Brief Report

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 (QoL) domains. Physical well-being, emotional well-being, 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.

Keywords

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

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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., 2019; WHO, 2018). These complex ageing processes inevitably lead to augmentation and changes in their support needs. Care as usual, that is, 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., 2019; 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 well-being and social inclusion) of older people with intellectual disabilities remains scarce (Albuquerque & 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., 2014). Despite the present lack of evidence, it is conceivable that support needs in other quality-of-life (QoL) domains – including emotional well-being, 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 well-being 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., 2016; Schepens et al., 2019). However, indications were found for an additional domain – existential well-being – 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 well-being 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 and occupational therapists), 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

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 well-being	Contentment (satisfaction, moods, enjoyment)
	Self-concept (identify, self-worth, self-esteem)
	Lack of stress (predictability, control)
Physical well-being	Health (functioning, symptoms, fitness, nutrition)
	Activities of daily living (self-care skills, mobility)
	Leisure (recreation, hobbies)
Material well-being	Financial status (income, benefits)
	Employment (work status, work environment)
	Housing (type of residence, ownership)
Existential well-being	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)

[a]Schalock (2004); Schepens et al. (2018).

both support staff (Albuquerque & Carvalho, 2020; Alftberg et al., 2019) 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 well-being, Physical well-being, Material well-being and Existential well-being). 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 min 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.

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 & 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 & Lewis, 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 & Lewis, 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 well-being, physical well-being, 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 well-being were rated as being least important (see Table 3).

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

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

QoL domain[a]	Most important needs	*Most relevant quotes*
1. Personal development	1.1 Support in stimulating and maintaining previously learnt 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"*
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 travelling becomes difficult"*

(continued)

Table 2. (continued)

QoL domain[a]	Most important needs	*Most relevant quotes*
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"*
6. Emotional well-being	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)"*
7. Physical well-being	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"*

(continued)

Table 2. (continued)

QoL domain[a]	Most important needs	*Most relevant quotes*
8. Material well-being	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"*
9. Existential well-being	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)"*

Note: The outcomes reported in this table are based on an exploratory study among 11 psychologists.
[a]Schalock et al. (2010); Schepens et al. (2018).

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 well-being	9.09	9	0.79	8–10
Physical well-being	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 well-being	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 well-being	6.82	7	1.11	5–9
Rights	6.45	6	1.56	3–9

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 lead to augmentation and changes in their daily support needs (Alftberg et al., 2019; 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 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 well-being, physical well-being, self-determination and interpersonal relationships as being the most important. The importance attached to support needs within the domain of physical well-being 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 well-being, as referred to in Social Production Function theory (Ormel et al., 1999), clarifies and highlights the established importance of the support needs regarding emotional well-being, 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 (Hermans and Evenhuis, 2012; Judge et al., 2010; Perkins and Moran, 2010). 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., 2019; 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 and 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., 2019), 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., 2019) 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 well-being, physical well-being, 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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References

Albuquerque CP and Carvalho AC (2020) Identification of needs of older adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 17, 123–131.

Alftberg A, Johansson M and Ahlström G (2019) Ambivalence among staff regarding ageing with intellectual disabilities: experiences and reflections. *Journal of Intellectual Disabilities*. Epub ahead of print 14 January 2021. Doi: 10.1177/1744629519874997.

Bigby C (2004) *Ageing with a Lifelong Disability: A Guide to Practice, Program and Policy Issues for Human Services Professionals*. London, UK: Jessica Kingsley.

Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.

Evenhuis HM, Hermans H, Hilgenkamp TIM, et al. (2012) Frailty and disability in older adults with intellectual disabilities: results from the healthy ageing and intellectual disability study. *Journal of the American Geriatrics Society*, 60, 934–938.

Fesko SL, Hall AC, Quinlan J, et al. (2012) Active aging for individuals with intellectual disability: meaningful community participation through employment, retirement, service, and volunteerism. *American Journal on Intellectual and Developmental Disabilities*, 117, 497–508.

Gómez L.E., Peña E., Arias B. and Verdugo M.A. (2016) Impact of Individual and Organizational Variables on Quality of Life. *Social Indicators Research* 125: 649–664. doi: 10.1007/s11205-014-0857-6, In this issue.

