The effect of technology assisted therapy for adults with intellectual and visual impairment suffering from separation anxiety and challenging behaviour

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Dissertation submitted in fulfilment of the requirements for the degree Magister Artium in Research Psychology at the Potchefstroom Campus of the North-West University

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Summary

The purpose of this study was to investigate the effect of a new intervention method, Technology Assisted Therapy for Separation Anxiety (TTSA), on the psychosocial functioning and quality of life of persons with intellectual and visual disability who experience separation anxiety and exhibit challenging behaviour. A pre-experimental within group design was used with randomised multiple baselines and staggered intervention start points. The data was collected at an institution in the Netherlands that provides long-term care and residence for persons with intellectual disability and visual impairment. Six participants took part in this study.

This research was informed by Bowlby’s attachment theory, which conceptualises the tendency of human beings to forge strong emotional bonds with others and explains how the disturbance of this bond might lead to various forms of emotional distress and personality disturbances. The interplay of separation anxiety and challenging behaviour with respect to the formation of attachment relationships provides the specific theoretical context in which this study is grounded.

The results indicate that both the separation anxiety experienced and the challenging behaviour exhibited by the participants decreased significantly after the implementation of TTSA. Their psychosocial functioning and quality of life also increased significantly.

This study demonstrates the first successful application of TTSA to treat separation anxiety and challenging behaviour in persons with intellectual and visual disability. TTSA therefore has the potential to be a valid intervention to address these disorders.

KEY WORDS: Intellectual Disability, Multiple case study, Psychosocial functioning, Quality of Life, Separation Anxiety, Technology, Treatment, Visual Disability
Hierdie studie het ten doel gehad om die effek van ‘Technology Assisted Therapy for Separation Anxiety’ (TTSA) op die psigososiale funksionering en die kwaliteit van lewe van persone met intellektuele en visuele gestremdheid wat aan skeidingsangs en probleemgedrag ly, te bepaal. ’n Pre-eksperimentele, een groep ontwerp met ewekansige veelvuldige basislyne is gebruik. Die data is in Nederland by ’n instansie wat langtermyn sorg en verblyf aan persone met intellektuele en visuele gestremdheid verskaf, ingesamel. Ses deelnemers is in hierdie studie ingesluit.

Hierdie studie is baseer op Bowlby se teorie oor gehegteidsbinding. Hierdie teorie beskryf die mens se neiging om emosionele bande met ander te vorm en bespreek die implikasies indien hierdie band ontwrig sou word. Die invloed van skeidingsangs en probleemgedrag op die vorming van die gehegteidsband word as die spesifieke teoretiese konteks vir hierdie studie beskou.

Die resultate toon ’n beduidende afname in skeidingsangs en probleemgedrag na die implementering van TTSA. Verder het die psigososiale funksionering asook kwaliteit van lewe van die deelnemers beduidend verbeter.

Hierdie studie beskryf die eerste suksesvolle toepassing van TTSA op skeidingsangs en probleemgedrag in persone met intellektuele en visuele gestremdheid. Die potensiaal om TTSA in ’n geldige intervensie metode wat hierdie probleme kan handel, te ontwikkeld is dus duidelik.

SLEUTELTERME: Behandeling, Intellektuele gestremdheid, Kwaliteit van lewe, Psigososiale funksionering, Skeidingsangs, Tegnologie, Veelvuldige gevallestudie, Visuele gestremdheid.
Preface

- This dissertation was written in article format as described in rules A4.4.2 as prescribed by the North-West University.

- The article will be submitted for possible publication in the *Journal of Applied Research in Intellectual Disabilities*.

- All but the article (section 2) is in accordance with the Publication Manual (6th edition) of the American Psychological Association (APA) style guide. The article was written in accordance with the author guidelines of the *Journal of Applied Research in Intellectual Disabilities*, which specifies the Harvard referencing system.

- The page numbering in this dissertation is consecutive, starting from the introduction.

- Consent for submission of the article contained in this dissertation for examination purposes in order to obtain an MA in Research Psychology has been granted by the co-authors of this article, Prof. E. van Rensburg and Dr. P.S. Sterkenburg.

- The dissertation received a Turn-it-in report within accepted norms.

- The numbering of the tables and figures is restarted in section B.
Permission is hereby granted for the submission by the first author, N. Hoffman, of the following article for examination purposes, towards the obtainment of a Magister Artium in Research Psychology:

The effect of technology assisted therapy for adults with intellectual and visual impairment suffering from separation anxiety and challenging behaviour

The role of co-authors were as follow: Prof. E. van Rensburg and Dr. P.S. Sterkenburg acted as supervisor and co-supervisor respectively. Dr. P.S. Sterkenburg assisted in the peer review, analysis and interpretation of the data, whereas Prof. E. van Rensburg assisted in the peer review.

Prof. E. van Rensburg
Co-supervisor and co-author
Dear Nadia Hoffman

Language editing

This is to confirm that I edited your master's dissertation, *The effect of technology assisted therapy on adults with intellectual and visual impairment suffering from separation anxiety and challenging behaviour*, and that I indicated the necessary grammatical corrections.

Although I took all reasonable precautions to ensure that all grammatical and stylistic corrections are indicated, you remain responsible for the final product. Therefore, please check these suggested corrections before applying them and, if possible, again perform a spell check after you have implemented them, in order to eliminate typing errors.

Please contact me if there are any queries or if I can be of further assistance.

Yours sincerely

Michelle Coetzee
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The effect of technology assisted therapy for adults with intellectual and visual impairment suffering from separation anxiety and challenging behaviour

SECTION 1: INTRODUCTION AND RATIONALE

1.1 Introduction

This study comprises an investigation into the effect of Technology Assisted Therapy for Separation Anxiety (TTSA) on the levels of separation anxiety experienced and the challenging behaviour exhibited by adults with intellectual disability (ID) and visual impairment, and how this intervention method affects their psychosocial functioning and quality of life.

The first section of this dissertation provides a general introduction to and rationale for the current study. The literature review provides an introduction to the existing literature on separation anxiety and challenging behaviour in persons with ID and visual impairment, and the nature of their psychosocial functioning and quality of life. The research paradigm from which this study was conducted is outlined, the methodology is described and the research questions and hypotheses for this study are listed.

1.2 Problem statement and orientation

Intellectual disability is a risk factor for developing separation anxiety (Emerson, 2003; Emerson & Hatton, 2007) and challenging behaviour (Schuengel & Janssen, 2006). Several variables and the interaction between these variables might cause the ID population to be vulnerable to the development of psychopathology. These include insecure attachment relationships, which are more often found among persons with ID (Cassidy, 1999; Greenberg, 1999), separation anxiety (Greenberg, 1999; Nauta & Emmelkamp, 2012), the limited cognitive
skills characteristic of ID (Janssen, Schuengel, & Stolk, 2002; Schuengel & Janssen, 2006) and challenging behaviour (Pruijssers, Van Meijel, Maaskant, Nijssen, & Van Achterberg, 2012). In addition, separation anxiety is four times more prevalent among persons with ID than among persons without ID (Emerson, 2003; Emerson & Hatton, 2007). Separation anxiety in itself, if left untreated, can be a risk factor for the development of psychopathology later in life (Greenberg, 1999; Nauta & Emmelkamp, 2012). The effect of psychopathology on the psychosocial functioning (Ansell, Sanislow, McGlashdan, & Grilo, 2007) and quality of life (Macaskill & Denovan, 2014) of the person living with a psychopathology can be devastating. It is therefore important to address separation anxiety in persons with ID to prevent the development of possible psychopathology in later life. However, at present there is a dearth of literature and empirical research studies on the treatment of separation anxiety among persons with comorbid ID and visual impairment (Hagopian & Jennet, 2008).

1.2.1 Intellectual disability

Intellectual disability is a neurodevelopmental disorder that has its onset in the developmental period (Mash & Wolfe, 2013). A diagnosis of ID can be made when intellectual functioning and adaptive functioning are affected (American Psychiatric Association [APA], 2013). Intellectual functions include academic learning, learning from experience and executive functions such as reasoning, attention, problem solving, planning, abstract thinking and judgement (Brookshire, 2007). Impaired adaptive functioning is characterised by insufficient personal independence and social responsibility, which limit functioning in daily activities, including communication, social participation and independent living (APA, 2013).
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The DSM-V (APA, 2013) specifies four categories of ID that indicate the intensity of the ID. This diagnosis does not rely only on IQ scores, but is rather specified by the impairment of adaptive functioning (APA, 2013; Maulik, Mascerenhas, Mathers, Dua, & Saxena, 2011). Two persons with matching IQ scores will not necessarily function on a similar level (Maulik et al., 2011). The level of impaired adaptive functioning predicts the degree of support needed in comparison with IQ scores, which provide little information regarding possible intervention. The four ID categories are mild, moderate, severe and profound (APA, 2013). The inclusion criteria for the current study specify that the participants be adults diagnosed with mild to moderate ID. According to the DSM-V, adults with mild ID often present with diminished abstract thinking, executive functions, short-term memory and functional use of academic skills. Social skills are usually immature compared to normally developed peers, with impediments in perceiving social cues and concrete communication content. Behaviour and emotion regulation could be impaired, with restricted risk assessment in social situations. Some support is needed with the tasks related to daily living, e.g. grocery shopping, food preparation, money management, etc. Adults with mild ID are able to maintain employment, but require support when making legal and health care decisions. Adults with moderate ID usually function academically at an elementary level, with support necessary to practice these skills in the work and personal domains of life. Other conceptual tasks related to daily living are accomplished with support, often leading to the supporting individual relieving the adult with ID from the tasks entirely. Communication skills are markedly less complex than those of normally developed peers. Relationship skills are similar to the skills displayed by adults with mild ID, but communication deficits might hinder these relationships. Adults with moderate ID can become self-sufficient in personal needs, e.g. eating, dressing, elimination and hygiene, but intensive training and teaching is required. Basic
employment can be achieved, but with significant support from caregivers, supervisors and co-workers. Challenging behaviour such as yelling, anger and hitting might be present, which negatively influences functioning in social contexts (APA, 2013).

About 1% of the global population is directly affected by intellectual disability (Maulik et al., 2011; Nevid, Rathus, & Greene, 2006). Factors contributing to the development of ID are clustered into two main categories, namely biological and psychosocial. Biological causes include chromosomal and genetic disorders, infectious diseases, premature birth, anoxia and maternal alcohol use during pregnancy. Growing up in an impoverished environment with little intellectual stimulation during childhood or exposure to hazardous chemicals or elements such as lead-based paint chips are some psychosocial factors that can contribute to the development of ID (Mash & Wolfe, 2013; Nevid et al., 2006).

Comorbidity of ID with mental and neurodevelopmental disorders are common. These include Attention Deficit Hyperactivity Disorder, depressive and bipolar disorders, anxiety disorders, challenging behaviour, including aggression and disruptive behaviour, and autism spectrum disorders (APA, 2013). In the current study, one of the exclusion criteria is that participants may not present with autism spectrum disorders.

1.2.2 Visual impairment

All the participants in the current study present with a degree of visual impairment, ranging from a mild visual impairment to complete blindness. In the current study, writing on the technology, namely a specially adapted mobile iPhone, was provided in Braille or by auditory means when necessary. “Visual impairment” includes various disorders of the visual functions that are caused by anomalies in the visual system. These cause diminished sight or complete loss
of sight. The visual system comprises the eyes, the optic nerves and the optic centre in the visual cortex. Any abnormality in this system might lead to impairment of the visual functions. The latter refers to depth and colour perception, light sensitivity, ability to perceive movement and contrasts, and the perception of shapes and objects (Bals, Gringhuis, Moonen, & Van Woudenberg, 2002).

