“One does not forget, it all comes back.”

Elderly people with intellectual disability review adversities and stress-protection in their lives

Abstract

Purpose: People with intellectual disability encounter many negative life events during their increasingly long lives. Given the reported negative effects of such adverse events on their quality of life (QoL), the perspective of older people with intellectual disability themselves may be of relevance.

Methodology: We questioned nine participants with mild intellectual disability, aged 61 – 88 years old, in four 90-minutes focus group sessions, and thematically analysed the data.

Findings: Many recent and bygone negative life events still weighed heavily on the participants. Negative interactions, experiences of loss, lack of control, and awareness of one’s disability caused stress. Their emotional response contrasted with their contentment, compliance and resilience. Several personal and contextual factors seemed to heighten resilience and protect participants from toxic stress or trauma.

Implications: Monitoring and preventing adverse (childhood) experiences, supporting active/emotional coping strategies, psychotherapy and life story work may facilitate coping with negative events and enhance QoL of elderly people with intellectual disability.

Originality/value: Elderly people with mild intellectual disability run a higher risk of experiencing (early) adverse events in life. They are very capable of talking about their experiences, quality of life, and the support they need. Focus groups were a reliable method to capture their insights.

Key words: elderly, intellectual disability, adverse experience, trauma, coping strategies, resilience, quality of life, focus group.

Introduction

While discussing the quality of life theme with elderly people with mild intellectual disability, participants' intense life stories revealed both stressful and valuable experiences. This article presents an analysis of these experiences, with the focus on adverse events, and on elements that protected them from toxic stress.

People with intellectual disability are reported to experience more negative, possibly traumatising life events than other people (Palusci et al., 2017), not only at young age (Berg et al., 2019), but during their significantly lengthening lifetime (Hughes et al., 2012; O'Callaghan et al., 2003). Discrimination, bullying, abuse, neglect and violent crime rates vary between 30% and almost 90% (Baladerian et al., 2013). In the study of Hermans and Evenhuis (2012), 71,6% of all participants had experienced (several) negative life events. These rates were significantly higher for participants over 65 years and for those with a mild or moderate intellectual disability. Moreover, people with intellectual disability are often poor and live more often in high-risk environments (WHO, 2001).

Such experiences may lead to toxic stress and, thus, to trauma (Franke, 2014). Trauma occurs whenever a person's resources fail to cope with stress (Masten and Barnes, 2018; van der Kolk, 2014). Not only 'large' traumatic events, such as war or a natural disaster, but also a series or chronicity of 'small' traumatic experiences, such as conflicts, moving, or financial troubles can strain a person's coping skills, cause feelings of helplessness and diminish one's quality of life (Murray and Doren, 2013; Southwick et al., 2014)

Early adverse childhood experiences (ACEs) are known to highly and negatively impact later life (mental) health. Such ACEs affect self-care, coping strategies and life expectancy and increase behavioural problems or substance abuse, in diverse populations (Berg et al., 2019; Felitti et al., 1998; Franke, 2014; Kalmakis and Chandler, 2015; Turner and Lloyd, 1995). Adverse events in later life have equally serious consequences, such as high levels of arousal, anxiety or affective disorders, and avoidance of threat. Emotion regulation and one's sense of identity may get hampered (Hastings et al., 2004; van der Kolk, 2014). de Winter et al. (2015) reported that older people with intellectual disability were more likely to have depressive symptoms, that those with mild and moderate intellectual disability were more anxious, and that levels of anxiety and depression were clearly linked.

Almost half of the participants in the study of Mason-Roberts et al. (2018) experienced one or more traumatic events during childhood ànd adulthood, and subsequently reported significantly higher levels of (self-)aggressive behaviours, depression and psychological distress.

A person, even when he has an intellectual disability, is not at the mercy of his or her adverse experiences. Individual characteristics such as personality, positive appraisal, good coping skills and problem solving strategies are known to help the person to successfully cope with or adapt to stressors. So do effective parenting and support, or having sufficient resources (Murray and Doren, 2013). These factors protect against toxic stress, temper effects of traumatic experiences and enhance resilience and quality of life (QoL) (Hall et al., 2012; Masten, 2001; Masten and Barnes, 2018;).

