

**UNIVERSITY OF TWENTE.**

**Needs and wishes of young carers  
with regard to an online self-help  
intervention based on PP with  
gamification**

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## Summary

**Background:** Young carers are young people living together with an ill family member. Being a young carer can have multidimensional impacts on their own current and later adult life. To cope with their situation, it appears to be important that they get support. One possibility of reaching a lot of young carers is to design an online intervention, which is easier to do and accessible in daily life. Regarding the content, the field of positive psychology (PP) is interesting here. PP interventions show effectiveness in enhancing well-being and learning how to cope. To make it more motivating for the target group, it is important to integrate representatives in the design or evaluation process of an intervention. It could be effective here to present the intervention in a playful manner, such as in a game version.

**Objectives:** The aims are (1) to estimate the situation of young carers and their need for support, (2) to examine how they appreciate exercises and topics from an existing intervention and (3) to examine their appreciation regarding a game version of the intervention.

**Methods:** The qualitative research contained semi-structured interviews with 15 young carers. The participants received a book with exercises and texts from PP and screenshots of a possible game version. After two weeks individual interview appointments were made. The topics were the usage of the book, the appreciation and learning effect of the book with exercises and the appreciation of the game version with persuasive elements. The transcripts were analysed through a deductive and inductive analysis.

**Results:** The current intervention with exercises and texts was appreciated positively and as being important. The young carers appreciated that it is about helping the young carer, and not the ill family member and mentioned positively that the content and topics are suitable for the support of young carers. The positive character of the intervention was appreciated positively. A large part of the participants was interested in using such an intervention. The game version was also appreciated positively, especially because of the motivational elements in it. Both, for a general intervention and the presentation of such an intervention, it was suggested to make two different versions with regard to different age levels.

**Conclusions:** An intervention for young carers, containing elements and exercises from PP, seems useful. A large part has the interest and need to use it. Furthermore, it seems to be practical to conduct a game version of the intervention. However, there could be offered a second version, without gaming elements. It should be stressed that such an intervention is not only useful for young carers who are highly impacted, but it is also useful in general to get more positive in life, to handle more or less difficult situations in life and to be happier.

## Samenvatting (Dutch summary)

**Achtergrond:** Jonge mantelzorgers (JMZers) zijn jongeren die met een zieke familielid samenleven. De situatie kan multidimensionale invloeden hebben op hun eigen huidige en later leven. Om beter om te gaan met de situatie blijkt het belangrijk te zijn dat ze steun krijgen. Een mogelijkheid om veel JMZers te bereiken is het ontwikkelen van een online interventie. Die is dagelijks makkelijker te doen en beter beschikbaar. De positieve psychologie (PP) is interessant voor de inhoud. PP interventies laten effectiviteit zien in het verhogen van welbevinden en leren om te gaan met situaties. Om het motiverend te maken, is het belangrijk om de doelgroep te betrekken in het design en evaluatie proces van een interventie. Het zou effectief kunnen zijn om de interventie in een spelvorm te presenteren.

**Doelstelling:** De doelen zijn (1) de situatie van JMZers en hun behoefte aan ondersteuning in te schatten, (2) te onderzoeken hoe ze oefeningen en topics van een bestaande interventie waarderen en (3) te onderzoeken hoe ze een spelvorm van de interventie waarderen.

**Methode:** De kwalitatieve analyse bevatte semi-gestructureerde interviews met 15 jonge mantelzorgers. De deelnemers kregen een boek met oefeningen en teksten van de PP en screenshots van een mogelijke spelvorm. Na twee weken worden individuele afspraken gemaakt voor de interviews. De topics waren het gebruik van het boek, de waardering en het effect van het boek met oefeningen en de waardering van de spelvorm met persuasieve elementen. De transcripties worden geanalyseerd door een deductieve en inductieve analyse.

**Resultaten:** De tegenwoordige interventie met oefeningen en teksten wordt positief en als belangrijk gewaardeerd. De JMZers waardeerden dat het over het helpen van de JMZER gaat, en niet om de zieke familielid, en ze noemden positief dat de inhoud en de topics passend zijn voor de ondersteuning van JMZers. Bovendien wordt het positief karakter van de interventie gewaardeerd. Een grote deel van de deelnemers is geïnteresseerd om zo een interventie te gebruiken. De spelvorm wordt ook positief gewaardeerd, vooral vanwege de motiverende elementen. Voor allebei, de interventie in het algemeen en de presentatie, wordt voorgesteld om twee verschillende versies te maken met betrekking tot verschillende leeftijdsniveaus.

**Conclusie:** Een interventie voor JMZers met elementen en oefeningen van de PP, blijkt nuttig te zijn. Een grote deel heeft interesse en nut om het te gebruiken. Het blijkt ook nuttig te zijn om een spelvorm te ontwikkelen. Maar er zou ook een versie zonder spelelementen kunnen worden aangeboden. Er zou moeten worden benadrukt dat zo een interventie niet alleen voor JMZers bedoeld is die zwaar belast zijn, maar dat het ook nuttig is om in het algemeen positiever te worden, beter om te gaan met situaties en gelukkiger te worden.

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## Introduction

### Young carers

Living with a chronic disease or condition does not only have multiple consequences for the life of the person affected. Living together with an ill family member is burdened, and often the family members have to take over the required support and caring. When children or adolescents get confronted with such a situation, we talk about ‘young carers’. Lots of different definitions exist of the term ‘young carers’ and its characteristics. Agreeing that it is about caring for an ill or disabled family member, the different definitions vary among descriptions of the age of young carers, the scope of caring and the specific illnesses and impairments of the family members. Cree (2003), for example, defines young carers as young people between five and 25 years old, who are influenced by the illness or impairment of a family member and who are giving physical or emotional support. Illness and impairments here include physical or learning difficulties, mental disabilities, chronic diseases and addiction to alcohol and other drugs. Other definitions include, for example, other age limits, as Becker (2007), defining young carers as being between 16 and 25 years old.

The large amount of definitions makes it difficult, firstly, to say which young people are young carers, and secondly, to find and address them. To make finding and addressing even more difficult, children and young adults living with an ill family member often do not identify with being in the role of a carer (Cooklin, 2006). Additionally, professional care providers often do not identify these children as young carers because of inability or unwillingness to identify their existence (Jenkins & Wingate, 1994). The situation and problems of young carers, which will be discussed later on, are often ignored, because there are no resources to support them. Because of not identifying with their role and not being identified as young carers, researchers often talk about a ‘hidden population’ in this connection (Kennan, Fives & Canacan, 2012).

The problems of not identifying and the varying definitions of the term young carer make it hard to guess how many young carers are living in the Netherlands. According to the Nivel-research ‘Opgroeien met zorg’ (de Veer & Francke, 2008) there are between 694.000 and 810.000 children in the Netherlands living together with a parent who has a chronic disease or a moderate to serious physical impairment. About 1.200.000 children have a parent with a psychiatric diagnosis and about 370.000 children live together with a parent who is addicted. There are not only young carers supporting their parents, but also about 250.000 to 400.000

children in the Netherlands who have a chronically ill or impaired sibling. Many of them are younger than 18 years (de Veer & Francke, 2008).

### **Role as a young carer**

Regardless of whether young carers identify with the role of caretakers, most of the children and adolescents have to do chores at home that go far beyond usual day-to-day chores that every child has to do (Jenkins & Wingate, 1994). The caring activities can be divided into different domains: Aldridge and Becker (1993) divide them into health and social care tasks and make a difference between domestic tasks and personal tasks. Examples of domestic tasks in social care are doing the dishes, doing the laundry, cooking meals or going shopping. Young carers also have to do personal tasks in social care, such as sitting and listening, hair care or manicure. Personal tasks in health care are, for example, helping someone sit up in bed, helping someone get upstairs, feeding assistance, help someone put on clothes, assisting in the shower or administering tablets. According to Joseph, Becker, Becker & Regel (2008), besides the domestic tasks and general care tasks, children often provide child care for siblings and provide help with activities such as paying bills and translating.

Both the caring activities the young carers are engaged in and how much time they have to invest, vary depending on different factors: the level of illness or impairment of the family member, the age of the young carer, the availability of alternative sources of support and other individual characteristics and circumstances in the family, such as level of resources in the household (Joseph et al., 2008; Warren, 2007; Hamilton & Adamson, 2013).

The situation of a young carer requires a higher than normal level of responsibility and often also higher than acceptable for their age (Jenkins & Wingate, 1994). The young people often have to take a lot of responsibilities, not appropriate for people their age and their usual role within the family. Usually there is not enough support (Warren, 2007), which also causes implications for their own development and life (Jenkins & Wingate, 1994).

### **Impact on the young carers' lives**

Young carers often face multiple difficulties and problems in their lives with regard to their home situation, their tasks and responsibilities (Pakenham, Chiu, Bursnall & Cannon, 2007). The circumstances in the family and their lives can result in a process called 'parentification': the young carer becomes part of the parental responsibilities within the family and gets more and more identified as 'little parent' (Ali et al., 2012).

Jenkins and Wingate (1994) also mention another known impact of the role as a young carer: the children and youngsters have a so-called ‘double responsibility’. Next to the practical daily tasks and responsibilities, they also face an internal pressure and attempt to do it “well enough” (Jenkins & Wingate, 1994). The perceived stress of caring or emotional distress could be one reason why it has attracted much interest in research (Joseph et al., 2008; Pakenham et al., 2007) and why researchers stress the **emotional impact** of the caring role as especially important (Thomas et al., 2003; Pakenham et al., 2007). All the impacts and tasks can be very stressful. The role of being a young carer puts extra pressure on the child or young adult in a phase in their lives that is already stressful (Cree, 2003). Young carers show higher levels of distress compared to other groups of young people (Pakenham et al., 2007) and the responsibilities as a young carer can result in feelings of anger, emotional exhaustion or a sense of isolation (Thomas et al., 2003). They also show a higher level of restlessness than children of the same age who are not in a caring role (Pakenham et al., 2007).

Moreover, young carers often face **impacts on health and well-being**, both physically and mentally. Their own health and well-being often worsens over time (Ali et al., 2012), for example, some young people report back problems because of lifting the disabled family member, get sick more frequently or feel exhausted because they suffer from sleeping problems (Thomas et al., 2003; Hamilton & Adamson, 2013). Further, they report effects on their mental well-being, experiencing feelings of depression, anxiety and stress (Hamilton & Adamson, 2013). On top of that, somatic problems and a lower self-confidence can be recognized (Kavanaugh, 2014). Reasons for this could be, for example, feeling guilty about the situation or problems within the family (Ali et al. 2012; Cooklin 2006).

Furthermore, there seems to be a **social impact**: as the young carers have to spend a lot of time supporting the ill family member and the family, there is less time for them personally. Additionally, it can negatively impact their social wellbeing: they have fewer opportunities to meet friends and to do leisure activities (Hamilton & Adamson, 2013; Thomas et al., 2003). In line with that, Kavanaugh (2014) states that some young carers also have problems being engaged in social interactions. This could result in social exclusion and isolation (Thomas et al., 2003).

The fourth type of impacts is the **educational impact**: poor school attendance and performance are possible effects. Young carers are more likely to miss out on out-of-school educational opportunities (Thomas et al., 2003). Because young carers often see their caring role as a priority, they face problems of balancing education and caring tasks (Hamilton & Adamson, 2013).

Finally, the caring role can have an **impact on their later adult life**. The decisions they made and also the effects on their health and well-being can impact their future (Ali et al. 2012; Cooklin 2006; Kavanaugh, 2014; Thomas et al., 2003). In line with that, Thomas et al. (2003) mention that negative impacts could be psychological consequences, such as stress and depression, an impaired psycho-social development or limited opportunities in social, educational and career developments.

The situation of a young carer is highly complex and besides all the immediate negative effects, such as sleep disturbances, feeling of loneliness, sadness, shame and fear, the children's entire development will be affected if the family does not get the much needed support (Metzing-Blau & Schnepf, 2008). Every young carer has capacity limits, according to Metzing-Blau and Schnepf (2008), and if these are touched or even exceeded there is need for support.

## **Support**

It appears to be important that young carers get supported in coping with their situation, tasks, problems, thoughts and feelings. According to Thomas et al. (2003) it is important not only to support the ill or impaired family member and the family as a whole, but also to include elements of individual support for the young carers to respect them as individuals.

A study from the Trimbos Institute shows that there is not enough cooperation with and support of family members of patients (van Erp, Place & Michon, 2009). There is only little research about the wishes and needs of young carers (van Erp et al., 2009). Existing studies about this topic stress that young carers would like to have information, both about the illness and its consequences and about opportunities for support, so that they are able to have a better idea of their own handling with the situation (Ali et al, 2014). They want to have support in their role as young carer, have a better understanding of the situation and get the possibility of getting answers to their questions (Cooklin, 2006). They want to do exercises for self-help (Weijkamp, 2015). Cooklin (2006) mentions that young carers furthermore would like to get in contact with other young carers.

Organizations, such as the 'Stichting Informele Zorg' (SIZ) in Hengelo (NL), give support to young carers, and combine elements of information giving, support, courses, conversations and the possibility of getting in touch with both other young carers and experts. About 800 young carers take the offer of the SIZ, showing that the courses and other offers are suitable for and valued by young carers.

The problem is that many affected people do not enlist support of such organizations yet. The first reason is that lots of young carers do not identify or do not want to identify with the caring role and do not want to show being a young carer (Kennan et al., 2012). There appears to be a lot of barriers: many young carers experience too much shame and fear to draw on such offers (Moore & Mc Arthur, 2007). Both the children and their families may fear, for example, to lose some privacy or a child protection intervention as a consequence (Kennan et al., 2012). Other studies show that some young carers fear to be bullied at school after being identified as young carer (Kennan et al., 2012). Some others had bad past experiences with identifying, such as that others cannot imagine that being a carer can be problematic and stressful (Moore & Mc Arthur, 2007).

Another problem seems to be that young carers do not know what services exist or how to access support. Others do not have the time to be personally present in such organizations, because they live too far away, for example (Moore & Mc Arthur, 2007).

The third problematic aspect is that service providers have difficulties identifying and reaching young carers (Kennan et al., 2012; Jenkins and Wingate, 1994). Reasons for this are first of all, that the young carers do not identify with their role as young carers. Secondly, there is a lack of awareness for this target group, and it is often difficult to distinguish between young carers and children doing normal tasks at home (Kennan et al., 2012). Finally, services do not always know how to deal with problems of young carers (Moore & Mc Arthur, 2007) or not have enough resources to provide support (Jenkins and Wingate, 1994).

One possibility of reaching young carers who feel shame and fear and also young carers who do not have the time or possibility of getting help from an organization is a support system via internet. The advantages of web-based interventions are that the internet becomes more and more important and that it has become a habit to search for information and support, especially for young people (Ali et al., 2014). Web-based interventions are accessible to more people in comparison to classic interventions. They are less time-consuming and can serve as device to give both information and communication (Ali et al., 2014). The young carers could take a look at the intervention at home and there would be a possibility of remaining anonymous. The anonymous character could be interesting for the young carers who do want to show themselves as carers or who do not want to get in contact with professional service providers. The threshold to do an anonymous online intervention is much lower than looking for professional help, especially for young people (van Rooijen, Zwikker & van der Vliet, 2014).

Therefore, the SIZ wants to develop an online self-help intervention to reach and support more young carers in the Netherlands. According to a previous study that is conducted via the SIZ, young carers would like to have an online self-help intervention (Weijkamp, 2015). Elements they would like to get offered in such an intervention are: information, tips, feedback, exercises and contact with fellow-sufferers.

Several Dutch websites already exist to support young carers, such as ‘SurvivalKid.nl’, ‘Bijzonderebroerofzus.nl’ or ‘Drankjewel.nl’. They all offer elements of information and some of them also offer the possibility of contacting other young carers or experts, but none of them offers an online self-help intervention to with (psychological) exercises. However, Ali et al. (2014) stress that it is important not only to give information and the possibility of communicating, but also little, accessible interventions for strengthening their well-being and learning to cope with their situation as young carers.

### **Positive psychology and interventions**

An approach to address both learning to cope with negative experiences and emotions and to increase well-being is through interventions based on positive psychology. Positive psychology is a field focussing on the well-being and optimal functioning of people (Schotanus-Dijkstra, Drossaert, Pieterse, Walburg & Bohlmeijer, 2015) with the aim to “cultivate positive feelings, behaviors or cognitions” (Sin & Lyumbomirsky, 2009). In other words, positive psychology is about maintaining or improving mental health. Mental health from a positive perspective is more than just the absence of psychological problems (Westerhof & Keyes, 2008), but it is, according to the World Health Organization “a state of well-being in which the individual realized his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make contributions to his or her community” (Bolier et al., 2013). According to Westerhof and Keyes (2008) the definition contains three central aspects of mental health: individual well-being, effective functioning of the individual and effective functioning in society. They stress that these elements are compatible with three concepts from psychological literature defining well-being: subjective wellbeing, psychological wellbeing and social wellbeing. Subjective wellbeing contains elements of life satisfaction and positive emotions, such as happiness. Psychological wellbeing is about optimal functioning through elements, such as self-acceptation, autonomy and goals in life. Finally, social wellbeing is also about optimal functioning, but in society, and contains elements of social acceptance and social integration (Westerhof & Keyes, 2008).

In positive psychology **interventions** the subjects of interest are the positive things in life, such as positive experiences, satisfaction, hope, optimism and happiness (Seligman & Csikszentmihalyi, 2000). Elements of all three concepts of well-being can be integrated. Research focussing on the effectiveness of such interventions show efficacy in enhancing well-being and reducing depressive symptoms (Bolier, Haverman, Westerhof, Riper, Smit & Bohlmeijer, 2013; Sin & Lyumbomirsky, 2009). For example, they are shown to be effective by “counting blessings, practicing kindness, setting personal goals, expressing gratitude and using personal strengths to enhance well-being and in some cases to alleviate depressive symptoms” (Bolier et al., 2013).

Positive psychology also seems to be important and effective in enhancing the development of children and adolescents (Marques, Pais-Ribeiro & Lopez, 2011; Shogren, Lopez, Wehmeyer, Little & Pressgrove, 2006). Elements of positive psychology, such as hope and optimism contribute to the life satisfaction of young people and life satisfaction is in turn predictive for quality of life and well-being (Shogren et al., 2006). Positive life-satisfaction has been linked to positive attitudes and behaviours (Shogren et al., 2006) and children who report higher levels of hope, satisfaction with life and self-worth show benefits in academic and behavioral development (Marques et al., 2011). Marques et al. (2011) stress that life satisfaction can be protective for young people experiencing stressful events of developing and showing externalizing behavior and “mediates the impact of stressful life events and parenting behavior”. Therefore an intervention focussing on elements of positive psychology may also protect young carers, so that the stressful experiences of their situation at home have less negative impact. Moreover, another advantage of this approach for the target group of young carers is that the positive character of such an intervention may appeal also to the young carers who do not want to get support or who do not want to talk about their problems, because they do not want to stir any pity.

