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Centrum voor Orthopedagogiek

REMINISCENCE IN AGEING PEOPLE WITH INTELLECTUAL DISABILITIES

Exploration of the phenomenon
and evaluation of adapted group work

Proefschrift aangeboden
tot het verkrijgen van de graad van
Doctor in de Pedagogische Wetenschappen
door
Joris Van Puyenbroeck
o.l.v. Bea Maes (promotor)

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Joris Van Puyenbroeck, Reminiscentie bij ouder wordende mensen met een verstandelijke handicap. Verkenning van het fenomeen en een evaluatie van aangepast groepswerk.

Proefschrift aangeboden tot het verkrijgen van de graad van Doctor in de Pedagogische Wetenschappen, Maart 2005

Promotor: Prof. Dr. Bea Maes

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Reminiscentie kan men omschrijven als het stil of uitgesproken verwoorden van herinneringen aan een ver verleden. Onderzoek heeft aangetoond dat mensen van alle leeftijden reminisceren, maar het fenomeen is voornamelijk bij oudere mensen onderzocht. Vooral de relatie met het psychisch (dys)functioneren werd een onderwerp van studie, mede door de algemeen verspreide opvatting dat reminiscentie of levensevaluatie noodzakelijk is om 'succesvol' ouder te worden (Butler, 1963). Het idee dat reminiscentie de ouder wordende persoon kan verzoenen met zijn verleden, werd echter in heel wat onderzoek genuanceerd. Reminiscentie kent verschillende functies en types, waarvan sommige inderdaad geassocieerd kunnen worden met 'een goede oude dag', maar andere helemaal niet (Wong & Watt, 1991). Reminiscentietherapieën werken vooral op 'integratieve' (verzoenende) en 'instrumentele' (probleemoplossende) reminiscentie. De methoden voor reminiscentiewerk stellen niet zozeer de evaluatie van het verleden, dan wel de overlevering van informatie, het sociale contact en het plezier van het vertellen voorop. Het vertellen over vroeger, met specifieke anekdotes, wordt door ouderen zelf als een aangename en zinvolle activiteit beschouwd. De wetenschap lijkt opnieuw aan te pikken bij het belang van deze simpele 'narratieve' vorm van reminiscentie door te onderzoeken hoe de vaardigheid om specifieke herinneringen te vertellen verband houdt met stemmingsniveau en -stoornissen. Effectonderzoek van reminiscentiewerk dat specifieke en anekdotische herinneringen stimuleert, is zeldzaam, en totnogtoe onbestaande voor mensen met een verstandelijke handicap.

De motivatie om de betekenis van reminiscentie(werk) precies bij oudere mensen met een verstandelijke handicap te onderzoeken was het gegeven dat deze groep een groter risico heeft op psychische problemen in het algemeen en op stemmingsstoornissen in het bijzonder (Davidson, Prasher & Janicki, 2003). Mensen met een verstandelijke handicap hebben een grotere kans op negatieve levensgebeurtenissen, stressoren waarover ze vaak geen controle kunnen uitoefenen Ze missen ook dikwijls de juiste cognitieve strategieën om tegenslagen te verwerken en hebben minder verbale en sociale vaardigheden om steun te zoeken en te vinden bij anderen (Oswin, 1991). Een goede begeleiding van familie en professionele begeleiders op vlak van omgang met het verleden kan daarom van groot (preventief) belang zijn. We maakten zelf een onderscheid in drie visies op begeleiding in dit verband: een sociaal-kritische, een persoonsgerichte (person-centered), en een klinisch/therapeutische benadering. We onderzochten reminiscentie bij ouder wordende mensen met een verstandelijke handicap voornamelijk vanuit het derde perspectief maar ook in het licht van een breder 'succesvol ouder worden'-kader. De relatie tussen reminiscentie en subjectief welbevinden stond centraal.

In *manuscript 1* wordt reminiscentie op een kwalitatieve manier verkend door middel van een inhoudsanalyse op levensevaluatie-interviews met 10 onderzoekssubjecten. De meest voorkomende onderwerpen en de grotere variatie in negatieve thema's en voorbeelden van alle reminiscentie types worden geduid en besproken. De conclusie is dat reminiscentietheorieën ook toepasbaar lijken bij mensen met een verstandelijke handicap.
Manuscript 2 schetst de beschikbare wetenschappelijke literatuur over reminiscentie bij mensen met een verstandelijke handicap, classificeert de publicaties in een sociaal-kritische, persoonsgerichte en klinische benadering, en duidt op het ontbreken van evaluatieonderzoek.
Manuscript 3 beschrijft de ontwikkeling van een aangepast narratief groepsreminiscentie programma door middel van een handelingsgericht onderzoeksopzet. Via een intensieve formatieve evaluatie in 1 case en een korte productevaluatie in 6 cases wordt de handleiding voor het programma op punt gesteld. Belangrijkste aanpassingen zijn de toevoeging van extra visuele stimuli, een vaste sessiestructuur en drie begeleiderrollen.
Manuscript 4 presenteert een evaluatie van het differentiële effect van groepsreminiscentie tegenover een alternatieve vorm van groepswerk op aspecten van subjectief welbevinden door middel van een quasi-experimenteel ABA-design. Levenstevredenheid en zelf waargenomen competentie konden niet beïnvloed worden. De toename in stemmingsniveau kon weliswaar niet experimenteel, maar wel door een tijdseffect verklaard worden. De mate van specifieke herinneringen van de deelnemers bleek geen covariaat, maar wel hun mate van extraversie en emotionele stabiliteit. De hypothese verschoof naar de positieve effecten van het groepswerk zelf.
Manuscript 5 rapporteert over een gemengde effect/proces-evaluatie van groepsreminiscentie met bijzondere aandacht voor activiteit, focus en uitgedrukt welbevinden tijdens de sessies. Een sequentiële analyse op gestructureerde gedragsdata leverde evidentie dat groepsreminiscentie activerend en betrokkenheidverhogend kan werken, en dat visuele strategieën daarbij efficiënter zijn dan verbale.

Joris Van Puyenbroeck, Reminiscence in ageing people with intellectual disabilities. Exploration of the phenomenon and an evaluation of adapted group work.

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Supervisor: Prof. Dr. Bea Maes

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Reminiscence can be defined as silently or explicitly expressing memories of a distant past. Research has demonstrated that people of all ages reminisce, but the phenomenon has been researched mainly in older people. Especially its relation to psychological (dys)functioning has become a subject of study, partly by the generally widespread opinion that reminiscence or 'life review' is necessary in order to age 'successfully' (Butler, 1963). The idea that reminiscence can reconcile the ageing person with his past has been questioned in a lot of research. Reminiscence has different functions and types; some of them may indeed be associated with 'a good old age', both others not at all (Wong & Watt, 1991). Reminiscence therapies have focused primarily on 'integrative' (reconciling) and 'instrumental' (problem solving) reminiscence. Reminiscence work on the other hand, does not involve an evaluation of the past, but concentrates on 'simple' reminiscence. The aims are to pass on information, to have social contacts and to enjoy the sheer pleasure of storytelling. Elderly people themselves regard telling of the old days, with specific anecdotes, as a pleasant and meaningful activity. Science seems to link up again with the importance of this simple 'narrative' form of reminiscence by researching how the skill of relating specific memories is linked to mood disorders. Research into the effect of reminiscence work stimulating specific and anecdotal memories, is rare, and until now inexistent as to people with intellectual disabilities.

The reason why we wanted to research the relevance of reminiscence (work) precisely in (with) elder people with intellectual disabilities was the fact that this group runs a greater risk of metal health problems in general and mood disorders in particular (Davidson, Prasher & Janicki, 2003). People with intellectual disabilities run a greater risk of negative life events, stressors they often cannot control. They also often lack the right cognitive strategies in order to deal with setbacks and have less verbal and social skills in order to seek and find support from others (Oswin, 1991). Good support by family and professional attendants as to dealing with the past is therefore of great (preventive) importance. We have distinguished three views on support in this context: a socio-critical, a person-centered, and a clinical/therapeutic approach. We have investigated reminiscence with ageing people with intellectual disabilities especially from the third point of view, but also in the light of a broader 'successful ageing'-framework. The connection between reminiscence and subjective well-being is the central issue in this doctorate.

In *manuscript 1* the quality of reminiscence is explored by means of a content analysis on life review-interviews with 10 research subjects. The most frequent subjects, the greater variation of negative themes, and examples of all reminiscence types are interpreted and discussed. The conclusion is that reminiscence theory also seems to apply to people with intellectual disabilities.
Manuscript 2 surveys the available scientific literature on reminiscence in people with intellectual disabilities, classifies the publications in a socio-critical, individual and clinical approach, and interprets the lack of evaluation research.
Manuscript 3 describes the development of an adapted narrative group reminiscence program by means of an action-oriented research design. By means of a formative evaluation in one case and a product evaluation in six cases the manual to the program was finalized. Major adjustments to the program included the addition of extra visual stimuli, a fixed session structure and three support roles.
Manuscript 4 presents an evaluation of the differential effect of group reminiscence as opposed to an alternative form of group work on aspects of subjective well-being by means of a quasi-experimental ABA-design. Life satisfaction and self-perceived competence could not be influenced. Although mood level could not be experimentally manipulated, it nonetheless seemed to increase over time. The participants' expressed level of memory specificity did not turn out to be a covariate, but the degree of extraversion and emotional stability did. The hypothesis shifted to the positive effects of the group work itself.
Manuscript 5 reports on a mixed effect- and process-evaluation of group reminiscence with attention to activities, focus and expressed well-being during the sessions. A sequential analysis of structured behavioural data gave provisional proof that group reminiscence may have an activating and involving effect, and that in that process visual strategies are more efficient than verbal ones.

Dankwoord

Een mens dierbaarste bezittingen zouden wel eens zijn herinneringen kunnen zijn. Een auto, een huis, een vrouw en kind, ... allemaal goed om rond je te hebben, maar wat zou je doen als je meteen zou vergeten dat ze er zijn? Het geheugen is ons eerste bezit, onze identiteit zelf. Reminiscentie is dan ook, als uitgesproken of stille verwoording van het geheugen, een zeer intieme vorm van zelfexpressie. We drukken ermee uit wat ons nauw aan het hart ligt. U let er misschien niet op -ik wel, noem het beroepsmisvorming- maar hoe vaak denkt u dat we een gesprek beginnen met een herinnering? Al was het maar een verwijzing naar de dag van gisteren. De herinneringen bijhouden is wat zoveel mensen zo graag doen. Mijn doctoraat is een bescheiden poging om mensen met een verstandelijke handicap in dat - hopelijk ook voor u - herkenbaar verlangen te helpen.

Wanneer ik straks doctor wordt, is de belangrijkste verworvenheid niet de titel, maar de herinnering aan ‘wat vooraf ging’. Ik houd aan mijn doctoraat zoveel mooie herinneringen over: vijf jaren van zoeken, vallen en opstaan, van collegialiteit, van ernst en plezier. Zovele bijdragen van mensen waren essentieel bij het totstandkomen van wat voorligt. Ik wil hen hier allen graag persoonlijk bedanken.

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Joris
24 maart 2006

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Facilitator: What did you play at the school yard?
Participant: Hide and seek!
Facilitator: Hide and seek?
Participant: I don't know anymore...We only ran... after each other. Till the bell rang. Our teacher didn't have a bell.
Facilitator: The teacher had a bell?
Participant: No, the teacher didn't have one.
Facilitator: How did you know then that playtime was over?
Participant: The teacher clapped his hands.
Facilitator: Ah! The teacher clapped his hands.
(Other participant starts clapping his hands)
Participant: He clapped in his hands for those in line.
Facilitator: So no bell?
Participant: No bell no. When the teacher approached they queued up.
(Facilitator starts drawing the teacher)
Participant: He was angry sometimes. He was really strict!

Nederlandse samenvatting

Dit doctoraat verkent het fenomeen van reminiscentie bij ouder wordende mensen met een verstandelijke handicap, beschrijft de verschillende vormen van begeleiding op dit domein en rapporteert over de ontwikkeling en evaluatie van een groepsreminiscentie programma. Dit proefschrift brengt chronologisch verslag uit van studies met een gevarieerde methodologische aanpak: beschrijvende exploratie door middel van interviews en een literatuurstudie (*manuscripten 1* en *2*), formatieve methodiekontwikkeling door middel van participerend onderzoek (*manuscript 3*) en effect- en procesevaluatie door middel van een quasi-experimenteel ABA-design (*manuscripten 4* en *5*).

In deze samenvatting schetsen we de achtergrond waartegen we deze studies uitvoerden. Eerst geven we een beknopte beschrijving van de doelgroep waarmee we werkten, daarna van het fenomeen reminiscentie. We geven vervolgens een overzicht van de studies, met een verantwoording van de keuzes die we maakten, en een schets van de onderliggende motieven. In de conclusies bespreken we de ruimere relevantie van dit doctoraat.

Doelgroep

Mede dankzij de medische vooruitgang in de laatste decennia is de levensverwachting van personen met een verstandelijke handicap gestegen tot gemiddeld 70 à 74 jaar (Herr & Weber, 1999; Strauss & Eyman, 1996). In 1931 was dit nog 22 jaar (Janicki, Dalton, Henderson & Davidson, 1999). Het aandeel 50-plussers in deze doelgroep is nu meer dan 25% geworden (Haveman, 1999). Net zoals in het breder maatschappelijk kader, baart de ‘vergrijzing’ van mensen met een verstandelijke handicap zorgen bij familie, verzorgers en begeleiders (Bigby & Balandin, 2004). We schetsen kort de dubbele problematiek van ‘verstandelijke handicap’ en ‘ouder worden’.

Men spreekt van een verstandelijke handicap wanneer een persoon belangrijke beperkingen ondervindt in het dagelijks functioneren. Er moet sprake zijn van significante beperkingen in het intellectueel functioneren (IQ<70) en in het adaptieve gedrag zoals dat tot ontwikkeling komt in conceptuele, sociale en praktische vaardigheden (Luckasson et al., 2002). De functioneringsproblemen moeten ontstaan zijn vóór het achttiende levensjaar. Dit om het onderscheid te kunnen maken bijvoorbeeld met mensen die een hersenletsel oplopen of mensen met dementie.

Het voorgestelde onderzoek richt zich op ‘ouder wordende’ personen met een verstandelijke handicap. Wanneer we het predikaat ‘ouder wordend’ gebruiken, verwijzen we naar het bereiken van een bepaalde levensfase. Soms spreekt men van de derde (50-75 jaar) en de vierde (>75 jaar) levensfase (Janicki, 1999). Criteria om de ouderdomsfase af te bakenen zijn echter zeer relatief. Mensen met Down-syndroom maken bijvoorbeeld vroeger dan gemiddeld een verouderingsproces door. De levensverwachting ligt bij deze mensen gemiddeld 20 jaar lager dan in de gemiddelde populatie. Literatuuronderzoek (Guilmin, 1998) leert dat >55 jaar het vaakst wordt gebruikt als criterium om te spreken over 'ouder wordende' mensen met een verstandelijke handicap. De beleving van de personen zelf kan echter zeer verschillend zijn. Uit onderzoek van Urlings, Claessens, Bernard en Vos (1993) blijkt bijvoorbeeld dat de ervaring van het zich oud voelen alleen tot uiting kwam bij de ondervraagde mensen met verstandelijke handicap van 70 jaar en ouder en niet bij de jongere groep tussen 50 en 70 jaar. Onderzoek toont aan dat het verouderingsproces voor mensen met een verstandelijke handicap niet enkel de ‘gewone’ ouderdomsproblemen, maar ook verschillende specifieke uitdagingen met zich meebrengt. Vaak vermelde gezondheidsproblemen zijn de grotere kans op auditieve en visuele beperkingen en het hogere risico op hartaandoeningen (Walsh, 2005). Bij mensen met Down syndroom komt daar een verhoogd risico op depressie, dementie, hypothyroïdie en orthopedische problemen bij (Evenhuis et al., 2001). Het vervroegd begin van dementie (bij sommige mensen met Down syndroom reeds vanaf de leeftijd van 30 jaar) en de moeilijkheden die rijzen bij de diagnostiek ten overstaan van depressie, zijn de speerpunten van het dementieonderzoek in de betreffende doelgroep (Evenhuis, 1992; Prasher, Krishnan, Clarke & Corbett, 1994). De groep van oudere mensen heeft tevens specifieke noden op vlak van huisvesting. Velen hebben een woonverleden in een grote instelling, of wonen nog steeds thuis bij hun ouder geworden ouders (Serneels, 1994). ‘Ageing in place’ betekent dat mensen in hun vertrouwde woonomgeving oud kunnen worden. Dit vergt aanpassingen op verschillende vlakken, bijvoorbeeld veiligheid en toegankelijkheid (Hogg & Lambe, 1998). Verdere uitdagingen bestaan in het zich aanpassen aan een veranderd dagpatroon inzake werk en vrije tijd (Bigby et al., 2004).

Een bijzonder aandachtsveld in de literatuur is de geestelijke gezondheid van ouder wordende mensen met een verstandelijke handicap. Eén van de belagrijkste thema’s in dit verband is de hogere prevalentie van depressie en stemmingsstoornissen (Maaskant et al., 1996; Smyer & Qualls, 1996). Als verklaring wordt gewezen op het grotere risico op traumatische ervaringen (Hastings, Hatton, Taylor & Maddison, 2004), een onverwerkt verleden (Oswin, 1991) en

vereenzaming (Lunsky, 2003). Een bijkomende complicerende factor is het verminderd cognitieve vermogen om situaties te begrijpen en te situeren. Onderzoek van Reynolds en Miller (1985) bevestigde dat mensen met een licht/matig verstandelijke handicap een grotere kans op depressieve symptomatologie hebben dan hun niet-gehandicapte leeftijdgenoten, wegens hun grotere kans op blootstelling aan stressoren waarover ze geen controle kunnen uitoefenen, en de moeilijkheid om gewone sociale interactiepatronen te ontwikkelen en te onderhouden. De prevalentie van depressie wordt geschat op 5-20%, terwijl slechts een vijfde van de mensen zou behandeld worden (Davidson, Prasher & Janicki, 2003).

De invloed van negatieve levensgebeurtenissen op stemming werd reeds uitvoerig onderzocht. Dit onderzoek spitste zich vooral toe op het 'coping'proces van mensen met verstandelijke handicap, dat wil zeggen hoe ze omgaan met verlieservaringen zoals het overlijden van een naaste, het afscheid van een vriend of een (gedwongen) verhuis (Blackman, 2003; Oswin, 1991; Read, 1996). Door het vaak ontbreken van een sterk sociaal netwerk en bijkomende communicatieproblemen kan de rouwbeleving problematisch worden. Verlies, verandering en dood zijn voor vele (oudere) mensen met een verstandelijke handicap moeilijk te begrijpen ervaringen, zodat specifieke ondersteuning vaak noodzakelijk, maar niet altijd beschikbaar of voldoende aangepast is (Clarke & Read, 1998). Hoewel veel verstandelijk gehandicapte personen voldoende flexibiliteit en veerkracht genoeg hebben om de spanningssituatie, resulterend uit een dergelijke verlieservaring, aan te kunnen, raken anderen erdoor uit hun evenwicht en maken een periode van verdriet, angst, verwarring, onzekerheid en zorgen over de toekomst mee (Ludlow, 1999).

Het belang van een positief zelfbeeld voor mensen met een verstandelijke handicap komt steeds terug (Seltzer, 1985; Schalock, 1997). Došen (1990) geeft een centrale plaats aan (de ontwikkeling van) het zelfbeeld in de verklaring van psychopathologische processen bij mensen met een verstandelijke handicap. Een continue levenssituatie van afhankelijkheid kan het zelfbeeld zodanig veranderen dat men gaat denken dat men nooit volledig is zonder de hulp van anderen (Levitas & Gilson, 1989). Gevoelens van fierheid (naar aanleiding van een prestatie) of veiligheid kunnen op die manier zeldzamer worden, wat risico's inhoudt voor de opbouw van een stabiele identiteit. Dagnan en Sandhu (1999) vonden dat bij mensen met een verstandelijke handicap een cognitief proces van sociale vergelijking aan het werk is, een proces dat het zelfwaardegevoel in belangrijke mate mee bepaalt. Gibbons (1985) bijvoorbeeld toonde aan dat mensen met een verstandelijke handicap de sociale status van hun

eigen ‘peers’ laag inschatten. Prestatie, sociale aantrekkelijkheid van de eigen positie en het gevoel in een groep thuis te horen zijn ook voor mensen met een verstandelijke handicap belangrijke protectieve factoren voor een positief zelfbeeld.

Ons onderzoek vertrok weliswaar vanuit de wetenschap dat de vermelde problemen zich voordoen bij de doelgroep, maar nam ze niet als uitgangspunt. We wilden de psychosociale dimensie bij de doelgroep niet tot voornamelijk deficitaire thema’s vernauwen. Het idee voor deze thesis is ontstaan vanuit een positieve ingesteldheid ten aanzien van ouder worden. Het gerontologisch onderzoek besteedt al langer aandacht aan de vraag hoe mensen ‘succesvol’ ouder kunnen worden (Baltes & Baltes, 1990). Het idee is dat oudere mensen niet enkel beperkingen, maar ook en vooral heel wat mogelijkheden hebben om ‘een goede oude dag’ te beleven. Dit voornemen sloot op twee manieren aan bij de onderzoekslijn ‘kwaliteit van leven’ aan ons onderzoekscentrum. Enerzijds draait de ‘positieve psychologie’ van het succesvol ouder worden rond het concept ‘welbevinden’ (well-being) - een begrip dat nauw verwant is aan, en zelfs als synoniem gebruikt wordt voor (subjectieve) kwaliteit van leven (Ryff, 1995). Anderzijds is het paradigma van ‘succesvol ouder worden’, net als dat van ‘kwaliteit van leven’ in normatieve zin een reactie op een eenzijdig deficitair mensbeeld. Waar kwaliteit van leven geregeld in één adem wordt genoemd met ‘empowerment’, als tegengewicht voor ‘handicapism’ (de discriminatie van mensen op basis van hun handicap), wordt ‘successful ageing’ gezien als een sensibiliserende hefboom tegen ‘ageism’ (discriminatie omwille van leeftijd). Het idee ontstond om binnen de geest van het ‘succesvol ouder worden’-paradigma te zoeken naar een onderwerp dat de oudere wordende personen met een verstandelijke handicap respecteert in hun ervaring en mogelijkheden. Bij oudere personen kan men er van uitgaan dat het subjectieve welbevinden sterk wordt mee bepaald door ervaringen uit het verleden (Diener, 1994). Onze interesse voor reminiscentie werd opgewekt door Marcoen (1989, 1996), die reminiscentie als een spilconcept beschouwt in de psychosociale ontwikkeling van oudere mensen.

Reminiscentie

De term ‘reminiscentie’ stamt van het latijnse werkwoord ‘reminisci’, wat ‘zich herinneren’ betekent. Het belang van reminiscentie voor het geestelijk welzijn van de mens werd reeds door Freud (Freud, Strachey, Freud, & Strachey, 1962) vooropgesteld. In zijn ‘Pychopathology of everyday life’ beschrijft hij hoe cruciaal het proces van herinneren (en

vergeten) is om de psychè van een mens te begrijpen. In de psychoanalyse was een belangrijke rol weggelegd voor de ‘wiederholung’ of het proces van ‘durcharbeiten’. Reminiscentie was voor Freud de toegang tot de oorsprong van conflicten (regressie). In de psychodynamische onderzoekslijn was de heersende geriatrische opvatting dan ook lange tijd dat openlijke reminiscentie een teken was van psychische dysharmonie tussen verleden en heden, en bijgevolg van mentaal dysfunctioneren.

Midden de jaren '60 stelde Robert Butler (1963) echter dat reminiscentie een adaptieve functie heeft. Hij stelde vast dat mensen die hun dood zien naderen meer reminisceren dan anderen. Butlers hypothese bestond er in dat reminiscentie ouderen toelaat conflicten uit het verleden te herevalueren en op te lossen. Butler poneerde drie stellingen: (1) elke persoon reminisceert, en maakt ter zijner tijd de balans op van het eigen verleden (universele karakter); (2) hoe dichter bij het eigen levenseinde, hoe meer men gaat reminisceren. Ouderen reminisceren dus meer dan jongeren (leeftijdsspecifieke karakter); en (3) de levensevaluatie is noodzakelijk als voorbereiding op de dood (adaptieve functie).

Butlers theorie sloot goed aan bij die van Erikson (1963), en diens concept van ego-integriteit. Erikson vestigde voor het eerst de aandacht op het belang van de ouderdomsperiode als een belangrijke positieve ontwikkelingsfase in het kader van de totale levensloop en op de specifieke ontwikkelingstaak die ouderen te vervullen hebben. Erikson ging daarbij uit van een bepaald groeiprincipe. Hij vatte de menselijke levensloop op als een opeenvolging van acht psychosociale crisissen. Het oplossen van een crisis brengt iemand in de volgende 'fase' van zijn leven (epigenese). Uit iedere crisis komt een bouwsteen voor de identiteitsvorming voort. Erikson noemde dit vitale deugden of vermogens. Bij de achtste en laatste levensfase van Erikson staan de thema's ‘integratie’ en ‘wanhoop’ tegenover elkaar. In deze fase is de oudere persoon op een punt aangekomen waarop hij de balans opmaakt in zijn leven, en al dan niet het leven erkent zoals hij/zij het geleefd heeft. Indien de oudere persoon het leven zoals het gelopen is erkent en accepteert dat het leven hem gebracht heeft tot waar hij nu is, dan is er sprake van integratie; wanneer dit niet lukt, dan kan dit leiden tot wanhoop, temeer daar dingen niet meer overgedaan of goedgemaakt kunnen worden. Eriksons notie van integriteit, de noodzaak om alles bij elkaar te kunnen zetten, om het eigen leven als levenswaard te kunnen beoordelen, klinkt door in Butlers postulaten. Het impliceerde, net als bij Butler, een positieve waardering voor ‘life review’.

Doorheen de jaren zijn life review en reminiscentie wel vaker door elkaar gebruikt. Er is echter een conceptueel verschil. We leggen dit uit aan de hand van enkele recente definities.

“Reminiscing then is a rich experience distinguished from the memory of less personal events by the fact that it involves the process of reliving the past rather than the factual recall of historic events. Reminiscence can involve a variety of senses and emotions, [it] reflects the personal way we remember things, [and it] can be 'public' or 'private' ” (Norris, 1988, p. 22); “Een proces van herinneren van reeds lang vergeten gebeurtenissen of ervaringen die voor de betreffende persoon gedenkwaardig zijn” (Burnside & Haight, 1992, p. 153); “Het terugdenken, het min of meer levendig ophalen van en verwijlen bij herinneringen aan gebeurtenissen uit het verleden” (Marcoen, 1996, p. 16); “Het zich herinneren van levensgebeurtenissen”. Voor narratieve reminiscentie wordt daar aan toegevoegd “...en het communiceren van deze herinnering” (Staudinger, 2001, p.149).
Life review wordt in de literatuur onderscheiden van reminiscentie. Butler (in Lewis & Butler, 1974) zegt dat het méér is, het is “a natural occurring, universal mental process characterized by the progressive return to consciousness of past experience, and, particularly, the resurgence of unresolved conflicts” (p.165). “Life review can thus be defined as that form of reminiscence in which the past is actively evaluated, and conflict is necessary for resolution to occur” (Molinari & Reichlin, 1984, p.83). Het evaluatieve deel van life review koppelen aan een noodzakelijke conflictueuze inhoud is eigen aan de psychodynamische traditie.

Butler (1963) stelde dat reminiscentie voor iedereen een positieve ‘adaptieve’ functie heeft. Life review moest volgens hem leiden tot integratie. Negatieve gevoelens -zoals angst of schuld- bij het reminisceren kwamen volgens hem voort uit het ontbreken van voldoende openheid ten aanzien van het verleden (bijv. bij mensen die herinneringen voor zich willen houden) en dit kon mits de juiste begeleiding (therapie) geremedieerd worden. Maar deze stelling kon niet weerhouden worden. McMahon en Rhudick (1964) maakten reeds een theoretisch onderscheid tussen verschillende types van reminiscentie waarvan er zeker één, de defensieve variant, geen positieve functie had. Ook Coleman (1974) vermoedde dat de verschillende types van reminiscentie verschillende functies hebben, die niet noodzakelijk adaptief hoeven te zijn. Hij vond inderdaad dat zowel mensen met een hoog als mensen met een laag welbevinden reminisceren; bij de één kan het betekenen dat men geoccupeerd is door negatieve ervaringen, bij de ander kan het zijn omdat men plezier put uit deze herinneringen. Op analoge manier kunnen er zowel positieve als negatieve redenen zijn waarom mensen niet reminisceren: bijv. omdat ze er het nut niet van inzien (mensen met een hoog moreel), of omdat ze de herinneringen trachten te vermijden (laag moreel). Webster (1993) toonde een aantal reminscentiefuncties empirisch aan. Hij ondervroeg jongeren en ouderen omtrent hun

redenen voor reminiscentie en kwam tot zeven functies: conversatie, verveling, onderwijzen, identiteit/zelfbegrip, herleving bitterheid, onderhouden van (verloren) contacten, en voorbereiding op de dood. Herleven van bitterheid was duidelijk een functie van reminiscentie, maar kon moeilijk als 'adpatief' gecatalogeerd worden. Het onderzoek van Wong en Watt (1991) betekende een belangrijke doorbraak in het onderzoek naar de functionele adaptiviteit van reminiscentie. Zij slaagden er in om een onderscheid te maken tussen reminiscentietypes die een adaptief effect blijken te hebben, en reminiscentietypes die een neutraal of negatief effect ressorteren. De adaptieve types waren integratieve (verzoenende) en instrumentele (probleemoplossende) reminiscentie. Obsessieve reminiscentie (gevoed door schuld) en escapistische reminiscentie (verheerlijking van het verleden) bleken in hun studie niet adaptief.

Een onderbelicht type in de literatuur na Wong & Watt (1991) bleef narratieve/simpele/conversationele reminiscentie. De narratieve vorm onderscheidt zich van de andere doordat er geen evaluatie, maar enkel een representatie van het verleden in betrokken is. Het gaat om autobiografische gegevens of feiten die interessant kunnen zijn voor de toehoorder. Van narratieve reminiscentie wordt verondersteld dat het vooral een sociale functie heeft: het leggen van contact, het delen van informatie.

Niet enkel vanuit de psychodynamische, maar ook vanuit de cognitief-gedragsmatige theorie werd de relatie tussen emotie en biografisch geheugen onderzocht. Zo stelden Lloyd en Lishman (1975) vast dat depressieve mensen meer en sneller negatieve herinneringen ophalen. Latere studies bevestigden dat deze resultaten zeker niet alleen door een verschil in voorgeschiedenis konden verklaard worden. De verklaring werd daarom gezocht in informatieverwerkingsprocessen. Bower (1981) verdedigde het 'mood state dependent memory'-effect: stemmingscongruente informatie zou beter worden herinnerd dan stemmingsincongruente informatie. De achterliggende gedachte is dat in het neurale netwerk gegevens sneller geactiveerd zouden worden door middel van affectieve associatie.

Een interessante evolutie op dit domein kwam er met het onderzoek van Williams en Broadbent (1986), die vonden dat mensen met suïcidale neigingen het moeilijker hadden om specifieke positieve herinneringen op te halen. Verder onderzoek wees uit dat ook depressieve mensen, mensen met een verleden van misbruik, en mensen die lijden aan het post-traumatische stress syndroom niet enkel hun traumatische, maar ook hun positieve

herinneringen blijken te veralgemenen (de Decker, Hermans, & Eelen, 2000). Een mogelijke verklaring voor deze vaststelling werd gegeven door Williams, Watt, MacLeod, and Mathews (1997): geconfronteerd met trauma's leren mensen hun herinneringen af te vlakken en enkel de algemene kenmerken ervan op te slaan, om op die manier de samenhangende negatieve gevoelens te vermijden. Omdat ook de positieve ervaringen gegeneraliseerd worden, komt een persoon tot een negatieve voorstelling van zichzelf en de wereld. Een belangrijk nadeel hiervan is dat succeservaringen worden gerelativeerd, en dat specifieke oplossingsstrategieën worden vergeten.

Pas in de tweede helft van de jaren '70 gaf het thema van reminiscentie aanleiding tot studies die het praktische nut ervan onderzochten. De invloed van reminiscentieactiviteiten op zeer verscheidene afhankelijke variabelen werd sindsdien onderzocht: (des)oriëntatie, aandacht, activiteit, activiteiten dagelijks leven (ADL), affectbalans/stemming, depressie, functioneringsniveau, levenstevredenheid, psychologisch welzijn, sociale adaptatie, ego-integriteit en zelfwaarde (Haight, 1991; Haight & Hendrickx, 1995, Hendrix & Haight 2002). De kwaliteit van het effectonderzoek werd pas medio/eind jaren tachtig op de korrel genomen (zie onder meer Rattenbury & Stones, 1989). Molinari en Reichlin (1984) vonden dat veel reminiscentieonderzoek eerder 'anekdotisch' van aard was. De voornaamste knelpunten waren (1) geen consensus over de verwachte effecten en dus geen uniformiteit inzake de keuze van uitkomstindicatoren, (2) weinig theoretische onderbouwing omtrent het werkzaam aspect van reminiscentie/life review en dus geen uniformiteit wat betreft interventie, (3) weinig experimentele designs met controle-conditie. Correlationeel onderzoek kan geen antecedenten vaststellen. Thornton en Brotchie (1987) vonden dat veel onderzoek gebiassed was, zowel in de manier waarop het uitgevoerd was, als in de manier waarop de outcome gemeten werd. Haight (1991) stelde op basis van haar literatuuronderzoek dat reminiscentie/life review weliswaar positieve resultaten kan hebben, maar zij beschouwde de lengte van een interventie als cruciaal, alsook de intensiteit waarmee deze gebeurt. Haight (1991) benadrukte verder het belang van een goede uitzuivering van termen: een scherpe definitie van de uitkomstindicatoren is noodzakelijk.

Er volgden verschillende beter gemanipuleerde studies bij ouderen zonder verstandelijke handicap. Ze toonden aan dat het organiseren van reminiscentiegroepen en gestructureerde levensinterviews (duurzame) positieve effecten kunnen hebben op levenstevredenheid (Cook, 1998; Haight, 1992; Rattenbury & Stones, 1989). Er kwamen ook aanwijzingen dat het

stimuleren van specifieke types van reminiscentie depressieve symptomen significant kan verminderen (Watt & Capelliez, 2000). Cooks onderzoek (1998) resulteerde bijvoorbeeld in een significant effect op levenstevredenheid in een experimentele reminiscentiegroep (vs. een 'current topics' controlegroep). Haight (1992) vond aanwijzingen voor een effect van reminiscentie op levenstevredenheid, ook bij een follow-upstudie na een jaar. Rattenbury en Stones (1989) bereikten een significant effect met een reminiscentiegroep (vergeleken met een controlegroep die groepsgesprekken voerde over de actualiteit) op een schaal voor psychologisch welbevinden, maar zij vonden ook een verband tussen vooruitgang op deze schaal en de mate waarin was deelgenomen aan de gesprekken. Betrokkenheid was dus een mediërende factor. Brooker en Duce (2000) gebruikten videoanalyse en stelden meer tekens van welbevinden en betrokkenheid vast tijdens de reminiscentiesessie dan tijdens de 'current topics' sessie.

Fry (1995) kwam tot de slotsom dat veel variatie in de geuite levenstevredenheid tijdens life review gesprekken te verklaren is door individuele persoonskenmerken zoals empathie, optimisme, humor, openheid en interne 'locus of control'. Cully, Lavoie, an Gfeller (2001) onderzochten ook de moeilijke relatie tussen persoonlijkheid en reminiscentiegedrag en vonden dat wanneer er sprake was van een algemeen gezond psychologisch functioneren, de kans op negatieve types van reminiscentie verkleint. Dit staaft de overtuiging dat reminiscentie niet zomaar een momentane reactiewijze is, maar eerder een langzaam gegroeid patroon, gevoed door een lange geschiedenis van persoonlijke ervaringen, die ook de persoonlijkheid gevormd hebben.

Een andere intermediërende variabele die naar voor komt is de kwaliteit van de interactie tussen de reminisceerder en de toehoorder. Dit kon aangetoond worden bij kinderen. Deze leren verhalen vertellen over vroeger doordat ze participeren in -door de ouder gestructureerde- conversaties over het verleden (Fivush & Reese, 2002). Men kon verschillen vaststellen tussen ouders die minder specifiek of algemeen (minder elaboratief) ingingen op de herinneringen, en ouders die daar zeer specifiek en uitgebreid op ingingen (meer elaboratief). Elaboratieve toehoorders - dat wil zeggen actieve toehoorders die de reminiscentie faciliteren - geven de reminisceerder de kans om verder in te gaan op een herinnering. Ze bevestigen de herinneringen en bouwen bepaalde details verder uit door relevante vragen bij te stellen. Het is aangetoond dat kinderen van elaboratieve ouders ook op latere leeftijd meer informatie geven tijdens het reminisceren (Fivush & Reese, 2002). We

gaan er dus van uit dat bij reminiscentiesessies de mate van elaboratie van de facilitator een mediërende rol zal spelen.

Kemp (DHSS, 1979) onderzocht hoe reminiscentieactiviteiten het isolement van oudere mensen konden doorbreken en hoe de relatie met het personeel zou kunnen verbeterd worden. Hij vergeleek een conditie waarin mensen een video te zien kregen en een conditie waarin met mensen over vroeger gepraat werd. Er werden een aantal interessante vaststellingen gedaan: dat mensen het fijn vonden om te reminisceren, dat reminiscentie een conversatie een spontaan karakter kan geven, dat het ook als een contactmiddel kan fungeren tussen een oudere en anderen, dat het de responsiviteit kan vergroten bij ouderen, en dat het gebruik van meerdere zintuiglijke modi voor een betere reproductie zorgt. Ook Bender, Bauckham en Norris (1999) merkten op dat reminiscentieactiviteiten niet enkel meetbare effecten ressorteren. Ze noemen niet minder dan 20 'bijwerkingen' van reminiscentie die dergelijke activiteiten zinvol maken. We noemen er enkele: het bevorderen van de spontane conversatie tussen deelnemers of tussen personeel en deelnemers, het verbeteren van de groepscohesie, het laten hergebruiken van oude vaardigheden, het uitdiepen van het diagnostisch proces en het verbeteren van het begrip van en voor een individu door het personeel. Deze doelstellingen leken ons ook voor de begeleiding van mensen met een verstandelijke handicap relevant en waren de aanleiding voor deze studie.

Overzicht van de studies

We percipieerden het doctoraat van bij het begin als een handelingsgericht onderzoek. De regulatieve cyclus van Van Strien (1986) namen we als leidraad voor de opeenvolging van de verschillende studies. De methodologische 'grondfiguur' voor probleemgericht praktijkdenken verloopt volgens deze auteur volgens de fasen: probleemstelling, diagnose, plan, ingreep en evaluatie. Bijgevolg beschrijven *manuscripten 1* en *2* twee exploratieve onderzoeken, brengt *manuscript 3* verslag uit van een studie waarin een plan wordt opgemaakt en een interventie wordt ontworpen, en rapporteren *manuscripten 4* en *5* over de evaluatie van deze interventie.

We kozen ook bewust voor gemengde kwalitatieve en kwantitatieve methoden ('mixed methods') (Tashakkori & Teddlie, 2002). Meer precies wil dit zeggen dat op delen van hetzelfde bronmateriaal zowel kwalitatieve als kwantitatieve analyses werden uitgevoerd. De

interviewdata werden voor sommige vragen bijvoorbeeld ook kwantitatief geanalyseerd, voor de gestructureerde video-observatiedata gold het omgekeerde.

Voor we het doctoraat aanvingen, wisten we niet of het theoretische kader van reminiscentie toepasbaar zou zijn bij mensen met een verstandelijke handicap. Dit bracht ons ertoe om in een eerste studie (*manuscript 1*) reminiscentie empirisch te gaan verkennen bij de doelgroep. We kozen voor een kwalitatieve aanpak: een grondige inhoudsanalyse van levensevaluatie-interviews met 10 onderzoekssubjecten. Het werd meteen duidelijk dat de (vrijwillige) deelnemers graag en veel vertelden over vroeger. De getranscribeerde interviews boden voldoende stof om een aantal 'kern'parameters van reminiscentie (voorkomen, inhoud, beleving en typologie) te toetsen. De inhoudsanalyse toonde het voorkomen en ontbreken aan van een aantal specifieke thema's voor mensen met een verstandelijke handicap. Wat opviel bij mensen die lang thuis verbleven, was het thema van de familie in het algemeen, het sterven van de ouders, de verhuis, en de plaatsen waar men verbleven heeft sindsdien. Verder viel op dat een groot deel van de verhalen doorspekt was met herinneringen aan negatieve levensgebeurtenissen. Tot slot vonden we voorbeelden van alle types uit de taxonomie van Wong en Watt (1991), behalve van escapistische reminiscentie.