From an empowering full citizenship-perspective, people with intellectual disability are recognized as experience experts about their own lives, and very able to speak for themselves (Schalock and Verdugo, 2002). Several researchers questioned elderly people with intellectual disabilities themselves on their changing needs and QoL as ageing persons (Schepens et al., 2019). These reports describe adverse life events, but seldom specifically analysed them on risk and protective factors and their long-term effects.

The aim of this study was to discuss with a group of elderly people with an intellectual disability what they feel and think about their life events. Such a clear narrative could increase our understanding of the nature and impact of their specific experiences, provide (unexpected) insights in stressful or protective elements, and guide QoL-enhancing support in intellectual disability, psychiatric, elderly and home care.

The main research question was: What do elderly people with a mild intellectual disability tell us about the adverse and possibly traumatising events and experiences in their life, and about the factors that protected them from toxic stress?

Methods

Focus group

We organized four meetings of one focus group with nine elderly people with intellectual disability (Savin-Baden and Major, 2013). The meetings were conducted according to Krueger and Casey's (2015) best practice suggestions. They were part of a larger project to determine specific indicators and determinants of their QoL. The participants were questioned about nine QoL-domains, and not specifically about adverse experiences or trauma. We chose for the focus group method because it can provide, in a relatively short period of time and through dynamic discussions between participants, a deeper understanding of how people experience their lives. This method has been proven feasible with verbally able persons with intellectual disability (i.a. Bigby et al., 2011; Brown and Gill, 2009; van Schijndel-Speet et al., 2014).

Participants

The inclusion criteria were: having an intellectual disability; being able to understand questions and to answer them in a group; being ≥ 65 years old or when having Down-syndrome, severe or profound intellectual disability: being ≥ 50 years old. The criterion of ≥65 years of age seems applicable to this population, but needs to be lowered for the latter group, because they have a well-documented lower life expectancy and a higher risk to age prematurely (Coppus, 2013).

We sent an invitation letter for caregivers and an adapted letter for possible participants to clinical practitioners of care services in one province in Flanders. We got a positive response from nine participants with a mild intellectual disability (i.e. having an estimated IQ between 50-70). Next, (easy-to-read) confirmation letters were sent to all interested participants and their caregivers. After they confirmed, we made all practical arrangements.

Three women and six men between the ages of 63-88 years participated. Table 1 summarises the demographics of the participants.

[Insert Table 1]

Course of the meetings

Four 90 minutes focus group sessions took place, between September 16 and November 4, 2016. The researchers provided coffee, a sandwich, and travelling assistance. Participation was free of charge, transportation was fully reimbursed and all participants received a personalised €30 gift voucher. At the start of the first session, easy-to-read informed consent letters, assuring anonymity, were talked through and signed by all participants. Participants' support staff provided minimal information on age and level of intellectual disability; staff and participants provided during the sessions more information on accommodation, intellectual disability support, work status and civil status. We did not request any results of IQ-tests or other diagnoses.

No existing questionnaire was used but we carefully devised, tried out, and sequenced a semi-structured interview guide on QoL. We presented pre-structured questions, presenting one by one the eight domains of the Schalock QoL-model (Schalock, 2004), with questions on existential/spiritual indicators added.

Per session, participants chose two or three domains they wanted to discuss. A moderator, skilled in working with persons with intellectual disability and trained in the focus group method, conducted the interviews (Krueger and Casey, 2015) and was assisted by the first author.
But the moderator used diverse techniques to facilitate the process of sharing experiences. We used easily formulated wordings, visualizations, drawings, paraphrasing techniques, open and closed questions, leading and non-leading questions, … We started each session with ground rules, such as not interrupting each other (because of the audio-taping). We shortly introduced each domain, e.g. by inviting participants to do a 5' bodyscan when addressing physical well-being. We prompted participants to talk to each other, took care to invite and provide time for every participant to share his experiences, to ask participants if they recognized each other's stories, to go back to a previous statement when a participant gave a delayed answer.

Thematic analysis

The first author made verbatim transcriptions of all focus groups and thematically analysed them a first time on QoL-information. To answer the research questions on adverse and protective elements, she re-analysed the transcribed interviews. All interviews were carefully read again, and in close collaboration with the research team we analysed all text through line-by-line coding. We ascribed sentences or short interview paragraphs to two main groups: the first on adverse events and experiences; the second on factors protecting against toxic stress. Within these two groups, a thematic analysis was performed. The emerging factors were inductively derived from the data-set, constantly compared, iteratively re-organised in (interrelated) (sub)themes, and exemplified by striking or expressive quotes (Savin-Baden and Major, 2013).

