Mediation between Staff and Elderly Persons with Intellectual Disability with Alzheimer Disease as a Means of Enhancing Their Daily Functioning

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Abstract: This study presents a new way of mediation between staff and elderly persons with intellectual disability (ID) and Alzheimer type dementia (AD), i.e., the MISC (Mediational Intervention for Sensitizing Caregivers (Klein, 1988, 2003) model. The MISC was adopted for interactions between staff and adults with ID and AD based on observations of interactions between staff and adults with ID. The overall objective is to help caregivers and direct staff relate to their dependents in a way that will enhance their cognitive, emotional, and behavioral functioning. It is based on the integration of the person-centered approach, the cognitive rehabilitation approach (Clare, Wilson, Carter, & Hodges, 2003) and the mediational approach (Feuerstein & Rand, 1979; Feuerstein, 2003). The five mediational parameters can be applied during daily activity: meal and medication time, work sessions and leisure activities. The cognitive, emotional, and behavioral parameters of the MISC, including their rationale, aim, strategies, and examples of their implementation in a population of adults with ID and AD, are included. A case study describing the efficacy of the MISC as applied to a person with ID/AD is presented.

Israel mirrors the worldwide trend of an increasing number of adults with intellectual disability (ID) who survive to old age. Of the 6,122 persons with ID in residential care centers, 42.65% are aged 21–39; 37.5% are over 40 and 6.38% are 60 years or older. Of those who are 40 and above, 16.3% have Down syndrome. Of these, 5% suffer from dementia (Merrick, 2009).

One of the serious problems resulting from the increase in lifespan is a concomitant rise in cases of dementia of the Alzheimer type (DAT) among adults with/without Down syndrome. Estimates of the age-specific prevalence of dementia in adults with Down syndrome have varied widely, from under 10% to over 75% (Zigman, Schupf, Sersen & Silverman, 1996). Virtually all adults with Down syndrome over 35 to 40 years of age who have been autopsied exhibited key neuropathological changes characteristic of Alzheimer’s disease, including deposition of beta-amyloid in diffuse and neuritic plaques and neurofibrillary tangles (Frasher & Chung, 1996; Holland, Hon, Huppert, Stevens, & Watson, 1998; Malamud, 1972; Mann, Yates, & Marcyniuk, 1984; Wisniewski, Wisniewski, & Wen, 1985). This association appears to be due to a triplication of the gene for the beta-amyloid precursor protein (β-APP) which is located on the proximal part of the long arm of chromosome 21 (Goldgaber, Lerman, McBride, Saffiotti, & Gajdusek, 1987; Robakis et al., 1987; Rumble et al., 1989).

Alzheimer’s disease presents three stages (Schapiro, 1988). At first, only cognitive functions decrease, manifested as senility. Later there is deterioration in routine and vocational activities and behavior, characterized by dementia. Finally, there is deterioration in ADL skills functioning.

Most studies dealing with elderly persons with ID and AD focus on estimates of dementia in populations with ID, detecting the signs of dementia, the age of the onset of the disease (Janicki & Dalton, 2000) and the biological signs of dementia (Goldgaber et al., 1987; Robakis et al., 1987; Rumble et al., 1989).

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Another issue that has been at the center of research interest is the development of diagnostic tools for identification of the disease (Burt & Aylward, 2000; Evenhuis, Kengen, & Eurlings, 1990; Frasher & Chung, 1996; Janicki, Heller, Seltzer & Hogg, 1996). Other studies focus on the stressors of the family caregivers or staff who take care of elderly persons with ID and AD (McCallion, McCarron, & Force, 2005). As far as we know there have been no attempts to relate to intervention or interaction between caregivers for persons with ID and AD in daily life. Our study aims to fill this void.

Cognitive Rehabilitation for People with Dementia

The concept of rehabilitation means ‘enabling people who are disabled by injury or disease to achieve their optimum physical, psychological, social and vocational well-being’ (Clare et al., 2003). This concept can be applied to people at different life stages and with different types of problems or disorders including people with dementia, especially in the early stages where changes in memory and cognitive functioning have a prominent impact on well-being.

