

ORIGINAL ARTICLES

Communication and burden in dementia care

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ABSTRACT

This paper provides an integrated discussion of the literature that addresses the effect of communication strategies on dementia care and caregiver burden. With the complexity and multiple symptoms associated with dementia, caregivers are exposed to increased burden which can affect their own health and wellbeing. Communication has been found to be a key to reducing burden and improving the quality of life for the person with dementia (PWD) and their caregiver. The literature review examines current and previous literature in order to acknowledge and synthesize the existing work done, and to identify areas for future research. The material was drawn from three databases; the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed and PsycINFO. The literature search was restricted to relevant studies published in English and available through electronic sources between 2000 and 2017. The search yielded 22 studies. Fourteen studies met the inclusion criteria. These studies focused on the use of communication strategies within the context of caregiver burden in dementia care. The qualitative and quantitative studies addressed verbal and nonverbal techniques used to guide caregivers in their communication with PWD and to decrease caregiver burden. The results of the review illustrate the importance of using effective communication techniques for PWD. It shows that using specific strategies improves relationships between caregivers and PWD and effective communication techniques reduce caregiver burden. The importance and significance of these findings indicate the need for further research in the effects that communication have on dementia and caregiver burden.

Key Words: Dementia, Caregiver burden, Communication strategies

1. INTRODUCTION

Effective communication is vital to the wellbeing of persons with dementia. Poor communication skills can lead to miscommunication, misunderstanding and unmet needs. These, in turn, can lead to undue strain on the caregivers of PWD.^[1] Successful communication, on the other hand, can help relieve the burden that caregivers of PWD have to deal with. This paper reviews and discusses the literature that connects the concepts of dementia, communication and caregiver burden. Communication strategies derived from the literature seek to improve dementia care. The challenges

that caregivers experience and the communication strategies used to assist them are explored. It is proposed that effective communication strategies can reduce misunderstandings and ambiguous situations that lead to problem behaviours which are a precursor to caregiver burden.^[2-4]

As adults age, their risk for developing dementia increases. More than 13 percent of the world's population will be over the age of 60 by the year 2020. This age cohort will represent over 20 percent of the world's population by the year 2050.^[5] In conjunction the global prevalence of dementia also will increase. Presently there are more than 35.6 million people

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living with dementia. This figure is expected to double every 20 years to about 65.7 million by 2030.^[6,7]

As people live longer in Canada the incidence of dementia will increase. In 2001 one in eight Canadians were 65 years old or over. By 2026 one in five will be over 65 years of age.^[8] The increase in the population of older adults in Canada and worldwide will have an impact on PWD and their caregivers. It is projected there will be an increase in Canada from 103,700 persons with new cases of dementia in 2008 to a total increase of 257,800 in 2038. The prevalence of PWD in 2008 in Canada was 480,600. It is projected it will grow to 1,125,200 by 2038 making up 2.8 percent of the population of Canada.^[9] In Canada and worldwide this issue is garnering increased attention and has been described as a growing tsunami.

1.1 Dementia and communication

Dementia is a syndrome that results from alterations in the physical structures of the brain associated with mental abilities. The most prominent symptoms of dementia are cognitive deficits, including memory problems and disturbances in executive functioning. Cognitive deficits in dementia often are severe enough to affect the individual's everyday functioning.^[9,10]

The most common type of dementia is Alzheimer's disease (AD) which accounts for approximately 64 percent of Canadians diagnosed with dementia.^[10,11] AD has a gradual onset with the continuous decline of cognitive, memory and communication. As AD progresses communication and memory deficits become more prominent while cognitive declines manifest as problems with executive function.^[9,10] Executive function relates to problem solving, critical thinking, planning activities, judgement decisions and other goal-oriented activities. Another type of dementia called vascular dementia has a step-wise deterioration associated with transient ischemic attacks. Lapses in cognitive abilities are followed by periods of stability.^[12,13] Vascular dementia accounts for approximately 20 to 30 percent of all dementia types.^[13] Another common form of dementia includes mixed dementia which accounts for approximately 24 to 28 percent of the cases.^[14] Mixed dementia consists of both AD and vascular dementia. Frontotemporal lobe dementia (FTD) is linked primarily to the frontal and temporal lobes which are responsible for personality, behaviour and language. FTD accounts for approximately 10 to 20 percent of all dementia types.^[15] A common feature among all types of dementia is a decline in the ability to communicate. Communication problems can lead to an increase in caregiver burden and a lower quality of life for the PWD. In fact, PWD are more likely to be placed in an institution or die prematurely as a result of unmet needs

sometimes linked to communication problems.^[16,17]

