Welcome to my world

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‘Cause in a sky, ‘cause in a sky full of stars

I think I see you

I think I see you

Coldplay

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CHAPTER 1

1

General introduction

The main objective of this thesis was to gain more insight into the support needs of older people with intellectual disabilities and to explore whether Integrated Emotion-Oriented Care (IEOC), a person-centred approach adopted from the field of dementia care, could be a good fit in supporting older people with intellectual disabilities. If this proved to be the case, the aim was to describe how to increase attention for the non-medical aspects of the ageing process when providing daily care to older people with intellectual disabilities. This introductory chapter consists of four sections. In the first section, the context of the thesis is outlined by describing what ageing with an intellectual disability implies and entails. The second section focuses on person-centred care and the development of IEOC for elderly with dementia. The third section describes the impact of ageing with an intellectual disability on the provision of daily care by support staff, and how IEOC can be applied to improve care for older people with intellectual disabilities. In the fourth section, further information about the thesis is provided, including its aim, research questions and an outline of its further content.

Section 1: Ageing with an intellectual disability: a complex process

Intellectual disability

Intellectual disability is characterised by significant limitations both in intellectual functioning and adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates during the developmental period, which is defined operationally as before the individual attains age 22 (WHO, 2023). In addition, intellectual disability is commonly categorised in four levels: mild, moderate, severe and profound (APA, 2013). This classification indicates the wide range of intellectual disabilities and the associated difference in care and support needs. Similar to the dynamics of ageing in the general population, the life expectancy of people with intellectual disabilities has increased in recent decades due to improved living conditions and better medical care (Mulryan et al., 2021).

Premature ageing

Although the life expectancy of both groups is increasing, the ageing process of older people with intellectual disabilities is different from that of older people in the general population as it is characterised by an increased risk of developing frailty due to their lifelong disabilities (Hermans & Evenhuis, 2014; Schoufour et al., 2014). Frailty is a state of increased vulnerability to adverse health outcomes because of decline in many physiological systems compared to others of the same age (Clegg et al., 2013). Research shows that the frailty of people with intellectual disabilities who are 50 years and older is comparable to the frailty of a 75-year-old nursing home resident. However, in case of more severe disabilities or the presence of Down syndrome, frailty may arise sooner (Schoufour et al., 2013). As the early occurrence of frailty is more common in older people with intellectual disabilities than in the general population and can be seen as an explanation for premature ageing, we used the following age criteria (see Table 1) in this dissertation (as also described by Maaskant et al. (2017)):

Table 1. Age criteria of older people with intellectual disabilities

Level of functioning	Age
People with mild intellectual disabilities	≥ 65 years
People with moderate intellectual disabilities	≥ 50 years
People with severe to profound intellectual disabilities	≥ 40 years
People with Down syndrome, regardless of level of functioning	≥ 40 years

Age-related physical health problems

Ageing in people with intellectual disabilities can lead to specific health problems and health risks as their lifelong disabilities place them at increased risk from an early age. In their study on 1,047 adults with mild to profound intellectual disabilities (≥ 50 years) and/or Down syndrome, Hermans and Evenhuis (2014) showed that multimorbidity (≥ 2 conditions) was prevalent in 79.8% and associated with age and severe or profound intellectual disabilities. Moreover, four or more chronic conditions were prevalent in 46.8% and associated with age, severe or profound intellectual disabilities, and Down syndrome. Several studies have reported a higher prevalence of diseases and health problems in people with intellectual disabilities than in the general population of the same age (Rondini & Bertelli, 2022). For example, diabetes and obesity were found to be more common in older people with intellectual disabilities aged 50 years and older than in people without intellectual disabilities aged 50 years and older (Winter et al., 2012; Winter et al., 2013). An unhealthy lifestyle and exceptionally low physical fitness levels (Hilgenkamp et al., 2012) and high use of antipsychotics in this group plays a significant role in the development of obesity and diabetes (Kuijper et al., 2013). The high prevalence of diabetes, obesity and hypertension (i.e. cardiovascular risk factors) in older people with intellectual disabilities also places them at increased risk for developing cardiovascular diseases, often leading to causes of death (De Winter et al., 2012). Furthermore, older people with intellectual disabilities and people with Down syndrome are at increased risk of visual impairment, blindness, hearing impairment or a combination of these (deaf blindness) (Dammeyer, 2014). In people with Down syndrome, there is a strong age-related increase in hearing impairment. This increase occurs about 30 years earlier than in people without intellectual disabilities and ten years earlier in people with intellectual disabilities without Down syndrome (Bent et al., 2015). Finally, another common condition is dysphagia. Bastiaanse et al. (2014) found that the prevalence of dysphagia was 77.4%, and that of severe dysphagia was nearly 52%, among older people with intellectual disabilities; comparatively, its prevalence in the general population aged 60 and over is 18-41% (Thiyagalingam et al., 2021). Therefore, ageing in people with intellectual disabilities is associated with more physical health problems than ageing in the general population.

Cognitive and psychosocial consequences

In addition to the presence of physical health problems in ageing with an intellectual disability, several cognitive and psychosocial consequences can also be identified during the ageing process. One of these age-related cognitive consequences is dementia. Studies of dementia in older people with intellectual disabilities have reported an increased prevalence of dementia compared to older people in the general population. This rate (particularly of Alzheimer's disease) is even higher among people with Down syndrome who are affected earlier in life (Deb, 2015). In a cross-sectional study involving adults with intellectual disabilities without Down syndrome (aged > 60 years), Alzheimer's disease was found to be the most common subtype (prevalence of 8.6%), followed by Lewy body, frontotemporal and vascular dementia (Strydom et al., 2007). In addition, a follow-up to this study showed that the incidence of dementia in older people with intellectual disabilities is up to five times higher than in older adults in the general population (Strydom et al., 2013). Furthermore, older people with mild or moderate intellectual disabilities reported significantly more symptoms of anxiety than participants with average intelligence. Specifically, Hermans and colleagues (2014) reported worrying, frightened feelings, tense feelings and feelings of panic occurring more often in people with intellectual disabilities than in the general older population. Research shows that even approximately 8% of older people with intellectual disabilities suffer from a clinical depression. This is five times higher than in older people in the general population (Hermans et al., 2013). The occurrence of psychotic disorders is also ten times higher for older people with intellectual disabilities, who are also more likely to experience personality disorders, and mood disorders, as compared to the general population (Axmon et al., 2017).

Regarding the psychosocial consequences of ageing, it is important to note that people with intellectual disabilities generally age in residential care facilities where they live throughout their lives, either in their current group home or in a group home specialised in ageing people with intellectual disabilities (Bigby, 2008; Shaw et al., 2011). As a result, many older people with intellectual disabilities have never lived independently, often have no partner or children to care for them and, as such, have smaller informal networks later in life (Ryan et al., 2014). Furthermore, the capacities of their informal networks to provide active support are likely to decrease, as their contacts are ageing too (McCausland et al., 2016). These limited informal networks may have repercussions for many aspects of their health and wellbeing. For instance, loneliness is associated with emotional health (Wormald et al., 2019). Limited social support is a major barrier to physical activities in this population, even though being physically active is universally acknowledged as a crucial factor for health and wellbeing, specifically for the elderly (van Schijndel-Speet et al., 2014). Their physical abilities decline, and many experience limitations in going out (Evenhuis et al., 2012). Relatively few older people with intellectual disabilities have worked in regular, well-paid jobs and, therefore, the majority of them do not have savings or regular pensions. Consequently, they often depend on others for transportation, the organisation of their lives, activities and finances (Bigby et al., 2014). Similar to the presence of physical health problems, older people with intellectual disabilities also appear to be more at risk of developing dementia, depression and other psychosocial problems compared to older people in the general population.

Section 2: Person-centred care approaches in elderly care

In various places in Europe and the United States, different person-centred care and support approaches for people with dementia have been developed simultaneously and relatively independently of each other, usually in response to dissatisfaction with care for ageing people with dementia. The criticism was aimed at support and care being exclusively provided using the ‘medical model’, which mainly focuses on what the person has (e.g. illness or condition) rather than who the person is (e.g. life history and needs) (Dröes et al., 2015). In the United States, Feil (1989) developed an approach called ‘Validation’. Validation is a method of empathic communication with older people with dementia involving validation of their experiences. Validation is designed to: (1) stimulate communication and prevent inward withdrawal; (2) restore wellbeing; and (3) facilitate the resolution of unresolved issues in preparation for death (Feil, 1989). Person-centred care is also strongly connected to Tom Kitwood’s concept of personhood in dementia. This was developed in the United Kingdom in response to the biomedical reductionist view of people with dementia (Kitwood, 1998). Personhood refers to the relational aspects of being human, and the importance of being in an inclusive psychosocial environment where people recognise you as a person with a unique personality and life history (Brooker, 2003; Kitwood, 1992). According to Kitwood (1997), meeting the whole cluster of needs enables a person to experience wellbeing.

In Sweden, the same kind of criticism emerged, resulting in the development of an intervention called ‘integrity promoting care’ (Brane et al., 1989; Kihlgren et al. 1994). The objection to the usual care for the elderly was that it was too instrumental and focused exclusively on hygiene and tidiness. Integrity promoting care is based on the developmental theory of Erikson (1963) and taught support staff not only to concentrate on the caring actions, but also on their relationship with the person with dementia (de Lange, 2004). This is in line with a growing tendency to approach professional care in terms of care relations based on care ethics. Professional loving care, for example, calls for a high-quality interpersonal relationship between care professionals and clients (e.g. people with dementia or intellectual disabilities) as this is considered a necessary condition for the quality of care (Van Heijst, 2005; 2008; Hermsen et al., 2014).

The theoretical perspectives used in these care approaches are developmental, social-emotional and psychosocial in nature, to which own convictions or emphases have been added. The practical approaches are based on core concepts from humanistic psychology and psychotherapy, such as genuineness, warmth and empathy. Common in all the approaches mentioned is, first, respect for the dignity of the person with dementia and their subjective perception of reality. Second, the emphasis is always on opportunities to communicate with people with dementia, despite their limitations. Finally, in all approaches, people with dementia are viewed as individuals with their own history, wishes and needs, and therefore their own care needs (de Lange, 2004). As every individual has their own specific needs within the quality-of-life domains (Schalock, 2004), person-centred approaches can also be used to personalise the needs and support within all life domains. Several studies have shown that experts advise the use of person-centred care as a guiding principle in providing quality of care for older people with intellectual disabilities (Campens et al., 2017; Cleary & Doody, 2017; Ouellette-Kuntz et al., 2019). Person-centred approaches are associated with psychosocial benefits for both people with dementia and their carers, as well as for people with intellectual disabilities – with or without dementia – and their carers through wellbeing and satisfaction with care and wellbeing and job satisfaction, respectively (Brown et al., 2016; Van der Meer et al., 2017).

Despite these commonalities, the different person-centred approaches and interventions in elderly care were initially applied strictly separately in Dutch nursing home practices (Kruyver & Kerkstra, 1996). People were strictly specialised in approaches to sensory activation ('snoezelen'), warm care, retrieving memories from the past through conversations or with the aid of images, objects or a game (reminiscence) or validation. However, not every approach was suitable for everyone in isolation, as the needs of older people or the stage of dementia could vary, and not every individual benefitted from solely sensory activation or reminiscence, for example. Gradually, the need arose to combine intervention components from one approach with those of others resulting in a more holistic, integrated emotion-oriented approach as developed by Van der Kooij (2001):

> *Integrated emotion-oriented care is a specific form of care that has been developed in psychogeriatric nursing home care and that can also be used by disciplines other than the nursing profession and in other sectors of health care. Integrated emotion-oriented care means the integrated use of experience-oriented approaches and communication skills tailored to the individual (demented) nursing home resident, taking into account his feelings, needs, and physical and psychological limitations, with the aim that the resident experiences as much support in the adaptation to the consequences of his illness and the nursing home admission that he actually feels safe and is able to maintain his self-esteem.*

Section 3: Integrated Emotion-Oriented Care (IEOC) as a support strategy for older people with intellectual disabilities

The increase in longevity of people with intellectual disabilities, the early onset and the complexity of the ageing process (i.e. increased vulnerabilities in all areas of life due to physical, cognitive and psychosocial limitations) of older people with intellectual disabilities intensify their reliance on support staff and pose challenges to healthcare organisations (Prasher et al., 2021). These complex ageing processes also inevitably lead to augmentation and changes in support needs, making older people increasingly dependent on support staff to maintain their quality of life (Alftberg et al., 2021). Support staff describe their work with people with intellectual disabilities as increasingly time consuming and stressful as their clients grow older (Cleary & Doody, 2017). Support staff who provide long-term care to the same clients may recognise changes in their actual needs because of their experience with and knowledge of clients' behaviour, habits, personality and life histories (Schaap, 2019). However, the nature and intensity of support needs can increase significantly, which can be challenging. For example, older people with intellectual disabilities require more assistance with daily living skills and maintaining acquired skills, and they are likely to need adjustments in the frequency and pace of daytime activities to correspond to their current abilities (Shooshtari et al., 2011).

However, research on the actual support needs of older people with intellectual disabilities remains scarce (Albuquerque & Carvalho, 2020). This prevents possible access to knowledge needed for support staff working with older people with intellectual disabilities to adequately adapt to their changes in needs and dependency (Cleary & Doody, 2016; Iacono et al., 2014). Whether support staff are prepared for their significant role in meeting the changing support needs of older people with intellectual disabilities is, therefore, uncertain (Kåhlin et al., 2016). Furthermore, the lack of professional knowledge and skills can lead to low job satisfaction on the part of staff, and reduced quality of life for people with intellectual disabilities who receive lifelong support (Ineland et al., 2017). Existing care and support strategies used for adults with intellectual disabilities no longer seem sufficient. Moreover, most support strategies and interventions suited for older people with intellectual disabilities are medically and physically oriented, aimed at assessing effects within the physical domain of wellbeing (Schepens et al., 2018). As explained in the first section, the implications of ageing extend beyond physical deficiencies (i.e. physical wellbeing) and the need for support in other domains of life (e.g. cognitive and psychosocial wellbeing) are likely to change as well.

Consequently, since ageing with an intellectual disability seems to have a major impact on support provision, it can be assumed that gaps in professional knowledge and feelings of uncertainty might arise among support staff supporting this population (Alftberg et al., 2021; Bigby, 2004). It can also be questioned whether the quality of life of older people with intellectual disabilities can still be guaranteed with the current support strategies, which tend to focus on development instead of retention of acquired skills and medical/physical conditions rather than psychosocial circumstances. Considering these challenges, psychosocial methods and interventions are needed urgently to provide support in addressing the changing support needs of ageing people with intellectual disabilities to ensure optimal care and support for good quality of life (Bowers et al., 2014; Cleary & Doody, 2016; Iacono et al., 2014). Support staff in disability care could, therefore, potentially benefit from the interventions for elderly people with dementia described in Section 2.

In the Netherlands, almost half (44%) of the approximately 73,000 people with intellectual disabilities in the research population are over 50 years of age (Maaskant, 2020). The Dutch service provider Philadelphia Care Foundation provides care and support to approximately 9,738 individuals with intellectual disabilities, of which 51.5% are above 40 years of age[1]. Considering that these numbers are expected to increase in the coming years, it is not surprising that this has led to a need for a more adequate support strategy and a search for a more integrated and person-centred approach, which has already been implemented in geriatric and dementia care (Campens et al., 2017; Van der Kooij, 2003; 2014). Adopting IEOC for older people with intellectual disabilities therefore serves a dual purpose. First, it gives more guidance to support staff to provide adequate support. Second, it improves the quality of life of older people with intellectual disabilities.

The practice-based nature of IEOC means that many support staff's actions or activities are often underpinned by their knowledge of IEOC and of older people with intellectual disabilities. This implicit knowledge can become valuable when analysed systematically with academic procedures. It can add to a better understanding of practice-based interventions, and underpin them with scientific knowledge (Embregts, 2017). There is a growing tendency to underpin the choice of interventions for particular target groups with current best evidence in many healthcare disciplines, including the care of people with intellectual disabilities (Embregts, 2014; Perry & Weiss, 2007; Schalock et al., 2011). As Embregts (2017) stated, close collaboration between science and practice is needed to achieve optimal knowledge development. As for IEOC, despite the positive findings in dementia care (Finnema et al., 2005; Van der Kooij et al., 2013) and its status as good practice, it has yet to be made clear what the intervention components of IEOC for older people with intellectual disabilities are and how these components should be used and applied to older people with intellectual disabilities on a daily basis.

Section 4: Objective of the thesis and research questions

The main objectives of this thesis were: (I) to gain more insight into the support needs of older people with intellectual disabilities and what they consider important, (II) providing an overview of available psychosocial interventions for older people with intellectual disabilities, and (III) defining and understanding the intervention components of Integrated Emotion-

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[1] Reference date February 2023

Oriented Care, an integrated person-centred approach, for older people with intellectual disabilities. This resulted in the following research questions:

I

1. Do older people with intellectual disabilities generally experience a need for support in all of the quality-of-life domains? What are the most important support needs that older people with intellectual disabilities experience within each quality-of-life domain? How important is each quality-of-life domain for older people with intellectual disabilities?
2. What do older people with intellectual disabilities consider most important in their daily lives (i.e. matters of importance) and what support needs do they encounter?

II

3. What is the focus of the psychosocial interventions documented in the international literature for caring for older people with intellectual disabilities? What role do support staff play in the application of psychosocial interventions?

III

4. What are the intervention components of IEOC for older people with intellectual disabilities? How can the intervention components of IEOC be applied in the day-to-day support of older people with intellectual disabilities?
5. To what extent were direct support workers able to apply a specific form of person-centred care (i.e. IEOC) when working with older people with intellectual disabilities during the COVID-19 pandemic?

Outline of the thesis

This thesis consists of seven chapters, of which this general introduction (**Chapter 1**) is the first, and the general discussion (**Chapter 7**) is the last. The chapters in between report on the studies performed. The study in **Chapter 2** presents the results of the mixed-method study that was conducted among 11 psychologists to gain insight into the support needs of older people with intellectual disabilities in all quality-of-life domains. **Chapter 3** explores in detail what ten older people with mild to moderate intellectual disabilities consider as most important in their daily lives (i.e. matters of importance) and what support needs they encounter. In **Chapter 4** the results of a systematic review of qualitative and quantitative studies focusing on available psychosocial interventions for older people with intellectual disabilities and the role of support staff are described. A narrative, integrative method was conducted to synthesise both quantitative and qualitative data. **Chapter 5** contains a descriptive study in which the five intervention components of IEOC for older people with intellectual disabilities are defined. Subsequently, an in-depth description of the intervention components in the day-to-day support of older people with intellectual disabilities using narrative summaries is provided. These summaries include examples of associated actions, activities and aspects that should preferably be considered when providing integrated emotion-oriented care. Considering recent events, **Chapter 6** examines the extent to which six direct support workers were able to apply integrated emotion-oriented care while working with older people with intellectual disabilities during the COVID-19 pandemic. Finally, the findings, strengths and limitations of the current thesis are summarised in the general discussion in **Chapter 7**. Furthermore, implications for future research, policy and practice are discussed.

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CHAPTER 2

2

Support needs of older people with intellectual disabilities: An exploratory study among psychologists in the Netherlands

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Abstract

Background

Information regarding the common-daily support needs of older people with intellectual disabilities remains scarce, despite the necessity of such knowledge to the provision of adequate support. This exploratory study aims to identify the most important support needs.

Method

A mixed-method design was conducted, in which 11 semi-structured interviews were held with psychologists to gain insight into the support needs of older people with intellectual disabilities.

Results

The data provide an overview of the support needs of older people with intellectual disabilities in all quality-of-life domains. Physical wellbeing, emotional wellbeing, interpersonal relationships, and self-determination were identified as the most important domains for older people with intellectual disabilities.

Conclusions

The findings of this study may guide the development of a specific training for support staff and constitute a valuable contribution to raising awareness among support staff concerning the broad range of support needs existing among older people with intellectual disabilities.

Key words

Ageing, intellectual disability, older people, quality of life, support needs

Introduction

The life expectancy of people with intellectual disabilities has increased in recent decades (Shoostari et al., 2012). As a result, more people with intellectual disabilities are dealing with age-related difficulties. For example, they might experience declines in physical and/or cognitive ability, suffer substantial losses in their social networks, and encounter increasing limitations in their social movements (Evenhuis et al., 2012; McCausland et al., 2016). In addition, due to premature ageing and a higher prevalence of multiple chronic health impairments (e.g. respiratory diseases) and psychiatric disorders (psychotic disorders) in older people with intellectual disabilities compared to the general population of the same age, ageing with intellectual disabilities is considered to be a complex process (Alftberg et al., 2021; WHO, 2018). These complex ageing processes inevitably lead to augmentation and changes in their support needs. Care as usual i.e. existing care and support strategies) seems no longer sufficient and, therefore, it can be assumed that gaps in professional knowledge and experiences of uncertainty might arise among support staff dealing with ageing people with intellectual disabilities who receive lifelong support (Alftberg et al., 2021; Bigby, 2004). To be able to adjust to these changes, support staff need insight into the broad range of support needs of older people with intellectual disabilities and the question how to keep providing adequate support at this stage of life.

However, research on the common-daily support needs (e.g. day-to day needs regarding activities of daily living, self-determination, physical and emotional wellbeing and social inclusion) of older people with intellectual disabilities remains scarce (Alberquerque & Carvalho, 2020). If available, studies mainly have a delineated focus on medical/physical domains of life (Navas et al., 2019), needs during the end-of-life phase (McNamara et al., 2020), housing (Shaw et al., 2011), and/or support for ageing family caregivers (Ryan et al., 2012). Despite the present lack of evidence, it is conceivable that support needs in other quality-of-life (QoL) domains - including emotional wellbeing, interpersonal relationships, and social inclusion - undergo significant changes as people with intellectual disabilities age as well. The term ‘quality-of- life domains’ refers to the set of factors composing personal wellbeing and thus define the multidimensionality of a life of quality as proposed by Schalock (i.e. QoL model; 2004). This multidimensional QoL model has been well described, researched and validated in the field of support for people with intellectual disabilities and matches the current supports paradigm (Gómez et al., 2014; Schepens et al., 2018). However, indications were found for an additional domain—existential wellbeing—given its particular importance to older people, who are likely to examine their past lives and ask questions about the afterlife (Schepens et al., 2018). Therefore, this additional domain was also adopted in the current study (see Table 1). The identification of needs in all domains is important, given the necessity of optimising both physical and social wellbeing to improve QoL (Social Production Function theory; Ormel et al., 1999). To date, however, the existing literature includes few studies with a broad focus on the entire range of age-related, common-daily support needs of older people with intellectual disabilities, or on what constitutes adequate support in this regard across all QoL domains.

Psychologists are regarded as a valuable source of information for monitoring the support needs of older people with intellectual disabilities. It is part of their profession to provide insight into the entire range of support needs of this specific population across all domains of life. Psychologists have direct contact with individuals with intellectual disabilities on a regular basis, they coach and collaborate with support staff, they consult and are in close contact with experts in other specialist areas (e.g. doctors, occupational therapists etc.), and they possess the competencies needed to analyse cases at the meta-level (Stenfert Kroese & Smith, 2018). Psychologists represent an as yet under-exposed source of professional knowledge that could complement the reported experiences of both support staff (Albuquerque & Carvalho, 2020; Alftberg et al., 2021) and older people with intellectual disabilities themselves (Schepens et al., 2019). These studies indicate that support staff acknowledge that older people with intellectual disabilities are a profoundly diverse group representing different needs and older people with mild intellectual disabilities are capable of talking about their experiences, quality of life, and the support they need. However, these studies also suggest that support staff still need more awareness and knowledge to be able to respond adequately to the different needs and signs of ageing in people with intellectual disabilities. In light of these findings, this study deliberately examined the views and perspectives of psychologists of various care organisations within the Netherlands on older people with intellectual disabilities (≥50 years), aimed at exploring and documenting the most important support needs across all QoL domains. The age criterion of ≥50 years was chosen in line with Hermans and Evenhuis (2014), in order to account for premature ageing and the early onset of age-related deficiencies.

Method

A mixed-methods design was applied in this study. In the qualitative part the support needs of older people with intellectual disabilities were explored and identified. The quantitative part of this study evaluated the importance of each QoL domain for older people with intellectual disabilities (Morse & Niehaus, 2009).

Ethics

After obtaining approval from the Ethical Review Board of Tilburg University (EC-2019.33), the first author selected and invited psychologists to participate. Participants were provided with written and oral information about the nature and purpose of the study. They were further informed that their responses would be audio recorded and processed anonymously, and that they could withdraw from the study at any time.

Participants

All participants are working as psychologist (n=2 clinical psychologists; n=9 developmental psychologists) across 11 different residential-care organisations for people with intellectual disabilities in the Netherlands with an average working experience of 10.3 years (SD=6.8; range: 5-27). Participants were identified and selected through a process of nominated expert sampling (Trotter, 2012) based on their extensive expertise and experience regarding older people with intellectual disabilities. All but one of the participants were female and all participants met the following inclusion criteria: (1) being involved for at least 5 years in the direct care of older people with intellectual disabilities (≥50 years of age) who are living in residential care facilities for people with intellectual disabilities and (2) selected by stakeholders within different care-organisations in the Netherlands because of their unquestionable expertise in the field of older people with intellectual disabilities. No further inclusion or exclusion criteria were applied.

Measures

A semi-structured interview guide based on the QoL model (Schalock et al., 2010) was developed in advance to guide the individual interviews (i.e. Personal development, Self-determination, Interpersonal relationships, Social inclusion, Rights, Emotional wellbeing, Physical wellbeing, Material wellbeing, and Existential wellbeing). The interview consisted of three parts. First, in the qualitative part, participants were asked whether older people with intellectual disabilities in general experience a need for support in each of the nine QoL domains (see Table 1). Then, they were asked to mention the most important support needs that older people with intellectual disabilities experience within each QoL domain based on their own estimation. Finally, they rated the importance of each QoL domain for older people with intellectual disabilities more generally along a scale ranging from 1 (not important) to 10 (very important).

Procedure

Nominated expert sampling was applied by contacting stakeholders within different care organisations in the Netherlands. Researchers asked them for their assistance by nominating potential participants (i.e. psychologists in the support of older people with intellectual disabilities). For each nominated participant, the first author ensured that this person met the inclusion criteria. If the criteria were met, the participant was invited to participate and written information about the study was provided.

After obtaining informed consent from all participants, the first author conducted individual semi-structured interviews by telephone. Each interview lasted 45–60 minutes and was held at a time convenient to the participant. By using a predetermined, semi-structured interview guide, participants were asked to provide details about the most important support needs older people with intellectual disabilities experience on all domains of QoL. The number of interviews was based on the principle of data saturation (Guest et al., 2006). After 11 interviews, all domains were thoroughly explored in detail, no new information emerged in subsequent interviews, and data saturation had been achieved.

Table 1. Quality-of-life (QoL) domains and core indicators

QoL domain †	Indicators
Personal development	Education (achievements, status)
	Personal competence (cognitive, social, practical)
	Performance (success, achievement, productivity)
Self-determination	Autonomy/personal control (independence)
	Goals and personal values (desires, expectations)
	Choices (opportunities, options, preferences)
Interpersonal relationships	Interactions (social networks, social contacts)
	Relationships (family, friends, peers)
	Supports (emotional, physical, financial, feedback)
Social inclusion	Community integration and participation
	Community roles (contributor, volunteer)
	Social supports (support network, services)
Rights	Human (respect, dignity, equality)
	Legal (citizenship, access, due process)
Emotional wellbeing	Contentment (satisfaction, moods, enjoyment)
	Self-concept (identify, self-worth, self-esteem)
	Lack of stress (predictability, control)
Physical wellbeing	Health (functioning, symptoms, fitness, nutrition)
	Activities of daily living (self-care skills, mobility)
	Leisure (recreation, hobbies)
Material wellbeing	Financial status (income, benefits)
	Employment (work status, work environment)
	Housing (type of residence, ownership)
Existential wellbeing	Spirituality and religious beliefs (thoughts and feelings regarding ageing, end of life, death, and dying)
	Meaning in life (life story, meaningful day activities, feeling valuable)

†Schalock, 2004; Schepens et al., 2018

Data analysis

In line with the standards for qualitative research (Kratochwill et al., 2010), each of the two authors (MT and WvO) analysed the transcripts of two interviews independently using inductive thematic analysis (Braun and Clarke, 2006), which is a method for identifying, analysing and reporting patterns in data. Each interview yielded a list of most important support needs and corresponding quotes for each QoL domain. Subsequently, the two authors discussed overlaps and divergences with regard to their interpretations and coding decisions until inter-coder consistency was reached and the procedure was further strengthened (Ritchie et al., 2014; Thomas & Harden, 2008). The first author then analysed the remaining nine interviews. To mitigate any potential bias due to working with a single researcher (Zhang & Wildemuth, 2009), the results of all interviews were also discussed within the research team (MT, WvO, KV and PE) until full consensus was reached. Finally, a member check was conducted by sending the lists with the most frequently mentioned support needs in each QoL domain to each participant, to verify that the lists accurately reflected their knowledge and experience (Ritchie et al., 2014). In the quantitative part, descriptive statistics were performed by using SPSS to assess means, standard deviations, median and range for the grades of importance (1-10) of each QoL domain according to the participants. The mean scores were used to rank the QoL domains by importance.

Results

Support needs

According to the participants, older people with intellectual disabilities experience support needs in all nine domains of QoL. An extensive overview of the support needs that the participants mentioned as being the most important within each domain is presented in Table 2. The support needs and corresponding quotes are listed in order of frequency (i.e. the number of times a need was described by a participant). The support needs within the domains of emotional wellbeing, physical wellbeing, self-determination and interpersonal relationships were rated as being of the greatest importance for this population, whereas those within the domains of rights and material wellbeing were rated as being least important (see Table 3).

