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Substitute Decision-Making and End of Life Planning: Hot Topics from a Care Provider Perspective

SCENARIO 1

You are a risk manager at an acute care institution. Part of your job involves working closely with staff during discharge planning. The hospital has an elderly patient who, according to clinical staff, can go home. Her son, who is her SDM, and with whom she lives, says he cannot manage her at home because of his own health issues. Staff have a significant concern that the patient is at risk of abuse from her son. The patient insists that everyone defer to her son's views on the issue. Staff worry that deferring to him in this context is against her best interests, and will lead her to be needlessly placed in a long term care facility. What do you do?

Issues to consider:

- Can the patient truly be capable if she insists on deferring to a potentially abusive child?
- What if anything can or should you do about the patient's choice of SDM?
- As a practical matter, what can or should you do to get her out of hospital, given that she no longer needs to be there, and in the view of her care team will do better emotionally if she is in a familiar environment?
- How do we balance her autonomy versus her physical/emotional safety given the fears that her son is abusive?

SCENARIO 2

You are a palliative care manager at a long term care facility. Your unit has a 70 year old male patient with two children. One of them, the son, is the patient's power of attorney for personal care. The patient used to live with his daughter. The patient's son believes that his sister did not take good care of their father when their father lived with her. You are aware that the daughter has some kind of psychiatric history but you do not know the details. Your staff tells you that the daughter is not taking her father's illness well and does not appear to believe or understand that her father is in palliative care. The son does not want his sister to visit. How do you respond to his demand that his sister be barred from visiting?

Issues to consider:

- Is the son, as the power of attorney for personal care for his father, entitled to control who visits his father?
- Does the fact that the daughter is known to have some psychiatric history change how this situation should be managed?

Some weeks later, you have managed to work out an arrangement whereby the daughter agrees that while she can visit her father, she cannot take him off the unit. One day, your staff informs you that she has in fact taken her father off the unit nonetheless. What do you do?

Issues to consider:

- Do you inform the police?
- Do you inform the son?
- What suggestions do you make to the son in terms of how to handle the situation?

SCENARIO 3

You are a front line nurse in an elder care facility. One of your patients is an 80 year old woman. She has a daughter who was originally her power of attorney for personal care. She also has a male friend, who is 50 or so. This friend has told you that one day he was in a coffee shop, sat down, looked across the room, saw the patient having her coffee, and knew immediately that she was someone who needed his help. He befriended her and has been her sole source of support ever since then. Your "gut" tells you that he may be trying to take advantage of this patient, but you have no concrete information to either support or disprove that feeling; it is just what your intuition tells you. The daughter is no longer involved in decision making and you do not know if the power of attorney she once had is still valid or has been replaced by a power of attorney in favour of the patient's male friend. The patient still wants to see her daughter, but defers all decision making to her friend. You do not know whether a capacity assessment has been done on the patient, or when. The daughter does visit, but only when the male friend is not on the unit. The patient is becoming weaker. You are nervous about how to help her daughter stay involved in her life and her care, how to honour the patient's apparent wish to have her male friend make decisions, and how to plan for any end of life-related decision making that may be required. What do you do?

Issues to consider:

- What do we know about this patient's capacity to make her own decisions, from the information provided?
- Can the patient truly be capable if she insists on deferring all decision making to someone who may be trying to take advantage of her?
- How do we determine who the appropriate decision maker is for this patient, if she lacks capacity?
- If we determine that the male friend is the proper SDM, what if anything do we do about our "gut feeling" that he may not be acting in her best interests? How if at all do we involve the son in this issue?
- How do we keep the son informed and let him be with his mother as much as possible as her health declines, while still honouring the patient's apparent wish to defer to her male friend's decision making?

SCENARIO 4

You are a risk manager in an acute care hospital. The hospital has a 90 year old post-stroke patient with mild dementia who is going to long term care. Earlier in her hospitalization, she was content with the plan to go to long term care and had completed the appropriate paperwork. However, as time went on, her demeanour changed markedly; she became angry and unhappy and refused to be transferred to a long term care home, instead voicing a preference to go home. She does not remember having ever signed a power of attorney. You anticipate that a long-term care bed will become available soon. Some members of the team are worried that, given the patient's recent change of heart, she will refuse a bed when one becomes available. The team has tried three times to assess the patient's capacity. On the first two occasions she refused to participate. On the third, she gave a few answers, which did not allow any firm conclusions to be drawn, but suggested that she did not understand the "big picture" in terms of what going back to her own home in her current condition would entail. The patient's daughter, who is her power of attorney for personal care, meets with you and the team to help plan for discharge. At the meeting, her daughter tells you that she does not want to take her mother home because she can be challenging and the daughter does not have the resources to look after her properly. She wants the team to just tell her what to do, as she is finding the situation extremely stressful. Her husband tells you that you should simply make the patient go to a long-term care home. The team's view is that, clinically, this patient will be better off in a long term care home. You are worried about how to deal with things when a long term care bed becomes available. What do you do?

Issues to consider:

- What do we know about the patient's capacity, from the information provided?
- What challenges does dementia pose for assessing capacity?
- Can you just tell the daughter what to do, as she would like?
- Can you just make the patient go to a long-term care home, as the son-in-law would like?
- What do you do about the fact that the team feels this patient will be better off clinically in a long term care home?
- Should you deal with this issue now, or when a bed becomes available?

SCENARIO 5

You are a nurse manager in a cancer care hospital. You have an elderly patient whose prognosis is very grave. Her family does not want her to know the prognosis. They tell you that, for cultural reasons, they feel this information should be kept from her, and that she would want to not be told. You have no reason to doubt the patient's capacity, and everything she has said to her treatment team suggests she does want to know her overall prognosis. How do you manage this situation?

Issues to consider:

- What determines whether this information should be disclosed to the patient or not?
- How might you handle the family's culture-based concerns?
- What do you do about the fact that the family believes this patient would not want to be told, given the choice?

SCENARIO 6

You are a risk manager of an elder care facility. One of your clients, an elderly female, has just been admitted. You are aware that there is some kind of restraining order in place against her husband due to a long history of verbal, financial, and possibly physical abuse on his part. The client has significant dementia and her capacity is considered questionable though no formal capacity assessment has been done. Her finances are being managed by the PGT. The current power of attorney for personal care is scared of the client's husband and therefore reluctant to carry out her duties. The client's husband is now trying to resume control of her finances and personal care, and he and his lawyer have been trying to get her to sign a power of attorney. Her team is strongly of the view that if she is allowed to go home into the sole care of her husband there will be extreme risk to her health and safety. What do you do?

Issues to consider:

- What resources are out there to potentially assist you with this situation?
- Who is the appropriate decision maker for this patient as things currently stand? (i.e. no POA yet signed by the client in favour of the husband)
- How, if at all, can you prevent her from being sent home under the sole care of her husband?

QUESTION

You are a nurse manager at a long term care facility. One of your staff members suggests that, since many patients are admitted without clear plans in place regarding substitute decision making and end of life care, all patients should be required to create advance directives upon admission, if they do not already have such directives in place. What do you do?

Issues to consider:

- What is an advance directive?
- At whom is it aimed? (i.e., who is "bound" by the directive?)
- Is it a good idea to require them from all patients in your facility?
- In practice, if a patient has an advance care directive, how is that going to shape the approach caregivers take to him or her? Will they always refer to the directive first?