University of Groningen

Self-management in rehabilitation practice

Jansma, Feyuna

DOI:
10.33612/diss.808975265

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2023

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):
Jansma, F. (2023). *Self-management in rehabilitation practice: On the design and implementation of a serious theory-based analogue problem-solving game called 'Think Along?'.* [Thesis fully internal (DIV), University of Groningen]. University of Groningen. https://doi.org/10.33612/diss.808975265

Copyright
Other than for strictly personal use, 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), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment.

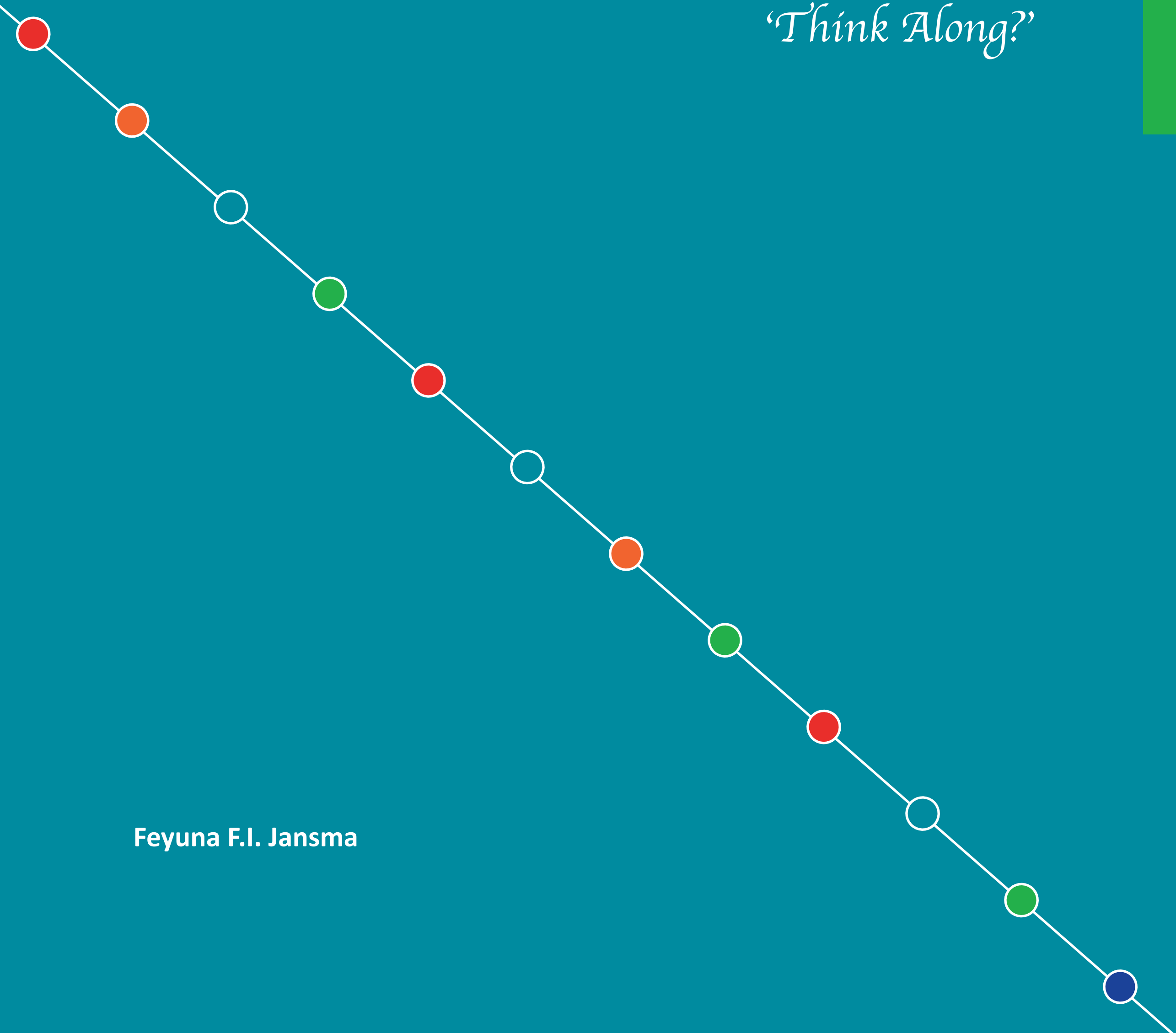
Take-down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

Download date: 01-11-2023

Self-management in rehabilitation practice

On the design and implementation of a serious theory-based analogue problem-solving game called *‘Think Along?’*



Feyuna F.I. Jansma

Self-management in rehabilitation practice

On the design and implementation of a serious theory-based analogue problem-solving game called *'Think Along?'*

Feyuna F.I. Jansma

Auteur
Feyuna F.I. Jansma

Grafisch ontwerper
Caro Helder

Illustrator
Idsander Vroom

Drukker
Gerrit van Ark

2023

rijksuniversiteit
groningen

Self-management in rehabilitation practice

On the design and implementation of a serious theory-based analogue problem-solving game called ‘Think Along?’.

Proefschrift

ter verkrijging van de graad van doctor aan de
Rijksuniversiteit Groningen
op gezag van de
rector magnificus prof. dr. ir. J.M.A. Scherpen
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op

woensdag 8 november 2023 om 14.30 uur

door

Feyuna Femke Ietsje Jansma

geboren op 18 augustus 1971
te Dordrecht

Promotor
Prof. dr. R. Sanderman

Copromotor
Dr. I. Wenzler

Beoordelingscommissie
Prof. dr. M. Hagedoorn
Prof. dr. M.W.M. Post
Prof. dr. I.S. Mayer

PART ONE

PART TWO

PREFACE

Dear reader, this is an unusual way of beginning a dissertation. It is even a rather personal beginning and yet, I believe that I should share with you, my reader, a life-altering event, as it has changed my perspective on the subject of this study. The attentive reader may have already noticed that it took some time for this dissertation to become the book that you are now reading. To assess the information in this dissertation, and certainly the contents of the second part, you will need a glimpse into my personal life and the process I went through. This process has shaped me and changed my view about various things. So, let me continue after this disclaimer.

In 2012, I was in the final year of my research (Self-management in rehabilitation practice - On the design and implementation of a serious theory-based analogue problem-solving game called 'Think Along?') and I had been given an extension of a year to finish my dissertation. I was happy to be granted this opportunity, but I was also doubtful. There was still so much work to do, and I was very tired. So, besides the relief, I also feared the hard work that lay ahead of me. I was afraid that I lacked sufficient energy and stamina. Well, dear reader, as you may have already deduced, 2012 was not the year in which I would finish my PhD, but it became the year in which my life changed forever.

On the 16th of April 2012, I was 40 years old at the time, I was admitted to the emergency room with the symptoms of a heart attack. Fortunately, it was not a heart attack. Nevertheless, there was still something seriously wrong, but the doctors did not know what was going on. I can assure you that this is a very uncomfortable position to find yourself in. Nine months later, after several visits to different doctors, all kinds of examinations and another emergency room scare, with the recurrence of the symptoms of a heart attack, I was finally diagnosed at the Radboud University Medical Centre, Nijmegen. Nijmegen specialises in heart problems specific to women. Professor A.H.E.M. Maas was able to tell me that all of this pain and misery had been caused by a disease called Coronary Microvascular Dysfunction (CMD). CMD entails a disruption in the function of the capillaries of the heart. CMD causes these small blood vessels to constrict, often involuntarily, causing a shortage of oxygen in the heart muscle. This can result in symptoms such as chest pain (angina pectoris), radiation of the pain to the right arm, back and jaw and inexplicable fatigue. The more blood vessels constrict, more symptoms occur. I was diagnosed with a chronic cardiovascular disease, which in my case is related to early preeclampsia during both of my pregnancies, which fortunately resulted in two beautiful, healthy sons.

I found myself in a bizarre position. In the blink of an eye, I became a patient with a chronic heart condition and, ironically, I had to become a self-manager myself. As a scientist in the field of self-management focusing on people with a chronic disease and behavioural changes, I was probably the most well-read and best-educated patient in the Western Hemisphere, but now, all of a sudden, I had to put all of this knowledge into practice as a patient. I stumbled upon a huge knowledge-action gap. It took me years to come to terms with the diagnosis, but even more time to reconcile with the changes that this diagnosis caused in my life.

As Kate Lorig, an expert on self-management education, once wrote, disease management is not the most difficult part of self-management; role management and emotional management are. All of the roles I had previously fulfilled in my life had changed. First of all, I had to deal with all of the changes in my personal life; in my roles as a spouse, mother, daughter and friend, and my environment had to adapt to a 'new' me. I changed from being an active woman with a very full life to being a woman who, on a good day, only had the energy to cook dinner. Another significant adaptation was the fact that I did not have the energy to do my job and after three years, during which I learned to master most of the three domains of self-management, I was approved for 100% work disability.

After all of this, it was time for me to look at my life and define some possibilities instead of the obvious limitations. It was time for me to look at what I could still do and to what I wanted to devote my limited energy to. Soon, the urge arose to finish my dissertation. So, I started writing again in 2016. I started with a few hours a month and very slowly, I was able to write a few hours a day. In your hands, dear reader, you will find the results of these efforts.

CHAPTER ONE

Introduction

Feyuna F.I. Jansma

INTRODUCTION

From the moment I started this PhD research, I had a lot of questions. Questions like: "What is self-management exactly?", "Are there any self-management elements present in the daily rehabilitation practice?", and "Can we design an intervention that contributes to the success of implementing self-management in the daily rehabilitation practice of people with a chronic disease?". However, the first question to be answered was: "Why is the rehabilitation practice so interested in the concept of self-management that the plan arose to implement self-management in the daily rehabilitation practice of people with a chronic disease?".

The answer to this last question proved to be twofold. The first part of the answer turned out not to be specific to rehabilitation, whereas the second part was. The first part of the answer to my question revolved around a wider issue affecting the entire health care system, namely the fact that in Western countries the prevalence of chronic diseases has been rising rapidly because of the ageing population. In addition to the ageing population, other contributing factors are good health care and relative prosperity, which together ensure that people with one or more chronic diseases live longer. These combined factors, leading to an increase in the number of people with one or more chronic diseases, poses major and complex challenges to our health care system. The massive pressure placed on the health care system by large numbers of patients and the associated costs are a major source of concern (McPhail, 2016; *Toekomst Verkenning 2018 Een gezond vooruitzicht, 2018*; Van Oostrom et al., 2016).

Over several decades, the concept of self-management has been viewed as one of the promising approaches for addressing the above-mentioned challenges. For it is suggested that, considering self-management aims to improve a patient's ability to manage him or herself, it might also be able to reduce the strain currently put upon the health care system. Afterall, or so it is claimed, patients who are able to manage their disease might also be less inclined to call upon the health-care system. The scientific literature thus describes the promising results of self-management programmes both within and outside the health care sector (Barker et al., 2018; Kuijpers et al., 2013; Lenzen et al., 2016; Liddy et al., 2014; Lorig et al., 2001). Therefore, at first glance, the idea that the better equipped patients are to manage their chronic disease, the less often they call on health care services appears to be a promising one.

The answer to the more general part of my twofold question was now clear, but the part focusing specifically on rehabilitation was not. This part of the answer has to do with the level of functioning of patients who undergo rehabilitation. Rehabilitation is a multifactorial treatment aimed at raising people with a disability or chronic disorder up to the highest possible level of functioning they can achieve (Amatya et al., 2019; Tesio & Nunes, 2018; Wade, 2020). When patients leave the rehabilitation centre, most of them have reached a significantly higher level of functioning. However, when the level of functioning of patients is examined at a later time in their home environment, a significant decline can be observed (Meijering et al., 2016; Pringle et al., 2008; Van Twillert et al., 2014). It should not come as a surprise that rehabilitation practitioners would like to see this situation changed. It therefore seems that the concept of self-management could also be relevant specifically within the existing field of the rehabilitation practice. The assumption, derived from the literature, of teaching skills to patients that will make them better self-managers and the premise that they will apply these skills in their home environment could prove to be a fruitful one.

On 1 September 2007, I embarked on this inquiry, beginning by researching literature to determine what was covered under the concept of self-management. The results of this endeavour are described in **chapter two** of this dissertation. At the beginning of this literature research, I assumed that a general idea about what the concept of self-management would entail must exist. I also assumed that there would be a consensus about its content among scientists working in this field. In addition, I was convinced that my own notion of self-management would fit seamlessly within that prevailing general concept. Well, I was completely wrong, and in retrospect, perhaps very naive.

The variety of self-management interventions reported in the literature was and continues to be extensive. Interventions ranged from group programmes implemented in community centres, individual coaching programmes, all the way to do-it-yourself packages that patients could follow at home (Lenferink et al., 2017; Richardson et al., 2014). In addition, at the time when I conducted this literature research, there were scholars who articulated that the idea of self-management was already naturally a part of health care processes (Kralik, 2008; Troosters et al., 2005; Turk et al., 2008), which made me wonder whether there was any need at all for the implementation of self-management within rehabilitation practice.

To answer the question as to whether self-management could be important for rehabilitation, I studied the various self-management programmes in depth. It became clear that they were not comparable in a way that would enable a systematic review to be performed. This meant that another approach was needed. While reading the texts, I was struck by the fact that the languages used in self-management and rehabilitation practice texts were very similar but seemed to have different meanings. I therefore decided to analyse and compare these 'two different' languages used in the bodies of literature relating to rehabilitation practice and self-management to gain a better understanding of the subject matter. To investigate this, we based our comparative analytical work on discourse analysis and actor network theory. So, we had to choose two pieces of work representing both practices to make an actual comparison possible. For the factual and comprehensive description of rehabilitation practice, we chose *The White Book on Physical and Rehabilitation Medicine in Europe* (Gutenbrunner et al., 2007) that had just been published at the time. The language used in *The White Book* provided us access to the content of rehabilitation practice. Alongside *The White Book* we placed the oeuvre of Kate Lorig and her colleagues, which describes the development, implementation and evaluation of the self-management approach known as *Self-Management Education* (SME). Both approaches are important for enhancing individuals' ability to live a good life despite the experience of injury or chronic disease and were therefore suitable subjects for a comparative analysis. Careful comparison of texts on SME and rehabilitation medicine revealed that, although both approaches share common ground, different logics were nevertheless at work (Jansma et al., 2010).

After several attempts to publish the literature research, described in chapter two, it was finally accepted in the *Journal of Rehabilitation Medicine*. To my surprise and pleasure, Prof. C. Gutenbrunner, one of the editors of *The White Book*, wrote a commentary on the article. This commentary has been added as an addendum to chapter two. My letter addressed to the editor in response to it is the topic of **chapter three** of this dissertation.

Having obtained a clearer view on how rehabilitation practice and self-management theoretically related to each other, I now needed to conceptualise rehabilitation practice and determine if and how self-management was implemented within that practice. Consequently, I decided that it was necessary to observe the rehabilitation process within daily practice. I was welcomed on the ward for lung diseases. The results of this endeavour are presented in **chapter four** of this dissertation.

To get an idea of what form self-management would take in such a multidisciplinary setting as rehabilitation practice, I did not attempt to predefine self-management; rather, I adopted an ethnographic approach for its investigation. This approach involved the study of guidelines, and long-term observation, typically through participant observation in which the researcher becomes immersed in the daily lives of those involved as well as one-on-one interviews conducted with members of the multidisciplinary team (Creswell, 2007). Self-management was explored not as an abstract ideal, but rather from the perspective of its embeddedness in therapeutic practices (Pols, 2004; Mol, 2002). Accordingly, the way self-management manifested itself in actions was revealed by observing rehabilitation treatments and asking therapists how they gave content and meaning to self-management in daily pulmonary rehabilitation. Months spent conducting ethnographic research led to the conclusion that self-management is intertwined with rehabilitation practice in various ways. Moreover, different and sometimes conflicting ideals regarding self-management became clear.

This time spent in the COPD ward proved fruitful, but to acquire a completer and more in-depth picture of how self-management in rehabilitation practice was portrayed, it was necessary to extend the research to another category of patients in a different ward. In addition to obtaining a more complete image, we also wanted to observe a rehabilitation practice where already an attempt had been made to implement a self-management programme. We knew from literature and experience that due to the gap between scientific research and the daily practice, it is not easy to implement a concept such as self-management. I was welcomed at the oncology department of the rehabilitation centre, where a previous attempt had been made to implement a self-management programme. Thus, oncological rehabilitation constitutes the subject of **chapter five**.

The relative survival rate of individuals diagnosed with cancer is increasing (Brenner, 2002; Karim-Kos et al., 2008; Siegel et al., 2019). Although this development is undoubtedly a very positive one, it also entails a new critical challenge for health care. A large group of cancer survivors live with the side effects of their treatments, such as massive fatigue, loss of stamina and reduced quality of life (Coolbrandt et al., 2016; Lagergren et al., 2019; Van Weert et al., 2008). In recent decades, there has been a growing focus on providing cancer survivors with treatments to address these side effects. Developments within the field of rehabilitation practice have led to targeted oncological rehabilitation programmes designed to help patients get their lives back on track during and after medical treatment. At the Centre for Rehabilitation of the Groningen University Hospital (Beatrixoord) in Haren, professionals are trying to increase the effects of these programmes through the incorporation of self-management elements. The aim of the research described in chapter five was to gain insight into the self-management programme, implemented under scientific, professional supervision in the daily practices of the oncology ward, and to improve the programme if needed. To get a clear picture, focus group interviews were held with the therapists, patients and ex-patients. Questions about the rehabilitation process that specifically focused on the topic of self-management elicited the necessary data. This information provided insight into current daily practice while also clarifying to what extent the previously implemented self-management programme had been integrated into the rehabilitation practice. Ultimately, the gathered data provided deeper insight into the topic of self-management within daily rehabilitation practice.

In the course of observations and interviews that were held to answer the central research questions, as discussed in the first five chapters of this dissertation, it became strikingly apparent that the daily practice of rehabilitation revolves around teaching and learning. Patients and professionals are entangled within a process of constant giving and taking of information, treatments and learning and teaching skills. Following the completion of this research and the rich insight that it yielded, it was time now to think about an intervention. I wanted to do something different; something new and innovative. In any case, I wanted to develop an intervention that would give health care providers an extra opportunity, in addition to existing treatments, to help their patients to acquire and sufficiently master self-management skills that they could also apply at home. My supervisor at the time alerted me to a course titled 'Serious Gaming for Professionals' offered at Delft University of Technology. I was immediately captivated. Developing a serious game for use in rehabilitation that focused on the theme of problem solving, which, according to Kate Lorig, is the most important skill in the self-management repertoire, met all of my aspirations.

Therefore, the central question addressed in **chapter six** was: How do we design a serious game which can assist patients in becoming aware of their problem-solving skills so that they can hopefully apply them in their home environment? To answer this question, deeper insight into the subject matter of learning and teaching was needed. The literature study not only revealed the many ways in which people learn but it also uncovered various reasons why the transfer of information between patients and health care providers may be hindered. In this chapter, serious gaming is introduced as a possible addition to the treatment already provided during the rehabilitation process. Serious gaming can help in the transfer of knowledge, as it offers an extra way to transfer this knowledge. Keeping this in mind we designed a serious game called 'Think Along?'. This serious game was designed as a facilitator-led game that enhances the problem-solving skills of the players. Participation in 'Think Along?' gives players the opportunity to execute, experience and learn the first two steps in the problem-solving model, which Nezu and D'Zurrila described as defining a problem and generating alternatives (Nezu, 2004). In addition, players are encouraged to support each other, with the game fostering interactions between players and health care professionals. Finally, 'Think Along?' is aimed at helping players to acquire insight into their own orientations, positive or negative, to problems.

Chapter seven presents a detailed description of the serious game. In addition to this description of 'Think Along?', it includes additional images and, for the game-enthusiast, the rules for playing 'Think Along?'. After the design phase and creating

‘Think Along?’ it was time to implement the serious game into the daily practice of rehabilitation. This process is described in **chapter eight**.

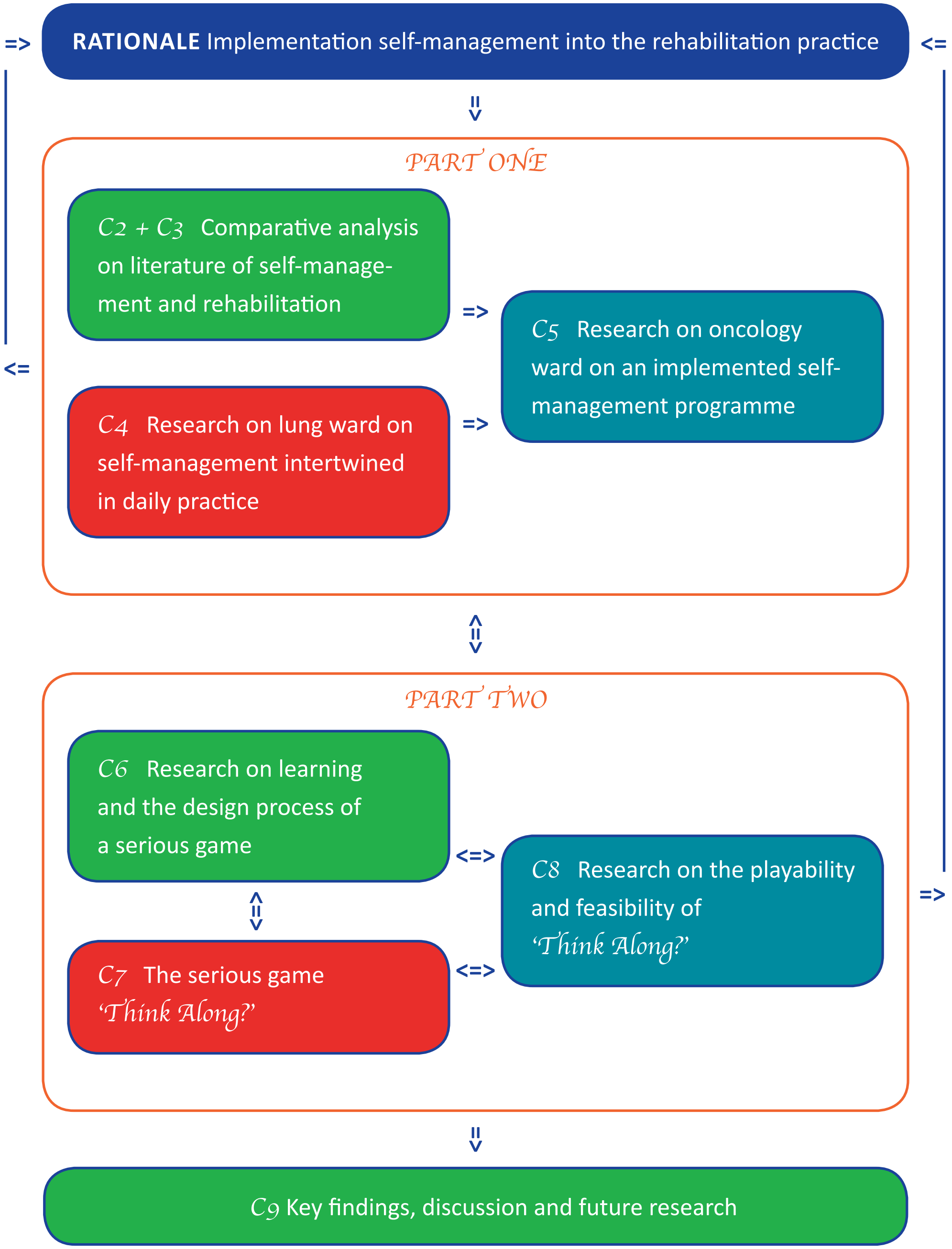
To implement ‘Think Along?’ for long-term use, five key questions were considered during the implementation process. The first three questions focused on playability. These are: (1) Is the serious game playable at all? (2) Would the serious game work with real patients? (3) Can the serious game be played by another patient population? The final two questions focused on feasibility, being: (4) Is there added value in playing the serious game with significant others? (5) Can patients with different diseases play the serious game? During the implementation process, two additional questions arose and were added. The first question emerged during an expert meeting and focused on feasibility: Can patients play the serious game focusing on their own problem? The second supplementary question, which focused on playability, was the outcome of playing the serious game with patients during daily practice: Does the serious game work better with a therapist as the facilitator? All seven questions prompted an experiment that was run in the lung and oncology wards of the rehabilitation centre. This circular, step-by-step process of implementing ‘Think Along?’ and learning from each step proved fruitful for both the implementation of the serious game into the daily practice as the development and the finetuning of ‘Think Along?’.

Finally, in **chapter nine**, the significance of the findings done in part one of this dissertation for the design process of ‘Think Along?’ will be explicitly described. Likewise, the research done during the implementation of the serious game and its current state in contemporary rehabilitation practice at Beatrixoord will be considered. Finally, opportunities for future research with ‘Think Along?’ will be discussed.

GUIDE TO EXPLORE

To make reading this dissertation easier for the reader, I have created a systematic representation of this dissertation. Figure 1 shows that this dissertation consists of two parts: a rehabilitation part and a serious gaming part. The lines and arrows in the figure indicate which chapters and parts influenced each other. How these parts influenced each other is described in detail in this dissertation.

Figure 1: A systematic overview of the chapters and parts in this dissertation in their mutual relationship



REFERENCES

Amatya, B., Khan, F., & Galea, M. (2019). Rehabilitation for people with multiple sclerosis: An overview of Cochrane Reviews. *Cochrane Database of Systematic Reviews, 2019*(1). https://doi.org/10.1002/14651858.CD012732.pub2

Barker, I., Steventon, A., Williamson, R., & Deeny, S. R. (2018). Self-management capability in patients with long-term conditions is associated with reduced healthcare utilisation across a whole health economy: Cross-sectional analysis of electronic health records. *BMJ Quality and Safety, 27*(12), 989-999. https://doi.org/10.1136/bmjqs-2017-007635

Brenner, H. (2002). Long-term survival rates of cancer patients achieved by the end of the 20th century: A period analysis. *Lancet, 360*(9340), 1131-1135. https://doi.org/10.1016/S0140-6736(02)11199-8

Coolbrandt, A., Dierckx de Casterlé, B., Wildiers, H., Aertgeerts, B., Van der Elst, E., van Achterberg, T., & Milisen, K. (2016). Dealing with chemotherapy-related symptoms at home: A qualitative study in adult patients with cancer. *European Journal of Cancer Care, 25*(1), 79-92. https://doi.org/10.1111/ecc.12303

Gutenbrunner, C., Ward, A. B., Chamberlain, M. A., Bardot, A., Barat, M., Bensoussan, L., ... Viton, J. M. (2007). White Book on Physical and Rehabilitation Medicine in Europe. *Journal of Rehabilitation Medicine, 39*(SUPPL. 45), 1-48. https://doi.org/10.2340/16501977-0028

Jansma, F.F.I., van Twillert, S., Postema, K., Sanderman, R., Lettinga, AT. (2010). Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches. *Journal of Rehabilitation Medecine 42*: 808-814.

Karim-Kos, H. E., de Vries, E., Soerjomataram, I., Lemmens, V., Siesling, S., & Coebergh, J. W. W. (2008). Recent trends of cancer in Europe: A combined approach of incidence, survival and mortality for 17 cancer sites since the 1990s. *European Journal of Cancer, 44*(10), 1345-1389. https://doi.org/10.1016/j.ejca.2007.12.015

Kralik, D. (2008). Poodle skirts, lava lamps and hot pants... is chronic condition self-management another fad?: Editor's Choice. *Journal of Advanced Nursing, 62*(1), 2. https://doi.org/10.1111/j.1365-2648.2008.04595.x

Kuijpers, W., Groen, W. G., Aaronson, N. K., & Van Harten, W. H. (2013). A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: Relevance for cancer survivors. *Journal of Medical Internet Research, 15*(2). https://doi.org/10.2196/jmir.2281

Lagergren, P., Schandl, A., Aaronson, N. K., Adami, H. O., de Lorenzo, F., Denis, L., ... Ulrich, C. (2019). Cancer survivorship: an integral part of Europe's research agenda. *Molecular Oncology, 13*(3), 624-635. https://doi.org/10.1002/1878-0261.12428

Lenferink, A., Brusse-Keizer, M., van der Valk, P., Frith, P., Zwerink, M., Monninkhof, E., Effing, T. (2017). Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease (Review). *Cochrane Database of Systematic Reviews,* (1-148). https://doi.org/10.1002/14651858.CD011682.pub2.www.cochranelibrary.com

Lenzen, S. A., van Dongen, J. J. J., Daniëls, R., van Bokhoven, M. A., van der Weijden, T., & Beurskens, A. (2016). What does it take to set goals for self-management in primary care? A qualitative study. *Family Practice, 33*(6), 698-703. https://doi.org/10.1093/fampra/cmw054

Liddy, C., Blazkho, V., & Mill, K. (2014). Challenges of self-management when living with multiple chronic conditions: Systematic review of the qualitative literature. *Canadian Family Physician, 60*(12), 1123-1133.

Lorig, K. R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., Holman, H. R. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care,* 39(11), 1217-1223. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11606875

McPhail, S. M. (2016). Multimorbidity in chronic disease: Impact on health care resources and costs. *Risk Management and Healthcare Policy, 9*, 143-156. https://doi.org/10.2147/RMHP.S97248

Meijering, L., Nanninga, C. S., & Lettinga, A. T. (2016). Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health and Place, 37*(1), 35-42. https://doi.org/10.1016/j.healthplace.2015.11.006

Nezu, A. M. (2004). Problem solving and behavior therapy revisited. *Behavior Therapy, 35*(1), 1-33. https://doi.org/10.1016/S0005-7894(04)80002-9

Pringle, J., Hendry, C., & McLafferty, E. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing, 17*(18), 2384-2397. https://doi.org/10.1111/j.1365-2702.2008.02372.x

Richardson, J., Loyola-Sanchez, A., Sinclair, S., Harris, J., Letts, L., MacIntyre, N. J., & Ginis, K. M. (2014). Self-management interventions for chronic disease: A systematic scoping review. *Clinical Rehabilitation, 28*(11), 1067-1077. https://doi.org/10.1177/0269215514532478

Siegel, R. L., Miller, K. D., & Jemal, A. (2019). Cancer statistics, 2019. CA: *A Cancer Journal for Clinicians, 69*(1), 7-34. https://doi.org/10.3322/caac.21551

Tesio, L., & Nunes, R. (2018). White book on physical and rehabilitation medicine (PRM) in Europe. Chapter 7.The clinical field of competence: PRM in practice. *European Journal of Physical and Rehabilitation Medicine, 54*(2), 230-260. https://doi.org/10.23736/S1973-9087.18.05151-1

Toekomst Verkenning 2018 Een gezond vooruitzicht. (2018). *Ministerie van Volksgezondheid Welzijn en Sport.*

Troosters, T., Casaburi, R., Gosselink, R., & Decramer, M. (2005). Pulmonary rehabilitation in chronic obstructive pulmonary disease. *American Journal of Respiratory and Critical Care Medicine, 172*(1), 19-38. https://doi.org/10.1164/rccm.200408-1109SO

Turk, D. C., Swanson, K. S., & Tunks, E. R. (2008). Psychological approaches in the treatment of chronic pain patients - When pills, scalpels, and needles are not enough. *Canadian Journal of Psychiatry, 53*(4), 213-223. https://doi.org/10.1177/070674370805300402

Van Oostrom, S. H., Gijsen, R., Stirbu, I., Korevaar, J. C., Schellevis, F. G., Picavet, H. S. J., & Hoeymans, N. (2016). Time trends in prevalence of chronic diseases and multimorbidity not only due to aging: Data from general practices and health surveys. *PLoS ONE, 11*(8), 1-14. https://doi.org/10.1371/journal.pone.0160264

Van Twillert, S., Stuive, I., Geertzen, J. H. B., Postema, K., & Lettinga, A. T. (2014). Functional performance, participation and autonomy after discharge from prosthetic rehabilitation: Bariers, facilitators and outcomes. *Journal of Rehabilitation Medicine, 46*(9), 915-923. https://doi.org/10.2340/16501977-1846

Van Weert, E., Hoekstra-Weebers, J. E. H. M., May, A. M., Korstjens, I., Ros, W. J. G., & Van der Schans, C. P. (2008). The development of an evidence-based physical self-management rehabilitation programme for cancer survivors. *Patient Education and Counseling, 71*(2), 169-190. https://doi.org/10.1016/j.pec.2007.11.027

Wade, D. T. (2020). What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical Rehabilitation, 34*(5), 571-583. https://doi.org/10.1177/0269215520905112

PART ONE

CHAPTER TWO

Physical and rehabilitation medicine and self-management education: A comparative analysis of two approaches

Journal of Rehabilitation Medicine, Vol 42, 2010

**Feyuna F. I. Jansma, MSc, Sacha van Twillert, MSc, Klaas Postema, MD, PhD,
Robbert Sanderman, PhD and Ant T. Lettinga, PhD**

ABSTRACT

Background: Discussion surrounds the publication *The White Book on Physical and Rehabilitation Medicine in Europe* as to whether the medical specialty termed 'physical and rehabilitation medicine' is in fact a reality.

Objective: To disclose previously undiscussed issues related to *The White Book on Physical and Rehabilitation Medicine in Europe* by juxtaposing its content with a body of work from a related healthcare approach termed 'self-management education'.

Methods: Inspired by discourse analysis and actor network theory, texts on both approaches were contrasted as having vocabularies of their own expressed under certain material conditions.

Issues: Four issues arose: (i) the difference in illness trajectories between a sudden transition from an able to disabled person after a disease with acute onset and the indefinite and unpredictable course of a chronic disease; (ii) the different material and social set-up of clinical and community rehabilitation settings; (iii) the influence of these different implementation environments on goal-setting; and (iv) the relative neglect of social theory in physical and rehabilitation medicine.

Conclusion: If a bio-psycho-social functional approach to patients with acute and chronic conditions is regarded as essential for the identity of physical and rehabilitation medicine, the discourse on chronic illness should be paid more explicit attention.

Key words: rehabilitation; chronic disease; qualitative research; goals; self-efficacy; problem-solving.

INTRODUCTION

The White Book on Physical and Rehabilitation Medicine (WB) describes the specialty of physical and rehabilitation medicine (PRM) in Europe (1, 2). The publication of the WB was a catalyst for lively discussion of the identity, position and foundation of PRM. Some researchers made the discussion worldwide by arguing that its content deserved to be examined across European boundaries (3, 4). Others still did not consider the specialty of PRM to be a reality, thereby questioning the increased value it should have over other medical specialties and health professionals involved in rehabilitation. They suggested that the shaping of PRM specialists' self-concept and identity in the WB would profit from interdisciplinary dialogue with other specialities (5, 6). The editors of the WB, in their turn, did not see a specialty with an identity problem, but instead the reality of a thriving PRM profession both inside and outside Europe (7). Incorrect use of language was another issue discussed. Participants in debate were called to account for not using the core concepts of PRM's underlying conceptual framework - the International Classification of Functioning, Disability and Health (ICF) - according to accepted definitions (8, 9). Interested readers were invited to engage in a discussion to determine a universally accepted conceptual description for PRM (8). A common approach to complex terminology in medicine is indeed to try to define its key words unambiguously. Conversely, that a single language suffices to describe, in a unifying way, all processes in medicine has been questioned in social studies of science and medicine (10-12). Thus, we aim to contribute to the discussion from a somewhat different angle, thereby gratefully embarking on the actual and comprehensive description of PRM in the WB. Instead of trying to define away all ambiguity in terminology, we took the language in the WB as the starting point for further analysis. The language in which the WB describes the content of PRM, was therefore juxtaposed with that of a body of work from a related healthcare approach, termed self-management education (SME). Therefore, what we say about PRM and SME is not new *per se.* What is new is the comparison of the two fields. Both approaches are significant for people's opportunities to have a good quality of life despite injury or disease. Both also focus on the consequences of injuries and diseases as were set out in ICF's predecessor, the International Classification of Impairments, Disabilities and Handicaps. At the same time the two approaches are not synonymous. By pinpointing differences in approach, we hope to enrich the discussion surrounding the PRM specialty.

METHODS

Our comparative analytical work draws on discourse analysis and actor network theory (13-16). In some types of discourse analysis and compared with self-management education all actor network theory, the meanings of words within a discourse inform each other and are part and parcel of a material network. Rather than applying predetermined definitions of terminology, language is thereby analysed as something that is expressed under certain material conditions (17). We explored PRM- and SME-texts as if these were written in different languages and compared their key words in order to determine similarities and differences in knowledge practices. In Law's words, we unravelled how PRM and SME are performed, embodied and related in different material environments (14). The WB was chosen as primary document on PRM (1, 2), as it is a thorough and up-to-date discussion document on PRM (3-9). To this we added articles on rehabilitation that addressed issues of significance to the study (18-28). From the overwhelming volume of literature on SME we restricted our comparative study to the work of Kate Lorig (29-41), because she is one of the founders of SME and has played a considerable role in the SME debate to date. Her work served as source of inspiration for many other self-management programmes, such as the Expert Patient Programme in the UK (42), although there is also some concern about the effectiveness of her programmes; for example, the Chronic Disease Self-Management Programme (43). With respect to SME, we added some literature that helps to explain its conceptual underpinnings (44-46). The PRM- and SME-texts were analysed as a set of juxtaposed grids, each of which was considered to have a history and momentum of its own (15). This resulted in several readings with a different focus. Our first reading focused on current definitions, problems and related goals in PRM- and SME-texts in order to build up an image of the target group. To further open up the content of PRM and SME, we searched in a second reading for predecessors to PRM and SME, analysing the arguments for and against these earlier practices. In a third reading text fragments about the material and social set-up of both approaches were compared in order to explore how they are embodied and related to these environments. In the final reading, the principles and practices were the object of comparative analysis as they also give each other content in a discourse. This form of triangulation provided a detailed picture of both discourses.

FIRST READING

What problems do PRM and SME wish to address? What do they endeavour to achieve? Our first reading was focused on text fragments that portrayed the target group and desired outcomes of both approaches.

Optimal physical, mental and social potential

According to the WB, the definition of rehabilitation is: "An active process by which those disabled by injury or disease achieve full recovery, or if full recovery is not possible, realize their optimal physical, mental and social potential and are integrated into their most appropriate environment." (1, p. 39). "The person's well-being and their social and vocational participation" are described as fundamental outcomes (1, p. 7). PRM's overall aim is articulated as: "To enable people with disabilities to lead the life that they would wish, given any restriction imposed on their activities by impairments resulting from illness or injury as well as from their personal context." (1, p. 7). In short, the WB construes the target group of PRM in terms of "disabling conditions" and "impairments" caused by injury or disease and regards functional recovery or optimal physical, mental and social function as desired outcome.

Greatest physical capability and pleasure from life

Lorig defined SME as "programmes that are built on patients perceived disease-related problems and assist patients with problem solving and gaining self-efficacy or the confidence to deal with these problems" (37, p. 699). The main purpose is "learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition" (29, p. 11) with, as main outcome: "the greatest possible physical capability and pleasure from life" (33, p. 1). According to Lorig: "a healthy way to live with a chronic illness is to work at overcoming the physical and emotional problems caused by the disease" (33, p. 1). Thus, Lorig speaks about the target group of SME in terms of patients with chronic illnesses, with the intention of making them as active, confident and physically capable as possible in order to live a meaningful and pleasurable life as desired outcome.

Reflection

The quotes above reveal that the respective problems the two approaches wish to address are not very different. Whether patients with "impairments and disabling conditions" differ from patients with "chronic illness" is not very clear. This is also the case with respect to desired outcomes, for example, "optimal physical, mental and social potential" or "functional recovery", compared with "the greatest physical capability and pleasure from life".

SECOND READING

New approaches arise as reactions to previous endeavours to counter particular problems. Tracing these predecessors and analysing the arguments advanced for and against them in terms of their different wordings, is another way of opening up the content of PRM and SME. Restoring disabling consequences of injuries and diseases with acute onset Physical rehabilitation arose to counter the problems faced by victims of a worldwide polio epidemic in the first half of the 20th century and the wounded of the Second World War. Injured soldiers entered rehabilitation programmes aimed at restoring the disabling consequences of the damage caused by gunfire and other acts of war (18). Following the experiences of the war and polio epidemic, PRM was increasingly used to assist traffic accident victims and people with central neurological diseases, such as stroke survivors. Thus, the target group of rehabilitation in the past comprised people with disabling conditions due to injury and disease with acute onset. Its rehabilitative programmes were directed at making the "attitudes, habits, and values compatible with the normal behaviour patterns that war had disrupted and distorted" (18, p. 271). This was achieved through a progressive and graduated programme of calisthenics (cardiovascular exercise), active recreation, competitive team-play, and vocational training. Thereby "the patient learned not only what he liked to do but what he was able to do, both in terms of ability and in terms of any handicap he had" (18, p. 271). Those with disabilities had to be approached as being "able"; that is, by highlighting their potential rather than their limitations. This would help patients not only to readjust to everyday life but also to aid the process of post-war social reconstruction. Similarly, the WB designates traditional medicine as a predecessor, arguing that it is "not directed at curing single pathologies, but instead is targeted at treating a multitude of disabling consequences of different pathologies". Its aim "is to bring benefits no matter what the underlying diagnosis is" (1, p. 23). PRM is presented in the WB as "a holistic approach to people with acute and chronic conditions" (1, p. 10). Thus, PRM has further expanded its field. The WB speaks of the bio-psycho-social approach to disability, incorporating key terms, such as impairment, activity and participation, from the ICF. But the terms in which the WB describes the outcomes of rehabilitation, "the person's well-being and their social and vocational participation", are similar to those that explain the psycho-social and economic aspects of rehabilitation in the past, as described by Rusk (1946). Although present-day PRM-texts express greater freedom of choice, "to enable people with disabilities to lead the life that they would wish", changing the behavioural patterns of people with respect to their (dis)abilities still appears to be PRM's core business. The historical text thus reveals that rehabilitation discourse has always had a bio-psycho-social line of thought. Accessing psychological possibilities in chronic illness SME arose in the second half of the 20th century as a reaction to the failure of the medical world to deal with chronic diseases (30, 39). Traditional medicine was also a predecessor of SME.

With its primary focus on curing acute diseases, medicine did not do justice to non-curable chronic diseases. Lorig emphasised that "the lack of a regular or predictable pattern in chronic illness is a major characteristic in most chronic illnesses". And that "unlike most acute diseases where full recovery is to be expected, chronic diseases usually lead to persistent loss of physical conditioning" (33, p. 3). Chronically ill people were forced to give up activities they were used to carrying out, which lead to emotional distress "such as frustration, anger and depression" (38, p. 1).

This brings us to a second predecessor of SME: biomedical-oriented medicine within the healthcare programme of chronically ill people. Novel therapeutic and surgical techniques, such as insulin regulation in diabetes or bypass operations, meant that patients survived diseases that in former days were fatal. However, medical specialists neglected the psychological impact of the long-term consequences of chronic illness. An advantage of SME is expressed in terms of its helping patients with chronic disease "to maintain wellness in their psychological foreground perspective", rather than becoming overwhelmed by the unpredictable physiological course of their chronic illness (38, p. 1). Therefore, living in a healthy way with a chronic disease means, in the long-term, that self-management aims to improve the health status of chronically ill patients by teaching them the "psychological skills" required to deal with the physiological waxing and waning aspects of their chronic disease. A third predecessor detected is the healthcare system itself, which failed to address the long-term problems of chronically ill patients. Discontinuity and the fragmentation of healthcare became widespread. In order to cope with their chronic disease, patients constantly had to attend different healthcare practices, and this was experienced as a burden for patients and their proxies as well as for society (39). The healthcare system lacked organization and could not provide chronically ill people with the benefits resulting from the efficient use of time, funds and resources. SME was therefore supposed to be directed towards encouraging them to make appropriate use of healthcare resources.

Reflection

Both PRM and SME emerged as responses to the limitations of the traditional biomedical focus on "curing acute single diseases". Both shifted their focus of attention to the shared, multifaceted problems of people with "different pathologies", for whom the disabling condition was often not "fully curable" (PRM) or had an "unpredictable course" (SME). Nevertheless, PRM had a primary focus on restoring the physical or functional limitations of diseases with an acute onset, while SME's emphasis was more on accessing the psychological possibilities available to patients with a "chronic illness".

THIRD READING

PRM and SME not only have histories of their own; they are also performed and discussed in other environments, including different buildings, providers and equipment.

Multidisciplinary teams in a clinical setting

The material environment of PRM is traditionally a hospital in which the physical structure is designed to offer patients with disabling conditions the possibility to undertake intensive physical exercise, daily activity training and vocational education, and to engage in social interaction. PRM is currently delivered in various facilities, ranging from specialized rehabilitation centres and departments in hospitals to outpatient and community settings (1, 2). The provider is a team of rehabilitation professionals with different disciplinary backgrounds. Coordination occurs through structured team communication and regular team conferences led by a physiatrist (1, 2). Functioning and participation are enhanced by offering "a coordinated source of information, advice and treatment for the person with disabilities and the family, with the team acting as provider and catalyst" (1, p. 18).

The WB states that rehabilitation should be delivered in "an organized goal-oriented, patient-centred manner" (1, p. 7). It argues that "the team works with the person with disabilities and family to set appropriate, realistic and timely treatment goals within an overall coordinated rehabilitation programme" (1, p. 18). The setting of "treatment goals" implies that they must be adjusted over time according to the progress of the patient. "Patient-centred" means that treatment goals should be owned by the patients and their proxies rather than be set on a discipline-by-discipline basis. The multi-professional approach has to enable patients "to make informed choices of treatment" (1, 2).

Nevertheless, the literature reports difficulties associated with setting treatment goals in rehabilitation. Patients were not in the habit of setting themselves explicit goals and found it difficult to learn such skills (24, 27). Moreover, treatment goals are set for a future situation that may require activities that clash with the specificities of the present situation (22). Furthermore, professionals also develop goals for an environment that differs from that found in centres where people train to accomplish set goals (25). Despite the best intentions, many treatment goals are owned by the team, according to the literature (22).

Peer leaders in a community setting

SME started at the point where there was no further recovery to be gained according to the medical world. Lorig's SME began where hospital care stopped. Patients were sent home with, at best, the message that they must learn to live with their condition. SME aimed to help with that assignment: "Rather than telling people to 'learn to live with it', let us help them learn to self-manage" (37, p. 701). Lorig's SME-programmes are group practices provided in community centres, such as public libraries and healthcare facilities (32). The provider is often a volunteer, usually a lay person who, preferably, has been diagnosed with a chronic disease. This is because successful self-managing peers show how active self-management works and fellow sufferers may want to copy that behaviour to achieve similar results (34). In SME leaders act more as facilitators than lecturers. "Rather than prescribing behaviour changes, they assist participants in making management choices and achieving success in reaching self-selected goals" (32, p. 7). In this way peer leaders act as role models.

"Goal-setting" or "action planning" is an important skill offered in SME too (35). An assumption is that patients can learn to take responsibility for the day-to-day management of their chronic disease (32). Three self-management tasks are thereby distinguished: (i) medical management, such as taking medication and exercising; (ii) role management, maintaining and adapting important life roles, such as those of mother or worker; (iii) emotional management, dealing with anger, fear, frustration and depression that come with having an uncertain future (33, 38, 45). Self-selected goals can vary from "I will make an action plan to eat sweets no more than 4 times a week" to "I want to go to my daughter's birthday who lives 500 miles from here". Goal-setting in SME is about life goals. The patient and provider negotiate a specific action plan that assists in the attainment of a life goal (33). The initiative for the plan lies with the patient. "The action must be something you want to do, that you feel you can do realistically, a step on the way to your long-term goal" (33, p. 19).

Reflection

Both approaches describe goal setting and active participation of patients as being crucial. Nevertheless, there are differences to consider. In PRM there is a "multidisciplinary team", which needs to attune the interventions of the disciplines involved in a treatment plan that has to be agreed on by the patients and their families. In SME a peer leader assists patients in making action plans to achieve self-selected goals in order to be able to deal with the unpredictable course of their chronic condition. PRM- texts speak of "treatment goals", while SME-texts are focused on "life goals". The multidisciplinary team can be considered to be experts in the disabling consequences of chronic conditions and the patients to be experts of their own lives.

