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ORIGINAL ARTICLE

Conversations about self-identity in Alzheimer disease: Augmentative and alternative Communication memory books as an aid

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KEYWORDS

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Abstract Alzheimer disease (AD) is a progressive and degenerative neurological disorder that affects memory, language and communication, thinking, and social skills. The inability to recall incidents and events, especially when symptoms become more prevalent and severe, can cause a person to experience a loss of self or to have doubts about his or her identity. One approach to helping these patients with their memory and language problems is to use memory books, a kind of Augmentative and Alternative Communication (AAC) tool. The aim of this study was to verify whether the introduction of AAC books could have an impact on conversations about self-identity through an increase of 'self'-positive conversational contents and on improving conversational skills.

Three single case studies were carried out with three elderly women with mild, moderate and severe AD, respectively. Each participant was involved in a conversation about their 'selves' in an alternating treatment design (ABAB) without a memory book in phase A and with the aid of this AAC tool in phase B. The results showed a similar conversational response pattern in all participants. AAC aids increased the number of 'self'-positive conversational statements with a reduction in negative, ambiguous and repetitive utterances. In conclusion, AAC memory tools seemed to help participants with dementia to focus their attention on relevant personal information, allowing them to centre the conversation on core positive identity contents, thus improving the quality of the conversations with fewer ambiguous utterances.

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PALABRAS CLAVE

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y Alternativa;
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de Alzheimer

Conversaciones sobre la propia identidad en la Enfermedad de Alzheimer: ayuda de los libros de memoria de Comunicación Aumentativa y Alternativa

Resumen La Enfermedad de Alzheimer es una enfermedad neurológica degenerativa y progresiva que afecta a la memoria, el lenguaje y la comunicación, el pensamiento y las habilidades sociales. La incapacidad para recordar incidentes y acontecimientos, cuando los síntomas son más prevalentes y severos, puede causar que la persona experimente una pérdida del self o tenga dudas sobre su identidad. Un enfoque que ayuda con los problemas de memoria y de lenguaje es el uso de los libros de memoria, herramientas de Comunicación Aumentativa y Alternativa (CAA). El objetivo de este estudio es comprobar si la introducción de libros de CAA tiene un impacto en las conversaciones sobre la propia identidad, a través del incremento de contenidos conversacionales positivos sobre "si mismo", y en la mejora de habilidades conversacionales. Se llevaron a cabo tres estudios de caso único con tres mujeres mayores con enfermedad de Alzheimer, leve, moderada y severa, respectivamente. Se implicó a cada participante en una conversación sobre "si misma" en un diseño de tratamientos alternos (ABAB) sin libro de memoria en la fase A y con apoyo de la CAA en B. Los resultados muestran un patrón de respuesta conversacional similar para las tres participantes. Con las ayudas de CAA se incrementaron las frases positivas sobre "si misma" en la conversación y se redujeron las declaraciones negativas, ambiguas y repetitivas. La conclusión es que parece que las herramientas de memoria han ayudado a enfocar la atención sobre información personal relevante, permitiendo centrar la conversación en contenidos básicos de su identidad y mejorando su calidad con menos ambigüedades.

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Introduction

Communication deficits associated with dementia are often attributed to significant memory deficits (Swihart & Pirozzolo, 1988). The provision of prosthetic memory aids or Augmentative and Alternative Communication (AAC) is one remedial approach to Alzheimer's disease (AD) memory deficits. AAC basic goal is to help persons with communication impairments increase their participation in desired activities and create opportunities for social interaction (Beukelman & Mirenda, 2005). AAC in the form of external aids that incorporate stimuli highly relevant to a person's daily life may include, among others, memory wallets, memory books, or notebooks that provide cues for interaction and support communication participation of persons with dementia (Bourgeois, Fried-Oken, & Rowland, 2010). Bourgeois, Burgio, Schulz, Beach, and Palmer (1997) have pointed out some forms of long-term memory (procedural, non-declarative, and episodic) that remain relatively intact until later stages can be harnessed for maintaining desired behaviours as conversation. Due to limitations of AD individuals to learn new skills and strategies to encode new information, these AAC interventions have been designed to maintain conversation skills taking advantage of the relatively intact repetition and oral skills of patients with AD. Moreover, memory AAC aids provide desired or needed information in an obvious, visible way becoming part of the environment, and provide an alternate pathway to the stored information allowing for encoding and retrieval processes (Bourgeois, 2002). Pairing the external aid that contains personally relevant picture and sentence stimuli to the person with AD with familiar and spared skills based on intact procedural memory, such as page turning, reading aloud, or autobiographical memories, should

maximize a person's opportunity for success (Bourgeois, 1994).

The usefulness of memory aids to improve conversational skills has been demonstrated in a variety of settings such as private settings, personal care and nursing homes, and with a variety of conversational partners as spouse, adult children, nursing staff, friends, and day-care centre volunteers (Allen-Burge, Burgio, Bourgeois, Sims, & Nunnikhoven, 2001; Bourgeois, 1990, 1992, 1993, 1996; Bourgeois & Mason, 1996). With the use of memory aids, moderate AD patients significantly increased the frequency of factual statements, made significantly more sense, stayed on the topic better, provided more unambiguous information and used more appropriate referents. Subjects also decreased the amount of counterproductive speech, such as ambiguous, perseverative, erroneous, and unintelligible utterances said during the same conversation (Bourgeois, 1990, 1992; Bourgeois & Mason, 1996). Similar results on the improvement of the quantity and quality of conversations were obtained by Bourgeois (1993) and Hoerster, Hickey, and Bourgeois (2001) when a prosthetic memory aid was introduced in dyads with moderate to severe dementia. Andrews-Salvia, Roy, and Cameron (2003) results revealed that all severe dementia subjects stated more on-topic facts using the memory books than during the baseline condition. Bourgeois, Dijkstra, Burgio, and Allen-Burge (2001) also found improvements on conversational measure, such as duration of speaking time and frequency of utterances, between treatment and control conditions as a function of memory book use. A replication of previous research conducted by Wan-Zu (2011) with 3 Chinese mild, moderate and severe dementia participants found an increase of number of on-topic factual statements and a reduction of ambiguous, unintelligible, and perseverative utterances with a memory book.

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