The approach of positive psychology also fits to the findings that, besides the range of negative outcomes and experiences, young carers also report positive outcomes of their role and situation. For example, an increased sense of self-esteem, a close relationship between children and parents, the feeling of being well-prepared for life and an early maturity can be observed (Metzing-Blau & Schnepp, 2008). Others also report learning to take responsibility and developing life-skills as positive outcomes (Thomas et al., 2003) and that being in the role of a young carer can be pleasant (Kavanaugh, 2014). Joseph et al. (2008) stress that the understanding that caring can lead not only to negative but also to positive outcomes is consistent with the trend of positive psychology. Support should address the positive

outcomes and experiences of caring instead of focussing on the negative ones. Young carers should be encouraged to think about positive changes, emotions, and thoughts.

Besides, the advantage of using exercises of the field of positive psychology is that they are short-lived and the appeal is universal (Schueller & Parks, 2012). As a result, doing them does not interfere with daily life (Schotanus-Dijkstra et al., 2015). Therefore, the exercises are very suitable to be involved in online self-help interventions (Schotanus-Dijkstra et al., 2015; Schueller & Parks, 2012). Also Bolier et al. (2013) stress that many positive psychology interventions are in a self-help format and that this is in accordance with the goals of positive psychology. Furthermore, using self-help interventions is a cost-effective mental health promotion and a large population can be reached (Bolier et al., 2013).

One example of an intervention based on positive psychology is the book “Dit is jouw leven” (This is your life) (Bohlmeijer & Hulsbergen, 2013). Schotanus-Dijkstra et al. (2015) stress that specific exercises from this book are effective as a self-help intervention for adults. The exercises in this book focus on six domains of positive psychology: positive emotions, use of talents, optimism, self-compassion, resistance and positive relations (Schotanus-Dijkstra et al., 2015).

### **Motivation and motivational elements**

One approach to make a final product that fits the interests of the target group and therefore is also more appealing to use, is the ‘user-centered design’ (UCD). UCD is an approach in which the development of a product is based on the information about the ultimate users (Orji & Mandryk, 2014). The goal is to maximize usability. The main reference of usability is according to Jokela, Iivari, Matero and Karukka (2003) the definition of usability from ISO: “The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use”. In other words, by using UCD it should be achieved that the users use the product in the right way and with satisfaction. To achieve this, it is important to involve representatives from the target group in the design process: for example, they can be involved directly in the development, in redesigning an intervention or in the evaluation of interventions (Orji & Mandryk, 2014).

Another way to maximise usability of an intervention is to use persuasive technology (PT) (Kelders, Ossebaard & van Gemert-Pijnen, 2012; Lyon & Koerner, 2016). By using persuasive elements, such as self-monitoring, personalization or rewarding, PT has the aim to bring the desirable change within users, whether it is a behavioral change, a change in attitude or a change in thinking (Lyon & Koerner, 2016). One example of PT being used in design

processes is the persuasive systems design model (PSD model) Oinas-Kukkonen & Harjumaa, 2009). The model describes four dimensions of persuasion in technology, which can be used in all steps of the design process, from planning to evaluation. The four dimensions (1) primary task support, (2) dialogue support, (3) system credibility support and (4) social support contain different persuasive elements (Törning & Oinas-Kukkonen, 2009). Törning and Oinas-Kukkonen (2009) describe the dimensions as follows: in “primary task support”, elements such as tunneling, tailoring or personalization address the target behaviours of the intended users. In “dialogue support”, the designers deal with the feedback from system to user, guiding the user to reach the intended behaviour. Examples of design elements are praise, rewards or reminders. The “system credibility support” as dimension contains persuasive elements, like expertise or trustworthiness, to maximise credibility of the intervention. Finally, “social support” aims to improve the overall persuasiveness of a system by using elements, such as social comparison or social facilitation.

The aim of using the PSD model is to make the interaction between user and system as good as possible and to produce a medium which is convincing and attracts the attention of the target group. Therefore the target group should get motivated to use the medium. (Lehto & Oinas-Kukkonen, 2011). The PSD model can be combined with a user-centered approach to improve the usefulness and user-friendliness of interventions (Beerlage-de Jong, Eikelenboom-Boskamp, Voss, Sanderman & van Gemert-Pijnen, 2014). The early integration of the intended users allows early detection and prevention of user problems. The combination with the PSD model then allows motivating and supporting the end-users by making the intervention as persuasive as possible (Beerlage-de Jong et al., 2014).

One example of PT, wherein both the PSD model and the UCD can be combined, is **gamification**. Gamification is an “umbrella term” describing the usage of ‘gaming’ elements in non-game contexts, for example in health interventions, with the goal to motivate and engage people (King, Greaves, Exeter & Darzi, 2013). There is currently an increasing interest in the potential of such ‘gaming’ elements in influencing the health behavior of people by “integrating software design and game mechanics with public health theory and behavioural insights” (King et al., 2013). The advantage of presenting an intervention in a game version is that exercises feel more like a game and therefore, are not so serious (Theng, Lee, Patinadan & Schubert, 2015). The playful manner encourages users to do the exercises to achieve a certain outcome in the game (Theng et al., 2015). You can achieve to entertain the users and simultaneously help them with important self-help exercises.

Lyon and Koerner (2016) stress that such a system should be natural or common among the intended users. Especially within the target group young people, playing computer games is a common activity. Most children nowadays are using computers, smart phones or tablets and most of them also play games (Baranowski and Frankel, 2012). Baranoskwi and Frankel (2012) stress that children are not only comfortable with media and games, but even prefer to use electronic media. That is why such an intervention seems to be appropriate for the target group of young carers. A second reason for using a game as an intervention tool for young carers is that it is more common and more pleasant to play a game than doing a so-called self-help intervention. That would fit the point that young carers often do not identify or do not want to identify with the role and problems of young carers.

A game version of the intervention “Dit is jouw leven” has also been conducted. It has not been published yet, but it is still in a test run. The game is based on the original book and contains some of the topics and exercises from the book. This game version is an example of gamification. The goal of the project was to make a digital version of a self-help intervention book with exercises from the field of positive psychology (Ludden, Kelders and Snippert, 2014). To ensure that intended users are motivated to use the intervention and to continue working on the training, the researchers used a user-centered design approach, persuasive and gameful design elements and a metaphorical design (Ludden et al., 2014). For example, they presented the intervention as a journey as one motivating element. Furthermore, there will be a social support element included, such as a chat room or forum to get in contact with other players.

### **This research**

There is currently no online self-help intervention for young carers. But it seems to be important to develop an online self-help intervention to reach more young carers, to support them in coping with their situation and to enhance their well-being. There seems to be a need for a version that includes elements of positive psychology. The main goal is to make suggestions for designing an online self-help intervention for young carers based on their interests and needs. To provide a step in the development of an online self-help intervention, this research aims to examine to what extent elements of an existing intervention fit the interests and needs of young carers.

This study aims to investigate three aspects of interest: Firstly, we want to form an impression of the caring situation of the young carers. Getting to know the target group is important for designing an intervention which is appropriate for the target group. Secondly, we want to

know whether a modified version of the existing intervention “This is your life” fits the interests of young carers with regard to an online self-help intervention. Thirdly, we want to investigate which preferences young carers have regarding a game version of such an intervention.

Thus the research questions (RQs) of this study are:

1. How are the young carers impacted by their caring situation and tasks, and do they have a need for a supportive intervention?
2. How do the young carers appreciate the current intervention book with exercises and texts and what do they learn from it?
3. Which preferences do the young carers have regarding a game version of a self-help intervention and how do they appreciate the current prototype?

## **Method**

### **Design**

To find answers to the exploratory study questions, a qualitative research design was conducted by using semi-structured face-to-face interviews.

After five interviews, some changes were made to the interview scheme and in the book with exercises and texts described below. Then ten further interviews followed.

### **Participants & procedures**

The first five participants were recruited via the organization “Stichting Informele Zorg Twente” (SIZ). After that, participants were recruited via snowball sampling. The five participants and employees of SIZ were asked to inform other well-known children and adolescents living with an ill family member about the study. They were given an invitation letter of the study which they could forward to possible participants. Interested young carers then had the possibility of contacting the researcher.

The possible participants had to meet the following inclusion and exclusion criteria:

### **Inclusion criteria:**

- (1) living with a family member with a chronic (somatic or psychotic) disease or condition
- (2) being between 12 and 21 years old
- (3) being able to speak Dutch

**Exclusion criteria:**

- (1) having much experience with exercises and courses for young carers
- (2) having been involved in a research about their role as a young carer before

The participants involved in the study were sent the book with exercises and pictures through e-mail and were invited to read the book and to do the exercises within a period of two weeks. The letter of consent and a shorter version of the interview scheme were sent along. After these two weeks, individual appointments were arranged with the participants.

First of all, the participants and parents had the chance to ask questions about the material. They were informed about the aim and background of the study, the procedure, the anonymous data processing and the digital recording of the interview. After that, they were asked for permission through the informed consent. When they were younger than 18 years the parents had to sign it too.

During the interviews, an interview scheme (described below) was used. There was also time and space to ask additional questions, to react to the participants' answers spontaneously and to summarize their answers. The interviews were recorded with a mobile phone and later transcribed by the researcher.

The duration of the interviews varied between 32 and 90 minutes. With the exception of one interview, which was done at the university, all interviews were done at the participants' homes.

**Materials****Book**

We developed a document with exercises and text elements from the field of the positive psychology, summarized below in table 1. The basis for that was the book, "This is your life" ("Dit is jouw leven") (Bohlmeijer & Hulsbergen, 2013), whose effectiveness as a self-help intervention was proven for adults (Schotanus-Dijkstra et al., 2015).

In a first step the researcher and supervisor of the organization chose at least one exercise from each of the eight chapters which could fit the wishes and needs of young carers with regard to their age, intellectual capacity and interest to do the exercises. The original book, "This is your life" was written for adults, not for children or adolescents. So the next necessary step was to determine to what extent the exercises and texts fit the language of children and young adults. In several steps both exercises and texts were simplified in

wording and layout and made more childlike. By doing so we maintained the order, the topics and core messages of the different chapters. Possible situations and examples out of the lives of young carers were used to make the texts and exercises more attractive and interesting for the target group.

After a brief analysis of the first five interviews, we made the book more fitting for the target group and made some changes in the choice of exercises. Regarding the first appreciation of the young carers, some exercises were deleted and some others were added.

Table 1. *Overview of the chapters with topics and exercises (translated from Dutch)*

Chapter	Topic	Exercises		
1	<b>“High time for pleasure”</b>	<b>Positive emotions:</b> the importance of pleasant emotions and recognizing them in daily life.	“Three good things”	(Daily diary of positive experiences of the day)
			“How many pleasant emotions do you have?”	(Questionnaire about the experience of pleasant emotions in the last 24 hours)
2	<b>“Show your talents”</b>	<b>Use of talents:</b> getting to know one’s talents and qualities, and thereby getting a better image of yourself.	“Your qualities”	(Questionnaire about one’s qualities which should be filled in by the participant and a second person)
3	<b>“A different perspective on yourself”</b>	<b>Flow:</b> looking at oneself from another, less critical, perspective. Searching for positive aspects and pleasure in daily activities.	“Change ‘having to do’ into ‘wanting to do’”	(Summarizing of unpleasant activities and trying to find pleasure or motivation in it)
4	<b>“The glass is always half full”</b>	<b>Optimism:</b> learning to think more positive instead of negative and trying to get more optimistic.	“Keep a diary”	(Diary of negative situations in three steps: situation, thoughts and emotions; learning to examine if negative thoughts are realistic)
5	<b>“Be kind to yourself”</b>	<b>Self-compassion:</b> being more kind and sympathetic to yourself and appreciate yourself. Being less critical.	“Bring back being kind to yourself”	(Writing down situations of the last week when you were kind to yourself or others)
			“Be your best friend”	(Trying to look at a negative situation from the perspective of a good friend)
6	<b>“I am not the same anymore”</b>	<b>Resistance:</b> handling difficult situations. Getting to know your own way of dealing with problems, situations and emotions and learning to improve it.	“How do I handle difficult situations?”	(Questionnaire about one’s ways to handle difficult situations + trying to change negative ways)
7	<b>“Share your positive life”</b>	<b>Positive relations:</b> building up or improving relationships to others and being grateful.	“Express your gratitude”	(Expressing gratitude to another person, e.g. by writing a letter)
8	<b>“Relax”</b>	<b>Body image and relaxation:</b> learning to relax and being connected to yourself and your body.	“Abdominal breathing”	(Relaxing through learning how to breathe abdominal)
			“Muscle relaxation”	(Relaxing through tensing and relaxing muscles)
			“Egg-exercise”	(Relaxing through trying to imagine that an egg protects against negative influences)

## Game

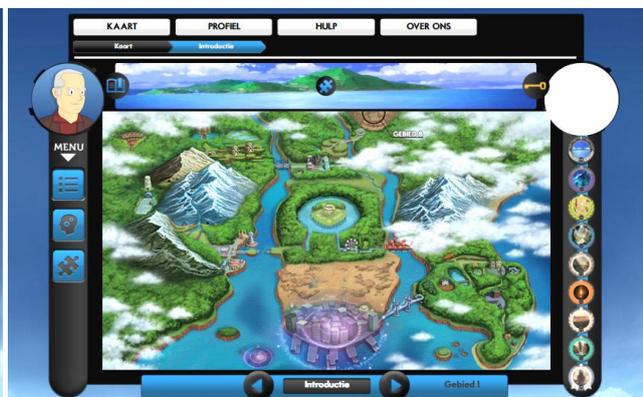
In addition to the texts and exercises, screenshots were shown of the possible game version of the intervention, “This is your life” designed by Prof. Dr. Ernst Bohlmeijer, Dr. Hester Trompetter, Dr. Saskia Kelders and Bas Snippert, which is still in progress.

First of all, screenshots were presented showing the general design of the game version. For example, an image of the instructions of the game and an image of the overview of the islands were shown to the participants.

Image 1. Image of game structure



Image 2. Image of overview of islands

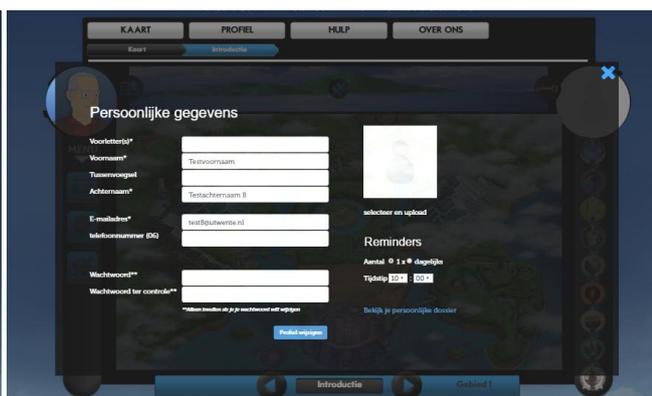


Furthermore, motivational elements of the game were presented in screenshots, which are further described below in table 2.

Image 3. Image of a reward-element



Image 4. Image of personal account



The game version contained motivational elements from three different principles according to the PSD model: primary task support, dialogue support and social support, which are summarized in table 2.

Table 2. *Overview of motivational elements in the game version*

Principle according to PSD framework	Element in game version
<b>Primary task support</b>	
Tunneling	Delivering the content in a step-by-step format with a predefined order by presenting the chapters as islands.
Personalization	The user of the intervention gets his own personal account for logging in and playing the game.
Self-monitoring	The game contains a list in which the user can see which levels (islands) he has already completed.
<b>Dialogue support</b>	
Rewards	The user gets a key when he has finished a level (island).
Reminders	The user can get reminders about levels/exercises which have not been finished yet or new elements, for example.
Liking	Asking the possible users for feedback on the design.
Social role	The game contains an avatar representing a professor who guides the user through the interventions by giving information and instructions.
<b>Social support</b>	
Social facilitation	The game might contain a group forum or chat room for the users.

### **Interview scheme**

After an introduction first of all, the participants were asked about their demographic data. The next part of the interview contained questions regarding the participants' caring role and situation at home. Topics of interests were the characteristics of the ill family members, the young carers' tasks and activities and the impact of the caring role on their lives.

The following interview was divided into three parts: the first part was about the book as a whole and contained questions about (1) the use of the book (2) the appreciation of the book, for example the wording and the comprehensibility, (3) the possible impact of the book on the reader and possible learning effects and (4) suggestions for improvement. The second part contained similar questions about use, evaluation and possible effects per chapter separately. The third part then contained questions about (1) the appreciation of the idea of presenting the intervention online, (2) the idea of presenting the intervention as a game and (3) a game version and (4) the appreciation of the current prototype of a game version. The participants were asked about their general opinion about the game version as a whole and their preferences about the specific motivational elements, which are presented above in table 2.

## **Data analysis**

The transcripts of the fifteen interviews were analyzed in a systematic manner through analyzing in four steps: Firstly, the data of all interviews was divided into three parts according to the different research questions: (1) impact of the role as a young carer, (2) appreciation of the book and exercises and (3) appreciation of the game. Secondly, the data was divided deductively according to the main categories from the interview scheme. Deductive here means that there is a predefined structure to find categories within the individual codes. Regarding the impact of the role as a young carer, the categories were (1) tasks and activities and (2) impact on their lives. With regard to the appreciation of the book and exercises, the categories were (1) use of the book, (2) general appreciation of the book, (3) appreciation of the different chapters, (4) learning experiences from the book and (5) suggestions for improvement. Regarding the appreciation of the game version, the categories were (1) appreciation of the idea of a game version, (2) general appreciation of the game version, (3) specific appreciation of the game version with regard to the motivational elements and (4) suggestions for improvement. In a third step the data in the different categories was coded openly. This means that all data was read and divided into fragments. The fragments of interest for answering the research questions were labelled, so that a list of codes was created for each category at the end of the step (Boeije, 2008). The fourth step was to subdivide the codes of each category into subcategories by using an inductive manner. Inductive here means that there is no predefined structure as a basis to find subcategories, but they were found and described by analyzing the individual codes and text fragments. The result of the fourth step was a list of categories and subcategories containing all relevant codes.

## Results

### 1. Description of the study group

Table 3 presents the demographic characteristics of the 15 participants in the study. The group of participants was heterogeneous with regard to gender, age and education. In total, the interviews from eleven female and four male participants were analysed. Their age varied from 12 to 19 years and the average age was 15.5 years. The educational levels of the participants ranged from medium to high levels of education. Most of the participants were in a level of medium education at the time of the interview.

All participants were living together at least with one parent at the time of the interviews. Two of the 15 participants had to care for more than one ill family member.

Table 4 presents the characteristics of the 17 ill family members. More participants have to care for a sibling (73.3%) than for a parent (40%). The family members are diagnosed with a variety of diseases. Autism is most frequently (41.2%). Most of the diseases were diagnosed more than five years ago (58.8%).

