Screaming and Wailing in Dementia Patients (Part 1)

Screaming is a behavioural problem that can be extremely overwhelming and create enormous stress, not only on other patients, but on staff as well. Despite the common concerns and frustrations with this behaviour, there is a scarcity of information available addressing this issue. Therefore, the purpose of Part 1 of this article is to address the issue of screaming, discuss possible causes for the behaviour and, perhaps, inspire thoughts/feedback from our readers on this subject.

by Bernard Groulx, MD, CM, FRCPC

Screaming patients, especially those in the late stages of dementia (i.e., totally or almost totally aphasic), comprise one of the most puzzling clinical paradoxes in clinical geriatrics. Every nurse and orderly who has had to take care of a “screamer,” especially at night, will tell you that this behaviour affects the well-being and quality of life of everyone around the patient.

It is surprising that such a difficult entity has not been explored on all facets and that more relief measures have not been found. And herein lies the paradox. While screaming is a major concern for everyone working in the field of dementia, there have been very few studies on this behaviour specifically, and even less attention has been given to the topic in academic literature. For example, the academic book I consider to be the best resource on Alzheimer’s disease (AD) and recommend for everyone in the field of AD management, entitled *Clinical Diagnosis and Management of Alzheimer’s Disease*, has only a little over 30 words on the subject of screaming.

Everyone knows how difficult it is to manage screaming patients. Yet, many approaches, plans of treatment or medications have been tried with little or no success; this, I am sure, has created a sense that nothing, or very little, can be done.

I must admit that, at times, a part of me shares this pessimism. To combat this sense of despair, I will review my approach to the difficult clinical problem of screaming, with the hope of stimulating some thoughts from our readers and being the catalyst for an exchange of information on this subject, including any interventions or approaches which have been successful for others.

Many people working in the field of AD have seen a number of screamers who are not very advanced in their dementia, who can speak readily with their care-
The Canadian Alzheimer Disease Review • January 2004

givers, yet still cannot explain why they scream. In these cases, with time and patience and the real possibility of communicating with these patients, it usually is much easier to determine the causes of the behaviour and eventually correct the problem. The purpose of this article, therefore, is to focus on those patients who cannot readily offer us information.

While screaming is a major concern for everyone working in the field of dementia, there have been very few studies on this behaviour specifically, and even less attention has been given to the topic in academic literature.

This article will be completed in two parts. Part 1 discusses approaches to evaluating behavioural and psychologic symptoms of dementia and contemplates the possible causes for screaming behaviour. Intervention (which will be covered in Part 2 of this article to be published in the next issue of the Review) cannot be possible without this knowledge.

Exploring the Causes

There are two basic approaches for evaluating behavioural and psychologic symptoms of dementia. These approaches evaluate the circumstances surrounding the episode.

a) The temporal approach. What seems to trigger the behaviour? What seems to help relieve it or make it less acute? What makes it stop completely?

b) The five “Ws.” Who is with the patient or, conversely, who is absent? What helps, makes it worse and/or accompanies the behaviour? Where does it occur (e.g., is there a particular milieu or event associated with it?) When does it occur (e.g., is it limited to specific times, such as bathtime, during hygiene care, bedtime, when the patient has to be physically moved, daytime, evening)?

The answer to these “Ws” and to the questions asked in the aforementioned temporal approach will certainly help in understanding the problem and in subsequent interventions. Unfortunately, sometimes no information can be gathered from these questions and we are left with the last terrible “W”: why?

Why?

There are possibly as many causes for screaming as there are individuals who scream. However, it still is possible to get answers to “why” by exploring the “basics” in terms of what could be going wrong either inside or outside the patient.

Inside. When trying to determine what is happening within a patient that makes him/her wail or scream, it is important to start by focusing on the most common causes of distress in patients with dementia:

1) Is the patient in pain? A patient in stage 6 of AD (unable to talk, unable to express pain) often shouts or screams.

2) Is the patient constipated? Decreased physical activity along with side effects from multiple medications are conducive to constipation. The constipation may cause discomfort or even pain and, therefore, result in screaming from the patient.

3) Is the patient undernourished? Hunger is a surprisingly common cause of physical discomfort and, therefore, a potential source of wailing. It is difficult to ask aphasic patients if they are hungry, let alone what is appealing or appetizing to them. An inquiry made with the spouse, family or friends will help in this regard. Attention also must be given to the environment in which the patient...
eats, as well as what he/she likes. Healthy snacks between meals also may be part of the solution in these cases.