FOURTH READING

The final reading focused on the principles and practices discussed in PRM and SME, for it is not only words and materials that interdefine each other; theories can also play such a role.

Motor learning principles and practices

The WB portrayed PRM specialists as teachers, especially when new concepts of plasticity and motor learning are required to support rehabilitation programmes: "Effective modern concepts of motor learning and recovery are developed with the aim of inducing skill-acquisition relevant to the patient daily life" (1, p. 18). It is argued that such an approach is beneficial, preventing "learned non-use phenomenon" and avoiding "mal-adaptation". Although "motor learning" is presented as a basic principle of PRM, the WB does not specify how rehabilitation professionals can bring such motor learning principles into practice. That is why we searched for answers in other rehabilitation texts dealing with "learned non-use" and "mal-adaptation".

"Learned non-use" is a phenomenon that is widely referred to in relation to stroke rehabilitation (28). Patients with stroke-induced hemiplegia can choose a variety of treatments to prevent "learned non-use" of their affected side, such as "constrained induced movement therapy" (20) and "task- and context-specific training" (21). "Avoidance" and "maladaptation" are frequently used terms in chronic pain rehabilitation. The consequences of long-lasting pain are thereby described in terms of "avoidance behaviour" and "maladaptive cognitions", resulting in decreased activity levels. A diverse range of cognitive behavioural treatments is delivered, all of which aim to increase patients' physical activity level despite the pain, e.g., "graded activity" (19) "exposure in vivo" (26) and "cognitive treatment of illness perceptions" (28).

Social learning principles and practices

Teaching and learning are also important ingredients of SME. However, self-management is more about "social learning", as expressed in Bandura's social cognitive theory (44). Bandura (44) asserted that most human behaviour is learned observationally by modelling. By observing others one forms an idea of how a new behaviour is performed, and on later occasions this coded behaviour serves as a guide for action (44). Inspired by Bandura's social cognitive theory, Lorig & Holman (38) considered "self-efficacy" as a hallmark of SME: "the teaching processes must be structured to include the four ingredients of efficacy enhancement: performance mastery; modelling; interpretation of symptoms; and social persuasion" (38, p. 4). Self-efficacy was defined as the individual's personal confidence beliefs about his or her capacity to undertake behaviour that may lead to desired outcomes such as improved health (40, 41). Watching people similar to oneself succeed through sustained effort may strengthen patients' belief in their own capabilities. "Problem-solving" is considered to be a core self-management skill. However, "this does not mean that people are taught solutions to their problems. Rather they are taught basic problem-solving skills" (38, p. 2). In Lorig's self-management programmes the problem-solving steps are: "problem definition, generation of possible solutions including the solicitation of suggestions from friends and healthcare professionals, solution implementation, and evaluation of results" (38, p. 2). These resemble the problem-solving skills that D'Zurilla developed for patients with depression (46).

Reflection

Both PRM- and SME-texts discuss learning principles and teaching skills. The focus of PRM is, however, on motor learning, neural plasticity and functional recovery, while the emphasis in SME is on social learning, problem-solving and self-efficacy. PRM-specialists attempt to prevent learned non- use and mal-adaptation with the help of a great variety of physical and cognitive behavioural treatments, while SME-teachers attempt to strengthen patients' self-efficacy by teaching them to apply basic problem-solving skills in managing life goals.

DISCUSSION

The aim of this paper was to contribute to the WB discussion by means of comparative analysis of rehabilitation- and self-management texts. The different contents of the texts were approached as having a vocabulary of their own, each ordering a characteristic set of problems, principles and practices expressed under certain material conditions. In doing so, we dissociated ourselves from the idea that in order to clarify the relationship between both knowledge practices we should give key terms a clear meaning in advance. Despite the restricted number of texts scrutinized, this comparative analytical style was a fruitful way of tracing similarities and differences between the two knowledge practices.

At first glance there was much common ground. Both PRM and SME were based on the premise that people with disabling or chronic conditions should be offered the opportunity to be able to function at the maximum of their potential. The idea of offering tools to develop to full potential stems from a shared discontent with the healthcare system at the time that both approaches originated. Both were responses to the limitations of traditional medicine, which focused on curing single diseases, thereby neglecting the disabling and long-lasting consequences of a multitude of conditions that were not yet fully curable. Closer examination of the language, however, made it apparent that PRM and SME use different wordings that are entwined with different material and organizational environments (see Table I). This helped us to discover the different logics at work and gave words to silenced issues in the WB.

A first issue that deserves to be attended to is the difference in illness trajectories between a sudden transition from an able to a disabled person after a disease with an acute onset (such as in stroke rehabilitation) and the indefinite and often unpredictable physiological course of a chronic disease (such as in pulmonary or diabetes rehabilitation). Although PRM is presented in the WB as a holistic approach to patients with acute and chronic conditions, it is still predominantly articulated in recovery-oriented terms (see first column Table I). It thereby silences issues that are important for people who have to deal with the waxing and waning of chronic conditions.

A second issue has to do with the different material and social set-up (see second column Table I) of a clinical and a community rehabilitation setting. Although present-day rehabilitation attempts to strengthen community-based rehabilitation, the transition from the clinical to the community setting after discharge is still experienced as difficult (47, 48). The introduction of peer leaders in clinical as well as community settings, who teach patients basic problem-solving skills, is an intervention that may assist PRM in equipping patients to cope more confidently with the transition after discharge.

A third issue concerns the importance of distinguishing treatment goals from life goals (23). Within PRM, a multi-professional team sets "treatment goals" with the patient and their proxies in order to streamline the functional recovery process. In SME, a peer leader facilitates the self-efficacy of patients in setting "life goals" to enhance a meaningful life. There is little doubt that patients need both sets of goals in order to grow to full potential. Nevertheless, treatment and life goals can be at odds with one another. To promote functional recovery, rehabilitation professionals, as experts of the disabling medical conditions, may make patients as independent as possible of others in all activities of daily living. This, however, reveals little about the extent to which patients, as experts of their lives, experience such independent living as meaningful in real life. For instance, if getting dressed in the morning exhausts a patient's energy for the day, it may be desirable for him/her to accept the assistance of caregivers in order to save energy for going to work (49).

Table 1: The differences in language used in the two discourses

Physical and rehabilitation medicine discourse	Self-management education discourse
Disabling conditions	Unpredictable course of illness
Diseases and injuries with acute onset	Chronic diseases
Impairments	Emotional distress
Physical limitations	Psychological skills
Functional recovery	Self-efficacy
Hospital setting	Community setting
Multi-disciplinary team	Lay person/successful peers
Treatment goals	Life goals
Motor learning	Social learning
Neural plasticity	Problem-solving, modelling

This brings us to a fourth issue: the lack of attention on social theory in PRM. The historical text revealed that rehabilitation discourse has always had a bio-psycho-social line of thought. Nevertheless, analysis of the WB and related texts showed that PRM is more about motor learning and cognitive behavioural principles than about social ones. Bandura's social cognitive learning theory was revealed as an issue that was not covered in the WB discussion. Why not profit from other social learning theories too? Social theory is about individuals, groups and organizations that reflect on the values, assumptions, policy that drive their actions and their efforts to change them. Thus, there is much to learn from social studies, particularly when the aim of PRM is to bring rehabilitation closer to real-life settings.

PRM and SME can thus mutually benefit, as can be illustrated by the analogy of a relay race in which professionals and patients pass the baton from one to the other. Both have to know when to grasp the baton and when to pass it on. The "responsibility" for, or "expertise" in, the condition can shift back and forth between patients and rehabilitation professionals depending on the status of a patient's disabling or chronic condition. When the condition is beyond the control of the patient - beyond self-management - rehabilitation professionals step in and provide the required expertise. The moment the disease or condition is regulated again, the patient, as self-manager, takes over. Coaching patients to carry the baton skilfully and with the necessary self-efficacy may give self-management a considered place in the rehabilitation process. Therefore, patients also need to be taught to rely on the expertise of professionals when the responsibility of carrying the baton becomes too demanding.

REFERENCES

1. Gutenbrunner C, Ward AB, Chamberlain MA, editors. White Book on Physical and Rehabilitation Medicine in Europe. J Rehabil Med 2007; 39 Suppl 45: 1-48.
2. Gutenbrunner C, Ward AB, Chamberlain MA, editors. White Book on Physical and Rehabilitation Medicine in Europe. Eura Medicophys 2006; 42: 292-332.
3. Negrini S, Ceravolo MG. The White Book on Physical and Rehabilitation Medicine in Europe: a contribution to the growth of our specialty with no boundaries. Am J Phys Med Rehabil 2008; 87: 601-606.
4. Melvin JL. Physical and rehabilitation medicine: comments related to The White Book on Physical and Rehabilitation Medicine in Europe. Eur J Phys Rehabil Med 2008; 44: 117-119.
5. Ebenbichler G, Resch KL. The dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. Am J Phys Med Rehabil 2009; 88: 165-167.
6. Resch KL, Ebenbichler G. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. Am J Phys Med Rehabil 2009; 88: 1039.
7. Gutenbrunner C, Ward AB, Chamberlain MA. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. Am J Phys Med Rehabil 2009; 88: 1037-1039.
8. Stucki G, Reinhardt JD, Gutenbrunner C, Bickenbach JE. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. Am J Phys Med Rehabil 2009;
9. Ebenbichler G, Resch KL. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. Am J Phys Med Rehabil 2009; 88: 1042-1043.
10. Berg M, Mol A. Differences in medicine, unraveling practices, techniques, and bodies. Durham and London: Duke University Press; 1998.
11. Lettinga AT, Mol A. Clinical specificity and the non-generalities of science: on innovation strategies for neurological physical therapy. Theor Med Bioeth 1999; 20: 517-535.
12. Law J, Mol A. Complexities: social studies of knowledge practices. Durham and London: Duke University Press; 2002.

13. Foucault M. The order of things: an archaeology of the human sciences. London: Tavistock Publication; 1973.
14. Law J. Organizing modernity. Oxford: Blackwell; 1994.
15. Mol A, Mesman J. Neonatal food and the politics of theory: some questions of methods. Soc Stud Sci 1996; 26: 419-444.
16. Mol A. The body multiple. Durham: Duke University Press; 2005.
17. Lettinga AT. Diversity in neurological physiotherapy: a content analysis of the Brunnstrom\Bobath controversy. Adv Physiother 2002; 4: 23-36.
18. Rusk HA, editor. Convalescence and rehabilitation. Proc Amer Philosoph Soc: 1946, p. 271-274.
19. Fordyce WE. Behavioural methods for chronic pain and illness. St Louis: Mosby; 1976.
20. Taub E, Crago JE, Uswatte G. Constraint-induced movement therapy: a new approach to treatment in physical rehabilitation. Rehabil Psychol 1998; 43: 152-170.
21. Lettinga AT, Siemonsma PC, van Veen M. Entwinement of theory and practice in physiotherapy: a comparative analysis of two approaches to hemiplegia in physiotherapy. Physiotherapy 1999; 85: 476-490.
22. Playford ED, Dawson L, Limbert V, Smith M, Ward CD, Wells R. Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting. Clin Rehabil 2000; 14: 491-496.
23. Sivaraman Nair KP. Life goals: the concept and its relevance to rehabilitation. Clin Rehabil 2003; 17: 192-202.
24. Siegert RJ, McPherson KM, Taylor WJ. Toward a cognitive- affective model of goal-setting in rehabilitation: Is self-regulation theory a key step? Disabil Rehabil 2004; 20: 1175-1183.
25. Struhkamp R. Goals in their setting: a normative analysis of goal setting in physical rehabilitation. Health Care Anal 2004; 12: 131-155.
26 Leeuw M, Houben RMA, Severeijns R, Picavet HSJ, Schouten EGW, Vlaeyen JWS. Pain-related fear in low back pain: a pro-spective study in the general population. Eur J Pain 2007: 11; 256-266.
27. Young CA, Manmathan GP, Ward JCR. Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff. J Rehabil Med 2008; 40: 190-194.
28. Siemonsma PC, Schröder CD, Dekker JHM, Lettinga AT. The benefits of theory for clinical practice: cognitive treatment for chronic low back pain patients as an illustrative example. Disabil Rehabil 2008; 30: 1309-1317.

29. Lorig KR. Self-management of chronic illness: a model for the future. Generations 1993; 17: 11-14.
30. Lorig KR. Chronic disease self-management: a model for tertiary prevention. Am Behav Sci 1996; 39: 676-678.
31. Lorig KR, Stewart AL, Ritter PL, Gonzalez VM, Laurent DD, Lynch J. Outcome measures for health education and other health care interventions. Thousand Oaks: Sage Publications; 1996.
32. Lorig KR, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter PL, et al. Evidence suggesting that a chronic disease self- management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999; 37: 5-14.
33. Lorig KR, Holman HR, Sobel DS, Laurent D, Gonzalez VM, Minor M. Living a healthy life with chronic conditions. Self-management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema and others. Boulder, CO: Bull Publishing Co.; 2000.
34. Lorig KR, Sobel DS, Ritter PL, Laurent DD, Hobbs M. Effect of a self-management program on patients with a chronic disease. Eff Clin Pract 2001; 4: 256-262.
35. Lorig KR. Partnerships between expert patients and physicians. Lancet 2002; 359: 814-815.
36. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self- management of chronic disease in primary care. JAMA 2002; 288: 2469-2474.
37. Lorig K. Self-management education. More than a nice extra. Med Care 2003; 41: 699-701.
38. Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003; 26: 1-7.
39. Holman H, Lorig K. Patient self-management: a key to effective- ness and efficiency in care of chronic disease. Public Health Rep 2004; 119: 239-243.
40. Marks R, Allegrante JP, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (Part I). Health Promot Pract 2005; 6: 37-43.
41. Marks R, Allegrante JP, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (Part II). Health Promot Pract 2005; 6: 148-156.
42. Donaldson L. Expert patients usher in a new era of opportunity for the NHS. BMJ 2003; 326: 1279-280.

43. Bury M, Newbould J, Taylor D. A rapid review of the current state of knowledge regarding lay-led self-management of chronic ill- ness. Evidence review. London: National Institute for Health and Clinical Excellence; 2005.
44. Bandura A. Self-efficacy: toward a unifying theory of behavioural change. Psychol Rev 1977; 84: 191-215.
45. Corbin J, Strauss A. Managing chronic illness at home: three lines of work. Qual Sociol 1985; 8: 224-247.
46. D'Zurilla T. Problem-solving therapy. A social competence ap- proach to clinical intervention. New York: Springer; 1986.
47. Pringle J, Hendry C, McLafferty E. A review of early discharge experiences in stroke survivors and their carers. J Clin Nurs 2008; 17: 2384-2397.
48. Cameron JI, Tsoi C, Marsella A. Optimizing stroke systems of care by enhancing transitions across care environments. Stroke 2008; 39: 2637-2643.
49. Struhkamp R, Mol A, Swierstra T. Dealing with in/dependence: doctoring in physical rehabilitation practice. Sci Technol Human Values 2009; 34: 55-76.

ADDENDUM

Commentary on
Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches

Journal of Rehabilitation Medicine, 2010 Oct; 42(9): 815-7

C. Gutenbrunner

Gutenbrunner, C. (2010). Commentary on "physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches". Journal of Rehabilitation Medicine, 42(9), 815–817. https://doi.org/10.2340/16501977-0614

COMMENTARY

Systematic comparison is a key tool in critical discourse in science. It is useful not only for statistical comparison of intervention effects and clinical outcomes of treatment and rehabilitation, but also for analysis of conceptual developments. Here qualitative methods are also appropriate (1). Jansma et al. (2) use such an approach by applying a linguistic method to compare the concept of Physical and Rehabilitation Medicine (PRM), as described in The White Book on Physical and Rehabilitation Medicine in Europe (3, 4), with the concept of Self-Management Education (SME), as described by Lorig (5, 6) and Lorig et al. (7). This approach may contribute substantially to the philosophy and concepts of PRM and to the development of professional practice in the field.

Although the approach chosen by Jansma et al. (2) is useful for the debate, it has some limitations. Firstly, a linguistic method cannot replace discussion of the contents that may need further explanation. Additionally, the linguistic method may highlight deficits in the description that do not necessarily substantially reflect the contents. Secondly, the subjects might differ substantially, so that the comparison does not tackle the core of the subjects. Both of these limitations are evident in the paper:

- Starting with the second limitation, there are substantial differences between PRM and SME. PRM is a concept based on a medical approach that includes prevention, therapy and rehabilitation. This approach includes the health condition as a key issue influencing functioning (8, 9). Within this context the definition of functioning refers to the model of the International Classification of Functioning, Disability and Health (ICF) that also aims at the health condition (10, see also 11, 12). SME does not include the medical approach of treating the underlying health condition (5). It focuses only on persons with chronic health conditions and is restricted to tertiary prevention (6). The concept is based on the principles of self-management and looks at the health system as kind of supply that has to be used in an efficient way. In contrast, PRM is part of the health system, of course using self-management approaches too. PRM is disease-related, whereas SME is not necessarily disease-related. PRM is a comprehensive concept of a medical specialty ("holistic approach"), whereas SME is "just" a self-management concept.
- Due to methods of linguistic analysis, a number of important contents are overlooked in the article. Although this is connected with some weaknesses of *The White Book*, some misinterpretations are obvious. First is that PRM is focused on disease. This may be true to some respect for the acute phase (13), but it does not fit for post-acute and long-term rehabilitation (Fig. 1). Here the functional approach is of special empha-

sis and quality of life is a main goal of intervention. The second is that the concepts of neuroplasticity and adaptation refer only to motor control. By contrast, recent results in neuroplasticity show that functional and even structural changes in the nervous system are strongly related to behaviour and behavioural learning is part of it (14 and others). This means that the reference to these concepts used by PRM interventions aiming at behaviour self-management and problem-solving capacities are, of course, included [1].

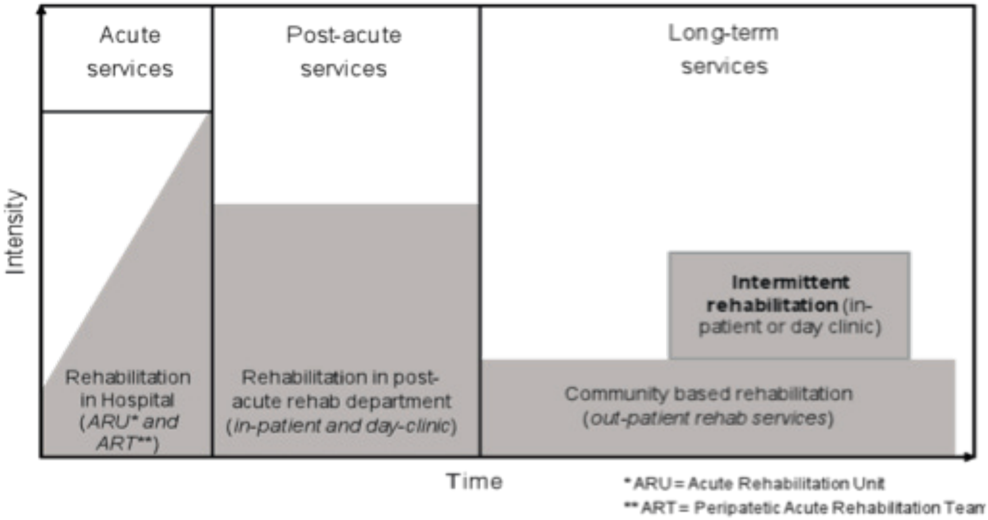
Thus, self-management concepts are part of PRM and are increasingly discussed in modern rehabilitation medicine (e.g., 15-17).

Despite these limitations Jansma et al.'s analysis (2) is important for future discussions of PRM concepts. Although PRM claims to use a patient-centred approach (3, 4, 8, 9) and includes enabling of the person with chronic illness and disability including self-management skills, PRM practice still tends to use a traditional medical-driven approach. This originates, on the one hand, in the traditional education of medical doctors. On the other hand, this is induced by the patient's expectations towards a doctor that his or her pathology will be treated. As it enables the persons with disability and chronic health conditions to independent living (3, 4). and self-management (7), the medical approach needs to be transferred into a shared decision-making process with the person in order that he or she can make his or her own decisions within his or her social environment. Thus, the terms "patient-centred" and "shared decision-making" have to be defined much more clearly in the descriptions of PRM strategies, and the consequences for daily PRM practice has to be elaborated in more detail. Approaches can already be found in the conceptual descriptions of the rehabilitation strategy and PRM that have recently been adopted by the European Union of Medical Specialists (UEMS)-PRM-Section and the European Society of Physical and Rehabilitation Medicine (ESPRM) (18, 19).

---

[1] *Some other (minor) misinterpretations from Jansma et all. 's table (2) are that: Body functions according to the ICF model also include mental functions and psychological skills (10). PRM also includes rehabilitation services in community settings (8). Treatment and rehabilitation goals of PRM include improvements in quality of life (3,4).Social learning is also part of PRM (9).*

Figure 1: Sectors of Physical and Rehabilitation Medicine (PRM) practice (8). Published with permission from Elsevier B.V.



Here the partnership between the person with disability and the service provider is part of the strategy, and the patient-centred problem-solving process is clearly addressed. In addition, the team-approach of PRM also includes the patient and his or her own wishes. (20). As mentioned above, the methods of reaching these goals need to be described in more detail. In addition, training in PRM, both at undergraduate and postgraduate level, should include techniques of shared decision-making and empowerment. Some approaches have already been developed in this respect, but more emphasis on this aspect is required.

Overall, the comparative analysis of PRM and SME makes a useful contribution to the debate on present and future concepts of PRM. Although some differences in the principles between

PRM and SME have to be taken into account, self-management should be an integrated part of PRM. Thus, in contrast to Jansma et al.’s conclusion (2), for PRM this means that self-management training should not start after medical care, but needs to be integrated into all aspects of rehabilitation and all processes of prevention.

Table 1: International Classification of Functioning, Disability and Health (ICF)-based conceptual description of Physical and Rehabilitation Medicine (PRM) (ICF terms are marked in bold text, rows are numbered in grey) (18).

1 Physical and rehabilitation Medicine is the medical specialty that, based on WHO’s integrative model of **functioning, disability and health** and rehabilitation as its core health strategy,

2 Diagnoses health conditions taking into account the International Classification of Diseases,

3 Assesses **functioning** in relation to **health conditions, personal and environmental factors**,

4 Performs, applies and/or prescribes biomedical and technological interventions to treat health conditions suitable to stabilize, improve or restore **impaired body functions and structures** prevent **impairments**, medical complications and risks compensate for the absence or loss of **body functions and structures**,

5 Leads and coordinates intervention programs to optimize **activity and participation** in a patient-centered problem-solving process in partnership between person and provider and in appreciation of the person’s perception of his or her position in life performing, applying and integrating biomedical and technological interventions, psychological and behavioural; educational and counselling, occupational and vocational, social and supportive, and physical environmental interventions,

6 Provides advice to patients and their immediate **environment**, service providers and payers over the course of a **health condition**, for all age groups along and across the continuum of care, including hospitals, rehabilitation facilities and the community and across sectors including health, education, employment and social affairs,

7 Provides education to patients and relatives to promote functioning and health,

8 Manages rehabilitation, health and multi-sector services,

9 Informs and advises the public and decision makers about suitable policies and programs in the health sector and across the other sectors that provide a **facilitative** larger **physical and social environment**; ensure access to rehabilitation services as a human right; and empower PRM specialists to provide timely and effective care,

10 With the goal to enable persons with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning in interaction with the environment and in partnership between person and provider.

REFERENCES

1. Schwarze M, Gutenbrunner C, Meyer T. Qualitative methods. In: Franchignoni F, editor. Research methods in physical and rehabilitation medicine. Advances in rehabilitation. Vol 19. Pavia: Maugeri Foundation Books, 2010.
2. Jansma FFI, van Twilert S, Postema K, Sanderman R, Lettinga AT. Physical and rehabilitation medicine and self-management education: a comparative analysis of two acquaintances. J Rehabil Med 2010; 42: 808-814.
3. Gutenbrunner C, Ward AB, Chamberlain MA (editors). White Book on Physical and Rehabilitation Medicine in Europe. J Rehabil Med 2007; 45, Suppl 1: 1-48.
4. Gutenbrunner C, Ward AB, Chamberlain MA (editors). White Book on Physical and Rehabilitation Medicine in Europe. Eura Medicophys 2006: 42: 287-332;
5. Lorig KR. Self-management of chronic illness: a model for the future. Generations 1993; 17: 11-14.
6. Lorig KR. Chronic disease self-management: a model of tertiary prevention. Amer Behav Sci 1996; 39: 676-678.
7. Lorig KR, Holman HR. Self-Management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003 26: 1-7.
8. Gutenbrunner C, Neumann V, Lemoine F, Delarque A. Describing and developing the field of competence in physical and rehabilitation medicine (PRM) in Europe - preface to a series of papers published by the Professional Practice Committee of the PRM section of the Union of European Medical Specialists (UEMS). Ann Phys Med Rehab 2010 (in press).
9. Gutenbrunner C. Physical and rehabilitation medicine - a changing specialty. Revista da Sociedade Portugesa de Medicina Física e de Reabilitação 2010; 19: 5-7.
10. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.
11. Stucki G, Melvin J. the International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of physical and rehabilitation medicine. J Rehabil Med 2007; 39: 286-292.
12. Stucki G, Cieza A, Melvin J. the International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of the rehabilitation strategy. J Rehabil Med 2007; 39: 279-285.
13. Ward AB, Gutenbrunner C, Damjan H, Giustini A, Delarque A. European Union of Medical Specialists (UEMS) section of Physical & Rehabilitation Medicine: a position paper on physical and rehabilitation medicine in acute settings. J Rehabil Med 2010, 42: 417-424.

14. Kolb B, Whishaw IQ. Brain plasticity and behavior. Ann rev Psychol 1998; 49: 43-64.
15. Faller H. Shared decision making: Ein Ansatz zur Stärkung der Partizipation des Patienten in der Rehabilitation. Rehabilitation 2003; 42: 129-135.
16. Körner M. Ein Modell der partizipativen Entscheidungsfindung in der medizinischen Rehabilitation. Rehabilitation 2009; 48: 160-165.
17. Simon D, Loh A, Härter M. Grundlagen der partizipativen Entscheidungsfindung und Beispiele der Anwendung in der rehabilitation. Rehabilitation 2008; 47: 84-89.
18. Meyer T, Gutenbrunner C, Bickenbach J, Cieza A, Melvin J, Reinhardt JD, et al. towards a shared conceptual description of rehabilitation as a health strategy. Approved by the General assembly of the Physical and Rehabilitation Medicine Section of the European Union of Medical Specialists and the European Society of Physical and Rehabilitation Medicine, Marseille, March 2010. Available from: www.euro-prm.org.
19. Gutenbrunner C, Meyer T, Stucki G. A conceptual description of physical and rehabilitation medicine - towards an internationally accepted conceptual description of physical and rehabilitation medicine. Approved by the General assembly of the Physical and rehabilitation Medicine Section of the European Union of Medical Specialists and the European Society of Physical and Rehabilitation Medicine, Marseille, March 2010. Available from: www.euro-prm.org.
20. Neumann V, Gutenbrunner C, Fialka-Moser V, Christodoulou n, Varela E, Giustini A, et al. Inter-disciplinary team working in physical and rehabilitation medicine. J Rehab Med 2010; 42: 4-8.
21. Gutenbrunner C, Schiller J, Schwarze M, Fischer V, Paulmann V, Haller H, et al. The Hannover Model for the Implementation of Physical and rehabilitation Medicine into Undergraduate Medical Training.

CHAPTER THREE

Letter to the editor

On making a difference: The case of self-management education and physical and rehabilitation medicine

Journal of Rehabilitation Medicine, 2011, 43, (5): 465-6

Feyuna F.I. Jansma and Ant T. Lettinga

LETTER TO THE EDITOR

We very much appreciate the comments of Gutenbrunner, one of the editors of the *White Book of Physical Rehabilitation Medicine*, on our article "Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches" (1-3). It gives us the opportunity to deliberate more intensively on the purpose, nature and results of our comparative analysis of physical and rehabilitation medicine (PRM) and self-management education (SME) (4). We are aware that the theoretical background that our analytical work draws upon (discourse analysis and actor network theory) is little-known in rehabilitation research, although there are inspiring examples of such analysis in the field of PRM (5-7). Nevertheless, it seems to us that Gutenbrunner does not completely understand the essence of our comparative work. With this letter to the editor, we hope to convince the reader that it is through grasping differences and similarities between diverging approaches that any dialogue (or other type of interaction) between them may be productive.

Firstly, it must be explained that our analytical approach is not merely a linguistic method. Instead, it must be considered as a content analysis that studies "reality" as it is formed within *material* semiotic networks. We approach science as a set of complex practices, of which the appropriateness of its terminology in any specific site is not to be taken for granted, but rather is open for investigation (8, 9). That is why the contents of PRM and SME was not explored in predetermined definitions of (International Classification of Functioning, Disability and Health (ICF)) terminology, but instead as a set of linguistic and material entities that mutually inform each other. This sociologically informed way of what science and medicine are and do moves away from traditional conceptions of science in which certain analytical privileges are granted, such as unity of language and research method.

Thus, the aim of our article was not to *replace* the discussion of PRM contents, as Gutenbrunner seems to suggest, but to *add* to that discussion from a very different scientific angle. By detailing differences and similarities in language, predecessors, material and social set up, we were able to examine issues that otherwise would have remained hidden. We agree with Gutenbrunner that PRM is a conglomerate of many principles and practices, and SME is, at most, a conglomerate of a few. However, this "inequality" did not hinder us in disclosing previously neglected issues related to the content of the *White Book on Physical and Rehabilitation Medicine in Europe*, such as social (learning) theory. It is true that current models used by rehabilitation, such as the ICF, do address the importance of involvement in a life situation. Nevertheless, they do not adequately address issues such as the role of environment, the nature of the community, the importance of meaning and choice when thinking about life situations, and changes in abilities across the life course in the chronic stage (10).

PRM is “interested” in SME for reasons such as; making the transition to the home-environment less difficult and striving for long-term independency of patients (11). However, our point is that discussions on the relationship between PRM and SME are too general; they lack specificity. Take Gutenbrunner, who articulates the benefits of SME in terms of cost- efficiency, as do many other policymakers and researchers. Based on a recent, as yet unpublished, study, we can say that in rehabilitation practice, next to cost-efficiency ideals, many self-management ideals prevail, such as patient’s autonomy and dealing with the boundaries accompanying a chronic disease. Thus, by articulating differences (in this study between PRM and SME), a more detailed picture emerges, which can help to improve rehabilitation practice as well as research (12).

To examine another example highlighted by Gutenbrunner, it goes without saying that neural plasticity research has shown that functional and even structural changes in the nervous system are strongly related to behaviour, and that behavioural learning is part of it. This, however, does not automatically imply that behavioural self-management and problem-solving capacities are of course included in PRM, as Gutenbrunner suggests in his commentary. It is, for instance, important to differentiate between problem-solving capacities focused on motor learning and those focused on social learning. An improvement study on prosthetic rehabilitation revealed that in task- and context-specific training patient’s problem-solving capacities are deployed to teach them the necessary *motor* skills, whereas in self-management education such capacities are offered to provide patients with the *psychological* skills to manage the complexities of life with a chronic illness (13). Thus, by articulating differences and exploring how co-existing approaches interfere with one another, blind spots and specificities come to the surface that need to be addressed in PRM. The detail that Gutenbrunner qualifies these blind spots in note 1 as (minor) misinterpretations of the authors demonstrates the drawback of a too-general stated view on PRM.

Finally, we cannot agree more with Gutenbrunner that SME needs to be integrated into all aspects of rehabilitation and prevention, with this remark that such an education needs specification in the different processes. Our metaphor of the relay race illustrates this statement clearly. We make a strong plea that patients should learn how to self-manage during rehabilitation, in the areas of physical as well as social and psychological functioning and obtain the necessary skills to make the transition to their home environment as smooth as possible. However, the process should not stop there, but should have a slightly different content. If functional recovery is no longer the primary focus, then the focus must shift to patients having to deal with the impact of their changed body and the social environment on personal factors such as defining their identity in relation to the waxing and waning of their chronic condition. If the illness or disability develops beyond the boundaries of control of individuals and their self-management capabilities across the course of their lives, they should have the opportunity to hand the baton back for a while to PRM or other professionals. In other words, a more productive interaction between rehabilitation and chronic disease management models is necessary.

REFERENCES

1. Gutenbrunner C. Commentary on "Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches". J Rehabil Med 2010; 42: 815-817.
2. Gutenbrunner C, Ward AB, Chamberlain MA, editors. White Book on Physical and Rehabilitation Medicine in Europe. J Rehabil Med 2007; 39 Suppl 45: 1-48.
3. Gutenbrunner C, Ward AB, Chamberlain MA, editors. White Book on Physical and Rehabilitation Medicine in Europe. Eura Medicophys 2006; 42: 292-332.
4. Jansma FFI, van Twillert S, Postema K, Sanderman R, Lettinga AT. Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches. J Rehabil Med 2010; 42: 808-814.
5. Struhkamp R, Mol A, Swierstra T. Dealing with in/dependence: doctoring in physical rehabilitation practice. Sci Technol Human Values 2009; 34: 55-76.
6. Winance M. Trying out the wheelchair: the mutual shaping of people and devices through adjustment. Sci Technol Human Values 2006; 31: 52-72.
7. Moser I. On becoming disabled and articulating the alternatives. Cult Stud 2005; 6: 667-700.
8. Mol A, Mesman J. Neonatal food and the politics of theory: some questions of methods. Soc Stud Sci 1996; 26: 419-444.
9. Lettinga A, Mol A. Clinical specificity and the non-generalities of science: on innovations strategies for neurological physical therapy. Theor Med Bioeth 1999; 20: 517-535.
10. Cott C, Wiles R, Devitt R. Continuity, transition and participation: preparing patients for life in the community post-stroke. Disabil Rehabil 2007; 29: 1566-1574.
11. Cameron JI, Tsoi C, Marsella A. Optimizing stroke systems of care by enhancing transitions across care environments. Stroke 2008; 39: 2637-2643.
12. Lettinga A, Siemonsma P, van Veen M. Entwinement of theory and practice in physiotherapy: a comparative analysis of two approaches to hemiplegia in physiotherapy. Physiotherapy 1999; 85: 476-490.
13. Van Twillert S, Postema K, Geertzen JHB, Hemminga T, Lettinga AT. Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation. Clin Rehabil 2009; 23: 938-947. Submitted December 20, 2010; accepted February 16, 2011.

CHAPTER FOUR

Self-management ideals in action in a local pulmonary rehabilitation setting: An ethnographic study

Feyuna F.I. Jansma, Klaas Postema, Sacha van Twillert,
Robbert Sanderman and Ant T. Lettinga

ABSTRACT

Aim: The aim of this study is to investigate how self-management is embedded in the practicalities of pulmonary rehabilitation practice.

Method: Ethnographic research was used to collect the data. Guidelines were analysed, interviews with therapists were held and their daily practice was observed, the material was analysed with Atlas.ti.

Results: Three ideals of self-management-in-action surfaced:

1. ‘Adhering to a healthy lifestyle’, most dominantly prevailing in guidelines and related to intended outcomes of less healthcare use and cost-reduction;
2. ‘Dealing with the unpredictability of chronic illness’, was most pronounced in the way self-management was practiced by therapists in the gym and sports hall and related to self-efficacy and disease control;
3. ‘Having freedom of choice’, related to the patient’s preferences. Striving for just one ideal - such as adhering to a healthy lifestyle - may limit the achievement of other self-management-ideals such as dealing with the unpredictability of chronic disease and having freedom of choice, which makes implementing self-management and its outcome measurement complex.

Recommendation: Reflection on the formulated ideals and the additional tensions when it comes to the implementation of self-management in rehabilitation practice can help therapists deal with these tensions more creatively and can activate therapists to make improvements.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) represents a health problem associated with a large disease burden (Heyworth et al., 2009; Quaderi & Hurst, 2018; Vos et al., 2012). Symptoms such as dyspnoea and muscle fatigue lead to exercise intolerance, which, together with behavioural issues, trigger physical in-activity, a key feature of COPD (Russell et al., 2018; Troosters, 2013). In the Netherlands, prevalence of COPD is increasing as is the demand on healthcare and related costs (Hoeymans et al., 2010). In this context, there is growing interest in self-management education for people with COPD. After all, scientific literature reports a better health status and at the same time a lower use of healthcare services in this group of patients, which in turn can contribute to a reduction in healthcare costs. (Bentsen et al., 2012; Bourbeau, 2009; Bourbeau et al., 2004; Lenferink et al., 2017; Monninkhof et al., 2003; Zwerink et al., 2014). Self-management for people with COPD is defined as educational programmes that include the necessary skills to carry out medical regimes, guide changes in health behaviour and provide emotional support. All these elements lead to outcomes such as disease control, improved wellbeing, and the ability of patients to lead functional lives. (Bourbeau, 2009; Lenferink et al., 2017). Self-management programmes vary from professional or lay-led group-based programmes at community centres to individual coaching programmes and do-it-yourself packages that patients can follow at home (Bentsen et al., 2012; Effing et al., 2016; Zwerink et al., 2014). Notwithstanding all the differences, the self-management programmes seem to pursue the same goals. Self-management seems related to increasing responsibility and health related autonomy, and therefore can be understood as a moral ideal one should oblige to (Schermer, 2009).

Self-management interventions are often incorporated in pulmonary rehabilitation programmes. The main objective of pulmonary rehabilitation (PR) is to restore muscle function and exercise tolerance, counteract non-respiratory consequences of the disease, and help patients to manage their chronic obstructive pulmonary disease with its exacerbations and symptoms (Garvey et al., 2016; Troosters et al., 2019; Troosters, et al., 2014). There is some evidence that PR with exercise training can relieve symptoms, improve emotional functioning, and enhance patients' feelings of control (Garvey et al., 2016; Mccarthy et al., 2015). Non-adherence to treatment and to healthy behaviour recommendations after treatment is a big concern in pulmonary rehabilitation. Many patients do not consistently follow the treatment plan, or even abandon treatment at all after an initial start. Non-adherence contributes to rising rates of hospitalization, death, and health care costs (Bender, 2014; George, 2018).

The above-mentioned outcomes of PR are in line with the aims of self-management, such as living a healthy life with a chronic disease (Lenferink et al., 2017; Zwerink et al., 2014). A comparison of self-management and physical medical rehabilitation (PMR) texts revealed that, although both approaches do share common ground, there is nevertheless a different logic at work in both fields (Jansma et al., 2010). A comparative analysis of self-management and PMR-text showed that the focus of self-management is on life goals, social learning, self-efficacy, the unpredictability of chronic illness, and is organized in lay-led interventions in the community. As the focus of PRM is on treatment goals, motor learning, functional recovery, the disabling conditions of diseases with acute onset, and organized in multidisciplinary intervention in the clinic. Although PMR primary focus has been disease with an acute onset it increasingly directs its attention to the multidisciplinary treatment of people with chronic illness such as COPD and diabetes. This begs the question how self-management and physical rehabilitation ideals meet each other in the management of chronic illness.

This article therefore presents the results of a qualitative study addressing the question how self-management came to the fore in guidelines and interventions of therapists working in a pulmonary rehabilitation setting in the Netherlands. The ethnographic approach was used to explore why self-management was worth to strive for according to the therapists, where it took place, and which dilemma's they struggled with. In this ethnographic study, we did not define self-management in advance. Instead, we observed whether and if so, self-management could be found in the actions of the various health professionals. We watched where self-management took shape and looked for the possible influence of the environment. In addition, we also included the care logistics in our observations for self-management in rehabilitation practice. So, rather than seeing self-management as an abstract ideal entangled with theoretical principles (A Mol, 2002; Pols, 2004), we explored it in terms of its embedding in everyday therapeutic practice. Furthermore, we did examine whether aspects of these so-called abstract ideals of self-management, entangled in the scientific literature, could be observed in the daily treatments of therapists, and by discussing with them how they gave content and meaning to self-management in PR. By unravelling and making knowledge and ideals explicit within rehabilitation practices, self-reflection of therapists engaged in these practices can be mobilised to bring about improvement (Pols, 2004).

METHODS

Ethnographic research methodology was used to articulate therapists' self-management ideals-in-action (Creswell, 2007; MacLeod et al., 2019; Pols, 2004). The research comprised: 1) a document analysis comparing self-management texts in national and international guidelines concerning physical therapy and PR; 2) participatory observation of physical rehabilitation practices of therapists working in a pulmonary rehabilitation team; 3) one-to-one interviews with therapists after every observation; 4) focus-group interviews to gain in-depth insight into how therapists looked at self-management in relation to their day-to-day practice. Since we did not have a concrete idea of how self-management would take shape in rehabilitation practice, we explored the everyday practice as open-mindedly as possible. Because of this starting point, all four sources of data collection were initially approached simultaneously and with the same open mind. Later in the process, when we could draw the first contours of self-management, the sources were naturally related to each other, such as the extent to which the self-management ideals found in the documents were reflected in the daily practice of the therapists and vice versa.

Setting & participants

A multidisciplinary pulmonary treatment department of a Dutch rehabilitation centre was the setting of this study, comprising an inpatient setting with 32 beds and an outpatient day centre that patients visited a couple of times a week. Approximately 250 patients per year with problems due to chronic respiratory diseases rehabilitate in the department. The majority of the patients treated have COPD varying from GOLD II to IV or are dealing with severe asthma. The multidisciplinary team consists of lung specialists, physician assistants, nurse practitioners, psychologists, dieticians, occupational therapists, social workers, social therapists, physical therapists, a psychomotor therapist, and registered rehabilitation nurses. The focus of pulmonary rehabilitation is the increase of physical functioning so therefore we concentrated on therapists that used physical exercise for increasing patients' capabilities to optimize their daily lives, being seven physical therapists and a psychomotor therapist.

Data collection

Document analysis

The first part of the data collection was a document analysis. Guidelines of major associations concerning PR were studied on embedded ideals of self-management. National guidelines included were a chapter on PR in the Dutch guidelines on diagnosis and treatment of COPD (DGDT-COPD) and the Dutch COPD guidelines for physical therapists (DGP-COPD) (Dekhuijzen et al., 2010; Vreeken et al., 2020). International guidelines, which underpin national guidelines, included were: the American Thoracic Society/European Respiratory Society (ATS/ERSG) (Spruit et al., 2013), the American Association of Cardiovascular and Pulmonary Rehabilitation/American College of Chest Physicians (ACCP/AACVPRG) (Ries et al., 2007), and the British Thoracic Society (BTSG) (Bolton et al., 2013).

Fieldwork

Fieldwork was conducted by the first author who became part of the day-to-day activities of the multidisciplinary team in PR for five months (three hours a day and three days a week) divided into two periods. In the first period, emphasis was on gathering data to obtain a general idea of how self-management manifested itself in the PR setting.

Observations

To collect data the first author participated in patient meetings, group sessions, and individual therapy. All three occurred with inpatients and patients attending day rehabilitation sessions. Focus in the second period was on self-management ideals-in-action of therapists who delivered physical exercise as a means to help patients become better self-managers. During observation, inquiries were made, and notes were taken. Notes and related comments of therapists were transcribed the same day to avoid memory loss.

Interviews

Two focus-group interviews with physical therapists and an in-depth interview with the psychomotor therapist were conducted. A discussion guide was constructed based on analysis of guidelines and transcribed observations. All therapists discussed their vision on and responsibilities for self-management in PR. In the second session, an actual transcription of an observation of self-management in-action became topic of debate providing a more complete picture of self-management ideals. Recorded tapes were transcribed verbatim. When saturation was achieved, in both observations and interviews, investigation ceased. The medical ethical committee exempted this study from being reviewed.

Data analysis

The data were analysed with Atlas.ti (Friese, 2019), which assists in extracting, coding and comparing meaningful fragments. Data collection and analysis were interlinked, meaning that analytic tasks already started during data collection (Hennink et al., 2011). Data analysis was inductive. Data from guidelines, observations and interviews were combined using triangulation. Self-management ideals and related themes that had surfaced from the material were thereby clustered. The material was coded by the first author who went through the material several times to ensure that codes assigned later in the analysis were cross-checked with earlier coded empirical material. The last author took the position of reflective questioner based on analysis of the material by hand. Finally, both authors agreed on the interpretation of the content of and relation between labelled ideals-in-action. By combining and triangulating analysis of guidelines and transcripts of observations and interviews, methodological quality was safeguarded.

RESULTS

Three ideals of self-management emerged from the ethnographic material: 1) Adhering to a healthy lifestyle, 2) Dealing with the unpredictability of chronic disease, and 3) Having freedom of choice. Where the ideals were articulated most strongly and how they were related, will be described in the following.

The first ideal: Adhering to a healthy lifestyle

Self-management in PR has found its way into national and international guidelines. The therapists stated that they worked according to these guidelines in order to act in an evidence-based manner. Most of the examined guidelines described self-management in terms of 'adhering to' and 'being compliant with' a healthy lifestyle. Guidelines based this self-management ideal and related recommendations on the available evidence reported in scientific literature. Therapists gave, during the interviews, next to an evidence-based outlook on self-management, also words to a more experience-based viewpoint.

Self-management according to evidence-based guidelines

When 'self-management' is used in the guidelines, it is related to the term 'patient education'. The British Thoracic Society Guideline (BTSG) emphasizes that education comes into every aspect of pulmonary rehabilitation and that *"educational components are fundamentally integral to the format and success of pulmonary rehabilitation programmes"* (Bolton et al., 2013)(p. ii12). The intention of these educational elements is *"to support the lifestyle and behavioural change and assist self-management to promote decision making and self-efficacy"* (Bolton et al., 2013) (p. ii12).

The American Association of Cardiovascular and Pulmonary Rehabilitation/American College of Chest Physicians (ACCP/AACVPRG) expresses the importance of self-management in a recommendation for patient education in the future, portraying patient self-management as *"a topic that should be addressed in patient education to achieve collaborative self-management and patient adherence to a healthy lifestyle"* (Ries et al., 2007) (p. 28S). The Dutch COPD guidelines for physical therapists (DGP-COPD) states that self-management is placed under the heading of *"information and education"*. The guideline states that *"self-management is linked to self-governance"*. To achieve this self-governance patients must learn about *"the impact of COPD"* and *"the effects of an exacerbation will have on their physical functioning"* and *"how to deal with it"* (Vreeken et al., 2020)(p.13). The DPG-COPD also advices to give "education on the patient's own role in the treatment" and "learning to cope with the condition" (Vreeken et al., 2020) (p 13.)

In addition, the American Thoracic Society/European Respiratory Society (ATS/ERSG) speaks of collaborative self-management as a multifaceted approach to *"promote self-efficacy through increasing the patients knowledge and skills required to participate with health care professionals in optimally managing their illness"* (Spruit et al., 2013) (p.28). Partnerships between patients and professionals are seen as pivotal in collaborative self-management interventions. Self-management training thereby involves *"collaboratively helping individuals acquire and practice self-management skills, such as goal setting, problem solving and decision making, to optimize and maintain benefits"* (Spruit et al., 2013) (p.28). The guideline illustrates these benefits with recommendations such as proper medication use and maintaining physical activity.

Adherence to healthy behaviour, according to most guidelines, cannot be achieved by only providing knowledge and education. The key to success is teaching skills that can lead to the enhancement of self-efficacy. The ATS/ERSG speaks of a change from *"traditional didactic approach to the promotion of adaptive behaviour change, especially collaborative self-management"* (Spruit et al., 2013) (p.28) as a means to enhance the self-efficacy of patients. Several strategies can be used by health professionals to enhance a patient's self-efficacy, such as for instance mastery experiences, peer models, social persuasion, and positive mood (Spruit et al., 2013). The DGP-COPD emphasises *"behavioural change focussed on optimising physical activity"* and draws the therapist's attention to the need to take into account *"the stages of behavioural change"*. To achieve behavioural change the guideline recommends *"motivational interviewing"* as a technique to stimulate the patients. The Dutch guidelines on diagnosis and treatment of (COPD DGDT-COPD) positions self-management in terms of teaching new behaviour and patients being responsible for maintaining that behaviour (Dekhuijzen et al., 2010).

