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Validation Therapy: Restoring communication between persons with Alzheimer's disease and their families

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Abstract

There are millions of families who are faced with the pains of Alzheimer's disease (AD) every day. One of the most salient and pervasive issues they encounter is related to their loved ones' decline in communication. As a person progresses through AD, their ability to communicate deteriorates. This paper offers the use of Validation Therapy (VT) as a tool for meaningful communication for families and persons with AD. The principles and techniques of VT are presented. A case study employing the use of VT between a man with AD and his daughter demonstrates the process of VT between family members. The benefits that VT holds for families specifically is explored. This paper emphasizes the need for families to be informed of options and of alternatives to standard communication and supports VT as a viable tool.

Introduction

Family members of persons with Alzheimer's disease (AD) or a related dementia often find themselves trying to overcome numerous losses. Families are faced with emotional, practical, financial, and ethical issues. AD has frequently been called a family disease, in that the family often has a more difficult time adjusting to the changes the disease brings than the person with AD. Families experience losses due to the cognitive, social, and physical decline of their loved one. The majority of persons with the diagnosis of AD are cared for by family members. It is estimated that every person with some form of dementia, most commonly AD, has an average of 1.5 family members who provide some sort of regular care.¹ This can be translated into an excess of six million caregivers in the United States. These caregivers

frequently cite communication as one of the most difficult issues they face in their caregiving duties.² The inability to communicate effectively can be both practically and emotionally challenging.

Communication encompasses verbal, nonverbal, and behavioral components. The behavioral symptoms that persons with AD may display are frequently tied to the inability to communicate their needs effectively. Therefore, communication refers not only to conversation but any attempt to interact by or with a person with AD. In some way, all interaction is expressing feelings, thoughts, or needs of families or of individuals with AD.

Validation Therapy (VT) is a form of communication that attempts to reopen communicative pathways between families and their loved ones with AD. It is often the case that little emphasis is placed on helping families maintain a meaningful relationship with their loved one with AD.³ VT serves as a tool for families that allows for an understanding of the behavior and communication of their loved ones. VT also offers an alternate view to inappropriate behaviors and communication. VT follows the belief that the behavior of persons with dementia are need-driven.⁴ Families who use this framework are better able to understand the communication of their loved ones with AD and thus form a rewarding relationship. Health care providers must help families address the challenges surrounding AD, not only on a surface level through support groups, respite care, and the use of chemical interventions, but through education of families in communicative techniques. Families must be given options that will help them strengthen their relationship with their loved ones with AD, not simply interventions that avoid interaction.

The behaviors that persons with AD exhibit as the disease progresses are frequently misunderstood. This paper stresses the need to offer families assistance in finding meaning in their loved ones' communication. Families able to decipher the communication of their loved ones may find that their relationship with the person with AD

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will improve. Improved communication may result in an increased quality of both the practical and emotional components of family relationships. The utilization of VT should be broadened to include not only health care professionals but also families faced with the realities of AD.

Communication in early, middle, and late stage AD

One of the most pervasive issues facing the nearly four million⁵ persons with AD is the inability to communicate effectively. As a person progresses through the stages of AD, the ability to communicate deteriorates. Families may find themselves struggling to make sense of their loved ones. This breakdown in communication affects both the emotional and practical aspects of the relationship. Families need to be aware of the expected communication difficulties they will face as the disease progresses and communicative abilities diminish throughout the course of the disease.⁶

In early stages, communication difficulties are related to short-term memory loss, reduced attention span and concentration, and a general inability to take in information. People with AD will often have difficulty finding words to explain something, have impaired abilities to comprehend conversation, repeat the same words, and have trouble reading and writing.⁷ A person in the early stages of AD is frequently aware of their communication problems. They may attempt to cover up the difficulties, ignore them, or acknowledge them.

As the disease progresses to the middle stages, the communication difficulties become more visible to the person with AD and to the family. Often it is at this stage that a person with AD engages in repetitive questioning and statements that make little sense to family members. The person with AD will also suffer from increased difficulty finding and using words, declined verbal communication, and difficulty maintaining conversation—and will retreat from social interaction when speaking is required.⁷

When a person has reached the end stages of AD, verbal and emotional communication are often nonexistent. Many studies suggest that a person in the late stages of AD retains only residual knowledge about the past, a time when life made sense.⁸ The late stages of AD will bring about an absence of communication of needs, scarce verbal comprehension, frequent babbling, and verbal expressions that are limited to a few words.⁷