Table 2. Overview of most important needs within each QoL domain identified by psychologists

QoL domain†	**Most important needs**	***Most relevant quotes***
1.Personal development	1.1 Support in stimulating and maintaining previously learned skills (n = 10)	*"Keep performing household tasks and self-care skills independently (or parts thereof)"*
	1.2 Adjustments and support in performing activities of daily living (or parts thereof) independently for as long as possible (n = 9)	*"Providing more physical support/using assistive devices (e.g. a shower card with pictures of the sequence to maintain independence)"*
	1.3 An environment that adjusts to the pace of older people with intellectual disabilities (n = 4)	*"Adjusting to the client's current pace and daily routine by reducing the number of activities in a day"*
	1.4 Encourage and focus on the implementation of wishes (n = 3)	*"Being supportive when a client wants to learn to use technology (e.g. operating an iPad)"*
	1.5 Match the client's possibilities and offer familiar activities (n = 3)	*"Focusing on the client's possibilities instead of impossibilities in order to avoid experiences of failure"*
	1.6 Support in understanding the environment (n = 2)	*"Providing more oral instructions and support in orientation in public spaces"*
2.Self-determination	2.1 Room and support to make individual choices and to experience autonomy (n = 9)	*"Maintaining the ability to cycle independently and to eat according to individual preferences"*
	2.2 More support in making difficult choices or decisions (n = 6)	*"Being supportive when clients become more dependent in making difficult decisions (e.g. medical matters)"*
	2.3 Adjustments in the daily schedule (n = 5)	*"Eliminating the requirement of going to the activity centre on a daily basis"*
	2.4 Environment that pays attention to the ageing process (n = 3)	*"Reflecting on why something no longer works or why the client feels tired"*
	2. 5 Offering suitable activities (n = 3)	*"Providing activities closer to home in order to avoid long journeys"*
	2.6 Attention to changes in needs and wishes (n = 2)	*"Attending to changes in tastes and sleeping times"*
	2.7 Room for privacy (n = 2)	*"Being allowed to bathe without the presence of support staff"*

Table 2. Continued

QoL domain†	Most important needs	*Most relevant quotes*
3.Interpersonal relationships	3.1 Support in maintaining and facilitating contact with family and social network (n = 10)	*"Helping the client remember a loved one's birthday and send a card"*
	3.2 Assistance in fulfilling needs in a different way (n = 6)	*"Expanding the client's network with volunteers as relatives fall away"*
	3.3 Support in preventing loneliness (n = 4)	*"Offering proximity through more attention and contact"*
4.Social inclusion	4.1 Support and guidance in continuing to participate in society or making use of social facilities (n = 9)	*"Going to the store or church together with the client for safety reasons"*
	4.2 Offering activities at home (n = 6)	*"Holding a music evening at home is more accessible, quieter and safer"*
	4.3 Attention to changing needs (n = 4)	*"Staying alert to changes in needs regarding participation in society (e.g. client might no longer feel safe going to the activity centre)"*
	4.4 Support in maintaining old habits (n = 3)	*"Having the hairdresser come to the client's home for weekly appointments when traveling becomes difficult"*
5.Rights	5.1 Medical care and/or support in overseeing medical consequences or providing insight into health complaints (n = 4)	*"Talking about health issues or going to the hospital with the client"*
	5.2 A nice, suitable place to live with appropriate care that meets the requirements of the client (n = 4)	*"Providing adapted facilities (e.g. wide, wheelchair-accessible doors)"*
	5.3 Clear, negotiable rights (n = 4)	*"Involving the client in decisions concerning where and with whom the client will live"*
	5.4 Attention to privacy in connection with increasing guidance (n = 2)	*"Helping the client go to the toilet, but remaining outside"*
	5.5 Maintaining the greatest possible sense of dignity (n = 2)	*"Taking the client seriously and treating the client with respect"*

Table 2. Continued

QoL domain†	**Most important needs**	***Most relevant quotes***
6.Emotional wellbeing	6.1 Actively offering safety, relaxation and comfort (n = 7)	*“Creating a safe environment by preventing agitation or by helping to regulate incentives”*
	6.2 A stable, predictable environment (n = 7)	*“Presenting a stable environment by maintaining fixed patterns and recognisable spaces”*
	6.3 Space to discuss and express things and feelings (n = 6)	*“Offering space to clients when the need to cry, want to talk about worries or experience loss and grief”*
	6.4 Feeling seen and heard (n = 5)	*“Offering more physical contact (e.g. hugs) and proximity in order to prevent isolation”*
	6.5 Attention from support staff to the needs and wishes of the client (n = 5)	*“Being aware of client’s needs and wishes, especially for clients who are no longer able to clearly explain such matters themselves”*
	6.6 More support and clarity in structure and maintenance of daily rhythm (n = 3)	*“Providing support in maintaining a daily rhythm by connecting to the client’s perceptions, experiences and life history”*
	6.7 Talk about the past (n = 2)	*“Talking about someone’s life history (e.g. reminiscence work)”*

Table 2. Continued

QoL domain†	**Most important needs**	***Most relevant quotes***
7.Physical wellbeing	7.1 Environment that reflects changes (n = 7)	*“Adjusting to physical health problems, food preferences, day and night rhythms”*
	7.2 Fall prevention (n = 4)	*“Paying attention to someone’s mobility (e.g. placing a side rail on the bed to prevent the client from falling out)”*
	7.3 Appropriate assistive devices (n = 4)	*“Arranging for a wheelchair, special cup for swallowing problems, special cutlery”*
	7.4 Help to maintain freedom of movement and stimulate movements that are still possible (n = 4)	*“Moving the cup further away or offering appropriate movement activities”*
	7.5 Involvement of specialists (e.g. doctors and physiotherapists) (n = 4)	*“Consulting specialists with regard to questions about physical health”*
	7.6 Environment that adapts to the pace of the client (n = 2)	*“Taking time to eat and prevent swallowing incidents”*
	7.7 More support with care/activities of daily living (n = 2)	*“Providing more support to clients when taking a shower or dressing/undressing”*
	7.8 Alertness to deterioration (n = 2)	*“Monitoring the risk of diabetes, obesity or reduced vision”*
8.Material wellbeing	8.1 Support with money/financial management (n = 6)	*“Providing guidance on what the client can/cannot buy”*
	8.2 Space for clients to choose for themselves how they will spend money or to have a say in the purchase of belongings (n = 3)	*“Providing space for shared decision-making regarding money or purchases (e.g. on which easy chair to buy for comfort)”*
	8.3 Space for the client’s own belongings (n = 3)	*“Arranging for the client to have a private room”*
	8.4 Adjusted arrangements for holidays and days out (n = 3)	*“Organising appropriate transport and accommodation for the client when going somewhere”*

Table 2. Continued

QoL domain†	**Most important needs**	***Most relevant quotes***
9.Existential wellbeing	9.1 Opportunities for the client to experience a sense of being meaningful to others, being useful and being involved (n = 6)	*“Involving the client in meaningful activities (e.g. allowing the client to help with household tasks)”*
	9.2 Support in maintaining self-esteem (n = 5)	*“Finding ways to maintain client’s self-esteem (e.g. having the client serve coffee at home instead of in the community centre when that is no longer possible)”*
	9.3 Appropriate daytime activities, activities or daily structure (n = 4)	*“Exploring which daytime activities are still appropriate for the client”*
	9.4 Attention/sensitivity to issues of meaningfulness or the ageing process (n = 4)	*“Identifying the client’s possible fear of illness or death”*
	9.5 Talk about what the client likes to do or would still like to do (n = 3)	*“Exploring what a client still experiences as meaningful in this phase of his/her life (e.g. gardening)”*

Table 3. Mean scores, SD, and range for the grades of importance of each QoL domain according to psychologists

QoL domain	Mean scores (*M*)	Median	Standard deviation (SD)	Range
Emotional wellbeing	9.09	9	0.79	8-10
Physical wellbeing	8.91	9	0.99	7-10
Self-determination	8.27	8	0.62	8-10
Interpersonal relationships	8.00	8	0.95	6-9
Existential wellbeing	7.45	7	0.99	6-10
Social inclusion	6.91	7	1.08	5-9
Personal development	6.91	7	1.62	4-10
Material wellbeing	6.82	7	1.11	5-9
Rights	6.45	6	1.56	3-9

Ageing with an intellectual disability: Contextual information

In addition to identifying and prioritising support needs within the QoL domains, the participants provided more general but relevant insights related to ageing with an intellectual disability. These insights provide contextual information that can enhance the interpretation of the results of this study. The psychologists repeatedly emphasised that, in addition to changes in the type and extent of needs throughout the ageing process (e.g. from making coffee or taking a shower independently to being highly dependent on support staff when performing these tasks), the support needs of people with intellectual disabilities increase in number. Second, participants repeatedly highlighted that the majority of older people with intellectual disabilities have been living in residential facilities for most of their lives and that they therefore have no spouses or children who can take care of them. As a result, their social networks become significantly smaller as they age. Third, the participants acknowledged that experiences of grief and loss call for adequate, specialised support, as do questions concerning the end of life.

Discussion

Due to increased longevity more people with intellectual disabilities experience age-related difficulties which continuous lead to augmentation and changes in their daily support needs (Alftberg et al., 2021; Bigby, 2004; Shoostari et al., 2012). The present study provides an overview of the most important, common-daily support needs of older people with intellectual disabilities, based on the professional knowledge of 11 psychologists. This overview can be seen as an addition to existing knowledge based on the perspectives of support staff and older people with intellectual disabilities themselves as psychologists approach this matter from a different angle (i.e. meta-level). The support needs identified, are related to the entire range of nine QoL domains, and therefore consistent with the gerontologic concept of successful ageing (Fesko et al., 2012). Successful ageing implies that both physical, psychosocial, material and existential aspects enable older people to experience increased longevity, QoL, and life satisfaction while retaining their functional capabilities. Present data confirm the presence of support needs regarding these specific aspects.

In addition to demonstrating the presence of support needs across all QoL domains, the results underline the importance of each QOL domain for older people with intellectual disabilities. The ratings assigned by the participants suggest that psychologists regard support needs relating to emotional wellbeing, physical wellbeing, self-determination, and interpersonal relationships as being the most important. The importance attached to support needs within the domain of physical wellbeing is not surprising, given that older people with intellectual disabilities experience greater physical health needs (e.g. a strong focus on medical and physical domains of life). This is also reflected in the international literature (Navas et al., 2019). Furthermore, the need for social wellbeing, as referred to in Social Production Function theory (Ormel et al., 1999), clarifies and highlights the established importance of the support needs regarding emotional wellbeing, interpersonal relationships and self-determination, as indicated in the current study. In particular, older people with intellectual disabilities are likely to encounter emotional life events, due to age-related decline, loss of significant others, forced relocations and difficulties in maintaining their autonomy and self-determination (Judge et al., 2010; Perkins & Moran, 2010; Hermans & Evenhuis, 2012). Moreover, as the social networks of older people with intellectual disabilities shrink, their remaining interpersonal relationships become more important (McCausland et al, 2016). It is, therefore, understandable that the psychologists in this study rated the support needs in these domains as valuable.

Implications for practice

Previous studies demonstrated the multiple and complex nature of the support needs of older people with intellectual disabilities and the significant challenges that they pose for support staff, including the possible lack or requirement of specific knowledge and skills to support this population (Alftberg et al., 2021; Innes et al., 2012; Ryan et al., 2014). With this context in mind, the findings of our study provide several important implications for improving clinical practice and add to existing knowledge. First, the results of this study indicate that psychologists stress the importance of meeting support needs in the entire range of QOL domains (i.e. both the physical and social needs). Psychologists then have the task to effectively coach support staff based on these insights (Stenfert Kroese & Smith, 2018). Additionally, it is also important for support staff themselves to stay aware of the support needs occurring across all QoL domains. Although signs of ageing are mainly associated with medical aspects and physical abilities (Alftberg et al., 2021), the results of our study indicate that the support needs in other QOL domains are equally important. Our overview of concrete, common-daily support needs within each domain could serve as a practical tool that psychologists can use in coaching support staff in the direct care of older people with intellectual disabilities. The results could also be valuable for implementation studies. For example, it would be interesting to investigate ways in which support staff can meet the particular needs of older people with intellectual disabilities and improve their QoL throughout the ageing process. Finally, it might be interesting for future intervention studies to combine the different perspectives (e.g. support staff, psychologists, older people with intellectual disabilities and their informal network) available to develop an integrated approach (i.e. policy development, staff training) which support staff can apply in their daily work. In this approach or training, special attention can be paid to the elements (e.g. support needs) that were reported by all parties, as well as elements that were not collectively revealed.

Study limitations and justifications

This exploratory study is subject to several limitations, which might affect the generalisability of the findings. First, during data collection, no distinctions between levels of intellectual disability (e.g. mild, profound or severe), dual diagnosis with psychiatric disorders or behavioural challenges were made. The level of functioning and differences in behaviour might nevertheless influence the intensity and quantity of support needs experienced by a particular individual. Second, in addition to the experiences of both support staff (Albuquerque & Carvalho, 2020; Alftberg et al., 2021) and older people with intellectual disabilities themselves (Schepens et al., 2019), this study is based solely on the professional knowledge and experiences of clinical and developmental psychologists. For future studies it may, be interesting to outline the experiences and professional knowledge of medical health disciplines regarding the broad range of QOL domains as well.

Conclusion

This study adds to the existing knowledge concerning the support needs of older people with intellectual disabilities from the perspective of psychologists. The interviews provide an overview of broad-ranging daily support needs of older people with intellectual disabilities across all QoL domains. It further identifies the domains of emotional wellbeing, physical wellbeing, self-determination and interpersonal relationships as the most important with regard to support needs. The outcomes of this study thus make an important contribution to raising awareness among support staff in the direct care of older people with intellectual disabilities and improving QoL throughout the ageing process.

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3

CHAPTER 3

Perspectives of older people with intellectual disabilities on matters of importance and their current support needs: An in-depth interview study

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Abstract

As ageing with an intellectual disability is increasingly common and the ageing process inevitably lead to changes in support needs, the need for more knowledge about the wishes, values and needs of older people with intellectual disabilities is increasing as well. However, research regarding the perspectives of older people with intellectual disabilities themselves remains scarce. In this qualitative study, we aimed to explore the perspectives of ageing people with intellectual disabilities regarding matters of importance and current support needs. Ten semi-structured interviews were conducted and transcripts were analysed thematically. Feeling connected to others and feeling at ease and meaningfully engaged played an important role in their daily lives, as well as feeling autonomous. Furthermore, support was needed to be able to do everyday things, to maintain self-esteem, autonomy and personal care, and achieve emotional wellbeing. The findings of this study add to existing knowledge on ageing with an intellectual disability.

Keywords:
Ageing, intellectual disabilities, older people, support needs, quality-of-life

Introduction

The life expectancy of people with intellectual disabilities has been increasing in recent decades due to improving living conditions and better medical care (Mulryan et al. 2021). Their life expectancy is now close to that of people without intellectual disabilities (Albuquerque & Carvalho 2020). Due to this increased life expectancy, the number of older people with intellectual disabilities has increased substantially, and they currently represent nearly half of all people with intellectual disabilities (Doody et al. 2011; Albuquerque & Carvalho 2020). Ageing with an intellectual disability is considered a complex process due to premature ageing, a higher prevalence of multiple chronic health impairments (e.g. respiratory diseases) and psychiatric disorders (psychotic disorders) in comparison with the general population (WHO 2018). In addition, older people with intellectual disabilities also experience declines in cognitive ability, suffer substantial losses in their social networks and encounter increasing limitations in their social movements (Evenhuis et al. 2012; McCausland et al. 2016). As ageing with an intellectual disability is increasingly common and complex, the need for more specific knowledge about the perspectives on the ageing process, wishes, values and needs (in terms of support and otherwise) of older people with intellectual disabilities is increasing as well.

In line with these complex ageing processes of people with intellectual disabilities, it is conceivable that changes in and an intensification of support needs will occur. For example, there may be changes in needs regarding daily living activities, mobility, social contacts and emotional wellbeing (Thalen et al. 2023). Research on the support needs of older people with intellectual disabilities remains scarce, and it often focuses specifically on medical/physical domains of life (Navas et al. 2019). However, in a previous study by Thalen et al. (2023), psychologists indicated that older people with intellectual disabilities might experience support needs in all quality-of-life domains. The term ‘quality-of-life domains’ refers to the set of factors composing personal wellbeing, and the term defines the multiple facets necessary to having a life of reasonable quality as proposed by Schalock (i.e. Personal development, Self-determination, Interpersonal relationships, Social inclusion, Rights, Emotional wellbeing, Physical wellbeing, Material wellbeing; QoL model 2004). To be able to adjust to these changes, support staff need insight into the broad range of support needs of older people with intellectual disabilities in order to continue to provide adequate care and support (Alftberg et al. 2021; Thalen et al. 2023).

In general, it is the care professionals themselves (e.g. support staff and psychologists) or relatives who are often questioned about the wellbeing of older people with intellectual disabilities and give voice to the support that they need (Albuquerque & Carvalho, 2020; Alftberg et al. 2021; Thalen et al. 2023). Although these informants can be seen as valuable sources of information, people with intellectual disabilities may have different perspectives to care professionals and relatives, or place different emphasis on the wishes and needs they experience or on how other people should take care of them (Bekkema et al. 2016;

Albuquerque & Carvalho 2020). Although studies including the perspectives of people with intellectual disabilities themselves are increasing (Nijs et al. 2022; Lokman et al. 2022), studies on the perspectives and experiences of older people with intellectual disabilities remain scarce. Among the few exceptions is the work of McCausland et al. (2021), which explored different perspectives from multiple informants on the physical health, mental health and social care needs of older people with intellectual disabilities. Using a qualitative approach, a total of 20 interviews with individuals with intellectual disabilities aged 50 years and older were conducted separately. Schepens et al. (2019) questioned nine older people with mild intellectual disabilities about what they felt and thought about the adverse and possible traumatising events and experiences in their life. The participants proved very capable of reflecting on all aspects of their own life histories, and it appeared that many recent and bygone negative life events still weighed heavily on the participants. Kahlin et al. (2015) also explored how 12 older people with intellectual disabilities who lived in group accommodation described their lived experience in relation to ageing and later life. The topics focused on the informants' thoughts on ageing in general, their own ageing processes and the future. Another relevant study was performed by Strnadova et al. (2015), who studied the perspectives of 15 older women with intellectual disabilities on life satisfaction, factors influencing wellbeing and strategies they used to cope with the ageing process. Although the findings of these studies did include some elements of wellbeing, as well as older peoples' perspectives on ageing, life events, physical and mental health, and social care needs, they did not focus specifically on older peoples' daily priorities at this stage of their lives. Open questions, such as 'what is most important in your daily life' and 'what makes you happy' were not asked. This information is especially important in terms of providing adequate support and meeting the current wishes and needs of older people with intellectual disabilities.

In addition to focusing on the perspectives of older people with intellectual disabilities themselves, this study has opted for an inclusive approach in which a co-researcher with an intellectual disability works in an equal partnership with academic researchers (Bigby et al. 2014; Embregts et al. 2018; Van den Bogaard et al. 2023; Walmsley et al. 2018). The research team thus consisted of both academic researchers and a co-researcher with an intellectual disability. The co-researcher participated in the research in an active way, meaning they were involved in decision-making. This inclusive approach was explicitly chosen to better connect with older people with intellectual disabilities and capture their experiences in the most optimal way possible. Walmsley et al. (2018) conclude that inclusive research adds value when there is a distinctive contribution that only co-researchers with intellectual disabilities can make, when it highlights the contributions of people with intellectual disabilities, or when it contributes to improving the lives of the wider population of people with intellectual disabilities. Furthermore, the involvement of people with disabilities in research brings more perspectives into the research process and fosters growth within the research team, for researchers both with and without experiential knowledge (Embregts et al. 2018; Frankena, 2019; Nind, 2014). Moreover, the participation of people with intellectual disabilities in inclusive research can also enrich the research process and its outcomes by including and reflecting on their experiential knowledge and insights (Puyalto et al. 2016; Woelders et al. 2015). All things considered, by including the perspectives of the target group and doing this in an inclusive way, we hope to gain more insight into what is important to older people with intellectual disabilities in this phase of their life, hopefully benefitting everyone concerned.

The current study was designed to give an in-depth account of the experiences of people with intellectual disabilities who are ageing. Hence, the aim of this study is to explore what older people with mild to moderate intellectual disabilities consider as most important in their daily lives (i.e. matters of importance) and what support needs they encounter.

Method

This study used a qualitative research design, in which individual, semi-structured interviews were conducted with the aim of gaining more insight into the individual experiences of older people with intellectual disabilities regarding matters of importance and their current support needs (Green & Thorogood 2014). The research team consisted of four academic researchers and one co-researcher with intellectual and developmental disabilities. The co-researcher was actively involved in identifying and clarifying the research topic, constructing the interview guide, recruiting participants, planning and conducting the interviews, and data analysis.

Participants

The participants were selected by a purposive sampling strategy (Patton, 2005). In the composition of the entire sample, variables such as gender, age and place of residence were considered to achieve as much variation within the participant group as possible. To be included in the study, all participants had to: (1) be older than 65 years of age, (2) live in a residential care facility for people with intellectual disabilities, (3) be able to decide about participation and give informed consent, (4) have the communication and interaction skills required for participating in an interview, which meant that participants had mild to moderate intellectual disabilities, and (5) have the ability to reflect on their daily lives. For the last three criteria, consultation was sought with involved caregivers of the intended participants (i.e. support staff members and psychologists).

Ten participants – four men and six women – from six residential care facilities for older people with intellectual disabilities located in the centre of the Netherlands were included. The participants ranged in age from 65 to 90 years (*M* = 75.0 years; *SD* = 7.84) (see Table 1).

Table 1. Characteristics of the Participants

Pseudonym†	Gender	Age	Intellectual disabilities level
Emily	Female	80	Moderate
Olivia	Female	78	Moderate
Anne	Female	66	Moderate
Jacqueline	Female	69	Mild
George	Male	72	Mild
Adam	Male	71	Mild
Vivienne	Female	82	Mild
Carly	Female	90	Mild
Michael	Male	77	Mild
David	Male	65	Mild

†Pseudonyms are used to protect participant anonymity.

Data collection

Between May and July 2022, a total of ten semi-structured interviews were conducted to collect data. Although studies indicate that people with mild to moderate intellectual disabilities can talk about their own experiences, quality of life and the support they need (Albuquerque & Carvalho 2020; Alftberg et al. 2021; Schepens et al. 2019), specific methodological challenges involved in interviewing people with intellectual disabilities were thoroughly discussed. To achieve reliable and valid data, the researchers discussed participants potentially showing acquiescence, social desirability and suggestibility, or having difficulty in understanding the content of the questions being asked or how they were asked (Beail & Williams 2014; Sigstad, 2014). The information and confirmation letter and the interview guide in this study were therefore developed in close collaboration with the co-researcher. Moreover, an advisory board of three experts by experience with a mild intellectual disability of the Academic Collaborative Centre Living with an intellectual disability provided advice on the entire research proposal and the interview guide during a group discussion.

Advice was given on the formulation of the questions in the interview guide, language use, recruitment procedures and interview setting (i.e. quiet place, presence of a caregiver). Input from the co-researcher and the members of the advisory board was crucial to the final development of the interview guide and how the interviews were conducted. The interviews were initiated using open-ended questions in the first part, inviting older people with intellectual disabilities to talk about matters of importance, followed by more specific questions related to their current support needs in the second part, using the nine domains based on the QoL-model (i.e. personal development, self-determination, interpersonal relationships, social inclusion, rights and emotional, physical, material and existential wellbeing; Schalock et al.

2010; Schepens et al. 2018; Thalen et al. 2023). Examples of questions were: What is important to you in daily life? What makes you happy? Can you indicate whether you need support with anything you have mentioned? Can you indicate whether you need support in this particular domain? How could caregivers best help you with this? The entire interview guide can be requested from the authors.

Procedure

Participant recruitment took place within one large healthcare organisation covering multiple residential facilities for people with intellectual disabilities throughout the Netherlands. First, a researcher and co-researcher (MT and MK) contacted caregivers (i.e. psychologists and support staff members) from 21 residential care facilities to verify which participants were eligible to participate in the study based on the inclusion criteria. An adapted, accessible information letter was sent to potential participants, and the caregivers involved were asked to discuss the study with them. The participants were given time to consider giving informed consent before the researchers (MT and MK) asked if the participants wanted to take part. Next, an easy-to-read confirmation letter was sent to all interested participants and their caregivers. After confirmation, all practical arrangements for the interviews were made.

Each interview was conducted by a researcher and a co-researcher (MK and MT or MK and KV). The co-researcher had prior experience with interviewing and received training in interview techniques. Two pilot interviews were held to test the interview guide as an essential point of preparation to effectively conduct the research interviews. The role of both the researcher and the co-researcher during the interviews was then discussed based on the experiences of the pilot interviews. While the co-researcher observed and made field notes during the pilot interviews, their role shifted during the research interviews towards taking the lead, asking all the questions in the first part of the remaining interviews. Before the interview, the participant was given the opportunity to decide if a caregiver or another support person should be present. The interviews took place at a location that was most convenient for the participant. The interviews lasted an average of 49 minutes each (range 28 – 97 min), with all but one of the participants being interviewed alone. All interviews took place at the participants' own homes (i.e. the residential care facility). After each interview, the co-researcher immediately made a summary of the interview.

Data analysis

The interviews were audio-recorded with participant approval and transcribed verbatim afterwards. The qualitative data analysis framework used was based on Braun and Clarke's (2006) thematic analysis. This is an analytical approach used to find patterns across transcripts. In the thematic analysis, an inductive approach was adopted in which codes and themes emerged from the data. The inductive approach enabled the researchers to identify key themes of interest by reducing the material to a set of themes or categories. Thematic analysis is a useful method to examine participants' perspectives, and it emphasises similarities and differences (Braun & Clarke, 2006). Themes were identified at the latent level and examined the underlying assumptions or ideas behind participants' descriptions of what was important to them in daily life and the support needs they experience.

The analysis was conducted by following these six steps: (1) four researchers (MT, MK, KV and LH) familiarised themselves with the transcripts, and independently and inductively coded the same part of one transcript by assigning codes to relevant statements concerning the participants' perspectives on matters of importance and current support needs. The coded part was compared for consistency by discussing overlaps and divergences (Ritchie et al. 2014). (2) Four randomly selected transcripts were coded independently in two pairs (MT and MK or MT and KV or MT and LH) as a reliability check. The level of agreement was 84.4% (range 81.8% – 89.2%). Again, the codes and the emerging subthemes were discussed until full consensus was reached. (3) The first author analysed the remaining six interviews. (4) Subsequently, the results of all interviews were compared with the co-researcher's corresponding summaries to see if additional information could be obtained from them. (5) After coding all transcripts, potential themes and subthemes were formulated. These themes and subthemes were then reviewed in relation to the coded text fragments and discussed by all authors. (6) Finally, themes and subthemes were refined and recorded. All authors jointly produced a narrative structure with accompanying descriptions. As the interviews were carried out in Dutch, the initial analysis was conducted in the same language. To ensure the meaning of what participants discussed was retained during the translation process, the findings and the final paper were discussed with an English native speaker who was fluent in Dutch.

Ethical procedure

This study was approved by the Ethical Review Board of Tilburg University (TSB_RP533). Prior to the interviews, participants received a letter informing them of the study's aim and course, as well as an accessible informed consent form. The information letter explained that participation was voluntary. If needed, a caregiver helped the participants read the information. The study's goal and procedure were repeated orally before the start of the interview. All participants gave written informed consent. The interview transcripts were made anonymous and non-traceable to individuals. Pseudonyms are used to protect participant anonymity.

Results

Following the setup of the interview guide, first, the matters of importance of older people with mild to moderate intellectual disabilities are described. Their current support needs are discussed afterwards.

I. Matters of importance of people with mild to moderate intellectual disabilities

After analysing the interviews regarding matters of importance, three overarching themes emerged: (1) Feeling connected to others; (2) Feeling at ease or meaningfully engaged; and (3) Feeling autonomous.

Theme 1: Feeling connected to others

All participants indicated that it was important for them to feel connected to other people in their environment. This feeling of connection may be related to the need for personal attention, enjoying each other's company or receiving emotional support. Participants mentioned one-on-one conversations with support staff and contact with family members particularly often. These moments of connection make them feel seen and heard:

> *That they listen to you, how things are going. And have a chat; about what you did that day ... I think attention is important. Then you will be asked something again. I think it is important that they sympathise with you here. [Olivia, 78 years]*

Participants also indicated that this connection can also be found in contact with other residents or volunteers. For example, you can tell your story to a fellow resident, or you can seek comfort with or offer comfort to each other, as expressed by the following participant:

> *Looking after each other. And if you are sad, that you are comforted and so on, that's the case here, that happens here too ... With those people in the living room ... I'm also participating in it myself. Comforting people. If I hear someone crying, I will cry too. And then I like to give them water. [Adam, 71 years]*

Another way in which most participants indicated that connection with others was important in their daily lives was by undertaking joint activities while enjoying each other's company. For example, these can be joint activities with another resident or a volunteer, indoors (e.g. drinking coffee, watching television or having dinner together) or outdoors (e.g. going to the shopping mall or the zoo):

> *A volunteer comes to see me, and she sometimes comes to pick me up to go to places, to have a nice coffee somewhere in the village … I always really enjoy doing that … Usually every two weeks yes, on Wednesdays … With Jenny, who is a volunteer. [Carly, aged 90]*

Finally, the participants frequently mentioned spending time with family members or friends was of great importance to them in daily life, despite the fact that these visits or activities seemed to occur relatively rarely:

> *Yes, I go visit them [i.e. brother and sister-in-law] on birthdays and New Year's Eve and holidays. Then they pick me up by car … Yes, on those occasions I get to see them again. [Anne, 66 years]*

Theme 2: Feeling at ease or meaningfully engaged

All but one of the participants mentioned a specific hobby or activity when asked about what was important in their daily lives. For some it was listening to or making music; for others it was playing games. Cycling, walking and going to church or the café were frequently mentioned by the participants. Most of these activities had the aim of relaxation as stated by the following participant:

> *From walking and stuff, when I'm outside, that I clear my head. I've been doing that ever since I retired. [Adam, 71 years]*

Even though the activities, as described earlier, could be either passive or active in nature, a quiet environment and privacy were often also mentioned as important in daily life. For example, some participants expressed preferring smaller groups of people because of the tranquillity:

> *I prefer small groups. I can handle them better. Because I also have crying spells sometimes, and that's all because of the tension and stuff, that's why I'm very quiet here, I think. I'm lucky to have this place here, see? [Vivienne, 82 years]*

One participant liked to spend time at the daytime activity centre because it is more peaceful there than at home. Furthermore, participants valued having their own rooms and bathroom facilities. Some participants stated that they preferred to spend time in their own rooms instead of in the shared living room because it could get too busy there. During mealtimes, for example:

> *I eat in my own room ... Those people [i.e. other residents] have something to say about everything, about the food and stuff. Well, I don't want that. I can eat in my own room in peace. It's way too busy for me in my head. And that's why I don't want to sit there. [Jacqueline, 69 years]*

Another important theme that could be distinguished based on the interviews was that participants valued being able to participate in meaningful activities throughout the day. Participants indicated that it was important to them to have a goal during the day. For example, participants mentioned that having a job or going to a daytime activity centre would fulfil this need. In addition, helping with household tasks, such as setting the table, making coffee or doing the laundry would also contribute to the feeling of being of value, as explained by this participant:

> *Setting the table and I always clear the table here when we have eaten bread. I'll bring everything here, put everything on the counter ... then I'm glad I can help with something. [Anne, 66 years]*

Participants also pointed out that being active or creative during the day was important to them. For example, they stated that activities, such as painting or knitting, could be considered meaningful activities that they felt gave them purpose. Despite the fact that some participants were retired, they wanted to remain active:

> *Doing chores. Stringing beads, yes ... I really like that, yes. Because if you do nothing all day, it's not nice either, is it? ... We're keeping ourselves busy, you know. [Carly, 90 years]*

Theme 3: Feeling autonomous

More than half of the participants indicated that it was important to remain self-reliant in their daily lives, despite their ageing. In other words, being able to do certain things independently for as long as possible, such as dressing themselves, doing groceries, contributing to the household or being able to go to the bathroom by themselves:

> *But here you have a shower in your room, and that's much nicer. So I can go to the toilet myself. [Olivia, 78 years]*

For some participants, remaining self-reliant was closely related to staying fit, mobile and healthy. A few participants pointed out that the deterioration of health was to be expected given their age, which would in turn affect their self-reliance. It was, however, still valuable to them to remain independent and mobile, as explained the following participant:

> *I hope I don't end up in a wheelchair ... I hope not, I won't, because I'm still too healthy for that. [Emily, 80 years]*

Finally, participants mentioned the actual experience of autonomy. For some participants, having a say in the food served to them or how their medication was administered was very important in their daily lives. Other participants stated that it was important to experience freedom of movement (e.g. being able to cycle somewhere or going to the store whenever they wanted) or determining their own pace (e.g. sleeping in):

> *No, I do all that by myself ... I don't want to be dragged everywhere, I'm not a tow, tow truck. [George, 72 years]*

II Current support needs

After analysing the interviews regarding current support needs, four overarching themes emerged: (1) Support to be able to do everyday things; (2) Support regarding personal care; (3) Support to achieve emotional wellbeing; and (4) Support to maintain self-esteem and autonomy.

Theme 1: Support to be able to do everyday things

When asked about their current support needs, participants mentioned help with financial matters. The participants indicated that they needed help with payments or needed to consult family or a curator about making purchases:

> *Sandra [i.e. the participant's niece] takes care of mail from that account of that [bank account]. And now I've just had a pedicure, and that is then taken care of automatically with a giro. I have my own giro; Monique takes care of it all. [George, 72 years]*

In this context, making appointments and arranging transport were also frequently discussed by the participants. These included help with planning appointments with the hairdresser, pedicures, and arranging and agreeing times with taxi companies when visiting family or church. However, in some cases, participants indicated that they also needed physical assistance from caregivers when going somewhere. This included doctor and hospital appointments, and going outside due to safety concerns:

> *Yes, caregivers will come with me because I am not allowed to go out on the street by myself. Because if I am on the street and I have a seizure, they cannot help me if support staff is not there. No, I am not allowed to go to the shops without caregivers and also not to do any groceries, caregivers will go along if I want to do those things. [Anne, 66 years]*

A final form of practical support that was discussed was the actual organisation and facilitation of social or daytime activities by support staff. Participants preferred it when activities were offered by support staff and there were activities to freely choose from, either individual activities (e.g. knitting, painting, drawing) or more group-related social activities and outings (e.g. drinking coffee together or going to the zoo). Participants also mentioned the opportunities to do things with other residents. Participants also stated that, in some cases, they needed help in the maintenance or organisation of contact with family or volunteers:

> *Yes, every Sunday I call my sister ... Sunday around eight o'clock in the evening ... They do help ... because the connection is sometimes bad. And there is no internet here, the internet here is there for a bit ... then [the connection] is lost, then it has to be set up again. [Olivia, 78 years]*

Theme 2: Support regarding personal care

First, participants mentioned support in care and with daily living activities. They need caregivers to provide support when taking a shower or with dressing and undressing. The same is also true when their clothes need to be washed or food needs to be prepared (e.g. making a sandwich):

> *He always comes to get me out of bed and helps me with showering, washing my back and so on, because you can no longer reach there, you know. Yes, they always help me. [Carly, 90 years]*

Furthermore, participants also spoke about the need for support by caregivers that was more medically in nature. In some cases, help was needed because they were not capable of managing their medication themselves. In other cases, they were not allowed to do it themselves due to safety reasons. For example, preparing medication, administering eye drops or taking care of a stoma:

> *I am no longer allowed to use medicines myself ... I get medicines here at home now ... because they are very precise about that. It absolutely must go well. They think it is very important that this is done well. [Vivienne, 82 years]*

A final form of support with personal care indicated by participants was household support. According to the participants, they need help with chores like cleaning their rooms, preparing coffee, cooking food, setting and clearing the table, and washing windows. As these two participants stated:

> *[I need assistance] with making coffee because I'm not allowed to do it alone. Look, I've been burned once already. Burnt on the teapot. And I'm not allowed to do that alone. Then they help me. [Anne, 66 years]*

Theme 3: Support to achieve emotional wellbeing

Participants indicated that they had needs related to support to achieve a certain level of emotional wellbeing, and they pointed out that they need personal attention from others. It is important that someone pays attention to them and that they are able to have a chat about day-to-day business. It is important that caregivers make time for these moments of contact, as this participant put it:

> *Sometimes it bothers me, I would like to have more conversations, that they pop in for a bit … Then she [i.e. caregiver] wants to see how I'm doing. [Emily, 80 years]*

Participants also indicated that it was important to make room for the themes of grief and loss. Participants wanted to be given the opportunity to share experiences of loss with others, and for caregivers to help them deal with these feelings:

> *My sister and my parents died [and] that sometimes makes me sad. I tell support staff I miss them. But afterwards the caregivers say, let's talk about the nice things again. Because that's always possible that happens even though when you're deceased right ... I like that, then you have something different [to talk about] right? [Carly, 90 years]*

Finally, participants mentioned that caregivers should pay attention to feelings they have about the ageing process and the possible loss of skills, as the following participant explained:

> *I can hardly get my words out sometimes. Then I just get stuck on my words... I do notice to some extent that I'm getting older... With all things, that I'm very tired too... I'm not functioning like I used to, you know? Or am I saying it wrong? I'm not twenty anymore... Sometimes I don't know where I stand. [Emily, 80 years]*

Theme 4: Support to maintain self-esteem and autonomy

The fourth theme the participants discussed was the support needs regarding maintaining self-esteem and autonomy. First, participants indicated that it was crucial that caregivers facilitate freedom of choice in the context of remaining self-control. They stated this was not only about being able to make their own choices, but also about determining their own rhythms or having a say in the food or medication given to them, as explained here:

> *I hate it when they bring me my medicine while I'm still in bed... Then they want to come, but that won't happen anymore. I corrected that and I said it. And also, for the evening, for the morning, simply in the middle of the day, in the afternoon. And in the evening, I eat there, and then I get medicine there. And they do that very well. [Vivienne, 82 years]*

Moreover, there were also participants who stated that they needed a quiet environment or privacy. They indicated that caregivers needed to respect and facilitate this by providing activities they could do in their rooms, for example. It was also important that caregivers left them alone at set times and offered physical space. For example, two participants indicated that they preferred to eat in their own rooms instead of in the living room with other residents:

> *I prefer to watch television here, preferably in my own room. Because sometimes people sit here, they sit and watch in the evening, and I don't like that very much, because they decide what to watch and so on. Then I like being here more. [Adam, 71 years]*

Participants pointed out that they would like to remain self-reliant despite ageing, but that they needed help from caregivers in doing so. When caregivers support them, it is possible to continue doing certain activities (e.g. shopping and buying clothes), to contribute to the household (e.g. doing laundry and making coffee) or to maintain physical skills (e.g. walking and cycling):

> *Walking and doing my own laundry myself, with the help of a caregiver. Yes, myself ... It's a little bit like, still doing things that I want to do. [Emily, 80 years]*

Discussion

The present study established an in-depth account of the experiences of ten older individuals with mild to moderate intellectual disabilities living in six residential care facilities located in the centre of the Netherlands regarding (1) matters of importance to them, and (2) their current support needs. This study can thus be seen as an addition to the studies in which care professionals or relatives are questioned about the wellbeing and support needs of older people with intellectual disabilities (Albuquerque & Carvalho, 2020; Alftberg et al. 2021; Thalen et al. 2023). It is important to include the perspectives of older people with intellectual disabilities since their perspectives may differ to those of care professionals and relatives, and they may harbour different wishes, experience different needs, and have different opinions on how other people should take care of them (Bekkema et al. 2016; Albuquerque & Carvalho 2020). The thematic analysis of the data identified three overarching themes regarding matters of importance: (1) Feeling connected to others, (2) Feeling at ease or meaningfully engaged, (3) and Feeling autonomous. Four overarching themes emerged from the analyses concerning current support needs: (1) Support to be able to do everyday things, (2) Support regarding personal care and support, (3) Support to achieve emotional wellbeing, and (4) Support to maintain self-esteem and autonomy.