Table 3. *Characteristics of the participants (N=15)*

Characteristics	n	%
<b>Gender</b>		
Male	4	26.7
Female	11	73.3
<b>Age</b>		
Mean (SD)	15.5 (2.1)	
Range in years	12-19	
<b>Living situation</b>		
Parents	13	86.7
One parent	2	13.3
<b>Education</b>		
Medium	10	66.7
High	5	33.3
<b>Number of ill family members</b>		
One	13	86.7
Two	2	13.3

Table 4. *Characteristics of the ill family member (N=17)*

Characteristics	n	%
<b>Person affected</b>		
Father	2	11.8
Mother	2	11.8
Brother	6	35.3
Sister	3	17.6
Sister + Father	1	5.9
Sister + Mother	1	5.9
<b>Type of disease</b>		
Autism	7	41.2
ADHD	2	11.8
Kidney disorder	2	11.8
Alzheimer's disease	1	5.9
Heart attacks	1	5.9
Down's syndrome	1	5.9
Multiple sclerosis	1	5.9
Rheumatism	1	5.9
Burnout	1	5.9
Oppositional Defiant Disorder	1	5.9
Mental handicap	1	5.9
Manic-depressive	1	5.9
<b>When diagnosed</b>		
3-6 months	2	11.8
1-5 years	5	29.4
>5 years	10	58.8

## 2. Impact of the role as a young carer and need for support

To get an impression of their caring situation and the impact on their lives, the participants were asked about their tasks at home and how these tasks and the responsibility of being a young carer affect them. Furthermore, we asked about their need for support in general and the need for a supportive intervention. As presented in table 5, the results are divided into three subcategories: (a) caring activities, (b) impact on their lives and (c) need for support.

Table 5. Overview of the categories to answer RQ 1

RQ 1	2 Impact of the role as a young carer and need for support
	<i>Caring activities</i>
	<i>Impact on their lives</i>
	<i>Need for support</i>

### *Caring activities*

Most of the young carers answered that the role as a young carer does not require many other role specific tasks and activities at home, but it requires doing more of the normal daily tasks any child has to do at home. The majority reported doing additional tasks in the household, such as shopping, cleaning or cooking. Having an ill family member means more work for the whole family, “more planning” (P 2) and trying to combine the schedule of the ill family member with their own. Next to the additional tasks, the young carers also mentioned other additional role specific tasks and activities they have to do at home. The ill family members have to be supported, as they often cannot do many things on their own and are dependent. For example, there is the need for help with lunch or putting on clothes. The young carers often have to support the healthy family members in supporting the ill one. Many of the participants mentioned the task of staying home and keeping an eye on the ill family member.

It was noticeable that most of the participants mentioned relatively small tasks and activities they have to do and they also mentioned only relatively few tasks. Four of the 15 participants also mentioned not having many additional tasks at home or even not having additional tasks at all in the role as a young carer.

### *Impact on their lives*

Regardless of whether there are a lot of additional tasks or only a few, most of the young carers felt they are more or less affected by being a young carer. First, the young carers described that the **situation at home** was different from that of families without a chronically ill family member. According to them, it was more stressful at home, there was less time or opportunity to relax and the mood was more strained. Also going out spontaneously, as for example, going to dinner, was more difficult or even not possible.

Another influence on their lives was the **relational impact**: the relationship with the ill family member is often more difficult, and requires more sensibility in their interactions. Especially the young carers with an ill sibling mentioned that they had to be careful in their choice of words or that they had to be more sensible towards the affected person. Sometimes the behavior of the ill family member was difficult to understand for the young carers.

They also reported elements of a **social** influence: some of them felt they were limited in their freedom in regard to doing their own activities. As they have to do additional tasks, they often do not have as much free time as other youngsters. Some reported feeling restricted to invite friends, because the ill family member could get disturbed and react in an inappropriate manner, or the friends may feel uncomfortable because of the caring situation at home.

The **emotional impact** of being a young carer was not mentioned dominantly but it was mentioned that being a young carer involves being worried more often. Moreover, sometimes the feeling of being alone was mentioned sometimes and also the disappointment of getting less attention from the parents than the ill family member.

Generally speaking, most of the young carers in this study saw themselves as not being much influenced, because of “having a good family supporting them” (P 2) and “getting external support” (P 2), for example. Others reported that there had not been much influence yet. Reasons were that they were too young, or the ill family member was currently still able to do things on his own. Others learned to handle the situation over time and thus the situation does not have much impact anymore, or the ill family member lives somewhere else already.

### *Need for support*

It was asked whether the participants would like to have and use such a self-help intervention, because of the need to have one or the interest to use it. Nine of the 15 young carers mentioned that they would like to use a self-help intervention, because they were interested in an intervention and wanted to explore if it could help them in their role as a young carer. Another reason was that the current book version had already helped them in thinking and getting more positive, and so they would also like to have the final version.

The other six participants mentioned that they did not feel the need to use an intervention. The reason for that was, according to the majority, that they had already learned to handle their situation as a young carer by themselves and therefore did not have the need to learn other ways anymore. However, they stated that it would have been fine if they had such an intervention when they were younger and in the beginning phase of their role as a young carer.

### 3. Participants' appreciation of the current intervention book

To answer the second research question, we asked the participants about the appreciation of the current intervention book and what they had learned from it. As can be seen in table 6, the results are divided into three subcategories: (3.1) use and appreciation of the current intervention, (3.2) impact of the book on the reader and their learning experiences and (3.3) the participants' intention to use and recommend the book. The first subcategory is further divided into four different aspects: (a) use of the book, (b) general appreciation of the book, (c) appreciation of specific elements in the book and (d) suggestions for improvement.

Table 6. *Overview of the categories to answer RQ 2*

RQ 2	3	<b>Current intervention book</b>
	3.1	Use and appreciation of the current intervention
		<i>Use of the book</i>
		<i>General appreciation of the book</i>
		<i>Appreciation of specific elements in the book</i>
		<i>Suggestions for improvement</i>
	3.2	Impact of the book on the reader and learning experiences
	3.3	Intention to use and recommend the book

#### 3.1 Use and appreciation of the current intervention

##### *Use of the book*

In table 7 it is described to what extent the participants read the book and individual chapters, and examined the game version. The table shows that almost everything was read by all participants. Most of them said that they were “curious of the content of the book” (P 5) or they thought “to help other young carers by reading the book” (P 2). All participants read the book chronologically from cover to cover. Seven participants estimated that it had taken them about one to three hours to read the book, three estimated that they had read the book in less than one hour and one person estimated the reading time had been longer than three hours. Eight participants read the book at the same time every day or read the book all at once, whereas the other seven participants read the book at different points of time.

Table 7. *Extent of reading the book*

	Read completely		Read partly	
	N	%	N	%
Book read	14	93.3	1	6.7
C1 read	15	100	-	-
C2 read	14	93.3	1	6.7
C3 read	14	93.3	1	6.7
C4 read	13	86.7	1	6.7
C5 read	14	93.3	-	-
C6 read	14	93.3	1	6.7
C7 read	15	100	-	-
C8 read	13	86.7	1	6.7
Screenshots	15	100	-	-

Table 8 shows the extent of reading and doing the exercises in the different chapters. In the third column it is mentioned whether the exercise could be done by ten or 15 participants.

Table 8. *Extent of reading and doing the exercises (translated from Dutch)*

Chapter	Exercise	N	Read		Done	
			N	%	N	%
1	“Three good things”	10	10	100	4	<b>40</b>
	“How many pleasant emotions do you have? “	10	10	100	9	90
2	“Your qualities”	15	15	100	11	73.3
3	“Change ‘having to do’ into ‘wanting to do’”	15	15	100	10	66.7
4	“Keep a diary”	15	14	93.3	5	<b>33.3</b>
5	“Bring back being kind to yourself”	15	14	93.3	5	<b>33.3</b>
	“Be your best friend”	10	10	100	1	<b>10</b>
6	“How do I handle difficult situations?”	10	10	100	8	80
7	“Express your gratitude“	15	15	100	7	<b>46.7</b>
8	“Abdominal breathing“	10	9	90	5	50
	“Muscle relaxation“	10	9	90	2	<b>20</b>
	“Egg-exercise“	10	9	90	3	<b>30</b>

The motivation for reading the exercises was high. The motivation for doing the exercises, however, was apparently different for each exercise. The percentage of the number of participants who have done the exercise is more than 50% for seven of the twelve exercises: (1) “Three good things“, (2) “Keep a diary“, (3) “Bring back being kind to yourself“, (4) “Be your best friend“, (5) “Express your gratitude“, (6) “Muscle relaxation “ and (7) “Egg-exercise“. Especially noticeable is that the exercise “Be your best friend” was done by solely one single person and the exercise “Muscle relaxation” only by two participants. According to the participants, they based their choice of doing an exercise on their interest in the topic, on how much time they had to spend on doing the exercise, or on the level of difficulty. The two most common reasons for not doing an exercise were that the exercise was personally not appealing or the exercise was too difficult or incomprehensible.

### *General appreciation of the book*

In general, the participants were positive about the book. It was said to be interesting and pleasant to read and that it contained good exercises and information for young carers.

The participants made both positive and negative remarks regarding the suitability, comprehensibility and attractiveness of the book with different topics and exercises, which are summarized in table 9.

Table 9. *Overview of positive and negative remarks about the book*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Suitability</b>						
Book in general	15	15	Suitable for helping young carers in general.			
	1	1	Content is similar to other courses for young carers.			
Addressing target group	3	3	The book directly addresses the target group of young carers and their needs.			
	3	3	Book describes typical elements of the situation of young carers.			
Regarding age group				1	1	Book is too childlike.
				1	1	Book is sometimes too difficult for children.
<b>Comprehensibility</b>						
Book in general	15	14	In general well explained.	7	5	Sometimes not fully comprehensible.
Regarding age group				5	5	Too difficult for children.
Exercises				4	4	Some exercises difficult to understand.
<b>Attractiveness</b>						
Choice of words	9	8	Choice of words suitable.	5	4	Choice of words too childlike.
				3	3	Choice of words too difficult for children.
				2	2	Words sometimes difficult.
Presentation of the book/layout	6	3	The layout is appealing.	4	2	Layout could be friendlier and more colourful.
Texts	2	2	The content of the texts is good.	2	2	Some spelling mistakes.
	2	2	Structure of the texts is good.	1	1	Texts are sometimes boring.
				1	1	Too much text.

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

### **Suitability**

According to all 15 participants the book with texts and exercises was, in general, a suitable medium to help young carers. One argument was that the book would be helpful in difficult situations at home. Further, the idea of thinking more about the positive things in life instead of having many negative thoughts was very suitable, according to some participants.

One positive remark about the suitability was that the content and the exercises in the book are similar to those of other courses for young carers. Further, three participants pointed out

that it was good that the book directly addresses the target group and their needs. It was appreciated that the book was about the young carer and helping the young carer, instead of about helping the ill family member. One participant mentioned that “it is [...] really about the carer himself, to help him, and not about the child he has to care for” (P 7). The participants liked that the book described typical elements of the situation of young carers, and by that tried to address the target group with their experiences and problems. The content of the book contained “many typical elements of being a young carer”, according to participant 14.

One negative point about the suitability of the book was mentioned by participant 4. The participant doubted the suitability with regard to the different age levels in the target group: the book in total was, according to the participant, not suitable for all ages, because on the one hand it was too childlike for the older ones, and on the other hand it can be too difficult for the younger ones at times.

### **Comprehensibility**

Predominantly, the book was comprehensible for the young carers, in general. The majority was entirely positive about the comprehensibility of the exercises and texts in the book and understood everything. One aspect that was seen as positive was that the topics and exercises are well-explained and that there is a step by step explanation of what the reader has to do.

Five participants had some difficulties understanding specific parts of the book. They mentioned both problems with understanding some words in general and some specific explanations of exercises. Moreover, five participants had doubts about the level of difficulty and felt that the complexity could be too high for children. Some of them mentioned the possibility that children would not understand the content of all chapters, words and exercises. Participant 5 stressed: “I found that the book is clear, but for [children] of 12 years it is perhaps a little bit too difficult sometimes.” With regard to the different exercises in the book, four participants said that it was sometimes difficult to understand them. They referred both to the explanation of some exercises and also to some ways of doing the exercises. Participant 13, for example, found it difficult to do some exercises. Participant 5, however, said that “the explanation of some exercises [were] difficult [to understand]”.

### **Attractiveness**

The majority of the participants mentioned positive aspects about the choice of words in the book. It was appreciated as being good, suitable for the target group and understandable. However, there was a discrepancy in the appreciation of the choice of words with regard to

the suitability for the different age levels. On the one hand, the words in the self-help book were, according to two participants, too childlike and not really suitable for both the younger and the older ones. On the other hand, four participants mentioned that the words were too difficult for children and that more simple words should be used. Participant 9 pointed out: “Regarding some [parts], I thought that it was more for older children, also how it was written, with more difficult words. If my brother would read it, he would not understand it.”

Two other participants also said that the choice of words was too difficult for them personally. One reason was that the sentences were not written in correct Dutch at times.

Regarding the presentation of the book, many participants were positive about the layout, they mentioned that it could be read easily and that the layout in total was friendly. They were positive about the structure and design of the book, for example, about the images. The images would “make it more comprehensible” (P 5). One negative aspect that was mentioned was that more colours could be added to the layout of the book and the layout in general could be “more pleasant” (P 6). Besides this, the book was, according to one participant, too childlike, referring to both the layout and the texts.

The texts in the book were predominantly appreciated positively with regard to length and content. But two participants mentioned that there were some spelling mistakes in the text, making it sometimes more difficult to understand. Furthermore, one participant thought that the total length of the book with all texts and exercises was too long.

### *Appreciation of specific elements in the book*

With regard to specific elements in the book, the results focus on the different topics and exercises from positive psychology. Before asking about the specific topics and exercises in the different chapters, some remarks were made about the topics and exercises in general:

#### **Topics**

According to four participants the topics were important and relevant to the situation of young carers and therefore fit the target group. Participant 1, for example, stressed that “there are more children who need to think more positively”. The participants rated the following topics to be especially important for young carers: thinking more positively, thinking about emotions, becoming aware of positive things, relaxation and thinking about the tasks you have to do.

## **Exercises**

Regarding the general appreciation of the exercises, it was mentioned that although some exercises were more appealing than others, based on subjective judgement, the exercises in general were good and important. Participant 1 pointed out that “exercises which are personally not appealing, could however [appeal to] and help other young carers”. The participants were positive about being able to choose between exercises and about specific types of exercises, as for example, the “tests and quizzes” (P 4). Some of the young carers also thought that the exercises in general could help. A few negative aspects about the exercises in the book were also mentioned: the main point was that some of them were personally not appealing, relevant or necessary. Reasons for that were that the participants did not like the exercise, that they were already familiar with the exercise because of other courses, or that the exercise was too difficult. Participant 6 said: “I would recommend some exercises, but some [others] not, because with some exercises I can’t do anything.”

## **Topics and texts in the different chapters**

Following, a more detailed overview is given of remarks being made about the different topics and exercises in the eight chapters. Regarding the different chapters in the book, the participants were positive about the different topics of positive psychology. All topics were considered to be important by at least 10 participants, except for the topics optimism and resistance: less than 10 participants thought that these two were important. Furthermore, the image in chapter 6 was not comprehensible with regards to the topic, according to two participants. Besides that, the title in chapter 7 was said to be unrelated to the topic.

The texts in the different chapters were also generally appreciated positively. The only negative comments were that the texts in chapters 3 and 6 are a little bit too long. Regarding the comprehensibility of the texts, most of the participant stressed that almost everything was comprehensible. Merely the texts in chapter 2 and chapter 4 were a little bit more difficult to understand, according to one participant.

## **Exercises in the different chapters**

Table 10 gives a more extended overview of positive and negative comments that were made about the different exercises in the chapters. To get an even more extended and better image of the appreciation of each chapter and each exercise, an more extended analysis is added in appendix 2 (for example, as a basis for further decisions about using specific contents and exercises in an online self-help intervention).

Table 10. *Overview of the appreciation of the different chapters*

		Positive appreciation		Negative appreciation	
	np	Content of appreciation	np	Content of appreciation	
<b>Chapter 1: Positive emotions</b>					
Exercise 1 "Three good things"	4	Good to learn how to think more about positive things in life.	8	Exercise is personally not appealing (not wanting to do it daily; too difficult)	
Exercise 2 "How many pleasant emotions do you have?"	10	The exercise is good/important/personally appealing.			
		Exercise can be done easily and fast and you get a score as result.	1	Not wanting to get a score.	
<b>Chapter 2: Use of talents</b>					
Exercise "Your qualities"	11	The exercise is good (get to know your own qualities and getting a better image of yourself with all your talents)	2	Topic of exercise is personally less appealing.	
			2	Aspect of having to ask a second person (with regard to time)	
			3	Problems with understanding the exercise.	
<b>Chapter 3: Flow</b>					
Exercise "Change 'having to do' into 'wanting to do'"	9	Intention and type of exercise is good and fits needs of young carers (having to do a lot of things)	4	Exercise is personally not appealing.	
	3	You learn to see tasks more positively.	1	Problems with understanding the exercise.	
<b>Chapter 4: Optimism</b>					
Exercise "Keep a diary"	12	Good exercise, especially for difficult situations.	12	Exercise is personally not appealing (writing a diary as type of exercise)	
			4	Problems with understanding and doing the exercise.	
<b>Chapter 5: Self-Compassion</b>					
Exercise 1 "Bring back being kind to yourself"	7	The exercise is simple and not time consuming. You learn to have more positive of yourself.	3	The exercise is personally not attractive (not necessary; time-consuming; difficult)	
Exercise 2 "Be your best friend"	5	The exercise is short, but strong and important.	5	The exercise is personally not appealing.	
<b>Chapter 6: Resistance</b>					
Exercise "How do I handle difficult situations?"	8	The way of doing the exercise is good and you can find out how to handle situations.	2	Some options to choose are not appropriate for younger young carers (e.g. drinking alcohol)	
<b>Chapter 7: Positive relations</b>					
Exercise "Express your gratitude"	9	The exercise offers a way to express your gratitude, which is important.	7	The exercise is personally not attractive or not necessary.	
<b>Chapter 8: Relaxation</b>					
Exercise 1 "Abdominal breathing"	6	The text is a good relaxation exercise.	2	The exercise is personally not attractive (takes too much time)	
Exercise 2 "Muscle relaxation"	3	The exercise helps to calm down.	2	The exercise is personally not appealing.	
Exercise 3 "Egg-exercise"	4	It can help to concentrate on the positive things and to forget the negative ones and thus it is relaxing.	1	The exercise can personally not help.	

### *Suggestions for improvement*

Next to the suggestions mentioned above, the young carers made some more suggestions to improve the book with texts and exercises.

One aspect for improvement was mentioned by three participants: making two different versions of a self-help intervention with regard to different age groups. They suggested making a childlike and easier comprehensible version for younger young carers and a second less childlike version for the older ones. For the child version both the words and texts and also the exercises should be easier. For the version for older young carers the layout should be less childlike.

Furthermore, suggestions were made about adding information. Firstly, one participant suggested adding a list of information about what the different chapters are about. The participant would like to have a brief summary of each chapter in one or two sentences with the aim to have a better idea of the different topics in the book. This list could be added on page two which already contains the overview of the different headings. Secondly, participant 3 suggested adding a part with information about the different diseases. The participant would like to have information about the diseases, how you could help people with this disease and what you can do. Another suggestion about adding information was to stress more that it is important and right to think of oneself, and not to think of the ill family member all the time. It should be stressed that you do not always have to adapt to the wishes of the ill family member, but also to your own wishes and needs.

