KU LEUVEN

FACULTEIT GENEESKUNDE
BIOMEDISCHE WETENSCHAPPEN

De ontwikkeling en effectiviteit van een interactief spel “SERES™ schizofrenie” met als doel de belasting bij de mantelzorger te verminderen

(The development and effectiveness of an interactive game “SERES™ schizophrenia” to decrease the burden on caregivers)

Masterproef voorgedragen tot het behalen van de graad van Master in de biomedische wetenschappen door

Julie VANDECANDELAERE

Promotor: Prof. dr. Ruud VAN WINKEL

Begeleider: Geert VANDER STICHELE

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PREFACE

In this preface, I want to thank everyone for their help and support during the realization of this Master's Thesis. Because of their guidance and professional advice, this Master's Thesis could be realized.

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LIST OF ABBREVIATIONS

GABA	γ-AminoButyric Acid
fMRI	functional Magnetic Resonance Imaging
WHO	World Health Organization
QoL	Quality of Life
HIV	Human Immunodeficiency Virus
ICD-10	Tenth Revision of the International Classification of Diseases
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Forth Edition
BITs	Behavioural Intervention Technologies
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorders
UPC	University Psychiatric Centre of Kortenberg
BSFC	Burden Scale for Family Caregivers
PFBS	Perceived Family Burden Scale
LMS	The Learning Management System

ABSTRACT

Schizophrenia is a severe disorder of the brain and the mind. The disorder is characterized by positive and negative symptoms and is typically presented in late adolescence. In most cases, the family is responsible for the daily care of the patient. This task can be experienced as very stressful and often there are not enough or no easy accessible support tools. This causes burden. To answer this unmet need for family caregivers, a new interactive tool called ‘serious gaming’ has been introduced recently. Several studies have shown that this digital tool is ameliorating the learning process and can lead to a successful behaviour change because of its interactive nature. A serious game for caregivers of people with schizophrenia called ‘SERES™ schizophrenia’ has been developed. Apart from knowledge, this game aims at teaching practical skills. A randomized controlled trial with ten daily caregivers was performed to assess whether the game is decreasing the caregiver’s burden. This burden was measured with the BSFC and PFBS. The schizophrenia e-learning, developed to purely inform, was used as the control intervention. Even though in this pilot study, no significant results were found, a trend towards a lowering in the PFBS mean burden score could be observed. This trial indirectly suggests that providing knowledge and skills reduces the burden better than only providing knowledge. Larger studies with a longer duration should assess if these suggestions can be proven with significant results. These studies can be carried out with an updated and more engaging SERES™ schizophrenia game.

1. Introduction

Schizophrenia affects over 24 million people worldwide and has severe consequences for those who suffer from it. With the right treatment, however, the symptoms can be reduced to a minimum and people can regain their function in society. Due to the de-institutionalization process, patients are moved out of long-term psychiatric hospitals into social and family care. Of these patients, 40 to 90% live at home, leaving family members with the day-to-day care. The family caregivers provide their loved ones with support, structure, emotional balance and future objectives. This family support improves treatment compliance and reduces the relapse rates, which enhances the outcomes of mentally ill patients. Therefore family care is of the utmost importance for the long-term outcomes of mental health patients.

Caregivers face many challenges both in terms of making sure the person they care for has access to treatment and services, as well as taking care of themselves. These many challenges and responsibilities are the cause of a significant burden on the individual. Literature shows that >40% of caregivers who live and/or work with people with schizophrenia report a significant burden. Family caregivers experience both practical and psychological problems.

Very few support tools are available for the schizophrenia caregiver, other than peer support networks and counselling. Therefore, MindBytes has developed a technology and serious gaming concept (SERES™), which is validated and commercially available with applications in several areas of mental health, such as SERES™ bipolar. A SERES™ game can help empower caregivers and reduce their burden while improving relationships with their loved ones. The game aims to create a change in behaviour and enhance caregivers' coping strategies, reducing the burden of mental illnesses on all stakeholders and enhancing the outcomes of patients.

The main objectives of this thesis are to develop this serious game for caregivers of people with schizophrenia and to validate the serious game by means of a clinical trial.

2. Introductory literature overview

2.1. What is schizophrenia?

Schizophrenia is a disorder of the brain and the mind. It affects a person's thoughts, feelings and acts (1). The disorder arouses a lot of anxiety and confusion in the general public, because of the misconception that schizophrenia is characterized by a 'split personality'. This misconception has been established by the early observation that the psychiatric disorder is typified by "the disconnection or splitting ('schizo') of the psychic functions ('phrenos')". This is not how the disorder is defined nowadays (2–4). Schizophrenia is a disorder with diverse manifestations in several domains of cognition and behaviour (5).

2.2. Clinical features

Schizophrenia is characterized by two kind of symptom dimensions: positive and negative symptoms (3,5–9) (see table 1). It evolves in cycles of remissions and relapses (1,9). Delusions or false beliefs, hallucinations or perceptual experiences not shared by others, thought disorders and bizarre behaviour are considered positive symptoms (3,5,6,8,9). People with schizophrenia can experience lots of diverse types of hallucinations, including auditory, visual, olfactory, gustatory or tactile hallucinations. Auditory hallucinations are most common (6). Voices may speak to a person or criticize his actions during such sort of hallucination. People who hear these voices try to make sense of what they experience. This effort can lead to a distortion of the reality, also called delusions (2). The positive symptoms can appear during an acute psychotic episode (5,6). They are called 'positive' because these symptoms are not part of the normal behaviour pattern, they are extra (3).

The negative symptoms represent states in which basic emotional and behavioural expressions are absent or reduced (6,8). They can be characterized by impairments in motivation, blunted affect, anhedonia or lack of pleasure, poverty of thought and speech, poor self-care and apathy or the loss to initiate plans (3,5,6,8,9). These symptoms are called 'negative' because they represent a loss of normal functional behaviour (3). Negative symptoms are more pervasive and fluctuate less over time than positive symptoms (6). They are mostly present in between acute psychotic episodes and can sometimes co-exist with them (5). Negative symptoms are less troubling for the patients themselves than the positive ones, but they can be very stressful to relatives. It's important to notice that mild symptoms can also occur in healthy people, without being associated with an illness (2).

Table 1 Overview of the most known positive and negative symptoms.

Positive symptoms	**Negative symptoms**
• Delusions	• Impairments in motivation
• Hallucinations	• Blunted affect
• Thought disorders	• Anhedonia
• Bizarre behaviour	• Poverty of thought and speech
	• Poor self-care
	• apathy

The onset of the disorder is often preceded by a sub-clinical prodromal state. This prodromal state is characterized by cognitive impairments. This can include social and occupational withdrawal, concentration problems, decline in psychomotor speed, learning and memory problems, loss of interest in activities, change in personality, altered mood and paranoid ideas. The prodromal state can have a duration of several weeks to months (5,6,8). The cognitive impairment is in most cases stable after onset of the disorder (6). The step towards psychiatric services is often made because of the presentation of bizarre behaviour, deliberate self-harm or attempted suicide, substance abuse or involvement with the police or criminal justice system, since these symptoms are strongly associated with functional impairment (5,6). It's important to keep in mind that not every patient experiences every symptom mentioned above (3).

2.3. Epidemiology

Schizophrenia is typically introduced in late adolescence or early adulthood (2,5,10). Disease onset is rare before the age of 16 and uncommon after the age of 50 (5). The incidence of schizophrenia is a little higher in men than in women, and men tend to have an earlier age of onset than women (6,10). This later onset in women is hypothesized to be the result of the effects of oestrogen on reduced sensitivity of dopamine receptors in the central nervous system (6). Men also tend to experience a more serious form of schizophrenia, with more negative symptoms, less chance of a full recovery and a generally worse outcome (2). In general, women have fewer hospitalizations and a better social functioning (6).

The prevalence and incidence of schizophrenia varies depending on the diagnosis that is used (2,5). The stricter the diagnostic criteria for schizophrenia that are used, the more the intercultural differences are reduced. The annual incidence of schizophrenia can be set at 0.2-0.4 per 1000 people, with a lifetime prevalence of about 1% (1,6,9). The relatively high prevalence of schizophrenia can be assigned to early adult life onset and the chronic nature of the psychiatric disorder (2,11).

2.4. Pathophysiology

The observation that schizophrenia is differentially distributed in certain populations has led to the identification of risk factors (12). Both genetic and environmental factors seem to play a role in the development of schizophrenia (6,10,13).

These environmental risks include prenatal and perinatal events and obstetric complications (2,5,6,12–15). But also several sociodemographic factors are linked to an increased risk of developing psychotic disorders (6). Also children who grow up in an urbanized environment, have a higher chance to develop schizophrenia than those growing up in rural regions (5,6,14). Drugs like cocaine, amphetamines and cannabis are associated with an increased risk for the development of psychotic disorders or psychotic symptoms too (2,5,14). When these risk factors are combined with a sensitized dopamine system, it can cause a lasting vulnerability to psychotic disorders (14).

The fact that schizophrenia is a multifactorial disorder, with rates higher among family members of patients than in the general population, contributes to the risk factor of genetic vulnerability (2,6,12,15). The exact nature of the genetic transmission is unclear but it does not seem to follow simple Mendelian single-gene inheritance patterns. More probably, schizophrenia is polygenic, with multiple risk genes, which can interact with epigenetic factors and the environmental factors mentioned before to cause schizophrenia once a critical threshold is crossed (2,6,12,14,15).

Despite this genetic association, it has not been easy to identify the specific molecular genetic variations responsible for the onset of schizophrenia (14). It is assumed that numerous genes with each a small effect are the cause of the difficulties encountered (5). Recent findings have suggested that rare structural variations could be responsible for a small percentage of the incidence of schizophrenia. These variations seem to be copy number variants such as small duplications, deletions or inversions. These copy number variants appear to have an over-representation in schizophrenia compared with controls. This is particularly the case in regions carrying genes involved in neuronal development (5,14).

The pathophysiological changes of schizophrenia have been increasingly studied, since the advent of modern neuroimaging techniques (14). The most frequently used theory in the neurobiological course of schizophrenia is the dopamine hypothesis. It attributes the symptoms of schizophrenia to a disturbed and hyperactive dopaminergic signalling. This hypothesis is supported by the observations that drugs that reduce the firing rates of dopamine neurons have an antipsychotic effect, whereas drugs such as amphetamine, which stimulate dopamine release, can increase the symptoms of psychosis (5,12). Amphetamines can also induce psychotic symptoms in individuals without schizophrenia. Several neurochemical imaging studies have shown increased dopamine synthesis and release during an acute psychotic episode (3,5,12,14). Antipsychotic medications that block dopamine D2 receptors, such as haloperidol and chlorpromazine, have the ability to ameliorate psychosis. The most likely interpretation of these findings is that activation of the D2 receptor is associated with the positive symptoms and not the negative symptoms or cognitive impairment. The fact that clozapine, a weak D2 receptor antagonist, reduces negative symptoms and enhances cognitive impairment supports the theory that additional neurotransmitter systems are involved in the pathology of schizophrenia (16).

There is also evidence for dysfunction of glutamate, serotonin and γ-aminobutyric acid (GABA) systems (5,12). These findings can make a link to the fact that all current pharmacological treatments block dopamine receptors (14). Although there is no conclusive evidence for the hypothesis, it has the most solid explanation for the biochemical pathophysiology of schizophrenia (12).

But the question remains why a change in dopamine reactivity results in psychotic symptoms. One theory that attempts to explain this phenomenon is based on the fact that neurons in the dopamine system fire in response to novel rewards in the environment. This causes dopamine release that leads to a change in attention and behaviour towards the rewarding situation. It combines the stimulus with a motivational salience. Variations in the firing of the dopamine system might lead to the variations in the assignment of motivational salience to observed things. In an attempt to make sense of these aberrant experiences, the patient composes theories. These alterations in the way of thinking might lead to the psychotic symptoms (14,17) (see figure 1).

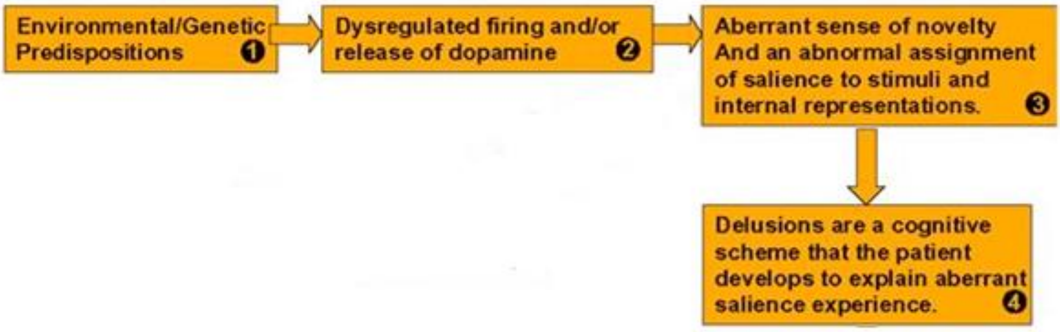


Figure 1 ***A pictorial depiction of the hypothesis linking dopamine to psychosis.*** *The diagram shows the chronological evolution of symptoms as a consequence of alterations in dopamine transmission. The number in each box provides the relative order of the event in the sequence (adapted from* (17)*).*

Structural brain imaging studies have shown an overall decrease in grey matter in the brain (5,6,14). Especially the volume of the hippocampus, thalamus and amygdala has been reduced (5,6,12) (see figure 2). These studies have also shown an enlargement of the lateral ventricles and an alteration of the white matter tracts (5,6,12,14) (see figure 2). These observations can't be explained by the chronic nature of the illness or treatment, as they are also present in newly diagnosed patients and in unaffected relatives at risk for schizophrenia (6). With the help of functional magnetic resonance imaging (fMRI) studies, a diminished prefrontal cortex response to new stimuli and a reduced ability to suppress brain activation in response to repeated stimuli, could be observed (12,14). These findings suggest a disruption in functional circuits rather than a dysfunction of a brain region (6,12). White matter myelination pathology has been introduced as an explanation for these connectivity problems between functional brain regions. This proposal is supported by an observed decrease in anisotropy in a number of brain regions in people with schizophrenia. Anisotropy can be comprehended as a way to measure the coherence of white matter. Demyelination during adolescence or early adulthood is suggested to be critical for the onset of schizophrenia (6).

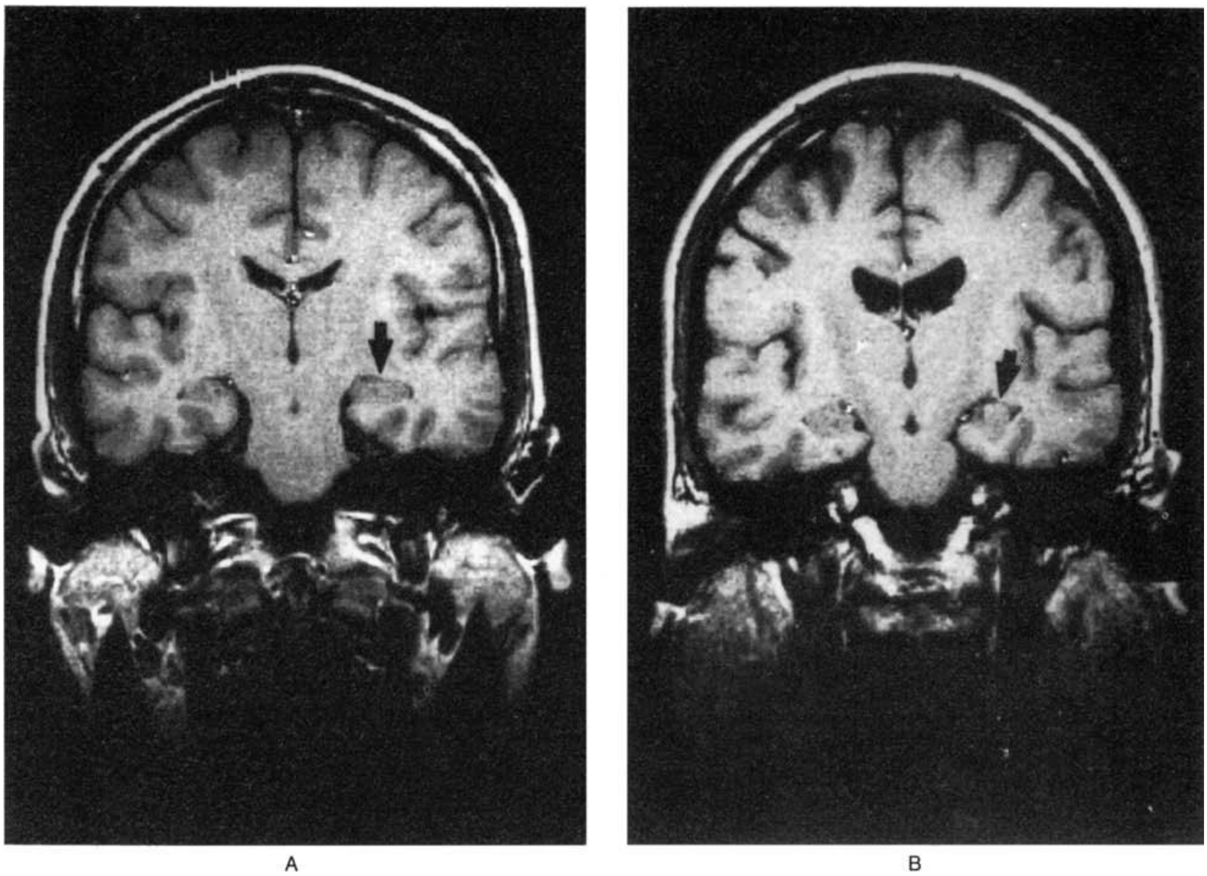


Figure 2 ***MRI Scans of the left and right hippocampus in a normal control (Panel A) and patient with schizophrenia (Panel B).*** *The shape and size of the hippocampus, especially the left hippocampal area (arrows), are altered and the lateral ventricles are enlarged on both sides in the patient with schizophrenia (adapted from* (12)*).*

2.5. Management

2.5.1. Diagnosis

Since there are no well-known pathophysiological markers of schizophrenia, the diagnosis is made based on identification of the clinical criteria and after exclusion of other diagnoses (3,5,12,14). Kraepelin and Bleuler laid out the basis for the clinical diagnosis of schizophrenia (4,6,12). But nowadays, two major criterion-based systems for schizophrenia are used: the Tenth Revision of the International Classification of Diseases (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders, Forth Edition (DSM-IV) (2,3,5,6,12,14,15) (see table 2). A fifth edition is made, in which the criteria with limited diagnostic stability and clinical utility - paranoid, hebephrenic and catatonic subtypes - are removed (5). Both these systems have improved the reliability of diagnostic assessments. They use observable symptoms and characteristic impairments instead of more subjectively based approaches (6). DSM-IV has a narrower definition of schizophrenia than ICD-10, but the reliability between the two systems is high (3,6).