The communication problems of PWD can go undetected during the early onset of the disease, but as the dementia progresses word retrieval, staying on the conversational topic and other language functions become more prominent.^[18-20] The communication problems become worse in the middle stages and there can be complete incoherence in the later stages of the disease.^[21] Communication interactions involve both the PWD and caregiver. A breakdown can ensue when the PWD loses abilities such as word finding or not understanding various words. This coupled with the caregiver not being able to make changes which are necessary to support these symptoms leads to communication breakdown, frustration and burden.

Problem behaviours and communication

Authors have used the terms "problem behaviours" and "challenging behaviours" to describe characteristics exhibited by PWD such as agitation, wandering and aggressiveness.^[22] Another term used is "responsive behaviours"^[23] because the behaviours reflect a response due to something unpleasant or frustrating situation. The three terms are similar in meaning and may arise due to the unmet needs associated with the communication challenges of the PWD.^[1,17,24]

Caregivers often enter the role of caring for PWD without fully understanding the consequences of ineffective communication which are linked to problem behaviours. Goldberg^[25] pointed out that problem behaviours exist among PWD who live in the community as well as among those who live in institutions. The prevalence and characteristics of the behaviours differ for each of the three clinical stages of dementia (i.e., early/mild, middle/moderate, and late/severe) and exhibit different symptoms in the presence of underlying comorbidities. It is unknown how PWD adapt or respond to the changes in the disease. For example, psychotic symptoms include paranoid delusions or visual hallucinations. These symptoms combined with the PWD inability to communicate can increase anxiety and lead to problem behaviours. Effective communication can be used as a mediator to minimize problem behaviours. Savundranayagam et al.^[26] demonstrated significant correlations among communication problems and three types of caregiver burden (i.e., objective, demand and stress) suggesting that ineffective communication was related to problem behaviours and increased burden.

1.2 Caregivers

There are different types of caregivers for PWD. These include informal caregivers such as family members or friends who are not paid for their services.^[27-29] Professional care-

givers are paid to care for those living with the illness or who volunteer their time and expertise. In Canada approximately 70 percent of PWD are cared for by informal caregivers.^[11] Family caregivers consist mainly of spouses, daughters and daughters-in-laws.^[29,32] To care for their loved ones, informal caregivers often leave familiar and rewarding roles or occupations. This shows how dementia can tremendously impact family members of PWD.^[3,31] They experience feelings of frustration and stress. Studies show caregivers to PWD are prone to more co-morbidities, such as depression and decreased physical health, than those caring for individuals with other chronic diseases.^[29,32]

Ory et al.^[30] documented differences in the nature of care between caregivers who looked after those with dementia versus those who looked after individuals without dementia. The authors examined over 1,500 cases from a 1996 National Caregiver Survey Registry. The data included descriptions of the caregivers, the impact of strain and family conflict, the hours spent on care, the effects on employment, service utilization and whether they were caring for someone with dementia. Results indicated that caregiving produces greater negative effects on those looking after PWD than those looking after relatives who are ill with other diseases. This finding was evident in terms of hours spent in assisting, employment issues, mental and physical health problems, time for leisure with other family members and family conflict. Another reason contributing to the added strain was behavioural problems such as wandering and screaming. Ory et al.^[30] noted that the unpredictable behaviours of PWD play a significant part in the added distress and burden of the caregiver and the entire family. The study found these caregivers were more inclined to use formal assistance such as home care services.