For young carers who feel a high need to do such an intervention, there could be some extra exercises which are more extensive, regarding time and content, according to participant 3.

### **3.2 Impact of the book on the reader and learning experiences**

One part of the appreciation of the current intervention book was the impact of the book on the reader and the learning experiences from it. It was retrospective not always clear, if the remarks of the participants were made with regard to their own personal experiences with the book or regarding the general ability of the book to support and to teach something. Therefore, firstly, some remarks are presented, which were definitely about own experiences of the book, and then further remarks are presented about (1) the general supportive ability of the book and (2) learning effects from the book in general.

### **Own experiences of the impact of the book**

With regard to their own experiences, five participants recapitulated that the book with exercises helped them personally already by reading it once. They learned from the book to think about the positive things in life, learned new ways to handle situations and emotions and to find time for themselves. Participant 5 mentioned that he had learned something “[about] the different emotions [...] and how to handle them in the best way”. Participant 9 pointed out that he had learned to have a different view on tasks he has to do at home, and to see them more positively. Participant 1 emphasized that she had learned from the book to think more of the positive things she has reached in life and on which she could be proud of.

### **General supportive ability of the book**

With regard to the general target group of young carers, eight participants mentioned that the book in general could help in situations of a young carer. Five participants thought that the book could help to get calm or keep calm, by thinking about the topics or simply by doing something and taking time for you. Furthermore, it was mentioned by the participants that you could feel better after reading the book, because you could learn to focus more on the positive things in your life. The book could also give you a feeling of not being alone, as you recognize that there are more young people, struggling with similar problems and you do not have to think that your situation is strange, according to the participants.

Regarding the exercises, ten participants said that the exercises could help, regardless of whether they were offered in a book or game version. Some of them referred to all exercises in general, and some of them said that some of the exercises could help and that it was, for example, “depending on the situation” (P 2) or “depending on the user” (P 6) which exercises could help. However, they also stressed that exercises that could not help them personally, might help other young carers with other needs and interests.

### **Learning effects from the book**

In table 11, at the end of this paragraph, remarks of the participants are summarized about the learning effect you can have through reading the book and doing the exercises.

According to the participants, the book can teach you how to think more about the positive things in life, for example on successes, and to think less about the negative ones, for example on problems. You can, therefore, “learn to think positively and not to be kept down by the negative [things]” (P 9). Additionally, the book helps to learn techniques or ways to keep calm or get calm in difficult situations and in general. Furthermore, it was mentioned that you

could learn to handle emotions and thoughts, which might be difficult or negative in some situations. You could also learn to handle difficult situations, for example, with regard to your role as a young carer, according to four participants. Through reading the book and doing the exercises the readers could also learn to appreciate themselves and to respect themselves more. Moreover, it was stressed that you could learn that the ill family member is not the only one that matters, but that you and your interests matter as well (P 7). Additionally, the book teaches you to think more deeply about yourself and perhaps in a way you have not thought about yourself before. By getting to know your qualities and talents you can think about yourself more deeply and maybe learn something new about yourself. One participant stressed that you could also learn to take your time to rest.

Table 11. *Overview of the learning effects from the book on the reader*

	nc	np	Quotation translated from Dutch
<b>Learning effect</b>			
Think more about positive things (and less about the negative ones)	11	6	To think more positively. I am always quite negative when something happens, then I think something like 'this is going wrong and this and this'. And when you then also think about successes of the last week, then you can think back more positive. Then you have something positive between the negative things (P 1)
Keep/get calm	7	5	When you think a lot about specific things before going to bed, that you can get more calm through it (P 3)
Handle emotions and thoughts	5	4	And that you can think more clearly again in this moment. And that you know that you are still the same happy person (P 3)
Handling difficult situations	4	4	[...] but I think, if I had this in a period of time when I really did not know how to handle the situation, that this would have helped (P 9)
Appreciate/respect yourself	4	4	Well, that it is not only about the ill children, but also about yourself (P 7)
Thinking about yourself	4	3	In one exercise you had to do your qualities, I think, and then you see what you all have, what you can, which qualities [you have] (P 10)
Take a rest	1	1	To take a rest (P 8)

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

### 3.3 Intention to use and recommend the book

The ten participants who read the second version of the book were asked if they wanted to use the book again. Three of them mentioned that they would like to use the book again, for example, “at a moment in which it is really too much” (P 3). Four participants said that they would like to use some of the exercises in the book, but not the entire book. The last three young carers mentioned that they thought that they would not use the book again. Reasons were that it was enough to use it once, that there were not many noticeable effects on the participant, or that the participant did not feel that much impacted as a young carer. However, it was stressed that the book could nevertheless help other young carers with their situation.

Twelve of the 15 participants of the study would recommend the self-help book to other young carers. Two of them would like to give it to other family members, one to their little brother and one to their mother. Some mentioned that the exercises could help in the situation as a young carer and that “you can feel better” (P 3) after reading the book and “get more positive” (P 13). Furthermore, the young carers would recommend the book because they thought that the reader can learn something by reading the book and doing the exercises. They would argue to other young carers that “you can learn to handle different things” (P 10) or that you can learn something new about yourself and your own life (P 4).

The other two participants would not recommend the book as whole, but only parts of it. The reason for that is that some parts were more attractive than others to them, and so they would only recommend the parts that were personally attractive and helpful to them.

#### 4. Game version

The third research question was about the appreciation of a possible game version as an online self-help intervention. As presented in table 12, the results are divided into three subcategories: (4.1) appreciation of the idea of an online intervention, (4.2) appreciation of the idea of a game version and (4.3) appreciation of the current game version. The last subcategory is further divided into three different aspects: (a) general appreciation of the current game version, (b) appreciation of specific motivational elements from the current game version and (c) suggestions for improvement.

Table 12. *Overview of the categories to answer RQ 3*

<b>RQ 3</b>	<b>4 Game version</b>
	4.1 Appreciation of the idea of an online intervention
	4.2 Appreciation of the idea of a game version
	4.3 Appreciation of the current game version
	<i>General appreciation of the current game version</i>
	<i>Appreciation of specific motivational elements from the current game version</i>
	<i>Suggestions for improvement</i>

##### 4.1 Appreciation of the idea of an online version

The majority liked the idea of presenting the self-help intervention as an online version. According to them, the advantages of an online version would be that it is more accessible as many young people spend much time online. Therefore young people, and also some of the participants, would prefer it to a paper version. Furthermore, it would be available to more people and would be interesting “for people who do not have much time” (P 6). An online

version is, according to some young carers, easier, because you can choose when and to what extent you want to do it. Participant 8 also liked that an online version has more possibilities, such as showing little movies. But even though an online version does have advantages, the component of personal contact was also important to the participants, and should be added in an online intervention, as for example, by means of a chat.

Only one participant would choose a paper version instead of an online version, because he personally prefers having a book, compared to a digital version.

The idea of also presenting the self-help intervention as an app was appreciated positively by most of the participants. As many people and especially young people spend much time on their mobile phones, an app version could make it easier to use the intervention and it could be “useful to get messages [via the app]” (P 4). Three of the 15 participants would prefer a version on the computer or a paper version and have no need of an app version.

#### **4.2 Appreciation of the idea of a game version**

In this paragraph, results are presented of the appreciation of the general idea of presenting the intervention as a game version. It is not about the appreciation of the current game version, presented in screenshots.

In general, the young carers in this study liked the general idea of presenting the content of the self-help intervention in the form of a game. Nearly all participants (13 out of 15) made positive comments about the presentation as a game version. Especially for younger young carers it would be good to present the content in a gaming context, as they usually like games. In addition, the combination of playing and learning was considered to be appealing.

Regarding the question about possible advantages of a game version, compared with a non-gaming version, the participants mentioned four aspects, which are summarized in table 13, presented further down in the paragraph. The first aspect which was mentioned is that a game version would be more attractive. It would be “more laid back” (P 4) and “not so serious” (P 4). It would be furthermore “not so boring [and therefore also] more captivating” (P 2) than a non-gaming version and just “reading, reading and reading” (P 6). A second advantage was, according to the participants, that it would be easier to do the exercises when they are presented in a game version. Arguments for this were that you “do [the exercises] in a playful manner [in a game]” (P 9), that “you want to play through [the game]” (P 1) or because “it is more pleasant” (P 4) to do the exercises in this way. A third advantage was, according to the participants, that it would more effective to do the exercise in such a setting: you don’t have to be as much intensively busy, because “as you sit in an adventure, you do the things more

unconsciously” (P 2) and “keep the things in mind more unconsciously” (P 2). Furthermore, some of the young carers also agreed on the point that it would be easier to understand instructions of an intervention when it would be presented in a game setting, because things could be better described in a game version, by “[using] more animation”, for example (P 6). One participant did not like the idea of a game version, because it does not fit the personal preferences of an intervention. The participant felt too old to do it in a playful manner.

Table 13. *Overview of remarks about the advantages of a game version*

	nc	np	Quotation translated from Dutch
<b>Advantages of a game version</b>			
More attractive	13	11	I think they would think more deeply because everyone like gaming, online games, and if you do it there may be more interest to play it [...] (P 7)
Easier to do the exercises in a game version	8	8	Yes, yes, because you do it in a playful manner (P 9)
More effective	6	5	[...] that you are busy with the content implicitly [...] so that you keep in mind more things implicitly. That you are busy such intensively that it creeps in your mind slowly (P 2)
Easier to understand instructions	3	3	Then you can use more animation, so that [the user] can understand it better (P 6)

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

Although ten participants thought that a game version was in general suitable for young carers, most of them also thought that it was most suitable for younger young carers. Young carers between about 10 and 16 years were the most fitting target group according to them. Other participants not only thought that it was suitable for the younger ones, but they directly said that it was consequently not suitable for the older ones. Most of them were talking about the age group older than 16 or 18. Participant 2 stressed that he thought “that someone who is 16 years old would use such a game [and] that the majority [in this age group] would like to have a book instead of a game”.

Four participants would not play the game, because it does not fit their needs and wishes with regard to an online self-help intervention. Three of them would prefer a version which is not a game version, but a (digital) book version, because according to them a game is more suitable for children. One of them has no need for a self-help intervention in general.

### 4.3 Appreciation of the current game version

The following paragraph answers the question how the participants appreciated the current prototype of the game version. First of all, they were asked about their appreciation of the game version in general, and secondly, we asked them about some specific elements in it.

### *General appreciation of the current game version*

The first version of the game version, which was presented in screenshots, was according to the majority appealing. The participants made both positive and negative remarks about the layout and the comprehensibility of the first version, which are summarized in table 14:

Table 14. *Overview of positive and negative remarks about the current game version*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Layout</b>	15	13	The game is well designed and pretty.	9	6	The game has to be more colourful.
				3	2	Layout too childlike.
				1	1	Missing an appealing start page
				1	1	More noticeable images.
				1	1	Layout is taken from another existing game.
<b>Comprehensibility</b>	13	12	The game is comprehensible.	1	1	Image 5 is not comprehensible.
				1	1	The texts are too long.

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

Regarding the layout of the game, 13 of the 15 participants made comments that the first version was pretty. They appreciated positively that the version really looked like a game (P 1) and that you could see that a lot of energy and time had been put into designing the game (P 2). Positively mentioned was furthermore, that “the idea of keys and islands [is] amusing” (P 7) and that “the degree of it being childlike is good” (P 8). Negative remarks about the layout were that the game had to be more colourful to be more pleasant and appealing. According to two participants, the presentation was too childlike for the older young carers and could be improved with regard to different age groups. It was additionally stressed that it was important to have an appealing and interesting start page to motivate them to play the game. The game should also contain more noticeable images, making it more interesting. Moreover, one participant criticized that the layout had been taken from an already existing game.

Regarding the comprehensibility, the majority mentioned that it was comprehensible. One argument was that you got “good explanations about what you have to do in the game” (P 7). Four participants also pointed out that the layout was clear and contained good elements, such as the menu helping to understand the game.

Screenshot 5 was not clear for one participant. Another negative aspect and suggestion about the comprehensibility was to reduce the amount of text in the game version to make it clearer and more comprehensible.

### *Appreciation of specific motivational elements from the current game version*

The next paragraph is about the appreciation of specific motivational elements in the game version. We asked the participants about their opinion on motivational elements from the PSD model, mentioned in the introduction. The current game version contains motivational elements from the following three principles from the PSD framework: social support, primary task support and dialogue support.

#### **Social support**

Regarding social support, eleven out of the 15 participants mentioned that they would like to have contact with other gamers (**social facilitation**). Participant 1, additionally, stressed that it would be especially helpful “for children who have difficulties looking for support”. The advantage of social support would be to get in contact with people being in a similar situation and experiencing similar things. There would also be the possibility of exchanging experiences, with regard to the intervention, for example, or in general with regard to their caring situations. It would make you attentive to the fact “that there are more children who also have an ill family member” (P 10).

Regarding a medium for getting in contact with other players, more participants preferred a forum than a chat.

#### **Primary task support**

From the dimension of primary task support, the game contains the motivational elements ‘personalization’, ‘self-monitoring’, ‘tunneling’ and ‘rehearsal’. Remarks about these elements are listed in table 15, at the end of this paragraph.

The majority of the participants liked the idea of having a personal account of their own to play the game (**personalization**). The advantage, according to one participant, is that nobody else can play your game. One other participant mentioned positively, that such an account symbolized that the game was about helping you, and not helping someone else. Three participants, however, stressed that there should be an opportunity to use the game in an anonymous way if the user preferred to do so. Two of the participants explicitly wanted to use

such a game in anonymously and one other participant did not want to fill in all data, for example, his personal phone number.

In the game version, there is a list showing the completed levels and exercises with your personal results (**self-monitoring**). The majority of the participants liked this idea, because it gives an overview about what the player has already done and accomplished in the game. It was considered to be positive that the overview offers the possibility of comparing between results, if the exercises are repeated later on. Participant 4 stressed that “you can compare the results and [estimate] ‘Did I make any progress?’, ‘Do I feel more positive?’, ‘Am I able to relax more effectively?’ [...]”. The overview of your results can also offer the opportunity to estimate what you can improve in your life, according to two participants.

The participants appreciated the idea of the islands as steps to do the exercises (**tunneling**) positively. Advantageous would be that the gamer is busy with one exercise and not with different levels and exercises simultaneously. The chronological order makes it “more structured” (P 10). Two participants mentioned that it made you more attentive to the exercises while doing them. Participant 5 said: “Yes that you are able to do the exercises in steps and not to start with the first one and then to jump to the last one. So you can do everything slowly”.

The participants disagreed on the point of being free in choosing and doing the exercises. Seven of the participants mentioned that it was better to have to finish one island before you start another one. Arguments for that were that the intervention “may not help if you deal with the topics in a wrong order” (P 3) and it would not be practical to be busy with more than one level simultaneously. The idea of first finishing one island makes it certain, according to the participants, that you do the exercises in the right order, that you do not miss important exercises and that you are focused on one exercise. Participant 3 stressed that you would not do all exercises, if it was not mandatory to finish the islands one after another. Five other participants, however, would prefer to have the opportunity to choose exercises they want to do and to skip exercises that are not appealing. These five participants agreed that they did not want to do exercises that do not seem to be appealing or helpful for them, while more appealing exercises came right after. Other two participants pointed out that it would be useful to have a combination of finishing one level and choosing exercises. According to participant 6, an opportunity to choose between different exercises in one island would be good.

The participants also described the possibility of repeating exercises as being useful, for example, to have the opportunity to compare the results and to judge if anything has changed since then (**rehearsal**).

Table 15. *Overview of the appreciation of motivational elements (primary task support)*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Primary task support</b>						
<b>Idea of personal account (Personalization)</b>	8	8	Personal account is good in general.	3	3	There should be the opportunity to do it anonymously.
	1	1	Nobody else can use it.	3	2	Wanting to do it anonymously.
	1	1	Symbolizes that it is for helping you.	1	1	Not wanting to fill in all information (phone number).
<b>Idea of list of results (Self-monitoring)</b>	8	7	Good to see what you have already achieved.			
	2	2	Overview of results offers possibility of comparing later on.			
	2	2	Overview over 'good' and 'bad' results offers opportunity to improve some things.			
<b>Idea of steps in the game (Tunneling)</b>	7	6	Good to have an order and not to do more exercises at once.			
	4	4	Idea good in general.			
	2	2	Longer busy and more attentive with one exercise.			
First finishing one island	2	2	Makes sure that you do the exercises in the right order.	7	5	Not wanting to do exercises being personally not appealing (wanting to choose exercises).
	2	2	Makes sure you do not miss an important exercise.			
	2	2	Makes sure that you concentrate on one exercise.			
	1	1	If not mandatory, you will not do all exercises.			
<b>Repeating exercises (Rehearsal)</b>	3	3	Wanting to repeat exercises.			

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

### Dialogue support

From the dimension of dialogue support, the game contains the motivational elements 'reminders', 'rewards' and 'social role'. Moreover, we asked about the motivational element 'liking'. Remarks about these elements are listed in table 16, presented at the end of this paragraph.

With regard to **reminders**, most of the participants would prefer to get messages in the game version as reminders for playing on. Reminders could motivate to play the game and to "stay busy with gaming" (P 3). It could make sure that the young carers do not forget to continue the exercises. One participant stressed that it is practical to get information about new things in the game. Therefore, it could be useful to get the reminders on the mobile phone, according to two participants. But participant 9 stressed that there should not be too many reminders, because "that would be annoying". Two participants would not want to have reminders from the game anyway, because of two different reasons: one participant thought that reminders were personally not necessary and the other participant stressed that it was important that you did it because you were motivated, not because of reminders.

Regarding the ability of a game to motivate a participant to do the exercises (**liking**), eight participants thought that presenting an intervention in a game version motivated more to do the exercises than a non-gaming version. It was mentioned that it was more motivating because you wanted to move on in the game. A second motivator was that you saw the exercises as a game, which made it more fun and playful, and less serious. Doing the exercises in a game setting is more appealing, according to some participants, and you can decide when to do it. The animation in a game makes it easier to understand, according to participant 6, and so it is easier to do the exercises in this setting. Two participants did not think that they would personally be more motivated to do the exercises in a game, because they personally would not prefer a game version anyway.

Nine participants liked the idea of getting a key after finishing a level (**rewards**). It symbolizes and makes it clear that one step has been finished and you can continue. However, the idea is said to be worse if you are forced to do all the exercises in one level to get the key. Two participants liked the idea, but thought that it was only suitable for the younger ones and not for an older age group. One participant did not understand the aim of the keys.

Although the idea of 'the prof' as an expert (**social role**) is "a little bit childlike" (P 4) eight participants were positive about the idea of 'the prof' as fictitious supporting person. They stressed that it was good to get support in understanding the game and the different topics and exercises by the explanations of the professor. This function helps you to understand what you have to do and where to find all the different things, mentioned six participants. It would be "as if there is really someone who helps you" (P 3). Furthermore, would be a good way to get information, according to participant 7.

