2004.
38. van Krieken K, Hoeken H, Sanders J. Evoking and Measuring Identification with Narrative Characters - A Linguistic Cues Framework. *Front Psychol.* 2017;8:1190.
39. Werth P. *Text Worlds: Representing Conceptual Space in Discourse*. London: Longman; 1999.
40. King N. Doing template analysis. In: Symon G, Cassell C, editors. *Qualitative organizational research*. London: Sage; 2012. p. 426-540.
41. Brooks J, McCluskey S, Turley E, King N. The Utility of Template Analysis in Qualitative Psychology Research. *Qual Res Psychol.* 2015;12(2):202-22.
42. de Vries YC, Helmich E, Karsten MD, Boesveldt S, Winkels RM, van Laarhoven HW. The impact of chemosensory and food-related changes in patients with advanced oesophagogastric cancer treated with capecitabine and oxaliplatin: a qualitative study. *Support Care Cancer.* 2016;24(7):3119-26.
43. Frieze S. *Qualitative data analysis with Atlas Ti*. London: Sage; 2012.
44. la Cour P, Schnell T. Presentation of the Sources of Meaning Card Method: The SoMeCaM. *J Humanist Psychol.* 2020;60(1):20-42.
45. Frank AW. *Letting Stories Breathe: A Socio-narratology*. Chicago: University of Chicago Press; 2010.
46. Frank AW. *The Wounded Storyteller: Body, Illness and Ethics*. Chicago and London: University of Chicago Press; 1995.
47. West G. Reading the Bible in the Light of HIV/AIDS in South Africa. *Ecum Rev.* 2009;55(4):335-44.
48. West G. *Doing Contextual Bible Study: A Resource Manual*. KwaZulu-Natal: The Ujamaa Centre for Community Development & Research; 2015.
49. la Cour P, Hvidt NC. Research on meaning-making and health in secular society: secular, spiritual and religious existential orientations. *Soc Sci Med.* 2010;71(7):1292-9.
50. Köppe T. *Literatur als Sinnstiftung?* 2005;5(1):1-16.
51. Kidd DC, Castano E. Reading Literary Fiction Improves Theory of Mind. *Science.* 2013;342(6156):377-80.

CHAPTER 7

“I’LL BE YOUR ROCK” - A CASE REPORT FROM A MULTIMODAL NARRATIVE INTERVENTION FOR PATIENTS WITH ADVANCED CANCER

Zarah M. Bood, Yvonne Weeseman, Michael Scherer-Rath, Henny Dörr, Nirav Christophe, Hugo J.G. Vlug, Donna Risa, Jacqueline M. Tromp, Niels van Poecke, Mirjam A.G. Sprangers, Esther Helmich, Hanneke W.M. van Laarhoven

Based on:

Bood, Z.M., Weeseman, Y., Scherer-Rath, M., Dörr, H., Christophe, N., Vlug, H.J.G., Risa, D., Tromp, J.M., van Poecke, N., Sprangers, M.A.G., Helmich, E., van Laarhoven, H.W.M. “I’ll be your rock” - A case report from a multimodal narrative intervention for patients with advanced cancer. Submitted, 2022.

Abstract

Introduction: Having cancer can be disruptive to someone's life and making meaning of the event through a narrative intervention is believed to improve well-being. We developed the 'In Search of Stories' intervention that aims to improve meaning making in patients with advanced cancer by offering them a narrative intervention that makes use of literature and art. Here, we describe the intervention and present the implementation of the intervention by reporting a case.

Case presentation: The patient was a 50-year-old woman, diagnosed with metastasized cervical cancer, for which she received palliative treatment. The multimodal intervention consisted of multiple steps, including reading a literary text and a process of co-creative art-making. The intervention helped her to talk about her experiences and express emotions, gave her new insights, and allowed her to create something to leave behind for her loved ones.

Discussion: We found that the 'In Search of Stories' intervention helped the patient to make meaning of the cancer. We will continue to include more patients and collect more data to investigate how the intervention will stimulate meaning making.

Introduction

Having cancer can be very disruptive to someone's life.(1-3) It can be described as an experience of contingency. Contingency means that everything could have been different in life and that an event that has occurred, may not necessarily had to occur.(4-7) When an experience of contingency arises, someone needs to make meaning of his/her life again.(4, 5) Meaning making has been defined as the ongoing process of storytelling to maintain or create a coherent life story, in which life events are organized into an intelligible whole.(5, 8, 9) Narrative interventions are particularly appropriate for promoting meaning making, as storytelling forms the core of narrative interventions. Narrative interventions aim to let a patient tell his/her story and let the patient reconstruct his/her life story into a comprehensible story.(5, 10) Making meaning of a life event through a narrative intervention is believed to improve a patient's well-being.(5, 10, 11)

Currently, it is still unclear what type of narrative interventions cancer patients could benefit from.(5) For that reason we developed the 'In Search of Stories' (ISOS) intervention - a study that aims to improve meaning making in patients with advanced cancer by offering them a narrative intervention that makes use of literature and art. In the present case study, we describe the intervention and present the implementation of the intervention by reporting a case of a patient with advanced cervical cancer who participated in the ISOS intervention.

Case presentation

Eligibility criteria for the ISOS intervention were being above the age of eighteen, having a diagnosis of advanced cancer, and having a life expectancy of six months or more. The first participant to complete the ISOS intervention was chosen as the subject for this case report. For the purpose of this case report, we will call this patient Liv. Liv was a 50-year old woman, diagnosed with metastasized adenocarcinoma of the cervix in 2018. Palliative treatment was started, consisting of an experimental treatment of chemotherapy in combination with immunotherapy. At the time of this study, Liv was still undergoing this treatment. The patient was born in Germany, but she has been living in the Netherlands for many years. She has two teenage children and lives with her partner. At the end of 2020 Liv was invited to participate in the ISOS intervention, to which she consented.

Intervention

The ISOS intervention was a multimodal narrative intervention that consisted of multiple steps. Effects of the intervention (i.e. the extent of meaning making, spiritual health, and quality of life) were measured by questionnaires and by letting patients draw their experiences. Figure 1 shows a detailed flowchart of the contact moments Liv had throughout the intervention. The next paragraphs will describe these contact moments in more detail.

At the start of the intervention, Liv was asked to fill out the following questionnaires: a questionnaire on demographic information, The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ) short version of the QLQ-C30 for palliative care: QLQ-C15-PAL(12, 13), and the “Reconstruction of Life Events” Questionnaire (RE-LIFE)(11, 14). The RE-LIFE questionnaire invited Liv to draw a life line with the most impactful life events (positive and negative), to subsequently choose the most negative one, and to answer the questions with respect to the chosen life event.(14) After completion of the questionnaires, a first meeting with a spiritual counsellor took place. The spiritual counsellor discussed the questionnaires with Liv and instructed her to create a Rich Picture (RP). A RP is a visual representation of a situation, including all elements of a situation, relationships, and emotions.(15-20) We have previously demonstrated the potential of RPs to provide insight into (changes in) the experiences and quality of life of patients with (advanced) cancer.(19-21) Together, the questionnaires and the RP formed the baseline measurement of the experiences of the patient.

At the end of the first meeting with the spiritual counsellor, Liv was provided with a booklet that included a preselection of ten literary texts brought together in the bundle *Wellicht* (in English: *Perhaps*)(22). These ten stories all presented ways of dealing with a contingent life event and they functioned as a starting point to talk about the patient’s own life story.(22) Liv was instructed to choose one of ten exemplary stories before the next meeting. To aid her in selecting a story, we provided access to the project’s website, which had brief summaries and animated trailers of each story, developed by students at the University of the Arts, Utrecht. The website also contained an audio version of each story. We have described the process of selecting the ten stories, as well as a short description of each story, in a previous study.(22)

In the second meeting, the spiritual counsellor and Liv discussed the chosen story using a newly developed reading guide, as described previously.(22) Next, the authors YW, HD, and NC matched Liv to a professional artist from a pool of artists involved in the ISOS intervention. Liv had eight sessions of around two to three hours with the artist, after which they delivered a finished work of art. Thereafter, the patient drew another RP in a meeting with the spiritual counsellor, filled in the questionnaires, and had a meeting with the researcher YW to evaluate the intervention.

For this case report, we focused on the RPs, the discussion of the story, the process of co-creative art-making, and the experiences of this particular patient with the study. We did not assess the responses to the questionnaires, as these quantitative data only have meaning at the group level.

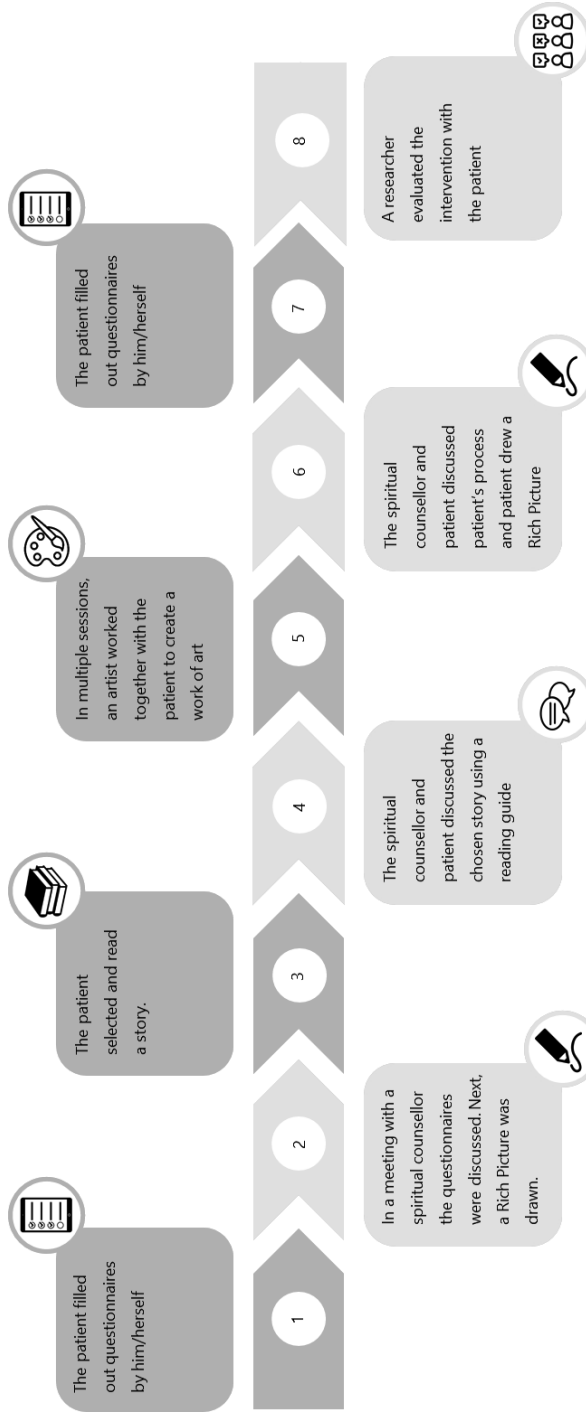


Figure 1. Flowchart of the contact moments of patients in the In Search of Stories intervention