Ethical approval

The KU Leuven Social and Societal Ethics Committee granted ethical approval (Nr. G-2019-1289).

Results

We present the results in two large themes, one on adverse events and one on factors protecting against toxic stress, and illustrate them with core quotes of the elderly participants.

The evaluation of one's past was not limited to recent events or relationships, and surpassed momentary emotional feelings. Participants reconstructed their long lives and had been evaluating *"more than before (F, S, P)"* if their existence had been meaningful, what had been good or bad. Some did think of the life they could have lived without their disability, and of the opportunities that were not given to them. Because past difficulties still weighed upon them, participants were grateful for the opportunity to tell their histories – which did not often happen, but which they actively requested and very much enjoyed. They listened attentively to each other's stories, and recognised each other's joys, anxieties, distress or sadness.

Adverse, possibly traumatising experiences

Physical well-being

Stories of lifelong physical problems accompanied descriptions of ageing in terms of health problems or physical deterioration. Most of the participants had already experienced severe pain.

A: "I have suffered since childhood of severe bowel and incontinence problems."

All participants agreed: "Really, [with ageing] nothing got better."

Several participants had frequently fallen, which had caused S. to move to elderly care, where nurses kept her safe. Most of the others did not go out alone in the dark or in winter anymore.

G1 had slipped on ice: "I used to be a bit scared, but if that happened to you once, falling and being hurt, thén you get scared."

Seeing others suffer and die has left a deep impression:

G1: "I have seen many people ageing. Once it starts, one can deteriorate rapidly."

The participants living in residential care often felt helpless, when having to wait for ADL or physical support.

S, G1: "One has to be patient."

School, work, activities

This theme produced a large amount of vivid comments. Early experiences of not being able to study as the other children, not having learned much, or being sent to far-away boarding schools made participants quickly aware of their intellectual disability.

G2: "I didn't like to go to school. I am bad at calculating, never could do it… They taught all kinds of things, but I was no man to…, I could not study, it was impossible."

Later in life, they had needed assistance to find meaningful and adapted work, and they easily lost such a meaningful job, without control.

E (angry): "I worked, yes, but at 53 years of age they pensioned me off."

Participants also intensely regretted and felt stressed by the loss of free time activities and community participation, due to financial restraints, decreased availability of companions, or not knowing the environment.

L.: "I used to go and see the football matches…, but that is all over, by lack of volunteers to push the wheelchairs."

The lack of opportunities to (continue to) learn and develop new skills, now and in the past, caused severe stress for some people. Mastered skills were not maintained when entering into professional care. None had been taught computer skills, using public transportation systems was scary.

S: "I can do a lot, but… I am not allowed to prepare meals, to iron, I cannot go anywhere. They are responsible for you, personally… Ah, in this way they are at ease." and

"If I still were able to learn, I would learn to be manager [of the elderly home]…"

Participants experienced a lack of control over their job, activities and use of their money.

F: "They sent me to the sheltered workshop."

P: "I have to ask for money."

(Daily) adverse treatment, exclusion

All participants expected that people treat them in a kind, patient, attentive, and respectful way. But negative interactions, recently or in the past, had often occurred, and still weighed heavily.

Not feeling accepted, for 'being handicapped', evoked strong emotions of resentment and sadness.

E (upset): "My family – pff- will not accept me. One remains afraid of being an outcast."

G1: "My father – I think he was my stepfather … he had a difficult character… It repelled me so much, that for a long time … I mulled over leaving. But I didn't live alone."

L. had moved to a home *"because I had troubles with the neighbours. Quarrels and quarrels again."* At times A. and E. found living with a partner difficult. They quibbled about and with their adult son, who still lived at home. Also, *"Sometimes people behind us say: 'Can't you advance a bit?', their tone meaning: 'What on earth is this?!'"*

Four participants talked about being financially abused by family or a friend.

A: "We really trusted a lady whom we knew well… but she ran off with our money... My brother found out about it.... We then called him in, but my brother also messed up our money a bit.... One day the Justice of Peace called us - I was a bit astonished - who said: 'Your brother has nothing to do with you anymore..., you have a lawyer now..."

Also, all participants recognised and detested not-forgotten tales about strict, impatient, belittling, punishing caregivers.

G2, on a staff member: "He thinks he is dealing with little children."