Table 16. *Overview of the appreciation of motivational elements (dialogue support)*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Dialogue support</b>						
<b>Messages of reminding (reminders)</b>	10	10	It is practical to stay busy with the game.	1	1	Too many reminders would be annoying.
	1	1	Practical to get information about new things in game.	1	1	Personally not necessary.
				1	1	You have to do it from out self-motivation.
<b>Game's ability to motivate (liking)</b>	8	8	Game motivates more to do the exercises.	2	2	Game does not motivate more to do the exercises.
<b>Idea of getting keys (rewards)</b>	7	7	Idea is appealing, in general.	2	2	Only appeals children.
	2	2	Makes it clear that one island has been finished.	1	1	Aim of the key not comprehensible.
<b>Idea of 'the prof' (social role)</b>	6	6	Idea is appealing, in general.	1	1	Only appeals children.
	6	6	Can help to understand the game and tasks in it.	1	1	Personally not appealing.
	1	1	Good for getting information.			

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

### *Suggestions for improvement*

Also with regard to the game version, the participants suggested making two versions, one version for the younger, and one version for the older ones. The current version could serve as the version for the children. The version for the older young carers could be an online version with a layout resembling a book version. Both versions should contain more colours and look friendlier and more positive, to fit the intent of making the users feel more positive.

The young carers also made some suggestions about explanations in the game: participant 8 suggested using short videos to introduce and explain the topics. That would be easier to understand. Another suggestion was that you do not have to click on an icon for explanations, but that it comes automatically, especially at the beginning of the game and each chapter.

Participant 2 further suggested using another name for the “islands”, because the areas in the game would not really look like islands. Besides, they would like to have information about possibilities for contacting someone if there were problems or questions.

One last suggestion for improving the game version is based on the idea of the keys you can earn during the game. Participant 7 suggested that there should be some kind of lock at the end where the gamer has to put in all the keys earned and behind the door there appears some kind of certificate to show that the gamer has reached the end of the game.

## Discussion

This study allowed gaining a first insight into the appreciation of exercises from the field of positive psychology and their presentation as a game version by young carers. From a practical point of view, the results and insights of this study can serve as a basis for the design process of an appropriate self-help intervention for young carers. The study focussed on the young carers' opinion about their wishes, needs and interests with regard to such an intervention. Thus the results of this study and further similar studies could help designing a self-help intervention which is as appropriate as possible for young carers.

From a scientific viewpoint, the study allowed gaining insight into the practicability of using the theoretical PSD model for gamification and motivation of intended users.

### **Young carers in this study and their characteristics**

It is important to have a concrete idea of how the young people in this study are impacted by their situation and role as a young carer. Getting to know the user group is essential to design an appropriate intervention for the target group later on (Orji & Mandryk, 2014). The group of young carers in this study is only a small group of representatives of a large population. It is necessary to get an idea of their personal characteristics for having an idea for which types of young carers the results are valid.

In line with previous researches, as the one from Aldridge and Becker (1993), the young carers in this study mostly take domestic tasks and some personal tasks at home. With regard to the impact on the young carers' lives, Joseph et al. (2008), Warren (2007) and Hamilton and Adamson (2013) point out that it can differ with regard to the age of the young carer and the availability of support sources and resources. In this study, both being older and having external support, also appeared to be factors that caused the impact to be less. Generally, most of the young carers in this study rated themselves as being not much impacted by the situation. Some felt not much impacted at all, others felt not impacted by the current situation anymore, after some years of being a carer and some others though do not feel impacted by the situation yet.

Even though the young carers rated themselves as being mostly lightly impacted, it appeared that the young carers have to do tasks that most people their age do not have to do, regarding both the type of tasks and the amount of tasks. In the case of some young carers in this study we could talk about some kind of 'parentification', as Ali et al. (2012) described it, because they have to take over tasks and responsibilities in a young age already, such as looking after the ill parent or sibling or go shopping, to relieve the parent(s). And although the impacts on

their lives are relatively small, it was recognizable that being a young carer is a stressor for the lives of young people. They reported consequences regarding different aspects, such as their home situation, relation to the ill family member or social life.

### **Need for support**

The young carers in this study stressed the importance of getting support in their caring role. They appreciated such an intervention as being especially important and helpful in the starting phase of being a young carer and said in line with Metzging-Blau and Schnepp (2008) that it is important to get support early. You can learn to handle the situation on your own, but it would be easier and better to have such an intervention, especially for young carers being highly burdened by the family situation. In line with previous studies (Cooklin, 2006; Weijkamp, 2015; Ali et al., 2014), the young carers want to have support in understanding and handling the situation, want to have information and want to do exercises. With regard to information, they preferred information both about the illnesses and their consequences and also about how to deal with the caring situation.

The current intervention appeared to be suitable for the elements of getting support in their situation as a young carer and for doing exercises, but it misses the element of giving information. When designing such an intervention, therefore this missing element of information about illnesses and consequences should be added.

### **Appreciation of the book with exercises and texts**

The basis of both, texts and exercises of the intervention book, were elements from positive psychology: positive emotions, use of talents, optimism, self-compassion, resistance and positive relations. All these elements and their intentions were appreciated as being important and appealing, in general or even especially for young carers. The young carers in this study saw the need to focus on the positive things and to get more positive in life. Their opinion corresponds with what Joseph et al. (2008) emphasize: that young carers should focus on the positive things in their life instead of focussing on the negative aspects of their caring role.

It can be concluded, that the positive character of the intervention is suitable for the group of participants in this study and might even be capable for the whole population of young carers. Therefore it is recommended that future interventions for young carers should use positive psychology topics and elements.

In line with that, the young carers appreciated the learning effects you can have by reading the book and doing the exercises from positive psychology. They praised the general supportive

ability of the book in learning how to think more about the positive things in life, keeping or getting calm and handling difficult situations or emotions and thoughts.

Schotanus-Dijkstra et al. (2015) stress that the exercises from the positive psychology can be done easily in daily life and are suitable for a self-help intervention. The young carers in this study appreciated as well that the exercises are not very time-consuming and are easily to embed in daily life. With regard to the usage and appreciation of the different exercises, it seems that one type of exercises was preferred: exercises which can be done relatively easily, without much recapitulation of past events or thoughts, and which give a clear result. Examples were two exercises in which the participants had to fill in things about themselves in the style of a questionnaire. Exercises which required more effort at intellectual capacity or creativity were appreciated less positively, such as keeping a diary about positive things of the last days or thinking about yourself from a different perspective. It could be concluded that an intervention thus should contain predominantly short exercises. In line with that Schueller (2010) stresses, that participants are more likely to do preferable exercises. But, there are also reasons against only integrating short exercises: firstly, the different exercises from the book are proven to be effective as a self-help intervention (Schotanus-Dijkstra et al., 2015). Sin and Lyubomirsky (2009) further stress, that it is more effective, when participants are engaged in different positive activities. In line with that the different exercises in the book are based on different topics of positive psychology and for having an effective self-help intervention it might be important to do at least one exercise from each topic. It is therefore recommended to not only integrate the preferable exercises, which are short and require less effort, but also the exercises which are more time-consuming and require more effort.

The task here then is to motivate the participants to do the exercises. To present the intervention as a game, what is discussed later on, could be one first step to make even the longer and taxing exercises more interesting. In a game version, an especially in an app version, it is easier to split longer exercises and remind participants to do them daily. The participants then do not have to remind themselves to do the exercises, and the exercises then appears to require less effort.

With regard to the suitability of the book with texts and exercises, the participants mentioned that it is suitable for young carers in general. In that respect, one important point was that the book directly addresses the target group, as it is about helping the young carer and not the ill family member. Thomas et al. (2003) also stress how important it is to have individual support for the carers, to respect their own needs. According to the participants, the book further contained many typical elements of being a young carer, and together with their

own experiences that the book helped them personally and their belief about the general supportive ability of the book, it can be concluded that the young carers are convinced that the book is appealing for the target group and a suitable supportive intervention.

It should be mentioned here that the young carers stressed that you had to pay attention to the different age levels in the target group. According to them, one idea is to design two different versions for two different age groups, for example from twelve to 16 years, and from 16 to 21. It was noticeable that the older young carers often mentioned that they were not sure if the younger ones would have understood all texts and exercises. Most of the younger young carers themselves, however, did not mention many problems with understanding. The older ones seemed to have a biased view on the intellectual capacities of young adolescents.

### **Appreciation of the game version**

Corresponding with Ali et al. (2014) the young carers mentioned that the advantage of a game was that it was more easily accessible and less time-consuming. They also appreciated what Theng et al. (2015) have already stressed: presenting an intervention as a game has the advantage that tasks and exercises feel more like a game and is less serious than a non-game intervention. It appeared that the participants' expectations of the advantages of a game version were fulfilled by the first version, presented in this study. Firstly, it was appreciated as being more interesting and pleasant. Secondly, the results verified that some of the young carers felt motivated by that playful manner, corresponding with what could have been expected from the research of Theng et al. (2015). This study verified the findings of Baranowski and Frankel (2012) that children and young carers do not only use electronic media often, but even prefer them. The last point was, however, not valid for the older young carers in this study: they preferred an online version resembling a paper version. Parallel to the conclusion of the book version, one idea would be to make two different versions for the online intervention: one game version and one online version without gaming elements. But beforehand, it would be interesting to examine if the older participants maintain their preference, if they would have the possibility of really playing the game, instead of only having a look at screenshots.

Regardless of their own personal preferences, the young carers appreciated the motivational elements of the game as motivating. The elements of self-monitoring, personalization, social role, rewards, reminders and social facilitation were appreciated mostly positively. These elements would make it more playful, interesting and informative, and therefore motivating. The elements of tunnelling and liking should be mentioned separately.

The element of tunnelling was appreciated generally positively, because it would give a structure, but the participants disagreed on the point of being able to choose exercises. In line with the results that some exercises are less appropriate than others, about half of the participants would like to choose exercises. The other half saw an advantage of having to do all exercises. One solution would be to offer the possibility of choosing between different exercises per level in the game, but that it is mandatory to do at least one per level, so that every topic comes up. In line with that Schueller and Parks (2012) stress that participants are more likely to use exercises, when there is a variety of options.

With regard to the element of liking, it is worth mentioning that not all young carers said that presenting a game would motivate more to do the exercises. The young carers who would not like to have a game version anyway, were also less convinced that a game version would motivate them to do the exercises. This corresponds with the fact that a pretty design alone is not enough to convince users to use an intervention (Whitten et al., 2008) and that it is important to include the intended users with their interests in the final product in the design process (Orji & Mandryk, 2014).

From this it can be concluded that presenting the intervention as a game version is a suitable method to make the intervention more interesting and motivating, but that there should be the consideration of a second version without game elements.

### **Own need for usage**

A large part of the participants in this study would like to use the final intervention and appreciated the current version as suitable and appealing. They saw the need of such a supportive intervention and would like to consider whether it can help them personally in their role as a young carer, although they personally do not feel much impacted.

It is interesting that the young carers in this study first stressed that they do not have much need for getting support, because of feeling not much impacted, but it appeared that the intervention appeals to them in such an extent, that they would like to use it for getting support in their daily life. One explanation, that they, nevertheless, appreciate the intervention that positively and would use it, is that the intervention has a low threshold. They mentioned the advantage that it did not require much effort to do some exercises in daily life in order to feel better. This corresponds with several studies showing that the threshold to use an anonymous online intervention is lower than, for example, searching for professional support (van Rooijen et al., 2014).

But although almost all participants appreciated the idea of such an intervention as important for young carers and the realization offered in this study as appealing, one third of the young carers, nevertheless, personally do not have the need to use it and four other participants would only use some of the exercises, but not the whole intervention. A first explanation might be that because most of the young carers in this study would describe themselves as being not impacted much, they do not see the need for such an intervention. In line with that, it was mentioned that they would use some exercises if they had more problems, or if they felt more impacted. Another explanation might be that most of the participants stressed that they were not much impacted anymore, because of the duration of their caring situation and because they had learned by themselves to handle it.

What it comes down to in both cases is that some young carers seemed to think that such an intervention is only necessary when young carers are in the starting phase of their role as a young carer, are highly impacted and have got problems with their caring situation. However, positive psychology is not only about improving mental health or reducing depression symptoms, but it is also about maintaining mental health (Sin & Lyumbomirsky, 2009). Interventions focussing on positive psychology also focus on coping with the normal stressors in life (Westerhof & Keyes, 2008) and on overall life satisfaction (Shogren et al., 2006). According to Seligman (2002), human strengths such as optimism, hope, the capacity for flow and insight or interpersonal skills, can function as buffers against mental illness. Based on the emphasis of Marques et al. (2011) that such interventions can be protective for young people experiencing stressful events, it should also be stressed in a new intervention that it is not only about reducing problems, but also about preventing problems. It should be stressed that it is important to learn to cope with stressors early to prevent problems. Patel, Flisher, Hetrick & McGorry (2007) also stressed in this emphasis that most mental disorders begin at the age between 12 and 24, but are often detected later in life. Thus, although the young carers might not feel that they are troubled now and do not feel as if they were impacted by the situation, this does not mean that they will not develop mental problems later on.

From this it can be concluded that there is the need to emphasize that the final intervention which is planned, is not per se offered as an intervention to reduce (psychological) problems, but as some kind of skills training to learn to focus on the positive things in life.

The tasks for offering a new intervention for young carers and the marketing of it should further be: first of all it has to be stressed that it is not about reducing existing problems, but it can generally help in the situation as a young carer. Although the young carer might feel lightly impacted, it can help in daily life to be more satisfied, to reach goals in life and to be

happier. It should be stressed that on the basis of the evaluation in this study, it can be assumed that they would also appreciate the intervention as suitable for young carers.

The low threshold of such interventions should be emphasized. The first step to do this is already done by presenting the intervention in a game version. A second step should be to find another motivator for the young carers, who would prefer a non-gaming version. Secondly, it should be considered where and when the intervention should be offered. It appears that it is necessary to reach young carers early in their caring situation, because the need for such an intervention seems to be the highest at that point. One possibility could be to integrate the doctors or clinics that diagnose and treat the ill family member. That would offer the possibility of reaching the young carers early in their starting phase of being a young carer. Furthermore, family doctors and schools can be integrated to inform about the existence of such an intervention and to emphasize the suitability for the target group of young carers.

### **Strengths and limitations**

The qualitative research design of face-to-face interviews makes it possible to gain information of the evaluation of the intervention. Additionally, it offers the possibility of examining why the intended users do or do not like the intervention. The study design in this study allowed asking more thoroughly for explanations about the young carers' opinions and evaluations about the intervention, allowed talking openly in the face-to-face interviews and asking for examples.

Worth mentioning is further the idea of integrating the representatives in the evaluation phase of designing an intervention. If the representatives would have been integrated earlier in the planning and design process, without having an existing intervention as a basis, and if the intervention was based solely on their own preferences, they surely would not have suggested using elements of positive psychology. But it appeared that just this positive character of the intervention was appreciated positively and as being important for young carers. Further, another gain is that some of the young carers in this study recognized the advantage of such an intervention and their own need to use it just after reading this current intervention book, although they stressed beforehand that they do not have much need for such an intervention.

The study also has some limitations. First of all, one limitation is, that it is not possible to estimate to what extent the results of the study are representative for the whole group of young carers. The first problem here is that almost all participants mentioned that they did not feel much impacted with regard to their caring role. The literature however shows that there are also young carers who feel more or even highly impacted. It would have been useful to

also take interviews with representativeness of this group of young carers. A second problem with the representativeness of the results is that some participants already knew some exercises and had already participated in courses for young carers. It would have been useful to take interviews with young carers having no experiences with supportive courses. That could be very difficult, because these representatives often do not identify with being young carers and belong to the 'hidden' population.

Another limitation of the study is that the young carers were asked about their opinion on the topics and exercises in a book version, whereas the aim of the study is to design an online version. First of all, the participants were sometimes confused whether the final version was a book, online or game version. Secondly, it can be assumed that an evaluation of a book version differs from an evaluation of an online version, and even more from a real game version. The game version here was presented as screenshots. It can be assumed that the evaluation of the game version would have been different when there was the opportunity to really play the game. It would have been optimal when the young carers had been able to play a test version of the intervention game.

Thirdly, the study has got limitations in the interviews. First of all, some participants could not remember all the context of the book and were not able to reproduce all their opinions and thoughts during the interviews. Originally, the time period between getting the book and the interview was slated for two weeks. Regarding the organization and time preferences of the participants, the duration was sometimes much longer. The duration of the interviews was not ideal, either: on the one hand, the time was too short to ask deeper questions and on the other hand, it was not really possible to make the duration of the interviews much longer with regard to the participants' opportunities and abilities to concentrate.

Finally, the coding and the analysis of the study were done by solely one researcher. To reach a higher level of quality of the results and the study in general it would have been useful to increase the inter-rater reliability by involving more researchers in analysing and discussing codes and fragments (Boeije, 2008).

### **Future research**

To further examine information about the needs and wishes of young carers with regard to an online self-help intervention and to optimize the basis for designing such an intervention, extended research is needed. It would be interesting to examine, if there are differences regarding the appreciation and need of an intervention between young carers who said they were not highly burdened in their caring role and young carers who see themselves as highly

influenced. Moreover, in this way we would be able to analyse the opinion of a larger and broader sample size of the target group, which would increase the representation of the results for the whole group of young carers. If the results of this study are found again, the internal validity, or in other words, the extent of representing the reality, increases (Merriam, 1995).

Another point of interest would be to investigate differences with regard to the appreciation and need of an intervention between young carers caring for a parent and those caring for a sibling. Furthermore, it would be interesting to examine what impact the duration of being a carer has on the appreciation and need of a self help intervention.

Additionally, it is recommended to add quantitative research to increase the reliability and validity of the results (Boeije, 2008). For example, it would be useful to make a test run of the game version under young carers, to examine the extent of usage and to test the effectiveness of the intervention. One method of examination is the use of log data: log data is a useful method to provide the creators of an intervention with objective, real-time information about the usage of the intervention and how the intervention works in practice (van Gemert-Pijnen, Kelders & Bohlmeijer, 2014). It is a communication tool between the server side and user side. You can gain insight into the interaction between system and user: for example, when the system is used, to what extent it is used and what actions are carried out during usage (van Gemert-Pijnen, Kelders & Bohlmeijer, 2014). It would be useful to collect log data about which exercises are carried out in the test run and to what extent, which exercises are skipped, and to what extent the participants are busy with the different chapters. Further, by recording the results of specific exercises at different point of times from the players separately, their development can be assessed: for example, if they report more positive things in life, report more positive feelings, have a higher score at positive emotions, et cetera. All this would give an image of the preferences of the gamers, if it works as intended, and the motivational ability of the intervention. In short, it would give information about the effectiveness of the intervention. On the basis of this data, then improvements can be made.

## **Conclusion**

It seems useful to design an online intervention for young carers, containing elements and exercises from the field of positive psychology. The young carers in this study noticed the possible benefits, advantages and effects of such an intervention. Effective elements were, for example, learning to think about the positive things in life instead of focussing on the negative ones or learning how to handle difficult situations. Furthermore, it seems to be practical to conduct a game version of the intervention, to make it more interesting and motivating.