Findings

First RP

Liv was asked to draw the most pressing life event that negatively impacted her life at this moment and how the chosen life event currently played a role in her life. She chose to focus her RP (figure 2) on her divorce with her husband and what the consequences of the divorce were for her life. Liv was surprised that she ended up drawing the RP about the divorce and not about her cancer. During the RP session she said: *“I was really surprised yesterday [at RE-LIFE session], that I said that my divorce is the main topic that comes up in this process. I did not expect that at all. [...] Because I actually already put that behind me.”*



Figure 2. First RP drawn by the patient

Story

Out of the ten exemplary stories, Liv was asked to choose the story that resonated most with her. After careful consideration, Liv chose the story “The Ant’s Departure” (“Het vertrek van de mier” in Dutch, by Toon Tellegen). The story described how each animal in the forest personally deals with the sudden absence of the ant. Liv immediately identified with the ant, as she would be gone when she would pass away, and her children were each one of the animals that had to cope with the ant leaving. While reading and discussing the story with the spiritual counselor, she came to realize that her greatest worry regarding her illness was having to leave her children behind. Reading the story forced her to think about how her passing away would affect her children. She started wondering if she needed to contact her ex-husband, so that her children would have their father to lean on when she is gone. Here, she made a connection between the story and her RP. Due to the divorce, her children did not have contact with their father, and now her illness made her wonder if she needed to restore that contact, because she was afraid to leave her children behind.

Process of co-creation

For the process of co-creation, Liv was matched to a visual artist, with whom she had eight sessions. The artist and Liv build upon the main themes that came up in the discussion about the “The Ant’s Departure”. The thought process for the co-creation started with the question: How can I leave without abandoning my children? Liv came up with the idea for an art piece herself - she wanted to make a rock that could be placed on her land. The visual artist and Liv designed and crafted the rock. On the rock they painted the word “Me” and an ant to refer to the “The Ant’s Departure”. They also installed a light inside of the rock. The idea behind the rock was that during the day the rock would look like a regular rock (figure 3a), but when it would get dark outside, the light inside the rock would turn on and the word “Me” and the picture of the ant would appear (figure 3b).

Initially, Liv felt like the rock had nothing to do with the starting question, because the rock was for herself. However, during conversations with the visual artist it became clear that the rock was not only for herself, but also for her children. Liv realized that the essence of her struggles was that she had been abandoned by her own parents, and that she did not want to do this to her own children. Now, when her children would need Liv after she has passed away, the rock would be there to remind them that Liv would always be there. As Liv described it herself - her body

will leave this world, but her energy will stay in the rock. The rock also literally formed a light in the darkness, sending her energy into the world.

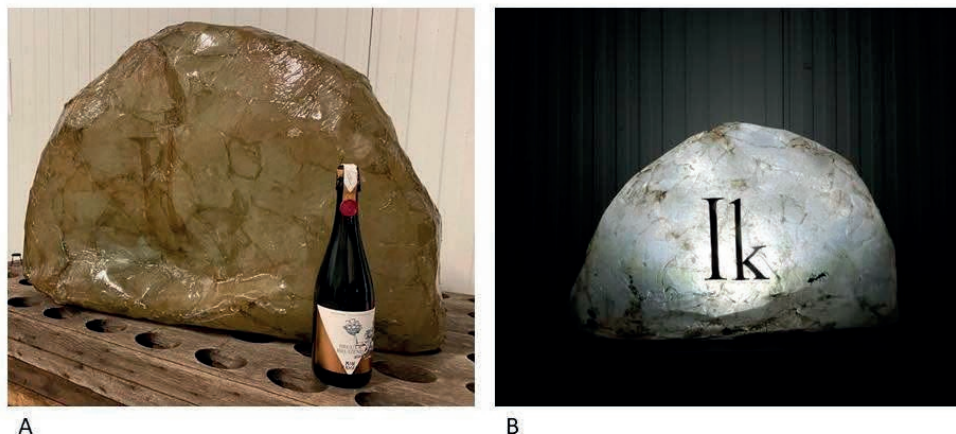


Figure 3. Finished work of art made by patient and artist
(A) The work of art during the day; (B) The work of art at night

Second RP

For her second RP session, Liv was again asked to draw how the chosen life event currently played a role in her life. Figure 4 shows the RP she drew. The most important theme in the RP was leaving something behind after her death.

The word “Ik” (Translation: “Me”) and the ant reoccurred in the RP - they are in a circle of energy, with lights and stars in it (right top of RP). The latter represented her system of energy that will live on after her death. There is a path of light that moves towards this system of energy, representing her death. Liv mentioned that she is not afraid to die, as her energy will stay in this world and the love for her children and her current husband will always shine.

Liv drew her garden as a symbol to celebrate life. She also made a reference to the Bible when explaining her RP - she shared her blood in the form of wine with others, in order to pass on joy to others. Next to the wineglass she drew tears, as she acknowledged that her death will bring sadness. The tears form a river and merge with wine droplets, symbolizing that both sadness and joy are required in life.



Figure 4. Second RP drawn by the patient

Liv's experience with the ISOS intervention

Liv experienced the first RP session as confronting. However, she also acknowledged that the session gave her more insight into what she was actually struggling with and helped her to release some emotions. Liv enjoyed reading and discussing the story. She explained that the story helped her to talk about her own experiences. The story also stimulated her to think about what it would mean for her children if she would pass away. The co-creation allowed for further exploration of how she could still provide support to her children after her death. Overall, Liv said that the intervention gave her wings - she was proud of the art piece and happy she could leave something behind for her family.

Interpretation of findings

The steps of the intervention provided Liv with multiple moments of reflection, which led to new insights and created opportunities to look at the contingent life event of having advanced cancer from new perspectives. For example, the intervention helped Liv realize how her biggest concern regarding the cancer (leaving her children behind) stems from previous contingent life events, such as

her own parents abandoning her and the failed marriage with her ex-husband. Because of these previous life experiences, that came up during the multiple steps in the intervention, “abandonment” was an important theme for her in relation to the cancer as well. The art piece was a way for her to address this theme by creating something that would manifest her place in the world, avoiding abandonment of her children. Hence, it could be argued that the ISOS intervention helped the patient to make (some) meaning of the cancer and prognosis.

Discussion

We presented a patient with advanced cervical cancer who participated in the ISOS intervention, a narrative intervention to improve meaning making. Currently there is still uncertainty about the potential of narrative interventions to promote meaning making and well-being. Kruizinga et al.(5) described a beneficial effect of narrative interventions for cancer patients directly after the intervention, but found no evidence for long term (three to six months after intervention) benefits. In contrast, Wise et al.(10) found no significant improvement of well-being in advanced cancer patients two months after their narrative intervention, but well-being was significantly improved four months after the intervention. Given the findings reported here, the ISOS intervention could potentially contribute to meaning making, and we will continue to include more patients and collect more data to investigate how the intervention is stimulating meaning making. As a next step, we envision a randomized controlled trial to shown the potential of our intervention to improve meaning making and well-being, both on the short and long term.

Two other observations in relation to this patient are worth mentioning. First, when asked about the most pressing life event that negatively impacted life at this moment, Liv chose her divorce and not the cancer. This case report presents an example of how the experience of getting cancer can bring up themes that stem from previous life experiences. The totality of someone’s life story can become visible as a result of being confronted with the finality of life. That this can happen is important for health care professionals to realize, as for patients, despite the severity of a disease, the disease may not be the most significant concern to the patient at that moment. Second, without aiming to, the intervention had a strong ‘legacy building’ component to it. Legacy is defined as that what a person leaves behind after deceasing.(23, 24) In this case, the patient left a work of art behind that would establish her place in the world and remind her loved ones that she

would always be there. We argue that the ISOS intervention may have potential to be designed as a legacy building narrative intervention.

Author contribution

Zarah M. Bood: Conceptualization, Methodology, Data collection, Formal analysis, Writing - original draft; **Yvonne Weeseman:** Conceptualization, Methodology, Data collection, Formal analysis, Writing - review & editing; **Michael Scherer-Rath:** Conceptualization, Methodology, Writing - review & editing; **H. Dörr:** Conceptualization, Methodology, Data collection, Writing - review & editing; **N. Christophe:** Conceptualization, Methodology, Data collection, Writing - review & editing; **Hugo J.G. Vlug:** Data collection, Writing - review & editing; **Donna Risa:** Data collection, Writing - review & editing; **Jacqueline M. Tromp:** Data collection, Writing - review & editing; **Niels van Poecke:** Writing - review & editing; **Mirjam A.G. Sprangers:** Conceptualization, Methodology, Writing - review & editing; **Esther Helmich:** Conceptualization, Methodology, Writing - review & editing; **Hanneke W.M. van Laarhoven:** Conceptualization, Methodology, Data collection, Funding acquisition, Writing - review & editing.