G2 had sharply observed his harsh schoolteacher, who corporally punished the children, *"but he enjoyed it."*

As visits to the GP or specialists had occurred frequently, participants explicitly expressed a need for kind treatment and clear, simple information, urged support workers to join them, but seldom straightforwardly requested better explanations.

E: "Doctors speak Latin. They throw you on the table…"

Loss of relationships

Every participant still suffered from important, recent and long past, losses of relationships.

All participants had been severely affected by the loss of their parents. They most dearly missed their (grand)mothers, and some fathers, who had accepted them and had guided them through their life.

All [sighing or silent, in this or other wording]: "I have missed them for so long."

Some siblings had taken over caretaking roles of deceased parents, but:

MR: "My sister is not my mother…"

F: "I have three brothers and four sisters, all dead."

Loss of formerly important people caused stress, even with the hairdresser who, due to organisational policy, was not allowed to come and dress S.'s hair in the elderly home. *P: "On Christmas, for my birthday I didn't even get a card… not a phone call … It is no longer a brother."*

Several participants did not know what had happened to their family members, due to crises or because families had kept things secret from them, and unveiled a persistent longing to know the past.

E: "According to my father, my mother had children before me, but I know nothing of them."

MR: "But that of my father I did not see, he died on an airplane crash… My father fell of the stairs. And my mother died in a car… She had little parts of glass in her face… I get up with these thoughts and go to sleep with them."

Living, moving

Participants experienced stress from living in too noisy places, or with residents they didn't like nor choose.

F: "At five in the morning he gets up, he starts eating and then moves the chairs around."

They had to move several times during their lives, which had caused extra loss, and was often beyond their control.

F: "They called me and told me: 'You have to move to H.' [a newly built home]."

S.'s return to residential care evoked old memories, and was recognised as an undesirable but inevitable prospect: *"I was not allowed to stay alone anymore, not by day nor by night…".*

War, terrorist attacks, robberies

S., 12 years old when WOII started, recounted vividly of what we could call 'big' traumatic event: *"Go running, GO RUNNING!... Where to go?... get away!! They stole everything… You don't forget… Bombs: here was our house and there fell the bomb [next to each other]…. All in the underground shelter… But if you have lived through such a thing… You're just a child, and you experience so much."*

Others had heard the stories of their families and friends, or had suffered from the war's consequences. F.'s parents had been lost and he had been moved to an orphanage with his brother: *"I could not stay calm, I am always thinking of them,"* and S.'s schooling had stopped at the age of twelve *"and I liked to learn."*

A new cause for anxiety were the terrorist attacks that took place in Europe, specifically in Brussels on March 22, 2016, and the risks of robberies and aggression in the city. Feelings of anxiety and unsafety held participants back, so all preferred the company of staff.

Awareness of disability and awareness of need of support

More than once, participants recognized and echoed each other's stories of great and small adversities, due to their intellectual disability and aggravated by a lack of control and by getting old. They demonstrated an early and sharp awareness of their limited abilities to deal with life's difficulties, which had raised their consciousness in that they needed more support 'than others'. Such feelings of insecurity and helplessness might, in itself, be seen as an adverse experience.

Participants were well aware that they had not built a family of their own.

G1: "I have never been married, that's right. I never felt like it… They told me that, if I had been younger now, I could have lived more independently, but I doubt that. The thing is, I have a mild mental [sic] disability. I cannot handle myself 100%... And anyway, I am too old now."

Participants needed and sought support throughout their lives, for various aspects.

G2 on moving from his farm: "I have been sitting there for ten years… and then I could not help myself anymore… So I said: 'I'm going to the home.'"

Anxiety, stress for the future

All previously mentioned factors rekindled feelings of stress and anxiety for the future. Participants worried about the decline of their non-paid support networks, and about their further physical deterioration and mobility, which would impact the support they needed in the future. They felt anxious and out of control about future chances for personal development, living arrangements and money issues.

E (anxious): "The minister is going to heighten prices… Then our caregivers will only come for two or three hours then, if things go bad".

Overall, the participants often used the more passive coping strategies, instead of speaking up for themselves or actively trying to change things. During the focus group conversations, their sighing, looking down and whispering displayed how they had learned to react in such emotional or avoiding ways.

Factors protecting against toxic stress and trauma

Throughout the stories about adverse experiences, participants also depicted those elements that had shielded them from toxic stress, and that had kept their overall quality of life at reasonable levels, leaving them to conclude that they were content about their lives. These protective factors include environmental aspects as well as personal characteristics and feelings.