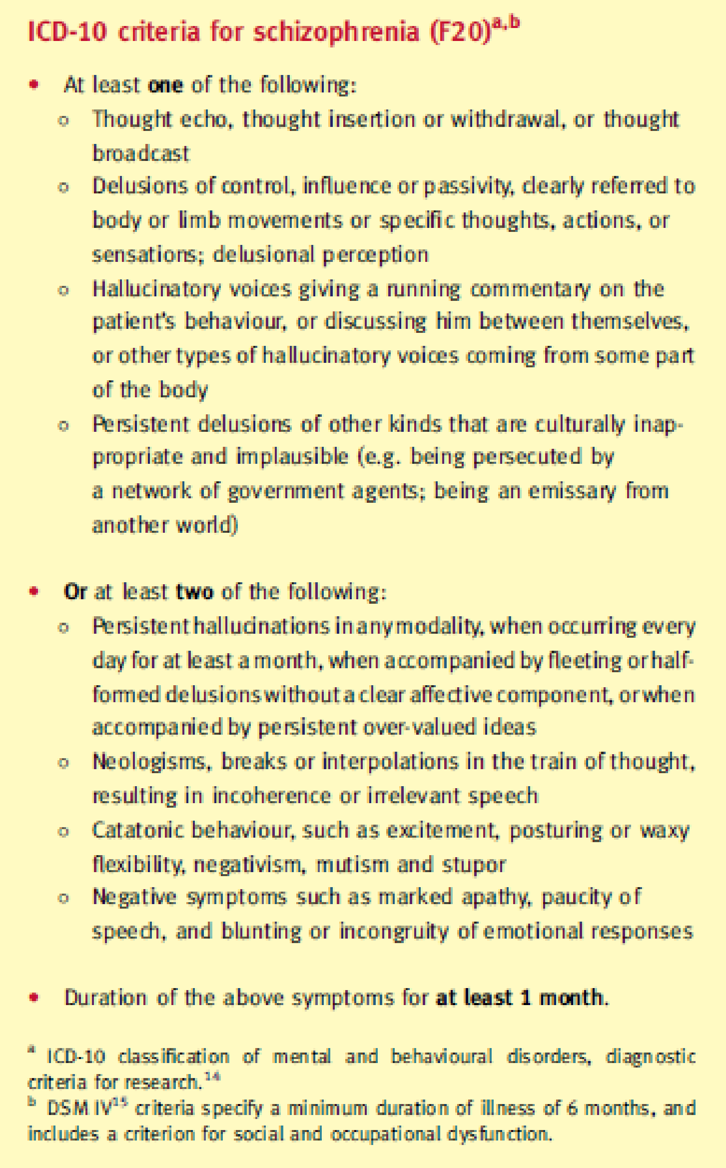
The clinical diagnosis of schizophrenia is based on three broad types of manifestations (6,12,14). These include the psychotic or positive symptoms, negative symptoms and cognitive impairments (3,6,12,15). The loss of contact with reality, including delusions and hallucinations, are part of the psychotic symptoms. Common negative symptoms include monotonous voice, anhedonia and apathy (6,15). Identification of schizophrenia often begins with the observation of the psychotic symptoms (12).

The differential diagnosis should begin with the exclusion of psychoses with a known organic cause, such as temporal-lobe epilepsy, metabolic disturbances, toxic substances or psychoactive drugs (3,5,12,14). The next step includes the identification of the psychotic symptoms. The identification is not difficult, but their classification is. Psychosis is not exclusive to schizophrenia and appears in diverse diagnostic categories of psychotic disorders (14). Schizophrenia or non-affective psychosis, is diagnosed as a syndrome characterized by long duration, bizarre delusions, negative symptoms and few affective symptoms. When fewer negative symptoms but more affective symptoms are expressed, patients are usually diagnosed with schizoaffective or bipolar disorder (12,14). But the symptoms are not sufficiently to make a definitive diagnosis of schizophrenia. It’s important to look at the psychiatric and medical history and to follow the longitudinal clinical course (5,12).

It’s essential to make an early diagnosis (2). Patients with psychotic symptoms should be treated as quickly as possible. Reducing the duration of untreated psychosis will reflect in an improved outcome of the disorder (2,6).

There is controversy as to whether the term schizophrenia should be retained or changed, since it refers to a state of so-called split mind. Psychiatrists that are using another name seem to have a better communication of the diagnosis to patients and an improved understanding of the disorder (4,14).

Table 2 ICD-10 criteria for schizophrenia.



ICD-10 criteria for schizophrenia (F20)[a,b]

- At least **one** of the following:
  - Thought echo, thought insertion or withdrawal, or thought broadcast
  - Delusions of control, influence or passivity, clearly referred to body or limb movements or specific thoughts, actions, or sensations; delusional perception
  - Hallucinatory voices giving a running commentary on the patient's behaviour, or discussing him between themselves, or other types of hallucinatory voices coming from some part of the body
  - Persistent delusions of other kinds that are culturally inappropriate and implausible (e.g. being persecuted by a network of government agents; being an emissary from another world)

- **Or** at least **two** of the following:
  - Persistent hallucinations in any modality, when occurring every day for at least a month, when accompanied by fleeting or half-formed delusions without a clear affective component, or when accompanied by persistent over-valued ideas
  - Neologisms, breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech
  - Catatonic behaviour, such as excitement, posturing or waxy flexibility, negativism, mutism and stupor
  - Negative symptoms such as marked apathy, paucity of speech, and blunting or incongruity of emotional responses

- Duration of the above symptoms for **at least 1 month**.

[a] ICD-10 classification of mental and behavioural disorders, diagnostic criteria for research.[14]
[b] DSM IV[15] criteria specify a minimum duration of illness of 6 months, and includes a criterion for social and occupational dysfunction.

2.5.2. Treatment

Once the diagnosis is made, the treatment of schizophrenia can start. Management can be categorized in pharmacological and psychosocial treatment (6,7,14,18). Pharmacotherapy is the mainstay treatment of schizophrenia (2,6,7,9,14). The goals of treatment are to manage acute psychosis by ameliorating a broad range of symptoms, bringing functional impairment to a minimum and improve quality of life. Maintaining the therapy aims to control symptoms and reduce the relapse rate and hospital admission, whilst keeping adverse effects to a minimum (5,7,12).

2.5.2.1. Pharmacological treatment

Antipsychotic drugs with the ability to block dopamine D2 receptors are the primary medication (5–7,12,14,16). This is the case because the psychotic or positive symptoms are the most defining symptoms of schizophrenia (18). These antipsychotic drugs are effective in diminishing these defining symptoms, but they are not curative (5–7,12,14,15). Antipsychotic drugs can be divided into two categories: the first-generation and second-generation antipsychotics (see table 3). The first-generation antipsychotics often lead to motor side-effects (1,2,5–7,10,14,15,18). These side-effects are caused because the antipsychotics block dopamine receptors non-selectively (5,15). New agents that are less frequently causing motor side-effects, because of their more diffuse receptor affinities, have been introduced. These are called second-generation or atypical antipsychotics (1,5–7,14,15,18). These atypical antipsychotics also block serotonin receptors (15). This is thought to lessen the negative symptoms, but in general negative symptoms are not responsive to antipsychotics (5,7,12,15). But these second-generation antipsychotics also tend to induce a high incidence of metabolic side-effects (1,2,5,7,14). Thus, the choice between the different categories of antipsychotic drugs needs an evaluation of the potential benefits, side effects, risks and costs (2,5,7,14,15).

Table 3 Overview of the comparison of anti-psychotic drugs.

	First generation anti-psychotics	**Second generation anti-psychotics**
Target	Dopamine receptors	Dopamine & serotonin receptors
Side-effects	Motor side-effects	Metabolic side-effects

Next to antipsychotic therapy, other pharmacological treatments are frequently used. These include antidepressants, mood stabilizers and benzodiazepines. This trend towards combination therapy is only supported by limited evidence. Despite this, polypharmacy has become common in the treatment of schizophrenia (6,7,12,18).

Medication adherence is a major challenge in schizophrenia (6,9,14). Many patients stop their medication because of stigmatization, the fact that dopamine-blocking medications dampen motivational drives and side effects. The medication stop increases the risk of relapse and worsens the symptoms (1,9,14). Hospital admission is made when necessary (5,9).

2.5.2.2. Psychosocial treatment

Medication alone is not the solution (9,12,14,18). The quality of response varies from patient to patient (12,15). Antipsychotic drugs are best administered in the context of other psychological and social supports (5,7,12,14,15,18). This is called a multi-disciplinary approach (5). Education in illness management skills, crisis intervention, training in problem-solving, supported employment, social skills training and cognitive-behaviour therapy are beneficial for patients (2,6,7,12,15,18). The combination of pharmacotherapy, psychological interventions and family psychoeducation leads to improved clinical outcomes (2,5,6,14,18). This is especially the case if treatment is started early, during the first episode of the disease (14). There is also evidence for improving medication adherence and preventing relapse with the use of psychological treatments (2,5)

2.5.3. Disease prognosis

The traditional clinical and societal view of schizophrenia is that it has a poor prognosis. This is not necessarily true (2,14). With effective treatment, remission of psychotic symptoms can be achieved in over 80% of patients (2,5). Without long-term maintenance of antipsychotic medication, more than 90% of patients will relapse (5). But outcomes are very heterogeneous, which makes it difficult to make accurate predictions (5,14). While many patients will have a lifelong vulnerability to recurrent episodes of psychoses, a large proportion will have few relapses and make a good functional recovery, in which the patient takes an active role (2,14). Although schizophrenia has a high burden, the prognosis often is relatively good since the disease is manageable with the right treatment and support.

2.6. Burden of disease

According to an estimation of the World Health Organization (WHO), schizophrenia is the fifth leading worldwide cause of global disease burden in males and sixth in females (1). Here we will focus on the humanistic burden of schizophrenia. The humanistic burden that schizophrenia causes, involves different dimensions (1) (see figure 3).

Figure 3 ***Impact of schizophrenia on the patient.*** *The burden that schizophrenia causes, involves different dimensions. All these dimensions are discussed below.*

2.6.1. Patients burden

2.6.1.1. Stigmatization

Aside from the burden of the disorder itself, which is handled in the following section, the stigmatization of schizophrenia has a robust effect on the patients. Stigma can be defined as distinguishing and labelling human differences. Cultural believes can link labelled persons to undesirable characteristics, we can call this negative stereotyping. Labelled persons are placed in distinct categories and are subject to negative emotional reactions. Because of this they can experience status loss and discrimination. Three different forms of discrimination can be distinguished: individual, personal and structural discrimination (1).

The first form, individual discrimination, refers to differential behaviours of one group that aim to have a harmful effect on members of another group. Among all mental disorders, with the exception of substance use disorders, schizophrenia faces the strongest rejection by the public (1).

Another form of discrimination works through the stigmatized person himself. In general, individuals who suffer from a mental disorder know which stereotypes about them predominate in society. If they consent with these stereotypes this may lead to negative emotional consequences (1).

Finally, structural discrimination is defined as institutional practices and policies that work to the disadvantage of the stigmatized group even in the absence of individual discrimination. These include the policies of private or governmental institutions that intentionally restrict the opportunities of people with a mental disorder as well as how these people are portrayed in the media (1).

2.6.1.2. Disease burden

Individuals who suffer from schizophrenia have a worse quality of life (QoL) than the general population and many individuals with physical and other mental disorders (1).

One category of symptoms of schizophrenia is the cognitive impairments. Since cognitive capacities are indispensable for school tasks or employment, individuals with schizophrenia often fail their tests at school or lose their jobs. These cognitive impairments can also result in social problems. These social cognitive problems can contribute to increased social isolation, stigmatization and discrimination (1).

These cognitive impairments are strongly associated with homelessness. A possible explanation can be that poor social skills sometimes are the reason why some landlords deny housing. Schizophrenia is over-represented in homeless populations when compared to non-homeless populations. Being homeless is a double risk in schizophrenia since these individuals already have particularly low QoL levels and homelessness even worsens it. Around 50% of the homeless people with schizophrenia receive no or little treatment (1).

Although schizophrenia is associated with a higher risk of non-violent and violent crime and of aggressive behaviour, according to Walsh et al. 99,97% of individuals diagnosed with schizophrenia will not commit serious violence (1,19). Often poor treatment is the origin of violence. An amelioration of the social environment of the individual and appropriate training for the caregiver is associated with the prevention of violence (1).

In comparison with the general population, a higher prevalence of several diseases have been reported amongst the schizophrenic population. These include human immunodeficiency virus (HIV) infections, hepatitis, osteoporosis, altered pain sensitivity, sexual dysfunction, obstetric complications, cardiovascular diseases, overweight, diabetes, dental problems and polydipsia.

This co-morbidity can be linked to side effects of the medication or to the lifestyle of these individuals. The majority is physically inactive because of negative symptoms, overweight and obesity. This outcome is linked to a reduced QoL. Comorbidity also includes substance abuse. This is associated with poor clinical and functional outcomes. Depression can also be mentioned as a common comorbidity in schizophrenia. Depression also leads to a decrease in the QoL since it adds to the disease burden they already experience. It's also linked with a higher risk of suicide. Between 4% and 13% of the individuals attempt suicide. Depressive symptoms can vary in scope and may occur at any time during the course of the disorder. People who suffer from a mental disorder are often not capable to manage the complexity of doctor visits and appropriate medication intake that comes with these co-morbidities (1).

The overall standardized mortality rate is much higher for people with schizophrenia than for the general population. There is a difference in life expectancy of 20 to 25 years. The main cause for this difference is of cardiovascular nature. Part of the explanation may be the long-lasting negative health habits and co-morbidities. Although antipsychotics can cause a higher mortality rate because of cardiovascular disease, they reduce overall mortality compared to no treatment. There is a need for prevention programs addressing social isolation, substance abuse, depression and disappointment about future perspectives in order to decrease the mortality and suicide rate (1).

2.6.2. Burden on other stakeholders

Schizophrenia is described as a disorder with a large cost for individuals and society. It has financial burden on society because of chronic use of treatments, hospitalizations, emergency room visits, housing and psychosocial support (1,9,20). The humanistic burden doesn't concern only the patient, but also the surrounding environment (1,9,11,21–25). Since schizophrenia has a long-term duration, individuals need long-term care from their family (11,20,24,26). In western countries the majority of these individuals depend on their families help and involvement (11,23,27). The burden this causes for the family or caregiver is considerable (1,20,27). On this particular burden, more information is given in section 2.7.3.

2.7. Role of caregiver within the disease management

2.7.1. Background

In earlier times, all patients with a mental illness were placed in a mental health institution. But because of a changing political and economic environment, a deinstitutionalization took place.

Deinstitutionalization is described as the process of shifting the care and support for patients with mental illness from institutions to community-based settings (28). Because of this deinstitutionalization process, the majority of the individuals with schizophrenia are cared for by their families (9–11,20–22,24,25,27,29–31) (see figure 4). Since health and social services are struggling with resources, the important role of the caregivers will carry on (11,29).

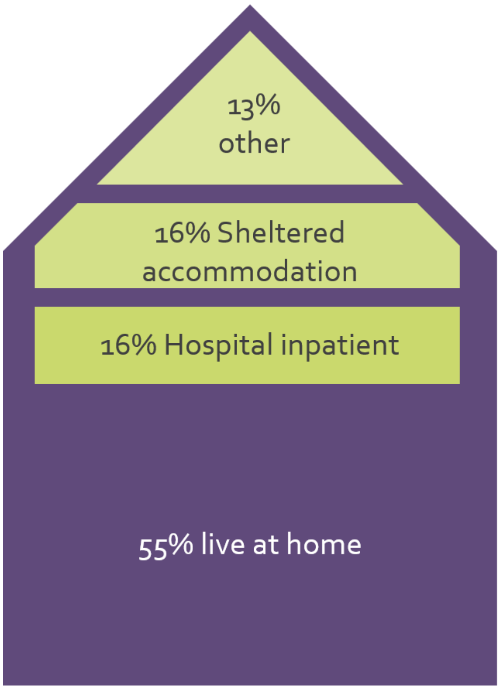


Figure 4 ***Most patients with schizophrenia live at home.*** *Because of the deinstitutionalization process, only 16% of all patients are still accommodated in a hospital (source percentages:* (10)*).*

2.7.2. Caregiving satisfaction

Caregiving can be a source of positive things in the life of caregivers (9,22,26,31). Caring for relatives with a disorder can lead to feelings of satisfaction and motivation (9,22,26). More positive feelings towards care activities were mentioned by caregivers who were men, older, more educated and had a greater number of friends and other family members helping with caregiving (22). Keeping the patient comfortable and maintaining his dignity is a key source of the satisfaction. Also expressing their love towards the patient is an important aspect of feeling satisfied (22,26).