References

1. Kyota A, Kanda K. How to come to terms with facing death: a qualitative study examining the experiences of patients with terminal Cancer. *BMC Palliat Care*. 2019;18(1):33.
2. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-11.
3. Nayak MG, George A, Vidyasagar MS, Mathew S, Nayak S, Nayak BS, et al. Quality of Life among Cancer Patients. *Indian J Palliat Care*. 2017;23(4):445-50.
4. Hartog I, Scherer-Rath M, Kruizinga R, Netjes J, Henriques J, Nieuwkerk P, et al. Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol*. 2017;25(6):1-17.
5. Kruizinga R, Hartog ID, Jacobs M, Daams JG, Scherer-Rath M, Schilderman JB, et al. The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis. *Psycho-Oncol*. 2016;25(3):253-65.
6. Kruizinga R, Hartog ID, Scherer-Rath M, Schilderman H, Van Laarhoven H. Modes of relating to contingency: An exploration of experiences in advanced cancer patients. *Palliat Support Care*. 2017;15(4):444-53.
7. Scherer-Rath M, Van den Brand J, Van Straten C, Modderkolk L, Terlouw C, Hoencamp E. Experience of Contingency and Congruent Interpretation of Life Events in Clinical Psychiatric Settings: A Qualitative Pilot Study. *J Empir Theol*. 2012;25(2):127-52.
8. McAdams DP, McLean KC. Narrative Identity. *Curr Dir Psychol Sci*. 2014;22(3):233-8.
9. Collie K, Bottorff JL, Long BC. A narrative view of art therapy and art making by women with breast cancer. *J Health Psychol*. 2006;11(5):761-75.
10. Wise M, Marchand LR, Roberts LJ, Chih MY. Suffering in Advanced Cancer: A Randomized Control Trial of a Narrative Intervention. *J Palliat Med*. 2018;21(2):200-7.
11. Hartog ID, Scherer-Rath M, Oreel TH, Netjes JE, Henriques JPS, Lemkes J, et al. Reconstructing Disruptive Life Events Using the RE-LIFE Questionnaire: Further Validation of the 'Narrative Meaning Making of Life Events' Model Using Multiple Mediation Analysis. *J Empir Theol*. 2019;32(2):251-80.
12. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst*. 1993;85(5):365-76.
13. Rojas-Concha L, Hansen MB, Petersen MA, Groenvold M. Content validation of the EORTC QLQ-C15-PAL with advanced cancer patients and health care professionals from palliative care services in Chile. *BMC Palliat Care*. 2020;19(1):81.
14. Kruizinga R, Scherer-Rath M, Schilderman JB, Sprangers MA, Van Laarhoven HW. The life in sight application study (LISA): design of a randomized controlled trial to assess

the role of an assisted structured reflection on life events and ultimate life goals to improve quality of life of cancer patients. *BMC cancer*. 2013;13:360.

15. Bell S, Berg T, Morse S. What is a Rich Picture. In: Bell S, Berg T, Morse S, editors. *Rich Pictures: encouraging resilient communities*. Abingdon, Oxfordshire; New York: Routledge; 2016. p. 1-36.

16. Berg T, Pooley R. Rich pictures: Collaborative communication through icons. *SPAR*. 2013;26(4):361-76.

17. Cristancho S. Eye opener: exploring complexity using rich pictures. *Perspect Med Educ*. 2015;4(3):138-41.

18. Cristancho SM, Helmich E. Rich pictures: a companion method for qualitative research in medical education. *Med Educ*. 2019;53(9):916-24.

19. Bood ZM, Scherer-Rath M, Sprangers MAG, Timmermans L, van Wolde E, Cristancho SM, et al. Living with advanced cancer: Rich Pictures as a means for health care providers to explore the experiences of advanced cancer patients. *Cancer Med*. 2019.

20. Bood ZM, Scherer-Rath M, Sprangers MAG, Timmermans L, van Wolde E, Cristancho SM, et al. Repeated use of rich pictures to explore changes in subjective experiences over time of patients with advanced cancer. *Cancer Rep*. 2021:e1428.

21. Bood ZM, van Liemt F, Sprangers MAG, Kobes A, Weeseman Y, Scherer-Rath M, et al. This is what life with cancer looks like: exploring experiences of adolescent and young adults with cancer using two visual approaches. *Support Care Cancer*. 2022.

22. Kamp A, Bood Z, Scherer-Rath M, Weeseman Y, Christophe N, Dorr H, et al. Narrative recognition and identification: a qualitative pilot study into reading literary texts with advanced cancer patients. *J Cancer Surviv*. 2021.

23. Breitbart W. Legacy in palliative care: Legacy that is lived. *Palliat Support Care*. 2016;14(5):453-4.

24. Boles JC, Jones MT. Legacy perceptions and interventions for adults and children receiving palliative care: A systematic review. *Palliat Med*. 2021;35(3):529-51.

CHAPTER 8

GENERAL DISCUSSION

General discussion

In this dissertation we have explored ways for patients to express their feelings and experiences beyond questionnaires and regular in-depth interviews. We have examined the visual tools RPs and photovoice to gain insight into the experiences of patients with cancer. Subsequently, we have investigated art-based interventions to stimulate meaning making. In this discussion section we will consider two statements: 1) The application of visual tools for gaining insight into patients' experiences should be expanded; 2) Interventions that invite patients to create something material, either an RP, photovoice, or an art-piece, should be more widely adopted. We will discuss these two statements by means of an RP (figure 1). The left side of the RP will focus on the first statement, and the right side of the RP on the second statement.

The application of visual tools for gaining insight into patients' experiences should be expanded

Demonstrated added value

Our findings have repeatedly demonstrated that visual tools are able to present large amounts of information in one single snapshot. The RP in figure 1 confirms this once again, as it provides a visual summary of the present discussion section, making it easier to grasp the information. As demonstrated in chapter two to four, RPs and photovoice are able to present the story of a patient in one image (RPs) or a collection of images (photovoice), instead of providing large amounts of text. Visuals can also be used to explore the experiences of patients over the course of the disease, instead of just at one moment in time (chapter four). For this reason, visuals could be a valuable tool for health care professionals to gain insight into the experiences of a patient (in RP, an RP is laying on a table; a magnifying glass with a dotted line to enlarged RP shows what is drawn). Visuals can show a health care professional (in RP, sitting with his/her face directed to the patient and viewer) what is most important to an individual patient and make relations between elements visible at a glance (in RP, thought cloud on the left depicting podium with first, second, and third place, and thought cloud (below) that shows relation between family and sadness).

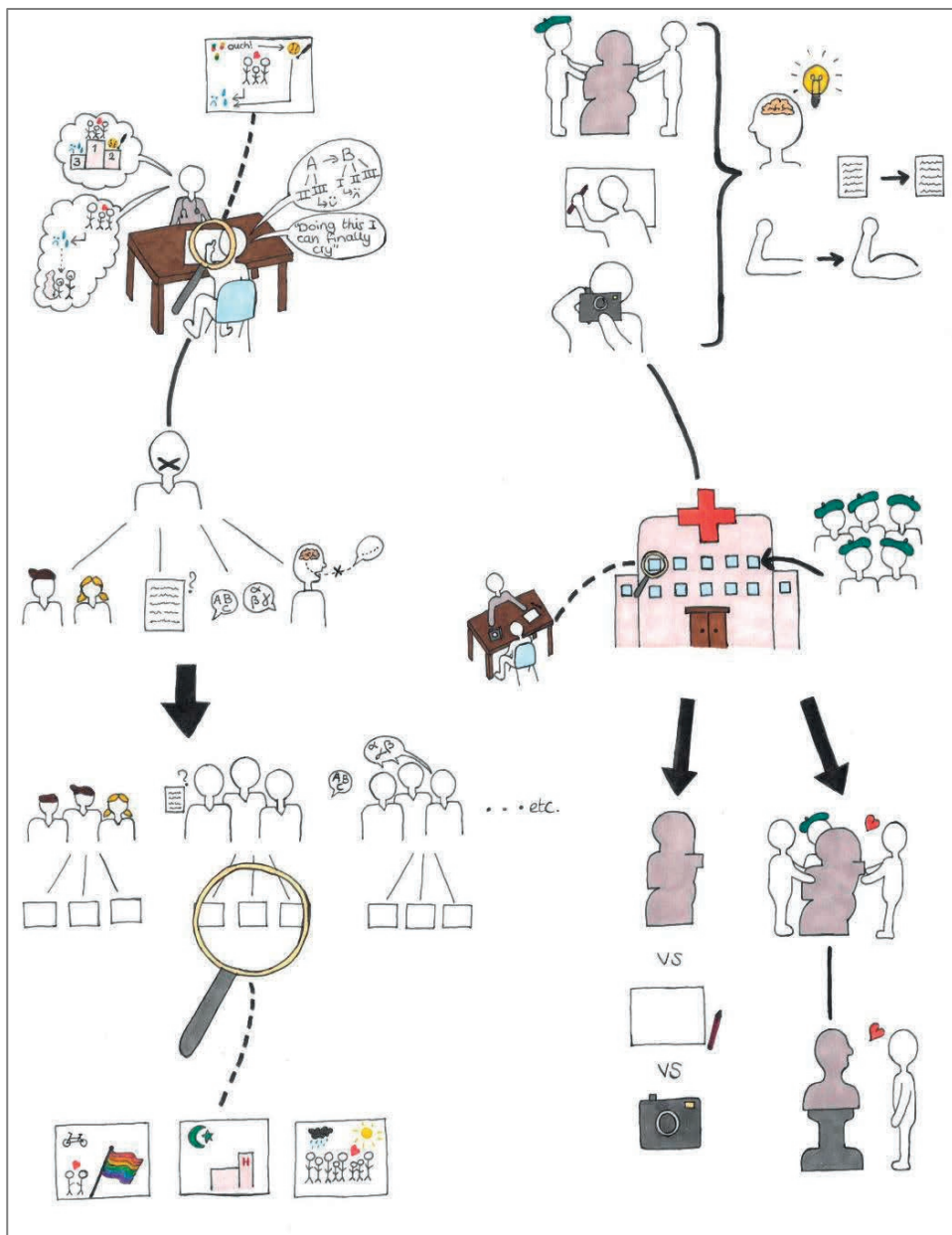
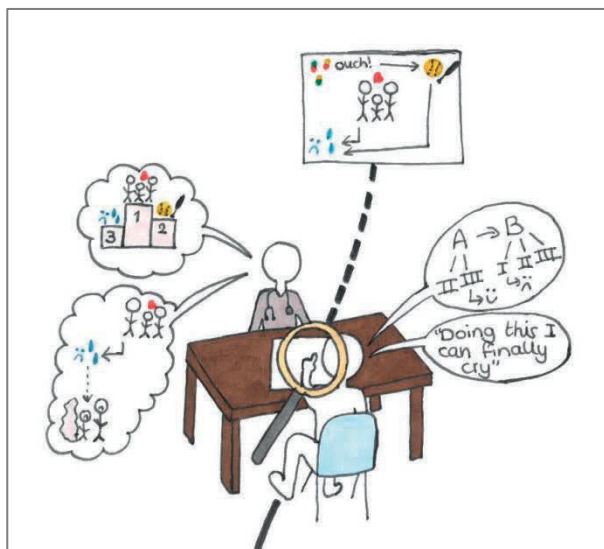


Figure 1. RP on two statements we make in the discussion section

On the left side: the application of visual tools for gaining insight into patients' experiences should be expanded; On the right side: interventions that invite patients to create something material, either an RP, photovoice, or an art-piece, should be more widely adopted.