Om een beter overzicht te krijgen op bestaande begeleidingsstrategieën in functie van reminiscentie, werd door middel van een literatuurstudie het beschikbare wetenschappelijke onderzoek onder de loep genomen. *Manuscript 2* schetst en classificeert de publicaties in een sociaal-kritische, persoonsgerichte en klinische benadering. Het duidt verder op het ontbreken van evaluatieonderzoek, en een evenwichtig theoretisch model. Het bestaande onderzoek benadrukt teveel het problematische karakter van het verleden of van de reminiscentie: de voornaamste functies blijken de omgang met verlies of de kritische afstandname ten aanzien van het verleden.

Na *manuscript 2* werd conceptueel duidelijk dat individuele 'life review' onder de titel 'levensboekwerk' reeds tot de bekende mogelijkheden voor begeleiding van ouder wordende mensen met een verstandelijke handicap behoorde. Over de mogelijkheden van (narratieve) groepsreminiscentie was in de literatuur veel minder bekend. Met groepsreminiscentie bedoelen we een groepsgesprek waarbij een begeleider bewust het thema verleden inbrengt, om de ouder wordenden aan te zetten om herinneringen op te halen. Bij groepsreminiscentie is het de bedoeling dat ouderen *samen* herinneringen ophalen (Norris, 1988). De programma's

die in de praktijkgerichte gerontologische literatuur beschreven worden gaan doorgaans uit van een groepsgrootte van een zes- à achttal mensen en één begeleider.

Na het 'probleemverkennende' en 'diagnosticerende' deel in *manuscript 1* en 2 begon het handelingsgerichte deel van het onderzoek: een methodiek ontwikkelen voor groepsreminiscentie en deze vervolgens uitgebreid (effect- en procesmatig) toetsen. Als doelgroep kozen we mensen met een licht/matige verstandelijke handicap omwille van de benodigde verbale vaardigheden.
De eerste stap in dit project bestond uit het aanpassen van een bestaand reminiscentieprogramma (Bruce, Hodgson, & Schweitzer, 1999) in een pilootstudie. In deze studie testten we ook de video-observatietechnieken uit voor de latere evaluatiestudie. *Manuscript 3* beschrijft hoe we in een groep met zeven deelnemers, gedurende een drietal maanden 'al doende' leerden hoe we reminiscentie, groepswerk en doelgroepspecifieke kenmerken succesvol met elkaar konden combineren. We leerden door 'trial and error' (een formatieve evaluatie) wat zinvol, haalbaar en wenselijk was. Een voorstelling van het uiteindelijke reminiscentieprogramma en de specifieke strategieën die werden gebruikt (extra visuele stimuli, een vaste sessiestructuur en drie begeleiderrollen) werden vervolgens gebundeld tot een handleiding. Met deze handleiding werden nieuwe voorzieningen aangeschreven met de vraag of ze mee wilden werken aan een langdurige evaluatie. De vaste medewerking van een begeleider werd als voorwaarde gesteld. Toen de benodigde zes voorzieningen gevonden waren, doorliepen de vrijwillige begeleiders een trainingsdag en een proefsessie in hun eigen voorziening samen met de onderzoeker. Daarna werd het programma opnieuw ter goedkeuring voorgelegd door middel van een semi-gestructureerd interview. De formatieve elementen van deze bevraging komen eveneens aan bod in *manuscript 3*.

Tijdens en na de studie die wordt beschreven in *manuscript 3*, werd veel tijd geïnvesteerd in het ontwikkelen van de procedure waarmee we het op te nemen beeldmateriaal gestructureerd zouden kunnen analyseren. Structurele gedragsobservatie werkt met kleine 'meeteenheden' die de variabiliteit beter dan vragenlijsten kunnen aantonen. Een vragenlijst schat het voorkomen van een bepaald gedrag in een bepaald tijdsbestek over situaties heen, terwijl gedragsanalyses nauwkeurige steekproeven kunnen nemen, en verschillen in omgevingskenmerken in rekening brengen. Voor psychische variabelen, waar observeerbare gedragingen aan verbonden zijn, wordt deze methode beschouwd als de meest betrouwbare optie. Ze wordt echter weinig of niet toegepast, vanwege de hoge investeringskost en het

gebrek aan standaardisatie en protocollering. De huidige algemene beschikbaarheid van digitaal opnamemateriaal maakt echter een vlotte verwerking van observatiedata veel laagdrempeliger.
Voor groepswerk was observatie geen evidente keuze. Het studieobject (wat er gebeurt in de groep en bij elke deelnemer apart) kan niet vanuit één standpunt in beeld worden gebracht. Het eerste probleem dat moest opgelost worden was dus de synchronisatie van de dubbele video-input. Een tweede probleem bestond uit het vinden van een geschikt instrument voor de vlotte gestructureerde verwerking van de videodata. We ontwikkelden daarom zelf, met de deskundige hulp van een vrijwillige programmeur, een software programma, genaamd 'Vitessa', om de data gemakkelijker en gebruiksvriendelijker te structureren (Van Puyenbroeck, Maes, & Laeremans, 2005).

Na de proefsessies startten we in zes groepen, met een totaal van 41 deelnemers, met een reminiscentieprogramma van 12 wekelijkse sessies. We voorzagen twee hoofd-informatiebronnen voor de dataverzameling: enerzijds vragenlijsten voor, tussen en na de sessies; en anderzijds video-observaties tijdens de sessies. De vragenlijsten werden ingezet om de vraag naar het differentiële effect op subjectief welbevinden van groepsreminiscentie tegenover een alternatieve vorm van groepswerk te beantwoorden. Om alle mensen te kunnen motiveren voor de studie, en ook omwille van deontologische redenen, gebruikten we een quasi-experimenteel ABA-design: drie sessies alternatief groepswerk (hedendaagse topics), zes sessies reminiscentie, en weer drie sessies groepswerk zonder focus op reminiscentie. De resultaten worden beschreven in *Manuscript 4*. Samengevat leerde de analyse ons dat levenstevredenheid en zelfwaargenomen competentie niet konden beïnvloed worden door het groepswerk. De vastgestelde toename in stemmingsniveau kon niet door een conditie-, maar mogelijks wel door een tijdseffect verklaard worden. De deelnemers zelf evalueerden het programma positief, zonder voorkeur echter voor het reminiscentiedeel. Daarmee verschoof de hypothese naar de positieve effecten van het groepswerk zelf. Deze hypothese zijn we nagegaan in een analyse van de videodata (*manuscript 5*). In *manuscript 4* gingen we ook nog na of de mate van specificiteit van de herinneringen bij de deelnemers covarieerde met hun scores op stemming. Dit bleek niet zo te zijn. De persoonlijkheidskenmerken extraversie en emotionele stabiliteit bleken wel sterk samen te hangen met het stemmingsniveau.

Omdat er voldoende redenen zijn om aan te nemen dat het gebruik van vragenlijsten bij mensen met een verstandelijke handicap onbetrouwbaar kan zijn, werd reeds van bij het opzet

van de evaluatie óók gekozen voor gedragsobservatie. *Manuscript 5* rapporteert over de analyse van de videodata, waarvoor telkens een kwartier of half uur (afhankelijk van de variabele), uit een sessie werd geselecteerd. De deelnemersvariabelen 'activiteit', 'focus' en 'lach', en de begeleidersvariabelen 'visuele' en 'verbale strategieën' werden per 15 seconden gescoord.

We vonden een impact van conditie (reminiscentie versus hedendaagse onderwerpen) op de activiteit- en focusscores. Een sequentiële analyse op de data leverden het voorlopig bewijs dat groepsreminiscentie activerend en betrokkenheidverhogend kan werken, en dat visuele strategieën daarbij efficiënter zijn dan verbale.

Conclusies

Na dit onderzoek kunnen we concluderen dat mensen met een licht/matig verstandelijke handicap in staat zijn hun autobiografisch geheugen aan te wenden om herinneringen aan een ver verleden aan te spreken. Deze conclusie is niet nieuw, getuige daarvan de toegepaste literatuur over 'oral history' en 'life story work' (*manuscript 2*). Nieuw is dat in dit doctoraat het reminiscentieproces van mensen met een verstandelijke handicap meer in detail is beschreven.

We hebben in *manuscript 2* verschillende vormen van reminiscentiewerk beschreven die zinvol zijn voor volwassen mensen met een verstandelijke handicap: het optekenen van verhalen als middel tot geschiedschrijving, zelfbewustwording en empowerment, het opstellen van een levensboek om verhalen te bewaren en door te geven, en praten over vroeger als een middel om verlieservaringen en andere moeilijke overgangsperiodes te verwerken.

In *manuscript 3* ontwikkelden we een aangepast reminiscentieprogramma voor mensen met een verstandelijke handicap. Een kort overzicht van de sessies is te vinden in appendix B. Een uitgebreid overzicht in appendix C. De selectie van thema's is niet exhaustief; meerdere thema's kunnen toegevoegd worden. We raden wel het gebruik van een soortgelijke tijdsindeling, een klemtoon op visuele stimuli en vooraf gedefinieerde begeleiderrollen aan.

Met *manuscript 4* plaatsten we ons in een onderzoekstraditie om het effect van reminiscentie na te gaan op levenstevredenheid. Men veronderstelt, geïnspireerd door het Eriksoniaanse 'integratie'-denken, dat reminiscerende oudere mensen zich niet enkel met zichzelf verzoenen, maar ook met hun levenssituatie. Onze studie vond echter geen zichtbaar effect van het reminiscentiewerk op levenstevredenheid. We verklaren dit door de theorie dat de subjectieve kwaliteit van leven enkel wordt bepaald door factoren die groot genoeg zijn om de

ingebouwde ‘homeostatische’ controle van mensen te ontwrichten (Cummins, 2001). Een activiteit zoals groepsreminiscentie kan een stabiel gegeven als levenstevredenheid niet of moeilijk beïnvloeden. Het oordeel over de eigen levenssituatie was bij de deelnemers bij voor– en nameting even positief of even kritisch; indien de levenssituatie niet verandert zal ook het oordeel niet veranderen. De effecten van reminiscentiewerk moeten volgens ons niet gezocht worden in de richting van levenstevredenheid.

Met de keuze voor waargenomen zelfcompetentie als tweede uitkomstvariabele plaatsten we ons eveneens in een traditie van onderzoek dat de effecten van reminiscentie op zelfbeeld en zelfwaarde heeft onderzocht (Perrotta & Meacham, 1981; Haight, 1991). Dit effect wordt voorspeld door meerdere theoretische modellen: reminiscentie bevordert ego-integriteit, neemt schuldgevoelens weg, of kan via retrospectieve vergelijking de continuïteit van de identiteit versterken (Watt & Cappeliez, 2001). Toch werd in onze studie geen enkel verschil gevonden tussen voor- en nameting van zelfwaargenomen competentie. De deelnemers beoordeelden zeer kritisch wat ze konden en wat niet. Aangezien hun competenties niet veranderd waren op een termijn van vier maanden, veranderde ook hun subjectieve oordeel niet. Het probleem is dat het gehanteerde instrument eerder ‘zelfbeeld’ (‘self-concept’) dan zelfwaardegevoel (‘self-esteem’) mat. Waar het eerste weinig of niet door reminiscentie kan beïnvloed worden, is een effect op het tweede niet uitgesloten.

Meer nog dan levenstevredenheid en zelfwaargenomen competentie stond de variabele ‘stemming’ in het brandpunt van ons onderzoek. We kozen voor een ‘hedonistische’ invulling van welbevinden: we hebben getoetst of groepsreminiscentie de stemming verhoogt, of het meer positieve ‘affecten’ met zich meebrengt. We baseerden onze verwachtingen op voorgaand onderzoek, dat positieve effecten vond voor stemming en affect (Haight, 1992; Rattenbury & Stones, 1989). Ook een vermindering van depressieve symptomen werd reeds vastgesteld (Watt & Cappeliez, 2000). Onze verwachting was ook gegroeid na *manuscript 3*; we hadden de indruk dat reminiscentie groepswerk veel interesse en plezier kon opwekken tijdens de sessies. We wisten echter niet of dit effect geëxtrapoleerd zou kunnen worden naar de dagdagelijkse leefsituatie.

Onze hoop bleek onterecht. We konden geen positief effect vinden van reminiscentie op stemming. De toets voor het conditie-effect leverde geen significant resultaat. Een mogelijke oorzaak ligt in het feit dat in onze studie de reminiscentie- en alternatieve groepsactiviteit sterk op elkaar leken, behalve inzake de situering van het onderwerp: verleden versus heden.

In voornoemde studies werd de controle-activiteit ‘hedendaagse onderwerpen’ (‘current topics’) ingevuld als een ongestructureerde bespreking van de krantenkoppen. Dit leek ons vooraf te verschillend van de reminiscentie-conditie. De inhoud diende in onze controle-conditie ook persoonlijk en door visuele stimuli ondersteund te zijn.
We vonden wel een significante verhoging van de stemmingsscores naar het eind van het programma. Dit hebben we geïnterpreteerd als een uitgesteld ‘tijds’effect. Omdat we geen vergelijking kunnen maken met een groep die hetzelfde programma doorliep in een andere periode van het jaar, kunnen we kalendergebonden effecten niet uitsluiten. Bovendien kunnen we niet bepalen wat nu juist heeft gewerkt, het reminiscentiewerk of het alternatieve groepswerk. De meest plausibele verklaring (naast de mogelijkheid van ‘toeval’) leek ons een geleidelijk effect van het totale groepswerk programma (reminiscentie- én andere onderwerpen). We stelden inderdaad vast in alle groepen dat na verloop van tijd de deelnemers bijzonder gesteld raakten op hun wekelijkse activiteit. We hoorden ook van de begeleiders dat de meeste mensen er naar uitkeken.

Voor zover we weten is dit de eerste studie die effecten van groepswerk op het gedrag van deelnemers in termen van activiteit, focus en geuit welbevinden nauwkeurig vastlegt, en het verband met strategieën van de begeleider sequentieel analyseert. Groepswerk wordt doorgaans geëvalueerd in termen van effectiviteit; hoe men met de groep een bepaald produkt of resultaat kan halen (West, 1996). Wat gebeurt tijdens de sessies zelf wordt uitgedrukt in termen als groepscohesie, -rollen, -taak, -communicatie, -leiderschap, enz. Deze begrippen worden aangeduid als procesvariabelen. In onze studie behandelden we drie individuele gedragingen als *uitkomsten* van het onderzoek. Ingewikkelde relaties om het groepsfunctioneren te modelleren hebben we niet gebruikt. We zijn er van uitgegaan dat activiteit, focus, en (glim)lach, geschikte indicators zijn voor goed groepswerk. De keuze voor deze gedragsvariabelen in de context van ons onderzoek was niet onlogisch: activering, betrokkenheid en (geuit) welbevinden zijn nastrevenswaardige doelen op zich voor onze doelgroep. In gerontologische literatuur wordt de zin van groepswerk reeds lang onderkend. Met de conclusie dat reminiscentie meer activiteit en focus tot stand brengt, hebben we aangetoond dat waarschijnlijk niet zomaar elk onderwerp activerend en betrekkend is voor oudere mensen. Het gevoel dat veel praktijkdeskundigen hebben over groepsreminiscentie wordt bevestigd in ons onderzoek: reminiscentie is en blijft vooral een *zinvol* onderwerp voor groepswerk met ouderen. Het is aangepast aan de leeftijd van de betrokkenen; door de inhoud

te laten aansluiten met de vroegere belevingswereld van de deelnemers toont men respect voor deze mensen.
De conclusie dat visuele strategieën superieur zijn ten opzichte van verbale strategieën mag geen verwondering wekken. De deelnemers werden duidelijk meer aangesproken door visuele dan verbale 'triggers'. We gaan er niet van uit dat dit effect doelgroepgebonden is. We stellen hier duidelijk dat herinneringen makkelijker kunnen opgeroepen worden door visuele stimuli. Deze bevinding kan nuttig zijn voor onderzoek naar de determinerende factoren en beïnvloedbaarheid van specifiek geheugen.

Het door ons geëvalueerde groepsreminiscentie programma is slechts een voorbeeld van hoe men oudere mensen kan activeren op een zinvolle manier. Het is ontwikkeld als een vorm van ondersteuning, een instrument waarmee kan bijgedragen worden aan de kwaliteit van leven van de mensen met een handicap. We hebben dit gelinkt aan 'succesvol ouder worden'. We hebben een aantal methoden besproken om reminiscentie te ondersteunen bij de doelgroep, en zijn we ervan overtuigd dat deze op één of andere manier kunnen bijdragen aan meer continuïteit in het leven en de begeleiding van ouder wordende mensen met verstandelijke handicap. We zijn daarbij bewust uitgegaan van een 'instrumenteel' perspectief: (een) instrument(en) afleveren waarmee begeleiders zelf aan de slag kunnen. Elk verouderingsproces verschilt immers van het andere. Het is zinvol zich af te vragen : 'wat is een goede oude dag voor deze persoon?', en in functie daarvan de functie van reminiscentie(werk) te beoordelen.

General introduction

This doctoral thesis explores the phenomenon of reminiscence in ageing people with intellectual disabilities, describes the different forms of support in this domain and reports the development and evaluation of a group reminiscence program. This dissertation gives a chronological account of studies that used a varied methodological approach: descriptive exploration by means of interviews and a study of the literature (*manuscript 1* and *2*), a formative evaluation by means of participant research (*manuscript 3*) and an effect/process evaluation by means of a quasi-experimental ABA-design (*manuscript 4* and *5*).

In this introduction we want to sketch the background against which we carried out these studies. First we give a brief description of the target group we have worked with, subsequently of the phenomenon 'reminiscence'. Finally we give a chronological survey of the studies, with a justification of the decisions we have made, and a sketch of the underlying motives.

Risks for 'successful' ageing

Partly thanks to medical progress these last decennia life expectancy of people with intellectual disabilities has risen to an average of 70 to 74 years (Herr & Weber, 1999; Strauss & Eyman, 1996). In 1931 this was only 22 years (Janicki, Dalton, Henderson & Davidson, 1999). The percentage of those over 50 in the target group has now surpassed 25% (Haveman, 1999). As in general society, the 'graying' of people with intellectual disabilities is a source of concern to family, and care and support staff (Bigby & Balandin, 2004). We briefly outline the double issue of 'intellectual disability' and 'ageing'.

'Intellectual disability' or 'mental retardation' (a depreciated term) is a disability characterized by significant limitations both in intellectual functioning (IQ<70) and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills (Luckasson, Borthwick-Duffy, Buntinx, Coulter, Craig, & Reeve, 2002). The limitations must manifest themselves before the eighteenth year of their life, in order to make the distinction with -for instance- people who have brain damage or people with dementia.

Our research project is aimed at ageing people with intellectual disability. When we say 'ageing', we usually refer to a person reaching a later stage in life. Common classifications mention a 'third age' (50-75 years) and a 'fourth age' (>75 years) (Janicki, 1999). But the

criteria to define a certain life stage are very relative. Life span theories define 'ageing' as a combination of growth and decline, a process that differs for each person (Baltes & Baltes, 1990). Moreover, the life expectancy for people with intellectual disabilities varies, dependent on the underlying genetic syndrome. People with Down syndrome are ageing more rapidly; their life expectancy is 15-20 years less than the general population. Finally, ageing people with intellectual disabilities do not necessarily perceive themselves as ageing. Urlings, Claessens, Bernard and Vos (1993) found that the self-perception of 'ageing' was only present in people with intellectual disabilities older than 70, and not in their younger colleagues who were aged 50-70. A study of literature by Guilmin (1998) found that most authors use >55 year as a pragmatic age criterion.

Research shows that for people with intellectual disabilities the ageing process involves not only common problems that are associated with old age, but also several specific challenges. Health problems that are often mentioned are the higher risk of auditory and visual impairments (Walsh, 2005). For people with Down syndrome, there is a higher risk of depression, dementia, hypothyroidism and orthopedic problems (Maaskant, 1994; Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001). The early incidence and course of dementia (for some people with Down Syndrome already in their thirties) and the difficulties to detect depression, are the spearheads of research (Evenhuis, 1992; Prasher, Krishnan, Clarke & Corbett, 1994). The group of elder people also has specific needs in the field of accommodation. Many have a past of living in a big institution, or at home with their ageing parents (Serneels, 1994). 'Ageing in place' means that people may age in their familiar environment. This requires many adaptations on different life domains, for example security and accessibility (Hogg & Lambe, 1998). Another specific challenge is the adaptation to a changed day's schedule with regard to work and leisure (Bigby, Balandin, Fyffe, McCubbery, & Gordon, 2004).

The mental health of ageing people with intellectual disabilities is a topic that draws special attention in research literature. One of the most important themes in this regard is the higher prevalence of depression/mood disorders (Maaskant, Haveman, van Schrojenstein Lantman-de Valk, Urlings, van den Akker, & Kessels, 1996; Smyer & Qualls, 1996). Causes that are pointed out are the greater risk of traumatic experiences (Hastings, Hatton, Taylor & Maddison, 2004), a past that has not yet been dealt with (Oswin, 1991), and loneliness (Lunsky, 2003). What furthermore complicates the matter is that the cognitive ability of people with ID may not be sufficient to understand and place situations. Research by Reynolds and Miller (1985) confirms that people with a mild/moderate intellectual disability

run a greater risk of depressive symptomatology than their non disabled peers, because they are more exposed to stressors they can not control, and they have difficulties developing and maintaining normal patterns of social interaction. The prevalence of depression in the target group is very difficult to estimate. Authors agree that the problem is under diagnosed. Figures vary between 5 and 20% (Janicki, Dalton, Henderson, & Davidson, 1999). Finally, it is estimated that only a fifth of the people that are diagnosed receives proper treatment (Davidson, Prasher & Janicki, 2003).

The influence of negative life events on the state of mood has already been extensively researched. Research especially concentrates on the coping process of people with intellectual disabilities, i.e. how they handle losses such as the death of a family member or a friend, a sudden retirement or a (forced) move (Oswin, 1991; Read, 1996; Blackman, 2003). Because there often is no strong social network and because of additional communication problems, the bereavement process may become problematic. Many (elder) people with intellectual disabilities have such difficulties understanding loss, changes and death, that specific support often is necessary, but not always available or sufficiently adapted (Clarke & Read, 1998). Although many people with intellectual disabilities have enough flexibility and resilience in order to cope with the tense situation that results from such a loss, others are thrown off balance and experience a period of grief, fear, confusion, uncertainty and concerns about the future (Ludlow, 1999).

The importance of a positive self-image for people with intellectual disabilities returns often in literature (Seltzer, 1985; Schalock, 1997). Došen (1990) gives a central place to (the development of) the self-image in his explanation of psychopathologic processes in people with intellectual disabilities. A life of continuous dependence may change the self-image in such a way that one gets the idea that one is never complete without the help of others (Levitas & Gilson, 1989). In that way, feelings of pride (as a result of a performance) or security may become rare; this, in turn, is a risk factor for a stable identity. Dagnan and Sandhu (1999) found that in people with intellectual disabilities a cognitive process of social comparison is at work, a process that defines self-esteem to an important degree. Gibbons (1985) for instance has demonstrated that people with intellectual disabilities have a low esteem with regard to the social status of their own peers. Performance, the social appeal of one's own position and the feeling of belonging to a group are important protective factors for a positive self-image. This is not different for people with intellectual disabilities.

Although our research started in the knowledge that the problems mentioned occur in the target group, we did not want to take them as a starting point. We did not want to narrow the target group's psychosocial functioning to mental health deficits. The idea for this thesis originated from a positive attitude towards ageing. For some time now, gerontological research is paying attention to the question of how people can age 'successfully' (Baltes & Baltes, 1990). The idea is that elder people not only have limitations, but also and especially a lot of opportunities to live 'a good old day'. This intention concurred with the research line 'quality of live' of our research centre. The 'positive psychology' of successful ageing is about the concept 'well-being' - a notion that is closely related to, and even used as a synonym for (subjective) quality of life (Ryff, 1995). Mental health is not only a question of psychological problems; it also pertains to matters of happiness and meaningfulness. The paradigm of 'successful' or 'constructive' ageing, as well as that of 'quality of life' are -in a *normative* sense- a reaction to a one-sided negative portrayal of mankind. Whereas quality of life is regularly called in the same breath as empowerment, as a counterpart for 'handicapism' (the discrimination of people on the basis of their handicap), successful or constructive ageing is seen as a sensitizing leverage against 'ageism' (discrimination because of age). The idea arose to look for a subject in the vein of the 'successful ageing'-paradigm that respects the experience and potential of ageing people with intellectual disabilities. With regard to elder people, one can assume that subjective well-being is also strongly defined by experiences from the past (Diener, 1994). Our interest in reminiscence was stimulated by Marcoen (1989, 1996), who considers reminiscence to be a key concept in the psychosocial development of elder people.

The function of reminiscence

The term 'reminiscence' originates from the latin verb 'reminisci', which means 'to remember'. The importance of reminiscence for the mental well-being of man has already been proposed by Freud (Freud, Strachey, Freud, & Strachey, 1962). In his 'Pychopathology of everyday life' he describes how crucial the process of remembering (and forgetting) is in order to understand a man's psyche. In psychoanalysis an important role was reserved for the 'Wiederholung' or the process of 'durcharbeiten'. For Freud reminiscence was the entry to the origin of conflicts (regression). In the psychodynamic line of research the ruling geriatric conception therefore has for a long time been that overt reminiscence was a token of

psychological disharmony between past and present, and as a consequence of mental dysfunctioning.

Halfway the sixties Robert Butler (1963) observed that reminiscence may also have an adaptive function. He found that people who feel death drawing near, in general have more reminiscences than other people. Butler's hypothesis was that reminiscence allows elder people to re-evaluate and to solve conflicts from the past. He called this 'life review'. Butler advanced three propositions: (1) each person reminisces, and in due course draws up the balance sheet of one's past (universal character); (2) the nearer the end of one's life, the more reminiscence. Elder people reminisce more than younger people (age specific character), and (3) the evaluation of one's life is necessary as a preparation for death (adaptive function).

Butler's theory concurred with Erikson's (1963), and his concept of ego-integrity. Erikson was the first to draw attention to the importance of old age as a positive developmental stage in the framework of the entire life span and on the specific developmental tasks elder people must fulfill. Erikson started from a principle of growth. He interpreted the human life span as a sequence of eight psychosocial crises. Solving a crisis brings one in the next phase of one's life (epigenesis). Each crisis produces material for identity building. Erikson called those results 'virtues'. At Erikson's eighth and last stage of life the themes 'integration' and 'despair' face each other. In this phase the elder person has reached the point where he draws the balance sheet of his life, and yes or no acknowledges the life as he has led it. If the elder person acknowledges life as it has been and accepts that life has brought him to where he is now, there is integration; when he does not succeed to do so, it may lead to despair, all the more because life can not be done over or redressed. Erikson's notion of integrity, the necessity of being able to put it all together, to assess one's own life as worth living, can be heard in Butler's postulates. It implies, as with Butler, a positive appreciation of life review.

Over the years the concepts of life review and reminiscence have been mixed quite often in literature. There is however a conceptual difference. We explain this by means of a few recent definitions. "Reminiscing then is a rich experience distinguished from the memory of less personal events by the fact that it involves the process of reliving the past rather than the factual recall of historic events. Reminiscence can involve a variety of senses and emotions, [it] reflects the personal way we remember things, [and it] can be public or private" (Norris, 1988, p. 22); "A process of remembering long forgotten events or experience that are memorable for the person in question" (Burnside & Haight, 1992, p. 153); "Thinking back, more or less lively recalling events from the past and dwelling on these memories" (Marcoen,

1996, p. 16); "Remembering life events". For narrative reminiscence is added "...and communicating this memory" (Staudinger, 2001, p.149).

In the literature, life review is distinguished from reminiscence. Butler (in Lewis & Butler, 1974) says it is more: it is "a natural occurring, universal mental process characterized by the progressive return to consciousness of past experience, *and, particularly, the resurgence of unresolved conflicts*" (p.165). "Life review can thus be defined as that form of reminiscence in which the past is actively evaluated, and conflict is necessary for resolution to occur" (Molinari & Reichlin, 1984, p.83). Linking the evaluative part of life review to mental conflict is a typical feature of the psychodynamic tradition.

Butler postulates that reminiscence has a positive 'adaptive' function for each of us. According to him life review must lead towards integration. In his view, negative feelings -such as fear or guilt- during reminiscing, stem from the absence of sufficient openness with regard to the past (e.g. in people who want to keep memories to themselves). This problem can be remedied on the condition that adequate support (therapy) is given.
Butler's postulates did not remain uncontested. McMahon and Rhudick (1964) already made a theoretical distinction between different types of reminiscence of which certainly one, the defensive variant, had no positive function. Coleman (1974) too suspected that the different types of reminiscence have different functions that need not necessarily be adaptive. He found that people with a high morale as well as people with a low morale reminisce; in one person this means that one is occupied by negative experiences, in another person it signifies that one draws pleasure from these memories. Analogously there may be positive as well as negative reasons why people do not reminisce: e.g. because they do not see its use (people with a high mood level), or because they try to avoid memories (people with a lower mood level). Webster (1993) empirically indicated a number of reminiscence functions. He questioned younger and elder people about their reasons for reminiscing and arrived at seven functions: conversation, boredom, teaching, identity/self-image, resurgence of bitterness, maintaining (lost) contacts, and preparation for death. Resurgence of bitterness was a function of reminiscence, but it clearly is difficult to catalogue it as 'adaptive'. A study of Wong and Watt (1991) was an important breakthrough in the exploration of the functional adaptiveness of reminiscence. They succeeded in distinguishing between reminiscence types that turn out to have an adaptive effect, and reminiscence types that have a neutral or negative effect. The adaptive types were integrative (conciliatory) and instrumental (problem solving)

reminiscence. In their study obsessive reminiscence (fed by guilt) and escapist reminiscence (glorification of the past) turned out to be non-adaptive.
Narrative reminiscence remains a type that has been paid less attention to in the literature after Wong & Watt (1991). The narrative form is distinct from the other forms in that no interpretation, but only a representation of the past is involved. It is about autobiographical data or facts that may interest the listener. Narrative reminiscence is mainly supposed to have a social function: making contact and sharing information.

The relation between emotion and biographical memory was researched not only from a psychodynamic, but also from a cognitive-behavioural point of view. Lloyd and Lishman (1975) observed that depressive people are faster in recollecting more negative events. Later studies confirmed that these results could certainly not be explained by a difference in case history only. The explanation therefore was sought in information processing processes. Bower (1981) supported the 'mood state dependent memory'-effect: information that matches the state of mood can be better remembered than information that does not match the state of mood. The idea behind it is that in the neural network data are sooner activated by means of affective association.

Research by Williams and Broadbent (1986) brought an interesting evolution in this domain. They found that people with suicidal tendencies have more difficulties to produce specific memories. Further research showed that depressive people, people with a past of abuse, and people who suffer from a post-traumatic stress syndrome also turn out to 'over'generalize not only their traumatic, but also their positive memories (de Decker et al., 2000). A possible explanation for this observation is given by Williams et al. (1997): when they are confronted with traumata people learn to smooth their memories and to remember only their general features, in this way they avoid the negative feelings connected to them. Because also positive experience is generalized, a person arrives at a negative representation of oneself and the world. Successful experiences are put into perspective, and specific solving strategies are forgotten.

Effects and mediating factors of reminiscence work

It is only in the second half of the seventies that the theme of reminiscence gave cause to studies that researched its practical use. The influence of reminiscence activities on varied

dependent variables has since then been researched: (dis)orientation, attention, activity, activities daily living (ADL), affect-balance/mood, depression, level of functioning, satisfaction with life, psychological well-being, social adaptation, ego-integrity and self esteem (Haight, 1991; Haight & Hendrickx, 1995, Hendrix & Haight 2002). It was only in and after the eighties that quality of effect research was criticized (see a.o. Rattenbury & Stones, 1989). Molinari and Reichlin (1984) found that the nature of much research into reminiscence was rather anecdotal. The chief bottlenecks were (1) no consensus on expected effects and therefore no uniformity with regard to choice of outcome indicators, (2) weak theoretical support for the active aspect of reminiscence/life review and therefore no uniformity with regard to intervention, (3) few experimental designs with control-condition. Correlational research can not find antecedents. Thornton and Brotchie (1987) found that much research was biased, the way it was conducted as well as the way the outcome was measured. Haight (1991) on the basis of her search of the literature stated that reminiscence/life review may have positive results, but she considered the length of an intervention to be crucial, as well as its intensity. Haight (1991) further stressed the importance of well purging the terminology: a precise definition of outcome indicators is necessary.

Several better conducted studies on elder people without intellectual disability followed. They showed that the organization of reminiscence groups and structured life interviews may have (lasting) positive effects on life satisfaction (Cook, 1998; Haight, 1992; Rattenbury & Stones, 1989). There also were indications that the stimulation of specific types of reminiscence may significantly decrease depressive symptoms (Watt & Capelliez, 2000). Cook's research (1998) for instance resulted in a significant effect on life satisfaction in an experimental reminiscence group (compared to a control group who held a group conversation on current events). Haight (1992) found indications for an effect of reminiscence on life satisfaction, also on occasion of a follow-up study one year later. Rattenbury and Stones (1989) reached a significant effect with a reminiscence group (vs. a 'current topics' control group) on a scale for psychological well-being, but they also found a connection between progress on this scale and the degree of participation in the conversations. Involvement therefore was a mediating factor. Brooker and Duce (2000) used video-analysis and observed more indications of well-being and involvement during the reminiscence session than during the 'current topics' session.

Fry (1995) came to the conclusion that much of the variation in life satisfaction expressed in life review interviews can be explained by individual personality features such as empathy, optimism, humor, openness and internal locus of control. Cully, Lavoie and Gfeller (2001) also investigated the difficult relation between personality and reminiscence behaviour. They found that when there is question of a general healthy psychological functioning, the risk of negative types of reminiscence decreases. This supports the conviction that reminiscence style is not just a momentary way of reacting, but rather a slowly developed pattern, fed by a long history of personal experiences that have also formed personality.

Another mediating variable that emerges is the quality of the interaction between the reminiscent and the listener. This has be shown in children. They learn to tell stories about the past at those moments when they participate in conversations -structured by the parents- on the past (Fivush & Reese, 2002). Differences could be noticed between parents who were less specific or general (less elaborate) when entering into the memories, and parents who entered into it in a very specific and extensive way (more elaborate). Elaborating listeners – i.e. active listeners who facilitate reminiscence – give the reminiscent the opportunity of further entering into a memory. They confirm the memories and further the elaboration of certain details, by asking more relevant questions. It has been shown that children of elaborative parents even at an advanced age gave more detailed information when reminiscing (Fivush & Reese, 2002). We therefore assume that in reminiscence sessions the degree of elaborating by the facilitator may play a mediating role.

Kemp (DHSS, 1979) examined how reminiscence activities could break through the isolation of elder people and how it might improve the relation with the support staff. He observed a situation where people were shown a video and a situation where people talked about the past. A number of interesting conclusions were made: people enjoyed to reminisce, reminiscence made conversations spontaneous, it was a means of contact between elder people among themselves and with care staff, it could increase responsiveness, and the use of multi-sensory stimuli could induce a better reproduction. Bender, Bauckham and Norris (1999) too observed that reminiscence activities produce more than just measurable effects. They mention no less than 20 benefits of reminiscence that make such activities worthwhile and meaningful. We name some of them: it stimulates spontaneous conversation between participants or between personnel and participants, it improves group cohesion, it allows to re-use old skills, it deepens the diagnostic process and it increases the personnel's understanding for their clients.

It seemed to us that these objectives were also relevant for the support of people with intellectual disabilities and they were the reason for this study.

Chronological survey of the studies

From the start we saw this doctoral thesis as an action-oriented research project. We took Van Strien's (1986) regulative cycle as a guideline for the succession of our different studies. According to this author, the methodological 'basic figure' for problem-oriented practical thinking has the following stages: formulation of the problem, diagnosis, planning, intervention and evaluation. Consequently, *manuscript 1* and *2* describe two explorative studies, *manuscript 3* reports on the drafting of a plan and the development of an intervention, and *manuscripts 4* and *5* deal with the evaluation of this intervention.

We intentionally choose a mix of qualitative and quantitative methods (*4* and *5*) ('mixed methods') (Tashakkori & Teddlie, 2002). To be more precise: we performed qualitative as well as quantitative analyses on parts of the same source material.

Manuscript 1: analysis of the content of life evaluation interviews

When starting this doctoral research, we did not know whether the theoretical framework of reminiscence would be applicable to people with intellectual disabilities. We therefore first made a study to empirically explore reminiscence in the target group.

We preferred a qualitative approach: a content analysis of life review-interviews with 10 research subjects. It immediately became clear that the (volunteer) participants were happy to tell about their past. The transcription of the interviews offered enough material to test a number of 'core' parameters of reminiscence (occurrence, content, perception and typology). The results are presented in *manuscript 1*. This manuscript's general conclusion was that the above mentioned aspects of the reminiscence theory can also be applied to people with intellectual disabilities.

In the first study, we not only interviewed 10 'experts by experience', but we also conducted interviews with 14 'experts by practice' (support workers) (not reported on in *manuscript 1*). It was our intention to check their perspective on reminiscence support in the target group. The results of these interviews are described in Van Puyenbroeck and Maes (2004), a publication that is not included in this doctoral thesis. Its main conclusions were that there are important reasons for support workers to pay attention to reminiscence in their elder clients: extensive knowledge of their life story can lead to more individual support and better understanding of (especially negative) life events, to a more personal and continuous support

relationship, and to a better future planning. Most support workers already knew the method of 'life story books', whereas 'group reminiscence' turned out to be rather unknown. There was a consensus however that this group work, as an organized form of an often spontaneously occurring recreational (group) activity, might give a surplus value to practice.

Manuscript 2: known reminiscence work and -therapy with the target group

In order to get a better survey of the existing support strategies in connection with reminiscence, a closer look was taken at scientific research available by means of a study of the literature. *Manuscript 2* outlines and classifies the publications in a socio-critical, person-centered and clinical approach. It furthermore points out the absence of evaluative research and of a well-balanced theoretical model. The existing research puts too much emphasis on the problematic character of reminiscence in the target group (the main functions turn out to be dealing with loss or becoming self-aware from a disempowering past).

After *manuscript 2* it was conceptually clear that individual life review under the title 'life story work' already belonged to the known methods for supporting ageing people with intellectual disabilities. Much less was known of the potential of (narrative) group reminiscence. By group reminiscence we mean a group conversation where the theme of the past is intentionally introduced by a group leader, in order to prompt the ageing persons to reminisce. In group reminiscence it is the intention that elder people reminisce *together* (Norris, 1988). The programs that are described in practice-based gerontological literature generally assume that a group consists of 6 to 8 people and one support worker.

Manuscript 3: development methodology group reminiscence

After the explorative and diagnosing part in *manuscript 1* and *2* the action-oriented part of our research began: to develop a method for group reminiscence and subsequently to test it extensively (as to effect and process). For our target group we selected people with a mild/moderate intellectual disability because of the verbal proficiency that was needed.

The first step in this project consisted of the adaptation of an existing reminiscence program (Bruce, Hodgson, & Schweitzer, 1999). In this study we would also test the video-observation techniques for the subsequent evaluation studies. *Manuscript 3* describes how we learned 'by experience' how we could successfully combine reminiscence, group work and target group specific characteristics in a group of seven, for three months. By trial and error, in a formative evaluation, we learned what made sense, what was feasible and advisable. A presentation of the final reminiscence program and the specific strategies that were used (extra visual stimuli,

a fixed session structure and three support roles) were then collected in a manual. Other new care facilities were then sent this manual and asked whether they were willing to collaborate in a long term evaluation. It was stipulated that the permanent collaboration of a support worker was required. As soon as the necessary six services were found, the volunteer support staff member went through a training day and a test session in his or her own care facility together with the researcher. Next, the program was again submitted for approval by means of a semi-structured interview. The formative elements of this questionnaire are also discussed in *manuscript 3*.