However, one idea could be to offer a second non gaming version: the current study showed that some participants preferred having two different versions for two different age groups. Finally, it should be stressed that the intervention is not per se developed for reducing (psychological) problems, but as a skills training in daily life, to get more positive in life, to handle more or less difficult situations in life and to be happier. So it is not only useful for young carers who are highly impacted and having problems, but it is also useful in general for feeling better.

## References

- Aldridge, J. & Becker, S. (1993). *Children who care – inside the world of young carers*. Leicester: Department of Social Sciences, Loughborough University.
- Ali, L., Krevers, B., Sjöström, N. & Skärsäter, I. (2014). Effectiveness of web-based versus folder support interventions for young informal carers of persons with mental illness: A randomized controlled trial. *Patient Education and Counseling* 94, 362-371
- Ali, L., Krevers, B., Sjöström, N. & Skärsäter, I. (2012). Daily life for young adults who care for a person with mental illness: a qualitative study. *Journal of Psychiatric and Mental Health Nursing* 19, 610–617
- Baranowski, T. & Frankel, L. (2012). Let's get technical! Gaming and technology for weight control and health promotion in children. *Childhood obesity* 8(1), 34-37
- Becker S. (2007). Global perspectives on children's unpaid caregiving in the family: research and policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy* 7, 23–50
- Beerlage-de Jong, N., Eikelenboom-Boskamp, A., Voss, A., Sanderman, R. & van Gemert-Pijnen, L. (2014). Combining User-Centered Design with the Persuasive Systems Design Model; The Development Process of a Web-Based Registration and Monitoring System for Healthcare-Associated Infections in Nursing Homes. *International Journal on Advances in Life Sciences* 6
- Bijzonderebroerofzus. (2016, February 9). Retrieved from <http://bijzonderebroerofzus.nl/site/brusjes/Home/>
- Boeije, H. (2008). *Analyseren in kwalitatief onderzoek*. Den Haag: Boom/Lemma.
- Bohlmeijer, E.T. & Hulsbergen, M.L. (2013). *Dit is jouw leven*. Amsterdam: Boom

- Bolier, L., Haverman, M., Westerhof, G.J., Riper, H., Smit, F. & Bohlmeijer, E. (2013). Positive psychology interventions: a meta-analysis of randomized controlled studies. *BioMed Central Public Health* 13
- Cooklin, A. (2006). Children as carers of parents with mental illness. *Psychiatry* 5, 32-35
- Cree, V.E. (2003). Worries and problems of young carers: issues for mental health. *Child and Family Social Work* 8, 301-309
- De Veer, A.J.E. & Francke, A.L. (2008). Opgroei met zorg. Quick scan naar de aard en omvang van zorg, belasting en ondersteuningsmogelijkheden voor jonge mantelzorgers. *NIVEL Utrecht*. Retrieved from <http://www.nivel.nl/sites/default/files/bestanden/Rapport-Quick-scan-aard-en-omvang-zorg-jonge-mantelzorgers.pdf>
- Drankjewel. (2016, February 9). Retrieved from <http://www.drankjewel.nl/>
- Hamilton, M.G. & Adamson, E. (2013). Bounded agency in young carers' lifecourse-stage Domains and transitions. *Journal of youth studies* 16, 101-117
- Jenkins, S. & Wingate, C. (1994). Who cares for young carers? Their invisibility is the first problem to be addressed. *British Medical Journal* 308, 733-734
- Jokela, T., Iivari, N., Matero, J. & Karukka, M. (2003). The Standard of User-Centered Design and the Standard Definition of Usability: Analyzing ISO 13407 against ISO 9241-11. *Proceedings of the Latin American conference on Human-computer interaction*, 53-60
- Joseph, S., Becker, S., Becker, F. & Regel, S. (2008). Assessment of caring and its effects in young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child: Care, Health and Development* 35, 510-520

- Kavanaugh, M.S. (2014). Children and adolescents providing care to a parent with Huntington's disease: disease Symptoms, caregiving tasks and young carer well-being. *Child and Youth Care Forum* 43 (6), 675-690
- Kelders, S.M., Kok, R.N., Ossebaard, H.C. & van Gemert-Pijnen, J.E.W.C. (2012). Persuasive system design does matter: a systematic review of adherence to web-based interventions. *Journal of medical internet research* 14(6)
- Kennan, D., Fives, A. & Canavan, J. (2012). Accessing a hard to reach population: reflections on research with young carers in Ireland. *Child and Family Social Work* 17, 275-283
- King, D., Greaves, F., Exeter, C. & Darzi, A. (2013). 'Gamification': Influencing health Behaviours with games. *Journal of the royal society of medicine* 106(3), 76-78
- Lehto, T. & Oinas-Kukkonen, H. (2011). Persuasive features in web-based alcohol and smoking interventions: A Systematic Review of the Literature. *Journal of medical internet research*, 13
- Ludden, G.D.S., Kelders, S.M. & Snippert, B.H.J. (2014). 'This is your life!' The design of Positive psychology intervention using metaphor to motivate. *Persuasive Technology* 8462, 179-190
- Lyon, A.R. & Koerner, K. (2016). User-centered design for psychosocial intervention development and implementation. *Clinical psychology: science and practice* 23(2), 180-200
- Marques, S.C., Pais-Ribeiro, J.L. & Lopez, S.J. (2011). The role of positive psychology constructs in predicting mental health and academic achievement in children and adolescents: a two-year longitudinal study. *Journal of Happiness Studies* 12(6), 1049-1062
- Merriam, S.B.M. (1995). What Can You Tell From An N of 1?: Issues of validity and reliability in qualitative research. *PAACE journal of lifelong learning*, 4, 51-60

- Metzing-Blau, S. & Schnepp, W. (2008). Young carers in Germany: to live on as normal as possible- grounded theory study. *BMC Nursing* 7(15)
- Moore, T. & McArthur, M. (2007). We're all in it together: supporting young carers and their families in Australia. *Health & Social Care in the Community* 15(6), 561-568
- Oinas-Kukkonen, H. & Harjumaa, M. (2009). Persuasive systems design: Key issues, process model, and system features. *Communications of the Association for Information System*, 24
- Orji, R., Vassileva, J. & Mandryk, R.L. (2014). Modeling the efficacy of persuasive strategies for different gamer types in serious games for health. *User Modeling and User-Adapted Interaction* 24(5), 453-498
- Pakenham, K.I., Chiu, J., Bursnall, S. & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology* 12(1), 89-102
- Patel, V., Flisher, A.J., Hetrick, S. & McGorry, P. (2007). Mental health of young people: a global public-health challenge. *The Lancet* 369, 1302-1313
- Schotanus-Dijkstra, M., Drossaert, C.H., Pieterse, M.E., Walburg, J.A. & Bohlmeijer, E.T. (2015). Efficacy of a Multicomponent Positive Psychology Self-Help Intervention: Study Protocol of a Randomized Controlled Trial. *JMIR Research Protocols* 4 (3)
- Schueller, S.M. (2010). Preferences for positive psychology exercises. *The Journal of Positive Psychology* 5(3), 192-203
- Schueller, S.M. & Parks, .C. (2012). Disseminating self-help: positive psychology exercises in an online trial. *Journal of medical internet research* 14(3)
- Seligman, M.E.P. (2002) Positive psychology, positive prevention, and positive therapy. In C.R. Synder & S.J. Lopez (Eds.), *Handbook of positive psychology* (pp. 3-12). New York: Oxford University Press.

- Seligman, M.E.P. & Csikszentmihalyi, M. (2000). Positive Psychology: An introduction. *American Psychologist* 55(1), 5-14
- Shogren, K.A., Lopez, S.J., Wehmeyer, M.L., Little, T.D. & Pressgrove, C.L. (2006). The role of positive psychology constructs in predicting life satisfaction in adolescents with and without cognitive disabilities: an exploratory study. *The Journal of Positive Psychology* 1(1), 37-52
- Sin, N.L. & Lyubomirsky, S. (2009). Enhancing well-being and alleviating depressive symptoms with Positive psychology interventions: a practice-friendly meta-analysis. *Journal of clinical psychology: in session* 65(5), 467-487
- SurvivalKid. (2016, February 8). Retrieved from <https://www.survivalkid.nl/>
- Theng, Y.-L., Lee, W.Y.L., Patinadan, P.V. & Schubert, S.B.F. (2015). The use of videogames, gamification, and virtual environments in the self-management of diabetes: a systematic review of evidence. *Games for Health Journal* 4(5), 352-361
- Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire, S. & Webb, A. (2003). 'Your friends don't understand': Invisibility and unmet need in the lives of 'young carers. *Child and Family Social Work* 8, 35-46
- Torning, K., Oinas-Kukkonen, H. (2009). Persuasive system design: state of art and future directions. *Proceedings of the fourth international conference on persuasive technology, ACM international conference proceeding series* 350
- Van Erp, N., Place, C. & Michon, H. (2009). Familie in de langdurige GGz deel 1: Interventies. *Trimbos instituut*. Retrieved from <https://assets.trimbos.nl/docs/412cc38d-e6c1-47bb-b0b7-7cca6ea4b02d.pdf>
- Van Gemert-Pijnen, J.E.W.C., Kelders, S.M. & Bohlmeijer, E.T. (2014). Understanding the Usage of Content in a Mental Health Intervention Depression: An Analysis of Log Data. *Journal of Medical Internet Research*, 16 (1)

- Van Rooijen, K., Zwikker, N. & van der Vliet, E. (2014). Wat werkt bij online hulpverlening? *Nederlands jeugd instituut*. Retrieved from [http://www.nji.nl/nl/Download-NJi/Wat-werkt-publicatie/Wat\\_werkt\\_Online\\_hulp.pdf](http://www.nji.nl/nl/Download-NJi/Wat-werkt-publicatie/Wat_werkt_Online_hulp.pdf)
- Warren, J. (2007). Young Carers: Conventional or Exaggerated Levels of Involvement in Domestic and Caring Tasks? *Children & Society* 21, 136-146
- Weijkamp, E.W. (2015). Online steun voor jonge mantelzorgers: Wensen- en behoeften van jongeren voor een online zelfhulpprogramma. (Bachelor thesis, University of Twente, Enschede) Retrieved from <http://essay.utwente.nl/68576/>
- Westerhof, G.J., & Keyes, C.L.M. (2008). Geestelijke gezondheid is meer dan de afwezigheid van geestelijke ziekte. *Maandblad Geestelijke Volksgezondheid*, 63, 808-820
- Whitten, P., Smith, S., Munday, S. & LaPlante, C. (2008). Communication assessment of the most frequented breast cancer websites: evaluation of design and theoretical criteria. *Journal of Computer-Mediated Communication*, 13

# Appendix

## Appendix 1 – Tables and images from the text

Table 1. *Overview of the chapters with topics and exercises (translated from Dutch)*

Chapter	Topic	Exercises		
1	<b>“High time for pleasure”</b>	<b>Positive emotions:</b> the importance of pleasant emotions and recognizing them in daily life.	“Three good things”	(Daily diary of positive experiences of the day)
			“How many pleasant emotions do you have?”	(Questionnaire about the experience of pleasant emotions in the last 24 hours)
2	<b>“Show your talents”</b>	<b>Use of talents:</b> getting to know one’s talents and qualities, and thereby getting a better image of yourself.	“Your qualities”	(Questionnaire about one’s qualities which should be filled in by the participant and a second person)
3	<b>“A different perspective on yourself”</b>	<b>Flow:</b> looking at oneself from another, less critical, perspective. Searching for positive aspects and pleasure in daily activities.	“Change ‘having to do’ into ‘wanting to do’”	(Summarizing of unpleasant activities and trying to find pleasure or motivation in it)
4	<b>“The glass is always half full”</b>	<b>Optimism:</b> learning to think more positive instead of negative and trying to get more optimistic.	“Keep a diary”	(Diary of negative situations in three steps: situation, thoughts and emotions; learning to examine if negative thoughts are realistic)
5	<b>“Be kind to yourself”</b>	<b>Self-compassion:</b> being more kind and sympathetic to yourself and appreciate yourself. Being less critical.	“Bring back being kind to yourself”	(Writing down situations of the last week when you were kind to yourself or others)
			“Be your best friend”	(Trying to look at a negative situation from the perspective of a good friend)
6	<b>“I am not the same anymore”</b>	<b>Resistance:</b> handling difficult situations. Getting to know your own way of dealing with problems, situations and emotions and learning to improve it.	“How do I handle difficult situations?”	(Questionnaire about one’s ways to handle difficult situations + trying to change negative ways)
7	<b>“Share your positive life”</b>	<b>Positive relations:</b> building up or improving relationships to others and being grateful.	“Express your gratitude”	(Expressing gratitude to another person, e.g. by writing a letter)
8	<b>“Relax”</b>	<b>Body image and relaxation:</b> learning to relax and being connected to yourself and your body.	“Abdominal breathing”	(Relaxing through learning how to breathe abdominal)
			“Muscle relaxation”	(Relaxing through tensing and relaxing muscles)
			“Egg-exercise”	(Relaxing through trying to imagine that an egg protects against negative influences)

Table 2. *Overview of motivational elements in the game version*

Principle according to PSD framework	Element in game version
<b>Primary task support</b>	
Tunneling	Delivering the content in a step-by-step format with a predefined order by presenting the chapters as islands.
Personalization	The user of the intervention gets his own personal account for logging in and playing the game.
Self-monitoring	The game contains a list in which the user can see which levels (islands) he has already completed.
<b>Dialogue support</b>	
Rewards	The user gets a key when he has finished a level (island).
Reminders	The user can get reminders about levels/exercises which have not been finished yet or new elements, for example.
Liking	Asking the possible users for feedback on the design.
Social role	The game contains an avatar representing a professor who guides the user through the interventions by giving information and instructions.
<b>Social support</b>	
Social facilitation	The game might contain a group forum or chat room for the users.

Table 3. *Characteristics of the participants (N=15)*

Characteristics	n	%
<b>Gender</b>		
Male	4	26.7
Female	11	73.3
<b>Age</b>		
Mean (SD)	15.5 (2.1)	
Range in years	12-19	
<b>Living situation</b>		
Parents	13	86.7
One parent	2	13.3
<b>Education</b>		
Medium	10	66.7
High	5	33.3
<b>Number of ill family members</b>		
One	13	86.7
Two	2	13.3

Table 4. *Characteristics of the ill family member (N=17)*

Characteristics	n	%
<b>Person affected</b>		
Father	2	11.8
Mother	2	11.8
Brother	6	35.3
Sister	3	17.6
Sister + Father	1	5.9
Sister + Mother	1	5.9
<b>Type of disease</b>		
Autism	7	41.2
ADHD	2	11.8
Kidney disorder	2	11.8
Alzheimer's disease	1	5.9
Heart attacks	1	5.9
Down's syndrome	1	5.9
Multiple sclerosis	1	5.9
Rheumatism	1	5.9
Burnout	1	5.9
Oppositional Defiant Disorder	1	5.9
Mental handicap	1	5.9
Manic-depressive	1	5.9
<b>When diagnosed</b>		
3-6 months	2	11.8
1-5 years	5	29.4
>5 years	10	58.8

Table 5. *Overview of the categories to answer RQ 1*

RQ 1	2 Impact of the role as a young carer and need for support
	<i>Caring activities</i>
	<i>Impact on their lives</i>
	<i>Need for support</i>

Table 6. *Overview of the categories to answer RQ 2*

RQ 2	4	Current intervention book
	4.1	Use and appreciation of the current intervention <i>Use of the book</i> <i>General appreciation of the book</i> <i>Appreciation of specific elements in the book</i> <i>Suggestions for improvement</i>
	4.2	Impact of the book on the reader and learning experiences
	3.3	Intention to use and recommend the book

Table 7. *Extent of reading the book*

	Read completely		Read partly	
	N	%	N	%
Book read	14	93.3	1	6.7
C1 read	15	100	-	-
C2 read	14	93.3	1	6.7
C3 read	14	93.3	1	6.7
C4 read	13	86.7	1	6.7
C5 read	14	93.3	-	-
C6 read	14	93.3	1	6.7
C7 read	15	100	-	-
C8 read	13	86.7	1	6.7
Screenshots	15	100	-	-

Table 8. *Extent of reading and doing the exercises (translated from Dutch)*

Chapter	Exercise	N	Read		Done	
			N	%	N	%
1	"Three good things"	10	10	100	4	<b>40</b>
	"How many pleasant emotions do you have? "	10	10	100	9	90
2	"Your qualities"	15	15	100	11	73.3
3	"Change 'having to do' into 'wanting to do'"	15	15	100	10	66.7
4	"Keep a diary"	15	14	93.3	5	<b>33.3</b>
5	"Bring back being kind to yourself"	15	14	93.3	5	<b>33.3</b>
	"Be your best friend"	10	10	100	1	<b>10</b>
6	"How do I handle difficult situations?"	10	10	100	8	80
7	"Express your gratitude"	15	15	100	7	<b>46.7</b>
8	"Abdominal breathing"	10	9	90	5	50
	"Muscle relaxation"	10	9	90	2	<b>20</b>
	"Egg-exercise"	10	9	90	3	<b>30</b>

Table 9. *Overview of positive and negative remarks about the book*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Suitability</b>						
Book in general	15	15	Suitable for helping young carers in general.			
	1	1	Content is similar to other courses for young carers.			
Addressing target group	3	3	The book directly addresses the target group of young carers and their needs.			
	3	3	Book describes typical elements of the situation of young carers.			
Regarding age group				1	1	Book is too childlike.
				1	1	Book is sometimes too difficult for children.
<b>Comprehensibility</b>						
Book in general	15	14	In general well explained.	7	5	Sometimes not fully comprehensible.
Regarding age group				5	5	Too difficult for children.
Exercises				4	4	Some exercises difficult to understand.
<b>Attractiveness</b>						
Choice of words	9	8	Choice of words suitable.	5	4	Choice of words too childlike.
				3	3	Choice of words too difficult for children.
				2	2	Words sometimes difficult.
Presentation of the book/layout	6	3	The layout is appealing.	4	2	Layout could be friendlier and more colourful.
Texts	2	2	The content of the texts is good.	2	2	Some spelling mistakes.
	2	2	Structure of the texts is good.	1	1	Texts are sometimes boring.
				1	1	Too much text.