Thus, although self-management is not described in the different guidelines in an unequivocal language, we found the ideal of self-management manifesting itself in most guidelines in terms of therapeutic knowledge and skills necessary for patients so they can adhere to and be compliant with a healthy lifestyle. The aim is a shifting of responsibility from therapists providing knowledge and training in healthy behaviour of chronic ill patients, to patients taking charge of their health themselves by willingly adhering to and maintaining a prescribed healthy behaviour regime. The underlying premise is that COPD-patients, who follow the healthy behaviour regime prescribed in evidence-based guidelines, become less dependent on therapists in that they know and do what is best for them from a therapeutic perspective.

Shared management according to the experience of therapists

Adherence to a healthy lifestyle was also discussed by physical therapists in focus-group interviews. They emphasised the importance of training according to evidence-based exercise-physiology principles as this is considered the best way to become and stay fit. They were in agreement with the guidelines stating simply providing knowledge and skills by means of patient education was not enough. In addition to exercise-physiology principles, internal motivation was an important cognitive principle as is illustrated by the following quote:

"Obviously our focus is mainly on exercise and how to train properly. We try to provide knowledge about how to exercise in a certain way and also try to give this meaning for the patient. What is in it for you? What are the benefits? We want to create internal motivation". (Focus-group interview)

By tapping into the internal motivation of patients, therapists hoped to achieve a situation in which the responsibility for training is taken over by patients. Therapists further stated that self-management and not just education is the best way for patients to obtain the necessary insight to transfer what is learned during rehabilitation to the home environment.

"That is why our beginner's group (given in the first weeks of rehabilitation -FJ) had no value, because it was only education. It is not self-management if you cannot apply and understand it in a certain context...". (Focus-group interview)

Self-management was seen as a means of helping to increase patients' ability to take on the responsibilities mentioned above, such as getting and staying fit. Therapists felt that not only factual education and skills were needed. Only if therapists succeeded in translating self-management knowledge and skills to patients' own lives, then they felt they contributed to the ability of patients to take responsibility for managing their own healthy lifestyles. In addition, therapists expressed their apprehension about the realization of full self-management for everyone. One therapist said:

"I think that a large group of patients could achieve self-management if they receive coaching once in a while. By self-management, I mean that they can keep out of the medical world, so to speak. But what we do here is not the form of self-management where someone learns to be fully able to stand on his/her own two feet". (Focus-group interview)

So, therapists supported the shift in responsibility concerning adherence to a healthy lifestyle and implicitly acknowledged related cost reductions by defining self-management in terms of keeping out of the medical world. They believed in shared management rather than full self-management after patients complete the initial rehabilitation process. Patients are taught in the relative safety of a rehabilitation centre to take over responsibility for a healthy life with COPD but may need therapists' help once in a while after discharge. According to the therapists, self-management for patients with COPD needs to be shared management because of the unpredictability and progressive course of COPD. As will be shown in the next paragraph.

The second ideal: Dealing with the unpredictability of a chronic disease

This second self-management ideal - dealing with the unpredictability of chronic disease - became most apparent in action in the practicalities of therapists observed in the fitness room and sports hall. This ideal emerged at the two places in different ways, 1) as learning to deal with physical boundaries in the fitness room, and 2) as learning to deal with cognitive and emotional boundaries in the sports hall.

Learning to deal with physical boundaries in the fitness room

From the many observations made, we have chosen some very illustrative transcripts. For example, this observation during a physical training session in the fitness room:

Eight home trainers are arranged in a circle with a table and some chairs in the middle. The physical therapist has given the group the task of exercising for half an hour on a home trainer, each with their own schedule based on scores of their maximum test. They have to be active for thirty minutes, that is a must, but they are allowed to adjust the intensity of exercise. The physical therapist makes a round and asks a man how he is doing. He tells her that he has a fever and that he has adjusted his training schedule, otherwise he cannot make *it for half an hour. A woman tells the physical therapist she has sore legs and is therefore almost unable to continue training. The physical therapist uses the Borg Scale to check her scores on dyspnoea and muscle fatigue and asks her what she might do to continue training for half an hour taking into account her high Borg scores. After discussing it for a while, the woman decides to train at a lower intensity.*

All patients received pre-set, personal schedules based on exercise-physiology principles referred to in the guidelines. However, within training sessions, patients' scores on the Borg Scale determined their actual level of activity. High scores meant that patients were exercising to the maximum of their capabilities which is not a good idea, according to the therapists, because this would make their recovery time too long and actually have a detrimental effect. In contrast, scores which were too low meant that no training effect could be expected. Within these limits, patients had to learn to adjust the intensity of a training session to their condition of the day.

For example, the man with a fever exercised anyway, juggling with the boundaries set for him that day. The Borg Scale also made the boundaries experienced by the woman visible. Rather than a ready-made solution, the physical therapist worked with the woman to help her find a solution herself. Although the physical therapist monitored everyone, it was clear from observations that she did not decide what patients should do. In addition to an awareness about the best training for 'good' days, patients were also taught to train in an adjusted manner on 'bad' days to prevent a total set back. By implicitly providing patients with problem-solving skills in the fitness room, the therapist taught patients skills to manage these physical boundaries in other environments as well.

In this observation we see a form of 'practise the physical activities together' as described in the Dutch guidelines for physical therapists (Vreeken et al., 2020). This 'doing it together' was given specific content in the fitness room so the patient could 'experience' it together with the therapist and hopefully use what was learned outside the rehabilitation setting (Vreeken et al., 2020) (p.13). The physical therapists taught patients with help of the Borg scale to deal with physical boundaries created by the unpredictability of their chronic disease. So, self-management in the fitness room is not only a matter of applying knowledge and skills, but also of experiencing them.

'Having a healthy lifestyle' and 'dealing with the unpredictability' seem to be naturally related. However, therapists acknowledged friction between both ideals, which is articulated in the following comment:

"Sometimes I find it difficult ..., I mean in fitness training you have a training schedule, you have to put in a certain amount of effort to gain fitness, but you also want patients to make a contribution. So, how do you cope with the fact that there is both an obligation to recover through training in just nine weeks, and that we want patients to learn how to make choices within their training schedule? These two goals are at odds with each other...". (Focus-group interview)

So, in the fitness room, therapists struggled with their attempts to contribute to the healthy behaviour of their patients because of the tension between implementing evidence-based exercise principles and their obligation to work on the functional recovery of patients on one hand, and teaching patients the skills to cope with the unpredictability of their illness on the other.

Learning to deal with cognitive and emotional boundaries in the sports hall

Another clarifying and exemplary observation happened during psychomotor therapy in the sports hall:

The psychomotor therapist and a male patient meet for the first time in the sports hall. After some discussion, the man agrees to the therapist's proposal to play a game of badminton. The man wants to know which court to use as he sees three badminton courts marked on the floor. The psychomotor therapist wants to use the centre of the hall ignoring the existing lines. The man has told the therapist during preparation that badminton is, like any other ball game, no fun at all. However, when you can go all out and win, it is somewhat acceptable. Before they start, the therapist tells him that she wants the shuttle to be returned within arm's length. She wants to take it easy, because she has to play a volleyball match the same evening. The man accedes to her request and the situation develops as follows. The man runs like crazy, he is going to the max but does not score any points, while the therapist stands almost still and scores without effort. At one stage the shuttle flies way over the psychomotor therapist. 'That shuttle is out' states the man. 'Oh' says the therapist 'did we have an agreement on lines then?' 'No, but then it is not fair', responds the man. Then the man has to rest because he is completely out of breath.

By using a game of badminton, situating a lineless 'court' in the middle of the hall, the psychomotor therapist confronted the man with the fact that he does not address his personal boundaries. Firstly, because he goes along with the therapist notwithstanding the fact that he does not like badminton, and secondly, because he accepts the therapist enforcing her own boundaries fiercely, despite the resulting unfair inequality of the game causing irritation.

The game of badminton indicated characteristic behaviour which could be counterproductive when dealing with the unpredictability of the disease. The psychomotor therapist attempted to provide the man with insight into his behaviour and possibly change it by internalizing skills such as assertiveness. In the sports hall, it became apparent that, next to gaining insight into physical boundaries, patients also learned how to deal with cognitive and emotional boundaries set by their chronic illness. Living with COPD takes a lot of patients' time and a great deal of their practical and emotional energy. In order to accept and attune to that, they were encouraged to state their wishes, needs, and boundaries regarding their illness clearly so that others take notice.

Being able to deal with physical, cognitive, and emotional boundaries is seen as necessary in PR as it assists patients to cope with the changeable nature of their illness. The intended outcomes are self-efficacy and illness control. Therapists saw it as their main priority to offer patients skills to deal with the effects of the unpredictability of their condition on all aspects of living a healthy life. These two different ways of dealing with boundaries are not at odds with each other but seem to directly reinforce each other. Exercise-related skills are trained more explicitly by the therapists in the fitness room and psycho-social skills in the sports hall. Cognitive skills such as problem-solving, motivation-enhancing techniques, and assertiveness training were intertwined with exercise and sports activities; and offered in an implicit manner by therapists through coaching and conversation. In this way, the therapists tried to make a translation to the home environment and leave the actual adaptation, transition and implementation of these skills in the home environment by patients themselves.

Thus, the ideal of dealing with unpredictability is oriented towards an overall shift from a chronic disease controlling the life of patients to individuals controlling the instability of their illness. Concluding from the findings in the fitness room and the sports hall one could say that self-management programmes should not only teach patients 'how to adhere to a healthy lifestyle', but also 'when and where' to adhere to that lifestyle in order to be able to translate this knowledge and skills to different often changing situations. The interviews subsequently revealed that patient's own life goals and preferences or freedom of choice must thereby also be taken into consideration.

The third ideal: Having freedom of choice

The third ideal - having freedom of choice - came to the fore explicitly in the interviews with therapists. The importance of being able to live life according to individual preferences was emphasised here. The dilemma inherent in this ideal emerged from two different angles, namely that of the almost incalculable choices of patients and their own values they want to live by, and the limitations and values set upon the therapists by the therapeutic framework they are guided by.

Patients living according to one's own preferences

What if the requirement for responsibility of healthy behaviour and illness control becomes too great, is not felt, or contradicts with patients' own requirements to live life? Therapists argued that they did not pressure patients in lifestyle prescriptions or other rules that they did not felt up to or did not want to do. The importance of living life according to individual preferences was emphasised and put next to evidence-based healthy behaviour prescriptions and rules. Take the following quote:

"It is not that they have to follow our ideas. We tell them what healthy behaviour should entail and what we think is right with regard to exercise, nutrition, and so on. But they have the autonomy, they have control, they are making the choices". (Focus-group interview)

This therapist talked about freedom of choice and autonomy of patients in controlling their rehabilitation almost as a metaphor for living a life with a chronic disease. Therapists stated that they provide patients with knowledge and skills to live a healthy life, but leave decisions to them. Patients have to incorporate all information and skills offered and decide what is compatible with what they want out of life. Therapists saw it as their responsibility to make patients aware of consequences of their behaviours.

"It is about making conscious choices. If someone completely loses control during a soccer game, then I immediately make the transfer to a home situation, to a room full of guests wanting coffee. If you are willingly crossing the borders and you know that you have to pay the price over the following two days... then I am fine with it". (Focus-group interview)

Therapists talked during the interviews about the shift from patients living by the rules learned in the rehabilitation centre to making rules themselves, living by them or feeling free to change them in their own environments. During observations, the emphasis on this transition was however much less obvious. In the rehabilitation centre, therapists taught patients to become aware of what they are doing and confronted them with choices they implicitly made. According to therapists, information and knowledge about consequences of their 'chosen' behaviours are important ingredients for making right decisions. It was also argued that knowledge and information were not enough to become a good self-manager. Patients also have to feel self-assured enough to be able to make choices. As one therapist commented:

"Patients do need the confidence that they can face problems, feeling the necessary self-efficacy to change their behaviour. People often believe that they do not have any influence at all". (In-depth interview)

So, despite all information and skills provided during rehabilitation, the consequences of a chronic disease can be so overwhelming that patients do not have confidence to exercise freedom of choice and let alone live by their own or recommended healthy lifestyle rules. They may lack cognitive skills or emotional ability to make informed choices and act on their decisions. To make informed decisions, patients indeed have to consider the relevant arguments and weigh up the advantages and disadvantages of the options available in the information offered. Choosing thoughtfully is not easy if you are not used to do it, if you do not know where to choose from, if you are afraid your choices will harm you, or if you are depressed and feel that you cannot enjoy anything. Making informed choices about how to live life well each day also takes lots of energy that people with COPD may not always have at their disposal.

Professional working according to therapeutic perspectives

It was thus argued by the therapists that patients should be allowed to make their own decisions. Therapists ought to leave value laden decisions to patients. They encouraged patients to simultaneously 'choose' a healthy lifestyle and deal with the uncertainty of living life with COPD. They felt at the same time they should give the patients the freedom to deviate from recommended behaviour.

"Patients do know quite well what is good for them. We often think, as therapists, that we are the ones that know what is good for our patients, but this is not necessarily true. Based on our professionalism, we think we know, but the patient does not have to feel it in the same way". (In-depth interview)

Simultaneously, therapists admitted that it was difficult to put this ideal of freedom of choice into practice. They confessed that, despite the importance, they were at times quite directive in their therapy to meet recovery obligations which are also set within a limited time frame.

They thereby left not much room for their patients to explore their own choices and solution directions, as is illustrated by the following quote:

"I know of myself that I can be directive in a way like…. well let's do it this way today or try this specific solution". (Focus-group interview)

Therapists reasoned that evidence-based healthy behaviour prescriptions will not automatically lead patients to choose their own healthy lifestyle. Nor does it grant patients to deal with the unpredictability of their chronic illness, let alone assist patients to develop a capacity for self-determination. The patients' liberty to make choices was set within an almost normative rehabilitation framework in which exercise and improving your abilities despite the disease are seen as ultimate goods. Consider the following quote:

"When a patient continuously chooses not to exercise… well then you don't. Then I ask…. do you have another option or is it really that you do not want to exercise...If the answer is "No, I do not want to exercise" … then I ask why are you here? What are you trying to accomplish here?". (Focus-group interview)

So, matching therapeutic values with patients' values is not easy and may lead to tensions in the rehabilitation process. Tensions that arise, because the ideal freedom of choice needs to be executed within the margins of therapists' professionalism. Their professionalism urges therapists to deliberate about the ideal of freedom of choice within the context of daily practice of rehabilitation in which exercise and improving your abilities is the norm.

Thus, therapists' own professional knowledge, directives, values, and blind spots may hinder the capacity to execute the ideal freedom of choice to its 'full' potential. Because they are encouraged to work in an evidence-based manner, therapists rely on clinical guidelines that recommend physical activity to promote a healthy lifestyle. They implicitly assume that when patients make choices, they will be making them in the direction of a healthy lifestyle. However, this is not always possible or desirable for patients. Healthy lifestyle directives articulated in guidelines and professional knowledge from therapists should at least be filled out with practical knowledge of patients and their caregivers. This may ease the tensions between the articulated self-management ideals in-words and in-action.

DISCUSSION

In this ethnographic study, it became obvious that putting self-management into practice in pulmonary rehabilitation is not without its complications. Different, sometimes conflicting ideals-in-action related to self-management became apparent. The first ideal, most obvious in the guidelines, emphasises knowledge and skills necessary for adhering to a healthy lifestyle and focuses on the benefits of a shift in responsibility from therapists to patients. The second ideal, dealing with the unpredictability of chronic disease, gives words to the translation of self-management knowledge and skills in facing the physical, cognitive and emotional boundaries in living life well with COPD; all with the intention to make a shift away from the disease controlling the patient's life to a situation in which individuals can deal with the changeability of their chronic illness. The third ideal, having freedom of choice, focuses on the right that patients have to live their own lives despite the demands of the other two ideals. This ideal came to the fore in focus and individual interviews with therapists. So, striving for just one ideal - such as adhering to a healthy lifestyle - may limit the achievement of other self-management-ideals such as dealing with the unpredictability of chronic disease and having freedom of choice.

Despite the local character and narrow focus of this study, the articulated self-management ideals-in-action challenge the discussion on how to improve and evaluate self-management in physical rehabilitation with respect to several issues.

The first issue concerns the insulated nature of the guidelines when self-management is largely defined by adhering to a healthy lifestyle. This somewhat one-sided interpretation does not take into account the complexity of living with a chronic condition. By promoting adherence to healthy lifestyle rules, guidelines tacitly take 'healthy people' as standard, and not 'people with a chronic disease' who have to be attentive to their body in order to be able to live a good life despite the whimsicality of their COPD. The line of reasoning in health promotion guidelines is that: if each individual does what is prescribed, we might, added together, form a healthy and cost efficient collective (Mol, 2008). The moral good is that living in a society with a publicly funded healthcare system obliges its citizens to live as healthily as possible, otherwise it would be an unfair waste of other people's money (Schermer, 2009). From a therapeutic or care point of view, however, collectives do not result from adding individuals together, but from making helpful differentiations between groups and individuals. Patients in therapeutic and care practices are considered as individuals with different needs and problems rather than equals that can be added together (Mol, 2008). There should thus be room in clinical and daily practices for deviating from evidence-based healthy lifestyle prescriptions and giving patients more freedom to integrate lifestyle advices and instructions according to their own values in their lives.

The second issue we want to discuss is the fact that the three ideals of self-management, adhering to a healthy lifestyle, dealing with the unpredictability of chronic disease and having freedom of choice, have been shaped differently by different therapist at different locations (e.g., fitness rooms and sports hall), as this study has shown. A physiotherapist gives another interpretation to the concept of self-management than a psychomotor therapist does, among other things because of training and profession-specific guidelines. When looking at the ideals of self-management we have found and the fact that they are shaped by different members of the multidisciplinary team and in different places in the rehabilitation centre, we will have to take these differences into account. If we want patients treated at the rehabilitation centre to be exposed to all three ideals of self-management, including all their frictions, patients should be treated by these different therapists and at these different locations in the rehabilitation centre. In short, maximum use should be made of the multi-disciplinary team and the spaces the rehabilitation centre has to offer.

This brings us to the third issue that needs consideration: the ideal of freedom of choice implicated in self-management. This ideal assumes that choice is good; it offers patients autonomy. It also supposes patients to be active and competent in weighing pros and cons of all the options to manage, implicating that it is clear for them where to choose from. What follows from self-determined choices is responsibility. The difficulty is however that not everything can be (self)-managed. The natural course of a chronic disease and the fickleness of life itself are hard to deal with in any case. Certainly when the high prevalence of depression and anxiety in patients with COPD (De Voogd et al., 2009; Gordon et al., 2019) and natural capabilities of patients and related concepts such as health illiteracy are taken into account (Nutbeam, 2008; Roberts et al., 2008; Yadav et al., 2020). Self-determined choices can even lead to a blame game of patients being responsible for their chronic disease getting out of control and should literally pay the price for not being a successful self-manager. But when patients do deviate from their obligation of ‘adhering to a healthy lifestyle’ intentionally, because it conflicts to much with their own preferences - for instance skip training for a while because they want to help their daughter who just got a baby - it is an act of a human being self-determent in choosing to manage life instead of a disease.

The fourth issue that needs reflection concerns healthcare policy and the problematic nature of related outcome measurements. Both researchers and therapists as became apparent from the interviews see self-management as a solution which could decrease pressure on the healthcare system. Scientific research uses healthcare dependency as an outcome to weigh the success of self-management programmes. However, when looking at most self-management programmes for patients with COPD, action plans, for instance to manage exacerbations, are an important part of the programme. In these plans, there are always steps incorporated that encourage patients to ask for help whenever the boundaries of their own capabilities are reached (Hill et al., 2013; Lenferink et al., 2017; Van der Heide et al., 2018). This shifting back and forth of responsibility for handling the chronic illness seems to lead to better health for the patient and a higher quality of life, but will not necessarily mean an overall massive decrease in the use of the healthcare system (Lenferink et al., 2017). The relationship between therapist and patient should therefore not be considered as one of compliance, but rather one of collaboration, concordance, and shared management (Schermer, 2009; Van der Heide et al., 2018; Visse et al., 2010). It probably will entail a different use of the healthcare system (Bourbeau et al., 2004). Reduction of healthcare costs as an outcome measure for the success of self-management may thus need to be considered too narrow (Bourbeau & Van der Palen, 2009).

As a fifth issue, the term 'self' in self-management will be deliberated on. Therapists are urged to educate COPD patients self-management knowledge and skills with which they can act according to the prescribed healthy lifestyle rules, but they, the patients, are left somewhat empty handed about how to put these prescribed rules into practice. In order to make patients better prepared, therapists could explicitly and systematically incorporate self-management skills, which are described in scientific literature as evidence-based and which should improve rehabilitation practice, into their daily practice. This could include, for example, problem-solving skills, asking for help and communicating with health care professionals and so prepare patients more explicitly with these skills for the transfer to the home environment. Furthermore, as has been shown in this ethnographic study, articulating different ideals of self-management hidden in therapists' words and practicalities makes also critical (self-)reflection, and therewith improvement from within practical rehabilitation work possible. It may help therapists to deal more obviously with the challenging effects of the different self-management ideals in the contexts of patients' everyday lives.

Finally, we would like to elaborate on the fact that both therapists and patients experience difficulties in the transfer of knowledge and skills from the rehabilitation centre to the home environment (Cameron et al., 2008; Pols, 2012; Pringle et al., 2008). They find it difficult to translate the 'know how' taught in rehabilitation centres to 'know now' required to decide about when and where to use the acquired knowledge and skills in specific situations (Meijering et al., 2016; Pols, 2012). The constant tinkering of 'what' to use and what to do 'when' and 'where' takes lots of energy of patients and appears to be an effort that many patients cannot make alone. Living with a chronic disease such as COPD leads to recurring transitions, which require support from professionals during vulnerable periods in the patient's illness trajectory, certainly because COPD might at times be an invisible disability to both self and others (Halding & Heggdal, 2012; McMillan Boyles et al., 2011). The term self-management then may put policymakers and outcome researchers on the wrong track. Why not replace the term with something that does more justice to the togetherness of managing a disease. In analogy of the African proverb 'it takes a village to raise a child', it takes a community of people, professionals and non-professionals to cooperate with each other to help a person manage a chronic disease.

REFERENCES

Bender, B. G. (2014). Nonadherence in chronic obstructive pulmonary disease patients: What do we know and what should we do next? *Current Opinion in Pulmonary Medicine, 20*(2), 132-137. https://doi.org/10.1097/MCP.0000000000000027

Bentsen, S. B., Langeland, E., & Holm, A. L. (2012). Evaluation of self-management interventions for chronic obstructive pulmonary disease. *Journal of Nursing Management, 20*(6), 802-813. https://doi.org/10.1111/j.1365-2834.2012.01469

Bolton, C. E., Bevan-Smith, E. F., Blakey, J. D., Crowe, P., Elkin, S. L., Garrod, R., ... Walmsley, S. (2013). British Thoracic Society guideline on pulmonary rehabilitation in adults. *Thorax, 68*(SUPPL. 2). https://doi.org/10.1136/thoraxjnl-2013-203808

Bourbeau, Jean. (2009). The role of collaborative self-management in pulmonary rehabilitation. *Seminars in Respiratory and Critical Care Medicine, 30*(6), 700-707. https://doi.org/10.1055/s-0029-1242639.

Bourbeau, Jean, Nault, D., & Dang-Tan, T. (2004). Self-management and behaviour modification in COPD. *Patient Education and Counseling, 52*(3), 271-277. https://doi.org/10.1016/S0738-3991(03)00102-2

Bourbeau, J., & Van Der Palen, J. (2009). Promoting effective self-management programmes to improve COPD. *European Respiratory Journal, 33*(3), 461-463. https://doi.org/10.1183/09031936.00001309

Cameron, J. I., Tsoi, C., & Marsella, A. (2008). Optimizing stroke systems of care by enhancing transitions across care environments. *Stroke, 39*(9), 2637-2643. https://doi.org/10.1161/STROKEAHA.107.501064

Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches.* Los Angeles: SAGE Publications Inc.

De Voogd, J. N., Wempe, J. B., Koëter, G. H., Postema, K., Van Sonderen, E., Ranchor, A. V., ... Sanderman, R. (2009). Depressive symptoms as predictors of mortality in patients with COPD. *Chest, 135*(3), 619-625. https://doi.org/10.1378/chest.08-0078

Dekhuijzen, P. N. R., Smeele, I. J. M., Smorenburg, S. M., & Verhoeven, M. A. W. M. (2010). Richtlijn Diagnostiek en behandeling van COPD Actualisatie maart 2010, 374. Retrieved from http://www.cbo.nl/Downloads/938/rl_copd_beh_onderh_10.pdf

Effing, T. W., Vercoulen, J. H., Bourbeau, J., Trappenburg, J., Lenferink, A., Cafarella, P., ... Van Der Palen, J. (2016). Definition of a COPD self-management intervention: International expert group consensus. *European Respiratory Journal, 48*(1), 46-54. https://doi.org/10.1183/13993003.00025-2016

Friese, S. (2019). *Qualitative data analysis with Atlas.ti* (third edit). Los Angeles: SAGE Publications Ltd.

Garvey, C., Bayles, M. P., Hamm, L. F., Hill, K., Holland, A., Limberg, T. M., & Spruit, M. A. (2016). Pulmonary Rehabilitation Exercise Prescription in Chronic Obstructive Pulmonary Disease: Review of Selected Guidelines: An official statement from the American association of cardiovascular and pulmonary rehabilitation. *Journal of Cardiopulmonary Rehabilitation and Prevention, 36*(2), 75-83. https://doi.org/10.1097/HCR.0000000000000171

George, M. (2018). Adherence in asthma and copd: New strategies for an old problem. *Respiratory Care, 63*(6), 818-831. https://doi.org/10.4187/respcare.05905

Gordon, C. S., Waller, J. W., Cook, R. M., Cavalera, S. L., Lim, W. T., & Osadnik, C. R. (2019). Effect of Pulmonary Rehabilitation on Symptoms of Anxiety and Depression in COPD: A Systematic Review and Meta-Analysis. *Chest, 156*(1), 80-91. https://doi.org/10.1016/j.chest.2019.04.009

Halding, A. G., & Heggdal, K. (2012). Patients' experiences of health transitions in pulmonary rehabilitation. *Nursing Inquiry, 19*(4), 345-356. https://doi.org/10.1111/j.1440-1800.2011.00573.x

Hennink, M. M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods.* London: SAGE Publications Inc.

Heyworth, I. T. M., Hazell, M. L., Linehan, M. F., & Frank, T. L. (2009). How do common chronic conditions affect health-related quality of life? *British Journal of General Practice, 59*(568), 833-838. https://doi.org/10.3399/bjgp09X453990

Hill, K., Vogiatzis, I., & Burtin, C. (2013). The importance of components of pulmonary rehabilitation, other than exercise training, in COPD. *European Respiratory Review, 22*(129), 405-413. https://doi.org/10.1183/09059180.00002913

Hoeymans, N., Melse, J., & Schoemaker, C. (2010). *Gezondheid en determinanten Deelrapport van de VTV 2010 Van gezond naar beter.*

Jansma, F. F. I., Van Twillert, S., Postema, K., Sanderman, R., & Lettinga, A. T. (2010). Physical and rehabilitation medicine and self-management education: A comparative analysis of two approaches. Journal of Rehabilitation Medicine, 42(9), 808-814. https://doi.org/10.2340/16501977-0606

Lenferink, A., Brusse-Keizer, M., van der Valk, P., Frith, P., Zwerink, M., Monninkhof, E., ... Effing, T. (2017). Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease (Review). *Cochrane Database of Systematic Reviews*, (1-148). https://doi.org/10.1002/14651858.CD011682.pub2.www.cochranelibrary.com

MacLeod, A., Cameron, P., Ajjawi, R., Kits, O., & Tummons, J. (2019). Actor-network theory and ethnography: Sociomaterial approaches to researching medical education. *Perspectives on Medical Education, 8*(3), 177-186. https://doi.org/10.1007/s40037-019-0513-6

Mccarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E., & Lacasse, Y. (2015). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews, 2015*(2). https://doi.org/10.1002/14651858.CD003793.pub3

McMillan Boyles, C., Hill Bailey, P., & Mossey, S. (2011). Chronic obstructive pulmonary disease as disability: Dilemma STORIES. *Qualitative Health Research, 21*(2), 187-198. https://doi.org/10.1177/1049732310383865

Meijering, L., Nanninga, C. S., & Lettinga, A. T. (2016). Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health and Place, 37*, 35-42. https://doi.org/10.1016/j.healthplace.2015.11.006

Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham: Duke University Press.

Mol, Annemarie. (2008). *The logic of care: Health and the problem of patient choice*. New York: Taylor & Francis.

Monninkhof, E., Van der Valk, P., Van der Palen, J., Van Herwaarden, C., & Zielhuis, G. (2003). Effects of a comprehensive self-management programme in patients with chronic obstructive pulmonary disease. *European Respiratory Journal, 22*(5), 815-820. https://doi.org/10.1183/09031936.03.00047003

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine, 67*(12), 2072-2078. https://doi.org/10.1016/j.socscimed.2008.09.050

Pols, J. (2004). *Good care: Enacting a complex ideal in long-term psychiatry*. Enschede: University of Twente.

Pols, J. (2012). *Care at a Distance. On the closeness of Technology*. Amsterdam: Amsterdam University Press. https://doi.org/10.1163/9789460910838_003

Pringle, J., Hendry, C., & McLafferty, E. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing, 17*(18), 2384-2397. https://doi.org/10.1111/j.1365-2702.2008.02372.x

Quaderi, S. A., & Hurst, J. R. (2018). The unmet global burden of COPD. *Global Health, Epidemiology and Genomics, 3*, 1-3. https://doi.org/10.1017/gheg.2018.1

Ries, A. L., Bauldoff, G. S., Carlin, B. W., Casaburi, R., Emery, C. F., Mahler, D. A., ... Herrerias, C. (2007). Pulmonary rehabilitation: Joint ACCP/AACVPR Evidence-Based Clinical Practice Guidelines. *Chest, 131*(5 SUPPL.), 4S-42S. https://doi.org/10.1378/chest.06-2418

Roberts, N. J., Ghiassi, R., & Partridge, M. R. (2008). Health literacy in COPD. *International Journal of COPD, 3*(4), 499-507. https://doi.org/10.2147/copd.s1088

Russell, S., Ogunbayo, O. J., Newham, J. J., Heslop-Marshall, K., Netts, P., Hanratty, B., ... Kaner, E. (2018). Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: Views of patients and healthcare professionals. *Npj Primary Care Respiratory Medicine, 28*(1). https://doi.org/10.1038/s41533-017-0069-z

Schermer, M. (2009). Telecare and self-management: Opportunity to change the paradigm? *Journal of Medical Ethics, 35*(11), 688-691. https://doi.org/10.1136/jme.2009.030973

Spruit, M. A., Singh, S. J., Garvey, C., Zu Wallack, R., Nici, L., Rochester, C., ... Wouters, E. F. M. (2013). An official American thoracic society/European respiratory society statement: Key concepts and advances in pulmonary rehabilitation. *American Journal of Respiratory and Critical Care Medicine, 188*(8). https://doi.org/10.1164/rccm.201309-1634ST

Troosters, T. (2013). Physical inactivity in patients with COPD: The next step is... action. *Primary Care Respiratory Journal, 22*(4), 391-392. https://doi.org/10.4104/pcrj.2013.00099

Troosters, T., Blondeel, A., Janssens, W., & Demeyer, H. (2019). The past, present and future of pulmonary rehabilitation. *Respirology, 24*(9), 830-837. https://doi.org/10.1111/resp.13517

Troosters, T., Demeyer, H., Hornikx, M., Camillo, C. A., & Janssens, W. (2014). Pulmonary rehabilitation. *Clinics in Chest Medicine, 35*(1), 241-249. https://doi.org/10.1016/j.ccm.2013.10.006

Van der Heide, I., Poureslami, I., Mitic, W., Shum, J., Rootman, I., & FitzGerald, J. M. (2018). Health literacy in chronic disease management: a matter of interaction. *Journal of Clinical Epidemiology, 102*, 134-138. https://doi.org/10.1016/j.jclinepi.2018.05.010

Visse, M. A., Teunissen, T., Peters, A., Widdershoven, G. A. M., & Abma, T. A. (2010). Dialogue for air, air for dialogue: Towards shared responsibilities in COPD practice. *Health Care Analysis, 18*(4), 358-373. https://doi.org/10.1007/s10728-009-0139-7

Vos, T., Flaxman, A. D., Naghavi, M., Lozano, R., Michaud, C., Ezzati, M., ... Murray, C. J. L. (2012). Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: A systematic analysis for the Global Burden of Disease Study 2010. *The Lancet, 380*(9859), 2163-2196. https://doi.org/10.1016/S0140-6736(12)61729-2

Vreeken, H.L., Beekman, E., Doormaal, M.C.M. van, Post, M.H.T., Meerhoff, G.A.,& Spruit, M.A. (Red.) (2020). KNGF-richtlijn COPD. *KNGF-Richtlijn COPD*, 70.

Yadav, U. N., Lloyd, J., Hosseinzadeh, H., Baral, K. P., & Harris, M. F. (2020). Do chronic obstructive pulmonary diseases (COPD) self-management interventions consider health literacy and patient activation? A systematic review. *Journal of Clinical Medicine, 9*(3), 1-17. https://doi.org/10.3390/jcm9030646

Zwerink, M., Brusse-Keizer, M., van der Valk, P., Zielhuis, G., Monninkhof, E.,M., Van der Palen, J., ... Effing, T. (2014). Self management for patients with chronic obstructive pulmonary disease (Review). *Cochrane Database of Systematic Reviews*, (3), 1-116. https://doi.org/10.1002/14651858.CD002990.pub3.www.cochranelibrary.com

CHAPTER FIVE

Lost in translation: A case study on how an evidence-based self-management programme is being translated into practice in a local setting over time

Feyuna F.I. Jansma and Robbert Sanderman

ABSTRACT

Background: Thanks to ever-improving diagnoses and treatment techniques, the number of people surviving a cancer diagnosis is increasing. Although these are primarily positive developments, they also contribute to the emergence of a new group of people with chronic disabilities due to the treatment's side effects. Consequently, in recent decades, educational programmes have been developed that are specially designed to support these individuals in coping with their limitations.

Objective: This article examines a previously implemented educational programme comprising both a physical component and a psycho-educational component in which self-management plays an important role. The aim of this study is to explore how self-management is shaped within this educational programme and to identify areas of possible improvement.

Methods: Training sessions were observed, informal discussions were held with members of a multidisciplinary team, and existing written material on the programme was examined. Moreover, the literature on oncological rehabilitation in general, especially when it related to the concept of self-management, was examined. In light of the research findings, guidelines were drawn up for conducting focus group interviews and in-depth interviews with therapists and patients.

Results: The professionals articulate self-management as the ability of cancer survivors to live a fulfilling life. To live this way, patients need knowledge and skills to engage in healthy, active living, deal with emotions and cope with newly established boundaries. Patients relate self-management to different skills that they have learnt in rehabilitation, such as making good choices, asking for help and solving problems. According to the professionals, a clear and mutual shared vision on self-management is needed that is supported by all therapists and efforts should focus on determining how to embed these shared ideas in both the physical and psycho-educational components of the self-management programme. Optimal group size and homogeneity to stimulate group dynamics were suggested by both professionals and patients as important considerations. Finally, patients recommended extending the programme's duration.

Conclusion: Focus group interviews, observations and in-depth interviews were conducted to explore how self- management was integrated into the daily rehabilitation practice of a local oncology ward. Through these interviews this study managed to reveal how self-management was intertwined with several program components as well as several potential areas of improvement.

INTRODUCTION

The relative survival rate of people diagnosed with cancer keeps increasing. Consequently, the number of people surviving cancer and the average age of patients are also rising. Improved early detection methods and more effective treatment regimens have also led to rising numbers of cancer survivors. While this development is primarily a positive one, it has also generated a critical issue in health care concerning the existence of a large group of cancer survivors who have to deal with the chronic side effects of their treatment, including massive fatigue, loss of stamina and reduced quality of life (Cuthbert et al., 2019; Lagergren et al., 2019; Mix et al., 2017; Shapiro, 2018). Although the number of cancer survivors is growing, the concept of cancer survivorship is not new. The term cancer survivor was first introduced by Mullan (1984), who used it to describe a patient who had survived cancer and had to learn to deal with *"fear of recurrence, learning to live with compromise, and economic and social shunning"* (p. 88). Because these problems are predictable Mullan recommended that patients should be offered education to cope effectively and proposed the development of interventions that *"promote mental as well as physical healing in the cancer patient"* (Mullan, 1984: 88).

Since the publication of Mullan's article in 1984, the range of programmes targeting this specific group has expanded. Moreover, there have been developments that have given rise to rehabilitation programmes specifically designed to provide oncology patients with the necessary skills to keep their lives on track during and after their cancer treatment. The aim of these programmes is to enable survivors with enduring and often chronic side effects to achieve the highest possible level of functioning. In recent decades, as self-management is seen as one of the concepts that could be helpful for patients to acquire the necessary skills to be a successful cancer survivor, these programs have started to incorporate elements of self-management to enhance their effects (Boogaard et al., 2016; Reb et al., 2017; Smith-Turchyn et al., 2016). A person with a chronic condition spends significantly more time at home than in a hospital or rehabilitation centre, where care is provided by professionals. Therefore, learning how to deal with the day-to-day consequences of a chronic disease in the absence of professional help is essential and the development of self-management skills could be beneficial to such a learning process. The success factors and pitfalls of various oncology self-management programmes have been identified within the literature. On the one hand, self-management programmes are generally effective in reducing fatigue and enhancing the quality of life, especially those that include a physical activity component. On the other hand, the effects of the programmes on psychological states like anxiety, depression and self-efficacy are more difficult to ascertain (Bjørkedal et al., 2021; Kim et al., 2017).

Another noteworthy finding described in the literature is a pitfall that relates to lack of tailoring the self-management programme to the patients. The research shows that, given the diverse personal life circumstances of patients and different adaptational tasks to be accomplished, the need to customise self-management is becoming increasingly apparent. A more advanced stage of cancer corresponds to a greater need for an adapted self-management programme. Therefore, customisation appears to be a factor contributing to the success of self-management programmes (Fredette, 1990; Kidd, 2014; Kim et al., 2017; McCormack et al., 2011; Van Dongen et al., 2020). A third important finding in the literature, which could be defined as both a pitfall and a success factor, has to do with the duration of the programme. In light of findings reported in the literature, it can be concluded that a longer programme duration corresponds to more effective outcomes (Boogaard et al., 2016). Lastly, the literature shows that theoretically grounded self-management programmes are more effective than those that lack a theoretical foundation (Boogaard et al., 2016; Cuthbert et al., 2019; Smith-Turchyn et al., 2016).

Having now elaborated upon the success factors and pitfalls of a successful self-management programme, the question arises whether there are existing self-management programmes that are designed with the above-described success factors and pitfalls in mind. A critical look at the self-management programmes described in the literature leads to the conclusion that long-term, theoretically informed self-management programmes designed with attention to both the physical as well as the psychological aspects of self-management do exist (Cuthbert et al., 2019). However, a more detailed examination of the results of these programmes reveals that it is very difficult to elucidate the actual effects of these programmes. It also appears that in practice, these programmes are very difficult to implement effectively, especially in the long term. So, what is happening here? Has the value of incorporating self-management skills into rehabilitation programmes for oncology patients been overestimated, or is something else going on?

It would appear that there is something else going on. As the literature shows, there is evidently a gap between scientific evidence and its translation into daily routine (Green, 2008; Menon et al., 2009; Mol, 2006). Although health care providers are expected to be aware of the latest scientific findings and to be able to implement these findings in their daily work, practical application has proven to be extremely difficult. It is becoming increasingly clear that the task of synthesising available evidence into coherent advice is highly complicated, let alone incorporating such advice within an existing practice (Van Twillert et al., 2009). This challenge seems especially prominent when it comes to the implementation of self-management programmes.

This chapter presents a case study of the experiences of a multidisciplinary team working in a long-term, theoretically-driven oncology rehabilitation programme, which has an explicit focus on self-management skills. At the time of this research, the members of the multidisciplinary team had already worked with this specific programme for several years and felt the need to investigate whether they could improve the programme.

As a first step, the current integration of the studied self-management programme was mapped out by eliciting answers to the following research questions: (1) What is the vision of the participants (professionals and patients) in this local setting on self-management? (2) How is self-management incorporated into the different components of the programme? (3) Which elements of the programme relating to self-management do participants find satisfactory, and which elements do they feel need improvement? Focus group interviews with therapists, patients and former patients and observations of the programme in action were conducted to acquire the required in-depth insight for this analysis.

METHODS

Design

The self-management programme under investigation was a 15-week group-based programme. A group of approximately 10 patients with different types of cancer participated together in the programme, which comprised of four components: (a) individual exercise, (b) sports, (c) psycho-education and (d) information (Van Weert et al., 2005). To acquire a thorough understanding of the programme, training sessions were observed, informal discussions were held with the members of the multidisciplinary team and written material available on the programme as well as the literature on oncological rehabilitation, especially in relation to the concept of self-management, were studied. The investigations resulted in, an interview guide, focusing on three topics, that was composed to answer the research questions.

Participants

All members of the multidisciplinary team, comprising a physical therapist, two psycho-motor therapists, a psychologist and a dietician participated in study. At the time of the study, this multidisciplinary team was treating approximately 80 patients with various forms of cancer in an outpatient setting each year. Along with the multidisciplinary team members, 13 cancer survivors who had been diagnosed with various kinds of cancer participated in the focus group interviews. Patients who met the following criteria were included in the study: (1) current or previous participation in the programme, (2) the ability to speak and understand the Dutch language and (3) willingness and motivation to take part in the study. The research population was divided into two groups. The first group comprised of five women who were still active participants in the rehabilitation process and the second group comprised of eight former patients (three men and five women). Both groups were interviewed separately and all of them signed an informed consent form.

Procedure

Inspired by the work of Krueger (1998), the focus group interviews were prepared and moderated (Krueger, 1998). The assistant moderator (Sacha van Twillert) who, as her function required of her, had done a limited amount of preparation, was tasked with getting the members of the focus group to explain the content of the programme and problems associated with its implementation. The other moderator, the first author, had already acquired a considerable amount of knowledge on the subject matter and therefore adopted a more contemplative and reflective role. The focus group interview topics were derived from the content of the manuals, literature and informal discussions held with members of the oncology rehabilitation team. Both focus group interviews were recorded and transcribed verbatim.

Analysis

The first author analysed the collected data with a qualitative software programme, Atlas-ti (Friese, 2019). Atlas-ti includes tools for managing, extracting, comparing, exploring and reassembling meaningful segments from large amounts of data. Information from one source can thus provide background information or can otherwise be used to refine or supplement other data sources. The focus group interviews were coded by the first author, who read them several times. Codes that were assigned later in interview texts were also examined for their alignment with earlier coded texts. Subsequently, the transcribed focus group interview texts were subjected to content analysis. An inductive approach was applied during the data analysis, which entailed the interweaving of data from the different focus group interview to enable the clustering of related codes. These codes were then compared and contrasted, in order for elements of self-management to emerge from the material. Finally, illustrative quotes were identified to highlight the issues discussed in this chapter.

RESULTS

In the first part of the results section, the perceptions of the professionals and their patients on the intertwining of self-management in their daily practice will be presented. Next, elements of self-management within specific programme components will be discussed. The third part of this section will report on the satisfaction levels of both the therapists and the patients concerning the programme. Lastly, the question of whether and where any improvements could be made shall be addressed.

Self-management in general

Therapists' views on self-management in general

During the interviews, it became apparent that there was a consensus among the professionals that patients are able to become self-managers. Moreover, they unanimously affirmed the importance of the concept in general. When asked to grade this importance, all of the professionals assigned the maximum score (10). At the same time, the professional team identified tension that arose from the disconnect between the importance accorded to the concept and the difficulty they had in determining a clear and mutually held vision of self-management that could be conveyed throughout their programme, as illustrated by the following quotes:

"Self-management is managing your life... on everything, like... medication, illness, social life, lifestyle, everything... asking for help,...the goals of a person, that for me is managing your life". (Professional 1)

"We tell them that we use self-management... and we link it immediately to thinking, feeling and doing as a means to an end to see... well... the problems that are experienced or the limitations; the things in life that are not going smoothly - how can you turn them around?". (Professional 2)

"Being in control, taking more initiative... being responsible or feeling more responsible for their own choices". (Professional 4)

"... Giving knowledge that people need to have to make choices, we have to give that". (Professional 1)

The quotes above illustrate the difficulties faced by professionals who work with the concept of self-management. They have to bring different aspects of self-management to the fore, all of which are somehow related to aspects of the lives of cancer survivors. To enable cancer survivors to handle that life, self-management needs to be connected to a set of skills required by patients to regain control of their lives after cancer treatment. Furthermore, they mentioned elements connected to a healthy lifestyle and those needed to deal with limitations. Sometimes, self-management was even seen as an attitude when it means taking responsibility for being a cancer survivor. Explicit skills relating to self-management that were mentioned were making choices and setting deliberate goals. Implicit problem solving was foregrounded in the notion of 'turning things around'. The professionals commented that 'setting goals' and 'problem solving' were previously explicit elements of the self-management programme currently being studied.

Patients' views on self-management in general

During the interviews, the patients discussed self-management from different perspectives, but they always referred to it implicitly. They did not talk about explicit self-management skills, such as solving problems or asking for help. This absence of named explicit self-management skills could be a consequence of the failure to impart these specific explicit skills within the programme, as indicated by the professionals discussed above. Moreover, the lack of agreement on the content of the concept of self-management among the professionals could play a role in the evident implicitness of self-management skills imparted to patients during the rehabilitation process.

That said, it was interesting to observe how the patients described self-management during the interviews. They related elements they had learnt during the physical training and psycho-education components to the concept and described how they had integrated them into their daily lives. An example is the so-called traffic light; a metaphor used by professionals to teach patients how to indicate their own limits. The green light represents the level that is attainable by the patient, orange is the level at which limits are understood and action must be taken, and red is the zone that the patient should avoid. When the patients' limits are exceeded, there are consequences, such as physical discomfort. However, some patients stated that the traffic light did not apply to them but that the term 'self-management' was very powerful in itself. As the following quotation illustrates, these patients' understanding of the concept had become part of their lives.

"Those words do help. I cancelled something this week. I never do that. I am very dutiful that way. But I was so tired that morning and we had some evening plans. I thought I am not going to make it; I do not have the energy. So, I skipped rehabilitation for a day. I was so surprised that the professionals were proud of me that I made that choice". (Patient 1)

The fact that this patient economised the little energy she had that day by skipping rehabilitation was seen as a valid act of self-management by the professionals.

Contentment and improvements on self-management in general

Evidently, the professionals considered self-management very important and clearly saw the value that it added for their patients, but they had difficulty imparting the concept in a uniform way. They saw the need to make an effort to clarify their mutual vision. Because of the ambiguity resulting from a lack of uniformity, the patients individually extracted elements they considered important from the self-management programme. As a result, patients do go home with some self-management tools. However, considering that self-management skills were offered predominantly in an implicit manner, room for improvement still remains. For example, by making the providing self-management skills in a (more) explicit way.

The professionals also talked about several improvements that needed to be made to the programme. Firstly, they felt that more attention should be paid to acquiring insight into the internal motivations of patients prior to their admission to the rehabilitation process. It was believed that this might positively influence the group dynamics. The second improvement they proposed related to the ambiguity mentioned earlier. As the following quote illustrates, the professionals were well aware of where improvements could be made within the programme.