During and after *manuscript 3,* much time was spent on the development of a procedure to arrive at a structured analysis of the video recordings. Observation is not an obvious option for group work. The object of the study (what happens in the group and in each participant separately) can not be shown from one point of view. The first problem was the synchronization of the double video input. The second problem was finding an appropriate instrument for processing the video data in an easy structured way. To this cause, we developed, with the expert help of a volunteer programmer, a software program named Vitessa, in order to structure the data in an easier and user-friendly way (Van Puyenbroeck, Maes, & Laeremans, 2005).

There are two traditions in measuring subjective well-being (Marcoen, 2002). The hedonistic approach stresses happiness (well-being is the maximization of satisfaction and positive affects), while the eudaimonic tradition sees well-being rather as successfully pursuing or realizing a number of basic needs (on different domains of life). Although the second tradition's theory is superior, its operationalization is not easy. Because we needed adapted questionnaires and in addition had the prospect of a behaviour analysis, we opted for the 'hedonistic'-approach. In evaluation studies of reminiscence, life satisfaction, self-esteem and an affect indicator (mood) are the most frequent (chosen) outcome-variables.

Manuscript 4: effect of group reminiscence on life satisfaction, self-perceived competence and mood

After the test sessions, a reminiscence program of 12 weekly sessions was started in all groups, with a total of 41 participants. We provided two main sources of information for the assessment: questionnaires before, in between and after the sessions on the one hand; video-observations during the sessions on the other hand. The questionnaires were used in order to answer the question of the differential effect of group reminiscence against an alternative form of group work ('current topics') on subjective well-being. In order to motivate all people

for the study, and also for deontological reasons, we have used a quasi-experimental ABA-design: three sessions of alternative current topics group work, six sessions of reminiscence, and again three sessions of group work without a focus on reminiscence. The results are described in *Manuscript 4*. To sum them up: the analysis taught us that satisfaction with life and self-perceived competence could not be influenced. Neither could the increase in mood level be explained by an effect of condition, but possibly so by an effect of time. The participants themselves evaluated the program as positive, however without a preference for the reminiscence part. As a consequence, the hypothesis shifted to the positive effects of the group work itself. This we wanted to check this result in an analysis of the video-data (*manuscript 5*). In *manuscript 4* we also checked whether the degree of specificity of the participants' memories co-varied with their mood scores. This was not the case. The personality characteristics extraversion and emotional stability turned out to have a strong correlation with mood.

Manuscript 5: effect and process evaluation of (reminiscence) group work

Because there are sufficient reasons for assuming that the use of questionnaires with people with intellectual disabilities may be unreliable, we have opted for behavioural observation from the start of this research project. *Manuscript 5* reports on the analysis of video data, for which a quarter of an hour or half an hour (dependent on the variable), from a session was selected. The participants' variables activity, focus and smile, and the support variables visual and verbal strategies were scored every 15 seconds. A sequential analysis of the data gave provisional proof that group reminiscence may have an activating effect and increase involvement, and that visual strategies are more efficient than verbal ones in that process.

“I began early in the morning, every day they came to pick me up. There were other men on that bus too. I had to leave home at seven. And when the bus had completed its round, we arrived at work, and then we started, around half past eight, I think, till five o’ clock. Well, till four, actually, cause the bus needed to pick up everybody again to bring them home.
Once in a while, I had to give directions to the driver. Those drivers, they didn’t do the same route every day, sometimes they didn’t even know where they were. Luckily I was there to help them!”

Manuscript 1:
Reminiscence in ageing people with intellectual disabilities: an exploratory study[1]

This study explores the occurrence, content, feelings and types of reminiscence in ageing people with mild/moderate intellectual disabilities. It searches to find out whether and how ageing people with intellectual disabilities think and talk about their pasts, what themes arise during their reminiscences, and why they talk about these memories. A limited number (N=10) of people with mild or moderate intellectual disabilities were interviewed. Transcripts were analysed in depth. Results show that reminiscence, whether in a verbal or non-verbal form, occur regularly or often in our sample of participants. Most frequent themes of reminiscence were 'important others', 'work/education' and 'living at home'. The content analysis further resulted in a rather large variety of negative themes, which can be directly or indirectly related to the individual's disability. Instances of all types of reminiscence, derived from the taxonomy of Watt and Wong (1991), were found. The results feed the assumption that reminiscence theory is also applicable to ageing persons with mild/moderate intellectual disabilities.

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[1] Published as Van Puyenbroeck, J., & Maes, B. (2005). Reminiscence in ageing people with mild intellectual disability. *British Journal of Developmental Disabilities, 51*(1), 3-16.

Introduction

Reminiscing can be defined as ‘remembering memorable events or experiences of long ago’ (Burnside & Haight, 1992). It is a concept widely explored in psychological literature (Haight, 1991; Haight & Hendrix, 1995; Hendrix & Haight, 2002), with different terms being used: life review, oral history, life history, life reflection, auto-biography, and narratives. The reason for this widespread interest is the belief that reminiscence can help a person to age 'successfully' (Butler, 1963). It is described as: a means to understand and come to terms with one’s own past; a pleasant, satisfying activity; a way to communicate and make contact; a way to earn recognition; and finally, a means to get a better understanding of changes (Coleman, 1986; Gibson, 1994).

Until now, research into the process and method of reminiscence in people with intellectual disabilities has focused primarily on gathering life stories from a socio-historical and critical point of view, and on supporting life transitions and/or bereavement. ‘Life history’-research has drawn attention to the ‘lost voices’ of persons with intellectual disabilities in (re)writing the history of care and (de)institutionalization (Atkinson, Jackson & Walmsley, 1997). Auto-biography is also seen as a suitable way to raise critical consciousness regarding the past and to reach self-representation (Atkinson & Walmsley, 1999). A link can also be made with research into the bereavement-process of people with an intellectual disability. Since Oswin's pioneering work (Oswin, 1991), the body of literature in this area has been growing steadily, with many links to the concept of reminiscence (Read, 1996). A lot of research has focused on the analysis and support of ‘atypical’ bereavement behaviour, including obsessive reminiscing (Summers & Witts, 2003). Bereavement therapy therefore involves the support of coping with loss and successfully integrating the past into the present. Stimulating reminiscence is supposed to aid in preparing for and coping with important life transitions (Husain & Raczka, 1997).

Many examples of attention being paid to reminiscence can also be found in the practice of care. In most cases, the emphasis is put on charting the life story of the elderly. Reminiscence then is seen as an indirect means to gather information, for example to help a person making plans for the future (Stuart, 1998), or simply as a recreational activity (Porter, 1998). For ageing persons with severe intellectual disabilities and/or dementia -who cannot speak for themselves anymore- it is also regarded as a way to protect their life story from getting lost (ENIDA, 2000).

We want to make a conceptual difference between reminiscence as a natural occurring psychological phenomenon and reminiscence as a guided activity, aimed at stimulating reminiscence. Types of ‘natural’ reminiscence are described by Wong and Watt (1991). Simple, or narrative reminiscence can be seen as 'storytelling'. Integrative reminiscence refers to an evaluative form of reminiscence, with signs of successful reconciliation, while instrumental reminiscence means recall of successful problem-solving. Transmissive reminiscence, which completes the row of positive forms of reminiscence, is conceived as a transfer of important beliefs and values. Negative forms of reminiscence include defensive reminiscence, in which the past is idealised, and obsessive reminiscence, when one cannot overcome traumatic experiences.

Reminiscence activities can best be defined as ‘guided reminiscence’. It includes methods such as group reminiscence, individual life review therapy, the compilation of a scrapbook or photo album, auto-biography, a reunion or pilgrimage to former living homes, or a museum visit. Watt and Capelliez (2000) point out that reminiscence activities should focus on integrative and instrumental reminiscence, because only these types were found to be clearly associated with positive emotional well-being. Integrative reminiscence can counter a negative self concept by creating a balance between positive and negative memories, by diminishing feelings of guilt by new external attributions (situated in the past), by generating internal instead of external standards for self judgement, and finally, by giving meaning to one’s life. Instrumental reminiscence can raise self esteem by bringing back into memory experiences of successful problem-solving and by learning to see the importance of earlier goals in a historical perspective.

In this explorative research project we wanted to learn how ageing persons with intellectual disabilities reflect upon their personal past, i.e. talk about it. Our research questions more specifically focused on 1) occurrence: how often do persons with intellectual disabilities reminisce spontaneously; 2) content: what themes from the past are ageing persons with intellectual disabilities talking about in their reminiscence conversations? 3) feelings: how do people feel about their pasts? and 4) type of reminiscence: can we find all reminiscence types mentioned above?

Methods

Given the explorative aim of our research questions, a qualitative approach was chosen. We conducted semi-structured interviews with a limited number of persons (N=10). This way we were able to analyse reminiscence thoroughly by means of a multiple case content analysis.

Selection

Persons with mild/moderate intellectual disabilities were selected. The aim was to have as much variation as possible regarding the variables sex, age, region (every interviewee was living at a different address) and setting of support. A number of services, all over the region of Flanders were addressed (N=24). The invitation to participate stated that we would like to interview persons with a mild/moderate intellectual disability older than 50, willing to tell about their pasts. In a separate letter, intended for the people themselves, the aim of our research was explained in clear, simple language, and permission to visit them was sought. 11 persons responded positively, but 1 person turned out to be younger than 50. This person was interviewed, but the interview was not analysed afterwards. The average age was 58.5 years. IQ scores for each individual were derived from individual dossiers, after we received a written permission from each care provider. WAIS-scores varied between <50 and 71.

Table 1.1. Characteristics of the participants

N°	Sex	Age	Form of care	Intellectual functioning†
P1	F	58	residential care***	moderate intellectual disability†
P2	M	50	living independently*	mild intellectual disability†
P3	F	51	residential care	moderate intellectual disability†
P4	M	57	community care**	mild intellectual disability†
P5	M	66	residential care	mild intellectual disability†
P6	F	53	living independently	mild intellectual disability†
P7	M	56	community care	moderate intellectual disability††
P8	F	52	living independently	moderate intellectual disability†
P9	F	70	residential care	mild intellectual disability†
P10	F	72	living independently	moderate intellectual disability†

Note:

* *living in a community embedded house, alone or living with 1 or 2 cohabitants, with occasional support*
** *living in a community embedded house (sheltered environment), with less than 5 cohabitants, with permanent support*
*** *living in a residential home (sheltered environment), with less than 7 cohabitants, with permanent support, not community based*
† *derived from IQ –scores in individual dossiers*
†† *clinical judgement by staff*

Procedure and data-gathering

Our research questions and methods were evaluated by the ethics committee of our faculty to ensure that several important ethical conditions were met, the most important being 'informed consent' (Stalker, 1998). Apart from obtaining a handwritten acknowledgement before we visited the participants, permission was also asked at the beginning of each interview. The participants were interviewed at a location of their own choice. The interview always started with an extensive round of acquaintance. The aim of the interview was explained each time and permission was asked to use the data later for analysis. If, during the interviews, there was any sign of emotional distress, the subject of the conversation was abandoned, unless the participant explicitly expressed his desire to continue. At the end of an interview pictures were taken from interviewer and interviewee. These pictures were sent back afterwards, along with a thanking note, a transcription and a summary of the interview.

Previously drafted guidelines were used for the interviews. These guidelines included both questions about the personal life story and questions about occurrence of or reasons for thinking/talking about the past. Using these interview guidelines did not imply however that the interview was completely structured. The interview always began with an open question like 'What do you remember about your past?'. If the interviewee asked what he had to say, it was always made clear to this person that this was something he or she could choose for him- or herself, to avoid social acquiescence (Finlay & Lyons, 2001). All conversations were held in a spontaneous atmosphere. When certain topics of interest, cited in our interview guidelines, arose during the interview, additional questions were asked. If necessary, these questions were paraphrased to ensure that the participants understood them (cf. appendix A).

At 8 of the 10 interviews a coach who had been chosen by the interviewees themselves, was present. In all cases this coach was the personal, professional caregiver. The average duration of the interviews was approximately 1 hour. Interviews were digitally recorded and fully transcribed. Sometimes it was difficult to understand the participants because of their dialect or speech-problems.

Transcription

The interviews were fully transcribed, including fragments that didn't relate to the past. Recorded fragments that were not understandable, due to dialect or speech problems, were annotated with a special symbol [], and not 'filled in' based on the context of the fragment. Silences, explicit emotions, and volume of speech were also transcribed. Repeated sentences were fully transcribed. The names of the participants were substituted by numbers (P1-P10),

the name of the interviewer abbreviated to FAC (facilitator), the name of the coach to COA. The quotations used in this text were literally translated to English. Paragraph numbers refer to the original Dutch transcription.

Analysis

The transcriptions were processed using the NUD*IST program (QSR, 1998). The original scheme included codes for several theoretical aspects of reminiscence, the most important being: 1 code for 'occurrence ', 10 codes for ‘content’ and 6 codes for 'types'. In order to help determine the type of reminiscence, another two concepts were added to the scheme during analysis, namely 'past feelings' (8 codes) and 'present feelings' (5 codes).

As suggested by Kovach (2001) the paragraph was taken as a unit for analysis. The reason for taking a fairly large unit of analysis was to be able to assess the meaning of an event in a sensible way. The content or type of reminiscence was determined by examining a number of combined sentences that describe an event, situation or relationship. The meaning of the content was derived from one or more paragraphs and non-verbal annotations in the transcript. Interview fragments relating to the present (e.g. present activities, hobbies, ...) were not coded, unless they appeared to have an origin in the past. At a certain moment during analysis, the coding scheme was adapted when it became clear that too many fragments could not be integrated into a particular sub-scheme (concerning content of reminiscence), without losing a great deal of their specific meaning. These fragments were double-coded: one time with the existing scheme, and another time with an alternative, inductively developed scheme.

Results

Occurrence

The first research question pertained to the occurrence of reminiscence in persons with intellectual disabilities. It should be noticed that the interview was not only about verbal reminiscence; we were also interested in non-verbal reminiscence (thinking of the past, keeping and watching pictures, ...). The question whether persons with intellectual disabilities are actively occupied with their past, can be answered in the affirmative on the basis of the interview data. As to the nonverbal, individual-reflective form of reminiscence ('thinking of'), 8 out of 10 respondents testified that they are regularly occupied with the past. Two respondents confirmed that they think daily of the past. As to the verbal forms of reminiscence a slightly different picture emerged. All participants said they talk to others about their pasts, but that this depends on a number of factors: the urge one feels to talk about

the past, a group where one feels at home, a trusted person or a caregiver who is able, available and/or willing to converse, and the nature of the remembered event or circumstance.

Content

Themes

In order to answer the second research question, we used the same taxonomy as O'Leary en Nieuwstraten (2001). Their classification includes: childhood memories, domestic life and relocation, education and work, significant others (those people who have relatively important relationships with the participant), dating and marriage, children and grandchildren, societal events, health, death and existential beliefs. The percentages in table II reflect the proportional number of paragraphs coded with a certain topic, relative to the total amount of paragraphs in an interview.

Table 1.2. Percentages of paragraphs coded or double coded with a certain topic, relative to the total amount of paragraphs in the interviews.

%	Childhood memories	Domestic life and relocation	Education and work	Significant others	Dating and marriage	Children and grandchildren	Societal events	Health	Death	Existential beliefs
P1	4,8	13	31	18	8,5	0	5,4	1,6	2,4	4,4
P2	6,8	7,4	2,7	8,4	11	0	4,1	5,2	0	0
P3	1,5	4,2	4,2	15	5,4	0	1,0	14	2,1	0
P4	2,1	6,5	29	14	5,7	0	2,2	9,1	6,0	0
P5	12	2,7	28	17	1,7	0	6,9	2,4	1,8	0
P6	3,8	8,1	5,5	35	3,0	0,73	6,1	2,4	7,3	0
P7	2,8	7,1	7,7	24	0	0	1,9	6,6	5,3	0
P8	5,8	6,3	1,2	9,2	0	0	3,4	0,5	7,8	2,1
P9	0,17	12	13	23	1,7	0	3,1	6,5	5,3	1,7
P10	0	13	9,4	19	2,0	0	2,3	2,3	2,3	0,33
Mean	*3,977*	*8,03*	*13,17*	*18,26*	*3,9*	*0,073*	*3,64*	*5,06*	*4,03*	*0,853*

Inter-rater agreement turned out to be 'moderate' (κ =0.54) (Altman, 1991). Disagreement was mainly due to the fact that the coding scheme included other topics than merely 'content'-codes, resulting in a greater chance for overlap. Also, a number of fragments could justly be coded to different categories at the same time. Therefore, these numbers have to be interpreted with care. They can merely give an impression of which themes occurred more than others during the interviews.

The first striking feature is that certain themes did not or did not often get a mention. This applies to, among others, ' existential beliefs' and ‘children and grandchildren’. None of the participants has children. The analysis further revealed that there is very frequent talk of ‘significant others' and ‘education/work'. They were part of each participant’s regular subjects. As to ‘significant others', the parents turned out to be the most important source of memories. An interesting feature of people who have been living at home for a long time, is the theme of their parents’ death, their moving, and the places where they have been staying since. Several participants especially talked about the special 'bond' with their mother, and also about the feeling of 'belongingness' in this relationship. Several persons constructed their life story mainly by citing the places where they had been living ('domestic life and relocation'). The topic 'dating and marriage' had always to be asked after explicitly, except for P2. The topic ‘death’ was mentioned most in the context of the parents’ passing away.

Working activities covered work at the parents’ home, activities in a day centre or sheltered workshop. According to Verwoerdt (1988) men are more inclined to emphasize activities and performance, whereas women tend to put more emphasis on ties and relationships. This explorative research project has confirmed this to be true to a certain degree. P5 put much emphasis on his year long work in a sheltered workshop, P4 remembered himself being an aid to his father (a farmer), and P7 stressed his and his parents’ responsibility in running a business. The female respondents on the other hand emphasized the relationships with others, especially the family. The female respondents (P6, P8, and P9) had the highest scores on this topic. There can however be no question of a strict division. All male interviewees, and certainly P5, also spoke of important persons and relations. Furthermore, some female respondents (P1 and P8) talked quite a lot about their past activities. However, it appeared that they merely reported their activities as information, without the specific intention to communicate a feeling of self-respect or performance.

Feelings

The content of the interviews was not only analysed thematically, but also according to how the participants experienced their memories (third research question). A distinction was made between ‘past feelings’ (feelings one experienced in the past) and ‘present feelings’ (feelings regarding the past). The attribution of feelings to memories was mostly based on explicit wordings (e.g. [P5: 836] “I became angry”, [P4: 332] : “We had fun”), in some cases on interpretation (e.g. [P1: 420] “I think a lot about my mom […] In winter, when leaves are falling, it becomes difficult, I get touchy”). Interrater agreement was calculated: for the

classification of present feelings this agreement was "moderate" (κ= 0.58), for past feelings it turned out to be "good" (κ = 0.72) (Altman, 1991).

Similarly to the classification method of Kovach (2001), we categorised the memories of feelings as 'positive' or 'negative' (κ= 0.88, "very good"), and related these to broad categories of reminiscence content.

Table 1.3. Memories with a positive or a negative feeling attached to it

	Positive	**Negative**
Persons	mother, father, brother, sisters, professional care-giver	father, mother, brother
Relationships	education, protection, caring	being a victim of : authoritarian treatment, abuse of trust, patronising protection, pestering, group treatment, banning/ordering
Circumstances or time periods	time with parents, work at home or in sheltered workshop, good transport facilities	bad accommodation, heavy work rhythm or harsh work circumstances, health, psychiatry, handicap, exclusion, loneliness, army, clothing, money/possession, nourishment
Personal characteristics	ability to cope, memory, stubbornness/resistance, ability to work hard	handicap, booze, responsibility as a burden, ignorance, disorientation
Events	visits, joke, party, a test, act of courage	punishment, theft, war, deceit, fight, victim of joke, accident, revenge, gossip, danger, crisis (e.g. during transition period), pain, injustice

It is striking that from a qualitative point of view a greater variety of negative rather than positive memories came forward during the interviews. The negative memories were also often directly or indirectly related to the person's disability. Negative feelings included anger, sorrow, fear/anxiety, shame, regret, envy, disappointment and compassion. Yet there were also many memories about joy, pride, love and relief.

```
[ P10 : 319 - 322 ]
*FAC:   And then you left that place, that home for the elderly, [and
        you went] to …
*P10:   Yes, [I moved] to M. I was happy then ! Oh!  As happy as can
        be!
```

'Present feelings' included: anger, sorrow, anxiety, nostalgia, guilt/regret, bitterness, prudence/shame, but also resignation, happiness, pleasure, pride, satisfaction and relief. The participants exhibited very individual strategies to cope with their own traumatic experiences (positive, negative, neutral or discrepant). P6 for example was still grieving about her mother, but she showed rather determined not to get carried away too much:

```
[ P6 : 784 - 797 ]
*FAC:   You went to the funeral?
*P6:    Yes. Yeah... yeah (silence, sigh, silence, P6 starts to cry a
        little)
*FAC:   You don't have... it's not pleasant to recall this, is it?
*P6:    No.
*FAC:   Then we will not continue talking about it…
*P6:    (decisive) No.
```

Negative present feelings about the past seemed never really problematic, except for P7.

The advantages of this 'experiential' analysis are that it shows a past that is 'lived through' and that it proves how a similar memory can be experienced very differently by different persons. It also helped us in determining the type of reminiscence.

Types

Regarding the last research question, the taxonomy of Wong and Watt (1991) was used. We wanted to check whether the usual types and possibly other forms of reminiscence could be distinguished. All cited quotations were agreed upon by two independent raters.

Narrative reminiscence

This type of reminiscence is most frequent in our analysis. It is also described as simple reminiscence, because it means nothing more than relating a fact, a simple story. Memories are passed on as information for the listener. These memories describe certain events, circumstances, persons. To give a few examples: P1 described all the places where she worked in detail, P3 talked about the problems in marriage of her brother, P9 described the pub where she used to stop by and have a drink.

Integrative reminiscence

Erikson (1963) stated that integration is a developmental task for the elderly. At the end of one's life, one needs to resolve past conflicts, in order to achieve reconciliation. The hypothesis is that, when this integration is successful, self-understanding, personal meaning, self-esteem and life satisfaction will increase. It should be noted that conflicts need to be resolved in a reflective way, i.e. by putting the past in its right perspective. If integration doesn't succeed, feelings of guilt, failure and depression can arise (Butler, 1963).

```
[ P4 : 865 – 886 ]
*FAC:   And your mother was at home, when you arrived drunk?
*P4:    Yes
*FAC:   Did she like that?
*P4:    I gave it up for her. I said:[]. And I gave up drinking.
*FAC:   I didn't understand what you just said.
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*P4:    I said:' I'll stay with my mother, instead of drinking'. 'Just
        go and drink, you're not worried about your mother at all', she
        said.
*FAC:   Yes...yes. And then you stayed home for the sake of your
        mother?
*P4:    Yes.
*FAC:   And your friends kept on drinking?
*P4:    Yes. [silence]
        During the last years of her life, I have taken good care of my
        mother.
```

P4 lived many years with his mother. Several negative incidents (going out and coming home drunk) are still matter of conflict to him. In the interview however he emphasized his decision not to drink any more. This decision reconciles him with the past, although it is still not easy for him to think of his mother's grief (cf. silence). P4 finds comfort in the fact that for years he has taken care of his mother.

Instrumental reminiscence

This form of reminiscence means that one recalls former plans, objectives, and attaining these objectives. Such reminiscence is said to add to feelings of competence and continuity (the feeling of being master of the situation having learned from the past). Instrumental reminiscence means recalling past coping strategies, to communicate a sense of pride, of mastery. It can also help to overcome present stressful problem situations (Billings & Moos, 1981). Past knowledge and skill are emphasized in order to convey to the (young) listener the importance of an achievement. For example, P5 loved to talk about the work he did at home, on a farm. He remembers pitching the hay up onto the hay wagon:

```
[ P5 : 1678 - 1687 ]
*P5:    In those days all was still done by hand, with a pitchfork...
        loading the wagons...
*FAC:   All by hand
*P5:    By hand... corn ...everything, with a pitchfork
*COA:   Yes.
*P5:    Up the wagon. Unloading the wagon. That was one of my
        specialties... unloading them.
```

Both P4 and P5 had several memories from which they drew self-esteem. The fact that they had been able to do some heavy work made them proud of themselves.

Transmissive reminiscence

'Transmissive reminiscence' involves the transfer of values or ideas that are felt to be important. It answers a need to preserve an inheritance of culture or wisdom. Instructive stories that tell about the past belong to this category. It is said to increase self-esteem (McMahon & Rhudick, 1964). This form of reminiscence may be moralizing. P4 for example,

showed satisfaction with the fact that somebody, who works with him in a day centre, respects his love of work. Another example was found in P1, who talked about hard work conditions, much different to what young people have to go through now. She sought an agreement with the facilitator (a younger person) on this particular past-present contrast:

```
[ P1:   167-168 ]
P1:     I did my share of work, and I know what it means [to work
        hard]. I did it all. It was all a bit of misery. Now they
        [youngsters] are spoiled. They don't know, do they?
```

Escapist/defensive reminiscence and nostalgia

Idolization of the past, possibly along with a depreciation of the present, can be characterised as 'escapist' or 'defensive' reminiscence (LoGerfo, 1980-1981). It is considered to be a pathological form of reminiscence, although it may help someone to keep one's self-esteem. No clear examples of this form were found after analysis.

Obsessive reminiscence

Obsessive reminiscence is also known as 'lamenting' reminiscence (Kovach, 2001). This form is said to have its origin in feelings of guilt (LoGerfo, 1980-1981). One repeatedly comes back to past events, expressing feelings of guilt, bitterness and despair. This kind of reminiscence is supposed to generate depression, irritation, panic, and even suicide. One never has come to terms with the event(s) of the past, one always comes back to them.

P7, P9 and P10 spoke very bitterly of the past. P10 always came back to a certain period in a home, for P9 the loss of father, brothers and sisters in a bombardment during the war was the central event, to such an extent that even now she can burst out in tears, and P7 introduced the same topic of 'impotence' by exclusion in many subjects.

P7 remembered several family deaths. Every time he remembers a certain death, he gets bitter about the fact that his family didn't share these events with him. His despair and fatalism were present during the whole conversation. Not so much in one expression of bitterness, but through repeated lamenting [underline] a pathological picture emerged:

```
[P7 : 71 - 74 ]
*FAC:   And your father, your dad?
*P7:    Well, my father was even worse. He died and I didn't know how
        he died. He didn't let me know. Firstly, I didn't know how he
        died. I didn't know to whom he had called. I didn't know to
        which family member he had called.
```

The negative memories are revived, but from a psychological point of view not in a constructive-explanatory (interpreting) way, but in a rather repetitive-alarming way.

Discussion

As this research project was carried out on the basis of a limited sample of volunteers who were interested in the subject, the results must not be generalized in a sense that all people with a mild or moderate intellectual disability often reminisce. Butler's thesis that all ageing people (want to) reminisce (Butler, 1963) was already refuted by several studies (Merriam, 1993). However, we did find ageing persons with intellectual disabilities willing to reminisce about several themes, with a lot of sentiments involved, resulting in a variety of types of reminiscence. This study was not intended to prove that people with intellectual disabilities reminisce similarly to people without intellectual disabilities, but it nevertheless showed that general reminiscence concepts are applicable to their stories.

The participants' memories were often quite simple, grave reflections were scarce. Their life review did not appear as an intellectual labour, driven by the prospect of mortality (Butler, 1963). Such reminiscence would imply an abstract understanding of the concept of death ánd a high level of mental state reasoning, skills that are both quite difficult for people with intellectual disabilities (McEvoy, 1989; Benson, Abbeduto, Short, Nuccio, & Maas, 1993). The participants rather wanted to talk about bad memories, and the feelings involved. Based on their stories, we interpreted succesful integration as 'being able to talk about the past in a positive, resigned way, even if it is traumatic'. Before the study, we had some doubt whether we could ask people to talk about the past, including the bad memories, but it quickly became clear that the participants turned out be quite willing to share their most personal memories. This study showed that reminiscence feelings could be interpreted quite convincingly during analysis. Still, we only included people with mild/moderate intellectual disabilities. Further research could try to gain insight into the phenomenon of reminiscence in people with more severe forms of intellectual disability. Life story research is already making great progress in this field (Middleton & Hewitt, 1999). Speech analysis then is replaced by behavioural observation, and adequate forms of communication have to be sought to let memories be expressed in an authentic way (Jones, Pring & Grove, 2002).

An implicit objective of this study was to check whether it makes sense from a caregiver's perspective to focus on reminiscence in people with intellectual disabilities. We will give some examples based upon our results.

Regarding reminiscence topics, the results show that social relationships from the past were very important to the participants. Adequate coaching must therefore have an eye for this (early) social network. This may imply a reconstruction of the past social network.

Another interesting finding was the occurrence of obsessive reminiscence. Detecting and analyzing such reminiscences can possibly help in bereavement counselling (Blackman, 2003). To help P7 cope with his grief is to help this person to grasp the context of a negative event: his family prudently excluding him from sad news. A reminiscence approach clarifies this; it can help P7 by stressing positive instead of negative family relations, and trying to re-establish old contacts.

We want to make a pledge for broadening the interest in reminiscence from a pathological view (bereavement, coping with loss) to a more positive approach, which pays attention to stimulating 'successful' (integrative and instrumental) reminiscence. Both types of reminiscence were already successfully stimulated by means of group reminiscence therapy, resulting in an increased emotional well-being (Watt & Capelliez, 2000). Considering the higher risk of psychosocial problems in ageing people with intellectual disabilities (Tyrell & Dodd, 2003), future research on how reminiscence activities can effect emotional well-being in this target group, could prove to be very useful.

Besides this, reminiscence activities like group reminiscence or creating life story books don't necessarily have to be therapeutic. Bender, Bauckham and Norris (1999) give more than twenty reasons for stimulating reminiscence in elderly who live in a care setting. Being a pleasant and satisfying activity, it can improve mutual understanding between the elderly and their carers. It can facilitate social contacts, and it can help to personalize every aspect of care. Similar to the effect of reminiscence on subjective well-being (and hence, quality of life), reminiscence activities can result in very individual support strategies, respectful to an individual's life story, contributing moreover to a person-centered quality of care.

Respondent: My brother had five of those cars, first a green one, then a black one, than one with … err… you know, things on top [spoilers], and he asked us: "Hey, why don't you go for a ride with me?". You see, I had to laugh. He drove in our street; I said to my mum: "Let's not get in the same car with him". And oh boy, he drove like mad in our street, and suddenly, the car was upside down… beside the road.

Facilitator: He drove too fast?

Respondent: For sure! We had such great fun!

Manuscript 2:

A review of critical, person-centered and clinical approaches to reminiscence work for people with intellectual disabilities[2]

This article reviews reminiscence research with regard to people with intellectual disabilities (ID). Although the term 'reminiscence' is not often used in intellectual disability research, the concept offers a good framework for charting the different approaches in literature, thanks to its multidisciplinary character and eclectic theoretical background. Three main perspectives are identified: a critical approach, in which reminiscence work is used to give a voice to people with ID on their lived experience, a person-centered approach, in which reminiscence work serves informational and social purposes, and a clinical approach, in which reminiscence work is presented as an alternative diagnostic instrument and/or a 'low-threshold' narrative counselling method for people with ID with emotional problems. The three approaches differ in terms, aims and backgrounds, but all agree that reminiscence work can strengthen the identity of people with ID, raise self-esteem and enhance social contacts. The review concludes that a more balanced view on reminiscence, better methodological procedures and more evaluation studies on the effect and process of reminiscence work are needed in future research.

[2] Manuscript submitted for publication. Co-author: Bea Maes.

Introduction

Quality of life is commonly conceived of as being a 'life-span' concept (Schalock, Brown, Brown, Cummins, Felce, Matikka, et al., 2002). A person's perceptions of life quality are time-related and situation-dependent and tend to vary according to changing life circumstances. Subjective well-being is not only determined by what people experience today, but also by what happened to them in the past, and their retrospective view on those life events (Diener, 1994; Westerhof, Dittmann Kohli, & Thissen, 2001). This also applies to people with intellectual disabilities (ID). Their own accounts of what life has brought to them show the negative impact of certain life events, but are also evidence of their competence to accomplish a better quality of life (Hunt, 1967; Deacon, 1974).

In this study, we want to present a review of what is known about the perceptions of people with ID regarding their pasts, and the reported benefits of different types of support to help people with ID to look back on their lives. This review will highlight studies from different research traditions. Because of that, different terms will be mentioned: 'life review', 'oral history', 'life history', 'autobiography' and 'narrative'. As a unifying framework, we will use the concept of 'reminiscence'.

Reminiscence is a term with multiple meanings. It can refer to the spontaneous occurring (social) human behaviour of recalling the past, or to a practice (reminiscence work or therapy) in which this behaviour is intentionally stimulated. If we say that somebody reminisces, we mean that this person relives past experiences in detail. Reminiscence is not simply recalling some 'facts'. It reflects the personal and subjective way in which we remember things. It can be 'public' or 'private' (Norris, 1988).

The advantage of using the concept of 'reminiscence' for the analysis of the literature is that it permits an eclectic approach. It is now agreed upon that reminiscence is a pre-eminently multidisciplinary research subject (Bornat, 1994; Haight & Webster, 1995). Although the term originated in the psychiatric/psychological research tradition (Butler, 1963; Coleman, 1986), its application has become widespread in a variety of human sciences.

Looked upon as a psychological phenomenon, reminiscence not only refers to the cognitive or social function of memory, but also to its relation with subjective well-being. Since Erikson postulated that reminiscence is a means to reconcile the past self with the present self (Erikson, 1963), and Butler asserted that life review is a means to age 'successfully' (Butler,1963), research has tried to get a grip on the benefits of reminiscence work or -therapy, applying different theoretical frameworks. A psycho-analytical view separates 'life

review' from reminiscence as (being) not only the recall of past events but also a process of conflict resolution (reconciliation of past and present self) (Haight, Bachman, Hendrix, Wagner, Meeks, & Johnson, 2003). An experiential approach was introduced by Webster (1998) by linking reminiscence functions to different attachment styles. There has also been an increasing interest from cognitive-behavioural psychologists in inner and outer reminiscence behaviour. In this context the term 'autobiographical memory' is preferred (Serrano, Latorro, & Montanes, 2004). Overall, there is a consensus that reminiscence has different functions and types, of which some are indicators for a good mental health, while others are not (Webster, 1993; Wong & Watt, 1991).

Reminiscence has not only been studied or used with psychological interest. In historiographical research, reminiscence work is seen as a method that can provide verbal information about non-written past events. 'Oral history' describes the past not as a series of objective facts, but as the 'lived experience' of witnesses. The narrative analysis of personal, authentic stories helps to understand the impact and human context of historic events (Dunaway & Baum, 1997).

Reminiscence work has also become a method of data gathering in ethnographic research, which combines participatory observation with in-depth interviews to describe a person in a context and with a history. In this approach, the narrative analysis of individual stories is aimed at an authentic description of the life circumstances of a certain human (sub)culture (Pole & Morisson, 2003).

We want to give a review of the different approaches to reminiscence work with regard to people with intellectual disabilities. A systematic overview can point us to differences, commonalities and hiatuses in research that otherwise would have stayed hidden. We are especially interested in: (1) the different terms that are used for the reminiscence concept, (2) the different kinds of reminiscence work in terms of theoretical approach and work method, and (3) the benefits that reminiscence work can bring to the target group.

Method

A computerized literature search was performed on the PSYCINFO, ISI and ERIC databases (1985-2005) using the following sets of keywords: (set 1) reminiscence, oral history, autobiography, life history, life review, life reflection or life story; (set 2) memory, recollection, recall, remembrance, life events, storytelling or narrative; and (set 3) intellectual disability, mental retardation, learning disability or learning difficulty. These sets were

combined as follows: a ‘narrow’ search (set 1 and 3), and a ‘broad’ search (set 2 and 3). For the broad search we applied some additional criteria. If an article was about storytelling or narratives, it also had to relate to ‘the past’ or some other notion of change, transition or continuity. Such an article became excluded if the concept of ‘literacy’ was predominant. The same applied for memory solely as ‘skill’ (working memory, long term memory, etc.). We only included peer-reviewed articles in the selection, although we will make reference to other literature (books, chapters, etc.).

Results

After application of the above mentioned criteria, 16 articles were identified on the subject of reminiscence in people with ID. Most articles are descriptive (and single case) studies; 12 studies employ qualitative methodology, five others are essays or reports of own experience in work or private life. We made a breakdown of the studies into three main categories. A ‘critical’ approach describes reminiscence work as an aid to empowerment. A ‘person-centered’ approach describes informational and social purposes for reminiscence work. Since we also found references to diagnostic and (psycho)therapeutic applications of life story work, we will also discuss a ‘clinical’ approach.

The overview is made from an instrumental perspective, that is to say, we especially focused on how reminiscence work is presented as a valuable support strategy and how people with intellectual disabilities can benefit from it. By superimposing this framework to the articles, we may have wronged the unique and original intentions of the authors, but it enabled us to point out the commonalities and differences between the different approaches. Each survey of studies within a particular approach is first situated by a short description of seminal works in that area.

Table 2.1. Studies listed according to terms with type of reminiscence work, research method, -discipline, -aim and benefits

Term	Study	Reminiscence work	Research method	Research discipline/aim	Benefits for people with ID
Autobiography	Atkinson, D., & Walmsley, J. (1999)	One-on-one conversations with people with ID A facilitator helps the individual in writing his/her biography	Participatory co-research Interviews Oral history	Trying to change power relationships in disability research by giving a voice to people who have been silent about their lives. Inspired by an interdisciplinary (social) perspective on disability.	Being able to represent one self as survivor and not as victim. Being able to speak on one's own behalf and not being talked about in stereotypes.
Autobiography	Medved, M. I., & Brockmeier, J. (2004)	One-on-one conversations with a person with Fra(x)	Semi-structured interviews Narrative and conversational analysis	Illustrating five narrative functions of an autobiographical story, namely communication, coherence, distancing, exploration and evaluation, from a linguistic point of view. Defending that narrative analysis can complement neuropsychological assessment.	Being understood as a person, not with standardized instruments, but in terms of actions, interactions and constructed meaning. Being able to reveal oneself to professionals as having different cognitive and communicative abilities rather than deficiencies.
Life history	Atkinson, D. (2004)	Group conversations with people with ID	Participatory co-research Group interviews Oral history	Reconstructing learning disability history from the perspective of eye witnesses for historiographical and educational purposes.	Becoming empowered through knowledge, understanding and historical awareness. Being able to maintain one's identity and emerging as a person, rather than a case.
Life history	Angrosino, M. V. (1994)	One-on-one conversations with man with ID	Participatory observation Ethnography	Writing a contextualized, naturalistic account of a person with intellectual disabilities' life from an anthropological perspective.	Being able to make sense of life outside an institution. Being able to use metaphors rather than retrospective narratives to sustain self-image.
Life history	Di Terlezzi, M. (1994)	One-on-one conversations with relatives, staff and ex-staff	Interviews Multiple sources Longitudinal approach	Reconstructing the life history of Sue, a woman with intellectual disabilities and severe challenging behaviour, and identifying links between significant life/support events and problem behaviour. Inspired by an interdisciplinary (social) perspective on disability.	Having professional support workers who know of one's life history and what life events have had an impact on their QOL. Being able to make progress in life because support workers know which activities are meaningful, and who have learned that social interaction is crucial in that respect.

Term	Study	Reminiscence work	Research method	Research discipline/aim	Benefits for people with ID
Life history	Gillman, M., Swain, J., & Heyman, B. (1997)	One-on-one conversations with people with ID, relatives and staff	Interviews Participatory research	Investigating the autonomy of adults with intellectual disabilities and deconstructing the professional discourse of objectivation (life history vs. case history) from an interdisciplinary (social) perspective on disability.	Becoming empowered through the process of re-authoring the own life story. Becoming liberated from the practice of 'professional' objectification through 'narrative therapy'.
Life review	Porter, E. (1998)	One-on-one conversations with people with ID Gather stories from friends and family Field trips to significant locations. Compilation of a life story book	Essay/paper Report of own clinical work	Illustrating from a psychological perspective the relevance of life review theory and work for/with ageing people with ID. Describing the process of creating a life story book, including desirable and necessary conditions, benefits and difficulties.	Being able to create a life story book and to do a life review, which is important for one's emotional health. Becoming more self-aware, having a greater self-esteem and better ability to transcend loss. Being able to name one's own strengths and natural talents.
Life story work	Hewitt, H. (2000)	Conversations with family and staff Compilation of a life story book	Interviews Discours analysis	Illustrating how life story books can present people who can not express themselves verbally as having their own unique life, instead of being just patients. Conveying this message to nurses from a non-medical point of view.	One's background becoming known in a relatively short term, being described as a person in relationship with others, one's personality being displayed in a continuous, unique and non-standardized way.
Life story work	Hussain, F., & Raczka, R. (1997)	One-on-one conversations with person with ID A keyworker asks questions about several aspects of the person's life and uses a variety of media.	Essay/paper Report of own clinical work	Examining the ways in which life story work can ameliorate transition stress for clients from a psychological point of view. Describing various practical aspects of life story work as a relevant counselling technique for people who are less - or non verbal.	Being able to develop a sense of present-day security where previously life events were too unstable to achieve this. Being able to develop a sense of identity and to deal with sadness experienced in response to personal loss.