Professional support

Participants highly esteemed the – frequently mentioned –support provided by professional caregivers.

F, G2: "We have a good doctor, he respects us."

The lifelong, and because of their age increasing help with (I)ADL skills provided security, as did the safeguarding presence of caregivers.

F: "Every day, B. comes to cook our diner."

G1: "When I once had to go to a specialist, I asked my mentor to join me…"

Participants reported interactions with caregivers often to be good and liked them to control group disputes, to stand up for them or at least acknowledge their stress or sadness.

G1: "So we are a whole group of residents… When problems arise, they [staff] try to solve the problem between inhabitant and staff."

Social relationships and belonging

Having nice relationships, doing things together, and specifically receiving support in a kind, respectful way from people in their social network or in the street, made participants feel valuable, capable, connected or safe.

P: "When I fall on the street, often young ladies come to help me up."

Good, long-standing relationships with (old) friends, co-residents and supportive professional caregivers were highly appreciated. Such staff was part of the intimate relationship-circles of the participants. Meaningful new relationships had emerged over time, countering the many losses.

F and S: "We are old-time comrades, I regularly go visiting S in the elderly home."

Also, past relationships with families, staff, friends, schoolmates and colleagues remained essential, even when people had moved away or died.

Participants liked meeting old or new people, and going out.

P: "I play in that brassband, it is for ordinary people ànd for people with a disability."

The core element in both professional and non-professional relationships, and the best, repeatedly mentioned antidote to stressful experiences of all kinds, was the feeling of being connected to beloved people. Positive interactions with parents and other family members countered the stress of loss or feeling rejected, and on the importance of a partner and child, E. and A. added: *"I sought a wife such as A to stand by me (E)"*, and *"My son means a great deal to me (A)"*.

S: "You must write down N [professional caregiver], she has always stood by me."

Material and financial security

While opinions diverged on whether to live in a calm or busy place, with or without co-residents, most participants felt safe having a roof over their head, and at ease where they lived now.

G2: "And I remember well: good food and good drinks is all what you need…"

Having enough money provided security, and the choice to use it according to their own wishes increased feelings of being in control. Most participants stated that they could live reasonably well of their pension, allowance or inheritance. Participants realized that they could not manage their finances on their own, and having been abused, they felt safe when a legal administrator managed their finances and staff supported their financial administration, overlooking their expenses and handing out small amounts of (pocket)money.

Planning, information and time

All participants could cope better with change when well informed.

G.1's mother reduced his stress about a future move to a home, when she involved him in planning the whole thing. She informed him on a meeting at a nearby newly built home:

"I was not planning to go. But mother said: 'I will go.' 'Well, I'll come along', I said. After the meeting, the manager asked me what I would do when mother passed away. 'I don't know,'... And then I was registered, and… when all was ready, I moved."

On time to adapt after moving:

G2: "In the beginning it was bad, you know. Strange, every- and anything... But I adapted anyway."

Personality, attitude and coping strategies

Having a positive, courageous and calm personality and attitude in life, combined with positive coping strategies counter-balanced the many stressful events in life.

S: "If you don't agree as you would like to, then you should get to agree and that is the best."

F had learnt: "If you are naughty and the boss tells you' 'Go to your room,' than I stay calm."

G1 addressed staff with his problems: "But if that doesn't work… we have to make an appointment – but we can go to J., the ombudsman."

But, as mentioned before, participants reduced stress with particularly compliant reactions when they had to wait long for a meal, to be washed, …. They explained that their staff was busy and excused them.

S sometimes fled: "Then I go to my room… I prefer silence to too much noise…" But she also reacted more actively: "Is does not help, not being content – 'alas this' and 'alas that'. Just do it!"

Positive stories and experience

G2's statement *"I know of a man who has been operated of bowel cancer, he is healthy as a fish now"* reveals the importance of hope or optimism, deduced from positive stories.

Personal experiences of recovering for adversities, and the recollection of what had been helpful, made them feel proud and more confident in the face of new, stressful events.

F. had survived the stress of a very unexpected move to a new home: *"I didn't feel well. I go to Mme L., I say: 'I feel ill'… I throw up in the corridor… She immediately sent for the doctor… the cook made me milk with honey. He told me: 'Drink it all up.' Is was a large pot…".*

Spirituality and religion

All participants had thoughts of spiritual or religious nature, and felt hopeful when acting upon these.