4) Finally, there often is a multitude of medical or physiological factors which combine and lead to a patient’s discomfort and eventual screaming behavior. A standard “medical checkup” should always be a part, if not the beginning, of an evaluation for any behavioral problem, including screaming.

Outside. Causes for a patient’s wailing or screaming also may involve the patient’s external environment. Therefore, it is important to consider common external stressors:

1) Does the patient feel secure or unsafe?
2) Are the schedules of the care unit made to accommodate the patient’s rhythms? In other words, are the patient’s routine activities (hygiene, meals, treatments, tests, etc.) designed, where possible, to fit the patient’s schedule or only the staff’s schedule?
3) Is the patient in an environment that overstimulates him/her? Considering the patient’s diminished cognitive capacities and the stresses inherent to dementia, are too many demands being made on the patient, or do certain demands correspond to capacities that he/she has lost?
4) On the contrary, is the patient understimulated? Is his/her screaming or wailing a way to create sounds and stimulations that decrease anxieties? For that matter, is the patient experiencing sensory deficits that nobody around him/her has noticed? I have seen patients almost lose their vision or hearing without anybody noticing, simply because the patient could not speak. These patients started making certain loud noises as a way to compensate for their sensory losses and inability to speak.
5) Has there been a recent change in the patient’s environment (e.g., change of rooms or change of nursing homes)? For patients with advanced dementia, having lost the capacity to make new memories, a sudden intense disorientation can be so frightening that it may trigger screaming behavior.
6) Has the patient been restrained in some form? The debate surrounding restraints could—and should—be the subject of a whole other article; in short, study after study has shown that restraints rapidly increase the risk of delirium and worsen behavioral problems, etc. Sometimes restraints are perceived (by professional caregivers) as true security measures—ways to protect the patient. But how can a severely demented patient be anything but totally mystified, stressed and scared by these restraints? Restraints are a significant source of stress conducive to wailing and screaming.

A standard “medical checkup” should always be a part, if not the beginning, of an evaluation for any behavioral problem, including screaming.

The nature of dementia. The nature of dementia is, itself, a cause for periods of wailing, shouting or screaming. Consider that, as nondemented individuals, we are uncomfortable when we are disoriented even for short periods of time, or when we have to face people who may have a connection to us but who we don’t recognize. Imagine living this way not just for a moment or two, but for weeks and months at a time. This is what patients with advanced dementia experience upon exposure to a new environment.

Imagine entering a confusional or delirious state (history of dementia is the most common
cause of delirium) and nobody notices or can do anything about it. Imagine a cloud of confusion coming over you, day after day, culminating with Sundowner’s Syndrome. These considerations can help us understand the fears and psychic pains plaguing some screamers.

Psychiatric causes. At the risk of sounding too philosophical, it is said that the most basic human need is the need to love and be loved. The most difficult cases of wailing or screaming patients that I have seen may be attributed to this "philosophy." Nothing seems to relieve or soothe these patients. Right or wrong, I have the impression that, at a deep and mysterious level, these patients feel their basic needs for love will never be nourished again. There is also, perhaps, a deep sense of loneliness and/or abandonment, combined with a lack of the intellectual capacity to make sense of it. Even in these cases, there are certain interventions that can be approached. Beforehand, however, we must always make sure there is not a bona fide psychiatric illness behind the behavior.

Psychosis, with its accompanying psychic pain and symptoms (e.g., delusions, hallucinations), is certainly enough to make any-body, moreso someone suffering from severe dementia, want to scream. But, for reasons I have never understood, people generally dismiss the possibility of a clinical depression. However, after eliminating any possible “inside” and “outside” causes, I always consider the possibility of clinical depression. It makes more sense, to me, that wailing or screaming becomes, in such situations, the only way for patients to express the despair caused by a major affective disorder.

Summary
As noted at the beginning of this article, there might be as many reasons for screaming in dementia as there are individuals who scream. This article was not meant to be an exhaustive list of possible reasons, but a simple attempt at organizing my thoughts, and perhaps yours, on the subject. In Part 2 of this article, we will explore interventions for screaming—both pharmacologic and nonpharmacologic.

For patients with advanced dementia, having lost the capacity to make new memories, a sudden intense disorientation can be so frightening that it may trigger screaming behavior.

Further reading: