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

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Objectives

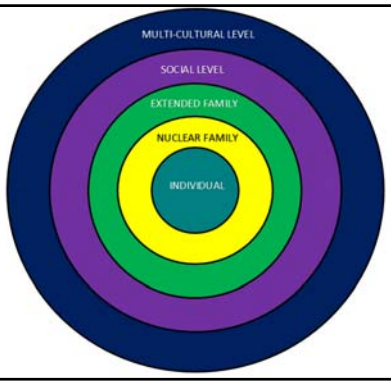
- Describe 3 concrete tools/interventions to be used by multidisciplinary members and patients and/or caregivers that have potential to improve interactions.
- Articulate how to engage patients and families in personalizing such tools/interventions.
- Explain how to get multidisciplinary teams to realistically 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.

Turner, J.C. (2009). The Handbook of Childlife: A guide for pediatric psychosocial care. Springfield, IL: Charles C. Thomas Publisher, LTD.

- Family that lives in the home
- Grandparents, Extended family
- Classmates, Coworkers, Friends, Neighbors, Faith Community
- Socioeconomic, Cultural, Ethnic, Racial, Geographical framework



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 in Patients:

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
Irritability: With providers, RNs, staff, the patient, other family members
Anger Outbursts: verbal or physical
Non-Compliance: Related to inpatient unit rules, discharge and/or medication instructions, appointments etc.

Rolland, J. (1994). *Families, Illness and Disability: A bio-psychosocial intervention*, New York, NY: Ingram Publishers Services US.

They Don't Know What They Don't Know: Educating your Multidisciplinary Team

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.

Hull, S.K., & Broquet K. (2007). How to Manage Difficult Patient Encounters. American Academy of Family Physicians: Family Practice Medicine, 14 (6). Retrieved from https://www.aafp.org/fpm/2007/0600/p30.html

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

Clinical Social Worker: "I see, that must be frustrating. Have you thought about…"

- "the fact that this mother, who is generally on top of things, is overwhelmed with all of this new information, being separated from her other children, and has a million things she is trying to remember? Sometimes it is hard to remember everything. What are some ideas about how to help her with that?"
- "the fact that in their culture, having soiled items in the same place they pray may be considered egregious? Maybe we can talk with her and come up with an idea that will work for everyone."
- Other examples from the audience?

Back, A., Arnold, R., & Tulsky, J. (2009). Mastering Communication with Seriously Ill Patients: Balancing honesty with empathy and hope. New York, NY: Cambridge University Press.

Challenges to Our Personal Values and Standards

As Clinical Social Workers, we understand that our patients may have different values or standards than our own. It is part of our role to encourage our multidisciplinary teams to understand this as well.

Nurse: "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."

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?"

Factors that May be at Play:

- Religion
- Culture
- Denial
- Fear
- Examples from the audience?

Patient/Caregiver Interventions

- Caregiver Agreements and Personalized Caregiver Agreements
- Scripted Responses
- About Me
- Behavior Contracts

Caregiver Agreements: Standard Agreement

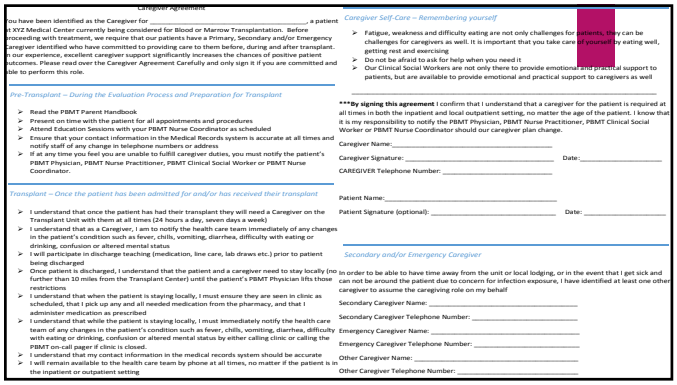
What is a Standard Caregiver Agreement?

A standard caregiver 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 treatment facility. This 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.

Schank, R.C. & Abelson, R. (1977). Scripts, plans, goals, and understanding. Hillsdale, NJ: Erlbaum.

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 Agreement

You have been identified as the Caregiver for _____, a patient at XYZ Medical Center currently being considered for Blood or Marrow Transplantation. Before proceeding with treatment, we require that our patients have a Primary, Secondary and/or Emergency Caregiver identified who have committed to providing care to them before, during and after transplant. In our experience, excellent caregiver support significantly increases the chances of positive patient outcomes. Please read over the Caregiver Agreement Carefully and only sign it if you are committed and able to perform this role.

Pre-Transplant – During the Evaluation Process and Preparation for Transplant

- Read the PBMT Parent Handbook
- Present on time with the patient for all appointments and procedures
- Attend Education Sessions with your PBMT Nurse Coordinator as scheduled
- Ensure that your contact information in the Medical Records system is accurate at all times and notify staff of any change in telephone numbers or address
- If at any time you feel you are unable to fulfill caregiver duties, you must notify the patient's PBMT Physician, PBMT Nurse Practitioner, PBMT Clinical Social Worker or PBMT Nurse Coordinator.