For patients (in RP, sitting with back to viewer), sharing their story and experiences may also be facilitated by the use of visual tools. With both RPs and photovoice, patients are given the opportunity and time to individually determine what and how they want to depict their experiences in the visual. As stated by multiple patients in chapter two to four, preparing the interview like that and having the visual

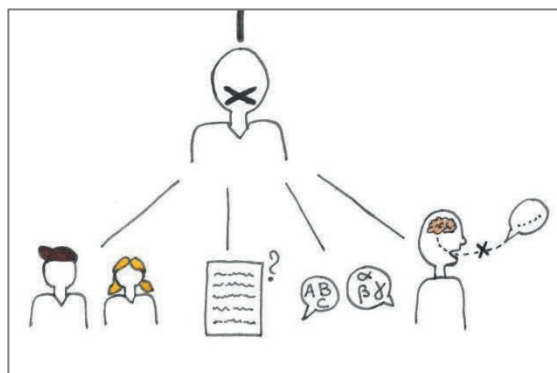
available during the interview to refer to, can help patients to tell their story in a more coherent way and reduces the chance of them forgetting to address certain topics (in RP, upper speech cloud with structure from A to B). A patient in chapter three mentioned that explaining her RP also made the conversation less superficial and allowed her to connect with the emotions more than she would have done without the RP (in RP, lower speech quote containing quote made by the patient: "Doing this I can finally cry").

In conclusion, visuals can provide health care professionals with a visual summary of the experiences of a patient and give patients the opportunity to better communicate their experiences and potential needs to the health care professional.

Potential ways to expand use

This dissertation provided evidence of the added value of visuals in a group of patients with (advanced) cancer. Our data suggests that visuals are particularly beneficial in communication about topics that are difficult to talk about. Therefore, we expect that in the same way, visuals could be helpful for patients with other conditions who struggle with issues that are hard to talk about and patients who are limited in verbal communication due to age, illiteracy, illness, or another reason.

Regarding patient groups that struggle with verbal communication (in RP, person with cross over mouth) and that could benefit from the use of visual tools, an obvious patient group is (young) children, as their command of language is limited (in RP, two children on the left). Traditional methods, such as questionnaires and

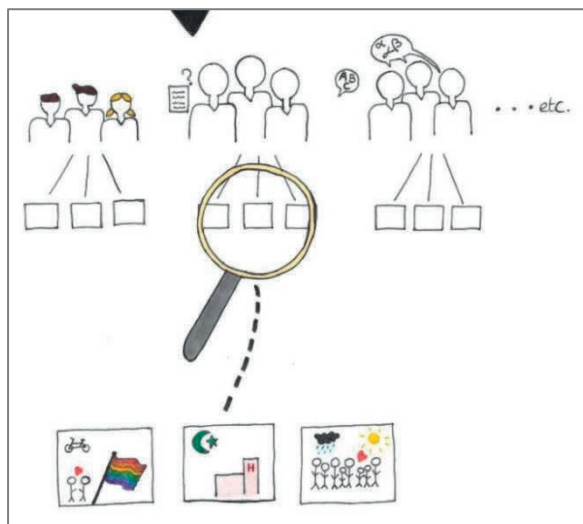


interviews, are widely available for adults, but there are fewer for children.(1) Other patient groups that could benefit from communicating with the help of visual tools are illiterate and migrant patients (in RP, illiterates are depicted by a sheet with text and a question mark and immigrants by two speech clouds with different languages in them).(2-4) Visuals have been applied to transfer medical- and health educational messages to illiterates and migrants, but not as much the other way around - illiterates and migrants sharing their experiences.(2, 5-8) Verbal communication can also be impaired as a result of a disorder (in RP, a disturbed pathway from brain to speech cloud at the far right in the RP). Examples include brain injury, developmental disabilities, Alzheimer's disease, and schizophrenia.(9) We argue that the use of visual tools as a research tool could be specifically beneficial to these patient groups.

Open research questions

To be able to expand the application of visual tools as a research tool to these other patient groups, more research needs to be conducted. Needless to say, the visual tools need to be tested within those specific patient groups. It should be noted that even within certain patients groups, there may exist significant differences that can influence the use of visual tools greatly (magnifying glass showing three different RPs as an example within the group of illiterates in RP). For instance, during the analysis of the RPs in chapters two and three, we realized that the RPs were very Dutch culture-orientated. A non-Dutch colleague made a comment that it was striking that bicycles were visible in many RPs. As most of our research team was Dutch, and bicycles are such an integral part of Dutch culture, we had not yet realized that this is culture-specific. After this awareness, we realized that Dutch culture shines through in the RPs and the photovoice. Other

examples are that the immediate family (partner and/or children) was often a central focus in the visual, not necessarily extended family as in more collectivistic cultures, that there are hardly any references to religion, and that (online) dating, sexual orientation, and sexual intercourse are openly depicted and talked about. However, what and how things are depicted, and how suitable the use of visuals

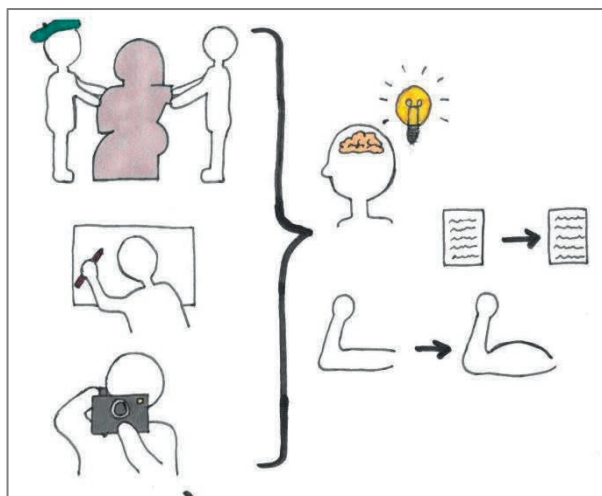


is, depends on the culture. (10, 11) For example, in some Islamic cultures it is not allowed to depict human beings and animals, making the use of visuals way less applicable. (12) Consequently, more research needs to be conducted regarding cultural differences that would need to be considered when adopting visual tools in patients with different cultural backgrounds.

Interventions that invite patients to create something material should be more widely adopted

Demonstrated added value

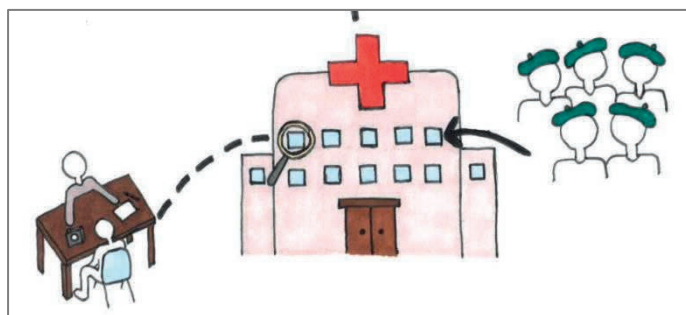
Throughout this dissertation we have demonstrated that creating something material (in RP, person sculpting clay, drawing, and making photos) can give a patient insight into his/her own experiences, stimulate meaning making, and help rewriting one's life story (in RP after accolade, respectively, brain with lightbulb next to it, an arm with a small bicep with an arrow to an arm with a grown



bicep, and a written page with an arrow to a new written page). In chapters two to four the main aim of the visual tools was for researchers to gain insight into the experiences of patients. However, making and discussing an RP also gave patients insight into their own experiences. Furthermore, the RP session already started the process of meaning making. Another example was provided by the case study in chapter seven; creating and discussing an RP made the patient more aware of what her main concern around the loss of her life was - having to leave her children behind. Subsequently, the process of co-creative art-making provided an opportunity to address this concern by creating something to leave behind for her children. The process also made the patient feel more autonomous and confident. The extent to which meaning making had taken place seemed to increase during the process of the intervention.