1.3 Caregiver burden

Caregiver burden is defined as the emotional strain and physical stress that occurs when caring for another person.^[33,34] The term burden refers to the emotional, psychological and social costs of caregiving. Burden also impinges on the caregiver's quality of life.^[35,36] Caregiver burden can be conceptualized in three dimensions (a) subjective demand burden; (b) subjective stress burden; (c) objective burden.^[37] These dimensions distinguish the different experiences of caregivers. Subjective demand burden refers to how the caregiver feels when the PWD is being manipulative or intentionally disturbing. Subjective stress burden refers to the caregiver's emotional strain of having to look after the individual. Objective burden denotes the extra time spent with the individual and the time lost from the caregiver's own interests.^[37] The three dimensions of burden are linked via

communication and problem behaviours. Savundranayagam et al.^[26] showed that difficulties with communication deficits simultaneously impact problem behaviours on the different dimensions of burden. There were links among dementia, declining communication skills and three different types of caregiver burden (demand, stress and objective burden).

1.4 Statement of the problem

Researchers studying communication with PWD have identified the need for effective communication interventions in dementia care. Before they can develop effective interventions, researchers have to acknowledge the link between communication strategies and caregiver burden. Current published research findings show that PWD experience specific changes in the cognition and memory centres of the brain dealing with communication.^[38-40] There is little empirical evidence, however, that links the concepts of dementia, caregivers and declining communication skills with caregiver burden. By linking these concepts researchers can study the effects associated with communication skills and caregiver burden that can lead to effective communication strategies.

The purpose of this paper is to provide a critical analysis of the relevant literature on the topic of dementia and communication and to discuss the links among effective communication, dementia care and caregiver burden. The following research question guided the review: "Does effective communication in dementia care reduce caregiver burden?". Two sub questions related to this over-arching question are (a) "Is there a link between communication and caregiver burden in the different types of caregivers of PWD?" and, (b) "Can education and training programs designed to improve communication strategies reduce caregiver burden?"

2. METHOD

2.1 Search strategies

Literature searches were conducted July 2017 using CINAHL, PubMed, and PsycINFO databases. These databases were chosen because they contain citations for biomedical, life science, behavioural science and mental health literature relevant to this topic. Medical, nursing and allied health disciplines were represented to reflect a multidisciplinary approach in literature. The literature search was restricted to relevant studies published in English and available through electronic sources between 2000 and 2017 to capture the more recent and up-to-date information about this topic.

2.2 Search outcomes

The terms used in the search were dementia, communication strategies, and caregiver burden. These are common key words used by researchers who conduct and publish find-

ings in the area of communication, caregivers and dementia. This search yielded 22 different publications. The quantitative and qualitative research studies included descriptive, correlational and experimental designs.

2.3 Inclusion and exclusion criteria

Fourteen of the 22 articles were included because the published results establish whether there were links among dementia, communication and caregiver burden. Five articles did not meet the criteria because they included pharmacological treatments that are not within the scope of this paper. One article dealt with spiritual issues which also did not correspond to the objective of this paper. Two were literature reviews, and two focused on geriatric hospital units as illustrated in Figure 1. The participants were PWD and caregivers. The interventions had a communication component and had single or multiple interventions. Outcome measures often included non-standardized but objective measures of communication and objective measures of caregiver burden.

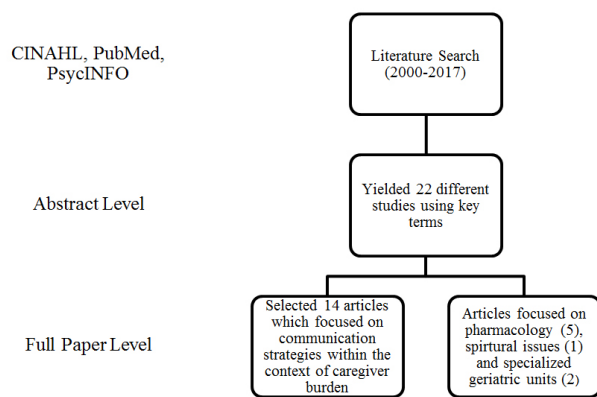


Figure 1. Literature search process
The literature search yielded 22 articles at the abstract level where key terms were present in the abstracts of the articles. Fourteen articles met the inclusion criteria at the full paper level and six articles were excluded.

3. RESULTS

The sub questions addressed whether there is a link between communication and dementia caregiver burden, and whether education and training programs based on effective communication strategies can improve caregiver burden. The links between communication and dementia caregiver burden were established in the studies on the effects of dementia in general. The education and training programs were also addressed in the studies which dealt with specific interventions and outcomes, such as giving one instruction at a time to determine whether the message was or was not conveyed (see Table 1). The different terms used in the descriptions reflect the study’s language. For example paid caregivers were

also called professional caregivers, and problem behaviours were also referred to as responsive behaviours. The PWD term was used to describe those participants who showed any form of dementia.