The family

As previously stated, families provide the majority of care for loved ones with AD. A recent survey by the Alzheimer's Association reported that familial caregivers

spend up to 100 hours a week providing active care.⁹ In a study of family members who care for persons with AD, 87 percent reported chronic depression, fatigue, family conflict, and anger.¹⁰ In examining the degree of emotional, physical, and financial strain weathered by caregivers, emotional stress was reported to be the most difficult aspect of caregiving.¹⁰ The breakdown in communication can be a very disheartening experience for loved ones of someone with AD.¹¹ Not only does the decline in understandable communication affect the patient/caregiver relationship, but it also has a correlation with other negative symptoms in the family members' everyday lives.¹⁰ Caregivers of persons with AD in middle to late stages report their attempts to communicate as "frustrating" (90 percent), "draining" (87 percent) and "painful" (87 percent).⁹

Families are at times faced with the difficult decision of moving their loved ones to a long term care facility. Many familial caregivers who place their loved ones in one of these facilities continue to visit and maintain a relationship with their family member.¹² Families often experience extreme guilt and sadness in relation to moving their loved one. It is a decision that is often lingering and the cause of frequent emotional turmoil. According to the Alzheimer's Association, families whose loved ones reside in a long term care facility are more likely to be depressed than families whose loved ones reside with them.⁹ These families continue to need support in enhancing their relationship with their loved one with AD.

As the incidence of AD continues to increase, families are saturated with health care options. There are numerous agencies that exist to help families survive the challenges they experience. However, families who feel understandably overwhelmed often state that the information they receive is inadequate. In a study by Chenoweth and Spencer, only 16 percent of familial caregivers reported receiving specific suggestions for addressing behavioral difficulties or for coping with personality changes in their loved one with AD. The research also reported that fewer than one percent of caregivers encountered a physician who arranged a family conference to discuss the disease or to answer questions and address concerns.¹ A family needs to be adequately informed of all aspects related to AD. The issues surrounding communication difficulties, along with many others, are frequently overlooked.

Validation Therapy

VT is a style of communication that deserves attention for fostering meaningful communication between persons with AD and their families. VT is a style of communication that focuses on allowing disoriented persons

to vocalize their feelings. It calls for behaviors and words of the person with AD to be treated as expressions of meaning and purpose. VT assumes that all behavior holds some meaning for the person exhibiting the behavior.¹³ Behavioral VT was developed in the 1960s by Naomi Feil, a gerontological social worker. Feil has engaged in VT with elderly persons diagnosed with AD for over 30 years. She reports that when people with Alzheimer's-type dementia are validated, they do not regress to vegetation, the final phase of AD.¹³ Feil asserts that familial loved ones need to find some way of understanding and communicating with persons with AD.¹⁴

VT is rooted in the belief that a person with AD is valuable and deserves respect. Feil established a list of six principles that demonstrate this philosophy:

- The validating caregiver never argues with or confronts the person (with AD).
- The validating caregiver does not try to give the person insight into his or her behavior.
- The validating caregiver does not try to orient the person to time or place, if the person does not wish to be oriented.
- The validating caregiver does not use positive or negative reinforcement to affect the person's behavior.
- The validating caregiver does not use individual or group therapies that require precise rules or orientation to present time.
- The validating caregiver is not an authoritative teacher, but a nurturing facilitator.¹³

Family members must understand that their loved one's messages may be communicated in a manner that has no obvious meaning to them. Caregivers must be able to internalize the belief that regardless of the person's level of disorientation, there is a logic behind all behavior.¹⁵ VT will not be successful if the family member does not abandon the idea of trying to teach the person with AD to communicate logically.

Families should be taught specific validation techniques. The ability to use these techniques will allow for increased quality communication between families and the person with AD. Some of the techniques are:

- Using nonthreatening, concrete, factual words to build trust;

- Using polarity so a person expresses feeling fully and gains a sense of relief;
- Encouraging reminiscing;
- Maintaining genuine, comfortable eye contact;
- Using a clear, soft, caring voice tone;
- Mirroring a person's emotions to gain trust;
- Identifying a person's preferred sense;
- Linking the person's behavior with the unmet human need; and
- Appropriate touching.¹³

These techniques, when used properly, have been found to aide in increased communication, and decreased likelihood of agitated or withdrawn behavior.¹⁶ In her books and videotapes, Feil describes these and other techniques in detail. She explains which techniques are appropriate for specific stages that a person with AD may progress through.

A case study

The concept of VT was explored through a case study in a Monterey, California skilled nursing facility that featured a resident with middle stage AD, Mr. H, and his daughter, Mary. Mr. H frequently displayed "inappropriate" social behavior. His behavior made little sense to people who came in contact with him. Mary often tearfully expressed that seeing him made her feel very depressed. She was considering significantly reducing her visits to see her father. The social worker at the nursing home asked Mary if she could observe Mr. H and her interaction together. Though she was apprehensive, Mary agreed to work with the social worker.