Feeling connected to others was one of the most commonly mentioned themes addressed in this study. This is in line with the study by Nolan et al. (2014), who found that quality of life was highest for people aged over 65 years who were 'most integrated' in terms of social networks and lowest for those 'most isolated'. For most participants, the feeling of connection mainly manifested in receiving personal attention from family members, other residents and above all support staff. As their social network (i.e. family and friends) is ageing too (McCausland et al. 2016) and many have no partner or children to care for them later in life (Ryan et al. 2014), it is not surprising that older people with intellectual disabilities are more reliant on support staff to receive personal attention and maintain their quality of life. This is also in keeping with other research showing that one of the closest and most significant social relationships people with intellectual disabilities have is with support staff, who provide them instrumental support and emotional support (Van Asselt-Goverts et al. 2013), and significant and meaningful social contact (Kwekkeboom et al. 2006).

Although some participants indicated they took things slightly slower after reaching retirement age, others clearly expressed a desire to be able to do everyday things. From active, passive or creative leisure-time activities, to meaningful daily activities with a purpose, and the opportunity to do things together with staff, friends, family or volunteers. Although the purpose of the activities may differ (e.g. relaxation vs. feeling valuable), earlier research (Schepens et al., 2018) indicates that engaging in activities seems to affect quality of life positively, both in general and in specific QoL domains. Similarly, McCausland et al. (2016) describe the findings of the Irish Longitudinal Study on Ageing (TILDA) in which the engagement in each area of social participation measured (intimate social relationships, formal activity outside work, active and social leisure, and passive and solitary leisure) was associated with better quality of life.

Finally, participants emphasised the need for autonomy, even as they grew older. More than half of the participants indicated that it was important to remain self-reliant and potentially delay increasing their support needs, despite the ageing process. The importance attached to self-determination is not surprising: autonomy is considered a basic psychological need, along with relatedness and competence, and a central characteristic of healthy functioning for people in general (i.e. the Self-Determination Theory – SDT; Deci & Ryan 2000; Ryan & Deci 2006). Older people with intellectual disabilities are likely to encounter even more difficulties in maintaining their autonomy and self-determination, especially when they can no longer fully keep up and there is a risk that support staff take over from them completely (Judge et al. 2010; Perkins & Moran 2010).

The support needs identified in this study were often related to matters of importance. For example, feeling connected to others or meaningfully engaged seems to be inextricably linked to other support needs the participants pointed out as well, such as achieving emotional wellbeing and the support to be able to participate in everyday activities. Consistent with previous research, people with intellectual disabilities often require support in participating in community activities, self-advocacy and engaging with others (Bigby et al. 2018; Duggan & Linehan 2013). In addition, there is a substantial body of evidence that argues that positive social encounters make a significant contribution to the health and wellbeing of all people, with and without intellectual disabilities (Hong et al. 2018; Roll & Bowers 2019).

A similar link can be found with regard to the theme ‘feeling autonomous’; to be able to experience phenomena of having choice or remaining self-reliant, it actually has to be offered or made possible by others. Older people with intellectual disabilities in the Netherlands often live in residential settings and experience difficulties in maintaining their autonomy and self-determination due to age-related decline (Perkins & Moran 2010). Consequently, support staff have a significant role in providing this kind of support. Autonomy support implies creating an environment that minimises control and pressure while supporting self-initiatives, offering pertinent information, providing choices and taking other people’s perspectives into account (Williams et al. 2006).

Finally, support needs surrounding being able to participate in everyday things and personal care were also identified in this study, such as help with financial matters, arranging transport and support with medication or daily living activities. Needs concerning personal care were expected because, as people with intellectual disabilities age, they are more likely to require more assistance with daily living skills, such as personal hygiene (Shooshtari et al. 2012). Even though there was no direct link between matters of importance and the need for practical support and personal care, overall, the support needs participants mentioned touch on multiple QoL domains. This is consistent with the findings of a previous study by Thalen et al. (2023), which demonstrated the presence of support needs of older people with intellectual disabilities across all QoL domains. Apart from the individual differences and preferences between the participants in this study, present data confirm the presence of support needs in different domains, including physical wellbeing (e.g. support in ADL-activities), emotional wellbeing (e.g. someone paying attention to you), existential wellbeing (e.g. experiencing a meaningful day) and self-determination (e.g. freedom of choice). This is in line with the gerontologic concept of successful ageing (Fesko et al. 2012). Successful ageing implies that physical, psychosocial, material and existential aspects enable older people to experience increased longevity, QoL and life satisfaction while retaining their functional capabilities.

In line with previous studies (e.g. Nijs et al. 2022; Lokman et al. 2022), this study demonstrates the value of including people with intellectual disabilities themselves in research by providing rich data on their lived experiences. For example, compared to the studies conducted among care staff (Albuquerque & Carvalho 2020; Alftberg et al. 2021), this study provides a different point of view and a broader picture of the matters of importance and the support needs that older people with intellectual disabilities encounter. In addition to similar findings, such as the presence of support needs regarding help with financial matters and participating in daytime activities, this study showed that older people experience needs regarding personal attention, room for feelings of grief and loss, self-reliance and freedom of choice. This emphasises the importance of paying attention to the emotional wellbeing and self-determination of older people with intellectual disabilities.

Our inclusive approach, in which a co-researcher with an intellectual disability collaborated in an equal partnership with academic researchers (Bigby et al. 2014; Embregts et al. 2018; Van den Bogaard et al. 2023; Walmsley et al. 2018) throughout all phases of this study, proved to be very valuable. It helped us formulate more accessible interview questions, gain the trust of participants during interviews and incorporate a broader view by interpreting the transcripts together.

The findings of this study should be interpreted within the context of its limitations. First, although the number of participants in our study meets the recommendations of Braun and Clarke (2013), our sample was relatively small. However, the use of a small sample can be regarded as both a strength and a limitation. While it allowed for a more in-depth engagement with each individual participant and exploration of the experiences of older people with intellectual disabilities from a validity point of view, it also limits the generalisability of our findings. Second, besides being small, our sample was specific, in some respects. All participants had a mild or moderate intellectual disability and lived in a residential care facility in the Netherlands with access to 24-hour support. As support arrangements vary within and across countries, future research might address support experiences of older individuals with intellectual disabilities in different living arrangements to consider possible differences in experiences. Third, during data collection, no distinctions were made in advance between the possible various stages of the ageing process (i.e. the degree of vitality), possible dual diagnosis with chronic health impairments or psychiatric disorders. The various stages of the ageing process and differences in the presence of health issues or psychiatric conditions might influence the intensity, quantity or importance of support needs experienced by a particular individual.

In future studies, it would be important to look for larger samples to include and compare the experiences of a broader group of ageing people with intellectual disabilities, including ageing people with moderate to severe intellectual disabilities, ageing people with different living arrangements (e.g. who receive outpatient support) and focus more broadly on the different phases of the ageing process. Nevertheless, the findings of this current study provide valuable knowledge on aspects regarding matters of importance and current support needs that can also be included in such studies.

This study's findings provide several important implications for improving clinical practice and add to existing knowledge. First, our study demonstrates that, in addition to the similarities with the findings in previous studies regarding the support needs of older people with intellectual disabilities, many individual differences regarding matters of importance and support needs also exist. Previous studies indicate that meeting the support needs of older people with intellectual disabilities can lead to significant challenges for support staff, including the possible lack or requirement of specific knowledge and skills to support this population (Alftberg et al. 2021; Innes et al. 2012; Ryan et al. 2014). It is therefore important for staff to be aware and acknowledge that older people with intellectual disabilities have their own specific preferences, even within the same theme, and that support should be attuned to each person's needs.

Even though signs of ageing are mainly associated with needs regarding medical aspects and physical abilities (Alftberg et al. 2021), the outcomes of the present study endorse a broader picture, as older people with intellectual disabilities themselves also indicate that they have wishes and needs regarding their social-emotional wellbeing, existential wellbeing, and self-determination. This means it is important for support staff to remain aware of support needs across all QoL domains (Thalen et al. 2023). In this context, the findings provide an important addition to existing knowledge and implications for the further improvement of supporting older people with intellectual disabilities: being able to adequately adjust to the changing support needs.

This study provides valuable information that could be used to set up implementation studies regarding the wishes and needs of older people with intellectual disabilities. For example, it would be interesting to investigate how support staff can structurally map what is important in daily life for every ageing individual and the possible support they need to improve their QoL throughout the ageing process. Finally, it might be interesting for future intervention studies to combine the different perspectives (e.g. support staff, psychologists, older people with intellectual disabilities and their informal network) to develop an integrated approach (i.e. policy development, staff training) that support staff can apply in their daily work. In this approach or training, special attention can be paid to the elements (e.g. support needs) that were reported by all parties, as well as elements that were not collectively revealed, such as the attention for social-emotional wellbeing and self-determination.

Conclusion

This qualitative study provided an in-depth account of the experiences of ageing people with mild to moderate intellectual disabilities regarding what they consider most important in their daily lives and what support needs they encounter. The interviews provide an extensive overview of these matters of importance and support needs, and they add to the existing knowledge. The outcomes of this study make an important contribution to raising awareness among support staff in the direct care of older people with intellectual disabilities and improving QoL throughout the ageing process.

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CHAPTER 4

4

Psychosocial interventions for older people with intellectual disabilities and the role of support staff: A systematic review

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Abstract

Background

The life expectancy of people with intellectual disabilities has increased. The implications of ageing have resulted in changes in their support needs and challenges to support staff. Access to evidence based strategies for support staff providing care to elderly with intellectual disabilities remains scarce. A systematic review was conducted to provide an overview of available psychosocial interventions.

Methods

Four databases were searched and assessed according to the PRISMA guidelines. A narrative, integrative method of analysis was conducted to synthesise quantitative and qualitative data.

Results

The 36 studies included in the review reported on interventions aimed at either identifying and meeting the needs or perceptions of older individuals or at improving their behaviour and skills. Furthermore, the role of support staff in the implementation of interventions was either active, assisting or undefined.

Conclusions

This overview of studies could contribute to the existing body of knowledge and help to optimise psychosocial support for a growing population.

Keywords:

Ageing, intellectual disability, psychosocial interventions, support, systematic review

Introduction

Similar to the dynamics of ageing in the general population, the life expectancy of people with intellectual disabilities is increasing, due to improved living conditions and better medical care (Mulryan et al., 2021). The ageing process is different for older people with intellectual disabilities, however, as their lifelong disabilities place them at increased risk of developing age-related deficiencies (e.g. multiple chronic health impairments, including cardiovascular and respiratory issues) at a relatively young age (Hermans & Evenhuis, 2014). Furthermore, the occurrence of psychotic disorders is 10 times higher for older people with intellectual disabilities, who are also more likely to experience dementia, personality disorders, anxiety and mood disorders, as compared to the general population (Axmon et al, 2017; Hermans, Beekmans, & Evenhuis, 2013). The early onset of age-related physical and cognitive declines is especially common amongst individuals with severe or multiple impairments or specific genetic syndromes (e.g. Down syndrome) (Coppus, 2013). In summary, older people with intellectual disabilities are considered a particularly vulnerable group. Their ageing processes are relatively complex and, as such, they pose challenges to their overall healthcare (WHO, 2018).

The early onset and complexity of the ageing process result in changes to the support needs of people with intellectual disabilities as they grow older. For example, older people with intellectual disabilities require more assistance with daily living skills (e.g. personal hygiene) and maintaining acquired skills, and they are likely to need adjustments in the frequency and pace of daytime activities to correspond to their current abilities (Shoostari et al., 2012; Thalen et al., 2023). In addition to posing new challenges for older people with intellectual disabilities and their families, the implications of ageing pose challenges to support staff and healthcare organisations (e.g. mental health problems; Prasher, Davidson & Santos, 2021). A different approach is needed in order to ensure optimal care and support. Along with the changing support needs of older people with intellectual disabilities, the capacities of their social networks to provide active support are likely to decrease, as their contacts are ageing as well (McCausland et al., 2016). In addition, older people with intellectual disabilities face the loss of loved ones, and many have no partner or children to care for them later in life (Ryan et al., 2012). Such changes in social networks intensify their appeal to support services, thus making them increasingly dependent on support staff to maintain their quality of life (QoL) (Thalen et al., 2023).

It is unclear whether support staff are prepared for their significant role in meeting the changing support needs of older people with intellectual disabilities (Heslop et al., 2013). Although many Western countries have a long tradition of supporting older people (e.g. through person-centred care), access to evidence-based support strategies remains scarce (Innes et al, 2012; Alftberg et al, 2021). Moreover, most available interventions are medically/physically oriented and aimed at assessing effects within the physical domain of wellbeing (e.g. a treadmill walking programme to improve leg muscle strength; changing medication to decrease the risk of falling; Schepens et al., 2018). The implications of ageing extend beyond physical deficiencies (i.e. physical wellbeing), however, and the need for support in other domains of life (e.g. social wellbeing) are likely to change as well (X. et al., submitted). For this reason, interventions other than those of a medical nature are also relevant to the support of older people with intellectual disabilities. Additional knowledge regarding available psychosocial interventions that can help to optimise support for older people with intellectual disabilities would be beneficial, especially for support staff who must address the changing support needs of older people with intellectual disabilities on a daily basis.

To help address this gap in the available knowledge, we conducted a systematic literature review aimed at providing an overview of existing non-pharmacological and non-physical interventions for older people with intellectual disabilities. We directed particular attention to the various foci of psychosocial interventions and the role of support staff in the application of these interventions. The central research questions in this review study are as follows:

I. What is the focus of the psychosocial interventions documented in the international literature for serving older people with intellectual disabilities?
II. What role do support staff have in the application of these psychosocial interventions?

Method

Search strategy

In accordance with the PRISMA statement (Liberati et al., 2009), the databases of Embase, Psych INFO, MedLine and Cochrane were systematically searched on 12 April 2019, using a search string constructed with assistance from an experienced information specialist. To be included, studies had to be published in English in peer-reviewed journals between January 2000 and April 2019. An updated search was conducted on 24 September 2020. Table 1 provides an overview of the search terms and strategy that were employed in the Embase database, using Emtree terms (i.e. a controlled vocabulary thesaurus used for indexing papers) and additional text words for ‘ageing’, ‘intellectual disability’, and ‘(psycho) social wellbeing’. The other databases use similar thesaurus systems (e.g. Medline uses MeSH terms). We used these terms, as we were interested in sourcing all studies that applied psychosocial interventions to older people with intellectual disabilities (Bramer et al., 2017).

Table 1. Search strategy for Embase database

Embase final search strategy
('intellectual impairment'/de OR 'mental deficiency'/exp OR 'learning disorder'/de OR 'mentally disabled person'/de OR 'developmental disorder'/de OR (((intellect* OR learning OR development*) NEXT/1 (defect* OR deficit* OR deficien* OR dysfunction* OR disab* OR impair* OR disorder* OR retard* OR handicap*)) OR ((mental*) NEXT/1 (defect* OR deficit* OR deficien* OR dysfunction* OR disab* OR impair* OR handicap*)) OR retard* OR idiocy OR (down* NEAR/3 syndrome*) OR prader-willi OR fragile-x):ab,ti,kw) AND ('aged'/exp OR 'middle aged'/exp OR 'aging'/de OR 'dementia'/de OR 'elderly care'/de OR (elder* OR ((aged OR older) NEAR/6 (care OR subject* OR person* OR adult* OR women OR woman OR female* OR men OR man OR male*)) OR very-old* OR frail* OR old*-age* OR oldest-old* OR ((aged OR older) NEXT/1 (people OR subject* OR person* OR population*)) OR senior* OR dementia OR aging OR ageing OR late-life):ab,ti,kw) AND ('quality of life'/exp OR 'wellbeing'/de OR 'psychological wellbeing'/de OR 'personal development'/de OR 'self determination'/de OR 'autonomy'/de OR 'personal autonomy'/de OR 'human relation'/de OR 'social participation'/de OR 'daily life activity'/exp OR 'adaptive behavior'/exp OR 'social adaptation'/exp OR 'social competence'/exp OR 'social interaction'/de OR independence/de OR 'self esteem'/de OR 'self concept'/de OR 'satisfaction'/de OR ((quality NEAR/3 life) OR wellbeing OR wellbeing OR (adapt* NEAR/3 behav*) OR (psychological* NEAR/3 adjustment*) OR wellness OR (personal NEAR/3 development) OR self-determin* OR autonomy OR ((human OR personal* OR interpersonal* OR social*) NEAR/3 (relation* OR interaction* OR contact)) OR ((social* OR communit*) NEAR/3 (participat* OR abilit* OR skill* OR adapt* OR competenc* OR interaction*)) OR ((everyday* OR every-day* OR daily) NEAR/6 (activit* OR participat*)) OR existential* OR meaningfull OR independence OR (self NEXT/1 (esteem OR image)) OR relaxation OR relatedness OR comfort OR satisfied OR satisfying OR satisfaction*):ab,ti,kw) NOT (parent/exp/mj OR (child* OR young*-adult* OR parent* OR mother* OR father* OR paternal):ti) NOT (juvenile/exp NOT adult/exp) NOT ([animals]/lim NOT [humans]/lim) NOT ([Conference Abstract]/lim) AND [English]/lim

Study selection

To determine the inclusion and exclusion criteria and achieve an accurate and structured selection of studies, we applied the approach of Population, Intervention, Comparison, Outcomes and Study Design(s) (PICOS; Liberati et al., 2009), as shown in Table 2. Population was specified as older people (≥50 years of age) with intellectual disabilities. The age criterion was chosen in line with Hermans and Evenhuis (2014), in order to account for premature ageing and the early onset of age-related deficiencies. No distinction was made between specific sub-groups within the population of older people with intellectual disabilities (e.g. Down syndrome, dementia or level of functioning). Three additional criteria were applied for the inclusion of studies involving participants both older and younger than 50 years: (1) separate results for the participants of ≥50 years, or (2) a specific focus on the population of ageing people with intellectual disabilities (in those cases, a lower age limit of ≥40 years was allowed), or (3) evidence that there were no statistically significant differences between the younger and older participants. With regard to the intervention, studies were required to address psychosocial, non-medical/physical interventions. The comparison component was not applicable to this review. The outcome of studies referred to all possible measures that directly or indirectly concerned an aspect of the psychosocial wellbeing of older people with intellectual disabilities. Finally, in light of the research questions and the aim of this review, both quantitative, qualitative and mixed-method studies were included, and therefore the study design component referred to all empirical studies.

The selection process for studies consisted of four phases: identification, screening, eligibility and inclusion (see Figure 1). In the identification phase, records were identified in four different databases, according to the search strategy described above, and duplicates were eliminated. This phase was followed by a two-step process for screening the remaining 5,378 studies. In the first step, each study was screened independently based on the exclusion criteria (see Table 2) by the first author and one of two senior researchers experienced in conducting and supervising systematic reviews on title and abstract (Pair 1: MT and WvO; Pair 2: MT and KV). Studies clearly meeting the exclusion criteria (e.g. studies about the general population or review studies) were excluded. The agreement between the three researchers was 96.9%. In case of disagreement within pairs, the third researcher was consulted or, when in doubt, the study was included for further assessment of the full text.

Table 2. Inclusion and exclusion criteria applied in the present study

Inclusion criteria

- Studies focusing on people with intellectual disabilities ≥50 year
- Studies focusing on ageing people with intellectual disabilities ≥40 years
- Studies focusing on psychosocial, non-medical interventions
- Studies focusing on (individual) psychosocial outcomes (e.g. subjective wellbeing, mood, self-esteem, QoL, psychological distress and improvement adaptive and social skills in daily life)

Exclusion criteria

Participants:

- Studies focusing on people without intellectual disabilities
- Studies focusing on people with intellectual disabilities ≤50 years
- Studies focusing on support staff or managers

Intervention:

- Studies focusing on medical, pharmaceutical interventions
- Studies focusing on physical interventions
- Studies not reporting psychosocial outcomes

General:

- Studies not presenting empirical data (e.g. policy documents, conference papers) or opinion papers
- Studies presenting only psychometric data (i.e. validity and reliability of an instrument)
- Studies not published in English

In the eligibility phase, the remaining studies were distributed amongst the same pairs for independent review of the full text. In this phase, 214 full-text articles were assessed based on both the inclusion and the exclusion criteria (see Table 2). The agreement between the three researchers was 92.0%. Disagreements regarding full-text articles were first discussed with a third researcher to reach consensus. In case of persistent doubt and complex decisions, a fourth researcher (PE) was consulted until full consensus was reached. After the full-text studies were included, the reference lists of these remaining articles were hand searched and checked by the first author for potentially other relevant intervention studies. This resulted in the screening of two additional full-text articles, which were assessed for eligibility according to the methods outlined above.

Finally, in the inclusion phase, the authors assessed the quality of the 38 eligible studies based on the Multi-Method Appraisal Tool (MMAT, Hong et al., 2018). This instrument can be used to assess the quality of studies with different research designs. It has demonstrated good content validity and reliability (Pluye et al., 2011). The appraisals were discussed by three authors (MT, WvO and KV), and the quality criteria were rated as either positive or negative. In case of persistent doubt and complex decisions, a fourth researcher (PE) was consulted until full consensus was reached. Studies with a negative score on at least one of two MMAT screening questions or negative scores on all five MMAT quality criteria were classified for exclusion. As a second check, studies that had been classified for exclusion were assessed by an independent researcher experienced in conducting systematic reviews. If the independent researcher confirmed the absence of positive scores on MMAT indicators, the study was excluded from further analysis (see Figure 1). As a result, two studies with lower-than-acceptable quality were eliminated from further analyses, in accordance with the MMAT guidelines. Finally, outcome scores of the remaining studies were converted to three levels of quality: high (score 5 out of 5), moderate (score 3 or 4 out of 5), and low (score 1 or 2 out of 5) (see Table 3).

Data extraction and analysis

Both general information (i.e. study and participant characteristics) and main results were presented briefly in order to provide a clear overview of the studies included (see Table 3). Subsequently, a narrative, integrative method of analysis was used to synthesise the quantitative and qualitative data (Whittemore & Knafl, 2005) addressed in the studies. The structure of the results was determined by the review questions and based on themes emerging from the analysis.

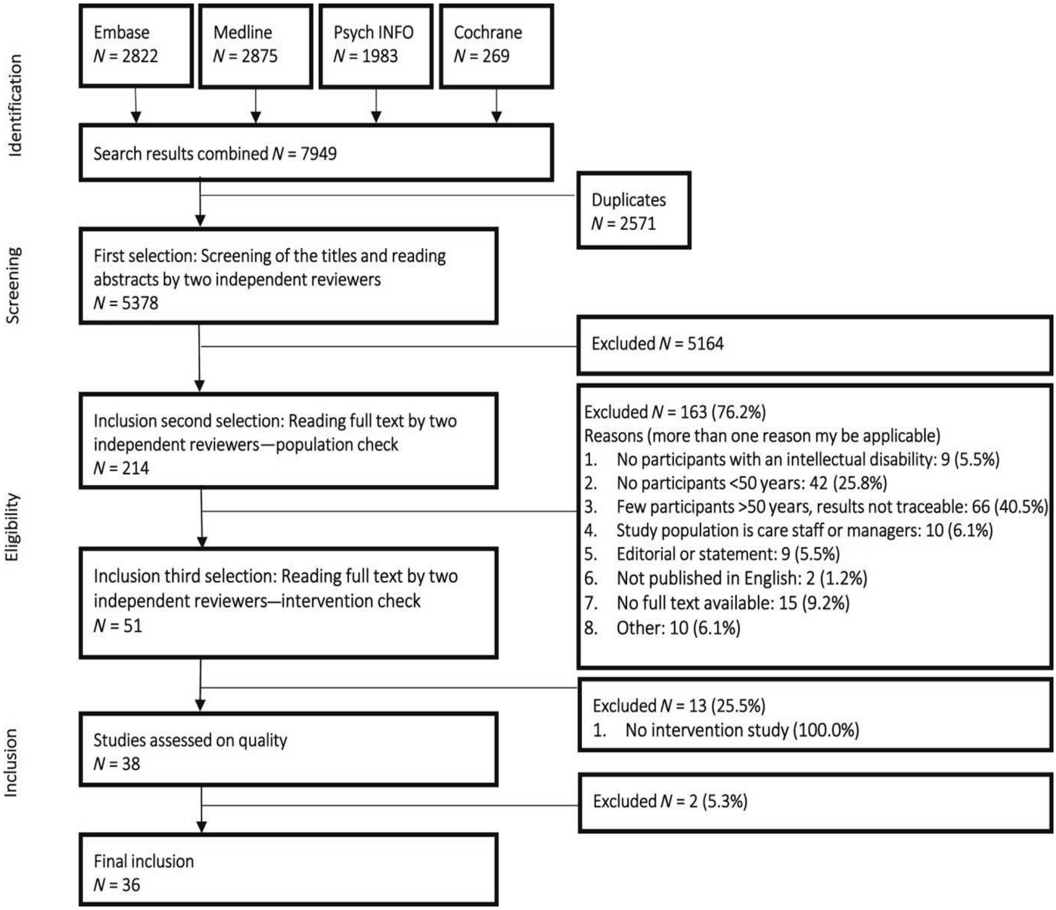

Figure 1. Flowchart of the study selection for this systematic review

Results

The results of this review are divided into three parts. First, a brief overview of the study characteristics is presented. This is followed by a description of the themes emerging from the analysis with regard to the focus of the psychosocial interventions included. Finally, the role of support staff in the application of these interventions is explained further.

1. Background and research quality

An overview of descriptive information for the 36 studies included is provided in Table 3. Of these studies, 14 were conducted in the USA, with 7 having been conducted in the UK, 7 in the Netherlands, 2 in Ireland, 2 in Australia and 1 each in Belgium, Hong Kong, Israel and New Zealand. The studies were based on a variety of designs. A quantitative approach was used in 29 studies (i.e. 12 multiple baseline designs, 9 case studies or case series, 4 quasi-experimental designs, 3 pre-post intervention designs and 1 controlled trial), with 4 studies using a mixed-methods design and 3 being qualitative (i.e. 2 observational studies and 1 case study). Regarding the type of interventions, 11 behavioural interventions, 8 modeling and (social) skills interventions, 6 multi-component interventions, 6 therapeutic interventions, 4 cognitive interventions and 1 social network intervention were included in this review. The quality assessment with the MMAT (Hong et al., 2018) resulted in 4 studies of high quality, 24 of moderate quality and 8 of low quality (see Table 3). Overall, the main methodological limitation concerned the lack of information of the origin of the measures and/or the relationship between the context of the study and its influence on the results (e.g. the researcher's perspective, role and interaction with participants). Studies with a score 2 out of 5 frequently lacked validation for both of these themes. In general, sample sizes were small, often no follow-up data was collected or in some cases, outcome data was incomplete and information on procedural reliability was scarce resulting in the majority of studies being rated with moderate quality.

In all, 296 individuals (161 male and 135 female) aged ≥50 years with intellectual disabilities were involved in these studies, although only 11 studies focused specifically on the ageing population with intellectual disabilities. The remaining 25 studies either provided separate results for the group of participants aged ≥50 years or demonstrated that there were no statistically significant differences between the younger and older participants. In 26 studies, the participants' level of functioning was specified (e.g. mild, moderate, severe or profound). The other studies mentioned only that participants had intellectual disabilities. The focus of 16 studies was on participants with an intellectual disability and an additional diagnosis (e.g. dementia, Down syndrome, autistic disorder or visual impairment). All of the studies were conducted within the context of community and residential services for people with intellectual disabilities.

Table 3. Characteristics of the included studies

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
1. Anderson & Kazantis (2008); NZ	Multiple single-case; Low (2/5)	N = 1 male with a mild intellectual disability and schizophrenia, ≥50 years	To evaluate a social problem-solving training on an individual basis	Social Problem-Solving Skills training; 15 sessions	Psychologists	Assisting	AAMR (Nihira et al., 1993); Adapted Anxiety Inventory (Lindsay & Mitchie, 1988); Adapted Zung Depression Scale (Reiss & Benson, 1985); Adapted Rosenberg Self-esteem Scale (Dagnan & Sandhu, 1999); Social Problem-Solving Skills Measure (Loumidis, 1993)	All participants showed improvement in social problem-solving skills (0.47-0.57% change), and two participants showed improvement in depression (0.31-0.40% change). No effects were found for anxiety or self-esteem. Improvement was maintained at 4-week follow-up.
2. Bai et al. (2014); HK †	Quasi-experimental research; Moderate (4/5)	N = 32, 15 males and 17 females with mild to moderate intellectual disabilities, ≥50 years	To develop a training protocol of LSWp designed especially for older adults with mild-to-moderate levels of intellectual disability, and to evaluate the effectiveness of LSW	Life Story Work programme (LSWp); 6 months	Support staff (LSWp instructors)	Active	MIPQ, Petry et al., 2010); VABS (Sparrow et al., 2005); PWI-ID (Cummins & Lau, 2005)	The LSWp showed potential for improving QoL and preventing loss of interest and pleasure for older adults with intellectual disabilities. It also showed promise for enhancing their socialisation skills. Participants with better communication skills seemed to benefit more from the LSWp.
3. Bidwell & Rehfeldt (2004); USA	Multiple-baseline across three participants; Moderate (4/5)	N = 1 female with a severe intellectual disability, ≥50 years	To determine whether adults with severe mental retardation would acquire, generalise and maintain a domestic skill with an embedded social initiation by observing a model on a computer demonstrating the chained task	Video Modelling Intervention; 30 sessions	Researchers	Undefined	Observations of the percentage of steps performed accurately during baseline sessions and with regard to intervention, generalisation, and maintenance probes	All participants mastered the task and demonstrated generalisation across settings, stimuli and people.