Psychoeducational programs tailored to facilitate effective communication between the family caregiver and the cared-for person about the caregiving situation would improve the mutuality, hereby mitigating the perceptions of burden and augmenting the feelings of satisfaction (22).

2.7.3. Caregiver burden

But beside giving satisfaction, the care activities demand a lot of effort, energy and empathy for the caregivers (11). They experience loads of stress and a high level of burden because this has a big influence on their daily lives (8,11,20,21,23–25,27,30–32). This burden can be defined as the negative impact of the individual's mental disorder on the caregiver (9,11,21,22,27,30,33). Caregivers can experience both objective and subjective burden (9,11,29,31–33). The negative consequences on the family routines are called objective burden, whilst subjective burden relates to emotional impact on the caregiver (9,11,32,33).

The care activities are perceived more negative by caregivers of relatives with schizophrenia in comparison with other psychiatric disorders. Older caregivers, female caregivers and not having a lot of friends and other family members to help with the care activities, are factors that increase burden (22).

Schizophrenia affects different dimensions of the life of the patient's caregiver and his general and mental health (1,21,33) (see figure 5). Caregivers have difficulties to balance their work, family and the care activities (11,21,27,29). This leads often to a neglect of their own physical and emotional health (1,11,21,27). Often, they receive no recognition for their efforts and no financial, personal and emotional help and support for their care services are provided. This emotional, personal and possibly financial burden is often underestimated and is globally observable (1,11,30).

Specifically, caregiver burden can be associated with work overload, sleep disturbance, financial problems, less spare time, change in household routine, stigmatization and social isolation by neighbours or other acquaintances (1,8,11,21,23,25–27). They can also experience emotional troubles such as guilt, anxiety, helplessness and family conflicts (8,11,23,25–27,30,32). The burden can lead to loss of social contact outside the family and some people are forced to quit their jobs or to reduce their working hours because of the intense care required (1,8,21,29,30). Caregivers can feel overloaded and may show symptoms of burnout or other mental health issues (1,11,24,26).

Figure 5 ***Impact of caregiving on the family caregiver.*** *The burden that the caregiving causes, involves different dimensions. All these dimensions are discussed above.*

The burden arises because a lot of caregivers don’t have the necessary knowledge and skills. This makes it hard to cope with a great number of the responsibilities of the caregiving (11,23). The inadequate caregiving can lead to relapse in the patient (11,21). The relationship between the caregiver and the patient has an important influence on the burden (8,11). Interventions that helped strengthen this family network were found useful. In order to reduce stigmatization, community education is necessary (11). Since the burden seems to emanate more from the relatives’ knowledge of the patient’s condition than on the patient’s deficiencies itself, interventions that increase the relative’s knowledge about schizophrenia are very promising (33).

2.7.4. Current caregiver support tools

With the current support tools, families receive information about the disease itself and its treatment. Also communication and problem solving skills are taught (23,35). These interventions are an important and effective tool for caregivers (23). But it’s also important for the patients. There is a decreased recurrence of the disease and re-admission of the patient and an increase in medication compliance as a result of these interventions (9,23,25,29,35).

2.7.4.1. Psychoeducation

This support method gives family members information about the condition, diagnosis, treatments and coping techniques (11,18,22,36). This improves the caregiver's understanding of the caring demands by informing and provides guidance (22,36). Also problem solving and communication techniques are discussed in order to facilitate the communication within the family (11,22,25). These interventions aim at increasing the coping ability of the caregivers and therefore reducing their experienced burden (11,25,29,36). Psychoeducation tends to have a positive outcome on the burden and increases feelings of satisfaction (9,11,18,22,25,29,36). It also has a positive effect on the number of relapses and hospitalizations of the patients (9,11,18,21,23,25,29,36).

2.7.4.2. Mutual support groups

During these support group sessions, family members are participating in a conversation with other caregivers in which giving and receiving help, sharing experiences and knowledge are central (11,23,35). It's a flexible, interactive and peer-led kind of support (11). These sessions are being conducted under the guidance of an expert or a caregiver (23). They give family caregivers an opportunity for social support and to enhance their social network (11,23). Caregivers who participate in these support groups experience an improvement in their ability to cope and their caregiving role (11,23,29,35). This improvement also leads to an improvement in the patient's physical and mental well-being and functioning (11,23,29). But unfortunately, also barriers for participating in these kind of support groups exist. These barriers can be lack of time, hesitation of sharing feelings in a group, getting along with other members, transportation and worrying about being accepted in the group (11).

In order to support people who experience these barriers and to offer the opportunity for new kinds of interventions, behavioural intervention technologies are being developed. These technologies are making support tools more accessible and offer an active learning component, which tends to have an improved outcome for the caregiver (37).

2.8. Behavioural intervention technologies

Behavioural intervention technologies or BITs are intervention strategies of behavioural and psychological nature that use information and communication technology in order to address behavioural and psychological health outcomes (37,38). They are being used to help with self-assessment, self-monitoring, psychoeducation, goalsetting, skill building and feedback

(37,39,40). BIT's can use different types of technologies for this (37,40). Telephone, videoconferencing, web-based interventions, mobile devices, sensors, social media, virtual reality and gaming are currently being used (37,38,40). BIT's are a part of the eHealth field, which is broader (37).

They can reach otherwise not accessible populations. A lot of people experience barriers to access behavioural treatment. BIT's have the potential to overcome these barriers (37,41). Traditional as well as new interventions can be delivered through BIT's (37,38). Gaming, for example, can provide more engaging teaching methods (37,39,42,43). A lot of BIT's are brought to the market without efficacy or utility evaluation. There is a need to validate these interventions (37,40).

2.8.1. Serious gaming

Serious gaming is one way of delivering the behavioural intervention techniques (37). Serious games are digital simulations that aim to improve a person's knowledge, skills or attitudes in the real world (39,40,42,44–46). Gaming can use a virtual, online or offline, world that helps with exploration and therapeutic role-playing (37,42,43). The games can be considered brain training tools capable of ameliorating a whole range of abilities (42,46,47). Because games have the potential to have a real grip on someone's attention, they can enhance the motivation to start and continue support (37,39,42,43). This can lead to a successful behaviour change (37,42,46). These games use an entertainment factor, but combine this with non-entertainment outcomes, such as promoting mental health (37,40,42,43,45,47–49). The games can be used alone or as an extra therapeutic tool, in combination with standard psychological approaches (39,40,42,43,45,48).

Research around this serious gaming indicates that the interactivity of playing a game might enhance the uptake of interventions (37,39,43,44). Gaming offers an active way of learning (46). Studies have shown that those playing the game experienced an activation in reward-related neural circuits, whilst participants who had to watch the same game did not have an activation in these circuits. This suggests that a game-play setting can strengthen the benefits that people receive from therapeutic interventions (37). According to Mayer, people can process new information via a pathway for verbal input and one for visuals inputs. These pathways are additive, meaning that information provided both as images and words will be better remembered than information provided through only one of those pathways. Since both of these inputs are being used in serious gaming, this could be an exceptional learning method. Furthermore, the dynamic feature of a game helps the learning process too (46).

2.8.2. Current applications

The amount and types of serious games used for medical or health-related purposes are growing fast (40,42–44,49) (see table 4). These games have been examined as a treatment for attention deficit hyperactivity disorder (ADHD), autism spectrum disorders (ASD), anxiety disorders, asthma and reduction of aggression in children (37,39,40,43,48,49). It has also been examined for improving behavioural outcomes related to medical issues such as diabetes, cancer and alcohol abuse (37,44–46). These games can also promote physical activity, medication adherence and weight loss (37,41,42,44). The cognitive abilities in the elderly can be improved with the help of a game too (44,45). A game for decreasing depressive symptoms has also been developed (47). Serious gaming is being used as a tool to train and educate healthcare professionals (40,42,46). Therapy techniques that aim at strengthening families engagement to therapy can be delivered by serious gaming. Family caregivers can be helped to talk and discuss about their experiences with caregiving (39).

Table 4 List of current applications in the field of serious gaming.

Treatment of:
- ADHD
- ASD
- Anxiety disorders
- Asthma
- Aggression reduction in children

Improve behavioural outcomes of:
- Diabetes
- Cancer
- Alcohol abuse

Promotion of:
- Physical activity
- Medication adherence
- Weight loss

Improving:
- Cognitive abilities in the elderly
- Depression
- Families engagement to therapy

Training and education of:
- Health care professionals
- Familial caregivers

Most of the serious games that already exist, have been developed for children and adolescents (37,39,48). More research is needed to assess whether gaming is also a good approach for adults (37,39). This is thought to be promising, since gaming measures up to four elements important to adult learning proposed by Knowles (39,46). The first element is that adults want independence in their learning, they are autonomic. Gaming allows independence. Next, gaming offers scenarios to which adults can relate, using their past experiences. Further, adults are goal-orientated and a game provides that goal. Finally, the games offer learning experiences in a problem-based way, which is great because adults tend to be problem-based learners and not content-oriented learners (46).

Games that have been developed for mental health therapeutic methods, often lack an evaluation of their efficacy (37,40,44,47,49). Next to this scarcity of scientific evidence, the implementation of serious gaming in health care is impeded by lack of understanding of this concept by professionals. There is a need for an organized source where information can be found about which problem is being addressed by the game, the safety and effectiveness. By possessing the information needed, health care professionals and patients can consider using these games as a solution for their problems (44).

2.8.3. Serious gaming in schizophrenia caregiver setting

Since most of the existing serious games are developed for patients or health care professionals, there is a need for games for familial caregivers. During this thesis project, I developed, in cooperation with MindBytes, SERES™ schizophrenia, an interactive, virtual-based game scientifically designed to positively influence psychological and social challenges experienced by caregivers for people with schizophrenia. There is envisioned that SERES™ will improve caregiver coping by not only providing information (facts), but also skills (know-how) how to handle daily situations. The design of SERES™ and the clinical validation is outlined in the next part.

OBJECTIVES

This master's thesis project has different objectives.

Main objectives first part of the thesis

- Creation and development of the SERES™ schizophrenia game for caregivers in cooperation with MindBytes.

- Setting up a clinical trial: defining trial design, looking for organizations that want to cooperate, creating a protocol and getting approval of the ethical commission and clinical trial commission.

Main objectives second part of the thesis

- The effectiveness of SERES™ schizophrenia
    - check whether SERES™ schizophrenia has an effect on caregiver burden

- Subjective evaluation of SERES™ schizophrenia
    - Did they talk about the tool to other caregivers?
    - Would they recommend the game?
    - Chance to give general remarks

3. Materials and methods

3.1. Creation and development of schizophrenia e-learning

An e-learning is an educative learning program, delivered by electronic means. Its goal is to inform the caregivers about schizophrenia and all its aspects. This e-learning was developed in collaboration with MindBytes and with the help of healthcare professionals.

For the creation of the schizophrenia e-learning scientific literature, website information and popular scientific materials such as brochures for both patients and caregivers and education materials were used (50,51). The most relevant information was bundled and rewritten into an informative text, which formed the base for the creation of the e-learning. This base text was integrated into an educative graphic movie that had a duration of 10 minutes.

This e-learning was than externally validated by Prof. Dr. Van Winkel. Based on his professional feedback, the base text was updated. This updated version is the one that has been used in the clinical trial described in this masters' thesis.

The purpose of the e-learning is to inform the caregiver. The e-learning is taking care of the know-what of schizophrenia, this is also called the explicit knowledge. This is in contrast to the SERES™ schizophrenia game, who's primary purpose is to teach the caregiver skills. The game covers the know-how of schizophrenia, also called the tacit knowledge (see figure 6).

Figure 6 ***Schematic overview of the difference between the schizophrenia e-learning and SERES™ schizophrenia.*** *The e-learning covers the know-what, whilst SERES™ is taking care of the know-how of schizophrenia.*

3.2. Creation and development of SERES™ schizophrenia

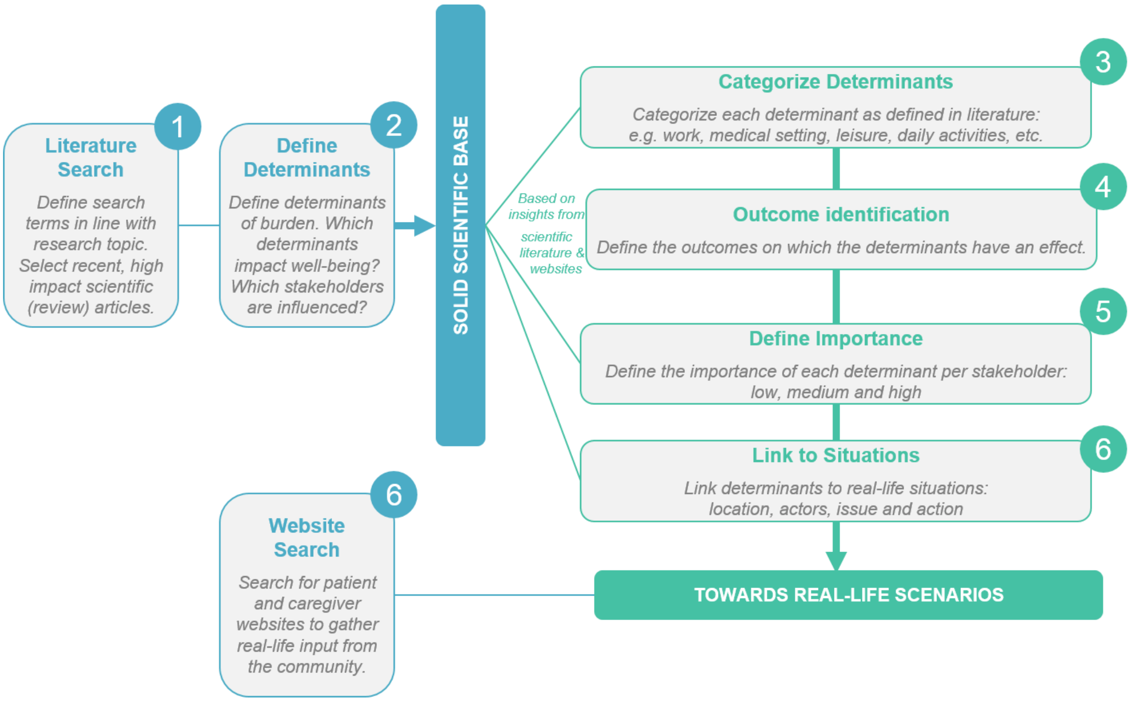


Figure 7 ***Schematic overview of the development of SERES™ schizophrenia.*** *The development occurred according to some well-defined steps. First a literature search was performed (1). From this literature, determinants were defined (2). This is the scientific base. Next the determinants were categorized (3), outcomes defined (4), the importance of the determinants defined (5) and linkage to situations was made. Finally, all these previous steps were combined with a website search to end up with real-life scenarios (6).*

The serious game was developed in cooperation with MindBytes and health care professionals. The game has family caregivers of people who have been diagnosed with schizophrenia as a target audience. The aim of the SERES™ game is to create a change in behaviour and enhance caregiver's coping strategies to primarily reduce the burden of psychoses on the caregivers, with the final purpose to enhance the outcomes of patients.

The creation and content of the SERES™ schizophrenia game is scientifically based (see figure 7).

3.2.1. Literature search

The development started with a search for high impact factor or frequently cited scientific articles. More specifically, a systematic literature study in PubMed, google scholar, science direct, web of science and Medline was performed. The following criteria were used as keywords in this search: schizophrenia AND soci* AND integration; schizophrenia AND caregive* OR carer AND social; schizophrenia AND caregiver; schizophrenia AND caregiver

AND burden; schizophrenia AND AND caregiv* AND econ* AND schizophrenia AND guidelines. The terms ‘English language’ and ‘2000-2015’ were used as inclusion criteria. No exclusion criteria were defined. Eventually, three review articles, two clinical guidelines and a patient resources and tools document were selected to define the determinants.

3.2.2. Define determinants

Then, all of this gathered information was used to define some determinants that were put forward in this literature as important factors for the caregiver’s burden. These included determinants that impact well-being and the determination of which stakeholder they influence. Important determinants for the SERES™ schizophrenia game were: coping strategies, caregiver emotional support, problem-solving tasks, types of support for carers, family education, monitoring adherence, family well-being and caregiver shame.

3.2.3. Categorize determinants

Next, these determinants from the literature were being divided into categories. These categories were named in public language, so that everyone can understand what they cover. Examples of categories for the SERES™ schizophrenia game were: carer support, carer coping, patient behaviour, emotional stress, family dynamics, patient social functioning, carer social functioning and patient feeling of trust.