The social worker observed the two at lunch one day. Mr. H communicated in his typical fashion. Mary tried to reorient her father every time he said something that was factually incorrect. Mr. H appeared agitated and distressed when his daughter told him that what he was saying was wrong. For instance, Mr. H was resolute in expressing that he wanted to see his infant grandchildren, that he had missed work two days in a row because he was sick, and that he had no arms. Mary explained that his grandchildren were grown adults, that he had been retired for 17 years, and that he did indeed have arms. Mr. H did not falter from his stance, continuing to voice his beliefs.

The social worker interacted with Mary for the next month. The social worker taught Mary various validation techniques to try with her father and made sure Mary was comfortable with the techniques and the logic behind them. Mary was initially apprehensive to the techniques and voiced a fear in not wanting to perpetuate her father's confusion. The social worker explained to Mary that VT respects the reality of the person with AD, which may or may not be present-day reality. Mary admitted that her attempts to help her father see things through her eyes were unsuccessful.

Mary gradually began employing the various validation techniques she had learned over the past month. Mary reported that it was hard to get used to validating her father's emotions rather than arguing them. However, she was happy to report that after approximately two weeks of using VT with her father, she began to notice a marked change in his mood. She was overjoyed when she was able to make more sense out of what she had once deemed "senseless gibberish." Mary told the social worker about a time when her father said he had no arms. She explained that she made direct eye contact, used a low voice, mirrored her father's obvious concern, and said, "You have no arms?" Mr. H sat quietly. Mary stated that she took her father's hand and said, "That must be very difficult, Dad." Mr. H then said, "I just can't do it on my own anymore. I wet all over myself if they don't come." The daughter approached her father's nursing aid with this information. The aid reported that Mr. H frequently says "I have no arms" when she comes to toilet him. Mary was able to discern that her father was relating the feeling of helplessness to having no arms. She identified his unmet human need, the difficulty surrounding his loss of autonomy, by validating his words.

Mr. H also frequently spoke of being late for his job. Through the utilization of VT, Mary was able to work with her father in helping him settle the unresolved issue related to his retirement. He had retired against his will 17 years ago because of health problems. Mary fostered communication surrounding her father's work. She would say, "You don't like to be late for work, do you?" or "What do you like most about work?" Mr. H would begin to reminisce about his duties at work and how much he had enjoyed what he did. Mary complimented him on his work ethic and his dedication. A few days after Mary had her last conversation with her father about work, he never brought it up again. He had successfully resolved the issue that had always remained unfinished in his life.

Mary expressed that she now looks forward to seeing her father, and that she feels a sense of closeness with him that she has not felt in a long time. He hugs her every

time she comes to see him, something he has not done in years. She is someone who accepted him at face value, and he recognized her nonjudgemental ways. She admits that there are still instances in which she cannot figure out the meaning behind his words, yet she continues to validate him. She acknowledges that she knows he is trying to communicate and that what he expresses to her holds meaning to him. Though she may not understand it all, she recognizes the therapeutic effect of respecting her father's reality.

Validation Therapy in Skilled Nursing Facilities

VT was initially created to serve the skilled nursing facilities (SNFs) population. Its success has been demonstrated in a number of SNFs throughout the world. A SNF in Baltimore reports that residents display less unmanageable behaviors, that they sleep better at night, and that scores on standard mental tests improved in 60 percent of the residents after the implementation of VT.¹⁵ Another study of four SNFs reported reduced physical and verbally aggressive behavior in residents who received VT.^{16,17} Staff at these facilities cited increased success in their interventions to decrease problem behaviors.¹⁵

Despite the numerous cases of success, the usefulness of VT is often questioned due to the lack of controlled studies.¹⁸ Though VT is widely used in SNFs throughout the world, it has been neglected in the area of research.¹⁶ However, many studies have been done that suggest very strong positive changes in behavior and communication of residents following VT.¹⁹⁻²¹

What does VT do specifically for families?

Increasing meaningful communication

Families able to internalize the underlying principles of VT may have a better relationship with the person with AD and a better overall quality of life. It was found that families able to accept the decline in communication of the person with AD were less depressed.² The strain of attempting to resist the disorientation of the person with AD was related to increased interpersonal strains among caregivers and their loved ones.² The implementation of validation techniques requires an acceptance of loss of cognitive decline. Though other communicative modalities main goals are to slow cognitive decline, VT's main mission compliments the goal of increased meaningful communication for families. VT allows the validating caregiver to gain an understanding of deep expression and feeling from their loved one.²¹ Families may be resistant at first (as Mary was with her father), yet once the family is able to interact using validating techniques, communication can once again gain a sense of purpose.