Term	Study	Reminiscence work	Research method	Research discipline/aim	Benefits for people with ID
Life story work	Kristoffersen, G. (2004)	Compilation of an 'identity book' and a 'life board'	Essay/paper Report of a mother's experiences	Giving a message to professionals and politicians that individualized support is necessary, that life story work is a good instrument to reach this goal, that there are multiple creative ways to make communication easier and that an identity book is never finished.	Especially for those who cannot easily speak for themselves: having a life story that is written down in an accessible format, so that it will not vanish. Having a strengthened identity and sense of belonging; finding compensation for one's shortcomings, and gaining a circle of friends.
Life story work/ (Life) narratives	Meininger, H.P. (2005)	Compilation of a life story book Social contacts in connection with the book Activities of information collecting	Essay/paper Report of spiritual work Phenomenological and hermeneutic-interpretative method	Describing the relationship between life story work and the key characteristics of narrative ethics. Describing life story work as a social and moral practice. Posing that narratives have a 'gift'-like character that may not be subjected to interventionist approaches.	Having one's life story put into words and communication with others open, even when having severe ID. Having an improved relationship with the practitioner, who can learn to know the person behind the disability. Being able to experience the meaning of life by asking questions of life like 'who am I?'.
Life story work	Middleton, D., & Hewitt, H. L. (1999)	Compilation of a life story book with no fixed format, ranging from a scrapbook to an electronic document	Narrative analysis Report of own clinical work	Examining the way life story work is used as a resource in providing continuity to people with profound intellectual disabilities. Posing from a philosophical perspective that a life story is not a subjective representation of coherence across time and space, but a result from social practices of remembering and forgetting in daily life.	Being presented as participating in the social practices of daily life, so that one's identity becomes more clearly visible, especially when one can't speak for one's self. Having family and other carers share memories and present somebody as an individual who has a memory, who interacts, participates, and is aware.

Term	Study	Reminiscence work	Research method	Research discipline/aim	Benefits for people with ID
Narrative	McClimens, A. (2002)	One-on-one conversation with person with ID	Interviews	Arguing that narrative analysis can be used to renegotiate the identity of people with ID, and illustrating that a previously marginalised person, represented by others, can become the representer of her own experience. Inspired by an interdisciplinary (social) perspective on disability.	Being able to have 'a voice' again, by authoring and owning the own story. For those people who have fragmented and/or extended careers in care, where the narrative thread of their lives is easily lost in transit: having a story about one's life that puts events in a context and 'organises' the past.
Narrative	Roets, G., & Van Hove, G. (2003)	One-on-one conversations with people with ID	Interviews Ethnography Narrative inquiry and analysis	Writing a naturalistic account of life in an institution, illustrating power dynamics, resilience and resistance in the lives of two women with ID. Paving the road to social change, inspired by an interdisciplinary (social) perspective on disability.	Being able to speak up for one's self. Overcoming learned helplessness by raised awareness. Becoming confident and emerge from the experience as 'survivor'.
Reminiscence	Van Puyenbroeck & Maes (2005)	One-on-one conversations with people with ID	Semi-structured interviews Content analysis	Illustrating several theoretical reminiscence concepts: occurrence, content, feelings and types of reminiscence from a psychological point of view.	Being able to reminisce 'successfully', feeling better about one's life, and hence also ageing 'successfully'. When having pathological types of reminiscence, being detected as having emotional problems.
Storytelling	Croft, S.E. (1999)	One-on-one conversations with people with ID	Participatory observation Interviews Content analysis Ethnography	Illustrating from an anthropological point of view how people use stories to resist constraining factors in their lives and create "locales" (localized tellings).	Being able to use stories to tell about one's identity and to exert 'localized power'. Being able to adapt to a constraining environment by creating meaning for one's self through the use of stories.

The critical approach: (re)connecting the individual to the social

Studies from the critical approach rely on the idea that insider's perspectives of people with ID should be given a central place in research (Bogdan & Taylor, 1976). They are closely related to other studies that have narrative analysis and empowering practice as key features (Booth & Booth, 1996; Cattermole, Jahoda, & Markova, 1988; Cheston, 1994). The 'life history method' applies narrative methods to the life stories of people with ID to reconstruct their pasts from a critical point of view. It has become the study of the 'the lives that exist behind the label' (Goodley, 1996). Most common terms to describe reminiscence in this approach are 'life history', 'autobiography' and 'narrative'.

A central theme in life history research is giving a 'voice' to people with ID. It wants to enable them to tell their own stories, after years of living in constraining circumstances where they were unable to do so (Atkinson, 2004). Dorothy Atkinson has been a pioneer in this area. She developed an 'autobiographical approach' to disability research. Her work involved stimulating people with ID to express their identity and their pasts in creative work (Atkinson & Williams, 1990; Atkinson, 1993). Afterwards, she began to support people to become self-advocates, based on reminiscence group work (Atkinson, 1997; Atkinson & Walmsley, 1999). Gillman, Swain & Heyman (1997) continue on the issue of empowerment, by arguing that the stories of people with ID have too often been told by professionals. They criticize a positivist, objectivist and individualistic approach, by stressing that any knowledge is subjective, social and historical, and in that sense 'biased'. This idea is shared by Medved & Brockmeier (2004), who discuss autobiography as an alternative to standardized assessments. They want to give counterweight to medical and psychological discourses in the care for people with ID, arguing that any generalisation of the 'lived experience' is doomed to fail.

The critical approach defends that the individual cannot be seen separately from his social and historical context, especially not in the case of people with ID. This also has some methodological consequences. Angrosino (1994) and Croft (1999) combine participatory observation with interviews to create narratives that do justice to the intrinsic 'local' character of a story. Di Terlezzi (1994) adopts a longitudinal approach to identify how personal growth or decline are connected to significant life events.

Finally, the critical approach adds an activist aspect to research: it wants to make people conscious about submissive mechanisms of power in their past and present lives, and support them to become agents again (Roets & Van Hove, 2003). McClimens (2002) points at the

emancipatory task of narrative research, as it illustrates social (constraining) conditions with individual stories.

The person-centered approach: information, communication and social contact

The idea of 'life story work' is attributed to Ryan and Walker (2003); its application to people with ID to Atwell (2003). This method, in which memories are elicited to clarify past events in terms of the present, is not meant as some kind of therapy. It is a way of person-centered working in which life facts are gathered, recorded, and displayed. It is done with people who have trouble in gathering these facts by themselves, for example because they are not able to do so, or because they have been separated from their birth's family. The main objective is to give a person the opportunity to know what happened to him or her, and for what reasons. A second aim is that others too can learn the history of that person, in order to improve communication and social contact. Life story work may result in a book or a video, but the method 'does not have to result in a product – it is the process rather than just the product which will yield most benefits for the people involved' (Ryan & Walker, 2003, p.5).

Kristoffersen (2004) reports on how she used life story work in many creative ways to personalise her own caring and supporting practice. In her view, memories of meaningful events in the life of a person with ID should be written down in a book by a family member or a carer, so that this information can be used later for recreational or communicational purposes. Similar work has been done by Stuart (1998), who uses reminiscence to let people explore their dreams and expectations of the future. In this regard, life story work is much related to 'person-centered' support, as described by O'Brien & O'Brien (1998).

Life story work presupposes that people are interdependent. The participants search each others identities, create stories together, and doing so, engage in a 'social practice' (Hewitt, 2000; Middleton & Hewitt, 1999). Meininger (2005), who investigates life story work from a narrative-ethical point of view, argues that the social practices of life story work are a narrative ethics in action. In other words: listening to and talking about each other's life stories are good things to do. Life story work is able to bring about moments of recognition, insight and engagement. In this view, reminiscence work is not seen as a method, but more as a desirable moral attitude for practitioners.

Clinical applications of reminiscence work

There are some, but not many references to reminiscence work as an instrument for diagnostic and therapeutic purposes. This is fairly strange, since research on bereavement in people with ID has shown that reminiscence work can be helpful, and that a person's own perception and

story of the past are crucial elements to take into account (Oswin, 1981; Oswin, 1991). Quite some studies mention 'coming to terms with the past' as a function of reminiscence work (Atkinson & Walmsley, 1999; Medved & Brockmeier, 2004; Porter, 1998). Porter (1998) explicitly describes life story work as a means to do life review, aiming at enhancing self-esteem and self-awareness. Hussain & Raczka (1997) work out the idea that life story work can help people to cope with loss and transition. It can diminish stress for clients who are in transit from an institution to a community setting. It can also be a relevant counselling technique at a time when staff support and understanding are vital. Gillman, Swain & Heyman (1997) state that life history work can be some sort of 'narrative therapy', that enables people to externalize the problems in their lives and become more self-aware and confident. Roets & Van Hove (2003) add that narrative practice can help people with ID to overcome their learned self-helplessness and avoid a 'loss of identity'.

As for diagnostic purposes, Medved and Brockmeier (2004) state that analysing autobiographical life stories can reveal abilities, rather than deficiencies of people with ID. Van Puyenbroeck and Maes (2005) suggest that assessing whether a person displays defensive or obsessive types of reminiscence, can be helpful to detect mental health problems.

Discussion

Although we are confronted with different research traditions, theories and methodologies, we would like to compare the studies and describe some commonalities and differences, but also some hiatuses and directions for future research.

The reported benefits of reminiscence work in all studies show that not only the clinical, but also the critical and the person-centered approach are 'instrumental' in one way or another. All try to accomplish certain desired goals. This is similar to the conclusions of Bornat (1994), who reviewed all (general) reminiscence literature, and saw only small differences between therapeutic reminiscence work (directed at comprehension of the past), educational reminiscence work (with a focus on development and learning outcomes) and oral history (aimed at retrieval and preservation of memories). However, critical and person-centered approaches are non-instrumental too in their self-declared stress on the process, rather than the product. Reminiscence work is not only useful, but also 'just' meaningful. Meininger (2004) argues that stories bring about methods, not the other way around. This is clearly in contrast with the aims of Hussain and Raczka (1997), who investigate life story work as a relevant counselling technique.

A clear difference exists between the approaches regarding the role of the facilitator: more directive in the clinical perspective, more coaching in the critical approach, and more supportive in person-centered reminiscence work. This difference originates from the respective views on agency and autonomy of the participants in reminiscence work. The therapist treats clients who are distressed, the critical educator coaches active agents to claim authorship of their own life story, the support worker or carer initiates dialogue in order to strengthen relationships. We do not want to simplify the differences here, but questions nonetheless arise about the priorities of reminiscence work: independence or interdependence, support or care, individual empowerment or social practice, conflict or reconciliation. Related to the different aims of reminiscence work and the different roles of the facilitator, is the status of the knowledge about reminiscence itself. Both critical and person-centered approaches are inspired by the phenomenological school of thought, considering reality as a world of (socially) constructed meaning, instead of a series of facts that can be related causally to each other (positivism). McClimens (2002) defends that 'life history' should be kept 'well away from the positivist influence of medicine and psychology' (p.74). We did not find any positivist therapeutic studies in our review, but the possibility of an alternative, causal approach to reminiscence nonetheless exists. In that case, researchers do not try to find coherence in various subjective narratives, but attempt to analyse the 'factual' mechanisms of memory, in order to determine the success of any intervention.

Nearly all studies agree that reminiscence work can have an important positive effect on the quality of life of people with ID, especially on the domain of psycho-social well-being: better self-esteem, greater self-awareness, empowerment, better contacts with family or support workers... The term 'identity' is mentioned across all approaches: identity as a renegotiation of the common understanding of oneself/another person (Middleton & Hewitt, 1999), identity as an internal representation of the self (Kristoffersen, 2004) and identity as the essence of a person that continues over periods of change and transition (Hussain & Raczka, 1997). Croft (1999) and Angrosino (1994) convincingly demonstrate that people with ID use concrete stories about their lives to tell others about who they are, without the need to generalise, or to considerate their identity in an abstract manner.

Reminiscence work is clearly being applied in many different ways, but still there are some gaps to be filled in future research. We name four subjects:

[1] A more balanced theoretical model of reminiscence in people with ID. In the critical as well as the clinical approach, reminiscence in people with ID is mainly associated with negativity: constraining environments, experiences of loss, learned helplessness … A broader vision on supporting reminiscence in people with ID would also include positive evaluations of the past, even if it would seem traumatic for outsiders. For example, Hussain & Raczka (1997) state that people can have positive memories about their stay in large-scale institutions. Also, our own experiences (Van Puyenbroeck & Maes, 2005) learn that instrumental reminiscence is possible in people with ID, so methods for stimulating memories of gains (e.g. accomplishments) should receive as much attention as methods for keeping alive memories of loss (e.g. death of a parent).

[2] The link between reminiscence work and emotional well-being for people with ID. What strikes us is that research has not focused more on the extensive possibilities of reminiscence/life review therapy, mentioned in generic reminiscence literature (Bender, Bauckham, & Norris, 1999). The negative impact of stressful life events on mental health and problem behaviour has been described and demonstrated (Hastings, Hatton, Taylor, & Maddison, 2004). While we don't aspire to explain the increased risk of mental health problems in ageing people with intellectual disabilities (Davidson, Prasher, & Janicki, 2003) by solely pointing at the presence of traumatic pasts, we do want to give heed to the facts that support has given too little attention to people with ID's own retro- and introspection, and that there has been a lack of 'talking cures' because the people involved were not considered to be 'suitable' for that (Blackman, 2003). Oswin (1981, 1991) was the first to state that people with learning disabilities review their lives as others do, that they go through the same stages of mourning, and that they should therefore be given consideration when relatives and friends die. Several practice-oriented researchers have developed their own methods to help people cope with the experience of loss (Read, 1999). While we cannot discuss all possible counselling methods for bereavement here, we do want to highlight the idea that reminiscence work or therapy can be a crucial element in helping people to overcome a period of morning (Blackman, 2003). From an experiential view, memory can serve as an 'anchor' to keep attachments to the deceased alive (Buchsbaum, 1996), from a cognitive-behavioural view, reminiscence can 'unstuck' people from negative emotional states, by connecting them to positive resource states from the past, in order to create a new 'match' (Kunz, 2002). Evaluation of reminiscence therapy in people with ID, however, is still non-existent.

[3] Clear methodological procedures and more methodological variety. Qualitative research is not 'easy' research. Reviews of general reminiscence research (Bornat, 1994; Hendrix & Haight 2002) report too many anecdotal studies. Goodley (1996) made a review of 'life history' research, and summarized the possibilities as well as the difficulties of the narrative method. Its greatest merit is that it can expose the experiences of people with intellectual disabilities from their own perspective, but it also struggles with issues of methodology (more specifically with problems regarding the collection of stories from inarticulate people in a valid manner) and issues of power (the involvement of a researcher with his or her own preoccupations can lead the person with ID to rehearse a story or in some cases just lie to conform with the expectations). These critiques evidently also apply to person-centered and clinical approaches to reminiscence. Critical self-awareness of the researcher in these matters is absolutely necessary. We would also like to make a plea for more methodological variety. All research is descriptive, more evaluative research is needed. This argument is not a wake-up call to implement only randomized controlled trials from now on (cf. Lai, Chi & Kayser Jones, 2004; Schrijnemaekers, van Rossum, Candel, Frederiks, Derix, Sielhorst, et al., 2002), but for 'mixed' methods that do justice to the effects as well as to the process of reminiscence work (cf. Finnema, Droes, Ribbe, & Van Tilburg, 1998). Scott & Clare (2003) reviewed the literature on reminiscence work in people with dementia and arrived at the same conclusions: more evaluative research, better methodology, and –given the special features and situation of the target group- more study into individual differences.

[4] Learn from reminiscence research in other target groups. Following mainstream theory and practice, reminiscence work/therapy has been diversified and applied to various specific target groups, especially people with chronic and life-threatening diseases like dementia, AIDS and cancer (Bornat, 1994). Reviews in the domain of dementia conclude that too little experimental research has been done to confirm all hypotheses, but that non-pharmaceutical treatments like reminiscence therapy are promising alternatives to reduce dementia symptoms like apathy, agitation and certain negative behaviour (Scott & Clare, 2003). Brooker & Duce (2000) found positive effects of reminiscence therapy on subjective well-being. These therapeutic effects may be transferable to people with ID, given some similarities in cognitive and verbal functioning, living and supporting environment, history of loss and higher risk for mood disorders.

Participant 1: When she baked “bekkem”…

Coach: That’s kind of a herring, is it?

Facilitator: Never seen or eaten that!

Participant 1: Oh… and the fat that came off… that was good. But those days have gone. It still exists, but you don’t get to see it anymore.

Coach: And you <name>, do you know that herring?

Participant 2: Yeah, herring.

Participant 3: When it was baked, there was fat all over the stove plate…

Manuscript 3:
Program development of reminiscence group work for ageing people with intellectual disabilities[3]

The goal of this study was to adapt a narrative reminiscence program to the special needs of ageing people with mild/moderate intellectual disabilities. Research has shown that stimulating reminiscence in the elderly can be a meaningful activity, and that it promises well to have effects on subjective well-being. In the first stage (10 weeks), the program was developed in one group. Evaluation and adjustments of the program were based on video-recordings, the researcher's log and feedback by participants and support workers. Formative evaluation was performed by means of a within-case analysis. In the second stage (3 weeks), the program was introduced to 6 other groups. Interviews with professional support workers were subjected to a cross-case analysis. The final program consists of 13 sessions covering different reminiscence themes. The success of reminiscence group work relies on (a) well prepared and structured sessions (b) adequate use of visual triggers and (c) facilitating, coaching and moderating. The program is perceived as a valuable, meaningful activity by all participants. Although reminiscence group work is not therapeutic in nature, it may have therapeutic use for ageing people with intellectual disabilities, and is, in that sense, worth evaluating.

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[3] Manuscript in press. Van Puyenbroeck, J., & Maes, B. (in press). Program development of group reminiscence work for ageing people with intellectual disabilities. *Journal of Intellectual and Developmental Disability*.

Introduction

When people remember personal life events and relate their memories to each other, they are 'reminiscing'. Reminiscence is a psychological phenomenon that occurs spontaneously at all ages, but it has been mainly studied in the elderly. Erikson's proposition that recalling the past is a means to reach 'integration' -to reconcile the past self with the present self- (Erikson, 1963) triggered the widespread belief that reminiscence contributes to 'successful ageing'. Originally, reminiscence studies were inspired by psychodynamic theory, with 'life review' as the main term (Butler, 1963). Through the years however, authors have adopted other psychological theories, in an attempt to explain the cognitive, emotional and social impact of reminiscence (for an overview, see Haight, 1991; Haight & Hendrix, 1995; Hendrix & Haight, 2002). Different kinds of activities have been developed, all aiming at the stimulation of reminiscence (Bender, Bauckham, & Norris, 1999; Gillies & James, 1994).

In the context of supporting people with intellectual disabilities (ID), reminiscence work has been described as a meaningful activity for a number of reasons. Life story work has become quite popular with support workers as a means to help those who cannot (easily) speak for themselves to remember their past and compile a life story book based on this experience (Hewitt, 2000; Meininger, 2000; Porter, 1998). Life history work focuses on the history of institutionalization as seen by eye witnesses, and tries to raise critical consciousness about it (Atkinson & Walmsley, 1999). Also, since Oswin's pioneering work (Oswin, 1991), the body of literature that explores the possibilities of reminiscence work for bereavement counseling has been growing steadily (Read, 1996; Blackman, 2003; Bigby, 2004; Husain, 1997; Stuart, 1998; Summers & Witts, 2003).

In the above studies, reminiscence is conceived mainly as individual 'evaluative' reminiscence: people are asked to evaluate (negative) life events in order to achieve reconciliation with the past (for a more extensive definition, see Lo Gerfo, 1980-1981). The benefits of 'simple' (narrative, 'storytelling') reminiscence, in which people share memories for informational and recreational purposes (Lo Gerfo, 1980-1981, Wong & Watt, 1991), are yet to be explored with regard to persons with intellectual disabilities. We took an interest in reminiscence group work, which elicits memories in a group context and does not necessitate a discussion or evaluation of traumatic life events (Norris, 1988). This method uses all kinds of triggers (ancient photos, vintage objects, etc.).

The main problem however was that present reminiscence group work methods are not very well suited for people with intellectual disabilities in terms of content and supporting

materials. The basic assumption of handbooks on the matter (Osborn, 1994; Gibson, 1994; Rainbow, 2003) is that the group members have the necessary (verbal) skills to contribute equally to, and to engage in dynamic group work. In regard of people with intellectual diabilities, we anticipated a need to facilitate the group process, but we did not know whether group supporting roles as defined in various person-centered planning methods, could be effective for that purpose (Holburn & Vietze, 2002). Neither did we know which reminiscence themes would be interesting and relevant for the target group. Ageing people with intellectual disabilities may have very special personal backgrounds (for example: living 30 years in an institution or with parents), so their major reminiscence topics may differ from those of people without intellectual disabilities (Van Puyenbroeck & Maes, 2005). A final motivation for this study was that, if we want to carry out future evaluation studies about the effects of reminiscence group work on subjective well-being, we need a well defined program, with concrete guidelines for a series of reminiscence sessions. The main purpose of this pilot study therefore was to adapt a narrative reminiscence program to the special needs of ageing people with mild/moderate intellectual disabilities, and to write a manual. Hence, the main research question was: what modifications, in terms of content, structure, materials and support strategies, have to be made to a basic reminiscence group method in order to make it an accessible, enjoyable and engaging activity for ageing people with intellectual disabilities?

Method

We wanted to develop the program in concert with support workers and people with intellectual disabilities. We have preferred to conduct a formative process evaluation, bearing in mind the principles of action research. In action research, the researcher teams up with the people who have a 'stake' in his research subject (Cohen, Manion, & Morrison, 2000). Together they plan, implement, review and evaluate the interventions of the researcher. In our study this meant that the support workers were actively involved in the process of designing the method. The consecutive group work sessions were submitted to a cyclic process of formative evaluation. Formative evaluation is a method of judging a program's worth while the program activities are taking shape or happening (Scriven, 1991). The intent of this kind of evaluation is not only to assess a program, but above all to improve it. The ultimate stakeholders, the people with ID, were involved in the final steps of the development, when they could evaluate the whole program. The ethics committee of the faculty of Psychology and Educational Sciences of the University of Leuven approved the design of this study.

Sampling

We developed the program first in one group (case 1), and then extended the implementation to six more groups (cases 2-7). The cases were all located in facilities that provide support for a relatively large part of ageing persons (older than 55) with an intellectual disability (>10 persons). As to the first case (stage one), we looked for a facility that was near enough our research centre to facilitate intensive co-operation. The next six cases (stage two) were spread over the Flemish region. In all cases we made agreements on the participation of a support worker. All contacted support workers had more than five years of work experience with people with ID. Table 1 lists their respective ages and training qualifications. Concerning the 'recruitment' of participants for the group work, the following procedure was followed: each support worker went out to explain the aim of the study to the people visiting or living in his or her facility, and asked them individually if they would like to come to a reminiscence session. In this first session, the researcher introduced himself, the aims and the details of the program, bearing in mind the necessity of 'informed consent' (Stalker, 1998). A 'dummy' reminiscence theme was then demonstrated, after which the participants were asked whether they liked the activity or not. It was explained to the participants that they could help develop the method by participating in the program, but also that they could quit at any time. Two persons decided to stop after the first introductory session. Table 1 describes all participants in terms of age, sex and level of ID. All participants were able to speak, 32 using full sentences, 13 using short phrases, and 3 communicating with single words.

Table 3.1. Demographic information of participants and support workers

	Stage 1	*Stage 2*						
Variables	*Case 1*	*Case 2*	*Case 3*	*Case 4*	*Case 5*	*Case 6*	*Case 7*	*Total*
Support workers								
Age	42	34	30	49	28	39	45	
Training	BEd*	BEd	BEd	BEd	BSW**	BEd	MEd***	
Participants								
N	7	7	8	7	5	6	8	48
Age								
Mean	55,1	64	60,3	62,1	59,4	57,7	69,8	61,5
SD	6,2	6,2	7,1	8,2	3,2	6,3	3,5	7,4
Range	48-64	58-77	53-72	54-78	56-64	50-67	65-74	48-78
Sex								
Male	3	1	6	3	3	4	0	20
Female	4	6	2	4	2	2	8	28
ID								
Mild	5	5	6	5	4	2	7	34
Moderate	2	2	2	2	1	4	1	14

Note * Bachelor in Education, ** Bachelor in Social Work, *** Master in Education

The outset

The reminiscence program we started from is described in a handbook for group reminiscence among people with dementia (Bruce, Hodgson, & Schweitzer, 1999). Important characteristics of that program are: weekly group work sessions, reminiscence themes (set and prepared in advance), and abundant use of visual triggers that are kept in a reminiscence suitcase. We collected vintage objects and photos as triggers for the following themes: 'childhood home and family', 'my neighbourhood', 'school days', 'work', 'hobbies and music', and 'holidays'. A list of the triggers used can be found in the appendix B. 'Courtship and marriage' was not retained as a theme because we knew that very few participants (only one) had been married. This decision did not imply that the important subject of 'friendships' was omitted from the program. It was incorporated in session 1 ('Who am I?').

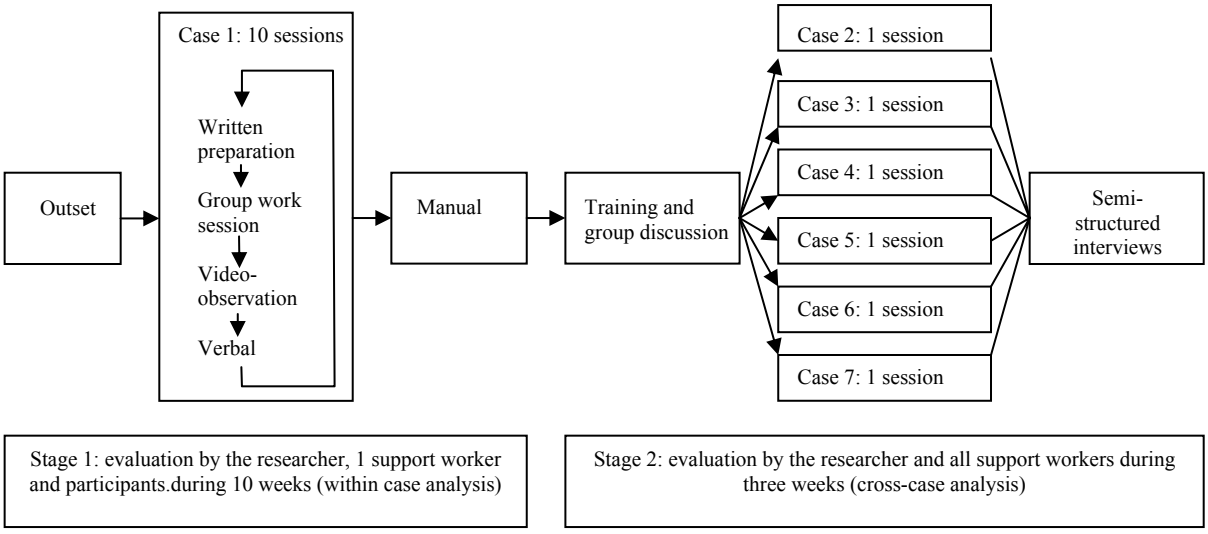
Inspired by the principles of person-centered planning (O'Brien & O'Brien, 1998), we defined two major support 'roles': facilitating and coaching. These two roles can be found in various person-centered approaches (Holburn & Vietze, 2002). The facilitator is conceived of as a creative group leader who stimulates creativity in the group, while the coach is thought of as a personal assistant who is supportive to each of the group members. The researcher and the support worker made agreements to swap these two roles. Sometimes 'mind maps' were drawn during conversation, to 'map' the thoughts and memories of the participants.

Procedure

The study was carried out in two stages: an intensive single-case 'in depth' evaluation (duration: nearly 3 months), and a broader, 'generalising' cross-case evaluation (duration: three weeks). In the first stage the group reminiscence program was implemented in a daycare facility. After a 'trial' session (to introduce the group work to the participants, and to let them get used to the cameras), the researcher and the support worker put the reminiscence program into practice during 10 weekly group work sessions of one hour,. During each session, video recordings were made from two opposite angles (two cameras). After each session, the method was briefly evaluated by the support worker and the researcher. This assessment resulted in proposals for adjustments concerning structure, content, materials, and support strategies. The researcher kept a log to record whether a strategy worked or not, what changes had to be made, and whether problems had to be solved in the next session. During the week that followed, the researcher reviewed the video recordings, and made a written proposal for the next session. This was sent to the support worker, who could comment on it before the

next session took place. This cycle went on during the 10 sessions of the first stage. In the last session of the first stage, the reminiscence group members evaluated the program. We arranged a quiz, with questions that related to all the previous sessions. An evaluation conversation was then initiated. At the end of this stage, we drafted a manual, a work document with a detailed description of the strategies used for group reminiscence. In the second stage, six new support workers were given the manual and were introduced to the method on a training day with all support workers. Next, they implemented the method in six new reminiscence groups together with the researcher. After every group had completed one reminiscence session, a semi-structured interview was conducted with all support workers. The data of stage two were submitted to a cross-case analysis. Figure 3.1. depicts the successive steps in our procedure and the methods we used.

Figure 3.1. Procedure for program development



Analysis

For the within-case analysis of the first stage, several data sources were combined: the researcher's log entries, a global revision of the video material, verbal feedback from the support worker after each session and feedback from the participants during the evaluation session. Furthermore detailed information was gathered by analyzing the video recordings in terms of 'accessibility' (did the participants understand the aim of the session?), 'activity' ('how active were participants when a certain strategy/trigger was used?'), 'well-being' ('were the participants enjoying this session?') and 'group functioning' ('was the group behaving like a group and not as a collection of individuals?'). The researcher watched the

two-angle recordings and observed all participants to check whether a session had been successful, keeping in mind the comments of the support worker and the four criteria. The video recordings were used to confirm or deny the subjective impressions that arose immediately after the session. For example, in preparation of the 'holiday' session we invited the participants to bring along personal holiday pictures. Both the researcher and the support worker felt that this session was not a success because most of the group members didn't enjoy themselves. A video analysis of the holiday session showed that only those participants who had (several) holiday pictures to show, remained active during the session, while the others grew quite disinterested after a while. Moreover, the active participants mainly interacted with the support worker or the researcher, and not so much with the other group members. Because the method failed to match the three criteria mentioned, we changed the instruction 'bring as much pictures as you can' to 'bring one picture that is important to you' in our manual.

The cross-case analysis of the findings of the second stage consisted of summarizing the group discussion of a communal training session and synthesizing the support worker's answers to the questions of a semi-structured interview. Topics of the interview guideline included: target group, content and structure of sessions, materials, support methods, weak/strong points of the program, expectations for possible outcomes and suggested adaptations of the program.

Results

Stage one: within-case analysis

The cyclic formative evaluation in stage one implied interim decisions regarding the use of different content, materials, and support 'techniques'. The following points turned out to be important.

Content

In agreement with the support worker two themes were added ('Introduction' and 'TV'), two were merged ('neighbourhood' and 'hobbies' into 'games and toys'), and one was split ('childhood, home and family' into 'household' and 'who am I?/family') (for a complete list, see the appendix B). In one session, the facilitator guided the memories towards a certain theme, but certainly not in a compelling way. The participants could stray from the subject as much as they wanted, but most of the time, the reminiscence subject returned spontaneously. Memories didn't have to be 'pushed'; although sometimes a 'round' was initiated ('do you

remember …?'), it more frequently happened that memories triggered new memories spontaneously.

Not all sessions were about 'remembering the past'. For example, we started with a session of getting acquainted. The two major purposes were 'getting to know one another' and 'getting used to the camera'. This proved to be absolutely necessary in order to gain the participants' trust. It also proved necessary to introduce every reminiscence theme by referring to the present. As a consequence all sessions were mixed past/present in one way or another.

Personal content on the basis of personal triggers had to be reduced from time to time. For example, in session three personal photo albums were being used for more than two thirds of the session, and it turned out to be quite boring for the rest of the group. In stage one, the most successful themes (according to the four criteria above) were: 'games', 'school', 'food', 'church' and 'holidays'.

Structure

The structure of a session was a key element for success. After session three (household), the coach and the facilitator felt a strong need to put a structure into the session. From that moment on every session consisted of an introduction (usually a game of some sort), two or three main discussion topics and several side topics. Using 'main' and 'auxiliary' goals, it was easier to have a well-balanced amount of content. The participants eventually got used to a structure consisting of a game as introduction, a reminiscence theme, and a closing activity.

Materials

A lot of preparation went into the packing of the reminiscence suitcase. It became a familiar instrument after four or five sessions. At first, this suitcase was filled with triggers, which were all laid out on the table. The underlying assumption being that at least one of these specific objects would be recognized. But in this way, the participants were 'flooded' with triggers. We learned that the objects have to be introduced one at a time and situated in detail. Sometimes memories were stirred up after a while, sometimes not. But eventually one trigger or another always resulted in a story, and as a consequence the need to artificially add too many triggers to the session disappeared.

The problem with triggers is that they can be too specific. For example: a prayer book that isn't recognized because it is too thin, or a holiday picture that's too personal and therefore doesn't appeal to the group. Another problem may be that drawing attention to a trigger can be difficult because of other triggers that surround it. Contrary to our preconception that

triggers had to be simple, multimedia content on a portable computer also turned out to be a good trigger from time to time.

At the start the mind maps were difficult to manage because we tended to draw everything. Colours are useful to distinguish between past and present. The map can be structured in more than one way. For example: person – memories, or memory – persons. This should be planned in advance. The strategy of mind mapping proved to be a useful strategy for keeping the conversation at the right pace.

Facilitating, coaching and moderating

In the course of the program, we learned how to facilitate, coach and moderate group reminiscence. Facilitating in this context means making it easier for people to join the group and to share memories. The facilitator sets out a theme for a reminiscence session, uses visual aids called 'triggers' to elicit memories relating to the topic in question, makes drawings and somehow structures the session. He/She also elaborates on what is said in the group. Elaboration means asking questions to elicit additional memories or to make a memory more specific. It is a key instrument for the facilitator. The facilitator also respects the subjective perspective of the participant. For example, he certainly does not point people to their so-called 'false' memories. It must be avoided that group reminiscence is seen as a test; it can easily turn into a school lesson, for example because the facilitator is asking too many questions ('Do you know this?', 'Did you know that?').

Another support role is coaching: helping the individual group members to contribute. The coach's task is to focus on the degree of activity/involvement of participants and to support them in finding the right words, in remembering an event, a person, a name. As a coach, the support worker sometimes needs to slow down the group's conversational pace to help a person to express his or her own memory. This can be done by drawing the memories on a mind map. It helps the less eloquent to articulate their memories.

Moderating implies that an eye is kept on the group aspect of a conversation. This sometimes meant for example curbing an active group member to make room for a more passive group member to contribute. Guiding the group conversation was very difficult to learn. For example, sometimes a participant started talking to the coach, and another one at the same time to the facilitator. One particular strategy to moderate group conversation is a 'round': allowing everybody to speak in his or her turn. Although this might seem a rigid approach, this strategy is sometimes necessary to give personal attention to everybody, and not only to

those who were trying to be at the centre of attention. The moderator also notices differences and resemblances in the stories of participants and tries to let them exchange experiences.
The researcher and the support worker constantly had to switch between three roles: that of a coach paying attention to each individual participant, that of a facilitator focusing on the content and that of a moderator keeping a group conversation going. After stage one the question rose whether –on the one hand- this would be feasible for one support worker, and – on the other hand- how two support workers can learn to complement each other in this matter.

Client and support worker satisfaction with the program

Client evaluation was carried out in the last session (1 support worker and 6 persons with intellectual disabilities). Not a single negative comment was made by the persons with intellectual disabilities themselves. It was difficult to assess whether or not these positive opinions were given out of a desire to acquiesce. A detailed behavioural analysis of some video recording fragments clearly showed that some participants were bored during certain parts of some sessions. The researcher having noticed this, requested the support worker to ask the participants on other occasions (other than the group work sessions) whether they liked the activity. But these comments too were very positive.
After stage one, the support worker's view was very positive. She felt that nearing the end of stage one reminiscence 'output' increased. She thought that our reminiscence facilitating strategies grew better, and that group coherence increased remarkably. Clients teamed up to explain things to each other or to the support worker. A group identity emerged: presence and absence of the members didn't go unnoticed. She also learned new things about the life stories of the participants, although she knew them for several years already.

Stage two: cross-case analysis

Target group

All support workers (N=7) were asked what in their opinion were the important criteria for successful reminiscing by people with intellectual disability. Obviously the first criterion they all mentioned turned out to be 'individual freedom to participate'. Does a person like to talk about his/her past? Is he/she willing to talk about personal memories in a group? Other personal features that were said to be important included verbal proficiency (N=5), age (N=4), social competence, being able to listen to another person (N=2), cognitive abilities (N=1), and emotional (in)stability (N=1).

Content, structure and materials

Five out of seven support workers agreed that the content of a group reminiscence session has to be prepared in advance: choice of theme, selection of visual stimuli, clear instructions. The other two support workers thought that the sessions themselves must not be 'over-structured'; otherwise they risk becoming school lessons. Variation in stimuli and flexible moderating should overcome too much steering of natural, spontaneous group conversations. When asked whether sensitive subjects (like WWII) can be discussed in a reminiscence group, all but one support worker answered affirmatively. Concerning the materials, there was only enthusiasm; there was one remark that the means should serve the goal. Mind mapping, for example, can be very helpful as a means to visualize, but it is not always necessary when everybody knows how a particular thing from the past looked like.

Facilitating, coaching and moderating

Three support workers thought that moderating the group was their most important task, while two others stressed the importance of elaborating, which is part of the facilitating task (getting the details of a memory). The interviewees were divided on the question whether one support worker can assume all these different roles. Three gave an affirmative answer, one a negative one, three added some mediating conditions such as the number of participants, their cognitive and/or additional disability, or the quality of the relationship between facilitator/coach/moderator and the participants (how well do they already know each other?). For all interviewees, the main focus of the person guiding the group reminiscence should be on 'keeping the right pace': slowing down to explain a reminiscence theme or specific memory by drawing a mind map, or speeding up the conversation by using new triggers at regular times.

Strong/weak points of the program

All support workers considered the method to be (potentially) very worthwhile. Five out of six support workers independently from each other mentioned one or more aspects of positive group dynamics. According to them, group reminiscence can enhance mutual respect and facilitate social contact. They found the participants to be very considerate of one another (solidarity), and had noticed that all participants contributed in one way or another, whether by sharing their own memories or listening to others. The support workers also remarked that new group members were accepted from the beginning. They felt reminiscence group work was fun; they also thought it can make the participants feel better and increase their self-

esteem. For themselves they found it a meaningful learning experience and they considered integrating their newly acquired knowledge into their daily work.

Discussion

Supporting reminiscence in people with intellectual disabilities boils down to 'keeping pace with the participants'. The cyclic action research design in stage one proved very useful in finding the right techniques to facilitate reminiscence in all participants, not only in those who were already articulate about their pasts. We have made several adjustments to the original program. Firstly, some themes were discarded and others added. Secondly, the sessions got a clearer structure. Thirdly, mind maps were used strategically to slow down the tempo of the group conversation and to represent the memories of the participants in a structured way. Fourthly, the reminiscence suitcase turned out to be an appealing instrument to elicit memories, but the triggers had to be used in a well-balanced manner. Finally, three support roles –facilitating, coaching and moderating- proved to be necessary in order to maintain group work and to ensure the recall of rich (detailed and specific) memories. An essential part of facilitating was elaboration: asking for details, asking to describe an event as if it were reading-out a movie script. Reminiscence work can teach people how to tell a story and how to let other people enjoy it. These adjustments were confirmed and corroborated by the support workers in stage two.

