MDs must help eliminate 911 calls after "expected" home deaths, medical examiner advises

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In brief

MORE AND MORE CANADIANS ARE CHOOSING TO DIE AT HOME**.** Unfortunately, family members may not know how to respond when death does occur. Some call 911 seeking advice, and soon find police, ambulance and fire services arriving at their door. If calls are made before terminal patients die, they may even be rushed to hospital for emergency care. The wasted energy wastes money and creates additional stress. Dr. John Butt, Nova Scotia's chief medical examiner, says physicians must help educate the public and emergency services about how to respond after an expected death occurs at home.

En bref

DE PLUS EN PLUS DE CANADIENS DÉCIDENT DE MOURIR À LA MAISON. Il se peut malheureusement que les membres de la famille ne sachent pas comment réagir au moment de la mort. Certains composent le 911 pour demander conseil et trouvent rapidement les représentants des services de police, d'ambulance et d'incendie sur le pas de leur porte. Si l'appel est placé avant la mort du patient en phase terminale, il se peut même qu'on le transporte d'urgence à l'hôpital. Ce gaspillage d'énergie et d'argent entraîne un stress supplémentaire. Le Dr John Butt, médecin légiste en chef de la Nouvelle-Écosse, affirme que les médecins doivent aider à éduquer le public et les services d'urgence sur la façon de réagir lorsqu'une mort prévue se produit à la maison.

The middle-aged woman from Nova Scotia's Annapolis Valley knew she was dying. Her cancer was advanced and when medication and therapy failed, she made the decision to die at home. Although her family and physician knew death was imminent, when it happened one of her flustered children dialled 911.

Within minutes a police car was at the door. Despite the protests of a funeral director who arrived at the same time, a police officer entered the woman's home and took photographs of her body. Her distraught son was asked to sit in the police car, where he was questioned as neighbours watched.

The troubling scene had devastating implications for a family that had provided loving home care for a dying parent. The grieving relatives, who had merely been seeking guidance about what to do next when the 911 call was made, certainly weren't prepared for the kind of response associated with a suspicious death.

Unfortunately, similar scenes have

been played out across Canada, with significant ramifications both for survivors and for a health care system that is trying to meet the growing demand for palliative home care.

Needless cost, needless worry

In the past, expected deaths at home would be handled by doctors and funeral directors. Today, the advanced technology associated with the 911 emergency-call system can result in an expensive and unnecessary invasion by police and fire or ambulance personnel, even when the death is the anticipated consequence of a known illness. Emergency-response teams are obliged to respond quickly to a call indicating that a death has taken place.

The College of Physicians and Surgeons of Ontario is aware of the growing concern about inappropriate 911 calls involving patients who die at home. Particularly worrisome is that some terminally ill patients are being rushed to emergency departments, where futile, costly and unwanted medical intervention is provided.

In May 1996 the college published an article reminding physicians that inappropriate use of the 911 service represents a sizable expense for the province. The college and the province's chief coroner have been sponsoring meetings of managers of home palliative care, including the Ontario Medical Association's sections on General and Family Practice and Palliative Care, the Ministry of Health, the coroner's office, police and fire services, and the Ontario Funeral Services Association.

The group has proposed that a registry be established for palliative home care and similar programs. An educational component would help patients, families and health care providers prepare for an expected death. A special package, kept with the patient, would identify the physicians, caregivers and community agencies involved in the case. Pertinent medical information would be included so that any physician would be able to complete the death certificate with confidence. A comparable project is under way in British Columbia, involving a variety of professionals who handle the complex issues associated with anticipated home deaths.

In Nova Scotia the province's chief medical examiner, Dr. John Butt, says other dimensions of home palliative care need to be addressed, but it is essential to keep anticipated deaths out of the medicolegal system.

The doctor's duty

"I think doctors should make a point of telling a family that they should not plug into a system that involves resuscitation. This means everyone in the home should know what is going on — not only discussing the dying patient's care, but also making sure there is a full understanding of the inevitability of death. I wonder if some doctors are timid about telling families that 'your dad will not be going back to the hospital, and when he dies you will have to engage a funeral service and his body will be removed from the home.' It goes without saying that this will require a great deal of sensitivity by the physician."

Butt is convinced that over-reaction by emergency-response teams can be attributed to misunderstanding or widespread misconceptions. He discovered that some police forces in rural Nova Scotia insist that a body cannot be removed from a residence without notifying a medical examiner or coroner — a mistaken assumption that he is working to correct.