Barnes^[42] conducted a descriptive correlational study by using a questionnaire based on measures for appraisal of effective communication. Relatives of PWD appraised their communication strategies on caregiver burden. Two hundred and thirty-nine participants were administered questionnaires assessing family perceptions of communication behaviours, communication strategies, problem behaviours and caregiver burden. Building on the current view that communication is affected by dementia, the authors linked communication problems with aberrant behaviours. They stated these problems can arise due to miscommunication; for example, the difficulties of word finding to express the wishes of PWD. The idea that PWD still desired interaction throughout the course of their disease guided their study. The authors investigated four objectives:

- (1) The relationship between frequency of dementia-related communication behaviours and caregivers’ appraisals of frustration.
- (2) The relationship between caregivers’ use of communication strategies and appraisals of helpfulness.
- (3) The structural relationships between communication behaviour appraisal, problem behaviours, and caregiver burden.
- (4) Caregiver education level as a moderating variable of the final structural model.

The results showed that there was a correlation between frequency and appraised frustration of the relatives’ communication behaviours. Failure to retain instructions and repeated questions/comments were the two behaviours rated highest for both frequency and frustration. Frequency of use and appraised helpfulness of the caregivers’ communication strategies were also correlated. Paying attention/actively listening and asking one question/giving one instruction at a time were the two strategies rated highest for both use and helpfulness. Caregivers’ education level did not have an effect on moderating the relationship and caregivers’ appraisals of communication strategies did not predict problem behaviours or caregiver burden.

Small et al.^[53] investigated the effectiveness of communication strategies used by family caregivers of PWD. The authors focused on the caregivers and their management of communication breakdown. They examined this relationship using a social interactive theoretic framework concerned with the relationship of the spousal caregiver and the PWD. Small et al.^[53] reviewed literature with suggested effective

strategies to compensate for the decline in communication abilities of PWD. One objective of their study, relevant to the purpose of this comprehensive paper, was to illustrate the empirical value attached to strategies already used to improve communication and to provide practical examples to manage communication breakdowns.

Table 1. Studies addressing the link between dementia, communication and caregiver burden along with strategies to decrease burden

