

Caregivers frequently struggle to manage challenging behaviours associated with dementia, often without a good understanding of why these behaviours occur. This article presents a simple framework to help build understanding as well as a systematic approach to dealing with resistance to care.

Key words: dementia, caregiver, systematic approach, understanding behaviour, resisting care

Dementia: A Systematic Approach to Understanding Behaviour

Sylvia Davidson, MSc, BSc, Dip Ger, OT Reg.(Ont.), Psychogeriatric Resource Consultant, Toronto Rehabilitation Institute, Toronto, ON.

Background

Dementia is a disease of growing concern as our society ages. The behaviours that many individuals with dementia exhibit as the disease progresses may trouble formal caregivers and family members, whether these individuals are in the community or in long-term care facilities. The challenges associated with managing these behaviours lead to caregiver frustration as well as physical and emotional exhaustion, and caregivers often turn to a physician, or a hospital emergency room, looking for solutions. Pharmacological treatment of behaviours associated with dementia may have some success, although recent research suggests that there is limited evidence to support pharmacological intervention and that there may even be an increased risk of mortality in some individuals treated with typical or atypical antipsychotics.^{1,2}

The range of nonpharmacological interventions for the management of behaviours associated with dementia is vast. Treatments include, but are not limited to, approaches based on identifying an individual's unmet needs, stress reduction, or environmental manipulation.^{3,4} A recent systematic review of nonpharmacological interventions strongly recommended that increased funding is necessary in order to more thoroughly conduct and monitor research.⁵ Once again, it would appear that the evidence for success with such approaches is inconsistent.

This article presents a simple framework to help caregivers who struggle with the challenges of dementia. The issues facing caregivers are complex and a range of relationships exist between individuals with dementia and their caregivers. A challenge for physicians and other members of the

health care team is to engage and support caregivers while offering them the assistance they seek. Research suggests that caregiver characteristics influence the behaviours of those they care for and that increasing the confidence and sense of self-efficacy of caregivers can have a positive impact on the individual with dementia.^{6,7,8} Caregivers benefit significantly from a basic understanding of why the individual they care for is doing certain things. Without this understanding, certain care approaches may be ineffective. This can complicate the relationship the caregiver has with the person with dementia, and with members of the health care team. Caregivers need to be encouraged by physicians to gather information and reflect on challenging situations. Such a process engages the caregiver in the individual's care in a meaningful way, which may also help to ease caregiver burden. Taking the time to examine a problem may lead to a strategy that is tailored to that specific problem, increasing the likelihood of the strategy's effectiveness. What follows is a framework to guide this process.

Fundamental Approach

When an individual with dementia demonstrates challenging behaviour, resists attempts at care, and becomes aggressive, the tendency is for caregivers to seek a quick fix. Physicians are aware that the system can rarely offer that quick fix and caregivers are frustrated by this perceived lack of support. Caregiver frustration is also compounded by efforts to provide the best care possible for the individual and the lack of success of specific strategies. Caregivers need to be encouraged to understand the fundamentals of why such behaviours may be occurring. Figure 1 presents a simple schematic, out-

Understanding Behaviour

lining four basic principles to aid our understanding of challenging behaviours.

The Behaviour Is Part of an Illness

While the link between dementia and much behaviour can be understood at a neurological level, the key point that caregivers may not grasp is that the behaviour causing the difficulties is often a manifestation of illness. Physical evidence of damage to the brain in people with dementia is not as evident as the physical paralysis that someone suffering from a stroke might experience. Caregivers need to be reminded that the person with dementia also suffers from brain damage; otherwise the behaviour may be taken personally.

All Behaviour Has Meaning

It is not always easy to know the true meaning of an individual's behaviour, yet people with dementia often act on their internal feelings of discomfort; they may be hungry, in pain, or need to go to the bathroom. They may be lonely or afraid. Alternatively, they may only be aware of the fact that they are somehow uncomfortable. Communication difficulties also associated with the disease hinder the individual's expression of these feelings. The challenge for those of us working with the individual is to try and discover the meaning behind the behaviour.

