Nonverbal communication of individuals with dementia: An overview

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Nonverbal communication of individuals with dementia

# ABSTRACT

Individuals with Alzheimer's type dementia will have diminished ability to communicate verbally as the disease progresses. Therefore, nonverbal communication (NVC) through the use of and facial expression, gestures, and body language is essential for connecting with others and expressing wants and needs. The purpose of this SPA 900 project was to examine the current state of the literature relating to NVC and dementia. A comprehensive review of the literature was performed across nine databases. Four hundred and fifty-four articles were identified in the initial search. After applying exclusion criteria based on title and abstract, 65 articles remained. Several themes across the literature were revealed including emotions and facial expressions of people with dementia, interpersonal communication interactions with caregivers, pain assessment, and intervention relating to the arts. Areas for future research are discussed.

#### INTRODUCTION

## Communication

Communication refers to 'any act in which information is given to or received from another person concerning that person's needs, desires, perceptions, knowledge, or affective states' (Bauman-Waengler, 2012, p. 1). Communication is comprised of at least four components; sender, receiver, medium, and message. A sender converts and idea in a message (verbal or nonverbal) through a medium such as speech or gestures to the receiver (Nelson, 2010, p. 27).

Verbal communication is the use of written or spoken language, such as words and phrases, to communicate information and ideas.

- Nonverbal communication (NVC), also known as nonlinguistic communication, is described as communicating 'without words' spoken or written (Nelson, 2010). Neslon (2010) also describes two mechanisms for nonverbal communication: proxemic and kinesic. Proxemic mechanisms are based on spatial relationships such as how far to stand apart from a communication partner that is socially acceptable and comfortable. Kinesic mechanisms are related to body movement and gestures and include five specific types: Emblems - meaning gestures such as head shakes, or putting a hand out palm forward to represent 'stop'.
- Illustrators these gestures are often paired with a verbal message, such as holding your hands apart to symbolize the size of a fish you caught.
- Affective Displays body and facial gestures that portray affect such as happiness or sadness that may vary in intensity and frequency depending on culture and other personal factors.
- 4) Regulators signs that regulate conversational turn-taking, such as eye contact.
- 5) Adaptors movements made with low awareness by the sender, such as body positioning and changing, biting on one's nails, or casually twisting one's hair to relieve tension and stress.

## Dementia

In a comprehensive summary by Mahendra & Hopper (2011), dementia is defined as an acquired syndrome that severely impairs cognitive function and in turn affects competence in Hickey Page **3** of **22** 

daily living. It can limit functioning across several domains, including memory and attentional resources, executive function, language and communication (both verbal and nonverbal functioning), and visuospatial abilities. Alzheimer's disease (AD) is the most common type of dementia. Other common causes of dementia include Vascular Dementia (VaD), dementia with Lewy Bodies (DLB), Parkinson's Disease (PD), and frontotemporal lobar degeneration (FTLD), and mixed dementias.

## Alzheimer's Disease

AD's effect on cognition often begins with impairments in attention, working memory, and episodic memory (Mahendra & Hopper, 2011). As the disease progresses, it slowly causes degeneration of semantic memory and lastly nondeclarative memory. Due to the link between memory and language, as memory fails linguistic communication is also impacted. Decline in memory often results in deterioration to semantic aspects of language, while sparing phonological and syntactic components. Individuals with middle to later stage AD have difficulty producing meaningful language with word-finding difficulties that result in irrelevant speech that lacks content. Auditory comprehension is also negatively affected. Written language declines in complexity and spelling, while reading ability declines with respect to drawing inferences from text and answering content questions. Little is known about the state of NVC in AD or other types of dementia.

### Purpose

The primary purpose of the study was to assess the state of the science related to NVC and dementia. The first phase of this purpose was addressed in this 900 project. This phase comprised a literature review and categorization of the results. The emphasis was on research Hickey Page 4 of 22

in which the focus was production and/or comprehension of NVC of individuals with dementia. The research questions of interest were as follows: What aspects of nonverbal communication in dementia are addressed in the literature?

What types of study designs are represented in the literature on nonverbal communication in dementia?

## METHODS

A literature review was conducted in consultation with a research librarian. The librarian assisted in refining search terms and procedures, and setting up a RefWorks account to store findings of database searches. Step 1 involved accessing the University of Alberta library website and selecting *Health Sciences* under the *Browse by Subject* tab. Then, *Speech-Language Pathology & Audiology was selected and nine databases were chosen for searching.* 

Several variables were selected to limit our search terms for each initial database search. The terms 'nonverbal communication' OR 'non-verbal communication', dementia\*and the connector "AND" were used. For the initial search on the database called Scopus, the search was narrowed by selecting the following limits before proceeding: journal article, review, and English (language). These terms and limits were adapted as necessary for the eight other databases which included CINAHL, ComDisDome, EMBASE, LLBA: Linguistics and Language Behaviour Abstracts, MEDLINE (EBSCO), MEDLINE (OVID), PsychInfo, and Web of Science. All of the articles that were compiled from the initial search in each database were then exported into a RefWorks account.

To be included in the review, articles had to meet the following criteria: Hickey Page 5 of 22

- Be published in peer-reviewed journals between 1999-2012
- Be experimental, quasi-experimental or descriptive research studies or reviews in which the primary purpose was to study NVC in dementia (production and/or comprehension)

In an effort to narrow the number of articles from the initial searches to only those specific to our topic, exclusion criteria were used. Articles were excluded after a review of the title and abstract. Articles were excluded if the title indicated the study was focused on individuals who did not have dementia (e.g., school-age children, autism, Rett Syndrome) or was not related to the production or comprehension of NVC (e.g., memory tests, caregiver communication strategies, test validity). However, if there was any uncertainty based the title alone then the article abstract was reviewed. Articles were excluded if the abstract indicated that the full article was based solely on caregiver communication strategies or training. If there was no abstract available for review for a particular article, the decision was made solely based on the title. If there was uncertainty based on the title then the article was included.

# RESULTS

The results of the initial database search and subsequent exclusion based on search criteria are outlined below in Table 1.

Table 1				
Exclusion of Articles Based on Search Term Criteria				
	Remaining Articles (N)			

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Database	Initial Search	Exclusion of duplicates	Exclusion before 1992	Exclusion based on title and/or abstract
CINAHL	45	24	23	11
ComDisDome	5	0	0	0
EMBASE	116	87	77	14
LLBA	17	13	11	9
MEDLINE(EBSCO)	72	33	34	8
MEDLINE (OVID)	12	2	1	0
PsychInfo	38	25	18	11
Scopus	130	31	28	5
Web of Science	19	10	10	7
Total	454	225	202	65

Four hundred and fifty four articles were compiled after the initial database searches. After applying the exclusion criteria, 65 articles remained (only eight of these articles from the EMBASE database did not have abstracts). Within the context of dementia and NVC, several overarching themes were identified in the (see Appendix).

Research question 1: What aspects of NVC and dementia are addressed in the literature?

The expression and recognition of emotions through facial expression and gesture was assessed in 21 of the articles. Bucks and Radford (2004) investigated the recognition of NVC signals of emotions in facial stimuli pictures for 12 'probable' AD patients and 12 matched Hickey Page 7 of 22

controls. The authors found that participants with AD had relatively preserved identification of nonverbal emotional facial expression and recognition of differences in emotion. Similar findings were identified by Guaita et al. (2009) for understanding of facial emotions in others by people with dementia. Other authors reviewed the situational and social contexts for identifying nonverbal emotional expression in people with dementia (see Bar, Kruse, & Re, 2003; Cruz, Marques, Barbosa, Figueiredo, & Sousa, 2011). Similarly, six articles dealt with expressive affective displays (or lack thereof) through gestures, eye gaze, laughing, negative behaviours such as yelling or crying, or remaining silent ( see Carlomagno, Pandolfi, Marini, Di lasi, & Cristilli, 2005; Glosser, Wiley, & Barnoski, 1998; Herman & Williams, 2009).

Another major theme in 18 of the articles was interpersonal communication interactions and strategies used between people with dementia and their caregivers. This theme relates to the complexity of social exchanges with NVC as information needs to be expressed and understood by the person with dementia and the communication partner. Acton, Mayhew, Hopkins, and Yauk (1999) revealed that people with dementia are able to produce meaningful communication through nonverbal behaviours and advocated for the necessity of interpretation of these behaviours by caregivers to create appropriate clientcentred treatment for people with dementia. Communication interactions could often also be frustrating for both the caregivers and persons with dementia if nonverbal aspects of communication were not considered. Likewise, the importance of caregivers recognizing and attending to NVC behaviours in people with dementia was paramount for meeting the needs of the patient as well as to creating positive communication interactions.

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Another major theme found in 11 of the articles was the importance and necessity of pain assessment for people with dementia. In the late stages, there is often limited meaningful verbal output by people with AD, making it difficult to communicate pain. It is often left up to the caregiver to assess the client's pain through NVC including facial expressions, gestures, agitation, and any negative vocalizations. However, as Eritz & Hadjistavropoulos (2011) demonstrated in a study of informal family caregiver pain evaluation of their loved ones with AD, caregivers often disregarded nonverbal pain cues by people with dementia. Hence, caregiver training to identify nonverbal pain cues was an important conclusion across the majority of the articles reviewed. There was also an emphasis in the literature on the use of assessment tools and scales to aid in pain assessment (see Husebo, Strand, Moe-Nilssen, Husebo, & Ljunggren, 2009). These findings highlighted the importance of pain assessment to improve quality of life (QOL) in the middle and end stages of AD.

The use of music (Engstrom, Hammar, Williams, & Gotell, 2001; Manzon & Bianco, 2006) and dance (Coaten, 2001) in therapies for people with dementia was another main topic discussed in six articles in the literature. The facilitation of nonverbal expression of thoughts, emotions, musicality, and memories through these alternative therapies was assessed to improve NVC across participants with dementia.

Finally, a broader 'other' category was identified for the remaining nine articles with multicomponent features. These themes included the use of games to encourage nonverbal expression (Seifert, 1999), the important of increasing QOL (Killick & Allan, 2005) and meeting the needs of patients with dementia (Kovach, Noonan, Schlidt, Reynolds, & Wells, 2006),

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conversational and sociolinguistic analysis (Hamilton, 2008), intonational patterns, and using robotics to facilitate nonverbal communication (Marti, Giusti, Lund, & Henrik, 2009).

Research Question 2: What types of designs are used in the studies included in this review?

Of the 65 studies included in the review, 22 could be classified as descriptive studies and 42 were quasi-experimental or experimental. The latter category included 7 single-case designs, with 1-4 participants, 42 group designs with as many as 103 participants in 1-3 groups.

# DISCUSSION

The focus of this study was to determine the current state of the literature concerning the study of NVC in people with dementia. After the exclusion criteria were applied, the remaining 65 articles were analyzed to answer the research questions of interest. These themes included the study of the expression and understanding of facial expression and emotion by people with dementia, the interpersonal interactions and NVC between caregivers and individuals with dementia, the role of NVC in pain assessment, music and dancing as forms of NVC, as well as other interventions and QOL concerns. The focus was mainly on the caregiver– patient communication relationship and the ability of the caregiver to understand NVC expressed by the individual with dementia through gestures, facial expressions and vocalizations.

There was a large number of articles related to NVC and pain assessment of individuals with dementia. Certain NVC behaviours such as facial expressions, agitation or aggression,

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negative vocalizations (crying or moaning), social withdrawal, and fidgeting were all documented.

On the basis of this initial phase of the literature review and classification of articles, there was a lack of information related to conversational analysis of NVC as well as effective NVC strategies for use with individuals who have dementia.