Reference	Objective(s)	Research design (Number of participants)	Result
Barnes ^[42]	To explore family caregivers' perceptions of communication behaviors and strategies in relationships to caregiver burden	Quantitative cross-sectional study using questionnaires (N = 239)	Failure to retain instructions and repeated questions/comments rated high for frequency and frustration Pay attention/actively listen and ask one question/give one instruction at a time rated highest for use and helpfulness Problem behaviors partially mediated the relationship between communication behavior and caregiver burden
Basnyat & Chang ^[43]	To investigate the impact of having hired support on coping and caregiver burden.	Qualitative cross-sectional study using in-depth interviews (N = 24)	Hired support can assist with coping and caregiver burnout
Gitlin et al. ^[44]	To evaluate the ACT intervention on managing distressing behaviours with PWD	Quantitative two-group randomized trial (N = 272)	The ACT intervention can improve problem behavior, reduce upset and improve confidence in managing behaviour
Haberstroh et al. ^[45]	To evaluate the TANDEM communication intervention training program on burden and quality of life	Quantitative control group using pretest-posttest and time series analysis (N = 22)	TANDEM training can improve communication and quality of life
Hepburn et al. ^[46]	To examine the views of caregiving by spouses of PWD	Qualitative comparative analysis using open-ended interviews (N = 132)	Showed that wives of PWD have increased levels of distress than husbands
Kurz et al. ^[47]	To examine an internet-based resource for caregivers of people with early onset dementia	Randomized unblinded control pilot study (N = 60)	Developed a resource to assist younger persons with dementia
Liddle et al. ^[48]	To investigate the effectiveness of a DVD-based training program on caregiver experience and the well-being of the PWD	Quantitative randomized control trial using pretest-posttest (N = 29)	DVD training provided increased knowledge and contributed to reduced disruptive behaviours and increased positive aspects of caregiving
Macleod et al. ^[49]	To examine the barriers and facilitators of services among family caregivers of PWD	Qualitative descriptive study using semi-structured interviews and thematic analysis (N = 24)	Main barriers include finding information about services/support, mistrust of the services, the inflexibility of services, caregivers' beliefs regarding obligations to their caregiving role and resistance by the PWD Key facilitators include having good communication and beliefs about the caregiving role
Mamo et al. ^[50]	To test a hearing intervention for PWD and their family caregivers	Quantitative longitudinal randomized control study (N = 20)	Improved communication may reduce caregiver burden and improve quality of life
Prick et al. ^[51]	To evaluate a multi-component dyadic intervention on the mental and physical health of PWD and their family caregivers	Quantitative longitudinal randomized trial using pretest-posttest (N = 111)	Multi-component intervention showed to be effective on the mental and physical health of PWD and their family caregivers
Riedijk et al. ^[52]	To examine caregiver burden and the quality of the partner relation in frontotemporal dementia	Quantitative longitudinal study using questionnaires and structured interviews (N = 63)	Caregiver burden decreased Coping and social support changed unfavorably
Small et al. ^[53]	To investigate the effectiveness of 10 frequently recommended communication strategies	Self-report questionnaire	Validated effectiveness of communication strategies
Smith et al. ^[54]	To develop RECAPS (for memory) and MESSAGE (for communication) program for everyday use by caregivers	Used a knowledge-translation framework to guide work	Information and strategies can be given caregivers to help optimize remaining memory and communication skills
Watson et al. ^[55]	To address the complex relationships among communication problems in dementia, the burdens suffered by family caregivers, and the effects of communication education and training programs designed to enhance communication and to minimize caregiver burden	Qualitative descriptive study	To reduce caregiver burden, clinicians must provide education and training to caregivers

In this cross-sectional study caregivers were assessed on ten most frequently used strategies ranging from eliminating distractions, to speaking slowly, to asking close-ended questions (yes/no questions). Eighteen spousal dyads recruited from an AD clinic participated in the study. The researchers gathered data using self-report questionnaires and audio-recorded interactions and analyzed the frequency of communication breakdowns. One objective was to learn which strategies improved communication and social interaction. The findings showed that some strategies were effective and some were ineffective. Fewer breakdowns occurred when distractions were eliminated, when the caregiver spoke in simple sentences and when closed-ended yes/no questions were used. The authors noted that the communication process is complex and has to take multiple factors into consideration. For example, approaching the PWD slowly with eye contact was effective but using slow speech was not. The significance and implications of the findings from Small et al.^[53] are that while some communication strategies are effective, others can be problematic. Only through research can one distinguish the relevant strategies to use.

A study linking caregiver burden and communication was conducted by Riedijk et al.^[52] The authors of this prospective study examined the change in degree of caregiver burden and quality of life. This two-year study began with 63 informal caregivers of individuals with FTD. PWD and caregivers were assessed at baseline and after 24 months using a questionnaire and structured interview. Between baseline and follow-up, three semi-structured telephone interviews took place at 6-month, 12-month and 18-month intervals. Caregivers and PWD were assessed for characteristics such as behavioural problems, caregiver burden, quality of life, coping strategies and relationship quality. Measures used for assessment included the Neuropsychiatric Inventory^[56] which assessed behavioural problems. Other measures included the Revised Symptom Checklist^[57] and the Global Deterioration Scale^[58] to assess the severity of dementia. The results showed that caregiver burden decreased and psychological well-being remained at about the same levels throughout the two year testing period. There was no overall significant change in the quality of the relationship, however, communication was dramatically reduced indicating a decrease in ability to exchange ideas and to keep the PWD engaged. Communication was measured as part of one of the domains in the relationship quality measure of the University of Southern California Longitudinal Study of Three-Generation Families.^[59] Caregivers were asked questions relating to how effective their communication was with PWD and how well were ideas exchanged. All 63 dyads also completed the Neuropsychiatric Inventory^[56] which assessed behavioural

problems. By the 24-month follow-up period, only 31 participants had completed the NPI while the other participants left the study. The authors reported that persons who left the study prior to completion had higher levels of behavioural problems at baseline than those who remained in the study. Consequently, their caregivers felt an increase in burden. The authors went a step further and compared overall caregiver burden for PWD living at home, in a nursing home and those who had died. They found that for caregivers living at home the burden increased after 24-months. It decreased for caregivers of PWD living in the nursing home and of PWD who died. The authors found that extra support was needed when caring for PWD.