3.2.4. Outcome identification

The different outcomes on which these determinants have an impact were then defined. In the SERES™ schizophrenia the outcomes were: patient’s general well-being, supportive environment, caregiver burden, caregiver social integration and patient integration.

3.2.5. Define importance

Subsequently, the impact of each category of determinants on these different outcomes was defined. First, this was done for each article of the literature study individually. Each category was given a weight, which ranges from 0-3, with three being the highest impact. Second, the average of all the impact scores was calculated to have the aggregated score. This score was important for the later stages of this development.

3.2.6. Link to situations

Next, the determinants were linked to real-life situations. A location, actors, an issue and an action were defined for each determinant. Inspiration for these situations was drawn from a website search for blogs and testimonials to gather real-life input from patients and their caregivers. This basic scenario information was now transferred into a real scenario. For each issue the scenario deals with, the caregiver could choose between three possible actions. These actions were connected to the impact scores, that were earlier mentioned. During the game, the caregiver could check which influence his or her decisions had and on which stakeholder. He or she got feedback on how health care professionals, other caregivers and patients propose to handle the issue.

Finally, the scenario was transferred to the creative team of MindBytes, who was mainly responsible for the visualisation of the scenarios and the technical integration of the game aspect.

3.2.7. External validation

This game was externally validated by prof. Dr. Van Winkel and Dr. Buntinx. Their professional feedback was integrated into the development and the scenario’s. This final, validated version was used in the trial described in this masters’ thesis.

3.3. Clinical trial

3.3.1. Study design

The design of the study is described in this section of this masters’ thesis and is illustrated by figure 8.

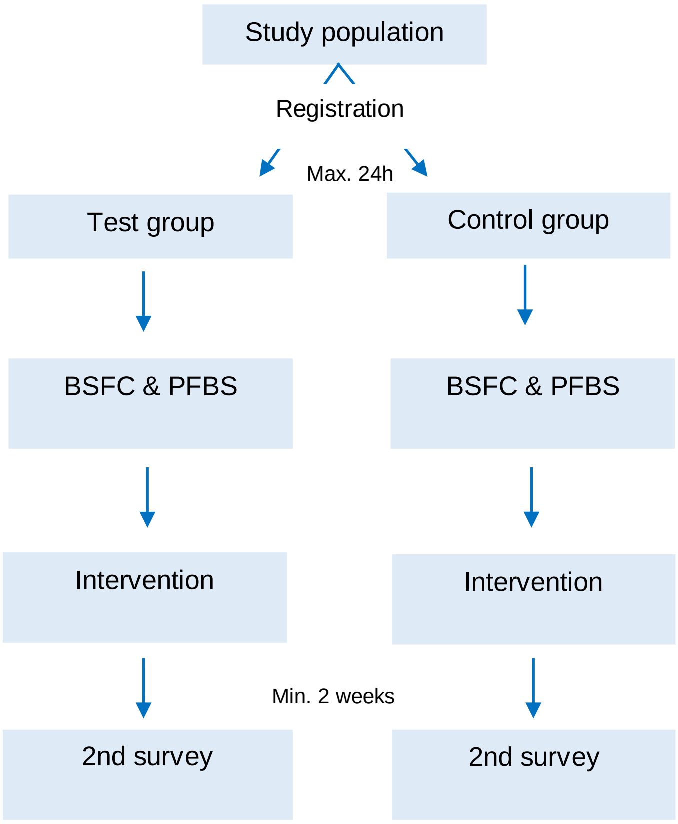


Figure 8 ***Flow diagram of the study design.*** *The design includes a study population, registration, burden scales, intervention and a second survey section.*

3.3.1.1. Study population

This study was carried out from the beginning of March till the end of April 2016. The participants were family members or informal caregivers of people with schizophrenia. These caregivers were recruited through the University Psychiatric Centre of Kortenberg (UPC) KU Leuven campus Kortenberg, Similes, an association for family members and people who are closely involved with people with psychiatric problems, and on social media sites from other associations. They were informed of the nature and purpose of the study. They were all invited to participate on a voluntary basis.

Inclusion criteria were as followed: (1) person who takes care for a family member or loved one who suffers from schizophrenia on a daily basis; (2) participant has to have sufficient knowledge of Dutch; (3) participant has at least moderate burden on the used burden scale: burden scale for family caregivers (BSFC), so that a potential improvement in burden can be shown. Participants who have a serious physical or mental problem of their own were excluded.

In total, 52 people registered for this study (see figure 9). These people were randomly divided into a test and a control group in sequence of registration. Of this 52 registered people, 22 never actually participated. Of the 30 registered people, 12 people only participated with the first part of the study; 18 people completed the entire study. Of these 18 people, 13 met the inclusion criteria ‘person who takes care for a family member or loved one who suffers from schizophrenia on a daily basis’. This resulted in eight participants who take care for their loved one on a daily basis in the test group and five in the control group, that participated in the whole study. An informed consent was obtained for all these participants. From the test group, two participants did not have at least moderate burden on the BSFC, so these were excluded from the study. From the control group, one participant was excluded, based upon this same inclusion criterion. No single participant had a serious physical or mental problem of their own.

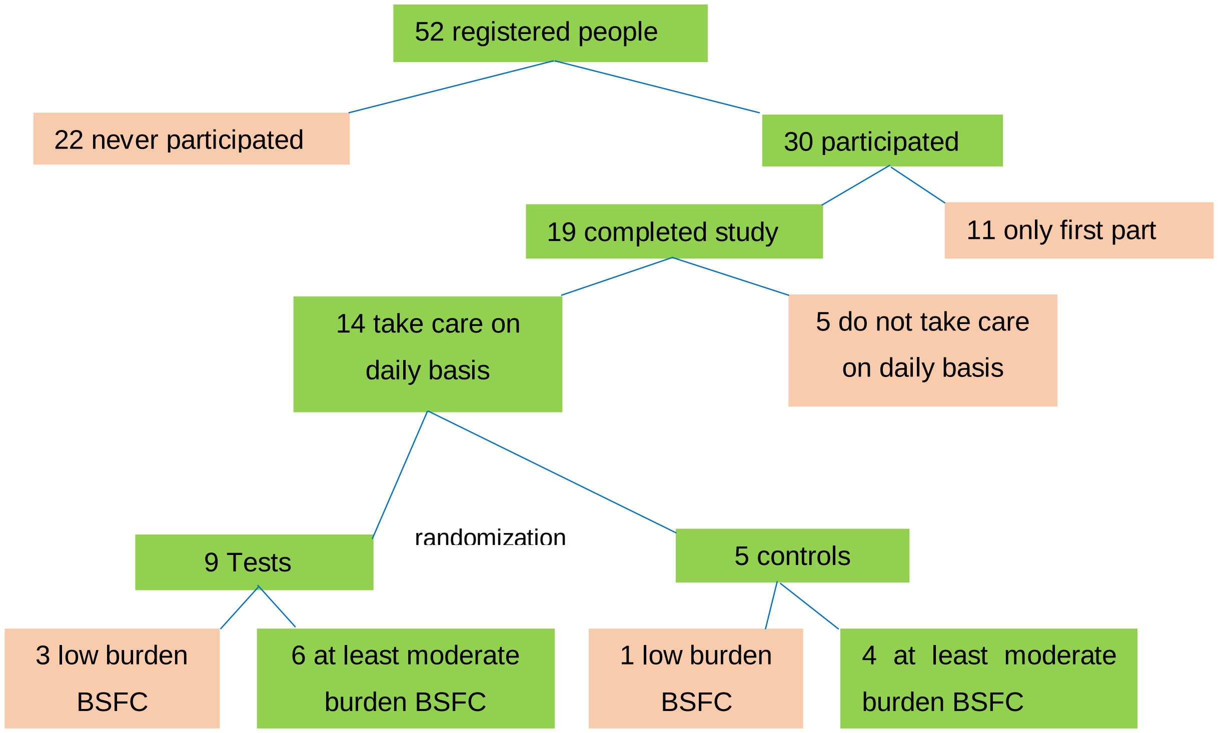


Figure 9 ***Flow diagram of the study participants.*** *Of the 52 registered people in total, eventually 6 test and 4 control participants could be used for analysis.*

Because this was a pilot trial with this serious game, we wanted as many people as possible to play the game. A lot of people who do not take care for their family members or loved ones on a daily basis, showed their interest in the game. The decision was made to let them all participate in the test group of the trial. This way more people could play the game and give their opinion and more information was obtained. This resulted in five caregivers not taking care for their loved one on a daily basis, who also completed the entire study.

3.3.1.2. Registration

People who heard about this study and wanted to participate could register on the following webpage “seresgame.com”. This webpage is currently offline. During this registration personal information was collected. They had to tell their relationship status towards the patient (husband/wife, brother/sister, father/mother, boyfriend/girlfriend, other), how long their family member has been needed help (1 to 5 years, 5 to 10 years, 10 to 20 years or more than 20 years) and if they take care of the patient on a daily basis or not. Those people that registered and said they were not talking care for their loved one on a daily basis, were allocated automatically to the test intervention, as mentioned earlier in section 3.3.1.1.

After the online registration, the participants received an e-mail with a personal participation number and a link to either the test or the control intervention.

3.3.1.3. Burden scales

Next, caregiver’s subjective burden was measured by the Dutch burden scale for family caregivers (BSFC) and the Dutch translation of the perceived family burden scale (PFBS). This was done in both the test and control group. The measurement of subjective burden is proven to be a very good outcome measure to evaluate changes before and after an intervention targeted on family caregivers (52).

3.3.1.3.1. *BSFC*

The BSFC is a scale that consists of 28 questions or statements with four possible responses, ranging from one extreme (strongly agree) to the opposite extreme (strongly disagree). The participants were asked to rate the statements in relation towards the current situation. The questions inquire after the physical and psychological well-being of the caregiver. For the rating of this scale, the questions are divided into two groups (see table 5). Questions 1, 6, 8, 9, 11, 14, 15, 17, 19, 22 and 28 are inversely presented. This means that the degree of physical and psychological burden is expressed by the degree of disagreement. In questions 2, 3, 4, 5, 7, 10, 12, 13, 16, 18, 20, 21, 23, 24, 25, 26 and 27 the questions are not inversely presented. This way of presenting the questions, prevents the ‘yes-saying effect’, which can falsify the findings (52). In both groups, the answers are rated from zero to three.

Table 5 Overview on how to rate the statements of the BSFC (adapted from (53)*).*

Statements numbered 1, 6, 8, 9, 11, 14, 15, 17, 19, 22 and 28		**Statements numbered 2, 3, 4, 5, 7, 10, 12, 13, 16, 18, 20, 21, 23, 24, 25, 26 and 27**	
Response	Points	Response	Points
Strongly agree	0	Strongly agree	3
Agree	1	Agree	2
Disagree	2	Disagree	1
Strongly disagree	3	Strongly disagree	0

For the interpretation of the total score a division was made between caring for people with dementia and caring for people with another disorder. With schizophrenia as the disorder, the total score should be interpreted as followed. A total score from 0 till 41 means that the caregiver is experiencing no or low burden. This infers no higher risk of psychosomatic complaints. The caregivers with a score from 42 to 55 are experiencing moderate burden and therefore have a higher risk of psychosomatic complaints. When the total score ranges from 56 to 84, the caregivers are suffering from heavy to very heavy burden. This implements a strongly heightened risk of psychosomatic complaints. This interpretation is summarized in table 6.

Table 6 Interpretation of the BSFC score for caregivers of individuals with schizophrenia (adapted from (53)*).*

BSFC Score	**Subjective burden categories**	**Risk of psychosomatic symptoms**
0 – 41	none to mild	not at risk
42 - 55	moderate	increased risk
56 –84	severe to very	at very high risk

The scientifically developed BSFC can be used in both clinical settings and in research studies. The instrument has been validated and is considered very reliable (52).

3.3.1.3.2. *PFBS*

The PFBS was used to distinguish between objective and subjective family caregiver burden (54). This scale is build out of 24 behaviour statements associated with schizophrenia and psychoses. The caregivers have to rate these for the presence or absence of the behaviour described. This part is called the objective component of the burden measurement. The caregivers also have to score the statements to the extent to which the behaviour is bothering them (not at all, a little, considerably, a great deal, don't know). This is the subjective half of the burden measurement. Eventually these measurements are scored on a five point scale, with a range from zero to five (see table 7). Zero means that the behaviour isn't present in the patient. When the behaviour is present but it doesn't bother the relative, the statement is rated with a score of one. The statement is scored with two when the presence of the behaviour bothers the relative a little. A score of three is given when the behaviour is present and bothers the relative considerably. Finally, a score of four is given when the behaviour is present and bothers the relative a great deal. The more the existing behaviour bothers the caregivers, the higher the sum of the scores will be.

Table 7 Instructions for the rating of the PFBS (adapted from (55)*).*

0 = the behaviour isn't present and doesn't bother the relative

1 = the behaviour is present and doesn't bother the relative

2 = the behaviour is present and bothers the relative "a little".

3 = the behaviour is present and bothers the relative "considerably".

4 = the behaviour is present and bothers the relative "a great deal".

The perceived family burden scale is validated as a brief, useful, valid and reliable self-report instrument for the measurement of the degree of burden experienced by relatives (54).

3.3.1.4. Intervention

Participants in the test group got access to the schizophrenia e-learning and the SERES™ schizophrenia game after filling in the burden scales. Meanwhile, people could continue to go to their counsel and support groups, if they wanted to. Participants in the control group got access, after filling in the burden scales, to the schizophrenia e-learning only. All participants who said that they weren't caring on a daily basis, received access to the test intervention after filling in the burden scales. They had to go through all the same steps as the caregivers who do care on a daily basis.

3.3.1.4.1. *Test intervention*

The intervention that was investigated during this trial is SERES™ schizophrenia. This is a serious game or an interactive online game-based learning experience, based on real-life scenarios and dilemmas. Principles of psychoeducation and behavioural therapy were implemented. The development of this serious game in cooperation with MindBytes and with the help of health care professionals was explained in section 3.2.

3.3.1.4.2. *Control intervention*

The intervention to which the test intervention was compared to was the schizophrenia e-learning. This e-learning explains the facts about schizophrenia. The development of this e-learning in cooperation with MindBytes and with the help of health care professionals was explained in section 3.2.

3.3.1.5. Second survey

After a minimum of two weeks, all participants got a new e-mail in which they were asked to fill in both the burden scales again. They also had an opportunity to give some personal comments/feedback about the game. The participants were also asked if they had a serious mental or physical problem themselves, since this is an exclusion criteria, and if they talked about this with other caregivers. This is the last step of the study.

3.3.2. Data analysis

Data of both surveys were collected by Articulate Online, a learning management system (LMS). The SERES game was also linked to this LMS system, on which data about play frequency and duration were registered for each participant.

The statistical analyses were performed with SPSS. Frequency analyses were performed on the participants personal information.

The burden scale answers were processed with excel in order to get the final burden value on both scales. This was done with both the pre- and post-intervention data. In SPSS a Shapiro-

Wilk test was performed on the data from the PFBS to check whether they were normally distributed (Statistic=0,956; p=0,739).

Since BSFC values were categorical, they were analysed with non-parametric tests. A Fisher's exact test was executed to check if there was a difference in the control and test group between the pre- and post-intervention data. To analyse of there was a difference in the pre- and post-intervention data within the test and group control, a McNemar test was performed. To analyse the normally distributed PFBS values, an unpaired t-test was executed to examine if there was a difference in the control and test group between the pre- and post-intervention data. A paired t-test was executed to assess if there was a difference in the pre- and post-intervention data within the test group and the control group.

4. Results

4.1. Analysis SERES™

An overview of the game answers can be found in table 8. This analysis is based upon the six participants in the test group, those who played the SERES™ schizophrenia game. Only five answers never got chosen by any participant. In all the scenarios there is one answer who is favoured by the participants. The possible answers don't get picked equally. An extended overview of the detailed questions can be found in appendix 4.

Further, there could also be measured that the mean time to complete the control intervention was 14 minutes and 12 seconds and the mean time to complete the test intervention was 43 minutes and 23 seconds. The participants in the test group all completed this study in two parts.

Table 8 Overview on how many times an answer of the SERES™ schizophrenia game got picked, in percentages (%).

M1Q1	**percentage**	**M1Q2**	**percentage**	**M1Q3**	**percentage**		
A	66,67%	**A**	66,67%	**A**	16,67%		
B	16,67%	**B**	16,67%	**B**	33,33%		
C	16,67%	**C**	16,67%	**C**	50,00%		
M2Q1	**percentage**	**M2Q2**	**percentage**	**M2Q3**	**percentage**	**M2Q4**	**percentage**
A	0,00%	**A**	0,00%	**A**	66,67%	**A**	0,00%
B	66,67%	**B**	33,33%	**B**	0,00%	**B**	33,33%
C	33,33%	**C**	66,67%	**C**	33,33%	**C**	66,67%
M3Q1	**percentage**	**M3Q2**	**percentage**	**M3Q3**	**percentage**		
A	16,67%	**A**	16,67%	**A**	50,00%		
B	83,33%	**B**	16,67%	**B**	33,33%		
C	0,00%	**C**	66,67%	**C**	16,67%		
M4Q1	**percentage**	**M4Q2**	**percentage**	**M4Q3**	**percentage**		
A	16,67%	**A**	16,67%	**A**	16,7%		
B	16,67%	**B**	33,33%	**B**	66,7%		
C	66,67%	**C**	50,00%	**C**	16,7%		

4.2. Analysis population

The six test and four control participants had to register and fill in some questions. They had to tell if they are a daily caregiver or not, their relationship status towards the patient and the duration of their role as a caregiver. These questions were analysed in figure 10 and 11.