Table 3. Continued

Author (year); country	**Study design; MMAT score**	**Older participants**	**Study aim**	**Intervention; duration**	**Practitioners**	**Role of support staff**	**Outcome measures**	**Results**
4. Brooks & Paterson (2011); UK	Observational (qualitative); Low (2/5)	N = 1 male with an intellectual disability and autistic spectrum disorder, ≥50 years	To consider the usefulness of using contact work with adults with learning disabilities and autistic spectrum disorders living in a residential setting	Contact work; 8 sessions	Speech and language therapists	Undefined	Observations using a measurement tool based on the categorisation of Prouty et al. (2002)	The data collected suggest that the approach had an immediate impact on the participant's contact behaviours, but it did not result in carry-over from one session to another or to different contexts.
5. Bucholz et al. (2008); USA †	Multiple-baseline across periods; Moderate (4/5)	N = 1 male with an intellectual disability and Down syndrome, ≥50 years	To expand the body of research on the use of social stories and Literacy-Based Behavioural Interventions, and on the improvement of work behaviour	Literacy-Based Behavioural Intervention; 22 sessions	Support staff	Active	Observations during baseline and intervention sessions	The participant made substantial improvements in his work behaviour as a result of the LBBI. It could be useful for reducing prompt dependence and increasing timely return to work
6. Chng et al. (2013); AUS †	Non-concurrent multiple-baseline across participants: Moderate (3/5)	N = 3 females with moderate intellectual disabilities, ≥50 years	To evaluate whether training mentors in Active Mentoring would yield (1) increased engagement in mainstream community group activities by older adults with ID, and (2) increase help from mentors for participation	Active mentoring; Active Support style training Intervention; n/a	Support staff, group members and volunteers	Assisting	Observations during community group activities using software (MOOSES; Tapp, 2009)	Active mentoring was effective in improving activity engagement, while showing no effect on social engagement. Overall, increases were observed in total engagement, supported engagement and independent activity engagement, relative to pre-test.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
7. Conklin & Mayer (2011); USA	Multiple-baseline across three participants; Moderate (4/5)	N = 1 female with a severe intellectual disability, ≥50 years	To document the outcomes of the learning and use of PECS, and to monitor associated target behaviours	Picture Exchange Communication System (PECS); 20 sessions	Researchers and students	Undefined	MAS (Durand, 1990) and observations during baseline, intervention and follow-up sessions	Participants taught through the PECS increased their initiation of requests, thereby enhancing their independence and choice-making. However, the majority of participants did not master all phases.
8. Cooper & Browder (2001); USA †	Multiple-baseline; High (5/5)	N = 8, six males and two females with severe to profound intellectual disabilities or dual diagnosis of mental retardation and mental illness, ≥46 years*	To utilise a self-management staff-training package to teach staff members to use the least intrusive assistance and honour choice in a community-purchasing routine, and to evaluate the effect of the level of staff assistance on the learner's level of independent response	Multi-component staff training package; n/a	Support staff	Active	Observations during baseline, post-intervention and maintenance sessions	After staff members had received the intervention, participants increased the number of choice responses they made, in addition to enhancing their level of performance.
9. Crook et al. (2016); UK †	Randomised single-case series; Moderate (4/5)	N = 5, two males and three females with intellectual disabilities and dementia, ≥50 years	To evaluate aspects of Reminiscence Therapy in the form of life-story books and rummage boxes, as compared to no intervention	Life-story book and rummage box; 9 sessions	Researchers	Assisting	DCM (Bradford Dementia Group, 2005)	Combined data for all participants indicated that the two reminiscence conditions were associated with higher wellbeing scores, as compared to the no-intervention condition.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
10. Crowley et al. (2008); UK	Pre-test/post-test; Moderate (3/5)	N = 2 males with mild intellectual disabilities and a diagnosis of schizophrenia or bipolar disorder, ≥50 years	To evaluate a psychoeducation group programme by adapting programmes developed within the context of mental health services	Psychosis and intellectual disability psycho-educational groups; 6 sessions	Group leaders	Assisting	Crown Self Esteem Scale and 'What Do You Know about Psychosis?' Questionnaire based on existing questionnaires (Smith & Birchwood, 1990)	All participants completed the programme and measures of psychosis knowledge showed increases post-group. However, data on the measures were not collected from all participants (1 older person).
11. Cuvo et al. (2001); USA	Controlled-experimental; Moderate (3/5)	N = 2 males with profound intellectual disabilities, ≥50 years	To test the effect of a room with sensory equipment (i.e. Snoezelen Room) on stereotypical behaviour and engagement, as compared to a living room or outdoor activities	Snoezelen Room; 12-18 sessions	Researchers	Undefined	Observations during baseline and intervention sessions	An increase in engagement was observed for the two older individuals (Snoezelen Room vs living room), along with a decrease in stereotypical behaviour (outdoors, Snoezelen Room vs living room).
12. Darling & Circo (2015); USA	Multiple-baseline across participants; Moderate (3/5)	N = 2, one male and one female with profound multiple intellectual disabilities, ≥50 years	To assess whether the repeated presentation of preferred items and activities during multiple periods of the day increases scores on happiness indices	Presenting preferred items and activities; 7-12 sessions	Support staff	Active	Observations during baseline and intervention sessions	The presentation of preferred items and activities increased scores on the indices of happiness, as compared to baseline rates.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
13. Dollar et al. (2012); USA	Multiple-probe across three behaviours; Moderate (3/5)	N = 1 male with a severe intellectual disability, ≥50 years	To examine the effectiveness of simultaneous prompting to teach chained tasks (i.e. independent living and leisure skills) to individuals in their home environments	Simultaneous prompting; 28 sessions	Researchers	Undefined	Observations during baseline, intervention and maintenance sessions	Simultaneous prompting was effective in teaching independent living skills, but modifications were made throughout this study to reduce the number of errors during instructional and probe sessions.
14. Fox et al. (2009); USA	Case series; Moderate (4/5)	N = 1 male with a severe intellectual disability and autistic disorder, ≥50 years	To conduct a pilot study of an accommodation programme for adults with autism, severe to profound mental retardation and significant behaviour problems	A Community-Based Accommodation Programme; 5 years	Support staff	Active	Observations using daily data sheets during the baseline period and each year of participation in the programme	Following three to six years of participation in the accommodation programme, a significant treatment-effect size was obtained for all participants (80% reduction in the targeted behaviour).
15. Golisz et al. (2018); USA	Double-baseline case study; Moderate (4/5)	N = 1 male with a moderate intellectual disability, ≥50 years	To address the limited evidence of the potential effectiveness of an approach involving the selection of activities and goals in order to support learning for adults with intellectual disabilities in the completion of a selected ADL task using ordinary technology	Task-specific learning support; 1 month	Occupational therapy graduate students	Undefined	Modified participant-centred interview (Law et al., 1998); BRIEF-A (Goia et al., 2000) and direct performance-based observations during baseline, intervention and post-intervention	The functional performance of all participants on a task related to an activity of daily living improved in terms of accuracy and efficiency as cues from support workers were tapered off.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
16. Harper et al. (2013); USA	Multiple-baseline across subjects; Moderate (4/5)	N = 1 male with a severe intellectual disability, ≥50 years	To evaluate a series of treatments designed to replace social avoidance with appropriate forms of social interaction	(a) vicarious reinforcement, (b) conditioning of social interactions, (c) stimulus fading, and (d) DRA plus EXT; 45 sessions in total	Therapists	Undefined	Observations during baseline and intervention sessions	DRA plus EXT was the only condition in which decreases in problem behaviour and increases in social interactions were observed reliably. Not all phases were implemented.
17. Hoffman et al. (2019); NL	Pre-experimental within-group; Moderate (4/5)	N = 3 males with mild-to-moderate intellectual disabilities and visual impairment, ≥50 years	To determine the efficacy of technology-assisted therapy for separation anxiety in reducing separation anxiety and challenging behaviour	Technology assisted therapy for separation anxiety; 17 to 18 weeks	Support staff	Active	ABCL (Tenneij & Koot, 2007); BSI (Wieland et al., 2012); PIMRA (Van Minnen et al., 1994); IDQOL (Hoekman et al., 2001)	Indications that the separation anxiety and challenging behaviour experienced by the participants decreased significantly, while their psychosocial functioning and QoL increased significantly.
18. Horovitz et al. (2010); USA †	Case study; Moderate (3/5)	N = 1 male with Down syndrome, profound intellectual disability, dementia and anxiety disorder, ≥50 years	To examine the effects of using contingent reinforcement of compliance as an intervention	Compliance Training; 16 weeks	Therapists and support staff	Assisting	Functional Assessment Interview (O'Neill et al., 1997); Questions about Behavioral Function Scale (Singh et al., 2009) and observations during baseline, intervention and follow-up sessions	Non-compliance had decreased by 85.22% at follow-up.

Table 3. Continued

Author (year); country	**Study design; MMAT score**	**Older participants**	**Study aim**	**Intervention; duration**	**Practitioners**	**Role of support staff**	**Outcome measures**	**Results**
19. Kruithof et al. (2018); NL	Theory-based evaluation (qualitative research); Low (2/5)	N = 8, six males and two females with mild intellectual disabilities, ≥50 years	To bridge the knowledge gap regarding group-oriented interventions intended to include the socially excluded in general and, more specifically, regarding social work interventions aimed at expanding networks and increasing societal participation	The Communal Table (social network intervention); 6-18 months (1 session per month)	Support staff	Active	Observations using field notes and interviews with participants	Although participants experienced conviviality and warmth, the intervention neither fulfilled its intended aims of expanding social networks and/or increasing societal participation, nor did these intended effects match the participants' motivations for participation.
20. Lifshitz & Klein (2011); ISR †	Mixed-method; Low (2/5)	N = 1 male with an intellectual disability, Down syndrome and dementia, ≥50 years	To describe a new method of mediation between staff members and adults with intellectual disabilities, and between staff members and elderly people with intellectual disabilities, either with or without dementia; MISC model	Mediational Intervention for Sensitising Caregivers (MISC); one time implementation	Support staff	Active	DRM (Evenhuis et al., 1990) and observations	Although the participant's memory difficulties remained, his daily life became somewhat easier and less stressful. He was able to learn new strategies to compensate for the deterioration in his short-term memory and orientation in time and space

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
21. Martens et al. (2017); NL	Multiple-baseline across subjects; Moderate (4/5)	N = 1 male with an intellectual disability and congenital deaf blindness, ≥50 years	To examine whether the IMAI-based intervention is effective for people with congenital deaf blindness and intellectual disabilities	Intervention Model of Affective Involvement (IMAI); 20 sessions	Support staff	Active	Observations during baseline, intervention and follow-up sessions	Indications that affective involvement increased after communication partners had been trained.
22. Marwood & Hewitt (2012); UK	Mixed-method; Moderate (3/5)	N = 2, one male and one female with mild intellectual disabilities and anxiety issues, ≥50 years	To investigate the effectiveness of a cognitive behavioural group intervention for individuals with learning disabilities who are experiencing anxiety	Anxiety group (cognitive behavioural therapy); 6 sessions	Psychologists	Assisting	Quality of Life Scale (Andrews & Withey, 1976); Glasgow Anxiety Scale (Mindham & Espie, 2003); HoNOS-LD (Roy et al., 2002) and interviews with participants	Indications that the intervention was successful in treating anxiety for people with intellectual disabilities. However, no follow-up was conducted, but interviews were held.
23. McManus et al. (2014); IER	Case series; Moderate (3/5)	N = 3, two males and one female with mild intellectual disabilities and a chronic pain condition, ≥50 years	To examine the utility of some of the standard components of cognitive behavioural therapy for pain management, modified for use with people with intellectual disabilities	Feeling better (cognitive behavioural therapy for chronic pain in people with intellectual disabilities); 8 sessions	Psychologists	Assisting	The Pain Self-Efficacy Scale for children (Bursch et al., 2006); Wechsler Abbreviated Scale for Intelligence (Wechsler, 1999); Pain Knowledge Scale; Coping Strategies questionnaire	Indications that participant scores on pain management knowledge, wellness-focused coping and effectiveness of coping increased following intervention. However, these gains were generally not maintained at follow-up. The intervention did not have the predicted beneficial effect on self-efficacy or reduced use of illness-focused coping strategies.

Table 3. Continued

Author (year); country	**Study design; MMAT score**	**Older participants**	**Study aim**	**Intervention; duration**	**Practitioners**	**Role of support staff**	**Outcome measures**	**Results**
24. Mevissen et al. (2010); NL	Case study (qualitative research); Moderate (3/5)	N = 1 female with a moderate to mild intellectual disability and PTSD, ≥50 years	To explore the applicability and efficacy of EMDR in people with mild intellectual disabilities who have experienced various types of negative life events	EMDR treatment; 13 sessions	Clinical psychologists	Assisting	Observations	In all cases, PTSD symptoms decreased, and the outcomes suggest the applicability of EMDR. Treatment effects remained at follow-up and appeared to be most beneficial for the older person.
25. Raftery et al. (2016); IER	Case studies; Low (2/5)	N = 2, one male and one female with mild intellectual disabilities and psychosis, ≥50 years	To ascertain the clinical benefits of an IPS programme over an 18-month period and to examine its cost-effectiveness	Intensive Personalised Support (IPS); 18 months	Researchers (IPS workers)	Undefined	CANDID-R (Xenitidis et al., 2000); AMPS (Fisher et al., 2010); SAI-E (Sanz et al., 1998), GAF (Spitzer et al., 1994); LQoLP-EU (Van Nieuwenhuizen et al., 2001); BAI (Beck et al., 1988); Mental Health Recovery Star (Killaspy et al., 2012)	Reductions in psychopathology including anxiety symptoms, increased functioning and QoL were noted in all individuals. The IPS approach was clinically effective, particularly in addressing the psychosocial needs, psychological functioning, daily living skills and overall QoL of the participants.
26. Randle-Philips et al. (2016); UK	Mixed-method; Low (2/5)	N = 1 female with an intellectual disability, ≥50 years	To explore whether an adapted tree-of-life narrative approach helped people with intellectual disabilities	Tree-of-life group (narrative therapy); 5 sessions	Clinical psychologists	Undefined	CORE-LD (Brooks et al., 2013); Adapted Rosenberg Self-Esteem Inventory (Dagnan & Sandhu, 1999); Tree of Life Questionnaire	No change was found on the quantitative measures of wellbeing and self-esteem. Participants reported benefitting from the peer support and social connectedness that the group offered, especially in relation to themes of loss and change in their lives.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
27. Samuel et al. (2008); UK	Multiple-baseline across time-series; Moderate (3/5)	N = 1 female with a profound intellectual disability, ≥50 years	To address a gap in the accumulated evidence on the effectiveness of Intensive Interaction	Intensive Interaction; 55 sessions	Support staff	Active	PVCS (Kiernan & Reid, 1987); questionnaire based on Interactive Sequence (Downs & Craft, 1997) and Physical Sociability Scale (Kellet, 2001); observations	Slight improvements or gains in communication and social abilities were noted. However, each participant developed differently. There was less evidence for improved quality of relationship.
28. Schaap et al. (2019); NL †	Quasi-experimental; High (5/5)	N = 113, 64 males and 49 females with intellectual disabilities and a mean age of 67 years	To examine the effect of DCM, as compared to care as usual, on the wellbeing and QoL of older clients with intellectual disabilities	Dementia Care Mapping; 2 sessions	Support staff (DCM mappers)	Active	MIPQ (Petry et al., 2010); Quality of Living-Questionnaire (CCE, 2013)	DCM achieved no significantly better or worse QoL than did care as usual.
29. Stancliffe et al. (2015); AUS †	Pre-test/post-test; Moderate (4/5)	N = 29, 18 males and 11 females with intellectual disabilities, ≥46 years*	To examine the feasibility, types and duration of the attendance of participants in a mainstream community group, and to examine the outcomes of such attendance	Active mentoring; 3-6 months	Mentors (volunteers) and support staff	Assisting	HRQOL (Ware et al., 1993); UCLA Loneliness Scale (Russel, 1996); Worker Loneliness Questionnaire (Chadsey-Rusch et al., 1992); GDS (Cuthill et al., 2003); Mini PAS-ADD (Moss et al., 1998) and weekly logs	The members of the intervention group increased their community participation, made new social contacts and decreased their working hours. Intervention participants were more socially satisfied post-intervention than were the members of the comparison group.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
30. Stannis et al. (2019); USA	Non-current multiple-baseline across participants; Low (2/5)	N = 1 male with a severe intellectual disability, ≥50 years	To evaluate a behavioural-skills training programme that teaches adults with intellectual disabilities a response to bullying, and to evaluate *in-situ* training if the skills taught in behavioural-skills training fail to generalise to the natural environment	Behavioural skills and *in-situ* training; 11 sessions (15-30 minutes)	Researchers	Assisting	Observations during baseline, intervention and follow-up sessions	Behavioural-skills training alone was successful in teaching the response to bullying to two participants. When behavioural skills training did not result in the use of the response to bullying, *in-situ* training was effective for one participant, and *in-situ* training plus an incentive was partly effective for the older person.
31. Taber-Doughty et al. (2010); USA	Single-case, alternating treatment; Moderate (4/5)	N = 2, one male and one female with mild intellectual disabilities, ≥50 years	To evaluate and compare the effectiveness and efficiency of prompting when provided by on-site standard care and by remote telecare staff on the independent performance of consumers when completing a series of novel, functionally related household tasks in their own homes	(Auditory) prompting; 20 sessions	Support staff	Active	Observations during baseline, intervention and follow-up sessions	Telecare support had a positive effect and resulted in a greater percentage of task steps completed independently and greater levels of independent task performance for each task.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
32. Underwood et al. (2009); USA	Multiple-baseline across subjects; Moderate (3/5)	N = 1 male with an intellectual disability, ≥50 years	To examine the efficacy of a systematic process for matching behavioural interventions to assessed function (or functions) of problem behaviour in a community-based day programme	Function-Based interventions; 8 weeks	Researchers and support staff	Assisting	Observation during baseline, intervention and maintenance sessions	The mean response rates of all the participants' replacement behaviours (appropriate interactions) increased immediately when the intervention was introduced, whereas the mean response rates of their target behaviours decreased.
33. Van Puyenbroeck & Maes (2009); BE †	Quasi-experimental pre-test/post-test; High (5/5)	N = 41, 17 males and 24 females with mild to moderate intellectual disabilities, ≥50 years	To evaluate the effect and goal attainment of a narrative-reminiscence group programme	Reminiscence Group Work; 12 sessions	Researchers and support staff	Assisting	IDQOL (Hoekman et al., 2001); PSPC (Goverts et al., 2001); MIPQ (Ross & Oliver, 1999); FFPI (Hendriks et al., 1999); VITESSA (Van Puyenbroeck et al. 2005), interviews with participants and a group evaluation	No changes were detected in life satisfaction or perceived self-competence. Mood did not yield an experimental treatment effect, but a significant increase in scores was observed over time. Interviews resulted in positive appraisals (i.e. worthwhile and meaningful).
34. Vlaskamp & Van der Putten (2009); NL	Quasi-experimental; Moderate (4/5)	N = 3, one male and two females with profound multiple intellectual disabilities, ≥50 years	To determine how ISP actually works in practice	Individualised Support Programmes (ISPs); 2 years	Support staff	Active	QES (Zijlstra, 2003)	The effects on all participants were generally positive for aspects of communication, mood, contact, interaction and alertness. In addition, age had no significant influence on the number or content of the goals that were set.

Table 3. Continued

Author (year); country	Study design; MMAT score	Older participants	Study aim	Intervention; duration	Practitioners	Role of support staff	Outcome measures	Results
35. Wagemaker et al. (2017); NL †	N = 1 study; Low (2/5)	N = 5, two males and three females with moderate to severe intellectual disabilities, ≥50 years	To explore the potential and efficacy of robot-based AAT in adults with moderate to severe intellectual disabilities using the robot seal Paro	Robot-based Animal Assisted Therapy (AAT); 4 weeks	Support staff	Active	Young Child Session Rating Scale (Duncan et al., 2011); AOL (Vlaskamp et al., 2010)	For one participant, Paro had a positive influence on mood and alertness. For the other participants, no significant beneficial effects of Paro were observed.
36. Watchman et al. (2020); UK †	Mixed-method participatory action approach; High (5/5)	N = 14, five males and nine females with intellectual disabilities and dementia	To identify the effectiveness of psychosocial interventions in social care settings, and, uniquely, to explore the use of photo-voice methodology to develop dialogue about dementia	Individualised psychosocial interventions; 6 months	Support staff	Active	QUALID (Weiner et al., 2000); NPI-Q (Cummings et al., 1994); Goal Attainment Scale (Kiresuk & Sherman, 1968), interviews with participants and photo-voice technology (Kiresuk & Sherman, 1968)	The results provide evidence from a range of data-collection methods to support the effectiveness of person-centred psychosocial interventions as part of a goal-setting process in reducing agitation or distress and increasing QoL associated with dementia. Individualised psychosocial interventions have the potential to reduce distress or agitation.

†Studies specifically focused on ageing people with intellectual disabilities.

2. Focus of psychosocial interventions for older people with intellectual disabilities

To answer the first research question, relating to the focus of psychosocial interventions for older people with intellectual disabilities, the psychosocial interventions identified in the studies were subdivided into two main themes. The first theme covers interventions focusing on understanding older people with intellectual disabilities by identifying and meeting their individual needs and perceptions. The second theme covers interventions aimed at improving specific behaviours or skills in older people with intellectual disabilities.

2.1 Interventions for identifying and meeting unique and individual needs or perceptions of older people with intellectual disabilities (N = 17)

2.1.1 Interventions focusing on the perceptions of older people by identifying their individual preferences (N = 4). Four studies were based on identifying the preferences of individual participants. First, two studies concerned interventions aimed to use active mentoring to meet the individual interests of 32 older people with moderate intellectual disabilities (Chng et al., 2013; Stancliffe et al., 2015). The results suggest that active mentoring generated sufficient improvements in activity engagement and increased community participation, thereby preventing inactivity, isolation and loneliness in retirement. Second, one study described the implementation of a standardised procedure for assessing the repeated presentation of preferred items and activities of participants (including two older people) with profound multiple disabilities during multiple periods of the day (Darling & Circo, 2015). Although this intervention led to a slight increase in the participants' scores on happiness indices, the relationships between variables were limited. Finally, the fourth study involved the implementation of an intervention examining the affective behaviour of participants (including one older person) with intellectual disabilities and congenital deaf blindness (Martens et al., 2017). Support staff members were trained to recognise individual affective behaviours, attuning to interactive behaviours and sharing meanings in order to improve the understanding of emotions. Although this training increased dyadic affective involvement, levels of affective involvement decreased during follow-up.

2.1.2 Interventions aimed at understanding the perceptions of older people by exploring their individual life histories (N = 4). In all, four studies described interventions in which 79 older participants with mild to moderate intellectual disabilities were invited to talk about their lives in general, as well as about memorable life events. Three studies implemented a variety of reminiscence techniques, including life-story work and books (Bai et al., 2014), rummage boxes (Crook et al., 2016) and group sessions (Van Puyenbroeck & Maes, 2009), to explore outcomes in terms of life satisfaction, mood, wellbeing and/or behaviour. All of the reminiscence techniques exhibited potential to improve the wellbeing of participants. A fourth study involved the implementation of a narrative group therapy for people (including one older person) with intellectual disabilities (Randle-Philips, et al., 2016), inviting them to describe what they identified as important and significant in their lives. Although the older participant reported that the group had elevated her mood and that she had benefited from the peer support and social connections within the group, no changes were observed with regard to wellbeing or self-esteem.

2.1.3 Interventions aimed at adjusting the level of assistance for individual older people (N = 3). Three interventions involved some form of focusing on the type and level of assistance provided to older individuals with intellectual disabilities. In one study, staff members were trained to provide the least intrusive form of assistance and to honour the choices made by eight older service users with severe to profound intellectual disabilities (Cooper and Browder, 2001). This intervention increased the number of choice responses, in addition to enhancing the participants' level of performance. In a second study, two different prompting procedures (physical presence and online assistance) were assessed. Although both procedures resulted in an increase in the completion of novel household tasks by people (including two older participants) with mild to moderate intellectual disabilities (Taber-Doughty et al., 2010), the participants completed tasks more independently when the assistance was provided online. Finally, the third study explored the assistance potential of a robot seal, 'Paro', for five older individuals with intellectual disabilities. Paro had a positive influence on mood and alertness in only one participant (Wagemaker et al., 2017).

2.1.4 Intervention approaches involving the implementation of support focusing on the individual needs of older people (N = 6). Whereas the previous sub-themes concerned single interventions (i.e. one-time interventions focusing on a single outcome), six studies described the implementation of a more comprehensive approach. These interventions were aimed at meeting individual needs by making structured observations and adjusting the support accordingly, broadly implementing a psychosocial approach and/or combining psychosocial interventions. One study examines the effect of Dementia Care Mapping on the wellbeing and QoL of 113 older people with intellectual disabilities by coding what happened to these individuals during observations in communal areas of a group home (Schaap et al., 2019). The intervention did not generate any changes in QoL, as compared to care as usual. Another study was intended to make life less stressful for an older man with Down syndrome and dementia by implementing a mediational intervention for sensitising caregivers (MISC) (Lifshitz and Klein, 2011). The MISC provided support staff with strategies concerning the participant's individual emotional and cognitive needs, thereby helping them to improve their connection and interaction with him. A third study involved the development of an individual support programme (ISP) for people (including three older participants) with profound intellectual and multiple disabilities (Vlaskamp & van der Putten, 2009). The outcomes were generally positive with regard to communication, mood, contact, interaction and alertness. A fourth study concerned the implementation of a community-based accommodation programme for participants (including one older person) with severe to profound intellectual disabilities and autism (Fox et al., 2009). This programme aimed to create a highly predictable environment that was customised to the unique characteristics, preferences and needs of each individual, thereby strengthening adaptive and pre-vocational skills, while preventing the onset of challenging behaviour. The participant showed progress and reductions in challenging behaviour. Finally, two studies examined the implementation of multiple psychosocial interventions with people (including two older participants) with mild intellectual disabilities and psychotic disorders (Raftery et al., 2016) and 14 older people with intellectual disabilities and dementia (Watchman et al., 2020). These personalised approaches (e.g. social skills intervention, reminiscence, photo-voice technology) apparently directed particular attention to the participants' psychosocial needs, psychological functioning, daily living skills and overall QoL. One study (Raftery et al., 2016) reported reductions in psychopathology (e.g. anxiety) and an increase in psychological functioning and QoL. Another study (Watchman et al., 2020) suggested that individualised psychosocial interventions could have the potential to reduce distress or agitation in older participants.

2.2 Interventions aimed at improving the behaviour and skills of older people with intellectual disabilities (N = 19)

2.2.1 Interventions aimed at decreasing or improving particular behaviours in older people (N = 3). Two studies focused on decreasing particular behaviours—one by implementing a behavioural treatment for non-compliance and public stripping in an older man with Down syndrome and dementia (Horovitz et al., 2010), and the other by evaluating the effect of a sensory-equipment room ('Snoezelen Room') and outdoor activities on stereotypical behaviour (e.g. body-rocking, mouthing and pica) of people (including two older participants) with profound intellectual disabilities (Cuvo et al., 2008). A third study evaluated the use of a literacy-based behavioural intervention to improve employment behaviour in one older man with an intellectual disability and Down syndrome (Bucholz et al., 2008). A personalised story was read to him twice a day (prior to his morning break and lunch) for several days, in order to increase independence and improve returning to work on time. All three of these studies reported decreases in non-compliance or stereotypical behaviour, as well as improvements in timely return to work.

2.2.2 Interventions aimed at teaching domestic and self-care skills to older people (N = 3). Behavioural interventions aimed at the improvement and mastery of various daily living skills by older people with intellectual disabilities were described in three studies. One study focused on teaching behaviour chains (e.g. folding clothes and turning on a CD/DVD player) to people (including one older participant) with severe intellectual disabilities in their home environments (Dollar et al., 2012). Another study involved the implementation and embedding of social initiation (i.e. serving coffee and sitting down with a peer) by using video modelling for people (including one older person) with severe intellectual disabilities (Bidwell & Rehfeldt, 2004). The third study aimed to improve the self-care skills (e.g. tooth brushing and tying a necktie) of participants (including one older person) with moderate intellectual disabilities (Golisz et al., 2018). All three of these studies indicated positive outcomes following completion of the interventions.

2.2.3 Interventions aimed at teaching social and communication skills to older people (N = 7). Seven studies focused primarily on improving social and communication skills or increasing social inclusion in order to prevent social isolation and expand social networks and societal participation. One study outlined an intervention in which the contact behaviour of people (including one older person) with intellectual disabilities and autism was explored and supported individually (Brooks & Paterson, 2010). A second study examined the learning and use of a picture exchange communication system by people (including one older person) with intellectual disabilities and severe communication deficits, as described by Conklin and Mayer (2011). This intervention was intended to increase the initiation of requests, independence and choice-making of participants. A third study involved the application of principles of caregiver-infant interaction (i.e. intensive interaction) to enhance the communication and social abilities of people (including one older person) with profound intellectual disabilities, as well as to enhance the responsiveness of support staff (Samuel et al., 2008). The results of these studies indicated that the interventions could potentially contribute to or improve participants’ communication, initiation of requests and social abilities. Another study involved administering 15 individual training sessions in order to improve the social problem-solving skills and reduce psychological distress of people (including one older person) with mild intellectual disabilities (Anderson & Kazantis, 2008). Although the older participant showed improvement in social problem-solving skills after receiving the training programme, no changes were observed with regard to anxiety, self-esteem or depression. Two other studies involved the implementation and evaluation of a series of behavioural interventions aimed at replacing social avoidance and inappropriate social interaction with appropriate forms of social interaction (e.g. verbal communication skills) in people (including two older participants) with severe intellectual disabilities (Harper et al., 2013; Underwood et al., 2009). Both of these studies reported increases in social and appropriate behaviour and decreases in problem behaviour following the intervention. In the study by Harper et al. (2013), however, this was true for only one of the five behavioural interventions that were conducted. Finally, one study evaluated a group-oriented intervention (i.e. 'Communal Table'), in which monthly dinners were organised for people (including eight older participants) with mild intellectual disabilities at various community centres (Kruithof et al., 2018). Although the participants experienced conviviality and warmth, the intervention did not lead to any increase in their societal participation or the expansion of their social networks.

2.2.4 Interventions aimed at improving the coping skills of older people (N = 6). The applicability of cognitive behavioural therapy (CBT) for improving the coping strategies and techniques of people (including six older participants) with mild intellectual disabilities was evaluated in three studies. In all cases, dual diagnoses (e.g. anxiety, chronic pain and symptoms of posttraumatic stress disorder) constituted reason to apply these interventions. Participants received multiple sessions intended to decrease symptoms of trauma (Mevissen et al., 2010), develop pain-management skills (McManus et al., 2014) or learn about various concepts of anxiety and coping techniques (Marwood and Hewitt, 2012). Although all three of these studies indicated the applicability of CBT, the outcomes were somewhat variable. The use of CBT seemed to be most beneficial for the participants with regard to decreasing symptoms of trauma and anxiety. It was less successful for developing pain-management skills, as the older participant showed lower levels of knowledge.

Three studies also described coping-related interventions other than CBT. One evaluated the use of group-wise psycho-education for people (including two older participants) with mild intellectual disabilities and psychosis to increase their understanding of the concept of psychosis, the need for medication, the role of stress and early signs of relapse (Crowley et al., 2008). The older participants exhibited increased knowledge about psychosis following the intervention. Another study examined the ways in which a group of people (including three older participants) with mild to moderate intellectual disabilities coped with separation anxiety by applying technology-assisted therapy (i.e. using a mobile phone and application) and teaching the concept of person permanence through repetition and the provision of a secure base and safe haven (Hoffman et al., 2019). The results indicate that the separation anxiety and challenging behaviour exhibited and experienced by the participants decreased significantly, while their psychosocial functioning and QoL increased significantly. The last of these three studies evaluated a response to bullying training for 4 victims of bullying (one older man with severe intellectual disability) (Stannis et al., 2019). To teach the older man some intended response to bullying, a behavioural skills training, an in situ training and an incentive phase were all necessary.

3. The role of support staff in interventions

To answer the second research question, relating to the role of support staff in the application of psychosocial interventions, the researchers deductively categorised all 36 of the identified interventions into three themes: interventions in which support staff had (1) an active role, (2) a mediating or assisting role or (3) no significant role or a role that remained undefined.

3.1 Interventions in which support staff have an active role (N = 15)

Fifteen of the studies described interventions in which support staff had an active role because they carried out the intervention themselves (see Table 3). Distinctions can nevertheless be made with regard to the intensity of their role and the skills that were required before the intervention could be applied (e.g. staff training). One distinct category consists of the nine studies that involved training staff members before they carried out the intervention (Bai et al., 2014; Bucholz et al., 2008; Cooper & Browder, 2001; Darling & Circo, 2015; Fox et al., 2009; Hoffman et al., 2019; Kruithof et al., 2018; Lifshitz & Klein, 2011; Martens et al., 2017; Samuel et al., 2008; Schaap et al., 2019; Taber-Doughty et al., 2010; Vlaskamp & Van der Putten, 2009; Wagemaker et al., 2017; Watchman et al., 2020). For example, in a personalised day programme for adults with intellectual disabilities and autism (Fox et al., 2009), support staff were involved in both the selection of participants and the implementation of the programme. Before staff members implemented the programme independently, however, they were required to take specialised training, which consisted of several phases (e.g. an overview of autism and its implications for working with these individuals, role-play exercises and feedback sessions). A similar approach was described in studies by Cooper and Browder (2001) and by Vlaskamp and van der Putten (2009), in which staff members were trained before starting the actual implementation of the intervention. A more extensive and comprehensive role for support staff was described in a study by Schaap et al. (2019), in which they examined the effect of Dementia Care Mapping on the wellbeing and QoL of older people with intellectual disabilities. More specifically, staff members were selected to become trained observers, which subsequently enabled them to carry out the intervention. Following the observations, these staff members reported the results to other support staff members in order to help them to understand the behaviour of clients.

In contrast to the nine studies mentioned above, two studies described interventions in which support staff members played an active role, in addition to describing the competences that the staff members needed in order to carry out the intervention successfully. No staff training was included in these interventions. More specifically, Lifshitz and Klein (2011) implemented a customised programme involving the five parameters of the mediational intervention for sensitizing caregivers (MISC) with a person with intellectual disabilities and dementia. As clearly described in the article, support staff members needed to be conscious of the key issues in their relationship with the client (i.e. their own perceptions of the client, themselves as caregivers and the emotional and cognitive needs of the client) before they were able to implement the parameters during daily activities. In another study, Bai et al. (2014) demonstrated that, in addition to being responsible for carrying out the intervention (i.e. the Life Story Work programme, or LSWp), support staff members helped participants to express their feelings concerning their life stories within a caring and accepting atmosphere.