The studies also supported the second sub question. They mostly showed a decrease in caregiver burden due to interventions of education and training programs which led to effective communication strategies. The study conducted by Gitlin et al.^[44] provides a communication education and training program to reduce caregiver burden. The authors of this longitudinal randomized controlled trial assessed interventions that targeted problem behaviours, caregiver upset and the management of confidence. Secondary outcomes included caregiver well-being, management skills and perceived benefits. The authors associated caregiver burden with problem behaviours. The intervention called the Advanced Caregiver Training (ACT) was designed to target problem behaviours of PWD and to provide caregivers with effective strategies to manage the symptoms that could be contributing to the behaviours. The investigators hypothesized that the caregiver and PWD dyads enrolled in the ACT program would experience the targeted problem behaviours and associated caregiver upset less frequently than a control group. In addition, the authors hypothesized that the intervention group would have greater caregiver confidence, well-being and enhanced skills after the 16-week intervention. The authors sought to identify triggers, such as communication factors, and to teach caregivers strategies to contain the triggers and to reduce burden. Two hundred and seventy-two informal caregiver and PWD dyads participated. The dyads were randomized into ACT caregiver treatment group or to a no-treatment control group. Assessment was done at baseline, 16 weeks and 24 weeks. The ACT intervention was based on three domains that conceptualized problem behaviours as a consequence of interacting factors:

- (1) Patient based (unmet needs, pain, comorbidities).
- (2) Caregiver based (stress, communication).
- (3) Environment based (clutter, hazards).

The purpose of the ACT intervention was to identify the potential problem behaviour triggers and to prevent, reduce, or

eliminate the problem behaviours. The authors' motivation was to improve care to the PWD and to decrease burden. The 16-week intervention consisted of one in-home teaching session, one telephone training session and three brief telephone contacts to reinforce learned strategies. Occupational therapists and registered nurses facilitated the sessions. A program goal was to get away from automatically resorting to a pharmacological medical treatment model and to move toward a less intrusive intervention; for example, using communication strategies such as eliminating distractions, making eye contact, repeating key words and keeping sentences short and clear. The results showed a reduction in problem behaviours after the 16-week program and improved confidence in the management of behaviour. Caregivers reported less negative communication, reduced burden and better well-being. Similar outcomes occurred at 24-weeks. The significance and importance of the ACT intervention is that it proved to be an effective intervention for caregivers of PWD that incorporated communication strategies as well as other non-pharmacological strategies.

Similar to Gitlin's study, Haberstroh et al.^[45] developed and evaluated a communication training program for informal caregivers of PWD. Their program focused on enhancing the quality of life of PWD and reducing caregiver burden through an effective communication teaching program. The program was comprised of a randomized control trial with twenty-four informal caregivers. It consisted of five, two- and one half-hour weekly sessions. The authors in this article hypothesized:

- (1) Caregivers would report strategy use more frequently after completing the TANDEM intervention.
- (2) Caregivers who completed the TANDEM would report a reduced caregiver burden and an increased quality of life.

The authors used the TANDEM communication model^[60] as the framework to guide the training. The TANDEM Model intervention techniques focused on improving communication skills and supporting the remaining communication skills of PWD. It is a communication model by which the sender and receiver continually switch roles. Information transmission is divided into four steps (presentation, attention, comprehension, remembering). Communication strategies are attached to each step in order to meet the needs of the PWD according to her/his clinical stage. A pre-test and post-test measure was used to evaluate the effects of the intervention. Interrupted time-series analyses were conducted. These analyses involved filling out a diary each day for five weeks. The data from the first week were collected prior to the intervention and used as a baseline to compare with the data from the

following weeks. The study measures included 4-point Likert scales for caregivers' mood, frequency of strategy use and caregiver burden. The care receivers' quality of life was measured using a pre-post proxy report provided by their caregivers. The findings showed there were an increase in the use of the strategies taught and a significant improvement in the quality of life of PWD in the treatment group compared to the control group. Burden was not significantly reduced. The authors suggested another burden measure may have been more appropriate. The one they used was very general and not geared particularly to dementia. Although burden did not decrease significantly, this study supported the use of effective communication strategies to improve the quality of life for PWD.