Visual impairment, as with any other permanent disability, will affect every developmental stage of the child (Gringhuis, 2002). During the first 18 months of life, children rely on their senses to form cognitive representations of their world (Piaget, 1964). Diminished function or the absence of one of the senses will necessarily influence the development of the child, as has been demonstrated by copious research studies which indicate that visual impairment predicts poor overall developmental outcomes (Cass, Sonksen, & McConachie, 1994; Dale & Sonksen, 2002; Evenhuis, Sjoukes, Koot, & Kooijman, 2009; Rossetti, 2001). Specific delays in global learning difficulties, expressive and receptive language, sensorimotor understanding, emotional bonding, personality and self-concept, sound and tactile localisation skills, fine and gross motor skills, object permanence (Dale & Sonksen, 2002), independent living skills, communication and social skills (Evenhuis et al., 2009) were found to be consequences of diminished or absent sight. Contributing to this certainty is research proving the protective role of the presence of vision, though limited, on the cognitive and language development of the infant during the first 18 months of life (Dale & Sonksen, 2002). The delay that visual impairment causes to the cognitive development of humans (Bals et al., 2002) during this developmental stage is of particular interest to the current study. During the sensory-motor stage, which normally occurs during the first 18 months of life, various abstract concepts are mastered, including object and person permanence (Piaget, 1964). Object and person
permanence is an abstract cognitive concept which reassures one that an object or person does not cease to exist when this object or person is no longer within sight (Mayekiso, 2008). The development of this cognition is delayed by up to 10 months in visually impaired or blind infants (Rogers & Puchalski, 1988) and the impact of this delay on the formation of secure attachment relationships and the development of separation anxiety is evident (Janssen et al., 2002). For an in-depth explanation of the relationship between these variables, refer to section 1.2.3 below.

In the current study, all the participants were diagnosed with ID and suffered from a visual impairment. As noted above, both these diagnoses increase the risk of delays in cognitive development. Visual impairment is often comorbidly found in persons with ID (Dale & Sonksen, 2002; Evenhuis et al., 2009). It can therefore be deduced that the risk factors for cognitive disability are increased in comorbid ID and visual impairment. ID and visual impairment found comorbidly might furthermore contribute to the development of interpersonal and mental health-related problems (Emerson, 2003; Emerson & Hatton, 2007; Janssen et al., 2002).

1.2.3 Attachment theory and separation anxiety

Attachment theory conceptualises the tendency of human beings to forge strong emotional bonds with others, and explains how the disturbance of this bond might lead to various emotional distress and personality disturbances. The attachment system comprises attachment behaviour and the response to the behaviour. Attachment behaviour is defined by the function these behaviours have in the social context. Within a healthy attachment relationship, attachment behaviour is any behaviour that aims to obtain proximity to the attachment figure to enhance the bond or call out to the attachment figure in times of distress. In the case of children, this includes crying, eye contact, smiling and running towards the attachment figure, and is determined by the
child’s developmental stage. A three-month-old infant who is not able to walk or run will use crying to signal the caregiver, while a three year old will use his/her motor skills to achieve proximity to the attachment figure. A healthy attachment is established when the attachment figure responds consistently and predictably to the attachment behaviour (Bowlby, 1980).

The child’s attachment system will be activated at any moment in which he/she perceives danger or discomfort, e.g. anxiety, fatigue, strangeness or pain, and it will be deactivated only by the response of the attachment figure (Bowlby, 1980; Cassidy, 1999). The core intent of the attachment system is thus to ensure the safety of the child (Cassidy, 1999). Ainsworth elaborated on Bowlby’s theory of attachment by developing the Secure Base and Safe Haven theory (Ainsworth, Blehar, Waters, & Wall, 1978). Marvin, Cooper, Hoffman and Powell (2002) developed a visual representation of this theory, which they named “the circle of security”.

![Circle of Security](image)

Figure 1. Circle of security by Marvin et al. (2002).
The top half of the circle represents the exploratory needs of the child. The child is free to explore the world around him/her to the extent that his/her motor development allows. The child will feel comfortable to embark on this journey only if he/she is ensured of his/her attachment figure’s availability in case of a stressful or dangerous situation. The attachment figure thus provides a safe base from which the child can explore and develop. The bottom part of the circle represents the attachment system of the child. The attachment figure serves as a permanent source of protection, comfort and delight to which the child can return. The attachment figure organises the child’s feelings and behaviour when they surpass his/her point of self-regulation. The attachment figure therefore provides an unconditionally safe place for the child to return to in moments of stress. A healthy attachment system, with attachment figures who respond consistently and predictably, will result in the formation of a healthy attachment relationship between the caregiver and the child, and later facilitate child’s establishment of relationships as an adult (Bowlby, 1980). If this system is significantly disrupted, the child might develop an insecure attachment relationship to his/her attachment figure (Cassidy, 1999) which has far-reaching implications for the child’s future interpersonal relationships (Cassidy & Shaver, 2008; Fraiberg, 1977) and mental health (Greenberg, 1999; Nauta & Emmelkamp, 2012).

Three categories of insecure attachment relationships have been identified. Avoidant attachment relationships are characterised by emphasised independence on the part of the child, while resistant attachment relationships are characterised by behaviour that shows increased dependence of the child on the attachment figure. Attachment behaviour shown in disorganised attachment relationships contradicts the emotion regulation function of the attachment figure. The child will, for example, show fearful behaviour when in the presence of the attachment figure (Schuengel, De Schipper, Sterkenberg, & Kef, 2013). In these relationships, compared to a
healthy attachment relationship, the child does not feel safe and is not assured of the attachment figure’s consistent and predictable response. Avoidance of the attachment figure during a reunion between the child and attachment figure and failure to greet can be classified as attachment behaviour in an insecure attachment relationship. The child does not feel safe within his/her attachment relationship and therefore avoids contact in order to limit the risk of rejection by the attachment figure (Ainsworth et al., 1978). Attachment behaviour is goal-corrected behaviour aimed at establishing the safety of the child. The child will therefore adapt his/her behaviour as he/she develops on the basis of the reaction or lack of reaction shown by the attachment figure. The attachment figure’s failure to react or recurrent rejection will cause the child to develop attachment behaviour to protect him- or herself from the rejection, causing an insecure attachment relationship to be formed (Cassidy, 1999).

Insecure attachment relationships are often found among persons with ID (Clegg & Sheard, 2002). This is due to the limited cognitive skills characteristic of ID (Janssen et al., 2002). The developmental delays in persons with ID include a developmental delay in the attachment system, partly because persons with ID either struggle to identify and select attachment behaviour to suit the situation, or struggle to adequately exhibit the appropriate behaviour due to a limited behavioural repertoire. Moreover, the subtle manner in which attachment behaviour is often exhibited might conceal its intended purpose and might cause it to go unnoticed by the attachment figure, leading to a malfunction in the attachment system. If this pattern persists long enough, it might cause an insecure attachment relationship between the attachment figure and the child (Cassidy, 1999).

An insecure attachment relationship is in turn a risk factor for the development of psychopathology, including separation anxiety (Greenberg, 1999). According to the DSM-5,
separation anxiety disorder can be diagnosed when excessive worrying about separation from the caregiver or home is observed (APA, 2013). The theoretical underpinnings of separation anxiety disorder are that, during a stressful situation, a child will locate his/her attachment figure in order to make use of the safe haven found within the relationship. If the attachment figure is not available and responsive, another source of fear is established. The fear experienced because of the stressful situation now turns into anxiety (Kobak, 1999). Due to the cognitive and attachment system delays characteristic of ID and visual impairment, persons with both these problems are at risk of developing separation anxiety (Emerson, 2003; Emerson & Hatton, 2007). Research shows that separation anxiety disorder is up to four times more prevalent among persons with ID compared to persons without it (Emerson, 2003; Emerson & Hatton, 2007).

Children might forge more than one attachment relationship. Attachment relationships can even develop in adulthood between two long-term romantic partners (Cassidy, 1999). Persons with ID often attend day care or reside in caring facilities where they are cared for by professional caregivers. Attachment behaviour has been noticed between such persons and their caregivers (Clegg & Sheard, 2002; De Schipper & Schuengel, 2010). The risk factors for the development of separation anxiety in persons with ID and visual impairment might be further increased by this living arrangement because the caregivers often have more than one client to take care of and need to alternate between these clients. This causes the caregiver or attachment figure to be physically absent for some parts of the day. During these times, the inability to understand the abstract concept of person permanence could cause the client to feel that his/her caregiver or attachment figure is lost forever. Additionally, in professional care giving for persons with ID, attachment bonds can be disrupted due to the high turnover of staff. This is problematic for persons with ID, as well as the caregiving system itself (Schuengel et al., 2013).
The caregiving system might thus cause anxiety and sorrow in persons with ID due to disrupted attachment relationships, which might increase these clients’ caretaking needs.

**1.2.4 Challenging behaviour**

Challenging behaviour can be caused by several factors. In the current study challenging behaviour is defined as intrusive and aggressive behaviour (Tenneij & Koot, 2007). The self-regulatory system of the individual might give rise to this behaviour. In times of stress, an automatic response occurs based on the individual’s primary appraisal of threat. If the threat is perceived as real, the amygdala, the emotion generating location in the brain, will automatically identify and mobilise neuropathways to counter the threat (Schuengel & Janssen, 2006). These pathways are formed in response to previous experiences and emotions, and will lead to undifferentiated arousal. Physiological changes take place to supply the body with the energy needed to react, such as raised blood pressure, faster respiration, increased muscle tone, transpiration and endocrine output, and accelerated heart rate (Schuengel & Janssen, 2006). If the threat is appraised as real, the individual continues to the second phase of stress management, namely secondary appraisal. The individual appraises the availability of problem-solving skills and resources. If the individual’s secondary appraisal is negative, whereby the person evaluates his/her available problem-solving skills and resources as insufficient to address the issue, the perception of a threat is increased. The threat is perceived on a more conscious level compared to the automatic response during primary appraisal. The undifferentiated arousal experienced in the primary appraisal now becomes an identified emotion, e.g. sadness or anger, which will most likely be acted on. In addition, a physiological response is triggered again, arming the body for
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fight or flight, which is a state of hyperarousal. Many forms of challenging behaviour require a state of hyperarousal (Schuengel & Janssen, 2006).

Psychopathology (Schuengel & Janssen, 2002), specifically anxiety disorders (Pruijssers et al., 2012) can also cause challenging behaviour. Persons with separation anxiety disorder might perceive a separation from his/her attachment figure as a threat and consequently show anger or aggression toward the person instigating the separation. Social withdrawal, apathy, sadness and difficulty concentrating are frequently observed when the separation is successful. Children with these disorders are typically described as demanding, intrusive and needy (APA, 2013).

Anxiety disorders and challenging behaviour have a direct relationship – an increase in the one can lead to an increase in the other (Pruijssers et al., 2012). Attachment theory might well explain the high prevalence of challenging behaviour co-occurring with anxiety disorders. The attachment system serves as a protective mechanism for the child (Cassidy, 1999). In a normal developing child, this system will be activated once a threat is identified. This is a normal and well-adjusted response (Bowlby, 1980). When this response deviates from the norm for some reason, the child might be diagnosed with separation anxiety disorder. In these cases, anxiety brought about by the threat of the loss of an attachment figure might give rise to anger, which, when acted on, can be observed as challenging behaviour (Bowlby, 1980).

Challenging behaviour is frequently found among persons with ID (APA, 2013; Schuengel & Janssen, 2006), who often experience more psychological stress due to their intellectual handicap, problems with appraisal and processing, and a limited behavioural repertoire (Gardner & Sovner, 1994). In addition, persons with ID more frequently appraise situations as threatening than normally developed persons (Clark & Wilson, 2003). Combined
with decreased problem-solving skills, a high risk of separation anxiety and the lack of a safe haven provided by a secure attachment relationship, the person with ID might frequently make negative secondary appraisals, causing them to become hyperaroused and present with challenging behaviour. Recurrent and prolonged states of stress could activate the biological response system almost permanently. This conditions the formation of new neuropathways, resulting in ingrained maladaptive responses to even the slightest stressor (Perry, Pollard, Blakley, Baker, & Vigilante, 1995) which could result in the further deterioration of affect regulation (Schuengel & Janssen, 2006).