Finally, four studies examined interventions in which support staff members were responsible for applying interventions by following instructions (Bucholz et al., 2008; Kruithof et al., 2018; Taber-Doughty et al., 2010; Wagemaker et al., 2017). No additional staff training was provided prior to the implementation of the intervention. For example, in their study, Bucholz et al. (2008) described that support staff members had been responsible for accompanying a male participant to a private location, where they would read him a personalised story prior to his lunch break. In addition, support staff members were asked to use various levels of prompting if the participant was not returning to work. In the study by Wagemaker et al. (2017), support staff members were responsible for introducing, creating interaction with and withdrawing the robot seal Paro each day for a period of eight weeks.

3.2 Interventions in which support staff have a mediating or assisting role (N = 12)

The second theme refers to 12 intervention studies in which a psychologist or researcher was largely responsible for carrying out the intervention (Anderson & Kazantis, 2008; Chng et al., 2013; Crook et al., 2016; Crowley et al., 2008; Horovitz et al., 2010; Marwood & Hewitt, 2012; McManus et al., 2014; Mevissen et al., 2010; Stancliffe et al., 2015; Stannis et al., 2019; Underwood et al., 2009; Van Puyenbroeck & Maes, 2009). In these studies, support staff had a mediating or assisting role. The extent of their role and the level of their involvement in these interventions varied, and they were not always described in detail. For example, in three studies, the role of support staff changed over time, as they were expected to apply a number of intervention techniques, on the instruction of the therapist or researcher, in order to continue implementing the intervention (Horovitz et al., 2010; Underwood et al., 2009; Van Puyenbroeck & Maes, 2009).

In three other studies, the role of support staff was smaller than that described in the studies mentioned earlier within this theme (Marwood & Hewitt, 2012; McManus et al., 2014; Mevissen et al., 2011). More specifically, staff members played an important role as a source of information, and they were asked to assist with generalisation outside the treatment session and to assist participants with homework assignments, if necessary, and to practice skills with them between sessions.

Finally, the smallest mediating or assisting roles played by support staff were described in three studies, in which support staff members were present to assist, motivate or transfer information to the participant while the psychologist or researcher delivered the intervention (Anderson & Kazantis, 2008; Crook et al., 2016; Crowley et al., 2008). For example, although Anderson and Kazantis (2008) did not explicitly mention the role of support staff in their study on training in social problem-solving skills for adults with intellectual disabilities, they did report that the presence of support staff during the intervention sessions was associated with greater continuity and follow-through in problem solving.

3.3 Interventions in which support staff have no significant role or a role that remains undefined (N = 9)

The third category of interventions included nine studies in which the role of support staff remained undefined (Bidwell & Rehfeldt, 2004; Brooks & Paterson, 2011; Conklin & Mayer, 2011; Cuvo et al., 2001; Dollar et al., 2012; Golisz et al., 2018; Harper et al., 2013; Raftery et al., 2016; Randle-Philips et al., 2016). The interventions addressed in these studies focused largely on teaching new, adaptive skills to individuals with intellectual disabilities or improving their behaviour (e.g. social avoidance). In the majority of the studies within this theme, the interventions were applied in separate settings (e.g. classrooms or therapy rooms) by therapists, researchers or students/undergraduates. The studies did not provide any information about the role of support staff in these psychosocial interventions for older people with intellectual disabilities.

Discussion

The life expectancy of people with intellectual disabilities has increased in recent decades, due to improved living conditions and better medical care (Mulryan et al., 2021). Despite these advances, however, the implications of ageing with an intellectual disability are also posing new challenges for older people, their support staff and healthcare organisations (Prasher, Davidson & Santos, 2021). It is unclear whether support staff are prepared to fulfil their significant role in meeting the needs of older people with intellectual disabilities (Heslop et al., 2013). For this reason, and because the existing body of overview studies focuses primarily on medical/physical interventions (Schepens et al., 2018), additional knowledge is needed with regard to the psychosocial interventions that are available and that could help to optimise support for older people with intellectual disabilities. This systematic review is intended to provide an overview of the available psychosocial, non-medical/physical interventions for older people with intellectual disabilities. The review began by examining the focus of the interventions available in the international literature. The second step consisted of describing the role of support staff in the application of these interventions.

With regard to the focus of interventions, we were able to categorise all 36 interventions into two groups. The first group consisted of 17 interventions that focused primarily on identifying the unique needs and perceptions of older individuals with intellectual disabilities. Many of the studies in this group had been developed specifically for the target group of older people with intellectual disabilities. Despite differences in design, all of these studies were aimed at either gaining more insight into older individuals with intellectual disabilities (e.g. their life histories), recognising or meeting individual needs (e.g. the emotional and cognitive support needs of individuals), or implementing appropriate/adjusted care and support. The attention focused on individual needs and perceptions is consistent with the principles of person-centred care (Kitwood, 1997). The concept of person-centred care originated within the field of healthcare for older people without intellectual disabilities. Kitwood (1997) developed the theory of person-centred care within the context of dementia care, thereby underscoring psychosocial needs and 'seeing the person'. The results of this review, suggest that various aspects of person-centred care have since been adopted within the context of psychosocial care and support for older people with intellectual disabilities. The emergence of person-centred interventions that address the psychosocial support needs of older people may help caregivers to broaden the focus of their practice, which may tend to over-emphasise the medical aspects of care (Fazio et al., 2018).

In our review, we also identified 19 interventions aimed at improving the behaviour and skills of older people with intellectual disabilities. Although these studies were generally not designed specifically for older people, the participant groups did include older people. The interventions within this theme focused largely on teaching self-care or other skills, in order to enhance independence and social skills, while promoting problem-solving abilities, coping skills for dealing with anxiety or chronic pain, and behavioural treatments aimed at decreasing inappropriate behaviour. In light of the possible cognitive and physical decline of older people with intellectual disabilities, it is interesting to note that a large share of the available psychosocial interventions that are offered to older individuals continue to focus on the development of new skills. This finding suggests that support staff members are likely to consider applying existing interventions aimed at improving the skills and behaviour of adults within the context of care for older people with intellectual disabilities as well. In addition, it is not uncommon for psychosocial interventions that were initially developed for adults to be translated to the population of older people in general. The literature on regular healthcare contains examples of applications of a treatment for depression aimed at teaching skills to participants in order to improve their mood, change negative thinking patterns and increase their engagement in enjoyable activities. Although this intervention was originally developed for adults between the ages of 20 and 55 years, a variant of the course has been successfully implemented with older individuals (Cuijpers, 2004; 2011). These insights offer possibilities for the further development of interventions that are appropriate for older people with intellectual disabilities.

The second aim of the current review was to examine the role of support staff in the application of these interventions. As evidenced by the results, we were able to distinguish three types of roles for support staff in psychosocial interventions for older people with intellectual disabilities: active, mediating and undefined. The extent of the role, the level of involvement and the skills that must be acquired (e.g. through staff training) before the intervention could be applied varied, and these aspects were not always described in detail. In only 15 of 36 studies, support staff members were at least partially responsible for applying the actual intervention. At the same time, however, the results suggest that this group of professionals is particularly likely to be confronted with the changing support needs of older people with intellectual disabilities on a daily basis, and they have a particular need to know how to address matters of ageing in the care and support of people with intellectual disabilities (Kahlin et al., 2016; Thalen. et al., 2023). Support staff may therefore have a considerable need for psychosocial interventions aimed at expanding their knowledge and their ability to provide sufficient care and support to older people with intellectual disabilities (Alftberg et al., 2021).

This review demonstrates that in scientific databases, relatively few psychosocial interventions are available for support staff members to apply directly in their daily work with older people with intellectual disabilities, which implies that they have little choice and opportunities to work with psychosocial interventions. In addition, the majority of psychosocial interventions were often carried out during a short period of time (e.g. a few individual sessions), with the aim of affecting a single outcome variable (e.g. happiness). Only a few interventions are part of larger, integrative and holistic support approaches that focus simultaneously on multiple aspects of the lives of older people with intellectual disabilities and the support provided to them. A few studies did describe the implementation of a more comprehensive approach that combined several psychosocial elements (e.g. Fox et al., 2009; Schaap et al., 2019). Future studies should therefore focus on developing and strengthening the theoretical base of integrative psychosocial interventions that involve support staff in an executive role. Support staff should ideally receive training in order to increase their relevant knowledge and skills in advance, thereby ensuring that they will be able to carry out the intervention appropriately (Innes et al., 2012). Finally, when it comes to the support of older people with intellectual disabilities, a lack of an evidence base is still present (Thalen et al., 2020). The overview presented in this study provides valuable insights that may contribute to further research into the actual efficacy of the available psychosocial interventions and the implications for older people with intellectual disabilities or into topics not yet addressed and, thereby, increase the evidence base. Furthermore, in future research contextual factors should be taken into account, such as the potential differences in the access or delivery of support of older people with intellectual disabilities (e.g. rural vs. urban) or the role and involvement of family members in providing psychosocial support.

Limitations

It is important to acknowledge several limitations to this review. The exclusion of grey literature and studies published in languages other than English may have introduced a bias toward significant results and information from specific regions of the world. The consultation of four databases and the screening of the reference lists of included studies may be considered as limited. However, an additional hand search by the first author on Google Scholar did not lead to any new results. With regard to efficacy, we found indications that a great number of psychosocial interventions have the potential to make positive contributions to one or more of their established goals (e.g. identifying the needs and perceptions of older people with intellectual disabilities and improving their skills). In our review, however, we did not attempt to provide a thorough assessment of the effectiveness of the interventions that we identified. In the future, additional studies could further examine the effectiveness of the identified interventions for older people with intellectual disabilities. Furthermore, this review did not focus on the perceptions and experiences of older people themselves when receiving psychosocial interventions, as most interventions relied on observational methods to assess outcomes. Future review and empirical studies might therefore provide a more complete image by concentrating more on the actual experiences of older individuals with regard to receiving psychosocial interventions. Despite its limitations, this review provides an extensive overview of the available psychosocial interventions for older people with intellectual disabilities, as well as the focus of these interventions and the role of support staff in their application.

Conclusion

A systematic literature review was conducted with the goal of providing an overview of the available, non-pharmacological and non-physical interventions for older people with intellectual disabilities. We examined the various foci of existing psychosocial interventions for older people with intellectual disabilities, as well as the role of support staff in the application of these interventions. This overview may serve as a supplement to existing knowledge, thereby contributing to the optimisation of care and support for older people with intellectual disabilities. It could also enhance the further development of and theoretical support for evidence-based psychosocial interventions.

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5

CHAPTER 5

Integrated Emotion-Oriented Care for Older People With Intellectual Disabilities: Defining and Understanding Intervention Components of a Person-Centred Approach

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Abstract

An increase in descriptive evidence regarding person-centred approaches for older people with intellectual disability (ID) is important, due to increased life expectancy and the present lack of sufficiently underpinned interventions. This is especially true of interventions designed to increase wellbeing and quality of life. A specific Dutch example is the Integrated Emotion-Oriented Care approach. Despite its status as a good practice, its effectiveness has not yet been proved, nor has descriptive evidence been made available. The primary aims of this qualitative study are to identify the intervention components, to provide demonstrative illustrations and to gain an in-depth understanding of the use of these components in the day-to-day support of older people with ID. A content analysis of five key documents was carried out. Five semi-structured interviews were then conducted with early adopters, followed by a concept mapping study with daily users. The final stage in the data collection process was a series of five focus-group interviews with experts and experienced support staff. The five intervention components of Integrated Emotion-Oriented Care for older people with ID have been systematically identified and described in detail in five narrative summaries drawn up in collaboration with early adopters, experts and experienced support staff. This study provides valuable insights that offer descriptive evidence for Integrated Emotion-Oriented Care in the care for older people with ID. Both implications and possible opportunities for future research are discussed.

Key words

Ageing, intellectual disability, person-centred approach, quality of life, support staff

Introduction

A growing tendency to underpin the choice of interventions for particular target groups with current best evidence is noticeable in many health-care disciplines, including the care of people with intellectual disabilities (e.g. Embregts, 2014; Perry & Weiss, 2007; Schalock et al., 2011). In their paper on evidence-based practice in developmental disabilities, Perry and Weiss (2007) clearly conclude that "evidence-based practice means that we question what we do so that we can help clients be the best they can be. We collect evidence to evaluate our work and we strive to be open to the answers we get. We make decisions based on the best data available and we share our knowledge with others and learn from each other" (p. 171). In other words, clinical initiatives (e.g. practice-based interventions) with a lack of scientific underpinning should therefore be systematically evaluated and improved by creating a clear framework of its content based on knowledge and experiences of current users (Newman et al., 2003). The current study provides a first step towards evaluating and improving the evidence base of a clinical initiative in the care for older people with intellectual disabilities.

In line with the developmental model for practice-driven evaluation developed by Van Yperen et al. (2017) and the impact theory put forward by Rossi et al. (2004), a first bottom-up step that eventually results in the underpinning of interventions consists of the identification and understanding of intervention components (i.e. essential elements of the intervention, such as methods and activities which form part of the intervention). This requires researchers to work with service providers to gather information with the aim of clarifying and specifying the intervention components for a particular target group. Identifying and understanding intervention components is relevant: it adds to descriptive evidence, contributes to the development of evaluative measures at an individual level (Schalock et al., 2011), and helps in conducting procedural-reliability measurements that indicate whether intervention components are implemented as intended (e.g. Gresham et al., 2000).

A lack of evidence base is present in the field of care and support for older people with intellectual disabilities (e.g. Innes et al., 2012; Schaap et al., 2018). A specific Dutch example in this context concerns the Integrated Emotion-Oriented Care (IEOC) approach for older people with intellectual disabilities. This person-centred approach was adopted from the field of dementia care (Van der Kooij, 2014). According to the definition given by Droës, 'emotion-oriented care' concerns "care aimed at improving emotional and social functioning, and ultimately the quality of life, of persons suffering from dementia by assisting them in coping with the cognitive, emotional and social consequences of the disease, and by linking up with the individual functional abilities and the subjective perceptions of the individual" (as cited in Finnema et al., 2005, p.330). The 'integrative aspect' of IEOC refers to the integration of emotion-oriented elements (e.g. validation and reminiscence) in daily nursing home care. IEOC has proved effective in the care for people with mild/moderate dementia and implementation of IEOC resulted in an increase in caregiver knowledge and skills in the field of dementia care

(Finnema et al., 2005; Van der Kooij et al., 2013). Considering the increasing life expectancy of people with intellectual disabilities and additional physical and cognitive decline, it is not surprising that this has led to a need for adequate support and for a more integrated and person-centred approach (Campens et al., 2017), which in this case was derived from standard geriatric and dementia care.

Although IEOC has proved effective in dementia care, it has yet to be made clear what the intervention components of IEOC are and how these components should be used and applied to older people with intellectual disabilities. The aim of this qualitative study is therefore (1) to identify the intervention components of IEOC for older people with intellectual disabilities, and consequently (2) to obtain an in-depth understanding and illustration of the use of these components in the day-to-day support of older people with intellectual disabilities. The researchers used data triangulation by combining sources and methods to reduce bias and increase the trustworthiness of our findings (Wilson, 2014).

Method

Aim 1. Identifying IEOC intervention components for older people with intellectual disabilities

Data triangulation of three sources in health care for older people with and without intellectual disabilities was used to identify IEOC intervention components: (Source1) information in key documents, (Source 2) knowledge and experiences of early adopters, and (Source 3) knowledge and experiences of daily users.

Content analysis of key documents (Source 1)

Procedure. First, a search in Dutch intellectual disabilities and geriatric literature was conducted by the first author to identify available documents with relevant theoretical models and peer-reviewed, empirically based descriptions of IEOC. Since this resulted in only two PhD theses that address the use of IEOC in nursing home care for older people without intellectual disabilities (De Lange, 2004; Van der Kooij, 2003), an additional search in the Dutch collection of grey literature was conducted. Documents were included as key document if the document contained (1) relevant information regarding the intervention components of IEOC for older people with or without intellectual disabilities (i.e. the choice of the content must be justified by what you want to know), and (2) was suitable for qualitative analysis (i.e. unitized, written text) (Zhang & Wildemuth, 2009). This resulted in three extra key documents i.e. two Dutch books on IEOC for older people with intellectual disabilities (Groen & Weidner, 2015; Van der Kooij, 2014), and one Dutch policy document about IEOC produced by a nursing home care provider (De Waalboog, 2015). For example, the researchers excluded short descriptions on websites as key documents. Finally, the researchers asked the early adopters (Source 2) to validate the selection of key documents to ensure that no scientific or grey literature has been overlooked. All early adopters confirmed that Source 1 contained all available relevant key documents with regard to IEOC.

Then a systematic qualitative content analysis was conducted that combined inductive and deductive reasoning (Zhang & Wildemuth, 2009). Three researchers (MT, WvO, and KV) independently and repeatedly immersed themselves in the data. They marked relevant quotes, coded them, and clustered the codes into subthemes and themes (i.e. intervention components). To ensure intercoder consistency, colleague debriefings were used to confirm overlaps and divergences with regard to the interpretations and coding decisions, including the development of categories, of the three researchers (Thomas & Harden, 2008; Ritchie et al., 2014). A fourth researcher (PE) was consulted in cases where any doubts arose during the process. Both WvO and PE had no prior experience of the IEOC approach for older people with intellectual disabilities. Since no new or additional information was found in the fifth key document, the authors concluded that data saturation had been achieved, resulting in an initial list of IEOC intervention components (Marshall & Rossman, 2016).

Semi-structured interviews with early adopters (Source 2)

Procedure. Following the content analysis of key documents (Source 1), the researchers conducted individual semi-structured interviews with early adopters of IEOC (inside and outside the field of intellectual disabilities) with the aid of a brief interview guide. The interview guide was not based on the outcomes of the analysis of key documents, but merely intended to retrieve additional information regarding the intervention components of IEOC from another source (i.e. next to the information retrieved from the key documents). Each interview lasted on average 45 minutes and was facilitated by the first author. By asking the early adopters, what they thought were the most important intervention components of IEOC, the researchers tried to validate and complete the list of intervention components with professional-expert knowledge. Audio recordings of the interviews were made, and these were transcribed verbatim. Three researchers (MT, KV and ET) then systematically analysed the interview transcripts to find confirmatory and new information which could be added to the list of IEOC intervention components that was derived from Source 1.

Participants. A convenience sample of five early adopters with expertise in IEOC participated: two clinical experts, two policymakers, and one researcher. Participants were employed at three different Dutch health-care organisations for older people with (*n* = 2) and without intellectual disabilities (*n* = 3).

Concept mapping with daily users (Source 3)

Procedure. Subsequently, a concept mapping method (Trochim, 1989) was applied to identify the factors that support staff and psychologists consider most important when carrying out the IEOC approach for older people with intellectual disabilities on a daily basis for further validation and identification of the IEOC intervention components. The concept-mapping procedure required the participants to answer one central question: What is IEOC for older people with intellectual disabilities? This resulted in 24 unique items with information regarding IEOC intervention components, which were consequently generated, prioritised, and sorted by the participants using the software program Ariadne 3.0 (Severens, 1995). Multidimensional scaling and cluster analysis were then applied to construct a concept map, which was interpreted by three researchers (MT, KV and ET). If any doubts arose, a fourth researcher (PE) was consulted. All relevant information, both confirmatory and new, was added to the list of IEOC intervention components derived from Sources 1 and 2 (see Table 1).

Participants. A convenience sample of five support staff members and three psychologists were recruited from three different residential locations within one Dutch health-care organisation for people with intellectual disabilities. All participants provided IEOC on a daily basis for an average of 11 months. Seven participants were female (M_{age}= 47 years, SD_{age}= 11.4 years, $\text{range}_{\text{age}}$ 32–63 years). Participants had an average of 16 years' working experience (*SD*= 9.9 years; range 6–38 years) of caring for people with intellectual disabilities.

Aim 2. In-depth understanding of IEOC intervention components for older people with intellectual disabilities

Following the three methodological steps used to achieve Aim 1, focus groups were held to better understand and make explicit how intervention components of IEOC (as identified under Aim 1) could be applied in the day-to-day support for older people with intellectual disabilities (Aim 2).

Focus groups with experts and experienced support staff to create narrative summaries

Procedure. Two sessions with a group of eight experienced support staff and three sessions with a group of 13 experts (see participants) were organised. Each session lasted about two hours and was facilitated by a researcher with an overall understanding of the study to keep the sessions on track (Nassar-McMillian & Borders, 2002). Based on the final list of intervention components and subthemes (see Table 1), a semi-structured interview guide was developed. Each group successively discussed each intervention component, by responding to the question: How do you perform this in daily practice? Audio recordings were made of the sessions and these were transcribed verbatim.

Subsequently, systematic analysis of transcripts was carried out to determine the meaning of and possible actions and activities associated with each IEOC component in day-to-day support for older people with intellectual disabilities. First, the transcripts were independently and deductively analysed by three researchers (MT, WvO and KV) to mitigate any bias that might arise from a single researcher (Zhang & Wildemuth, 2009). Second, the analyses of transcripts were discussed in colleague debriefings until full consensus was reached on how to apply the IEOC intervention components in daily practice (Krueger & Casey, 2000; Ritchie et al., 2014). Third, this consensus led to a draft version of five narrative summaries in which the researchers tried to explain each intervention component as specifically as possible. A fourth researcher (PE) acted as peer reviewer to check the credibility and validity of the summaries. In addition, the summaries were then submitted to four members of the focus groups to verify that the summaries were accurate representations of their experiences (Ritchie et al., 2014; Zhang & Wildemuth, 2009). All of the researchers involved agreed on the final version of the narrative summaries.

Participants. A convenience sample of 21 participants was recruited from one Dutch health-care organisation serving older people with intellectual disabilities. Eight experienced support staff and 13 experts in the field of IEOC participated. Among these participants, two early adopters (Source 2), and seven of eight support staff members and psychologists who participated in the concept mapping procedure (Source 3) were again recruited for the focus groups. Support staff had an average working experience of 16 years (*SD*= 14.8 years; range 6–38 years) in caring for people with intellectual disabilities. Six support staff members were female (M_{age}= 47 years; *SD*= 13.2 years; range 33–58 years), and two were male (M_{age}= 56 years; *SD*= 2.6 years; range 49–63 years). Of the IEOC experts, 11 were female (M_{age}= 50 years; *SD*= 7.4 years; range 34–60 years), and two were male (M_{age}= 56 years, *SD*= 2.7 years; range53–58 years). IEOC experts had an average working experience of 24 years (*SD*= 9.5 years, range 8–37 years).

Ethical procedure

Ethical approval to conduct this study was granted by the Ethical Review Board of Tilburg University (EC-2016.29 and EC-29-2016.29a2). Participants were provided with written and verbal information about the nature and purpose of the study. They were informed that their responses would be processed anonymously and that they could withdraw from the study at any time.

Findings

Aim 1. Identifying IEOC intervention components for older people with intellectual disabilities

Data triangulation (Sources 1-3) ultimately led to the identification of five IEOC intervention components and 32 subthemes in total as shown in Table 1. The findings will be further explained step by step.

First, content analysis of key documents (Source 1) resulted in 119 unique codes with information regarding the IEOC intervention components. To structure the findings, these codes were grouped into 30 subthemes. Subsequently, the subthemes were merged into four themes, called: intervention components (see Table 1; #1-4). Following, the analysis of the semi-structured interviews with experts (Source 2) resulted in 85 codes. The majority of these codes (*n* = 82) confirmed the information that was already available from the content analysis of the key documents (Source 1). The remaining three codes contained new information about IEOC and led to the creation of two new subthemes, called *Be aware of one's own perception* and *Create space for the needs and perceptions of the client's informal network* (see Table 1; #1.5 and (#5.9).

Table 1. List of Identified IEOC intervention components

#	Intervention components (themes)	Subthemes
1.	Support staff focus on the client’s perspective to better understand the wishes, needs and behaviour of the client	1.1 Find your way into the client’s perceptions 1.2 Pay attention to/connect with the client’s feelings 1.3 Have knowledge of/connect with their life story 1.4 Support the client’s experience of this new phase of life 1.5 Be aware of one’s own perception
2.	Support staff try to adequately adjust to the client’s current needs when practising IEOC	2.1 Consider the individual client’s wishes 2.2 Meet the client’s changing support needs 2.3 Take the time to organise work based on what the client wants 2.4 Get a clear picture of the client’s needs 2.5 Be flexible and continually adjust to the client’s current needs 2.6 Continue to search for the client’s needs and possibilities 2.7 Offer support while maintaining the client’s autonomy 2.8 Involve the client in an active way 2.9 Pay attention to the client’s own initiatives
3.	Support staff connect with the client in order to build a relationship with them	3.1 Connect with the client 3.2 Reciprocate 3.3 Give the client recommendations and explanations
4.	Support staff work in a team culture that is based on safety and trust	4.1 Speak the same language 4.2 Be on the same page/know each other’s reasons on a team 4.3 Share personal experiences in a systematic way 4.4 Empower your own team 4.5 Create a climate of safety on the team 4.6 Collaborate
5.	Support staff create room for participation and perceptions from the client's informal network	5.1 Inform the informal network 5.2 Understand and acknowledge the involvement of the informal network 5.3 Make full use of the possibilities within the informal network 5.4 Support each other (support staff-informal network) 5.5 Solve problems together 5.6 Reflect in a continuous dialogue 5.7 Search together and meet the client’s changing needs 5.8 Learn from each other (support staff-informal network) 5.9 Create space for the needs and perceptions of the client’s informal network

Finally (Source 3), concept mapping with daily users resulted in 24 codes, all of which confirmed the IEOC intervention components and the list of related subthemes drafted after Source 2. However, the prioritisation of items that had emerged from the concept mapping procedure (Source 3) indicated that the collaboration with and involvement of informal network members were seen to be the most important items of all. This finding led to the decision to place all the subthemes relating to the informal network into a separate, fifth component, called *Support staff create room for participation and perceptions from the client's informal network* (see Table 1; #5).

Aim 2. In-depth understanding of IEOC intervention components for older people with intellectual disabilities

For each IEOC intervention component, a narrative summary was created to give a detailed description of its meaning in the day-to-day support of older people with intellectual disabilities. The summaries also include examples of associated actions, activities and aspects that should preferably be taken into account, and which provide information about the integrative nature of components.

Narrative summaries

#1: Support staff focus on the client's perspective to better understand the wishes, needs and behaviour of the client

General meaning. The first IEOC component refers to the client's perspective. In order to be able to focus on the client's perspective, it is important that support staff continuously and actively explore the question of who the client is. This search will enable support staff to better understand the wishes, needs and behaviour of the client (e.g. why someone has a certain taste in music), and to consciously adjust their support to the client (e.g. play the client's favourite music).

Actions and activities. To focus on the perspective of the client, support staff consult the client, their informal network, historical archives, photo albums, colleagues and/or support-care files. Personal life history, habits, interests, religion and traditions are all relevant to developing a better understanding of the client. Support staff get to know the client by imagining themselves in their situation ('place yourself in their shoes') and by taking time to make real contact with the client. All positive and negative moments of contact with the client are important in terms of achieving a better understanding of the client. It is necessary for support staff to continuously share these meaningful moments and situations (e.g. through integrated emotion-oriented consultation) with network members (Note: #1 thus links with #5) and team members (links with #4), to work together to interpret them with a view to achieving unanimity in how the client is perceived, and to report them (e.g. in an electronic care file and/or life book).

#2: Support staff try to adequately adjust to the client's current needs when practising IEOC

General meaning. In addition to taking the perspective of the client (see Component 1), support staff try to adequately adjust to the client's current needs when practising IEOC (e.g. when the client wakes up anxious, the client might have had a restless night and is probably still tired). In addition, support staff approach each client both consciously and with an open mind, in order to comply as much as possible with their wishes and needs at that moment (e.g. let the client sleep late today, because it will help them recover). Support staff should have the confidence to allow time for this (e.g. by putting aside their own concerns and frustrations).

Actions and activities. Providing support based on the client's current wishes and abilities requires creativity, flexibility, courage, self-reflection, openness, vulnerability and a willingness to depart from the standard routine or from set agreements (e.g. taking a walk because the client wants to enjoy the fresh autumn air, even though the laundry still has to be done). Support staff try to fulfil the client's wishes and needs insofar as this is possible by thinking in terms of possibilities. When a wish is really unfeasible for this client at this moment or when the client's health or safety is at stake, it is important to give an explanation to the client, search for alternatives (e.g. let the client sleep late, but do not let them stay in bed all day) or in some cases go against their wishes (e.g. they are not allowed to go out alone because their safety cannot be guaranteed). It is important to carefully discuss these (sometimes ethical) dilemmas in a multidisciplinary team, with the client and/or the client's informal network (links with #5) in order to make well-considered choices together (e.g. what to do about a client's wish to eat their favourite burgers, despite the impact on their health due to diabetes).

#3: Support staff connect with the client in order to build a relationship with them

General meaning. When practising IEOC, support staff need to connect with the client in order to build a relationship with them. In doing this, it is important to be both honest and sincere in all dealings with the client, as well as seeing and appreciating the client as an individual (regardless of their behaviour and history), showing respect, taking the client seriously and approaching them in a way that they understand. Sharing certain personal information with a client can also be helpful (e.g. I have become a grandmother) without overstepping boundaries and losing sight of one's professionalism. What support staff want to share may differ from client to client (e.g. with one client support staff might talk about their favourite holiday destination, with another about football).

Actions and activities. Making contact with a client can be done verbally or non-verbally (e.g. getting down to eye level to make eye contact). In doing this, it is important to know about the client’s life story (links with #1), adjust to the client’s pace and reaction time (e.g. talk slowly, wait for an answer, repeat the question if the client does not understand) and to check continuously whether there is actual contact with the client (e.g. the client could be distracted and no longer listening to what you are saying). The relationship between support staff and client can differ per person. Some have a better ‘click’ with one client than with another; this also applies to the client’s perspective. It is important to share this information in a team (links with #4), because forming a good connection with clients makes the work more enjoyable.

#4: Support staff work in a team culture that is based on safety and trust

General meaning. Working according to IEOC requires a team culture in which support staff dare to be open and honest with each other based on safety and trust. Team members develop a bond in which they experience this safety and trust, as well as genuine interest in and attention to the wellbeing of all colleagues (e.g. each team consultation starts with the question ‘How is everyone doing?’). The individual qualities of each support staff member are brought into play; team members learn from each other and enjoy their work.

Actions and activities. Support staff are able to share their personal norms, values, and situations with the team (e.g. I have not fully recovered from my knee injury, so I would prefer not to go for a walk with the client today) or others can identify a situation (I see that your knee injury is still giving you problems, shall I go out with the client instead?). At team level, it is important to know which support staff and clients share similar interests and preferences, and with which client they feel an individual connection (links with #3). By being transparent about this, support staff can take over tasks and activities from one another, complement each other and provide feedback. The support staff do not have to do this on their own. The team manager and behavioural expert are also on hand to support the team. Team members can ask colleagues for feedback, but might also give colleagues unsolicited positive feedback (e.g. a compliment) and constructive feedback (e.g. asking how a situation might have been handled differently). By exchanging feedback, support staff can learn from each other, keep each other alert to changes in the wishes and needs of the client, and prevent actions from becoming routine (links with #1).

In addition, the team jointly bear responsibility for their actions. For example, if a support staff member forgets that a client prefers to shower in the morning instead of in the evening; other team members will kindly remember him/her next time instead of getting agitated. When providing IEOC it is important that there are no negative consequences for the staff members in similar situations. Furthermore, other situations may arise in which support staff need to depart from the agreed approach (e.g. because the client's need has changed; links with #2). This might lead to tension between team members, but they can work towards a solution by explaining to each other why they made certain choices (e.g. I didn't do the laundry because the weather was nice so I decided to take a walk with the client instead). By consciously sharing experiences with the client and the client's informal network (links with #2 and #5), the team continuously develops a more accurate and complete picture of the client (links with #1) to create alignment between all individual support staff members (e.g. are we looking at this client in the same way; are we trying to reach the same goals?).

#5: Support staff create room for participation and perceptions from the client's informal network

General meaning. When practising IEOC, it is important to create room for participation and perceptions from the client's informal network. Support staff work together with informal network members (e.g. family members, friends and volunteers) in order to understand and support the client as effectively as possible. It is therefore advisable to explain the nature of IEOC to the network members, to discuss everyone's expectations beforehand and record them if appropriate (e.g. the family finds hygiene very important and expects to receive a telephone call when the client's hygiene is at stake). As a result, the team and care organisation(s) are actively involved in providing IEOC as an approach to ageing individuals with an intellectual disability.

Actions and activities. When exploring the question of *who* the client actually is (links with #1 and #2), the informal network serves as a source of information and knowledge (e.g. by augmenting the client's life history, or by sharing pleasant and less pleasant experiences). Network members can also be involved in the way IEOC is provided (e.g. having the network members prepare dinner with the client because they enjoy that activity). To ensure effective collaboration between support staff and network members, it is important that support staff take the initiative in discussing aspects such as possible changes in the client's behaviour or state of mind. During a conversation, support staff and network members work together in an effort to understand what might explain the client's behaviour or mood at a given moment and how they can adapt their approach accordingly. It is also important to explain one's own considerations; why do support staff act as they do? In addition to connecting with the client, it is also important to acknowledge the specific role (e.g. a lifelong brother-sister relationship is different from a professional relationship), experience, and the wishes and needs of the individual network members (some of which may have a cultural dimension).

Furthermore, working according to IEOC might lead to dilemmas, resistance or tensions between support staff and network members, for example in cases where the wishes of the informal network appear to be out of step with the client's own wishes. At times, it may be necessary for network members and support staff to 'take a look in the mirror' (e.g. how would they feel if they could no longer dress themselves because they are unable to button up a shirt?) or try to reach a compromise (e.g. by having the client wear a smart sweater instead of a shirt with buttons). By inviting everyone involved in the client's life to focus on the client's own perceptions, needs and wishes, the network members might feel more at ease and experience greater trust in the support offered to the client. In addition, sharing experiences and staying connected with each other improves mutual understanding and leads to greater involvement of the network members.

