Dementia caregivers often find themselves "walking a tightrope" when it comes to making ethical decisions about intervention options in resident care and management. A meticulous approach in gathering all the facts, and becoming familiar with the pertinent principles or guidelines involved, will make it possible to walk the tight rope with confidence.

By Lori Schindel Martin

Walking the tightrope

Ethical decision-making in dementia care

Care providers often find themselves on a "tightrope" when faced with challenging behaviours associated with dementia.

Care situations are often difficult, requiring interventions such as physical and chemical restraint. This is particularly the case with residents who are cognitively impaired.

Caregivers feel obligated to consider the rights and safety of co-residents over the autonomy of the individual displaying behaviours that are considered noxious.

Professional expertise, in the management of aggression for example, can lead caregivers to make clinical decisions that ignore resident preference, or that deny the resident the opportunity to make choices. Even if a person is deemed incompetent, it does not give caregivers license to design an intervention or management plan that disregards the resident's preferences and desires.

Ethical principles

Often, in an effort to control high risk behaviours, caregivers will restrict resident autonomy more than can be ethically justified.

When care teams are faced with challenging behaviours, management strategies are often selected using the traditional ethical *principles of paternalism and harm.*

A paternalistic action in health care includes restricting autonomous behaviour in order to prevent a person from self-harm.

The harm principle guides caregivers in their judgement as to whether the potential harm that a person may do to others represents a risk as to justify restricting that person's autonomy.

Considering these principles alone or in isolation can contribute to a "rigid" view of the problem, abandoning creative problem-solving along the way, and resulting in the sacrifice of the resident's personal autonomy.

The limitations of this thinking are best illustrated in the case of Smith and Jones. **(See box below)**

Principle of paternalism

The principle of paternalism directs heath care providers in their duty to prevent persons from doing harm to themselves - even though this may restrict their personal autonomy.

The care team has decided that Mrs. Jones cannot understand the full circumstances of her "intimacy" behaviours, since they might result in more overt sexual activity. The staff have

The Smith and Jones case

Mr. Smith is a 78-year-old resident with Alzheimer's dementia. He has taken quite a shine to Mrs. Jones, a co-resident who, he believes, is his wife.

Mr. Smith will walk closely beside Mrs. Jones. He will hold her hand and often kisses her. He has been observed on occasion to pat her behind and fondle her breasts and genital area.

Mrs. Jones receives his advances with no concern or negative emotional response. She actively seeks out his company, kisses him, and spontaneously reaches for his hand.

decided to disregard Mrs. Jones' preferences and desires, and despite her protests, and combativeness during personal care, keep her separated from Mr. Smith's company.

In walking the "tightrope," a dilemma has been created:

Did the desire to prevent self-harm result in an outcome that was ethically justified?

One alternative strategy to this behavioural challenge could include a meeting with the families to determine their level of comfort with the relationship developing between the two residents.

Another strategy would be to plan specific activities for the two residents such as dancing, walking out-of-doors, or eating meals together that would allow physical closeness in a socially appropriate context.

The harm principle

The principle of harm directs caregivers in their duty to prevent residents from injuring a third party. In our example, the harm principle would guide the care team to decide that Mr. Smith's behaviour is a potential risk to Mrs. Jones, since his behaviour may escalate to include "assault."

Prevention of harm to others is sometimes considered sufficient reason for limiting a person's autonomy. Using the harm principle, staff believe that separating the two residents will reduce the risk of blatant sexual behaviour. They consider this behaviour to be socially unacceptable between two residents who are cognitively impaired. They believe that the two residents do not have the capacity to give consent to an intimate involvement.

Thus, the staff, acting on behalf of the two residents, keep them separated.

The team also questions whether it is prudent to include psychoactive medication to control the sexual impulses experienced by Mr. Smith.

The tightrope walkers believe that, in this case, it is necessary to desexualize the behaviours. It is important that the decision to intervene in this way is made for the right reasons; otherwise, the interventions are ethically unjustified.

Balancing act

A reasonable way to approach the "tightrope" is to look at the situation from a number of different angles. It is critical that the care team define the risk associated with the residents' behaviours in terms related both to the resident and the providers of care. The issues must be separated at this level so that the team can appreciate which interventions are truly related to the resident issues, and which interventions are targeted at their own values, beliefs and feelings of discomfort.

The team must identify the frequency, intensity, severity and duration of an episode of concern. A "level of risk" related to the behaviour can be assigned, and an intervention that balances with the "level of risk" can be selected.

Using this approach, the team can work toward an ethical practice that ensures that management of resident behaviours is based on objective data, and not impressions, opinions, or personal values and beliefs.

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Summary

In summary, the approach to the assessment and management of challenging resident behaviours, is to assess the following:

- separate "risk to resident" from "risk to care provider;"
- identify frequency, intensity, severity and duration of the behaviour;
- assign a "level of risk" to the behaviour;
- select an intervention that balances with the "level of risk;"
- put the risk behaviour in the staff's point of view;
- put the risk behaviour in the resident's point of view;
- identify unmet needs that might explain the high risk behaviour;
- select interventions that address unmet needs at the root of the behaviour;
- select interventions that maintain the resident's personal autonomy whenever possible.

Care providers who choose to work in dementia care have taken on a challenging calling. The clinical situations that we find ourselves in often represent ethical dilemmas for us; but if we are meticulous about approaching the information in an objective manner, we may cross the "tightrope" with success. ■

About the author

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