1.2.5 Psychosocial functioning and quality of life

Insecure attachment relationships (Berlin, Cassidy, & Appleyard, 2008), psychopathology (Ansell et al., 2007; Ormel et al., 1994; Rodriguez, Bruce, Pagano, & Keller, 2005), including anxiety disorders (Ansell et al., 2007; Beard, Weisberg, & Keller, 2010; D’Avanzato et al., 2013; Essau, Lewinsohn, Olaya, & Seeley, 2014; Olatunji, Cisler, & Tolin, 2007; Ormel et al., 1994; Quilty, Van Ameringen, Mancini, Oakman, & Farvolden, 2003) and challenging behaviour (APA, 2013) can impair the psychosocial functioning of persons experiencing these difficulties. The current author divided psychosocial functioning into psychological and social functioning. Impaired psychological functioning is defined by the presence of psychopathological symptoms, while impaired social functioning is defined as impaired interpersonal relationships. Occupational dysfunction (Ansell et al., 2007; D’Avanzato et al., 2013; Essau et al., 2014; Ormel et al., 1994; Rodriguez et al., 2005), physical disability (Essau et al., 2014; Ormel et al., 1994), decreased recreational activities (Ansell et al., 2007; D’Avanzato et al., 2013; Rodriguez et al., 2005) decreased responsibility for household duties,
increased stress levels and decreased coping skills (Essau et al., 2014) can result due to impairments in psychological functioning. Interpersonal relationships such as family relationships with parents, siblings, children and relatives (Ansell et al., 2007; D’Avanzato et al., 2013; Essau et al., 2014; Rodriguez et al., 2005), marital relationships and relationships with friends (Ansell et al., 2007, D’Avanzato et al., 2013; Rodriguez et al., 2005) can be compromised due to impaired social functioning.

Decreased psychosocial functioning due to insecure attachment relationships (Berlin et al., 2008), psychopathology (Quilty et al., 2003), anxiety disorders (Barrera & Norton, 2009; Beard et al., 2010; D’Avanzato et al., 2013; Olatunji et al., 2007; Ormel et al., 1994; Quilty et al., 2003; Stein & Heimberg, 2004) and challenging behaviour (Janssen et al., 2002) can jeopardise the quality of life of the person affected by these complications. A meta-analysis by Olatunji et al. (2007) investigating the effect of anxiety disorders on quality of life found that participants with anxiety disorders subjectively rate their value of life, health, social relationships, occupation and home and family life significantly lower than the control groups. Furthermore, decreased quality of life, especially in the social domain, might be a risk factor for the development of other mental health problems such as depression. Moreover, the risk of developing impairments in social functioning for persons who suffer from separation anxiety are further exacerbated by their tendency to withdraw socially when separated from their attachment figure (APA, 2013). It is therefore important to include social interaction in the intervention program of persons suffering from anxiety.

In short, the high prevalence of insecure attachment, psychopathology, separation anxiety and challenging behaviour in the ID population, and the significant risk that these factors
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constitute for decreased psychosocial functioning and quality of life among this population, serve as motivation for the current study.

1.2.6 Treatment of separation anxiety and challenging behaviour

The relevance of improving psychosocial functioning and optimising quality of life as part of the clinical treatment of mental health-related issues has been emphasised by the biopsychosocial perspective on clinical treatment. The aim of treatment is no longer only to alleviate symptoms, but to also increase psychosocial functioning and quality of life (Caldirola et al., 2014). This argument is reinforced by a study that demonstrates that persons who have recovered from anxiety are at an increased risk of relapse due to poor psychosocial functioning (Rodriguez et al., 2005). The importance of incorporating intervention methods to address psychosocial functioning and quality of life in the treatment plan for psychopathology is thus evident (Moitra et al., 2014). Improved quality of life among persons suffering from anxiety disorders should indicate successful treatment, but research shows that low quality of life is still present even after successful treatment of anxiety disorders. It is therefore recommended that future research regarding the development of intervention methods for anxiety disorders attend more to quality of life as an outcome variable (Olatunji et al., 2007).

The existing literature on the treatment of separation anxiety among persons with ID and comorbid visual impairment is insufficient (Hagopian & Jennet, 2008). While the therapy techniques developed to address anxiety in persons without ID can be applied to persons with ID (Didden et al., 2012; Hagopian & Jennet 2008), the focus of these intervention methods are primarily on the treatment of phobic disorders. Treatments for other anxiety disorders such as separation anxiety are not as copiously available (Hagopian & Jennet, 2008). Research shows the
successful application of behaviour-based therapy, such as graduated exposure and reinforcement, in the treatment of anxiety in persons with ID (Hagopian & Jennet, 2008). Other researchers suggest that new therapy methods for addressing anxiety in children and adults with ID can be modelled on existing interventions used to address anxiety in normal developing children and adults (Schuengel et al., 2013). Relaxation and desensitisation methods were proven to be effective in reducing anxiety and phobias, but the lack of existing intervention methods to address complex phobias and general anxiety disorder is accentuated (Didden et al., 2012). Self-help guides that inform the caregiver about his/her role in the process of establishing a secure attachment relationship with clients with ID have been developed (e.g. Sterkenburg, 2012). However, the shortage of intervention methods specifically developed to address anxiety disorders in the ID population partly serves as motivation for the current study.

It is known that high stress levels in persons with ID might increase challenging behaviour (Schuengel & Janssen, 2006). However, assessing subjective experiences of stress in persons with ID is often difficult due to their limited communication skills and low levels of affect expression. This complicates the studying and development of prevention and treatment methods for stress-related disease (Janssen et al., 2002). It is therefore significant that the body’s automatic primary appraisal response during psychological stress can change one’s physical state (Schuengel & Janssen, 2006), because the measurement of these physiological changes in heart rate, blood pressure, respiration, muscle tone, transpiration and endocrine output offers an alternative for measuring stress levels in persons with ID. Researchers are therefore no longer dependent on low affect expression and limited communication skills characteristic of persons with ID when measuring levels of perceived stress (Janssen et al., 2002). Early caregiving experiences might, however, play an important role in the nature of a person’s parasympathetic
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regulation. Disruptions in attachment relationships could cause a decrease in parasympathetic responses to stressful situations, lowering the reliability of these measurements (Porges, 2004).

Existing psychological intervention can successfully decrease challenging behaviour in persons with ID. For example, therapy based on attachment theory might be useful in treating the prevalence of challenging behaviour in persons with ID (Sterkenburg, Janssen, & Schuengel, 2008). De Schipper and Schuengel (2010) found that as attachment behaviour increases, challenging behaviour decreases. In addition, the attachment behaviour shown by a child increases significantly when a secure attachment relationship is present (De Schipper & Schuengel, 2010). Insecure attachment relationships increase the risk of developing separation anxiety (Greenberg, 1999). Therefore, one could reason that a secure attachment relationship and attachment-based therapy might lead to increased attachment behaviour, resulting in a decrease in challenging behaviour and separation anxiety experienced by the person with ID.

In short, the lack of intervention methods specifically aimed at addressing anxiety among persons with ID, compared to phobic disorders (Hagopian & Jennet, 2008), the lack of interventions specifically developed for persons with ID and visual impairment and the influence that separation anxiety (Ansell et al., 2007; Beard et al., 2010; D’Avanzato et al., 2013; Essau et al., 2014; Olatunji et al., 2007; Ormel et al., 1994; Quilty et al., 2003) and challenging behaviour (APA, 2013) can have on psychosocial functioning and quality of life serve as motivation for the current study.

1.2.7 The experimental treatment used in this study

Cellular technology holds many benefits for the user and the field of psychopathology intervention has started to use it for treatment interventions. However, persons with ID are
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currently excluded from the social, vocational, health and safety benefits offered by cellular technology (Davidson, 2012; Stock, Davies, Wehmeyer, & Palmer, 2008). There are two primary reasons for this. Firstly, while the use of technology in various fields has been researched, including in education (Davidson, 2012), skill attainment, learning and task management (Mechling, 2011), these studies regarding the inclusion of technology in intervention methods for persons with ID are only introductory (Mechling, 2011). Further research examining the full extent to which technology can be incorporated into the treatment of the ID population, and the benefits and limitations thereof is needed (Scherer, 2012).

Secondly, the complexity of the software and the often small physical attributes of the hardware of modern cellular technology prevent persons with ID from optimally utilising these technologies (Bryan, Carey, & Friedman, 2007). This is partly due to the limited research done by the designers and manufacturers of cellular technology into the needs of the ID population, resulting in the development of technology that excludes this vulnerable population (Gutiérrez & Martorell, 2011). Stock et al. (2008), however, developed a cellphone prototype specially adapted for the ID population in response to this problem. This prototype has facilitated more independent use of cellphones by persons with ID, providing the means by which this population can be included in the benefits of cellular technology.

Moreover, Den Brok and Sterkenburg’s (2015) systematic review of the existing pioneering research indicates promising possibilities. Five studies incorporating mobile technology to teach cognitive concepts such as vocational skills, daily living skills, time perception, safety skills and imagination were included. Emotion concepts were successfully taught through mobile technology in two of these studies. Mobile technology might thus hold the potential to be employed in the process of teaching abstract cognitive concepts such as person
permanence, thereby overcoming separation anxiety. Studies of this nature are yet to be conducted.

These developments, deficiencies and considerations informed the adoption of the experimental treatment used in this study. Technology assisted Therapy for Separation Anxiety was developed specifically for the purposes of this study to address separation anxiety and challenging behaviour in visually impaired clients with a mild to moderate intellectual disability. An iPhone touch cellphone, specifically adjusted for the needs of the ID and visually impaired population, was used in combination with reality bound communication. An application was downloaded on the phone that enabled the participants to send messages to their caregivers regarding their moods when the caregivers were not physically present. Five set messages could be sent to the caregiver, four of which communicated the emotions happy, sad, angry and anxious, with the fifth being an option to ask for help. In response to these messages, the caregiver could send a fixed message back to the client on a similar device. The caregiver could, for example, respond with a fixed message “you are happy” whenever the participant sent the message “I am happy”. All the messages sent during the time spent apart from each other were discussed at a subsequent meeting between the caregiver and the participant. A child lock function prevented the participant from accidentally exiting the application. A cellphone pouch with Braille words was provided for the participants who struggled to read the screen.

This experimental study aimed to determine the efficacy of TTSA in lowering separation anxiety and challenging behaviour in persons with ID. The main aim was to determine whether the separation anxiety levels and challenging behaviour of the participants decreased throughout the therapy and whether this reduction had an influence on the psychosocial functioning and quality of life of the participants. It was expected that the separation anxiety levels and
challenging behaviour of the participants would decrease during therapy, which would in turn result in an increase in psychosocial functioning and quality of life.

1.3 Research paradigm

This study made use of the data collected during the Mobile Technology to Support Relationship Development, Well-being and Social Participation study, which took place from July 2011 to July 2012. The study utilised a quantitative means of data collection and analysis. This methodology aims to quantify social phenomena, stipulate and test hypotheses and predict behaviour (Creswell, 2003; Sanders, 1982).

1.4 Research Design

A pre-experimental within group (Campbell & Stanley, 1963), randomised multiple-baseline design (Kratochwill & Levin, 2010) with staggered intervention start points (Bulté & Onghena, 2009) was used. The multiple baseline design expands on the single case design by replicating the single case design and administering it simultaneously to multiple participants. Individual start points for every participant, differing in the time of commencement, were implemented to ensure a staggered design (Bulté & Onghena, 2009) (Refer to Table 1). According to Kratochwill and Levin (2010) randomisation can be advantageous when included in case study designs. It reinforces the internal validity and methodological integrity, and facilitates the possibility of more statistical manipulation. In the current study, the six participants were randomly assigned to the six staggered start points.
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Table 1
*Randomised Multiple-baseline Blocked Phase-order Randomly Paired with 21 Time Periods, and 14 C1 Potential Start Points*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Block</th>
<th>Time period</th>
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<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>B1 B1 B1 B1 B1 B1 C1* C1 C1 C1 C1</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>B1 B1 B1 B1 B1 B1 C1 C1 C1 C1 C1</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 C1* C1 C1 C1 C1</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 C1 C1 C1 C1 C1</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 C1* C1 C1 C1 C1</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 B1 C1 C1 C1 C1 C1</td>
</tr>
</tbody>
</table>

Note
Potential C1 start points are between time periods 8 and 21 inclusive.*randomly selected start-point
B1: Intervention phase 1
C1: Intervention phase 2

1.5 Participants and context

The data from the Mobile Technology to Support Relationship Development, Well-being and Social Participation study was gathered at an organisation in the Netherlands that provides long-term care for adults and children with intellectual and visual impairment. Six participants were selected by means of purposive sampling. According to Ritchie, Lewis and Elam (2003), this method is suitable for small studies. The inclusion criteria specified for this study were that all the eligible participants had to be older than 18 years, had been diagnosed with a moderate to mild ID, had an IQ of between 40 and 70, experienced separation anxiety when removed from a caregiver, had a visual impairment and the ability to operate a mobile phone. Persons with autism or who were deaf were excluded. The caregivers who participated in this study were trained to provide specialised care. More than one participant was included so as to increase the external validity of the study (Kratochwill & Levin, 2010).
1.6 Data collection

Four standardised instruments were used in this study to monitor changes in the variables:

**Adult Behaviour Checklist for ages 18-59 (ABCL) (Achenbach & Rescorla, 2003):**

The changes in separation anxiety experienced, challenging behaviour exhibited and psychosocial functioning were measured by the anxious/depressed, aggressive behaviour, intrusive and withdrawn syndrome scales of the ABCL. The reliability and validity of this measurement was found to be appropriate for the assessment of psychopathology in persons with mild ID (Tenneij & Koot, 2007). A .89 Cronbach Alpha correlation proved the inter-rater reliability of the anxious/depressed and aggressive behaviour scales to be good. A fair result was found when the withdrawal and intrusive scales were tested, with .73 and .79 correlations respectively. The anxious/depressed scale scored .62 on ICC calculations, which is considered to be a good score. The aggressive behaviour scale scored .75 (excellent), the withdrawal scale achieved a fair score of .56 and the intrusive scale fared excellent with a score of .75 (Tenneij & Koot, 2007).

**Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982):**

Psychosocial functioning was measured using the BSI total scale and the anxiety subscale was employed to monitor changes in anxiety symptoms. An independent mentor supported the participants in the process of completing the questionnaire. The internal consistency of the BSI total scale and the anxiety subscale were calculated to be $\alpha = .96$ and $\alpha = .82$ respectively (Wieland, Wardenaar, Fontein, & Zitman, 2012). The subscales were found to differ significantly, with the correlations ranging from $\alpha = .39$ to $\alpha = .79$. The BSI could therefore identify psychopathology and differentiate between diagnoses (Wieland et al., 2012).
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Psychopathology Inventory for Mentally Retarded Adults (PIMRA) (Kazdin, Matson, & Senatore, 1983):

Changes in anxiety levels experienced by the participants were monitored using the anxiety subscale of the PIMRA. This subscale was completed by the caregiver. The internal consistency of the anxiety scale was found to be modest to adequate (α = .63) (Van Minnem, Savelsberg, & Hoogduin, 1994).

Intellectual Disability Quality of Life (IDQOL) (Hoekman, Douma, Kersten, Schuurman, & Koopman 2001):

The quality of life of the participants was evaluated by means of the IDQOL. Independent mentors supported the participants in the completion of this questionnaire. A 5-point Likert-type scale, which included a graphic rating scale, was used. The IDQOL was found to present with an adequate internal consistency (α = .86) (Hoekman et al., 2001).

The frequencies of the messages sent by the participants were recorded throughout the intervention phases and the caregivers rated the participants’ behaviour on a daily basis using the ‘Qualtrics’ database.

1.7 Data analysis

The three data sets were statistically analysed. The standardised questionnaires were analysed using a non-parametric Friedman test. The Friedman test is considered more powerful when the number of treatments exceeds five (Theodorsson-Norheim, 1987). The current study includes six treatment phases, rendering the Friedman test appropriate. The frequency of messages sent by the participants was analysed using a non-parametric Friedman test. Descriptive statistics were used to illustrate the behaviour exhibited by the participants during
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the intervention phases. Statistical analysis was conducted for every phase in the intervention in order to compare the results. Missing data in the data set generated by the standardised questionnaires were imputed by calculating the mean score of the two scores adjacent to the missing score. The data sets generated by the messages sent and the ‘Qualtrics’ program were visually checked for outliers. Outliers were removed from the data sets.

The first aim of this study was to determine whether TTSA could decrease separation anxiety and challenging behaviour in persons with ID and visual impairment. The p-values of the Friedman test done on the standardised questionnaires measuring separation anxiety and challenging behaviour experienced by the six participants were meta-analytically combined according to Fisher’s method (De Weert & Van Geert, 2002). This method stipulates that the p-values of the Friedman test must be combined and that a natural logarithm must be calculated for each p-value. Multiplying the sum of the natural logarithms by -2 determined the chi-square deviations. The degrees of freedom were determined by multiplying the number of p-values by 2. In order to avoid skewed representation of the p-values, those smaller than .005 were substituted with .01. P-values that indicated a change in the variable that was not in the anticipated direction were substituted with .5 (Birnbaum, 1955; De Weert & Van Geert, 2002). The results of the Friedman test on the data related to the angry and anxious messages of the six participants were meta-analytically combined according to Fisher’s method. The results generated by the data related to the frequency and intensity of the anxiety behaviour and challenging behaviour, as recorded by the caregivers on a daily basis, were described. Behaviour classified as anxious included stress, anxiety and clinging behaviour, whereas challenging behaviour was defined as anger, yelling and hitting.
The second aim of this study was to investigate whether TTSA had an effect on the psychosocial functioning and quality of life of the participants. The p-values generated by the Friedman test done on the standardised instruments measuring psychosocial functioning and quality of life were meta-analytically combined according to Fisher’s method (De Weert & Van Geert, 2002). The results delivered by the Friedman test done on the frequencies of the happy messages sent were meta-analytically combined for the six participants. The results relating to the data generated by the positive behaviour recorded by the caregivers were described. Positive behaviour included happiness, positive experiences and obedience. Table 2 contains a description of the analyses for each data set. In addition, Cohen’s d value was determined.

1.8 Research hypotheses and research questions

The following research hypotheses were formulated for this study:

- Regarding the first aim of this study, it was hypothesised that TTSA would decrease separation anxiety and challenging behaviour in adults with intellectual and visual disabilities.

- As regards the second aim, the psychosocial functioning and the quality of life of the participants were expected to increase due to the implementation of TTSA.
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The following research questions were formulated for this study:

- Can technology assisted therapy for separation anxiety (TTSA) decrease separation anxiety and challenging behaviour as experienced by adults with ID and visual impairment?
- Does TTSA have an effect on the psychosocial functioning and quality of life of the participants?

1.9 Ethical considerations

This study forms part of a larger study for which medical ethical approval was obtained from the Vrije University Medical Centre Medical-Ethical Review Board (NL33646.029.11). Please refer to the attached letter (Addendum).

Furthermore, all the participants agreed to partake in this study by providing written, informed consent. Information letters were read and explained to each participant and hard copies were provided which they could take home to be read by another person. Data gathering started in July 2011 and concluded in August 2012. In order to ensure confidentiality, each participant was given a participant number.

1.10 Outline of the study

Section I of this document provides a general introduction to separation anxiety experienced and challenging behaviour exhibited by adults with ID and visual impairment, and their psychosocial functioning and quality of life, as well as a description of the methodology used to conduct this study. Section II specifies the author guidelines for the Journal of Applied Research in Intellectual Disability and includes the article titled: *The effect of technology assisted*
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therapy for adults with intellectual and visual impairment suffering from separation anxiety and challenging behaviour. Section III includes a critical reflection by the researcher on the research and a complete reference list.
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References


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SECTION 2: ARTICLE:

The effect of technology assisted therapy for intellectually and visually impaired adults suffering from separation anxiety: conquering the fear
2.1 Guidelines for authors: Journal of Applied Research in Intellectual Disabilities

General

The Journal of Applied Research in Intellectual Disabilities is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.
Ethical guidelines

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of
the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

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Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

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Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

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TECHNOLOGY ASSISTED THERAPY FOR SEPARATION ANXIETY

The effect of technology assisted therapy for intellectually and visually impaired adults suffering from separation anxiety: conquering the fear

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2.2 MANUSCRIPT

Abstract

**Background:** Persons with an intellectual disability are at risk of developing separation anxiety and, if left untreated, this can be a risk factor for the development of psychopathology. The effects of an intervention, namely Technology Assisted Therapy for Separation Anxiety, were examined on the separation anxiety, challenging behaviour, psychosocial functioning and quality of life experienced by moderate to mild intellectually and visually disabled adults.

**Materials and Methods:** A case study (N=6) pre-experimental within group design with randomised multiple baselines and staggered intervention start points was used. The variables were monitored with standardised instruments. The frequencies of each participant’s use of the technology and the frequency and intensity of their behaviour were recorded over time.

**Results:** The separation anxiety and challenging behaviour experienced by the participants decreased significantly and their psychosocial functioning and quality of life increased significantly.

**Conclusions:** Technology assisted Therapy for Separation Anxiety has the potential to be a valid intervention to address separation anxiety in adults with visual and moderate to mild intellectual disabilities.

**Keywords:** Intellectual Disability, Multiple case study, Psychosocial functioning, Quality of Life, Separation Anxiety, Technology, Treatment, Visual Disability
The effect of technology assisted therapy for intellectually and visually impaired adults suffering from separation anxiety: conquering the fear

Persons with an intellectual disability (ID) are at risk of developing separation anxiety (Emerson 2003; Emerson & Hatton 2007). This can be explained by insecure attachment relationships, which are more often found among people with ID than among normally developed peers (Clegg & Sheard, 2002). The limited cognitive skills characteristic of ID is identified by Janssen et al. (2002) as a risk factor for the development of an insecure attachment relationship in this population. An insecure attachment relationship in turn might put this population at risk for developing psychopathology, including separation anxiety (Greenberg 1999). The limited cognitive skills typically found in persons with ID refer to developmental delays regarding object and person permanence, and identifying and selecting attachment behaviour to suit the situation (Cassidy 1999). Object and person permanence are abstract cognitive concepts that involve the understanding that an object or person continues to exist when removed from the visual field (Mayekiso 2008). During the sensory-motor phase, which is normally associated with the first 18 months of life, the abstract concept of object and person permanence is mastered. Throughout this phase children rely on their senses to form cognitive representations of their world (Piaget 1964). Attachment behaviour is used by the infant to signal the caregiver in times of distress, resulting in proximity between the infant and the caregiver. Denial of proximity to the caregiver in stressful situations could give rise to anxiety (Cassidy 1999). A visual impairment might cause a delay in this cognitive development (Bals et al. 2002), as shown in a study by Rogers and Puchalski (1988), with the construction of the schema of object permanence in visually disabled children being delayed by up to 10 months. Limitations regarding these cognitive skills, person permanence and selection of attachment behaviour might
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thus cause persons with ID and a visual impairment to function in a nearly fixed condition of separation distress (Janssen et al. 2002). Separation anxiety is up to four times more prevalent among persons with ID compared to persons without it (Emerson 2003; Emerson & Hatton 2007) and, if left untreated, can be a risk factor for the development of psychopathology later in life (Greenberg 1999; Nauta & Emmelkamp 2012). However, little research has been done on the treatment of separation anxiety among persons with ID, and even less on the treatment of members of this population who have a comorbid visual impairment (Hagopian & Jennet 2008).

Research indicates that therapy techniques for treating anxiety in persons without ID can be applied to persons with ID (Hagopian & Jennet 2008; Didden et al. 2012), but these studies focussed primarily on phobic disorders, while treatments for other anxiety disorders are not as profusely considered (Hagopian & Jennet 2008). These studies suggested that therapy based on behavioural components such as graduated exposure and reinforcement can be used to address anxiety in persons with ID (Hagopian & Jennet 2008). Schuengel et al. (2013) indicated that interventions effective for normal developing children and adults might be used as a foundation for the development of new therapy methods for children and adults with ID. Didden et al. (2012) found relaxation and desensitisation methods to be effective in reducing symptoms of anxiety and phobias, but emphasise the lack of intervention methods for complex phobias and general anxiety disorder. Self-help guides have been developed for professional caregivers that aim to increase caregivers’ knowledge regarding their role in establishing secure attachments in clients with ID (e.g. Sterkenburg 2012). However, further research is needed to confirm the effect of these guides (Schuengel et al. 2013). The lack of intervention methods specifically aimed at addressing anxiety, compared to phobic disorders, as well as the lack of interventions specifically developed for persons with ID, motivated the current study.
In a review by Pruijssers et al. (2012) it was concluded that anxiety in persons with ID can be associated with challenging behaviour, but that this association is rather complex. Both anxiety and challenging behaviour could cause an increase in the other, depending on the situation, which might limit treatment options (Janssen et al. 2002). Psychological intervention can address challenging behaviour in persons with ID. In particular, research shows that attachment therapy might be useful in treating the prevalence of challenging behaviour in persons with ID (Sterkenburg et al. 2008). In a study by De Schipper and Schuengel (2010), a negative association between challenging behaviour and attachment behaviour in persons with ID was found. The same authors emphasised the positive association between the security of an attachment relationship and the attachment behaviour exhibited by persons with ID. It is known that insecure attachment relationships increase the risk of developing separation anxiety (Greenberg 1999). It can thus be reasoned that a secure attachment relationship and attachment-based therapy might lead to an increase in attachment behaviour, which will in turn decrease challenging behaviour (aggressive and intrusive behaviour) and separation anxiety experienced by the person with ID (see Figure 1).