"We agree with the big picture concerning self-management, but we do not know in detail what the other team members do". (Professional 5)

Therefore, they see the concept of self-management as being too loosely defined in the context of their teamwork.

The patients were also asked whether they saw any room for improvement in the self-management programme now that they had completed it and had a clear idea of what they could achieve. A major improvement that they suggested was a significant prolongation of the programme. They felt that such a prolongation could perhaps be done intuitively, indicating that the behavioural changes necessary to live with residual symptoms of cancer and the treatments they had endured had been initiated but that in the near future, they would welcome some further support.

Self-management in the physical part of the programme

The physical part of the rehabilitation programme comprises a cycling protocol and sports activities offered in the sports hall. This section describes how self-management takes shape both within the cycling protocol as well as the activities offered in the sports hall.

The cycling protocol

The therapists mentioned that within the cycling protocol, the patients use heart rate monitors and the Borg Rating of dyspnoea and exertion along with training logs to track and evaluate their progress during the cycling exercise. The training intensity during the cycling activity is determined using the Karvonen protocol, which enables the heart rate to be calculated during training, from the peak heart rate obtained during the baseline graded exercise test to the resting heart rate. These elements are in line with the original programme (Korstjens et al., 2008; May-de Groot, 2008).

During the interviews, the professionals mainly expressed satisfaction with the monitoring of progress during the cycling protocol and the workbook that they used for this purpose, as is illustrated by the following quote:

"The workbook contains some theory which we lecture in the information module, so people can read it again if they have problems remembering all the information at once. There are also worksheets in the book. For example, they write down before their bicycle training starts how they score on fatigue and dyspnoea based on the Borg Scale. Also, the results of the training are written down. During sports and games, they write down how much fun they had during these activities". (Professional 4)

Patients also spoke about the monitoring of their activities in the cycling protocol, noting that monitoring leads to insight into the training and their progress. This view is expressed in the following quote:

"... And then you take the next step, the next time. I mean... it is written down on paper, you have it all there... You have it all clear how it is and what you do... and that is stimulating". (Respondent 11)

In addition to monitoring, professionals also associated the fact that patients are given opportunities to make choices concerning the workload of the training with self-management. However, the opportunity to make these choices is only offered to patients later in the rehabilitation process.

For example, the professionals stated that they envisaged a patient making choices on the percentage of the Karvonen protocol that is incorporated into the bicycle protocol according to whether they were having a good or a bad day as an act of self-management, as expressed in the following quote:

"It is also visible in the bicycle training. At the end of the rehabilitation process, you give them more options, so they can choose for instance the percentage of training". (Professional 2)

The sports hall

Professionals feel that with the activities performed in the sports hall they can teach their patients how to deal with the limitations that having or having had cancer entails. The professionals indicated that patients' experience of 'success' is essential in this part of the programme.

"It is all about people experiencing success and exploring from there, because if you have had success, then I can teach you something new and provide you with a new challenge". (Professional 5)

To create the right circumstances, the professionals tuned into the competences of their patients at both the physical and the emotional levels, as illustrated by the following quote:

"We are fairly good at tuning in at the level of the patient group and also at an emotional level... By observing really closely and looking at the way patients participate, we can make little adjustments in the programme, so it becomes just a bit more fun and they are addressed at their level". (Professional 5)

Thus, through their ability to tune into the capabilities of the patients, the professionals felt that they were creating a safe environment in which self-management could be addressed. The professionals stated that by excluding failure and enabling patients to experience success, the patients regained the necessary confidence to address those boundaries by making appropriate choices and decisions. Here, the professionals referred to Bandura's Social Cognitive Theory in which the importance of the experience of success and mastery is stipulated. This theory is also among the foundational theories underlying the concept of self-management in the original programme (Bandura, 2005; Bandura & Adams, 1977; Lorig & Holman, 2003).

Contentment related to the physical component of the programme

The professionals expressed satisfaction with the physical component of the programme. They explicitly mentioned the cycling training protocol in which patients strictly follow steps for getting fit. Peak heart rates obtained from baseline graded exercise testing and heart rates at rest are used to calculate training heart rates. The training of participants who chose improvement of exercise intensity gradually increased. During the training sessions, a computerised system is used to monitor the patients' heart rates to adjust the workload if necessary, to prevent over or under training by the patients. Their level of contentment is illustrated by the following quote:

Professional 4: *"I love our cycling training protocol, which makes our approach very standardised. I feel the protocol brings great results, but I also love the flexibility we have to deviate from the protocol."*
Moderator: *"Can you tell us more about that protocol?".*
Professional 4: *"We follow a strict protocol implementing the bicycle training, I mean in time; what steps have to be taken by the patients, and it really works for this group. But there are always people who are the exception, and then we have the flexibility to adjust the protocol".*

The professionals also had a positive view of the sports activities in the sports hall. They felt that in the sports hall, they could teach their patients how to deal with the consequences of having had cancer. By performing these sports activities, patients learnt to recognise, acknowledge and explore the newly established boundaries. Skills like making choices are central elements in these activities. The professionals offer patients several techniques to help them address these boundaries, for instance, the previously mentioned traffic light metaphor. This is illustrated by the following quote:

"Often people who get sick have the notion that everything has to be as it was before they got sick. They forget that they have had intensive treatment, and they do not know any more what their body can do. What they can rely on. By using 'the traffic light', they can give more meaning to what they feel and, on that basis, they can make choices". (Professional 4)

Patients also spoke highly about the physical component of the programme and the effects that physical exercise had on them. Apart from pointing to physical fitness, reduced fatigue and the regaining of muscle strength, the patients addressed the more psychological effects of the training. Elements like regaining confidence and having fun exercising were some of the effects that were mentioned, as illustrated by the following quote:

Patient 1: *"... She had a world record last week!"*
Patient 2: *"Yes, I did! Yes, it is because you are having fun that you get the courage to go on... Half October... no, at the end of August... I still needed a wheelchair so uhm... Now I have the courage and I think that I can do it and I have the courage".*
Patient 5: *"Yes, yes, I feel the same".*

Improvement related to the physical component of the programme

Few remarks were made on improving the physical component of the programme. However, professionals did observe that although the cycling training protocol gave patients an opportunity to train safely according to evidence-based physiological principles, they felt a tension existed between the strictness of the protocol and their wish to implement self-management within the physical component of the programme. They could not indicate clearly in what manner and where to put self-management into practice within the strict format of the cycling protocol. Although this protocol produces great results to the therapists' satisfaction, this satisfaction can hardly be linked to self-management. Following a strict protocol to get patients fit and offering self-management, where adapting to the capriciousness of a chronic disease is most important, seem to be at odds with one another.

The general views of therapists and patients on the psycho-educational component of the programme

The psycho-educational component consists of peer contact focused on learning from each other's experiences during organised group sessions. The topics discussed are brought to the fore by the therapist, but patients can also bring their own topics to the table. Common topics are work, children, relationships with loved ones and the negative experiences of patients with doctors in the hospital and with occupational physicians during their reintegration into a work situation. The professionals related peer contact and the accompanying group dynamics to self-management. They told us that the group dynamics are a very important aspect when it comes to making modelling and peer contact a success. One of the professionals said:

"Sometimes there is a group, they are already so in tune with each other, that as professionals you step down. You only guide what is happening, but that is all". (Professional 2)

So, it seems that the group dynamics thrive, sometimes even without interventions by the professionals. The professionals also connect peer contact with modelling, and both are seen as important elements of self-management. When asked if they explicitly take action to enhance group dynamics, they responded that in the case of modelling, they sometimes explicitly ask for recognition within the group, which refers to the component of social comparison, an element of modelling (Bandura, 2011).

The professionals also expressed some reservations concerning the composition of groups in relation to self-management, which is an important consideration for achieving maximum benefit from peer contact as can be extracted from the following quotes:

"But there is also the aspect wherein we put young and elderly persons together in one group... and that does not make it easy at times". (Professional 3)

"Yes, putting the young and the elderly together can work out positively, but also negatively". (Professional 4)

"... And especially the different stages of coping with experiences can have a negative influence". (Professional 2)

When asked if the group composition was controlled, the professionals told us that this was not the case, as the composition of the groups was determined by the patient inflow. The patients also valued peer contact as one of the most important elements. The following view of a patient is illustrative:

"Yes, I felt supported. Yes, you hear tips and tricks, and you do find recognition regarding a great variety of topics... uhm... the little pains, things you bump into or... yes, I thought that was really nice". (Patient 5)

However, the patients also expressed the view that group composition is an essential factor for maximising the success of peer contact, as illustrated in the following quote:

"... And it frustrates me you know... with breast cancer well... there is so much information available and everybody... uhm... and what I have, well there is nothing. And that is... well, that is lonely". (Patient 4).

The patients stated that there were considerable differences among the various kinds of cancer and that relating to each other only on the basis of having had cancer was not enough to recognise commonalities in each other's process. The issue of age was not mentioned by the patients.

The professionals also connected self-management with the ability to control emotions. Being a cancer survivor was considered by the team to be an event accompanied by overwhelming emotions like anxiety and uncertainty about the future. Patients can be completely overwhelmed by these emotions, as illustrated by the following quote:

"Sometimes you talk about what has happened in someone's life; what has been difficult. And sometimes old wounds burst open again, which is not that strange. It is annoying, but not strange... and telling someone that the brain works that way... and that they will find an adequate coping strategy.... taking some rest or just finding distraction... and then it will become clear to someone like... yes that happened to me before and I coped with it in a certain way, and I can do that again". (Professional 3)

By naming these emotions and normalising them, the professionals helped their patients to put them into perspective. By reflecting with their patients and teaching them how to deal with their emotions, they supported them in the area of emotional management, which is one of the three domains of self-management as defined by Lorig and Holman (2003).

The patients articulated the view that getting a grip on all of the emotions associated with getting and having cancer was definitely part of the programme and that it had helped them a lot, as expressed in this quote:

"The psychologist said to me when I was speaking of my fear, "Why don't you say I am scared and leave it at that"? No buts, just a period. It was a simple thing, but it really helped me". (Patient 2)

By just letting the patient be afraid and leaving it at that, the psychologist provided validation for these feelings. After all, it is quite normal to be afraid when recovering from cancer.

Contentment related to the psycho-educational component of the programme

The professionals were pleased that the programme was offered in a 'closed group', as this structure created an environment in which the peer contact that they valued was possible. This point was highlighted in the following quote:

"I really think that . . . the fact that it is a closed group [means] that people can learn a lot from each other. Having peer contact is very important". (Professional 3)

The patients expressed their satisfaction in terms of their accomplishment of the mostly social and psychological 'goals'. There is a cluster of quotes centring on the topic of acceptance of survivorship or dealing with being a cancer survivor. Examples included the following:

"I am not 100% recovered, but I do have balance for 100%". (Patient 8)

"Having the courage to go on". (Patient 3)

"I have to stop fighting so much and [to stop] crossing my boundaries all the time". (Patient 1)

"I have learnt that doing one thing means letting another one slide". (Patient 13)

"I have more acceptance that the situation from before I had cancer will not come back". (Patient 12)

These were all considered achievements by the patients, who also said that they were content to have the insight needed to execute cognitive skills like planning and talking with other people.

Improvements related to the psycho-educational component of the programme

The professionals saw room for improvement regarding the composition of the groups. They stated that patients with comparable personalities and levels of internal motivation should be placed together, as they felt that this would influence group dynamics positively. The patients also spoke about the composition of the group, expressing their preference for adequate group size and greater group homogeneity relating to their diagnoses. Another aspect that they considered relevant to the success of acquiring self-management skills, and even for the rehabilitation process in general, was their perception that patients should not start their rehabilitation too soon after the cancer treatment. This point is highlighted in the following extract from the transcript of a conversation among the patients:

Patient 1 (talking to Patient 4): *"I think in your situation, you started too early".*
Patients 2 and 5: *"Yes!".*
Patient 4: *"Yes. I think so too now, but...".*
Patient 2: *"I think maybe even two months... At least two months too soon...".*
Patient 1: *"Yes... I think you have to recover first, and you started immediately... when your chemo was done; you started here, and I really felt that it was too much too soon".*

Finally, the patients suggested that psycho-education should be offered within a more standardised programme. They stated that a 'protocol' should be developed for the psycho-education component of the programme, just like the one they had during the cycling training, that would be considered an improvement by them.

CONCLUSION

By using the technique of focus group interviews we were able to articulate how self-management is embedded into the daily practices of a local oncology rehabilitation practice. Giving words to the views of professionals and patients on how self-management was intertwined with several programme components revealed that implementation of self-management within oncology rehabilitation is a complex process.

It became clear that professionals relate self-management to the capacity to live a satisfying life as a cancer survivor. To do so, patients need to be equipped with the knowledge and skills needed to live a healthy active life, manage their emotions and deal with newly established boundaries. These aspects are dealt with within different components of the rehabilitation programme. Patients related self-management to different elements and skills learnt in rehabilitation like making choices, asking for help and problem solving.

Both professionals and patients expressed their satisfaction with the physical component of the programme. The cycling training protocol provides the necessary inputs to get fit, while the activities in the sports hall give patients the opportunity to deal with the boundaries imposed on them. In the psycho-educational programme component, peer contact was highly valued both by professionals and patients. Speaking of possible improvements, the professionals stated that a clear and mutually agreed vision on self-management in general was needed, and that these ideas needed to be embedded in the physical as well as the psycho-educational programme components. Another improvement suggested by both professionals and patients concerned the composition of groups, which they felt should be of an appropriate size and more homogeneous to stimulate group dynamics. Finally, patients noted that they would like the psycho-educational programme component to be more structured and, importantly, of longer duration.

DISCUSSION

Although the sample for this study was relatively small, with the accompanying methodological consequences, its findings can make a valuable contribution to the central discussion, namely how a complex concept like self-management is implemented in the daily activities of an oncology rehabilitation practice. The words of the professionals and patients clearly reveal that self-management is interwoven into the various components of daily practice in ways that are predominantly implicit. Moreover, the implementation of the concept of self-management was found to be fairly complex, with the ambiguity of the concept, both within the scientific literature and in practice, creating a gap between evidence and practice, leaving much room for its (mis-)interpretation by therapists. Thus, in order to improve self-management practices in the future, it is important to resolve issues that make it possible for these 'misinterpretations' to arise. Before a possible solution is presented, however, two examples of the aforementioned 'misinterpretations' and an unresolved problem that was highlighted by interviewees will be presented.

The first 'misinterpretation' has to do with monitoring progress, making choices and related decisions. All of these issues were mentioned by the interviewees and can be linked to self-management as described in the literature (Lorig & Holman, 2003; Lorig et al., 1999). Monitoring the progress of patients is explicitly addressed in the physical component of the programme, namely the cycling protocol. For example, to safeguard patients' well-being during the cycling protocol, they are attached to a heart rate monitor and their activity is supervised using a computerised programme. If their heart rate exceeds a certain limit, the training workload is automatically adjusted by this computer programme. The cycling protocol is set up in this way to lift the patients to a higher level of physical functioning within a relatively short time without overloading them. Especially at the beginning of the rehabilitation process, patients still have to learn to guard their newly set limits.

However, when this protocol is examined from a self-management perspective, it becomes apparent that the patients cannot actually take any action themselves. Therefore, it can be concluded that the elements of making choices and decisions, which are important for self-management, are marginalised. Consequently, the tension indicated by the therapists during the interviews about where self-management should fit within the cycling protocol is completely understandable.

That being said, the activities in the sports hall afford much more leeway, as monitoring and making choices and decisions are all interwoven into this component of the therapy. According to the way that the activities in the sports hall were presented, patients experienced their often-new-found boundaries and learnt to address and respect them themselves, independently from a computer programme.

The second misinterpretation concerns the psycho-educational component of the programme. As the results have shown, self-management in the eyes of the professionals is mainly about acquiring cognitive behavioural skills. To teach their patients these skills, they offer them opportunities to address various problems that they encounter in their daily lives. Techniques mentioned by the professionals to stimulate this process included peer contact, modelling, questioning and coaching. Although peer contact and modelling have quite different meanings, the professionals used these terms interchangeably. Having peer-to-peer contact means that, amongst other things, patients can learn from and find recognition in each other (Lockhart et al., 2014). Although this can be very enlightening for them, it does not automatically lead to a situation in which modelling can take place. In order for modelling to be possible, certain conditions, such as the existence of the possibility of social comparison and a close resemblance to the model, must be met (Bandura, 1977; Lorig & Holman, 2003; Maine et al., 2017). When choosing to implement the modelling possibility in practice, these specific conditions have to be considered.

Finally, an unresolved issue that came to the fore in the interviews needs to be addressed. Professionals indicated that they sometimes have to deal with the ‘unmotivated patient’. They stated that they do everything they can to get these patients on board, but one group of patients could not be persuaded to do the work necessary to ensure that the rehabilitation process was a success. What the professionals also pointed out was that with this particular group of patients, they found it very difficult to determine the real reason(s) why this group remained unmotivated. If a patient is not motivated, they will not get the most out of the rehabilitation process and will be more likely to be referred to rehabilitation for a second or third time. This situation is problematic from several perspectives. Firstly, from the perspective of the patient, an unsuccessful rehabilitation process does not yield any benefits. Secondly, from the perspective of an already increasingly burdened health care system, patients having to undergo a rehabilitation process multiple times is far from cost effective. It is therefore important to determine what factors cause a patient to be ‘unmotivated’.

In light of the above discussed misinterpretations and unresolved problem, the discussion will now focus on one of the solutions put forward in the scientific literature.

Some scientists have suggested that closer cooperation between scientists, health professionals, patients and other stakeholders could potentially narrow the gap between scientific evidence and practice (Green, 2009; Thomas et al., 2014; Van Twillert et al., 2009). The assigning of professionals to guide these collaborations could be included as an additional part of this solution. Professionals who are able to translate scientific information applicable to practice and are able to involve therapists, patients and other stakeholders in the development and implementation of valuable interventions. How such a 'knowledge translator' could bring about potential benefits and thus contribute to the clarification of the aforementioned misinterpretations and problems is explored below.

In the case of the first misinterpretation, the knowledge translator could resolve the tension felt by the therapists by demonstrating that the achievement of aspired self-management goals in the cycling protocol are better served in a setting that is more compatible with these goals. The physical goals set by the cycling protocol require a safe and standardised setting, in which there is not a lot of leeway for making choices and decisions and therefore not that valuable to the education of self-management skills. The knowledge translator could make a contribution by clarifying where and when the offering of self-management skills could benefit patients the most in the rehabilitation process.

To resolve the second misinterpretation, a knowledge translator could support therapists by helping them to identify and understand factors that could influence group dynamics, in addition to those already mentioned in the results. Then, together with the therapists, the knowledge translator could assist in creating groups that take these specific factors into account, instead of using the order on the waiting list (as is currently often the case in health care).

Finally, the possibilities brought to the table by such a knowledge translator in solving the problem of the 'unmotivated patient' merit some discussion. This individual could facilitate the gathering of insight into this specific group of patients. For example, a knowledge translator could contribute by searching for factors that could be of importance in explaining a lack of motivation. One such factor could be the grieving process that accompanies the acquisition or worsening of a chronic condition (Murray, 2001). Grief can lead to behaviour such as loss of concentration, anger, irritability and lack of interest in taking action (Walsh, 2022). When mourning is a factor that plays a role in explaining why a patient is unmotivated, it could be wise to incorporate theories about mourning explicitly into the practice of rehabilitation (Eisma & Stroebe, 2017; Murray, 2001). The 'different stages of coping' of patients, as noted by the interviewees, could also be investigated. Such patients may not yet be ready to start a rehabilitation process. If this explanation for patients being 'unmotivated' is valid, then theories on behavioural change ought to play an explicit role in rehabilitation (Prochaska et al., 2008; Wen et al., 2019).

To conclude, this research has shown that explicitly translating evidence into practice in a cancer rehabilitation programme requires both science-based and practice-oriented perspectives (professionals and patients). The findings of this study have shown that this type of research clarifies and concretises concepts such as self-management when applied in practice. These concrete ideas are also important for developing interventions to integrate self-management skills explicitly into practice so that professionals can convey an unambiguous message and patients can go home equipped with concrete skills. This research has also illustrated the possible added value of having a knowledge translator act as a mediator in the process of narrowing the gap between knowledge and practice.

REFERENCES

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*. https://doi.org/10.1037/0033-295X.84.2.191

Bandura, A. (2005). The Evolution of Social Cognitive Theory. In Smith, K.G. & Hitt, M.A.(Eds), *Great Minds in Management*, 9-35, Oxford: Oxford University Press.

Bandura, A. (2011). Social cognitive theory. In: Van Lange, Paul A.M., Higgins. E. Tory, Kruglanski, Arie. W. (Eds), *Handbook of Theories of Social Psychology*, 349-373. https://doi.org/10.1037/13273-005

Bandura, A., & Adams, N. E. (1977). Analysis of self-efficacy theory of behavioral change. *Cognitive Therapy and Research, 1*(4), 287-310. https://doi.org/10.1007/BF01663995

Bjørkedal, S. T. B., Eplov, L. F., & Møller, T. (2021). The missing link-participants' perspectives on transfer from psychosocial interventional contexts to everyday community life: a qualitative synthesis of interventional studies. *BMC Psychology, 9*(1), 1-15. https://doi.org/10.1186/s40359-021-00567-w

Boogaard, L., Gater, L., Mori, M., Trincao, A., & Smith-Turchyn, J. (2016). Efficacy of self-management programs in managing side effects of breast cancer: A systematic review and meta-analysis of randomized control trials. *Rehabilitation Oncology, 34*(1), 14-26. https://doi.org/10.1097/01.REO.0000475835.78984.41

Cuthbert, C. A., Farragher, J. F., Hemmelgarn, B. R., Ding, Q., McKinnon, G. P., & Cheung, W. Y. (2019). Self-management interventions for cancer survivors: A systematic review and evaluation of intervention content and theories. *Psycho-Oncology, 28*(11), 2119-2140. https://doi.org/10.1002/pon.5215

Eisma, M. C., & Stroebe, M. S. (2017). Rumination following bereavement: an overview. *Bereavement Care, 36*(2), 58-64. https://doi.org/10.1080/02682621.2017.1349291

Fredette, S. L. (1990). A model for improving cancer patient education. *Cancer Nursing,13* (4),207-215. https://doi.org/10.1097/00002820-199008000-00001

Friese, S. (2019). *Qualitative data analysis with Atlas.ti* (third edit). Los Angeles: SAGE Publications Ltd.

Green, L. W. (2009). Making research relevant: If it is an evidence-based practice, where's the practice-based evidence? *Family Practice, 25*(SUPPL. 1), 20-24. https://doi.org/10.1093/fampra/cmn055

Kidd, L. A. (2014). Consequences, control and appraisal: Cues and barriers to engaging in self-management among people affected by colorectal cancer - a secondary analysis of qualitative data. *Health Expectations, 17*(4), 565-578. https://doi.org/10.1111/j.1369-7625.2012.00785.x

Kim, S. H., Kim, K., & Mayer, D. K. (2017). Self-management intervention for adult cancer survivors after treatment: A systematic review and meta-Analysis. *Oncology Nursing Forum, 44*(6), 719-728. https://doi.org/10.1188/17.ONF.719-728

Korstjens, I., May, A. M., Van Weert, E., Mesters, I., Tan, F., Ros, W. J. G., ... Van Den Borne, B. (2008). Quality of life after self-management cancer rehabilitation: A randomized controlled trial comparing physical and cognitive-behavioral training versus physical training. *Psychosomatic Medicine, 70*(4), 422-429. https://doi.org/10.1097/PSY.0b013e31816e038f

Lagergren, P., Schandl, A., Aaronson, N. K., Adami, H. O., de Lorenzo, F., Denis, L., ... Ulrich, C. (2019). Cancer survivorship: an integral part of Europe's research agenda. *Molecular Oncology, 13*(3), 624-635. https://doi.org/10.1002/1878-0261.12428

Lockhart, E., Foreman, J., Mase, R., Heisler, M. (2014) Heart failure patients' experience of a self-management peer support program: A qualitative study. *Heart & Lung: Journal of acute and critical care 43* (4). 292-298.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P. L., ... Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med. *Medical Care, 37*(1), 5-14. https://doi.org/10.1097/00005650-199901000-00003

Lorig, K. R., & Holman, H. R. (2003). Self-Management Education : History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01

Maine, A., Dickson, A., Truesdale, M., & Brown, M. (2017). An application of Bandura's 'Four Sources of Self-Efficacy' to the self-management of type 2 diabetes in people with intellectual disability: An inductive and deductive thematic analysis. *Research in Developmental Disabilities, 70*(April), 75-84. https://doi.org/10.1016/j.ridd.2017.09.004

May-de Groot, A. (2008). *Rehabilitation in cancer: Training and talking? Effects of physical training versus physical training combined with cognitive-behavioural therapy.* University of Utrecht.

McCormack, L. A., Treiman, K., Rupert, D., Williams-Piehota, P., Nadler, E., Arora, N. K., ... Street, R. L. (2011). Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach. *Social Science and Medicine, 72*(7), 1085-1095. https://doi.org/10.1016/j.socscimed.2011.01.020

Mix, J. M., Granger, C. V., LaMonte, M. J., Niewczyk, P., DiVita, M. A., Goldstein, R., ... Freudenheim, J. L. (2017). Characterization of Cancer Patients in Inpatient Rehabilitation Facilities: A Retrospective Cohort Study. *Archives of Physical Medicine and Rehabilitation, 98*(5), 971-980. https://doi.org/10.1016/j.apmr.2016.12.023

Mullan, F. (1984). Re-entry : The Educational Needs of the Cancer Survivor. *Health Education Quarterly* , SPRING 1984 , Vol . 10 , Special Issue: Cancer Patient Published by: Sage Publications , Inc . Stable URL : https://www.jstor.org, 10 (Spring), 88-94.

Murray, J. A. (2001). Loss as a universal concept: A review of the literature to identify common aspects of loss in diverse situations. *Journal of Loss and Trauma, 6*(3), 219-241. https://doi.org/10.1080/108114401753201679

Prochaska, J. O., Wright, J. A., & Velicer, W. F. (2008). Evaluating theories of health behavior change: A hierarchy of criteria applied to the transtheoretical model. *Applied Psychology, 57*(4), 561-588. https://doi.org/10.1111/j.1464-0597.2008.00345.x

Reb, A., Ruel, N., Fakih, M., Lai, L., Salgia, R., Ferrell, B., ... Sun, V. (2017). Empowering survivors after colorectal and lung cancer treatment: Pilot study of a Self-Management Survivorship Care Planning intervention. *European Journal of Oncology Nursing, 29*, 125-134. https://doi.org/10.1016/j.ejon.2017.06.003

Shapiro, C. L. (2018). Cancer survivorship. *New England Journal of Medicine, 379*(25), 2438-2450. https://doi.org/10.1056/NEJMra1712502

Smith-Turchyn, J., Morgan, A., & Richardson, J. (2016). The Effectiveness of Group-based Self-management Programmes to Improve Physical and Psychological Outcomes in Patients with Cancer: A Systematic Review and Meta-analysis of Randomised Controlled Trials. *Clinical Oncology, 28*(5), 292-305. https://doi.org/10.1016/j.clon.2015.10.003

Thomas, A., Menon, A., Boruff, J., Rodriguez, A. M., & Ahmed, S. (2014). Applications of social constructivist learning theories in knowledge translation for healthcare professionals: A scoping review. *Implementation Science, 9*(1). https://doi.org/10.1186/1748-5908-9-54

Van Dongen, S. I., de Nooijer, K., Cramm, J. M., Francke, A. L., Oldenmenger, W. H., Korfage, I. J., ... Rietjens, J. A. C. (2020). Self-management of patients with advanced cancer: A systematic review of experiences and attitudes. *Palliative Medicine, 34*(2), 160-178. https://doi.org/10.1177/0269216319883976

Van Twillert, S., Postema, K., Geertzen, J. H. B. B., Hemminga, T., Lettinga, A. T., Van Twillert, S., ... Lettinga, A. T. (2009). Improving rehabilitation treatment in a local setting: A case study of prosthetic rehabilitation. *Clinical Rehabilitation, 23*(10), 938-947. https://doi.org/10.1177/0269215509338125

Van Weert, E., Hoekstra-Weebers, J., Grol, B., Otter, R., Arendzen, H. J., Postema, K., ... Van Der Schans, C. (2005). A multidimensional cancer rehabilitation program for cancer survivors: Effectiveness on health-related quality of life. *Journal of Psychosomatic Research, 58*(6), 485-496. https://doi.org/10.1016/j.jpsychores.2005.02.008

Walsh, Katherine. (2022). *Grief and loss theories and skills for the helping professions* (third edit). Long Grove, Illinois: Waveland Press, inc.

Wen, S. L., Li, J., Wang, A. N., Lv, M. M., Li, H. Y., Lu, Y. F., & Zhang, J. P. (2019). Effects of transtheoretical model-based intervention on the self-management of patients with an ostomy: A randomised controlled trial. *Journal of Clinical Nursing, 28*(9-10), 1936-1951. https://doi.org/10.1111/jocn.14731

PART TWO

CHAPTER SIX

Serious gaming in rehabilitation practice: Could it solve a problem?

Feyuna F.I. Jansma, Robbert Sanderman and Ivo Wenzler

ABSTRACT

Background: Rehabilitation is a process of teaching and learning. Research has shown that many of the more psychosocially oriented aspects of rehabilitation are offered implicitly in the daily workplace. Since self-management also consists of psychosocial skills, this is also the case for these skills, which can be prohibitive in becoming a good self-manager.

Objectives: This chapter consists of two parts. The first part describes a literature study of the challenges in educational processes in healthcare and specifically in rehabilitation practice. In addition, we investigated whether gaming theories could offer a solution to the challenges in daily rehabilitation practice. The second part consists of describing the design process of a serious game called 'Think Along?'.

Results: The literature study shows that the information transfer between professionals and patients does not run smoothly. We articulated four reasons that make the information transfer difficult. The first reason is the shift in the patient's role from a passive consumer to an active participant. The second reason is that people learn in different ways, but in healthcare the number of ways of conveying information is limited resulting in a suboptimal learning environment. The third reason is that the skills patients learn are not taught in a comparable environment as their homes, not always in the right context, taught sometimes long before they can be used, and are not one-on-one transferable to the home environment. The fourth reason is that a rehabilitation centre is a care facility where the patient's health is a shared responsibility. Once at home, the patient is solely responsible with the accompanying difficulties. We also can articulate that adding gaming theories into the already existing network of theories could solve some of the information transfer issues.

Using the design process of Vincent Peters, we developed a theory-based analogue boardgame, called 'Think Along?', with the goal to offer problem-solving skills in an innovative and explicit way. The serious game will offer an opportunity to be an active patient, offers a new manner of information transfer, and gives patients the opportunity to experiment with different possible futures in a safe environment.

INTRODUCTION

The day-to-day practice of rehabilitation is about teaching and learning. Patients and professionals are together in a 'game' of providing or receiving information, treatments, and skills. The main goal is to enable patients to live their lives with their condition(s) and accompanying limitations to a maximum of functioning on physical, psychological, and social level. However, these outcomes are not that easy to accomplish. Sure, most patients leave the rehabilitation centre functioning satisfactorily, however it is well known that there is a decline of functioning when people are at home (Meijering et al., 2016; Pringle et al., 2008; Van Twillert et al., 2014). Being home and maintaining an active level of functioning is apparently not that easy.

One of the reasons for this decline could be that rehabilitation, despite all the efforts, is still a fairly biomedical oriented treatment, focused mainly on physical functioning. It seems that there is a lack of training in skills which patients enable to maintain newly adapted behaviour in the home environment. To address this issue rehabilitation embraced the concept of self-management. As described in our earlier research we know that the concept aims at the same major outcomes as rehabilitation does, but from a different, more social and psychological, point of view (Jansma et al., 2010).

The main assumption has always been that if patients learned the necessary skills to self-manage their condition in the rehabilitation centre, they should be able to execute these skills in their home-environment. The core skill of a good self-manager is problem solving (Lorig & Holman, 2003). Living with a chronic disease leads to daily challenges, so when patients are skilled in problem solving, they can meet those challenges head on. In the rehabilitation practice problem solving is offered as well in courses as in more implicit ways like coaching activities and communications in the day-to-day affairs (chapter four and five of this dissertation). Despite the efforts to educate patients in self-management skills the translation of these skills into the home environment is still hard.

So, the question at hand is how do we make people internalize self-management skills and translate these skills into their home environment? How do people become successful self-managers not only at the rehabilitation centre, but also at home? While trying to find answers to those questions we realized that providing information to patients about self-management is obviously all about teaching, learning and didactics. In order to get more insight into the subject matter of learning and teaching we looked over the fences of healthcare. We studied not only teaching and learning within health care but also in general. Having explored these subjects, we will introduce serious gaming as a potential treatment element in rehabilitation and we will look at opportunities and the potential serious gaming could have for the rehabilitation practice. Finally, we will illustrate this by describing the design process of 'Think Along?' as a theory-based analogue serious game, developed to enhance problem solving skills for people with a chronic condition.

Learning in general and specific in health care

When we look at how learning and teaching is done within health care over the years there are some essential reasons that might explain why the information given by the professionals is not always received by their patients as desired. The first reason is one of a historical nature. It was up into 1960s that physicians were the authority, responsible for the diagnosis, treatment and healing of patients (Hoving et al., 2010). A lot of patients in a rehabilitation centre today are very familiar with this approach; since it was the approach they grew up with. At that time there was no tradition of educating patients at all. Patients were seen as passive and were not expected to participate in their own treatment. There has been a shift away from a passive patient to an active, educated patient who is equal to their physicians and is expected to make decisions concerning their treatment.

Self-management is seen as an important approach to equip patients with the necessary knowledge and skills to become an active patient (Bodenheimer et al., 2002). There is no debate in literature about the importance of knowledge and skills and it is acknowledged that their acquisition is not easy. Changing behaviour is a process. The same goes for being an active patient. Both take effort and time. (Hill-Briggs, 2003).

The second reason of interest is the way patients process information. Kolb, for instance, identifies nine different manners of learning (Kolb & Kolb, 2009). All these different manners of learning described by Kolb have one thing in common, a spiral of experiencing, thinking, reflecting, and a sort of acting in a repeating manner. Even if the rehabilitation centre offers three or four different ways of information transfer, e.g., lectures, coaching, talking with each other and following bicycle protocols, some patients still do not get the information in the manner they process information best (chapter four and five of this dissertation).

The third reason that could explain why patients have trouble transferring information to the home environment is the difference between the learning environment (rehabilitation centre) and the execution environment (the home). Kriz states that learning always takes place in a concrete situation or environment (Kriz, 2003). In addition to that he points out that it is necessary to learn under multiple perspectives because that creates flexibility when crossing domain-specific knowledge is essential (Kriz, 2003).

It is safe to say that these elements are hard to achieve in the rehabilitation process. The rehabilitation centre is a care environment, and it is adjusted to its inhabitants. For example, in a rehabilitation centre help is never far away, the building in itself is adjusted by being among other things wheelchair accessible and day-to-day hassles like preparing your food are being taken care of. However, most of the houses of patients are not adjusted to the needs of patients. In addition, people are in general not that good in understanding and remembering information they receive out of context or long before they can make use of it (Barsalou, 1999). So, the skills patients learn are not taught in a comparable environment, not always in the right context, taught sometimes long before they can actually be used, and are not one-on-one transferable to the home environment.

In alignment with the third, lies the fourth reason. The rehabilitation centre is, as stated before, a care facility. During the time patients are treated there, there is a sense of shared responsibility between patients and their health care professionals. When patients are at home this shared responsibility is gone (Pringle et al., 2008). This can make the transfer of skills challenging since the patient is on his or her own in an environment that can be perceived as challenging (Meijering et al., 2016)

Finally, the fifth element is that we all know that knowledge does not automatically lead to action. The phrase knowledge leads to action suggests that this is a one-way street. This is not the case according to Crookall and Thorngate (2009). Action is as much the basis for knowledge as the other way around (Koestler, 2009; Phungoen et al., 2020) In addition, Gee (Gee, 2008) tells us that it is not effective to tell new learners everything. First, it is hard to get the message across by finding the right words to make people understand the new situation. Second, the new learners are without the actual context to really understand these words. Patients have not done the activities to which these words refer to in their new situation. Gee (Gee, 2008) addresses with his views the gap between knowledge and action. This gap may also be related to a split between the rational and the emotional part of human beings. Furthermore, it seems that emotions have a stronger impact on our actions than knowledge (Plass et al., 2020; Plass & Kalyuga, 2019; Tyng et al., 2017). In our Western culture we have an emphasis on supplying knowledge and the rationale while maybe the actual 'doing and the emotional' could lead to more action in the home environment.

So, getting the necessary information across is not simple. What can we do to make taking in of information more effective? During our research, the idea of developing a serious game became more and more relevant and interesting. Serious gaming has already had its entrance in health care including rehabilitation (Burke et al., 2009; Kato et al., 2008; Kharrazi et al., 2009; Martos-Cabrera et al., 2020; Thomas et al., 2020). There are serious games that specifically aim at the motor skills of patients, but also serious games that focus more on a psycho-social level. For instance, the game 'Re-mission', a video game in which young adults with cancer control a nanobot named Roxxie inside their own bodies. This serious game was designed to enhance treatment adherence like oral chemotherapy. Not only did the game improve treatment adherence, but also indicators of cancer-related-self-efficacy. In addition, playing Re-mission increased the knowledge of cancer in young adults and adolescents who were undergoing cancer therapy (Kato et al., 2008). Another more recent example is the serious game "Strong Together". Despite the fact that this serious game is not yet fully developed, the first results are encouraging. It seems that players are indeed learning how to better advocate for themselves in the complicated process of making decisions regarding their own care (Thomas et al., 2019).

Why serious gaming?

So, the question is can serious games help make patients the transfer from a passive patient to an active and educated self-manager? To get an answer to this question we need to look closer to what make games work. In the last decades there has been a lot of research on the working mechanisms of gaming. More than forty years ago (Malone, 1981) already claimed that people can learn through gaming. He demonstrated how games use challenge, fantasy, player control and curiosity to create intrinsically motivating environments. Richard Duke (2008) articulates that maybe the one most significant 'active substance' of gaming and simulation is that it is fun to participate in them. They employ hands-on learning and through group interaction they encourage mutual support (Hofstede et al., 2010). Notwithstanding this positive statements, the outcomes of the research on the working mechanism of gaming are lacking consensus (Caluwé De et al., 2008).

As we described in the previous paragraph the second reason that could hinder information transfer is that information is being processed in many ways (Kolb & Kolb, 2009). Gaming has the potential to develop a tight connection between thinking and doing (De Caluwé et al., 2008). Even more so, the learning cycle of Kolb is very useful in designing games, using games, and also in explaining the working mechanism of gaming. A game is constructed as a series of successive cycles with each cycle covering the Kolb learning cycle (Kolb & Kolb, 2009). These cycles are actually a spiral. This spiral learning is incorporated in most games through the structure of levels, with every next level being harder to do and to finish one level you need the experiences from the previous levels. Often leading to the ultimate challenge defeating an end-boss. De Caluwé emphasizes that the cycle of 'what will the decision be and how will I act' is executed by participants very frequently in games. This way of thinking and doing becomes tightly linked because people become aware of what they do and what their motives are (Caluwé De et al., 2008).

We also described in our third reason the problem that the learning environment (the rehabilitation centre) does not represent the living environment of the patients. According to Wenzler (Wenzler, 2008) simulation games are capable of providing a manner of visualizing and identifying the critical elements of a complex problem, in our case the problems of patients in their home environment. Games enable players to envision alternative futures and help them to get the big picture of their changed life. The fact that patients can better understand their problems and opportunities awaiting them in the future to the full, helps them build cognitive bridges to that future. The result is not only an increased awareness of possible futures, but also an increased ability to deal with complexity and uncertainty in general. Because games are iterative and experiential by nature, they allow patients to test different approaches within a safe setting. Games can help them learn how to perform in the future. By facilitating such rehearsals of the possible future and by helping them envision and explore a multitude of time paths, serious games can effectively help patients build 'memories' of the future. This experience then results in an increased ability to adapt to the changing environment, called home.

When discussing the fifth reason we described the gap between knowledge and action. This topic is also addressed with serious gaming. Gee states that good games give information 'just in time' and 'on demand', not out of the context of actual use or apart from peoples purposes and actual goals (Gee, 2008). He also expresses that any domain of knowledge is first and foremost a set of activities. Perhaps that is why the emotional elements of events within simulation and gaming give them such power and make them memorable long after the information has been exposed to the players.

When we compare the list of possible working substances connected with gaming and the reasons, we defined that could hinder information transfer in the rehabilitation process, we see a lot of similarities. This highlights the possibility that for the rehabilitation practice gaming could be a way to incorporate different manners of learning, making learning more situational and maybe narrowing the gap between knowledge and action. And as Gee articulated motivation is the most important factor that drives learning. If motivation dies, learning dies and the playing stops (Gee, 2003). That alone is reason enough to try.

The design process

As we demonstrated above serious gaming has great potential for the transfer of information in the rehabilitation practice. Because of this we set out to develop a simulation game in order to enhance the potential of learning problem solving skills by patients with a chronic condition. To stimulate these problem-solving skills, we created the serious game 'Think Along?' (in Dutch: 'Denk je mee?') based on the problems patients face on a daily basis. We called it 'Think Along?' because the game is about triggering the players to come up with solutions to their own problems and demonstrates to them through playing the serious game that when you think about problems together with other players that there are many solutions to one problem. Thereby tapping into another skill important in self-management, namely asking for help. To develop a good serious game a lot of decisions were to be made and a lot of material had to be organized. It is important to structure the design process to guide designers in making the right choices. For the design process of 'Think Along?' a structured design framework was used (Peters & Van de Westelaken, 2008). The steps in this framework are shown in table one and will be described in the paragraphs below.

Table 1: Checklist for the specifics of design

Steps	Topic of the steps
Step 1	Input for the background of the problem
Step 2	Goals of the simulation game
Step 3	The design process
Step 4	General considerations during the design process
Step 5	Elements of the simulation game
Step 6	Playing the game

Based on Peeters and Van de Westerlaken, 2011

Step 1: Input for the background of the problem

As stated in the introduction the rehabilitation practice deals with a decline in functioning when patients are at home. A more explicit attention to psycho-social elements could help, like self-management (Jansma et al., 2010). So, in the case of 'Think Along?' the focus is on problem-solving (D'Zurilla & Nezu, 2010; Nezu, 2004) as it is being recognized as one of the most important self-management skills (Hill-Briggs, 2003; Lorig & Holman, 2003). The general underlying assumption is that when patients get insight in their problem orientation and evolve their problem-solving skills, they will enlarge their self-management potential and the transition to their home environment should be smoother and more successful. To achieve this, the serious game must address problem solving skills in a way that will motivate and enable patients to incorporate these skills in their daily lives. This incorporation requires the serious game to be as realistic as possible. It has to be very easy for patients to connect the game to their own real-life situation. To ensure the required realism we used the observation notes the first author (F.F.I. Jansma) made during the years she worked in the rehabilitation centre as a human movement researcher, looking for self-management-stimulating and self-management-inhibiting elements in this specific setting. The encountered and perceived problems, which patients mentioned during interviews, were very useful during the development of the serious game as well. In addition to that we have asked some professionals from different wards of the centre to join a taskforce, with the goal of sharing experiences and expertise associated with the most common problems patients encounter in their home environment. This taskforce gave input during the whole design process, for instance every card made for the game has been put up for approval. The members of the task force also came up with new problems that our target group faces, and these have been added to the game. Based on their efforts, we have developed a serious game that is workable and effective in its intended setting.

Next to the closeness to patients' reality we also wanted to account for the fact that patients are not the only ones affected by a chronic condition. Their significant others, like partners, family and friends, have to be able to be part of the serious game. They also want their loved ones to be as well as possible. 'Think Along?' is designed in a way that allows this group to easily participate in the game. In doing so they get an idea of how their loved ones look at problems (negative or positive) and they experience and execute the problem-solving steps as well. Having experienced this process together in the game, they can be of help in the home environment, reminding their loved ones about the necessary steps to be taken.

Step 2: Goals of the serious game

It is very important, when designing a game, to have specific goals in mind. What are the objects of change that you as designer want to see in the target population, either individual players or the group as a whole? With 'Think Along?' we want to achieve four goals:

1. The players learn, execute, and experience the first two steps of the problem-solving model.
2. Create an engaging atmosphere where patients can learn from each other.
3. Create an atmosphere were health care professional and patients could share experiences and expertise.
4. Patients learn about their own problem-orientation.

The first goal is that the players learn, execute, and experience the steps of the problem-solving model (Nezu, 2004). The model consists of five steps. Namely, (1) problem definition and formulation, (2) generation of alternatives (creating a large pool of possible solutions), (3) best solution selection for a problem in each specific situation, (4) execution of the solution, and (5) the evaluation of results of the chosen alternative solution. If the problem was not solved, players had to go back to the alternative solutions they made up in step 2. 'Think Along?' incorporates the first two steps, definition and formulation and the generation of alternatives. Choosing the best solution, the actual implementation of the solution and the evaluation of results are not part of the serious game.

The second goal was to create an atmosphere in which the patients should discover that they can support each other, namely experiencing that the problems they encounter in their lives are not that unique and that they are not alone in their struggle with a chronic disease. We wanted patients, while playing the game, to start a dialogue with each other about the problems they perceive amongst each other. One of the ideas was that patients who are dealing with a disease longer, for instance, can help patients that were recently diagnosed.

The third goal. Whereas in the second goal we wanted to stimulate the interaction between patients, with the third goal we aimed at the interaction between health care professional and the patients. We wanted to create a situation where a health care professional could start a conversation with the patients about an already observed problem but had not yet discussed it with them. So, we wanted to stimulate a dialogue between patients and professionals, a sharing of experiences and expertise. To achieve this, the environment where the serious game is played must be safe. While at the same time playing the game will make even difficult problems more explicit and therefore to really learn, the serious game has to strike some nerves.

The fourth goal is that patients will get an idea about their problem orientation. Problem orientation is defined as a set of relatively stable cognitive-affective schemes that represent the person's generalized beliefs, attitudes, and emotional reactions about problems in his or her life and his or her ability to successfully cope with such problems. A problem orientation can be both positive and negative. When patients have a positive problem orientation, it means that they have the tendency to see problems as challenges, that they are optimistic and believe that problems are solvable. They perceive their ability to solve problems as strong, and they believe that successful problem-solving involves time and effort. Patients with a negative problem orientation have the tendency to see problems as threats. They expect problems to be unsolvable, and they have serious doubt about their ability to solve problems successfully (Nezu, 2004). Problem orientation has influence on patients' motivation to address problems in their daily life. The specific goal related to problem orientation within the serious game is that we, fully realizing that the problem orientation is quite fixed, wanted to make players aware of their problem orientation and that there is another way of looking at things. However, by playing the serious game with other people every participant sees and experiences both problem orientations. This way patients observe that there are different ways of perceiving a problem and this can be insightful.

Step 3: The design process

This is the step where the designer and the client decided on organizational and financial matters. This step was not about the content during this design process. The project of 'Think Along?' was part of a PhD trajectory and supported by a collaboration with scholars from a study course at the Delft University of Technology. In our case, the client, being the first author, and the designer were the same person, so deciding on organizational matters was not necessary. Financial matters were non-existent, because the designing of the serious game was part of the job of the first author.

Step 4: General considerations during the design process

After defining the background, goals and the design process, a lot of considerations had still to be made. We had to make decisions about players, group size, if we wanted to play with an avatar or not, how to create a safe environment, the logistics of the serious game in health care and finally the sensitivity of some problems the patients must deal with.