In another study included in this review, Smith et al.^[54] developed a teaching DVD in order to assist caregivers to support memory and communication for PWD. The rationale for their work came from earlier reports that declining memory and communication skills can lead to behavioural problems which can result in increased levels of caregiver stress and burden and a decrease in the quality of life.^[61] The project team was comprised of researchers, clinicians and psychogeriatric educators. They sought to structure an educational tool according to the research findings to show that declining memory, cognition and communication in dementia were the areas of greatest concern. They included strategies to enhance memory and communication from the literature as part of the training.

The purpose of developing an educational DVD was to deliver a product not only to teach communication and memory strategies to PWD, but also to bridge the gap between the external researcher providing recommendations and the caregiver implementing them while caring for PWD. A knowledge translation framework was used to utilize the existing literature and mold it into a practical tool. The outcome of the project was the development of a versatile memory and communication teaching aid for informal and professional caregivers. A study using this caregiver education program revealed significant improved knowledge of strategies to support communication between caregivers in a nursing home and PWD. There were also higher levels of caregiver satisfaction.^[62]

4. DISCUSSION

The aim of this paper was to answer the research question, "Does effective communication in dementia care reduce caregiver burden?" There were also two sub questions. The first was whether there is a link between communication and caregiver burden in different types of caregivers of PWD, and the second was whether education and training programs

designed to improve communication strategies can reduce caregiver burden. The following discussion focuses on the understanding of the importance of effective communication in caring for PWD to reduce caregiver burden. Communication is critical in our daily lives. Messages that are sent to each other have great impact, however the changing abilities associated with dementia can make communication increasingly difficult. Education and awareness about the importance of this topic is vital to prevent burden as well as to promote caregiver self-esteem and quality of life. A caregiver is under enormous pressure to understand the needs of the PWD and to provide care. This role is challenging and puts heavy demands on coping strategies to deal with the unpredictable dementia behaviours. The role requires patience, discipline and effective communication skills.

The studies reviewed in this paper included both qualitative and quantitative designs and methods to evaluate the connections among dementia, communication and caregiver burden. The studies provided empirical data which indicate the relationship between the three concepts; dementia, eroding communication skills and caregiver burden. Only the Riedyk et al.^[52] study did not support the link between communication and caregiver burden. The authors suggested, that as long as the levels of symptoms remained stable, the caregivers were able to adapt to the changing behaviours. However, the researchers confirmed that effective communication declined as the dementia progressed and this made the relationships less cohesive. Recognizing the different types of dementia and their etiology, education programs can be designed and evaluated according to the goals of communication and how effective information is conveyed. For example, if transferring information is the goal, a person in the early stages of AD would require different techniques than a person in the later stages of the disease, such as using more non-verbal cues. In the later stages the meaning of words become more difficult to comprehend.

Most studies reviewed showed that effective communication techniques had an effect on behavioural symptoms and resulted in reduced caregiver burden. Gitlin et al.^[44] made the argument that using communication based non-pharmacology intervention methods with PWD can reduce their problem behaviours. Their ACT program was tested with professional caregivers. Ripich's^[63] FOCUS program revealed similar results while outlining benefits such as improved attitudes and increased knowledge of PWD. The Haberstroh et al.^[45] study showed effective communication strategies on the quality of life of PWD. The teaching aids developed by Smith et al.^[54] showed a communication and memory based program can benefit all caregivers. Smith et al.^[54] also pointed out that more novel ways of teaching

caregivers could be beneficial. They developed a DVD that is assessable to caregivers. A secondary unforeseen outcome from the literature showed an improved quality of life for the caregivers. Preserving self-identity with the PWD is an important communication goal as their dependence increase. Only Prick et al.^[51] did not show any benefits with their interventions tested. The authors felt that this may due to the translation and adaptation of the intervention. Future research will need to address the different strategies and their effect.