Rehabilitation can focus on a range of different areas of need, and goals can be adjusted flexibly in response to changing needs. This is based on the understanding that despite difficulties with memory and other cognitive functions, people with dementia still have the ability to learn new associations and information, and to adjust their behavior and responses.

Cognitive rehabilitation aims to ‘enable clients or patients, and their families, to live with, manage, by-pass, reduce or come to terms with deficits precipitated by injury to the brain’ (Clare et al., 2003). Cognitive rehabilitation for people with dementia does not typically aim to cure or reduce impairment at the neurological level. Rather, it aims to find ways of dealing with the problems that arise as a result of cognitive changes, so as to enable the persons to participate in interactions and engage in desired activities as best they can, within their own personal and social context. This means that cognitive rehabilitation needs to identify specific strategies for dealing with difficulties resulting from changes in memory or other cognitive domains.

A key strength of the cognitive rehabilitation approach is that interventions are individually tailored and focus directly on real everyday situations and difficulties in a collaborative manner. The starting point involves identifying desired outcomes. This means that interventions focus on things that cause concern to the person with dementia and his or her family members or staff, and goals relevant to improving their quality of life. Specific interventions are then devised, based on an understanding of the profile of cognitive functioning that indicates both strengths and difficulties, taking into account the person’s preferred coping styles, other psychological and emotional needs, and support system.

Cognitive rehabilitation is also associated with the cognitive reserve concept. This term is defined as the ability to optimize performance by ‘recruiting’ alternative brain networks and reflecting the use of different cognitive strategies (Corral, Rodriguez, Amenedo, Sanchez, & Daz, 2006; Katzman, 1993; Scarmeas & Stern, 2003). This brain reserve capacity is defined in terms of the synapse count or brain volume. Recent studies show a positive relationship between brain size and cognitive functioning in pathological and healthy samples (Katzman).

Interaction between Caregivers and Persons with AD

Caregiver intervention studies among the general population have been conducted to address multiple negative outcomes such as emotional distress, burden and depression experienced by caregivers of adults with Alzheimer disease (Brodaty, Green, & Koschera, 2003). Most of these studies focused on the psychological emotional stress or skills needed for daily living (with only modest success, see Sorensen, Pinquart, & Duerstein, 2002). Research on family caregiving of persons with ID has been strongly influenced by stress and coping models (Lazarus & Folkman, 1984) which recognize that there are subjective as well as objective stress factors, that a variety of coping mechanisms may be effective, and that appraisals and resources may mediate. These
studies were anchored in the “Pearlin Model” (Pearlin, Mullan, Semple, & Skaff, 1990), which has emerged as most prominent in framing suggestions for avenues to assist families to cope more effectively. This model has supported the development of interventions to deal with behavioral problems, environmental modification to address the issues of increased dependency, and safety needs and outside support and education for reducing physical demands of care tasks (Schneider, Murray, Banerjee, & Mann, 1999). McCallion et al. (2005) adapted the Pearlin model for measuring stress and burden among caregivers of elderly persons with ID. It was found that staff caregivers experienced greater subjective burden than burden that has been reported for family caregivers.

A literature search in ERIC and PsycINFO (1995-2004) yielded attempts to implement intervention programs designed to improve the quality of the staff/residents’ interactions in facilities administering to adults with ID. These interventions focused on three major aspects: emotional components that could promote the residents’ emotional well-being (Golden & Reese, 1996; Leidy, 2004; Singh et al. 2004); social interaction, with a special focus on conversation between staff and residents (Kuder & Bryne, 1993); and strategies, aimed at improving the involvement of residents in daily activities (Felce et al. 1996).

The above interventions lack a holistic approach which encompasses emotional, behavioral, and cognitive components of the interaction. Furthermore, they focus on interaction between staff and adults with ID but not on elderly persons with ID, especially those suffering from Alzheimer type dementia. However, these interventions lack operative strategies, including mediation and interaction between staff and participants with ID and AD in daily life activities. This led us to advocate the MISC model: A new way of mediation between staff-adults with ID, and between staff-elderly persons with ID with and without dementia.