This study has several limitations. Because of its qualitative nature and small sample size, the results cannot be generalized to the wider group of ageing people with intellectual disabilities. For now, the fact that we have obtained similar results in multiple and different cases, increases the likelihood that our results can be brought to bear on other contexts or settings (Lincoln & Guba, 1985). We may conclude that group reminiscence among people with intellectual disabilities is possible in similar conditions, given the supporting materials and techniques we specified. However, the multicultural relevance of the themes and materials that we used has yet to be validated. Another major limitation of our study is that we could test the program only on adults who liked to talk about their past and who volunteered for this activity. The clients' satisfaction with the program should be carefully interpreted, not only because of their tendency to social acquiescence, but also because they liked to reminisce of their own accord. A final limitation of our study is that we applied action research in a restricted sense: we asked the stakeholders to judge the program, but we did not let them

question the research design itself. The utility of involving people with ID to a much greater extent has been discussed elsewhere (Atkinson and Walmsley, 1999; Walmsley & Johnson, 2003).

There are some caveats for group reminiscence. The program requires time and efforts from the support worker. First of all, the sessions need to be prepared in advance (for example, gathering the triggers). Second, when there's only one support worker to carry out the program, that person has to combine three support roles at the same time. This is certainly not easy, but still considered to be manageable when one is familiar with the group members. Other factors jeopardizing the success of a reminiscence group are diminished or lacking communicative and/or group skills in one or more participants. Also, since autobiographical memory is believed to have its origin at the developmental age of four, this program is not suited for people with severe intellectual disabilities.

This study was meant to develop and adapt a version of reminiscence group work for ageing people with intellectual disabilities. The main reason for this was to create the possibility of a future process and effect evaluation that assesses the benefits of such a program on subjective well-being. Although the support workers in stage two gave their opinion after only one session, they already saw the merits of reminiscence group work, especially that of raising self-confidence. These hypothesized effects are yet to be evaluated. But after this study, we can already give -as Bender, Bauckham and Norris (1999) did- other reasons for conducting group reminiscence with the target group than mere therapeutic considerations: the sheer fun of remembering something and sharing it with others, the potential for group building, and the opportunity to initiate or strengthen social contacts. Group reminiscence is a valuable, meaningful activity. It is not a game, nor is it a school lesson. The participants are respected as people who have a lot of life experience. In group reminiscence they have the opportunity of saying things like 'I knew this', 'I was able to do that', and perhaps more importantly: 'I still know it' and 'I can still do that'. Being experts concerning the past, they explained several old customs to me, a young researcher. It proved very rewarding to observe older people having a great time in sharing memories, showing clear satisfaction when telling us about the past as something they know (and younger people do not). We did not attempt to quantitatively measure changes in subjective well-being, but it would be meaningful to evaluate such effects in future research.. Given the alarming finding that the rate of psychiatric problems in older people with intellectual disabilities is two to four times higher than that in other older people in the general population, and that depression is one of the

most common conditions (Davidson, Prasher & Janicki, 2003), researchers, together with support workers, need to find simple strategies to strengthen subjective well-being. If reminiscence work can raise self-esteem and life satisfaction, it may contribute to the overall quality of life and successful ageing of people with intellectual disabilities.

Facilitator: The monks, what were they wearing?

Participant 1: A black… errr…. A black belt and a paternoster

Facilitator: And do you still know what that thing the belt held together was called? Wasn't that a robe?

Participant 2: Yes, a robe…

Participant 1: …and a paternoster!

Participant 2: Yeah, a paternoster.

Facilitator: They had those hanging at the side, didn't they?

Participant 3: Yes, at their side.

Facilitator: Attached to the belt.

Participant 3: At both sides, they had deep pockets!

Facilitator: Deep ones, yes. They could hide their arms in it.

Participant 3: They were well-protected. They didn't need hand gloves in the winter.

Manuscript 4:
The effect of reminiscence group work on life satisfaction, self-esteem and mood of ageing people with intellectual disabilities[4]

This study evaluates the effects of reminiscence group work on the subjective well-being of ageing people with intellectual disabilities. Life satisfaction, perceived self-competence, and mood/interest/pleasure were chosen as dependent variables. The content of the successive group work sessions was manipulated as follows: a control-phase with three 'current topics'-sessions, an experimental phase with six 'reminiscence'-sessions, and finally three 'current topics' sessions to conclude the program. A quasi-experimental pretest-posttest design (N=41) did not detect any changes in life satisfaction and perceived self-competence. For mood/interest/pleasure, a quasi-experimental ABA-design (N=41) did not yield an experimental treatment effect, but a significant increase in scores was observed over time. The effect seems to be building up over the total duration of the program (control plus experimental sessions), and not only during the experimental phase. Personality characteristics 'extraversion' and 'emotional stability', but not memory specificity were found to be significant covariates for the mood scores. Although the study's design did not allow us to confirm the effect of reminiscence group work, the analysis nonetheless revealed some useful indications for further research. Also, interviews conducted before and after the program resulted in positive appraisals of the program as a worthwhile and meaningful activity for ageing people with intellectual disability.

[4] Manuscript submitted for publication. Co-author: Bea Maes.

Introduction

Reminiscing, defined as telling stories about personal past experiences or other memorable events, is a commonplace and normal human activity. Most of us have experienced (group) conversations in which storytelling proved to be quite pleasurable both to the raconteur and the listener or wider public, or witnessed more serious conversations about painful memories. In both cases, the term 'reminiscence' refers to a process in which the past is not merely recalled, but also 'relived'. Reminiscence reflects the personal and subjective way in which we remember things (Norris, 1988).

The relation between reminiscence and subjective well-being has been the object of study for a long time (Coleman, 1994), but it received renewed interest since Butler (1963) stated that reminiscence is a natural adaptive mental process for the elderly. Inspired by the psychodynamic theory of Erikson (1963), Butler asserted that, in order to reach ego 'integrity', ageing people need to evaluate their lives and reconcile their past selves with their present selves. To help people with their 'life review', he proposed the use of different stimuli to trigger memories, e.g. photographs, written or taped autobiographies, pilgrimages/reunions, genealogies, etc. Butler stated that all older people need to go through a stage of life review to prepare their death. However, this universal 'claim' became contested (Merriam, 1993), and soon different types and functions of reminiscence were acknowledged. Coleman (1986) found that people differ in their reminiscence behaviour: some reminisce, others do not. In addition, he found that the occurrence of reminiscence does not predict successful ageing adequately: reminiscing elderly may fail to resolve their problems with the past and continue to be unhappy about it. Their ruminative reminiscence over problems without solution appears to be unhelpful to them. Wong and Watt (1991) took the discussion further by identifying six types of reminiscence, all with different aims: narrative (storytelling), instrumental (problem solving), integrative (reconciliation), transmissive (education), defensive (denial or ignoration) and obsessive reminiscence (idealization or negative preoccupation). They demonstrated that two of these types are related with successful ageing -integrative and instrumental reminiscence-, while two other types -defensive and obsessive reminiscence- can be interpreted as signs of non-adaptive mental functioning. Inspired by this finding, clinicians have assessed the effects of different kinds of individual- and group reminiscence therapies. A literature study of Haight (1991) concluded that out of 39 studies, 18 found positive effects, 1 found no or negative effects and 7 studies actually did not evaluate reminiscence. Experimental comparative research found significant positive effects

on self-esteem, life satisfaction, mood and depression (Cook, 1998; Watt & Cappelliez, 2000). So far, the interventions used in the above mentioned studies revolve around life review (=integrative reminiscence) and/or problem resolving reminiscence. These therapies can be considered as emotion- and/or cognition oriented (Staudinger, 2001). By contrast, reminiscence *work* has developed a particular interest in narrative, i.e. 'simple' or anecdotal reminiscence, with a focus on positive remembrances. There is a wide consensus that stimulating people to tell stories about the past, without the need to evaluate one's own decisions, is not a therapy, but that this activity may have therapeutic effects (Bender, Bauckham, & Norris, 1999). An important aspect of reminiscence group work is its social function: people get to know one another, have fun together, and find each other in a 'shared' identity (Gillies & James, 1994). Yet there may be another explanation why people enjoy taking part in 'simple' reminiscence. Williams and Scott (1988) showed that if depressed people are presented with a cue word, they retrieve less specific and more general memories than non-depressed persons. This key finding led to the belief that the higher the recall of specific memories, the less likely rumination occurs and depression is maintained (Brittlebank, Scott, Williams & Ferrier, 1993). It is now hypothesized and partly proven that the sheer stimulation of specific memories (positive or negative) can have beneficial effects on mood and signs of depression (Serrano, Latorre, & Montanes, 2004).

The effects of reminiscence therapy or -work on subjective well-being of people with intellectual disabilities (ID) have not been evaluated so far. Numerous studies have been done involving people with dementia, with mixed results (for a review, see Finnema, Drŏes, Ribbe & Van Tilburg, 2004). Inconsistencies are usually attributed to methodological limitations (e.g. measuring subjective well-being by means of questionnaires in a valid way) and/or conceptual incompleteness (e.g. lack of precise theoretical underpinning, resulting in confusion about the effects that need to be looked after). Because cognitive disabilities are not seen as a counter-indication for reminiscence group work, we created a reminiscence group program adapted to the specific needs of people with ID (Van Puyenbroeck & Maes, in press).

Ageing people with intellectual disabilities are at an increased risk of having mental health problems, especially depression/mood disorders (Davidson, Prasher, & Janicki, 2003). Their higher prevalence for mood disorders is attributed to the target group's higher chance at being exposed to stressors that they can't control, and their difficulties in developing and maintaining stable patterns of social interaction (Reynolds & Miller, 1985). Although many people with ID show remarkable levels of resilience to traumatic life events, they do carry

their history with them and many have trouble in coping with it (Oswin, 1991; Hussain & Raczka, 1997; Van Puyenbroeck & Maes, 2005).

We modelled subjective well-being as a composite of life satisfaction, self-perceived competence and mood/interest. Life satisfaction and mood/interest were included as two general indicators, representing two major conceptions of subjective well-being: satisfaction and affect balance/happiness (Schalock & Felce, 2004). Self-perceived competence was added because we hypothesized that group reminiscence makes people aware that they can contribute in the reconstruction of a shared past, while establishing new or strengthening existing social relations with peers. Moreover, memories of past achievements and positive relationships may strengthen feelings of self-worth.

We also included two intermediating variables. First of all, personality has to be taken into account. Fry (1995) concluded that the expressed level of life satisfaction during life review conversations can be explained by individual personal traits like optimism, openness, humor and internal locus of control. Cully, Lavoie, and Gfeller (2001) investigated the (complex) relation between personality and reminiscence behaviour and found that conversational (narrative) reminiscence correlates with extraversion, and bitter reminiscence with emotional (in)stability ('neuroticism').

Another mediating variable we that considered was memory specificity. Although it is widely agreed upon that people who are depressed have more general memories than those who are not (Williams & Scott, 1988), there is still discussion about the nature of the relation. Depression severity (mood-level) and scores on memory specificity do not correlate (Kuyken & Brewin, 1995). The fact that an overgeneral memory may be a characteristic of a depression, does not necessarily mean that the most depressed are also the most general in their memory-retrieval. In this study, we wanted to verify the relation between mood and memory specificity, not by using a memory specificity questionnaire, but by analyzing the quality of (to some degree) spontaneous memory retrieval during the sessions.

The main question of this study was: what is the effect of a narrative reminiscence group program on life satisfaction, self-perceived competence and mood of ageing people with intellectual disabilities, taking into account personality and memory specificity?

In addition to this, we felt that a reminiscence work program cannot be seen as 'useful' only when it has a measurable effect on subjective well-being. Its meaningfulness is also dependent on the question whether the participants like the activity or not, and the question as to what level the program can rise to the expectations of the support workers who implement it. These matters of goal attainment were also evaluated in this study.

Methods

Sample

The target group of this study were people with mild or moderate intellectual disabilities, older than 50. Subjects were recruited from 6 long-term care facilities in the Flemish region of Belgium[5]. With regard to 'informed consent' (Stalker, 1998), the following procedure was followed. First we made agreements on the participation of a support worker in all care facilities. Next, each support worker explained the aim of the study to a selection of people that were visiting or living in the facility, and asked them individually if they would like to come to an introductory session.

Table 4.1. Demographic information of the participants (*N*=41)

Variables	*Group 1*	*Group 2*	*Group 3*	*Group 4*	*Group 5*	*Group 6*	*Total*
Support workers							
Age	34	30	49	28	39	45	*37,5*
Training	BEd	BEd	BEd	BSW**	BEd	MEd***	
Participants							
N	7	8	7	5	6	8	41
Age							
Mean	64	60.3	62.1	59.4	57.7	69.8	*62,7*
SD	6.2	7.1	8.2	3.2	6.3	3.5	7
Range	58-77	53-72	54-78	56-64	50-67	65-74	50-78
Sex							
Male	1	6	3	3	4	0	17
Female	6	2	4	2	2	8	24
ID							
Mild	5	6	5	4	2	7	29
Moderate	2	2	2	1	4	1	12

Note * Bachelor in Education, ** Bachelor in Social Work, *** Master in Education

In total, 43 subjects agreed to participate in the first, introductory session. In this session the researcher introduced himself, the aims and the details of the program. A 'dummy' reminiscence theme was then demonstrated, after which the participants were asked whether they liked the activity or not. It was made clear to them that they could quit the program at any time. One person decided not to enter the program after this 'dummy' session, without mentioning a particular reason. Another participant quitted the program after 6 sessions. The

[5] Data on the ageing population in care facilities in Flanders were provided by the research unit of the 'Flemish Fund for the Social Integration of People with disabilities'.

supporting staff was asked for the reason of the participant's drop-out. It turned out that another weekly activity interfered with the program sessions for her group. The final participation rate was 41 subjects (95%). In each facility, the recruiting support worker helped the researcher to conduct the group work. Six groups (sub-samples) were formed, one in each care facility. A selection of demographic statistics for the samples is listed in table 4.1.
Several factors prevented us to match the groups on the demographic variables mentioned: the particularity of our treatment program (group work), pragmatic factors like the limited mobility of the participants, and ethical considerations like the necessity of voluntary participation. We accounted for the sub-sample differences in our statistical analyses.

Instruments

[1] The short version of the Intellectual Disability Quality Of Life (IDQOL) (Hoekman, Douma, Kersten, Schuurman, & Koopman, 2001) consists of 16 items, measuring self-perceived satisfaction with different aspects of life (health, day activities, choice, family, friends, work, colleagues, housing, home-mates, and neighbourhood). Respondents answer each of the items on a 5-point scale ('very dissatisfied', 'little dissatisfied', 'indifferent', 'little satisfied' and 'very satisfied'). Each point is represented by a small icon, depicting a corresponding facial expression (very sad looking person → very happy looking person). Cronbach's alpha as a measure for internal consistency reliability is 0.85 (Hoekman et al., 2001).

[2] The Pictorial Scale of Perceived Competence and Social Acceptance of People with Intellectual Disabilities (PSPCSAPID) (Goverts, et al, 2000) is an adapted Dutch version of the scale that Harter and Pike (1984) developed to assess children's perceptions of their own abilities and social acceptance. The item format of the PSPCSAPID is as follows: the person with ID is shown two pictures about an everyday activity. One picture depicts a person who is not very good at the activity while the other picture shows a person who is good at it. The person with ID is then asked to decide which depicted person he or she resembles. Thereafter, the person is asked to indicate whether he or she is a lot or just a little bit like that person. The items are scored along a four-point scale. Subscales included perceived cognitive competence (PSPC_C) (Cronbach's α=0.82), perceived physical competence (PSPC_M) (α=0.89), perceived

social acceptance support workers/parents (PSPC_S1) (α=0.66) and perceived social acceptance by peers (PSPC_S2) (α=0.76). The internal consistency of the total score has proved to be quite high (α=0.93). There are separate versions of the scale for men versus women. In what follows, we will abbreviate the name of this variable to PSCP.

[3] The Mood Interest & Pleasure Questionnaire (MIPQ) (Ross & Oliver, 1999) is a 25-item, Likert scale, informant questionnaire. The items of the two subscales (mood and interest & pleasure) pertain to behavioural signs of affective state, respectively engagement in activities of adults with ID. Originally, this scale was designed for adults with severe and profound intellectual disabilities. We adapted it by means of small targeted changes in order to make it suitable for people with mild or moderate intellectual disabilities (e.g. vocalization → verbal utterance). An example item : "In the last two weeks, would you say that this person (1) smiled every day, (2) smiled nearly every day, (3) smiled 3 to 4 times/week, (4) smiled 1 to 2 times/week, or (5) smiled less than 1 time/week". The internal consistency of the original version is reported to be 0.94 (Ross & Oliver, 2003).

[4] The Five Factor Personality Inventory (FFPI) (Hendriks, Hofstee, & De Raad, 1999) is an instrument to assess a person's position on the dimensions extraversion, agreeableness, conscientiousness, emotional Stability, and autonomy (the so called 'big five' factors of personality). Sources can be self-report as well as informant-report. The latter possibility made this questionnaire suitable for our target group. The FFPI consists of 100 brief and simple behaviourally descriptive items in the third person singular (e.g. 'takes risks', 'avoids company'). Ratings are made on a five-point scale running from not at all applicable to entirely applicable. Both internal consistency (α =0.83–0.89) and six-month test–retest reliability (r=0.79–0.83) of the factor scores are reported to be satisfactory to high and correlations with convergent measures substantial (e.g. self/peer: r=0.54–0.72) (Hendriks, Hofstee, & De Raad, 2003).

[5] We used Vitessa (Video Time/Event Sampling Software) (Van Puyenbroeck, Maes, & Laeremans, 2005) to code the memories of the participants for their level of specificity (SPEC). Vitessa is a software program that features controlled playback of digital video data, so that the content of this data can be analyzed in a structured manner. Program sessions were recorded from two opposite angles (two cameras), so that every

participant could be heard and observed at any time. Half an hour of each recording (starting after the first quarter) was analyzed with intervals of 15 seconds, resulting in 60 observations per person. Reminiscence specificity of the participants during an interval was scored as follows: (0) no memory (1) general memory, confirmation of a suggestion (2) general memory, provision of additional information (3) specific memory (date and place). The variable that was constructed out of these observations was calculated for each person by taking the average of the highest observation-score in each reminiscence session (SPEC). We did not take into account the frequency (quantity) of memories during a session: SPEC is an aggregate of the highest (qualitative) levels of memories a subject achieved during the sessions. The interrater agreement for this variable was good (κ=0.67).

[6] Structured interviews were conducted with the support workers before and after the program. Among other questions, two were especially important for this report, because they addressed the issue of goal attainment: (1) (before the program) What are your expectations about the effects of group reminiscence? (2) (after the program) Were your previous expectations fulfilled with regard to the effects of group reminiscence?

[7] Group evaluation was conducted with the participants during the last session. They received 3 green and 3 red cards. Then they were shown objects/triggers from all previous sessions (the dummy session + 11 sessions of the program) and asked to give the green cards to the sessions they liked most, and the red cards to the sessions they didn't like (so much). The session that received the first green card was scored +3, the second +2, and the third 1. Similarly, the first session that was given a red card, received a handicap of -3, the second -2 and the third -1. By adding all scores, we got a rough measure for the participants' relative session preference.

Procedure

For the variables IDQOL (life satisfaction) and PSPC (perceived self-competence) a non-experimental pretest-posttest design was used (no control group, measurements before and after the program). Both questionnaires were administered by the researcher. For the variable MIPQ (mood, interest and pleasure), a quasi-experimental time series design was used, with 6 measurements: 1 before and 1 during the first control phase, 2 during the experimental phase,

and 2 during the second control phase (see the horizontal axes of the graph in figure 4.2. for a timeline with sessions and trials). The MIPQ was completed by the personal support workers of the participants (single blind). The variable FFPI (personality) was also completed by these support workers during the first control phase. The variable SPEC was measured during the reminiscence sessions.

The total program consisted of 12 sessions: 3 'current topics' sessions (control phase), namely 'Who am I?/Family' (with a thematic stress on the present situation), 'My house/My room' and 'Television', 6 group reminiscence sessions on different reminiscence topics (experimental phase), namely 'Household', 'Games and toys', 'School days', 'Food', 'Church – Religion' and 'Travels – Holidays', followed by –again- 3 'current topics' sessions (control phase), namely 'Music – Parties', 'Video-mail' and 'Evaluation'. The sessions were all comparable regarding setting, visual materials and structure of the group conversation. The reminiscence sessions explicitly handled topics from the past, the other sessions did not.

The reminiscence group work sessions (experimental sessions) were based on a method for group reminiscence among people with dementia, as described by Bruce, Hodgson and Schweitzer (1999). Important characteristics of that method are: weekly group work sessions, reminiscence themes (set and prepared in advance), and abundant use of visual triggers that are kept in a reminiscence suitcase. This program was adapted to the needs of people with ID (Van Puyenbroeck & Maes, in press). Major adaptations were: (1) the selection of themes so that they were relevant for the target group, (2) more structure added to the course of the sessions, (3) use of mind maps, and (4) implementation of three supporting roles: facilitating (including elaborating), coaching and moderating. The main goal of the experimental sessions was to elicit specific and 'positive' remembrances about the past, making use of the trigger objects in the reminiscence suitcase. Negative past experiences were not elaborated on. Although not denied nor ignored, these bad memories were 'reframed' as quickly as possible to positive memories. By means of elaboration, we tried to gain detailed information about the triggers, in order to get the reminiscences as specific as possible. The researcher took the role of facilitator, stimulating the participants in various ways to share memories, while a practitioner, employed by the support facility where the group gathering was held, assumed the role of coach, which meant assisting people to express themselves.

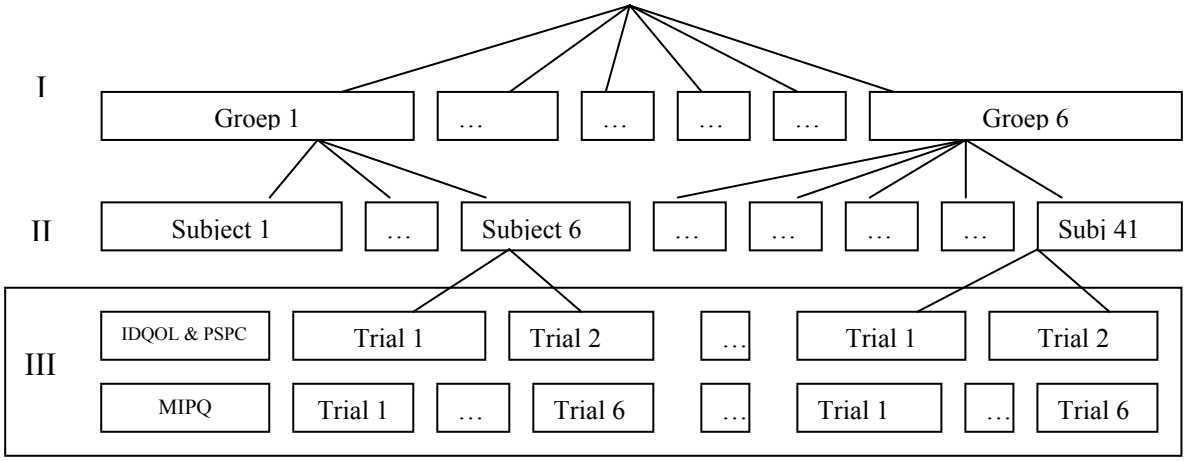
Ethical considerations shaped the design of our study. We wittingly did not choose for a separate control group, because we knew that it would be very difficult to explain the purpose of our study and the reason for administering questionnaires to our research subjects, when they could not participate in the project. Instead of a cross-sectional design, we therefore opted for a longitudinal ABA-design. This enabled us to measure the changes in a variable factor like mood (MIPQ) over time. However, because we felt that short successive measurements (intervals of 1 or 2 months) of more constant factors like life satisfaction (IDQOL) and perceived self-competence (PSPC) would not be meaningful, the design was limited to a pre- and post-test design for these variables. The implications for the interpretation of the results are outlined in the discussion. The design of this study was approved by the ethics committee of our faculty.

We tried to implement the program exactly the same in all groups. However, the groups were not totally equivalent with regard to demographic variables. Besides that, group dynamics were impossible to control. Group differences will therefore have to be accounted for during analysis.

Analysis

We executed multi-level/mixed-model regression analyses (1) to determine whether IDQOL and PSPC measurements differed between pre- and post-test (repeated) trials (TRIAL) (2) to evaluate whether the MIPQ scores showed an increase during the experimental reminiscence phase/condition (COND), and (3) to explore the relative importance of age (AGE), level of intellectual disability (ID), sex (SEX) and personality extraversion (FFPI_EXT) and emotional stability (FFPI_STAB) scores as predictors for MIPQ. We used multi-level regression analysis to model our data, because the scores on the different questionnaires were clearly not totally independent (Goldstein, 2003). We had (repeated) trials nested in subjects, and subjects nested in groups. On each of these ‘levels’ we expected ‘interfering’ factors. We wanted to exclude the impact of these from our model. The MIXED model procedure in SAS (2003) allowed us to ignore them as ‘random’ effects. This way, the model estimated the main effect(s) more correctly. All variables were standardized (suffix ST) in order to be able to compare the different impacts of predictors. Figure 4.1 depicts the level structure of our analysis.

Figure 4.1. Level structure for regression analysis



We would like to point out that a 'group effect' in our design is not a synonym –as in many cross-sectional experimental studies- for 'treatment effect'. We will consider GROUP merely as a covariate. To avoid misunderstanding, we will refer to the 6 reminiscence groups as 'sub-samples'.

Results

Sub-sample differences

As stated above, we could not match the sub-samples on a number of demographic variables, resulting in observable differences. Although we will control for all group-related differences later on, we will first shortly describe them. A Fisher's exact test revealed a difference in the six sub-samples for SEX, FET= 0.00000679, p=0.01. Multiple one-way ANOVA's revealed significant differences between the groups regarding AGE, $F(5,40)=3.63$, p=0.0094, FFPI_AGR, $F(5,40)=3.31$, p=0.014 and FFPI_STAB, $F(5,40)=2.72$, p=0.035. The sub-samples did not differ on all other variables (ID, FFPI_EXT, FFPI_CON, FFPI_AUT, PSPC and IDQOL). We feel that the reported differences had no consequences for group dynamics and/or the implementation of the program. In all groups the same methods could be used.

Treatment effects

Life satisfaction and perceived competence

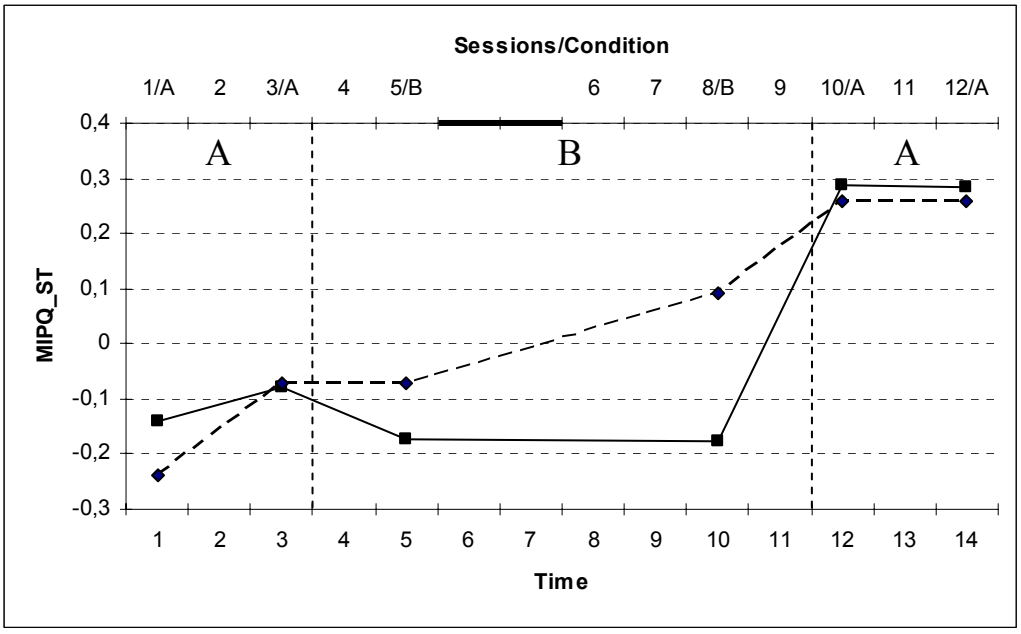
Life satisfaction (IDQOL_ST) did not change after the intervention. The effect of TRIAL (two values: before and after) was not significant, $F(1,39) = 2.20$, p=0.15. The same applied

for general perceived competence (PSPC_ST), F(1,39), p=0.21, perceived cognitive competence (PSPC_C), F(1,39)=0.15,p=0.69; perceived physical competence (PSPC_M), F(1,35)=2.10, p=0.15; perceived social acceptance by family/support workers (PSPC_S1), F(1,39)=3.03, p=0.09; and perceived social acceptance by peers (PSPC_S2), F(1,39)=1.80, p=0.18. The pre- and post-test measurements of IDQOL and PSPC-scores were very stable over time. The first trial of IDQOL (auto)correlated strongly with the second trial, with a regression estimate β (in this case, also Pearson's correlation) of 0.63, p<0.001. The two PSPC trial scores correlated even more, with β=0.98, p<0.001. This essentially means that the first trial score of PSPC could predict approximately 96% (R^2) of the scores on the second trial, nearly 4 months later. We can safely conclude that both life satisfaction and perceived competence were very stable over time, and obviously not influenced by the reminiscence program.

Mood, interest and pleasure

The MIPQ was scored during six trials (TRIAL). Within the scope of an ABA-design, the first two trials were assigned to condition A ('current topics'), to the second two trials a B value was assigned ('reminiscence'), and the last two trials were marked with A ('current topics') again. We tested the impact of COND on MIPQ_ST in a three-level model, with repeated trials nested in subjects, and subjects nested in groups (random intercepts for both subjects and groups), while controlling for AGE, SEX and ID. This model predicted a significant effect for COND, unfortunately in the opposite direction. The estimate for the experimental condition was -0.18, F(1,139)=2.15, p=0.05, which can at the same time be interpreted as its negative effect size. This result was very counterintuitive at first, so we investigated this finding more thoroughly. Figure 4.2. plots the standardized MIPQ_ST means and medians of the consecutive trials.

Figure 4.2. Mean and median MIPQ_ST-scores per TRIAL



Note ___ = mean scores, ---- = median scores

While the first 4 trials were found to be fairly stable, a sudden significant gain in MIPQ-scores was observed after trial 4. More than one explanation could be found to explain or ignore this finding (see the discussion section), but we analyzed the MIPQ-scores further, working within the assumption that what we were looking at was a *delayed* effect of the reminiscence program. Trial 3 –scores were obtained immediately after the first reminiscence session, trial 4 after the fifth reminiscence session (and Christmas holidays), trial 5 one week after the sixth reminiscence session, trial 6 another two weeks later. In order to test an alternative AB-hypothesis, the first two trials were coded with A, the next four trials with B. Complementary to this, a time variable, measured in weeks, (TIME) was added to model 1 as a continuous variable . In the second model, we added level of intellectual disability (ID), sex (SEX), two personality dimension scores on extraversion (FFPI_EXT) and emotional stability (FFPI_STAB), and memory specificity (SPEC). Multi-level analysis was again executed. Table 4.2. shows an empty model, and 2 models with subject level variables.

Table 4.2. Multilevel regression model for MIPQ_ST

	Empty 3-level model		Model 1		Model 2	
Parameter	Estimate	SE	Estimate	SE	Estimate	SE
FIXED						
Intercept	-0.034	(0.219)	-0.506	(0.281)	-0.904**	(0.315)
COND (B)			-0.238	(0.156)	-0.238	(0.157)
TIME			0.06**	(0.019)	0.062**	(0.02)
ID (MOD)					-0.443	(0.241)
SEX (M)					-0.079	(0.261)
FFPI_EXT					0.309*	(0.109)
FFPI_STAB					0.39**	(0.108)
SPEC_ST					-0.055	(0.133)
RANDOM						
Group level	0.186	(0.161)				
Subject level	0.489	(0.149)				
Trial level	0.316	(0.038)				
DEVIANCE	371.3		349.7		325.6	

Note * $p<0.05$, ** $p<0.01$

The empty model shows that 19% of the variance was located at group level, 49% at subject level, and 31% at trial level. The significance of the reversed effect of COND was not found in the 2 new models. We did see a significant effect for TIME, suggesting a gradual increase in mood/interest/pleasure scores over the total span of the program. The TIME parameter estimate seems rather small, but should be interpreted as a 0.06 increase of MIPQ_ST scores per week. Comparing the last trial to the first, the effect size was 0.74, which is considered a medium effect (Cohen, 1988). As expected, the scores for extraversion and emotional stability are two significant covariates for mood/interest/pleasure.

Calculating differences between the deviance scores allowed us to compare the models. Model 1 turned out to be a better fit than the empty model, $\chi^2(2)=21.6$, $p<0.001$. Adding the covariates in model 2 also increased the 'fit' of the model, $\chi^2(5)=24.1$, $p<0.001$.

Goal attainment

The program was briefly evaluated in a qualitative manner. The practitioners (N=6) who worked with the researcher to organize the group work sessions, all felt that group reminiscence was a meaningful activity for people with intellectual disabilities, for it fulfilled most expectations they had before the program. The most common heard evaluation was that reminiscence group work increased social contact. For three respondents, this meant the achievement of remarkable social cohesion in a group of people who didn't know (all) the other group members from the start. In three other cases (involving groups that already shared a history) this meant, from the perspective of the support workers involved more respect and a

more friendly, gentle approach towards one another. One practitioner thought the sessions would be more reflective, evaluative 'life review' therapy, instead of recreational, anecdotal 'animation' work. Another support worker stressed the importance of the non-intrusive, enjoyable character of group reminiscence. Yet another practitioner was convinced that not the reminiscence part, but the group work as such was the element of success. Some practitioners had expected that the participants would start talking about the past in other contexts (of daily living), but only one support worker observed this transfer afterwards. In this matter, we would like to mention that the researcher observed more 'associated' memories during the second trial of the IDQOL and PSPC-questionnaires. Four out of six support workers planned to continue the activity in their own support facility, with the same group members (in three cases the participants requested this), or even on a wider inter-facility scale. At the time of writing this manuscript, already three follow-up programs were actually implemented.

The participants themselves were very satisfied with the program, but did not have a clear preference between reminiscence (*M*=9,5) and current topics themes (*M*=12,5). In all groups the majority of the participants said that 'all sessions were good'. The researcher had to insist to differentiate between the sessions. 'Travel' was rated highest (+38), 'video-mail' came second (+28). The 'household'-topic was evaluated as a considerably negative (-19), 'food' as a very positive theme (+21). The session about religion had much advocates, but also a lot of opponents, resulting in a mediocre score of 8. The researcher as well as the support workers felt that the evaluation did not especially measure satisfaction with the program, but rather the feelings towards the different topics.

Discussion

Before this study, we already knew that reminiscence group work can be a valuable and meaningful activity for ageing people with intellectual disabilities (Stuart, 1998; Van Puyenbroeck & Maes, accepted). In this study, we tried to evaluate whether this kind of group work also can have a 'surplus value', i.e. a positive effect on different aspects of subjective well-being. We think the answer to this question is two-fold. Firstly, it seems that a weekly group activity cannot easily alter stable characteristics like life satisfaction and self-perceived competence. When one is not satisfied with a certain aspect of one's life, this perception will not change if the problem is still there after four months. Similarly, a person's perception

about his/her competence will not change if that person does not feel that he/she hasn't become more competent. The aim of our study was probably too ambitious in this matter. Secondly, concerning the index for mood/interest/pleasure, the analysis provided an unexpected answer to our main research question. The observed mood level decreased slightly during the first experimental phase and then suddenly rose afterwards. We have conducted the analysis from the hypothesis that the data reflect a delayed effect. Yet, another time-related explanation is perfectly valid: a Christmas 'blues' during staff holidays, and higher spirits after that, when normal daily activities recommenced. A contra-indication for this hypothesis is that the program began when daily activities were business as usual. The quasi-experimental ABA-design is vulnerable to the impact of time-related events. A lesson for future research is that, after a phase, a small time-interval should be inserted, before starting the next phase. More alternations of A en B (e.g. ABABA) could also solve this problem. If we were asked whether the program is *able* to affect mood/interest/pleasure, we would answer that question affirmatively. We've seen a lot of positive involvement and signs of well-being during the sessions. We heard from staff support workers that people looked forward to the next session, and that they generally felt good about it. We think it is *not* a coincidence that the gain in mood scores was obtained after the eight program session. At that point, people really got to know the researcher and other participants better and signs of group cohesion became observable. Whether these positive group dynamics really influenced the level of mood/interest/pleasure of our subjects, is a question that remains open. Our design did not yield decisive answers, but we feel that many, more subtle aspects of group work and reminiscence group work in particular, remained undetected through the use of questionnaires. This brings us to the validity of our data.

Finlay and Lyons (2001) demonstrated that the practice of administering questionnaires to people with ID involves many dangers regarding validity. We found that the IDQOL and COMP questionnaires indeed were prone to a mild acquiescence bias. Also, the FFPI and MIPQ questionnaires were completed by proxies of the people with ID, which poses a risk for construct validity. The validity of FFPI-by-proxy has been examined, and was repeatedly found to be good, but the same might not apply for the fairly new MIPQ-instrument. The MIPQ's convergent validity with a self-reported measure was tested only once (…), and found to be satisfactory. In this study, we found a significant correlation between the MIPQ and FFPI_STAB, which might be a confirmation of this finding, although we must add that the perspective of the latter was also the same proxy. An important feature of the MIPQ is that

it only includes mood indicators that can be observed. Better still would be to observe people with ID in real life to detect behavioural signs of their mood, interest and pleasure.
Another important concern regarding this study is the small number of subjects, and its consequences for multi-level analysis. There is some discussion whether it is appropriate to apply this method of analysis, given the small number of units on the first and the third level (N=6). We can defend our choice of analysis as follows: 1) ageing people with intellectual disabilities, willing to participate in research, and care facilities, willing to lend long term co-operation, are hard to find; 2) in most research projects the group level is ignored, and the required sample size is calculated for one level only. This study acknowledged the existence of grouped ánd repeated data and adopted a 3-level approach. We still found significant results. When we added GROUP as a controlled predictor and not as a level, similar results were obtained (a TIME and a FFPI_EXT effect). We have presented some of the sub-sample differences, which we deemed theoretically irrelevant to our research question. However, in future research other variables on the group level might be added in the analysis, for example characteristics of the care facility, behaviour of the support worker who acted as coach, and perhaps even more important group dynamics.

The finding that group (reminiscence) work may influence levels of mood/interest/pleasure in people with ID over time, is a promising finding. We learned from the interviews and evaluation session that all who were involved did not experience the program as a therapy. The superficial handling of memories is not considered a weakness, but rather a strong point. A therapist is not needed to implement the program. Future research could investigate whether (reminiscence) group work can help depressed people.
In our study we did not find a significant correlation between memory specificity and mood scores. We hypothesized that general/specific memory is a continuous variable that covaries with mood scores. That, in other words, it is related to the severity of depressive symptoms. This assumption was not confirmed. As in other studies, our data also suggest that memory specificity is not mood-state dependent. This does not mean that it might not be a trait or vulnerability marker for depression. Future research with depressed people with ID could give some indications for this alternative hypothesis.

Facilitator: Ever done any mischief?

Participant 1: No.

Participant 2: You're an angel, aren't you?

Participant 3: […]

Coach : I didn't understand that…

Participant 3: I put an onion under my armpit. Then I didn't have to go to school.

Coach: Yes, I heard about that.

Participant 4: Yes, it works.

Manuscript 5:

Involvement, well-being and group functioning in relation to facilitator's strategies during reminiscence group work[6]

This study analyses the (group) behaviour of elderly people with intellectual disabilities (ID) while taking part in a reminiscence group work program. Firstly, it seeks to describe this in terms of activity, focus and expressed well-being. Secondly, it aims to compare 'reminiscence' and 'current topics' group work in their effect on these behaviours. Thirdly, it explores the sequential relation between the group leader's strategies and the group members' behaviour. Finally, it qualitatively describes relevant inter-group and intra-group differences from the perspective of the group leaders. Forty-one ageing people with mild/moderate ID (>50 years) volunteered to participate in a program of 12 group work sessions. The two kinds of group work ('reminiscence' and 'current topics') were implemented in a quasi-experimental ABA-design. All sessions were recorded on video, which allowed for an applied behavioural analysis afterwards. The data were coded with a self-developed software program, named Vitessa, and analysed with multi-level lag sequential regression techniques. In general, the participants were highly focused and fairly active during all sessions, but they did not express their well-being very often. Reminiscence sessions significantly activated and involved the participants more than current topics. Concerning group leader strategies, a significant effect was found for visual strategies on the level of consequent group activity and focus even when controlling for antecedent group activity and focus. This study suggests that group work 'works' for ageing people with intellectual disabilities. It also demonstrates how applied behavioural analysis can be of use in the field of group work research.