So, the first consideration concerns the players of the serious game which are patients of the rehabilitation centre. They will be adults who have a chronic disease that needs treatment. Some of them will be working, others won't. Some will have a progressive disease, others don't. When the game is being played for a specific group, it is most likely the players will have the same disease, because the rehabilitation is organized in a disease specific manner. Within the group people will differ on gender, age, life phase, stage of the disease and so on. Despite the disease specific organization of the rehabilitation, the serious game addresses a generic skill, being problem-solving. The intention during the design process has always been to play the game on every ward of the rehabilitation centre and preferably with patients with different diseases because we believe that there lies an additional opportunity to learn. The serious game is designed first and foremost for patients who are treated in a rehabilitation centre to improve their problem-solving skills. Nonetheless, as already stated before, the game is also designed for the health care professionals and for the social environment of the patients, for instance the spouses of the patients. As stated in literature a chronic disease affects the whole family (Fisher, 2006; Rosland & Piette, 2010)

The second consideration had everything to do with the group size. How many people can play the game at the same time? Important for us was that we wanted to incorporate the effect of learning from each other. So, the teams had to consist of minimum two persons. Playing the serious game one-on-one is possible, but probably less productive. Modelling is one of the ways to increase self-efficacy. For productive modelling people of widely differing characteristics are needed for patients to have a reasonable basis for increasing their own sense of self-efficacy (Bandura, 1977, 2011). As common sense tells us that there is a limit to a group size; learning by means of playing a serious game is best in smaller groups (Hromek & Roffey, 2009). For instance, with a too large number of players the game can get chaotic and provides the patients with the opportunity to sit back, which is of course detrimental to learning.

The third consideration was around the question if we wanted to play with real people having real problems. There were two options we considered. The first was that a player (patient) could bring a problem of his or her own to the fore. The second one was to let players deal with an avatar having a problem. We have chosen for an avatar, primarily based on the assumption that with an avatar there is some detachment from patients' personal life and that makes it easier to think about the problem itself. The consequence of choosing an avatar was that the problems are pre-set. As stated earlier, the problems presented in the serious game were extracted from the qualitative research done by the primary author.

The fourth consideration was linked with the fact that we wanted to create a safe environment where the players could learn. To do so we had to do something with the actual winning and losing of the game. The idea, based on the theories we used, is that patients when the serious game has ended, need to have more confidence in their problem-solving skills and may not be discouraged in any way. Therefore, we made it so that the winning of one team included a price that (a) did not mean that much and (b) was sort of for everybody. To meet those terms, we used something typically Dutch. We made tiles with a saying on it, so called Wisdom-tiles (see figure 1). This saying must be read out loud. So, the wisdom of it was for everybody. However, the stimulus to play and compete should not be forgotten, so the team with the largest number of Wisdom-tiles gathered during the game was the winner.

Figure 1: Examples of Wisdom-tiles

Je kunt wel voor elke
boom een beer zien,
maar dan durf je het bos niet
meer in.

(Erik Hulzebosch)

You can see a bear for every tree,
but then you won't dare to go
into the forest anymore.

(Erik Hulzebosch)

Wees niet bang om
langzaam voorwaarts te gaan,
wees alleen bang om stil te
staan.

(Oosterse wijsheid)

Don't be afraid to move forward
slowly, only be afraid to stand still.

Alle dingen zijn moeilijk
voordat ze makkelijk worden.

(Horatius)

All things are hard
before they become easy.

(Horatius)

The fifth consideration was about the logistics of playing the serious game. Therapy sessions last an hour in the rehabilitation centre, and we could not deviate from that. To use that hour as efficiently as possible the problems used in the serious game are very concrete and easy to understand. We did not want to lose too much time with the problem definition phase and wanted to save as much time as possible for playing the generation of solution phase. The last ten minutes of the hour are reserved for debriefing which is a very important element of serious gaming. During the debriefing we look back on what happened during the serious game and the reflection and coupling to the patient's own situation and home environment also takes place.

The sixth consideration was about the sensitivity of some problems. Can we address sensitive topics like, smoking, lifestyle or stigmas patients feel they have to deal with? Can we do that without interfering with the process of building their self-efficacy in their problem-solving skills? We decided that also the sensitive problems should be covered in the serious game. The therapist facilitating the game is the one deciding in the end if some problems are in the game or not. If the professionals consider a particular problem cannot be safely introduced in a specific group, they should be able to leave it out.

Last but not least, we had to deal with the fact that problems had to be formulated in such a way that they were easy to read for the players; meaning that the language used had to be comprehensible for everybody. We sought contact with experts on comprehensible language and used their guidelines to describe the problems in the serious game. In addition, to support the written language, we have added pictures that relate to the problem and thus provide additional clarification and visual assistance (see figure 2).

Step 5: Elements of the serious game

In this step we needed to think about the freedom of the players during the game. We decided to make the scenario of this serious game quite structured and therefore limit somewhat the freedom of the players for two reasons. One is practical and the other is theory based. The practical reason is that a structured game ensures that we don't lose a lot of time, which is important due to the way health care is organized in the Netherlands like we mentioned before. The theory-based reason is that we needed the patient to make and experience specific steps within the problem-solving model. So, the rules of the game are strict and do not give our players a lot of freedom. The players will be offered a couple of problems that they could very well experience in their own life. The problems are divided in three areas in which they have to self-manage; disease management, role management and emotional management (Lorig & Holman, 2000; Lorig & Holman, 2003) (see figure 1).

Figure 2: Examples of problem-cards as used in the game

Esmée is 25 kilo afgevallen. Ze voelt zich een stuk beter. De mensen om haar heen zijn trots op haar, maar ze denken dat het afvallen nu klaar is. Ze krijgt weer taartjes, patat, kaasjes en lekkere worst aangeboden. Ze vindt deze versnaperingen allemaal heerlijk en het wordt steeds moeilijker voor haar om nee te zeggen. Hoe kan ze de verleiding blijven weerstaan? Denk je mee met Esmée?

Desirée durft niet goed meer met haar vriendinnen af te spreken. Ze weet niet zeker of ze fit genoeg zal zijn op de dag van de afspraak. Ze vindt het heel erg om af te zeggen. Dan maar geen gezellige koffieochtendjes en leuke dinertjes meer afspreken. Maar dat kan toch eigenlijk niet! Denk je mee met Desirée?

Corné is na een lange periode van behandelingen en revalidatie weer voorzichtig aan het werk. Met de Arbo-arts heeft hij een re-integratie plan opgesteld. Maar zijn collega's lijken het idee te hebben dat hij weer helemaal terug is. Corné merkt dat hij hierdoor toch te veel doet en dat hij na een dag werken weer vreselijk moe is. Corné weet niet hoe hij dit moet veranderen. Denk je mee met Corné?

The problems are articulated in the same manner; a person (the avatar) has a problem and is bound to give up, but with help from the patients there might be a solution after all. Then the generation of solutions in the form of brainstorming commences. This is also limited in time. In this phase the players are as free as they wish to. We invite them to find as many solutions as possible for the stated problems. The serious game is cyclically structured with an increasing level of difficulty (spiral). The increasing difficulty of the serious game lies in the fact that the time in which the players can think about the actual problem they are going to play with and the time they can use to think of solutions becomes shorter with each round. This process of offering problems and finding solutions is repeated until the half hour play time is over. After debriefing the serious game is over.

Step 6: Playing the game

For the actual playing of the serious game there were some conditions to be met. As stated before, we wanted to design a serious game that was easy to play almost anywhere within the rehabilitation centre. To play this serious game, what we called 'Think Along?', all we needed is a table and chairs for the players and pen and paper. The game is embedded in the larger process of rehabilitation. The facilitators of the game will be the health care professionals. To be able to facilitate the game correctly they need didactic skills, observational skills and be able to generate a good and safe atmosphere. So, to equip the professionals with the necessary skills a workshop was developed by the first author. In this workshop, next to building the required facilitation skills attention is given to the theoretical basis behind facilitating the game in the manner we intended to. The serious game is based on the problem-solving model (D'Zurilla & Nezu, 2010; Nezu, 2004) and the social learning theory of Bandura (Bandura, 1977, 2001). It is eminent that the players leave the game with their self-efficacy intact. This will be part of the workshop the professionals have to take.

CONCLUSION

We wanted to explore the field of learning and didactics for reasons of improving the transfer of knowledge and skills from health care professionals to patients, which are necessary for the patients to become better self-managers in their home environment. We defined several pitfalls that had to be avoided during that process. First, we learned from a historical perspective that the expectations we have according to the active attitude of patients is recent. Only a few decades ago patients were expected to display an opposite behaviour, namely, to be passive and do as the doctor told them. Older patients need to actively make this shift from a more passive to an active attitude and this is something to be aware of as a health care professional. We all know that behavioural change takes time. We also learned that we have to take into account that patients have different learning styles. So, information should be offered in different manners if we want to get our information across. Next to that we found out that patients need to learn skills from multiple perspectives, and preferably learn them in various environments, since that creates the flexibility patients need in transferring knowledge and skills to the different domains in their lives. In addition, we articulated that the rehabilitation centre is a care facility and as such can inhibit the process of patients becoming good self-managers. For instance, the building is made to meet the needs of the patients and health care providers are educated to act accordingly, which is quite different from the home environment. In order to tackle some of the pitfalls mentioned before, we finally looked for a manner to expand the arsenal of health care professionals in providing the information needed. Serious gaming is a tool that could tackle some of the pitfalls articulated above. It contains a learning spiral and has the ability to create alternative futures, for instance. In addition, it is another way of getting the information across and it helps patients think about different problems they might encounter. And last but not least, gaming can help make patients motivated. Playing a serious game is fun for most of us and enables the players to move forward. In the following chapters the actual serious game, 'Think Along?', will be described and will implemented into the rehabilitation practice.

REFERENCES

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review.* https://doi.org/10.1037/0033-295X.84.2.191

Bandura, A. (2001). Social cognitive theory : An Agentic Perspective. *Annual Review of Psychology, 52*(1), 1-26. https://doi.org/10.1146/annurev.psych.52.1.1

Bandura, A. (2011). Social cognitive theory.In: Van Lange, Paul A.M., Higgins. E. Tory, Kruglanski, Arie. W. (Eds), *Handbook of Theories of Social Psychology*, 349-373. https://doi.org/10.1037/13273-005

Barsalou, L. W. (1999). Language comprehension: Archival memory or preparation for situated action? *Discourse Processes, 28*(1), 61-80. https://doi.org/10.1080/01638539909545069

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient Self-management of Chronic Disease in Primary Care. *Journal of the American Medical Association, 288*(19), 2469-2475. https://doi.org/10.1001/jama.288.19.2469

Burke, J. W., McNeill, M. D. J., Charles, D. K., Morrow, P. J., Crosbie, J. H., & McDonough, S. M. (2009). Optimising engagement for stroke rehabilitation using serious games. *Visual Computer, 25*(12), 1085-1099. https://doi.org/10.1007/s00371-009-0387-4

Caluwé de, L., Hofstede Gert Jan, & Peters, V. (2008). *'Why do games work?' In search of the active substance.* Deventer: Kluwer.

Crookall, D., & Thorngate, W. (2009) Acting, Knowing, Learning, Simulating, Gaming. *Simulation and Gaming. 40*(1), 8-26.

Duke, Richard. (2008). One perspective on the 'active substance' of gaming simulations. In: Caluwé de, L., Hofstede Gert Jan, & Peters, V. (Eds). *'Why do games work?' in search of the active substance.* 27-30. Deventer:Kluwer.

D'Zurilla, T. J., & Nezu, A. M. (2010). *Handbook of Cognitive-Behavioral Therapies*, Third Edition. (K. S. Dobson, Ed.). New York: The Guilford Press.

Fisher, L. (2006). Research on the family and chronic disease among adults: Major trends and directions. *Families, Systems and Health, 24*(4), 373-380. https://doi.org/10.1037/1091-7527.24.4.373

Gee, J. P. (2003). What video games have to teach us about learning and literacy. *Computers in Entertainment, 1*(1), 20. https://doi.org/10.1145/950566.950595

Gee, J. P. (2008). Game-like learning: An Example of Situated Learning and Implications for opportunity to learn. In Moss, P.A. et al. *Assessment, Equity, and Opportunity to Learn.* 200-221. Cambridge: Cambridge Universtiy Press.

Hill-Briggs, F. (2003). Problem Solving in Diabetes Self-Management: A Model of Chronic Illness Self-Management Behavior. *Ann Behav Med, 25*(3), 182-193. https://doi.org/10.1207/S15324796ABM2503_04

Hofstede, G. J., de Caluwé, L., & Peters, V. (2010). Why Simulation Games Work-In Search of the Active Substance: A Synthesis. *Simulation & Gaming, 41*(6), 824-843. https://doi.org/10.1177/1046878110375596

Hoving, C., Visser, A., Mullen, P. D., & van den Borne, B. (2010). A history of patient education by health professionals in Europe and North America: From authority to shared decision making education. *Patient Education and Counseling, 78*(3), 275-281. https://doi.org/10.1016/j.pec.2010.01.015

Hromek, R., & Roffey, S. (2009). Promoting Social and Emotional Learning with Games: "It's Fun and We Learn Things". *Simulation and Gaming, 40*(5), 626-644. https://doi.org/10.1177/1046878109333793

Jansma, F. F. I., Van Twillert, S., Postema, K., Sanderman, R., & Lettinga, A. T. (2010). Physical and rehabilitation medicine and self-management education: A comparative analysis of two approaches. *Journal of Rehabilitation Medicine, 42*(9), 808-814. https://doi.org/10.2340/16501977-0606

Kato, P. M., Cole, S. W., Bradlyn, A. S., & Pollock, B. H. (2008). A video game improves behavioral outcomes in adolescents and young adults with cancer: A randomized trial. *Pediatrics, 122*(2), e305-e317. https://doi.org/10.1542/peds.2007-3134

Kharrazi, H., Faiola, A., & Defazio, J. (2009). Healthcare game design: Behavioral modeling of serious gaming design for children with chronic diseases. *Lecture Notes in Computer Science* (Including Subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics), 5613 LNCS(PART 4), 335-344. https://doi.org/10.1007/978-3-642-02583-9_37

Kolb, A.Y., & Kolb, D.A. (2009). The Learning Way: Meta-cognitive Aspects of Experiential Learning. *Simulation & Gaming, 40*(3), 297-327. https://doi.org/10.1177/1046878108325713

Kriz, W. C. (2003). Creating Effective Learning Environments and Learning Organizations through Gaming Simulation Design. *Simulation & Gaming, 34*(4), 495-511. https://doi.org/10.1177/1046878103258201

Lorig, K R, & Holman, H. (2000). Self-Management Education: Context, Definition and Outcomes and Mechanisms. First Chronic Disease Self-Management Conference, (August), 1-19. Retrieved from http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/chronicdisease-conference.htm

Lorig, Kate R, & Holman, H. R. (2003). Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01

Malone, T. W. (1981). Toward a theory of intrinsically motivating instruction. *Cognitive Science, 5*(4), 333-369. https://doi.org/10.1016/S0364-0213(81)80017-1

Martos-Cabrera, M. B., Membrive-Jiménez, M. J., Suleiman-Martos, N., Mota-Romero, E., Cañadas-De la Fuente, G. A., Gómez-Urquiza, J. L., & Albendín-García, L. (2020). Games and health education for diabetes control: A systematic review with meta-analysis. *Healthcare, 8*(4), 1-12. https://doi.org/10.3390/healthcare8040399

Meijering, L., Nanninga, C. S., & Lettinga, A. T. (2016). Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health and Place, 37*(1), 35-42. https://doi.org/10.1016/j.healthplace.2015.11.006

Nezu, A. M. (2004). Problem solving and behavior therapy revisited. *Behavior Therapy, 35*(1), 1-33. https://doi.org/10.1016/S0005-7894(04)80002-9

Peters, V., & Westelaken, M. van de (2011). *Spelsimulaties & gaming een beknopte inleiding in het ontwerpproces.* Nijmegen.

Phungoen, P., Promto, S., Chanthawatthanarak, S., Maneepong, S., Apiratwarakul, K., Kotruchin, P., & Mitsungnern, T. (2020). Precourse preparation using a serious smartphone game on advanced life support knowledge and skills: Randomized controlled trial. *Journal of Medical Internet Research, 22*(3), 1-11. https://doi.org/10.2196/16987

Plass, J. L., & Kalyuga, S. (2019). Four Ways of Considering Emotion in Cognitive Load Theory. *Educational Psychology Review, 31*(2), 339-359. https://doi.org/10.1007/s10648-019-09473-5

Plass, J. L., Homer, B. D., MacNamara, A., Ober, T., Rose, M. C., Pawar, S., ... Olsen, A. (2020). Emotional design for digital games for learning: The effect of expression, color, shape, and dimensionality on the affective quality of game characters. *Learning and Instruction, 70*(101194). 1-13. https://doi.org/10.1016/j.learninstruc.2019.01.005

Pringle, J., Hendry, C., & McLafferty, E. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing, 17*(18), 2384-2397. https://doi.org/10.1111/j.1365-2702.2008.02372.x

Rosland, A. M., & Piette, J. D. (2010). Emerging models for mobilizing family support for chronic disease management: A structured review. *Chronic Illness, 6*(1), 7-21. https://doi.org/10.1177/1742395309352254

Thomas, T. H., McLaughlin, M., Hayden, M., Shumaker, E., Trybus, J., Myers, E., ... Cohen, S. M. (2019). Teaching patients with advanced cancer to self-advocate: Development and acceptability of the strong togetherTM serious game. *Games for Health Journal, 8*(1), 55-63. https://doi.org/10.1089/g4h.2018.0021

Thomas, T. H., Sivakumar, V., Babichenko, D., Grieve, V. L. B., & Klem, M. Lou. (2020). Mapping behavioral health serious game interventions for adults with chronic illness: Scoping review. *JMIR Serious Games, 8*(3). https://doi.org/10.2196/18687

Tyng, C. M., Amin, H. U., Saad, M. N. M., & Malik, A. S. (2017). The influences of emotion on learning and memory. *Frontiers in Psychology, 8*(AUG). https://doi.org/10.3389/fpsyg.2017.01454

Van Twillert, S., Stuive, I., Geertzen, J. H. B., Postema, K., & Lettinga, A. T. (2014). Functional performance, participation and autonomy after discharge from prosthetic rehabilitation: Bariers, facilitators and outcomes. *Journal of Rehabilitation Medicine, 46*(9), 915-923. https://doi.org/10.2340/16501977-1846

Wenzler, I. (2008). The role of simulation games in transformational change. In: Kritz. W.C. (ed). *Planspiele für die Organisationentwicklung.* (63-74) Berlin: WVB.

CHAPTER SEVEN

The mechanics of *'Think Along?'*

Feyuna F.I. Jansma, Robbert Sanderman and Ivo Wenzler

ABSTRACT

Background: Research has shown that within rehabilitation practice, the skills needed to become a good self-manager are often offered implicitly. This makes it difficult for part of the patients to master these skills properly. To take a step towards offering self-management skills more explicitly, a serious game called ‘Think Along?’ was developed.

Objective: ‘Think Along?’ is an analogue theory-based serious game. The serious game is based on the problem-solving model of Nezu and D’Zurilla and the social cognitive theory of Bandura. ‘Think Along?’ has two main purposes. The first purpose is game-related. Through ‘Think Along?’, players can solve problems in a playful, enjoyable way. The second objective is educational. By letting people think up solutions for various problem situations related to their own home situation, they gain insight into their own problem-solving orientation and can also increase their problem-solving skills.

Results: The format of ‘Think Along?’ is an analogue multi-player boardgame. The serious game is designed as an old Dutch board game and invites the players to brainstorm to find as many solutions as possible for the presented problems. The serious game consists of a game board, problem-cards, Bomb-cards, Joker-cards, Wisdom-tiles, Action-cards, two pawns, a dice, a flipchart, pens to write down the solutions and an egg timer. The serious game is played with two teams with a minimum of two and a maximum of eight players. It is played in three stages of increasing difficulty. The team that has collected the most Wisdom-tiles at the end has won. By incorporation of basic gaming elements and key features extracted from the problem-solving model, Bandura’s social cognitive theory, the work of Lorig et al. and qualitative research on the specific problems people with chronic conditions have to deal with, a coherent, specifically targeted and theory-driven serious game was designed.

INTRODUCTION

People with a chronic disease can have a hard time living their lives according to their preferences. To meet the challenges of everyday life, people with a chronic disease need skills on physical, psychological, and social level. Self-management is seen as one of the approaches to provide patients with those skills (Muscat et al., 2020; Ozkaynak et al., 2021; Quaderi & Hurst, 2018). UMCG Beatrixoord rehabilitation centre in Haren in the Netherlands focuses on helping their patients acquire self-management skills in various ways. One such way is the serious game called 'Think Along?' (Denk je mee?). It was designed to help patients acquire problem-solving skills in a fun and engaging way, with problems covering disease management, role management, and emotional management, which are the three domains of self-management as defined by Lorig (Lorig & Holman, 2003a; Lorig & Holman, 2003b).

Each of these three domains cover specific tasks and require certain skills. The domain of disease management covers general tasks that patients have to perform in order to achieve the healthiest possible lifestyle. In addition, this domain covers specific tasks related to a specific disease. Patients with diabetes face different tasks than patients with a lung disease, such as COPD. The domain of role management focuses on the many roles a person fulfils in his/her everyday life, and these roles can differ for every patient. For instance, some patients still have a job, while others do not. Some have a family with young children; others have already grown-up kids, and some could be even grandparents. The management of their role as family members will be different. The last domain covers emotional management. This is a much more generic domain. The emotions accompanying a loss of health such as frustration, anger and grief are fairly similar, despite the underlying disease.

Within all three domains the skills such as problem-solving, asking for help, decision making and communicating with health care professionals are crucial (Lorig & Holman, 2003a). While these skills might be natural for some, the reality is that not everyone is a born self-manager.

As it would be too complicated to include all self-management skills in one serious game, we concentrated on problem solving. This is one of the most important skills, if not the most important one, for adequate self-management (Jansma et al., 2010; Lorig & Holman, 2003a). In this chapter the serious game 'Think Along?' will be described through its context, the objectives we wanted to achieve, a description of the serious game, and the materials used. The rules of the game are described in the addendum at the end of this chapter.

The context of ‘Think Along?’

‘Think Along?’ was developed in the context of healthcare and specifically aimed at the rehabilitation of people with chronic conditions. The serious game is designed to create an environment in which patients can safely experiment with finding solutions to the problems they encounter in their daily lives. ‘Think Along?’ is a theory-based, analogue serious game. An analogue game format was chosen because within a rehabilitation centre, most of the patients are no longer in their twenties, and therefore it was safe to assume that the majority of our target audience would be more familiar with board games than with digital games. Moreover, serious gaming as an intervention is fairly new within the rehabilitation process, so in order to make the threshold for both patients and professionals as low as possible, we created a serious board game. The theories on which the content of the game is based are also central to the work of Kate Lorig (Lorig et al., 2001; Lorig et al., 1999; Lorig & Holman, 2003a; Lorig & Holman, 2003b). Her work was chosen as the basis for the development of the self-management interventions (Jansma et al., 2010). The minimum number of players is two and the maximum is eight. With two or more participants two competing teams are created.

The objectives of ‘Think Along?’

There are several objectives we wanted to achieve with this theory-based serious game. We have used two theories to base our design choices on: the problem-solving model of Nezu and D’Zurilla (D’Zurilla & Goldfried, 1971; Nezu & D’Zurilla. 1981; Nezu, 2004) and the social cognitive theory of Bandura (Bandura, 1977, 1978, 2004, 2011). We will describe our objectives using these two theories, starting with the problem-solving model. First, we wanted to provide patients with the opportunity to increase their problem-solving skills. To achieve that we used the problem-solving model of Nezu and D’Zurilla, as this model is intertwined in the work of Lorig (Jansma et al., 2010). The problem-solving model consists of several steps: defining the problem, generating alternatives, choosing the best solution, implementing the solution and evaluating the results. The serious game is designed in such a way that the players get acquainted with the first two steps of the problem-solving model.

Secondly, we wanted to increase patients’ awareness of their problem-orientation. The problem-solving model defines two forms of problem-orientation. A positive and a negative one. Especially a negative problem orientation can have a limiting effect when one is daily confronted with several problems, as is in the case of living with a chronic disease. By playing ‘Think Along?’ people become aware of their problem orientation, especially by comparing themselves to the other players.

Finally, we wanted to create an environment in which players are able to experiment safely with several possible futures concerning the problems they encounter and give them the opportunity to link these possible futures to their home situation. To make the environment in which the participants play as realistic as possible, they play with problems that are strongly related to their own life situation. We distilled the problems central in 'Think Along?' during our earlier qualitative research into how self-management takes shape in rehabilitation practice (see chapter four and five of this dissertation). During the debriefing at the end of the game the participants reflect on the problems played under the guidance of the facilitator. In addition to discussing the problem orientation of the players, they are asked whether the problems played are recognisable in relation to their own lives. By discussing this, a link is made between the game environment and the daily lives of the players. The players are then asked if they can apply what they have learned during the game to their own home situation. These discussions enable the players to link the possible futures they have experimented with to their everyday lives. In this way we wanted to provide a positive contribution to an easier transition from the rehabilitation centre to the home environment. We wanted to reinforce this effect by giving the players the opportunity to learn from each other in addition to the competition elements already in place. To do so the second theory, the social cognitive theory of Bandura, was added to guide additional design choices.

Self-management is about "social learning", as articulated in Bandura's Social Cognitive Theory (Bandura, 2004, 2011). Bandura describes that most human behaviour is learned through observation, by modelling. He states that by observing other people, humans form an idea of how new behaviour is performed, and on later occasions, this behaviour can serve as a guide for action (Bandura, 1977, 2004). So, by playing 'Think Along?' with a group of fellow patients gives our players ample opportunity to observe and form ideas on solving problems. Inspired by Bandura's Social Cognitive Theory, Lorig considered "self-efficacy" a hallmark of self-management education. Self-efficacy was defined as the individual's personal belief and confidence in his or her capacity to undertake behaviour that may lead to desired outcomes such as improved health. Watching people like oneself succeed through sustained effort may strengthen patients' belief in their own capabilities. Through the design of 'Think Along?', we also attempted to boost the self-efficacy of our players by first looking at the problem to be played together as a group and reaching consensus on its impact, before the bidding war breaks loose between the two competing teams. Moreover, we did our best during the design phase to influence self-efficacy positively, for example by means of the Wisdom-tiles. By sharing the wisdom on the tiles by the winning team, there is no real loser or winner.

Through this we tried not to influence the self-efficacy of the players in a negative way.

The description of 'Think Along?'

As 'Think Along?' is developed in Delft (a city in The Netherlands), we incorporated the colours of this city, being the Delfts Blue. This helped us in creating a typical Dutch appearance of 'Think Along?'. The board was printed on a wax cloth to give it a homey feeling. So, when we play, we literally set the table with the serious game. The pawns are created out of a salt and pepper set. The idea behind this was to make the serious game as accessible as possible for the players. When players are ready to play, they see on the board three differently coloured circles being red, blue and green. These three colours correspond with the three domains of self-management (Lorig & Holman, 2000; Lorig & Holman, 2003a), red corresponds with the disease management, blue with the role management and green with the emotional management (see figure 1).

Figure 1 The game bord of 'Think Along?'

Red = Disease management
Blue = Role management
Green = Emotional management

For each domain, problem-cards have been developed containing situations close to the players' reality (see figure 2). So, when a player ends up on a red circle by throwing the dice, he or she and the rest of the team must find as many solutions as possible for a specific problem within the domain of disease management. The problems presented within this domain can entail a generic situation including topics like fatigue, nutrition, exercise, and smoking. The disease-specific problems will entail topics like blood sugar controls necessary when you have diabetes, specific medication use for lung disease, or pain management, something we see in rheumatoid arthritis. When the pawn ends up on a blue circle, the problems will be within the domain of role management. The problems within the blue domain will be about how to fulfil all the real-life roles one has (a wife or a husband, a mother, a father, a grandfather, an employee, a friend, etc.) in the changed situation the players find themselves in. Finally, when the players end up on a green circle, they get a problem related to emotional management. The green cards will invite players to find solutions for problems like anger, fear, shame, frustration, and insecurity.

Figure 2: Examples of problem-cards

Esmée is 25 kilo afgevallen. Ze voelt zich een stuk beter. De mensen om haar heen zijn trots op haar, maar ze denken dat het afvallen nu klaar is. Ze krijgt weer taartjes, patat, kaasjes en lekkere worst aangeboden. Ze vindt deze versnaperingen allemaal heerlijk en het wordt steeds moeilijker voor haar om nee te zeggen. Hoe kan ze de verleiding blijven weerstaan? Denk je mee met Esmée?

Red (Disease management):

Esmée has lost 25 kilos. She feels a lot better. The people around her are proud of her, but they think it's over now. She is offered cakes, chips, cheese, and tasty sausages again. She loves all these delicacies, and it is becoming increasingly difficult for her to say no. How can she resist temptation? Think along with Esmée?

Corné is na een lange periode van behandelingen en revalidatie weer voorzichtig aan het werk. Met de Arbo-arts heeft hij een re-integratie plan opgesteld. Maar zijn collega's lijken het idee te hebben dat hij weer helemaal terug is. Corné merkt dat hij hierdoor toch te veel doet en dat hij na een dag werken weer vreselijk moe is. Corné weet niet hoe hij dit moet veranderen. Denk je mee met Corné?

Blue (Role management):

Corné is cautiously back at work after a long period of treatment and rehabilitation. He has drawn up a re-integration plan with the occupational health and safety doctor. But his colleagues seem to think he is completely back to work. Corné notices that he is doing too much and that he is terribly tired after a day's work. Corné does not know how to change this. Think along with Corné?

Desirée durft niet goed meer met haar vriendinnen af te spreken. Ze weet niet zeker of ze fit genoeg zal zijn op de dag van de afspraak. Ze vindt het heel erg om af te zeggen. Dan maar geen gezellige koffieochtendjes en leuke dinertjes meer afspreken. Maar dat kan toch eigenlijk niet! Denk je mee met Desirée?

Green (Emotional management):

Desiree no longer dares to go out with her friends. She is not sure whether she will be fit enough on the day of the appointment. She hates to cancel. So, no more cosy coffee mornings and nice dinners. That's just not on! Think along with Desiree?

Next to the problem-cards, there are four other cards the players use during the serious game. The Joker-card, the Bomb-card, the Wisdom-tile and the Action-card (see figure 3). The first three cards are part of the basic game. The Action-card is optional, suitable for more experienced players. The Joker-card (see figure 3) can be used as a substitute for one solution for a problem but can only be used once per round. The Bomb-card, in Dutch a '*BOM-kaart*' is used when the opposing team articulates that a solution to a problem is not *Betamelijk* (which means decent or proper in Dutch), *Onderscheidend* (which means unique or not distinctive enough) and *Mogelijk* (which means possible). The other team may defend their proposed solution, and a discussion starts. The facilitator is the referee and decides if the Bomb-card is legitimate or not. The Wisdom-tile is based on a typical Dutch wisdom (ceramic) tile and is the prize for the winning team. They receive a tile in a colour corresponding to the problem-card they have played. The receiving team reads the tile out loud and by sharing the wisdom on the tile everyone wins. This way, we do not undermine the self-efficacy of the 'loosing' team and still give the winning team a prize. The team that collects three Wisdom-tiles from all three self-management domains, wins the round.

Finally, the Action-card. This card is developed to do justice to the capriciousness of a chronic condition. The Action-cards can provide the players with an advantage or not at all. For example, a card can give your team the solution of the other team or will give away your team's Joker-card to the other team. The Action-cards have been developed as a supplement for the more advanced players.

Figure 3: Additional cards: Bomb-card, Joker-card, Wisdom-tile, and Action-card

Logica brengt je van A naar B, verbeelding brengt je overal

(Albert Einstein)

Wisdom-tile:
(Albert Einstein)

Logic takes you from A to B,
imagination takes you everywhere.

Actiekaart

Hulp vragen

Deze kaart geeft jullie recht op een oplossing bedacht door een behandelaar.

Action-card:
Asking for help

This card gives you the right to a solution devised by a health care professional.

Why should ‘Think Along?’ work?

There are many reasons why we believe ‘Think Along?’ will work. First, there are basic game elements to describe that will contribute to the effectiveness of ‘Think Along?’. Second, the fact that the design of this serious game has been theory-driven. In this case this means that the foundation of the game is formed by Nezu and D’Zurilla’s problem-solving model (D’Zurilla & Nezu, 2010; A. Nezu & D’Zurilla, 1981; A. M. Nezu, 2004), Bandura’s Social Cognitive Theory (Bandura, 1978, 2005, 2011) and the oeuvre of Kate Lorig et al. (Jansma et al., 2010; Lorig et al., 1999; Lorig & Holman, 2003a). This foundation has guided the design choices which has led to a serious game that is consistently put together. Finally, these decisions have led to eight key elements of ‘Think Along?’ (all based in the theoretical framework of the game) which we believe will contribute positively to the effectiveness of ‘Think Along?’ (fig. 1) In the sections below, we successively describe the basic elements of gaming that have been incorporated in the game and the key elements of the serious game linked to the theoretical framework and design choices.

Basic gaming elements

The first basic game element is that we work with two teams, preferably with more than one person in each team, because we considered the modelling principle as important (Bandura, 1975, 2011). Therefore, the game is more effective when a team consists of more than one person, so the opportunity where the players can actually model by observing and comparing is larger. However, the game is designed that it can be played with two teams, each consisting of only one person.

The second basic game element is what we call the bidding element. The bidding is put in the serious game because we wanted the players to feel the competition and immersion. The first reason is that these two elements can ensure that the players are absorbed during play and can experience the magic circle. Within this circle, safe experimentation and learning can take place without direct consequences for reality (Huizinga, 2014). The second reason why we added competition and immersion elements to ‘Think Along?’ is that by wanting to win, we hope that players will tend to overbid. So, they will claim to have more solutions than they actually have. This creates a situation called a discomfort zone (Peters et al., n.d.). The discomfort zone comes into existence when players cannot rely on their competencies, they have to improvise and be creative. They have to feel challenged to learn something new, to develop themselves. That is what we are after in the design of this game, because this challenge will make the player better problem solvers.

Third basic game element is the fact that with every round the time to come up with solutions to the problem will decrease. The idea behind decreasing the time per round is that the players will experience a learning effect during play of the serious game. They will get faster in analysing the problems. Adjusting to and even stimulating this learning process, the time per round is shortened and keeps the game exciting and inspiring for the players. The facilitator can always adjust the timing. When a group of players is having difficulty generating sufficient solutions, the time will not decrease. The main focus of playing 'Think Along?' is always about solving problems and thus enhancing competencies. To achieve that, the players need a sense of mastery (Bandura, 1978, 2004) and that sense of mastery can only be achieved by doing and re-doing and experiencing success.

The last basic gaming element we made a design decision on was the choice to have the players live the serious game experience from a third-person perspective through so-called avatars. We did want the players to be touched by the problems the avatars encounter and make the link to their own lives, i.e. make a switch from the avatars to the first person perspective. To make this as effective as possible and therefore as easy as possible for the players, the literature indicates that it is important to bring the avatars very close to the players' lives in terms of content. That way, players can relate to the avatars most easily and make the step to their own situation faster (Birk et al., 2016; Lakhmani & Bowers, 2011). To achieve this, we based the avatars on the people we interviewed and observed in the aforementioned qualitative study.

Key-elements specific to 'Think Along?'

The first key element of 'Think Along?' worth mentioning is that the serious game gives the players the opportunity to practice the first two steps of the problem-solving model by playing the problem-cards (D'Zurilla & Goldfried, 1971; A. M. Nezu, 2004). The players get the opportunity to practice these two steps in all three domains of self-management as defined by Lorig et al (Lorig & Holman, 2003a). The problems described on the problem-cards, which form the serious content of 'Think Along?', were extracted from previously done qualitative research in the rehabilitation center. So, the problems players face during game play are actual problems that their fellow patients have indicated as difficult to solve in their home situation and which negatively have affected their lives.

The second key-element that 'Think Along?' aims at is that the players gain insight into their problem orientation (Nezu, 2004). The opportunity to gain this insight is created by giving players the chance to play multiple problem-cards spread across the three domains of self-management over several rounds with other players. Insight in one's own problem orientation is important, because it will influence the way a patient will face a life with a chronic disease. A person with a more negative problem orientation will approach life with a chronic condition differently, than a person with a more positive problem orientation. Although, research has shown that problem orientation is more or less fixed, like a character trait, understanding one's own problem orientation can help with adjusting it a little (Nezu, 2004).

The third key element we will describe is that players participating in 'Think Along?' will face real-life problems extracted from qualitative research done in the rehabilitation centre. With each problem-card that the players try to solve during the game, they are confronted with problems that they could potentially encounter in their home-situation. By playing these problem-cards, players are given the opportunity to experiment with possible futures in a safe situation with peers (Gillert, 2008)

The fourth key element involves the fact that throughout the design process, each step has always taken into account that, after playing, players leave the treatment room with more self-efficacy about their problem-solving skills than they entered (Bandura, 1978, 2001). This is reflected in the design by the fact that we give players the opportunity to solve multiple problems per session. So, if one of the problems does not immediately suit a player, it is no big deal, because there will be more. Next, we have framed winning and losing in such a way by designing Wisdom-tiles that even if a team has lost the wisdom of the tile is still for this group too.

The fifth key element of the serious game is that it encompasses all three domains of self-management and is designed to guide players along these domains with each game. The problem-cards are divided into red, blue and green cards corresponding respectively to the disease domain, the role domain and the emotional domain. To win a round, a team must play and win three different problems, each from a different domain, to collect three different coloured Wisdom-tiles. Also, the fact that multiple rounds can be played means that players will encounter the different domains more than once which can only benefit the players when it comes to mastering problem-solving skills.

The sixth key element of 'Think Along?' has to do with the fact that it provides players with an opportunity to practice dealing with the erratic nature of chronic illness. The content of the problem-cards has been developed in such a way that this capriciousness is amply covered while playing the serious game. In addition, 'Think Along?' has an expansion set consisting of so-called Action-cards. When these cards are part of the game, they will sometimes make it harder for players to solve a problem and sometimes easier. All to mimic the unexpectedness of the course of a chronic condition.

The seventh key element of the serious game is that by designing the game in such a way that multiple problems are played per round and that multiple rounds can be completed, makes it possible for players to practise problem-solving and thus gain a sense of mastery when it comes to their problem-solving skills (Bandura, 1978, 2005). To make practising problem-solving skills as safe as possible, the Joker-card has been designed. As stated before, losing will not enhance their sense of mastery and therefore not enhance their self-efficacy (Bandura, 1977, 2004, 2011). Adding this card to the game will give players room to take a risk when bidding with the other team when it comes to the number of solutions. After all, the Joker-card represents one solution.

The eight and last key element involves both promoting and facilitating communication among the players themselves and between the players and practitioners. By choosing to distil the content of the problem-cards from the previously conducted qualitative research, the problems the players face closely match their own perceptions. This design choice ensures that these problems will touch the players more, which we believe will ensure that the problems will be the subject of conversation between the players but also between patient and practitioner. A second design choice to promote communication is the development of the Bomb-card. This card allows a solution given by one team to be contested by the other which will generate the necessary discussion. We assume that emotions will run high on both the defending team and the disputing team, which can only enhance learning (Plass & Kalyuga, 2019; Tyng et al., 2017).

Figure 1: Key-elements of 'Think Along?'

CONCLUSION

In this chapter we have described the end product of a search that ultimately led to the development of a serious game, 'Think Along?'. The game is specifically and explicitly aimed at enabling problem-solving skills and introducing the players to one of the most important self-management skills. 'Think Along?' is a theory-based serious game. The serious game is based on the theories that are central to Lorig's work on self-management, namely Bandura's social cognitive theory (Bandura, 1975, 2011; Bandura & Adams, 1977) and the problem-solving model of Nezu and D'Zurilla (Nezu & D'Zurilla, 1981; A. M. Nezu, 2004). This specific theoretical basis for 'Think Along?' is founded in extensive qualitative research (Jansma et al., 2010).

That same qualitative research also provided the problems that form the content of the problem-cards used while playing 'Think Along?' These problems were collected during observations in different departments and emerged during interviews with professionals and patients. By basing 'Think Along?' on well-known theories on self-management and focusing on the problems collected during the qualitative research, we hoped to come as close as possible to the reality of the players, namely the patients in the rehabilitation centre.

Now, with an actual intervention in hand, it is time to test the game against the relativity of rehabilitation practice. Questions such as whether 'Think Along?' is playable, whether people enjoy playing a serious game, and whether they actually learn something need to be answered.

REFERENCES

Bandura, A. (1975). Analysis of modeling proceesses. *The School Psychology Digest, 4*(1), 4-10.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review.* https://doi.org/10.1037/0033-295X.84.2.191

Bandura, A. (1978). Self-efficacy: Toward a unifying theory of behavioral change. *Advances in Behaviour Research and Therapy, 1*(4), 139-161. https://doi.org/10.1016/0146-6402(78)90002-4

Bandura, A. (2001). Social Cognitive Theory : An Agentic Perspective. *Annual Review of Psychology, 52*(1), 1-26. https://doi.org/10.1146/annurev.psych.52.1.1

Bandura, A. (2004). Health Promotion by Social Cognitive Means. *Health Education & Behavior, 31*(2), 143-164. https://doi.org/10.1177/1090198104263660

Bandura, A. (2005). The Evolution of Social Cognitive Theory. In: Smith, K.G. and Hitt, M.A. (Eds.) *Great Minds in Management.* (p 9-35). Oxford: Oxford Universtity Press.

Bandura, A. (2011). Social cognitive theory. In: Van Lange, Paul A.M., Higgins. E. Tory, Kruglanski, Arie. W. (Eds), *Handbook of Theories of Social Psychology*, 349-373. https://doi.org/10.1037/13273-005

Bandura, A., & Adams, N. E. (1977). Analysis of self-efficacy theory of behavioral change. *Cognitive Therapy and Research, 1*(4), 287-310. https://doi.org/10.1007/BF01663995

Birk, M. V., Atkins, C., Bowey, J. T., & Mandryk, R. L. (2016). Fostering intrinsic motivation through avatar identification in digital games. *Conference on Human Factors in Computing Systems - Proceedings*, 2982-2995. https://doi.org/10.1145/2858036.2858062

D'Zurilla, T. J., & Goldfried, M. R. (1971). Problem solving and behavior modification. *Journal of Abnormal Psychology, 78*(1), 107-126. https://doi.org/10.1037/h0031360

D'Zurilla, T. J., & Nezu, A. M. (2010). *Handbook of Cognitive-Behavioral Therapies,* Third Edition. (K. S. Dobson, Ed.) (third edit). New York: The Guilford Press.

Gillert, A. (2008). Ivo Wenzler: 'Simulations as learning from the future.' *Develop, 2*, 60-64.

Huizinga, J. (2014). *Homo Ludens: A Study of the Play-Element in Culture*, 1-220. Routlegde, Abingdon, Oxon. https://doi.org/10.4324/9781315824161

Jansma, F. F. I., Van Twillert, S., Postema, K., Sanderman, R., & Lettinga, A. T. (2010). Physical and rehabilitation medicine and self-management education: A comparative analysis of two approaches. *Journal of Rehabilitation Medicine, 42*(9), 808-814. https://doi.org/10.2340/16501977-0606

Lakhmani, S., & Bowers, C. (2011). Reflected in a liquid crystal display: Personalization and the use of avatars in serious games. *Lecture Notes in Computer Science (Including Subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics), 6774 LNCS*(PART 2), 237-242. https://doi.org/10.1007/978-3-642-22024-1_26

Lorig, Kate R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P. L., ... Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med. Medical Care, 37*(1), 5-14. https://doi.org/10.1097/00005650-199901000-00003

Lorig, K R, & Holman, H. (2000). Self-Management Education: Context, Definition and Outcomes and Mechanisms. *First Chronic Disease Self-Management Conference*, (August), 1-19. Retrieved from http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/chronicdisease-conference.htm

Lorig, K R, Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., … Holman, H. R. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care*, 39(11), 1217-1223. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11606875

Lorig, Kate R, & Holman, H. R. (2003a). Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01

Lorig, P. H., & Holman, H. R. (2003b). Self-Management Education.pdf. *The Society of Behavioural Medicin.*

Muscat, D. M., Song, W., Cvejic, E., Ting, J. H. C., Medlin, J., & Nutbeam, D. (2020). The impact of the chronic disease self-management program on health literacy: A pre-post study using a multi-dimensional health literacy instrument. *International Journal of Environmental Research and Public Health, 17*(1). https://doi.org/10.3390/ijerph17010058

Nezu, A. M. (2004). Problem solving and behavior therapy revisited. *Behavior Therapy, 35*(1), 1-33. https://doi.org/10.1016/S0005-7894(04)80002-9

Nezu, A., & D'Zurilla, T. J. (1981). Effects of problem definition and formulation on the generation of alternatives in the social problem-solving process. *Cognitive Therapy and Research, 5*(3), 265-271. https://doi.org/10.1007/BF01193410

Ozkaynak, M., Valdez, R., Hannah, K., Woodhouse, G., & Klem, P. (2021). Understanding gaps between daily living and clinical settings in chronic disease management: Qualitative study. *Journal of Medical Internet Research, 23*(2). https://doi.org/10.2196/17590

Peters, V., Westelaken, M. van de, & Bruining, J. (2012). Simulation games as a safe environment. *Simulation and Games studies, 22*, 59-64.

Plass, J. L., & Kalyuga, S. (2019). Four Ways of Considering Emotion in Cognitive Load Theory. *Educational Psychology Review, 31*(2), 339-359. https://doi.org/10.1007/s10648-019-09473-5

Quaderi, S. A., & Hurst, J. R. (2018). The unmet global burden of COPD. *Global Health, Epidemiology and Genomics, 3*, 1-3. https://doi.org/10.1017/gheg.2018.1

Tyng, C. M., Amin, H. U., Saad, M. N. M., & Malik, A. S. (2017). The influences of emotion on learning and memory. *Frontiers in Psychology, 8*(AUG). https://doi.org/10.3389/fpsyg.2017.01454

ADDENDUM

Rules of the game *‘Think Along?’*

Feyuna F.I. Jansma

THINK ALONG

The serious game ‘Think Along?’ is a problem-solving game. The game has two main goals. The first goal is game-related. Through ‘Think Along?’ people can solve the problems of, amongst others, José, André, Esmée and René, in a playful, fun way. By using the principle of you-know-it-all-for-one-another, players are stimulated to think up solutions for the challenges that the game presents them with.

The second objective is of an educational nature. By letting people think up solutions for various problem situations, they gain insight into their own problem-solving skills. In addition, it becomes clear to the participants that there are often many more solutions possible than previously thought. Even though the participants think about the problems of José, André, Esmée and René the problems are very close to their own experiences. The challenges that emerge centrally in the serious game are the result of long-term qualitative research into the possibilities of self-management in rehabilitation for people with a chronic condition. This recognisability makes it easier for the participants to translate the problem played into their own situation.

What do the participants need?

- Game board
- Red problem-cards
- Blue problem-cards
- Green problem-cards
- Bomb-cards
- Joker-cards
- Wisdom-tiles
- Action-cards
- Pawns
- Dice

What does the facilitator need?

- Flipchart
- Pens
- Egg timer

How many people play this game?

Two teams of 2 to 8 players

Where do we start?

The salt and pepper set are placed in the centre circle of the game board.

Who is allowed to start?

Add up the house numbers of each team. The team with the lowest number may begin.

Step 1

The starting team throws the dice, chooses a pawn (salt or pepper), starts at the starting point, and moves around the game board according to the number of eyes thrown with the dice. This can be done to the left or to the right. The team ends on a red, blue or green dot on the game board. The team receives a problem-card corresponding to the colour where the team stands from the facilitator. The team reads out the card. Both teams then work together as one group (not against each other, but with each other), in order to get a good picture of the problem at hand. The facilitator guides this process where necessary. Step 1 of the game is over when both teams agree on the problem posed.

However, when the team comes to an Action-card (orange cow), this is taken. This card is also read out loud. This card can be used the next turn. The team's turn is over after reading out loud and the dice goes to the other team.