MISC—Mediational Intervention for Sensitizing Caregivers

The overall objective of the MISC (Klein, 1988, 2003) is to help direct staff or caregivers relate to their dependents in a way that will enhance their cognitive, emotional, and behavioral functioning. The MISC aims to provide caregivers with operative strategies, including mediations that are implemented during daily life activities. Based on the efficacy of the MISC among younger individuals (Greenspan & Weider, 1996; Klein, 1992, 2003), it has been applied to children with DS (Sobleman-Rosenthal & Klein, 2003) and PDD (Greenspan & Weider).

The essence of the MISC is sensitization and raising consciousness of key issues in the caregivers-adults with ID and AD relationship, i.e. trying to raise the caregivers’ awareness of their perceptions of the persons with ID, of themselves as caregivers and of the person’s emotional and cognitive needs. The five mediational parameters can be implemented during daily activity, i.e. meal and medication time, vocational time and leisure activities (Klein, 1992, 2003).

The MISC is an integration of three major theoretical frameworks:

Person-centered cultural approaches which emphasize individual identity and selfhood: The interaction with demented persons plays an important role by empowering their sense of self-identity and enhancing their feelings of being in control. Cultural attitudinal differences towards Alzheimer’s disease are taken into consideration when designing interventions between caregivers and persons with dementia.

Rehabilitation approach: The MISC adopted the cognitive rehabilitation approach (Clare et al., 2003) which aims to find ways to deal with the problems that arise as a result of cognitive changes of persons with AD, and to find strategies that would help these persons compensate and overcome memory loss and deterioration.

Mediational approaches (Feuerstein & Rand, 1974; Feuerstein, 2003): Klein’s (1992) mediational program is an outgrowth of Feuerstein’s theories of structural-cognitive modifiability and of mediated learning (Feuerstein & Rand; Vygotsky, 1978), emphasizing the importance of reciprocal relations between both parties in any interaction. Mediated learning, as distinct from direct learning through the senses, occurs when the environment is interpreted for an individual by another person.
The mediator is trained to take an active role in structuring meaningful components of that environment, as well as of past and future experiences. The above theories assume that the human organism is a system open to its environment and accessible to change, even in the presence of three obstacles believed to prevent change: age, etiology, severity of limitation (Feuerstein & Rand).

Klein (1992) identified five teaching parameters relating to cognitive, emotional and behavioral components necessary for creating experiences of mediated learning. These parameters were adapted by Lifshitz and Klein (2007) for interaction between staff and adults with Alzheimer’s disease. The cognitive, emotional, and behavioral parameters will be presented, including their rationale, aim, strategies, and examples of their implementation in a population of adults with ID with/without AD.

The Cognitive Component

The cognitive component includes two parameters: focusing and cognitive expansion.

Focusing: Acts of the mediator directed toward affecting individuals’ perceptions or behavior referring to explicit or declarative memory (Cohen & Squire, 1980; Schacter & Tulving, 1994), i.e., remembering new events and facts becomes more difficult and even impossible for individuals with Alzheimer’s disease. Mediation plays an important role in helping them remember and recognize people, objects and events. Focusing includes selecting, accentuating, emphasizing, scheduling, grouping, organizing, sequencing, and naming in relation to objects, people, as well as time and space orientation.

Objects should be named and activities should be scheduled according to a definite and not a relative time. Rooms should be mapped using drawings (kitchen, bedroom, etc.) with precise directions, fixed location of objects such as watch, calendar, keys in ADL (activity daily living skills), leisure or other activities.

Expanding-Transcendence

Rationale: Behavior directed toward expanding cognitive awareness beyond what is necessary to satisfy the immediate need that triggered the interaction. This parameter is expressed by clarifying processes, attributing past and future needs to the present situation, critical interpretation, inductive/deductive reasoning.

Following the theory of cognitive reserve, cognitive enrichment among adults with ID cannot be reduced to one or two hours a week, but needs to be integrated in all daily activities. The aim is thus to insert literacy during daily life activities, i.e. mealtime, work session, leisure activities, etc even in a population with ID and AD.

