

Strategies to Improve Communication during ADLs in Dementia: A Short Review

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ABSTRACT

Dementia is a progressive condition affecting primarily memory, cognition and communication. With increasingly ageing population, it is reported to take significant proportions worldwide in near future. That places a huge burden not only on health care facilities, community support network but also on the families which forms the fabric of the society. Caregivers both professional and informal ones including family ,relatives etc. and the care recipients with dementia have to put up a lot of effort in facilitating everyday tasks due to dementia related issues like memory, communication and behavioural problems. A majority of the problems are attributed to communication difficulties. Even with sizeable body of evidences on intervention strategies targeting communication related issues in dementia, best practice guidelines are non-existent. In this context, this paper reviews a few upcoming research based programs and summarises on communication enhancement strategies which will empower the caregivers during ADLs (Activities of Daily Living) and improve quality of life of persons living with dementia in general.

Keywords: dementia, communication, caregivers, ADLs, communication strategies.

INTRODUCTION

Dementia is a degenerative condition affecting memory, cognition and communication. Estimates suggest that 50 million people suffer from dementia worldwide;¹ among it 4.1 million people are in India.² As per WHO report (2017) these

numbers are going to increase three folds by 2050.¹ Hence, In order to meet the multi-faceted needs, dementia care would require multi-level planning in near future.

Empirical evidence shows that caregiver's burden is quite high in dementia. ADLs in particular can be a cause of everyday struggle for both the caregivers and the persons with dementia. Memory and communication difficulties have been identified as a major cause of distress and contributing to problems encountered during ADLs.³ In fact many of the behavioural problems can be attributed to communication difficulties.

The literature suggests that functioning in activities of daily living often deteriorates below what would be expected by the illness alone. Caregivers need to give optimal opportunities to practice whatever skills they poses at that time.

Few authors have even advocated provision of unwavering support to informal caregivers (unpaid) of persons with dementia including family members, relatives, neighbours and to professional/formal (paid) caregivers such as health care aides, nurses, occupational and physical therapists, recreational therapists, speech therapists, social workers among other. As both the groups have much in common considering the difficult social roles undertaken with minimum training and preparation;⁴ all caregivers paid or unpaid should be valued by the society and hence should be supported with good quality

programs.

Enhanced communication strategies are one of the core interventions which can be used along with ADL skills training and activity planning to facilitate maximal independence.⁵ A study by Gueidetti and Tham⁶ described communication strategies employed by occupational therapists during self-care training. Many of these strategies are intuitively appealing, but they lack empirical support.⁷

Despite sizeable body of research into nature of memory and communication difficulties in dementia and potential intervention methods to help these, there has been limited application of the research findings in practice.³

This article discusses few such programmes compiling research knowledge base into practical strategies within the context of communication enhancement education and training which can facilitate performance during ADLs.

Dementia, Communication Issues and Caregivers Perceptions

Communication is a two way process and can be defined as “person to person” transmission of ideas through language or non-verbal media.⁸ In dementia progress in language impairment with advancing disease makes day to day communication increasingly difficult. Language deficits ranges from word finding problems in early stages to exceedingly vagueness in moderate stages to little or no verbalisation in late/severe stages.

Owing to such deficits elder speak or over-accomodated communication including inappropriate speech and language mediations and non-verbal behaviours is usually noted as dominant pattern of communication with older adults with dementia. The Communication Predicament of Aging Model (Ryan, Giles, Bartolucci & Henwood, 1986) describes such inappropriate method of communication and its impact due to stereotyped beliefs about ageism. There is constrained opportunities

at communication which results in loss of self esteem for the elderly.⁹

Time constraint has also been attributed for such faulty communication method used by both formal and informal caregivers.

Rabins et al¹⁰ stated that over two third of family members reported that their relatives having dementia had communication difficulties, out of those caregivers 74% reported that communication difficulties were problematic too.

In an extensive 14 nation investigation conducted by Murray et al¹¹ in which they found that loss of understanding and conversation was considered more distressing than taking responsibility for their partners’ basic activities of daily living by majority of carers.