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[6] Manuscript submitted for publication. Co-author: Bea Maes.

Introduction

The number of ageing people with intellectual disability (ID) has been growing steadily during the last decennia (Ansello & Janicki, 2000). The 'graying' of people with ID has led to a substantial increase in programs and services offered to this target group. Among the many challenges for professional support services is the need for adequate socio-emotional support and meaningful day-care activities (Bigby et al., 2004). In elder care, group work is extensively used as a service modality for this purpose. One of the more popular kinds of group work with the elderly is reminiscence group work, in which people are invited to share long-past memories about a common past (Gillies & James, 1994). Taking part in a reminiscence group is regarded as a pleasant, satisfying activity, a way to make contact with peers and a way to earn recognition (Gibson, 1994). Reminiscence group work, with its stress on simple, narrative reminiscence, is not seen as a therapy. The long research tradition that tries to grasp the therapeutic effects of reminiscence activities, focuses rather on evaluative types of reminiscence (Haight, 1991). Since Butler's positive appraisal of 'life review', various individual and group therapies have been developed, in order to support people in trying to understand and come to terms with their own past (Butler, 1963; Coleman, 1986). The primary outcomes researchers have focused on have been aspects of subjective well-being (self-esteem, life satisfaction, decrease of depression symptoms, etc.). Unwittingly, the 'soft' social and activating effects of reminiscence group work have come to be described as secondary side-effects. In contrast to this, Bender, Bauckham & Norris (1999) defended that a focus on well-being outcomes is a too narrow approach of reminiscence group work. It has several other merits, especially those that are happening during the gatherings: recreation, social contact, activation and the sharing of a (cultural) identity.

In our own research, we developed an adapted version of a narrative reminiscence group work program for ageing people with ID (Van Puyenbroeck & Maes, in press). We evaluated the effects of this program on life satisfaction, self-perceived competence and mood/interest and pleasure (Van Puyenbroeck & Maes, submitted). In the latter study, we compared two different conditions, namely 'current topics' and 'reminiscence' in a quasi-experimental (longitudinal) ABA-design. We found no effects of the program on self-perceived competence or life satisfaction, but a possible effect on mood/interest and pleasure. Although there was no significant difference in mood scores between the two conditions mentioned above, a steady increase was observed over time. The results indicate that not so much the

reminiscence content, but rather the group work itself may have been important in establishing this effect. Moreover, both the researcher and the support workers who helped to implement the program, felt that the effect evaluation, which was based on questionnaires, could not grasp the positive energy that arose *during* the group work. A more in depth analysis of the group work suggested itself. The video recordings enabled other behavioural analyses of the group work sessions.

The tradition to support older persons to engage in social and recreational activities is more than 50 years old (Toseland, 1995). From an educational gerontological point of view, group work is seen, not only as an occasion for the elderly to talk, c.q. reminisce about the past, but also as a way to understand the modern world, to share their experiences in modern times, their concerns about their lives and their future, and to have fun with peers. 'Groups offer a medium for human contact and human relatedness' (p.17). Major aims of group work are the improvement of interaction patterns, social cohesion, and more generally 'having fun'.
Those variables are not easy variables to operationalise. In their review, Evans & Dion (1991) suggest to take the level of participation as an indicator for group cohesion and involvement. For people with ID, engagement in activity is regarded as a valid outcome indicator for physical and mental health (Felce & Emerson, 2004). Research has demonstrated clear links between activity levels and mood; there is evidence that increasing activity levels may be effective in reducing depression and problem behaviours among clinical and non-clinical populations (Allison, Faith & Franklin, 1995; Brosse, Sheets, Lett & Blumenthal, 2002). The effect of reminiscence group work can therefore also be evaluated by means of behavioural observation. Brooker and Duce (2000) used this approach to test whether reminiscence therapy can induce behavioural signs of well-being in elderly patients with dementia. For people with profound multiple disabilities, similar research has been done by Green and Reid (1996), who succeeded in defining, validating and increasing behavioural signs of happiness in that target group.

The research questions of this study were as follows: (1) Firstly, we wanted to describe three behavioural indicators, namely activity, focus and expressed well-being during the group work sessions. (2) Secondly, we wanted to know how the two conditions would perform in a comparison for the variables mentioned. One might hypothesize that it is the group work aspect of reminiscence that makes it a success, and not the reminiscence part. If so, current topics sessions would elicit the same level of activity, focus and expressed well-being than

reminiscence sessions. (3) Thirdly, eliciting involvement of people with ID in group work requires different verbal and visual strategies of the facilitator. We wanted to find out how effective the facilitator was in activating the participants, in stimulating them to reminisce? What strategies were best? (4) Finally, keeping in mind that research has shown that group dynamics are an important factor to take into account when doing group work (Toseland & Rivas, 1995), we wanted to know how well the groups performed on this aspect. We were interested in relevant inter-group differences and intra-group dynamics (from the perspective of the researcher and/or support worker).

Methods

Sample

Forty-one participants with mild/moderate intellectual disabilities, older than 50, participated. Subjects were recruited from six long-term care facilities in the Flemish region of Belgium[7]. In each facility, a volunteering support worker with more than five years of work experience was found to assist the researcher in conducting the group reminiscence work. Their respective ages and training qualifications can be found in table 5.1.

Table 5.1. Demographic information of the participants and support workers

Variables	*Group 1*	*Group 2*	*Group 3*	*Group 4*	*Group 5*	*Group 6*	*Total*
Support workers							
Age	34	30	49	28	39	45	*37,5*
Training	BEd	BEd	BEd	BSW**	BEd	MEd***	
Participants							
N	7	8	7	5	6	8	41
Age							
Mean	64	60.3	62.1	59.4	57.7	69.8	*62,7*
SD	6.2	7.1	8.2	3.2	6.3	3.5	7
Range	58-77	53-72	54-78	56-64	50-67	65-74	50-78
Sex							
Male	1	6	3	3	4	0	17
Female	6	2	4	2	2	8	24
ID							
Mild	5	6	5	4	2	7	29
Moderate	2	2	2	1	4	1	12

Note * Bachelor in Education, ** Bachelor in Social Work, *** Master in Education

[7] Data on the ageing population in care facilities in Flanders were provided by the research unit of the 'Flemish Fund for the Social Integration of People with disabilities'.

The following procedure was followed for the recruitment of the participants: each support worker explained the aim of the study to the people visiting or living in his or her facility, and asked them if they would like to join a reminiscence group. In this first session, the researcher introduced himself, the aims and the details of the program. He demonstrated a 'dummy' reminiscence theme, after which he asked the participants whether they liked the activity or not. He explained that they could quit the program at any time. In total, 43 subjects agreed to participate in the first, introductory session. After this session, one participant in group 1 decided not to continue with the program. In group 4, another participant decided to quit the program after four sessions, yielding a participation rate of 0.95. Six groups were formed, one in each care facility. All participants were able to speak, 32 using full sentences, 13 using short phrases, and 3 communicating with single words. A selection of demographic statistics for the sample is listed in table 5.1. Table 5.2. lists the attendance of the participants at the sessions. Overall attendance rate was 0.92.

Table 5.2. Number of attendances per session and average proportion of attendance per group

		Session												
Group	*(max)*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*Mean*
1	(7)	7	7	7	7	6	7	6	7	7	6	7	7	0.96
2	(7)	6	7	7	6	4	7	7	7	7	7	7	7	0.94
3	(8)	7	7	8	8	7	7	6	8	8	7	7	7	0.91
4	(6)	6	6	6	6	5	3	5	5	4	5	5	5	0.85
5	(6)	6	6	6	6	6	6	6	6	6	6	6	6	1.00
6	(8)	6	7	7	7	8	8	7	7	7	8	8	8	0.92
Total	(42)	37	39	40	38	36	38	37	40	39	39	40	40	0.92

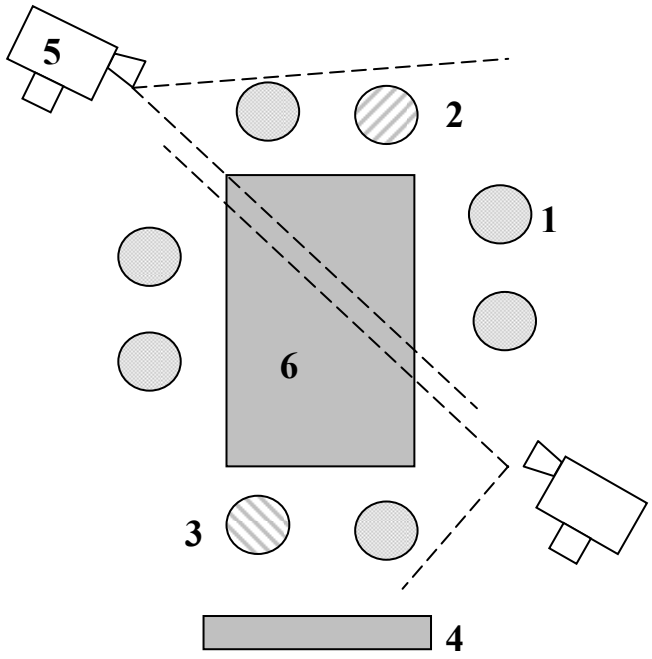
Procedure

Two kinds of group work were implemented in a quasi-experimental ABA-design: 3 current topics sessions (control phase), 6 group reminiscence sessions (experimental phase), and again 3 current topics sessions (control phase). The themes of the consecutive sessions were: [1] 'Who am I?/Family', [2] 'My house/My room' and [3] 'Television'; [4] 'Household', [5] 'Games and toys', [6] 'School days', [7] 'Food', [8] 'Church – Religion' and [9] 'Travels – Holidays'; [10] 'Music – Parties', [11] 'Video-mail' and [12] 'Evaluation'.

The sessions were all comparable regarding 1) setting and group size 2) group leadership, 3) visual/verbal strategies of the group leaders and 3) time structure of the group conversation. In all groups, the *setting* was a separated quiet room, separated from other daily activity. Disturbances from outside were very rare. All reminiscence groups were relatively small (5-8 participants). In every session, two *group leaders* were present. The researcher led all

sessions, mostly as a 'facilitator', as someone who stimulated creativity in the group, who tried to elicit memories, and who used different visual and verbal strategies to accomplish that. Most of the time, the support worker took the role of 'coach', as someone who supported the individual group members to contribute. Sometimes the facilitator and coach roles were swapped, as can be expected in the course of a natural group conversation. Both group leaders also had to moderate the conversation from time to time. Concerning *visual strategies*, we used a suitcase with objects in it to 'trigger' group conversation (contemporary items in the 'current topics' condition, vintage objects in the 'reminiscence' condition), and mind maps to clarify the thoughts of the participants. With regard to *verbal strategies*, the facilitator especially tried to elaborate on a memory if it was too general first. With additional questions he tried to elicit more specific memories. The sessions' course of time was structured: 10-15 minutes to introduce the theme, 30-45 minutes for group discussion, and 5-10 to conclude with a 'reward' (mostly a preview of the video recordings). The 12 sessions only differed in their content: the different themes for each session, and the current topics versus reminiscence themes. The reminiscence sessions (sessions 4-9) handled topics from the past explicitly; the other sessions (1-3 and 10-12) did not. For a more extensive description of the program, see Van Puyenbroeck and Maes, in press).

Figure 5.1. Standard stage setup for a group work session



Note 1 Participants, 2 Researcher, 3 Support worker, 4 Flip-over chart (mind maps), 5 videocamera, 6 Table

All sessions were recorded with two analogue cameras, so that the facial expressions of every participant could be observed at any time. Figure 5.1. depicts the 'stage' setup for a session. The recordings were digitalized for playback on a computer. We mixed the two video sources into one recording, using Avisynth (Rudiak-Gold, 2006).

Analysis

For the measurement of behaviour, we chose applied behavioural analysis. In this approach, behavioural units have to be of practical and social importance to the person and to others around the individual. When they're only of theoretical significance, they cannot be the focus of attention. The behaviour is assumed to serve a reinforcing function. It occurs for a good reason in the immediate environment (Thompson, Felce & Symons, 2000). Like other types of structured behavioural observation it uses small units of measurement that can represent the variability of behaviour better than questionnaires. A one-time occurrence of a striking behaviour can strongly influence a subjective evaluation of the total behaviour, while multiple observations can show its relative frequency. Event sampling, which means simply tallying the behaviour, can already accomplish that. The methods of time sampling and interval recording preserve the chronology of events by adding a time dimension. Either behaviour that occurs at the stroke of the time interval (time sampling), or behaviour that occurs during the interval is coded (interval recording). Time and event sampling are becoming increasingly popular as alternative methods to reliably measure behaviour in people with ID. The time and interval sampled data in our study was sequentially analysed afterwards. Sequential analysis involves the identification of antecedents for the behaviour of interest. Previous studies have focused mainly on problem behaviour, but also on conversational participation (Yoder, Short-Meyerson, & Tapp, 2004).

We used Vitessa (Video Time/Event Sampling Software) (Van Puyenbroeck, Maes, & Laeremans, 2005) to control the playback of our digital video data, so that it could be analyzed in a structured manner. We used it to count moments of active participation (ACT), focus (FOCUS) and smile/laughter (SMILE) of the participants, and to tally the use of verbal (VERB) and visual (VISU) strategies of the facilitator. The interval for the dichotomous coding (1 = 'occurrence' or 'true' value, 0 = 'no occurrence' or 'false' value) of every variable was set at 15 seconds. The total observation time was fixed at 30 minutes for ACT, FOC and SMILE (120 observations in each of the 12 sessions) and 15 minutes for VERB and

VISU (60 observations in each of the reminiscence sessions). The middle half or quarter of an hour was analysed, because only the group work in the middle of the session (after the introduction) was of interest to us. For some sessions, small disturbances (for example, when a person in a wheelchair needed assistance to have a drink) were left out of the analysis.
We recorded 3 behaviours: activity, focus and smile; either direct or indirect indicators of the above mentioned theoretical constructs (activity as indicator for participation, focus and activity as indicators for involvement, smile as an indicator for well-being).

Activity

The occurrence of a participant saying or doing something (ACT) was recorded over each 15 second interval (interval recording). 'Saying' also included non-verbal body language: for example nodding or shaking the head. 'Doing' included taking a closer look or pointing at an object. Inactivity or activity that didn't bear relation to the group work (for example, holding a cup of coffee) was coded as a 'non-occurrence'. The activity had to be momentaneous and purposeful.

Focus

The participants' focus on a speaker or an object (FOC) was evaluated based on the still image after the 15 seconds interval (time sampling). If a person looked away from what was happening (for example, looking outside the window, fiddling with one's fingers, looking at the corner of the table, not interested in what was happening at the other side) it was coded with a 'false' value. For those participants who were physically unable to turn their head, the coding was based on eye direction only.

Smile/laughter

Smiling (SMILE) was operationalised by determining whether the corners of a participant's mouth were pulled upwards at the end of the interval (time sampling). For this variable, the context was also very important: a 'true' value was attributed only when a participant was smiling or laughing because someone had said something funny in relation to the conversational subject or another relevant cause (for example, when someone succeeded in demonstrating something). The observation was not coded as 'true' when smiling or laughter was due to external causes. Some participants never met the 'mouth corners pulled upwards'-criterion. It was very difficult to assess this behaviour.

Verbal strategies

Verbal stimulation (VERB) of the facilitator was assessed for the whole interval (interval recording). At first, we differentiated between general comments, specific comments and no comments. Because the relative frequency of the first category was very low, we only retained the difference between specific verbal interventions - which we labelled 'elaboration' – and no verbal strategy.

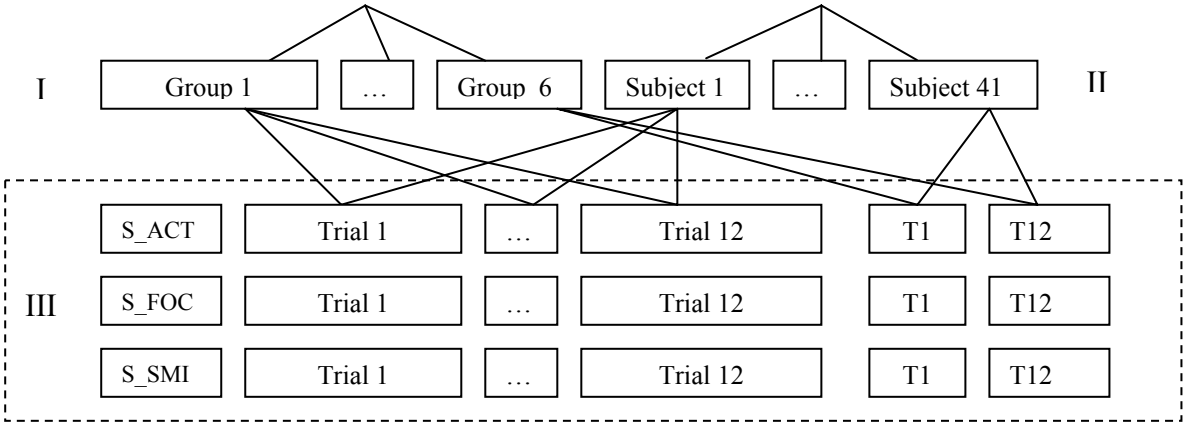
Visual strategies

For this variable we recorded the presentation of objects and mind maps during an interval (interval recording). VISU was scored with a 'true' value when the facilitator showed or held an object meant for 'triggering' a reaction of the group members, or when he mapped the thoughts of the participants on a flip-over chart.

A second observer rated the video recordings independently. Inter-rater agreement was calculated on a twelfth of all observational data: the first 10 observations for ACT, FOC and SMILE of every participant in every session, and the first 5 observations for VISU and VERB of the facilitator in every session. Kappa measures were: 0.72 for ACT ('good'; Altman, 1991), 0.86 for FOC ('very good'), 0.53 for SMILE ('moderate'), 0.91 for VERB ('very good') and 0.95 for VISU ('very good'). Some (external) factors obstructed a perfect agreement on the behaviour scores: recordings were not that sharp all the time due to bad lighting and lesser quality of the used hardware, differing camera positions in *situ*, and voices that sounded very similar. Coding 5-8 participants at the same time (after an interval) required full attention.

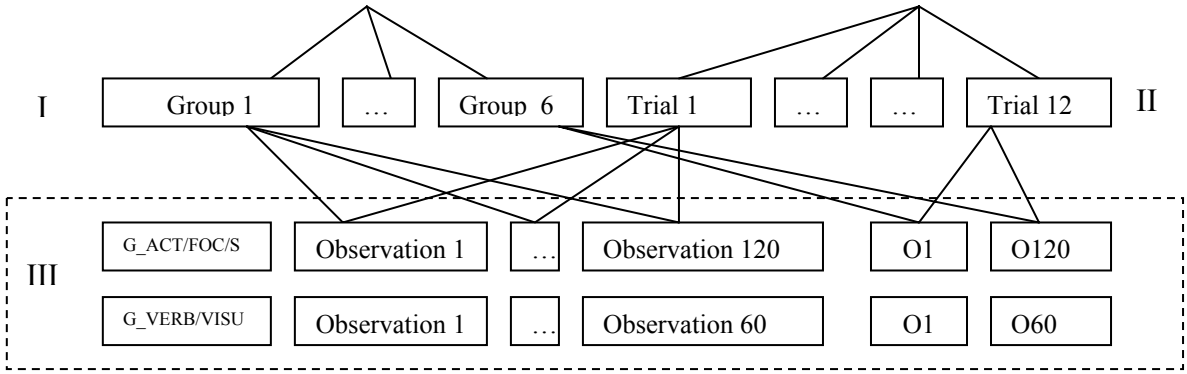
We opted for multi-level analysis to model our data, because the behavioural indices were clearly nested and not independent (Goldstein, 2003). The level structure of the first analysis in this study was a three-level cross-classification that can be summarized as: trials in groups and trials in subjects. A trial represents the subjects' average on a variable in a certain session (prefix S_). There were 12 sessions, so there were also 12 trials for S_ACT, S_FOC and S_SMILE.

Figure 5.2. Multi-level structure for test condition reminiscence - current topics



The level structure of the second analysis in this study was also a cross-classification and can be written as follows: observations in groups, and observations in trials. For the variables G_ACT, G_FOC and G_SMILE there were 120 observations, for the variables VERB and VISU we did 60 observations.

Figure 5.3. Multi-level structure for sequential analysis behaviour – strategies



We chose to discuss aggregated (average) findings, because the amount of data was quite large (3 variables x 41 participants x 120 observations x 12 sessions). All numbers mentioned in the results section must be interpreted as proportions: the average amount of a subject's behaviour during the observed fixed session time (test condition), the average amount of a certain behaviour among group members on a specific time during the observation (sequential analysis).

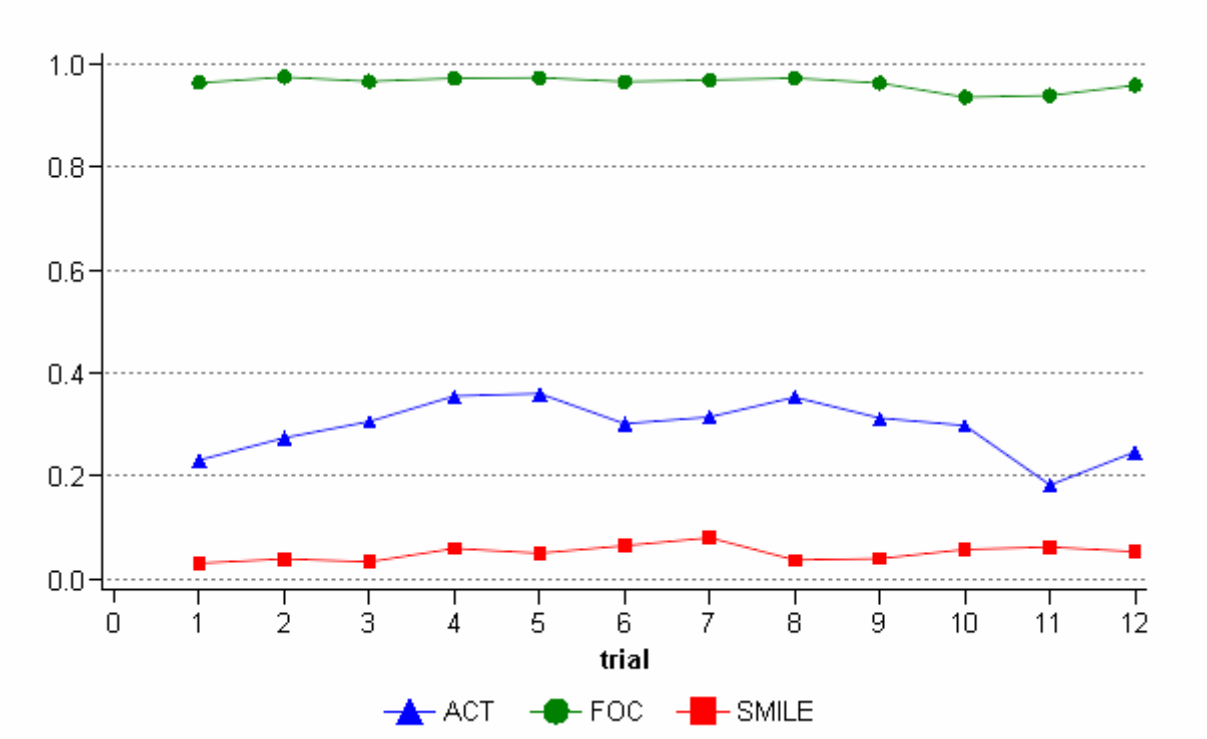
Apart from the quantitative behavioural analysis, we also reviewed the video data with a qualitative approach in mind, to derive general descriptions of group dynamics. The opinions of the support workers on the group functioning of their own reminiscence group and group work in general were gathered during session evaluations and a semi-structured interview.

Results

Participant behaviour across and between groups

We will first highlight some global results across groups and then test group differences. Figure 5.4. depicts the relative frequency of the average participant behaviour per session (=trial).

Figure 5.4. Relative frequency of ACT, FOC and SMILE per session



As we can see, the focus (FOC) of the participants was very high. Overall, the participants looked at what was happening during an average ratio of 0.96 of the observed time. This was a very stable finding, *SD*=0.06. The six groups did not differ on averaged focus scores across sessions, $F(5,35)=0.83$, $p=0.54$. For the analysis of SMILE, five subjects were left out of the sample, because the expression of their mouth could not be reliably scored. These subjects' lips were almost continuously stretched upwards (possibly due to a spastic inclination),

resulting in relative high values for them on the variable SMILE. This way they seemed to be in a continual state of 'compliance', but in fact, we don't know. Their expressed well-being was hard to assess. In the corrected sample, the frequency of smiling was relatively low (*M*=0.05, *SD*=0.06, *N*=36). Groups did not differ significantly in this matter, *F*(5,29)=1.54, *p*=0.21.

There was more variation in activity scores than in focus or smile rates. In figure 5.4. we can see an upwards trend during the first sessions of the program, a relative 'dip' for sessions 6 and 7, a short break back up to session 8 and then down again for sessions 9, 10, 11 and 12. The remarkable lower average score for session 11 ('video message') can be explained by the fact that the group conversation was about preparing the video-mail message, resulting in a great deal of 1-1 talk (facilitator – participant). The overall mean for ACT was 0.29 (SD=0.19), meaning that the average participant was active during nearly one third of the observed time. Again, the groups did not differ significantly for average ACT across sessions, F(5,35)=0.81, *p*=0.55.

'Reminiscence' - versus 'current topics' condition

We compared the subjects' averaged session scores on activity (S_ACT), focus (S_FOC) and smile (S_SMILE) between the current topics sessions (1-3,10-12) and reminiscence sessions (4-9). Three-level models were estimated (trials in subjects, subjects in groups). Table 5.3 lists parameter estimates for the impact of COND on the three dependent variables, controlling for a time effect.

Table 5.3. TIME and COND impact on S_ACT, S_FOC and S_SMILE

	S_ACT		S_FOC		S_SMILE	
Parameter	Estimate	SE	Estimate	SE	Estimate	SE
FIXED						
Intercept	0.343***	(0.025)	0.979***	(0.007)	0.043***	(0.009)
TIME	-0.001	(0.0008)	-0.0009*	(0.0003)	0.0008	(0.0003)
COND (B)	0.07***	(0.011)	0.012*	(0.004)	0.009	(0.005)
RANDOM†						
Group	0%		0%		0%	
Subject	54%		36%		42%	
Trial	46%		64%		58%	
DEVIANCE						
Empty	-499.5		-1478.7		-1148.4	
Model	-551.3		-1510.6		-1159.5	
Gain	51.8***		31.9***		11.1**	

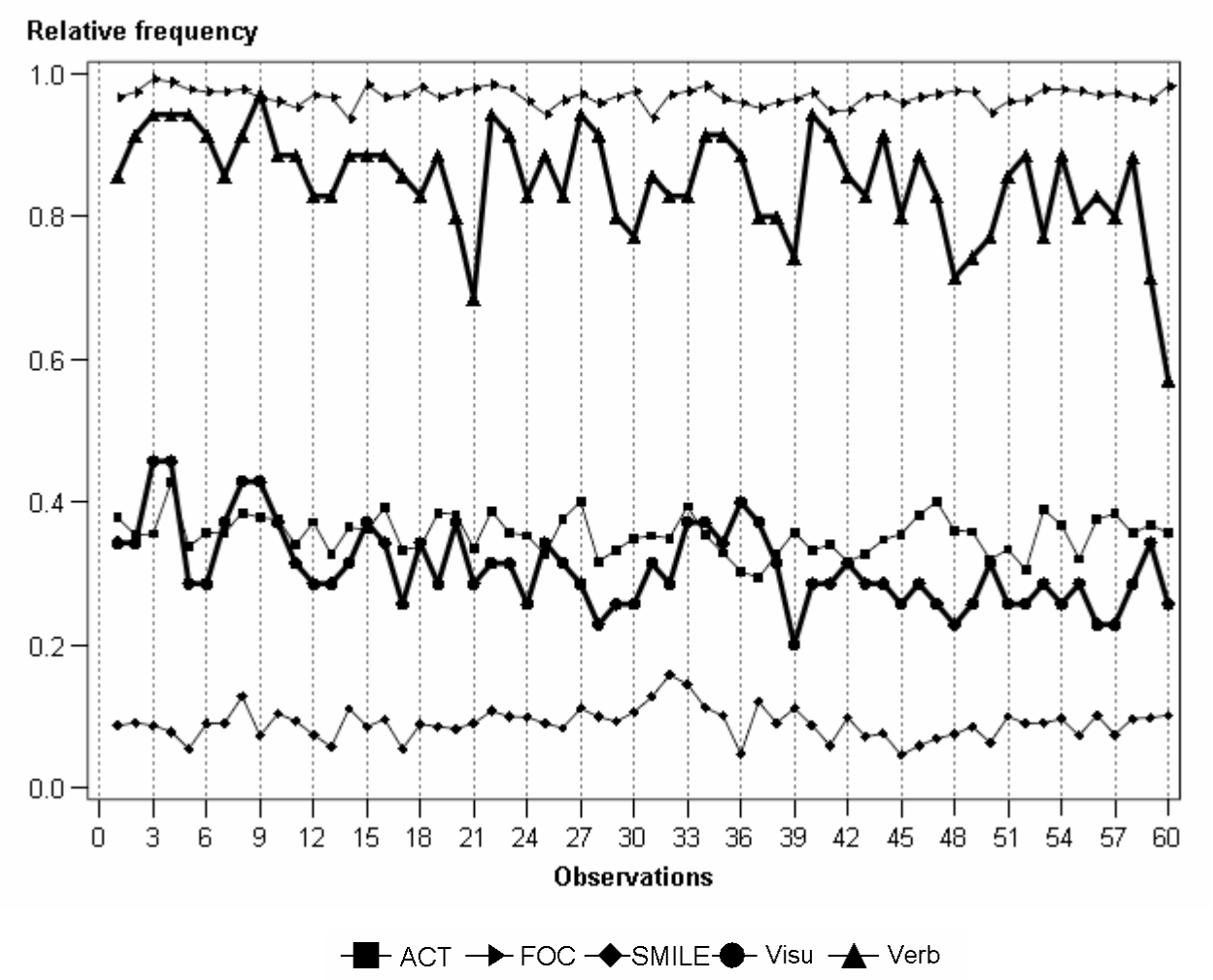
Note * $p<0.01$, ** $p<0.001$, *** $p<0.0001$ † Random part calculated for empty model, †† Deviance gain in relation to deviance of the empty model (indication of fit)

We may conclude that 'reminiscence' sessions (COND) had a very significant effect on the average occurrence of participant's activity during a session, a modest significant effect on focus, and no significant effect on smile. In other words, the reminiscence themes were able to activate and involve the participants more than the current topics sessions, but could not increase expressed well-being. No share of the total variance in scores on the three variables could be attributed to the group level; the estimated variance was quite evenly divided between the subject and trial level. The addition of the two predictors TIME and COND resulted in a much better fit of the models, in comparison with their 'empty' equivalents (cf. gains in deviance scores).

Sequential analysis of group behaviour and facilitator strategies

Before we analysed the sequential relation between the facilitator's strategies and the group's behaviour, we took a look at what actually happened during a reminiscence session. Figure 5.5 represents average group scores for activity, focus and smile, and the average occurrence of visual and verbal strategies across time samples of 15 minutes (all points depict averages: group and facilitator scores across sessions). Compared to average individual scores (figure 5.4.), a similar picture emerges here: a high frequency for focus, a low proportion of smiles and a medium occurrence of activity. We can see that all variables stay within a fairly constant range during the observed time, but showing a 'cyclic' trend. While group focus scores only have relatively small 'bumps', group activity and -smile have more 'ups' and 'downs'. We conclude that these group behaviours were more influenced by the session circumstances than group focus. One of those circumstances was the strategy selected by the facilitator. Figure 5.5. shows that the facilitator was quite verbal during the session (M=0.85), and that he made a fair use of visual strategies too (M=0.31). We remind the reader that the presentation of verbal and visual strategies was not manipulated. We can see that -again- there seems to be an (averaged) 'cycle' of presentation. The question now arises whether the facilitator's verbal and visual stimulation have sequentially affected group behaviour.

Figure 5.5. Average group behaviour and facilitator strategies during 15 minutes of a reminiscence session



In order to learn something about this sequential relation, we created three lagged versions of all group behaviour variables (suffix "_1", "_2" and "_3"). The original variables received a suffix "_0" (lag 0). We analysed the variance of G_ACT_1/2/3, G_FOC_1/2/3, and G_SMILE_1/2/3 in 4 level regression models. We evaluated the impact of VERB and VISU, while controlling for the 'previous' group behaviour (lag-1, lag-2, lag-3). The interaction term VERB x VISU was left out of the model after analysis showed it had no impact. Estimates for all models are shown in table 5.4.

Table 5.4. Multilevel lag sequential regression models to predict G_ACT, G_FOC and G_SMILE

	G-ACT-0		*G-ACT-1*		*G-ACT-2*		*G-ACT-3*	
Parameter	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
FIXED								
Intercept	0.3827***	(0.028)	0.302***	(0.0237)	0.2590***	(0.02221)	0.2267***	(0.02210)
VERB	0.0019	(0.0104)	0.006	(0.0103)	0.0134	(0.01034)	0.0001	(0.01045)
VISU	0.0435***	(0.0082)	0.036***	(0.008)	0.0186*	(0.00813)	0.0064	(0.00822)
G-ACT-0			0.208***	(0.0214)	0.1176***	(0.02196)	0.0631**	(0.02243)
G-ACT-1					0.1858***	(0.02205)	0.1107***	(0.02268)
G-ACT-2							0.1919***	(0.02247)
DEVIANCE								
Empty	-1509.0		-1494.6		-1486.1		-1441.6	
Model	-1537.8		-1615.8		-1621.2		-1583.1	
	G-FOC-0		*G-FOC-1*		*G-FOC-2*		*G-FOC-3*	
Parameter	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
FIXED								
Intercept	0.9776***	(0.006)	-0.12***	(0.0126)	-0.1177***	(0.01376)	-0.1264***	(0.01487)
VERB	0.004	(0.0049)	0.007**	(0.0023)	-0.0039	(0.00239)	0.0006	(0.00241)
VISU	0.0138***	(0.0039)	0.0008	(0.0018)	0.0023	(0.00181)	0.0024	(0.00183)
G-FOC-0			1.1197***	(0.0128)	-0.0246	(0.04052)	0.0656	(0.04182)
G-FOC-1					1.1409***	(0.03752)	-0.0754	(0.05359)
G-FOC-2							1.1356***	(0.03750)
DEVIANCE								
Empty	-4638.3		-4532.3		-4427.0		-4326.3	
Model	-4652.4		-7723.5		-7552.6		-7415.6	
	G-SMILE-0		*G-SMILE-1*		*G-SMILE-2*		*G-SMILE-3*	
Parameter	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
FIXED								
Intercept	0.0948**	(0.0244)	0.0664**	(0.01765)	0.0578**	(0.01572)	0.0527**	(0.01551)
VERB	0.0012	(0.0088)	-0.008	(0.00863)	-0.0046	(0.0087)	-0.0038	(0.00879)
VISU	0.0035	(0.0069)	0.0018	(0.00674)	0.0027	(0.00678)	-0.0066	(0.00684)
G-SMILE-0			0.278***	(0.02116)	0.1090***	(0.02202)	0.0222	(0.02230)
G-SMILE-1					0.2518***	(0.02208)	0.1063***	(0.02291)
G-SMILE-2							0.2440***	(0.02239)
DEVIANCE								
Empty	-2215.2		-2172.0		-2124.3		-2081.3	
Model	-2215.4		-2337.9		-2313.7		-2265.3	

Note: * $p<0.05$, ** $p<0.01$ *** $p<0.001$

When we look at the four models for G_ACT, we can see that the VISU, which was recorded *during* the interval, affects G_ACT_0 (sampled at the *end* of the interval) significantly (model 0). We can see that the lagged variables are also significantly affected by VISU, even when controlled for the previous lag(s) (models 1 and 2). Model 2 has the best fit. It can be read as follows: the level of group activity at a certain time is affected greatly by the level of activity in the previous 30 seconds and still influenced by the occurrence of a visual strategy of 30 seconds ago. Model 3 suggests that the effect of a visual strategy on G_ACT does not last more than 30 seconds. The fact that G_ACT_0 ánd G_ACT_1 influence G_ACT_2 hints at the cyclic nature of this variable: to predict the next interval score, a researcher not only needs the current score, but also the previous score. It is possible that a change in level of activity is 'postponed' over two intervals (with a possible 'dip' in between). If the series of ACT-scores would have been very constant over time, the models would indicate that only one lag is sufficient to predict the 'next' score. This can be illustrated with the models for G_FOC. Being a fairly constant variable, it can be predicted solely by its lag 1-transformed variant. The first model has the best fit, suggesting that verbal strategies keep the focus of the participants for the next 15 seconds, even when we control for the previous level of focus. G_SMILE could not be predicted by any strategy of the facilitator. The best fitted model (model 3) indicates that the two previous occurrences (lag 1 and 2) are the only determining predictors. In general, most of the explained variance was situated at the trial level, meaning that the correlations we just presented didn't differ much between groups or sessions.

Group functioning and group dynamics

Even an extensive structured observation cannot fully grasp the complexity of a group's functioning. It is possible that even very active, focused and smiling people may not constitute a successful group. The success of a group depends on how the group members interact with each other. The concept of group dynamics refers to group processes that describe these interactions, whether and how people work together towards a common goal and which 'atmosphere' surrounds them while they are doing that. The group dynamics were assessed on the one hand by the support workers (SW), and on the other hand by the researcher while reviewing the sessions when coding. We'll first focus on what the SW thought to be critical factors for positive group dynamics. An important issue for them that arose during the interviews was whether they knew their participants in advance or not.

They had the feeling that it was easier when the group members (including themselves) already knew each other (some groups indeed consisted of some people who were already

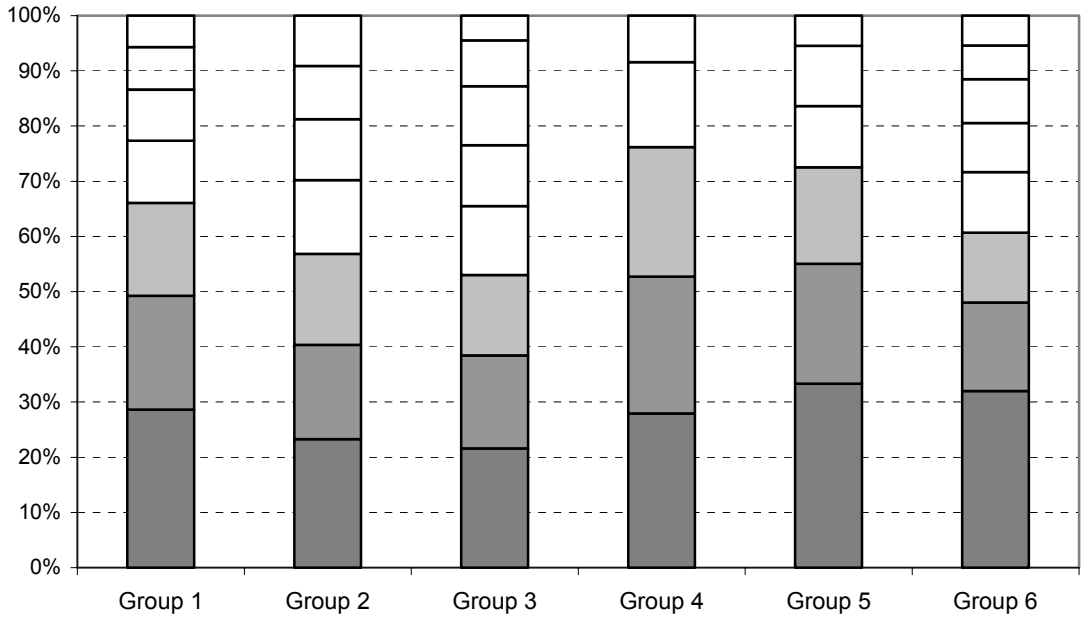
acquainted with each other, and other groups didn't). At the same time they thought that this was just a minor handicap for the group; after a few sessions, people got to know each other well enough. Another mediating factor according to the SW was their own life experience in general and experience with group work in particular. Younger people (like the researcher and the SW of group four) had not 'handled' many groups before, and above that, raised the past more as a question than as a fact. An older facilitator or coach could share more memories and elaborate on them better. Likewise, age homogeneity of the participants was thought to be important. People with the same age shared the same memories and were 'peers' in that sense. Furthermore, according to the SW group size does matter. Five persons are a minimum and eight a maximum. Finally, the verbal skills of the participants are deemed to be important, although a mix of eloquent and less eloquent people may still constitute a good group.