Consider the Individual

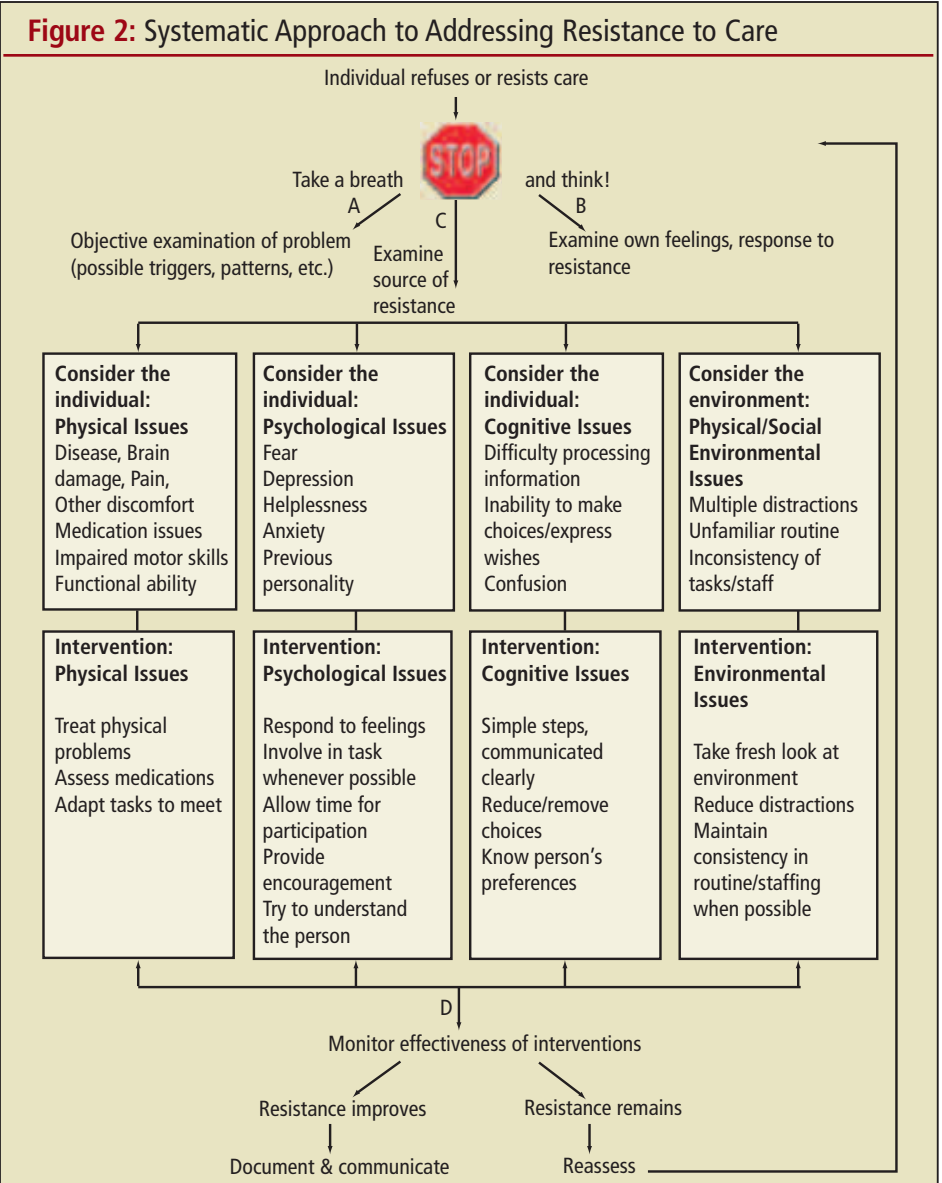
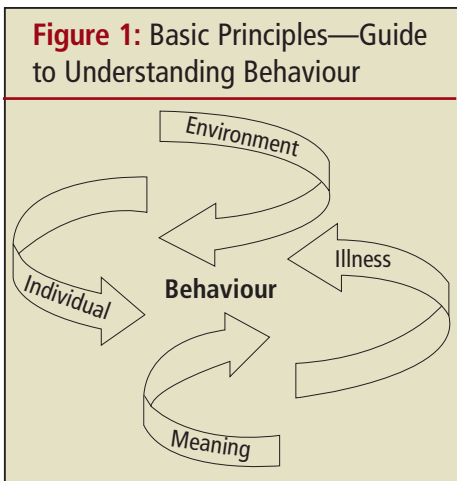
In order to understand the behaviour, and what it really means, it is necessary to understand the individual. Learning about the person with dementia—his or her interests, previous roles, as well as

things that frustrate and calm the person—gives a better grasp of what may be causing challenging behaviours. Significant people around the individual with dementia need to be engaged in sharing this information. Only when armed with this knowledge will it be possible to effectively identify factors that contribute to successful intervention.