In fact a recent survey of the needs of family caregivers of people with moderate to severe dementia indicated that many felt they had specific educational needs, with 83% stating they needed education about effective communication strategies¹²

Dementia care in Indian Context

In September 2010, the national body for dementia in India, ARDSI, published the Dementia India Report 2010.¹³ This report acknowledges that the public awareness about dementia in India is low as a result there is delayed diagnosis, poor support system available for the caregivers etc. there are some research on the burden of caregiving on family members but there is less or no research on caregiving in different communities and population groups. There is a need to develop culturally suitable programs including communication strategies for caregivers and on various aspects of caregiving in India to make caregiving a positive experience.¹⁴

Communication Enhancement Strategies Appearing in the Caregiving Literature:

Literature review on communication intervention in dementia across various disciplines identified a few programs for improvement in communication strategies

of informal and formal caregivers with the mode of delivery and outcomes.

Though there are numerous studies on communication enhancement strategies; they are usually case studies or studies with very small sample size, describing a specific communication strategy.

A study by Done and Thomas¹⁵ on thirty family caregivers of individuals with dementia receiving two short training sessions of 60 mins duration in a group, each separated by a week and the control group of 15 family caregivers receiving only an information book showed equal reduction in emotional distress.

In 1994 Ripich¹⁶ developed a functional communication program called FOCUSED for caregivers of persons with Alzheimer's disease which described strategies like F-face to face, O-orientation, C-continuity, U-unsticking, S-structure, E-exchange and D-direct showed significant decrease in communication problems.

TANDEM- a psychosocial communication intervention strategy developed by Haberstroh, Neumeyer et al¹⁷ was administered to a group of 9 participants who reported increase frequency of communication and significant improvement in mood as compared to control group of 13 participants. The TANDEM program was highly structured weekly education program of two and half hrs. session in 5 weeks. It also demonstrated improvement in care recipients' quality of life.

A review article by Egan et al¹⁸ investigated effectiveness of methods to improve verbal communication of individuals with Alzheimer's disease with their caregivers. Databases searched were PsychInfo, CINHALL, EMBASE, MEDLINE, REHABDATA and COMDIS. They reviewed 13 articles meeting inclusion criteria of experimentally based, quantitative results and interventions aimed at increased verbal communication. Results showed only one technique was found to be potentially effective i.e. use of memory aids

and specific caregivers training program but had poor strength of evidence due to methodological limitations¹⁶.

Aizawa¹⁹ critically reviewed the outcomes of communication skills training for the familial caregivers of people with dementia of the Alzheimer's type. The author reported that despite few studies none have gone beyond pilot study stage. Also they opined that it adds to economic benefit as positive communication increases family support and decreases institutionalisation.

Since cognitive rehabilitation approaches are often overlooked within the framework of a largely medical approach to dementia. Hence, there is a paucity of research based education programs addressing memory and communication difficulties.

Recently a group of authors used a knowledge translation approach by which a team of neuropsychology, speech pathology, nursing and psychogeriatrics collaborated with aged care providers and consumers at home to translate research based knowledge into practice via a DVD based education program to help caregivers to enhance memory and communication in people with dementia. The program consists of 20 mins of RECAPS strategies and 30 mins of **MESSAGE** communication related strategies to be administered to informal and professional caregivers either individually or in a group format.²⁰

In a later study the same author and colleagues evaluated the effect of a DVD based training program based on research based strategies for memory and communication for informal caregivers. 29 dyads (13 training group and 16 control group with treatment as usual) received the training in two 45 mins sessions. They reported that the program significantly improves knowledge of strategies and thus contributed to positive perceptions of caregiving. Being DVD based it was easy to administer and had an educational format but failed to consider individualised need.²¹

Further, Caregivers’ perceived use of communication strategies indicated that person-centred dementia care is a central aspect to facilitating the completion of ADLs. They reported that it’s not only the task focussed communication strategies but also the context surrounding the communication which matters.²²

DEMTEC- The authors argued that though a number of communication training and guidance packages are currently available, but these exhibit shortcomings, including a lack of user input and cross-referencing to other communications theory or to relevant empirical evidence; a lack of individualisation; and high context-specificity. They felt that their uptake and level of application was hence low. Thus, they tried to develop a new communication intervention with direct involvement of variety of lay and professional stakeholders. Resultant inter-group dialogue produced an agreed free to user, user informed and user relevant dementia communications toolkit (DEMTEC) which is not only evidence

based but adaptable to different socio-cultural and care environments.²³

Another program worth a mention is the **TRACED** (Training in Communication Enhancement for Dementia) developed by Jeff Small and Jo Ann Perry²⁴ that integrates two empirically ,theoretically informed and compensatory approaches to enhance communication in family partnering contexts, compensatory approaches address to cognitive and communication limitations and encompasses of standard care while connecting approaches address the relational level of family care and has a skill building component that is unique to each family need.

