Who will speak for me?

People generally don't like to think about how their life may end and few consider the possibility of dying in a hospital intensive care environment connected to tubes and monitors where they are unable to express their wishes. In these circumstances, doctors and nurses must rely on a patient's family to assume the role of a Substitute Decision Maker (SDM) to be the patient's advocate and to reflect their wishes and values.

Little research appears to have been undertaken to explore how a SDM is chosen by a patient and particularly for an incompetent adult in an intensive care unit (ICU). Outpatient based studies in France, Iran and USA reveal that the Next Of Kin (NOK) is not the preferred SDM in 30-50% of patients and the SDM is often unaware of the patient's wishes.

Differing cultural practices are important considerations. The expectation for a paternalistic approach from physicians remains common for patients from some European, Asian and Middle Eastern backgrounds and this can create challenges. Also, the principle of enduring power of attorney is not recognised in some countries when a person lacks competency. This would have implications in western culture where respect for a patient's autonomy is the guiding principle impacting a SDM's role.

The researchers appraised data in the medical record of patients who died in an Australian ICU over a 12 month period and identified when there was a discrepancy between nominated SDM and NOK.

This study found discrepancies between the identified NOK and the preferred SDM which reflected previous studies in that 30% of patients preferred another SDM rather than their spouse, and unmarried patients often choose someone outside their family. The choices made by patients included:

> A man nominated a girlfriend over his wife as NOK and SDM.
> A single man nominated a friend as NOK and SDM. Family from whom he was estranged challenged this and tried to bully the friend to relinquish this role.
> A man nominated a friend as person responsible, however his daughter and sister both claimed that they should be the SDM and were in conflict with each other over what they saw as ownership of this role.

The examples described also show families frequent lack of understanding of the role of SDM and it was often difficult for a family member to separate their own needs and wishes from what those of the patient might be. They often perceived the SDM to be the most important person in the family and thus desired this status, rather than having regard for, or being able to truly reflect the patient's values and wishes, for end of life care. Further, patients had not considered preferences for end of life care prior to the ICU admission and had not shared their feelings or wishes with close

family members, thus making the task of the SDM very challenging. Physicians should be mindful of this when they seek broader family consensus around end of life care issues.

The NOK of patients admitted to ICU should not be assumed to be the preferred SDM. The question of the most appropriate SDM needs to be addressed by families long before a hospital admission. This may require innovative health promotion strategies in order to facilitate greater awareness of the need for families to discuss their wishes for end of life care and for the value of advanced care directives, particularly for older patients and those suffering a chronic or life limiting illness.

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