Potential ways to expand use

In this dissertation we applied RPs, photovoice, and art-making within a research setting. We argue that the opportunity for patients to create something material should become available in clinical practice. For this purpose, a clinically practical and feasible form would need to be developed. Of the described visual tools in this dissertation the RP is the least time-consuming tool, making it most practical for clinical practice. RP sessions could be conducted by spiritual counsellors in the hospital in less than 1,5 hours (in RP magnifying glass in left hospital window showing a spiritual counsellor in a meeting with a patient with drawing material on the right corner of the table). Photovoice would take slightly more time, but could also be relatively easily implemented when patients receive a photo camera, or could use their smartphone, and are instructed to make the photos by themselves (in RP, camera on left corner of the table of spiritual counsellor). Spiritual counsellors could instruct the patients and discuss the taken photos with them. An art-making intervention would be most difficult to implement in clinical practice, as it is a time-consuming process and it requires the involvement of

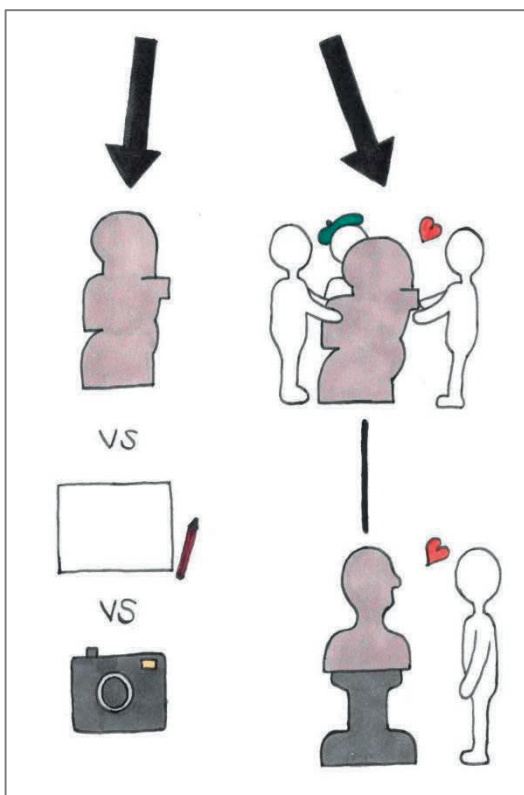


artists, but could possibly also stimulate meaning making the most. Including a team of three to five artists (with varying disciplines) in a hospital department

and allocating a private space where they can work with patients, could be a first step to making art-making interventions feasible in clinical care (in right part of RP, arrow from a group of five artists to the hospital).

Open research questions

A relevant research direction would be to investigate which intervention is most efficient (in RP from left top to left bottom: block of clay vs. drawing material vs. camera). In other words, investigating which intervention has the best time- and cost-effectiveness ratio for stimulating meaning making. Another research direction could be to examine the added value of including loved one(s) in the process of creation, not only in terms of meaning making but also in legacy building (in RP: patient working on clay sculpture together with loved one - person with heart - and below that, loved one looking at the finished sculpture after the patient has passed away). Legacy is defined as that what a person leaves behind after deceasing.(13, 14) In hospital settings 'legacy building' is often referred to as an intervention that aims to help patients and families create a legacy and to make



meaning of their situation.(14) Although our studies were not designed as legacy interventions, the case report in chapter seven shows that the process of co-creative art-making had features of legacy building. The patient invited her son to be present at the presentation of her art piece, wanting to experience it with a loved one. The art piece was a rock she placed on her land. During the day it looked like a normal rock, but as it got dark outside, the light in the rock would turn on and the word 'Me.' would be visible in the middle of the rock. Consequently, without intending to, the intervention already had a legacy building

component to it, demonstrating the potential of adopting art-making for legacy building. These findings raised the question whether an art-making intervention and an art-making legacy building intervention are equally sufficient for promoting meaning making, or whether one is more effective than the other. Research comparing the two types of art-making interventions could be conducted to answer this question.

Concluding remarks

The conclusions of this dissertation are twofold: 1) The visual tools RPs and photovoice can give a comprehensive view of the experiences of patients with cancer, at one moment in time and over time; 2) Creating something material (i.e. RPs, photovoice, art-making) can potentially stimulate meaning making of patients with cancer. For this reason, we argue that visual tools should be more widely adopted within research and clinical practice. Among other things, future research should focus on investigating cultural differences that could influence the use of visuals and whether including loved ones in the process of creation could make an art-based intervention even more beneficial to a patient.

References

1. Driessnack M. Children's drawings as facilitators of communication: a meta-analysis. *J Pediatr Nurs*. 2005;20(6):415-23.
2. Butow PN, Sze M, Dugal-Beri P, Mikhail M, Eisenbruch M, Jefford M, et al. From inside the bubble: migrants' perceptions of communication with the cancer team. *Support Care Cancer*. 2011;19(2):281-90.
3. Hyatt A, Lipson-Smith R, Schofield P, Gough K, Sze M, Aldridge L, et al. Communication challenges experienced by migrants with cancer: A comparison of migrant and English-speaking Australian-born cancer patients. *Health Expect*. 2017;20(5):886-95.
4. Cleland JA, Watson MC, Walker L, Denison A, Vanes N, Moffat M. Community pharmacists' perceptions of barriers to communication with migrants. *Int J Pharm Pract*. 2012;20(3):148-54.
5. Daghighi M, Fattori G, Ciardullo A. Use of pictorial advice to promote compliance to diet and drugs among illiterate and migrant patients. *J diabetol*. 2010;3(3):1-4.
6. Barclay PA, Bowers CA, editors. Design for the illiterate: a scoping review of tools for improving the health literacy of electronic health resources. Proceedings of the Human Factors and Ergonomics Society Annual Meeting; 2017: SAGE Publications Sage CA: Los Angeles, CA.
7. Onwuekwe C. Visual Communication Design and Public Health: towards Containing the Outbreak of Ebola Virus Disease in Nigeria. *IAAJAH*. 2018;4(1):52-65.
8. Garcia-Retamero R, Cokely ET. Communicating health risks with visual aids. *Curr Dir Psychol Sci*. 2013;22(5):392-9.
9. Berryhill ME, Peterson D, Jones K, Tanoue R. Cognitive Disorders. In: V.S. R, editor. *Encyclopedia of Human Behavior (Second Edition)*: Academic Press; 2021.
10. Gernhardt A, Rübelling H, Keller H. "This Is My Family": Differences in Children's Family Drawings Across Cultures. *J Cross Cult Psychol*. 2013;44(7):1166-83.
11. Ahmad JF. Children's drawings in different cultures: an analysis of five-year-old Jordanian children's drawings. *Int J Early Years Educ*. 2018;26(3):249-58.
12. Minowa K, editor *Restriction and Freedom: Reconsidering Figural Representation in Islam*. Art & Design Session Proceedings; 2016.
13. Breitbart W. Legacy in palliative care: Legacy that is lived. *Palliat Support Care*. 2016;14(5):453-4.
14. Boles JC, Jones MT. Legacy perceptions and interventions for adults and children receiving palliative care: A systematic review. *Palliat Med*. 2021;35(3):529-51.

CHAPTER 9

SUMMARY

SAMENVATTING

Summary “What is your story? Exploring narratives of patients with cancer using visual tools, literary texts, and art”

This dissertation focused on the application of visual methods, literature, and art to support patients with cancer. In **chapter one** we described the rationale, key concepts, objectives, and the outline of the dissertation.

Having cancer impacts people in many ways, from physical discomfort to the loss of life goals. Therefore, it can be described as an experience of contingency. Contingency means that everything could have been different in life, that what happened was not impossible, but also not necessary. When an experience of contingency arises, patients need to make meaning of their life with cancer and integrate the diagnosis and prognosis in their life story. In other words, they need to adjust their life story. To be able to support patients with cancer with such adjustments, insight into their experiences is needed first. However, talking about what it means to have cancer can be difficult. For this reason, the present dissertation had two objectives. First, we explored the potential of using visual tools to gain insight into the story of patients with cancer. Second, we examined how patients may adapt their story using literature and art-based interventions.

We adopted two visual tools to gain insight into the stories of patients with cancer: rich pictures (RPs) and photovoice. RPs are visual representations in the form of a drawing, that attempt to capture an individual’s perspective of a difficult or complex situation, including all elements that are relevant to the situation. In photovoice, participants are invited to make photographs to document meaningful aspects of their experience. We investigated two examples of interventions in which art is used to adapt the story of patients with cancer: art therapy and co-creative art-making, the latter being developed in the context of the In Search of Stories (ISOS) project. In the ISOS project, the process of co-creative art-making is preceded by discussing literary texts.

In **chapter two** we presented the findings of our first pilot study - using RPs to gain insight into the experiences of patients with advanced cancer. We asked eighteen patients (mean age of 62) to make an RP that depicted how they experienced their life with advanced cancer, followed by a semi-structured interview. A qualitative approach to data analysis, including the examination of all elements in the drawings and their interrelationships, was used to analyze the RPs. The RPs clearly showed what was most important to an individual patient and made relations

between elements visible at a glance. Identified themes included: medical aspects, the experience of loss, feelings related to loss (i.e. sadness, anger, insecurity, and hope), support from others, meaningful activities, and integration of cancer in one's life. The added value of RPs lies in the ability to represent these themes in one single snapshot. In conclusion, RPs allow for a complementary view on the experiences of patients with advanced cancer, as they show and relate different aspects of patients' lives, providing health care professionals with a visual summary of the experiences of a patient. Additionally, for patients, telling their story may be facilitated by drawing RPs.

Whether RPs could also be used to give insight into changes in experiences over the disease course, was explored in **chapter three**. We performed a prospective study with a qualitative approach that was mostly informed by the process of grounded theory. We applied purposive sampling and started data analysis alongside data collection to inform subsequent sampling and data collection. We invited patients to make an RP twice, at the start of the study, and again after two months. The patients were divided into three interview conditions, differing in instructions for making the second RP, including: 1) Making a new RP; 2) Making a new RP, but being allowed to look at RP from first RP interview; 3) Working on RP from first RP interview. All RP drawing sessions were directly followed by a semi-structured interview. Patients with all types of solid tumors, above the age of eighteen, and with a diagnosis of advanced, incurable cancer, were eligible. Eighteen patients participated and thirteen patients were able to draw an RP twice. In eight RP-sets, considerable differences between the first and second RP were noticeable. Two patterns emerged: (1) a change (decline or improvement) in physical health (five patients), and/or (2) a change in the way patients related to cancer (three patients). All three interview conditions were able to show those patterns, leading us to suggest that all three are suitable for further RP research. The conclusion of chapter three was that RPs can be used to explore the experiences of patients with advanced cancer, not only at a single point in time but also over the course of the disease.

