MANAGING DIFFICULT CASES

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Presenter / Disclosures
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  Kindred at Home:
  Vice President of Medical Affairs, and
  Chief Medical Officer
  - No relevant financial disclosures
  - No discussion recommending off-label treatment utilization of medications or treatments
  - Details of example cases have been changed to protect PHI and for teaching purposes

Objectives
- Describe the context of “Difficult Patients” within hospice
- Discuss examples of difficult cases found in hospice with strategies for management

What is a “difficult case”
- Often we think in terms of who is a difficult case
  - Better to think in terms of the situation
- Patients (& families) are undergoing significant stress when dealing with a terminal prognosis
  - They bring with them:
    - All their past history of how they cope (or don’t) with stress
    - All the “good and bad” of their experiences with healthcare
    - All their hopes and fears for the future
- One defining characteristic of difficult cases is that the above has created a management situation that is not straightforward and requires above-normal effort by the interdisciplinary team

Overview
- Be sensitive to the presence of a difficult case
  - These are the cases that make you feel uncomfortable
- We’ll review examples of how to manage
  - Patient remains the prime focus, but family and others (including our own staff) also must be considered
  - Utilize the entire interdisciplinary team for management
  - Think and plan in terms of the entire picture before acting
  - Anticipate likely outcomes and consider desired outcome
  - Adjust plans as the enfolding situation dictates
  - Recognize that sometimes a “better than it would have been” outcome is the best that can be accomplished
- Such cases are often ‘received’ in the midst of the crisis
  - Generally not helpful to assign blame
  - Just need to resolve

Again, for emphasis!
- Make use of the whole team
  - No awards for being a “lone ranger”
### Case 1

- You’re on call for your hospice program when you are called about an issue with a patient on the other team
- Pt found unresponsive by caregiver daughter
- 66yo M admitted to hospice 4w ago for colon CA with liver/lung mets
- 2d ago: PPS 40%; BMI 18 ↓ ing slowly; A&Ox3 withdrawn; Pain 2/10
- Meds are checked by our on-call nurse:
  - MS-ER 100mg q 12h (bottle contains 0 of 30 tabs; filled – 8d ago)
  - MS-IR 15mg q 2h prn (bottle has 23 of 60 tabs, filled – 5w ago)
  - Lorazepam 1mg q 2h prn (bottle has 2 of 60 tabs, filled – 5w ago)
  - Sertraline 50mg q day (bottle has 7 of 15 tabs, filled – 8d ago)
- Other meds with proper amounts present in bottles; no other sedatives
- Nurse assessment:
  - RR 8-10/m; HR 86; BP 104/62; pupils pinpoint
  - Nonspecific movement with sternal rub, but o/w unresponsive
  - Has valid-in-your-state AD with order for DNR

### Case 1 continues

- You review recent entries via remotely accessed electronic health record
- IDT recently discussed worsening depression; started sertraline
- SW screened pt, who denied suicidal ideation / no guns in home
- SCC: pt was became a widow 2m ago; “Angry at God!”
- Caregiver daughter lives with patient, but works days
- Decision is made to manage at home:
  - Continuous care is started
  - Naloxone is ordered/obtained to give in small aliquots for respirations < 6 breaths/minute
- Patient awakens 7 hours later with no naloxone given
- Patient is very angry at being alive

### Case 1 considerations

- What is patient’s medical prognosis?
- Is patient “medically cleared” for psychiatric inpatient care?
- What is caregiver daughter’s current state/opinion?
- What arrangements can be made for monitoring patient at home (around the clock)?
- Are there legal implications involved?
- Are there ethical implications involved?

### PAD Considerations

- My organization’s policy
  - Recognizes PAD is now legal in 3 states where we have locations (and likely will have more states added)
  - Recognizes that PAD is a legal option for patients in those states, who may also be receiving our services
  - Our primary focus is providing care, as we would for all our hospice pts
  - Staff may choose not to participate in care of such patients, without expressing reason why
  - Physicians may attend patients pursuing this option, but in their capacity as private practitioners (not as hospice medical directors)
  - No official corporate stance otherwise because it is legal in those states with the decision being the individual’s
  - How would you handle requests from someone wishing to make use of this ‘option’?
  - Thoughts? Remember to involve other IDG members!