S: "If you lost something, you can say: I'll burn a candle for that Saint…."

Participants were brought up in the Roman Catholic tradition. Some found strength in attending mass, and church rituals remained important to cope with challenging emotions.

G2: "My parents have been dead since a long, long time. I pray for them every week… in my bedroom… Exactly every week."

Most of the participants thought actively about their dying and what might happen afterwards. They wondered where all the dead people were, and countered their fears with the words of a Flemish song they all knew well: "*Hope brings life"*, or with *"It is a mystery"*. Whereas most hoped to go to heaven (somewhere in the sky), G1- unafraid - didn't believe a thing of heaven, hell or purgatory, *"since such places have never been found."* G2 knew where to find heaven: *"Having lived well, eaten and drunk well, and not having annoyed others is heaven on earth."*

All without exception (ritually) remembered their beloved deceased by visiting graves, holding on to a photo or funeral card, or praying, and hoped to meet again. S. and MR. valued pilgrimages, and lighting candles made them feel hopeful and at ease.

E: "It feels good to remember, I had only one mother."

Being active, feeling competent and able to contribute

The best cure for negative school experiences had been getting a meaningful, not always self-chosen, yet accepted job. That provided an income for some, made participants feel important and able to learn after all. Some had done (low-)paid jobs, most had worked in sheltered workshops, about which shared lively stories.

F: "Afterwards I worked for the A. B. [psychiatric hospital near orphanage]. I did night shifts there. Patrolling every hour with my key, looking out if nobody got up or quarreled. And then I worked in the chicken business, three big henneries. In one hennery there are more than 5000 chickens… collecting eggs."

All participants, except for MR. and A., were officially retired, which had been felt as inevitable, and welcome to some but not to all. After retirement, a good remedy against negative feelings seemed to be to remain active, to do things with and for others. Several participants had important, self-esteem-enhancing (community) roles as a volunteer or caregiver, visiting friends, doing chores for an old mother, producing Smyrna tapestries *“for everyone” (S, MR)*.

G2: “I am proud of my housemates... I have to bake eggs for them every week… They don’t understand how to do that, so they leave it up to me… And then they thank me several times. I learned this easily.”

Participants oversaw their skills, school and employment histories and compared themselves to others. Personal development and experiences of meaningful activity seem to have led after all to quite good self-esteem and self-worth.

Self-determination and feeling in control

Over the years participants’ say over their lives had increased, paralleling shifting views of their (professional) caregivers. Some participants were happy to make more own choices than before, after moving away to more independent living, or after retirement.

F: “I look forward to go living with my friend in a new, fully accessible and supported living area”.

Living in a well-known neighbourhood enabled them to go out on their own, and support to find the best housing was appreciated.

S: “That is why N. [professional caregiver] looked out for me, to settle me somewhere, and there I am content.”

Participants were less frustrated when they had a say in who would be their professional caregiver, and in the amount of support provided. Small decisions seemed to make them happy, e.g. on how their room was cleaned or how they spent their money. Taking things in control at first felt a bit awkward, but unexpectedly rewarding.

G2:“And I always say, when he [his hairdresser, ed.] *cuts my hair: ‘Not too short!’”*

Discussion

The participants in this study discussed several topics with regard to their lives with a moderator and each other, through a focus group method. The stories told by nine elderly persons with mild intellectual disability revealed what adverse events had caused stress, and what had prevented this stress to become toxic or traumatising. They have lived the history of care, and have developed specific vulnerabilities which demand attention, next to relatively adequate coping strategies and resilience.

On adverse events and protection against trauma

It is clear that participants had to cope with important stressors, both as a child and as an adult. Although the lively accounts of stressful events may be proof of their high impact, the labeling of such stressful event and its consequences as ‘big’ or ‘small’ proved to be subjective.

The experienced adverse events are diverse and spread throughout their whole life-course. The stories of the participants made it clear that adverse events did seldom come ‘alone’. Being exposed to multiple stressors may exacerbate the consequences, among others on mental and physical health (Masten, 2001; Murray and Doren, 2013; Southwick et al., 2014). Our participants’ stories about the diversity of stressors corroborate other studies, that point out multiple and interrelated risks for persons with intellectual disability.

