"I Can't Go Back into That Room!" Strategies to Help Multidisciplinary Team Members Work With Difficult Patients and Families

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Have no Conflict of Interest to Declare

Objectives

- Describe 3 concrete tools/interventions to be used by multidisciplinary members and patients and/or caregivers that have potential to improve interactions.
- Articulate how to engage patients and families in personalizing such tools/interventions.
- Explain how to get multidisciplinary teams to realistically consider using these tools/interventions.
- Distinguish between situations that would benefit from implementation of a concrete tool/intervention vs. situations that require education and coaching for team members.
Family Systems Theory

- Each person is viewed as part of a bigger circle, with different combinations and complexity of relationships.
- When there is change, the family and subsystems will be affected. The entire system will attempt to retain and sustain balance.
- Variations exist in ability of each family member's capacity to adjust to change.
- Assessment and interventions are carried out with consideration of the impact on all family members.
- The psychosocial team attempts to develop relationships with the primary figures in the child's life.


Family Systems Illness Model

- John S. Rolland, known for his Family Systems Illness Model, states “Most families dealing with disabling or life threatening conditions can become symptomatic, regardless of how well they initially appear to be functioning in all aspects of family life” (Rolland, 1994).

Symptoms to look for:
- Non-Compliance: Teens and young adults
- Resistance/Refusal: Toddlers, school-age children, teens, young adults
- Combative Behavior: Toddlers, school-age children, teens, young adults
- Manipulative Behavior: School-age children, teens, young adults

Symptoms to look for in caregivers:
- Disengaging During Discussions with Providers: Often looks as if they are “ignoring” providers, staff, the patient, other family members.
- Irritability: With providers, RNs, staff, the patient, other family members.
- Non-Compliance: Related to inpatient unit rules, discharge and/or medication instructions, appointments etc.

Oncology physicians and nurses have extensive knowledge about the medical aspects of treatment. They may struggle when it comes to understanding the mental, emotional, social, and spiritual aspects that come with an oncology diagnosis and subsequent treatment. Also, many may struggle to understand the impact on the patient and those who love them.


Nursing Assistant: "I have told this mother on multiple occasions that we need to measure in and out, but she keeps throwing away the diapers. You have to do something about this!"

Clinical Social Worker: "That must be frustrating. Have you thought about...

Clinic Social Worker: "Yes, that mother is abusive!"

Clinical Social Worker: "Oh my, can you give me an example?"

Nurse: "That sweet 3 year old peed in her diaper, and mom screamed at her and popped her leg. Do you think we should call Child Protective Services?"

Clinical Social Worker: "Did it leave a bruise? If so, are her platelets low? Has mother been educated about bruising risks with low platelets?"

Nurse: "No, there is not a bruise and her platelets are fine. Do you think I should tell mom when her platelets are low that she will bruise very easily?"

Clinical Social Worker: "Yes, that education would be beneficial, even now when her platelets are okay, for future reference. I understand it is hard when someone utilizes parenting techniques we do not agree with, but there is nothing Child Protective Services will do about a mother screaming at and popping her child for peeing in her diaper. Let's talk about how we can try to model different responses for this mother."

Challenges to Our Personal Values and Standards

As Clinical Social Workers, we understand that our patients may have different values and standards that may influence our interactions with them. It is important to acknowledge and respect these differences while also maintaining our own professional standards and values. It is part of our role to encourage our multidisciplinary teams to understand this as well.
Factors that May be at Play:
- Religion
- Culture
- Denial
- Fear

Examples from the audience?

Physician: "That child is suffering, the parents are refusing a Do Not Attempt Resuscitation order. Isn't there anything you can do? Why do these parents not understand they are hurting their child?"

Patient/Caregiver Interventions
- Caregiver Agreements and Personalized Caregiver Agreements
- Scripted Responses
- About Me
- Behavior Contracts

Caregiver Agreements: Standard Agreement

What is a Standard Caregiver Agreement?

A standard care agreement is a document reviewed and signed by the patient's identified caregiver. This type of agreement is typically not personalized and therefore can be used with any patient/caregiver seen in the treatment clinic or facility. The agreement is reviewed with the caregiver by the Clinical Social Worker, Nurse Coordinator, or Nurse Practitioner. The caregiver is then asked to sign the agreement and told that by signing, they are stating that they understand the caregiver expectations within the agreement and commit to following those expectations.