In **chapter four** we explored the experiences of another study population - adolescents and young adults (AYAs, 18-35 years old) with cancer. We aimed to obtain a comprehensive view of AYAs' cancer experiences by using RPs and photovoice. AYAs who had any type or stage of cancer, or whose cancer was in remission, were eligible. AYAs drew RPs about their experience of living with

cancer and participated in photovoice, spending two days with a photographer to make six photos. RPs and photos were first analyzed separately, using open coding, after which the identified themes were compared. Twelve AYAs made RPs, of whom seven also participated in photovoice. Two predominant themes emerged: 1) concerns related to the future, including future relationships, education, and employment; 2) defining one's identity, as related to the cancer's negative impact on their body- and self-image. These main themes were visible in the RPs as well as in the photovoice, however, subtle differences in sub-themes were found. Subsequent research is needed to explore how these themes play a role in the lives of AYAs with cancer, and how visual tools can aid this exploration.

In **chapter five**, we provided a systematic literature review of interventional studies that investigated the effects of art therapy interventions on anxiety, depression, and quality of life in adults with cancer. The databases PubMed/MEDLINE, PsycINFO, and EMBASE were searched for articles on art therapy among adult (eighteen years and above) cancer patients, published between September 2009 up to September 2019. Search terms were established for each database specifically. A total of 731 publications was assessed for relevance by title and abstract. Full text screening of 496 remaining articles was conducted for inclusion using three criteria: interventions were guided by an artist or an art therapist, participants were actively involved in the creative process, and, anxiety, depression, and/or quality of life were one of the outcome measures. The methodological quality of the included studies was appraised using specific checklists. Seven papers met the inclusion criteria - three non-randomized intervention studies and four randomized controlled trials, which all used a quantitative measure. Four articles described significant positive effects of art therapy on anxiety, depression or quality of life in adults with cancer. The other three studies did not identify any significant results. Hence, art therapy could possibly help decrease symptoms of anxiety and depression, and improve quality of life in adult cancer patients. However, because of the heterogeneity of the interventions and limited methodological quality of the studies, further research using stringent methods is needed.

Chapter six described a pilot study to evaluate the first part of the ISOS intervention - reading and discussing exemplary narratives in the form of literary texts. These exemplary narratives, which present ways of dealing with a contingent life event, are a starting point for the conversation about a patient's

own life story. We aimed to investigate the discussion of selected exemplary narratives between spiritual counsellor and patient. Five patients with advanced cancer participated. Participation consisted of reading a selected story, after which each patient was interviewed, using a newly developed guide as a conversation template. The interviews were analyzed for their conceptual content using a template analysis. All five participants chose a story that was close to their personal experiences and all showed some form of recognition in reaction to the chosen text, which led to personal identification of experiences of contingency, such as loss of life goals, impending death, or feelings of uncertainty. Our conclusion was threefold. Firstly, the stories enabled patients to express their own experience of contingency and stimulated reflection on these experiences. Secondly, the interaction between literary texts and the story of patients enabled patients to initiate the process of meaning making and placing their experiences into their life's story. Thirdly, the reading guide demonstrated its potential as a conversation tool to activate the recognition of experiences of contingency.

In **chapter seven**, we presented a case report of a patient who participated in the ISOS intervention. We described the intervention and presented the implementation of the intervention by reporting the case. The patient was a 50-year-old woman, diagnosed with metastasized cervical cancer, for which she received palliative treatment. The ISOS intervention consisted of multiple steps, including reading a literary text and a process of co-creative art-making. The patient was also invited to create an RP at the start and at the end the intervention. The intervention helped her to talk about her experiences and express emotions, gave her new insights, and allowed her to create something to leave behind for her loved ones. We found that the ISOS intervention helped the patient to make meaning of their disease. To further investigate how the intervention could stimulate meaning making, more patients will be included in the ISOS intervention.

In the final chapter, **chapter eight**, we discussed two statements: 1) the application of visual tools for gaining insight into patients' experiences should be expanded; 2) interventions that invite patients to create something material, either an RP, photovoice, or an art-piece, should be more widely adopted. Regarding the first statement, we argued that the application of visual tools could also be relevant for other patient groups, such as illiterates, immigrants, and patients whose illness limits verbal communication. Regarding the second

statement, we describe how such interventions could be designed to make them more feasible in clinical practice. Finally, we propose directions for future research regarding both statements. A direction for future research could be to investigate cultural differences that would need to be considered when adopting visual tools in patients with different cultural backgrounds. Another research direction could be to examine if including loved ones of a patient in an art intervention could stimulate meaning making more compared to not including loved ones in the process.

Samenvatting “Wat is jouw verhaal? Verkennen van verhalen van patiënten met kanker door middel van visuele methoden, literaire teksten en kunst”

Dit proefschrift ging over het gebruik van visuele methoden, literatuur en kunst om patiënten met kanker te ondersteunen. In **hoofdstuk één** hebben wij de motivering, de belangrijkste concepten, de doelen en de opbouw van dit proefschrift beschreven.

Het hebben van kanker heeft op vele manieren invloed op het leven van een persoon, van fysieke ongemakken tot het verliezen van levensdoelen. Om deze reden wordt het vaak omschreven als een ervaring van contingentie. Contingentie betekent dat alles anders had kunnen zijn in het leven. Dat wat is gebeurd was niet onmogelijk, maar ook niet noodzakelijk. Wanneer zich een ervaring van contingentie voordoet, is het nodig dat patiënten betekenis geven aan hun leven met kanker en de diagnose en prognose integreren in hun leven. Met andere woorden, de patiënten moeten hun levensverhaal aanpassen. Om patiënten hierin te kunnen ondersteunen, is er eerst inzicht nodig in hun ervaringen. Het praten over wat het betekent om met kanker te leven kan echter als moeilijk worden ervaren. Dit proefschrift had daarom twee doelen. Ten eerste hebben wij de potentie van visuele methoden om inzicht te krijgen in het verhaal van patiënten met kanker onderzocht. In de tweede plaats hebben wij gekeken hoe patiënten hun verhaal kunnen aanpassen door middel van het gebruik van literatuur- en kunstinterventies.

Wij maakten gebruik van twee visuele methoden om inzicht te krijgen in de verhalen van patiënten met kanker: rich pictures (RP's) en photovoice. RP's zijn visuele weergaven in de vorm van een tekening die als doel hebben om het perspectief van een individu op een ingewikkelde of complexe situatie vast te leggen. Alle elementen die relevant zijn voor de situatie kunnen hierin worden meegenomen. In photovoice worden participanten uitgenodigd om betekenisvolle aspecten van hun ervaring vast te leggen door het maken van foto's. Wat betreft de vraag of kunstinterventies gebruikt kunnen worden om patiënten met kanker te helpen hun levensverhaal aan te passen, onderzochten wij twee vormen van kunstinterventies: 'art therapy' en 'co-creative art-making'. Deze laatste vorm hebben wij ontwikkeld in de context van het 'In Search of Stories' (ISOS) project. In het ISOS project wordt het proces van 'co-creative art-making' voorafgegaan door het bespreken van literaire teksten.

In **hoofdstuk twee** beschreven wij de bevindingen van de eerste pilottest, namelijk het gebruik van RP's om inzicht te krijgen in de ervaringen van patiënten met uitgezaaide kanker. Wij vroegen achttien patiënten, met een gemiddelde leeftijd van 62, om een RP te maken die laat zien hoe zij het ervaren om met uitgezaaide kanker te leven. Na het tekenen van de RP hebben wij hen in een interview gevraagd uit te leggen wat zij hadden getekend. Voor de analyse van de RP's pasten wij inhoudsanalyse toe, wat betekent dat wij onder andere hebben gekeken naar getekende elementen en de relaties tussen deze elementen. De RP's lieten zien welke thema's elke individuele patiënt momenteel het belangrijkste vond in zijn of haar leven en hoe deze thema's in verbinding staan met elkaar. De thema's die wij vonden in de RP's waren: medische aspecten en de fysieke gevolgen van de kanker, het ervaren verlies, gevoelens rondom dit verlies (met name verdriet, boosheid, onzekerheid en hoop), steun van geliefden, betekenisvolle activiteiten en het integreren van de kanker in het leven. De toegevoegde waarde van RP's ligt met name in het vermogen van RP's om alle relevante thema's voor een patiënt vast te leggen in één beeld. RP's kunnen gezondheidsprofessionals een veelomvattend beeld van de ervaringen van een patiënt met uitgezaaide kanker geven. De RP's kunnen patiënten helpen in het gesprek over hoe kanker hun leven beïnvloedt.

Of RP's ook gebruikt kunnen worden om inzicht te geven in veranderingen in de ervaringen van patiënten over de loop van de ziekteperiode, hebben wij onderzocht in **hoofdstuk drie**. Wij voerden een prospectief onderzoek uit waarbij wij gebruik maakten van een kwalitatieve benadering die gebaseerd was op facetten van 'grounded theory'. Wij voerden een doelgerichte steekproef uit en begonnen al met data-analyse tijdens dataverzameling. Op deze manier kon de data-analyse de verdere inclusie van patiënten informeren. Wij vroegen patiënten tweemaal om een RP over hun ervaring te maken, namelijk aan het begin van het onderzoek en twee maanden later. De patiënten werden onderverdeeld in drie interviewsituaties, die elk een eigen instructie hadden: 1) Maak een nieuwe RP; 2) Bekijk de eerste RP en maak daarna een nieuwe RP; 3) Werk verder met de RP van het eerste interview. Aansluitend aan een RP-sessie vond steeds een semigestructureerd interview plaats. Patiënten met een solide tumor, die ouder dan achttien jaar zijn en met een diagnose van uitgezaaide kanker, waren geschikt om mee te doen. Er deden achttien patiënten mee, waarvan er vijftien in staat waren om twee keer een RP te maken. Van de dertien RP-series (RP's van eerste en tweede interview), was er in acht series duidelijk verschil te zien tussen de

eerste en tweede RP. Wij konden twee patronen onderscheiden: een verandering (verslechtering of verbetering) in fysieke gezondheid en/of een verandering in de manier waarop de patiënten zich verhouden tot de kanker. Alle drie de interviewinstructies waren in staat om deze patronen in beeld te brengen. Dit wijst erop dat ze alle drie geschikt zouden zijn voor toekomstig onderzoek met RP's. De conclusie van hoofdstuk drie was dat RP's gebruikt kunnen worden om inzicht te krijgen in de ervaringen van patiënten met uitgezaaide kanker, zowel op één moment in het ziekteproces als over het verloop van de ziekte.