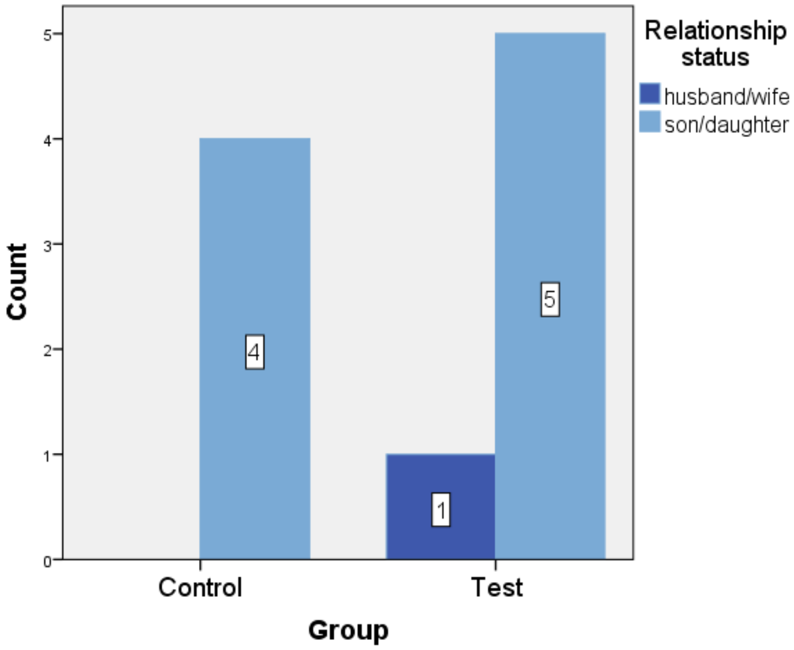


Figure 10 ***The answers of the participants on the question 'What is your relationship status towards you loved one you are taking care of?' presented in a bar chart.*** *The test and control group are analysed separately.*

In the control group the observation can be made that all the participants (n=4) are taking care of their son or daughter. This is also the biggest category in the test group (n=5). One person in the test group is responsible for the daily care of his/her husband or wife (see figure 10). Apart from the categories husband/wife and son/daughter, the following relationship statuses were possible: father/mother, friend, brother/sister and other.

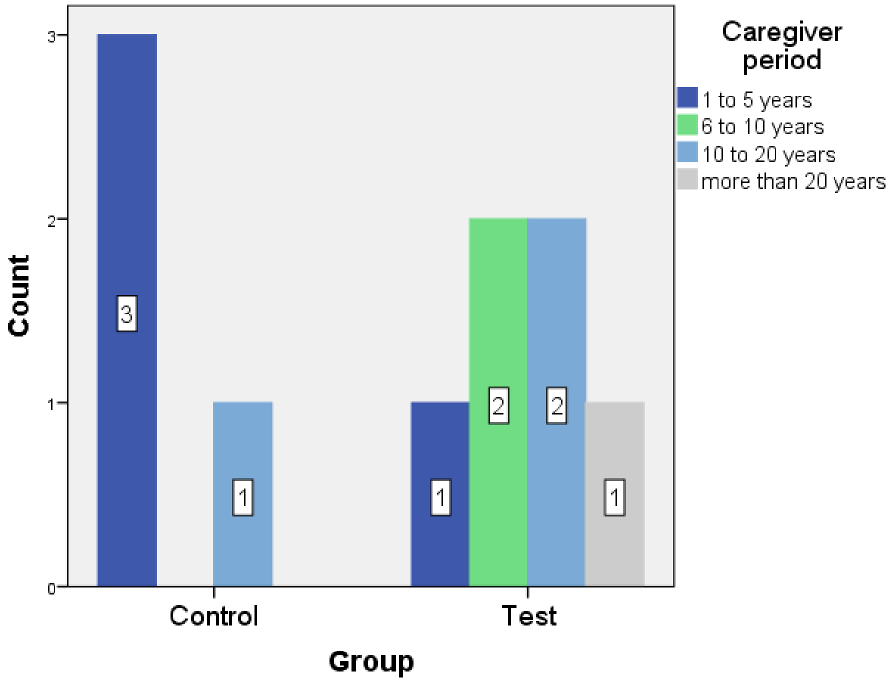


Figure 11 ***The answers of the participants on the question 'How long are you already taking care for your loved one?' presented in a bar chart.*** *The test and control group are analysed separately.*

On figure 11, there can be noticed that the participants in the control group are rather recent caregivers. Three of them are caregiver since one to five years and one participant is caregiver since 10 to 20 years. The caregiving periods from the caregivers in the test group are more divided. Only the category with daily caregivers since less than one year are absent in the study.

4.3. Statistical analysis burden scales

4.3.1. BSFC

The values of this burden scale were divided into three categories: none to mild burden, moderate burden and severe to very sever burden. We want to know whether our intervention made the participants change to a lower category after the intervention. Since these data are categorical, the non-parametric Fisher's exact test was performed on these pre- and post-intervention data to assess whether there is a difference in control and test group before and after the intervention (see table 9 and 10).

Table 9 Analysis Fisher's exact test on pre-intervention values of the BSFC.

		Group			Statistics
		Control	**Test**	**Total**	**p-value**
Pre-intervention	Moderate burden	1	5	6	
	severe to very severe burden	3	1	4	
Total		4	6	10	0,190

Table 10 Analysis Fisher's exact test on post-intervention values of the BSFC.

		Group			Statistics
		Control	**Test**	**Total**	**p-value**
Post-intervention	Moderate burden	2	5	7	
	severe to very severe burden	2	1	3	
Total		4	6	10	0,500

Both p-values (p=0,190 and p=0,500) are bigger than 0,05, so in both pre- and post-intervention data, there is no statistically significant difference between control and test group.

Further, also the non-parametric McNemar test was performed on the test and control group data to assess if there is a difference in burden value before and after the intervention (see table 11 and 12).

Table 11 Analysis McNemar test on BSFC control values pre- and post-intervention.

			Post-intervention			Statistics
			Moderate burden	**Severe to very severe burden**	**Total**	**p-value**
Pre-intervention	**Moderate burden**	Count	1	0	1	
		% within pre-intervention	100,0%	0,0%	100,0%	
		% within post-intervention	50,0%	0,0%	25,0%	
	Severe to very severe burden	Count	1	2	3	
		% within pre-intervention	33,3%	66,7%	100,0%	
		% within post-intervention	50,0%	100,0%	75,0%	
Total		Count	2	2	4	1,000
		% within pre-intervention	50,0%	50,0%	100,0%	
		% within post-intervention	100,0%	100,0%	100,0%	

Within the control group, no statistical difference between pre- and post-intervention values could be measured (p=1,000). However, the observation can be made that one participant changed from the moderate burden category to the severe to very severe burden category post-intervention.

Table 12 Analysis McNemar test on BSFC test values pre-and post-intervention.

			Post-intervention			Statistics
			Moderate burden	**Severe to very severe burden**	**Total**	**p-value**
Pre-intervention	**Moderate burden**	Count	5	0	5	
		% within pre-intervention	100,0%	0,0%	100,0%	
		% within post-intervention	100,0%	0,0%	83,3%	
	Severe to very severe burden	Count	0	1	1	
		% within pre-intervention	0%	100,0%	100,0%	
		% within post-intervention	0%	100,0%	16,7%	
Total		Count	5	1	6	1,000
		% within pre-intervention	83,3%	16,7%	100,0%	
		% within post-intervention	100,0%	100,0%	100,0%	

Within the test group, no statistical difference between pre- and post-intervention values could be measured (p=1,000). Actually, no single participant's burden value changed from category after the intervention. In the category of moderate burden there are five caregivers and there is one caregiver in the severe to very severe burden group in the pre- and post-intervention group.

4.3.2. PFBS

There needs to be tested whether the intervention made the value of this burden scale decrease in the test participants. Since these data are normal distributed, Shapiro-Wilk test (p=0,739), the parametric unpaired t-test was used on the pre- and post-intervention data (see table 13).

Table 13 Analysis unpaired t-test on PFBS pre- and post-intervention values.

	Groups	**N**	**Mean**	**St. Dev.**	**Statistics**		
					t	**df**	**p-value**
Pre-intervention					-0,721	8	0,492
	Control	4	42,75	14,15			
	Test	6	47,83	8,42			
Post-intervention					0,081	8	0,937
	Control	4	41,75	8,26			
	Test	6	41,17	12,54			

Both p-values (t=-0,721; p=0,492 and t=0,081; p=0,937) are bigger than 0,05, so in both pre- and post-intervention data, there is no statistically significant difference between control and test group. We can see that the mean score at baseline is lower in the control group (mean 42,75; SD 14,15) than in the test group (mean 47,83; SD 8,42). In the post-intervention situation, the mean score is lower in the test group (mean 41,17; SD 12,54) than in the control group (mean 41,75; SD 8,26).

Further, also a paired t-test was performed on the test and control group data to assess if there is a difference in burden value before and after the intervention (see table 14 and 15).

Table 14 Analysis paired t-test on PFBS control values pre- and post-intervention.

	Values	**N**	**Mean**	**St. Dev.**	**Statistics**		
					t	**df**	**p-value**
Control					0,260	3	0,812
	Pre-intervention	4	42,75	14,15			
	Post-intervention	4	41,75	8,26			

Within the control group, no statistical difference between pre- and post-intervention values could be measured (t=0,260, p=0,812). However, a small drop (2,3%) in the mean value can be observed (mean 42,75; SD 14,15 → mean 41,75; SD 8,26).

Table 15 Analysis paired t-test on PFBS test values pre- and post-intervention.

	Values	N	Mean	St. Dev.	Statistics		
					t	**df**	**p-value**
Test					1,555	5	0,181
	Pre-intervention	6	47,83	8,42			
	Post-intervention	6	41,17	12,54			

Within the test group, no statistically significant difference between pre- and post-intervention values could be measured (t=1,555 p=0,181). However, a decrease (14%) in the mean value could be noticed (mean 47,83; SD 8,42 → mean 41,17; SD 12,54).

4.4. Analysis additional questions

During the second survey, the participants had to answer a few additional questions, aside from the burden scales. They were asked if they would recommend the tool to other caregivers and if they exchanged information about this tool with other caregivers during this trial. These questions assess the subjective opinion of the participants about this new tool.

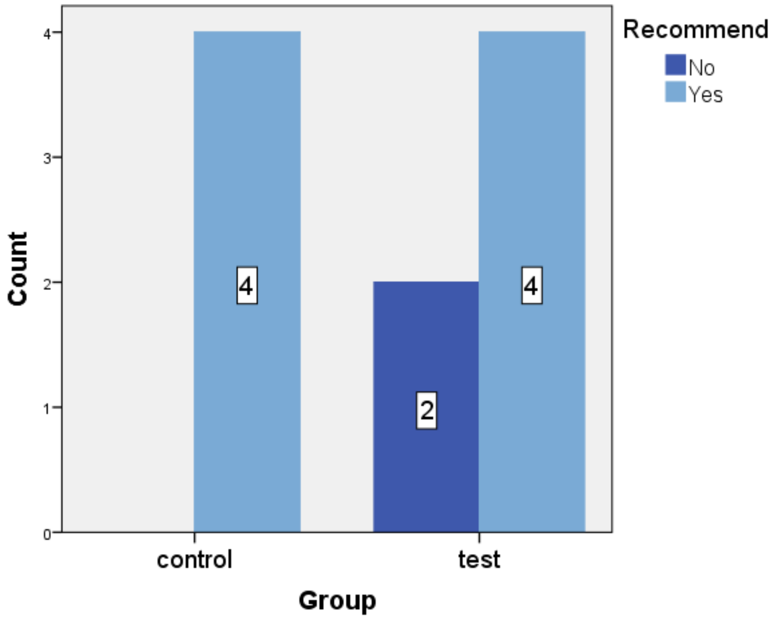


Figure 12 ***The answers of the study participants on the question: "Would you recommend the tool to other caregivers?" presented in a bar chart.*** *The test and control group are analysed separately.*

The control group and four people from the test group would recommend this tool to other caregivers (see figure 12). This means that both the schizophrenia e-learning and the SERES™ schizophrenia game would be recommended, since the control group only got the schizophrenia e-learning.

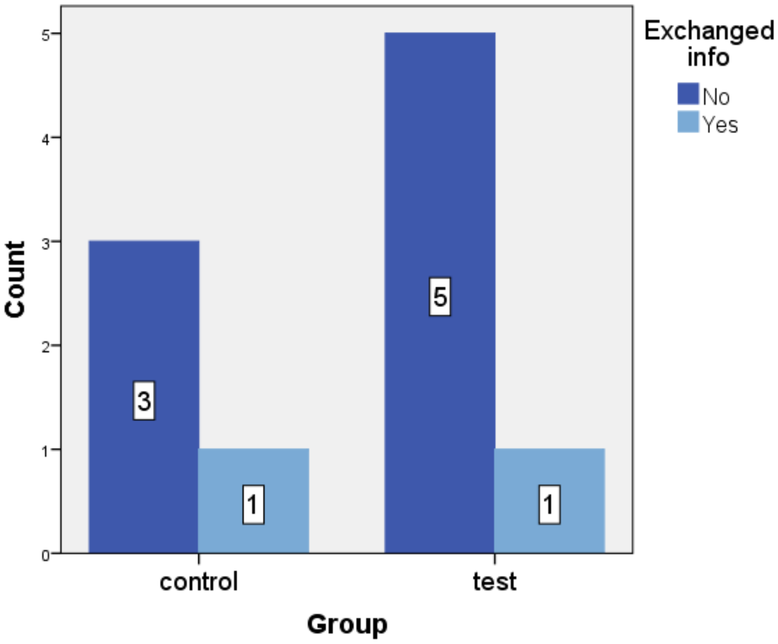


Figure 13 ***The answers of the study participants on the question: "Have you exchanged information about this tool during the study with other caregivers?"*** *The test and control group are analysed separately.*

Only one participant in the control group and one participant in the test group talked about this tool with other caregivers during the trial (see figure 13). This number, two in total, is very low.

5. Discussion and conclusion

5.1. Discussion

This master's thesis is an explorative pilot study with the schizophrenia e-learning and the SERES™ schizophrenia serious game. First, the participants were analysed. It's important to know which caregivers are the most interested in this new technological tool, to define the target population for the future. Next, this study assessed whether a serious game about schizophrenia can reduce the unformal caregiver's burden. Since schizophrenia is a disorder with a long-term duration it can cause a high burden on the familial caregivers (1,20,27). Finally, also a small subjective analysis was performed. The analysis is performed only on the daily caregivers. The non-daily caregivers were allowed to play the game as well, in an attempt to obtain further data. But, there was no use in extending the evaluation towards the non-daily caregivers, since only one out of five of these caregivers showed at least moderate burden and hereby don't meet the inclusion criteria.

5.1.1. Analysis SERES™

Overall, the answer possibilities of the SERES™ schizophrenia game seem well drafted. Only five of the 39 possibilities in total never got picked (see table 8). These five questions can be updated to more realistic possibilities so that people can more relate to this reactional behaviour. In all scenario's there is always one answer that get picked the most. These results are just suggestions since only six participants played the game. It's a positive thing that the game could be resumed at any time, since every participant completed the intervention in two times. This is probably because the mean time to go through the entire test intervention is quite high (43 minutes and 23 seconds).

5.1.2. Analysis population

Most of the participants (9/10, 90%) of this study are caring for their son or daughter. An explanation for this could be that most patients with schizophrenia are still in the care of their parents when they are experiencing the first symptoms of schizophrenia, since the age of disorder onset is puberty to late adolescence (2,5,10). Out of this data we can suggest that the caregivers that are taking care of their son or daughter is the category that seems to have the biggest need for this interactive tool. The biggest category of participants are caregiver since one to five years. It is possible that these quite recent caregivers are still looking for the right support, for the support that fits their needs. That's why they are willing to try out new tools.

5.1.3. Analysis burden scales

5.1.3.1. BSFC

This study couldn’t show a significant difference between pre- and post-intervention values of the BSFC in the test group. More precisely, the burden level of not a single participant changed. This could have several explanations. First of all, a very small sample size was used (n=6). The time of the trial was also very short (t=min 2 weeks). In the control group one caregiver changed from the moderate category group to a higher burden category. This change could be caused by the disease state of the patient at the moment on which the burden scale was answered.

5.1.3.2. PFBS

In the analysis of the PFBS values, a trend towards a lowering in the burden score can be observed in the test group. There was a reduction of 14%. This could indicate that the game has indeed an effect on the burden of the caregivers. Because of the small sample size, no statistical difference could be found. Also in the control group a small decrease (2,3%) in burden score could be noticed. This could indicate that the schizophrenia e-learning itself also contributes to the support of the caregiver, resulting in lower burden scores. At baseline, the burden of the test group (mean 47,83; SD 8,42) was higher than in the control group (mean 42,75; SD 14,15). This could be caused by the longer duration of caregiving in the test group (66,67% in the category six to twenty years) compared to control group (75% in the category one to five years). Previous studies have shown that caregivers are experiencing more burden with a longer duration of caregiving (56–58).