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

Table 10. *Overview of the appreciation of the different chapters*

		Positive appreciation		Negative appreciation	
	np	Content of appreciation	np	Content of appreciation	
<b>Chapter 1: Positive emotions</b>					
Exercise 1 "Three good things"	4	Good to learn how to think more about positive things in life.	8	Exercise is personally not appealing (not wanting to do it daily; too difficult)	
Exercise 2 "How many pleasant emotions do you have?"	10	The exercise is good/important/personally appealing.			
		Exercise can be done easily and fast and you get a score as result.	1	Not wanting to get a score.	
<b>Chapter 2: Use of talents</b>					
Exercise "Your qualities"	11	The exercise is good (get to know your own qualities and getting a better image of yourself with all your talents)	2	Topic of exercise is personally less appealing.	
			2	Aspect of having to ask a second person (with regard to time)	
			3	Problems with understanding the exercise.	
<b>Chapter 3: Flow</b>					
Exercise "Change 'having to do' into 'wanting to do'"	9	Intention and type of exercise is good and fits needs of young carers (having to do a lot of things)	4	Exercise is personally not appealing.	
	3	You learn to see tasks more positively.	1	Problems with understanding the exercise.	
<b>Chapter 4: Optimism</b>					
Exercise "Keep a diary"	12	Good exercise, especially for difficult situations.	12	Exercise is personally not appealing (writing a diary as type of exercise)	
			4	Problems with understanding and doing the exercise.	
<b>Chapter 5: Self-Compassion</b>					
Exercise 1 "Bring back being kind to yourself"	7	The exercise is simple and not time consuming. You learn to have more positive of yourself.	3	The exercise is personally not attractive (not necessary; time-consuming; difficult)	
Exercise 2 "Be your best friend"	5	The exercise is short, but strong and important.	5	The exercise is personally not appealing.	
<b>Chapter 6: Resistance</b>					
Exercise "How do I handle difficult situations?"	8	The way of doing the exercise is good and you can find out how to handle situations.	2	Some options to choose are not appropriate for younger young carers (e.g. drinking alcohol)	
<b>Chapter 7: Positive relations</b>					
Exercise "Express your gratitude"	9	The exercise offers a way to express your gratitude, which is important.	7	The exercise is personally not attractive or not necessary.	
<b>Chapter 8: Relaxation</b>					
Exercise 1 "Abdominal breathing"	6	The text is a good relaxation exercise.	2	The exercise is personally not attractive (takes too much time)	
Exercise 2 "Muscle relaxation"	3	The exercise helps to calm down.	2	The exercise is personally not appealing.	
Exercise 3 "Egg-exercise"	4	It can help to concentrate on the positive things and to forget the negative ones and thus it is relaxing.	1	The exercise can personally not help.	

Table 11. *Overview of the learning effects from the book on the reader*

	nc	np	Quotation translated from Dutch
<b>Learning effect</b>			
Think more about positive things (and less about the negative ones)	11	6	To think more positively. I am always quite negative when something happens, then I think something like 'this is going wrong and this and this'. And when you then also think about successes of the last week, then you can think back more positive. Then you have something positive between the negative things (P 1)
Keep/get calm	7	5	When you think a lot about specific things before going to bed, that you can get more calm through it (P 3)
Handle emotions and thoughts	5	4	And that you can think more clearly again in this moment. And that you know that you are still the same happy person (P 3)
Handling difficult situations	4	4	[...] but I think, if I had this in a period of time when I really did not know how to handle the situation, that this would have helped (P 9)
Appreciate/respect yourself	4	4	Well, that it is not only about the ill children, but also about yourself (P 7)
Thinking about yourself	4	3	In one exercise you had to do your qualities, I think, and then you see what you all have, what you can, which qualities [you have] (P 10)
Take a rest	1	1	To take a rest (P 8)

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

Table 12. *Overview of the categories to answer RQ 3*

RQ 3	4 Game version
	4.3 Appreciation of the idea of an online intervention
	4.4 Appreciation of the idea of a game version
	4.3 Appreciation of the current game version
	<i>General appreciation of the current game version</i>
	<i>Appreciation of specific motivational elements from the current game version</i>
	<i>Suggestions for improvement</i>

Table 13. *Overview of remarks about the advantages of a game version*

	nc	np	Quotation translated from Dutch
<b>Advantages of a game version</b>			
More attractive	13	11	I think they would think more deeply because everyone like gaming, online games, and if you do it there may be more interest to play it [...] (P 7)
Easier to do the exercises in a game version	8	8	Yes, yes, because you do it in a playful manner (P 9)
More effective	6	5	[...] that you are busy with the content implicitly [...] so that you keep in mind more things implicitly. That you are busy such intensively that it creeps in your mind slowly (P 2)
Easier to understand instructions	3	3	Then you can use more animation, so that [the user] can understand it better (P 6)

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

Table 14. *Overview of positive and negative remarks about the current game version*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Layout</b>	15	13	The game is well designed and pretty.	9	6	The game has to be more colourful.
				3	2	Layout too childlike.
				1	1	Missing an appealing start page
				1	1	More noticeable images.
				1	1	Layout is taken from another existing game.
<b>Comprehensibility</b>	13	12	The game is comprehensible.	1	1	Image 5 is not comprehensible.
				1	1	The texts are too long.

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

Table 15. *Overview of the appreciation of motivational elements (primary task support)*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Primary task support</b>						
<b>Idea of personal account (Personalization)</b>	8	8	Personal account is good in general.	3	3	There should be the opportunity to do it anonymously.
	1	1	Nobody else can use it.	3	2	Wanting to do it anonymously.
	1	1	Symbolizes that it is for helping you.	1	1	Not wanting to fill in all information (phone number).
<b>Idea of list of results (Self-monitoring)</b>	8	7	Good to see what you have already achieved.			
	2	2	Overview of results offers possibility of comparing later on.			
	2	2	Overview over 'good' and 'bad' results offers opportunity to improve some things.			
<b>Idea of steps in the game (Tunneling)</b>	7	6	Good to have an order and not to do more exercises at once.			
	4	4	Idea good in general.			
	2	2	Longer busy and more attentive with one exercise.			
First finishing one island	2	2	Makes sure that you do the exercises in the right order.	7	5	Not wanting to do exercises being personally not appealing (wanting to choose exercises).
	2	2	Makes sure you do not miss an important exercise.			
	2	2	Makes sure that you concentrate on one exercise.			
	1	1	If not mandatory, you will not do all exercises.			
<b>Repeating exercises (Rehearsal)</b>	3	3	Wanting to repeat exercises.			

*Note.* **nc**= number of codes; **np**= number of persons who said something with regard to this code

Table 16. *Overview of the appreciation of motivational elements (dialogue support)*

	Positive appreciation			Negative appreciation		
	nc	np	Content of appreciation	nc	np	Content of appreciation
<b>Dialogue support</b>						
<b>Messages of reminding (reminders)</b>	10	10	It is practical to stay busy with the game.	1	1	Too many reminders would be annoying.
	1	1	Practical to get information about new things in game.	1	1	Personally not necessary.
				1	1	You have to do it from out self-motivation.
<b>Game's ability to motivate (liking)</b>	8	8	Game motivates more to do the exercises.	2	2	Game does not motivate more to do the exercises.
<b>Idea of getting keys (rewards)</b>	7	7	Idea is appealing, in general.	2	2	Only appeals children.
	2	2	Makes it clear that one island has been finished.	1	1	Aim of the key not comprehensible.
<b>Idea of 'the prof' (social role)</b>	6	6	Idea is appealing, in general.	1	1	Only appeals children.
	6	6	Can help to understand the game and tasks in it.	1	1	Personally not appealing.
	1	1	Good for getting information.			

Note. **nc**= number of codes; **np**= number of persons who said something with regard to this code

Image 1. *Image of game structure*



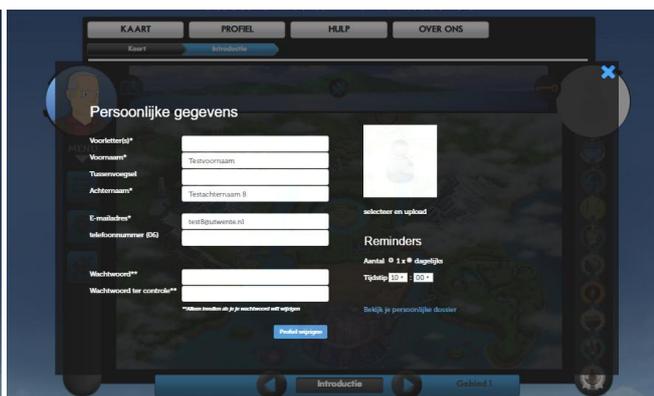
Image 2. *Image of overview of islands*



Image 3. *Image of a reward-element*



Image 4. *Image of personal account*



## Appendix 2 – Additional appreciation of the chapters

### Chapter 1: “De hoogste tijd voor vreugde” (High time for pleasure)

According to 13 participants, the topic of chapter one, to focus on the positive emotions, is important for young carers. By reading the chapter, eleven of the participants recognized that it is important in general to think more about the positive things in life, instead of the negative ones. This could be one method to learn how to stay or how to get more positive in life, which is also one important aspect according to eight young carers. Another aspect which some of the participants recognized as important in this chapter is to get to know your own emotions. The text in this chapter was appreciated as good (14 participants) and understandable (13 participants). There were not mentioned any negative aspects about the text. The two exercises were also appreciated as understandable.

**Exercise 1: “Drie goede dingen” (Three good things):** Ten of the fifteen participants could read and do the exercise. According to four of them, the exercise is in general good to learn how to think more about the positive things in live. But the exercise was mainly appreciated as being personally not attractive. Eight of the ten participants mentioned that the exercise is personally not appealing to them. For example, some did not like that the exercise had to be done daily and some others find it too difficult. They would suggest that the reader do not have to do the exercise daily. Only one participant would like to do the exercise again.

**Exercise 2: “Hoeveel plezierige emoties ervaar je?” (How many pleasant emotions do you have?):** Exercise 2 was also available only for ten participants. It was appreciated mainly positive. All ten participants mentioned that they evaluate the exercise as good, or important, or personally appealing. Two main positive aspects of the exercise being mentioned were that the exercise can be done easily and fast and that you can get a score as a result. One participant did not like to have a score and would suggest leaving out the result. Furthermore, the young carers suggest adjusting the options to choose in the exercise: one would like to have more options, another participants would like to have some other options, because they are too similar. Another suggestion is to add another category for the scoring: the step between “1=een beetje” (a little bit) and “2=redelijk sterk” (quite much) is too big according to participant 2.

## **Chapter 2: “Leef je talenten uit” (Show your talents)**

The second chapter was appreciated positively by the participants. The majority of the participants mentioned that the topic of talents and qualities is important especially for young carers, and other two participants mentioned that it is an important topic anyway.

According to the majority of the participants, the most important aspect in this chapter is to become aware of own qualities (11 participants). But you can not only get to know your talents in this chapter, but it would help also to think more intensively about yourself and to get more self-confident. According to the participants, the reader of this chapter can learn what qualities he has, get a better image of the self, and maybe learns also to work on the self. The text in the chapter was appreciated as good by seven participants and as comprehensible by 12 participants. One participant had some trouble to understand the text in total.

**Exercise „Jou kwaliteiten“ (Your qualities):** All 15 participants could read and do the exercise. Eleven participants rated the exercise as being a good exercise. The exercise can help to get to know your qualities and to have a better image of yourself with all your talents. It can show, for example, that you are good in much more things that you may think before. Two participants found the topic less appealing. The exercise would be especially good and important for people who are dissatisfied or with a low self-confidence. Some of the participants especially stressed that it is fine to ask another person about your qualities. Participant 7 stressed that the exercise has personally helped, because he asked another person and become aware of some extra qualities. The exercise can furthermore help to feel better, because you may have less self-doubts (P 11), have more positive energy (P 13), have a self image which is more positive (P 1) and can feel proud of yourself (P 10). The aspect of asking another person was nevertheless also appreciated negatively by two participants, because sometimes it could be some difficult to ask another person to do the exercise, for example with regard to the opportunity to ask someone or having the time to ask.

The majority found the exercise comprehensible. One participant had problems to understand the exercise. Third other participants said that they had to read the exercise twice or ask another person to understand it. Participants 2 and 9 furthermore expressed the doubt if younger children would understand the exercise or if they would be able to think about the questions of the exercise appropriately. The third column was not understood by everyone. Some had to read the instruction again to understand it and some did not understand it anyway. It seemed that some of the words are a little bit too difficult.

Eight participants would use the exercise again, for example to compare two different moments in life and to judge if there has changed something. Six participants said that it is enough to do the exercise once, as the talents and qualities do not change that fast.

Suggestions for improvement were: writing a more comprehensible and clear instruction, using less difficult words and stressing that it is not bad to be less good in some things (P 3).

### **Chapter 3: “Een andere kijk op jezelf” (A different perspective on yourself)**

The third chapter is about having energy and fun by doing tasks and activities you have to do and thereby changing “having to do” in “wanting to do”. 13 participants stressed that this topic is important for young carers, because young carers have a lot to do and it would be easier to do the tasks if you see them in a more positive way. This would help “to be less critical” (P 13, 14) and would “reduce brooding” (P 14). Two other participants said that it is an important topic anyway in life. According to the participants it is furthermore important in this chapter to be kind to yourself and also to do your own things next to the mandatory ones (P 1, 3, 15). It is important to recognize that you often also want to do some things, however it seems that you have to do them (P 3, 4, 10) and this awareness you could get in this chapter according to four participants. You learn to see the positivity in tasks and activities and why you do them, for example that you help someone by doing them.

The text was appreciated positively, as being good (10 participants) and comprehensible (14 participants). One participant appreciated negatively that the text is very long.

**Exercise: “‘Moeten’ veranderen in ‘willen’” (Change ‘having to do’ into ‘wanting to do’):** All fifteen participants were able to read and do the exercise. Nine of the fifteen participants appreciated the exercise in this chapter positively. They liked the intention of the exercise and how to do it. They found the exercise appealing to them, because they also have to do a lot of things at home and are really critical about themselves. Some learned how to appreciate all the tasks more positively. The tasks and activities then are easier to do (P 3) and you get more positive by realising that you do all the things for a specific reason (P 13), for yourself or for someone else. This could be useful especially for younger young carers (P 4). Four participants appreciated the exercise as being not appealing to them: one said that it is unnecessary to think about tasks and activities in this way, one said that it is personally not appealing because he/she still has the feeling of having to do all the things afterwards and the exercise is too long, one does not like the exercise anyway, and one found the exercise too

similar to the ones in chapter 1 and 2. One participant mentioned not wanting to do the exercise again. Ten participants however would do the exercise again, for example, in a situation wherein you do not feel good.

The majority of the participants did not have problems understanding the exercise. One had first problems to understand it, but could do the exercise after asking a parent. One participant did not understand the exercise anyway.

There was made only one suggestion for this chapter, namely to offer an exercise with the same topic as now, but which is shorter.

#### **Chapter 4: “Het glas is altijd half vol” (The glass is always half full)**

The topic of optimism of chapter 4 is according to nine participants important for young carers. Further, the chapter introduced other important aspects according to the participants: next to staying optimistic it would be important to have an appropriate way to handle thoughts and emotions, to handle negative situations in a more positive way and to not thinking that everything is the own fault. Through reading the chapter and doing the exercise you can learn to get more positive, said four participants. Furthermore, you can learn to look at negative things from a more neutral perspective and may recognize that some things are not as bad as they seemed to be.

The text in this chapter was appreciated as good by eight participants and as understandable by 11 participants. Three participants mentioned the worry that younger reader may find it too difficult and one participant said that it was more difficult for him to understand the text.

**Exercise “Houd een dagboek bij” (Keep a diary):** This exercise was available for all 15 participants. Generally, the exercise in this chapter was evaluated to be a good exercise by 12 participants, especially for difficult situations. But also 12 participants mentioned that the exercise is not appealing to them. They did not like the way of doing the exercise, namely to write a diary. Often they mentioned the topic being interesting and important, but the exercise did not fit their interest. They do not want to do the exercise daily and do not want to think about some situations retrospective. They do not think that it is necessary to write down such things, but would prefer to do it in their mind.

Seven participants made comments that the exercise is comprehensible, but four participants mentioned that they had problems understanding the exercise. The participants suggest using less difficult words and to choose an exercise which does not have to be done daily or weekly. Only three participants would use the exercise again.

## **Chapter 5: “Ben vriendelijk tegen jezelf” (Be kind to yourself)**

Eleven of the fifteen participants stated that the topic of being kind to you is an important one for young people being carers. According to some of them, it is important to take your time, especially when you have much to do as a young carer. Further, it is important not to be too critical and appreciate yourself and what you do, even when there is something going wrong sometimes. You can learn to think about yourself, your life and your performances from another perspective and may appreciate and evaluate yourself in another way: “sometimes others think more positively about you, while you think about the same thing negative” (P 1). The text in this chapter was good, according to 12 participants, and also comprehensible.

**Exercise 1: “Wakker vriendelijk in jezelf aan” (Bring back being kind to yourself):** The first exercise in this chapter was available to all 15 participants. It was appreciated as good by seven participants. They liked that it is a simple and not much time consuming exercise and that you learn to have a more positive look on yourself. It is good to “write down [positive] things where you otherwise would not think about” (P 10). Three participants did not like the exercise or found it personally not attractive. One thought that the things you have to write down are so daily and usual that it is not necessary to think about and write it down. One other participant did not want to waste about five minutes on the exercise and the last one found it difficult to think about the positive things. He would suggest to make a list of negative things instead of the positive ones and to give you an advice for improvement in handling these things for the next time.

One participant found it a little bit difficult to understand the exercise before getting explanation from a parent. The other participants were positive about the comprehensibility. Three young carers would use the exercise again.

**Exercise 2: “Ben je beste vriend/in” (Be your best friend):** The second exercise could be read and done by ten participants. It was appreciated both positive and negative by each five participants. The five young carers who did like the exercise said that it is a “short but strong exercise” (P 4), that it is “important to know how others think about you” (P 4) and that you “give yourself some kind of advice for doing it better next time” (P 5). The other five participants would not do the exercise, because they find it strange to think in this way or simply do not appreciate the exercise as appealing to them personally. One participant found it a little bit difficult to understand the exercise, the others understood everything.

Four of the participants want to do the exercise again.

## **Chapter 6: “Ik ben dezelfde niet meer” (I am not the same anymore)**

Seven of ten participants thought that the topic of chapter 6 is important for young carers. Six of the ten participants mentioned that it is important for young carers to realize how they handle difficult situations, and that knowledge then could help in future difficult situations.

Furthermore, the chapter tells according to three participants that it is important to remain yourself, by “not changing yourself because of your situation” (P 3), for example.

The text in this chapter was according to six participants ‘good’, according to six participants ‘comprehensible’ and according to two participants a little bit too long.

A negative comment was made by two participants about the image in this chapter. They did not understand the connection between image and topic.

## **Exercise: “Hoe ga jij met moeilijke situaties om?” (How do I handle difficult situations?):**

The exercise was available for ten participants. Eight participants appreciated the exercise positively. They made positive aspects about the way of doing the exercise by marking with crosses and that they could find out how they handle situations. According to the participants, you can learn to handle situations and that you have to change your methods sometimes: participant 1 recognized that he should not always try to handle all problems on his own, and participant 8 mentioned having learned that he has to talk more about problems.

There were also mentioned a negative aspect about the exercise: the exercise could be too difficult for younger young carers and some of the options to choose from are not appropriate according to two participants. Thereby both named especially the option “drinking alcohol”. They suggest changing the options for younger young carers.

Three participants did not think that it is necessary to repeat the exercise, but six participants would like to do the exercise again, for example, to compare the handling of difficult situations at two different points of time.

The majority mentioned that the exercise was comprehensible. Two participants mentioned that they had some problems understanding the exercise: participant 2 said that some options are not fully comprehensible, for example option three in table 1, and participants 6 found it difficult to understand the results of the exercise.