"There is nothing in the law that says this is so. I have said to the police, 'if you put a heavy hand on this, you will also have to attend every nursing home death in this province.' I don't think the police are unreasonable, but when they don't have guidelines, or if those guidelines are blurred, they may seem to act in an officious manner.

"When 911 is called [because of] a misunderstanding by a family, it is appropriate for the police to respond but it isn't appropriate for them to initiate an investigation. Sure, they are going to have to ask a few questions because they have a responsibility to the community, but we certainly are not going to ask the police to investigate cancer deaths and other lingering deaths because they occur in a home.

"But again, I want to stress that it is up to doctors to counsel families about the terminal aspects of an illness and make sure emergency services aren't involved."

Butt points out there are also mistaken assumptions about the pronouncement of death. "There is no need to pronounce death," he said. "If one is in a position to resuscitate but there is no apparent pulse or breathing and one does not do anything, you are, *de facto*, pronouncing death. The family should be told what death is going to be like: the absence of respiration will be the first obvious thing, the pulse will cease at the same time or shortly after, and that should be the time when no emergency response is necessary.

"The question will be, do we bring someone in to do this officially, to ensure all vital signs have ceased and to determine the fact of death? The answer is no, and here the funeral business needs to be educated. It must understand that the law does not say anything about the pronouncement of death. Indeed, nowhere on the death certificate is there a statement about the fact of death. The certificate states that to the best of a doctor's knowledge and belief, the information provided is accurate.

"This includes who the patient was, when and where he or she died, the cause of death and, of course, in the case of the attending physician, it has to be an entirely

natural death or it goes over to the coroner-medical examiner's system. No province requires a statement about the pronouncement of death. It is essential families understand that this need not be done officially."

Butt points out that problems can arise for the family and funeral home if the physician who has been caring for a dying patient is not available at the time of death and has not prearranged for a colleague to sign a death certificate. Physicians who have terminally ill home-care patients should make sure their replacements are aware of the situation and any arrangements the family plans.

The financial burden

Butt agrees with the College of Physicians and Surgeons of Ontario that inappropriate 911 calls place a heavy financial burden on health care budgets. "It is a total waste of money and it creates a psychological strain in a home that puts [an expected] death in a completely negative context. I know it is difficult to have a positive context associated with death, but I believe this can be the case if a loving family anticipates it and understands exactly what is going to happen. However, if they mistakenly call 911, it immediately causes problems for them. They will have neighbours wondering why emergency vehicles have suddenly arrived at their home. This kind of situation is terrible and that is why preparation by the palliative care team, which must include the doctor, is the only thing that is going to stop what may be a most traumatic episode."

Butt is enthusiastic about the development of educational packages to give families step-by-step instructions for dealing with the many responsibilities associated with a death at home. He also sees merit in having physicians or home-care professionals contact a provincial coroner-medical examiner's office to register an impending death.

"It is not a breach of confidentiality, but the reasonable thing to do," Butt said. "When I was in Alberta I sometimes would receive a call from a doctor who would tell me about a forthcoming benign death, or occasionally I would hear from a person who would let me know that a family was preparing for the death of a relative who had a fatal illness such as cancer.

"I think [that] in a small community it is a good idea for a doctor, family member or someone in the caregiving team to contact the local police department or RCMP office to tell them a certain individual's death could happen at any time. It is also reasonable for the caller to say that they have arranged for a funeral director to remove the body directly from the home so that there is no need for police involvement."

Butt wholeheartedly supports the team approach and encourages the involvement of professionals such as the Victorian Order of Nurses, palliative caregivers and home-care workers. "These people are on the front lines and they have the opportunity to help make a family facing the death of a loved one avoid the anguish that may result from an inappropriate 911 call."

He expects physicians will have to address this troublesome issue as more and more patients begin choosing to die at home instead of in clinical settings.

Butt cites his father's anticipated death as an example of how a death at home should be handled. "[My father] wanted to die at home. When his sister, who was at his bedside, recognized that his life was over, she called a funeral director who removed his body. But first she contacted our father's doctor who, on his own accord, came to the house to offer his support and consolation.

"He did this because of the great respect he and my father had shared. There was no 911 call, no involvement of the police or fire department and no ambulance was summoned. It was a tranquil closure of a fine man's life, and I feel that is the way it should be." ?