Important Elements of a Standard Caregiver Agreement

- An explanation as to why it is important to have an identified caregiver
- A description of what will be expected of the caregiver throughout the treatment process
- A description of the training the caregiver will receive
- Contact information for identified caregiver
- Name and contact information of a secondary caregiver in the event that the identified caregiver is ill or otherwise unavailable
- Signature lines for patient (if age appropriate), caregiver, and secondary caregiver (if possible)

Caregiver Agreements: When a Personalized Agreement is Needed

When to use a Personalized Caregiver Agreement

A personalized caregiver agreement is typically issued when there are specific barriers identified that have the potential to negatively impact care of the patient. Barriers may involve non-adherence to caregiver expectations or the treatment plan by the caregiver (non-adherence by the patient will be addressed later in the presentation). This can include, but is not limited to: leaving the patient alone on the treatment unit for long periods of time, failing to fill inpatient and outpatient prescriptions for patient, failing to call clinic appointments or presenting late to appointments, and/or not filling pre-authorization for patient care.

This agreement should be reviewed with the caregiver in a Family Meeting or Patient Care Conference. The components are: Caregiver, Physician, and one other member of the medical team (Nurse Practitioner, Fellow, Nurse Manager of CBSC, or Inpatient Unit Nurse, etc.) should be present.

Important Elements of a Personalized Caregiver Agreement

- A statement as to why a Personalized Caregiver Agreement is being utilized
- Identification of the expectations surrounding the specific barriers identified
- Contact information for identified caregiver
- What steps will be taken if the expectations listed in the Personalized Caregiver Agreement are not met
- Signature lines for Primary Physician and second member of the Medical Team, the Clinical Social Worker, and the caregiver(s).

Sample Personalized Caregiver Agreement

An 11 year old post Matched Unrelated Donor Transplant patient was being cared for by his maternal grandmother, who is his legal guardian. Patient and grandmother were often late or did not present for appointments. Grandmother often did not answer her phone. When grandmother's phone was answered, it was usually the patient answering, who would report grandmother was sleeping or in the shower. Patient was not participating in school, as the homebound teacher was also having difficulty getting in touch with grandmother. There were incidents where grandmother would report patient had fever, etc. after the fact, when the expectation is for caregivers to call to report fevers when they occur. Additionally, it was discovered that grandmother took patient out of the state before the physician released the patient to leave a 10-mile radius of the transplant facility.

Scripted Responses

Scripted Responses are helpful when dealing with a patient or caregiver’s disruptive or inappropriate behavior that interferes with the patient’s care. These types of behavior can hinder or prevent Multidisciplinary Team Members from carrying out their professional responsibilities related to patient care. Scripted responses have their basis in Script Theory. Script Theory was formulated by Roger Schank and Robert Abelson (1977). Following a script can be useful because it could help to save the time and mental effort of deciding on appropriate responses to behaviors each time a situation is encountered.

Humans learn scripts through repetitive social interaction and use them to interpret new experiences (Nelson, 1986). Once a script has been internalized, it influences one’s intentions, expectations, interpretations, and behaviors (Anderson, 1983).
**Example: Scripted Responses to Inappropriate Comments**

- 16 year old female unrelated cord blood transplant patient transplanted to treat a genetic disorder which can cause symptoms such as hyperactivity, visual or auditory problems, impaired coordination, seizures, and loss of neurologic function.
- This patient presented as hypersexual with impulsivity.
- Parents asked that MDT immediately address inappropriate comments in a consistent, direct, and simple way.

**SCRIPTED RESPONSES utilized when patient makes inappropriate comments.**

Parents requested that all responses ended with “So not cool.”

"You asked me if my boyfriend and I have sex. That’s not appropriate. So not cool."

"You asked me if I thought Dr. Robert was a good kisser. That’s not appropriate. So not cool."

"You asked me to show you my breasts. That’s not appropriate. So not cool."

**Example: Scripted Responses to Disruptive Behavior**

- Mother of newly diagnosed oncology patient who interacted with MDT by typically ignoring their presence, unless she perceived them to be neglectful or harmful toward her daughter; she would respond with arguments, yelling, and occasional physical threats.

If mother yells or threatens, staff will calmly say “I’m leaving” and leave the room after first insuring the patient is safe. Staff will not argue or discuss things when mother is upset enough to yell. Staff will notify the physician so that they can provide support if needed.

Staff will let mother know when they will be unavailable for a period of time (i.e. who will do bath, bed, mouth care etc.). Staff will also communicate tasks as they are done or let mother know if they can’t do it and ask mother to help with the task.

Staff will over-communicate to mother about the plan at the start of each shift (i.e. who will do bath, bed, mouth care etc.). Staff will also communicate tasks as they are done (i.e. who will do bath, bed, mouth care etc.). Staff will notify the physician so that they can provide support if needed.