[Place Figure 1 here]

Insecure attachment relationships (Berlin et al. 2008) and psychopathology (Ormel et al. 1994; Rodriguez et al. 2005; Ansell et al. 2007), including anxiety disorders (Ormel et al. 1994; Quilty et al. 2003; Ansell et al. 2007; Olatunji et al. 2007; Beard et al. 2010; D’Avanzato et al. 2013; Essau et al. 2014) can impair the psychosocial functioning of persons experiencing these difficulties. In this study psychosocial functioning was categorised in two domains, namely
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psychological and social functioning. The degree of psychological functioning was determined by establishing the presence of psychopathological symptoms. The degree of social functioning was investigated by evaluating symptoms of withdrawal, as well as social interaction with friends. Furthermore, insecure attachment relationships (Berlin et al. 2008), psychopathology (Quilty et al. 2003), anxiety disorders (Ormel et al. 1994; Quilty et al. 2003; Stein & Heimberg 2004; Olatunji et al. 2007; Barrera & Norton 2009; Beard et al. 2010; D’Avanzato et al. 2013) and challenging behaviour (Janssen et al. 2002) can compromise the quality of life of the persons suffering from these complications. The biopsychosocial perspective on clinical treatment has promoted the relevance of psychosocial functioning and quality of life in the treatment of psychiatric disorders. Thus the aim of treatment is no longer to only alleviate symptoms, but also to increase psychosocial functioning and quality of life (Caldirola et al. 2014). A study by Rodriguez et al. (2005) reinforces this argument by demonstrating that poor psychosocial functioning significantly increases the risk of relapse in recovered individuals who suffered from anxiety. It is therefore essential to address psychosocial functioning and quality of life in the treatment of psychopathology (Moitra et al. 2014). The prevalence of insecure attachment, psychopathology, separation anxiety and challenging behaviour in the ID population are significant risk factors for decreased psychosocial functioning and quality of life among this population. The current study therefore aimed to address separation anxiety and challenging behaviour through the use of an attachment theory-based intervention to increase the psychosocial functioning and quality of life of the ID participants.

A systematic literature review by Den Brok and Sterkenburg (2015) demonstrated that the use of technology in psychological intervention is becoming popular. Persons with ID, however, are often excluded from the social, vocational, health and safety benefits that
mainstream mobile phone technology offers (Stock et al. 2008; Davidson 2012). Bryan et al. (2007) suggested that persons with ID use mobile phone technology much less compared to persons without ID due to the complexity of the software and the physical attributes of the hardware of modern mobile phone technology e.g. small buttons and screens. Gutiérrez and Martorell (2011) attempted to explain this phenomenon by arguing that investigations into new communications technologies rarely include the ID population. In response to this, Stock et al. (2008) developed a mobile phone prototype specially adapted for persons with ID. The prototype proved to facilitate more independent mobile phone use among persons with ID. Various studies demonstrated the possibility of successfully incorporating the use of technology into education (Davidson 2012), skill attainment, learning and task management (Mechling 2011). However, Mechling (2011) correctly stated that research to date regarding the application of electronic technologies in intervention methods for the intellectually disabled population is merely preliminary. Further research is thus needed to explore the benefits of technology for the ID population (Scherer 2012). The recent systematic literature review by Den Brok and Sterkenburg (2015) reported five studies using mobile technology to teach cognitive concepts such as daily living skills, vocational skills, safety skills, time perception, imagination, etc. Two of these studies showed effective teaching of emotion concepts through the use of mobile technology. They also reported that advanced technologies such as virtual reality were used effectively to facilitate the attainment of cognitive and emotional concepts. Thus it follows that advanced technology could also contribute to learning an abstract concept such as person permanence. Although the use of cellular technology to improve even primary health care has been investigated (Hill et al. 2012), the use of technology aimed at teaching cognitive concepts such
as person permanence, and to thereby overcome separation anxiety in persons with ID, has not been studied.

Technology Assisted Therapy for Separation Anxiety (TTSA) was developed for the purposes of this study to address separation anxiety in visually impaired clients with mild to moderate intellectual disabilities. The therapy combined the use of a specifically adjusted mobile phone (iPhone touch) with reality bound communication. The mobile phone was adapted in such a way that it enabled optimal utilisation of the technology by the target group. A simplified application, which could be downloaded, made it possible for the participants to send fixed messages regarding their moods to their caregiver when they were physically apart from each other. These conveyed the emotions happy, sad, angry and anxious, with an option to ask for help. The caregivers responded to messages with a fixed message on a similar device. For example, if the participant sent the message “I am sad”, the caregiver replied with the corresponding option “you are sad”, thus acknowledging the sender’s emotion. During subsequent meetings between the participant and caregiver, each message exchanged was discussed according to a set protocol. A child lock function prevented the participant from accidentally exiting the application, while a pouch fitted with Braille words indicated the different message options.

This study intended to determine the efficacy of TTSA in lowering separation anxiety and challenging behaviour in persons with ID and visual impairment. The main aim of the study was to determine whether separation anxiety levels experienced and challenging behaviour exhibited by the participants decreased throughout the therapy and whether this reduction had an influence on the psychosocial functioning and quality of life of the participants. It was expected that the separation anxiety levels and challenging behaviour of the participants would decrease
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during therapy, which would in turn result in an increase in psychosocial functioning and quality of life.

**Methods**

**Design**

The study was conducted within a quantitative frame of reference. A pre-experimental-\((AB_1C_1B_2C_2D)\) within group design with multiple baselines and staggered intervention start points was used. Phase 1(A) was preceded by a two-week training period, during which the participants were introduced to the technology – an iPhone touch that was specially adapted for visually and intellectually impaired persons, and which contained tailor-made software. During phase 1 (A) the participants used the technology for two weeks without receiving any response. This phase established a baseline measure and provided the participant with an opportunity to become accustomed to the technology. The instrument can have a temporary stimulating effect on the participant that can distract them from their feelings of separation anxiety. Phase A thus provided a timeframe for this effect to pass before the data collection started. During the second phase (B\(_1\)) the participants sent messages and received an automatic response from a computer. The duration of this phase varied between 11 and 21 days. In the third phase (C\(_1\)) the computer response was replaced by a response from the caregiver. In addition, all exchanged messages were discussed during the subsequent meeting between the caregiver and participant. These discussions were guided by a set protocol. This intervention phase continued for three weeks. Phase 2 (B\(_2\)) and phase 3 (C\(_2\)) were repeated for three weeks each. The repeated design, firstly, determined whether the intervention effect seen in phase three ceased; and, secondly, prevented the possibility that the changes found in phases one, two and three could be ascribed to natural changes in the participants. Thus, any change in behaviour could be ascribed to the effect of the
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intervention (Kratochwill & Levin, 2010). At the beginning of phase D the participants returned the iPhones and a follow-up discussion was facilitated with the participants regarding their experience of the intervention, while the caregivers conveyed their perceptions by completing a questionnaire. The time allocated for this phase was three weeks. The timeframe allocated for the whole intervention process varied between 17 and 18 weeks.

Randomised multiple-baselines with staggered intervention start points were used. To determine the start point of the intervention phase, a randomised phase start-point model was used. According to Kratochwill et al. (2012), when a multiple baseline design is used to measure standards, a minimum of six phases must be included, each with a minimum of five data points. A random selection from points 8 to 21 determined the start point of the intervention phase. Thus 14 potential start points could be identified. To increase randomisation, the randomised phase start-point model was repeated to determine three final phase start points (blocks). To ensure a staggered design, the total amount of measure points in the B-phase differed with at least four measure points between the three blocks (Bulté & Onghena 2009). The start-point in the intervention phase of block 2 could therefore be initiated from measure point 12 onwards. Likewise the intervention phase (C1) of block three might have started from measure point 16 onwards. By means of the randomised procedure, it was decided that the B1 phase would last 10 days for block one, 15 days for block two and 20 days for block three. The first three participants were randomly assigned to a block each. Participants 4 to 6 where then allocated using the same procedure. Refer to Table 1 for an illustration of the staggered design.

[ Place Table 1 here ]
According to Kratochwill and Levin (2010), randomisation can be advantageous when included in case study designs because it reinforces the internal validity and methodological integrity, and allows for the possibility of more statistical manipulation.

Participants

The sample consisted of six adults with visual and intellectual disabilities who reside in group homes at an organisation in the Netherlands. The participants were selected by means of purposive sampling. The inclusion criteria specified that participants had to be older than 18 years, had a moderate to mild intellectual disability (IQ between 40 and 70) with a visual impairment, experienced separation anxiety in the absence of the caregiver and were physically able to operate a mobile phone. Potential participants who were deaf and/or presented with autism were excluded from the study. The participants’ demographical information is listed in Table 2. General complaints brought on by separation anxiety include physical symptoms (headaches, abdominal pain, back pain), nervousness, nightmares, behavioural problems, diminished social contact and excessive worrying, especially that something will happen to the caregiver causing them not to return. All the caregivers who participated in the study were well trained to provide specialised care.

All the participants agreed to partake in this study by providing informed consent. Information letters were read to each participant and hard copies were provided, which they could take home to be read by another person. Medical ethical approval for the study was acquired from the VU University Medical Centre Medical-Ethical Review Board (NL33646.029.11). The data collection started in July 2011 and concluded in August 2012.
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[Place Table 2 here]

Intervention

The current study aimed to determine whether a specific therapy method, namely Technology assisted Therapy for Separation Anxiety (TTSA), was efficient in decreasing separation anxiety in adults with a visual disability and ID. The TTSA was developed to address separation anxiety in visually impaired clients with mild to moderate ID by teaching the participants the concept of person permanence through repetition. A specifically adjusted mobile phone (iPhone touch) was used in combination with reality bound communication. A basic application enabled the participants to send predefined messages regarding their mood to their caregivers, to which the caregivers could respond, acknowledging the emotion, with a predefined message. These messages were discussed during a subsequent meeting between the participant and caregiver. The use of the technology in the caregiver’s physical absence, as well as the repetitive nature of the intervention, aimed to teach the participant the concept of person permanence and thus lower separation anxiety.

Measures and procedure

The effect of the intervention was determined by monitoring the changes in levels of separation anxiety, challenging behaviour, psychological functioning, social functioning and quality of life by administering a battery of standardised instruments at the end of each phase in the intervention. The frequency of each type of message was recorded for each participant throughout the intervention. The professional caregivers in the participants’ residential homes were instructed to record the frequency and intensity of the behaviour of the participants (e.g. distress, behavioural problems, clamping behaviour, anxiety) while the participants were at home.
and at work. A web-based computerised data collection system, ‘Qualtrics’, was used for the
daily reporting of challenging behaviour. The time needed for the daily scoring was
approximately five minutes and the caregivers were reminded by a computerised reminder to
record the behaviour. The reminder was visible on the computer on which the caregivers checked
their e-mails.

**Standardised instruments used to measure changes in variables**

*Adult Behaviour Checklist for ages 18-59 (ABCL):* The anxious/depressed, aggressive
behaviour, intrusive and withdrawn syndrome scales were used to measure the changes in
separation anxiety, challenging behaviour and loneliness. The observer rating scale was
completed by the caregiver. The ABCL was found to be a reliable and valid measure for the
assessment of psychopathology in persons with a mild intellectual disability (Tenneij & Koot
2007). A Cronbach Alpha correlation found the inter-rater reliability for the anxious/depressed-
and the aggressive behaviour scale to be good, with a correlation of .89 each. The withdrawal
and the intrusive scale was found to be fair, with results of .73 and .79 respectively. ICC
calculations for the anxious/depressed scale delivered results of .62, which can be described as
good, while the calculations for the aggressive behaviour scale were calculated at .75 (excellent).
The ICC calculations for the withdrawal scale were found to be fair (.56) and the intrusive scale
delivered excellent results (.75) (Tenneij & Koot 2007).