# Limitations

There are several limitations to consider when interpreting the results of this study. First, a single researcher completed the database searches and selection of articles based on the research requirements and exclusion criteria. Therefore, there is no measure of inter-rater reliability for the selection of the remaining articles based on the exclusion criteria. Second, only article titles and abstracts were reviewed in this phase of the research. Thus, the information derived is fairly superficial. Finally, there is a lack of a consistent framework from which to classify and study nonverbal communication, which made it difficult to limit the scope of the review.

# Conclusion

NVC is the use of gestures, facial expression, and nonverbal vocalizations to communicate. NVC is an important consideration when it comes to communicating with and understanding the needs of people with dementia. The findings of this study suggest that the study of NVC in dementia is gaining attention. Appropriate use and identification of NVC may aid in improving positive interactions, decreasing frustration for all those involved, and improving the QOL of those living with dementia. Likewise, this study has helped to identify the need for more in-depth article reviews and classification of the research literature. Hickey Page 11 of 22

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# APPENDIX

# Appendix A

Major Themes of Nonverbal Communication in Dementia Patient Articles

Themes	Article Citation
Emotions and Facial Expressions	Armstrong & Wright (2002); Bar, Kruse, & Re (2003); Bozeat, Lambon, Patterson, Garrard, & Hodges (2000); Bucks & Radford (2004); Carlomagno, Pandolfi, Marini, Di Iasi, & Cristilli (2005); Clark (1995); Cruz, Marques, Barbosa, Figueiredo, & Sousa (2011); Glosser, Wiley, & Barnoski (1998); Guaita et al. (2009); Herman & Williams (2009); Hubbard, Cook, Tester, & Downs (2002); Kessels et al. (2007); Kontos & Naglie (2007); Lefebvre & Arenas (2012); Lindholm (2008); Luzzi, Piccirilli, & Provinciali (2007); Roudier et al. (1998); Sabat & Cagigas (1997); Seidl, Lueken, Thomann, Kruse, & Schroder (2012); Starkstein et al. (1995); Wilson, Müller, & Damico (2007)
Interpersonal Communication Interactions with Caregiver	Acton, Mayhew, Hopkins, & Yauk (1999); Astell & Ellis (2006); Athlin & Norberg (1998); Blackhall, Hawkes, Hingley, & Wood (2011); Clarke (2005); Ekman, Norberg, Wahlin, & Winblad (1995); Ellis & Astell (2010); Kovach, Noonan, Schlidt, & Wells (2005); Feyereisen (1994); Killick & Allan (2006); Kobayashi, Masaki, & Noguchi (1993); McFadden & Lunsman (2010); Richter, Bottenberg, & Roberto (1993); Rousseaux, Seve, Vallet, Pasquier, & Mackowiak-Cordoliani (2010); Savundranayagam, Ryan, Anas, & Orange (2007); Schiaratura (2008); Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans (2010); Williams & Parker (2012)
Pain Assessment	Blomqvist & Hallberg, (2001); Cabassa, Guttman, Reineke, & Parietti (2011); Epps (2001); Eritz & Hadjistavropoulos (2011); Fink,R. (2001); Hadjistavropoulos & Craig (2002); ); Husebo, Strand, Moe-Nilssen, Husebo, & Ljunggren (2009); Kovach, Logan, Simpson, & Reynolds (2010); Kunz, Scharmann, Hemmeter, Schepelmann, & Lautenbacher (2007); Leysens, Noben, & de Maesschalck (2010); Ross (2008)

Appendix A (cont'd)

Themes	Article Citation
Music and Dance Therapies	Coaten (2001); Engstrom, Hammar, Williams, & Gotell (2001); Hammar, Emami, Engström, & Götell (2011); Manzon & Bianco (2006); Nyström & Lauritzen (2005); Raglio & Gianelli (2009)
Other	Hamilton (2008); Killick & Allan (2005); Kovach, Noonan, Schlidt, Reynolds, & Wells (2006); Marti, Giusti, Lund, & Henrik (2009); McCann (2000); Rexach (2012); Reynolds, King, & Herzberg (2006); Samuelsson & Hyden (2011); Seifert (1999)