The striking lack of self-determination, the awareness of ‘being different’ and needing support may have led to new anxieties and stress, which elicit the complying behaviour of participants. Fight or flight reactions, feelings of helplessness and less efficient avoidant coping strategies are reported to be more frequently used by people with intellectual disability (Schuengel and Janssen, 2006). Masten (2001), and Mevissen and De Jongh (2010) state that the presence of an intellectual disability may be seen as an adverse event in itself. Obviously the old value of compliance seems to have shifted over time towards more self-determination. Murray and Doren (2013) add evidence that the awareness and acceptance of one’s disability can also be a protective factor.

Participants also revealed several factors that shielded them from toxic stress. Childhood experiences of safe attachment bonds with a good parent, well-tailored support through later life, and good relationships with important people, who involved them in decisions, were helpful. All participants voiced the need to remain connected, but with ageing their family bonds rapidly disintegrate (Murphy et al. 2009), old parents get exhausted (Walker and Ward, 2013) and staff often changes, while key caregivers who age and die are seldom replaced (Hole et al., 2013). To connect actively with people was easier if one lived in a well-known community and a preferred place of residence. However, various authors pointed out that many people with intellectual disability have lived in residential services for most of their life, have been excluded from society and never built an adequate 'outside' network (i.a. Bigby, 2002; Laplante, 2014; McConkey and Collins, 2010; Thompson et al., 2004). Elderly people with intellectual disability live more often in larger groups, and in regular elderly care, which negatively influences their community involvement once more (Ager et al., 2001).

Themes and subthemes, both between and within adverse events and protective factors, seemed to interconnect and influence each other, and to be mediated by various elements. Protective elements mirrored, but did not annul the adverse ones. Relationships with other people recurred both as a stressor ànd as a protective element. Kind treatment by their family, for instance, had counterbalanced the harsh treatment by a school teacher. Feeling supported and connected linked with being active and feeling competent. As such, resilience is not a characteristic or a trait within someone, but depends on social connections, support and attachments and many other processes (Masten and Barnes, 2018).

Impact on Quality of Life

We did not measure health disparities, so our results cannot empirically demonstrate the impact of adverse life events on the health of our participants. Nevertheless, every story told revealed the impact of negative events on participants' emotional well-being or mental health, and as such confirm results of other studies (i.a. de Winter et al., 2015; Hulbert-Williams and Hastings, 2008; Murray and Doren, 2013).

Notwithstanding the high amount of (objective) adverse experiences, participants subjectively evaluated their quality of life to be generally high. This corresponds with the high contentment scores of elderly people in general (Carstensen et al., 2000), and might be interpreted as a sign of resilience. Mayordomo (2016) states that more active coping strategies and adaptive behaviour, combined with positive relationships and adequate support, link to resilience and, thus, to better QoL.

The broad questioning of nine domains of quality of life proved to be a well-suited entry point to explore the diversity of life histories, and the long-term impact of life time events. The multidimensional model of Schalock (Schalock, 2004; Schalock and Verdugo, 2002) provides a holistic and well-researched alternative to models used in general elderly care, such as validation (Feil, 2015) or person-centred care (Kitwood, 1997). Moreover, the present narratives confirmed participants' ability and strong desire to comment on their own lives, as demonstrated by previous research (Bigby et al., 2011; Hamilton and Atkinson, 2009; Schepens et al., 2019; Van Puyenbroeck and Maes, 2009). What is more, all of them had been reviewing their lives in a way Erikson's life stage theory describes (Bugajska, 2016; Hamachek, 1990).The focus group method proved a good way to reach this goal.

Practical implications

Some traumatising experiences are difficult to avoid, but many others are. And it is possible to foster resilience, both on personal and environmental levels (Southwick et al., 2014). Murray and Doren (2013) present research showing that protective factors, like adverse experiences, have cumulative effects too.

The stories of our participants revealed how – at an early age – they felt less able than their co-students. So, when organizing inclusive education, schooling and support of teachers in disability-specific aspects seems crucial, as projects such as SafePlace (2012) describe. Later in life, preparation of an active post-retirement lifestyle (Stancliffe et al., 2015), and training staff not to take over skills unnecessarily, especially in general elderly care (Schepens, 2019) may be stress-reducing. Participants requested a well-adjusted, flexible balance between protection against adversities (which wise caregivers had striven to spell out), and being given control over their – extending – lives.