*Brief Symptom Inventory (BSI):* The BSI total scale was used to measure psychosocial
functioning, while the anxiety subscale was used to measure changes in separation anxiety
symptoms. The participants were assisted by an independent mentor to complete the
questionnaire. The BSI total scale internal consistency and the anxiety subscale internal
consistency were calculated by Wieland *et al.* (2012) to be $\alpha = .96$ and $\alpha = .82$ respectively. The
degree of variation between subscales was estimated to range from $\alpha = .39$ to $\alpha = .79$, which depicts different inter-scale relations. Discriminant validity of the BSI proves that the instrument can be used to identify psychopathology, as well as to differentiate between various diagnoses (Wieland et al. 2012).

*Psychopathology Inventory for Mentally Retarded Adults (PIMRA):* The anxiety subscale of the PIMRA was completed by the caregiver. The internal consistency for the anxiety scale was found to be $\alpha = .63$, which is considered to be a modest to adequate internal consistency (Van Minnem et al. 1994).

*Intellectual Disability Quality of Life (IDQOL):* The IDQOL was used to examine the quality of life in persons with an intellectual disability. The participants were helped by independent mentors to complete the questionnaire. The questionnaire used a 5-point Likert-type scale and was adjusted for the specific population by making use of a graphic rating scale. The IDQOL measures quality of life in persons with intellectual disability and presents an adequate internal consistency ($\alpha = .86$) (Hoekman et al. 2001).

**Data analysis**

Non-parametric Friedman tests were used to compare the results of the various instruments at different time points for each participant. These instruments measure separation anxiety, challenging behaviour, psychological and social functioning, and quality of life. It was expected that the level of separation anxiety experienced and the challenging behaviour exhibited by the participants would decrease when measured across the entire intervention period and that the psychosocial functioning and quality of life of the participants would increase during the intervention period.
A meta-analysis according to Fisher’s method (De Weert & Van Geert 2002) was completed for each questionnaire by combining the p-values of the non-parametric Friedman tests respectively. A natural logarithm was calculated for each P-value. The chi-squared deviation was determined by multiplying the sum of the natural logarithms by -2. The number of P-values multiplied by 2 was used as the degrees of freedom. P-values of < .005 were substituted with .01 to avoid the possibility of grounding the significance on only the one P-value. In cases where the change in the variable was not in the anticipated direction, the P-value was replaced with .5 (Birnbaum 1955; De Weert & Van Geert 2002). It was hypothesised that the result would be an overall decrease in separation anxiety levels and challenging behaviour, with an increase in psychosocial functioning and quality of life.

To account for missing scores on the questionnaires, the mean of the scores adjacent to the missing value were calculated and imputed. In the case where two or more scores from a single item were missing, the item was removed from the results. Scores were imputed twice in the IDQOL to account for a single missing score in item eight and nine respectively. Item 122 of the ABCL-caregiver questionnaire was regarded as irrelevant because it pertained to the maintenance of a job. It was therefore not included in the questionnaire. Items nine and 39 of the ABCL-caregiver questionnaire enquired about life, dying and suicide, which made participant 3 extremely upset and resistant. These items were thus omitted in data collections with him.

Non-parametric Friedman tests were used to test the frequency of the various messages sent. These scores were meta-analytically combined according to Fisher’s method (De Weert & Van Geert 2002). The authors hypothesised that the frequency of anxious, sad and angry messages would decrease, while the frequency of happy messages would increase or remain stable. The frequency of the help messages sent was expected to decrease or stay constant. All
messages sent were recorded in a database. The data was inspected visually to identify outliers. A single data point was considered to be an outlier and was altered into a missing value. This data point can be found on the 14\textsuperscript{th} day of phase C\textsubscript{1}, when participant 1 sent 115 “I am happy” messages.

The various behaviour options in the list used for the daily observations of behaviour in the residential homes and work environment of the participants were grouped according to separation anxiety behaviour, challenging behaviour and positive behaviour. Separation anxiety behaviour included stress, anxiety and clinging behaviour. The frequency and intensity of these behaviours were recorded daily and analysed with descriptive statistics. It was hypothesised that the intensity and frequency of the separation anxiety behaviour would decrease.

**Results**

**Anxiety**

The separation anxiety experienced by the participants decreased significantly throughout the intervention. The Fisher’s combination of p-values showed a significant decrease on the PIMRA anxiety subscale using the non-parametric Friedman test results (combined $\chi^2$ deviation = 25.45, $p < .025$). The meta-analytically combined p-value results of the non-parametric Friedman test done on the anxiety subscale (subscale 5) of the BSI (combined $\chi^2$ deviation = 25.34, $p < .025$) showed a significant decrease over time. The combined result of the Friedman test p-values on the ABCL-caregiver anxiety subscale showed a significant decrease in anxiety (combined $\chi^2$ deviation = 31.8, $p < .005$). Table 3 shows the mean scores and $\chi^2$-values of the PIMRA and BSI, while Table 4 shows the mean scores and $\chi^2$-values of the ABCL. The meta-analytically combined result of the Friedman test done on the frequency of anxiety messages sent
showed a significant decrease during the course of the intervention (combined $\chi^2$ deviation = 36.89, $p < .001$). The meta-analyses were done according to the Fisher’s combination of p-values (De Weerth & Van Geert 2002). Figure 2 depicts the anxious messages sent by the participants per day. The frequency of the anxiety behaviour observed by the caregivers decreases for four participants (participant 3, 4, 5, and 6) in the living environment and three participants (participant 3, 4 and 6) at work. For three of the participants (participants 3, 4 and 5) the intensity of anxious behaviour (stress, anxiety and clinging behaviour) shows a decrease in the living environment and for three participants (participants 3, 4 and 6) the results show a decrease in the working environment.

Challenging behaviour

The challenging behaviour exhibited by the participants during the intervention also showed a significant decrease. The p-values of the non-parametric Friedman test done on the six participants on the total scale of the ABCL-caregiver questionnaire were meta-analytically combined and showed significantly less challenging behaviour from the start to the end of therapy (combined $\chi^2$ deviation = 34.89, $p < .001$). A similar result was found in the meta-analysis of the non-parametric Friedman results of the ABCL-caregiver aggressive subscale (combined $\chi^2$ deviation = 50.12, $p < .001$), as well as in the combination of the non-parametric Friedman results of the ABCL-caregiver intrusive subscale (combined $\chi^2$ deviation = 39.86, $p <$
The combined result of the Friedman test done on the frequency of angry messages sent indicated that angry messages were sent significantly less as therapy progressed (combined $\chi^2$ deviation = 29.37, $p < .005$).

**Psychosocial functioning and quality of life**

Psychological functioning increased significantly, as indicated by the combined scores of the non-parametric Friedman test done on the BSI total scale (combined $\chi^2$ deviation = 55.26, $p < .001$). The Friedman results of the ABCL-caregiver withdrawn scale, when meta-analytically combined, showed a significant increase in social functioning (combined $\chi^2$ deviation = 26.11, $p < .025$). The combined result of the non-parametric Friedman results related to the ABCL-friends questionnaire used in the measurement of social functioning did not indicate a significant change. The combined result of the Friedman test done on the frequency of sad messages sent during the intervention period showed a significant decrease (combined $\chi^2$ deviation = 24.97, $p < .025$).

Quality of life measurements increased significantly, as indicated by the combined scores of the non-parametric Friedman results for the IDQOL total scale (combined $\chi^2$ deviation = 48.46, $p < .001$). The combined result of the Friedman test done on the frequency of happy messages sent indicated a significant increase in happy messages sent throughout the intervention period (combined $\chi^2$ deviation = 23.96, $p < .005$). Lastly, the Friedman test done on the messages asking for help showed a significant decrease throughout the intervention period (combined $\chi^2$ deviation = 31.74, $p < .005$).
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Discussion

This study examined whether technology assisted therapy can aid adults with an intellectual disability and visual impairment to conquer their separation anxiety and overcome challenging behaviour, and whether overcoming these issues significantly enhanced their psychosocial functioning and quality of life. The results showed an overall decrease in separation anxiety levels and challenging behaviour, with an increase in psychosocial functioning and quality of life. TTSA is an attachment based therapy method which facilitates the formation of secure attachment relationships. Secure attachment relationships can lead to increased attachment behaviour (Cassidy 1999; De Schipper & Schuengel 2010), which is known to decrease separation anxiety (Greenberg 1999) and challenging behaviour (Sterkenburg et al. 2008). The results of this research indicate that Technology assisted Therapy for Separation Anxiety indeed has the potential to be considered a valid intervention to address separation anxiety in adults with visual and moderate to mild intellectual disabilities. One objection might be that the participants could become dependent on the device, but this was negated by the fact that none of the participants requested to use the technology after the final phase of the intervention. This indicates that technology can be successfully employed to teach abstract concepts such as person permanence.

The decrease in anxiety indicated by both the standardised instruments and the decreasing number of anxiety messages sent during the intervention indicate promising prospects for the treatment of separation anxiety in this population in the context of a dearth of existing research. The complete battery of instruments used to measure challenging behaviour and the frequency of angry messages sent also showed a significant decrease in challenging behaviour as therapy progressed. These results concur with other studies, which found that challenging behaviour in
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intellectually disabled persons decreased when attachment based intervention was applied (Sterkenburg et al. 2008; De Schipper & Schuengel 2010). The daily observations recorded by the caregivers also showed less frequent and intense anxiety behaviour for three participants. However, being a subjective rating, the larger number of caregivers rating behaviour, might have led to inconsistent results.

The regular experience of anxiety might greatly influence psychosocial functioning (Ormel et al. 1994; Quilty et al. 2003; Ansell et al. 2007; Olatunji et al. 2007; Beard et al. 2010; D’Avanzato et al. 2013; Essau et al. 2014) while challenging behaviour might be interpreted negatively by the social community, which can cause persons with ID to be excluded from social activities (Didden et al. 2012) and thus increase their risk of experiencing decreased quality of life (Janssen et al. 2002). The increase in social functioning, the decrease in sad messages sent, the increase in happy messages sent and the decrease in both separation anxiety experienced and challenging behaviour exhibited by the participants due to TTSA, reduced the risk of them experiencing diminished psychosocial functioning and quality of life. It is, however, noteworthy that one of the instruments measuring social functioning did not yield significant results. This instrument includes four questions regarding the participants’ friends. The questions enquiring about the frequency of visits or contact with friends require the participant to rate these monthly. Since the measurement of variables took place after each phase and the longest phase was 21 days, these questions were asked more than once in a month. The timeframe of the intervention was thus too short to measure change appropriately. This caused the non-significant result of this questionnaire. The results indicative of the increased psychosocial functioning and quality of life are, however, overwhelming and it can thus be concluded that TTSA, by successfully decreasing
separation anxiety and challenging behaviour, can increase the psychosocial functioning and quality of life of persons with ID.

The inclusion of mobile technologies in intervention methods for persons with intellectual disabilities has only recently become a topic of discussion, and the research available on this topic is scarce and still introductory (Mechling 2011). Mobile technology, however, proves to hold many benefits for the user (Stock et al. 2008; Davidson 2012) and it is therefore important to further the research exploring the inclusion possibilities of mobile technology in the treatment of persons with ID (Scherer 2012). This study proved the inclusion successful and worthy. A few obstacles were encountered during the research process. Similarly to what Bryan et al. (2007) point out, the physical attributes of the technology, as well as software complexity could inhibit persons with ID from using the technology optimally. Although the software for this technology was specially developed and the hardware adapted for the ID population, the high number of messages that were selected but then cancelled could indicate that the participants frequently made errors. Further research needs to be conducted to determine the reason for this. It is furthermore noteworthy that this is, to our knowledge, the only study thus far which explored the inclusion of technology in the treatment of separation anxiety in persons with ID. It thus stands to reason that more research in this field is necessary.