Step 2

Every problem has a solution, often more than one. In step two, the teams get two minutes in which they try to think of as many solutions as possible to the problem posed. After these two minutes, the teams must bid against each other. The team that has the turn, may bid first with solutions. Then the other team can outbid them. In the end, one team starts to state its alternatives, because the other team withdraws from the bidding war. The challenging team starts to name its solutions. The facilitator writes the mentioned solutions on the flipchart.

Not every solution is 'good' one. The solutions must comply with the following rules. The solutions need to be:

- *Betamelijk* (be respectable, decent, neat)
- *Onderscheidend* (Be distinctive, not a variant of the same alternative, asking brother, sister, niece, nephew for help = asking family for help)
- *Mogelijk* (possible - 'time travel' is not yet possible, so does not apply)

To monitor these three rules, there is the Bomb-card. When the team that presents its solutions mentions a solution, which does not meet these three rules, the other team may use a Bomb-card. With this Bomb-card they create a possibility to have a discussion about the validity of the solution between both teams. Depending on this discussion, it is determined whether the alternative counts. If the alternative is rejected, the team must come up with another alternative if they want to reach their predefined number.

The final decision on the validity of the Bomb-card lies with the facilitator. He or she decides whether a solution is allowed to stand or not. The Bomb-card can be used on any of the mentioned solutions. In addition to the Bomb-card, there is also a Joker-card in the game. The Joker-card has the value of one solution. So, if the team can name 6 alternatives but has bid 7, the Joker-card is enough to win. In case a solution is defeated by a Bomb-card by the other team, the Joker-card can be used to get the Wisdom-tile. However, each round the teams get one Joker-card. If this card is not used, it can be taken to the next round. This means that the team then has two jokers in round two.

Step 3

If the team succeeds in naming the pre-set number of solutions, it is the winner. If the team fails to name the set number of solutions, it loses. The other team will then be declared the winner. The prize for the winning team is a Wisdom-tile. This tile is read by the winning team, so that the other team can also benefit from this wisdom and will not really be a loser.

Step 4

Now the other team can throw the dice and look for the next challenge. The aim is for the two teams to collect one red, one green and one blue card per round on the game board. When these three colours have been played together, the two teams advance together to round 2.

What will we do in Round 2?

The same as round 1, but the time to come up with the solutions will be shorter. Instead of two minutes, the teams get 1.5 minutes to think up solutions. Again, the aim is for both teams to collect a red, green and blue card together. At the beginning of this round, the players receive a new Joker-card.

What are we going to do in Round 3?

The same as in round 1 and round 2, but the time to think up the solutions is again reduced. In round 3, the teams get only one minute to come up with solutions. Again, they have to collect three differently coloured cards with the whole group. At the beginning of this round, the players receive a new Joker-card.

Who wins?

The team that has collected the most Wisdom-tiles is the winner of the game. But in the end, everyone is a winner when it comes to insight into their own problem orientation and problem-solving skills.

CHAPTER EIGHT

'Think Along?' A confrontation with reality. A playability and feasibility research supporting the implementation of a serious game in rehabilitation

Feyuna F.I. Jansma, Robbert Sanderman and Ivo Wenzler

ABSTRACT

Objective: This chapter presents the results of a study to assess the playability and feasibility of implementing the serious game 'Think Along?' within rehabilitation practice over the longer term. We conducted a circular implementation process aimed at addressing five key preformulated questions and two additional ones.

Methods: Step by step, 'Think Along?' was implemented in daily practice. Using Kirkpatrick's model, each step was evaluated through observation and semi-structured interviews. The data collected was then analysed with Atlas/ti. For each step adjustments were incorporated.

Results: The first question was: "Is the serious game playable at all?". Our first study showed that 'Think Along?' is playable. According to the feedback that we received, we added some problem-cards, simplified the language, and added another research question, namely question five. The second question we asked was: "Would the serious game work with patients?". We found that patients were generally very enthusiastic about the game. They also articulated that there were more solutions to problems than they had previously anticipated. This study led to another additional research question. The patients responded to the content of the game to such an extent that we concluded that the facilitator should be a healthcare professional to optimise the therapeutic process. Therefore, we added a third question: "Does the serious game work better with a therapist as a facilitator?". Our assumption was confirmed by our research, as the therapeutic process improved significantly after some initial start-up problems with the newly trained facilitators.

As we had worked with lung patients in the second study, our fourth question was: "Can we play the serious game with another patient population?". In this next study, the serious game was played by oncology patients, whose responses were considerably less enthusiastic. They identified less with the problems presented and felt that there should be a referee who could determine what were right and wrong solutions. This group also indicated that having oncological problems was perhaps too serious to play a game with.

The fifth question was added on the basis of the results of the first study: "Can patients play the serious game with their own problems?". When patients play with their own problem our findings showed that it was all too close for both the owner of the problem and the other players. The shift to a first-person perspective makes it too difficult to play the serious game.

Because of the importance of significant others as prominent 'supporters' of self-management at home, we formulated a sixth question: "Is there an added value in playing the serious game with significant others?". Our findings indicated that playing

with significant others added considerable value. The serious game had a positive effect on the group-dynamics, gave the players and their significant others an experience they could discuss at home, and finally they all articulated that playing in a group with patients and their significant others had reassured them that they were not alone in their situation.

The seventh and final question was: "Can we play the serious game with a group composed of patients with different diseases?". The theoretical notion that the role domain and the emotional domain of self-management have generic elements made it interesting to play with a mixed group. In this study, the players indicated that while they were playing, they had not noticed that they had different diseases. However, the facilitator noted that because she was not treating all of the patients, she held back, even though she saw opportunities for therapeutic interventions. This finding indicated a loss of therapeutic value.

Conclusion: This research has shown that 'Think Along?' is well playable with different patient categories. It has furthermore become clear that when the practitioner takes on the role of facilitator, this is good for both the serious game's gameplay and the patients' treatment process. Likewise can be concluded that playing with an avatar was a good design choice. Playing from the first-person perspective was too confrontational for the patients. Also, the serious game can be said to have added value when played with significant others for the sake of group dynamics and sharing a specific experience that can be talked about at home. Finally, it was found that playing with patients with different diagnosis is quite possible, but it has the risk of loosing therapeutic value.

INTRODUCTION

In the rehabilitation process of people with a chronic condition, self-management is becoming increasingly important. It has been demonstrated that self-management programmes help participants improve their health behaviour and their use of care (Ahn et al., 2013; Anderson & Ozakinci, 2019; Smith et al., 2017). Self-management programmes focus on acquiring skills and behaviours needed to maximize a person's quality of life with a chronic disease. Self-management also has become part of the rehabilitation treatment over the past decades (Wade, 2020).

Various methods are used to help patients to learn the necessary self-management skills. Serious gaming is relatively new in this area. Because serious gaming has proven to be an effective way of acquiring skills and changing behaviour the introduction and implementation of serious gaming have become an opportunity within the context of rehabilitation (Gauthier et al., 2019; Kato, 2010; Kato et al., 2008; Thomas et al., 2019; Thomas et al., 2020). Therefore, we developed and evaluated a self-management oriented serious game called 'Think Along?'. It was designed and implemented in several steps to ensure it is well embedded in the existing rehabilitation practice and well suited to the patients' needs. In this chapter, we discuss several issues that had to be resolved before the serious game could be developed. These issues are described under the heading 'Conceptual Framework' in the first section of the chapter covering (a) the concept of self-management in the context of rehabilitation, (b) how self-management takes shape in daily practice and (c) how to transfer skills acquired during rehabilitation into the home situation.

We subsequently discuss our conception of what serious gaming entails, according to us. In the latter part of this chapter, we will elaborate on the playability and feasibility research that we have done, arguing that 'Think Along?' could be implemented in the rehabilitation practice for the longer term.

FRAMEWORK

The concept of self-management in the context of rehabilitation

The first issue discussed, appeared during literature research on self-management. We discovered that the concept of self-management originated outside of the healthcare sector, whereas rehabilitation practice was developed within the healthcare sector. Research showed that these different places of origin resulted in a substantial difference in connotation. Although the language used in both concepts looks the same at first sight, the words' connotation is certainly different. 'Goals' formulated in the context of self-management refer to life goals derived from social models, whereas in rehabilitation practice, ‘goals’ refer to the treatment goals derived from biomedical models. A critical comparison of the literature on self-management and on rehabilitation practice (Jansma et al., 2010) clearly showed that in order to implement self-management within rehabilitation practice, it was necessary to refine the concept of self-management to enable its fit within the conceptual framework used in rehabilitation practice. This fine-tuning of the self-management concept was also relevant for the serious game that was about to be developed, based on self-management notions but had to be implemented into the rehabilitation practice.

The oeuvre we analysed to understand the language used in self-management is the work of Kate Lorig and others (Lorig & Holman, 2000; Lorig et al., 2001; Lorig & Holman, 2003; Marks et al., 2005). Their approach has become a significant part of the theoretical framework used to define self-management in this dissertation and is incorporated into the serious game ‘Think Along?’.

As Lorig et al. defined good problem-solving skills as the most important aspect of self-management, ‘Think Along?’ aims at making players aware of their problem-solving skills (Lorig & Holman, 2003). To improve problem-solving skills, Lorig et al. (2001) developed their programme on the basis of two theories: the problem-solving model of Nezu and D’Zurilla (D’Zurilla & Goldfried, 1971; Nezu & D’Zurilla, 1981; Nezu, 2004) and Bandura’s social-cognitive theory (Bandura, 2011; Bandura & Adams, 1977). Two of the five steps of the model described by Nezu and D’Zurilla are explicitly incorporated in the game, namely ‘defining a problem’ and ‘generating alternatives.’ The social-cognitive theory provided input for the serious game design, by incorporating ‘mastery,’ ‘self-efficacy’ and ‘modelling’.

How self-management takes shape in daily practice

In addition to literature research and resolving the first issue, we did fieldwork to find out how self-management takes shape in the daily practice of a rehabilitation centre. During our observations, we identified the second issue that needed to be addressed before designing and implementing our serious game. We saw that self-management is shaped differently in daily practice by different healthcare professionals. This could be explained by varying backgrounds, treatment guidelines, and the difference in training of members of multidisciplinary teams. By choosing the work of Kate Lorig as a basis of our self-management intervention, we could articulate these variations. What we saw was that healthcare professionals focus on different domains of self-management. Professionals with a more medically oriented background, such as physiotherapists, focused more on managing the disease domain, while professionals with a more psycho-social education focused more on the management of the role- and emotion domain (See chapter four and five of this dissertation). It also became clear that although none of the professionals paid attention to all three domains equally, they did so as a multidisciplinary team. These differences in approach are essential to know for the plan of action for patients' rehabilitation process. With this knowledge, we can ensure that a balanced multidisciplinary team treats patients, and that self-management is offered holistically.

Our observations on the work floor regarding the second issue influenced the design of the serious game. We intended to ensure that the serious game's foundation was relevant, focused and coherent (Wenzler, 2020). Therefore, the serious game had to include all three self-management domains: disease management, role management, and emotional management. In this way, we aimed to do justice to the holistic approach which underpinned our aim. In addition, these three domains had to cover real problems of real patients.

In conclusion, we observed all multidisciplinary team members from different wards that had been involved at the rehabilitation centre for more than six months to determine how their approach to self-management had been shaped. During that period, we recorded all the problems patients were talking about. That provided us with qualitative data on all three domains for different diseases. Hence, these data provided the content the serious game.

The transfer from skills acquired during rehabilitation to the home situation

The third issue that we encountered that had consequences for the serious game design came up during both the literature research and fieldwork. This issue revolves around the fact that patients find it difficult to effectively apply the skills learned during their rehabilitation process in their home situation. Research shows that during the first six months in their home situation, patients experience a major relapse in their physical and psychological functioning, which is a particularly undesirable situation (Bratås et al., 2012; Meijering et al., 2016; Nanninga et al., 2015; Naylor et al., 2011; Pringle et al., 2008). Since self-management has its origins outside the medical world and is focused on functioning in the home situation, it can be valuable to facilitate the transition to the home situation (Lorig & Holman, 2000; Lorig & Holman, 2003; Marks et al., 2005). Solving this problematic transfer to the home situation requires more than designing and implementing a serious game. However, a serious game could very well contribute, and hopefully make it easier for patients to transition successfully to the day-to-day situation. After all, one way to learn something is to do it (Kolb & Kolb, 2009). You can start 'doing it' with the help of a serious game. The literature shows that serious games can create so-called memories of the future (Gee, 2003; Gillert, 2008; Wenzler, 2008) By helping players get insight into alternative futures through a serious game and providing them with the opportunity to test different approaches within a safe environment, careful steps can already be made towards the home situation, not in real life, but in their minds. Due to the repetitive nature of the serious game, players experience these possible futures more than once and they stay therefore more firmly in their memories. These memories of possible futures can be useful in the actual home situation. The serious game content is based on problems anchored in the real world, and therefore, the memories of the future could be authentic and helpful.

What is a serious game?

Scientific literature on serious games often refers to serious games as being an oxymoron (Garris & Ahlers, 2002; Mayer et al., 2014). An oxymoron is a stylistic device derived from Greek in which two words are combined that contradict each other in their literal meaning, here oxus (sharp) and mõros (blunt). Clark Abt was the first to use the oxymoron 'serious game' as such because of the tension in pursuing serious goals with an inherently non serious medium like a game (Abt, 1970). A serious game is a simulated and abstracted reality, which, driven by actions of players themselves, can be used as a learning intervention aimed at knowledge creation (research) or knowledge transfer (education). A game can be labelled as being 'serious' if there is an implicit (built into the game itself) or an explicit aspect of learning (briefing) transferred to the post-game reality.

A serious game can have a form of a video game, a role-playing game or a board game. The aspect all serious games have in common, despite their complexity or form, is that they all offer an opportunity for experiential learning (Caluwé De et al., 2008). Serious games can offer exemplary dynamic representations of real-world situations in which people learn (Kriz, 2003). A good serious game simulates the processes, networks, and structures of specific real-life situations in such a way that players can relate to them and learn from the interaction. So, for learning to take place the serious part of a serious game must be relevant to its players; in other words, that it solves real problems for real people (Wenzler, 2020).

Although a serious game is primarily intended for learning, it certainly needs elements of entertainment, enjoyment or fun (Clapper, 2018). This element of fun contributes to players motivation and engagement. Besides, having fun ensures that players get immersed in the game, which make them more motivated for the challenge. This immersion also ensures the longer retention of what has been learned and increases the commitment to act (Wenzler, 2020). Hence, in a good serious game, the balance between 'fun' and 'serious' is important. This means that during the design phase, expertise is needed to incorporate the 'fun' as well as 'serious' components (Baranowski et al., 2013) to create a learning environment that will trigger a learning cycle in an effective way.

All the above-described aspects were influential during the design phase of the serious game that is central to this dissertation. The content of the serious game, as said before, is derived from the reality of our players and therefore forms a solid foundation of the serious nature in our game. The fun element of the serious game was covered in the design, appearance, and game mechanics.

From concept to serious game

After addressing the problems described above, the findings (from literature and our own research) were used to design 'Think Along?'. It was important that the game reflected problems that were easily recognisable and related to the players' situations. Hence, to see if the serious game would live up to the expectations, the next step had to be its actual implementation. The challenge that surfaced in the early stages of the implementation process was how could we implement a serious game within an existing practice for it to be applied in the longer term. The literature indicates that implementing a long-term intervention in a complex situation, such as rehabilitation practice, is challenging (Jacobs et al., 2015; Moullin et al., 2015). There is a gap between what science develops in terms of practical interventions and what is actually applied in the workplace (Shelton et al., 2018).

In order to reduce this gap, an implementation framework has been created that consisted of five implementation questions extracted from the earlier described paragraph on Conceptual Framework. These implementation questions were examined and answered, covering five steps and are based on meta-questions concerning the playability and feasibility of the serious game in the rehabilitation practice. The meta-questions being:

1. Playability is defined by the workability of the foundation and the structure of the serious game. In short: "Does it work?".
2. Feasibility is defined in this research by how valuable, relevant, actionable, and scalable the serious game is for the rehabilitation practice patients. In short: "Can it be used to achieve a certain pre-set goal" (Wenzler, 2020).

The results of each step were critically assessed, and adjustments to the serious game were made on the basis of the findings. In this way, we wanted to create the conditions for long-term implementation of 'Think Along?'

The key questions at the outset, linked to seven studies

Before commencing the studies, we formulated five key questions, which seemed important for uncovering the value of the serious game and also for a successful implementation process. However, it is noteworthy that we added two additional questions (questions 3 and 5) during the implementation process according to our initial observations to answer the a priori questions. Thus, in total, we had seven questions, each of which was articulated and addressed in the corresponding study (i.e., questions 1-7 matched studies 1-7).

1. The first and obvious question was: "Is the serious game playable at all?". (Study 1: playability)
2. Since we planned to review the playability with professionals in the first study, the second question was: "Would the serious game work with patients?". (Study 2: playability)
3. The question that emerged from Study 2 was: "Does the serious game work better with a therapist as a facilitator?". (Study 3: playability)
4. Since we started with lung patients, we were also interested in: "Can we play the serious game with another patient population?". (Study 4: playability)
5. Based on an expert meeting, we came up with the question: "Can patients play the serious game with their own problem?". (Study 5: feasibility)
6. Given the importance of significant others as prominent 'supporters' of self-management at home, we formulated the following question: "Is there an added value in playing the serious game with significant others?". (Study 6: feasibility)
7. The seventh question originated in the generic aspect of self-management as defined by Lorig and Holman (2003). This question was: "Can we play the serious game with a group comprising patients with different diseases?". (Study 7: feasibility)

METHODS

The methods described below were used in all seven studies. In the first study, we played the serious game with professionals. In the second study, four different groups, varying in composition, played the game, as patients would enter and leave the rehabilitation process at different times. With these four groups we played in total nine sessions.

With the first group, we learnt that playing 'Think Along?' over three weeks in a row was too much. In the third session, we noticed that the players were less interested and got less deeply immersed in the game. In addition, the research results gathered during the third session did not provide any additional information in comparison to the first two sessions. Therefore, in light of these observations, we decided, henceforth, to have two game sessions per group. During the complete study (seven steps), we made similar changes according to the results we obtained during the implementation process. We describe these adaptations in the results section of this chapter, but first we will articulate the approach and evaluation model that we used.

Approach and evaluation model

To obtain the necessary information, we had to make choices about how to evaluate most effectively. Which tools or models are most appropriate for answering the previously described questions? Based on expert advice knowledge in our team (I.Wenzel) and literature research, Kirkpatrick's evaluation model (Alliger & Janak, 1989;, Kirkpatrick & Kirkpatrick-Kayser, 2016) was selected. The reason for choosing this model was twofold. The relative simplicity of this model helps people think about the evaluation criteria for an intervention. Kirkpatrick has defined four steps in his model to assess a training's effectiveness or, in our case, a serious game. These are:

Step 1 is called 'reactions'. The reaction is described as "the degree to which participants find the training favorable, engaging, and relevant" (Kirkpatrick & Kirkpatrick-Kayser, 2016) (p.19). In this step the players were asked if they 'like' and how they experience the serious game.

Step 2 is called 'learning' and is defined as "the degree to which participants acquire the intended knowledge, skills, attitude, confidence, and commitment based on their participation in the training" (Kirkpatrick & Kirkpatrick-Kayser, 2016) (p.19). In this step the players were asked whether they have learned something during the serious game.

Step 3 is called 'behavior' and is described as "the degree to which participants apply what they learned during training in their daily lives" (Kirkpatrick & Kirkpatrick-Kayser, 2016) (p.19). In this step the players were asked if they could see themselves using the skills they learned during the play in their daily lives.

Finally, step 4 is called 'results' and is defined as "the degree to which targeted outcomes occur as a result of the training" (Kirkpatrick & Kirkpatrick-Kayser, 2016) (p.19). In our case we wanted to gain insight into whether the players actually use what they have learned during the game in their daily lives.

Given the nature of this research, which is implementation oriented, we focused on steps 1 and 2 of the model. However, we also posed questions about steps 3 and 4, knowing that steps 3 and 4 are difficult to measure considering our research design. Besides, we were well aware that our serious game covers only a very small portion of the activities which take place in a multidisciplinary treatment setting, as in this case, a rehabilitation programme. We did ask these questions because we were curious as to whether patients were able to indicate if they would be able to use the skills, of which they had hopefully become aware by playing the serious game, in the future.

Questions/Interview

The choice for Kirkpatrick's model had consequences for determining our research instruments (Kirkpatrick & Kirkpatrick-Kayser, 2016). To use Kirkpatrick's model effectively, we developed an interview guide to be used during a short, recorded interview with the players directly after the serious game was played. Players were asked whether they enjoyed the serious game, if they learned something during the play and if they would use the things they learned in their daily lives. The tapes of each session were transcribed verbatim.

With an additional short questionnaire, we collected information on age, sex, disease, level of education, how many times they had been in rehabilitation, and if the player liked games in general. This questionnaire was handed out before each playing session.

Observations

As advised by Kirkpatrick and Kirkpatrick-Kayser (2016), we decided not only to interview the group but also to observe them while playing in order to obtain additional data. Since it was the first time we played 'Think Along?' with patients we did not know what to expect. So, we just observed and wrote down what happened. Although we went in with an open look, we were however not without questions. The questions we had and deemed relevant were, for example:

- How do the players react to the serious game?
- Do they enjoy the serious game?
- Do they play, or do they avoid participation?
- Which cards are played, and how are the cards received?
- Do the players recognize themselves in the presented problem?
- Do they comprehend the problem-cards?
- What are the solutions the patients brought up?

Analysis

The transcribed data of the interviews and the notes that were taken during observations the were analysed with the qualitative software programme Atlas.ti (Friese, 2019) which assists in extracting, coding, and comparing meaningful fragments from transcribed observations and interviews. Information from one source can thereby provide, refine or supplement background information from other data sources. The first author coded the material, who went through the material several times to ensure that codes assigned later in the initial analysis were cross-checked with the earlier coded texts. The study's methodological quality was safeguarded by combining and triangulating the analysis of the data of the observations and the group interviews.

RESULTS OF STUDIES 1 - 7

In all phases of the implementation process we worked closely with different stakeholders, i.e., the patients, their significant others, and the healthcare professionals - all to create a serious game that fits into the existing rehabilitation process. The results of the implementation are described below and are displayed in figure 1. The first four steps are part of the playability research, and the other questions are part of the feasibility research.

Figure 1: All steps taken in the implementation process of 'Think Along?'

Study 1: Is the serious game playable at all?

Adjustments: Added new problems, simplified the language on the problem cards and added an extra question to the implementation framework.
Added (Study 5): Can the players also play with their own problems?

Study 2: Would the serious game work with real patients?

Adjustments: Added an extra question to the implementation framework.
Added (Study 3) Will the serious game work better with a therapist as a facilitator?

Study 3: Will the serious game work better with a therapist as facilitator?

Adjustments: A flyer with the game rules was created.

Study 4: Can we play the serious game with a different patient population?

Adjustments: No adjustments were made.

Study 5: Can the players also play with their own problems?

Adjustments: No adjustments were made.

Study 6: Can we play the serious game with patients and their significant others?

Adjustments: No adjustments were made.

Study 7: Can we play the serious game with patients with different diseases?

Adjustments: No adjustments were made.

Study 1: Is the serious game playable at all?

A group of experts was formed to answer this question. The group consisted of research colleagues and colleagues on the work floor, and with them we started playing the serious game. After playing we asked about the serious game's playability and whether they thought it needed adjustments. We played until we reached the saturation point, which meant that no new adjustments were proposed.

Adjustments

Based on the information gathered, we made three adjustments. The first adjustment related to the content of the serious game. A number of additional problems, which patients have to deal with, were raised by colleagues. We added these problems to the content of the serious game by making extra problem-cards.

The second adjustment had to do with the level of difficulty of the language on the problem-cards. The feedback given was that the problems articulated on the problem-cards were certainly related to the patients' daily lives but that the language in which they were described was too complex. We were explicitly reminded of the presence of illiteracy and, more specifically, of health illiteracy within our patient group and thus within our future players. We had already taken health illiteracy into account by presenting the problems on the problem-cards in both text and images. Nevertheless, we simplified the language in consultation with an expert in communication and information sciences. (Prof. C.J.M. Janssen).

The third and final adjustment which we made was adding an extra question to our implementation framework. During an expert meeting, we put forward the idea of letting patients play with their own problem (first person perspective) instead of with the problem of a third-person perspective, which is the case in our serious game. The group members responded enthusiastically to this idea and saw potential added value for patients, so we decided to add this question: "Can patients play the serious game with one of their own problems?". (This question was addressed in Study 5).

Study 2: Would the serious game work with real patients?

In this study, we focused on the question of whether the serious game could be played with real patients. Luckily, we were welcomed to explore this on the lung ward of the rehabilitation centre. To answer this question, we had to create an environment in which we could play the game under optimal conditions for reaching our goal, which was to observe and determine what was happening while the game was being played. Consequently, we decided to put together a small team of facilitators, observers and healthcare professionals. In this way, we were able to organise the playing sessions so that the same facilitator, observer and healthcare professional participated in the same sessions as much as possible. The healthcare professional was present to answer any treatment-related questions from the players, which would have been very difficult for the facilitator. The interviewer was always the same person (the first author). In this way, we aimed to foster habituation, enabling the players to play freely while limiting any disturbing factors to a minimum.

Results

During the first couple of times we played with patients, the unravelling of the players' reactions was central. Most players said they liked playing 'Think Along?'. Words like 'it is fun' and 'we like it' were often used. 'Think Along?' was also recognized by the players as a serious game. They articulated that it was a 'mature game' and that you could 'learn' from this game. As observers, we also witnessed their enthusiastic reactions to the serious game, as well as to the fact that they were going to play a serious game at all, and their positive reactions to the design of the 'Think Along?' game. We saw the players make an instant connection to the problems on the problem-cards. There was a lot of laughter and emersion among the players during play. This was expressed in having fierce discussions while coming up with solutions. We also witnessed their determination and fighting spirit while playing the Bomb-card; a card which is especially designed to challenge the other team's solutions. Another striking observation was that most players reacted very positively to the Wisdom-tiles. The team that 'wins' a round had to get 'something,' and for this, we designed the Wisdom-tile as a prize. It was no more than a little prize because we aspired to make winning as unimportant as possible. We wanted everyone, both 'winners' and 'losers', to leave the therapy session with more self-efficacy in the area of problem-solving. To our great surprise many players responded very positively to these tiles. For some players, the wisdom expressed on the tiles was actually the most important thing they learned from playing 'Think Along?'

In addition to these positive comments some players said they did not like the serious game. We saw people sitting back in their seats and not participating. The comments and behaviours that expressed aversion to the serious game originated from the players who had answered on the questionnaire that they did not like games. During the interviews held at the end of a playing session, most of the players mentioned that they had become aware of their problem-solving skills. On multiple occasions, they articulated that a problem has more solutions than they had originally thought and that two persons would know more than one. In addition to problem solving, the players indicated that by playing 'Think Along?', they had become aware of two additional self-management skills: 'dealing with health care professionals' and 'asking for help'.

Quotes

"It is a mature game".

"The game is educational, and the Wisdom-tiles I really liked".

"The game contains questions we are confronted with all day, every day".

"Yes, I filled in the questionnaire that I do not like games, but that is okay... No, I felt it was very clarifying, this kind of game. I thought will they come with a sort of Ludo, but well... with cards?? This is an education game; it reveals issues, and it illustrates the complexities people have to deal with. And then finding solutions together. I like that about this game".

"For every problem is a solution".

"You also learn from how other people solve things, maybe this could be a guideline that is useful to yourself".

"Yeah, I should ask for help, but it has to come your way… you have to stand up for yourself... that is it in the end".

Respondent:*" I've been to the doctor's... I specifically asked for it... which is why I was a little late".*
Interviewer: *"Yeah, I know, but was it about something that happened here?".*
Respondent: *"Well... I mean you're becoming more conscious, and I dare to ask more... that's something you learn here...". Interviewer: "Well".*
Respondent: *"Well, I love it... so I thought about the game.. and I thought, I'm going to do it like this".*

Adjustments

During this step we discovered that the game touched the players in such a way that the questions and reactions the players had, were more suited in a patient-therapist-relation than in a player-facilitator-relation. The therapist had to join the discussion several times per playing session. It is, of course, very positive that the serious game impacted the players in that way. On the other hand, the gameplay was stopped because there was a constant interruption due to the interaction between the players and the facilitator. These interruptions seemed to have a negative effect on the players' experiences. For this reason, we decided to train the therapists to become facilitators, so that the therapeutic needs of the players could be better and more easily served.

Study 3: Does the Serious Game Work Better with a Therapist as a Facilitator?

We adapted the serious game based on the results obtained from the previous steps. Furthermore, we needed to answer the additional question: "Will the serious game work better with a therapist as a facilitator?". Before we could play with therapists as facilitators, we first had to train them to become one. Therefore, we developed a two-hour course during which we trained the therapists by teaching them the theoretical basis and the serious game rules. They also had to practice facilitating 'Think Along?'.

Results

After receiving this training, the therapists began to work as facilitators. During the observations of the serious game run by the therapist as facilitator, our assumption that the players' therapeutic questions would be addressed better was confirmed. The effects on gameplay, however, were more complex to articulate. Although this change of facilitator was important, it had an effect on the evaluation results. It became clear that the first few times a new facilitator led the serious game, there were some hiccups in explaining and leading the serious game due to inexperience. This led to uncertainty among the players and resulted in dissatisfaction with the serious game. Due to the inexperience of the new facilitator most players commented, during the evaluation interviews, that they to lacked sufficient insight into the serious game. Later during the implementation process, we observed that the therapists gained more experience facilitating the serious game and the game play also improved.

Quotes

Respondent 1: *"Because the explanation wasn't quite right either. That was a bit of a pity because I can't say I'm going to play this game with my family tonight, because I wouldn't know how to do it anymore".*
Respondent 2: *"I think the facilitator should be a little clearer."*
Facilitator: *"Yes, that's right".*
Interviewer: *"This was her first time".*

Facilitator: *"For the first time I'm doing it this way... also explaining the game myself and I do notice that a lot is missing".*
Respondent 1: *"But would it be something... you get a leaflet... that maybe explains the big picture a little bit".*

Adjustments

Because of the implementation problems with the new facilitators, the players were confused about the serious game rules. From this confusion, a new adjustment was suggested. Specifically, one of the players suggested that it would be nice to have a flyer presenting the rules as a guiding resource for the players. This suggestion resulted in the production of a flyer with the rules of 'Think Along?'

Study 4: Can we play the serious game with a different patient population?

The next step in the implementation process was to answer the question: "Can we play the serious game with a different patient population?". After all, the idea was to implement 'Think Along?' in all the departments of the rehabilitation centre, where people with a chronic disease are treated. The second population we played the game with were the patients in the oncology department. Here, too, we were curious about the reactions to the game.

Results

We soon noticed that the reactions of the players were different. The players were much less enthusiastic than we had become accustomed to in the lung ward. The amount of 'likes' and 'fun' were considerably more reserved and less unconditional. The players were very critical about the serious game. The first remark they made was that there should be a referee, who should indicate which solutions were right and which ones were wrong. One of the players indicated that there should be a list of the top ten solutions, so that players would know if they had done it right. The way the serious game was played, they argued, made it unclear to the players which team would win the serious game. What was striking was that for this group, it was really about winning. We never saw this sentiment so explicitly expressed by the players from the lung ward.

During an interview after a serious game session, the players articulated a possible explanation for this competitive atmosphere. They indicated that they had trouble identifying with the problems described on the problem-cards they played with. We had not observed this reaction before. This mismatch between the players and the serious game's content made it more difficult for the players to engage with the serious game.

Due to the lack of recognition, immersion was difficult, and players got more focused on the winning component of the gameplay.

The lack of recognition raised a further issue. As cancer is a collective term for many different forms of cancers and their specific symptoms, it could be that we were playing with too diverse a group. If this were the case, it would mean that adjustments had to be made to 'Think Along?' To check if all problem-cards had the same issue, being lack of recognition, we showed them all to the group. Fortunately, the other problem-cards were recognizable, and the players could relate to them much more easily. Because we only played with this patient population twice, we decided not to change the serious game yet and, instead, to wait and see if this issue reappeared during subsequent serious game sessions.

A final interesting remark made by some members of this patient population was that they thought that their disease was too severe to be addressed by a serious game. The fact that their problems were conveyed in an atmosphere of fun and play was something that they found difficult to accept. One of the players said that a good conversation would be more appropriate so they could talk about the problems they had to deal with. However, some players felt that thinking about someone else's problems through the medium of a serious game could certainly provide insight into their own situation.

Quotes

"Well, it is a game! Why can't we talk to each other?".

"At first, I thought well I don't know, ... but is a good way to be able to talk about things".

"Well, I liked the game, ... Yes, I really like it, but you really need to work on it, because it does not work yet...I mean there is no winner... and maybe there should be a sort of referee... telling what is right and wrong...".

"It is thrown into a game element of which I think this problem is too serious for a game".

"I think it very much has a function for people, who have a bit of trouble expressing themselves, so to speak. That they can crawl into someone else's skin".

Study 5: Can the Players also Play with Their Own Problems?

During our meetings with the experts in Study 1, we posed the question: "Can the players also play with their own problems?", which was received enthusiastically. The experts saw great therapeutic benefits in doing so. As researchers, we were also curious about whether the gameplay would be different if the avatar (a third-person perspective) was changed to a first-person perspective. What would be the impact of changing the players' perspective while playing the serious game?

We asked a group of lung patients if any of them wanted to play with a problem of their own. A young girl mentioned that a lady in the group had indicated a problem the day before that could be played well. The lady in question doubted whether she wanted this at all, but after some reflection, she was willing to offer her problem to play with. She then explained the problem that she was struggling with. In short, her children could not accept how sick their mother really was and still appealed to her as if she was healthy. She tried to explain that the situation is really different now, but the eldest son always trivialized the situation by waving everything away.

Results

After defining the above-mentioned woman's problem in a way that everybody could understand, we intended to start the serious game. When the facilitator wanted to press the stopwatch to start the game, one of the players immediately indicated that he could not do it. He could not play with the problem of the lady. He indicated that this problem was too big to play with. The facilitator and the observer (first author) immediately understood that this remark was genuine and was supported by the whole group. Therefore, we had to abandon the serious game and allow the players to talk to each other about the presented problem. This decision meant that we only had observation data for this step.

It was striking to observe that the group conversation was very constructive and solution-focused. It was also striking that hardly any obstacles were mentioned and that the players gave no reasons why the offered solutions eventually could not work. This was a totally different attitude then we had encountered many times during observations of patient-therapist conversations. We saw mostly that patients were mentioning obstacles and discarding the solutions offered.

From a gaming point of view, playing with 'one's own problem' seemed to be too personal. Moreover, the person with the problem was sitting across the same table. This seemed more confronting for the players than having an avatar on a problem-card. If we were to answer the question asked during this step according to the initial reaction, we would have to say that playing with 'your own problem' seems to be difficult. However, if you look at the situation in a more therapeutic way, there may be a different answer. In light of the conversation that took place between the players, it could be argued that playing with one's 'own problem' has an added value. We have decided to play the lady's problem at the end of a serious gaming session. The players had already 'solved' two problems from a 'third-person perspective.' It seems that this has brought the players into a solution-focused mindset. So, if, for whatever reason, a therapist would like to play with an actual problem of one of the group members, it would be advisable to play that problem as the last one of a serious game session. With the reserve that this insight is based on playing 'Think Along?' only once in this way.

Study 6: Playing the Serious Game with Patients and Their Significant Others

The sixth step of the implementation process consisted of an investigation of the effects of playing the serious game with patients and their significant others. Significant others are seen as very important in the rehabilitation process and the phase after that, the home situation. Therefore, the question addressed in this step was: "Is there an added value in playing with significant others?".

Results

We played with two groups of patients with their significant others on the lung ward. We saw that there was definitely an added value to do so. We noticed that all players, patients, and significant others participated without hesitation by playing the serious game. The therapist, who was the facilitator both times we played this step, had told us that it is often more difficult to act as a group when significant others come to visit. After all, the significant others come along for a day joining in an already existing group. This mostly disrupts the group dynamics. However, we witnessed that the game seemed to soften this unfamiliarity within the group. In addition, all the players also told us that the serious game had forced them to stay focused.

What further stood out was that the significant others made it clear that playing the serious game together with their loved ones had given them a shared experience that they could talk about. They also mentioned that playing with other 'couples' made it possible to learn from each other. It was very nice to see how others dealt with their loved ones' limitations caused by a chronic disease. 'Think Along?' seems to enable participants to make comparisons with others dealing with the same situation. It could be that 'Think Along?' offers the possibility for 'modelling', which is an important element of Bandura's social-cognitive theory (Bandura, 1975, 2011). Moreover, they articulated that it was a comforting thought knowing that they were not alone in this situation; other couples had to deal with the same issues.

Quotes

“No, but I find this quite enlightening. I thought at first we were going to do Ludo, ... but with cards? But this is an instructive game, and it exposes things and the complexity with which a human being can be confronted. And then come up with solutions together. That’s the beauty of this kind of game”.

“It’s more relaxed when you’re all sitting around the table, I think. You ask certain questions... this is just... you look for a solution together”.

“It’s nice to hear the experiences of others”.

“It obliges you to keep your attention, …. You are active, not passive”.

Study 7: Can We Play the Serious Game with Patients with Different Diseases?

During this phase, a more generic aspect of self-management, as defined by Lorig and Holman (2003), took centre stage. The theoretical notion that the role and the emotional domain of self-management have generic elements made playing with a mixed group interesting. The fact that rehabilitation care is very disease-specific in terms of treatments and organization made it even more interesting for possible future care innovations. The question we wanted to answer was: “Can we play the serious game with patients with different diseases?”.

We played ‘Think Along?’ only once, due to circumstances, with five patients with different diseases, being heart problems, diabetes, and lung diseases. The facilitator leading the serious game was a therapist who worked in the lung ward and had facilitated the serious game many times. Because an intervention involving patients from different wards was unique, we also interviewed the facilitator to elicit her vision and experiences.

Results

Although we only played in this constellation once, interesting findings emerged. The first point that stood out was that players indicated that while playing ‘Think Along?’, they had not noticed that they were playing with people with a disease other than their own.

Another aspect that stood out during observations was that the players translated problems on the problem-cards directly to themselves, almost as if they felt the need to profile themselves and their specific diseases. This need seemed much stronger than playing within a homogeneous group. The facilitator indicated that could be related to the players' personalities but that it could also be attributed to the fact that these players did not know each other. Evidently, there is a greater need for individuals to make themselves known in new groups than in an already existing group. To explore this aspect and the effects it seems to have on the group dynamics further, we would have to play with mixed groups more often.

The last striking point was that the facilitator stated that she dared to encourage less than in her own groups. She saw therapeutic opportunities but did not feel she could explore them in depth as she would have done had she known these players. Because she did not know the players, she did not know how far she could go. This fact poses an obstacle to the serious game's therapeutic value rather than to the game play. An idea that came up during the interviews with the facilitator was that if we were to repeat this step, we could assess whether repeating this step with two therapists present, who knew the players, would compensate for the loss of therapeutic value. Another advantage of having multiple therapists present was that the possibility arose for players and therapists to revisit what happened in the serious game during their therapy sessions. The facilitator perceived this advantage as a very positive asset.

Quotes

"We did not notice much of that... that we were different. No, not at all... ".

"It was a bit short, too, wasn't it? If you have someone here with a heart condition or someone after stroke, they all react differently".

"She had diabetes and she also... but she says that she is not suffering from anything and that she works all day. While she says that she has enough days that she cannot get out of bed. She is more like us in that respect".

DISCUSSION

Findings

From the answers to the questions aimed at playability, we have learned that 'Think Along?' is playable. Based on the meetings with experts, adjustments were made on content and language. Furthermore, we can conclude that 'Think Along?' is playable with patients with lung diseases and with patients with cancer and cancer-related problems. We can also state that most players enjoyed playing 'Think Along?' and became aware of their problem-solving skills. Moreover, the players stated that they became aware of skills such as ‘asking for help’ and ‘dealing with healthcare professionals’, which are self-management skills as defined by Lorig and Holman (2003). Furthermore, patients indicated that they could imagine using the learned problem-solving skills in the future. During the process of implementing steps relating to playability, we decided to adapt the facilitator’s role. It became clear that the facilitator had to be a therapist because of the unforeseen therapeutic impact that ‘Think Along?’ had on the players.

While implementing the steps relating to feasibility, we learned that players found it difficult to play with their own problems. The shift from a third-person perspective to a first-person perspective seemed too confrontational and made the players hesitant to play. We also learned that playing with significant others clearly had an added value. The players and their significant others expressed that having the shared experience of playing ‘Think Along?’ was valuable and that it had been pleasant to learn that other ‘couples’ experienced the same issues. Finally, we observed that it was possible to play ‘Think Along?’ with players having different diseases. There was some support for our initial assumptions that self-management has sufficient general aspects and that the serious game does not hinder players with different diseases.

Critical remarks

Although we learned a lot during our implementation process and answered many questions, we have also created new ones. In addition to new questions, critical comments were raised regarding the implementation process. In this section, we will first consider the possibilities for improvements in the implementation process in the context of future research. Then, we will discuss the questions that could be central to our future research.

The first critical remark concerns our evaluation model. We used Kirkpatrick’s model (Bates, 2004; (Kirkpatrick & Kirkpatrick-Kayser, 2016) because it suited our research very well. We were aware that this model is not without criticism (Bates, 2004; Moreau, 2017). Of the four steps of the model, the latter two are difficult to translate into concrete results. This was also the case in this study. The results that we obtained concerning ‘reactions’ and ‘learning’ were clearer and more consistent. We observed that the players found these questions easier to address. The outcomes for the ‘behavior’ and ‘results’ steps were harder to interpret because they required different research designs. If we want to know if the serious game ‘Think Along?’ contributes to the patients’ self-management abilities, we have to ask them that in retrospect. To do this, we need a design that requires more time and has at least one moment of measurement when the players are in their home environment.

The second critical remark is about measuring the specific results caused directly by the serious game 'Think Along?'. Measuring the specific contributing of 'Think Along?' on the behavioural changes patients make during their rehabilitation process are difficult. (Dijkers, 2019; Playford, 2010; Wade, 2006, 2020). The game sessions are only part of a much larger picture. Patients who undergo rehabilitation are in therapy for months. Patients are getting input from a multidisciplinary team day in and day out. 'Think Along?' is one of the many elements that contribute to the main goal being that the patient will go home with a higher level of functioning on a physical, social, and psychological level.

The third critical remark we want to make relates to improvement. We need to address the fact that the implementation of 'Think Along?' was a process that led to a switch from an assigned facilitator to a healthcare professional, who subsequently acted as a facilitator. This adaptation was made to serve the patients better. As stated earlier, the questions that the players raised were of a therapeutic nature such that the assigned facilitator, not being an expert, could not answer them satisfactorily. Although this change was necessary, it did affect the evaluation. The first couple of times that a new facilitator led the game, some hiccups occurred while she was explaining and leading the game. These start-up problems resulted in some interviews becoming more focused on explaining in hindsight what had happened. In future studies, the facilitators should be experienced so that the aforementioned teething problems are no longer an issue.

Finally, in addition, the moment at which a therapist becomes a facilitator coincided with the step of implementing the serious game in the oncology ward. Due to this coincidence, two changes within the implementation process happened, with negative consequences for the implementation process. Not all questions could be asked during the evaluation, and results were coloured because patients were not satisfied due to their lack of understanding of the game. After all, with an experienced facilitator, some of these problems may have been prevented. This situation must be avoided in future research. Researchers should be more alert to the fact that only one change occurs during each step in the implementation process.

Future developments and research

At the beginning of the implementation of 'Think Along?' within the rehabilitation process, we tested the serious game on two different wards: the lung and oncology wards. We observed a difference in how the patients received the game, although we have played significantly more times in the lung ward than in the oncology ward. The difference was striking, but we did not play enough times and with enough players in the oncology ward to interpret these differences fully. To be more explicit about the effects the serious game could have on the patients getting treatment in the rehabilitation centre, we need to play more often and in more wards. The game is also designed to be played with patients with a heart condition, diabetes, an amputation and with rheumatoid arthritis. To get a better idea of how the serious game can contribute to the rehabilitation process, we should start by playing with all patient categories and also enrol significantly more players.

In the results, we expected the players to express themselves in the direction of problem-solving, and they have done so. However, they also told us that they took other self-management skills such as 'asking for help' and 'dealing with health care professionals', from the serious game. These skills are defined in the work of Lorig and Holman (2003), which has always been the starting point of this research. The players further noted that they 'learned from each other' and developed 'the awareness that they were not alone in having a chronic illness' after playing the serious game. These insights are valuable and contribute to the process of becoming a good self-manager. This research has been a good start to test the serious game's playability and feasibility. However, to better substantiate the possibilities of 'Think Along?,' more research is needed.

In this light is it important to play more with the serious game using the four steps central to this research to substantiate the results with more data. Also, it is interesting to add other players to future research. As indicated earlier, 'Think Along?' has also been developed for people with other chronic conditions such as diabetes, rheumatism, and heart problems.

Furthermore, research into the possibilities of 'Think Along?' in the home environment of the patients could be a subject of study in the future. For instance, it would be interesting to look into the possibilities of making 'Think Along?' a digitally available serious game so that patients could play the game at home with their significant others, and with patients who also have the game at their disposal. All this with the underlying idea that players can learn from each other even after their rehabilitation process.

Another idea that comes to mind entails designing a problem-solving app that patients can use at home to help them solve the problems they face in their daily lives. To create such an app, we could use the data we collected during the game sessions. Next to the data we gathered on the effects of the serious game on our players, we also wrote down the solutions that the players came up with. Using those solutions could give patients a tool that can help them make life at home a bit easier. We think that it is safe to say that the possibilities of 'Think Along?' have yet to be discovered.

REFERENCES

Abt C.C. (1970). *Serious games.* London: The Viking Press.

Ahn, S., Basu, R., Smith, M. L., Jiang, L., Lorig, K., Whitelaw, N., & Ory, M. G. (2013). The impact of chronic disease self-management programs: Healthcare savings through a community-based intervention. *BMC Public Health, 13*(1). https://doi.org/10.1186/1471-2458-13-1141

Alliger, G. M., & Janak, E. A. (1989). Kirkpatrick ' s Levels Of Training Criteria : Thirty Years Later. *Personnel Psychology, 42*(2), 331-342. https://doi.org/10.1111/j.1744-6570.1989.tb00661.x

Anderson, N., & Ozakinci, G. (2019). "It all needs to be a full jigsaw, not just bits": Exploration of healthcare professionals' beliefs towards supported self-management for long-term conditions. *BMC Psychology, 7*(1), 1-14. https://doi.org/10.1186/s40359-019-0319-7

Bandura, A. (1975). Analysis of modeling processes. *The School Psychology Digest, 4*(1), 4-10.

Bandura, A. (2011). Social cognitive theory. In: Van Lange, Paul A.M., Higgins. E. Tory, Kruglanski, Arie. W. (Eds), *Handbook of Theories of Social Psychology*, 349-373. https://doi.org/10.1037/13273-005

Bandura, A., & Adams, N. E. (1977). Analysis of self-efficacy theory of behavioral change. *Cognitive Therapy and Research, 1*(4), 287-310. https://doi.org/10.1007/BF01663995

Baranowski, T., Buday, R., Thompson, D., Lyons, E. J., Lu, A. S., & Baranowski, J. (2013). Developing Games for Health Behavior Change: Getting Started. *Games for Health Journal, 2*(4), 183-190. https://doi.org/10.1089/g4h.2013.0048

Bates, R. (2004). A critical analysis of evaluation practice: The Kirkpatrick model and the principle of beneficence. *Evaluation and Program Planning, 27*(3), 341-347. https://doi.org/10.1016/j.evalprogplan.2004.04.011

Bratås, O., Espnes, G. A., Rannestad, T., & Walstad, R. (2012). Relapse of health related quality of life and psychological health in patients with chronic obstructive pulmonary disease 6 months after rehabilitation. *Scandinavian Journal of Caring Sciences, 26*(2), 219-227. https://doi.org/10.1111/j.1471-6712.2011.00921.x

Caluwé de, L., Hofstede Gert Jan, & Peters, V. (2008). *'Why do games work?' In search of the active substance.* Deventer: Kluwer.