Prevention of toxic stress further needs the deliberate application of strategies to reduce anxiety (Kurtek, 2016), to change avoiding or passive coping skills into more active ones (Masten and Barnes, 2018; van der Kolk, 2014), and to talk over experiences, such as Life Review and Life Story Work, (group)reminiscence, and (group)psychotherapy. These strategies have been proven useful for people with mild and moderate intellectual disability (Bai et al., 2014; Barber et al., 2000; Hamilton and Atkinson, 2009; Meininger, 2006; Van Puyenbroeck and Maes, 2009*)*, and, as our focus group method shows, need not be difficult to execute.

Because symptoms of trauma can easily be misinterpreted in people with intellectual disability (Mevissen and De Jongh, 2010), it is important to educate caregivers in trauma-informed care. Also, carers should avoid organizing negative life experiences and keep track of negative experiences, from early childhood to old age (Hermans and Evenhuis, 2012; Northway, 2017).

Methodological Issues and Further Research

Only people with mild intellectual disability, all in relatively good health and living in one region in Belgium, took part in this research, for several reasons. Repeating our sessions over time might yield different results.

Further research is needed to extend these results to elderly people with more severe intellectual disability or frailty, difficult-to-manage behaviour or psychiatric problems.

With Hughes et al. (2012), we conclude that more research is needed that looks into the incidence and impact of adverse (child) experiences in the lives of people with intellectual disability of all ages, the way these relate to (worse) coping strategies, and their link to higher incidences of physical or mental problems, health disparities, earlier physical deterioration and shorter life expectancy (Coppus, 2013; Dieckmann et al., 2015; McCarron et al., 2013). Also, good preventive and therapeutic strategies, adequate ways of teaching good coping strategies, even at adult age, need elaboration.

The deliberate pre-structuring of the questions in nine QoL-domains may have biased the answers, which we tried to overcome by iteratively refining our questions. As we did not directly question which adverse and protective elements participants had encountered, we might have missed factors. On the other hand, in our opinion the strength of this article lies in the spontaneous disclosure of such events and of the impact they had on participants' lives, when they were questioned on another topic.

Finally, we do not present data on psychiatric problems or difficult-to-manage behaviours, which do frequently occur in people with intellectual disability, nor on sexual needs or abuse of participants, although some commented on this topic. Individual interviews might offer a safer way to discuss such private matters.

Conclusion

This article adds to the existing literature on adverse (child) events that elderly people with mild intellectual disability have experienced, and on what has protected them from trauma. The focus group method demonstrated good properties to grasp these incidents, within the framework of a multidimensional model of quality of life. The participants proved very well capable of reflecting on all aspects of their own life histories. As elderly people with intellectual disability age in different settings, services do well to explicitly listen to clients' and key-caregivers' stories, to educate staff in trauma-informed care, and to provide verbal and non-verbal therapies, so that they can adequately address (old) traumatising experiences of this vulnerable and yet often remarkably resilient population.

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Name	Gender	Born	Accommodation and relationships	Civil Status	Intellectual disability-support	Work status	Attendance / four sessions
S	Female	°1928	Elderly care home. Friend of F, known by first author	No partner	Several times/month by former intellectual disability-key-worker	Retired	4/4
MR	Female	°1948	Intellectual disability-specialised group home	No partner	Daily intellectual disability-support	Working in day care center	4/4
A	Female	°1955	Own house with husband E and adult son	Married to E	Several times/week intellectual disability-support	Housewife, volunteering	2/4, due to another appointment
E	Male	°1947	Own house with wife A and adult son	Married to A	Several times/week intellectual disability-support	Retired	3/4, due to another appointment
G1	Male	°1949	Intellectual disability-specialised group home	No partner	Daily intellectual disability-support	Retired	4/4
G2	Male	°1942	Same intellectual disability-specialised group home as L	No partner	Daily intellectual disability-support	Retired	3/4, due to transportation problems
L	Male	°1950	Same intellectual disability-specialised group home as G2	No partner	Daily intellectual disability-support	Retired	1/4 due to emerging mental health problems
P	Male	°1947	Own apartment in town center	No partner	Several times/week intellectual disability-support	Retired	2/4 due to physical health problems
F	Male	°1938	Apartment in town center with two friends. Friend of S, known by first author	No partner	Daily intellectual disability-support	Retired	4/4

Table 1. Characteristics of participants with intellectual disability: Name, Gender, Year of birth, Living place and relevant relationships, Civil status, Frequency of intellectual disability-support, Work status, Frequency of attending the focus group session