As noted throughout the paper, communication based interventions were developed to reduce the impact of dementia symptoms and to reduce caregiver burden. Most communication intervention studies reviewed in this paper focused on reducing behavioural problems in PWD and improving the quality of life for caregivers. Communication interventions ranged from audio recorded and observed interactions to in-depth education and training. They were presented in formats that ranged from lectures and workshops to self-learning videos and were mostly successful in achieving the goals of the program. However, several important design and methodological shortcomings need to be mentioned which should be corrected in order to move forward in future research. Considerations for stronger future research should take into account (a) the follow-up evaluation phase of the education and training program; (b) interprofessional education (IPE); (c) the range of caregivers' learning needs based on different types of dementia.

Follow-up assessments of education and training programs need to be conducted in future research to see whether interventions have a long term effect. Haberstroh et al.^[45] conducted their study using a pretest-posttest design but did not have a follow-up evaluation phase. The authors compared groups of participants at only two particular points in time. A pretest-posttest design measures the change due to the dependent variable, in this case, the effects of a communication education and training program. The Tandem program, developed and tested by Haberstroh et al.^[45] was successful because the caregivers' use of communication strategies improved the quality of life of the PWD. However, caregiver burden did not decrease significantly in comparison to the control group. A follow-up assessment at a later point could provide evidence to determine whether the TANDEM program has a continuous impact. Ducharme et al.^[64] suggest a 3 to 6 month follow-up assessment to evaluate the sustained impact of the intervention and to discover any delay effects after the implementation stage such as changes that did not occur during the intervention but rather show up later after the intervention phase. Dementia is a degenerative disease where symptoms progressively worsen. A follow-up

assessment can capture delay effects that take place due to the progressive nature of the disease.

A second consideration for future research should include interprofessional education (IPE) approaches when teaching communication and other dementia care strategies. Different types of caregivers and multidisciplinary team members work together to deliver holistic care to PWD. Callahan et al.^[65] showed that collaborative care for PWD is effective in improving the quality of life for PWD and their caregivers. The multidisciplinary team collaborated in the care of the PWD. Behavioural and psychological symptoms improved as a result of collaborative care management.

Lastly, future research should acknowledge and take into consideration that effective communication strategies need to be studied in the context of different kinds of dementia. Riedyk et al.^[52] examined persons with FTD. Their study produced different results from other intervention studies that included participants with other types of dementia such as AD. FTD is characterized by changes in mood and personality. There is an early decline of emotion and social conduct, such as a decline in manners and inappropriate social, physical and sexual behavior.^[66] There is more disinhibition and a decline in language skills in persons with FTD.^[10,67] Riedyk et al.^[52] found that caregiver burden decreased with the FTD type over time whereas well-being did not change. The researchers suggested caregivers became accustomed to the behavior with FTD. Therefore, they ranked the burden as decreasing. Communication skills deteriorate dramatically with FTD. Moreover, FTD diagnosis can be linked to other debilitating diseases such as amyotrophic lateral sclerosis.^[68] This complexity of FTD illustrates the need for education and training programs which include communication strategies to target the different forms of dementias.

Collectively these studies provide findings to improve caregiver burden through measured education programs. No longer can the burden associated with dementia be dismissed. These studies illustrate the need for structured education programs focused on decreasing caregiver burden. There are multiple factors to consider when conducting research on the effects of education and training programs on caregiver burden for PWD and their caregivers. These should include types of dementia, design of the study and IPE. As researchers take these factors into consideration, the closer they will get in determining effective communication strategies which can reduce problem behaviours and caregiver burden. Taking into consideration follow up evaluations, IPE and the different types of dementia becomes increasingly important in future research as dementia continues to rise and reshape the social and economic makeup of hospitals and communities.

5. CONCLUSION

This literature review strongly suggests that there is a relationship among dementia, communication and caregiver burden. Dementia and ineffective communication result in multiple consequences adding to caregiver burden. Symptoms manifested by dementia mark the need to find practical ways to improve communication with PWD. By learning effective communication strategies, caregivers can improve interactions with PWD and lower the problem behaviours which, if unaddressed, can result in unmanageable caregiver burden. Empirically tested interventions have shown success in improving the relationship and quality of life for both caregivers and PWD.

CONFLICTS OF INTEREST DISCLOSURE

The author declares no conflicts of interests.

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