In **hoofdstuk vier** hebben wij de ervaringen in een andere onderzoeksgroep onderzocht. Deze groep bestond uit adolescenten en jongvolwassenen, AYA's (adolescents and young adults), tussen de 18 en 35 jaar. Ons doel was om een veelomvattend beeld van de ervaringen van deze groep patiënten te krijgen door gebruik te maken van RP's en photovoice. AYA's met kanker in elk stadium, of die in remissie waren, konden meedoen. De AYA's maakten een RP over hun ervaring met het leven met kanker en deden mee met de photovoice. Voor de photovoice bracht elke deelnemer twee dagen door met een fotograaf, waarmee hij/zij zes foto's maakte die de ervaring van de AYA lieten zien. Wij hebben de RP's en foto's eerst apart geanalyseerd door middel van open coding en de gevonden thema's daarna met elkaar vergeleken. Twaalf AYA's deden mee met de RP interviews. Zeven van de twaalf deden ook mee met de photovoice. De twee gevonden hoofdthema's waren: 1) zorgen over de toekomst (d.w.z. relaties, educatie en carrière) en 2) worstelingen met de eigen identiteit (d.w.z. lichaams- en zelfbeeld). Deze hoofdthema's waren zowel in de RP's als in de photovoice aanwezig. Echter, subtiele verschillen in sub-thema's konden worden gevonden. Meer onderzoek naar hoe de gevonden thema's een rol spelen in het leven van AYA's met kanker, en hoe visuele methoden hierbij kunnen helpen, is nodig.

In **hoofdstuk vijf** hebben wij de eerste stap gezet in het kijken naar hoe visuele methoden kunnen helpen bij het veranderen van het verhaal van de patiënt. Wij voerden een systematisch literatuuronderzoek uit naar de effecten van 'art therapy' op angst, depressie en de kwaliteit van leven van patiënten met kanker. Wij doorzochten de databases PubMed/MEDLINE, PsycINFO en EMBASE voor artikelen over 'art therapy' bij volwassenen (18 jaar en ouder) kankerpatiënten. Artikelen moesten tussen september 2009 en september 2019 gepubliceerd zijn. Zoektermen waren voor elke database specifiek opgesteld. In totaal hebben wij 731 publicaties beoordeeld op hun relevantie op basis van de titel en samenvatting.

Voor de overgebleven 496 artikelen hebben wij gekeken naar de gehele tekst en de artikelen beoordeeld op basis van drie inclusiecriteria: de interventie werd begeleid door een kunstenaar of kunsttherapeut, participanten waren actief betrokken in het creatieve proces en de uitkomsten van de interventie waren angst, depressie en/of kwaliteit van leven. De kwaliteit van de artikelen werd beoordeeld aan de hand van specifieke checklijsten. Zeven artikelen voldeden aan de inclusiecriteria - drie niet-gerandomiseerde interventiestudies en vier gerandomiseerde interventiestudies met controlegroep. Alle zeven studies gebruikten kwantitatieve onderzoeksmethoden. Vier van de zeven studies beschreven positieve effecten van 'art therapy' op angst, depressie en kwaliteit van leven bij volwassenen met kanker. De andere drie studies lieten geen significante resultaten zien. Samengevat kan 'art therapy' potentieel helpen met het verlagen van symptomen van angst en depressie en kan mogelijk de kwaliteit van leven verhogen van volwassenen met kanker. Omdat de interventies echter erg heterogeen waren en de methodologische kwaliteit van de studies beperkt was, is er meer onderzoek nodig dat gebruik maakt van gestandaardiseerde methoden.

Hoofdstuk zes beschreef een pilottest om het eerste onderdeel van de 'In Search of Stories' (ISOS) interventie te onderzoeken, namelijk het lezen en bespreken van voorbeeldverhalen in de vorm van literaire teksten. Deze voorbeeldverhalen bevatten contingente levensgebeurtenissen en dienden als een startpunt voor een gesprek over het eigen levensverhaal van een patiënt. Ons doel was om het gesprek over de geselecteerde verhalen tussen geestelijk verzorger en patiënt te onderzoeken. Vijf patiënten met uitgezaaide kanker deden mee met het onderzoek. Deelname hield in dat de patiënt een verhaal koos om te lezen en daarna een gesprek aanging over het verhaal met een geestelijk verzorger. Dit gesprek werd uitgevoerd met behulp van een leesgids. De gesprekken werden geanalyseerd door middel van template-analyse. Alle vijf de patiënten kozen een verhaal dat dicht bij hun persoonlijke ervaring lag en gaven een blik van erkenning als reactie op het gekozen verhaal. De verhalen hielpen de patiënten om hun eigen ervaring met contingentie te verwoorden, zoals het verliezen van levensdoelen, naderend overlijden en gevoelens van onzekerheid. Onze conclusie was drievoudig. Ten eerste hielpen de verhalen patiënten om hun eigen ervaringen met contingentie te delen en stimuleerden de verhalen de reflectie op deze ervaringen. Ten tweede gaf de interactie tussen de literaire tekst en het verhaal van de patiënt de patiënt de mogelijkheid om het proces van betekenis geven en het plaatsen van de ervaring in hun levensverhaal te beginnen. In de derde plaats liet de leesgids

potentie zien om als gesprekssjabloon de herkenning van ervaringen van contingentie te stimuleren.

In **hoofdstuk zeven** hebben wij een casus gepresenteerd van een patiënt die deelnam aan de ISOS interventie. Wij beschreven de interventie en gaven door de casus te bespreken weer hoe de implementatie van de interventie eruit zag. De patiënt was een 50-jarige vrouw, gediagnosticeerd met uitgezaaide baarmoederhalskanker, waarvoor zij een palliatieve behandeling ontving. De ISOS interventie bestond uit meerdere stappen, waaronder het lezen van een literaire tekst en een proces van 'co-creative art-making'. De patiënt is ook gevraagd om aan het begin en aan het einde van de interventie een RP te maken. De interventie hielp de patiënt om over haar ervaringen te praten en emoties te uiten, het gaf haar nieuwe inzichten en het gaf haar de kans om iets te creëren om achter te laten aan haar geliefden. Wij concludeerden dat de ISOS interventie de patiënt heeft geholpen om betekenis te geven aan de kanker. Om verder te kunnen onderzoeken hoe de interventie betekenisgeving kan stimuleren, zullen er meer patiënten geïncludeerd worden in de ISOS interventie.

Tenslotte kwamen in **hoofdstuk acht** een aantal discussiepunten aan bod. Wij bespraken twee stellingen: 1) het gebruik van visuele methoden om inzicht te krijgen in de ervaringen van patiënten met kanker zou uitgebreid moeten worden; en 2) interventies die patiënten uitnodigen om iets materieels te creëren, zoals een RP, photovoice of een kunstwerk, zouden meer toegepast kunnen worden. Met betrekking tot de eerste stelling beargumenteerden wij dat het gebruik van visuele methoden ook relevant zou kunnen zijn voor andere patiëntgroepen, zoals ongeletterden, immigranten en patiënten die door een ziekte lastig verbaal kunnen communiceren. Wat betreft de tweede stelling, schetsten wij hoe zulk type interventies opgezet kunnen worden, waarmee zij gemakkelijker toepasbaar zijn in de klinische praktijk. Ten slotte opperden wij voor beide stellingen richtingen voor toekomstig onderzoek. Onderzoeksrichtingen zouden onder andere kunnen zijn, het onderzoeken van culturele verschillen die invloed zouden kunnen hebben op het gebruik van visuele methoden en het onderzoeken of het includeren van geliefden van een patiënt bij een kunstinterventie betekenisgeving (nog) meer kan stimuleren.

APPENDICES

Acknowledgements (dankwoord)

Dit proefschrift was niet tot stand gekomen zonder de steun van een groot aantal mensen. Ik wil dan ook een aantal mensen die mee hebben gewerkt aan het ontstaan van dit proefschrift persoonlijk bedanken.

Ten eerste wil ik alle patiënten bedanken die aan de studie hebben mee gewerkt. Jullie verhalen hebben niet alleen dit onderzoek mogelijk gemaakt, maar hebben mijzelf ook enorm veel over het leven geleerd. Jullie vertrouwden mij jullie gedachten en gevoelens rondom zo'n heftige ervaring toe. Daarvoor ben ik erg dankbaar.

Daarnaast wil ik uiteraard mijn promotoren en copromotoren bedanken voor hun begeleiding en steun de afgelopen jaren:

Hanneke en Esther, jullie leerden mij kennen als een onzekere 22-jarige masterstudente die nog nul ervaring had met oncologiepatiënten. Onder jullie begeleiding ben ik de afgelopen jaren uitgegroeid tot een jonge onderzoekster die zowel op academisch vlak als op persoonlijk vlak enorm vooruit is gegaan. Hanneke, dankjewel voor alles wat jij mij geleerd hebt - van tips en tricks hoe je verder komt in de academische wereld en hoe je een onderzoeksproject coördineert, tot 'hoe hou ik een uur durende meeting met een groep mensen ook echt in een uur'. Esther, jij hebt mij zoveel geleerd over kwalitatief onderzoek, iets waar ik de rest van mijn carrière veel aan ga blijven hebben. En altijd als ik even vast zat, waren daar onze gezamenlijke sessies waarin wij samen de data bespraken en de puzzel probeerde te ontrafelen, die mij er altijd weer aan herinnerde waarom ik onderzoek doen zo leuk vind. Ik wil jullie beide ontzettend bedanken voor jullie begeleiding de afgelopen jaren.