### Looking beyond Case 1

- A 29 yo woman became a media celebrity when she died on November 1st, 2014
- Diagnosed with glioblastoma multiforme in her home state of California
- Established residence in Oregon to avail herself of that state’s “Death with Dignity” option
- She received my organization’s hospice services while waiting to qualify, and through the time of her death
- Hospice did not participate in actual physician-aid-in-dying actions, but staff were present in the room at the time of death

### Case 1 Teaching Points

- Requests for PAD will be more likely to encountered, whether in a state where this is legal or not
- Must consider all aspects, including:
  - Legalities
  - Patient’s capacity, including the presence of clinical depression
  - Has an adequate trial of optimal palliative care been provided
  - Will the patient even allow a trial of palliative care
  - Is the issue uncontrolled symptoms or issue of just control?
  - Other IDG members
  - Other organizations
Case 2 – Advanced pulmonary disease

83 yo M on hospice for advanced pulmonary disease (not going into details now – more on that shortly)

Routine medications:
- Hytrin® 5mg/d
- Flomax® 0.4mg/d
- Lasix® 40mg/d
- Metoprolol 25mg bid
- Mucinex prn
- Albuterol nebs
- Symbicort® MDI
- Lortab® 10/325 prn
- Morphine 10mg prn
- Xanax® 0.5mg prn
- Levsin® SL prn secretions
- Nystatin S&S qid

Just added for pruritic rash over the last 2 months:
- Prednisone 30mg/d
- Benadryl® 25mg prn
- Sarna® w/ Menthol
- Singular® 10mg/d
- Ranitidine 150mg/d
- Potassium CL
- Remeron® 15 → 30mg/d

Increased confusion/agitation:
- Seroquel® 75mg q hs
- DepoHaldol® 100mg IM q M

Case 2 – the rest of the story

- 2010 – Pt is 78 yo, undergoing CABG
- Found to have “lesion” on CXR
- Biopsy-proven non-small cell lung cancer (NSCLC) – Stage I
- Treated with stereotactic XRT; oral (unknown) CTX
- Mar 2012 – Routine surveillance exam by oncologist
- Recurrent disease: larger initial lesion + second lesion
- New biopsy EGFR mutation negative (so no erlotinib)
- Plan: return with repeat CXR in 6 weeks to determine plan

Case 2 – Med profile (again)

Routine medications:
- Hytrin® 5mg/d
- Flomax® 0.4mg/d
- Lasix® 40mg/d
- Metoprolol 25mg bid
- Mucinex prn
- Albuterol nebs
- Symbicort® MDI
- Lortab® 10/325 prn
- Morphine 10mg prn
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But here is the issue …

- If one considers the patient’s prognosis to be terminal, is that due to iatrogenic reasons?
- Does being terminal for iatrogenic reasons still mean a patient can be hospice eligible / appropriate?
- What would you do during the team discussion of this patient?
  - Would you recertify or discharge?
  - How would you manage this patient?
  - Would you report prior care ‘upstream’?

Case 2 – present day (May 2014)

- Note – it is now two years after hospice admission
- You are new member of the IDT managing Case 2
- Previous HMD has ‘moved on’
- Current findings that have not significantly changed over the past two years until recent weeks:
  - PPS stable at 50%
  - BMI stable at 22
  - Dyspnea at rest and with any exertion
- New findings over past several weeks (besides rash):
  - Increasing confusion
  - Increasing agitation (verbal abuse)
  - Unsteady on feet with several recent falls
- Most recent assessment show PPS 40%
- RN reports patient now has progressive terminal delirium

Case 2 Teaching Points

- In order to legally provide hospice care, we must continually monitor patient’s prognosis
- Routinely review the complete medication profiles of patients
- Consider whether delirium is potentially reversible before committing to a course of action based on a presumption of irreversible terminal delirium
- Being on hospice is not an excuse to provide less than optimal medical care, especially for individuals whose prognosis is more than a few weeks
### Case 3: Presentation