In relation to the study and completed group work, the SW thought that group dynamics improved as the program advanced. The group cohesion improved in all groups, except maybe in group four. The researcher/facilitator and support worker/coach in that newly composed group could activate all participants separately, but not often as a group. Another positive effect of the program was group trust: the feeling that people could share anything in the group. In group one, the support worker was very positive about her group in this regard; she said her reminiscence group was an instrument for her to learn what the participants thought about themselves and/or others. She said she could talk with the participants about these feelings outside the sessions.

The group reminiscence work had educational relevance. Information was being shared, and people were honoured for their knowledge. The group 'leaders' were actually the assistants of the participants, who gave direction to the session and determined the outcome themselves. The group work however may have remained a bit artificial. One support worker afterwards hypothesized that the effect of a 'scientific' study could have been enough to raise self-esteem and creative a positive 'group energy'. Her group may have felt special because the members knew they could assist in a research project.

The researcher himself had a perception of his own on the group dynamics after this study. We will briefly discuss our own 'impressions' of group functioning here, supported by some objective data on group member 'dominance' (defined as a participant's relative share of group activity) (see figure 5.6.).

Figure 5.6. Relative group member 'dominance'



Group one and two were both newly composed groups that worked out. People got to know each other and became friends after a while. In group one, two participants were quite verbally skilled in reminiscing; they were able to animate the other group members, without really opposing to other contributions. In group two, three members were quite eloquent, the group conversations were always very fluent. Group three consisted of people who already knew each other. It was also a 'family' group. The coach in this group had the same age as the participants, was very knowledgeable about local culture, and was able to talk the local dialect. A 'joker' always made fun of the facilitator; she made everybody laugh when she said she was in love with him. Group four had some troubles in making the program a success. First of all, the location of the reminiscence group was quite far from the group members' homes. People had to travel a relatively long distance before they could engage in reminiscence. One participant decided to quit after four sessions. The others stayed motivated to come to the sessions, but could never fully enjoy positive group dynamics. One participant had a lot of stories about the past, but he had some difficulties in sharing those adequately in a group. The other group members sometimes ignored him, or started private conversations with each other. Moderation was difficult in this group. Group five also knew each other for a long time, because they had been living together for a long time (another 'family' group). Members were very kind to each other. For example, one participant had speech difficulties, but everyone always waited for him to finish his stories. The group had one very active

participant, but she was accepted in her 'dominance' of the group conversation. In group six, the very active participants tried to draw the group's focus to themselves and angered each other this way sometimes. The group did not except that somebody 'stood out'. This was a group who already knew each other for a long time. There was an argument between several participants in the beginning of a session. The positive atmosphere of the group work made tempers decrease.

Discussion

This study analysed the behaviour of elderly people with ID taking part in reminiscence group work. We demonstrated that the participants were very focused and fairly active during all sessions, but more in the reminiscence sessions than in the current topics sessions. We were able, though not without difficulties, to record expressed well-being. Its overall lower frequency is difficult to interpret. The results suggest that well-being of the participants was low during the sampled session time. However, the ratios are misleading. For how many laughs are needed for a successful session or group? For example, one cannot expect that the frequency of smiling is similar to the focus rate. In fact, continuous smiling would seem rather suspicious (cf. the omitted outliers). To make sense of the data, we took a look at the average *absolute* number of smiles/laughs. The average participant laughed approximately 9 times in the most amusing session ('food'), and 3 times in the least entertaining session ('introduction/who am I?') in the course of one half an hour. We won't say that these are high numbers, but if we consider the expression 'having a good laugh', one smile or laugh may already be a sufficient indicator for the enjoyment of a participant.

We were able to demonstrate that reminiscence sessions are more activating and involving than current topics sessions. As in a previous outcome evaluation, where we made use of questionnaires (Van Puyenbroeck & Maes, submitted), this study too confirms the possible benefits of (reminiscence) group work for ageing people with ID.

This study furthermore attempted to describe the sequential relation between group member's activity, focus and expressed-well-being and the strategies of the group leader (the facilitator). Visual aids were more effective in triggering memories. This finding concurred with the subjective experience of the researcher and the support worker. The success of our reminiscence group work program can be attributed to the success of the reminiscence suitcase. With the visual triggers we were able to draw the attention of the participants, more

than with our verbal elaboration. For group work with ageing people and/or people with ID, this study advises the use of more visual materials.

We did not use complex relationships to model group functioning. We based ourselves simply on the assumption that activity, focus and smile/laughter are good indicators for good group work. Our approach was very 'atomic'. The question remains whether the ecological validity of the concepts we have tried to measure (activity, involvement, well-being) has suffered from this approach. We think that the variable 'activity' was fairly straightforward, that 'focus' indeed is very closely related to 'involvement', but that there may be some discussion about 'smile' as an indicator for well-being. 'Expressed well-being' is probably the better, more modest term to use.

In this study we used a quantitative structured observation and a multi-level lag sequential regression analysis. To our knowledge the combination of both has not yet been applied in any research regarding people with disabilities, or in the field of group work studies. We will first sum up the benefits of our methods, then point at some difficulties. An advantage of the video recording was that the group work did not have to be assessed in 'real-time'. The combination of digital video data and Vitessa allowed for a precise analysis afterwards. Two raters could judge the same imagery independent from each other. Another important benefit of structured observation was the possibility to obtain an objective perspective on the group members' behaviour. We were surprised at times to see that the time sampled data led us to other beliefs than our first subjective impressions immediately after a group work session. Moreover, the sequential analysis allowed us to draw causal conclusions with regard to the efficiency of the facilitator's strategies. Causal inference needs time-based data. Our observational method generated very long lists of such data. Finally, the multi-level approach accounts for the interdependence of repeated and otherwise 'grouped' measurements. A participant's behaviour in a group work context is very dependent on other group member's behaviour, the same naturally applies for within-subjects observations.

The main difficulty with structured video observation is that it is a very time-consuming and intensive method. Several hours have to be spent to code and prepare the data for analysis. Vitessa saved us some time, by allowing us to code more than one subject on more than one variable at the same time. Another problem is that the observed behaviour really needs to be operationalised in a very simple and transparent way in order to be analysed reliably. Interrater agreement depends heavily on clear criteria for classification; it needs strict mutually excluding categories. A third difficulty is the need for big-enough samples on *every*

level in a multi-level analysis. In our study, there were only six groups, which makes it difficult to generalize across groups.

A cross-study analysis revealed interesting correlations. The average activity of a participant during the sessions (this study) was significantly correlated with the 'extraversion' personality dimension (Van Puyenbroeck & Maes, submitted) (r=0.56, p=0.0002, N=39), an indication for the convergent validity of these measures. Similarly, expressed well-being (smiling) was connected with emotional stability (r=0.35, p=0.04). We could not find consistent correlations between the observations and the Mood Interest and Pleasure Questionnaire (MIPQ) (Hoekman et al., 2001). We have pointed at some difficulties of the 'proxy' method. No correlation between expressed well-being and MIPQ however does not necessarily mean that the MIPQ is unreliable or an invalid instrument for measuring mood/interest/pleasure. We compared average observation scores with the MIPQ-data. A more thorough triangulation would be a comparison of daily life observations at the same times the MIPQ was filled in by the proxies.

We did not analyse how the participants interacted during the sessions. Yet there were many differences in how people reacted to each other, the group work, the themes and the methods. Future quantitative analyses can try to model this complex reality, but we think we would never be able to represent the whole 'phenomenon' of (reminiscence) group work. Behind the multitude of figures, there are many individual stories of those who were very enthusiastic and eager sometimes and those who were occasionally very bored. Everyone had their own favourite issues, some were difficult to activate, others difficult to curb. We can tell these stories later, but we can also hope that the participants will tell them themselves to others. We hope they'll have the best memories regarding our study.

Conclusions

In our manuscripts, we have described the phenomenon of reminiscence in ageing people with mild or moderate intellectual disabilities, have made a classification of support strategies involving reminiscence, and have reported on the development and evaluation of a group reminiscence program. In this concluding chapter, we shall summarize the theoretical, methodological and practical relevance of our studies, and point out to their limitations as well.

Theoretical relevance

Autobiographical memory

A major assumption of our research was that people with intellectual disabilities possess the necessary cognitive abilities to reminisce. From a Piagetian perspective, we can think of several reasons that can cast doubts in this matter. Evaluative reminiscence requires some abstract reasoning. This in turn requires the formal operational stage in cognitive development, a stage that people with intellectual disabilities do not always achieve (Dougherty & Moran, 1983). Another doubt was that autobiographical memory itself may be underdeveloped in the target group. The average person with mild intellectual disabilities has an estimated cognitive developmental age of 6 to 7 years; the same equivalent for a person with moderate intellectual disability is estimated at 4 to 5 years. However, the origin of autobiographical memory is situated at the age of 4 (Nelson, 1992). Before that age, children tell about their memories as a general way to represent reality as they experience it. They 'reminisce' about something because they experience something similar at the same time. A memory of a past experience is just a part of a general representation of that experience. After the age of 4 this way of cognitive structuring changes; children will start to have specific memories and talk about those, thereby moved by extraneous motives, for example because they want to share them with others.

A first conclusion of our research is that people with mild or moderate intellectual disability are capable of using their autobiographical memory to reminisce about a distant past. This finding is not new in itself, witness the fact that 'oral history' and 'life story work' have been researched before (*manuscript 2*). The novelty of this doctorate lies in the start to a more detailed analysis of the reminiscence process (which underlies 'oral history' and 'life story

work'), not only in *manuscript 1*, but also in *manuscript 4*, where we included memory specificity as a covariate to predict mood. Narrative reminiscence implies the ability to relate specific memories; a person needs to be able to remember and retell the details of a past event. When we look at the maximum level of memory specificity of each participant in *manuscript 4*, we can conclude that 59% of the sample was able to recall at least one specific memory, and that 88% was capable of adding at least something 'new' to the suggestions of the facilitator. Only 12% didn't get any further than acknowledging or denying something that was already remembered by the facilitator or other group members. Or, should we interprete these findings differently? We could also say that for 12% of our sample, we do not know whether they had a memory 'of their own' during the sessions, and that 41% did not show that they were able to 'timestamp' an event. The level of memory specificity was not associated with the level of intellectual disability (mild versus moderate), but was instead found to be strongly connected to the personality dimension 'extraversion'. This might imply that our behavioural index for memory specificity was not specific enough, that it also measured verbal and (social) activity. Future research could be targeted at specific memory in people with intellectual disabilities to find answers to the questions raised here.

'Special' people, 'special' reminiscence?

Using only a small sample, we tested how some essential reminiscence concepts can be applied to the memories of ageing people with intellectual disabilities (*Manuscript 1*). The content analysis revealed the presence as well as the absence of certain specific reminiscence topics. People who have lived at home with their parents for a very long time, talk more about their family, the passing away of their parents, their relocation, and the places they had been living since. Their staying at home has usually been the longest episode in their lives, so family issues mark their history. But even for those who had not seen their parents very often -because they lived in an institution-, 'family' was the most preferred subject. This finding is in conformity with literature that describes bereavement in people with intellectual disabilities (Blackman, 2003). Adapting oneself to a changing living- or social environment is not an easy task for any of us, but for people with intellectual disabilities it might be just a little bit harder. The missing topic of 'children/grandchildren' in the life reviews has everything to do with the fact that most of the respondents didn't have the opportunity to start a family themselves. Under these circumstances, the 'lived experience' of ageing people with intellectual disabilities can be quite different from people without (intellectual) disabilities. Parenting is seen as an important building stone for a person's identity. We do not want to insist on

Erikson's theoretical model (again), but his perception on (the ability to) care as a virtue of human development is relevant here. The lack of the possibility to develop 'generativity' (an adult's ability to care for others) in people with intellectual disabilities, and its impact on their subjective well-being is worth further analysis. Our target group may be worth special attention in this regard. They have a history of parental or institutional protection. Inspired by new support paradigms, young people with intellectual disabilities are now supported in a better way to engage in social and sexual relationships, parenthood and education.

Another striking observation was that the majority of the life stories was larded with a big variety of negative memories. People with (intellectual) disabilities indeed run a greater risk at experiencing traumatic life events (Hastings, Hatton, Taylor, & Maddison, 2004). We observed a wide variety in reactions to negative life events: neutral responses, silent or expressed sadness, feelings of guilt, etc. An important addition to the theories on bereavement in people with disabilities, is that people who experienced negative life events do not necessarily need to be traumatised. Of all the people we spoke during our research, a fair part was able to talk about their 'traumas' in a normal way. A lot of respondents/participants spoke without hesitation and had no problems in telling 'sensitive' matters. Some tried to tell objective stories of what happened to them. In some people, we witnessed an exceptional amount of 'resilience' to cope with traumatic life experiences. Like other authors, we therefore stress the necessity for a positive psychology of people with intellectual disabilities; their strength in *successfully* coping with loss is worth receiving more attention from researchers (LeRoy, Walsh, Kulik, & Rooney, 2000).

We want to come back to the reminiscence type taxonomy of Wong and Watt (1991). We were able to find examples of all the different types, except for escapist reminiscence. Reminiscence as a way to flee the troubles of the present, seeking refuge in the past, was not observed in our limited sample of subjects, but we did notice a fair amount of nostalgia in the stories of the people we spoke with. Some clearly longed to go back to the past again. In this nostalgic type of reminiscence, the past was 'wanted', but not in a pathological sense. It was portrayed as a time that is lost. In this context, the participants preferred to talk about lost loved ones. We had the impression that in their reminiscence, people were trying to 'settle down', to create a feeling of emotional security for themselves, using the memories of their loved ones. Future research could further investigate the attachment representations of adult or ageing people with intellectual disabilities.

Effect of group reminiscence on life satisfaction, self-perceived competence and mood

Manuscript 4 has to be situated against the line of research that evaluates the effect of (group) reminiscence on life satisfaction. Experimental studies of Haight (1992) and Cook (1998) found a durable positive influence of life review and group reminiscence on subjects' satisfaction with life. Inspired by Eriksonian thought, it is presupposed that reminiscing elderly not only become reconciled with their past selves, but also with their present life circumstances. Our study did not find any effect of group reminiscence work on life satisfaction. Possible causes for this result are the relative short duration of the program (6 reminiscence sessions in total), the specific target group, or the 'coarseness' of our evaluation instrument (IDQOL; Hoekman et al., 2001). Based on qualitative impressions during the second administration of the questionnaire (listening to the comments of the research subjects), we dare to formulate yet another explanation. It is possible that the subjective experiences of quality of life are only influenced by factors that are big enough to disrupt the innate human homeostatic control of well-being (Cummins, 2001). We are thinking of physical health in the first place, the occurrence of major (negative) life events, and the absence of a social network. In another (master thesis) research project that we co-supervised, we were able to confirm the first two factors (health and life events) and the support attitude of professional support workers as correlates of life satisfaction (Denis, 2005). An activity like group reminiscence can hardly have an effect on a stable variable like life satisfaction. The participants' judgement about their life circumstances was equally positive or negative at both trials; their life circumstances had not changed very much between both assessments, so their opinion hadn't changed notably either. In our opinion, the effects of group reminiscence do not include life satisfaction.

The choice for an outcome variable like 'self-perceived competence' was based on studies that found an effect of reminiscence work on self-concept and self-esteem (Perrotta & Meacham, 1981; Haight, 1991). This beneficial effect is predicted by multiple theories: reminiscence promotes ego-integration, can take away feelings of guilt, or can strengthen the identity by retrospective comparison (Watt & Cappeliez, 2001). Yet no difference was found between the pre- and post-test measurements of self-perceived competence. Possible causes may be related to the nature of the instrument we used, a questionnaire that was originally developed for (young) adults with an intellectual disability (PCPS) (Goverts, et al, 2000). The subscale 'self-perceived motoric competence' seemed to be less applicable to our ageing sample, but there were no problems regarding 'face-validity' during administration. The

participants critically judged their abilities. Since their competencies did not or barely change during the study's duration of 4 months, their opinion about themselves didn't change either. One of the problems involved here may be that the instrument we used measured 'self-concept', but not 'self-esteem'. While it is possible that the first cannot be affected by reminiscence, an effect on the latter is not impossible. We were struck by the fact that people during the post-test measurement, while being equally positive or negative about their current competencies, referred more to their past abilities than during the first trial. The researcher, who administered the questionnaire, had become associated with 'talk about the past', which resulted in added 'off the record' retrospective nuances: "No, they were not able to do this or that anymore, but there was a time when they had those skills". If reminiscence therapy/work would be able to induce this type of reasoning in a better way than we did, so that it becomes an automatism, ageing people could benefit more from reminiscence. The reality of difficulties and limitations in later life could then be contrasted with past successes and abilities. Self-esteem might be influenceable this way.

The variable 'mood' was at the focus of our effect study. We opted for a 'hedonistic' approach to well-being: we tested whether group reminiscence can alter mood/interest/pleasure, in other words, whether it can bring about positive 'affects'. We based our expectations on previous research, which found positive effects on mood and affect balance (Haight, 1992; Rattenbury & Stones, 1989). In other studies, decreases in depressive symptoms had been established (Watt & Cappeliez, 2000; Serrano, Latorro, & Montanes, 2004). Our expectations had also risen after the study that we described in *manuscript 3*, in which we had the impression that our adapted version of reminiscence group work was able to raise quite some interest, pleasure and activity. We did not know however whether we could extrapolate this effect from the context of group work to the daily living environment.
Our expectations seemed to be unjustified. We were not able to find a significant positive effect of reminiscence on mood. A possible explanation for this finding may be the fact that in our study the 'current topics' control condition was very comparable to the 'reminiscence' experimental condition. Both conditions only differed in the time focus of the conversational subjects: past versus present. In the previous mentioned studies the control activity 'current topics' was operationalised as an unstructured conversation about the news headlines. Before our study, we thought that this condition was too different from the reminiscence condition. The content of the control condition needed to be attractive and supported by appealing visual materials.

In *manuscript 4*, we did find a significant increase in mood scores near the end of the program. We have interpreted this as a delayed 'time' effect. The number of weeks turned out to be a significant covariate for mood. Because we cannot compare these results with a control group that didn't participate in any program, we cannot exclude coincidental effects. Because we cannot compare these results with a group that went through the same program during another period of the year, we cannot exclude 'seasonal' effects. Moreover, we cannot know exactly what 'worked': reminiscence work or alternative ('current topics') group work. Yet a plausible explanation seems to us a delayed effect of the total group work program (reminiscence- ánd current topics). Indeed, in all groups we noticed that the participants after a certain amount of time became quite attached to the weekly group work sessions. We heard from the support workers that most people looked forward to these appointments.

We think there were some interfering factors that made it difficult for us to find an answer to the seminal question "can a reminiscence activity positively alter aspects of well-being in people with intellectual disabilities?". Some of these factors were related to the (longitudinal) ABA research design and the strict delineation of the conditions, others to our sample of subjects, and yet others to our pen-and-paper instruments for measuring well-being. In a ABA-design, one has to take 'carry-over' effects into account. A plain experimental design, with an experimental– and a control group would probably have been better, but we did not want to do that, mostly because of deontological reasons. A second difficulty was the short duration and narrow resemblance of our control and experimental condition. The control sessions had to resemble the reminiscence sessions as much as possible, except for the fact that they did not cover the past. By designing the control sessions as structured and attractive group activities, chances were that mood would increase or at least not decrease during the control phase. A third difficulty was the fact that we did not conceive the evaluation as a classic treatment evaluation. We did not select a subgroup of people with major life dissatisfaction, low self-esteem or mood disorders, in order to treat them with group reminiscence. By doing so, the maximum possible effect size was already smaller in advance. The people in our sample could benefit less from the intervention.

Finally, the use of the MIPQ (Ross & Oliver, 1999) in our research was not without problems. This instrument measures mood/interest/pleasure by means of an assessment of behavioural indicators, but it relies on indirect observation to accomplish that. A proxy is asked for his or

her opinion on the occurrence of behaviours that are indicative for depression or elation in the last two weeks. This judgement can be troubled by a memory bias. Therefore, we wanted to have an alternative measure for well-being. In the next study, we analyzed the observational behavioural data that were gathered during the sessions.

Effect of (reminiscence) group work on activity, focus and expressed well-being

As far as we know, *manuscript 5* describes the first study to record precisely the effects of group work on activity, focus and expressed well-being. To our best knowledge, it is the first study that uses structured observational techniques to relate that behaviour sequentially to the strategies of the group leader. Group work is usually evaluated in terms of efficiency: how the group performed in order to reach the desired product or result (West, 1996). What happens during the sessions is expressed in terms of group cohesion, -roles, -tasks, -communication, -leadership, etc. These concepts are defined as process variables. In our study we conceived three individual behaviours as *outcomes* of our program. This choice was relevant for our target group. Activation, focus and expressed well-being are relevant goals for ageing people with intellectual disabilities. In gerontological literature, the activating function of group work has been recognized (Toseland, 1995). In disability research 'engagement in activity' has been proposed as a good indicator for general well-being; '[it] may be considered as a fundamental aspect of life which underpins other quality-of-life outcomes' (Felce & Emerson, 2004, p. 363). After *manuscript 5*, we can conclude that reminiscence content causes ageing people with intellectual disabilities to be more active and focused than 'current topics' content. So we may have demonstrated that the content of group work is a relevant factor in motivating ageing people to participate and get involved into a group activity. The subjective view of support workers was confirmed by 'objective' observational data: reminiscence is not just 'another group work activity'; it is a meaningful, activating and involving activity. By adapting the content of the group work to the age of those concerned, we were able to respect the participants in their own 'world view'.

The conclusion that visual strategies are superior to verbal strategies can not surprise us. The visual triggers appealed more to the participants than the verbal ones. The reminiscence suitcase was a success. We don't assume that this finding is related to specific characteristics of our target group. We make a statement here that, in our view, memories are far easier to trigger with visual stimuli, than with verbal stimuli. This thesis may be fruitful for other autobiographical memory research.

Methodological relevance

Mixed methods

We gathered qualitative as well as quantitative data in the studies described in *manuscripts 1*, *4* and *5*. This strategy is usually referred to as 'mixed methods', a well-known concept in educational research, but not an obvious or easy choice (Tashakkori & Teddlie, 2002). Presenting quantitative and qualitative data as two sides of the same medal, is usually regarded as a surplus value of a research study, but the combination of two different 'truth claims' is not self-evident. Qualitative research does not aspire to acquire the same type of knowledge as quantitative research and vice versa. Lincoln and Guba (1985) posed that the choice for a certain research method depends on the choice of the paradigm a researcher wants to 'believe' and work in. Similar instruments may be used in different paradigms, but the aims of the analysis will be different. It is striking that in *manuscript 5* two representations of the same reality can differ that much, depending on whether we choose for a quantitative approach (counting behavioural events), or a qualitative approach (judging group dynamics). The first strategy aims at generalisation, the second at describing the unique character of a 'case'. In other words: explaining versus understanding, the 'scientific' versus the 'naturalistic'. As a researcher, I was sometimes trapped in this dichotomy. Depending on what I was looking at, I always 'believed' that the paradigm that I was *not* using at a certain moment, was actually the better one. The question that bothered me was whether I -or any researcher- could do both properly at the same time.

Yet, as a conclusion of the studies mentioned, we are convinced that the paradigms are not that incompatible as described in literature. Different methods and analyses *can* complement each other. To answer the main question in *manuscripts 3*, *4* and *5* ("is this a meaningful and useful program?"), both approaches were absolutely necessary. An experimental scientist wants to 'understand' (the lack of) his significant main effect. What happened when he operationalised the variables in a certain way? Do they really represent 'reality' in a valid way? What happened 'behind' the scenes? At the same time, a qualitative researcher certainly wants to obtain a thrustworthy, credible picture of the case he is studying. He may even want to generalise his findings to other cases. Lincoln and Guba (1985) talk about 'transferability': if results are described in detail, they may become recognised by people in similar contexts. Adding numbers to (or in) qualitative research can help to clarify a qualitative point to be made. Providing details does not necessarily mean that long descriptions are required. Summary descriptive statistics can also clarify the characteristics of a certain situation or

context. Statistical analyses provide indications whether a finding may be generalised (that is to say, whether 'inference' to the population is possible, under the conditions of a certain statistic). Qualitative analyses deliver the necessary feedback to the question "what has just happened here?". They make the research subject recognizable. Cohen, Manion and Morrison (2000) attribute this pragmatical point of view to Abraham Kaplan: "The aims of methods are to help us understand in the broadest possible terms, not the products of scientific inquiry but the process itself" (p. 45).

Interviewing people with intellectual disabilities

In intellectual disability research, it is necessary to involve people with intellectual disability. Not because they are the study 'object', but also because they are the 'stake-holders' who are entitled to benefit from the results. Although this proposition might seem obvious, it is not self-evident. In this paragraph, we would like to call attention to some issues regarding the methods for interviewing/assessing people with intellectual disabilities. We learned from experience that several factors may hamper an unbiased administration of a questionnaire, or the smooth course of an interview. First of all, one has to take into account that people with intellectual disabilities have limited abstraction capabilities, and therefore have trouble in understanding the purpose of the interview. This does not render the participant's answering of questions impossible, but it certainly does not make it easier. An inquiry can also be obstructed by communication problems. The interviewee may not understand a certain word, because it does not belong to his or her vocabulary or even does not exist in that person's reality (for example, some respondents never had a colleague at work, yet the concept occurred in our quality of life-questionnaire). Open-ended questions are not necessarily a problem, but the quality of the answer depends heavily on the verbal skills of the respondent. In the case of closed-ended questions, I occasionally witnessed they were uncertain whether the answer they had chosen was the 'right' answer, hence they were afraid to say something wrong. Adding a structure to the procedure of answering (cf. the PSPC, Goverts, et al, 2000) may help an insecure person, but it increases the chance that people immediately agree with the first or the last response option. The number of response options is also important, a multitude of alternatives can confuse a person with intellectual disability. Yes/no questions are preferred, although 'yea-saying' (known as 'acquiescence' - the tendency to say 'yes'), 'nay-saying (the opposite), or 'first or last response bias' can occur. They *did* occur in our studies. Closed-ended questions are good to retrieve facts, but not that efficient in triggering life stories. Occasionally, there were communication problems due to speech disorders or

hearing difficulties. Also, a good understanding of different speech dialects is no luxury for an interviewer. An interview in standard language can be a strange or artificial experience for an ageing respondent, who only knows his dialect language. We also learned that very strict interview guidelines are not always desirable. One has to show empathy and warmth by asking several small personal questions before or after the central questions. It makes the interview more personal and the results probably more valid. A stiff interview can easily become something like an interrogation, which can be perceived as very threatening. A researcher has to take into account that people with intellectual disabilities can be fixated on certain subjects. On occasion, a respondent may have a special liking for a certain topic, and not stray from it, not even when he or she is asked to. This can obstruct the focus of the interview.

For the open-ended interviews (individually and group wise) we preferred to have a 'coach' present. This was a helpful strategy, but it could complicate the 'negotiation of meaning' sometimes. With regard to communication, a coach is a big help: he or she can help in 'translating' the answers of the participant to the researcher. A coach can 'enrich' the interview by increasing the level of detail, by giving examples, adding names, dates, etc. The coach knows who the respondent is; he or she can point at essential 'things-to-know' about a person. This strategy however bears some fundamental risks. When a coach suggests a 'story-to-be-told' or completes a story with several details (thinking this is necessary), he can interrupt the answer of the person he is assisting. That person may be busy trying to formulate his own answer. In general, the presence of the coaches was a big advantage for my research. Without their help, the interviews and group conversations would not have been possible.

Applied behavioural analysis on video-data

In our evaluation study, we conducted a structured observation. The aim was to obtain more detailed information about the participants' behaviour during the group work sessions. By using smaller 'measuring units' we were able to show the variability better. Opposed to questionnaires that query the incidence of behaviours over time and across situations, a structured observation can take precise samples, and take into account environmental differences. This method is considered to be the most reliable one for psychological variables that include observable behaviour (e.g. problem behaviour).

In our research, we opted for applied behavioural analysis. In this approach, behavioural units have to be of practical and social importance to the person and to others around the individual. The behaviour is assumed to serve a reinforcing function. It occurs for a good reason in the

immediate environment (Thompson, Felce and Symons, 2000). In a group work context, activity, focus, expressed well-being and verbal/visual strategies seemed relevant to us. We processed these behaviours with 'interval recording' and 'time sampling', techniques that are increasingly becoming popular as alternative methods to reliably measure behaviour in people with intellectual disabilities (Yoder, Short-Meyerson, and Tapp, 2004). After we prepared the data like this, we could conduct a sequential analysis on them. This meant that we identified significant antecedents for our behaviours of interest. Quantifying the magnitude of a sequential (temporal) association between events or behaviours is not easy, given the number of indices of sequential association that various researchers have used (for an overview, see Yoder & Feurer, 2000). The most common indices are based on two-by-two contingency tables, using the frequencies of the four possible combinations of two behaviours: how many times did A and B co-occur? A, but not B? Not A, but B? Neither A or B? Odds ratio's and Yule's Q can be calculated from these figures. The chance that behaviour A occurs after behaviour B is then weighed against the chance that A occurs after other behaviours. These statistics assume categorical variables. We took another approach. We used (multi-level) lag regression analysis on a 'treated-as-continous' dependent variable (average activity, focus and expressed well-being). By adding lagged variables to the regression models, we could analyse the correlations of events that occurred with a fixed interval of 15 seconds. The multi-level approach enabled us to take into account the interdependency of the observations. As far as we know, a multi-level sequential regression analysis on observational data has not been executed before in our field of research.

Because nowadays digital shooting material is generally available, it was much easier for us to process the observation data. We did not use 'live observers'; we coded and analysed video recordings instead. To do that, we developed a software program called 'Vitessa' (Van Puyenbroeck, Maes, & Laeremans, 2005). This program enabled us to control the playback of the many digital video files we recorded, in order to analyse them in a structured manner. Vitessa supports event sampling, time sampling and interval recording. Vitessa is nothing more than an interface to code video data to structured data logs. It is not used for the analysis itself, although we plan to add basic statistical functionality to it. It may prove to be a meaningful addition to the current 'stock' of video analysis -installations, that are usually quite complex and expensive, or still working with analogue data. For a more detailed description of Vitessa, see appendix D.

On a side note, we'd like to point at our successful use of open source software during our research project. Avisynth allowed for precise video post production (e.g. combining and synchronizing video sources), Vitessa facilitated structured analysis. We were in every way *free* to use these and other open source software packages. We always stayed, in other words, 'on top of things'.

Limitations of our research

For our studies in *manuscript 1* and *manuscript 3*, we used a very small sample of participants (*N*=10, *N*=7). For the studies in *manuscripts 4* and *5* we had a somewhat bigger sample (*N*=41), but we were only able to work with (semi) existing groups (within care facilities). The reasons for working with existing groups were mainly pragmatic factors like the limited mobility of the participants, but also ethical considerations like the necessity of voluntary participation. We could not match the groups on any demographic variables. We therefore accounted for the sub-sample differences in our statistical analysis, using a multi-level approach. However, on the group-level, we had not enough units (6). In general, we have to be very careful in generalising our results.

With regard to the number of group units, there is some discussion among the experts about the size of this problem. Some say that for each level in the analysis a minimum number of units is necessary, others contradict this by saying that there is no problem if the dependent variable is measured on another level that has enough units. An additional precautionary measure to test the robustness of the main effect may be including the group variable as a predictor in the regression model. In our analyses, the main effect was still there even when controlled for group effects.

Another disputable choice was not to transform the dependent variable in our regression analyses. The distribution of a proportional variable (all values between 0-1) cannot be expected to be normal. However, the criterion for multiple regression is that the residuals need to be normally distributed. In our research, every model that is included, meets that criterion. Besides, a log transformation was not advised to us, due to the extra complexity, and difficulties in interpretation of the estimated parameters.

Practical relevance

Exploring 'ortho-gerontagogical' research

This doctoral thesis was explorative in a lot of ways. We started this project with a well-known study object from psychological gerontology research, but we had to apply this

concept to a very specific target group, and moreover, we planned to do that from an 'orthopedagogical' perspective. 'Orthopedagogy' however is primarily directed at children/adolescents (cf. the word part 'ped'). In addition, orthopedagogy refers to education, and its normative objective (cf. the word part 'ortho'). The 'right' course of development during the ageing process however, is not self-evident (Breckow, 1992). What needs to be developed, what aims are desirable? In other words, how does one have to interpret a 'gerontagogy' (Lemieux & Martinez, 2000; Geerts & Messelis, 1999), an agogy for the aged? Moreover, does an 'ortho-gerontagogy' even (has a right to) exist? We believe so. Firstly, the development of people does not stop after adolescence. 'Life-span' theory states that humans develop across all life stages, and that cumulative and innovative processes are still going on in the aged (Erikson, 1963; Baltes, 1987). The human developmental process is multidirectional: developmental changes do not always head in the same direction. Dependent on age and the type of behaviour, a person's functioning can improve, decline or become different. A developing person gains and looses skills. To be short, his development is changeable and not determined. This is an important presupposition for any educational or agogical thinking. Secondly, educational gerontology is a well-established discipline within the broad spectrum of gerontological research (Lumsden, s.d.). By consequence, ortho-agogy, as an accepted subfield of educational sciences, can develop theories and methods in relation to ageing people, hence a 'ortho-gerontagogical' perspective. But would this discipline also have a surplus value? Again, we think so. Firstly, we do not limit ortho-gerontagogy to the science of 'problematic educational contexts' in the aged, for example with regard to ageing people with developmental or behavioural disorders. Ortho-agogy or ortho-gerontagogy does not necessarily presuppose a 'problem' in the elderly themselves. It adopts the principles of the 'supports' paradigm (Luckasson et al., 2002), which means that it searches for optimization of the *interaction* between people with specific needs and their environments. It is directed at community participation and full inclusion. Ortho-gerontagogy therefore is the study of an optimized support for ageing people with special needs. In this perspective, our doctoral research was an attempt to let people with intellectual disabilities benefit from reminiscence theory and practice, which implied the development of adapted methods.

The ' usefulness' of group reminiscence

What is the meaning of group reminiscence as an 'activity'? We started this doctorate with a reflection on the problematic nature of the ageing process in people with intellectual disabilities. All studies discuss the 'thin line' between support and therapy in one way or

another. On the one hand, we developed a program with the intention to increase well-being, on the other hand, we did not set out from a problematic context (for example, we did not select people with mood disorders). We want to justify the development and evaluation of reminiscence group work as follows: (1) although the importance of narrative reminiscence is generally accepted, the theories underpinning their beneficial effects are underdeveloped. (2) Existing group reminiscence methods are not adapted in terms of content and support strategies. (3) We wanted to introduce support roles of the person-centered planning method. (4) We did not only want to describe a method, but also develop a guide for a series of sessions, a program.

Group reminiscence is not the same as group life review. This is strongly stressed in practice literature (Osborn 1994; Gillies & James, 1994). The aim is to talk about 'integrated' memories only. These may be positive or negative memories, but they may not bring about any conflicts anymore. Group reminiscence work is no psychotherapy because: (1) it was not intended this way (2) the theory underlying its beneficial effects is underdeveloped, and (3) there is no consensus on the proper training for reminiscence support workers, let alone for reminiscence therapists. The reminiscence 'worker' tries to establish positive effects with his methods, but since the participants usually do not know these intentions, we can not identify reminiscence work as therapy.

Notwithstanding these counter arguments, reminiscence work can have therapeutic effects: improving social contacts among people, activating and involving people, letting people experience the benefits of group functioning, teaching people to pick up old skills (and learn new ones), using reminiscence for diagnostical purposes, supporting people in their relationships with family and other loved ones, enhancing mutual understanding between clients and staff, etc.

In *manuscript 3* we developed a reminiscence group program for people with intellectual disabilities. An overview of the program can be found in appendix B, a more extended Dutch description can be found in appendix C. The selection of topics is not exclusive; reminiscence themes can be added at will. We do advise the same use of session structure, a focus on visual stimuli and pre-defined support roles. A disadvantage of our program was that it needed to be the same in each group where we implemented it. In future implementations, it is recommended that the choice of reminiscence topics will be dependent on the participants' preferences. At the time of publication of this, we know that three of the participating care facilities will extend the reminiscence program for their clients on a structural basis.

The applications of our group reminiscence program are threefold: (1) ortho-gerontagogical: supporting people with intellectual disabilities to experience the same meaningful activity as other ageing people (cf. supra). 2) Therapeutic: increasing mood, activity and (group) involvement as a remedial or preventive measure. If individual psychotherapies cannot be easily implemented, group reminiscence can open a window of opportunities for people to express their memories in a 'low threshold' activity, in a non-artificial, non-intrusive context, with extra support from a group, and with group leaders who can detect any emotional 'signals' a person is sending through his or her stories. (3) Recreative: providing ageing people with intellectual disabilities with a meaningful day-care activity, which is fun to do as well.

Reminiscence in the broader perspective of 'successful ageing'

In *manuscript 2*, we described three types of reminiscence methods that are useful in the context of supporting people with intellectual disabilities: writing their story to rewrite disability history, to become self-conscious and more empowered; compiling a life story book to tell and safe keep their story that would otherwise not be told, or as a means to cope with experiences of loss in times of transition. We add group reminiscence to this list, citing the functions we mentioned above. In the margin of our research, practice workers suggested other promising work methods related to reminiscence. For example, social network reconstruction in which an old circle of acquaintances and friends is restored, based on the reminiscences of the ageing person. Or 'retro' day-care activities, in which old work skills are picked up again. A true agogical method would be 'reminiscence based person-centered planning', in which reminiscence is used to work out plans for the future - meaningful for ageing people as well -, and to anticipate to upcoming changes in their lives.

Our group reminiscence program is merely an example of how people can be 'activated' in a meaningful way. It is developed as a means of support, an instrument that can add to the quality of life of people with intellectual disabilities. We have linked this to 'successful ageing'. In gerontological theory, three main tendencies are distinguished as 'recepies' for a 'good old age'. In disengagement theory, it is assumed that ageing people want to calm down (Cumming & Henry, 1961). According to this theory, people give up their active roles in society after they retire. They dis-engage from work and active leisure activities (like sports), in order to enjoy the delights of a well-deserved rest. In this perspective, 'life review' means a process of contemplation, a quiet reflection about one's life. We think that what we

described in *manuscript 2* as 'life story work' meets this description. The activity theory provides us with a totally different interpretation of the ageing process (Havighurst, 1961). It rejects the implicit idea in disengagement theory that older people should adopt a passive life style. It points at the need for an active lifestyle at later age. In this approach, reminiscence is not a tool for resignation, but an active reconstruction of the past, an active search for the 'meaning of life'. Apart from that, reminiscence can engage a person into social intercourse, and motivate him to actively involve others in the sharing of memories. A third (and final) perspective on 'successful ageing' is the theory of continuity (Atchley, 1972). In this perspective, the continuation of old habits, preferences, lifestyle and relationships is the central issue. We are aware that we did not present a full, encompassing theory framework for a 'continued' support of people with intellectual disabilities. In our opinion, this would imply that reminiscence is integrated in everyday support methods, that reminiscence should be the main inspiration for support or care workers. Yet, we did discuss some new methods to support reminiscence in the target group, and we are convinced that these might add to more continuity in daily support. Wittingly, we have worked to our aim from an instrumental perspective: we wanted to deliver (an) instrument(s) that those who support ageing people with intellectual disability can use as they think fit. Each individual ages and reminisces differently. It is useful to ask oneself: "What is a good old age for this person?", and to estimate the worth and function of reminiscence (group) work depending on that thoughtful consideration.

Appendix A

Interview guidelines manuscript 1

Introduction

My name is … and I am interested in memories. I would like to learn a little more about you, by listening to the memories you have. I will pose you some questions; you should always feel free to answer them. There are no bad answers. You cannot make mistakes.
I am recording our conversation, because I want to write down your memories, so I can recall them later. After our conversation, I can take some pictures of you and me together, if you want to. I can mail them to you later.

Reminiscence

Free recall
- Do you think about the past?
- What do you remember?

Additional questions
- Do you remember your home? Where did you live? Did you move away sometime?
- Do you remember the place where you worked? Where did you work?
- Do you remember your parents? What do you remember about them?
- Do you remember your friends? What do you remember about them?
- Do you remember your brothers or sisters? What do you remember about them?
- Do you remember the time when you were just a little kid? What is your earliest memory?
- Do you remember when you were in love? When you were dating someone?
- I heard you have (no) children. What memories do you have on your/other's children?
- Do you remember big events? Like parties? Or weddings, or …?
- How's your health? Has it always been like this?
- Have you lost someone dear to you?
- Do you remember praying and going to church? What do your remember about it?