Clapper, T. C. (2018). Serious Games Are Not All Serious. *Simulation and Gaming, 49*(4), 375-377. https://doi.org/10.1177/1046878118789763

D'Zurilla, T. J., & Goldfried, M. R. (1971). Problem solving and behavior modification. *Journal of Abnormal Psychology, 78*(1), 107-126. https://doi.org/10.1037/h0031360

Dijkers, M. P. (2019). An End to the Black Box of Rehabilitation? *Archives of Physical Medicine and Rehabilitation, 100*(1), 144-145. https://doi.org/10.1016/j.apmr.2018.09.108

Friese, S. (2019). *Qualitative data analysis with Atlas.ti* (third edit). Los Angeles: SAGE Publications Ltd.

Garris, R., & Ahlers, R. (2002). A Research and Practice Model. *Simulation and Gaming, 33*(4), 441-467. https://doi.org/10.1177/1046878102238607

Gauthier, A., Kato, P. M., Bul, K. C. M., Dunwell, I., Walker-Clarke, A., & Lameras, P. (2019). Board Games for Health: A Systematic Literature Review and Meta-Analysis. *Games for Health Journal, 8*(2), 85-100. https://doi.org/10.1089/g4h.2018.0017

Gee, J. P. (2003). What video games have to teach us about learning and literacy. *Computers in Entertainment, 1*(1), 20. https://doi.org/10.1145/950566.950595

Gillert, A. (2008). Ivo Wenzler : ' Simulations as learning from the future .' *Develop, 2*, 60-64.

Jacobs, S. R., Weiner, B. J., Reeve, B. B., Hofmann, D. A., Christian, M., & Weinberger, M. (2015). Determining the predictors of innovation implementation in healthcare: A quantitative analysis of implementation effectiveness. *BMC Health Services Research, 15*(1), 1-13. https://doi.org/10.1186/s12913-014-0657-3

Jansma, F. F. I., Van Twillert, S., Postema, K., Sanderman, R., & Lettinga, A. T. (2010). Physical and rehabilitation medicine and self-management education: A comparative analysis of two approaches. *Journal of Rehabilitation Medicine, 42*(9), 808-814. https://doi.org/10.2340/16501977-0606

Kato, P. M. (2010). Video Games in Health Care: Closing the Gap. *Review of General Psychology, 14*(2), 113-121. https://doi.org/10.1037/a0019441

Kato, P. M., Cole, S. W., Bradlyn, A. S., & Pollock, B. H. (2008). A video game improves behavioral outcomes in adolescents and young adults with cancer: A randomized trial. *Pediatrics, 122*(2), e305-e317. https://doi.org/10.1542/peds.2007-3134

Kirkpatrick, J.D., & Kirkpatrick-Kayser, W. (2016). *Kirkpatrick's four levels of training evaluation*, Alexandria: ATD Press, VA, USA.

Kolb, a. Y., & Kolb, D. a. (2009). The Learning Way: Meta-cognitive Aspects of Experiential Learning. *Simulation & Gaming, 40*(3), 297-327. https://doi.org/10.1177/1046878108325713

Kriz, W. C. (2003). Creating Effective Learning Environments and Learning Organizations through Gaming Simulation Design. *Simulation & Gaming, 34*(4), 495-511. https://doi.org/10.1177/1046878103258201

Lorig, K R, & Holman, H. (2000). Self-Management Education: Context, Definition and Outcomes and Mechanisms. *First Chronic Disease Self-Management Conference*, (August), 1-19. Retrieved from http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/chronicdisease-conference.htm

Lorig, Kate R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., & Holman, H. R. (2001). Chronic disease self-management program: 2-Year health status and health care utilization outcomes. *Medical Care, 39*(11), 1217-1223. https://doi.org/10.1097/00005650-200111000-00008

Lorig, Kate R, & Holman, H. R. (2003). Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01

Marks, R., Allegrante, J. P., & Lorig, K. (2005). A Review and Synthesis of Research Evidence for Self-Efficacy-Enhancing Interventions for Reducing Chronic Disability: Implications for Health Education Practice (Part II). *Health Promotion Practice, 6*(1), 148-156. https://doi.org/10.1177/1524839904266790

Mayer, I., Bekebrede, G., Harteveld, C., Warmelink, H., Zhou, Q., Van Ruijven, T., & Wenzler, I. (2014). The research and evaluation of serious games: Toward a comprehensive methodology. *British Journal of Educational Technology, 45*(3), 502-527. https://doi.org/10.1111/bjet.12067

Meijering, L., Nanninga, C. S., & Lettinga, A. T. (2016). Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health and Place, 37*, 35-42. https://doi.org/10.1016/j.healthplace.2015.11.006

Moreau, K. A. (2017). Has the new Kirkpatrick generation built a better hammer for our evaluation toolbox? *Medical Teacher, 39*(9), 999-1001. https://doi.org/10.1080/0142159X.2017.1337874

Moullin, J. C., Sabater-Hernández, D., Fernandez-Llimos, F., & Benrimoj, S. I. (2015). A systematic review of implementation frameworks of innovations in healthcare and resulting generic implementation framework. *Health Research Policy and Systems, 13*(1), 1-11. https://doi.org/10.1186/s12961-015-0005-z

Nanninga, C. S., Meijering, L., Schönherr, M. C., Postema, K., Lettinga, A. T., (2015). Place attachment in stroke rehabilitation : a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine, *Disability and Rehabilitation, 37*(13),1125-1134. https://doi.org/10.3109/09638288.2014.955136

Naylor, M. D., Aiken, L. H., Kurtzman, E. T., Olds, D. M., & Hirschman, K. B. (2011). The care span: The importance of transitional care in achieving health reform. *Health Affairs, 30*(4), 746-754. https://doi.org/10.1377/hlthaff.2011.0041

Nezu, A. M. (2004). Problem solving and behavior therapy revisited. *Behavior Therapy, 35*(1), 1-33. https://doi.org/10.1016/S0005-7894(04)80002-9

Playford, E. D. (2010). Rehabilitation in practice. *Clinical Rehabilitation*, 24, 291-292.

Pringle, J., Hendry, C., & McLafferty, E. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing, 17*(18), 2384-2397. https://doi.org/10.1111/j.1365-2702.2008.02372.x

Shelton, R. C., Cooper, B. R., & Stirman, S. W. (2018). The Sustainability of Evidence-Based Interventions and Practices in Public Health and Health Care. *Annual Review of Public Health, 39*(1), 55-76. https://doi.org/10.1146/annurev-publhealth-040617-014731

Smith, M. L., Towne, S. D., Herrera-Venson, A., Cameron, K., Kulinski, K. P., Lorig, K., & Ory, M. G. (2017). Dissemination of chronic disease Self-Management education (CDSME) programs in the United States: Intervention delivery by rurality. *International Journal of Environmental Research and Public Health, 14*(6). https://doi.org/10.3390/ijerph14060638

Thomas, T. H., McLaughlin, M., Hayden, M., Shumaker, E., Trybus, J., Myers, E., & Cohen, S. M. (2019). Teaching patients with advanced cancer to self-advocate: Development and acceptability of the strong togetherTM serious game. *Games for Health Journal, 8*(1), 55-63. https://doi.org/10.1089/g4h.2018.0021

Thomas, T. H., Sivakumar, V., Babichenko, D., Grieve, V. L. B., & Klem, M. Lou. (2020). Mapping behavioral health serious game interventions for adults with chronic illness: Scoping review. *JMIR Serious Games, 8*(3). https://doi.org/10.2196/18687

Wade, D. T. (2006). Rehabilitation in practice. *Clinical Rehabilitation*, 20, 93-96.

Wade, D. T. (2020). What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical Rehabilitation, 34*(5), 571-583. https://doi.org/10.1177/0269215520905112

Wenzler, I. (2008). The role of simulation games in transformational change. In: Kritz. W.C. (Ed). *Planspiele für die Organisationentwicklung*. (63-74) Berlin: WVB.

Wenzler, I. (2020). *What makes a serious game a seriously good game*, sl.

CHAPTER NINE

General discussion

Feyuna F.I. Jansma

GENERAL DISCUSSION

This dissertation has focused thematically on the development and implementation of a self-management intervention into an existing health care process, namely rehabilitation practice. As stated in the introduction of this dissertation, there were at the beginning of this journey many questions for which we hoped to get some answers. Some of those questions, listed below, became the main research questions of this dissertation:

1. What is known from in the scientific literature on the subject of self-management and self-management interventions in general, and for the rehabilitation practice in particular?
2. Are aspects of self-management already embedded in daily rehabilitation practice?
3. Can an effective self-management intervention be designed that contributes to the successful implementation of self-management in daily rehabilitation practice specifically for people with a chronic disease?

To answer these questions, an extensive study was conducted, as described in this dissertation. As our research was dived into two parts, so is this dissertation. The first part (chapters two to five) discusses research into self-management in general, the way in which self-management is already woven into existing practice and the added value the concept could have in the rehabilitation practice. In part one the first two questions of this project are answered. The second part (chapters six to eight) reports on the development and implementation of a self-management intervention, which eventually became an analogue serious game called 'Think Along?'. Thus, part two addressed the third question of this study.

We started this research with a literature study. Because of the great variety of self-management interventions, then and nowadays, we opted for a comparative analysis to gain insight into the content of both self-management and rehabilitation texts. We learned that despite the fact that they pursue the same ultimate goal, being living the best life with a chronic disease, they achieve this goal in different ways (chapter two).

In addition, we carried out an ethnographic study within the lung department of the rehabilitation centre to explore if and how self-management takes shape in daily practice. This part of the research yielded a number of valuable insights. We were able to extract three ideals of self-management that were intertwined in daily practice being adhering to a healthy lifestyle, dealing with the unpredictability of chronic illness and having freedom of choice. These three ideals are given shape in different places within the rehabilitation centre by different people. It also became apparent that these ideals are not fully in harmony with each other. Prioritising one can have a detrimental effect on another (chapter four).

After studying our literature and looking for embedded self-management in rehabilitation practice, the next part of our research had to be investigating a previously implemented self-management intervention in rehabilitation practice. We found this intervention in the oncology department of the rehabilitation centre. This study showed that although self-management was considered very important by the health care professionals, there were many uncertainties surrounding the concept. We did find during our research that parts of the original programme were certainly reflected in daily practice. However, we also saw that there were quite a few translation problems in different areas concerning the concept self-management. The transfer from scientific literature to practice, from therapists to patients and from the rehabilitation centre to the patient's home environment does not always proceed smoothly and evidently requires improvement (chapter five).

With this study on the oncology ward, we concluded the first part of this dissertation in which we learned that self-management and rehabilitation practice must be aligned for a successful implementation. Moreover, the study revealed that many self-management skills are offered implicitly, and that information is lost during moments of information transfer. The self-management intervention we wanted to develop therefore had to be in line with daily practice, offer explicit self-management skills and contribute to reducing information loss. In the second part, the steps that actually led to the serious game are described. For each step we took in the development of the serious game and its implementation, we used the insights obtained in the first part of this research.

The next step of the research (chapter six) consisted of taking a critical look at learning and teaching in health care, and the challenges we articulated in part one in these subjects. Through literature study we were able to identify the possible added value of serious gaming for that same health care. These findings could then be used in the actual design of the serious game.

The steps taken in the design process have led to a theory-driven analogue serious game, 'Think Along?' (Chapter seven). The theoretical foundation of the game is formed by the problem-solving model of Nezu and D'Zurilla (D'Zurilla & Goldfried, 1971; Nezu & D'Zurilla, 1981; Nezu, 2004) and the Social Cognitive Theory of Bandura (Bandura, 1977, 2011) The content of the serious game is based on the data collected during the qualitative research done in the first part of this research.

The serious game was evaluated for its playability and feasibility (chapter eight). This research has shown that the serious game is playable with different patient groups, that the game has an added value when played with patients and their significant others and, that it can be played with players with different diagnoses. Moreover, the game has a considerable impact on the players which resulted in questions that were related to treatment goals. As a consequence, we decided that the facilitator should be a therapist in order to maximise the therapeutic value of playing 'Think Along?'. Finally, we have also received an indication that it is difficult to play with one's 'own' problem instead of the avatars on which the serious game is based.

FINDINGS

All above mentioned studies have produced findings that have influenced and guided the implementation of a self-management intervention in daily rehabilitation practice. The findings are described in more detail below. Their influence on the development of the self-management intervention is also highlighted.

Finding one: Same end goals, but different approaches *(addresses question 1, as described in chapter two)*

To answer the first question of this research: "What is known in the scientific literature on the subject of self-management and self-management interventions in general, and for the rehabilitation practice in particular?" as we did as mentioned earlier a literature study. The literature on self-management was and still is diverse. (Cuthbert et al., 2019; Effing et al., 2016; Jansma et al., 2010; Smith-Turchyn, Morgan, & Richardson, 2016). Because of this diversity, we chose to examine self-management literature by means of a comparative analysis.

The aim of this analysis was to juxtapose self-management texts with rehabilitation medicine texts and to explore the content of both approaches through an examination of the language and concepts used in the chosen texts. At first sight, the language used in both approaches is very similar. However, even if the words are more or less the same, the meaning of the words is very different in both approaches. In order to do this analysis properly, we chose a body of work on which many self-management interventions are based, namely the work of Kate Lorig. We compared the texts of the work of Kate Lorig (K. Lorig, 2015; K. R. Lorig & Holman, 2003; Lorig et al., 2000) with *The White Book on Physical and Rehabilitation Medicine*. A work that describes the specialty of physical and rehabilitation medicine in Europe. (Gutenbrunner C & Ward AB, 2007; Jansma et al., 2010; Negrini & Ceravolo, 2008; Ward & Gutenbrunner, 2006).

This way of looking at the texts, a comparative analysis, made it possible to unravel the common ground and differences between self-management education and rehabilitation medicine. The first conclusion that could be drawn was that the rehabilitation practice and self-management education certainly share common ground when it comes to their end goals. Both approaches are focused on guiding their patients or their clients to achieve a maximum level of functioning. However, the way in which both approaches reach this end goal is very different. Whereas rehabilitation originated in the medical world, focuses on conditions with an acute onset, takes place in a clinical setting, and is aimed at functional recovery and motor learning, self-management on the other side originated outside the medical world, is specifically aiming at chronic diseases and uses theories of social learning, problem solving and self-efficacy (Jansma et al., 2010).

To implement a concept of self-management, that is based on social-cognitive theories, in a world that is still largely steered by medical based theories has significant consequences. To successfully implement the concept of self-management into the daily rehabilitation practice both approaches must be aligned in a way that the implementation of self-management in daily rehabilitation practice can provide the added value that we aimed at. Therefore, we wanted to develop an adequate intervention with explicit attention to this alignment of theories in a way that the social cognitive theories would become more accessible to patients. Since self-management focuses on learning skills such as problem solving, asking for help, and communicating with health care professionals (Lorig & Holman, 2003), the intervention must be able to create a setting within the medical care environment, in which patients can actually learn these skills so that they will be able to apply them in their home environment.

Finding two: Self-management is shaped differently in different places by different professionals *(addresses question 2, as described in chapter four)*

Simultaneous to the literature study we did ethnographic research. This ethnographic research was done with no predefined ideas of how self-management would be implemented in daily rehabilitation practice. In all honesty, it is impossible to be completely without forethoughts about self-management. Of course, I, as the observer, had notions about what self-management should entail. However, in this stage of research no choices had been made regarding any specific way of examining self-management within daily practice. Later in the process, when the choice was made to use Kate Lorig's work as a guide for self-management, a more focused view was adopted. However, during this ethnographic study conducted at the lung ward the focus was kept as wide and as open as possible.

Through this ‘undefined way of looking, it became clear that there are three different, and sometimes contradictory ‘ideals’ regarding self-management at work within the rehabilitation centre. These ideals are the following: adhering to a healthy lifestyle, dealing with the unpredictability of chronic diseases, and having freedom of choice. Our research showed that these different ideals were shaped by different care professionals at different locations in the rehabilitation centre, based on their training and education.

Furthermore, we discovered that the articulated ideals can be at odds with each other. For example, the tasks linked to dealing with the unpredictability of a chronic disease can be the opposite of elements that constitute having a freedom of choice. For example, a daughter, adhering to the ideal of having freedom of choice, could choose to ignore her personal boundaries to take care of her father, who has had major heart surgery; this ideal could be in conflict with the ideal of dealing with the unpredictability of a chronic disease. An ideal in which guarding those boundaries is important. This means that patients must become proficient in a constant balancing act in which they try to stay as healthy as possible, cope with the capriciousness of their condition and find room for their own interpretation of how to live. This is not an easy task for anyone, least of all for individuals with a chronic disease (see chapter four of this dissertation).

These findings had direct implications for how a patient’s treatment process should be structured. When it is decided that a patient needs to improve his self-management skills during the rehabilitation process in which all three ‘ideals’ are addressed, optimal use should be made of the multidisciplinary team. Indeed, this study has shown that in order to introduce patients to different self-management skills, one must be aware that the provision of the different skills is assigned to different members of the multidisciplinary team.

The discovery of the three ‘ideals’ and the fact that they could contradict each other gave direction to the content of the intervention. Clearly, each of the three ideals (adhering to a healthy lifestyle, dealing with the unpredictability of chronic diseases, and having freedom of choice) had to be represented in the intervention. Moreover, the constant balancing act that patients with a chronic condition must perform on a daily basis was perhaps just as important and needed to be included in the intervention.

Finding three: Self-management is probably not for everybody all the time *(addresses question 1, as described in chapters two and four)*

The combination of literature research and the ethnographic study on the lung ward provided another important insight. The expected positive effects attributed to self-management and to an educated patient with regard to alleviating the increasing pressure on healthcare are high. However, on studying the literature, it can be concluded that proving these effects is difficult. (Howell et al., 2017; Ng & Smith, 2017; Nolte et al., 2013). In addition to that, with our literature study and the ethnographic research, we identified the necessity to bring some nuance into these high expectations.

Self-management certainly seems to be a valuable addition to the existing rehabilitation practice, but it is not necessarily the solution to all of the problems relating to the transition to the home situation. The incorporation of self-management into rehabilitation practice means that attention is focused more explicitly on cognitive skills, such as problem solving, communication with health care professionals and asking for help, which are considered very useful when living with a chronic disease (Lorig & Holman, 2003). However, people with chronic diseases face complex situations because of the characteristic whimsicality of their diseases. Even when self-management is interwoven with rehabilitation practice, patients may experience a worsening of their disease, the handling of which extends beyond the acquired skills. Having a chronic disease will probably always imply a shared journey between persons with a chronic disease and their health care professionals (chapters two, three and four).

Although this insight did not dampen expectations about the impact of the intervention we wanted to develop, it did alert us to possible challenges that we should consider during the design process. Certainly, the goal was still to design an intervention that would help patients to explicitly learn and to practice self-management skills in a safe environment. We were determined to make an intervention that could offer an opportunity to experiment with so called possible futures and make the transfer to the home environment easier. Because of the results of these two studies, we became more aware that on one hand the whimsicality of the chronic disease should be incorporated in the intervention, but on the other hand this same whimsicality would define the limits of our intervention.

Finding four: Translation problems at different levels *(addresses question 3, as described in chapter five)*

The study conducted in the oncology department revealed several translation problems in rehabilitation practice relating to the implementation of complex constructs such as self-management. The first occurrence of a translation problem can be found in the gap between science and practice. The second occurrence of this problem is the moment when information gets lost in the transfer of knowledge between professionals and their patients. The last occurrence of translation problems comes to light when patients have to apply the knowledge acquired in the rehabilitation centre in their home environments. All three translation problems will be described in more detail below.

From science to practice

This research has shown that many self-management interventions have been described in the scientific literature and implemented in practice with varying degrees of success. But if one looks at what is left of such a self-management intervention after about five years, one sees a crumbling of a well-defined intervention. The healthcare professionals, in our case study were asked about the concept of self-management; a concept they had worked with for several years. Their responses revealed that there was no consensus within the health care team on the meaning of the term self-management, which - to be fair - is very understandable and not uncommon. (Green, 2009; Long et al., 2018; Menon et al., 2009; Mol, 2006; Van Twillert et al., 2009; Vieira et al., 2020). Health care professionals are trained to guide their patients in daily practice to a maximum level of functioning. They are not trained to translate abstract scientifically described interventions in a way that they are workable for the daily practice.

This finding calls for professionals who can bridge the gap between practice and science so that valuable interventions described in the scientific literature are secured in the workplace for the longer term. This means that these professionals should be able to guide the implementation of these interventions and align these interventions with daily practice (see chapter five of this dissertation).

This problems in the translation of knowledge had to be considered in the design of the self-management intervention. During the design phase the focus should be on the fact that the intervention will make a long-term contribution to everyday practice. This will mean that during the design process we will have to ensure that the intervention is as tailored as possible and will have to be so explicit and unambiguous as it can be. The end goal should be that the intervention can function independently. This means that even when the implementation of the intervention is completed and the scientists have moved their research practices elsewhere, the intervention can stand on its own.

From professionals to patients

The second moment in the rehabilitation process when the translation of information seems difficult is the process of teaching and learning between healthcare professionals and their patients. During the ethnographic studies (chapter four and five), it became clear that self-management skills were mostly offered to patients in an implicit manner. The skills were presented to the patients by the health care professionals through coaching and conversations and not by actually practicing the skills. A lot of patients will not be able to filter the necessary self-management skills from this implicit way of providing information. A more direct teaching method is therefore desirable. This insight provided us with another aspect we had to consider when developing our intervention. The intervention had to be explicit in the message it attempts to convey. Also, the intervention had to offer patients the opportunity to practice the skills needed to require a maximum level of functioning.

From the rehabilitation centre to the home

The third moment when translation problems can be encountered in the rehabilitation process occurs when patients have to transfer knowledge acquired during a rehabilitation process into their home situation. The differences between the environment of the rehabilitation centre and the home situation of a patient seems too big a hurdle for some. Recent research shows that adapting the knowledge learned in the safe and accommodated environment of a rehabilitation centre to the place our patients call home is challenging (Meijering et al., 2016; Ozkaynak et al., 2021). For example, the difference between patients' home environment not being as adapted as the rehabilitation centre and the fact that help cannot be reached at the touch of a button makes this transition difficult. This dissertation wants to contribute to making this transition to the home environment a little easier for patients by starting to explicitly apply self-management skills.

To make this possible, we wanted to develop an intervention that would allow patients to experiment with possible futures in their home situation, but in the safe environment of the rehabilitation centre (Gillert, 2008). To be able to create these possible futures and help patients practice skills as close as possible to reality, we added gaming theories to the arsenal of theories we had already collected for the development of the intervention (Gillert, 2008; Kriz, 2009). At this point, the interest in developing a serious game as our self-management intervention was raised. To really make this decision, we first researched the actual possibilities that serious gaming could offer for rehabilitation.

Finding five: Serious gaming can solve a problem *(addresses question 3, as described in chapter six)*

As stated at the beginning of this general discussion, we posed several questions. The first two have been answered but the third question; "Can we design an effective self-management intervention that contributes to the success of the implementation of the concept of self-management in the daily practice of rehabilitation, specifically for people with a chronic disease?" still needs to be answered.

In light of the research findings reported in chapters two to five, the self-management intervention had to meet a number of criteria: (1) the intervention should be fine-tuned on the daily practice of rehabilitation, (2) it needs to be as explicit as it can be, (3) the patients should get the opportunity to actually practice the skills on which the intervention focuses, and (4) the intervention should offer patients the opportunity to practice with possible futures so that the transition to the home situation might be easier.

From our interest into serious gaming, the question arose: "Can serious gaming solve these problems? To develop a good serious game, the process of teaching and the ways in which people learn needed to be studied first. Looking at the literature it became clear that there are many ways to define how people acquire knowledge and that everyone has certain preferences in gathering information (Kolb & Kolb, 2009). A critical examination of the rehabilitation process showed that there was certainly scope to broaden methods of providing information. Because of the limited ways in which information is offered, there is a real chance that patients will not acquire knowledge in the manner that is most effective for them. This insight indicates that wherever possible, it would be wise to expand the number of ways in which knowledge can be offered. So, adding a serious game, which is new to the already existing arsenal, could be a desirable step.

Besides the expansion of the already existing arsenal adding a serious game has more benefits. Firstly, during the development of a serious game, we can already take into account the possibilities and impossibilities of daily rehabilitation practice. With a serious game, it is achievable to implement the psycho-social theories very explicitly on which self-management is based into the more physically oriented rehabilitation.

Secondly, a serious game offers patients an explicit way to practice skills, in this case self-management skills. Patients need to learn problem-solving skills to become good self-managers, so a serious game can be developed that explicitly allows them to practice these necessary problem-solving skills. The game also can be designed in such manner that the problems to be solved by the players of the game resemble the problems patients encounter in their own home situation. Concluding we can say that a serious game would meet the above-mentioned criteria.

Finally, a serious game offers the possibility for patients to experiment within a safe environment with possible futures outside the rehabilitation centre. A serious game could thus be developed in such a way that players are able to experiment with problems that they are most likely to encounter in their home situation. If these problems have already been experienced in a game situation, then there is certainly the possibility that the transfer to home situation will be a little easier on that specific element.

Finding six: The serious game 'Think Along?' *(addresses question 3, as described in chapters six, seven and eight)*

As described in the paragraph above the opportunity to experiment with different possible futures could add value to the rehabilitation process. A serious game called 'Think Along?' was designed and implemented as a means of providing this added value. The aim was to design a serious game that would embody existing rehabilitation practices intertwined with patients' lives.

'Think Along?' is based on the social cognitive theories that Lorig used in her body of work, namely the social cognitive theory of Bandura and the problem-solving model formulated by Nezu and D'Zurrila. (Bandura, 1977, 2011; D'Zurilla & Goldfried, 1971; Nezu & D'Zurilla, 1981; Nezu, 2004). The serious game provides an explicit manner of practising the self-management skill of problem-solving. Patients practice with the first two steps of the problem-solving model developed by Nezu and D'Zurrila, namely problem definition and the generation of alternatives (Nezu & D'Zurilla, 1981). Furthermore, 'Think Along?' reflects the complexity of the world of patients with chronic illnesses. The use of data collected during the ethnographic studies and the problems that were introduced by patients themselves, which provided the contextual basis of 'Think Along?', enabled the patients to relate more easily to this serious game.

Based on our observations during the implementation process, we could conclude that during game play the patients recognized that the problems they were playing with appeared to come directly from their own lives. This realisation created the opportunity for them to practice solving problems that they were likely to encounter at home.

Moreover, the fact that patients experience these problems with fellow patients, who are so to speak in the same boat, can provide insight into how people view their problems, the so-called problem orientation (Nezu, 2004). The players also discovered that a problem usually had more than one solution. Both insights could be useful in the home environment.

Finally, this research showed that while playing 'Think Along?', in most cases the players got very involved in both the process and the content of the game. They were committed, had a lot of fun and reported that the serious game was highly educational. This immersion goes hand in hand with emotions. Experiences imbued with emotion stick better in people's memories. This would mean that what a player learned while playing ‘Think Along?’ would be stored in their memory, not least because of the iterative character of the serious game and could therefore be of use to them in the home environment. Further exploration of this aspect was beyond the scope of the research reported in this dissertation, but it would certainly be worthwhile to investigate to what extent players found playing ‘Think Along?’ valuable once they returned to their home environments.

Current status of ‘Think Along?’

As mentioned earlier, the research related to ‘Think Along?’ in the day-to-day practice of the rehabilitation centre stopped in 2012. At this point in time, ten years later, in most cases, an intervention would no longer be part of daily practice. However, ‘Think Along?’ is still being played on a regular basis. In the oncology ward and in the lung ward, the serious game has become a standard element of the treatment process. Thus, for almost ten years, the serious game has continued to function even in the absence of any kind of guiding inputs from researchers. It seems that the serious game has sufficient value to stand on its own, which is a fairly unique situation. It is rare for an intervention, such as this serious game, to be used over such a long duration and remain effective and relevant (Green, 2009; Long et al., 2018; Menon et al., 2009; Mol, 2006). This finding could say something about the way ‘Think Along?’ was developed and put into practice within the organisation. The iterative way in which all of the steps (chapter eight) were applied in the development and implementation of ‘Think Along?’ seems to have been beneficial.

We decided to interview two professionals who use ‘Think Along?’ on their wards. In February 2022 we asked our questions with the use of a semi-structured questionnaire. The interviews were recorded and typed out verbatim and the answers were compared. There results will be described in the following paragraphs.

The place of ‘Think Along?’ in the rehabilitation process

‘Think Along?’ fits well into the rehabilitation process. In the oncology rehabilitation process, it has become an integral part of the psycho-education module. This module comprises five or six weekly sessions, one of which is reserved for playing ‘Think Along?’. In the lung ward, ‘Think Along?’ is also a structural component of the rehabilitation process for patients assigned to the therapist who was interviewed. Once every five weeks, the serious game is played as an embedded part of the rehabilitation process. The respondent’s colleagues use the serious game at will. In conclusion, it can be said that ‘Think Along?’ has more or less acquired a structural place in both wards.

The manner ‘Think Along?’ is played

The second question was whether the way in which ‘Think Along?’ was played had changed. In the oncology ward, the serious game is still played as indicated by the rules of the game. The professional who was interviewed stated, however, that the rules were no longer applied as strictly. The problem-cards constitute the basis of the sessions. She also told us that the skill cards were used. On the lung ward, there have been greater changes. It became clear from the interview with the professional, that ‘Think Along?’ is no longer played according to the rules. One could say the serious game is hardly played as a game at all. The choice was made to use the problem-cards and the Wisdom-tiles only to initiate discussions. The reason given was that the serious game itself is too exhausting for the patients because of the severity of their disease. This is a surprising finding because this issue of the serious game being too heavy for its players was not previously observed during the implementation of ‘Think Along?’; rather, the opposite was the case. The therapist interviewed noted that the patients under her care were often in very poor physical condition. They were mostly oxygen-dependent and had extremely low energy levels, which were insufficient for engaging in something new like ‘Think Along?’. The problem-cards, however, were a good instrument to use to facilitating discussions about the problems associated with living with a serious lung condition.

In summary, even after ten years, the serious game is played as it was designed to be played in the oncology ward. By contrast, in the lung department, adjustments have been made in recent years according to the energy levels of the players. In particular, the problem-cards have proven their value there. Thus, within the lung department, the serious component of the game, namely the problem-cards, have found a place within the rehabilitation process.

The attitude of patients towards ‘Think Along?’

The third topic we were very much interested in was if the critical, almost negative attitude we encountered during the research phase, still remained during play on the oncology ward (chapter eight). This was not the case at all. Patients enjoy looking at their problems in a different and even playful way. So, it seems that our explanation of this critical attitude of the oncology patients in chapter eight has some value. It seems that the mistake we made in changing two factors in the research design, namely implementing the serious game in a different ward concurrently with the recruitment of a freshly trained professional as a facilitator at the same time, has caused too much confusion and has negatively influenced the experience of our players.

Changes in the serious game

Fourth, we were very curious about any changes that have been made to the serious game. After all, ten years of playing might well bring changes. The professional from the oncology department told us that only minor changes had been made. However, some time earlier, a player had indicated that the problems in the game were role-affirming. For example, a woman did the shopping, while a man played football. This is easy to explain when you realise that the cards are ten years old and that the data, we used, was brought to the fore by people who, at the time, were on average 65 years and older. The roles were more clearly differentiated at that time, certainly within the target group, which was the original source for the problem setting. This insight will lead to a critical look at the problem-cards and when there will be made a new version of 'Think Along?' these role-confirming aspects will be corrected. On the lung ward, as noted earlier, 'Think Along?' was mostly applied using the problem-cards to facilitate discussions. Most of the cards are still considered relevant, but the therapist articulated that there was a need for more problem-cards about what she called 'boundaries' for the specific group she interacted with. This means that there is a need for problem-cards that invite patients with severe COPD to reflect on the ever-changing and in their case very restrictive boundaries that a chronic lung condition entails. Ignoring and crossing these boundaries often have negative consequences and therefore, attention to these boundaries and teaching patients to recognize them and avoid crossing them has therapeutic value. Another issue was articulated during the interview with the therapist of the lung ward. It became clear that there is a group of patients treated who have lung problems due to, for example, a burnout. This group rightly does not recognize itself in the problems posed on the problem-cards. For this group extra problem-cards will have to be developed, which will fit the perceptions of this group of patients.

In conclusion, the problem-cards need a revision after ten years. Some problem-cards are seen as too role-affirming for this day and age. In addition, it is desirable to develop problem-cards for patients who have difficulty in recognizing and acknowledging the limits that their condition imposes on them. Finally, problem-cards will be developed for a specific target group in the lung department, which are currently not yet included in the serious game.

Added value of the serious game

Furthermore, we asked what the added value could be of 'Think Along?' According to the professional interviewed in the oncology ward the added value of the serious game lies in learning how to solve problems. For example, players came up with two solutions while playing with the first card. By the time they came to the third card during the same session, they would propose maybe eight solutions. The second point of added value that was mentioned by the therapist, is that by playing a game, a new, not known element for patients was introduced. A game that can bring some playfulness into the often serious issues that oncology patients must deal with. Also was mentioned that the game forces the players to step outside the box to some extent. Because they think about their own problems through an avatar, they are more daring to do so. The therapist in the lung ward told us that the added value of 'Think Along?' was in the apparent power of the Wisdom-tiles. When these cards were placed on the table the patients made the connection between the problem-cards and the discussion that applied to their own situation. The Wisdom-tiles were so popular that more than once, the therapist was asked by a patient if they could take the Wisdom-tile home. She also mentioned that 'Think Along?' can be played in parts. The fact that she has a group under her care that cannot handle playing the entire game, given their low energy levels, prompted her to make the adjustment of 'playing' with just the problem-cards and Wisdom-tiles, which proved successful. This, in her opinion, is a great added value. In conclusion, it appears that 'Think Along?' invites players to think outside the box and brings some joy into difficult situations. In addition, Wisdom-tiles were found to have an unexpected added value, and it appeared that the components of 'Think Along?' could function independently.

Transfer to the home environment

The final focus of interest was the transfer of knowledge acquired in the serious game to real life. When asked if patients had indicated that playing the serious game had helped them to cope in their home environment, the therapist in the oncology ward responded that it most likely had been helpful but that there were no concrete testimonies of this happening. In addition, the problems on the cards are also problems that are discussed in the psycho-educational module anyway. Whereas the game will certainly have an influence, it was difficult for the therapist to pinpoint that influence. The therapist in the lung ward was decisive in her response. The group she treated, with all its problems, probably did not. Although the problem-card could be used to trigger a discussion and the Wisdom-tiles were highly appreciated. This group seemed to be in such a poor physical condition that the transition from the serious game to their own lives was not feasible. Thus, the findings from these interviews indicate that 'Think Along?' has a relevant place in daily rehabilitation practice (Jacobs et al., 2015; Moullin et al., 2015). However, after ten years, some revisions are evidently necessary, as discussed below.

The future of 'Think Along?'

'Think Along?' has been developed for patients with a chronic disease and has been tested in the lung department and in the oncology department. However, the serious game has also been originally developed for the heart department, the rheumatism department, the diabetic department, and the department where people with amputations are being treated. So, the first and most logical step to take in future research is to test 'Think Along?' in these departments and use the feedback it will provide to improve 'Think Along?'. In addition to testing this game in wards where people with chronic conditions are treated, it would also be of interest to assess whether 'Think Along?' could be adapted for use in wards where people with conditions entailing a more acute onset are treated, such as those with spinal cord injuries and non-congenital brain injuries.

The second topic what would be of interest of investigation has to do with the fact that during the implementation research we did on the lung department, it became clear that the serious game could also have an influence outside the game situation. One of the players came back with the story that she had used what she had learned in the previous game session in a conversation she had with her doctor. It is interesting to investigate whether more players experienced this cross-over into their real lives and whether 'Think Along?' can play a role in easing the transition to the home situation. To investigate this question further, measurements would have to be taken when the players are in their home environment. This next phase of research on the home situation, which will look into the problems that patients encounter in this environment, will enable a further round of fine-tuning the serious game.

The third aspect we need to address in the future is not as much about research as it is about adjustments. One of the adjustments we certainly want to make has to do with the supporting visual material. The problem-cards each contain four or five pictures that visually support the problem written on the card. These visual depictions have been provided to make things easier for people with relatively low levels of literacy. However, the images used for the prototype of 'Think Along?' were derived from the internet, which raises the issue of copyrighted material, which will become pertinent when 'Think Along?' is distributed on a wider scale. To avoid this problem, the idea arose to replace the pictures with small comic strips made by students of Stenden University of Applied Sciences in Leeuwarden. In this way, the visual support remaining present, we continue to consider the less literate players and we solve the potential copyright issues. An additional advantage is that the visual information will likely be more transparent and consistent as a comic strip will probably hold a story better than four of five more or less separate pictures.

Another adjustment relating to 'Think Along?' that needs to be explored is the option of developing a digital version of this serious game. A digital version would be aimed at serving patients when they return home. There could be several advantages to a digital version. The first advantage we anticipate is that with the digital version we could create the possibility of making a list of the most frequently mentioned solutions for all the problem-cards, and if it is technically possible to make this list grow as new solutions are invented by the players. In this way, the players could create a database of solutions that they could consult when they encounter a problem for which a quick solution is lacking, but an answer is provided by the above-mentioned list. Providing patients with this digital version, which is basically a problem-solving tool, could make their lives at home somewhat easier. The second advantage of a digital version of 'Think Along?' could be that if we will be able to organise the digital version in such a way that multiple players have access to the serious game, for example, by means of an app. The added value of playing together and looking for solutions associated with the home environment could also be explored. In this way, the transition to the home situation may become a less lonely endeavour.

Concluding remarks

This dissertation has described the journey that ultimately led to the implementation of a sustainable theory-based intervention, the analogue serious game 'Think Along?'. This journey consisted of two parts. The first part focused on searching the literature, to extract data and, define the concept of self-management for rehabilitation practice in such a way that this concept of self-management and rehabilitation would reinforce each other. We learned during our search in the first part of this dissertation that despite the fact that rehabilitation practice and self-management pursue the same end goal of living as well as possible despite the limitations imposed by a chronic illness, they pursue this end goal in different ways. In order to accommodate these differences and make our intervention as successful as it could be, we learned that we had to make the intervention as explicit as possible and allow the patients to practice the skill they needed to obtain. We also learned that it is useful to make an intervention fit in with the perception of the user, in this case patients with a chronic disease. Another important element we learned is that when an intervention is easy to fit into existing practice, the chances of this actually happening are significantly higher. Therefore, the second part of the project focused on the development of a self-management intervention that was based on the findings of the first part of this dissertation. Each of these components was aimed at achieving the ultimate goal of developing an intervention that could be embedded in rehabilitation practice over a long period of time, with the ultimate goal of making the transition from the rehabilitation centre to the patient's home situation as smooth as possible.

Our research showed that a serious game has added value for rehabilitation practice. First, a serious game can provide lighter moments in a sometimes-difficult situation such as a rehabilitation process. It also offers professionals the possibility of explicitly teaching cognitive skills, such as those relating to problem solving. In addition, a serious game offers patients the possibility of experimenting with various scenarios that they will soon face in the home environment. Thus, it offers the possibility to experiment with possible futures.

REFERENCES

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*. https://doi.org/10.1037/0033-295X.84.2.191

Bandura, A. (2011). Social cognitive theory. In: Van Lange, Paul A.M., Higgins. E. Tory, Kruglanski, Arie. W. (Eds), *Handbook of Theories of Social Psychology*, 349-373. https://doi.org/10.1037/13273-005

Cuthbert, C. A., Farragher, J. F., Hemmelgarn, B. R., Ding, Q., McKinnon, G. P., & Cheung, W. Y. (2019). Self-management interventions for cancer survivors: A systematic review and evaluation of intervention content and theories. *Psycho-Oncology, 28*(11), 2119-2140. https://doi.org/10.1002/pon.5215

D'Zurilla, T. J., & Goldfried, M. R. (1971). Problem solving and behavior modification. *Journal of Abnormal Psychology, 78*(1), 107-126. https://doi.org/10.1037/h0031360

Effing, T. W., Vercoulen, J. H., Bourbeau, J., Trappenburg, J., Lenferink, A., Cafarella, P., ... Van Der Palen, J. (2016). Definition of a COPD self-management intervention: International expert group consensus. *European Respiratory Journal, 48*(1), 46-54. https://doi.org/10.1183/13993003.00025-2016

Gillert, A. (2008). Ivo Wenzler : ' Simulations as learning from the future .' *Develop, 2*, 60-64.

Green, L. W. (2009). Making research relevant: If it is an evidence-based practice, where's the practice-based evidence? *Family Practice, 25*(SUPPL. 1), 20-24. https://doi.org/10.1093/fampra/cmn055

Gutenbrunner C, Ward AB, C. M. (2007). White Book on Physical and Rehabilitation Medicine in Europe. *Journal of Rehabilitation Medicine, 2007*(39 Suppl 45), 1-48.

Howell, D., Harth, T., Brown, J., Bennett, C., & Boyko, S. (2017). Self-management education interventions for patients with cancer: a systematic review. *Supportive Care in Cancer, 25*(4), 1323-1355. https://doi.org/10.1007/s00520-016-3500-z

Jacobs, S. R., Weiner, B. J., Reeve, B. B., Hofmann, D. A., Christian, M., & Weinberger, M. (2015). Determining the predictors of innovation implementation in healthcare: A quantitative analysis of implementation effectiveness. *BMC Health Services Research, 15*(1), 1-13. https://doi.org/10.1186/s12913-014-0657-3

Jansma, F. F. I., Van Twillert, S., Postema, K., Sanderman, R., & Lettinga, A. T. (2010). Physical and rehabilitation medicine and self-management education: A comparative analysis of two approaches. *Journal of Rehabilitation Medicine, 42*(9), 808-814. https://doi.org/10.2340/16501977-0606

Kolb, a. Y., & Kolb, D. a. (2009). The Learning Way: Meta-cognitive Aspects of Experiential Learning. *Simulation & Gaming, 40*(3), 297-327. https://doi.org/10.1177/1046878108325713

Kriz, W. C. (2009). Bridging the gap: Transforming knowledge into action through gaming and simulation. *Simulation and Gaming, 40*(1), 28-29. https://doi.org/10.1177/1046878107310099

Long, K. M., McDermott, F., & Meadows, G. N. (2018). Being pragmatic about healthcare complexity: Our experiences applying complexity theory and pragmatism to health services research. *BMC Medicine, 16*(1), 1-9. https://doi.org/10.1186/s12916-018-1087-6

Lorig, K. (2015). Chronic Disease Self-Management Program: Insights from the eye of the storm. *Frontiers in Public Health, 2*(APR), 2014-2016. https://doi.org/10.3389/fpubh.2014.00253

Lorig, K. R., & Holman, H. R. (2003). Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01

Lorig KR, Holman HR, Sobel DS, Laurent D, Gonzalez VM, & Minor M. (2000). *Living a healthy life with chronic conditions. Self-management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema and others.* Boulder, CO: Bull Publishing Co.

Meijering, L., Nanninga, C. S., & Lettinga, A. T. (2016). Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health and Place, 37*(1) 35-42. https://doi.org/10.1016/j.healthplace.2015.11.006

Menon, A., Korner-Bitensky, N., Kastner, M., McKibbon, K. A., & Straus, S. (2009). Strategies for rehabilitation professionals to move evidence-based knowledge into practice: A systematic review. *Journal of Rehabilitation Medicine, 41*(13), 1024-1032. https://doi.org/10.2340/16501977-0451

Mol, A. (2006). Proving or improving: On health care research as a form of self-reflection. *Qualitative Health Research, 16*(3), 405-414. https://doi.org/10.1177/1049732305285856

Moullin, J. C., Sabater-Hernández, D., Fernandez-Llimos, F., & Benrimoj, S. I. (2015). A systematic review of implementation frameworks of innovations in healthcare and resulting generic implementation framework. *Health Research Policy and Systems, 13*(1), 1-11. https://doi.org/10.1186/s12961-015-0005-z

Negrini, S., & Ceravolo, M. G. (2008). The white book on physical and rehabilitation medicine in Europe: A contribution to the growth of our specialty with no boundaries. *American Journal of Physical Medicine and Rehabilitation, 87*(7), 601-606. https://doi.org/10.1097/PHM.0b013e31817fc160

Nezu, A., & D'Zurilla, T. J. (1981). Effects of problem definition and formulation on the generation of alternatives in the social problem-solving process. *Cognitive*

Therapy and Research, 5(3), 265-271. https://doi.org/10.1007/BF01193410

Nezu, A. M. (2004). Problem solving and behavior therapy revisited. *Behavior Therapy, 35*(1), 1-33. https://doi.org/10.1016/S0005-7894(04)80002-9

Ng, W. I., & Smith, G. D. (2017). Effects of a self-management education program on self-efficacy in patients with COPD: A mixed-methods sequential explanatory designed study. *International Journal of COPD, 12*, 2129-2139. https://doi.org/10.2147/COPD.S136216

Nolte, S., Elsworth, G. R., Newman, S., & Osborne, R. H. (2013). Measurement issues in the evaluation of chronic disease self-management programs. *Quality of Life Research, 22*(7), 1655-1664. https://doi.org/10.1007/s11136-012-0317-1

Ozkaynak, M., Valdez, R., Hannah, K., Woodhouse, G., & Klem, P. (2021). Understanding gaps between daily living and clinical settings in chronic disease management: Qualitative study. *Journal of Medical Internet Research, 23*(2). https://doi.org/10.2196/17590

Smith-Turchyn, J., Morgan, A., & Richardson, J. (2016). The Effectiveness of Group-based Self-management Programmes to Improve Physical and Psychological Outcomes in Patients with Cancer: A Systematic Review and Meta-analysis of Randomised Controlled Trials. *Clinical Oncology, 28*(5), 292-305. https://doi.org/10.1016/j.clon.2015.10.003

Van Twillert, S., Postema, K., Geertzen, J. H. B. B., Hemminga, T., Lettinga, A. T., van Twillert, S., ... Lettinga, A. T. (2009). Improving rehabilitation treatment in a local setting: A case study of prosthetic rehabilitation. *Clinical Rehabilitation, 23*(10), 938-947. https://doi.org/10.1177/0269215509338125

Vieira, A. C. G., Gastaldo, D., & Harrison, D. (2020). How to translate scientific knowledge into practice? Concepts, models and application. *Revista Brasileira de Enfermagem, 73*(5), e20190179. https://doi.org/10.1590/0034-7167-2019-0179

Ward, A. B., & Gutenbrunner, C. (2006). Physical and rehabilitation medicine in Europe. *Journal of Rehabilitation Medicine, 38*(2), 81-86. https://doi.org/10.1080/16501970500477777

SUMMARY

What is the structure of this thesis?

This dissertation consists of two parts. The first part describes how the concept of self-management relates to the concept of rehabilitation. To clarify this relation, three studies were conducted. At first, a literature study into the similarities and differences between self-management and rehabilitation was carried out. Next, the position of self-management in the daily routine on a rehabilitation ward was examined. Finally, research has been done into how an existing self-management programme has found its way into oncological rehabilitation. The second part of this thesis relates to the development and implementation of a serious game called 'Denk je mee?' ('Think Along?'). This part of the dissertation starts with the difficulties identified in part one when it comes to information transfer in health care. Next, attention has been given to whether serious gaming and the implementation of gaming theories could provide opportunities to improve this transfer of information. Finally, the design process of 'Think Along?', the game itself, and the circular implementation of the serious game are described.

What do we already know about self-management and how does it fit into rehabilitation practice?