- **66 yo M rancher**
- **Diagnoses:**
  - Hepatocellular carcinoma / Hepatitis C positive
  - Liver failure / lung metastases
  - Recurrent cellulitis of one lower extremity
  - Functional / Nutritional / Cognitive impairments
    - PPS 60%; Needs limited help bathing and dressing
    - BMI 29 with a 12% weight loss over 6 months
    - Cognitively intact
  - Referred late in day after hospital discharge upon completing course of IV vancomycin
    - Admitted by on-call nurse that night

### Case 3 continues

- Pain rated 8/10, at best
- Current medications include
  - HCA/PAP 10/500 1-2 tabs q 4h prn pain
    (averaging 8-10 tabs/24h)
  - Lorazepam 1mg q 4h prn anxiety
    (averaging 3-6 tabs/24h)
  - Olanzepine (Zyprexa®) 10mg daily
  - Promethazine 25mg q 4h prn nausea
  - Clindamycin 300mg q 6h for 3 more wks
  - Usually drinks 0.5L of whiskey a day
    - Though he is “slowing down on this”

### Case 3 continues

- Assigned RN case manager arrives at 12n the next day for follow-up
- Identifies KKK paraphernalia and markings around the entrance to the ranch
- Apparently these were not seen due to darkness the night before
- Multiple young men seen on the ranch
- Pt pleasant, cooperative and thankful for the care he is receiving
  - Admits he is a retired Grand Wizard of the KKK
  - Multiple guns noted on display in his home
- Case manager calls to report this to you

### Case 3 continues

- SW volunteers to go out
- Learns that pt has been in prison three times for drug-related convictions (including conspiracy to distribute narcotics)
- The men on the “compound” are KKK members assigned to “protect him” from rivals
  - He has issued instructions to them that the hospice team members are “non-combatants” and should not be harmed or harassed in any way
  - He knows he is dying – he just wants to die comfortably and non-violently

### Case 3 continues

- Admission nurse arrives at the end of IDG meeting
- She reports:
  - She did not feel threatened in any way at the ranch
  - She does not understand why anyone would deny a dying patient the right to a peaceful, comfortable death
  - She feels strongly enough about this that she volunteers to be the pt’s RN case manager
- Some team members are just as adamant that we should discharge this patient

### Case 3 continues

- Team members who are comfortable doing so provide care/support for the patient
  - Arrangements made that only these team members will respond to after hours calls
  - He readily agrees to and signs a PPA
    - Is started on Methadone 5mg q 8h
    - HC/APAP for BTP (is reluctant to give this up)
  - Information comes in from attending physician that he had no idea of this social history
  - Arrangements made for ethics committee meeting
Case 3 continues

- As the Ethics Committee was being convened, several staff expressed concern that a representative of “Administration” sat on the internal Ethics Committee
- Concerns included:
  - Felt this involved someone not really involved with the clinical management of the patient
  - Felt this presence would make them unable to freely express opinions
  - Felt that supervisory reprisals were possible if opinions were expressed
  - This would compromise any decisions

Case 3 concludes

- Ethics Committee (with ex officio administrative presence) meets and discusses case
- Endorsed current plan of care
  - Current team stays in place, including on-call
  - Pain mgmt within confines of pain mgmt agreement
  - Pt to keep guns locked & out of sight (pt agreed)
  - Designated ombudsman for staff to report concerns / issues / questions
  - Care proceeded similarly to standard hospice case (more or less)

Case 3 Teaching Points

- Difficult cases may not be appreciated until care has already started
- Whenever possible, major decisions should be made after communication and consideration of all the facts by the entire team / involved parties
- Ethics Committees are one way to try to ensure full communication occurs
- Trust is an important ingredient for providing optimal patient care, but having trust may not always be possible
- It is the role of true leaders to make decisions that ultimately the remainder of the team is comfortable following