5.1.4. Analysis additional questions

Most participants (8/10, 80%) were enthusiastic about this new interactive tool. They would recommend the tool to other caregivers. So, there can be concluded that this is a valuable tool. They think the tool is good enough to share with others. Further, only two participants, one in the test group and one in the control group, have talked about the trial with other caregivers. This could mean that caregivers don’t really know each other and don’t have contact with each other. This could be the consequence of the lack of support the caregivers often feel. If they know where to look for support, they are often experiencing barriers (11). They are ashamed or don’t like to share their problems and feelings with other people. This new interactive tool can help to overcome these barriers (37). The SERES™ schizophrenia can also be played in group during group counselling or group meetings. This way, this serious game can give the opportunity to discuss the choices and outcomes of the game in group with peers. This process is called social learning.

5.2. Study limitations and strengths

This study has some limitations and strengths. The biggest limitation in this study is the very small sample size (n=10). This is caused by several factors. First of all there was a short recruitment time (t=one month) because of the late ethical approval. Also, the informal caregivers of people with schizophrenia aren't easy to reach. Often, they are experiencing stigmatization and don't look for help that easily (1,8,11,21,23,25–27). Since the concept 'serious gaming' is rather new, caregivers can be sceptical towards it. A second limitation is the short period over which the burden is measured (t=min. 2 weeks), because of the time limit of the master's thesis. This two week period is too small to notice some real significant burden changes. Ideally, participants should be able to play the SERES™ schizophrenia game as many times as they want over a period of several months. This way they can really understand and apply the coping skills provided by the game and long-term effects of the SERES™ game on the burden can be measured. It's also unavoidable that the caregiver's burden is linked to the disease state of the patient they take care for at the moment of the study. The disease state could bias the amount of burden measured. Finally, there are no standardized protocols for offering a serious game. They best way on how the deliver such a game still needs to be discovered and improved by experience.

This study has also strengths. It is the first study investigating the effect of a serious game for informal caregivers of people with schizophrenia. Further, the study is controlling for placebo-effects, since the control group is receiving the schizophrenia e-learning as a therapy. To control for the effects of the e-learning, since this is a therapeutic tool as well, also the test group can watch the e-learning. Therefore, this study could not only be controlled for changes in time and effects of repeated measurements but also for placebo-effects. The study also allows the identification of outcome drivers. This trial indirectly suggests, that providing knowledge (schizophrenia e-learning) and skills (SERES™ schizophrenia) reduces the caregiver's burden better than only providing knowledge (schizophrenia e-learning). This is only a suggestion, since no significant differences were found. Finally, the questionnaires for assessing the burden were well validated and have showed good reliability (52,54).

5.3. Future perspectives

Future studies could measure the effect on the burden of caregivers over a longer period and include more participants. The avoid in the future that more than 80% of the registered patients turn out to be ineligible, there should be found a way to deliver the tool immediately to the participant, without a registration step. Because, of all the registered people, 42,30% of them didn't continue the study after this registration step. Further, an online informed consent instead of a written online consent should lower the barrier to complete the study. Also the short study duration (t=one month) is an obstacle that should be avoided in the future. All these measures should enable to obtain a more accurate image of the efficiency of the SERES™ schizophrenia game. Future research could also include more stratification factors, such as disease state of the patient, gender of the caregiver, social support network, socioeconomic status, age etc. to investigate whether these factors have influence on the burden and on the effectiveness of the serious game.

With regard to the development, an updated version is being created at the moment. The topics that are handled in the game used in this trial, are being implemented in some specific themes. These include going to a party, functioning in a work environment, having a romantic relationship and reintegrate into society after hospitalization. In the new game scenarios will include more branching and they will become 'worse' when 'wrong' choices are made. This will allow caregivers to learn by playing and repetition instead of learning by seeing result screens and feedback only. This new SERES™ schizophrenia game will be more engaging. Previous studies have proven that this enhances a behaviour change (37,39,43,44). Further, it can be considered to extend the game. Different variations could be made for different target audiences or games could be made more individualized by creating the option to choose gender, age, specific problems etc. to suit individual needs. For future development, there can also be kept in mind that the caregivers have a social unmet need, as discovered in figure 13. The SERES™ schizophrenia game can be delivered on a social platform, coupled to a forum or in combination with other opportunities to connect with peers.

5.4. Conclusion

In this study, the effect of the schizophrenia e-learning and SERES™ schizophrenia on caregiver's burden was assessed for the first time with the help of the BSFC and the PFBS. SERES™ schizophrenia represents a unique interactive intervention for caregivers. This intervention is making caregivers' support more accessible and offers an active learning component, which tends to have an improved outcome for the caregiver (37). Most of the existing serious games are made for children or health care professionals, but there is also a need for serious games for informal caregivers (37,39). The schizophrenia e-learning was used as a control intervention in this study. No difference in BSFC burden categories could be observed in both the test and control group. In the PFBS values a not statistically significant decrease could be observed in both the control (2,3%) and the test group (14%). The burden fall was noticeable bigger in the test group even though the burden at baseline was higher than in the control group. In this very small sampled sized trial (n=10), this can be seen as an indication that the SERES™ schizophrenia game has a positive effect on the burden. Further research with a bigger sample size and with a longer duration could show significant results. Most of the participants were enthusiastic about this new interactive tool and would recommend it to other caregivers. This study is the first step towards a major validation and effectiveness proof of the schizophrenia e-learning, SERES™ schizophrenia and serious gaming in general.

NEDERLANDSE SAMENVATTING

Schizofrenie is een ernstige aandoening van de hersenen. De aandoening beïnvloedt een persoon zijn gedachten, gevoelens en handelingen. Schizofrenie wordt gekenmerkt door positieve en negatieve symptomen. Wanen, hallucinaties, verstoorde gedachten en vreemd gedrag behoren tot de positieve symptomen. Deze worden positief genoemd omdat ze geen deel uitmaken van het normale gedragspatroon, ze zijn extra. De negatieve symptomen worden gekenmerkt door de afwezigheid of de afname van emotionele uitdrukkingen en gedragingen. Hiertoe behoren motivatie afwijkingen, anhedonie of de afwezigheid van plezier, weinig spreken, slechte zelfhygiëne en apathie of het verlies om plannen te initiëren. Deze worden negatief genoemd omdat ze een verlies van het normale gedragspatroon betekenen. Schizofrenie treedt meestal op in de late puberteit of late volwassenheid. Vaak komt de aandoening iets vaker voor bij mannen dan bij vrouwen en treedt het ook iets vroeger op bij mannen dan bij vrouwen. De jaarlijkse incidentie van schizofrenie bedraagt 0,2-0,4 op 1000 mensen, met een levenslange prevalentie van ongeveer 1%. Deze behoorlijk hoge prevalentie kan worden toegeschreven aan de jonge leeftijd bij het optreden van de eerste symptomen en de chronische aard van de aandoening.

Bij het ontstaan van schizofrenie spelen zowel genetische als omgevingsfactoren een rol. De meest gebruikte neurobiologische hypothese voor het verloop van schizofrenie is de dopamine hypothese. Deze hypothese schrijft de symptomen van de aandoening toe aan een verstoorde en hyperactieve dopaminerge signalering. De meest gebruikte medicatie bij de behandeling van schizofrenie blokkeert de dopamine D2 receptoren. De behandeling van schizofrenie kan ingedeeld worden in een farmacologische en een psychosociale behandeling. Het doel van deze behandelingen is de psychoses onder controle houden en het verbeteren van de symptomen zodat de kwaliteit van het leven wordt verbeterd.

Schizofrenie patiënten ondervinden heel wat rechtstreekse en onrechtstreekse belasting van hun aandoening. Ze kunnen last hebben van stigmatisatie, discriminatie, sociale isolatie, problemen met huizing, agressief gedrag, problemen met tewerkstelling, co-morbiditeit, middelen misbruik, depressiviteit en zelfmoord neigingen en een algemene verhoogde mortaliteit. Naast deze grote belasting voor de patiënten zelf, brengt schizofrenie ook een hoge belasting voor de omgeving met zich mee. De chronische aard van de aandoening vraagt heel wat zorgen. Vroeger werden deze mensen opgevangen in ziekenhuizen of mentale instituten, maar door een politieke en economische verandering, ontstond er een de-institutionalizering. Dit betekent dat in de meeste gevallen de naaste familie instaat voor de dagelijkse zorg van de patiënt. Deze worden mantelzorgers genoemd. Deze zorg vraagt heel wat energie wat tot heel wat stress en belasting kan leiden. Dit kan dan weer leiden tot negatieve gevolgen voor het dagelijks leven en de gezondheidstoestand van de mantelzorger. Dit kan dan op zijn beurt een negatieve impact hebben op de patiënt zelf. De belasting ontstaat vaak omdat de mantelzorger niet over de nodige kennis en handelingen bezit om met deze verzorgende taak om te gaan. Er bestaan verschillende soorten ondersteuning die deze zaken aan de mantelzorger aanbieden. Deze bestaan voornamelijk uit psycho-educatie en ondersteunende praatgroepen. Maar nog te vaak vinden mantelzorgers geen toegang tot deze diensten omdat ze niet weten dat ze bestaan of deze moeilijk toegankelijk zijn.

Recent is er een nieuwe manier van ondersteuning ontwikkeld, ‘serious gaming’ genoemd. Deze middelen bieden online simulaties aan met het doel de kennis, vaardigheden en gedragingen van de mantelzorger te verbeteren. Door hun interactieve aard kunnen ze het leerproces bevorderen. Er werden al heel wat serious games ontwikkeld voor verschillende aandoeningen zoals ADHD en diabetes. Maar er is nood aan validatie van deze nieuwe manier van ondersteuning.

Tijdens deze thesis werd een serious game ontwikkeld voor mantelzorgers van mensen met schizofrenie, genaamd ‘SERES™ schizofrenie’. Dit spel werd speciaal ontwikkeld om de psychologische en sociale uitdagingen die ze ervaren positief te beïnvloeden. Het doelt niet alleen op het informeren van de mantelzorger, maar ook op het aanreiken van verschillende vaardigheden.

Materialen en methoden

Er werden zowel een e-learning als een spel ontwikkeld tijdens deze thesis. Een e-learning is een digitale en educatieve leermethode. Het heeft het informeren van de mantelzorger als doel. De e-learning is gebaseerd op wetenschappelijke lectuur, websites en brochures. Deze informatie werd gebundeld en verwerkt in een grafisch filmpje van ongeveer 10 minuten.

In tegenstelling tot de e-learning biedt het spel niet alleen kennis aan, maar ook vaardigheden. Hierdoor hoopt het een verandering in het gedrag van de mantelzorger teweeg te brengen en de verwerkingsstrategieën te verbeteren zodat de belasting daalt. De ontwikkeling van het spel ontstaat uit verschillende fases. Eerst werd wetenschappelijke literatuur verzameld waaruit verschillende belangrijke determinanten werden gehaald die meermaals aan bod kwamen als belangrijke factoren voor de belasting van de mantelzorger. Belangrijke determinanten waren onder andere verwerkingsstrategieën, emotionele ondersteuning voor de mantelzorger, probleem-oplossende taken, soorten ondersteuning voor de mantelzorger, familie educatie en familie welzijn. Deze determinanten werden vervolgens in overkoepelende categorieën verdeeld. Uiteindelijk werd bepaald op welk resultaat deze determinanten een effect bleken te hebben en werd een graad van belangrijkheid toegekend. In de finale stap werden deze determinanten nu gelinkt aan echte situaties. Hiervoor werd inspiratie geput uit websites, blogs en getuigenissen. Met deze informatie werden scenario’s geschreven en werden telkens drie mogelijke reacties aangeboden waar de mantelzorgers vervolgens feedback op kregen. Dit alles werd nu mooi gevisualiseerd, technisch geïntegreerd en extern gevalideerd door experten.

Met deze nieuwe middelen werd een studie uitgevoerd met mantelzorgers van mensen met schizofrenie om na te gaan of het spel helpt om de belasting te verlagen. De inclusie criteria waren de volgende: (1) persoon verzorgt een familielid of geliefde met de aandoening schizofrenie dagelijks; (2) deelnemer heeft voldoende kennis van het Nederlands; (3) deelnemer ondervindt minimum een middelmatige belasting op de BSFC, zodat een verbetering kan worden aangetoond. Deelnemers die zelf een fysieke of mentale beperking hebben werden ge-excludeerd. In totaal registreerden 52 mensen zich voor deze studie, maar uiteindelijk bleven slechts 10 mensen over. De afvallers voldeden niet aan de inclusie en exclusie criteria of vervolledigden de studie niet. Alle geregistreerde mensen werden gerandomiseerd in test en controle groep op basis van registratie sequentie. Dit resulteerde uiteindelijk in zes mantelzorgers in de test en vier in de controle groep. Tijdens de registratie werd persoonlijke informatie verzameld. De deelnemers moesten aanduiden wat hun relatie is met de patiënt, hoelang ze al mantelzorger zijn en of ze instaan voor de dagelijkse verzorging. Deelnemers die niet instaan voor de dagelijkse verzorging werden automatisch toegewezen aan de testgroep met het doel meer subjectieve data te kunnen verzamelen rond het spel. Na de registratie kregen de deelnemers een mail met een link naar de controle of test interventie. De controle interventie bestond uit de e-learning terwijl de test interventie zowel uit de e-learning als het spel bestaat om de effecten van de e-learning te controleren.

De belasting van de mantelzorgers werd gemeten met behulp van de Nederlandse versies van de BSFC en de PFBS. Minimum twee weken na de interventie, kregen de deelnemers opnieuw een mail waarin ze gevraagd werden de vragenlijsten opnieuw in te vullen. Er werden ook enkele subjectieve vragen gesteld. De data van deze vragenlijsten werden verwerkt door Articulate Online. De statistische analyses werden uitgevoerd met SPSS.

Resultaten

Eerst werd de persoonlijke informatie van de deelnemers geanalyseerd. In de controle groep zijn alle deelnemers mantelzorger van hun zoon of dochter. Ook in de test groep is dit de grootste categorie (5/6 of 83,33%). Verder kan er opgemerkt worden dat de mantelzorgers in de controle groep eerder recente mantelzorgers zijn. Drie deelnemers uit deze groep zijn mantelzorger sinds een tot vijf jaar en een deelnemer sinds 10 tot 20 jaar. In de test groep is de duur van het mantelzorgen meer verspreid.

Bij het analyseren van de BSFC, worden de scores in drie categorieën verdeeld: geen tot milde belasting, matige belasting en ernstige tot zeer ernstige belasting. Er wordt onderzocht of de interventie er voor kan zorgen dat de mantelzorgers veranderen naar een lagere belastings-categorie. Aangezien deze data categorisch zijn, wordt de niet-parametrische Fisher's exact test uitgevoerd op de data om na te gaan of er een verschil is tussen de controle en test groep voor en na de interventie. Er kan geen statisch significant verschil aangetoond worden tussen controle en test groep (p>0,05). Vervolgens worden de data geanalyseerd met een McNemar test om na te gaan of er een verschil is in de controle groep voor en na de interventie. Hetzelfde wordt gedaan voor de test groep. Zowel in de controle als in de test groep kan er geen statisch significant resultaat worden waargenomen (p>0,05).

De scores op de PFBS worden geanalyseerd met de parametrische ongepaarde t-test, aangezien deze data normaal verdeeld zijn, Shapiro-Wilk test (p=0,739). Hiermee wordt na gegaan of er een verschil is tussen controle en test groep voor en na de interventie. Ook hier kan er zowel pre- als post-interventie geen statisch significant resultaat worden gevonden (p>0,05). Er kan echter wel worden vastgesteld dat de gemiddelde pre-interventie score bij de controle groep (gem. 42,75; SD 14,15) lager ligt dan bij de test groep (gem. 47,83; SD 8, 42). Bij de post-interventie scores, kunnen we zien dat de gemiddelde score van de test groep (gem. 41,17; SD 12,54) lager ligt dan de controle groep (gem. 41,75; SD 8,26), ook al was deze hoger bij aanvang. Vervolgens wordt er ook een gepaarde t-test uitgevoerd op zowel de test als controle data om na te gaan of er een verschil is in belasting voor en na de interventie. Alhoewel er in de controle en test groep geen statisch significant resultaat kan worden waargenomen (p>0,05), is er wel een kleine daling bij zowel de controle groep (2,3%) van de gemiddelde score (gem. 42,75; SD 14,15 → gem. 41,75; SD 8,26) en bij de test groep (14%) van de gemiddelde score (gem. 47,83; SD 8,42 → gem. 41,17; SD 12,54).

Uiteindelijk worden ook de subjectieve vragen 'Zou je de tool aanraden aan andere mantelzorgers?' en 'Wisselde u informatie omtrent deze tool uit met andere mantelzorgers tijdens de studie?' geanalyseerd. Alle deelnemers uit de controle groep zouden de e-learning aanraden en vier mensen uit de test groep zouden het volledig pakket aanraden aan andere mantelzorgers. Slechts twee deelnemers hebben over de tool gepraat tijdens het onderzoek.

Discussie

Er kon worden vastgesteld dat 90% van de deelnemers mantelzorger is voor hun zoon of dochter. Een reden hiervoor zou kunnen zijn dat de meeste patiënten nog onder de zorg van hun ouders vallen wanneer de symptomen van schizofrenie voor het eerst worden vastgesteld, aangezien deze vaak optreden tijdens de puberteit. Deze data suggereert dat deze categorie van mantelzorgers het meest nood heeft aan deze nieuwe interactieve tool. De meeste deelnemers zijn ook vrij recente mantelzorgers (1 tot 5 jaar). Dit zou zo kunnen zijn omdat deze vrij recente mantelzorgers nog op zoek zijn naar het juist ondersteuningsmiddel.