Decreasing caregiving difficulties

The difficulties familial caregivers face can be decreased through the use of VT.¹³ Studies have shown that while using VT, a decrease in behavioral problems and an increase in communication has occurred in many SNFs.¹⁶ These decreases in behavioral difficulties could also be applicable to familial caregivers. The author is unaware of any research done examining the incidence of behavioral and communication difficulties facing in-home familial caregivers of persons with AD and the use of VT. However, one can speculate that through encouraging their loved ones to communicate, families would be able to identify their loved ones' unmet needs and thus decrease behavioral problems by generating trust and understanding. Therefore, VT has a great magnitude of practical potential related to caregivers and the difficulties they face in their daily care of their loved ones.

Families can assist people with AD in unraveling unresolved issues

Feil believes that many of the inappropriate behaviors that persons with AD exhibit are related to unresolved life issues.¹³ VT holds to the belief that failure to complete a particular life task may lead to difficulty later in life.¹³ The psychologist Erik Erikson developed life tasks that he asserts people will face at various points in their lives.¹⁷ He believed that if persons did not successfully resolve their age-related task, they would have psychological difficulty in the future when attempting to tackle new life stages. According to his theory, a person with AD who had perhaps not resolved the young adult issue of intimacy versus isolation would come upon difficulty with this issue throughout his or her life. A person who does not have AD may be able to communicate this unmet need to others, seek out help, and attempt to resolve the issue. However, the person with AD is unable to communicate their unmet need through rational conversation. It may become very difficult for a person with AD to resolve unmet needs, simply because they cannot identify and communicate them.

The person with AD must rely on others to help him or her work through an unresolved issue. Families are able to employ VF in order to help bring unmet needs to the surface and help their loved ones resolve issues, as was the case with Mary and her father's unresolved issue of early retirement.

Re-establishing an emotional relationship

VT can also serve as a catalyst for re-establishing a meaningful relationship between the person with AD

and the family. The family may be able to feel closer to the person with AD due to an increased understanding of their communicative abilities. A person with AD may also feel trust and respect from the family that they did not feel before VT was initiated. When families respond in sincere, warm, nonjudgemental ways, the person with AD will perhaps feel more understood and an emotional, close relationship has the possibility of growth.⁴ The common complaints and sadness families report are often related to the absence of an emotional, connective relationship. The declines in cognitive and physical functioning of a loved one often take focus away from emotions and emphasize the grief surrounding the losses the disease brings. Validation Therapy helps reconstruct the missing aspects that families often encounter in their relationship with the person with AD.

Responsibility of health care professionals

Address the issue of communication

Health care professionals have a responsibility to address the gap in literature surrounding communication techniques for persons with AD and their families. Literature often offers suggestions such as use small words, use one-step commands, use appropriate pitch, have little background noise, etc.²² The literature seldom expands beyond helpful communication hints to include interactive theories or frameworks. Persons with AD are not viewed in a holistic sense.¹³ Little is done to help families see their loved one as an emotional, physical, psychological, social, and spiritual being. Persons with AD are often viewed in a way that causes professionals to hunt for cures, tips, and treatments. The author found that this tendency to attack the symptoms rather than seek out humanistic interventions is saturating the literature. Health care professionals must address the person with AD, first as a person with human needs and secondly as a person with an illness.

Educate families

Health care workers have a responsibility to families. They must provide them with sufficient information in all areas related to AD. The study conducted by Chenoweth and Spencer found that no one out of 289 caregivers of persons with AD reported receiving information about helpful community resources.¹ Health care professionals must recognize the need to link families with assistance at all levels. Families need to be given options at this difficult time in their lives in order to help combat the numerous biopsychosocial issues they are confronted with when a family member has AD.

Involve the entire client system in intervention

Health care professionals need to realize that the client system includes the family and the person with AD, and that families need to be viewed as a separate entity at times. In fact, intervention with families should focus on the psychological and physical health of the family as a separate client. The family and the person with AD also need to be viewed collectively, receiving assistance that helps strengthen the family as a system. The experience of having a loved one with AD will require intervention on many levels; omitting the family from therapeutic intervention is inappropriate.

Summary

AD brings a myriad of challenges for families. Family members are faced with countless losses, fears, and hardships when a loved one suffers from AD. One of the key hurdles a family must overcome is related to communication. Family members often concentrate much of their effort on resisting their loved ones disoriented behavior rather than focusing on understanding their communication. These families are often fixed on what they can do to help slow the disease process, to help their loved one be less confused, or to redirect inappropriate behavior. Misunderstood communication is often ignored or punished. It is often found that little is done to understand the reasons for the behavior of persons with AD.

VT offers an explanation for the communication of the person with AD. It asks families of persons with AD to shed their conviction that only one reality exists for all people. A person with AD may return to a time in life when things were much clearer and a lot less frightening. The reality of the person with AD often serves as a protection from that which they can no longer understand. Acceptance is often necessary in emotionally reconnecting families with the person with AD. The restoration of meaningful communication offers numerous benefits to families. Through the use of VT, families are able to increase the quality of life not only for their loved ones, but also for themselves.

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