The authors reported a successful piloting of the program which showed positive impact on communication within the care dyads though few recommendations were made regarding decreasing the length to 1-1.5 hrs from 2.5 hrs. They finally envisioned making evidence based TRACED program to be incorporated into existing intervention practice.

Table no. 1 Highlights of three research based programs

MESSAGE	TRACED	DEMTEC
<p>A DVD was made out of the guidelines & used for training professional caregivers</p> <p>M = Maximize attention</p> <ul style="list-style-type: none"> • Attract attention • Maintain Eye contact • Limit distraction <p>E = Expression & body language</p> <ul style="list-style-type: none"> • Relaxed & calm • Show interest <p>S = Keep it simple</p> <ul style="list-style-type: none"> • short, simple, familiar • Give clear choices <p>S = Support their conversation</p> <ul style="list-style-type: none"> • Allow time • Assist with finding words • Repeat then rephrase • Remind of the topic <p>A = Assist with usual aids</p> <ul style="list-style-type: none"> • Gestures & actions • Objects & pictures <p>G = Get their message</p> <ul style="list-style-type: none"> • Listen , watch & actively work out • Check behavior & non-verbal messages <p>E = Encourage & Engages in conversation .</p> <ul style="list-style-type: none"> • Interesting familiar topics 	<p>It describes 2 kind of strategies with vignettes for better learning</p> <p>1. Compensatory strategies</p> <ul style="list-style-type: none"> • one idea sentence • Ask questions that do not place demand on recent memory • Speak at normal rate & without exaggerated intonation • Eliminate distractions • Use focused conversational management & repair strategies – be specific in signaling repair avoid ambiguous reference & sudden topic shifts, report when necessary & according to whether the listener misunderstood Vs forget what was said <p>2. Connecting strategies</p> <ul style="list-style-type: none"> • Encourage – prompt, cue,validate, agree • Invite – giving choice asking about a preference ,restating providing an explanation, an open – ended style that doesn’t sound like “testing” • Facilitate – Supply a possible answer or approach but does not answer for. • Orchestrate – Uses context & or demonstration to enable family member to accomplish activities • Repair – states lack of understanding, seeking clarification of meaning, makes connection with past or with something familiar & continues the exchange • Partner – Use affectionate terms , drawing on shared memories ,asking gently, telling a story or doing a daily activity together • Honor – To use speech patterns, words ,gestures & facial expressions that demonstrate & acknowledge reverence, esteem & value 	<p>This toolkit consists of 3 levels .</p> <p>Level (1) – Beliefs & principles about importance of communication</p> <p>Level (2)- Eight components of good communicative practice considering</p> <p>what</p> <p>why</p> <p>how</p> <p>(1) conversation</p> <p>(2) Non verbal communication</p> <p>(3)Environmental considerations</p> <p>(4) Anxiety reductions</p> <p>(5) Mindfulness and empathy</p> <p>(6) Understanding behaviours</p> <p>(7) Retaining a sense of self</p> <p>(8) Checking understanding</p> <p>Level 3 – Actual communication with vignettes</p>

Implications:

There are many researches^(7,9,10) into various strategies enhancing memory and communication yet no concrete guidelines for clinical practice. A need for such training has long been felt for the caregivers. Though it may not have much impact on the actual process but it helps them deal better with the situation at hand and hence decrease caregiving burden.

CONCLUSION

Collectively the findings show equivocal benefits of educating and training in communication strategies with increased successful interactions and hence decrease in caregivers' burden. It even makes time of self care and ADLs be less of a struggle. Yet, many a questions still remains unanswered like specific caregivers population which can optimally benefit from these programs, mode of delivery, duration of follow up etc. It is crucial to direct future researches at quality programs which are low cost, comprehensive and also has consideration for individualised family/professional needs. Also given the different socio- cultural context of India adaptation of such programs is very much needed

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- How to cite this article: Ojha GJ, Moharana S. Strategies to improve communication during ADLs in dementia: a short review. *International Journal of Science & Healthcare Research*. 2020; 5(3): 286-291.