Case 4a

- You receive a call from admissions about a potential pt
- 56yo with recurrent renal cell carcinoma to both lungs
- Current findings:
  - Function: PPS 50%, Dependent in 2/6 ADLs
  - Nutrition: BMI 25, appetite fair, eats recommended diet
  - Cognition: intact; answers questions slowly but appropriately
  - sx’s: pain 0-2/10; dyspnea 0-3/10; fatigue 5/10
- PM/Soc Hx:
  - s/p bilateral nephrectomy 3y ago
  - Hypertension controlled with meds
  - On hemodialysis (HD) 3 x/wk x 3y, tolerating well at this point
  - Lives with spouse; on disability
- What do you want to know? Would you admit?

Case 4a possible considerations

- What is the patient's prognosis?
- When is treatment palliative vs. life-prolonging vs. both?
- What symptoms need management: now / later?
- What meds is patient on? Any proerythrogenics?
- How is patient transported to HD: now / later?
- Who is responsible for the cost of HD?
- Is HD being continued or discontinued (if so, when)?
- What advance directives are in place, including what to do in HD center?

Case 4b

- You receive a call from admissions about a potential pt
- 56yo with CHF d/t ischemic cardiomyopathy
- Current findings:
  - Function: PPS 50%, Dependent in 4/6 ADLs
  - Nutrition: BMI 25, appetite fair, eats recommended diet
  - Cognition: intact; answers questions slowly but appropriately
  - sx’s: pain 0-2/10; dyspnea 3-6/10; fatigue 7/10; 2+ edema BLE
- PM/Soc Hx:
  - Hypertension x 20 years, controlled with meds
  - Type 2 DM x 10 years, on insulin + oral meds
  - On hemodialysis (HD) 3 x/wk x 3y, with hypotension q 3 or 4 sessions
  - Lives with spouse; on disability
- What do you want to know? Would you admit?
Case 4b possible considerations
- What is the patient’s prognosis?
- When is treatment palliative vs. life-prolonging vs. both?
- What symptoms need management: now / later?
- What meds is patient on? Any proerythrogenics?
- How is patient transported to HD: now / later?
- Who is responsible for the cost of HD?
- Is HD being continued or discontinued (if so, when)?
- What advance directives are in place, including what to do in HD center?

Case 4c
- You receive a call from admissions about a potential pt
  - 86yo with advanced dementia d/t Alzheimers disease
- Current findings:
  - Function: PPS 30% Dependent in 6/6 ADLs
  - Nutrition: BMI 25, on PEG feeding
  - Cognition: nonverbal, FAST 7E
  - Sx’s: pain 0/10; Nonhealing stage IV heel decubiti x 2 for 6 months
  - PM/Soc Hx:
    - Hypertension x 20 years, controlled with meds
    - On hemodialysis (HD) 3 x/wk x 7y, with hypotension q other session
    - Lives in LTCF, transported to HD by ambulance
  - What do you want to know? Would you admit?

Case 4c possible considerations
- What is the patient’s prognosis?
- When is treatment palliative vs. life-prolonging vs. both?
- What symptoms need management: now / later?
- What meds is patient on? Any proerythrogenics?
- How is patient transported to HD: now / later?
- Who is responsible for the cost of HD?
- Is HD being continued or discontinued (if so, when)?
- What advance directives are in place, including what to do in HD center?

Other “Case 4 like” scenarios
- What about the following care situations?
  - Ventilators
  - High-flow O₂ administration
  - LVADs
  - AICDs
  - Pacemakers
  - Chemotherapy / Inotropes / etc.
  - While we would like to omit cost from consideration, sometimes that isn’t possible

Case 4 Teaching Points
- Prognosis should always be in mind in order to ensure ongoing hospice eligibility
- Prognosis is also one of the determinants for whether a diagnosis is related or not
- Seemingly small changes in patient characteristics may alter prognostic and relatedness determinations
- As before, get input from all members of the IDG, as well as other resources if needed
- Hospice has gone is increasingly involved with the management of a wide array of clinical conditions: anything that might cause an expected death
- While such cases may be difficult, the reward is in overcoming adversity and helping patients and families