Example: When persons with typical development sit in café or restaurant, the first part of the meal is devoted to reading the menu, talking about the nutritional composition, the contribution of the foods to health, the cooking and baking process and choosing the desired food. Experiencing knowledge of the food is an important part of the pleasure and the individual’s quality of life. Even when eating alone at home, a person is interested in the foods s/he is offered. However, observing a meal among adults with ID shows that there is no verbal interaction between the participants and between staff and their charges. On the contrary, the staff encourages them to eat quietly. Are we preventing our charges from doing what we do? Do we act contrary to the principle of normalization and the quality of life? Are we aware of the learning opportunity which our charges thus miss during daily activity?

Cognitive expansion is therefore derived from Wolfensberger’s (2002) principal of normalization and Schalock’s (1996) concept of life quality. It relates to expanding the knowledge of the current activity beyond the immediate need whether at mealtime (you are eating a tomato, a cucumber), during leisure activity (going to the sports club), relating to basic mathematical and scientific concepts (the pasta is round and shaped like the sun, the taste is sweet and sour). The staff should talk with the people with ID and AD, and should verbally or visually mediate these components for those who lack expressive language using pictures, word signs, and give them the opportunity to choose their preference from a written menu or from pictures.
Expanding the Communication Chain between Adults with ID and Their Staff

Rationale: A communication chain is defined as units of communication (verbal/nonverbal) that take place in one reciprocal sequence. Alzheimer’s patients have impaired declarative and episodic memory of recent facts, people, and events, while memories of the past are preserved (Fleischman, Wilson, Gabreili, Bienias, & Bennett, 2004). One of the causes of emotional burden for the caregivers of Alzheimer’s patients is the patients’ tendency to talk extensively of past events. The caretakers tend to stop the discourse with their loved ones.

Example: An attempt should be made by staff to expand the communication chain. This can be done by using the topic that was chosen by the individual for conversation, associate it to the past and to those of the present, and to expand the content of the discourse in terms of opinions, ideas, and world knowledge.

The Emotional Component

The emotional component includes three sub-parameters: Providing mediation of meaning (affecting), providing opportunities of choice making, and encouraging with explanation.

Providing mediation of affect relates to behaviors that express excitement, appreciation or affect in relation to the person in the interaction, other people, objects or processes. Kazui et al. (2000) found that emotional arousal may enhance declarative memory in patients with AD. Instructions and guidance given to patients with AD may therefore be easier to remember if emotionally aroused devices are used in intonation or other forms of expression.

Providing opportunities for choice making: Self-determination fulfills a basic human right and enhances the quality of life (Schalock, 1996). LeBlanc, Cherup, Feliciano, & Sidener, (2006) showed that choice preference for identifying items and activities increase engagement levels among clients in an adult daycare program. Providing opportunities for choice-making may contribute to the activities and behavior of individuals with dementia, would afford meaning to their life and would enrich their quality of life.

Encouraging or mediating feelings of competence relates to verbal/nonverbal behavior that expresses satisfaction with the individual’s behavior and identifies components of behavior contributing to that success. There are two ways of rewarding. One is to provide reward without explanation. This relates to careful timing of a gesture/verbal expression of satisfaction when the individual successfully completes a task or part of it, telling the reason for success (ADL, vocational, leisure activity).

Expanding and encouraging with explanation were found to be most predictive of cognitive performance of children with/without special needs such as Down syndrome (Klein, 1992, 1993; Soboleman-Rosenthal & Klein, 2002) and PDD (Greenspan & Wieder, 1996). The absence of this parameter from the staff-residents with ID interaction provides a poor “mental diet” for adults with ID and may prevent their benefiting from any learning experience.

The Behavioral Component: Regulation of Behavior

Rationale: Regulation of behavior relates to mediation of task performing through all stages of task analysis. A different pattern of performance emerges among persons with AD in implicit or procedural memory, when memory is assessed by performance of particular skills or acquiring new skills after training (Fleischman et al., 2004). Our observations of the interaction between caregivers and adults with ID and Alzheimer’s disease indicate that when patients tackle simple ADL or leisure skills, the caregivers give them physical assistance instead of guiding them on how to perform the task through the four stages of task analysis. This way of interaction prevents them from having the opportunity to internalize and assimilate the strategies of problem solving and transfer these strategies to similar tasks in the future.