Staff will let mother know when they will be unavailable for a period of time IF they know about it ahead of time. Otherwise, they will check in after they have been previously unavailable.

Staff will over-communicate to mother about the plan at the start of each shift (i.e. who will do bath, bed, mouth care etc.). Staff will also communicate tasks as they are done (i.e. who will do bath, bed, mouth care etc.). Staff will notify the physician so that they can provide support if needed.

**Important Elements of Scripted Responses**

- Whenever possible, first discuss inappropriate or disruptive behavior with the patient (if appropriate) and caregiver felt to be interfering with the patient’s care.
- Then, attempt to engage them in creating scripted responses for staff (verbal and behavioral), with a focus on improving communication and care for the patient.
- If not possible to discuss with patient or caregiver, engage affected members of MDT to identify when scripted responses will be utilized and what these responses will be.

In both instances, once scripted responses are established, they should be clearly understood, reviewed with the patient or appropriate caregiver, and re-done during a Family Meeting or Patient Care Conference, with Primary and/or Attending Physician, Nurse Manager, and Clinical Social Worker. Nurse Manager and Clinical Social Worker should also review with MDT members impacted. Additionally, all parties should have copies of the planned scripted responses.
About Me

- Provides insight into family dynamics and biopsychosocial information
- Let's the child describe who lives in the household
- Collaborate with Child Life
- Can be fun!
Behavior Contracts

- An intervention that focuses on strengths perspective and positive reinforcement
- Collaborative and allow input from the child to suggest goals and steps to change behaviors
- Be detailed and specific
- Spell out the expectations of the MDT/providers/hospital
- Negotiate between patient and MDT/parents
- Provide steps to be successful and rewards if compliant
- Sign and post where all can see it for reinforcement


Parent-Child Behavior Contract

This contract begins on and stops on . We agree to look at it after the , to see if needed to adjust any details or remove goals.

Goals

Goal 1:
- Step to success
- Step to success
- Step to success

Goal 2:
- Step to success
- Step to success
- Step to success
- Step to success

Rewards & Consequences

Reward: As a reward for meeting a goal or for following one of the steps for success, ____________________________.

Consequences: As a consequence for not following at least one of the steps for success, ____________________________.

Signatures

[Signatures]

[Signature]

[Signature]

[Signature]
Example: Behavior Contract

Goal 1: Take medication (oral liquid)
- Steps for success: Will count down from 3 and do
- Steps for success: have a snack or juice selected and ready after all medicine has been taken
- Reward: Sticker chart, window art, video game, or tablet time
- Consequence: no playroom or tablet time

Case Scenarios

Scenario 1
- Parent/Guardian
- Child
- Diversity of religion

Scenario 2
- Parent/Guardian
- Teen
- Cultural/Socioeconomic diversity

Scenario 1: Cultural Competency

A four-year-old female is admitted to the inpatient oncology unit to begin treatment for neuroblastoma. During a meeting with the MDT, her guardians disclose that they are Jehovah’s Witnesses, practicing members of a faith that prohibits the transfusion of blood products. They also state that they do not want their daughter’s upcoming birthday to be acknowledged, nor any holidays, specifying that they do not want holiday decorations in the immediate area surrounding her room. They appear suspicious of the clinical social worker, and minimally engage with medical personnel.

“Definition of Cultural Competence: One of social work’s core ethical responsibilities to clients; it affects a social worker’s responsibilities in understanding the relationship between culture and personal identity, exploring the uniqueness and strengths of varying cultures, and implementing the developing cultural and ethnic diversity.”

References:
A fifteen-year-old male is admitted to the inpatient bone marrow transplant unit for treatment of acute myeloid leukemia (AML). His mother is the only caregiver present at the time of admission, at which point she completed the standard caregiver agreement. The social worker on staff makes several attempts to contact the relative listed as the secondary caregiver on the agreement, but neither the phone number nor home address are valid. When the issue is addressed with the mother, she responds “It’s just me; I am the only one who can take care of him. There is no one else.” She has also personally violated the agreement, as she has left the unit without notifying the appropriate staff member and failed to respond to phone calls during times when she was absent. She has disclosed to several members of the MDT that she struggles financially, and that she fears she may lose her housing and employment due to the demands of treatment.

**Definition of Diversity:** Respecting and safeguarding the individuality of all people resulting from differences in factors such as race, ethnicity, sexual orientation, socio-economic level, age, gender, disability, among others.

**References:**