For decades, self-management has been identified as one of the major solutions for some pressing problems in health care. Its greatest contribution was and still is expected in the area of care consumption and specifically in reducing it. The underlying idea is that by increasing self-management skills of people with chronic conditions one creates independent patients. If people take better care of themselves, have better control of their chronic condition, this will, as a logical consequence, reduce the pressure on healthcare. This situation, as is assumed, can be achieved by training people with a chronic condition in self-management skills such as problem solving, asking for help, and communicating more efficiently with healthcare professionals. However, after years of research into these assumptions of what positive effects self-management could have on healthcare, one thing can be said with certainty: 'If only it was all that simple'.

What is self-management exactly?

After extensive literature research it appeared that there is no consensus on the concept of self-management. Self-management is defined and described differently by various scientists. The many self-management interventions that have been developed differ in their content, their length, and their place within healthcare. Similarly, the literature shows that the effects of the various self-management programmes cannot be determined so unambiguously. What can be said is that when a self-management programme focuses on encouraging a healthy lifestyle and proper medication use, the effects are easier to demonstrate than when a self-management programme serves the more psychological elements of having a chronic disease. It turns out to be considerably more difficult to get the psychological effects of these intervention transparent. Finally, it has become clear that the length of the programme has a positive impact on its effects. The longer the programme, the more effective.

How do self-management and rehabilitation relate to each other in the literature?

Because of the diversity of self-management programmes, we refrained from doing a systematic review and opted for a comparative language analysis. To perform this language analysis properly, two bodies of work were chosen to represent the two concepts. 'The White Book', as representative of rehabilitation, and the body of work of Kate Lorig, the developer of the Chronic Disease Self-Management Programme, as representative of the concept of self-management.

By conducting the language analysis, it became clear that both bodies of work seem to pursue a common goal, which is to make a positive contribution to the improvement of the life of a person with a chronic condition. However, how they do achieve this, differs. It also became clear that despite the similar use of words, both concepts do not mean and/or aim for the same things. Four major differences have surfaced. The first difference can be found in the disease trajectories the concepts focus on. The language used in 'The White Book' shows that rehabilitation focuses on the sudden transition from able-bodied to disabled after an illness with an acute onset, and the language used in the self-management literature shows a focus on the indeterminate and unpredictable course of a chronic disease. The second difference can be found in the material and social set-up of the two concepts. Whereas rehabilitation takes place in a clinical setting, self-management takes place in so-called community settings explicitly outside the clinical setting. The third difference that emerged is that importance should be given to the distinction between the treatment goals in rehabilitation and the life goals described in the self-management literature. As a fourth and final difference, it could be observed that relatively little attention is paid in the rehabilitation medicine literature to social theories while in the self-management literature these theories predominate.

How is self-management shaped in daily rehabilitation practice?

To gain insight into how self-management is shaped in daily practice the actions of healthcare professionals were observed for several months. In addition, interviews were conducted to gain insights on the place and content of self-management. This research took place on the lung ward of the rehabilitation centre. It was investigated where self-management was stimulated or was hindered by the professionals functioning within this healthcare environment. In addition, the medical guidelines of the various health care professionals were analysed to get a clear picture of the place of self-management in these guidelines. All these efforts have brought three 'ideals' to the surface.

The first ideal has been called 'Adhering to a healthy lifestyle'. This ideal is prominent in the guidelines and is mainly related to outcomes of reduced healthcare utilization and cost reduction within healthcare. The second ideal called 'Dealing with the unpredictability of chronic illness' was central to the activities in the gym and sports hall and is related to self-efficacy and management of the chronic condition. The third ideal called 'Having freedom of choice' emerged most clearly in the interviews and is related to patients' preferences and how they want to live their lives. It also became clear that this third ideal is often marginalized by the two aforementioned ideals. These results show that self-management is intertwined into daily practice and that due to three sometimes conflicting ideals, the implementation of self-management can become a complex undertaking for both patients and healthcare providers.

How does the implementation of a self-management programme progress in the longer term?

At the oncology department of the centre of rehabilitation, professionals had been working for several years with a theory-driven self-management programme where both physical and emotional aspects of having a chronic condition were served. The healthcare professionals wanted to increase the quality of their care through an evaluation of their actions focussed on enhancing self-management skills in their patients. This evaluation study was conducted by the author, who assumed the role of 'knowledge translator'. A knowledge translator is able to bring the scientific literature and daily practice closer together.

The study aimed to answer the question of how the self-management programme takes shape in daily practice. To this end, focus group interviews were conducted, by an independent interviewer, with the professionals, with a group of rehabilitants who were following the programme at the time and with a group of former rehabilitants. In addition, the first author observed all the components of the programme. The first finding was that there was consensus among the professionals on the great importance of self-management for their patients. Likewise, it was found that the skills put forward as important for patients corresponded to the self-management skills central to the implemented programme. However, it also became clear that there was no consensus on how patients should master these skills. The professionals each in their own way tried to bring the skills to the patients' attention through coaching and implicit tutoring. This lack of consensus and the implicit way of conveying the necessary skills caused the patients to put forward a wide variety of answers to the question posed to them by the researchers; 'What is self-management according to you'? A knowledge translator can bring more uniformity on the subject, by among other things, supporting the professionals by making the implicit explicit, by bringing concrete interventions to their attention, and when necessary, developing new explicit interventions in collaboration with the professionals.

Could serious gaming contribute to the implementation of self-management in rehabilitation practice?

The first part of this thesis has shown that information transfer between professionals and patients is not always smooth. There are several reasons why information transfer is difficult. The first reason has to do with the shifting role of the patient. A few decades ago, a patient was a passive consumer of care whereas today a patient is expected to actively participate in his care process. The second reason that hinders information transfer is that people learn in different ways. However, in healthcare, ways of offering information are not very varied, which can lead to a suboptimal learning environment. The third reason why information transfer can be laborious is the fact that the skills are offered to patients in the rehabilitation centre; an environment that is very different from the patients' home situation. Moreover, the skills are sometimes offered long before they can actually be used. The fourth and final reason that can be pointed out is the fact that a rehabilitation centre is a healthcare facility where the patient's health is, not without reason, a shared responsibility. However, once at home, the patient is once again solely responsible for his health with the associated difficulties. All four reasons mentioned make it clear that the skills that have been learned are not necessarily one-to-one transferable to the home environment. The translations that patients have to make turn out not to be so easy for everyone.

Literature research conducted for this thesis shows that adding game theories to the already existing network of theories on which rehabilitation is grounded could make a positive contribution to solving the problems that exist with information transfer between professional and patient. To give practical and explicit content to these game theories, a theory-based analogue board game called 'Think Along?' was developed, with the aim of offering players' problem-solving skills in an innovative and explicit way. The serious game provides the opportunity to be an active patient, offers a new way of transferring information and gives patients the chance to experiment with different possible futures in a safe environment.

What makes 'Think Along?' special?

By integrating game elements, key features from Nezu and D'Zurrila's problem-solving model, Bandura's social cognitive theory, the work of Lorig et al., and the results of the qualitative research conducted for this thesis into the specific problems faced by people with chronic conditions, a coherent, specifically focused and theory-driven serious game has been designed.

The format of 'Think Along?' is a multi-player analogue board game and is designed like an old Dutch board game. It invites players to brainstorm to find as many solutions as possible to the problems presented (problems that patients had indicated during the qualitative research conducted earlier, that they might encounter in their home situation). The serious game is played with two teams of minimum two and maximum eight players. It is played in three rounds, each with increasing difficulty. The team that comes up with the most solutions, wins.

What did the circular implementation process of 'Think Along?' in rehabilitation practice consist of?

Through five pre-formulated questions and two questions added later, 'Think Along?' was implemented in daily rehabilitation practice in seven steps. At each step the implementation was critically assessed whether adjustments were necessary. From step one professionals were involved in the implementation of 'Think Along?' so that they were always a party to integrating the serious game into their care practice. Using Kirkpatrick's model, each step was evaluated through observation and semi-structured interviews. The data collected were then analysed with Atlas/ti.

The first step of the implementation addressed the question, "Is the serious game playable at all?". To test the playability of the game we asked several professionals from different wards to come and play 'Think Along?'. The results of this first step were that 'Think Along?' is well playable. Following the feedback adjustments were made. Some problem-cards were added, the language on the problem-cards was simplified, and an extra research question was added being, "Can patients play the serious game with their own problems?".

The second step was to answer the question, "Would the serious game work with patients?". The answer on this question was found on the lung ward of the rehabilitation centre. The results were positive. Most patients were very enthusiastic about the serious game. They also indicated that they had found out while playing that there were more solutions to problems than they had expected beforehand. This second step also led to modifications, namely the addition of again an extra research question. The patients responded to the content of the serious game in such a way that therapeutic intervention was needed. It became clear that the facilitator of the game, in the future, had to be a healthcare professional in order for the therapeutic process to be optimal. Therefore, an extra step was added to the implementation process with the research question, “Does the serious game work better with a therapist as facilitator?”. That premise was confirmed by the implementation of this third step. The therapeutic process improved significantly albeit after some initial start-up problems with the newly trained facilitators.

Since the second step had worked with lung patients, the next research question became, “Can the serious game also be played with another patient population?”. To answer this question, the serious game was played with patients who were treated on the oncology ward. This group of players was considerably less enthusiastic. They found it difficult to identify themselves with the problems presented and felt that there had to be a referee who could determine what were right and wrong solutions. This group also articulated that they were missing a flyer with game rules. The flyer was created after the third step and added to the game. Finally, the group indicated that having oncological problems might be too serious to play a game with.

The fifth step was added based on the feedback obtained during the first research question and was “Can patients play the serious game with their own problems?”. When patients played with their own problem, it became clear that these problems were all too close for both the owner of the problem and the other players. The shift to a first-person perspective made it too difficult and too emotional to play the serious game.

Because of the importance of significant others as prominent ‘supporters’ of self-management at home, they were part of the sixth step with the research question, “Does playing the serious game with significant others add value?”. The findings indicated that playing with significant others had important added value. The serious game had a positive effect on group dynamics, gave the players and their significant others an experience they could talk about at home, and finally, they all said that playing in a group with patients and their significant others had made it clear that they were not alone in their situation, and this was found reassuring.

The seventh and final step focused on the research question: “Can we play the serious game with a group consisting of patients with different chronic conditions?”. The theoretical notion that the concept of self-management consists of generic elements as well as specific ones made it interesting to play with a mixed group (players with different conditions). In this study, the players indicated that they had not noticed that they had different diseases. However, the facilitator noted that because she did not treat all patients, she held back even though she saw opportunities for therapeutic interventions. From this finding, it can be concluded that there may be loss of therapeutic value when playing with a mixed group.

In short, it can be concluded that 'Think Along?' has been shown to play well with different patient categories. It is clear that when the practitioner takes on the role of facilitator, this is good for both the gameplay of the serious game and the treatment process of the patients. It can also be concluded that playing with an avatar (third-person perspective) has been good design choice. Playing from the first-person perspective was too confrontational for the patients. In addition, it can be said that the serious game has added value when played with significant others, because of group dynamics and sharing a specific experience that can be talked about at home. Finally, it was found that playing with patients with a different diagnosis is quite possible, but there is a risk of losing therapeutic value.

SAMENVATTING

Hoe is dit proefschrift opgebouwd?

Dit proefschrift bestaat uit twee delen. Het eerste deel beschrijft hoe zelfmanagement zich verhoudt tot de revalidatie. Om daarover helderheid te verkrijgen zijn een drietal onderzoeken uitgevoerd. Een onderzoek naar de overeenkomsten en verschillen tussen zelfmanagement en revalidatie. Vervolgens is gekeken wat de positie van zelfmanagement is in de dagelijkse routine op een revalidatieafdeling. Ten slotte worden de resultaten beschreven van een onderzoek naar de manier waarop een bestaand zelfmanagementprogramma zijn weg vindt in de oncologische revalidatie. Het tweede deel van dit proefschrift behandelt de ontwikkeling en de implementatie van een serious game genaamd 'Denk je mee?' ('Think Along?').

Dit deel start bij de in deel één geconstateerde moeilijkheden die er zijn wanneer het gaat om informatieoverdracht in de zorg. Vervolgens is gekeken of serious gaming en de implementatie van speltheorieën mogelijkheden zouden kunnen bieden om deze overdracht van informatie beter te laten verlopen. Vervolgens worden het designproces van 'Denk je mee?', het spel zelf en de circulaire implementatie van de serious game beschreven.

Wat weten we al over zelfmanagement en hoe past het in de revalidatiepraktijk?

Zelfmanagement wordt al decennialang aangemerkt als de Haarlemmerolie voor de gezondheidzorg. De grootste bijdrage werd en wordt nog steeds verwacht op het gebied van zorgconsumptie en dan specifiek aan het verminderen daarvan. Het achterliggende idee is dat door de zelfredzaamheid, met andere woorden zelfmanagement, van mensen met een chronische aandoening te vergroten men zelfstandige patiënten creëert. Als mensen beter voor zichzelf zorgen, hun chronische aandoening beter onder controle hebben, zal dit als logisch gevolg een verlaging van de druk op gezondheidszorg met zich meebrengen. Deze situatie kan worden bereikt door mensen met een chronische aandoening te trainen in zelfmanagementvaardigheden zoals bijvoorbeeld problemen oplossen, hulp vragen en efficiënter communiceren met zorgprofessionals. Echter na jaren van onderzoek naar deze assumpties welke positieve effecten zelfmanagement zou kunnen hebben voor de gezondheidszorg kan er één ding met zekerheid gezegd worden: 'Was het allemaal maar zo simpel'.

Wat is zelfmanagement nu precies?

Na uitgebreid literatuuronderzoek blijkt dat er geen consensus bestaat over het concept zelfmanagement. Zelfmanagement wordt door diverse wetenschappers verschillend gedefinieerd en beschreven. Vele zelfmanagementinterventies zijn ontwikkeld die verschillen qua inhoud, lengte en plaats binnen de zorg. Eveneens blijkt uit de literatuur dat de effecten van de diverse zelfmanagementprogramma's niet zo eenduidig zijn vast te stellen. Wel is vastgesteld dat wanneer een zelfmanagementprogramma zich richt op het stimuleren van een gezonde leefstijl en goed medicijngebruik de effecten makkelijker aan te tonen zijn dan wanneer een zelfmanagementprogramma de meer psychologische elementen van het ziek-zijn bediend. Dan blijkt het aanzienlijk lastiger de effecten van de interventie transparant te krijgen. Tenslotte is duidelijk dat de lengte van het programma een positieve invloed heeft op de effecten van het programma. Hoe langer het programma, hoe effectiever.

Hoe verhouden zelfmanagement en revalidatie zich tot elkaar in de literatuur?

Vanwege de diversiteit van de zelfmanagementprogramma's is afgezien van het doen van een *systematic review* en is gekozen voor een linguïstische taalanalyse. Om deze taalanalyse goed uit te kunnen voeren zijn twee *body's of work* uitgekozen om de beide concepten te representeren. 'The White Book', als representant van de revalidatie en het oeuvre van Kate Lorig, de ontwikkelaar van het Chronic Disease Self-management Program, als vertegenwoordiger van het concept zelfmanagement.

Door het uitvoeren van de linguïstische analyse is duidelijk geworden dat beide *body's of work* een gemeenschappelijk doel lijken na te streven, namelijk een bijdrage leveren aan het verbeteren van het leven van een persoon met een chronische aandoening. Echter hoe ze dat bewerkstelligen verschilt. Eveneens is helder geworden dat ondanks het vergelijkbare woordgebruik beide concepten niet hetzelfde bedoelen en/of nastreven. Vier grote verschillen zijn aan de oppervlakte gekomen. Het eerste verschil is te vinden in de ziektetrajecten waarop de concepten zich richten. Uit de taal gebruikt in 'The White Book' blijkt dat de revalidatie zich richt op de plotselinge overgang van een valide naar een invalide persoon na een ziekte met een acuut begin en dat de taal gebruikt in de zelfmanagementliteratuur laat zien dat de aandacht is gericht op het onbepaalde en onvoorspelbare verloop van een chronische ziekte. Het tweede verschil is te vinden in de materiële en sociale opzet van beide concepten. Waar de revalidatie plaatsvindt in een klinische setting vindt zelfmanagement plaats in zogenaamde gemeenschapssettingen expliciet buiten de klinische omgeving. Het derde verschil dat naar voren kwam, is dat er belang moet worden toegekend aan het onderscheid tussen de behandeldoelen in de revalidatie en de levensdoelen beschreven in de zelfmanagementliteratuur. Als vierde en laatste verschil is duidelijk geworden dat er relatief weinig aandacht wordt geschonken in de literatuur over revalidatiegeneeskunde aan de sociaalwetenschappelijke theorieën terwijl in de zelfmanagementliteratuur deze theorieën de boventoon voeren.

Hoe wordt zelfmanagement vormgegeven in de dagelijkse revalidatie praktijk?

Om zicht te krijgen op hoe zelfmanagement vorm krijgt in de dagelijkse praktijk is een aantal maanden, op de longafdeling in het centrum, het handelen van zorgprofessionals geobserveerd en zijn interviews gehouden om de plek van zelfmanagement transparant te krijgen. Er is onderzocht waar zelfmanagement stimulerend of zelfmanagement belemmerend wordt gehandeld door de professionals functionerend binnen een zorgomgeving. Daarnaast zijn de medische richtlijnen van de diverse beroepsgroepen geanalyseerd om de plek van zelfmanagement in deze richtlijnen duidelijk te krijgen. Al deze inspanningen hebben drie 'idealen' aan de oppervlakte gebracht.

Het eerste ideaal is 'Vasthouden aan een gezonde levensstijl' genoemd. Dit ideaal is prominent aanwezig in de richtlijnen en is vooral gerelateerd aan uitkomsten van minder zorggebruik en kostenreductie binnen de gezondheidszorg. Het tweede ideaal genaamd 'Omgaan met de onvoorspelbaarheid van chronische ziekte' stond centraal in de activiteiten in de fitnesszaal en de sporthal en wordt gerelateerd aan zelfeffectiviteit en beheersing van de chronische aandoening. Het derde ideaal dat 'Keuzevrijheid hebben' is genoemd, kwam het duidelijkst naar voren in de interviews en is gerelateerd aan voorkeuren van patiënten en hoe zij hun leven willen leiden. Tevens werd duidelijk dat dit derde ideaal vaak wordt gemarginaliseerd door de twee eerdergenoemde idealen. Deze resultaten maken duidelijk dat zelfmanagement is verweven in de dagelijkse praktijk en dat door de drie soms conflicterende idealen de implementatie van zelfmanagement een complexe onderneming kan worden voor zowel de patiënt als de zorgverlener.

Hoe verloopt de implementatie van een zelfmanagement programma op langere termijn?

Op de oncologie-afdeling van het centrum van revalidatie werkte men al een aantal jaren met een theoretisch gestuurd zelfmanagementprogramma waar zowel fysieke als emotionele aspecten van het hebben van een chronische aandoening werden bediend.

De zorgprofessionals wilden door middel van een evaluatie van hun handelen op het gebied van zelfmanagement de kwaliteit van hun zorg verhogen. Dit evaluatieonderzoek werd uitgevoerd door de auteur, die de rol van 'kennisvertaler' aannam. Een kennisvertaler is instaat om de wetenschappelijke literatuur en de dagelijkse praktijk dichter bij elkaar te brengen. Het onderzoek poogde de vraag te beantwoorden hoe het zelfmanagementprogramma vorm krijgt in de dagelijkse praktijk. Daartoe werden, door een onafhankelijke interviewer, focusgroep-interviews afgenomen bij de professionals, bij een groep revalidanten die het programma volgden op dat moment en een groep ex-revalidanten. Daarnaast zijn alle onderdelen van het programma geobserveerd. Als eerste bleek dat er consensus bestond onder de professionals over het grote belang van zelfmanagement voor hun patiënten. Eveneens bleek dat de vaardigheden die naar voren werden gebracht als belangrijk voor de patiënt overeen kwamen met de zelfmanagementvaardigheden die centraal staan in het geïmplementeerde programma. Echter werd ook duidelijk dat er geen consensus bestond over de manier waarop patiënten deze vaardigheden zich dan eigen zouden moeten maken. De professionals poogden ieder op hun eigen manier via coaching en impliciete bijsturingen de vaardigheden onder de aandacht van de patiënten te brengen. Dit gebrek aan consensus en de impliciete manier van het overbrengen van de noodzakelijke vaardigheden veroorzaakte dat de patiënten een grote variëteit aan mogelijkheden naar voren brachten op de door de onderzoekers aan hen gestelde vraag; 'Wat is zelfmanagement'? Een kennisvertaler kan hier een rol spelen door de professionals te ondersteunen door het impliciete expliciet te maken o.a. door concrete interventies opnieuw onder hun aandacht te brengen en wanneer nodig nieuwe interventies te ontwikkelen in samenwerking met de therapeuten.

Zou serious gaming een bijdrage kunnen leveren bij de implementatie van zelfmanagement in de revalidatie praktijk?

Uit het eerste deel van dit proefschrift is gebleken dat de informatieoverdracht tussen professionals en patiënten niet altijd soepel verloopt. Er zijn meerdere redenen aan te wijzen waarom informatieoverdacht moeizaam is. De eerste reden heeft te maken met de verschuiving van de rol van de patiënt. Een aantal decennia geleden was een patiënt een passieve consument van zorg terwijl vandaag de dag van een patiënt een actieve deelname in zijn zorgproces wordt verwacht. De tweede reden die de overdracht van informatie belemmert, is dat mensen op verschillende manieren leren. Echter in de gezondheidszorg zijn manieren om informatie aan te bieden niet zeer gevarieerd, wat kan leiden tot een suboptimale leeromgeving. De derde reden waarom informatieoverdracht moeizaam kan zijn, is het feit dat de vaardigheden de patiënten worden aangeboden in het revalidatiecentrum; een omgeving die in hoge mate verschilt van de thuissituatie van de patiënten. Bovendien worden de vaardigheden soms lang voordat ze daadwerkelijk gebruikt kunnen worden aangeboden. De vierde en laatste reden die kan worden aangewezen is het feit dat een revalidatiecentrum een zorginstelling is waar de gezondheid van de patiënt, niet zonder reden, een gedeelde verantwoordelijkheid is. Echter eenmaal thuis is de patiënt opnieuw alleen verantwoordelijk voor zijn gezondheid met de bijbehorende moeilijkheden. Alle vier genoemde redenen maken duidelijk dat wat aan vaardigheden is geleerd niet één op één overdraagbaar is naar de thuisomgeving. De vertaalslagen die patiënten moeten maken blijken niet voor iedereen even eenvoudig.

Uit voor dit proefschrift verricht literatuuronderzoek blijkt dat het toevoegen van speltheorieën aan het reeds bestaande netwerk van theorieën waarop de revalidatie gestoeld is, een positieve bijdrage zou kunnen leveren om een deel van de problemen die er bestaan met de informatieoverdracht tussen professional en patiënt op te lossen. Om deze speltheorieën een praktische en expliciete invulling te geven is een op theorie gebaseerd analoog bordspel ontwikkeld, genaamd 'Denk je mee?', met als doel de probleemoplossende vaardigheden van de spelers op een innovatieve en expliciete manier aan te bieden. De serious game biedt de mogelijkheid om een actieve patiënt te zijn, biedt een nieuwe manier van informatieoverdracht en geeft patiënten de kans om in een veilige omgeving te experimenteren met verschillende mogelijke toekomsten.

Wat maakt 'Denk je mee?' bijzonder?

Door op basis van spelelementen en belangrijke kenmerken uit het probleemoplossingsmodel van Nezu en D'Zurrila, de sociaal cognitieve theorie van Bandura, het werk van Lorig et al. en tenslotte de resultaten van het voor dit proefschrift verrichte kwalitatief onderzoek naar de specifieke problemen waar mensen met chronische aandoeningen mee te maken hebben, met elkaar te integreren, is een coherent, specifiek gericht en theorie gestuurd serious game ontworpen.

Het formaat van 'Denk je mee?' is een analoog bordspel voor meerdere spelers en is vormgegeven als een oud Hollands bordspel. Het nodigt de spelers uit om te brainstormen om zoveel mogelijk oplossingen te vinden voor de voorgelegde problemen (problemen waarvan patiënten tijdens het eerder gedane kwalitatieve onderzoek hadden aangegeven, dat zij die tegen zouden kunnen komen in hun thuissituatie). De serious game wordt gespeeld met twee teams van minimaal twee en maximaal acht spelers. Het wordt gespeeld in drie fasen van oplopende moeilijkheidsgraad. Het team dat de meeste oplossingen kan aandragen heeft gewonnen.

Hoe is het circulair implementatie proces in de revalidatie praktijk verlopen?

Door middel van vijf van tevoren geformuleerde vragen en twee later toegevoegde vragen is 'Denk je mee?' in zeven stappen geïmplementeerd in de dagelijkse revalidatiepraktijk. Bij elke stap is kritisch gekeken of er aanpassingen noodzakelijk waren. Vanaf stap één zijn de professionals betrokken bij de implementatie van 'Denk je mee?' zodat ze steeds een partij waren bij de integratie van het spel in hun zorgpraktijk. Aan de hand van het model van Kirkpatrick werd elke stap geëvalueerd door middel van observatie en semigestructureerde interviews. De verzamelde gegevens werden vervolgens geanalyseerd met Atlas/ti.

Tijdens de eerste stap kwam de vraag aan de orde: “Is de serious game überhaupt speelbaar?”. De resultaten van deze eerste stap waren dat ‘Denk je mee?’ goed speelbaar is. Naar aanleiding van de feedback zijn er aanpassingen gedaan. Er zijn enkele probleemkaarten toegevoegd, het taalgebruik is vereenvoudigd en er werd nog een onderzoeksvraag toegevoegd.

De tweede stap moest antwoord geven op de vraag: “Zou de serious game werken bij patiënten?”. De resultaten waren positief. De meeste patiënten waren erg enthousiast over het spel. Ze gaven ook aan dat ze erachter waren gekomen tijdens het spelen dat er meer oplossingen voor problemen waren dan ze van tevoren hadden verwacht. Deze tweede stap heeft ook tot aanpassingen geleid namelijk de toevoeging van een aanvullende onderzoeksvraag. De patiënten reageerden dusdanig op de inhoud van het spel dat er noodzaak was voor therapeutisch handelen. Het werd duidelijk dat de facilitator van het spel, in de toekomst, een zorgprofessional moest zijn zodat het therapeutische proces optimaal zou kunnen verlopen. Daarom werd een extra stap toegevoegd aan het implementatieproces met de onderzoeksvraag: “Werkt de serious game beter met een therapeut als facilitator?”. Die vooronderstelling werd bevestigd door de implementatie van deze derde stap. Het therapeutische proces verbeterde aanzienlijk na enkele initiële opstartproblemen met de nieuw opgeleide facilitators.

Aangezien er in de tweede stap met longpatiënten was gewerkt, werd de volgende onderzoeksvraag: “Kan de serious game ook met een andere patiëntenpopulatie gespeeld worden?” Om deze vraag te beantwoorden is het spel gespeeld door oncologiepatiënten. Deze groep spelers was aanzienlijk minder enthousiast. Zij identificeerden zich moeilijk met de voorgelegde problemen en vonden dat er een scheidsrechter moest zijn die kon bepalen wat goede en verkeerde oplossingen waren. Ook articuleerde deze groep dat ze een flyer met spelregels misten. De flyer is na derde stap gemaakt en toegevoegd aan het spel. Ten slotte gaf de groep aan dat het hebben van oncologische problemen misschien te ernstig was om een spel mee te spelen.

De vijfde stap werd toegevoegd op basis van de feedback die verkregen was gedurende de eerste onderzoeksvraag en is: “Kunnen patiënten de serieuze game spelen met hun eigen problemen?”. Wanneer patiënten met hun eigen probleem speelden, bleek dat het allemaal te dichtbij kwam voor zowel de eigenaar van het probleem als de andere spelers. De verschuiving naar een eerste-persoonsperspectief maakte het te moeilijk om de serious game te spelen.

Vanwege het belang van significante anderen als prominente ‘supporters’ van zelfmanagement thuis, waren zij onderdeel van de zesde stap met de onderzoeksvraag: “Heeft het spelen van de serious game met significante anderen een meerwaarde?”.

De bevindingen gaven aan dat het spelen met significante anderen een aanzienlijke meerwaarde had. De serious game had een positief effect op de groepsdynamiek, gaf de spelers en hun significante anderen een ervaring waarover ze thuis konden praten, en ten slotte zeiden ze allemaal dat het spelen in een groep met patiënten en hun significante anderen duidelijk had gemaakt dat ze niet alleen stonden in hun situatie en dat ze dit als geruststellend hadden ervaren.

In de zevende en laatste stap stond de onderzoeksvraag: "Kunnen we de serious game spelen met een groep bestaande uit patiënten met verschillende chronische aandoeningen?" centraal. De theoretische notie dat het concept zelfmanagement naast specifieke ook uit generieke elementen bestaat, maakte het interessant om met een gemengde groep (spelers met een verschillende aandoening) te spelen. In dit onderzoek gaven de spelers aan dat ze tijdens het spelen niet hadden gemerkt dat hun medespelers andere ziekten hadden. De facilitator merkte echter op dat ze, omdat ze niet alle patiënten behandelde, zich inhield, ook al zag ze mogelijkheden voor therapeutische interventies. Uit deze bevinding kan er worden geconcludeerd dat er verlies aan therapeutische waarde kan ontstaan wanneer er gespeeld wordt met een gemengde groep.

Kortom, er kan geconcludeerd worden dat is gebleken dat 'Denk je mee?' goed speelbaar is met verschillende patiëntencategorieën. Het is duidelijk dat wanneer de behandelaar de rol van facilitator op zich neemt, dit goed is voor zowel het spelverloop van de serious game als het behandelproces van de patiënten. Eveneens kan worden geconcludeerd dat het spelen met een avatar (derde-persoonsperspectief) een goede ontwerpkeuze is geweest. Het spelen vanuit het eerste-persoonsperspectief was te confronterend voor de patiënten. Daarnaast kan worden gezegd dat de serious game een meerwaarde heeft wanneer het met significante anderen wordt gespeeld, omwille van de groepsdynamiek en het delen van een specifieke ervaring waarover thuis kan worden gepraat. Ten slotte bleek dat spelen met patiënten met een andere diagnose goed mogelijk is, maar dat er het risico bestaat dat er therapeutische waarde verloren gaat.

DANKWOORD

Het dankwoord is misschien wel het stuk van mijn proefschrift waar ik me meest druk over heb gemaakt. Immers het dankwoord dat leest vrijwel iedereen die het proefschrift in handen krijgt. Ik voorzag vele hobbels op de weg. Wie bedank je nou wel en wie niet en wie eerst en wie laatst? Maakt het eigenlijk uit hoe je mensen bedankt? Is er een goede manier of juist een slechte? Kortom, ik vond het lastig. Wat wel direct duidelijk voor me was, was wie ik het eerste wilde bedanken. Dit zijn zonder enige twijfel alle professionals en patiënten die deel hebben genomen aan de verschillende deelonderzoeken. Want laten we even heel helder zijn, zonder hun medewerking was er nooit een proefschrift gekomen. Dus mijn hartelijke dank daarvoor!

Nee, mijn probleem zat meer in de groep die dan volgt, die ik dankbaarheid verschuldigd ben. Wanneer je pak 'm beet zo'n zestien jaar bezig bent met je proefschrift wordt de rij van mensen die een woord van dank waard zijn steeds langer. En geloof me, die rij is lang en gevuld met familie, vrienden, kennissen, oud-collega's en ook hulpverleners. Allemaal bijzondere, lieve en aardige mensen, die aandacht verdienen. Ik hoop echter wel dat eenieder begrijpt dat ik niet al deze mensen persoonlijk kan bedanken. Toch wil ik een algemeen woord van dank uitspreken voor iedereen die mij de afgelopen jaren op welke manier dan ook heeft geholpen, gesteund, gestimuleerd, naar me heeft geluisterd als ik enthousiast was of juist helemaal niet, me heeft getroost, met me heeft gevierd en met me heeft gehuild. Mensen, mijn dank is groot.

Goed, er is natuurlijk wel een aantal mensen die een extra woord van dank verdienen. Allereerst zijn dat Robbert Sanderman en Ivo Wenzler.

Beste Robbert, toen ik in 2016 bij je kwam met het idee om mijn proefschrift toch af te ronden was je, ondanks alle overduidelijke beperkingen, meteen enthousiast. Je stelde me direct gerust en gaf aan dat ik, of eigenlijk mijn hart, leidend zou zijn in het tempo. Jij zou mij volgen. Ik kan je niet zeggen hoeveel dat heeft uitgemaakt. In datzelfde eerste gesprek gaf je me een advies dat ik tot de dag van vandaag nog vaak ter harte neem. Op mijn opmerking dat ik niet alleen de kar kon trekken in dit proces zei je de illustere woorden 'dan moet je 'duwers' gaan zoeken'. Ik kan wel zeggen dat je één van de grootste duwers bent geweest de afgelopen jaren. Wanneer ik in de positie was om even stevig door te werken sloot je aan. Wanneer ik weer eens drie maanden uit de roulatie was en ik daar verdrietig over was, was je altijd een enorme steun. Robbert, bedankt voor alles, voor je kennis, de inspirerende gesprekken, je geduld en onze gedachtenspinsels over onze verbouwingen, die van jou in Spanje en die van mij in de achtertuin in Peize. Ik zal onze digitale bakjes koffie missen.

Beste Ivo, jij kwam later in het proces in beeld. We hebben elkaar ontmoet toen ik de cursus 'Serious gaming for Professionals' ging doen aan de TU Delft in 2010. Je was destijds één van de docenten. Het spel dat we toen gemaakt hebben is eigenlijk de basis geworden voor ons verdere contact. Vele jaren later toen ik weer was begonnen met mijn proefschrift, zocht ik contact met de woorden of je nog wist wie ik was. Ik wilde heel graag met je samenwerken in het tweede deel van mijn proefschrift waar serious gaming centraal staat. Ik wilde dat jouw kennis, vaardigheden en scherpe analytische blik gereflecteerd zouden worden in het tweede deel van dit proefschrift. Mijn wens werd vervuld, want gelukkig berichtte je terug met de woorden 'Zeker weet ik nog wie jij bent' en we hebben snel afgesproken. De rest is geschiedenis. Je bent zelfs co-promotor geworden. Ivo, ik ben je dankbaar voor je geduld, je begrip, je kennis, je scherpe blik en zelfs voor je zeer uitgebreide correcties in elk stuk dat ik je stuurde. Soms schrok ik van al het rood, maar dat was altijd terecht en het boek is er alleen maar beter van geworden. Ik verheug me op onze toekomstige samenwerking om het spel 'Denk je Mee?' te verbeteren.

Robbert en Ivo zijn niet de enige mensen die een grote rol hebben gespeeld. Er zijn er meer die hun creativiteit en kennis beschikbaar hebben gesteld. Dit zijn de begeleiders van het eerste uur, Ant Lettinga en Klaas Postema en mijn familie.

Beste Ant, jij was de eerste 5 jaar van dit proefschrift mijn dagelijks begeleider. We waren toen nog met zijn allen bij OKER gevestigd in het revalidatiecentrum UMCG Beatrixoord in Haren met een groep gedreven wetenschappers. Ant, ik heb het al eerder geschreven, jij slingert als een rode draad door het vormingsproces dat ik heb doorgemaakt om te worden tot de wetenschapper die ik nu ben. Dit educatieve avontuur begon in 1988 toen ik studeerde aan de Academie voor Fysiotherapie waar jij docent was. Daarna kwamen we elkaar opnieuw tegen bij Bewegingswetenschappen aan de RUG waar jij opnieuw een van mijn docenten was en tenslotte was je mijn dagelijkse begeleider in de eerste vijf jaar dat ik gewerkt heb aan dit proefschrift. Ik kan wel zeggen dat ik van jouw manier van naar de werkelijkheid kijken binnen de wetenschap veel heb geleerd en dat dit mede mijn eigen bril heeft bepaald. Ant, ik wil je bedanken voor de inspirerende gesprekken die we hadden over hoe we zelfmanagement binnen de revalidatie konden implementeren, over hoe de gezondheidszorg en specifiek de revalidatie zou kunnen worden verbeterd zodat de mensen die hun vertrouwen in de zorgprofessionals hadden gesteld ook daadwerkelijk weer naar huis konden gaan met een level van functioneren dat voor hen wenselijk was. Hier bewaar ik warme herinneringen aan.

De volgende die zeker aandacht verdient is Klaas Postema. Beste Klaas, de eerste zes jaar was je mijn eerste promotor. Jij was sceptisch toen ik langskwam om aan te geven dat ik opnieuw wilde beginnen. Jouw vraag, een terechte vraag overigens, was waarom ik het opnieuw wilde oppakken. Jij wilde dat er een element van plezier in het avontuur zou zitten en dat ik niet vanuit een soort van plichtsbesef het proefschrift zou moet willen afronden. Nou Klaas, dat is er zeker van gekomen. Ik heb de afgelopen jaren met veel plezier dit proefschrift afgeschreven. Gedurende het tweede traject ben je niet meer actief betrokken geweest, vanwege het feit dat je met pensioen ging. Je was, in 2016, direct bereid om Robbert de positie van eerste promotor te geven, zodat ik beter bediend zou kunnen worden de komende jaren. Mijn dank daarvoor. Eveneens wil ik je bedanken voor je begrip, je inzichten, je altijd analytische commentaar en je vermogen om de rode draad vast te houden.

De volgende groep mensen, die ik wil bedanken is mijn familie. Tja, mijn familie. Wat zeg je tegen mensen die het verschil maken. Lieve papa, mama, Folbert, Stefanie, Bert, Stijn en Sil. Ik bevind me in de gelukkige omstandigheid dat ik hou van eenieder in mijn familie en ik ben me bewust van het feit dat dit geen gemeengoed is en dat dit een reden is voor diepe dankbaarheid. Dit warme netwerk dat mij dagelijks omgeeft zorgt ervoor dat ik overeind blijf en dat geldt niet alleen op het gebied van het schrijven van een proefschrift.

Eerst wil ik mijn vader, Lammert Gosse Jansma en mijn moeder Mineke Jansma-Veenstra bedanken. Ik heb enorm geboft dat mijn vader, net als ik, social-wetenschapper is. Naast zijn rol als vader heeft hij ook de rol van sparringpartner op zich genomen. Een rol die anders door collega's zou zijn ingevuld. In de vier jaar dat ik te ziek was om aan het proefschrift te schrijven heeft hij door middel van gesprekken het toch levend voor me gehouden. Toen ik weer begon te schrijven was hij een van de belangrijke mensen die me stimuleerde, afremde, die meelas en eindeloos stukken heeft gecorrigeerd. Het heeft het traject een stuk minder eenzaam en zeker heel veel leuker gemaakt. Papa, Lammert, mijn dank is groot.

Daarna mijn moeder. Mama, jij bent altijd degene geweest die me wees op het feit dat promoveren leuk en belangrijk was, maar dat het wekelijkse sporten bij de fysio misschien nog wel belangrijker was. We kunnen als Jansma's nogal eens verdwijnen in hetgeen waar we de focus op leggen. Jij zorgde ervoor dat ik niet alleen schreef over zelfmanagement, maar dat ik ook aandacht bleef houden voor mijn eigen level van functioneren en dat er naast promoveren ook nog andere levensdoelen waren. Ik ben je daar bijzonder dankbaar voor.

Folbert en Stefanie, bedankt voor alle gesprekken en de belangstelling de afgelopen jaren. Folbert, ik vind het fijn dat je mijn paranimf bent.

Als laatste, maar zeker niet als minste: mijn drie mannen. Bert, Stijn en Sil, we hebben nogal een weg afgelegd met zijn vieren. Alle pieken en dalen die ik had de afgelopen jaren, hebben we met zijn vieren getrotseerd en ik had het niet zonder mijn drie mannen gekund. Ik houd van jullie.

Dan is er nog een derde groep die zeker een expliciet woord van dank verdient en dat zijn mijn oud-collega's. Ook al werken we al lange tijd niet meer met elkaar wil ik er toch een aantal noemen.

Lieve Christa, je bent in mijn OKER-tijd mijn kamergenootje geweest en ik had me er geen betere kunnen wensen. We konden en kunnen gelukkig nog steeds met elkaar brainstormen, van elkaar leren, en ook met elkaar lachen wat ook zeker niet onbelangrijk is. Je bent tot op de dag van vandaag erg waardevol voor me.

Beste Sacha, ik heb het altijd als een groot plezier ervaren om samen met jou promovenda te zijn. We hebben veel dingen samengedaan en het werd er altijd beter van.

Verder wil ik de volgende collega's van destijds noemen: Judith, Indra, Ilse, Ankie, Carina, Haitze, Ria, Anja, Berry, Ellen en Remco. Jullie maakten van mijn werkplek een plek waar ik graag naar toe ging. Alle gezellige gesprekken, maar ook zeker het uitwisselen van kennis en ervaringen hebben het niveau van mijn proefschrift zoveel verder gebracht. Als laatste is er een aantal collega's die ook de afgelopen jaren belangrijk zijn geweest. Truus, Fester en Annemieke dank voor alle steun in emotionele en praktische zin.

Dan komen we op de vierde groep en laatste groep mensen die aandacht verdient. Promoveren kost energie. Energie die ten koste gaat van belangrijke mensen, namelijk vrienden. Gelukkig heb ik vrienden die me altijd hebben gesteund gedurende dit proces. Die soms kritisch waren, maar altijd liefdevol. Caro, een expliciete dank voor het prachtige ontwerp van mijn proefschrift! Mensen, deze tour de force is klaar. Het is me gelukt. En dat is zeker mede dankzij jullie!! Mijn dank is groot.

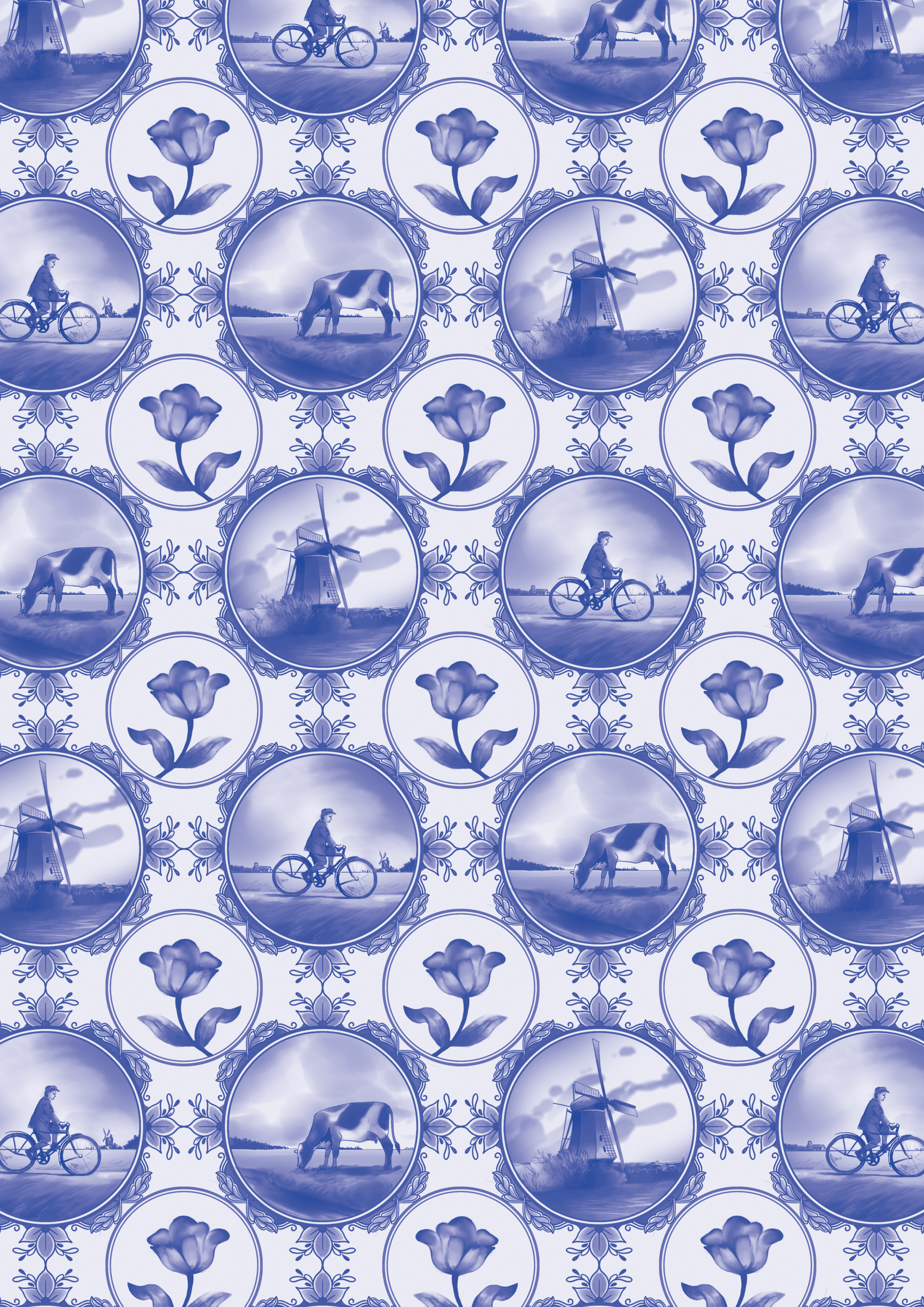
CURRICULUM VITAE

Feyuna Femke Ietsje Jansma is op 18 augustus 1971 geboren te Dordrecht. In 1988 behaalde zij haar HAVO-diploma en ging vervolgens studeren aan de Academie voor Fysiotherapie in Groningen waar zij in 1993 haar diploma behaalde.

Vervolgens studeerde ze van 1993 tot 1996 Bewegingswetenschappen aan de Rijksuniversiteit Groningen. Na haar studie Bewegingswetenschappen ging ze aan het werk als bewegingswetenschapper op dezelfde afdeling waar ze gestudeerd had met het onderzoek naar de effecten die outdoor activiteiten zouden kunnen hebben op de zelfwaardering van dove jongeren. De daarop volgende jaren heeft Feyuna gewerkt aan diverse projecten gecentreerd rondom gedragsverandering van en sportstimulering voor mensen met een chronische aandoening zoals SCALA (Sportstimulering voor mensen met een Chronische Aandoening: een Leven lang Actief), GALM (Groningen Actief Leven Model) en een onderzoek voor Hart in Beweging.

Na haar tijd bij bewegingswetenschappen is Feyuna verbonden geweest aan de afdeling Huisartsgeneeskunde waar ze onderzoek heeft gedaan naar de mogelijkheden voor ondersteuning van mantelzorgers van mensen met palliatieve kanker, wat resulteerde in een internationale publicatie. Gelijktijdig werkte ze een aantal dagen per week als fysiotherapeut in de praktijk voor Fysiotherapie en Acupunctuur van Erik Thole en Jacqueline Kok te Groningen en was ze IOF (Intercollegiaal Overleg Fysiotherapie) coördinator voor het KNGF (Koninklijk Nederlands Genootschap voor Fysiotherapie) waar ze fysiotherapeuten ondersteunde bij hun intervisie- en casuïstiek-bijeenkomsten.

Na een uitstapje als manager in de farmaceutische industrie is Feyuna in 2007 teruggekeerd naar het doen van onderzoek. Ze ging aan de slag bij het onderzoeksbureau OKER van het revalidatiecentrum UMCG Beatrixoord te Haren met de opdracht te onderzoeken in hoeverre het concept zelfmanagement een rol zou kunnen spelen in de revalidatiepraktijk. De resultaten van dit onderzoek worden beschreven in dit proefschrift. Zoals in het voorwoord wordt beschreven, is in 2012 veel veranderd in het leven van Feyuna wat de voortgang van het onderzoek en haar carrière heeft beïnvloed. Na haar promoveren zal ze haar tijd en creativiteit spenderen aan het schrijven van een roman, zal ze betrokken zijn met de verdere ontwikkelingen van de serious game 'Think Along?' en zal ze haar energie steken in wat de toekomst maar brengen mag. Feyuna woont in Peize. Ze is getrouwd met Bert en zij hebben twee zonen, Stijn en Sil.



Research Institute
SHARE