The inclusion of technology in therapeutic methods does pose some challenges, as identified by Davidson (2012) in an article exploring the impact of technology used in teaching everyday skills to persons with ID. Davidson found that, as with any other consumer of technological devices, the participants in her study were rather inclined to use the technology for transferring music, watching films and playing games than using it for learning purposes. This poses a challenge for future researchers who wish to include technology in therapeutic methods,
because participants might lose interest in the therapeutic application of the technology. This was not a problem in the current study, as indicated by the analysis of the help messages sent. These decreased during the intervention period, which indicates less dependent behaviour exhibited by the participants, but it did not fade entirely. The participants therefore used the technology for its intended purpose until the end of the intervention.

It is also worth noting that in a review of the technologies available for persons with ID and autism, Mechling (2011) discusses seven technological devices, each with a different function. Perhaps one device needs to be developed that includes all the technological therapeutic options, e.g. step-by-step learning videos, task management cues, alarm clocks, etc, as well as the basic features of a smartphone. It is well known by now that persons with ID are often excluded from the benefits that mainstream technology offers (Stock et al. 2008; Davidson 2012) for various reasons, including physical attributes and software complexities (Bryan et al. 2007). Compared to the time, money and effort spent on the development of smartphone technologies for the mainstream population, would it not be justified to develop a similar product suitable for the ID population?

It is acknowledged that while the hypothesis posited at the outset of this research, namely that the separation anxiety and challenging behaviour would decrease, resulting in an increase in psychosocial functioning and quality of life of the participants, was confirmed by the results, further research is necessary to determine the long-term sustainability of the intervention effects.
Acknowledgements

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References


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Sterkenburg P.S. (2012) *Developing Attachment: A Workbook for Building up a Secure Relationship with Children or Adults with Severe Intellectual or Multiple Disabilities.* Microweb Edu, Doorn, The Netherlands.


Table 1 Randomised Multiple-baseline Blocked Phase-order Randomly Paired with 21 Time Periods, and 14 C₁ Potential Start Points

<table>
<thead>
<tr>
<th>Participant</th>
<th>Block</th>
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</tr>
</tbody>
</table>

Note
Potential C₁ start points are between time periods 8 and 21 inclusive.*randomly selected start-point
B₁: Intervention phase 1
C₁: Intervention phase 2
### Table 2 Characteristics of the Six Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Living and working environment</th>
<th>Visual impairment</th>
<th>Mobility</th>
</tr>
</thead>
</table>
| 1           | Male | 27  | Resides in group home during the week.  
  Spends weekends with family.  
  Delivers mail during the day.  
  Needs constant supervision. | Visually impaired | Bound to wheelchair - spasticity |
| 2           | Male | 50  | Resides in a group home.  
  Works as paper shredder 3 days per week.  
  Attends day time activities 2 days per week.  
  No constant supervision needed.  
  Substitute caregivers used during study due to sick leave taken by full time caregivers. | Visually impaired | Mobile |
| 3           | Male | 48  | Resides in a group home.  
  Works 5 days per week (bicycle maintenance).  
  No constant supervision needed. | Visually impaired | Mobile |
| 4           | Male | 56  | Resides in a group home.  
  Works 5 days a week (logging).  
  No constant supervision needed.  
  Ill during study period. | Visually impaired | Mobile |
| 5           | Male | 53  | Resides in a group home.  
  Works 4 days a week (cleaning).  
  No constant supervision needed. | Differentiate only between light and dark | Mobile |
| 6           | Female | 38 | Resides in a group home.  
  Works 5 days a week (industrial).  
  Constant supervision. | Blind | Mobile |
### Table 3 Mean and Standard Deviation (SD) of the Anxiety Levels at the Start and End of the Intervention

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Participant</th>
<th>First phase of intervention mean (SD)</th>
<th>Last phase of intervention mean (SD)</th>
<th>$\chi^2$ (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BSI anxiety subscale</td>
<td>1</td>
<td>2.5 (1.05)</td>
<td>4.0 (0.0)</td>
<td>19.35 (6)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2.5 (1.05)</td>
<td>3.0 (0.0)</td>
<td>5.45 (6)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>2.33 (1.03)</td>
<td>3.00 (0.89)</td>
<td>8.19 (6)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>1.33 (0.52)</td>
<td>2.5 (0.84)</td>
<td>20.43 (6) **</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>3.17 (0.98)</td>
<td>3.33 (1.52)</td>
<td>4.78 (6)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>2.00 (1.55)</td>
<td>1.83 (1.33)</td>
<td>13.36 (6) *</td>
</tr>
<tr>
<td>PIMRA total scale</td>
<td>1</td>
<td>1.43 (0.53)</td>
<td>1.43 (0.53)</td>
<td>8.4 (6)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1.57 (0.53)</td>
<td>1.71 (0.49)</td>
<td>3.82 (6)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>1.57 (0.53)</td>
<td>1.43 (0.53)</td>
<td>12.00 (6)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>2.00 (0.00)</td>
<td>2.00 (0.00)</td>
<td>20.9 (6) **</td>
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<tr>
<td></td>
<td>5</td>
<td>1.43 (0.53)</td>
<td>1.29 (0.49)</td>
<td>6.55 (6)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>1.86 (0.38)</td>
<td>1.43 (0.53)</td>
<td>9.93 (6)</td>
</tr>
</tbody>
</table>

**Note**

- $a$ n = 6
- $b$ n = 7

High scores indicate decreased anxiety

- * $p < .05$
- ** $p < .005$
Table 4 Mean and Standard Deviation (SD) of the Anxiety Levels at the Start and End of the Intervention for the ABCL-Caregiver Anxiety Subscale.

<table>
<thead>
<tr>
<th>Participant</th>
<th>First phase of intervention mean (SD)</th>
<th>Last phase of intervention mean (SD)</th>
<th>$\chi^2$ (df 6, n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.36 (0.74)</td>
<td>0.71 (0.61)</td>
<td>17.56 **</td>
</tr>
<tr>
<td>2</td>
<td>1.36 (0.50)</td>
<td>1.43 (0.65)</td>
<td>26.3 **</td>
</tr>
<tr>
<td>3</td>
<td>0.71 (0.61)</td>
<td>0.64 (0.50)</td>
<td>10.57</td>
</tr>
<tr>
<td>4</td>
<td>1.93 (0.27)</td>
<td>2.00 (0.00)</td>
<td>55.20 **</td>
</tr>
<tr>
<td>5</td>
<td>0.79 (0.58)</td>
<td>0.50 (0.65)</td>
<td>7.96</td>
</tr>
<tr>
<td>6</td>
<td>0.64 (0.74)</td>
<td>1.14 (0.77)</td>
<td>16.52 *</td>
</tr>
</tbody>
</table>

*Note*

High scores indicate decreased anxiety

* $p < .05$

** $p < .005$
**Figure 1** Indication of the relationship between key constructs.
Figure 2 Anxious messages sent per day per participant.
SECTION 3: CRITICAL REFLECTION

Persons with ID are at risk of developing separation anxiety (Emerson, 2003; Emerson & Hatton, 2007) and challenging behaviour (Schuengel & Janssen, 2006) due to prevalent insecure attachment relationships found in this population (Cassidy, 1999; Greenberg, 1999) and their limited cognitive skills (Janssen et al., 2002). Persons with ID suffering from separation anxiety who do not receive treatment are at risk of developing psychopathology (Greenberg, 1999; Nauta & Emmelkamp, 2012). Psychopathology has the potential to significantly decrease the psychosocial functioning (Ansell et al., 2007) and quality of life (Macaskill & Denovan, 2014) of the sufferer. The scarcity of research studies investigating reliable and valid treatment options for persons with ID and comorbid visual impairment who are suffering from separation anxiety serves as a rationale for the current study (Hagopian & Jennet, 2008).

This study investigated the effect of TTSA on the separation anxiety experienced and challenging behaviour exhibited by adults with ID and visual impairment, and whether changes in these variables have an influence on the psychosocial functioning and quality of life of the participants. The TTSA was informed by Bowlby’s attachment theory. The intervention aimed to facilitate the formation of a secure attachment relationship between the participants and the caregivers. The rationale for this endeavour, in part, is that increased attachment behaviour often coincides with a secure attachment relationship (Cassidy, 1999; De Schipper & Schuengel, 2010), which decreases separation anxiety (Greenberg, 1999) and the challenging behaviour (Sterkenburg et al., 2008) exhibited by persons with ID. The results of this study indeed show a decrease in both separation anxiety and challenging behaviour due to the therapy and an increase in the psychosocial functioning and quality of life of the participants.
The nature of one of the standardised instruments might impose some limitations on this study. The ABCL-caregiver questionnaire did not yield significant results. The items on this questionnaire enquire largely about self-esteem. However, self-esteem is not related to separation anxiety. The non-significant results of this questionnaire could therefore be attributed to the focus of most of the items being on self-esteem rather than on separation anxiety. TTSA does not attempt to target self-esteem and it was thus not expected that this aspect would be influenced by the intervention. The non-significant results of this questionnaire are therefore appropriate. Two other standardised instruments were used to measure changes in separation anxiety, which indicated a significant decrease in separation anxiety among the participants. The significant decrease in the frequency of anxiety messages sent by the participants during the intervention phases supports these results. The frequency of anxiety behaviour exhibited by the participants during time spent in their living environment decreased for four participants (participants 3, 4, 5 and 6) while only three participants showed decreased anxiety behaviour at work (participants 3, 4 and 6). The intensity of anxious behaviour decreased in three of the participants in their living environment (participants 3, 4 and 5) and in their working environment (participants 3, 4 and 6). The scale on which the caregivers rated the participants’ behaviour requested an intensity rating on a Likert-type scale. This, being a subjective rating, could have been diversely interpreted by the nine different caregivers who rated the participants’ behaviour, which could have led to the inconsistent results of this data set.

Nevertheless, the entire battery of standardised instruments measuring challenging behaviour, the frequency of the angry messages sent and the frequency and intensity of the challenging behaviour displayed at home and at work indicated a decrease in this behaviour throughout the intervention phases. These results complement results found in other studies.
regarding the decrease of challenging behaviour in intellectually disabled persons due to attachment based intervention (Sterkenburg et al., 2008; De Schipper & Schuengel, 2010).

The psychosocial functioning of a person suffering from regular anxiety could become impaired (Ansell et al., 2007; Beard et al., 2010; D’Avanzato et al., 2013; Essau et al., 2014; Olatunji et al., 2007; Ormel et al., 1994; Quilty et al., 2003). Separation anxiety, being more prevalent in persons with ID (Emerson, 2003; Emerson & Hatton, 2007), is therefore a risk factor for decreased psychosocial functioning. In addition, this population often exhibits challenging behaviour, which society might interpret negatively, causing the ID population to be excluded from social activities (Didden et al., 2012). The influence of this social exclusion on the quality of life of the ID population is transparent (Janssen et al., 2002).

The results of the current study indicated a significant decrease in the frequency of sad messages sent and an increase in the social functioning of the participants. Combined with the decrease in separation anxiety and challenging behaviour, it is evident that TTSA significantly lowered the risk of the participants experiencing decreased psychosocial functioning and quality of life. The increase in the frequency of happy messages sent as the intervention progressed might even prompt one to deduce that TTSA has the potential to increase quality of life. The standardised instruments measuring social functioning did not, however, yield significant results. The nature of the instrument might account for this result. Four questions included in this questionnaire enquired about the frequency of visits or contact that the participant had with friends. Under normal circumstance, the participant is asked to rate these monthly. However, for this study the battery of standardised instruments were completed after each phase in the study and, with the longest phase being 21 days, the participants needed to answer these questions twice in one month. The timeframe within which the intervention took place was therefore too
short to adequately measure change in social activity with this specific instrument. This poses as a limitation on this study and it is recommended that this characteristic of the instrument be taken into account in future research with TTSA.

The overall results of this study indicate the potential of TTSA for treating separation anxiety and challenging behaviour in persons with ID and visual impairment. It is, however, recommended that this study be conducted on a larger sample to verify the results found in the current study. It is further recommended that the limitations discussed in this section be addressed in future studies that include TTSA.

This research not only contributed a potential intervention method to a field in which limited research has been conducted, but also contributed to a relatively new field, namely investigating the inclusion of technology in intervention with persons with ID (Mechling, 2011). The multiple benefits that mobile technology holds for the user (Stock et al., 2008) contribute to the relevance and rationale for conducting research to develop intervention methods supported by mobile technology (Scherer, 2012).