Aangezien er bij de analyse van de PFBS scores, een niet significante daling van 14% in de belasting kan worden vastgesteld bij de test groep, kan er gesuggereerd worden dan het spel wel degelijk een gunstig effect heeft. De kleine daling (2,3%) in de controle groep suggereert ook dat de e-learning een effect heeft. Bij aanvang van de interventie kon een hogere belastings-graad worden vastgesteld in test groep. Dit kan verklaard worden door de langere mantelzorg periode in deze groep. Studies hebben immers aangetoond dat mantelzorgers een hogere belasting ervaren naarmate ze langer mantelzorger zijn.

De grootste zwakte van deze studie is de kleine steekproef (n=10). Dit werd veroorzaakt door de korte rekruteringsperiode (t=1 maand) en de moeilijk te bereiken doelgroep. Ook de korte studieduur (t=min. 2 weken) is een zwakte aangezien deze periode te kort is om een echt belastings-verschil te kunnen bemerken. Verder kan de ziektestatus van de patiënt de belasting beïnvloeden. Het feit dat de studie controleert voor het placebo-effect door de controle groep de e-learning aan te bieden en controleert op het effect van de e-learning door ook de test groep de e-learning aan te bieden is een sterkte. Hierdoor suggereert de studie onrechtstreeks dat het aanbieden van kennis (e-learning) en vaardigheden (spel) een beter effect heeft op de belasting dan het aanbieden van kennis alleen.

Conclusie

In deze studie werd het effect van de schizofrenie e-learning en SERES™ schizofrenie voor het eerst getest met behulp van de BSFC en de PFBS. Er konden geen statistisch significante resultaten worden gevonden, maar bij de PFBS kon er wel een trend van een dalende belasting worden vastgesteld. Deze daling is duidelijk groter bij de test groep (14%) dan controle groep (2,3%), zelfs al was deze waarde hoger dan de controle groep bij aanvang van de studie. Deze studie met kleine steekproef (n=10) kan gezien worden als een indicatie dat SERES™ schizofrenie een gunstig effect heeft op de belasting van de mantelzorger. Verdere studies met een grotere steekproef en langere duur zouden mogelijk significante resultaten kunnen opleveren. Deze studie is de eerste stap richting validatie van de schizofrenie e-learning en SERES™ schizofrenie en serious gaming in het algemeen.

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APPENDIX 1: Try the schizophrenia e-learning and SERES™ Schizophrenia yourself.

You can use the following link to try the schizophrenia e-learning and SERES™ schizophrenia.

http://isms-hosting.com/SERES/story.html

APPENDIX 2: The Dutch version of the Burden Scale for Family Caregivers (BSFC), used in this trial.

	klopt precies	klopt overwegend	klopt minder	klopt niet
1. Ik voel me 's ochtends uitgeslapen.	☐	☐	☐	☐
2. Onder de hulp/zorg die ik verleen heeft de tevredenheid met mijn leven geleden.	☐	☐	☐	☐
3. Ik voel me vaak lichamelijk uitgeput.	☐	☐	☐	☐
4. Ik heb af en toe de wens om uit mijn situatie "uit te breken".	☐	☐	☐	☐
5. Ik mis het gesprek met anderen over de hulp/zorg die ik verleen.	☐	☐	☐	☐
6. Ik heb genoeg tijd over voor mijn eigen behoeftes en interesses.	☐	☐	☐	☐
7. Ik voel me door de zieke soms uitgebuit.	☐	☐	☐	☐
8. Ik kan buiten de situatie om, waarin ik hulp verleen, ontspannen.	☐	☐	☐	☐
9. Ik heb er geen moeite mee om de zieke bij de nodige dingen te helpen (b.v. bij het wassen of eten).	☐	☐	☐	☐

	klopt precies	klopt overwegend	klopt minder	klopt niet
10. Ik heb er geen moeite mee om de zieke bij de nodige dingen te helpen (b.v. bij het wassen of eten).	☐	☐	☐	☐
11. Ik voel mezef soms niet meer echt als “ik zelf”.	☐	☐	☐	☐
12. De hulp/zorg die ik verleen wordt door andere mensen op de juiste waarde geschat.	☐	☐	☐	☐
12. Mijn levensstandaard is door de hulp/zorg die ik verleen achteruit gegaan.	☐	☐	☐	☐
13. Ik heb het gevoel dat mij de zorg-/hulpverlening is opgedrongen.	☐	☐	☐	☐
14. De wensen van de zieke zijn naar mijn mening redelijk.	☐	☐	☐	☐
15. Ik heb het gevoel dat ik de zorg/hulp-situatie “beheers”.	☐	☐	☐	☐
16. Door de hulp/zorg wordt mijn gezondheid aangetast.	☐	☐	☐	☐
17. Ik kan me nog van harte verheugen.	☐	☐	☐	☐
18. Vanwege de zorg/hulp moest ik bepaalde toekomstplannen opgeven.	☐	☐	☐	☐
19. Het maakt mij niets uit wanneer buitenstaanders de situatie van de zieke meekrijgen.	☐	☐	☐	☐
20. De hulp/zorg kost veel van mijn eigen kracht.	☐	☐	☐	☐
21. Ik voel me “in tweestrijd” tussen de eisen van mijn omgeving (b.v. gezin) en de eisen die door de zorg/hulp aan mij worden gesteld.	☐	☐	☐	☐

	klopt precies	klopt overwegend	klopt minder	klopt niet
22. Ik ervaar het contact met de zieke als goed.	☐	☐	☐	☐
23. Vanwege de hulp/zorg zijn er problemen met andere familie-/ gezinsleden.	☐	☐	☐	☐
24. Ik heb het gevoel dat ik nodig weer eens zou moeten relaxen.	☐	☐	☐	☐
25. Ik maak me vanwege de hulp/zorg die ik verleen zorgen om mijn toekomst.	☐	☐	☐	☐
26. Onder de hulp/zorg heeft mijn relatie met gezinsleden, famieleden, vrienden en kennissen te lijden.	☐	☐	☐	☐
27. Het lot van de zieke maakt me droevig.	☐	☐	☐	☐
28. Naast de hulp/zorg kan ik mijn andere alledaagse taken naar mijn voorstellingen vervullen.	☐	☐	☐	☐

APPENDIX 3: The Dutch version of the Perceived Family Burden Scale (PFBS), used in this trial.

Instructie: Bepaal het volgende: 1) Geef aan of het gedrag tot uiting komt bij je naaste die lijdt aan schizofrenie; 2) Geef aan in welke mate dit gedrag je stoort.

A **B**

Duidt aan met een 'X' Geef aan in welke mate het gedrag je stoort

als het gedrag aanwezig is

		Helemaal niet	Een beetje	aanzienlijk	In grote mate	Ik weet het niet
Lijkt angstig						
Lijkt triest						
Is zwaarmoedig						
Weigert medicatie						
Weigert hulp						
Weigert voedsel						
Spreekt luid						
roept						
Blijft in bed						
spreekt amper						

Ziet er slordig uit						
Kraampt onzin uit						
Dreigt met zelfmoord						
Gedraagt zich achterdochtig						
Gebruikt beledigende taal						
Dreigt met geweld						
Gooit met dingen						
Valt anderen lastig						
Beschuldigt anderen						
Doet zichzelf pijn						
Lacht geregeld						
Misbruikt drugs						
ijsbeert						
Rookt te veel						

APPENDIX 3: The written script of the schizophrenia e-learning.

1. Wat is een psychotische stoornis?

2. Een psychotische stoornis is, net zoals depressie, het gevolg van een storing in de functie van de hersenen.

3. Ongeveer 1 op 100 mensen ontwikkelen deze storing. # Het komt iets vaker voor bij mannen dan bij vrouwen. # De eerste symptomen treden meestal op tussen de leeftijd van 16 en 30 jaar. # Bij mannen treden de eerste symptomen gewoonlijk iets vroeger op # dan bij vrouwen. # Niet iedereen ervaart dezelfde symptomen en problemen.

4. Een psychotische stoornis is het resultaat van een verstoorde communicatie tussen hersencellen. # Zenuwcellen communiceren met elkaar via chemische stoffen, neurotransmitters genoemd. # Bij een psychose is er vaak een te grote hoeveelheid van de neurotransmitter dopamine in bepaalde delen van de hersenen.

5. Het is niet zo dat er één specifieke gebeurtenis is die een psychose veroorzaakt. # Een combinatie van aangeboren en niet-aangeboren elementen is verantwoordelijk voor de ontwikkeling. # Omgevingsfactoren, zoals bv stress, kunnen de gevoeligheid voor psychoses versterken. # Vaak sluipt de aandoening heel traag in iemands leven, maar ze kan ook plots aangewakkerd worden door een schokkende gebeurtenis.

6. Bij een psychotische stoornis kunnen er heel veel verschillende symptomen de kop op steken. Voorbeeld 1. # Je kunt last hebben van achtervolgingswanen. Je bent op weg naar huis. # Op elke hoek van de straat staan mensen naar je te kijken. # Ze lijken jou te volgen. # Er komen telkens mensen bij. Je wordt bang en begint sneller te wandelen. # Tot ze plots verdwijnen…

7. Voorbeeld 2. Je wandelt rustig over straat. # Je ziet een man die een groene sjaal draagt. # Aan de overkant van de straat bemerk je een klein meisje met een groene jas. # Er komt een groene wagen voorbij. # Het huis op de hoek van de straat heeft een groene voordeur. # De vrouw naast je draagt een grote groene tas. # Wat betekent al het groen? Dit moet een speciale betekenis hebben! Zoveel groen kan geen toeval zijn. Ze willen je vermoorden.

8. Voorbeeld 3. Je bent rustig aan het koken. Plots hoor je een stem van een vreemde man: # “Wat doe je nu? # Je kunt er niets van! # Je bent niets waard! # Je kunt er niets van! # Niet zo! Niet dat! # Stop! Stop!” Zo gaat het de hele dag door. Je kunt de stemmen niet afzetten. Ze maken je triestig. Je voelt je waardeloos.

9. Dokters praten over deze symptomen als zijnde ‘positieve symptomen’. Deze symptomen komen tot uiting in periodes en zijn dus niet permanent aanwezig. Naast dit niet kloppend idee van de werkelijkheid kunnen er ook nog andere kenmerken optreden.

10. Je leeft meer teruggetrokken en hebt niet zo veel nood aan sociaal contact. # Je vertoont weinig emoties. # Als je spreekt, nemen je gedachten een niet logische volgorde aan of kom je niet duidelijk uit je woorden. # Je laat een verwarde indruk na # en verliest interesse in dingen. # Je bent minder hygiënisch. # Deze kenmerken worden gegroepeerd onder de term ‘negatieve symptomen’.

11. Hoe ervaar je een psychose als omstaander?

12. Het gezin is een belangrijke factor in de ondersteuning van mensen met een verhoogde gevoeligheid voor psychoses. # Dikwijls word je als familielid zorgverlener zonder dat je voldoende geïnformeerd bent.

13. Zorgen voor een persoon met een verhoogde gevoeligheid voor psychoses kan dus heel wat stress met zich meebrengen. # Je kunt geïsoleerd geraken doordat je minder tijd hebt voor hobby’s, vrienden, werk en jezelf. # Bovendien kun je je ook schuldig voelen omdat je je afvraagt of je niet méér had kunnen doen om de ziekte te voorkomen # én kunnen er financiële problemen ontstaan.

14. Maar zorgen voor een persoon met een verhoogde gevoeligheid voor psychoses, kan ook positieve gevolgen met zich meebrengen. # Het geeft heel wat voldoening. # Je ontwikkelt een stevige band met je geliefde. # En ook je innerlijke sterkte wordt verrijkt. # Veel zorgverleners geven ook aan dat ze meer aandacht hebben voor mensen met problemen dan vroeger.

15. Een psychotische stoornis heeft ook een impact op de maatschappij. # De medische kosten die ontstaan als gevolg van onaangepaste of onvoldoende zorg, kunnen hoog oplopen. # Ook de sociale opvang vraagt heel wat energie en organisatie. # Veel mensen weten niet wat een psychose is. Vaak krijgt de term ‘psychotische stoornis’ dan ook een negatieve bijklank en zijn er ongegronde vooroordelen. # Om te verhinderen dat personen met een verhoogde gevoeligheid voor psychoses en hun familieleden met deze stigma’s geconfronteerd worden, is het essentieel om de maatschappij te informeren.

16. De verminderde sociale capaciteiten van personen met een psychose, brengen heel wat sociale problemen met zich mee. # Vaak hebben ze weinig vrienden, # worden ze aangestaard bij bv een woede uitbarsting # of vinden ze moeilijk werk. # Mensen weten niet hoe ze moeten reageren in deze specifieke situaties…

17. De toekomst is echter hoopvol. # Dankzij anti-psychotische geneesmiddelen kunnen de meeste symptomen goed onder controle worden gehouden. # Er bestaan ook heel wat sociale programma’s die personen die gevoelig zijn voor het ontwikkelen van een psychose helpen integreren in de maatschappij. # Ook begeleid zelfstandig wonen behoort tot de mogelijkheden. De kans op een waardig, normaal leven in de maatschappij is dus realistisch.

18. Hoe kan een psychotische stoornis behandeld worden? # De behandeling bestaat uit 3 aspecten: # de stabiele omgeving van het gezin, # een goede ondersteuning door middel van gesprekken, # en een onderhoudsbehandeling met geneesmiddelen. #

Deze aspecten vullen elkaar aan. Op het belang van familie komen we zo meteen terug.

19. Door middel van gesprekken met professionele hulpverleners, leer je omgaan met de gedachtegang die ontstaat als gevolg van een psychose. Zo leer je dat als iemand op straat zijn handen in z'n zakken steekt, # hij niet grijpt naar een revolver, # maar naar bv een zakdoek. # Je leert jezelf corrigeren in het maken van verkeerde conclusies. Je kan je gedachten in eigen handen nemen.

20. Er kunnen gesprekken worden gevoerd over # problemen, # gevoelens, # ervaringen en # gedachten. # Er bestaat ook psycho-educatie. Dit helpt je om de aandoening beter te leren kennen. Deze leermomenten bestaan zowel voor personen met symptomen van een psychotische aandoening als voor hun familieleden.

21. Ook sociale training is belangrijk. Hierbij worden allerlei sociale vaardigheden ingeoefend. # Je traint hoe je je moet gedragen in bepaalde omgevingen: thuis, op het werk, op school en gewoon in het dagelijkse leven. # Er kan ook geleerd worden hoe je afspraken moet maken, hoe je moet solliciteren, of hoe je papieren moet invullen.

22. Geneesmiddelen onderdrukken # de belangrijkste symptomen, zoals hallucinaties en wanen. Dankzij deze medicatie kan iemand die soms te maken had met psychoses, weer functioneren zoals voorheen.

23. Iemand die een aanleg heeft voor psychoses, blijft er ook gevoelig voor. # Daarom is het van groot belang dat het medicatieschema goed wordt nageleefd. # De meeste medicatie moet dagelijks ingenomen worden. Hun effect is pas na minstens een maand zichtbaar. Het is dus belangrijk dat je een geneesmiddel de tijd geeft om te kunnen werken en niet meteen overschakelt naar een hogere dosis of een ander geneesmiddel. # Familie kan hierbij hulp bieden. Ze kunnen de medicatie klaarzetten zodat ze niet vergeten wordt en kunnen snel waarnemen of de medicatie problemen geeft.

24. De stabiele omgeving van het gezin biedt heel wat voordelen. # Deze vertrouwde omgeving zorgt voor een veilig gevoel # en zorgt ervoor dat sociale vaardigheden op peil blijven. # De familie speelt ook een belangrijke rol bij het verloop van de ziekte. # Zo werd wetenschappelijk bewezen dat er een kleinere kans is op herval als de familie steun biedt.

25. [studiegroep] Omdat het niet altijd eenvoudig is om te weten hoe je het best omgaat met personen met een psychotische aandoening, # bestaan er heel wat ondersteunende middelen. Via deze ondersteunende middelen kan je als zorgverlener leren hoe je je reacties, die volledig normaal zijn bij mensen zonder een psychosegevoeligheid, kan aanpassen, rekening houdend met de aandoening. # De SERES-game is hiervoor een perfect hulpmiddel. Via de SERES-game kun je aan de hand van real-life situaties kennis op doen over de verschillende aspecten van een psychotische aandoening. # Bij elke situatie moet je een keuze maken tussen verschillende reacties. Hierbij is geen goed of fout antwoord. Elke reactie heeft een impact op jezelf en op de persoon met symptomen van een psychotische aandoening

. # Na elke situatie kan je de impact van je beslissingen bekijken. # Klaar om het zelf te proberen?

26. [controlegroep] Omdat het niet altijd eenvoudig is om te weten hoe je het best omgaat met personen met een psychotische aandoening, # bestaan er heel wat ondersteunende middelen. Via deze ondersteunende middelen kan je als zorgverlener heel wat bijleren over psychoses en hoe te reageren in bepaalde situaties. # Vraag ernaar bij de hulpverlener van uw familielid!

APPENDIX 4: The written script of SERES™ schizophrenia.

Voorstelling personages

Welkom bij SERES!