We based the regulation of behavior on Gold’s (1978) four stages of task analysis: verbal instruction (i.e. “Use the spoon”), modeling (showing participants how to bring the spoon to the mouth with verbal instruction), practice (participants imitating the moderator) so that the behavior will be assimilated,
physical assistance (palm, hand, arm without imitation of the moderator).

In the light of the above, the questions posed by the present study were: (a) Are the MISC mediation parameters applicable in interactions between caregivers and persons with ID and AD? (b) What effects will using these parameters have on the quality of interaction between the caregivers and their relatives, on the cognitive, emotional and behavioral measures of the patients with dementia? An example of implementing the parameters with a person with ID who exhibits early signs of AD dementia is presented herewith.

Implementation of the MISC with a person with ID and AD

Jacob (54 years old), is a person with Down syndrome who was diagnosed with early-stage Alzheimer’s disease four years ago. He lived in an apartment with another four persons with ID for 10 years. However, when signs of deterioration appeared, he moved to a sheltered residence (hostel). He was independent in ADL skills, used to read and write, worked in supported employment and used to travel on a bus independently.

We used the Dementia Questionnaire for Mentally Retarded Persons (DMR) (Evenhuise et al. 1990) in order to determine the signs of dementia. The scale, which is based on DSM 3-R, includes 50 items in seven sections. The answers on each item are ranked on a 0–2 scale (0—exhibited no change in behavior in relation to the past and reflects independence, 2—exhibits great deterioration). The higher the score the greater the deterioration exhibited by the participant. Jacob’s profile in the seven sections of the DMR is presented below.

**Short term memory:** Jacob’s score in short-term memory was 3 out of 14. He tends to forget where he put something a minute ago, tends to forget where he put his personal things such as his glasses, watch, etc and does not remember special events that occurred last week.

**Long-term memory:** In this section his score was seven out of 16 (i.e. he does remember family members that he has not seen for a long time).

**Orientation in time and space:** His score was 6 out of 14. He forgets the days of the week and does not know which day it is today. He confuses the toilet and the bath. When walking on the streets he is in danger since he forgets to look at the traffic lights and crosses the street on red lights. The staff has a dilemma, since they are afraid to let him out on his own from the hostel.

**Speech:** His score was 1 out of 8, i.e. he functions well in this section and does not exhibit deterioration in this area.

**Practical skills:** His score was 3 out of 16. When taking a shower he sometimes puts his bathrobe over his clothes. He confuses between the hot and cold water taps and has become dependent in this area.

**Mood:** His score was 2 out of 12. From time to time he was readily upset, gloomy and sad.

**Activities and interest:** His score was five out of 12: he lost interest in outdoor activities such as parties, leisure activities, friends, etc. He has become more passive in the last years. He does not talk much and prefers to do things alone rather than with friends.

**Behavioral disturbance:** According to the scale he does not exhibit behavioral disturbances. However, the staff reported that when they went on their annual trip, he left the group and ran away.

In conclusion, according to the DMR, Jacob exhibits early signs of Alzheimer type dementia. Following Jacob’s deterioration, the staff exhibited a pessimistic approach dubbed by Feuerstein and Rand (1974) “passive acceptance,” according to which Jacob’s situation is irreversible and nothing can be done in order to change his function.

Based on the cognitive rehabilitation theory (Clare et al., 2003), a tailored program with the five parameters of the MISC was constructed in order to overcome Jacob’s weaknesses.

**Focusing:** This parameter was used to cope with Jacob’s deterioration in orientation in time and space and short-term memory.

**Time focusing:** We introduced Jacob to a calendar that he could consult whenever he wanted to know what day it was. A central part of the intervention involved getting Jacob into the habit of using his calendar. Following Clare et al. (2003), we positioned the calendar in a prominent place and the director of the community residence agreed to remind him
to look at his calendar twice each day and find out what day it was. We marked the date and time of our meetings (every Sunday at 4 PM) in his calendar. His score on orientation in time on the DMR increased by two points.

Orientation in space: The close surroundings near Jacob’s room, i.e. the shower, toilet, dining room, and infirmary were indicated by word signs accompanied by pictures. After two weeks he no longer confused between the bath and the toilet and knew the location of these places. We set aside a drawer in his closet for his watch and labeled it. His score in this section increased by two points.