Discussion

In recent years, there has been a growing interest to provide care and support based on evidence-based practices within many health-care disciplines, also in the care for people with intellectual disabilities (e.g. Embregts, 2014; Perry & Weiss, 2007; Schalock et al., 2011). When it comes to the support of older people with intellectual disabilities, there is still a lack of evidence-base (e.g. Innes et al., 2012; Schaap et al., 2018) which is a particular cause for concern when enabling support staff in maintaining high-quality care (Cleary & Doodey, 2016; Iacono et al., 2014; Janicki & Keller, 2012). Against this background, evidence-based practices from standard geriatric or dementia care, such as Integrated Emotion-Oriented Care (IEOC), could also be useful in the care for older people with intellectual disabilities (Campens et al., 2017). However, its intervention components and its application for older people with intellectual disabilities (i.e. descriptive evidence) had yet to be systematically analysed.

The present study identified five intervention components of IEOC for older people with intellectual disabilities and used data triangulation to produce five related narratives. To better understand the significance of the components and summaries identified, two generic topics will be discussed here. First, the rich content of the narrative summaries indicates the emphasis within IEOC on *general wellbeing* of older people with intellectual disabilities. This broad focus on general wellbeing is of added value: in the face of increasing life expectancy (Emerson et al., 2012; Bigby, 2004) and the frequent occurrence of physical decline (Haveman et al., 2010; Evenhuis et al., 2012) there is a risk of the focus on the physical wellbeing of older people with intellectual disabilities becoming dominant (i.e. what the person 'has' instead of 'who' that person is: Shoostari et al., 2012; Wark et al., 2014; Schepens et al., 2018) and overshadowing wellbeing in its broadest sense. However, the Social Production Function (SPF) theory (Lindenberg, 2013) emphasises that ageing is related to changing wishes and needs in other domains as well (e.g. social wellbeing). In line with SPF, IEOC might enable support staff to cope with the changing support needs of older people with intellectual disabilities in all domains of wellbeing (Schalock, 2004), and therefore contribute to their general quality of life.

The narrative summaries not only provide examples of how support staff can apply IEOC in caring for older people with intellectual disabilities on a daily basis, they also show that IEOC consists of several components that are closely connected and strongly interrelated (see links in the summaries). This is in line with the *integrative character* of IEOC, which refers to the integration of emotion-oriented care elements. In other words, IEOC is a multi-component, integrated and holistic approach in which one component is linked to another. As a consequence, a single initiative might be related to multiple components and can cause a chain of events in relation to more than one IEOC component at the same time (Rossi et al., 2004; Van Yperen et al., 2017).

Implications for practice and future research

This study collected and integrated relevant information about IEOC from multiple sources. Although the involvement of a larger number of organisations and the inclusion of a broader range of perspectives (e.g. clients and their informal network) would have further strengthened the design, this study still has a number of relevant implications for practice and future research. First, the findings contribute to the awareness of the complex character and the possible challenges of implementing a person-centred approach. Not only is it noticeable that the IEOC components address various levels of support, from daily care to the involvement of the informal network, but all intervention components are also likely to be interrelated (i.e. one component can be conditional on another and every action effects multiple components). Working according to the IEOC approach requires specific competencies from support staff and entails several dilemmas related to the provision of person-centred support. It may therefore be challenging for support staff to implement this intervention in daily practice. The descriptive evidence in this study can contribute to the development of staff-training programmes and consequently enhance the support staff's knowledge, skills and attitudes in providing sufficient IEOC for older people with intellectual disabilities. For example, the extended version of the narrative summaries can be used as educational input for programme developers (Van Yperen et al., 2017).

A second implication of our study concerns the future identification of professional and organisational preconditions that IEOC addresses. Applying the approach requires not only an understanding of the intervention components, their purpose and the target group, but also understanding the context in which the intervention is implemented (Rossi et al., 2004; Van Yperen et al., 2017). Both professional preconditions (e.g. specific characteristics of support staff, such as flexibility, courage and vulnerability) and organisational preconditions (e.g. providing all necessary opportunities for staff to apply the approach, such as time and adequate staff training) define the necessary requirements towards achieving the successful implementation of IEOC. Future research could further identify these conditions and thereby further complement the descriptive evidence of IEOC for older people with intellectual disabilities.

Finally, the promising experiences with IEOC for older people with dementia (Finnema et al., 2005; Van der Kooij et al., 2013) emphasise the need for further research into the effects of IEOC on the quality of life of older people with intellectual disabilities in the broadest possible sense, for instance by examining the extent to which these clients, their informal networks and all relevant professionals benefit from such an integrative, person-centred approach. This can be done by constructing observational studies and questionnaires that include their experiences. The present study serves as a methodological case description to illustrate how researchers, together with care professionals, can take their first steps towards underpinning a practice-based intervention. Furthermore, the content of this study makes it possible for those engaged in future research to formulate assumptions, select the right instruments, evaluate IEOC and expand the evidence base in caring for older people with intellectual disabilities (Rossi et al., 2004; Van Yperen et al., 2017).

Conclusion

Given the increased life expectancy of older people with and without intellectual disabilities, and the lack of sufficiently underpinned interventions aimed at increasing wellbeing and quality of life, there is a clear need to increase the descriptive-evidence base of the person-centred IEOC approach for this population. This study provides valuable insights that offer a first step towards improving the evidence base of IEOC in the care for older people with intellectual disabilities. The intervention components of IEOC for older people with intellectual disabilities have been systematically identified and described in detail in five narrative summaries drawn up in collaboration with early adopters, experts and experienced support staff. This study can therefore be seen as a preamble to the evaluation of IEOC, a contribution to the evidence base for an integrative approach for older people with intellectual disabilities and an important step towards making IEOC transmissible to other care providers. In addition, this study serves as a case description that illustrates how researchers can work with experienced support staff and experts to underpin their intuition-based knowledge.

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CHAPTER 6

6

Providing person-centred care to older people with intellectual disabilities during the COVID-19 pandemic: experiences of direct support workers

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Abstract

Background

Although the current preventive measures relating to COVID-19 can lead to challenges in the daily work of direct support workers (e.g. keeping 1.5 m distance), it remains vital to uphold the principles of person-centred care when working with older people with intellectual disabilities. The current study explores the extent to which direct support workers have been able to apply a specific form of person-centred care (i.e. integrated emotion-oriented care, or IEOC) when working with older people with intellectual disabilities during the COVID-19 pandemic.

Method

Six direct support workers from five facilities serving older people with intellectual disabilities in the Netherlands participated in this qualitative study. They participated in a two-hour focus group, which was transcribed verbatim, and the transcript was analysed thematically.

Results

Three themes emerged: (i) the negative impact of changes due to the COVID-19 measures on service users; (ii) the adaptation of direct support workers to changes due to the COVID-19 measures; and (iii) putting the needs and wishes of service users first.

Conclusion

This study provides first impressions into the experiences of direct support workers providing person-centred care to older people with intellectual disabilities during the COVID-19 pandemic.

Keywords

Person-centred care, integrated emotion-oriented care, COVID-19, coronavirus, older people with intellectual disabilities, direct support workers

Introduction

Since the start of the COVID-19 crisis, people with intellectual disabilities have been regarded as especially vulnerable to COVID-19 (World Health Organization 2020). For example, the greater prevalence of underlying health conditions in this population (Courtenay & Perera, 2020), as well as to the fact that they often depend on daily support from professionals or relatives, which often takes place in close physical proximity (Tummers et al., 2020) leads to a greater risk of contracting the COVID-19 virus. To prevent the rapid spread of infection and serious illness, or even death, many preventive measures have been adopted to daily life, including quarantine and other social distancing. In addition to these general measures, many support services for people with intellectual disabilities introduced strict measures for in-person contact with relatives, while their working and daytime services were closed (WHO, 2020). While the preventive measures obviously have had a great impact on the daily lives of many people with intellectual disabilities, including increased experiences of distress, loneliness and agitation (e.g. Courtenay, 2020, Drum et al., 2021, Embregts et al., 2020), they have also had a major emotional, practical, cognitive and professional impact on direct support workers leading, among other things, to challenges and changes in their daily work (Embregts et al., 2021).

Given that older people are at greater risk of more serious illness and death from COVID-19, the preventive measures are particularly restrictive for group homes accommodating older people, including those with intellectual disabilities (Garnier-Crussard et al., 2020, VGN, 2020). Preventive measures such as social distancing could lead to practical difficulties for both older people with intellectual disabilities and their direct support workers, especially in case there is a greater need for physical support. Furthermore, it is not inconceivable that the increased experiences of distress and loneliness of older people with intellectual disabilities due to restrictions on visiting of family members also impacts the dynamics between them and their direct support workers. For this reason, it has been particularly challenging for direct support workers to provide support to older people with intellectual disabilities during the COVID-19 pandemic (Vahia et al., 2020). The restrictions and social-isolation measures aimed at containing the virus are often at odds with the principles of person-centred care (Dichter et al., 2020). The World Health Organization (2018) defines person-centred care as care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health. Furthermore, person-centred care can be seen as a philosophical framework that guides delivery of healthcare and is based on individuals' values and preferences (Fazio et al., 2018). In the Netherlands, person-centred care is operationalised according to an approach known as integrated emotion-oriented care, or IEOC (Van der Kooij, 2014), which entails five intervention components: focusing on the perspective of service users, adjusting to the current needs of service users, connecting with service users, working in a safe and trusting team culture, and creating room for the informal networks of service users (Thalen et al., 2021). Despite the current COVID-19 preventive measures, it remains vital to uphold these principles when working with older people (Dichter et al., 2020). It is therefore important to arrive at a careful balance between infection management and person-centred care, in order to maintain the social participation, mental health and quality of life of older people with intellectual disabilities. To date, however, the extent to which direct support workers are able to apply person-centred care under the challenging circumstances resulting from the COVID-19 measures remains unclear. The current study therefore investigates the following research question: To what extent are direct support workers able to apply a specific form of person-centred care (IEOC) when working with older people with intellectual disabilities during the COVID-19 pandemic?

Method

Participants

A focus group interview was held with six female direct support workers from five geographically distributed residential care facilities for older people with intellectual disabilities operated by one large healthcare organisation in the Netherlands. At all five residential care facilities, IEOC was carried out. The inclusion criteria for the participants were (1) providing direct care to older people with intellectual disabilities and (2) applying IEOC for at least two years. After the focus group interview, demographic information (i.e. gender, age and working experience) and information regarding the level of disability of the service users was obtained from the participants by email. Three of the five residential care facilities had experienced internal outbreaks of COVID-19, and the direct support workers affiliated with these facilities thus had to cope with this situation. All participants were Dutch and their mean age was 37.3 years (SD = 13.7, range: 25–63). The participants had an average working experience of 13.6 years (SD = 9.2; range: 2–24) in the care of older people with intellectual disabilities and had been providing IEOC for an average of 6.9 years (SD = 8.2; range: 2–23). The service users of four of the participants had mild to moderate intellectual disabilities, those of one participant had moderate to severe intellectual disabilities, and the other participant worked with service users having various levels of intellectual disabilities.

The focus group was conducted on 4 February 2021 during the second lockdown period in the Netherlands (15 December 2020 to 5 June 2021). During this second lockdown, public places, schools, shops, and restaurants were closed, as well as working and daytime services for people with an intellectual disability. Moreover, citizens were obliged to wear a face mask outdoors for protection and always keep 1.5 m apart. Residential support services for people with intellectual disabilities only allowed face-to-face contact with relatives under very strict conditions and with a strict maximum of one person a day. The residential facilities included in this study which were affected by an internal COVID-19 outbreak were shut down immediately. Only direct support workers and physicians were allowed to enter and leave the facility when wearing fully protective equipment (e.g. masks and suits). In case an individual was infected with the COVID-19 virus, further restrictions such as room isolation (i.e. quarantine) were used.

Procedure

Ethics approval was granted by the Ethics Review Board of Tilburg University (EC-2016.29). Participants were recruited using convenience sampling through the managers of five residential care facilities for older people with intellectual disabilities, in which care and support is provided in accordance with the IEOC approach. The managers selected eligible direct support workers who had provided IEOC for at least two years to take part in an online focus-group meeting. After agreeing to transfer their contact details to the researchers, eligible direct support workers were contacted by the first author and provided with written and oral information about the nature and purpose of the study. They were also notified that their responses would be audio recorded and processed confidentially, and that they could withdraw from the study at any time. All six direct support workers voluntarily agreed to participate and provided written informed consent.

Focus group

To address the current research aim and capture the experiences of direct support workers with respect to COVID-19 and applying IEOC, a qualitative descriptive study design was chosen. Focus groups are group discussions, led by an experienced moderator, supporting people to discuss different aspects of a particular topic in a focused way (Krueger & Casey, 2015). Group dynamics are one of the characteristics of a focus group interview; therefore, the type and extent of data obtained through a focus group is often deeper and richer than data obtained from a one-to-one interview (Rabiee, 2004). The two-hour focus group was moderated by an experienced researcher (MT) with an overall understanding of the study to keep the sessions on track (Nassar-McMillan & Borders, 2002) following the focus group design of Krueger and Casey (2015).

The focus group started with a brief introduction of the participants and a PowerPoint® presentation explaining the present study. Following this presentation, the researchers explored the extent to which the direct support workers felt that they had been able to provide IEOC to older people with intellectual disabilities in their daily practice during the COVID-19 pandemic. A semi-structured topic list had been developed for this purpose, consisting of topics to explore what the participants had perceived as difficult or infeasible, what they had done differently as compared to before the pandemic and what had gone well with regard to providing IEOC during the pandemic. Questions such as: "How did you continue to explore for the service users' needs and possibilities? How did you connect with the service users? How did you meet the service users' changing support needs? How did you manage to take the time to organize your work based on the wishes and needs of service users? All questions were followed by a number of follow-up questions, such as: When concentrating on this topic, what worked well in daily care and support for older people with intellectual disabilities during the COVID-19 pandemic and what did not? Why did it work well and why not? Compared to the period prior to the COVID-19 pandemic, what is different in daily care and support for older people with intellectual disabilities? What remained the same? The focus group centred primarily on the first three interventions components of the IEOC approach (Thalen et al., 2021), which are directly related to service users.

Due to the COVID-19 pandemic and the corresponding preventive measures, the focus group was conducted using video-conferencing software (i.e. Zoom). Although we would have preferred to conduct this session in person, focus groups and interviews using video-conferencing software have been found to generate data of comparable quality (Braun & Clarke, 2013) and have been assessed particularly relevant in the context of COVID-19 (Boland et al., 2021).

Data analysis

The audio-recorded data were transcribed verbatim, and thematic analysis was used to identify themes (Braun & Clarke, 2006). Thematic analysis is a method for identifying, analysing, and reporting salient patterns within qualitative data and is considered to be a useful method to examine participants' perspectives, emphasising similarities and differences and generating unanticipated insights (Braun & Clarke, 2006). After reading the transcript of the focus group in detail, three authors (MT, WvO and KV) independently and inductively coded the same 20% of the transcript by assigning codes to relevant data concerning the perspectives of the participants with regard to the provision of person- centred care during the pandemic. The initial coding was followed by a discussion of similarities and differences regarding their interpretations and coding decisions until inter-coder consistency was reached and the procedure was further strengthened (Ritchie et al., 2014, Thomas & Harden, 2008). In case of disagreement, a fourth author (PE) was consulted. The remaining part of the transcript was coded independently in two pairs (MT and WvO or MT and KV). Again, the codes were discussed until full consensus was reached. The final set of codes was then grouped according to similarity, collated into potential themes by three authors, and subsequently reviewed jointly by all authors. Finally, the themes were named and defined, and the authors jointly developed a narrative structure with accompanying descriptions.

Results

Three distinct themes were identified in the thematic analysis: (i) the negative impact of changes due to the COVID-19 measures on service users; (ii) the adaptation of direct support workers to changes due to the COVID-19 measures; and (iii) putting the needs and wishes of service users first.

Theme I: The negative impact of changes due to the COVID-19 measures on service users

The direct service workers indicated that the preventive COVID-19 measures had led to a lack of social and physical contact for older people with intellectual disabilities. They also reported that their service users had become tenser and appeared to be more restless than before the pandemic, and that the preventive measures and the lack of exercise and other daytime activities had led them to become short-tempered, as they had to stay at home all day. Although the participants noted that some service users had responded well to the situation, others had experienced it as too hectic and decided to stay in their own rooms more frequently. Although this choice was voluntary, service users were also occasionally forced to stay in their rooms due to room isolation because of an actual or potential COVID-19 infection in the group home. This had a negative impact on the wellbeing of all older service users with intellectual disabilities, especially due to the restrictions on their freedom. Another consequence of the preventive measures was the fact that direct support workers had to take over certain tasks from service users that they normally do themselves (e.g. making tea and preparing meals). In other words, the preventive measures did not only affect the service user's feelings of independence and autonomy, it also led to situations in which direct support workers were forced to make choices in their caseload due to the increasing number of tasks:

> *Because they (i.e. service users) need more than they usually do, and you obviously don't have the time for that. It's just very busy, and then, you must make a well-considered decision…because, at that time, you're actually taking things over from them [Direct support worker 5].*

According to the participants, older people with intellectual disabilities in general needed clear and repeated explanations and reassurance to understand the current COVID-19 situation. Moreover, the continuously changing COVID-19 measures (i.e. scaling up and down the COVID-19 guidelines) were particularly difficult for these older service users to understand, let alone to comply with. This was especially the case when the measures were not communicated clearly. The direct support workers noted that referring to their own experiences was helpful in this respect:

> *It's usually the case that you make yourself vulnerable in a certain way. [I explained] It's the same with me. And I'm not allowed to visit my mum and dad either. My folks aren't allowed to hug my children or celebrate birthdays either [Direct support worker 2].*

Theme II: The adaptation of direct support workers to changes due to the COVID-19 measures
At the beginning of the COVID-19 pandemic, it was necessary for the direct support workers to become accustomed to the new reality. Due to the measures, direct support workers had to keep distance from their service users, in addition to restricting their freedoms. The participants experienced this situation as both difficult and undesirable, as it is diametrically opposed to the philosophy of IEOC. In addition to the need for adjustments and additional effort to maintain contact, the direct support workers noted that it had sometimes been essential to break the rules in order to provide IEOC and meet the needs of the service users. For example, they explained that physical contact (e.g. when assisting with personal care) constitutes a significant part of their work and, as such, it was inevitable. One support worker who also belonged to the at-risk group had initially felt somewhat unsafe, but eventually chose to not maintain the distance of 1.5 m:

> *No. I did try to keep them away from me in the beginning, didn't I? So really, no, 1.5 metres. But that scared them [service users], because it's not like me at all. That's also very weird [Direct support worker 3].*

The direct support workers identified flexibility and creativity as important skills that had helped them to work according to the philosophy of IEOC during the COVID-19 pandemic. For example, they tried to make the atmosphere in the group homes even more pleasant than usual by offering more group activities in the living room, in order to compensate for the preventive measures and create moments of positive contact. Despite the fact that in-person contact with informal network members was limited or not allowed, direct support workers observed an increase in dialogue and coordination with the informal networks of service users (e.g. through telephone and/or video calls). Support workers deliberately tried to involve the members of these networks by working with them to find solutions (e.g. arranging video conferences). In addition, various initiatives were taken to be active in informing and involving the informal network, including issuing a weekly newsletter and sending personal cards and flowers more often. The participants indicated that they would definitely like to continue these initiatives after the COVID-19 crisis has passed:

> *I don't think it will go away just like that. We've been doing that for months now, so we've sort of gotten used to it as a new way of working. Because the informal networks are so important to our service users, we want to keep those lines open [Direct support worker 6].*

Theme III: Putting the needs and wishes of service users first

In the focus group, the direct support workers indicated that care and support services have continued, despite the measures. Some direct support workers indicated that the COVID-19 pandemic has not changed their bond with service users. They recounted that, although service users sometimes seemed to dislike them because of the preventive measures that they had to impose on them, they stressed that this was only temporary. In some cases, they had even experienced that the measures had positive effects (e.g. valuing the positive contact moments even more because of the situation they were in). As described by one direct support worker:

> *I enjoy the moments of positive contact more intensely. This is because, tomorrow, there might be a contamination and, in three weeks' time, half the location will be gone, in the worst-case scenario. We just live—every day should be a celebration. It might be even more important in light of the COVID-19 pandemic [Direct support worker 2].*

The direct support workers participating in the focus group recalled that they had been present for their service users prior to the COVID-19 pandemic, and that they had continued to be present throughout the pandemic as well. In this case, being present meant not only that the direct support workers remained physically present, but they also provided emotional support by listening, reassuring, and explaining the situation to the service users when necessary. They were nevertheless limited in terms of the attention and closeness that they could offer to these older people with intellectual disabilities. Despite the high workload and frustration stemming from the preventive measures, the participants indicated that the needs and wishes of their service users remained paramount. To be able to meet these needs and wishes, they worked in close collaboration with their direct colleagues and others in multidisciplinary teams. Together, they discussed the risk of contamination in relation to the provision of the care and support to older service users with intellectual disabilities. After weighing the risks, they sometimes consciously chose to abandon certain restrictions, even if it resulted in running an increased risk of contamination. As explained by one direct support worker:

> *You have to dare to take risks…One of our service users is almost deaf and blind, and her communication consists largely of touching and cuddling. At first, we tried to discourage that a bit. Then she stopped wanting to eat…And then we decided, you know what? We'll go ahead and cuddle her, and just turn our heads a bit…And from that time on, she started eating well again. So now she eats very well and we can just keep communicating with her [Direct support worker 4].*

Discussion

In the present study, six direct support workers serving older people with intellectual disabilities shared their experiences concerning the extent to which they had still been able to provide person-centred care (according to the IEOC approach; Van der Kooij, 2014, Thalen et al., 2021) during the COVID-19 pandemic. Despite the negative impact of the changes resulting from the COVID-19 measures on service users, the support workers followed their natural tendency to adapt to the situation by trying to mitigate these negative effects. More specifically, when necessary, they sometimes broke the rules in order to provide IEOC and meet the needs of service users. They even indicated that they had remained present for their service users in the same way that they had prior to the COVID-19 pandemic, and that they had continuously tried to adjust to their needs in the changing situation. The needs and wishes of the older service users remained paramount. This sense of responsibility for and loyalty to their service users speaks to the vital role that direct support workers play in the lives of older people with intellectual disabilities, as also illustrated in a study by Embregts et al. (2020). In addition, direct support workers continued to search for other ways to continue connecting with service users, as required in order to provide high-quality care and effective support (Hermsen & Embregts, 2015). Finally, while putting the needs and wishes of service users first, direct support workers described the importance of coping with the COVID-19 pandemic with the entire team, such that they could discuss how to deal with strict measures and consult other disciplines within their organisations. The support workers also noted that they had continued to encourage the active involvement of members of the informal networks of service users, even though in-person contact was limited. Moreover, given the importance of communication during crises (WHO, 2020), it is interesting to note that the direct support workers participating in this study reported having maintained and facilitated communication with members of relevant formal and informal networks.

The present study has several implications for policy and practice. Overall, the direct support workers in this study stated that, despite COVID-19, they were able to apply all five components of IEOC: focussing on the perspective of service users, adjusting to the current needs of service users, connecting with service users, working in a safe and trusting team culture, and creating room for the informal networks of service users. This observation seems to be consistent with the integrative character of the person-centred IEOC approach. More specifically, IEOC is a multicomponent, integrated and holistic approach in which one component is linked to another. A single initiative might therefore be related to multiple components and can cause a chain of events in relation to more than one IEOC component at the same time (Thalen et al., 2021). In other words, IEOC is not a standard procedure that direct support workers can simply apply. It requires a basic attitude that helps them to adapt to constantly changing measures and, therefore, with the changing support needs of older people with intellectual disabilities throughout the COVID-19 pandemic. Although the support workers referred to the challenges and impact of the pandemic, working according to IEOC apparently offered them tools that helped them to cope adequately with the situation. The findings of this study offer suggestions for how direct support workers might cope with future crises (e.g. a new pandemic or internal crisis in a group home or healthcare organisation), while continuing to guarantee the provision of person-centred care and support for people with intellectual disabilities. For example, in line with previous studies (e.g. Embregts et al., 2021), creating space for personal creativity and improvisation to meet the needs and wishes of people with intellectual disabilities is imperative. Flexibility in order to cope with the challenging working environment is also important in this respect. Sharing such experiences by means of, for example, intervision and online webinars might be valuable.

Notwithstanding these implications, it is important to consider several limitations of the present study when interpreting its results. Although the number of participants in our study meets the recommendations of Braun and Clarke (2013), our sample was relatively small and included merely one focus group interview, due to the difficulties of conducting this type of research under the prevailing circumstances. Hence, future research should address the experiences of other direct support workers to gain more knowledge regarding the application of person-centred care during a long-term pandemic and in order to increase the reliability of our findings as this study serves as a first exploration. Second, the current study focused on the experiences of six direct support workers during the second lockdown period. Although this provides valuable insights for potential future lockdowns, it is important to continue studying their experiences during the ongoing COVID-19 pandemic. As government and societal responses to the COVID-19 pandemic evolve, it is conceivable that the experiences of direct support workers providing person-centred care may change during the COVID-19 pandemic. Third, it would be interesting to add the experiences of service users themselves to our body of knowledge. We were nevertheless able to address a variety of perspectives by including direct support workers from five residential facilities. The design of the study would have been strengthened by numerous focus group interviews, the involvement of a larger number of healthcare organisations and the inclusion of a broader range of perspectives (e.g. service users and their informal networks). Despite these limitations, this study can be seen as a valuable contribution to existing knowledge about the experiences of direct support workers during the COVID-19 pandemic and offers directions for future research exploring how an integrated, multicomponent approach like IEOC can be beneficial in light of challenges such as those raised by the current situation.

Conclusion

This study provides relevant first impressions into the experiences of six direct support workers providing person-centred care to older people with intellectual disabilities during the COVID-19 pandemic in the Netherlands. Despite the negative impact of changes due to the COVID-19 measures on service users, the direct support workers in this study experienced they were still able to provide person-centred care (i.e. IEOC) by successfully adapting to the COVID-19 measures and continuing to put the needs and wishes of service users first.

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7

CHAPTER 7

General discussion

The current thesis

The life expectancy of people with intellectual disabilities is increasing due to improved living conditions and better medical care (Mulryan et al., 2021). As a result, more people with intellectual disabilities are dealing with age-related difficulties. These include experiences with physical and/or cognitive decline, substantial losses in social networks and increasing limitations in social movements (Evenhuis et al., 2012; McCausland et al., 2016). Due to premature ageing and a higher prevalence of health impairments and psychiatric disorders compared to the general population, ageing as a person with intellectual disabilities is considered a complex process (Alftberg et al., 2019; WHO, 2018). Consequently, the early onset and complexity of the ageing process lead to changes to the support needs these people have as they grow older. This creates challenges for people with intellectual disabilities themselves and their families, but also for support staff and healthcare organisations (Prasher et al., 2021).

Existing care and support strategies seem inadequate: support staff indicate experiencing uncertainty, contradictions and inconsistency regarding ageing with intellectual disabilities due to a lack of knowledge (Alftberg et al., 2021). Accordingly, developing appropriate support strategies for older people with intellectual disabilities that respond to the changes involved with the ageing process is necessary to ensure optimal wellbeing and quality of life. However, signs of ageing are mainly associated with medical aspects and physical abilities (Alftberg et al., 2019). Research on the support needs of older people with intellectual disabilities remains scarce, and it often focuses specifically on medical and physical aspects of life (Navas et al. 2019). This presents an issue because the implications of ageing tend to extend beyond medical aspects and physical deficiencies: the need for support in other psychosocial, quality-of-life domains is likely to change too.

The main objective of this thesis is to expand the knowledge base surrounding the support needs of older people with intellectual disabilities and to explore whether Integrated Emotion-Oriented Care (IEOC) could be used to support older people with intellectual disabilities and help support staff to increase their attention for the psychosocial aspects of the ageing process when providing daily care to older people with intellectual disabilities. Five studies were conducted.

These focused on:

(I) gaining more insight into the support needs and matters of importance of older people with intellectual disabilities,

(II) providing an overview of available psychosocial interventions for older people with intellectual disabilities, and

(III) defining and understanding the intervention components of IEOC for older people with intellectual disabilities.

The following research questions were therefore included in this thesis:

I

1. Do older people with intellectual disabilities generally experience a need for support in all of the quality-of-life domains? What are the most important support needs that older people with intellectual disabilities experience within each quality-of-life domain? How important is each quality-of-life domain for older people with intellectual disabilities?
2. What do older people with intellectual disabilities consider most important in their daily lives (i.e. matters of importance) and what support needs do they encounter?

II

3. What are the foci of the documented psychosocial interventions in the international literature on caring for older people with intellectual disabilities? What role do support staff play in the application of psychosocial interventions?

III

4. What are the intervention components of IEOC for older people with intellectual disabilities? How can the intervention components of IEOC be applied in the day-to-day support of older people with intellectual disabilities?
5. To what extent were direct support workers able to apply a specific form of person-centred care (i.e. IEOC) when working with older people with intellectual disabilities during the COVID-19 pandemic?

The current chapter consists of three sections. The first section summarises the main findings in relation to each research question. The second section contains a reflection on these findings in their broader theoretical and practical context. Finally, in the third section, the strengths and limitations of this thesis are discussed, along with suggestions for future research and implications for policy and practice.

Summary of main findings

Part I: Support needs of older people with intellectual disabilities

In this thesis, we first aimed to gain more insight into the support needs of older people with intellectual disabilities. The perspectives of psychologists and older people with intellectual disabilities themselves were therefore included and are described in Chapters 2 and 3, respectively.

In Chapter 2, we explored and documented the most important support needs of older people with intellectual disabilities across all quality-of-life (QoL) domains using semi-structured interviews. We distinguished the following nine domains: Personal development; Self-determination; Interpersonal relationships; Social inclusion; Rights; Emotional wellbeing;

Physical wellbeing; Material wellbeing; and Existential wellbeing (Schalock, 2004; Schepens et al., 2018). The first eight domains are based on the QoL model as proposed by Schalock (2004). This has been well described and validated in terms of support for people with intellectual disabilities (Gómez et al., 2016; Schepens et al., 2018). We also added the domain of existential wellbeing since there are indications that this domain is very important for older people with intellectual disabilities (Schepens et al., 2018). In this mixed-method study, we approached psychologists with extensive expertise and experience with older people with intellectual disabilities. They worked at various care organisations throughout the Netherlands. Psychologists are regarded as a valuable source of information for monitoring the support needs of older people with intellectual disabilities. It is part of their profession to provide insight into the entire range of support needs of this specific population across all domains of life, and they possess the competencies needed to analyse cases at the meta-level.

The findings described in Chapter 2 show that, although signs of ageing are mainly associated with medical aspects and physical abilities (Alftberg et al., 2019), older people with intellectual disabilities experience support needs in all nine QoL domains. Furthermore, the ratings of each QoL domain assigned by the participants suggest that support needs relating to emotional wellbeing (e.g. actively offering safety, relaxation and comfort), physical wellbeing (e.g. environment that reflects changes in physical health), self-determination (e.g. room and support to make individual choices and to experience autonomy) and interpersonal relationships (e.g. support in maintaining and facilitating contact with family and social network) are considered the most important amongst this population. Support needs within the domains of rights (e.g. medical care and/or support in overseeing medical consequences or providing insight into health complaints), and material wellbeing (e.g. support with money/financial management) were rated as being least important. The support needs relating to existential wellbeing, social inclusion and personal development were rated moderately.

Chapter 3 focused on the perspectives of older people with mild to moderate intellectual disabilities, and it explored what they consider to be most important in their daily lives (matters of importance) and what support needs they experience. In addition, this study utilised an inclusive approach in which a co-researcher with an intellectual disability worked in equal partnership with academic researchers. This inclusive approach was explicitly chosen to better connect with the participants and optimally capture their experiences. One of the main themes regarding matters of importance addressed by the participants during the interviews was the need to feel connected to others. This concerns the need for personal attention, being in each other's company and receiving emotional support. Feeling at ease or meaningfully engaged and feeling autonomous were also considered valuable. With respect to current support needs, this study distinguished four themes. Participants indicated that they needed: (1) support to be able to do everyday things, (2) support regarding personal care, (3) support to achieve emotional wellbeing, and (4) support to maintain self-esteem and autonomy.

These results confirm the presence of support needs in different QoL domains, including physical wellbeing (e.g. support in ADL activities), emotional wellbeing (e.g. someone paying attention to you), interpersonal relationships (e.g. being able to participate in social activities), existential wellbeing (e.g. experiencing a meaningful day) and self-determination (e.g. freedom of choice). Overall, this is in line with the findings in Chapter 2.

Part II: Psychosocial interventions for older people with intellectual disabilities

The second part of the thesis aimed to provide an overview of existing non-pharmacological and non-physical interventions for older people with intellectual disabilities (Chapter 4). Particular attention was paid to the various foci of psychosocial interventions and the role of support staff in applying these interventions.

In Chapter 4, we conducted a systematic review of qualitative and quantitative studies focusing on available psychosocial interventions for older people with intellectual disabilities. An integrative method was conducted to synthesise both quantitative and qualitative data. The results of this systematic review (n = 36 studies) showed that the focus of the psychosocial interventions identified in the studies could be subdivided into two main themes. The first theme covers interventions focusing on understanding what ageing with an intellectual disability entails, by gaining more insight into the lives of older individuals with intellectual disabilities, recognising their individual needs or implementing appropriate care and support. The second theme covers interventions aimed at improving specific behaviours or skills in older people with intellectual disabilities, by focusing on teaching self-care, problem-solving abilities or coping skills for dealing with anxiety and behavioural treatments to decrease inappropriate behaviour.