Guest G, Bunce A and Johnson L (2006) How many interviews are enough?: An experiment with data saturation and variability. *Field Methods*, 18, 59–82.

Hermans H and Evenhuis HM (2012) Life events and their associations with depression and anxiety in older people with intellectual disabilities: results of the HA-ID study. *Journal of Affective Disorders*, 138, 79–85.

Hermans H and Evenhuis HM (2014) Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 35, 776–783.

Innes A, McCabe L and Watchman K (2012) Caring for older people with an intellectual disability: a systematic review. *Maturitas*, 72(4), 286–295.

Judge J, Walley R, Anderson B, et al. (2010) Activity, aging, and retirement: the views of a group of Scottish people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 295–301.

Kratochwill TR, Hitchcock J, Horner RH, et al. (2010) Single-case designs technical documentation. Available at https://files.eric.ed.gov/fulltext/ED510743.pdf (accessed 14 January 2021).

McCausland D, McCallion P, Cleary E, et al. (2016) Social connections for older people with intellectual disability in Ireland: results from Wave One of IDS- TILDA. *Journal of Applied Research in Intellectual Disabilities*, 29, 71–82.

Mcnamara B, Same A and Rosenwax L (2020) Creating person-centred support for people with intellectual disabilities at the end of life: An Australian qualitative study of unmet needs and strategies. *Journal of Intellectual Disabilities* 24(4): 543–558.

Morse JM and Niehaus L (2009) *Mixed Method Design: Principles and Procedures*. Walnut Creek, CA: Left Coast Press.

Navas P, Llorente S, García L, et al. (2019) Improving healthcare access for older adults with intellectual disability: what are the needs? *Journal of Applied Research in Intellectual Disabilities*, 32, 1453–1464.

Ormel J, Lindenberg S, Steverink N, et al. (1999) Subjective well-being and social production functions. *Social Indicators Research*, 46, 61–90.

Perkins EA and Moran JA (2010) Aging adults with intellectual disabilities. *Journal of the American Medical Association*, 304, 91–92.

Ritchie J and Lewis J (Eds), (2014) *Qualitative Research Practice. A Guide for Social Science Students and Researchers*. Thousand Oaks, CA: Sage Publications.

Ryan A, Taggert L, Truesdale-Kennedy M, et al. (2014) Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *International Journal of Older People Nursing* 9(3): 217–226.

Schalock RL (2004) The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research*, 48, 203–216.

Schalock RL, Keith KD, Verdugo MA, et al. (2010) Quality of life model development and use in the field of intellectual disability. In Kober R (Ed), *Quality of Life for People with Intellectual Disability*. Dordrecht: Springer, 17–32.

Schepens RMM, Van Puyenbroeck J and Maes B (2018) How to improve the quality of life of elderly people with intellectual disability: a systematic literature review of support strategies. *Journal of Applied Research in Intellectual Disabilities*, 32, 483–521.

Schepens RMM, Van Puyenbroeck J and Maes B (2019) “One does not forget, it all comes back”: elderly people with intellectual disability review adversities and stress-protection in their lives. *Quality in Ageing and Older Adults*, 20, 190–205.

Shaw K, Cartwright C and Craig J (2011) The housing and support needs of people with an intellectual disability into older age. *Journal of Intellectual Disability Research*, 55, 895–903.

Shoostari S, Naghipur S and Zhang J (2012) Unmet healthcare and social services needs of older canadian adults with developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 9, 81–91.

Stenfert Kroese B and Smith N (2018) How do psychologists experience working with staff in residential care settings for people with an intellectual disability? *International Journal of Developmental Disabilities*, 64, 144–157.

Thomas J and Harden A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 45. Available at http://www.biomedcentral.com/1471-2288/8/45 (accessed 14 January 2021).

Trotter RT (2012) Qualitative research sample design and sample size: resolving and unresolved issues and inferential imperatives. *Preventive Medicine*, 55, 398–400.

WHO (2018) Disability and health. Fact sheet No. 352. Available at https://www.who.int/news-room/fact-sheets/detail/disability-and-health (accessed 23 September 2021).

Zhang Y and Wildemuth BM (2009) *Qualitative Analysis of Content*. Santa Barbara, CA: Libraries Unlimited Inc.