Je zult door een aantal scenario's geleid worden die je als mantelzorger van iemand met psychosegevoeligheid in het dagdagelijkse leven kan meemaken. Doorheen het spel zal telkens gevraagd worden om een keuze te maken. Elke keuze beïnvloedt verscheidene parameters zoals jouw sociaal functioneren, het zelfvertrouwen van de persoon met psychosegevoeligheid of de harmonie binnen de familie. Uiteindelijk beïnvloeden deze parameters vijf sleutelfactoren: het algemene welzijn van de persoon met psychosegevoeligheid, de aanwezigheid van een ondersteunende omgeving, de belasting die je als mantelzorger ondervindt, en de sociale integratie van jezelf als mantelzorger en van de persoon met psychosegevoeligheid.

Klik "Start" om verder te gaan.

Veel succes!

Jouw personage is Sofie, een 45-jarige vrouw die gelukkig getrouwd is met de 47-jarige Filip. Je dochter heet Ella, zij is 14 jaar en gaat graag winkelen met haar vriendinnen. Je zoon Lucas is 21 jaar oud en is juist afgestudeerd aan de hogeschool en op zoek naar een job. Lucas zit in een jeugdbeweging en heeft veel vrienden. Recent echter werd Lucas gediagnosticeerd met een verhoogde gevoeligheid voor psychoses.

Je man en jij hebben beide een heel drukke job en bijgevolg slechts weinig vrije tijd. Bovendien reist Filip heel vaak voor zijn werk. Hierdoor komt het overgrote deel van de zorg voor Lucas op jouw schouders terecht.

Module 1

Scenario 1

De laatste tijd lijkt Lucas overdag stiller dan anders, ’s nachts daarentegen is hij zeer onrustig. Bij het klaarmaken van het ontbijt valt je oog op de medicatie van Lucas. De doos is nog steeds even vol als vorige week. Je spreekt er Lucas over aan.

Sofie: Lucas, ik denk dat je je medicatie niet neemt. Is er iets waar je over wil praten?

Lucas: Nee…

Sofie: Lucas, is er een reden waarom je je medicatie niet neemt? Verdraag je de medicatie niet goed? Ik merkte ook al dat je wat stiller bent dan anders en je niet zo vast slaapt.

Lucas: Ik vergeet ze gewoon in te nemen…

Het is belangrijk dat Lucas zijn medicatie regelmatig neemt om zijn symptomen onder controle te houden. Wat kan je doen om Lucas te helpen zijn medicatie niet meer te vergeten?

A. Je koopt een pillendoos met de dagen van de week op en vult deze elke dag zelf aan.
B. In overleg met Lucus stel je een alarm in op zijn smartphone.
C. Je beslist om Lucas er gewoon voldoende op te wijzen als hij zijn medicatie is vergeten in te nemen.

Overgang 2.1 B/C naar 2.2: Na enkele weken tevergeefs proberen, koop je alsnog een pillendoos die je dagelijks zelf aanvult.

Scenario 2:

De beslissing om een pillendoos te kopen en deze dagelijks zelf aan te vullen lijkt te werken. Lucas vergeet zijn medicatie niet meer in te nemen.

Lucas: Ik weet dat ik mijn medicatie niet meer vergeet sinds jij mijn pillendoos vult, maar ik voel me net een klein kind dat niet voor zichzelf kan zorgen…

Hoe reageer je:

A. Je laat het vullen van de pillendoos aan Lucas over. Je houdt wel zelf een kalender bij en verwittigt Lucas als hij zijn medicatie toch eens vergeet.
B. Je hebt in een infobrochure van de arts gelezen dat er een speciale supportgroep bestaat die mensen met psychosegevoeligheid helpt therapietrouw op te bouwen. Je stelt Lucas voor dat hij dit misschien eens kan proberen.
C. Je hangt een kalender op in de keuken waarop Lucas aanduidt wanneer hij zijn medicatie heeft genomen. Op deze manier is hij zelf verantwoordelijk, maar kan ook jij de situatie opvolgen.

Scenario 3:

Je komt voorbij Lucas zijn kamer en ziet dat hij aan het roken is.

Sofie: Lucas, sinds wanneer rook jij? Roken zorgt ervoor dat je medicatie minder goed werkt. Je dosis zal misschien moeten worden opgedreven en dit kan leiden tot meer bijwerkingen!

Lucas: Ik voel me er net beter bij. Het voelt alsof de bijwerkingen van de medicatie afnemen.

Sofie: Maar er zullen uiteindelijk veel meer bijwerkingen bijkomen… Ik zou heel graag hebben dat je ermee stopt!

Wat doe je?

A. Je verplicht Lucas buiten te roken. Op die manier hoop je dat het roken verminderd.
B. Je raadt Lucas aan het roken aan te kaarten tijdens zijn praattherapie met de psychiater.
C. Je laat Lucas doen en kaart het roken zelf aan tijdens jouw hulpgroepssessie en vraagt tips van andere mantelzorgers.

Feedback

Advies van andere mantelzorgers

Angst, medelijden, woede en schuld zijn veelvoorkomende gevoelens

Als mantelzorgers identificeer je je met verschillende emoties wanneer je geconfronteerd wordt met uitdagingen. Het is handig om met iemand over je gevoelens te praten, zij het met een familielid, echtgenoot of andere mantelzorgers binnen bijvoorbeeld een steungroep.

Advies van Lucas

Praat open en eerlijk met mij

Wederzijds vertrouwen en respect is belangrijk in elke relatie en zeker in de omgang met een persoon met psychosegevoeligheid. Als je mijn handelingen of gedragingen met mij wil bespreken, doe dat dan kalm en op een praktische manier.

Module 2

Scenario 1

Je merkt op dat Lucas de laatste tijd overal te laat komt. Hij is al enige tijd actief op zoek naar werk en had deze ochtend eindelijk een sollicitatiegesprek, maar hij is er veel te laat aangekomen. Hoe breng je dit aan bij Lucas?

A. Je geeft Lucas mee dat stiptheid belangrijk is en dat hij dit probleem kan aankaarten tijdens een sessie met zijn psychiater.
B. Je komt overeen met Lucas dat jullie samen dit probleem zullen aanpakken.
C. Je spreekt met Lucas over ‘jobsupport’, deze dienst helpt hem bij het zoeken naar een job of stage waar hij sociale en technische vaardigheden kan aanleren.

Scenario 2

Lucas loopt er de laatste tijd maar wat slonzig bij. Hij is ook veel minder dan anders begaan met de organisatie van jeugdbeweging activiteiten. Je realiseert je dat dit een teken van herval kan zijn.

Hoe reageer je in deze situatie?

A. Je wil Lucas heel graag motiveren om wat actiever te zijn, maar je hebt schrik dat Lucas hierdoor stress ondervindt waardoor een psychotische episode kan worden uitgelokt.
B. Je bespreekt met Lucas dat dit een teken van herval kan zijn en geeft mee dat je het vooral leuk zou vinden als de algemene huisregels, zoals eet- en bedtijden, gerespecteerd worden.
C. Je laat Lucas doen wat hij wil, maar je bent extra alert voor andere gedragswijzigingen, aangezien dit een trigger voor een nieuwe psychotische episode kan zijn.

Scenario 3

Lucas gaat door een moeilijke periode. Na zijn passieve gedrag, heeft hij nu ook weer last van hallucinaties en stemmen. Je wilt dit aankaarten bij Lucas, maar je hebt schrik om zijn vertrouwen te verliezen als je verkeerd reageert… Wat doe je?

A. Je twijfelt niet en maakt onmiddellijk een afspraak met Lucas zijn psychiater. Als psychotische symptomen optreden is het aangewezen zo snel mogelijk medische hulp in te schakelen.
B. Je probeert Lucas te overtuigen dat je niet dezelfde dingen ziet en hoort als hij.
C. Je gaat niet mee in het gedrag van Lucas. Wanneer je merkt dat hij minder last heeft van hallucinaties of stemmen, raad je hem aan hierover te praten tijdens zijn psychotherapie sessie. Daar kunnen ze hem leren begrijpen wat er precies gebeurt.

Scenario 4

De laatste tijd lijkt Lucas heel zwaarmoedig. Hij toont geen enkele intentie om actief aan iets deel te nemen. Terwijl je even het raam dicht doet in Lucas zijn kamer, valt je oog op z'n laptop. Je merkt dat Lucas websites over zelfmoord bezoekt. Wat doe je?

A. Je praat hier met Lucas over en hoopt dat een gesprek ervoor kan zorgen dat hij zich beter voelt.
B. Je contacteert de psychiater en geeft hem deze informatie. Een dokter kan je zeker advies geven.
C. Je praat hier met Lucas over en spreekt met hem af dat hij dit aankaart bij zijn psychiater. In tussentijd beslissen jullie samen om alle overbodige medicatie uit het huis te halen.

Feedback

Advies van andere mantelzorgers

Gedragsveranderingen opvolgen

Kleine veranderingen in Lucas zijn gedrag en symptomen opvolgen is een handige manier om belangrijke verschillen te identificeren. Dit laat u toe om vroegtijdige professionele hulp in te schakelen en een terugval te voorkomen.

Advies van Lucas

Verwachtingen aanpassen

Bepaalde verantwoordelijkheden kunnen te complex en uitdagend zijn voor mij. Het is aangenaam als je redelijke verwachtingen stelt en mijn inspanningen erkent.

Module 3

Scenario 1

Je gaat elke week 2 keer naar de fitness met je beste vriendin Suzan. Je hebt echter al 2 weken op rij moeten afzeggen omdat je op hetzelfde moment naar een hulpgroep voor mantelzorgers gaat. Suzan belt je op.

Suzan: Hey Sofie, ga je mee fitnessen vanavond?

Sofie: Hey Suzan! Vanavond wordt weer moeilijk... Ik mis niet graag mijn afspraak met de hulpgroep, ik haal daar veel steun uit.

Suzan: Dat begrijp ik, maar je moet toch ook af en toe eens op iets anders focussen. Mee gaan fitnessen zal je deugd doen!

Je denkt na over de woorden van Suzan. De hulpgroep biedt je veel steun, maar gaan fitnessen met Suzan werkt ontspannend. Wat doe je?

A. Je beslist om slechts 1 keer per week naar de hulpgroep te gaan en om 1 keer per week mee te gaan fitnessen met Suzan.
B. Jullie beslissen samen om jullie fitnessmomenten te verplaatsen, zodat je beide kan combineren.
C. Je stelt voor om tijdelijk niet meer te fitnessen omdat je echt graag je afspraken met de hulpgroep nakomt.

Scenario 2

Suzan is jarig en geeft een feestje deze avond. Je vreest dat je zal moeten afzeggen omdat Lucas net door een moeilijke periode gaat. Wat beslis je?

A. Je belt Suzan op en legt de situatie uit. Je bedankt vriendelijk voor haar feestje en stelt meteen een andere datum voor om samen iets te gaan drinken.
B. Je vraagt Filip om thuis te blijven zodat jij naar het verjaardagsfeestje van je beste vriendin kan gaan.
C. Je belt een vriend van Lucas op en vraagt of hij vanavond kan langskomen. Je denkt dat sociaal contact Lucas deugd zal doen.

Scenario 3

Je hebt het de laatste tijd echt moeilijk. De combinatie gezin, werk, huishouden, hulpgroep en vrije tijd eist zijn tol. Je zit er even door. Je bent bang voor de toekomst van Lucas.
Wat doe je?

A. Je kaart het probleem aan tijdens de volgende hulpgroepssessie.
B. Je stort je hart uit bij Filip, en vraagt of hij wat meer kan bijspringen in de dagdagelijkse zorg voor Lucas.
C. Je belt je broer op en vraagt of hij één keer per maand Lucas een weekend kan opvangen.

Feedback

Advies van andere mantelzorgers

Zorg eerst voor jezelf

Hoewel Lucas je nodig heeft, is het belangrijk dat je ook goed voor jezelf zorgt. Tijd doorbrengen met vrienden en het uitoefenen van hobby's of activiteiten komt zowel jezelf als Lucas ten goede.

Advies van Lucas

Ik begrijp dat je tijd neemt voor jezelf

Ik waardeer alle steun en hulp die je me geeft. Het is oké als je tijd neemt voor jezelf en dingen doet die je graag doet.

Module 4

Scenario 1

Je merkt dat er minder gepraat wordt thuis. Het blijft stil aan de keukentafel en iedereen doet vooral activiteiten op z'n eentje. Lucas zijn gedrag weegt op de familie en je vindt het jammer dat de familieharmonie lijkt verloren te gaan ….

Wat doe je?

A. Je stelt familietherapie voor om de familiebanden aan te sterken.
B. Je beslist om een familie bijeenkomst te houden waarbij iedereen zijn gedachten en gevoelens vrij kan delen.
C. Je organiseert een familieactiviteit zodat iedereen positief met Lucas leert om te gaan.

Scenario 2

Je bent gezellig een film aan het kijken samen met Ella. Het is jullie moeder-dochter momentje.

Ella: Waarom zit Lucas tegen zichzelf te praten? Wat is er eigenlijk aan de hand met hem? Hoe komt het dat ik niet ben zoals Lucas? We komen toch uit hetzelfde gezin? Heb ik misschien iets verkeerd gedaan waardoor hij ziek is geworden?

Hoe reageer je?

A. Je schakelt professionele hulp in en maakt een afspraak bij de psycholoog voor Ella. Correcte en volledige informatie is namelijk heel belangrijk om deze vragen te plaatsen.
B. Je verzamelt goede, duidelijke eenvoudige informatiebrochures en neemt die samen even door met Ella.
C. Je denk even na over hoe je het allemaal zal formuleren en geeft Ella uiteindelijk zelf een duidelijke uitleg.

Scenario 3

Lucas en Ella zijn beide om de beurt verantwoordelijk voor de afwas. De laatste weken echter lijkt Lucas niet veel zin te hebben om deze taak uit te voeren. Wanneer je in de keuken komt zie je dat de afwas van die avond niet gedaan is.

Ella: Het is nu al de derde maal dat Lucas de afwas niet doet als het zijn beurt is. Ik heb dit tot nu toe voor hem opgevangen, maar nu is het echt genoeg geweest. Er moet iets veranderen.

Wat doe je?

A. Je beslist om een schema op te stellen zodat deze situatie in de toekomst vermeden kan worden.
B. In plaats van commentaar te geven op Lucas, formuleer je positief en constructief waarom je graag zou hebben dat hij helpt met afwassen.
C. Je vraagt tips aan een professional en geeft deze tips door aan Lucas. Bijvoorbeeld: klusjes doen wanneer hij zich energiek voelt, regelmatig opruimen, plannen, enz.

Feedback

Advies van andere mantelzorgers

Creëer structuur en harmonie thuis

Thuis een kalme en praktische houding aannemen, kan helpen om een gevoel van samenhang te creëren. Ook een goed georganiseerde en functionele woonomgeving komt Lucas ten goede.

Advies van Lucas

Mijn ziekte toelichten aan de familie kan helpen

Door mijn ziekte eerlijk en open te communiceren naar Ella toe, kan zij zich beter inleven waardoor onze relatie kan verbeteren.

APPENDIX 5: Overview of the chosen BSFC answers by the control and test participants, given in percentages (%).

Question	Strongly agree	Agree	Disagree	Strongly disagree
1	0%	10%	60%	30%
2	50%	30%	20%	0%
3	60%	30%	20%	0%
4	50%	30%	20%	0%
5	30%	40%	20%	10%
6	0%	20%	30%	50%
7	10%	50%	40%	0%
8	10%	40%	40%	10%
9	20%	50%	20%	10%
10	100%	50%	30%	10%
11	10%	30%	50%	10%
12	0%	80%	20%	0%
13	0%	40%	40%	20%
14	0%	30%	50%	20%
15	0%	40%	30%	30%
16	30%	60%	10%	0%
17	10%	40%	30%	20%
18	60%	40%	0%	0%
19	10%	50%	30%	10%
20	60%	30%	10%	0%
21	10%	60%	30%	0%
22	0%	50%	40%	10%
23	10%	20%	70%	0%
24	60%	30%	10%	0%
25	60%	30%	10%	0%
26	30%	60%	10%	0%
27	60%	30%	10%	0%
28	0%	40%	30%	30%

APPENDIX 6: Overview of the chosen PFBS answers by the control and test participants, given in percentages (%).

Question	Not at all	A little	Considerably	A great deal	Don't know	Not present
1	10%	30%	30%	20%	0%	10%
2	10%	10%	20%	30%	20%	10%
3	20%	0%	40%	10%	10%	20%
4	20%	20%	20%	10%	0%	30%
5	0%	20%	60%	20%	0%	0%
6	20%	30%	0%	0%	0%	50%
7	10%	30%	30%	10%	0%	20%
8	10%	20%	30%	0%	0%	30%
9	20%	20%	20%	30%	0%	10%
10	20%	0%	40%	20%	0%	20%
11	0%	20%	20%	50%	0%	10%
12	10%	30%	40%	10%	0%	10%
13	20%	20%	10%	10%	0%	40%
14	0%	60%	20%	10%	0%	10%
15	0%	10%	30%	30%	0%	30%
16	10%	30%	10%	10%	0%	40%
17	20%	10%	20%	10%	0%	40%
18	20%	20%	20%	10%	0%	30%
19	10%	10%	30%	30%	0%	20%
20	30%	10%	0%	0%	10%	50%
21	0%	60%	0%	0%	10%	30%
22	10%	0%	0%	40%	10%	40%
23	10%	40%	30%	0%	10%	10%
24	0%	0%	20%	60%	0%	20%