While this study demonstrated the efficacy of using mobile technology in the treatment of separation anxiety and challenging behaviour among persons with ID and visual impairment, the use of mobile technology in this treatment did, however, present some obstacles. Bryan et al. (2007) found that the physical attributes of mobile technology and the complex software usually installed in mainstream mobile devices could decrease the possibility of persons with ID using such devices. For the current study, mobile devices were physically adapted and a simplified application was developed and downloaded into the device. In spite of these adaptations, it can be deduced from the multiple messages selected but cancelled that the participants made multiple errors. The reason for this is unknown and it is recommended that further research regarding the
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cause of the multiple errors made by the participants be conducted. This study, to the author's knowledge, is the first study that explored using mobile technology in an intervention for separation anxiety and challenging behaviour in the ID population. Further research regarding this subject is thus imperative.

Another inevitable challenge related to using mobile technology in therapeutic settings is posed by the various mainstream functions included in mobile technology, such as games, music and videos. Davidson (2012) incorporated mobile technology into the teaching of everyday skills to persons with ID. She found that the participants, not unlike any other users of mobile technology, were more interested in the use of these mainstream functions than using the technology for learning purposes. The challenge for any researcher who wishes to include mobile technology in his or her research is to keep the participant more interested in the therapeutic aspect of the technology than in the mainstream functions. This, however, did not pose a challenge in the current study, as shown by the frequency of the help messages sent. Although these messages declined throughout the intervention, showing a decrease in dependent behaviour, the participants did not cease to use the help message until the end of the intervention. It thus seems that the participants used the technology for its intended purpose throughout the entire intervention phase (despite the fact that they were also able to access iTunes).

Davidson (2012) nevertheless proposes that the mainstream functions of mobile technology be available to the participants in addition to the therapeutic application of the technology because this might serve as motivation to participate in such studies. The current study brings to light a further possible advantage of making mainstream functions available to participants; this research investigated psychosocial functioning and quality of life, and social participation and interaction with friends were consequently measured. If Davidson’s advice had
been followed in the current study, the participants would have been able to phone or text their friends, possibly increasing their social functioning and quality of life. It is therefore recommended that the inclusion of the mainstream functions of the mobile technology be included in any follow-up studies to determine the effect on the social functioning and quality of life of the participants.

Considering the possible benefits of acting on Davidson’s proposal to include the mainstream functions of mobile technology in intervention-based mobile technologies for persons with ID, as well as the multiple technologies available tofacilitate therapy with persons with ID (Mechling, 2011), the benefits that mobile technology provides (Stock et al., 2008) and the current exclusion of the needs of the ID population in the development of mobile technology (Bryan et al., 2007; Davidson, 2012), it seems reasonable to propose that one device, suitable for the needs of the ID population, be developed which includes the mainstream functions of a mobile phone as well as offering the possibility of downloading intervention applications.

Developing and owning multiple technological devices for each need of the ID population seems not only expensive, but also impractical for the owner. It is therefore recommended that the costly and time-consuming development of technological devices with only limited functions for the goal of a specific intervention be discontinued and that a single device, similar to the mainstream smartphone, should be developed for the ID population. Researchers would only then need to develop downloadable applications for their specific interventions, similar to the iPhone application developed for the current study. Compared to the money, effort and time invested in the development of mainstream smartphone technologies, is it not justified to spend some of those resources on the development of a suitable alternative mobile technology for the ID population?
A further consideration is that the current study was conducted in a developed country, which differs in political, economical and cultural context from a developing country such as South Africa (Solarz, 2012). To generalise the results of the current study with no regard for the distinction between the two contexts would render the results unreliable in a South African context. However, the theory and principles informing TTSA remains applicable regardless of social context. It is thus only the medium through which the therapy is provided that poses an obstacle with regards to generalisability of the therapy method to a developing country. The high cost of manufacturing the technological device, compared to other low-tech therapy methods, might impede the distribution of this medium in a developing country, which has fewer resources. The relatively high value of the therapy medium furthermore increases the risk of theft. An analysis of the 2009/10 crime statistics of South Africa shows that the increase in crime in the country is propelled by five categories, of which four are theft-related (Burger, Gould, & Newham, 2010). It is therefore risky to implement TTSA in a South African context. It is nevertheless suggested that further research be conducted to adapt TTSA to such an extent that it would be applicable in a South African context.

Despite these possible challenges in the South African context, the development of a successful intervention method for treating separation anxiety and challenging behaviour in adults with ID and visual impairment, along with the use of mobile technology, constitutes an innovative and valuable contribution to this field of study.


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ADDENDUM – ETHICAL CLEARANCE
Mw. dr. P.S. Sterkenburg
Van der Boechorststraat 1
Kamer 3b-11
1081BT Amsterdam

Geachte mevrouw Sterkenburg,

De Medisch Ethische Toetsingscommissie Vrije Universiteit medisch centrum (bevoegd tot oordenen op grond van WMO art. 2.2.a) oordeelt thans in positieve zin omtrent de uitvoering van het onderzoek met titel:

Mobiele technologie ter ondersteuning van relatieontwikkeling, welbevinden en sociale participatie van mensen met een visuele en verstandelijke beperking

Aanvrager van het onderzoek: dr. P.S. Sterkenburg
Verrichter: VU te Amsterdam
METc VUMc registratienummer: 2011/37

Vergadering en documenten
De goedkeuring, waartoe in principe besloten is in de vergadering van 10-3-2011, is gebaseerd op de volgende documenten:

- Informatiebrief t.b.v. volwassenen versie 2, d.d. 1-4-2011
- Informatiebrief t.b.v. ouders versie 2, d.d. 1-4-2011
- Informatiebrief t.b.v. kinderen versie 2, d.d. 1-4-2011
- ABR-formulier definitief versie 4, d.d. 6-4-2011
- Correspondentie tussen METc VUMc en onderzoeker, d.d. 6-4-2011 en 22-3-2011
- Verzoek tot ontheffing van verzekeringsplicht (in begeleidende brief)
- Faktuuradres (in begeleidende brief)
- Begeleidende brief, d.d. 18-2-2011
- Begrotingsverklaring
- Goedkeuring CWO EMGO, d.d. 26-5-2010 (inclusief correspondentie)
- Privacyreglement ten behoeve van onderzoek in het VUMc, d.d. 2-2-2011
- Protocol versie 1, d.d. 5-1-2011
- Toestemmingsformulier voor de verzorgende ouders/vertegenwoordigers, december 2010
- Toestemmingsformulier kinderen, december 2010
- Informatie voor de proefpersonen; informatie bij brief ouders (kopie artikel InZicht, oktober 2010)
- Informatie voor de proefpersonen; informatie bij brief ouders (handleiding aangepast mobiel, d.d. 29-9-2010)
- Vragenlijst voor begeleider 1: Psychopathology inventory for mentally retarded adults
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- Vragenlijst voor begeleider 2: Sociale redzaamheidschalen verstandelijk gehandicapten
- Vragenlijst voor begeleider 3: The health of the nation outcome scales learning disabilities
- Vragenlijst voor begeleider 4: The adult behavior checklist
- Gedragsvragenlijst voor kinderen van 6-18 jaar
- Vragenlijst voor begeleider 5: The secure base safe haven observations adult version
- Vragenlijst voor begeleider 6: Social validity scale
- Vragenlijst voor begeleider 7: Evaluatie cliënt
- Vragenlijst voor cliënt 1: Intellectual disability quality of life
- Vragenlijst voor cliënt 2: Brief symptom inventory
- Vragenlijst voor cliënt 3: Evaluatie mobielte door cliënt
- CV onafhankelijk arts, drs. C. van Afferen
- CV coördinerend onderzoeker, dr. P. Sterkenburg
- CV hoofdonderzoeker, prof. dr. C. Schuengel
- CV uitvoerend onderzoeker, Ir. W.L.J.E. den Brok MSc

Motivering
De commissie is van oordeel dat het onderzoek voldoet aan het bepaalde in de van toepassing zijnde wet- en regelgeving, met name de WMO en, voorzover relevant, het ICH/GCP richtsnoer.

Verzekering
De commissie verleent aan de verrichter van het onderzoek ontheffing van verzekeringsplicht, gelet op het bepaalde in het Besluit verplichte verzekering bij medisch-wetenschappelijk onderzoek met mensen. Naar het oordeel van de commissie gaat het onderzoek gepaard met geen enkel of verwaarloosbaar risico.

Deelnemende contra
De goedkeuring betreft de uitvoering in het VUmc.

Het betreft een multicenteronderzoek, dat wellicht ook in een of meer andere instellingen in Nederland zal worden uitgevoerd. De coördinator van het onderzoek dient de raad van bestuur/directie van deze instelling(en) om een advies over de lokale uitvoerbaarheid te vragen. Naar aanleiding van dit advies zal de METc VUmc een nader oordeel uitspreken over de participatie van die instelling(en).

Verplichtingen
De commissie verwacht dat
- de startdatum van het onderzoek de commissie ter kennis zal worden gebracht (de startdatum is de datum van het eerste bezoek van de eerste deelnemer)
- elke onverwachte bijWERking die zich tijdens het onderzoek voordoet bij de proefpersonen onverwijld aan de commissie gemeld wordt, voorzien van een toelichting betreffende de consequenties voor het onderzoek
- veranderingen in het onderzoeksprotocol aan de commissie worden voorgelegd, voorzien van een toelichting betreffende de consequenties voor de proefpersonen
- jaarlijks een rapport over de voortgang van het onderzoek aan de commissie zal worden toegestuurd
- de beëindiging van het onderzoek, hetzij omdat het onderzoek voltooid is hetzij om andere redenen, de commissie ter kennis zal worden gebracht (de einddatum is de datum van het laatste bezoek van de laatste deelnemer)
- de resultaten van het onderzoek aan de commissie zullen worden gemeld

Samenstellings commissie
prof. dr. J.A. Rauwerda
dr. K. Hoekman
mw. M. Baak
mw. dr. B. van Baarle, dr. M.L.P.A. Janissen en mw. dr. L.A.M. van der Scheer
mw. dr. C. Boer
mw. dr. M.A. Brummer
mw. prof. dr. A.M. Van Furth
dr. E.G. Haarmann
mw. mr. A.J.G.M. Janssen en mr. F.J. Faber
dr. D. de Jong
voorzitter, chirurg
pvd. voorzitter, interne-oncoloog
verpleegkundige
medisch etici
biomedica
psychiater
kinderarts-infektiolog
kinderendocrinol
juridisch
chirurg
neurochirurg
neuropsycholoog
neurologen
farmacoloog
ziekenhuisapotheekers
klinisch farmacologen
methodologen
bebouwkundigen
klinisch fysiotherapeuten
De commissie heeft de bevoegdheid haar positieve oordeel in te trekken als vaststaat dat de uitvoering van het onderzoek ernstig tekort schiet. Het vooriggend oordeel verliest zijn geldigheid indien de start van het onderzoek niet binnen 1 jaar plaatsvindt.

Brok
De commissie wijst de onderzoekers erop dat, conform landelijke afspraken, klinisch onderzoekers verplicht zijn de "Basiscursus regelgeving en organisatie van klinisch onderzoek" (BROK) te doorlopen en het bijbehorende certificaat te behalen. De commissie gaat ervan uit dat indien dit nu nog niet het geval is, de klinisch onderzoekers van deze studie maximaal zes maanden na aanvang van de studie aan deze verplichting voldaan hebben. Voor informatie over de inhoud van de BROK-cursus: drs. Jennifer Benit, tel. 020 4443345. Voor praktische informatie (zoals data waarop de cursus plaatstvindt en inschrijving): PAOG cursusorganisatie, tel. 020 4449372.

Administratief beroep
Tegen dit besluit kan een belanghebbende op grond van artikel 23 WMO binnen zes weken na de dag waarop het besluit is bekend gemaakt, administratief beroep instellen bij de Centrale Commissie Mensgebonden Onderzoek (CCMO). Het beroepschrift dient u te adresseren aan: CCMO, Postbus 16302, 2500 BH Den Haag.

Met vriendelijke groet,
namens de Medisch Ethische Toetsingscommissie,

prof. dr. J.A. Rauwerda, voorzitter

dr. P. de Haan, secretaris

c.c.: Centrale Commissie Mensgebonden Onderzoek te Den Haag (CCMO) - digitaal uploaden

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