As stated, Jacob tends to forget to look at the lights when walking in the streets. When walking together the first author realized that he tends to look at his watch very often. Based on this observation it was decided to use this habit as a strategy in order to remind him to look at the traffic lights. A little sticker was pasted on his watch with the word “Light” in red. Looking at the watch reminds him that he has to look at the traffic lights.

Cognitive expansion: In the past Jacob could read and write his name. This was not the case now. We decided to re-teach him to read and write his name. We wrote his name several times in thick magic marker and asked him to go over the name, then to go over dashed line, then copy his name. After three weeks he could again write his name.

Expanding the communication chain: It was difficult to expand the communication chain with Jacob. The length of conversation with him lasted a few seconds. Based on the MISC approach it was decided to find his favorite conversation topics and keep the conversation for 3–4 minutes. He liked to talk about the security and political situation in Israel. We asked questions and developed the conversation. When the chain was interrupted, we directed the conversation, associated it to the past and the present and succeeded in drawing out the conversation for 3–4 minutes. His second favorite topic was money. We spoke about money, uses of money, opening a bank account, etc. We succeed in expanding the conversation to five minutes, then to 10 minutes.

Mediation of meaning—providing opportunity for making choices: We gave Jacob an opportunity to choose the activities we would do together, including walking to the nearest coffee shop, having a drink, and sitting together for half an hour, then walking back to the hostel, working on his name, talking, arranging his family album together. He chose the schedule. Furthermore, when Jacob wanted to walk alone without company we respected his wish and enabled him do so.

Rewarding with explanation: We taught the staff to explain verbally, the reason for rewarding. We realized that positive behaviors were repeated.

Regulation of behavior: To overcome his confusing the stages of showering, we made a flowchart of the washing (taking a shower) stages accompanied by pictures and words signs. We also put signs on the hot and cold taps. We instructed the direct staff to go over these stages with him before washing. After two weeks he stopped the habit of putting on the robe after the shower and put on his clothes.

As stated, we wrote his name on a card and wanted to paste it on his bedroom door. He did not know how to paste the scotch tape. We went through the stages of task analysis, explaining the task and asked him to pull the scotch tape, cut it from its stand, hold it with both hands on the two edges, and paste it. He did not succeed. We modeled the task and only then gave him physical assistance. After three times he could perform the task independently. We regulated his behavior in other tasks as well.

In conclusion, the efficacy of the MISC among adults with ID and Alzheimer’s disease that is currently available is drawn mainly from case reports and supports our claim that persons with ID and AD behavior can be modified and can re-learn skills that had been in their repertoire previously before the deterioration. Although Jacob’s memory difficulties remained, his daily life became a little easier and less stressful. Jacob was coping with the onset of dementia by facing up to its impact and trying to adapt. As described above, he showed numerous important strengths, including the capacity and motivation for learning new skills. This suggested that he was able to learn new strategies that compensate for his deterioration in short-term memory, orientation in time and space.

Following the MISC intervention, Jacob’s
score on the DMR increased by only four points. However, not all of these achievements can be measured. Clare et al. (2003) assert: “It cannot be assumed that any gains that might result from training would have any clinically significant impact.” The MISC is a holistic approach relating to areas that are not covered in the DMR. However, we succeeded in improving his function and enriching his quality of life. Following Clare et al., our aim was to modify Jacob’s functioning and improve his quality of life in the cognitive, emotional and behavioral perspective.

Limitations, Implications and Future Research

The limited evidence currently available on the efficacy of the MISC approach among persons with ID and AD is drawn mainly from case reports. Experimental designs will enable examination of the effect of the MISC approach on the behavioral, cognitive, and emotional skills of adults with ID and AD.

In his Social Role Valorization theory, Wolfensberger (2002) asserts that “SRV relies on educational and persuasive strategies that change people’s perceptions and expectations” (p. 253). Interventions aiming at altering the attitudes of professionals and paraprofessionals towards the modifiability of adults with ID should be implemented in all facilities of persons with ID.

References


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