Consider the Environment

Various environmental factors have influences on the individual. Those factors can be physical, social, or cultural and may be of great personal importance. They may represent underlying causes as well as triggers to behaviour, and appropriate interventions may arise from information about them.

Keeping these basic principles in mind helps with development of a systematic approach to management of behaviours associated with dementia. If caregivers are encouraged to take the time to consider these principles, they will be stepping back from the behaviour, looking at the information gathered, and perhaps reflecting on the individual in a new way. This can be a very important first step. It provides simple structure and can help everyone working with the individual to be objective. Of course, because of brain damage, it may not always be possible to find the true meaning behind behaviour, especially if we do not know the individual well. However, trying to understand why someone with dementia is acting in a certain way and being as



Key Points

There is limited evidence to support pharmacological therapies for dementia; fortunately, nonpharmacological interventions for the management of behaviours associated with dementia are numerous and are receiving attention from researchers.

Research suggests that caregiver characteristics influence the behaviours of those they care for and that increasing the confidence and sense of self-efficacy of caregivers can positively affect the individual with dementia.

Caregivers need to be encouraged by physicians to gather information and reflect on challenging situations, a process that meaningfully engages the caregiver in the individual's care.

Understanding challenging behaviours involves four basic principles: one, understand that the behaviour expresses underlying illness; two, perceive the behaviour as meaningful and try to identify the true meaning; three, account for the unique characteristics of the person under care; and four, know that physical, social, and cultural factors may bear on symptoms and care approach.

Some form of behaviour recording (such as a specific behaviour log used by long-term care homes, or a journal kept by a caregiver) is useful.

Interventions must be monitored for effectiveness and refined as needed.

supportive as possible can be important parts of an overall approach. Such an approach can help to disentangle caregivers from the emotional turmoil they might be experiencing as they struggle with behaviours and their own frustrations.

Further Application

Building on the concept of a basic understanding of challenging behaviour, Figure 2 presents a schematic outlining the steps to follow when dealing with an individual with dementia who is resisting care. Of primary importance, the first step is to stop and ask why the individual is resisting. This very important first step is often overlooked as caregivers insist on completing the task or arguing with the individual, frequently making matters worse. The next step is a three-pronged approach:

First, following arm "A" in Figure 2, caregivers must try to look at the behaviour objectively, possibly recording observed behaviour. This may take the form of a behaviour log used by long-term care homes, or it may be something simple such as a journal kept by a caregiver in the person's own home. Such behaviour tracking may reveal patterns to the behaviour or identify triggers. This information can be crucial in planning next steps.

Another step in this process, as shown in arm "B" of Figure 2, supports caregivers taking the time to reflect on their own feelings. Too often, caregivers are frustrated and emotionally exhaust-

ed, they blame the individual for acting out, and they blame themselves for the way they feel. They need reassurance and support regarding these feelings.

As arm "C" of Figure 2 indicates, a thorough examination of the multiple physical as well as environmental issues that can contribute to the distress of an individual with dementia is necessary. Such an examination leads to a range of possible interventions, each tailored to a specific possible cause.

Managing resistance to care does not stop with an intervention. Rather, following arm "D" in Figure 2, interventions must be monitored for effectiveness. This step is reluctantly taken by some caregivers, as admitting failure is not easy. However, to increase the chances of long-term success, interventions must be constantly monitored and communication is imperative. If an intervention is successful, the approach must be shared with everyone involved, as consistency is a key to success when working with individuals who have dementia. Equally important is recognition of techniques that are not successful. However, rather than calling this a failure, caregivers should be encouraged to reconsider the approach, gather more information, and use this information in planning a new or different strategy.

Conclusion

Dementia and its associated behaviours present a growing concern for the health

care system. Enhancing the skills of caregivers is an important step in managing the problem. Gaining an understanding of why individuals demonstrate certain behaviours may increase caregivers' confidence. It is hoped that the four basic principles enumerated here offer a simple structure to begin with. As well, this systematic approach can offer a consistent way to gather information as caregivers look for strategies to help manage challenging behaviours. Adding these tools to the information that physicians and other health care providers have to share can offer caregivers a focus and an important role on the team as they contribute to the information-gathering process, with the common goal of enhancing the care of individuals with dementia.

For further information, contact your local chapter of the Alzheimer Society. They have programs and a wide range of resources to help.



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