This review also demonstrated that support staff were hardly involved in or responsible for the application or implementation of the interventions. Relatively few psychosocial interventions are available for support staff members to apply directly in their daily work with older people with intellectual disabilities. This implies they have little choice or opportunity to work with psychosocial interventions. Most psychosocial interventions were also only carried out for a short period of time (e.g. over a few individual sessions) with the aim of affecting a single variable (e.g. happiness).

Part III: Integrated Emotion-Oriented Care for older people with intellectual disabilities

The third part of this thesis focused on contributing to the descriptive evidence regarding IEOC, a person-centred approach, for older people with intellectual disabilities by creating a clear framework of its content, based on current users' knowledge and experience.

In Chapter 5, we took a first step towards evaluating and improving the evidence base of IEOC for older people with intellectual disabilities. First, data triangulation of three different sources (i.e. scientific knowledge, professional knowledge and knowledge by experience) regarding IEOC in healthcare for older people was carried out by conducting a content analysis, semi-structured interviews and by applying a concept mapping method. These steps led to the identification of five IEOC intervention components:
1) focussing on the perspective of older individuals with intellectual disabilities,
2) adjusting to the current needs of older individuals with intellectual disabilities,
3) connecting with older individuals with intellectual disabilities,
4) working in a safe and trusting team culture, and
5) creating room for the informal networks of older individuals with intellectual disabilities.

Subsequently, a total of five focus group discussions with experts and experienced support staff were held to better understand and make explicit how the intervention components of IEOC could be applied in the day-to-day support for older people with intellectual disabilities. For each IEOC intervention component, a narrative summary was created to provide a detailed description of its meaning. These summaries included examples of associated actions, activities and aspects that should be considered, and provide information about the integrative nature of the different components.

In Chapter 6, we examined the applicability of IEOC for older people with intellectual disabilities during crises (i.e. COVID-19 pandemic). We explored the extent to which support staff have been able to provide IEOC when working with older people with intellectual disabilities by conducting a focus group interview with direct support staff. Three distinct themes could be identified in the thematic analysis: (1) the negative impact of changes due to the COVID-19 measures on older people with intellectual disabilities, (2) the adaptation of direct support staff to changes due to the COVID-19 measures, and (3) putting the needs and wishes of older people with intellectual disabilities first.

The results showed that support staff members in this study were able to apply all five components of IEOC (Chapter 5) despite the COVID-19 pandemic. Even though support staff referred to the challenges and impact of the pandemic, working according to IEOC apparently provided them with tools that helped them to cope with the situation adequately. This finding confirms that the application of IEOC fosters a basic attitude that helps support staff to adapt to constantly changing circumstances and, therefore, to the changing support needs of older people with intellectual disabilities throughout crises.

Reflection on the findings

Three main points are discussed that follow from reflecting on the results of this thesis. First, the findings demonstrate the presence of support needs in all different QoL domains. Second, there appears to be a lack of knowledge and evidence-based interventions when it comes to supporting older people with intellectual disabilities. Third, the promising added value of IEOC for support staff working with older people with intellectual disabilities and their changing support needs is discussed.

The presence of support needs in all QoL domains

Regarding the support needs of older people with intellectual disabilities, this thesis showed that both professionals and older people with intellectual disabilities indicate that they experience support needs in all nine QoL domains. Furthermore, the matters that are most important in daily life for older individuals with an intellectual disability can be traced back to various QoL domains, and not just to the physical wellbeing domain that most of the previous research and developed support strategies focus on (Schepens et al., 2019). Accordingly, it is important to focus on the support needs in terms of emotional wellbeing, interpersonal relationships, self-determination, and existential wellbeing as well. The fact that these five domains are important for older people with intellectual disabilities is in keeping with previous research that shows that older people with intellectual disabilities are likely to encounter emotional life events due to age-related decline, loss of significant others, forced relocations, difficulties in maintaining their autonomy and self-determination, and have an increased chance of developing physical and cognitive health problems (Hermans and Evenhuis, 2012; 2014; Judge et al., 2010; McCausland et al., 2016; Perkins and Moran, 2010; Strydom et al., 2013).

Our finding – that support needs in the domains of emotional wellbeing, self-determination, and interpersonal relationships are rated as being of similar importance to physical wellbeing – also aligns with several theories. The first theory that corresponds to our findings is that of the Social Production Function theory (Ormel et al., 1999). This theory emphasises the need for social wellbeing, and it clarifies and highlights the established importance of support needs regarding emotional wellbeing, interpersonal relationships and self-determination, in addition to the more physical support needs. Second, the gerontologic concept of successful ageing (Fesko et al., 2012) arrives at a similar conclusion. Successful ageing implies that physical, psychosocial, material and existential aspects enable older people to experience increased longevity, QoL and life satisfaction while retaining their functional capabilities. Third, the findings also align with the theory of Subjective wellbeing (Kahneman et al., 2003) as a measure of the perceived QoL. This theory distinguishes three aspects of subjective wellbeing:

Evaluative wellbeing: evaluations of how satisfied people are with their lives;
Hedonic wellbeing: feelings or moods such as happiness, sadness, anger, stress, and pain;
Eudemonic wellbeing: sense of purpose and meaning in life.

Studies of older people in the general population show that assessments of QoL are affected by the person's state of health. However, recent findings indicate that self-reported life evaluation in the general population increases with age, despite the increasing chronic health conditions (Sprangers et al., 2000). This suggests that subjective wellbeing is affected by more factors than physical health alone. These factors include social and family relationships, and daily activities – factors that also change with age (Steptoe et al., 2015). Research suggests that subjective wellbeing might even be a protective factor for physical health, reducing the risk of chronic conditions and promoting longevity (Steptoe et al., 2015).

Ageing people with intellectual disabilities become increasingly dependent on support staff due to their changing support needs and age-related physical and cognitive decline, and also due to changes in their social situations. This involves their social network (i.e. family and friends) that is ageing as well (McCausland et al. 2016), and not having a partner or children to care for them later in life (Ryan et al. 2014). It is unsurprising that, in order to receive personal attention, older people with intellectual disabilities increasingly become reliant on support staff. One of the closest and most significant social relationships people with intellectual disabilities have is with support staff. Support staff provide them instrumental and emotional support, and significant and meaningful social contact (Giesbers et al., 2019; Van Asselt-Goverts et al., 2013; Kwekkeboom et al. 2006). Based on the outcomes of the studies on the support needs of older people with intellectual disabilities (Chapters 2 and 3) and the different theories surrounding wellbeing mentioned above, it can be assumed that healthcare providers should be concerned with chronic health conditions and physical disability, but also with supporting positive psychosocial interventions to improve emotional wellbeing, interpersonal relationships, self-determination and existential wellbeing.

A lack of psychosocial interventions for older people with intellectual disabilities

The second part of this thesis' findings concerns the fact that only a limited number of psychosocial interventions having been developed for older people with intellectual disabilities. Comparing the outcome of our review to available support strategies and interventions for other vulnerable target groups in the field of intellectual disability care (e.g. people with intellectual disabilities and challenging behaviour or autism; Sturmey & Didden, 2014), there are fewer clinical guidelines for professional caregivers and relatively few evidence-based interventions. Moreover, our study showed that only a few available psychosocial interventions can be used directly by support staff in daily care. As support staff play a crucial role in the support of older people with intellectual disabilities living in residential care facilities (Wiese et al., 2013), it is remarkable they seem to have little choice or opportunity to apply psychosocial interventions. With this lack of daily applicable psychosocial interventions, it is questionable whether support staff can maintain high-quality care for this target group, which is a particular cause for concern (Cleary & Doodey, 2016; Iacono, Bigby, Carling-Jenkins, & Torr, 2014; Janicki & Keller, 2012). Even though older people with an intellectual disability are considered a particularly vulnerable group owing to their relatively complex ageing processes (WHO, 2018), it is still necessary to bridge the gap regarding knowledge on ageing with intellectual disabilities and to provide appropriate care and support from a more psychosocial point of view.

Interestingly, regarding dementia care, the focus has been increasingly directed towards person-centred care (Boumans et al., 2021) instead of support and care provided exclusively according to the 'medical model', in which the focus is mainly on what the person has (e.g. illness or condition) rather than who the person is (e.g. life history and needs) (Dröes et al., 2015). Person-centred care has also become the gold standard for providing care in nursing homes (Muller-Schoof et al., 2022; WHO, 2015). This shift in approach to good care and support has led to the development of numerous, person-centred interventions with a psychosocial focus (e.g. Dementia Care Mapping; Brooker et al., 1998) that can be applied by support staff in daily care. These psychosocial interventions and innovations in elderly care can also be inspiring and helpful for developing person-centred interventions in the care of older people with intellectual disabilities.

Integrated Emotion-Oriented Care for support staff working with older people with intellectual disabilities

One of the promising person-centred interventions in geriatric and dementia care is Integrated Emotion-Oriented Care (IEOC) (Van der Kooij, 2003; 2014). However, despite this intervention's positive outcomes in dementia care (Finnema et al., 2005; Van der Kooij et al., 2013) and its status as good practice, it had yet to be made clear what the intervention components of IEOC for older people with intellectual disabilities entailed and how they could be applied in daily care. In our attempt to understand and define IEOC for older people with intellectual disabilities, we systematically identified the intervention components and described their application in practice using narrative summaries. We also outlined the integrative and holistic character of IEOC. In general, the application of IEOC does not seem to be linked to specific behaviours or disorders. Rather, it can be seen as a basic attitude from which a professional aligns with the person every day to find out what the person needs at that moment. This is in line with the WHO's description of person-centred care (2015): "Person-centred care is a comprehensive approach to care that takes into account the whole person and is underpinned by values of respect for personhood, the individual right to self-determination, mutual respect, and understanding".

Consequently, IEOC might be promising as a support strategy for support staff who are responsible for the daily care of ageing people with intellectual disabilities. The extensive description of the intervention components described in Chapter 5 can serve as an important tool to respond to the complexity of the ageing process and the corresponding expected changing support needs of older people with intellectual disabilities in all QoL domains. This is in line with the findings of Fazio et al. (2018), who stated that the emergence of person-centred interventions that address the psychosocial support needs of older people may help caregivers to broaden the focus of their practice beyond the medical and physical aspects of care. Moreover, the findings of our study regarding COVID-19 (Chapter 6) indicated that IEOC even served as a successful strategy to help support staff adapt to the COVID-19 measures. IEOC may also help them to continue to put the needs and wishes of older people with intellectual disabilities first, to search for other ways to connect with them and to cope with future pandemics as a team. In sum, the integrative and holistic character of IEOC could enable support staff to focus simultaneously on multiple aspects of the lives of older people with intellectual disabilities, which can be seen as an important addition to existing support strategies.

Strengths, limitations, and implications for future research

Method, data source and investigator triangulation

The research questions in the present thesis were as follows:

1) What are the most important support needs that older people with intellectual disabilities experience within each QoL domain and how important is each QoL domain?
2) What do older people with intellectual disabilities consider most important in their daily lives and what support needs do they encounter?
3) What are the foci of the available psychosocial interventions for older people with intellectual disabilities and what role do support staff play in the application of these interventions?
4) What are the intervention components of IEOC for older people with intellectual disabilities and how can they be applied in the day-to-day support of older people with intellectual disabilities?
5) To what extent were direct support workers able to apply a specific form of person-centred care (i.e. IEOC) when working with older people with intellectual disabilities during the COVID-19 pandemic?

The five studies were largely qualitative in nature and were carried out according to qualitative research principles (Green & Thorogood, 2014). Three forms of triangulation were used to enhance the credibility of our findings and to increase validity and reliability: method triangulation, data source triangulation and investigator triangulation (Carter et al., 2014; Green & Thorogood, 2014). Regarding method triangulation, this thesis included a mixed-method study, a systematic review and several studies with a qualitative design in which a variety of research methods were used (i.e. semi-structured interviews, concept mapping, focus group interviews) to approach the same phenomena. We provided a thorough description of the extensive data collection and analysis procedures for every research method used in this thesis. This included multiple coding, deductions of themes by experienced qualitative researchers, and member checks with participants.

Second, data source triangulation consisted of combining different sources of knowledge and methods to reduce bias and enlarge the trustworthiness of our findings with the aim to increase validity (Wilson, 2014). The results of this thesis are, therefore, based on three different sources of knowledge: scientific knowledge, professional knowledge and knowledge by experience. The professional knowledge of support staff members, psychologists and policymakers, the experiential knowledge of older people with intellectual disabilities, and scientific knowledge are all treated as being valuable and can be seen as equal (Embregts, 2017; 2018). The integration of these three sources of knowledge is referred to by the term evidence-based practice (Van Yperen et al., 2017) and its application is a strength of this thesis.

Finally, investigator triangulation was applied in two different ways. First, by including members with different backgrounds (e.g. in research, practice and with experiential knowledge) in the research team. Second, by having at least two members of the research team consistently perform the initial coding of raw data independently. All findings were also discussed with all members of the research team, which ensured different perspectives and helped to reduce researcher bias.

Perspectives of older people with intellectual disabilities

In addition to including the perspectives of psychologists and support staff members, we also included the perspectives of older people with mild to moderate disabilities. Although support staff and psychologists working with people with intellectual disabilities on a daily basis can be seen as valuable sources of information, people with intellectual disabilities may have different perspectives to care professionals or place different emphases on the wishes and needs they experience or on how other people should take care of them (Bekkema et al. 2016; Albuquerque & Carvalho 2020). People with mild to moderate disabilities are experts on their own lives, experiences and feelings (McDonald et al., 2013). These insights cannot be obtained from any other source. Accordingly, including the perspectives and experiences of a more vulnerable target group is considered a strength as well.

To better connect with older people with intellectual disabilities and capture their experiences in the most optimal way (Chapter 2), we collaborated with a co-researcher with an intellectual disability (Bigby et al. 2014; Embregts et al. 2018; Van den Bogaard et al. 2023; Walmsley et al. 2018). The co-researcher actively participated in the research, meaning that he was involved in overall decision-making, and conducting and analysing the interviews. An advisory board of three experts by experience with mild intellectual disabilities of the Academic

Collaborative Centre Living with an intellectual disability also provided advice on the study proposal and the interview guide during group discussions. They provided advice on the formulation of the questions in the interview guide, language use, recruitment procedures and interview setting (i.e. quiet place, presence of a caregiver). The involvement of people with intellectual disabilities (e.g. the co-researcher and advisory board) brings more perspectives into the research process and fosters growth within the research team (Embregts et al., 2018; Embregts & Beenhakker, 2023; Frankena, 2019; Nind, 2014). Despite these strengths, several general limitations should be mentioned alongside suggestions for future research.

Sampling and recruitment

In addition to the strengths outlined in the previous section, this thesis has some limitations regarding sampling and recruitment. First, throughout this thesis, we refer to older people with intellectual disabilities in general. We explain that due to premature ageing (i.e. early occurrence of frailty), we maintain certain age distinctions to clarify the onset of the ageing processes depending on the level of functioning. These distinctions are as follows: people with mild intellectual disabilities from 65 years and older, people with moderate intellectual disabilities from 50 years and older, and people with severe to profound intellectual disabilities or Down syndrome from 40 years and older. However, we only included older individuals with mild to moderate disabilities, which made our sample in Chapter 3 particularly select. While it allowed for an exploration of their particular experiences with the process of ageing, it also limits the generalisability of our findings.

Furthermore, in our studies we did not differentiate between possible various stages of the ageing process (i.e. the degree of vitality), potential dual diagnosis with chronic health impairments, psychiatric disorders or level of functioning of participants. The various stages of the ageing process, differences in the presence of health issues or psychiatric conditions and a lower level of functioning may still influence the support needs and individual experiences. A broader focus that takes the different stages of the ageing process into account and includes older people with moderate to severe intellectual disabilities would be recommended in future studies. This would enable a more complete picture of this vulnerable target group.

In keeping with the developmental model for practice-driven evaluations (Van Yperen et al., 2017), this thesis contributed to the body of descriptive evidence on IEOC for older people with intellectual disabilities (i.e. identifying and understanding its intervention components) and provided a first step for translating a practice-based approach into an evidence-based approach. However, exploring an existing support strategy could lead to the identification of undiscovered elements of the support strategy that are not mentioned by early adopters of IEOC and experienced professionals. Although we succeeded in using multiple methods and data sources to develop a comprehensive understanding of IEOC for older people with intellectual disabilities (i.e. data triangulation) (Chapter 5), we may have overlooked information or elements that have not been described or mentioned as part of IEOC. Furthermore, we did not focus on the perceptions and experiences of older people with intellectual disabilities while receiving psychosocial interventions (Chapter 4) or IEOC (Chapters 5 and 6). Although we collected and integrated relevant information about providing IEOC to older people with intellectual disabilities using multiple sources (Chapters 5 and 6), the inclusion of the perspectives of older people with intellectual disabilities and their informal networks would have further strengthened the descriptive evidence on IEOC.

Before conducting a clinical trial (e.g. a randomised controlled trial; RCT) with respect to IEOC for older people with intellectual disabilities, more research is needed to formulate assumptions about which components could relate to certain processes and outcomes, in order to develop evaluative measures at an individual level and select instruments (Van Yperen et al., 2017). It is also necessary to conduct procedural-reliability measurements that indicate whether intervention components are implemented as intended (Gresham et al., 2000). A similar systematic approach for further evaluating IEOC can be found in the Medical Research Council (MRC) framework (Campbell et al., 2000; Craig et al., 2008). This framework provides guidance for developing and evaluating complex interventions. It emphasises the importance of starting with theory and building an understanding of how interventions should have an effect. According to the MRC, high-quality evidence for complex interventions goes through five different phases: (1) the 'Pre-Clinical' or theoretical phase, (2) the modelling phase, (3) the exploratory trial, (4) the main trial, and (5) long-term surveillance (Campbell et al., 2000; Craig et al., 2008). Nevertheless, we believe that the overview of intervention components and the corresponding narrative summaries presented in this thesis can contribute to designing follow-up studies.

A limitation regarding the sampling and recruitment as applied in this thesis concerns the sample sizes of the studies described in Chapters 3 and 6. Although the number of participants in both studies met the recommendations of Braun and Clarke (2013), and determining sample size in qualitative research is often considered a pragmatic exercise (Braun & Clarke, 2021), our samples were still relatively small due to the difficulties involved in conducting this type of research under the circumstances (i.e. during the COVID-19 pandemic). However, the use of a small sample can be considered both a strength and a limitation of this type of research. While it allowed for more in-depth engagement with each individual participant and an exploration of their experiences from a validity point of view, it also limits the generalisability of our findings.

A final limitation concerns the fact the older people with intellectual disabilities involved in this thesis all lived in residential care facilities in the Netherlands with access to 24-hour support. Accordingly, future research should include older people with an intellectual disability with different support and living arrangements to consider possible differences in experiences of ageing compared to our findings. Subsequently, in our attempt to better understand IEOC for older people with intellectual disabilities (Chapters 5 and 6), we only recruited professionals from a single Dutch service provider (i.e. Philadelphia Care Foundation), which may have caused bias in their perspectives. Since IEOC is still considered a practice-based intervention for older people with intellectual disabilities, it is not clear if professionals who have experience with IEOC-like approaches in other healthcare organisations have different points of view. It would be interesting and we recommend other studies to further explore the possible other applications of IEOC and the experiences of professionals in other organisations in follow-up research. This study could serve as a case description that illustrates how researchers can work with experienced support staff and experts to underpin their intuition-based knowledge.

Implications for policy and practice

The findings of this thesis may suggest several directions for policy and practice. First, the findings of the studies regarding the support needs and matters of importance (Chapters 2 and 3) make an important contribution to raising awareness among direct care staff of older people with intellectual disabilities and to improving their QoL throughout the ageing process. More knowledge of the possible support needs throughout the QoL domains can help support staff provide effective support that focuses on the aspects of wellbeing that are relevant to their clients. Consequently, funding and policy support are essential to provide support staff with training and education to improve their knowledge, skills and attitudes regarding the changing support needs of older people with intellectual disabilities, as well as the complex ageing process in general, such as the higher prevalence of multiple chronic health impairments (e.g. respiratory diseases), psychiatric disorders (psychotic disorders) and psychosocial consequences (e.g. small informal networks).

Furthermore, regarding the presence of support needs in all different QoL domains, a broad support team in which various disciplines are represented seems necessary to provide adequate support (e.g. pedagogical staff and nursing staff). Changing the current composition of support teams should, therefore, be considered. In other words, staff who are vocationally trained in social or pedagogic education should be involved in support teams in addition to staff with nursing backgrounds. As such, knowledge and skills concerning the medical and physical aspects of ageing would be present, but there would also be sufficient attention paid to who the person is and other potential support needs in other QoL domains would be catered for as well (Schaap, 2019). As demonstrated in Chapter 5, especially with regard to the focus on the older person's perspective to better understand their wishes, needs and behaviour, IEOC can also help support staff to immerse themselves in the perspective of older people with intellectual disabilities and adequately adjust to all different support needs with the aim to maintain their QoL.

A final implication of our study concerns the future identification of professional and organisational preconditions that were addressed in this thesis regarding the application of a person-centred approach. In addition to the findings contributing to the awareness of the complexity and the possible challenges of applying a person-centred approach in daily practice, it was also found that it requires an understanding of the intervention components, their purpose and the target group, but also an understanding of the context in which the intervention is implemented (Rossi et al., 2004; Van Yperen et al., 2017). The results in Chapters 5 and 6 emphasise that IEOC is a multi-component, integrated and holistic approach in which every component is linked. For example, to be able to focus on the older person's perspectives to better understand their wishes, needs and behaviour (Component 1) and adequately adjust to their current needs (Component 2), it seems necessary that support staff connect and build a relationship with them first (Component 3). It is also important for support staff to consciously share their personal experiences with other members of the team (Component 4) and the older person's informal network (Component 5) to develop a more accurate picture of the older person and create alignment in support provision. To apply IEOC effectively, the combined use of all intervention components is strongly suggested. As a consequence, this also includes the need for different levels of an organisation to be involved in the application of IEOC, as both professional preconditions (e.g. specific competencies and characteristics of support staff, such as flexibility, courage and vulnerability) and organisational preconditions (e.g. providing all necessary opportunities for staff to apply the approach, such as time and adequate staff training) are necessary for successfully applying IEOC for older people with intellectual disabilities.

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Summary

The main objective of this thesis was to gain more insight into the support needs of older people with intellectual disabilities by including the perspectives of psychologists and older people with intellectual disabilities themselves (Part 1), to provide an overview of the available psychosocial interventions for older people with intellectual disabilities including the role of support staff in these interventions (Part 2), and to make Integrated Emotion-Oriented Care (IEOC) more explicit by creating a clear framework of its content based on current users' knowledge and experience and help support staff increase their attention to the psychosocial aspects of the ageing process when providing daily care to older people with intellectual disabilities (Part 3).

Chapter 1

The general introduction in Chapter 1 describes the background and societal impact of ageing with an intellectual disability, and the development of person-centred care approaches in elderly care. Integrated Emotion-Oriented Care (IEOC) is also introduced as a support strategy for older people with intellectual disabilities.

Ageing with an intellectual disability: Background and societal impact

Similar to the dynamics of ageing in the general population, the life expectancy of people with intellectual disabilities has increased in recent decades due to improved living conditions and better medical care. Although both groups' life expectancies are increasing, the ageing process of older people with intellectual disabilities is different from older people in the general population as it is characterised by an increased risk of developing frailty due to their lifelong disabilities. Consequently, older people with intellectual disabilities are at an increased risk of developing physical health problems, particularly diabetes, obesity, dysphagia, and visual and hearing impairment. Multi-morbidities (more than two conditions at the same time) are common for older people with intellectual disabilities too. In addition to the presence of physical health problems, older people with intellectual disabilities also seem to be at higher risk of developing dementia, depression, anxiety and psychotic disorders, and other psychosocial limitations compared to older people in the general population. It is also important to note that older people with intellectual disabilities have limited informal networks as a result of their living conditions (i.e. residential care facilities), and they often do not have partners or children. Consequently, they often depend on others for transport and to organise their lives, activities and finances. As such, the increased longevity of people with intellectual disabilities and the early onset and complexity of the ageing process for older people with intellectual disabilities intensify their reliance on support staff and pose challenges to healthcare organisations.

Person-centred care

Different person-centred care and support approaches for people with dementia have been developed in response to criticism of the support and care for ageing people with dementia being provided using the ‘medical model’. This model mainly focuses on what the person has (e.g. illness or condition) rather than who the person is (e.g. their life history and needs). Ageing with an intellectual disability also leads to changing support needs. This has a huge effect on support provision. Consequently, it can also be assumed that there are gaps in professional knowledge and feelings of uncertainty amongst support staff. It is also unclear whether the quality of life of older people with intellectual disabilities can still be guaranteed with the current support strategies. These tend to focus on development rather than retaining acquired skills, and medical and physical conditions rather than psychosocial circumstances. Considering these challenges, person-centred support strategies seem urgently required to address the support needs of ageing people with intellectual disabilities to ensure optimal care and to support good quality of life.

Integrated Emotion-Oriented Care

Most support strategies and interventions for older people with intellectual disabilities are medically and physically oriented, aimed at assessing wellbeing-related effects. However, several studies have shown that experts recommend using person-centred care as a guiding principle to provide quality care. Support staff in disability care could, therefore, potentially benefit from already-developed person-centred support strategies. One of these strategies is Integrated Emotion-Oriented Care (IEOC), developed by Cora van der Kooij for psychogeriatric nursing home care. IEOC means emotion-oriented approaches and communication skills are used, tailored to individual nursing home residents, considering their feelings, needs and physical and psychological limitations. Its aim is to support residents in adapting to the consequences of dementia, feeling safe and being able to maintain their self-esteem. Despite the positive findings in dementia care and its status as good practice, it has yet to be made clear what the intervention components of IEOC for older people with intellectual disabilities are and how these should be used and applied.

Part I: The support needs of older people with intellectual disabilities

The first part of the thesis aimed to gain more insight into the support needs of older people with intellectual disabilities.

Chapter 2

Chapter 2 explores and documents the most important support needs of older people with intellectual disabilities across the quality-of-life (QoL) domains. This was achieved by conducting semi-structured interviews with psychologists with expertise in working with older people with intellectual disabilities. The term ‘quality-of-life domains’ refers to the set of factors that make up personal wellbeing and thus define the multidimensionality of a life of quality as proposed by Schalock. This multidimensional QoL model has been thoroughly described, researched and validated in terms of support for people with intellectual disabilities, and it matches the current support paradigm. The following eight domains of QoL were included in the interview guide: Personal development; Self-determination; Interpersonal relationships; Social inclusion; Rights; Emotional wellbeing; Physical wellbeing; Material wellbeing; and Existential wellbeing. An additional domain of existential wellbeing was added since there are indications that this domain is particularly important for older people with intellectual disabilities, who are likely to examine their pasts and ask questions about the end of life.

Although signs of ageing are mainly associated with medical aspects and physical abilities in the literature, the results show that older people with intellectual disabilities experience support needs in all nine QoL domains. Furthermore, the ratings of each QoL domain assigned by the psychologists in this study suggest that support needs of older people with intellectual disabilities relating to emotional wellbeing (e.g. actively offering safety, relaxation and comfort), physical wellbeing (e.g. environment that reflects changes in physical health), self-determination (e.g. room and support to make individual choices and experience autonomy) and interpersonal relationships (e.g. support in maintaining and facilitating contact with family and social network) are considered the most important. Three other relevant insights related to ageing with an intellectual disability were also indicated. First, besides the changes in the type and extent of needs throughout the ageing process, the support needs of people with intellectual disabilities increase in number. Second, most older people with intellectual disabilities live in residential facilities most of their lives so they have no spouses or children who can take care of them. As a result, their social networks become significantly smaller as they age. Third, experiences with grief and loss require adequate, specialised support, as do questions concerning the end of life.

Chapter 3

Chapter 3 describes a study that uses an inclusive approach (i.e. one that was undertaken with a co-researcher with an intellectual disability) in which the perspectives of ten older individuals with mild to moderate intellectual disabilities (aged 65–90 years old) with respect to their matters of importance and support needs were examined. In-depth accounts of what older people with intellectual disabilities consider to be most important in their daily lives themselves and what support needs they currently experience were established using individual, semi-structured interviews. Due to the inclusive approach, we formulated more accessible interview questions for the participants, gained their trust during interviews and incorporated a broader perspective by interpreting the transcripts together.

The results of this study show that ‘the need to feel connected to others’ was important for the participants. This concerns the need for personal attention, being in each other’s company and receiving emotional support. ‘Feeling at ease or meaningfully engaged’ and ‘feeling autonomous’ were also considered valuable. With respect to current support needs, four themes arose. Participants indicated that they needed: (1) support to be able to do everyday things, (2) support regarding personal care, (3) support to achieve emotional wellbeing, and (4) support to maintain their self-esteem and autonomy. The results of this study confirm the presence of support needs in different QoL domains, including physical wellbeing (e.g. support in ADL activities), emotional wellbeing (e.g. someone paying attention to you), interpersonal relationships (e.g. being able to participate in social activities), existential wellbeing (e.g. experiencing a meaningful day) and self-determination (e.g. freedom of choice).

Part II: Psychosocial interventions for older people with intellectual disabilities

The second part of the thesis aimed to provide an overview of existing non-pharmacological and non-physical interventions for older people with intellectual disabilities.

Chapter 4

The study in Chapter 4 describes a systematic review of 36 qualitative and quantitative studies focusing on available psychosocial interventions for older people with intellectual disabilities (aged 50 and older). Although only 11 studies focused on the ageing population with intellectual disabilities specifically, the remaining 25 studies either provided separate results for the participants or demonstrated that there were no statistically significant differences between the older and younger participants. In all, 296 individuals with intellectual disabilities were involved in these studies. An integrative method was conducted to synthesise both quantitative and qualitative data.

The results of this systematic review show that the focus of the psychosocial interventions identified in the studies addressed two main themes. The first theme, covered in 17 interventions, focused on investigating and meeting the individual needs of older people with intellectual disabilities. It did so by gaining more insight into the lives of older individuals with intellectual disabilities, recognising their individual needs or implementing appropriate care and support. The second theme centred on improving specific behaviours or skills by focusing on teaching self-care, problem-solving or coping skills for dealing with anxiety and behavioural treatments to decrease inappropriate behaviour was covered in 19 interventions. This review also demonstrated that, overall, support staff had a limited role in the application of psychosocial interventions because they were hardly involved in or responsible for the application or implementation. Relatively few psychosocial interventions are available for support staff members to apply directly in their daily work. This implies they have little choice or opportunity to work with psychosocial interventions. Most psychosocial interventions were also only carried out for a short period of time (e.g. over a few individual sessions) and were only used with the aim of affecting a single variable (e.g. happiness).

Part III: Integrated Emotion-Oriented Care for older people with intellectual disabilities

The third part of this thesis focused on contributing to the descriptive evidence regarding IEOC by creating a clear framework of its content, based on current users' knowledge and experience.

Chapter 5

Chapter 5 describes a first step in making IEOC for older people with intellectual disabilities explicit by performing data triangulation of three different sources (i.e. scientific knowledge, professional knowledge and knowledge by experience) regarding IEOC in healthcare for older people and conducting five focus group discussions with daily users of IEOC. The aims of this qualitative study were: to identify the intervention components of IEOC; to provide demonstrative data; and to gain an in-depth understanding of the use of these components in day-to-day support. Next, a content analysis of five key documents was carried out (i.e. scientific knowledge). Each key document contained relevant information regarding the intervention components of IEOC for older people with or without intellectual disabilities and was suitable for qualitative analysis (i.e. unitised, written text). Next, five semi-structured interviews were conducted with early adopters of IEOC (inside and outside the field of intellectual disabilities) with the aid of a brief interview guide (professional knowledge). The Interview guide was not based on the analysis of the key documents, but merely intended to retrieve additional information regarding the intervention components of IEOC from another source. Finally, following the semi-structured interviews, a concept mapping study with eight daily users of IEOC was applied to identify the factors that were considered most important when applying IEOC to older people with intellectual disabilities on a daily basis for further validation and identification of the IEOC intervention components (knowledge by experience). Ultimately, due to these three steps (sources of knowledge), a number of central components in the underlying ideas of IEOC were distinguished, resulting in the identification of five IEOC intervention components: (1) focussing on the perspective of older individuals with intellectual disabilities to better understand their wishes, needs and behaviour, (2) adjusting adequately to the current needs of older individuals with intellectual disabilities, (3) connecting with older individuals with intellectual disabilities in order to build a relationship with them, (4) working in a safe and trusting team culture, and (5) creating room for the informal networks of older individuals with intellectual disabilities.

Subsequently, the final stage in the data collection process was a series of five focus group discussions. These were arranged with a total of 21 experts and experienced support staff regarding IEOC for older people with intellectual disabilities. They were intended to provide a better understanding of how the five different intervention components of IEOC could be applied in the day-to-day support for older people with intellectual disabilities. For each IEOC intervention component, a narrative summary was created to provide a detailed description of its meaning (e.g. how intervention components of IEOC could be applied in the day-to-day support for older people with intellectual disabilities). These summaries included examples of associated actions, activities and aspects that should be considered. They also provided information about the integrative nature of the different components.

Chapter 6

The study in Chapter 6 examined the applicability of IEOC for older people with intellectual disabilities during the COVID-19 pandemic. In light of the infection management and preventive measures (e.g. quarantine, social distancing) against COVID-19, it seemed crucial to uphold the person-centred principles of IEOC to maintain the social participation, mental health and QoL of older people with intellectual disabilities. A qualitative descriptive study design was chosen to address the experiences of support staff with respect to COVID-19 and applying IEOC. A focus group discussion with six support staff members was conducted to explore the extent to which support staff were able to provide IEOC under the COVID-19 restrictions. The main focus was on the first three intervention components of IEOC because they are directly related to older people with intellectual disabilities. These intervention components focus on: (1) the perspectives of older people with intellectual disabilities, (2) the adjustment to the current needs of older people with intellectual disabilities, and (3) the connection with older people with intellectual disabilities.