## **Chapter 7: “Je positieve leven delen” (Share your positive life)**

Eight participants mentioned that chapter 7 could be important for young carers to read, and two participants mentioned that it is important anyway for everyone. The young carers

mentioned two main topics which are important in this chapter: expressing thanks to other people (8 participants) and being kind to others (5 participants). Two other participants recognized also that the chapter wants to stress that it is important not to be alone. According to seven participants, you can learn in this chapter to say thank you to others. Further, one participant stressed that it can also help to show your emotions to others.

Eleven of the fifteen participants were positive about the text in the chapter and all fifteen young carers appreciated the text as comprehensible. One participant mentioned that the title of the chapter is not appropriate, because it is difficult to understand in the context. He would suggest choosing another title for this chapter.

**Exercise: “Dankbaarheid uiten” (Express your gratitude):** All 15 participants could read and do the exercise. According nine participants, the exercise in this chapter is in general a good exercise, because it is fine to say thanks to others and thus making others happy and because the exercise offers a way for doing it. Positive would be also that you yourself also would feel better after expressing your thanks to others and that it is fine to see the positive reactions of the other. The exercise is further some kind of reminder to say thanks more often. But nevertheless mentioned seven participants that they would not use the exercise, because they think it is not necessary to say thank you in this way. One participant stressed that it is more appropriate for younger children. Six participants mentioned wanting to do the exercise again, and three participants did not want to do it again.

For the majority of the participants the exercise was comprehensible. Two participants mentioned that they had some problems to understand. One person did not understand the last point of “not exaggerating”, one had problems to understand the aim of the exercise. Another young carer further suggested offering more examples how to say thanks to others.

### **Chapter 8: “Lekker relaxen” (Relax)**

All 15 participants mentioned that the last chapter is an important one. Thereby 14 of the 15 appreciated chapter 8 as being important especially for young carers. The topic of relaxing is according to the participants especially important for young carers, because young carers are more busy than other children and youngsters, both with tasks and also in your mind, and therefore have more need to take their time and relax.

The chapter teaches according to the participants that it is important to relax (8 participants), especially in of after stressful situations, to calm down (6 participants) and to take time for

yourself (4 participants). Through reading the chapter and doing (one of) the exercises you can learn to relax, to calm down and to take your time. That could also help “to forget everything [negative]” (P 15) for a moment.

The text in the chapter was appreciated positively. 13 participants were positive about the comprehensibility and nine participants also rated the text as being good. One participant found the text not as attractive as others, because of the topic in general.

Before asking them about their opinion of the different exercises, there were made some general comments: nine of the 15 participants said that they could fully comprehend the exercises, and three participants said that the exercises in general are good. One third of the participants mentioned that this kind of exercises is not appealing to them, because they have their own way to relax, such as sporting. But often they said that the exercises are nevertheless good and can help other people. But participant 6 stressed that such exercises “can help some people, and cannot help some other people” and it was stressed that it is “not necessary to do all three exercises” (P 3). One suggestion in general was to stress in the introduction that you should be in a calm situation and quiet room to do the exercises.

**Exercise 1: “Buikademhaling” (Abdominal breathing):** According to six participants this exercise is fine to do. It was appreciated to be a “good relaxation exercise” (P 6) and helped to breathe slowly and appropriately. Participant 10 also mentioned directly that this exercise is personally more appealing than the other two exercises in this chapter. Two participants said that exercise 1 is personally not attractive to them, because, it “takes too much time” (P 4). Six participants would like to use the exercise more often.

**Exercise 2: “Spierontspanning” (Muscle relaxation):** Three participants appreciated the second exercise positively. They mentioned that it can help to calm down and to “feel relaxed”(P 4). Two participants appreciated the exercise after reading as being personally not appealing. One participant would like to do the exercise again, and one participant stated that he would not use it again.

**Exercise 3: “Ei-oefening” (Egg-exercise):** Four participants appreciated the third exercise positively. It can help to concentrate on the positive things and to forget the negative ones and is thereby relaxing. One participant did not like the exercise, because he is convinced that it could not help him. Two participants would like to do the exercise more often, and other two participants would not do it again.

## Appendix 3 – Interview scheme (in Dutch)

### Interviewschema

Nummer respondent	
Datum interview	
Tijdstip aanvang interview	
Tijdstip einde interview	

#### Inleiding

Allereerst wil ik je bedanken voor je bereidheid en je interesse om deel te nemen aan dit onderzoek! Je hebt al de uitnodigingsmail gelezen, maar ik wil me wel nog even kort voorstellen: mijn naam is Alena Berger in ik studeer psychologie aan de Universiteit Twente.

Zoals je weet ga ik een interview met je houden om een onderzoek te doen voor de universiteit en SIZ Twente. In het onderzoek gaat het uiteindelijk om het ontwikkelen van een online zelfhulpmodule voor jonge mantelzorgers. Jij bent deel van dit onderzoek. Jij als expert kunt echt helpen om iets te zeggen over de behoeften en wensen van jonge mantelzorgers!

Het interview zal ongeveer 60 minuten duren. Gedurende het interview kijken we gezamenlijk naar het boekje en de voorbeeld plaatjes en ik wil je een aantal vragen stellen naar je mening en opvattingen.

Belangrijk! Mocht het zo zijn dat je een vraag niet begrijpt, aarzel dan niet om naar uitleg te vragen. En nog veel belangrijker: er zijn geen foute antwoorden of vragen, je kunt alles zeggen wat je vindt! Ik wil je vooral aanmoedigen open te spreken over je ervaringen en ideeën! Alles wat je zegt kan helpen om de zelfhulpmodule zo passend mogelijk te maken voor jonge mantelzorgers!

Je deelname is geheel vrijwillig en je mag altijd stoppen als je niet meer verder wilt. Als er vragen zijn waar je geen antwoord op weet of waar je geen antwoord wil geven, hoeft dat niet. Het interview wordt opgenomen, zodat ik later alles kan opschrijven en niets mis van wat jij hebt verteld. De opname wordt op de universiteit veilig bewaard. Nadat ik alle informatie heb uitgewerkt wordt de opname op mijn eigen computer verwijderd. Alles wat jij vertelt wordt anoniem verwerkt. Er worden nergens je persoonlijke gegevens vermeld.

#### Uitleg opbouw interview

Het interview bestaat uit zes onderdelen. Allereerst zal ik je een paar achtergrondvragen stellen. Vervolgens gaat het dan om je algemene indruk van het boekje als geheel en dan vervolgens om je indruk per hoofdstuk. Tenslotte wil ik je graag naar je mening over de vormgeving vragen. Aan het eind is er nog ruimte voor jouw suggesties, opmerkingen en vragen.

Heb je voor dat we beginnen nog vragen? Dan wil ik je nu vragen dit papier even door lezen en daarna je naam of je handtekening eronder zetten. Als je jonger bent dan 18, moet ook één van je ouders een handtekening eronder zetten.

## 1. Achtergrond gegevens

### Demografisch

(geslacht noteren)

- Zou je me kunnen vertellen hoe oud je bent?

*Indien < 16 jaar*

- Op wat voor een school zit je (basisschool of voortgezet onderwijs)?
  - Voortgezet onderwijs: Op welk niveau? (Vmbo, HAVO, Vwo)

*Indien > 16 jaar*

- Zit je op het voortgezet onderwijs of studeer je?
  - Voortgezet onderwijs: welk niveau? (Vmbo, HAVO, Vwo)
  - Studeren? Welk niveau? MBO, HBO, Universiteit
- Woon je thuis bij je ouders, heb je een eigen woning, of woon je in een woongemeenschap?
  - Eigen woning of woongemeenschap: sinds wanneer woon je daar?

### Type/omvang mantelzorg

- Van wie in je gezin ben je JMZ'er (vader, moeder, broer, zus)
- Wat heeft diegene voor een aandoening?
- Hoe lang heeft hij of zij deze aandoening al?
- Heb je het gevoel dat je anderen dingen en taken moet doen?
- Kun je uitleggen hoe deze aandoening invloed heeft op jou leven?

## 2. Algemeen

We beginnen met een aantal vragen over je algemene indruk van de oefeningen en teksten en het effect dat het mogelijk op je heeft gehad.

### 1. Vragen over het gebruik

- Heb je het boek gelezen?
- Welke delen van het boek heb je gelezen?
  - Waarom heb je ervoor gekozen deze delen te lezen?
  - Waarom heb je sommige delen niet gelezen?

- Kan je misschien zeggen hoeveel tijd je ongeveer hebt besteed aan het lezen van het document?
- Heb je de oefeningen alleen gelezen of heb je ook sommige daadwerkelijk uitgevoerd?
  - o Zo ja: Welke oefeningen heb je uitgevoerd?
  - o Waarom heb je voor deze oefeningen gekozen?
- Kan je misschien iets erover zeggen hoe je het lezen hebt aangepakt?
  - o Kan je misschien iets zeggen over de volgorde van lezen?
  - o Kan je misschien iets zeggen over de tijdstippen wanneer je hebt gelezen?

## **2. Vragen over de waardering**

### **Passendheid en algemeen oordeel:**

- Wat vond je van het boek?
- Wat vond je goed in het boek?
- Wat vond je slecht in het boek?
- Waarom zou je de oefeningen aan andere jonge mantelzorgers aanbevelen of waarom juist niet?
- Vind je het boek passend voor jonge mantelzorgers?
  - o Zo ja: Wat vond je goed? Waarom vond je dat goed?
  - o Zo nee: Wat vond je slecht? Waarom vond je dat slecht? Wat zou beter kunnen?
- Hoe zou het boek volgens jij beter aansluiten aan de behoeften en wensen van jonge mantelzorgers?
- Waarom denk je of denk je juist niet dat de oefeningen ook andere jonge mantelzorgers kunnen helpen?
- Was het boek duidelijk voor je?
- Waren de oefeningen en teksten duidelijk voor je?
- Wat vond je van de woordgebruik?
  - o Was het makkelijk of moeilijk?
  - o Had je soms problemen iets te begrijpen?
  - o Voorbeelden?

**Belangrijk:** doorvragen! Wat was positief? Wat was negatief? Probeer concrete voorbeelden boven tafel te krijgen.

### **3. Vragen over het effect**

- Hebben de oefeningen je op de één of andere manier geholpen?
  - o Zo nee: Waarom denk je dat ze niet hebben geholpen?
  - o Zo ja: Waarom denk je dat de ze jij hebben geholpen?
  - o Kun je dat eens toelichten
  - o Kun je daar een voorbeeld voor geven?
- Denk je dat je door de oefeningen iets hebt geleerd?
  - o Wat heb je door de oefeningen geleerd?
- Denk je dat je het boekje nog eens zult gebruiken?
- Denk je dat je de oefeningen nog eens zult gaan doen?
- Wat is de belangrijkste boodschap die je is bijgebleven?
- Zijn er onderwerpen of onderdelen die je hebt gemist?

### **3. Ervaringen (per hoofdstuk)**

We gaan nu je ervaringen en opvattingen per hoofdstuk van het boekje bespreken en gaan kijken waar en waarom je iets hebt opgemerkt en een plus of een min hebt geplaatst.

**Belangrijk:** Vragen per hoofdstuk opnieuw stellen en hoofdstuk en nummers hardop noemen.

#### **1. Vragen over het gebruik**

- Heb je dit hoofdstuk gelezen?
- Heb je de oefening uitgevoerd?
- Heb je de oefening één keer gedaan? Of vaker?
- Waarom heb je ervoor gekozen deze oefening ook echt uit te voeren?

#### **2. Vragen over de waardering**

- Wat vond je van de oefening?
- Wat vond je goed?
- Wat vond je slecht?
- Wat is volgens je het belangrijkste in dit hoofdstuk?
- Is dit hoofdstuk belangrijk voor jij als jonge mantelzorger? (of voor andere JMZ'ers?, waarom? Waarom niet?)
- Wat vond je van de teksten in dit hoofdstuk?
  - o Spraken de teksten aan, wat spreekt je aan? Wat juist niet??
  - o Vond je het makkelijk of moeilijk de teksten te begrijpen?

- Zo moeilijk: Wat heb je misschien niet begrepen? Wat vond je moeilijk?
- Wat vond je van de oefening?
  - Spreekt de oefening aan? Wat spreekt aan? Wat juist niet?
  - Vond je het makkelijk of moeilijk de oefeningen te begrijpen?
    - Zo moeilijk: Wat heb je misschien niet begrepen? Wat vond je moeilijk?
- **Vragen over het effect**
- Heb je iets geleerd door dit hoofdstuk door te lezen en de oefening te doen?
  - Zo ja: Wat heb je geleerd?
- Probeer je het geleerde toe te passen in je leven?
- Wil je de oefening vaker gaan doen in je leven? (waarom (wel/niet)?)
- **Vragen over tips, verbeteringen en aanpassingen**
- Wat voor tips voor verbeteringen of aanpassingen heb je nog?
- Wat voor punten heb je nog gemist?

#### 4. Suggesties

We hebben zojuist alle hoofdstukken per stuk besproken.

- Heb je in het algemeen nog suggesties voor verbetering?
- Heb je nog bepaalde dingen gemist?
- Zou je behoefte hebben aan een zelfhulpmodule als deze? Waarom wel/niet?
- Hoe zou je het vinden als een cursus als deze online werd aangeboden?
- Zou je het misschien ook als app willen hebben?

**Belangrijk:** doorvragen! Probeer concrete voorbeelden/ideeën boven tafel te krijgen.

#### 5. Vormgeving

Ik wil nu graag de mogelijke vormgeving van de zelfhulpmodule bespreken. Je hebt van tevoren een aantal plaatjes gezien hoe de module kan uitzien.

Heb je de plaatjes bekeken?

### **Algemeen:**

- Wat vind je van het idee om de oefeningen als een game te presenteren?
  - o Goed: Waarom vind je het goed?
- Wat is misschien het voordeel van een game-versie?
  - o Niet goed: Waarom vind je het niet goed? Wat zou je misschien beter vinden?
    - Waarom denk je dat het niet zo passend is?
- Denk je dat een game versie het makkelijker voor je maakt om de oefeningen te volgen?

### **Deze versie:**

- Wat vind je van de huidige eerste uitwerking van de game?
  - o Goed: Wat vind je goed aan deze versie? Ook als je deze versie goed vind, waarin zou die wat jouw betreft nog beter kunnen?
  - o Slecht: Waarom vind je het niet zo goed? Waarin zou die wat jouw betreft beter kunnen?

### **Per elementen:**

#### **Primary task support**

- Vind je dat je de oefeningen voldoende hebben geholpen om je beter te voelen?
- Vindt je het goed dat je stap per stap door de eilanden doorheen wordt geleid?
- Hoe vindt je het idee dat je eerst één eiland moet afsluiten om de volgende te kunnen bekijken?
  - o Zou je het beter vinden als je de oefeningen kunt kiezen die je doet?
- Vind je de game versie passend voor jonge mantelzorgers?
- Hoe vindt je het idee dat je een eigen persoonlijk account hebt?
- Hoe vindt je het idee dat je altijd kunt bekijken wat je al hebt bereikt in het game?

#### **Dialogue support**

- Vind je dat het systeem je motiveert om de oefeningen te doen?
- 
- Hoe vindt je het dat de prof je door het game geleit?
- Hoe vindt je het idee dat je een sleutel krijgt als je één eiland hebt afgesloten?
- Wat zou je ervan vinden om berichten ter herinnering te krijgen van de game? Bijvoorbeeld op je smartphone of via email.
- Vond je de huidige versie van de game aantrekkelijk?
- Vond je de huidige versie van de game duidelijk?

#### **Social support**

- Zou je het fijn vinden om sociale steun te krijgen via deze online interventie?
- Wat zou je ervan vinden om met andere spelers in contact te komen?
- Chat? / Forum?

**Afsluiting:**

- Heb je onderdelen gemist?
- Welke TIPS heb je nog voor ons?

**Belangrijk:** doorvragen! Probeer concrete voorbeelden/ideeën boven tafel te krijgen.

## 6. Afsluiting

Alle onderdelen van het onderzoek zijn nu besproken. Heb je nog vragen of opmerkingen?

**Uitleg vervolg en dank**

Het interview zal uitgetypt worden en geanalyseerd. Het verslag en dat van andere deelnemers zal mij helpen bij het beoordelen van de cursus voor jonge mantelzorgers. Wellicht zal er aan de hand van dit onderzoek een passende cursus ontwikkeld worden voor jonge mantelzorgers.

Indien je geïnteresseerd bent in de uitkomsten van dit onderzoek, zou ik je kunnen mailen. Zou ik in dat geval je e-mailadres mogen noteren?

E-mail:

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## Appendix 4 – Informed consent (in Dutch)

### **Informed consent formulier** (Verklaring dat je mee wil werken aan het onderzoek)

Onderzoek: “ **Hulp bij ontwikkeling van een online zelfhulpmodule voor Jonge Mantelzorgers** ”

*Uiteindelijk doel:* Het ontwikkelen van een online zelfhulpmodule voor Jonge mantelzorgers van 12 t/m 25 jaar, die goed aansluit bij *hun eigen* wensen, behoeften en ideeën.

*Hoofdvraag:* Hoe beoordelen jonge mantelzorgers van 12 t/m 25 jaar de (aangepaste) oefeningen uit van de bestaande interventie “Dit is jouw leven”? Wat vinden zij van de eerste opzet van een game-versie van deze interventie?

*Methode:* Semi- gestructureerd interview, zie de bijlage voor de vragen die we je zullen stellen.

*Duur:* Maximaal 60 minuten

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Lees onderstaande punten goed door. Voor elk genoemd punt staat een vierkantje, deze mag je inkruisen als het punt voor jou klopt. Als alle vakjes zijn ingekruist en de handtekeningen van jou, de onderzoeker en je ouders (als je jonger bent dan 18 jaar) erop staan mag je geïnterviewd worden.

- Ik ben een Jonge Mantelzorger.
- Het doel van het onderzoek is mij duidelijk.
- Ik weet hoe het interview zal gaan verlopen.
- Ik weet welke vragen mij gesteld gaan worden.
- Ik weet dat het interview wordt opgenomen.
- Ik weet dat de opnames bewaard worden op een plek waar alleen de onderzoekers bij kunnen.
- Ik weet dat mij naam nergens in het onderzoek zal worden genoemd.
- Ik weet dat ik de resultaten van het onderzoek mag weten als het is afgerond.
- Ik weet dat ik op elk moment in het onderzoek mag stoppen als ik dat wil.
- Ik heb al mijn vragen kunnen stellen en ik heb duidelijk antwoord gekregen.

Leeftijd Jonge Mantelzorger: ..... jaar

Invullen als je jonger bent dan 18 jaar:

- Ik heb toestemming van mijn ouders om deel te nemen aan het onderzoek.
- Mijn ouders hebben al hun vragen kunnen stellen en hebben duidelijk antwoord gekregen.

Handtekening Jonge Mantelzorger

Datum: .....

.....

Handtekening ouder (Vereist indien JMZ'er < 18)

Datum: .....

.....

Handtekening onderzoeker

Datum: .....

.....