

Family Meeting Role Play – Hedgepath Case

Community Health Navigator (Small Group Facilitator)

NOTES ON FACILITATION: If you don't have enough learners to play all the roles, eliminate Joe, explaining he can't come because he is too ill. You can also eliminate the Hospice Representative if needed, in which case the CHN (YOU) can describe Hospice services. If so, tell PCP not to "Call" the Hospice Rep, but to ask you to describe it.

- You open the meeting stating that everyone has been invited so that decisions about Mrs. Hedgepath's ongoing care can be discussed and goals for her care can be determined based upon her wishes.
- You ask everyone to introduce themselves.
- Then you ask the Primary Care Provider to discuss her condition.
- After the Hospice Representative speaks, ask the Behavioral Health Provider to discuss the types of support they can offer.
- Throughout the meeting you reassure the family that everyone will work together to meet their goals and they will not be abandoned.
- You note that the VA case manager will continue to coordinate VA in-home services for Mr. Hedgepath in addition to hospice services for Mrs. Hedgepath should the family decide to have hospice care.
- At the end of the meeting you summarize the meeting and plans going forward.
- You state that the family needs to decide about accepting hospice care as you realize they have gotten bad news and need time to accept Mrs. Hedgepath's limited life expectancy.
- You state that they can contact hospice using the number given them by the hospice representative if they feel they want to schedule an admission visit.
- You promise to call them in a day or two to follow up on today's meeting.

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Primary Care Provider (Physician or Nurse Practitioner)

You are responsible for Thelma Hedgepath's medical management. You are also familiar with Joe Hedgepath's medical management, as you have seen him for emergent care needs between his visits to the VA clinic where he is followed. You have received recommendations from the Case Conceptualization meeting where the couple's case was discussed and have incorporated the suggestions of the geriatrician and pharmacist into your plans for Mrs. Hedgepath's medical treatment going forward.

- When cued by the Community Health Navigator, start by asking Mrs. Hedgepath what she understands about her condition.
- After Mrs. Hedgepath replies that she does not see her cancer as anything too serious, you tell her that you must give her and her family some bad news.
- You state that her lung cancer is spreading rapidly and nothing more can be done to stop the disease.
- After she and her family have talked about this, you ask if they would like to know an estimate of how much time she has left.
- After they agree to this, you tell them that she most likely has only weeks to months to live. You advise against any further treatment for her cancer as it would be of little benefit and would negatively affect her quality of life. You say that the focus of her care should be to keep her as comfortable as possible.
- You allow silence to let the news "sink in" and then allow the family to express their emotions.
- Realizing that Mrs. Hedgepath's life-limiting prognosis makes her eligible for hospice care, you believe this is the best course of care for her going forward and you suggest this to the family. You state that you work closely with the hospice admission nurse; you have her cell phone number and would like to give her a call so she can explain hospice services to the family. With the family's agreement, you call the admission nurse, put the phone on speaker and ask the hospice representative to describe their services.
- You suggest a Behavioral Health Provider could help the family process the prognosis and manage the depression symptoms.
- At the end of the meeting, you ask if the family has any questions about her ongoing care. You reinforce the fact that if they choose hospice care, you will continue to follow Mrs. Hedgepath and get regular reports from the hospice nurse and medical director.
- You state you will work hard to insure that she is kept comfortable and has quality time with her family regardless of whether they elect hospice care, but you encourage them to seriously consider it as it is the very best care available for this time.

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Hospice Representative

- When called by the Primary Care Provider to discuss hospice services, you summarize what hospice can offer including: regular visits by team members (nurse, chaplain, social worker, nurse practitioner and/or physician), assistance with personal care by a nursing assistant, provision of supplies, equipment, medications related to her primary diagnosis, and a nurse available to talk with the family and make home visits if needed 24 hours a day.
- You explain that if Mrs. Hedgepath chooses hospice care, her Medicare will cover the costs of the services.
- You state that the goal of hospice care is to provide support and comfort to the patient and family.
- You explain that hospice care can be provided in the home, nursing home or hospital if inpatient care is needed. You ask if they have any questions.
- If the family asks if Mrs. Hedgepath is eligible for hospice care based on her prognosis, you say yes – hospice care is for the last six months of life – not just the very end.
- You reiterate that hospice would support Mrs. Hedgepath’s goal to stay home.
- You tell the family they can call the hospice if they want to have an admission visit to assess Mrs. Hedgepath and discuss services further. You ask the community Health Navigator to give them you the number.