The results show that support staff members were able to apply all five components of IEOC despite the COVID-19 pandemic. Three distinct themes were identified in the thematic analysis: (1) changes due to the COVID-19 measures had a negative impact on older people with intellectual disabilities, such as a lack of social and physical contact for older people with intellectual disabilities; (2) direct support staff were able to adapt to changes due to the COVID-19 measures such as keeping distance; and (3) the needs and wishes of older people with intellectual disabilities remained the priority despite the measures. Even though support staff referred to the challenges and effects of the pandemic, working according to IEOC apparently provided them with tools that helped them to cope with the situation adequately. This finding confirms that the application of IEOC fosters a basic attitude that helps support staff to adapt to constantly changing circumstances and, therefore, to the changing support needs of older people with intellectual disabilities throughout a crisis such as COVID-19.

Chapter 7

Finally, the main findings of this thesis are summarised and integrated, and the strengths, limitations and implications for future research and policy and practice are addressed in the general discussion in Chapter 7.

First, despite the recognition that the life expectancy of people with intellectual disabilities has increased due to improved living conditions and better medical care, and the implications of ageing have resulted in changes in their support needs, very little research has directly considered common daily support needs or included the perspectives of older people with intellectual disabilities themselves. This thesis shows that professionals and older people with intellectual disabilities experience support needs in all nine QoL domains, and not just in the physical wellbeing domain that most previous research and support strategies focus on. The current findings suggest that it is also important to focus on support needs in terms of emotional wellbeing, interpersonal relationships, self-determination and existential wellbeing to provide adequate support. It is important to make support staff aware of the needs and wishes of older people with intellectual disabilities in this respect. This is especially important as a number of studies acknowledge that older people with intellectual disabilities are likely to encounter emotional life events due to age-related decline, loss of significant others, forced relocations, difficulties in maintaining their autonomy and self-determination, and have an increased likelihood of developing physical and cognitive problems.

The current thesis also shows that only a limited number of psychosocial interventions have specifically been developed for older people with intellectual disabilities. Only a few available psychosocial interventions can be used directly by support staff in daily care because they have an active role in the implementation of the intervention. The majority of the psychosocial interventions were applied by psychologists or researchers in separate settings (e.g. therapy rooms). However, as support staff play a crucial role in the support of older people with intellectual disabilities living in residential care facilities, it is remarkable that they seem to have little choice or opportunity to apply psychosocial interventions themselves. With this in mind, this thesis explored whether IEOC could be a good tool to support older people with intellectual disabilities. This study shows that IEOC may be a promising support strategy for support staff. The extensive description and the integrative character of the intervention components can serve as important tools to respond to the complexity of the ageing process and the corresponding expected changing support needs of older people with intellectual disabilities in all QoL domains. IEOC may help support staff to broaden the focus of their practice beyond the medical and physical aspects of care. This can be seen as an important addition to existing support strategies.

Finally, several strengths and limitations of the study are discussed in Chapter 7. The current thesis included research studies that were largely qualitative in nature, which used different research methods (i.e. semi-structured interviews, concept mapping procedure, systematic review procedure). In addition to including the perspectives of psychologists and support staff members, we also included the perspectives of older people with intellectual disabilities themselves. In this study, collaboration was sought with a co-researcher with an intellectual disability to better connect with older people with intellectual disabilities and capture their experiences in the most optimal way. Although support staff and psychologists are considered valuable sources of information, people with intellectual disabilities may have different perspectives to care professionals or place different emphasis on the wishes and needs they experience or on how other people should take care of them. However, we only included older individuals with mild to moderate disabilities, limiting the generalisability of our findings. Furthermore, we did not differentiate between possible various stages of the ageing process (i.e. the degree of vitality), potential dual diagnosis with chronic health impairments, psychiatric disorders or level of functioning of participants, which may influence the support needs and individual experiences. A broader focus that takes the different stages of the ageing process into account and includes older people with moderate to severe intellectual disabilities would be recommended in future studies. The older people with intellectual disabilities involved in this thesis all lived in residential care facilities in the Netherlands with access to 24-hour support. Future research should also include older people with intellectual disabilities with different support and living arrangements. This should be done to evaluate potential differences in experiences of ageing compared to our findings. The current thesis contributed to the descriptive evidence surrounding IEOC for older people with intellectual disabilities based on the perspectives and experiences of professionals from a single Dutch service provider (i.e. Philadelphia Care Foundation). Future studies should further explore other applications of IEOC and the experiences of professionals in other organisations.

Samenvatting

Het onderzoek in dit proefschrift had als doel om (1) meer inzicht te krijgen in de ondersteuningsbehoeften van ouderen met een verstandelijke beperking door het includeren van de perspectieven van psychologen en ouderen met een verstandelijke beperking zelf, (2) een overzicht te geven van de beschikbare psychosociale interventies voor ouderen met een verstandelijke beperking, inclusief de rol van begeleiders bij de uitvoering van deze interventies, en (3) het explicieter maken van Belevingsgerichte zorg (BGZ) voor professionals in de dagelijkse zorg voor ouderen met een verstandelijke beperking door een duidelijk kader van de inhoud te creëren op basis van al bestaande kennis en ervaring en hiermee ook de aandacht voor de psychosociale aspecten van het verouderingsproces te vergroten.

Hoofdstuk 1

De algemene inleiding in hoofdstuk 1 beschrijft de achtergrond en maatschappelijke impact van het ouder worden met een verstandelijke beperking, en de ontwikkeling van persoonsgerichte zorgbenaderingen in de ouderenzorg. Ook wordt BGZ geïntroduceerd als ondersteuningsstrategie voor ouderen met een verstandelijke beperking.

Ouder worden met een verstandelijke beperking: achtergrond en maatschappelijke impact

Mensen met een verstandelijke beperking worden steeds ouder door verbeterde levensomstandigheden en betere medische zorg. Dit komt overeen met de toenemende vergrijzing in de algemene bevolking. Hoewel de levensverwachting van beide groepen toeneemt, verschilt het verouderingsproces van ouderen met een verstandelijke beperking van dat van ouderen in de algemene bevolking. Het verouderingsproces van mensen met een verstandelijke beperking wordt gekenmerkt door een grotere mate van kwetsbaarheid als gevolg van hun levenslange beperking(en). Hierdoor hebben ouderen met een verstandelijke beperking een verhoogd risico op het ontwikkelen van lichamelijke aandoeningen, vooral op het ontwikkelen van diabetes, obesitas, slikproblemen en visuele en auditieve beperkingen. Multimorbiditeit (het voorkomen van meer dan twee lichamelijke aandoeningen tegelijk) komt ook vaak voor bij ouderen met een verstandelijke beperking. Naast de aanwezigheid van lichamelijke aandoeningen lijken ouderen met een verstandelijke beperking ook een hoger risico te lopen op het ontwikkelen van dementie, depressie, angst- en psychotische stoornissen en andere psychosociale problemen. Ook hebben ouderen met een verstandelijke beperking vaak een kleiner informeel netwerk als gevolg van hun leefomstandigheden (d.w.z. het wonen in residentiele voorzieningen) en het ontbreken van partners en kinderen. De langere levensduur van mensen met een verstandelijke beperking, de vroege start en de complexiteit van het verouderingsproces vergroten hun afhankelijkheid van zorgprofessionals ten aanzien van het organiseren van hun leven en stellen gezondheidszorgorganisaties voor uitdagingen.

Persoonsgerichte zorg

Binnen de psychogeriatrische ouderenzorg zijn er verschillende persoonsgerichte zorg- en ondersteuningsbenaderingen voor mensen met dementie ontwikkeld als reactie op de kritiek op de ondersteuning en zorg die doorgaans werd geboden vanuit het ‘medische model’. Dit model richt zich vooral op wat de persoon heeft (bijvoorbeeld een ziekte of aandoening) in plaats van op wie de persoon is (bijvoorbeeld zijn levensgeschiedenis en behoeften). Uit verschillende onderzoeken komt naar voren dat professionals in de zorg voor mensen met een verstandelijke beperking het lastig vinden om te gaan met de veranderende ondersteuningsbehoeften die kunnen optreden bij het ouder worden vanwege ontoereikende vakkennis en mogelijke gevoelens van handelingsverlegenheid. De verandering in ondersteuningsbehoeften van ouderen met een verstandelijke beperking heeft grote gevolgen voor de manier waarop ondersteuning voor deze doelgroep vorm moet krijgen. Daarnaast is het onvoldoende duidelijk of met de huidige ondersteuningsstrategieën kwaliteit van leven van ouderen met een verstandelijke beperking gegarandeerd kan worden. Deze ondersteuningsstrategieën zijn doorgaans hoofdzakelijk gericht op het streven naar ontwikkeling en minder op het behouden van verworven vaardigheden, en richten zich voornamelijk op het medische en fysieke welbevinden in plaats van op het psychosociale welbevinden. Persoonsgerichte ondersteuningsstrategieën lijken daarom essentieel om tegemoet te komen aan de veranderende ondersteuningsbehoeften van ouderen met een verstandelijke beperking, om zo optimale zorg te garanderen en een goede kwaliteit van leven te waarborgen.

Belevingsgerichte zorg

Reeds ontwikkelde persoonsgerichte ondersteuningsstrategieën binnen de psychogeriatrische ouderenzorg zouden ook binnen de verstandelijke gehandicaptenzorg ingezet kunnen worden. Eén van deze ondersteuningsstrategieën is Belevingsgerichte zorg (BGZ), in Nederland ontwikkeld door Cora van der Kooij voor de psychogeriatrische verpleeghuiszorg: “Belevingsgerichte zorg is dat deel van de zorg dat te maken heeft met de kwaliteit waarmee je iemands persoonlijkheid recht doet en rekening houdt met de individuele behoeften van een bewoner en niet met de beperkingen en wordt er gezocht naar de aansluiting bij de belevingswereld van de bewoner.” Het doel is om ouderen te ondersteunen bij het omgaan met de gevolgen van dementie, bij het zich veilig voelen en bij het behouden van eigenwaarde. Ondanks de positieve ervaringen met BGZ in de psychogeriatrische verpleeghuiszorg en de status als ‘good practice’, kan deze ondersteuningsstrategie niet zonder aanpassingen aan de doelgroep, in dit geval ouderen met een verstandelijk beperking, worden overgenomen. Eerst zal duidelijk moeten worden gemaakt wat de interventiecomponenten van BGZ voor ouderen met een verstandelijke beperking zijn en hoe deze gebruikt en toegepast zouden kunnen worden door begeleiders in de dagelijkse zorg.

Deel I: De ondersteuningsbehoeften van ouderen met een verstandelijke beperking

Het eerste deel van het proefschrift had tot doel meer inzicht te krijgen in de ondersteuningsbehoeften van ouderen met een verstandelijke beperking.

Hoofdstuk 2

Binnen de studie in hoofdstuk 2 werden de belangrijkste ondersteuningsbehoeften van ouderen met een verstandelijke beperking op de verschillende domeinen van kwaliteit van leven (KvL) onderzocht. Dit hebben we gedaan door semigestructureerde interviews af te nemen met psychologen met expertise op het gebied van ouderen met een verstandelijke beperking. De term 'domeinen van kwaliteit van leven' verwijst naar acht domeinen die het persoonlijk welbevinden bepalen en daarmee de multidimensionaliteit van kwaliteit van leven definiëren, zoals beschreven door Schalock: Persoonlijke ontwikkeling, Zelfbepaling, Persoonlijke relaties, Sociale inclusie, Rechten, Emotioneel welbevinden, Fysiek welbevinden, Materieel welbevinden. Dit KvL-model van Schalock is uitgebreid beschreven, onderzocht en gevalideerd in termen van ondersteuning voor mensen met een verstandelijke beperking, en sluit aan bij het huidige ondersteuningsparadigma. Naast de acht domeinen van Schalock werd binnen het onderzoek existentieel welbevinden als extra domein toegevoegd aan KvL, omdat er aanwijzingen zijn dat dit domein vooral belangrijk is voor ouderen met een verstandelijke beperking, die waarschijnlijk regelmatig terugblikken op hun verleden en nadenken over het levenseinde.

De resultaten van deze studie laten zien dat volgens psychologen ouderen met een verstandelijke beperking ondersteuningsbehoeften ervaren in alle negen domeinen van kwaliteit van leven. De ondersteuningsbehoeften met betrekking tot de domeinen emotioneel welbevinden (bijvoorbeeld het actief bieden van veiligheid, ontspanning en comfort), fysiek welbevinden (bijvoorbeeld een omgeving die veranderingen in fysieke achteruitgang ondersteunt), zelfbeschikking (bijvoorbeeld ruimte en ondersteuning om individuele keuzes te maken en autonomie te ervaren) en persoonlijke relaties (bijvoorbeeld ondersteuning bij het onderhouden en faciliteren van contact met familie en andere informele netwerkleden) werden hierbij als de belangrijkste gezien. Er werden tevens drie andere relevante inzichten met betrekking tot ouder worden met een verstandelijke beperking gevonden. Ten eerste, naast dat de ondersteuningsbehoeften veranderen in soort en omvang gedurende het verouderingsproces, nemen ze ook in aantal toe zoals meer hulp bij algemeen dagelijkse levensverrichtingen (ADL). Ten tweede, de meeste ouderen met een verstandelijke beperking wonen het grootste deel van hun leven in residentiele voorzieningen, waardoor ze vaak geen partner of kinderen hebben die voor hen kunnen zorgen en wordt hun informele netwerk aanzienlijk kleiner naarmate ze ouder worden. Ten derde, rouw- en verlieservaringen en vragen met betrekking tot het levenseinde vereisen een adequate, gespecialiseerde ondersteuning.

Hoofdstuk 3

Hoofdstuk 3 beschrijft een onderzoek met een inclusieve aanpak (d.w.z. onderzoek dat is uitgevoerd samen met een co-onderzoeker met een verstandelijke beperking) waarin de perspectieven van tien ouderen met een licht tot matige verstandelijke beperking (in de leeftijd van 65-90 jaar oud) op voor hen belangrijke zaken in het dagelijkse leven en ondersteuningsbehoeften werden uitgevraagd. Door middel van individuele, semigestructureerde interviews was het mogelijk om informatie te verzamelen over wat ouderen met een verstandelijke beperking zelf het belangrijkst vinden in hun dagelijks leven en welke ondersteuningsbehoeften zij momenteel ervaren. Dankzij de samenwerking met de co-onderzoeker was het mogelijk om de vragen voor de participanten te formuleren in toegankelijke taal, de participanten op hun gemak te stellen tijdens de interviews en de data vanuit een breder perspectief te analyseren door de transcripties samen te interpreteren.

Uit de resultaten van dit onderzoek blijkt dat 'de behoefte om je verbonden te voelen met anderen' belangrijk was voor de participanten. Het ging hierbij om de behoefte aan persoonlijke aandacht, het in elkaars gezelschap zijn en het ontvangen van emotionele steun. Ook 'op je gemak voelen en zinvol bezig zijn' en 'je autonoom voelen' werden als zeer belangrijk ervaren. Met betrekking tot de huidige ondersteuningsbehoeften kwamen vier thema's naar voren. Participanten gaven aan het volgende nodig te hebben: (1) ondersteuning om alledaagse dingen te kunnen doen, (2) ondersteuning met betrekking tot persoonlijke verzorging, (3) ondersteuning om een hoog emotioneel welbevinden te ervaren, en (4) ondersteuning om zelfwaardering en autonomie te behouden. De resultaten van dit onderzoek bevestigen de aanwezigheid van ondersteuningsbehoeften in verschillende domeinen van KvL, waaronder fysiek welbevinden (bijvoorbeeld ondersteuning bij ADL-activiteiten), emotioneel welbevinden (bijvoorbeeld iemand die aandacht aan je besteedt), persoonlijke relaties (bijvoorbeeld kunnen deelnemen aan sociale activiteiten), en existentieel welbevinden (bijvoorbeeld het beleven van een zinvolle dag) en zelfbeschikking (bijvoorbeeld keuzevrijheid).

Deel II: Psychosociale interventies voor ouderen met een verstandelijke beperking

Het doel van het tweede deel van het proefschrift was om een overzicht te geven van bestaande psychosociale interventies voor ouderen met een verstandelijke beperking.

Hoofdstuk 4

Hoofdstuk 4 beschrijft een systematische review van 36 kwalitatieve en kwantitatieve studies die zich richten op beschikbare psychosociale interventies voor ouderen met een verstandelijke beperking (50 jaar en ouder). Hoewel slechts 11 studies zich specifiek richtten op ouder wordende mensen met een verstandelijke beperking, beschreven de overige 25 studies afzonderlijke resultaten voor de oudere participanten of toonden ze aan dat er geen statistisch significante verschillen waren tussen de oudere en jongere participanten. In totaal waren 296 ouderen met een verstandelijke beperking bij deze onderzoeken betrokken. Vervolgens werd er een integratieve methode uitgevoerd om zowel kwantitatieve als kwalitatieve data samen te voegen.

De resultaten van deze systematische review laten zien dat de focus van de psychosociale interventies zich op twee hoofdthema's richtten. Het eerste thema, behandeld in 17 interventies, was gericht op het onderzoeken en vervullen van de individuele behoeften van ouderen met een verstandelijke beperking. Dit gebeurde door meer inzicht te krijgen in de levens van ouderen met een verstandelijke beperking, door hun individuele behoeften te erkennen of door passende zorg en ondersteuning te bieden. Het tweede thema concentreerde zich op het verbeteren van specifiek gedrag of vaardigheden. In 19 interventies kwamen het aanleren van vaardigheden op het gebied van zelfzorg, probleemoplossende of coping-vaardigheden voor het omgaan met angst, en gedragsbehandelingen om ongepast gedrag te verminderen aan bod. Uit deze review bleek ook dat begeleiders in de directe dagelijkse zorg voor ouderen met een verstandelijke beperking over het geheel genomen een beperkte rol speelden bij de uitvoering van de psychosociale interventies, omdat zij nauwelijks betrokken waren bij of verantwoordelijk waren voor de toepassing of implementatie. Er zijn relatief weinig psychosociale interventies beschikbaar die begeleiders direct in hun dagelijkse werk kunnen toepassen. Dit impliceert dat zij weinig keuze of mogelijkheden hebben om met psychosociale interventies aan de slag te gaan bij ouderen met een verstandelijke beperking. Ook werden de meeste psychosociale interventies slechts gedurende een korte periode uitgevoerd (bijvoorbeeld verspreid over enkele individuele sessies) en alleen gebruikt met het doel één enkele variabele (bijvoorbeeld geluk) te beïnvloeden.

Deel III: Belevingsgerichte zorg voor ouderen met een verstandelijke beperking

Het derde deel van dit proefschrift richtte zich op het inzichtelijk beschrijven van de onderdelen van BGZ door een duidelijk kader van de inhoud te creëren, gebaseerd op de kennis en ervaring van huidige gebruikers zoals begeleiders en gedragskundigen.

Hoofdstuk 5

Hoofdstuk 5 beschrijft een eerste stap in het expliciet maken van BGZ voor ouderen met een verstandelijke beperking door het uitvoeren van triangulatie van drie verschillende kennisbronnen, namelijk wetenschappelijke kennis, professionele kennis en ervaringskennis met betrekking tot BGZ in de zorg voor ouderen. Het doel van dit kwalitatieve onderzoek was het identificeren van de interventiecomponenten van BGZ om hier vervolgens beschrijvende samenvattingen van te verstrekken en goed te kunnen begrijpen wat de toepassing van deze componenten in de dagelijkse ondersteuning omvat. Allereerst werd een inhoudsanalyse van vijf kerndocumenten (bijvoorbeeld boeken en beleidsstukken over BGZ) uitgevoerd (wetenschappelijke kennis). Elk kerndocument bevatte relevante informatie over de interventiecomponenten van BGZ voor ouderen met of zonder verstandelijke beperking en was geschikt voor een kwalitatieve analyse (d.w.z. samengevoegde, geschreven tekst). Vervolgens zijn vijf semigestructureerde interviews gehouden met 'early adopters' van BGZ (twee GZ-psychologen, twee beleidsmakers en een onderzoeker van binnen en buiten de VG-sector) met behulp van een korte vragenlijst (professionele kennis). De interviewguide had als doel om aanvullende informatie over de interventiecomponenten van BGZ op te halen. Tot slot werd, voor verdere validatie en identificatie van de BGZ-interventiecomponenten, een concept mapping-studie met acht (coördinerend) begeleiders en gedragskundigen met minimaal twee jaar ervaring met BGZ uitgevoerd (ervaringskennis). Hierin werden de belangrijkste elementen bij het dagelijks toepassen van BGZ bij ouderen met een verstandelijke beperking geïdentificeerd. Uiteindelijk was het dankzij deze drie stappen (kennisbronnen) mogelijk om vijf centrale interventiecomponenten in de onderliggende ideeën van BGZ te onderscheiden: (1) focussen op de beleving van ouderen met een verstandelijke beperking om hun wensen, behoeften en gedrag beter te begrijpen, (2) adequaat afstemmen op de huidige behoeften van ouderen met een verstandelijke beperking, (3) verbinding zoeken met ouderen met een verstandelijke beperking om van daaruit een relatie met hen op te bouwen, (4) werken in een teamcultuur gebaseerd op veiligheid en vertrouwen, en (5) ruimte creëren voor de rol en de beleving van het informele netwerk van ouderen met een verstandelijke beperking.

Om meer inzicht te krijgen in de manier waarop de vijf verschillende interventiecomponenten van BGZ kunnen worden toegepast in de dagelijkse ondersteuning van ouderen met een verstandelijke beperking hebben eveneens vijf focusgroepen plaatsgevonden met in totaal namen 21 ervaren zorgprofessionals (begeleiders, gedragskundigen en managers) met betrekking tot BGZ voor ouderen met een verstandelijke beperking. De inhoudsanalyse van de kerndocumenten, de interviews en de concept mapping (wat) en de focusgroepen (hoe) resulteerden in een uitgebreide samenvatting van ieder interventiecomponent waarin de betekenis ervan zo gedetailleerd mogelijk is beschreven (d.w.z. hoe de interventiecomponenten van BGZ kunnen worden toegepast in de dagelijkse ondersteuning van ouderen met een verstandelijke beperking). Deze samenvattingen bevatten voorbeelden van bijbehorende acties, activiteiten en aspecten waarmee rekening moet worden gehouden. Ze geven daarnaast ook informatie over het integratieve karakter van de verschillende interventiecomponenten.

Hoofdstuk 6

De studie in hoofdstuk 6 onderzocht de toepasbaarheid van BGZ voor ouderen met een verstandelijke beperking tijdens de COVID-19-pandemie. Was het ondanks alle beperkingen vanwege de infectie uitbraak en de preventieve maatregelen (bijvoorbeeld quarantaine, sociale afstand), mogelijk om de persoonsgerichte principes van BGZ te handhaven en de sociale participatie, geestelijke gezondheid en kwaliteit van leven van ouderen met een verstandelijke beperking te borgen. Door middel van een kwalitatieve focusgroep werden de ervaringen van zes zorgprofessionals (vier coördinerend) begeleiders en twee verpleegkundigen) met betrekking tot COVID-19 en de toepassing van BGZ onderzocht. Centraal in de focusgroep stond de vraag in hoeverre zij in staat waren belevingsgericht te werken ondanks de COVID-19 beperkingen en preventieve maatregelen.

Uit de resultaten blijkt dat de zorgprofessionals ondanks de COVID-19-pandemie alle vijf de componenten van BGZ konden blijven toepassen. In de thematische analyse werden drie verschillende thema's geïdentificeerd: (1) de veranderingen als gevolg van de COVID-19 maatregelen hadden een negatieve impact op ouderen met een verstandelijke beperking, zoals een gebrek aan sociaal en fysiek contact, (2) de zorgprofessionals konden zich aanpassen aan de veranderingen als gevolg van de COVID-19-maatregelen, zoals afstand houden, en (3) de behoeften en wensen van ouderen met een verstandelijke beperking bleven ondanks de maatregelen prioriteit houden. Ondanks de uitdagingen en gevolgen van de pandemie die benoemd werden door de zorgprofessionals, bood het werken met BGZ hen handvatten die hen hielpen adequate ondersteuning te bieden binnen deze context. Deze bevinding bevestigt dat werken met BGZ bij zorgprofessionals een basishouding bevordert die ze helpt zich aan te passen aan de voortdurend veranderende omstandigheden en de veranderende ondersteuningsbehoeften van ouderen met een verstandelijke beperking tijdens een crisis zoals COVID-19.

Hoofdstuk 7

Tot slot worden, in de algemene discussie in hoofdstuk 7, de belangrijkste bevindingen van dit proefschrift samengevat en geïntegreerd. Ook worden de sterke punten, beperkingen en implicaties voor toekomstig onderzoek, beleid en praktijk besproken.

Het is bekend dat de levensverwachting van mensen met een verstandelijke beperking is toegenomen door verbeterde levensomstandigheden en betere medische zorg. De gevolgen van het ouder worden resulteren in veranderingen in hun ondersteuningsbehoeften. Desondanks is er nog weinig onderzoek gedaan naar deze ondersteuningsbehoeften of het perspectief van ouderen met een verstandelijke beperking zelf. Dit proefschrift laat zien dat ouderen met een verstandelijke beperking ondersteuningsbehoeften ervaren in alle negen domeinen van kwaliteit van leven (KvL), en niet alleen in het domein van fysiek welbevinden waar het merendeel van eerdere onderzoeken en ondersteuningsstrategieën zich op lijken te richten. Het is daarom belangrijk om tevens te focussen op ondersteuningsbehoeften op het gebied van emotioneel welbevinden, persoonlijke relaties, zelfbepaling en existentieel welbevinden om adequate ondersteuning te kunnen bieden. Hierbij is het van belang om zorgprofessionals bewust te maken van de behoeften en wensen die ouderen met een verstandelijke beperking ervaren op deze domeinen. Te meer omdat mensen met een verstandelijke beperking in deze fase van hun leven hoogstwaarschijnlijk te maken krijgen met het verlies van vaardigheden als gevolg van het verouderingsproces, het verlies van familieleden, een verhoogde kans op het ontwikkelen van cognitieve problemen, en moeite zullen krijgen om hun autonomie en zelfbepaling te behouden.

Het huidige proefschrift laat eveneens zien dat slechts een beperkt aantal psychosociale interventies specifiek ontwikkeld is voor ouderen met een verstandelijke beperking. Slechts enkele beschikbare psychosociale interventies kunnen direct worden ingezet door zorgprofessionals in de dagelijkse zorg zoals begeleiders, omdat zij een actieve rol spelen bij de uitvoering van de interventie. Het merendeel van de psychosociale interventies wordt toegepast door psychologen of onderzoekers in een aparte setting (bijvoorbeeld therapieruimte). Begeleiders spelen echter een cruciale rol bij de ondersteuning van ouderen met een verstandelijke beperking die in residentiele voorzieningen wonen. Des te opmerkelijker is het dat zij weinig keuze of mogelijkheden lijken te hebben om zelf psychosociale interventies in te zetten. Op basis van deze bevinding werd binnen dit proefschrift onderzocht of Belevingsgerichte zorg (BGZ) een passende manier zou kunnen zijn om ouderen met een verstandelijke beperking te ondersteunen. Uit dit onderzoek blijkt dat BGZ een veelbelovende ondersteuningsstrategie voor zorgprofessionals kan zijn. De uitgebreide beschrijving en het integratieve karakter van de interventiecomponenten kunnen dienen als belangrijke handvatten om in te kunnen spelen op de complexiteit van het verouderingsproces en de verwachte veranderende ondersteuningsbehoeften van ouderen met een verstandelijke beperking in alle domeinen van KvL die daarmee samenhangen. Naast de aandacht voor de medische en fysieke aspecten van de zorg voor ouderen met een verstandelijke beperking kan BGZ professionals helpen hun aandacht te vergroten voor de psychosociale aspecten van het verouderingsproces bij het verlenen van dagelijkse zorg. Dit kan worden gezien als een belangrijke aanvulling op bestaande ondersteuningsstrategieën.

Tot slot worden in hoofdstuk 7 verschillende sterke punten en beperkingen van het onderzoek besproken. Het huidige proefschrift bevat studies die grotendeels kwalitatief van aard zijn, waarbij gebruik is gemaakt van verschillende onderzoeksmethoden (o.a. semigestructureerde interviews, focusgroepen, concept mapping, systematische review). In dit onderzoek is eveneens samengewerkt met een co-onderzoeker met een verstandelijke beperking om beter aan te kunnen sluiten bij ouderen met een verstandelijke beperking en hun ervaringen op de meest optimale manier vast te leggen. Naast de perspectieven van begeleiders, psychologen, verpleegkundigen, managers en beleidsmakers zijn ook de perspectieven van ouderen met een verstandelijke beperking zelf meegenomen. Hoewel professionals in de dagelijkse zorg voor mensen met een verstandelijke beperking een waardevolle bron van informatie zijn, kunnen de perspectieven van mensen met een verstandelijke beperking zelf anders zijn bijvoorbeeld omdat ze een andere nadruk leggen op de wensen en behoeften die zij ervaren of op de manier waarop anderen voor hen zouden moeten zorgen. Er zijn echter alleen ouderen met een licht tot matige verstandelijke beperking geïncludeerd, wat het lastig maakt om de bevindingen te generaliseren naar de complete groep van ouderen met een verstandelijke beperking. Bovendien is er geen rekening gehouden met de verschillende stadia van het verouderingsproces (bijvoorbeeld m.b.t. de mate van vitaliteit), mogelijke dubbele diagnoses met chronische aandoeningen, psychiatrische stoornissen of het niveau van functioneren van participanten. Al deze factoren kunnen van invloed zijn op de ondersteuningsbehoeften en individuele ervaringen. Toekomstig onderzoek zou de gevolgen van de verschillende stadia van het verouderingsproces op de ondersteuningsbehoeften kunnen onderzoeken en tevens ook ouderen met een matige tot ernstige verstandelijke beperking kunnen includeren. Daarnaast woonden de ouderen met een verstandelijke beperking die hebben deelgenomen aan dit onderzoek allemaal in Nederlandse residentiele voorzieningen waar 24-uurszorg geboden werd. Potentiële verschillen ten aanzien van de ervaringen van ouderen met een verstandelijke beperking die bijvoorbeeld in een ambulante setting wonen zouden ook verder uitgediept kunnen worden. Tot slot, het huidige proefschrift beschrijft een eerste stap in het expliciet maken van BGZ voor ouderen met een verstandelijke beperking, gebaseerd op de perspectieven en ervaringen van professionals van één enkele Nederlandse zorgorganisatie (d.w.z. Philadelphia Zorg). Toekomstige studies zouden andere toepassingen van BGZ en de ervaringen van zorgprofessionals in andere organisaties ook verder kunnen includeren.

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Curriculum Vitae

Marloes Thalen werd op 14 februari 1985 geboren te Apeldoorn. In 2003 behaalde zij haar VWO diploma aan het Stedelijk Gymnasium te Apeldoorn. Na het behalen van haar propedeuse Geschiedenis, studeerde ze Pedagogische Wetenschappen eveneens aan de Universiteit van Amsterdam. In 2009 heeft ze vanwege een buitenlandstage in social work langere tijd in Cambodja gewoond, voordat zij in 2010 haar bachelorsdiploma behaalde. In 2011 voltooide zij zowel de master Pedagogische Wetenschappen als de master Forensische Orthopedagogiek. Van 2010 tot 2015 heeft zij binnen een woonvoorziening en een dagbesteding van Philadelphia Zorg als coördinerend begeleider in de zorg voor kinderen met een verstandelijke beperking en moeilijk verstaanbaar gedrag gewerkt. Vanaf april 2015 liep dit over in een aanstelling als promovendus-onderzoeker bij Philadelphia Zorg en was zij vanuit deze aanstelling ook verbonden aan de Academische Werkplaats Leven met een Verstandelijke Beperking (Tranzo, Tilburg University), waar zij onder begeleiding van prof. Dr. Petri Embregts (Tilburg University) en dr. Karin Volkers (Philadelphia Zorg) haar promotieonderzoek heeft uitgevoerd. In september 2022 is Marloes gaan werken als ontwikkel- en implementatiemanager ouder wordende cliënt bij Stichting Philadelphia Zorg.

Marloes Thalen was born on February 14th, 1985 in Apeldoorn, the Netherlands. In 2003, she graduated from pre-university education at Stedelijk Gymnasium in Apeldoorn. After successfully completing her first year in University studying History, she subsequently studied Pedagogical Sciences at the University of Amsterdam. In 2009, she lived in Cambodia for a longer period of time because of an internship abroad regarding social work, before obtaining her bachelor's degree in 2010. She obtained a master's degree in Pedagogical Sciences (Studies of special education in the family and at school as well as a master's degree in Studies of Forensic child and youth care sciences in 2011. From 2010 to 2015, she worked as a coordinating support worker for children with intellectual disabilities and challenging behaviour at Philadelphia Care Foundation. As of April 2015, she started as a science-practitioner at Philadelphia Care Foundation from where she started her PhD research at the Academic Collaborative Centre Living with an intellectual disability, Tranzo, Tilburg University. Her supervisors were prof. dr. Petri Embregts (Tilburg University) and dr. Karin Volkers (Philadelphia Care Foundation). In September 2022, Marloes continued her work with Philadelphia Care Foundation as a development- and implementation manager for ageing people with intellectual disabilities.

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