Mirjam, jij bent wat later pas officieel mijn promotor geworden, maar van het begin af aan heb jij feedback gegeven op mijn teksten. Ik heb dit altijd als enorm waardevol beschouwd. Mijn teksten werden door jouw feedback altijd naar een hoger niveau getild. Daarnaast heeft het mij altijd gemotiveerd dat jij zo enthousiast was over het project.

Michael, jij hebt mij zoveel geleerd over theoretische concepten waar ik eerst geen weet van had. Jouw enorme kennis over de theorie achter mijn onderzoek heeft bijgedragen aan een vollediger en rijker onderzoek.

Mijn dank gaat ook uit naar mijn promotiecommissie. Ad, Yvonne, Jacqueline, Lia, Ellen en Dick, bedankt dat jullie bereid waren mijn proefschrift te lezen en te beoordelen.

Yvonne, ondanks dat wij alleen online met elkaar hebben gewerkt, voelde jij toch een beetje als mijn 'directe' collega. Wij hebben deels samen het In Search of Stories project gecoördineerd - een samenwerking die altijd soepel verliep en ik erg waardeerde. Bedankt voor het verlichten van mijn taken toen ik hiertoe niet in staat was, voor de sparsessies over het onderzoek, en ook niet onbelangrijk, voor je gezelligheid.

Nirav en Henny, dankjulliewel voor de enorm fijne samenwerking, met name omtrent het samenstellen van de verhalenbundel. Ik keek altijd enorm uit naar deze afspraken met jullie en het gaf mij altijd enorm veel energie. We waren oprecht een top team samen.

Ook nog niet genoemde coauteurs wil ik hartelijk bedanken voor hun bijdrage aan mijn artikelen.

Dank ook aan mijn fellow-PhD studenten van de medische oncologie voor de gezelligheid en de motivatie. Dankjewel Tom voor je blinde vertrouwen in mijn kwaliteiten en je altijd positieve houding, Steven voor je luisterend oor en je humor, Linde en Monique, voor de lach die jullie altijd weer op mijn gezicht wisten te toveren. Jullie, en de andere PhD studenten, hebben mijn PhD traject een mooie ervaring gemaakt.

Omdat COVID-19 mij voor een groot deel van mijn PhD dwong om thuis te werken, waren sommige vrienden en mijn huisgenoten Lisa en Caroline ook een beetje mijn collega's. Dank aan de vrienden die hun huis, om mijn PhD minder eenzaam te maken, voor mij open hebben gesteld tijdens de lockdown. Lisa, dankjewel voor je altijd nuchtere opmerkingen die mij scherp hielden en voor het verdragen van mijn uitingen van frustratie. Caroline, thank you for joining me at the home office,

making working from home less lonely, and thank you for always motivating me and believing in me.

Tenslotte, dank aan iedereen die er voor me is geweest tijdens de zwaarste periode in mijn leven. Zonder steun in mijn persoonlijk leven was deze PhD nooit tot stand gekomen. Daarom wil ik iedereen die mij heeft opgevangen, zijn huis open heeft gesteld, naar mij heeft geluisterd, mij heeft getroost, en mij heeft laten zien dat ik waardevol ben als persoon, vanuit het diepste van mijn hart bedanken. Dank aan het NPI: Soekie, Talitha, Jenni, Frans en Linda dankjulliewel voor 'keeping me sane', letterlijk. Pa, Ma, Lex, Marijke, Mira, Anandi, Inger, Samantha, Alina, Steffi, en vele anderen, zonder jullie was ik hier niet meer geweest en ik ben jullie eeuwig dankbaar voor jullie steun.

About the author (over de auteur)

Zoë Bood (geboren te Alkmaar, 1995), behaalde haar gymnasiumdiploma aan de Christelijke Scholengemeenschap Jan Arentsz in Alkmaar. Aansluitend begon zij aan de driejarige bachelor Gezondheid en Leven aan de Vrije Universiteit Amsterdam, waar zij vanaf haar tweede jaar de major Gezondheidswetenschappen volgde. Het derde jaar verdiepte zij zich in internationale gezondheidszorg, met een minor in Global health en een scriptie bij de Athena Institute VU Amsterdam. Na het behalen van haar bachelor diploma in 2016, werd Zoë toegelaten tot de tweejarige onderzoeksmaster Global Health aan de Vrije Universiteit Amsterdam. Voor haar afstudeerscriptie richtte zij zich op het gebruik van een visuele methode, rich pictures, om inzicht te krijgen in de ervaringen van patiënten met uitgezaaide kanker, bij de afdeling Medische oncologie bij het Amsterdam UMC. In september 2018 voltooide zij haar masteropleiding cum laude, waarna zij de helemaal de overstap maakte van internationale gezondheidszorg naar het onderzoeken van het gebruik van visuele methode in de zorg van patiënten. In oktober 2018 begon Zoë haar PhD bij de afdeling Medische oncologie bij het Amsterdam UMC in dit onderwerp.



PhD portfolio

PhD period: Oct 2018 - Jul 2022

1. PhD training

| Courses | Year |
|---|-------------|
| Scientific Writing in English for Publication, Amsterdam UMC, AMC | 2019 |
| Practical Biostatistics, Amsterdam UMC, AMC | 2019 |
| Project and Time Management, Amsterdam UMC, AMC | 2019 |
| Qualitative health (education) research, VU Amsterdam | 2019 |
| Summer School, VU University | |

Workshops and research meetings

| | |
|--|-------|
| Workshop: 'Illness, Image and Metaphor: Cancer in Public Discourse', Amsterdam UMC, VUmc | 2019 |
| Masterclass: Sharing Methods and Practices, Artistic Research Research Group, Amsterdam | 2019 |
| Webinar: Looking into Art/Science collaborations, KNAW, Amsterdam | 2020 |
| Research Meetings Literature and Medicine | 19-20 |
| Research Meetings Philosophy and Care | 2019 |
| Research Meetings Medical Psychology | 2019 |
| Research Meetings Rich Pictures UMCG | 19-21 |
| Research Meetings HKU | 18-21 |

Presentations

| | |
|--|------|
| New Directions in Qualitative Health Research, International conference University Medical Centre Groningen, The Netherlands Title: Using Rich Pictures to collect emotional responses (<i>oral presentation</i>) | 2018 |
| Gezondheid in Beeld: De rol van visuele communicatie, National conference University of Amsterdam, The Netherlands Title: Rich Pictures om de ervaringen van patiënten met vergevorderde kanker te verkennen (<i>oral presentation</i>) | 2018 |
| Expert meeting, Koninklijke Nederlandse Akademie van Wetenschappen, Amsterdam. Title: Uitdagingen van het gebruik van kunst binnen de oncologie (<i>oral presentation</i>) | 2019 |

Teaching

Supervising bachelor student with Medicine bachelor thesis: 19-20
 The Effects of Art Therapy on Anxiety, Depression and Quality of Life
 in Adults with Cancer: A Literature Review

2. Publications

Peer reviewed

Bood, Z.M., Weeseman, Y., Scherer-Rath, M., Dörr, H., Christophe, N., Vlug, H.J.G., Risa, D., Tromp, J.M., van Poecke, N., Sprangers, M.A.G., Helmich, E., van Laarhoven, H.W.M. "I'll be your rock" - A case report from a multimodal narrative intervention for patients with advanced cancer. *Submitted, 2022.*

Weeseman, Y., Scherer-Rath, M., Christophe, N., Dörr, H., **Bood, Z. M.**, Sprangers, M. A., ... & van Laarhoven, H. W. Co-creative art processes with patients: A theoretical framework and qualitative study among artists. *PloS one*, 2022, 17(4).

Bood, Z.M., van Liemt, F., Sprangers, M.A.G., Kobes, A., Weeseman, Y., Scherer-Rath, M., Tromp, J.M., van Laarhoven, H.W.M., Helmich, E. This is what life with cancer looks like: exploring experiences of adolescent and young adults with cancer using two visual approaches. *Supportive Care in Cancer*, 2021, 30(4):3353-3361

Bood, Z. M., Scherer-Rath, M., Sprangers, M. A., Timmermans, L., van Wolde, E., Cristancho, S. M., ... & Helmich, E. Repeated use of rich pictures to explore changes in subjective experiences over time of patients with advanced cancer. *Cancer Reports*, 2021, 5(1), e1428.

Kamp, A., **Bood, Z.**, Scherer-Rath, M., Weeseman, Y., Christophe, N., Dörr, H., ... & van Laarhoven, H.W. Narrative recognition and identification: a qualitative pilot study into reading literary texts with advanced cancer patients. *Journal of Cancer Survivorship*, 2021, 16(3):531-541.

Bosman, J. T., **Bood, Z. M.**, Scherer-Rath, M., Dörr, H., Christophe, N., Sprangers, M. A. G., & van Laarhoven, H. W. M. The effects of art therapy on anxiety, depression, and quality of life in adults with cancer: a systematic literature review. *Supportive Care in Cancer*, 2020, 29(5):2289-2298.

Bood, Z. M., Scherer-Rath, M., Sprangers, M. A., Timmermans, L., van Wolde, E., Cristancho, S. M., ... & Helmich, E. Living with advanced cancer: Rich Pictures as a means for health care providers to explore the experiences of advanced cancer patients. *Cancer medicine*, 2019, 8(11), 4957-4966.

Publications in Dutch:

Bood, Z. & van Laarhoven, H. (2021). Kunst ter ondersteuning van patiënten met kanker. In: Wetenschappelijke artikelen. Psychosociale Oncologie. Nederlandse Vereniging Psychosociale Oncologie (NVPO), (1), 18-19.

Bood, Z. & van Laarhoven, H. (2021). Rich Pictures: Tekeningen om inzicht te krijgen in de ervaringen van patiënten met uitgezaaide kanker. In: Wetenschappelijke artikelen. Psychosociale Oncologie. Nederlandse Vereniging Psychosociale Oncologie (NVPO), (4), 29.