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Behavioral Health Provider (Social Worker or Counseling Psychologist)

The role of the behavioral health practitioner is to conduct an assessment to understand the underlying drivers of the presenting mental health condition to adequately craft a treatment plan or make the necessary referrals to other services that may address the underlying mental health issues.

- When cued by the Community Health Navigator, state you are here to offer emotional support for the many stressors they have been facing as a family. Explain that you can offer individual and group/family assessment and treatment/counseling if they would like to take advantage of it. Your services are in addition to hospice services.
- Explain that upon reviewing her case, you noticed that Mrs. Hedgepath had mentioned being depressed before. Ask her if that is still the case. Probe for her to explain her symptoms and ask about the duration and intensity of the symptoms (e.g., how long has she been experiencing symptoms; how would she assess the intensity of the current symptoms; have the symptoms maintained the same intensity over time?). Ask about whether certain things make the symptoms worse or better to begin to identify risk and protective factors.
- When she explains her symptoms have been getting worse since their health problems have worsened, explain that it is very understandable, given what they have been facing, but that you can offer help. First you can consult with MD or Psych NP to start her on an anti-depressant, second you can offer to work with her over a few sessions on processing what she is going through and explore ways to treat her depression through therapy. Ask her if she would like to do that?

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Thelma Hedgepath

When you are asked by the primary care provider about what you understand about your illness, you explain that this cancer is just a temporary bump in the road. Explain that you plan to live a long life with your husband.

After the primary care provider explains your diagnosis and prognosis, you are surprised by the news that you only have weeks or months to live. You become tearful and ask if this is true.

Based on the Primary Care Provider's suggestion, you agree to talk with the hospice admission staff on the phone about hospice services.

After the hospice representative describes their services, you ask if you are eligible because you plan to live as long as you can and you thought hospice was for only the last weeks of life.

Towards the end of the meeting, you become more accepting. You state you know you were not getting better and agree that hospice care may be the best thing for you now because your goal is to be at home with your husband.

You also acknowledge that you have been depressed when the behavioral health provider brings it up. When asked about duration and intensity, respond that you have been experiencing:

- a lack of interest in things and extreme sadness for quite some time,
- sleep problems, lack of sleep
- irritability
- Trouble concentrating
- Frequent thoughts of dying
- The symptoms have been happening since you and your husband's health issues have worsened
- the worsening physical health has led to worsening depression.
- When asked what makes your depression worse, respond about having fears of death and suffering.
- When asked what makes it better, respond that time with family and other distractions help.

Agree to explore medication and therapy for your depression.

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Joe Hedgepath

- You don't want to believe what the primary care provider says about Thelma's prognosis.
- You insist she is going to get better and that you do not want to hear this news.
- You resist the idea of hospice care saying it is only for dying people and Thelma is not dying.
- You become a bit angry during the discussion and are resistive to plans not to do any further treatment of Thelma's cancer.

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Debbie Hedgepath – daughter

- You do not want to accept the prognosis or the idea of hospice care.
- You become tearful and keep telling your mother not to believe she is dying.
- You note that just last month, she was able to cook your favorite meal for your birthday dinner.
- You are totally resistive to the idea of hospice care.
- You blame yourself for not being there more to make sure Mom and Dad eat right.
- You promise you will help more in the future so that your mother will get well.
- You say your family doesn't need strangers to come in and care for their parents.
- You insinuate that your brother's inadequate care for your parents is the problem – not mom's condition.

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Danny Hedgepath – son

- You are more accepting of the prognosis and need for hospice care because you have seen your mother's recent decline.
- You know the family needs help – you have been doing it alone but you can't keep on.
- You encourage your parents and sister to consider enrolling in hospice saying that the services described are very much needed, will make life better for everyone and will help Mom stay home rather than being in a hospital.
- You get a bit angry and defensive with your sister for insinuating that your care for your parents has been inadequate.