C. Thinking about reminiscence

- How often do you think about your past?
- Why do you think about the past? Why do you think about <example: an important positive/negative memory> ?
- Do you like things better now? Or, do you wish you could go back to the time when …?

Appendix B

A reminiscence program for people with intellectual disabilities

Nr.	Theme	Description	Triggers	Adapted
0	Introduction - Clothing	Getting to know each other, learning what the program is all about (sample theme).	Sunday hat, farmer's hat, school uniform, clog,…	+
1	Who am I? - Family	Personal information, family background.	Photo albums	**
2	My house, my room	A safe topic to talk about.	One big group drawing based on individual descriptions.	++
3	Television	Favourite TV shows, difference between the past and present (news items).	Fragments of present and vintage TV programs/news items.	+
4	Household	The old living environment at home with parents.	Pipe, hand-watch, curling-iron, carpet-beater, …	**
5	Games and toys	The pleasure of and the skills used in old-style games and toys.	Top, knuckle-bones, marbles, skipping-rope, dice, …	**
6	School days	Skills and limitations, beloved and disliked teachers, mischief.	Slate and slate-pencil, school eraser, fountain pen, ink, …	*
7	Food	Grandmother's kitchen, favourite meals, receipts.	Coffee grinder, kettle, different smells, cookery book, waffle iron, …	*
8	Church - Religion	Church rituals and ceremonies, religious education, clergy/nun.	Missal, paternoster, holy water bottle, …	*
9	Travels - Holidays	Holiday destinations, different travel means.	Suitcase, pictures of different inland and foreign locations.	*
10	Music - Parties	Favourite music, celebrations, important social events.	Samples of different music styles (pop, rock, classical…)	++
11	Video-mail	Recording a personal souvenir of the program for oneself or a friend/family member.	A 'studio' (table and chair), a camera.	++
12	Evaluation	What did the participants think of the program?	One recognizable trigger from each theme.	+

Note. * Original theme from handbook, ** Modified theme, + Added before stage one, ++ Added after stage one.

Appendix C

Handleiding groepsreminiscentie

In wat volgt beschrijven we een concrete methodiek om vorm te geven aan groepsreminiscentie bij mensen met een verstandelijke beperking. We sommen de bouwstenen voor groepsreminiscentie op die we als essentieel beschouwen.

Selectie van deelnemers

Ideale groeps-grootte

Algemeen wordt aangenomen dat de ideale grootte voor groepsreminiscentie zich situeert tussen 5 à 9 deelnemers. Met meer dan 10 deelnemers wordt het moeilijk het gesprek te modereren. Met minder dan 5 kan het gesprek wat moeilijker gaande worden gehouden. Mensen met een lichte of matige verstandelijke beperking kunnen meestal zonder problemen deelnemen aan de sessies. Naast passieve en actieve verbale vaardigheid is ook en vooral de motivatie van een deelnemer belangrijk.

Voorwaarden tot deelname

Een kandidaat deelnemer dient vooraf duidelijk kenbaar te maken dat hij of zij iets wil vertellen over het eigen verleden.

Voorbereiding

Inhoudelijke voorbereiding

Gestructureerd vs. spontaan

Met groepsreminiscentie bedoelen we een activiteit die op voorhand gepland is, inhoudelijk voorbereid en duidelijk gestructureerd is. Het verschilt van een gewoon spontaan groepsgesprek (bv. tijdens of na het eten) door het thematische karakter (per sessie tracht men te werken rond een thema), de voorbereidingen die er aan voorafgaan (verzamelen materiaal, vooropstellen algemene topics, en 'side'–topics, enz. – zie verder), en de technieken die men gebruikt tijdens de gesprekken (elaboreren, modereren, coaching, mind mapping – zie verder). Het resultaat van een sessie – het geheel van opgewekte herinneringen- is vooraf niet te bepalen, maar de middelen die gebruikt worden om dat resultaat te bereiken, dienen toch vooraf uitgewerkt en gepland te worden.

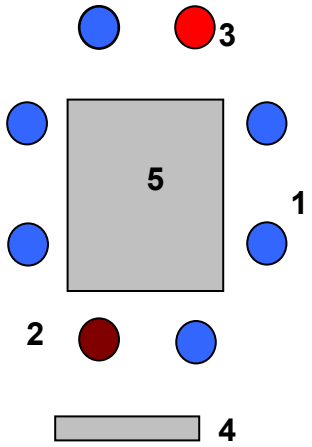
Inrichten van de gespreksruimte

Opstelling tafel

De verdeling van de zitplaatsen rond de tafel is niet onbelangrijk: een te gecentraliseerde opstelling (bv. waar de gespreksleider alleen aan het hoofd

van de tafel zit) maakt duidelijk wie de leiding heeft, maar kan ook minder uitnodigend zijn voor de deelnemers om actief deel te nemen. Gedecentraliseerde opstellingen zijn deze waarin aan elke tafelkant meer dan 1 stoel staat.

In het schema hiernaast is een voorbeeld van een tafelopstelling afgebeeld.
De coach en facilitator zitten tussen de deelnemers, eerder dan dat één van hen als enige aan een uiteinde van de tafel zou zitten. Symmetrische tafels (rond of vierkant) zijn te verkiezen.
De facilitator heeft de flip-over-chart snel bij de hand.



1. *Deelnemers*
2. *Facilitator*
3. *Coach*
4. *Flip-over chart (mind maps)*
5. *Tafel*

Belangrijke aandachtspunten wat betreft de ruimte zijn dat men niet gestoord wordt tijdens de sessie. Bordjes 'niet storen' zijn vaak geen overbodige maatregel.

Begeleiding

Combineren van functies

In wat volgt beschrijven we een aantal taken van de begeleider(s) tijdens een groepsreminiscentie sessie. We noemen deze taken ook wel 'functies'. Daarmee bedoelen we 'rollen' die je kan spelen als begeleider. De functies 'facilitering', 'coaching', 'moderering' en 'mind mapping' zijn rollen die in principe door 1 persoon tegelijkertijd kunnen uitgevoerd worden. In de praktijk is het combineren van al deze opdrachten echter vrij moeilijk, of vergt al heel wat ervaring. Het is daarom aangewezen in het begin de taken te verdelen tussen twee begeleiders.

Faciliteren

Faciliteren = vergemakkelijken

Faciliteren betekent letterlijk "iets makkelijk maken". De taak van de facilitator is dan ook het herinneringsproces bij de deelnemers te vergemakkelijken. Hij[8] moet zorgen dat het thema duidelijk is. Hij vertelt iets over vroeger, en vraagt of de deelnemers dit herkennen. Hij stelt vragen over een prent of een voorwerp. Hij is geïnteresseerd in het verleden en vraagt de deelnemers hem te helpen het verleden te reconstrueren. De facilitator zet de bakens uit waarbinnen het gesprek kan plaatsvinden. Hij is een element van 'structuur' voor de deelnemers. Hij zorgt echter ook dat er een klimaat van openheid en humor heerst tijdens de sessies.

[8] In het vervolg gebruiken we de aanduiding "hij" zowel voor de begeleider als de begeleidster.

Concrete vuistregels zijn:

- Het thema is een middel, geen doel. Het thema zal niet altijd gevolgd worden: n.a.v. bepaalde triggers kunnen persoonlijke verhalen aan bod komen die niet noodzakelijk passen in het thema van een bepaalde sessie. Dergelijke uitwijdingen moeten mogelijk zijn. De bedoeling van de sessies zijn herinneringen aan bod te laten komen, de thema's zijn slechts een middel. De facilitator kan zelfs gebruik maken van de gelegenheid en doorvragen naar meer persoonlijk herinneringen; dit eerder dan de verteller in kwestie terug op het 'juiste spoor te willen zetten'. *Thema als middel*

- Tracht verschillende manieren te vinden om iets duidelijk te maken: indien een woord niet volstaat, kan een synoniem, een andere formulering, een bijkomende vraag duidelijkheid bieden. Dit noemen we elaboratie. Het betekent letterlijk 'uitwerken': bv. een vage herinnering laten preciseren, vragen om meer details bij een algemene herinnering, polsen naar meer herinneringen door vergelijkingen te maken. De facilitator brengt door zijn vragen een dialoog op gang die de herinneringen rijker doet worden. Ook het gebruik van triggers past in het kader van elaboratie: de facilitator verlaagt voortdurend de drempel om herinneringen 'los te weken'. *Elaboratie* *Drempel verlagen*

- Indien je denkt dat iemand een 'valse' herinnering aanbrengt of het heden en verleden verwart, is het belangrijk niet noodzakelijk te willen corrigeren wat mogelijk fout is. Respecteer en accepteer wat de persoon zegt. Het is belangrijk er niet zomaar van uit te gaan dat er geen betekenis of bedoeling achter een 'pseudo'-herinnering zit. Soms is de emotie van een herinnering belangrijker dan de inhoud. *Valse herinnering*

- Taal is voor mensen met een verstandelijke handicap vaak een barrière om herinneringen goed te verwoorden. De facilitator moet dan ook eenvoudige taal gebruiken en de deelnemers helpen de juiste woorden te vinden. Kennis van het dialect kan een groot voordeel zijn. De facilitator kan ook gebruik maken van ondersteunende gebaren en lichaamstaal om een herinnering te illustreren (knikken, lichaam gericht naar participant). *Taal*

- Zeg één ding tegelijkertijd. Geef participanten de tijd om een idee of informatie te verwerken. Het tempo laag houden is een belangrijk aandachtspunt. *Tempo*

- Vermijd situaties waarin een persoon zich getest voelt. Het afvuren van vragen in het kader van elaboratie kan een sfeer van ondervraging creëren. Dit moet vermeden worden. *Geen test*

Coachen

Een andere belangrijke functie omschrijven we als 'coaching'. De taak van

de coach is de deelnemers voor te bereiden op de samenkomsten en hen te helpen met het formuleren van de herinneringen tijdens de samenkomsten. Coaching betekent het ondersteunen van de individuele deelnemers door te observeren, te motiveren en te bekrachtigen. De coach vangt kleine signalen van welbevinden of onwelbevinden op en probeert hierop in te spelen. Eventuele drempelvrees bij bepaalde opdrachten kan overwonnen worden door als coach het voortouw te nemen en te tonen dat men zelf bereid is zich kwetsbaar op te stellen (bv. als er iets moet naverteld of voorgedaan worden).

Taak van de coach

Concrete vuistregels:

1) Indien de coach de deelnemers vooraf niet kent, is het aan te raden de belangrijkste identiteitsgegevens (familiegegevens, woonplaatsen, medische voorgeschiedenis) vooraf te verzamelen. De coach kent de deelnemers bij voorkeur persoonlijk, zodanig dat hij een *extra* geheugen voor hen kan zijn, en hen eventueel kan beschermen in hun privacy tijdens de sessies.

Extra geheugen

2) De coach is bereid in de plaats van de deelnemers te spreken indien zij zich zichtbaar ongemakkelijk voelen op het moment dat van hen iets verwacht wordt. Stiltes moeten echter niet noodzakelijk 'opgevuld' worden.

Plaatsvervanging

3) De coach let op signalen van de participant: heeft hij/zij begrepen wat er gebeurt tijdens de sessie? Verbale reacties vragen is niet altijd noodzakelijk; non-verbale tekenen (zoals knikken of glimlachen) zijn voldoende aanwijzingen dat iemand betrokken is.

Signalen opvangen

4) De coach helpt de facilitator door vragen te verduidelijken, te situeren, of een voorbeeld te geven.

Verduidelijken

Modereren

De facilitator en coach zijn ook moderators, wat betekent dat ze soms iemand moeten aansporen een bijdrage te doen, en iemand anders moeten afremmen om niet teveel het gesprek te domineren. Niet iedereen is even spraakzaam. Men dient te bewaken dat iedereen eens aan bod komt, al is het enkel door de aandacht van de groep even te richten op een bepaalde persoon die tot dan toe niet aan bod is gekomen. De moderator is begaan met de groep, hij zorgt dat het gesprek geen aaneenknoping is van individuele verhalen. maar een echt groepsgesprek.

Modereren i.f.v. een groepsgesprek

Aandachtspunten:

1) Modereren is niet enkel modereren tussen de deelnemers, het is ook modereren met het gespreksthema voor ogen. Het gesprek dient zoveel mogelijk doelgericht te blijven, wat betekent dat de deelnemers moeten worden aangespoord hun verhaal te brengen ten dienste van het

I.f.v. een thema

gezamenlijke gesprek.

2) De moderator brengt mee structuur aan in het gesprek. Door iedereen aan beurt te laten komen bijvoorbeeld. Dat noemen we een ‘rondje’. Een goed groepsgesprek kan alleen als mensen willen samenwerken interesse tonen en ten volle aandacht schenken wanneer iemand spreekt. *“Rondje”*

3) Iedereen dient het gevoel te hebben dat hij/zij iets –hoe weinig dit ook is: een woord, een knikje- kan bijdragen aan een sessie. Indien iedereen aan de beurt komt, zal het gevoel vergroten dat men heeft kunnen bijdragen aan het welslagen van de sessie. De moderator ziet toe op de participatie van alle deelnemers. *Participatie*

4) Interactie tussen participanten kan gestimuleerd worden door op gelijkenissen en verschillen te wijzen. *Gelijkenissen en verschillen*

Mind mapping

‘Mind Mapping’ betekent dat men elke belangrijke gedachte (in ons geval herinnering) die wordt verwoord, tracht te vatten in een schematische tekening op een bord of groot stuk papier. *Mind map*

De eerste belangrijke functie van een ‘map’ is om de herinneringen zichtbaar te maken, minder abstract en herkenbaar voor anderen. Doordat de gedachten worden gevisualiseerd, kan men ze aanduiden, met elkaar linken (door lijnen te trekken tussen de verschillende gedachten), en structureren. Men kan bv. alle herinneringen tekenen van een bepaald persoon, of men kan een bepaalde herinnering linken aan meerdere personen. *Visualiseren*

De tweede functie van mind mapping is het vertragen van het tempo in het groepsgesprek, zodanig dat iedereen gemakkelijk kan volgen. Doordat iemands herinneringen worden getekend terwijl hij of zij vertelt, bepaalt deze persoon op dat moment het tempo van het gesprek. *Tempo*

Gebruik van triggers

‘Triggers’ zijn woorden, geluiden, tekeningen, foto’s, geuren of andere voorwerpen die herinneringen uitlokken. De geur van een sigaar kan iemand doen terugdenken aan zijn grootvader, een oud kerkboek kan verhalen opwekken over lange misvieringen en latijnse gebeden. *Triggers*

Praktijkervaring heeft geleerd dat triggers oudere mensen helpen om zich het verleden terug voor te stellen, ook en vooral in de ietwat bijzondere context van een groepsgesprek. Eigen ervaring heeft uitgewezen dat dit voor mensen met een verstandelijke handicap ook geldt. Triggers zijn essentiële hulpmiddelen om bijvoorbeeld de eerste herinnering op te wekken en de aanzet te geven tot een gesprek. Ook daarna kunnen ze gebruikt worden om het gesprek te stofferen.

Rol van triggers

Een handige manier om de triggers voor een bepaalde sessie te bundelen is een reminiscentiekoffer. De voorwerpen die allemaal met een bepaald thema te maken hebben worden in een (oude) koffer gestopt en meegenomen naar een sessie. Uit de koffer worden dan de voorwerpen één voor één uitgehaald, op het ritme van de herinneringen zelf. Het duurt soms wel even eer herinneringen opwellen bij de deelnemers. Soms wordt het object niet meteen herkend, of weet men niet goed of men ook iets mag zeggen over een soortgelijk voorwerp dat men heeft gekend. Triggers kunnen te specifiek zijn, bv. oude klompen met een heel kunstig motief, kunnen weinig reactie oproepen, terwijl gewone eenvoudige klompen dan weer wel herinneringen kunnen losmaken. De herkenbaarheid vergroot naarmate de trigger vroeger algemeen gebruikt werd/in een bepaalde vorm gekend was. Triggers die heel persoonlijk zijn, bv. een album met vakantiefoto's, zijn soms te specifiek. Hoewel 1 persoon er heel goede herinneringen aan kan hebben, is het meestal zo dat de rest van de groep, indien ze de persoonlijke gebeurtenissen -waarnaar op de foto verwezen wordt- niet hebben meegemaakt, afhaakt. Zij delen immers niet dezelfde beleving. Iemands vakantiefoto kan echter anderen aanzetten tot herinneringen over de eigen vakantie, indien de facilitator duidelijk het thema van reizen voorop heeft geplaatst, en de foto ook in die context kadert.

Reminiscentie-koffer

Specificiteit van triggers

Herkenbaarheid

Ook de authenticiteit (d.w.z. de echtheid) van de triggers kan belangrijk zijn: de beste triggers zijn vaak even oud als de herinnering. Een nieuw aangekochte lei en griffel is een goede trigger, maar oude, gebruikte exemplaren zijn, zo leert de ervaring, beter.

Authenticiteit

Triggers kunnen voor zichzelf spreken, maar moeten vaak wat gesitueerd worden. Een verhaaltje er rond vertellen, zeggen waar het voorwerp of de foto vandaan komt, een hint geven omtrent de juiste benaming: het zijn

Situeren van triggers

allemaal middelen waarmee de facilitator de drempel kan verlagen, en de deelnemers kan uitnodigen iets te zeggen.

Groepsreminiscentie: de dynamiek van een groep

Groepsdynamica

Een reminiscentiegroep is net als andere gespreksgroepen onderhevig aan de wetten van de groepsdynamica. Dit betekent dat wat een groep van mensen aan herinneringen produceert niet alleen afhangt van wat de deelnemers apart kunnen bijdragen, maar ook en vooral van hoe ze het met elkaar kunnen vinden, m.a.w. van de onderlinge relaties die vooraf al bestaan of geschapen worden tijdens de gesprekken.

Vragen voorafgaand aan de groeps-samenstelling

Er zijn daarom een aantal belangrijke vragen waar men vooraf rekening mee moet houden, bijvoorbeeld: hoe goed kennen de mensen elkaar bij aanvang?, heeft de groep als groep al een verleden?, is dat een positief of een negatief verleden?, welke positie nemen de deelnemers in in de groep: initiatiefnemer, volger?, enz.

Groepscontext

Een gespreksleider mag niet enkel focussen op wat er gezegd wordt, maar dient ook rekening te houden met 'verborgen' attitudes en ideeën binnen de groepscontext. Met dat laatste bedoelen we de achtergrond van waaruit mensen kunnen deelnemen aan de groep (bv. de context van een dagcentrum): is men zich bewust waarvoor men bijeengekomen is?, weet men hoe de groep tot stand is gekomen?, weet men wat men kan of juist niet hoeft te vertellen?, weten de deelnemers hoe een groep functioneert, bv. dat niemand zomaar het laken naar zich toe mag trekken?, weet men hoe en wanneer men uit de groep kan/mag stappen? enz. Indien deze vragen vooraf zijn geadresseerd, bv. in de kennismakingssessie, verkleint de kans dat er achteraf mensen afhaken omdat ze het bv. een te grote tijdsinvestering vinden, omdat ze bepaalde herinneringen niet willen delen, of omdat ze het verwachte engagement niet kunnen/willen inlossen.

Groepscohesie

De groepscohesie, d.w.z. de mate waarin de groep samenhangt, is een belangrijke factor in het welslagen van een reminiscentiegroep. Het groepsgevoel versterkt de motivatie en kan het onevenwicht in actieve deelname tussen deelnemers compenseren. De groepscohesie mag niet vervallen in extremen: bij een te kleine cohesie praten mensen door elkaar, en houden ze geen rekening met wat een ander zegt; bij een te grote cohesie primeert de gezelligheid, kan de focus op het thema verdwijnen en het resultaat is een te informeel gesprek over koetjes en kalfjes.

Een goede groepscohesie kan je afleiden uit de interacties tijdens de gesprekken, bv. wanneer deelnemers elkaar helpen een herinnering te vervolledigen of wanneer ze elkaar bevestigen in de juistheid van een herinnering. Participatie en groepscohesie gaan hand in hand.

Machtsverdeling

Machtsverdeling binnen de groep, namelijk dat één iemand binnen een groep meer invloed heeft dan andere, is op zich geen probleem als het de groep vooruithelpt, en als de persoon in kwestie gesteund wordt door de groep. De moderator heeft zo een positie, maar ook sommige deelnemers kunnen gaandeweg een belangrijkere rol gaan spelen: iets uitleggen, iets voordoen, op gang helpen.

Groepsevolutie

Tot slot is het belangrijk vooraf te beseffen dat elke groep verschillend evolueert. Er ontwikkelen zich gewoontes die eigen zijn aan de groep (bv. stoelverdeling, rituelen voor en het gesprek, begroeting, enz.). Ze zijn gekend door de deelnemers en versterken door dat gezamenlijk bewustzijn het groepsgevoel.

Verloop van een groepsreminiscentie sessie

Modelstappen

Een groepsreminiscentie sessie verloopt grofweg volgens de modelstappen van een groepsgesprek, namelijk:

1. *Taakbegrip:* uitleg waarom de groep bijeen is en omschrijving van de taak/doelstelling: het thema waarover de groep zal gaan praten, de geplande onderdelen enz.
2. *Informatie* verzamelen en delen: het vaststellen van de voorkennis, nagaan hoe de deelnemers over het thema denken. Zorgen dat iedereen deze voorkennis deelt.
3. In *dialoog* het thema aankaarten, bespreken, gebruik makend van allerlei ondersteunende middelen.
4. Werken naar een *eindprodukt*, bv. een tekening, een verhaal.

Een sessie duurt ongeveer 1 uur. Een langere sessieduur maakt dat de concentratie bij de deelnemers verslapt, in een kortere tijdspanne kan een degelijke opbouw (inleiding – hoofdgedeelte – afsluiting) moeilijk gerealiseerd worden.

Sessie 0: proefsessie en camera-gewenning	*Sessie 1: Wie is iedereen?*	*Sessie 2: Mijn kamer*
Materialen - camera - TV - papier, stift Structuur *Inleiding* - vragen of men weet waarom men uitgenodigd is - aanvullen en uitleggen: herinneringen ophalen in een groep, praten over vroeger *Hoofddeel* - Proefsessie: oude kleren - tonen camera en TV: de rode knop om op te nemen, het rode lampje dat brandt als er opgenomen wordt, het schermpje waarop je kan zien wat er in beeld is (uitleggen dat het belangrijk is dat alles wat je wil opnemen in beeld is) - tonen van de opname op monitor - commentaar op de activiteit (opnemen) *Afsluiting* - foto's nemen van elke deelnemer - uitleg over volgende sessies:	Materialen - flip-over chart - foto van elke deelnemer, facilitator en coach Structuur *Inleiding* - foto's laten zien die vorige keer genomen zijn. - De facilitator stelt zijn familie en werkplaats voor a.d.h.v. een filmpje/foto's en werkt daarbij alle details af. *Hoofddeel* - familie: kring van familieleden - werk/dagbestedingsplaats: waar is men overdag mee bezig? - woonplaats (plaatsnaam, adres): waar is dat? (geen beschrijving) *Uitdieping* - tekening van arbeidsbezigheid *Afsluiting* Bekijken video-opname van deze sessie.	Materialen - flip-over chart - foto van elke deelnemer, facilitator en coach Structuur *Inleiding* - De facilitator stelt zijn woonplaats voor a.d.h.v. een filmpje/foto's en werkt daarbij alle details af. *Hoofddeel* - woonplaats (plaatsnaam, adres): waar is dat? - vrienden/kennisen: kring van vrienden *Uitdieping* - hobbies: wat doet men graag ter ontspanning? - tekening van het huisplan, eventueel stratenplan *Afsluiting* Bekijken video-opname van deze sessie.

Sessie 3: Televisie: ontspanning en realiteit	*Sessie 4: De vroegere "thuis"*	*Sessie 5: Spel en vrienden*
Materialen - opgenomen fragmenten televisieuitzending, weekbladen met programma-overzicht - flip-over chart Structuur *Inleiding* - 10' luisteren naar tv-tunes, raden van welk programma (zonder beeld) *Hoofddeel* - 10' bekijken van een TV-fragment van de vorige avond, en avond daar voor (met beeld = oplossingen van de raadsels) - 20' uitleg over het thema: wat hebben we gezien op TV? hebben we het programma gezien waaruit het fragment komt? - 20': wat heeft men gezien op het televisiejournaal? *Uitdieping* - geloven we alles wat we zien? Waarom? Waarom niet? - naar welk journaal kijkt men? op welke nieuwszender? - op welk uur wordt er nieuws uitgezonden? - wie zijn de favoriete nieuwslezers/lezeressen? *Afsluiting* Bekijken video-opname van deze sessie.	Materialen - reminiscentiekoffer: kamerpot, waterkruik, wasborstel, zeepblok, olielamp, waterverdamper (kachel), zoutpot, lampetkan+kom+kamdoos, soda+melkzeep, ontstopper (waterafvoer +WC), raagbol, mattenklopper, houten wasspelden, plumeau Structuur *Inleiding* - '10: Elke familiefoto van de deelnemers kort bespreken - Wat deden de ouders toen de deelnemers klein waren? - Huishoudelijke karweitjes: - Hygiëne en verzorging *Uitdieping* - een huishoudelijke taak/ voordoen - disciplinering: moest men iets soms als straf doen? *Afsluiting* Bekijken video-opname van deze sessie.	Materialen - reminiscentiekoffer: boemerang, diabolo, jojo, kaatsballen, voetbal, houten bouwblokken, damspel, bikkels, speelkaarten, springtouw, knikkers, dobbelstenen, houten tol en balpijp - flip-over chart Structuur *Inleiding* - '10: foto's overlopen die men heeft meegebracht *Hoofddeel* - '10: uitleg over het thema: (1 voorwerp –tol- op tafel): wat is dit? (indien geen reactie, een ander voorwerp). - '40: welke spelletjes speelt men al eens, heeft men vroeger gespeeld? Met wie? *Uitdieping* - spelregels uitleggen - verschil tussen jongens- en meisjesspeelgoed - vergelijking met speelgoed nu - favoriete speelgoed: - Met welke vrienden heeft men gespeeld? Familie, broers of zussen? - kattekwaad en straf *Afsluiting* Bekijken video-opname van deze sessie.

Sessie 6: De school	*Sessie 7: Eten en maaltijden*	*Sessie 8: Kerk en religie*
Materialen - reminiscentiekoffer: Lei en griffel, Kartonnen lei, Sponsdoosje, Wisbordje, Prikvilt en priknaald, Meetlat+liniaal, Bordwisser, Krijt, Inktpot, … - flip-over chart - foto van elke deelnemer Structuur *Inleiding* - 10' : uitleg over het thema: (2 voorwerpen – lei en griffel – op tafel): wat is dit? *Hoofddeel* - '40: welke lessen heeft men gekregen in de school? Wat deed men in de klas? Met wie zat men samen in de klas? - *Uitdieping* - favoriete meesters en juffrouwen, minder leuke meesters en juffrouwen - tonen van oude klasfoto's en oude klaslokalen. - Ging men graag naar school? - Objecten uit het klaslokaal - Schrijven op de oude manier *Afsluiting* Bekijken video-opname van deze sessie.	Materialen - reminiscentiekoffer: kookboek, wafelijzer voor op het vuur, steriliseerbokaal, jeneverkruiken, wijn waterkruik, melkkannen, pannenlikker, en waterketel. - borden, eetgerei - kookboek, foto's van gerechten - flip-over chart Structuur *Inleiding* - '10: Een bord wordt doorgegeven en iedereen zegt vernoemt zijn meest geliefde en/of gehate recept. *Hoofddeel* - 40' Een aantal typische oudere gerechten: wat was het, hoe maakte men het, en was het lekker? - Wie kookte er vroeger? *Uitdieping* - hoe maak je een bepaald gerecht klaar? - Met wie eet/at men? - Rituelen ervoor, tijdens en erna? *Afsluiting* Bekijken video-opname van deze sessie.	Materialen - reminiscentiekoffer: missaal, wijwatervat, paternoster, kandelaar, constateur (duiven), hoed (dame+heer), pijp+pijpzak en bretellen - laptop-presentatie scherpenheuvel - flip-over chart Structuur *Inleiding* - '10: tv-uitzending eucharistieviering *Hoofddeel* - '40: naar de kerk gaan - hoe vaak gaat men naar de kerk? - kerkelijke feesten? Hoe ging dat vroeger? *Uitdieping* - pastoors : goeie en minder goeie? - zich vervelen in de kerk - bidden: hoe en wanneer ? Eten, slapengaan? - biecht: waarom ging men te biechten? - speciale feesten : kerstmis, pasen, sinterklaas, lichtmis, … *Afsluiting* Bekijken video-opname van deze sessie.

Sessie 9: Reizen en vakantie	*Sessie 10: Muziek en feest*	*Sessie 11: video-mail*

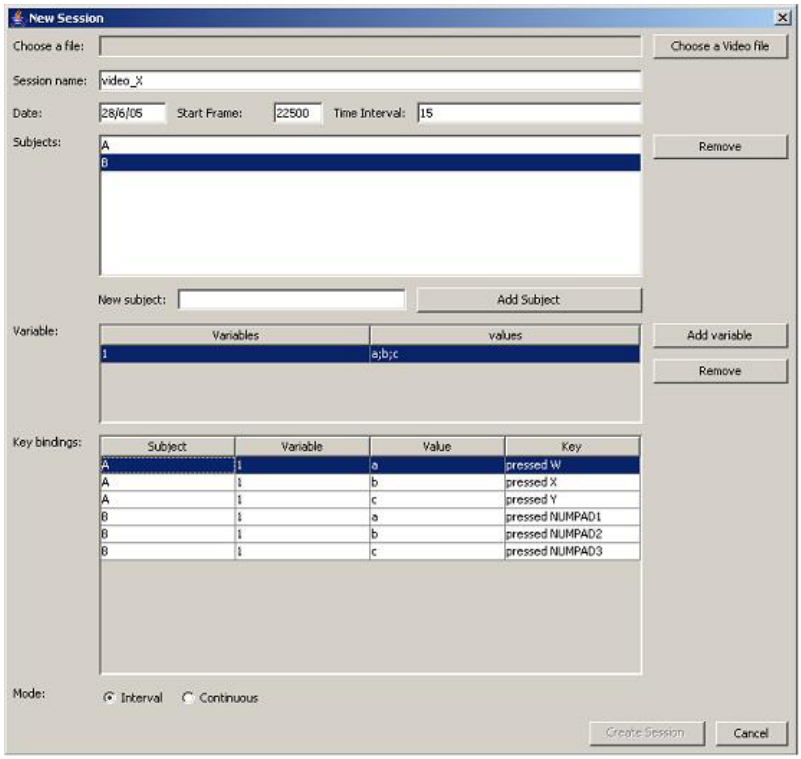
Materialen
 	
- reminiscentiekoffer met oude reis-gerelateerde voorwerpen: reisfolders, prentkaarten
- laptop-presentatie vroegere reismethoden en vakantiebestemmingen
- flip-over chart
 	
Structuur
 	
Inleiding
 	
- ’10: quiz vakantiebestemmingen (a.d.h.v. oudere foto’s)
 	
Hoofddeel
 	
- ’20: persoonlijke foto van de groepsleden: wie is waar naar toe geweest?
- ’20: reisroutes bekijken op een landkaart, welke route is men gevolgd?
 	
Uitdieping
 	
- met wie is men gegaan?
- hoe was het weer? het eten?
- reismethoden: te land, ter zee en in de lucht:
- wat neem je zeker mee op reis?
 	
Afsluiting
 	
Bekijken video-opname van deze sessie.
	Materialen
	
	- prentkaarten zangers, feesttoeters, feestslingers, confetti +serpentines, feestneus +masker, vlagjes
	- laptop-presentatie (muziekquiz)
	- flip-over chart
	
	Structuur
	
	Inleiding
	
	- ’10: muziekquiz (a.d.h.v. oude muziekfragmenten)
	
	Hoofddeel
	
	- ’20: favoriete muziek bespreken
	- ’20: feesten: verjaardagsfeesten, trouwfeesten, jubilea
	
	Uitdieping
	
	- bekende liedjes koppelen aan zangers
	- Welke kleding doe je aan op een feest?
	- Welke dansen kan je doen op een feest?
	
	Afsluiting
	
	Bekijken video-opname van deze sessie.
		Materialen
		
		- voorbeeld video-mail
		- flip-over chart (grote papieren op een bord die kunnen omgeslagen worden), stiften, knip en plak-materiaal
		
		Structuur
		
		Hoofddeel
		
		- ’40: voorbereiding videomail
		- inleiding: een brief schrijven aan …
		- tonen voorbeeld
		- wie zou wat willen vertellen?
		- keuze: voorbereid of niet voorbereid? samen met coach of niet?
		
		- ‘10: herinrichten lokaal (‘studio’ en publiek)
		- ’35 (5 minuten x7) : opname video-mails
		  o voorstelling
		  o wat men gedaan heeft met de groep/wie er in zat
		  o wat men er van vond
		  o groeten doen aan… (en waarom?)
		
		Afsluiting
		
		Bekijken video-opname van deze sessie.

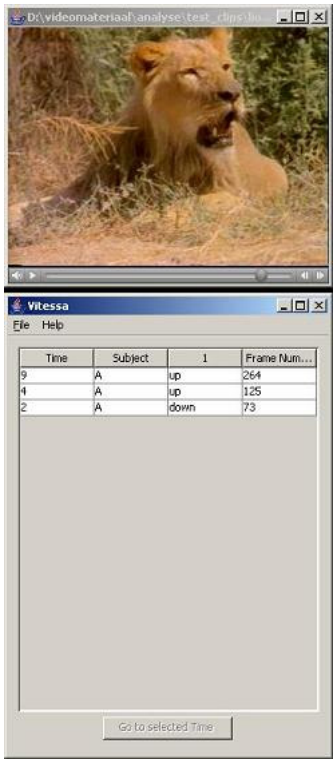
Sessie 12: Evaluatiesessie	
Materialen - reminiscentiekoffer met populaire triggers - videomateriaal van de sessies (fragmenten op laptop of tv) - tekeningen uit voorbije sessies (opgehangen in lokaal)	Structuur *Inleiding* - 15' bekijken videomail opnames *Hoofddeel* - '30: raadspel over de groepsleden: o van wie is deze tekening? o wie staat er op dit fragment? o kleine fragmenten uit transcripties: wie heeft wat gezegd? o Wat vond men van een bepaalde sessie? *Afsluiting* - '15: afronding met spijs en drank ('10: de beste momenten uit de groepsessies)

Appendix D

Vitessa is a simple computer program that enables you to control playback of digital video data on your computer in order to analyse the content in a structured manner. With Vitessa you can do event sampling, time sampling, interval recording on your video files, save your work in a universal format (XML), and export the data to a tabular format (importable into spreadsheet programs like MS Excel or OO Calc). Multiple variables, subjects and key bindings can be defined in a very intuitive way. Vitessa's frame-based coding implies that behavioural analysis can be done with a precision of 1/25 sec. Vitessa is a cross-platform application: it can run on both PC (Windows) and Mac (OS X) computers. Vitessa is not a replacement for comprehensive video analysis software like MacSHAPA or Noldus Observer, but it can perform elementary analyses, for which you don't need a lot of 'firepower'.

Screenshots





Quickstart

Suppose we're doing a study on the behaviour of thumbs. We have a video recording, called thumbs.mpg with thumbs (subjects) 'left' and 'right'. We want to count 2 instances (values) of thumb bending, named 'bend' and 'nobend' of both thumbs. We choose to do momentary time sampling (do the thumbs bend at time x?) with an interval of 3 seconds.

Creating a new session

In the file-menu: click 'new session'. A dialog box will appear. In the ‘new session' dialog box, you can:

- Choose the video-file you want to analyse. Click on 'Choose a video file'. A new dialog box will appear and allow you to select the file you want (thumbs.mpg is available for download, but also located in the program directory folder of Vitessa) (if you want to test MPEG-4 compatibility, try thumbs.avi).
- Give a name to the session, for example: 'thumbs up!'.
- Date the session.
- Choose a start frame. Perhaps you don't want to analyse the entire video-fragment. Let's say we want to start the time sampling after 3 seconds. There are 25 frames in one second. The starting frame then will be the 3 sec x 25 frames = 75th frame.
- Choose a time interval (in seconds). In this session this would be 3.
- Add the thumbs subjects you wish to analyze. Type their names 'left' and 'right' in the input box, and click 'Add subject'.
- Add the variable you wish to monitor by clicking 'Add Variable'. Click on the column 'Variable' and type the variable name 'bending'.
- Add (fixed) variable values in the 'Values'-column. This is only necessary when the range of values is known before you start monitoring. Adding variable values is necessary if you want to use key bindings (shortcuts for input of data). Values are separated with a semi colon (;). So we fill in 'bend;nobend'. Press Enter
- Add 'key bindings' for all values of all variables in all subjects. This is especially helpful for quickly inputting data. For ease of use, we use two keys at the left of our keyboard for subject 'left' and two keys at the right for subject 'right' (w, x and numpad 1, 2). Press Enter.
- Choose the mode Vitessa will work in. 'Interval mode' means that playback will be interrupted at regular intervals. 'Continuous mode' means that playback will not be interrupted, except when the user wants to input data. In this case, we want to work in interval mode.

When all parameters are filled in, click 'Create session' to start coding.

Coding the session

After you hit 'create session', Vitessa loads the video file you requested (thumbs.mpg). This can take some time. When the file is loaded, two windows appear: a video window and an input window.

- In 'interval mode' and 'continuous mode', F2 starts video playback when the input window is selected. The same happens when you double click on the video image in the video window.

- In 'interval mode', playback will stop automatically after the defined interval. In 'continuous mode' playback stops when either F3 or a key with a key binding is pressed. [Note: although the time column will display the correct time interval, it may happen that the frame column displays a frame number different than time interval x 25. This is due to programming restrictions. The problem is made transparent by showing the correct frame number.]
- To enter data, select the row (subject) you wish to add an entry for, and either insert the value manually or automatically using a key binding.
- To restart video playback in 'interval' as well as 'continuous' mode, use F2 or double click on the video image in the video window.
- You can go back to a specific time by clicking on 'Go to selected time'.
- You can re-edit every value in the input table.

You will notice that with momentary time sampling, we haven't recorded all occurrences of the observed behaviour (compare your results with this file thumbs.vts - right click, 'save as'). The two thumbs will have bended several times between the interval times. To solve this issue you can do interval recording (was there any bending during the interval?), or continuous event recording (when did the thumbs bend?).

Saving a session

During coding or after you coded the entire session, you can save your work by selecting 'Save session' in the file menu. Vitessa will save the coding you've already done, plus all the other session parameters (like key bindings) you defined.

Closing a session

You can close the session by selecting 'Close session' in the file menu.

Loading a session

You can reload the session by selecting 'Load session' in the file menu.
Thumbs.vts (right click - save as) for example is a session file that holds the results of the quickstart coding session.

Exporting a session

You can export the tabular data of a session to a comma or tabular separated text format that is importable in the most common spreadsheet programs (like MS Excel or OO Calc). To do this, select ‘Export session' in the file menu.

Quit Vitessa

You can quit Vitessa by choosing 'Quit' in the file menu.

License

Vitessa is free software under the restrictions of the Gnu General Public License. This means that you can dowload it, distribute it, give it away and use it as you like, as long as you refer to the original authors (see official reference). If you distribute modified copies of this program, whether gratis or for a fee, you must give the recipients all the rights that you have. You must make sure that they, too, receive or can get the source code. And you must show them these terms so they know their rights. Source code of Vitessa is available here:

http://pieter.laeremans.org/ . Be aware that some components of Vitessa like the JRE and QTJ libraries are not free software in the same way as Vitessa is.

Disclaimer and support

Please keep in mind that Vitessa is a product that is developed and maintained by volunteers. We cannot garantee that it is totally bug-free and will work flawlessly on your computer.
If you have questions, there is a mailinglist: Vitessa@ls.kuleuven.be. You can join that list by sending an email to listserv@ls.kuleuven.be with in the body of the message 'subscribe Vitessa'.

Reference

Please refer to Vitessa 0.1 as follows:

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Facilitator: Dat (dweilen), dat was allemaal op de knieën en met de dweil.

Deelnemer1: Dat was arbeid, hé.

Deelnemer2: Dan kreeg mama altijd een schop in haar achterste van papa. Maar niet te geweldig.

Facilitator: Een beetje vriendschappelijk dus. De profiteur.