Transplant – Once the patient has been admitted for and/or has received their transplant

- I understand that once the patient has had their transplant they will need a Caregiver on the Transplant Unit with them at all times (24 hours a day, seven days a week)
- I understand that as a Caregiver, I am to notify the health care team immediately of any changes in the patient's condition such as fever, chills, vomiting, diarrhea, difficulty with eating or drinking, confusion or altered mental status
- I will participate in discharge teaching (medication, line care, lab draws etc.) prior to patient being discharged
- Once patient is discharged, I understand that the patient and a caregiver need to stay locally (no further than 10 miles from the Transplant Center) until the patient's PBMT Physician lifts those restrictions
- I understand that when the patient is staying locally, I must ensure they are seen in clinic as scheduled, that I pick up any and all needed medication from the pharmacy, and that I administer medication as prescribed
- I understand that while the patient is staying locally, I must immediately notify the health care team of any changes in the patient's condition such as fever, chills, vomiting, diarrhea, difficulty with eating or drinking, confusion or altered mental status by either calling clinic or calling the PBMT on-call pager if clinic is closed.
- I understand that my contact information in the medical records system should be accurate
- I will remain available to the health care team by phone at all times, no matter if the patient is in the inpatient or outpatient setting

Caregiver Self-Care – Remembering yourself

- Fatigue, weakness and difficulty eating are not only challenges for patients, they can be challenges for caregivers as well. It is important that you take care of yourself by eating well, getting rest and exercising
- Do not be afraid to ask for help when you need it
- Our Clinical Social Workers are not only there to provide emotional and practical support to patients, but are available to provide emotional and practical support to caregivers as well

_____

*****By signing this agreement** I confirm that I understand that a caregiver for the patient is required at all times in both the inpatient and local outpatient setting, no matter the age of the patient. I know that it is my responsibility to notify the PBMT Physician, PBMT Nurse Practitioner, PBMT Clinical Social Worker or PBMT Nurse Coordinator should our caregiver plan change.

Caregiver Name:_____

Caregiver Signature: _____ Date:_____

CAREGIVER Telephone Number: _____

Patient Name:_____

Patient Signature (optional): _____ Date: _____

Secondary and/or Emergency Caregiver

In order to be able to have time away from the unit or local lodging, or in the event that I get sick and can not be around the patient due to concern for infection exposure, I have identified at least one other caregiver to assume the caregiving role on my behalf

Secondary Caregiver Name: _____

Secondary Caregiver Telephone Number: _____

Emergency Caregiver Name: _____

Emergency Caregiver Telephone Number: _____

Other Caregiver Name: _____

Other Caregiver Telephone Number: _____

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 inpatient unit for long periods of time, leaving the inpatient unit and not informing the care nurse, not being available by telephone, not bringing patient to clinic appointments or presenting late to appointments, and/or not filling prescriptions for patient.

This agreement should be reviewed with the caregiver in a Family Meeting or Patient Care Conference. The caregiver(s), Clinical Social Worker, Primary Physician, and one other member of the medical team (Nurse Practitioner, Fellow, Nurse Manager of Clinic, or Inpatient Unit Nurse, etc.) should be present.

Farrell, M., & Terry, W. (2016). Communication with Patients, Family and the Health Care Team. State of Washington Medical Quality Assurance Commission. Retrieved May 5, 2018, from https://www.doh.wa.gov/Portals/1/Documents/3000/MD201604CommunicationGuideline.pdf

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.

Caregiver Agreement

Caregiver: XXXX
Physician: Dr. PBMT
Nurse Practitioner: Sally Stem-Cell, NP
Clinical Social Worker: April Advocate, MSW, LCSW, OSW-C

To facilitate comprehensive care and safety for the duration of transplant treatment at XYZ Hospital for patient YYYY the following expectations have been discussed with and agreed to by Caregiver XXXX.

1. XXXX will be accessible by personal cell phone and Ronald McDonald House room phone, returning calls within _____ minutes if a provider or team member leaves a message.
2. XXXX and YYYY will arrive at the CHC clinic by 11:00 A.M. on clinic days to ensure time to repeat labs or administer infusion as necessary.
3. XXXX will ensure YYYY participates in school by creating a supportive school environment at the Ronald McDonald House and arriving timely to clinic so school can be conducted on clinic days as necessary.
4. XXXX and YYYY will use the Ronald McDonald House shuttle to attend clinic appointments if a personal vehicle is not usable.
5. XXXX and YYYY will not leave the Durham area without informing providers so that a medical letter can be provided to them to use in the event of a medical emergency.
6. XXXX will communicate any and all concerns and needs to medical providers and Clinical Social Worker as they arise, including any concerning symptoms or health events.

If these expectations are not met, potential weekend passes may be impacted. In the event that it is felt that additional support is needed to help XXXX meet these expectations, the medical team may contact the identified secondary caregiver, ZZZZ, to assist.

XXXX	Sally Stem-Cell, NP
Dr. PBMT M.D.	April Advocate, MSW, LCSW, OSW-C

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 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 OR let mother know if they can't do it and ask mother to help with the task.

Important Elements of Scripted Responses

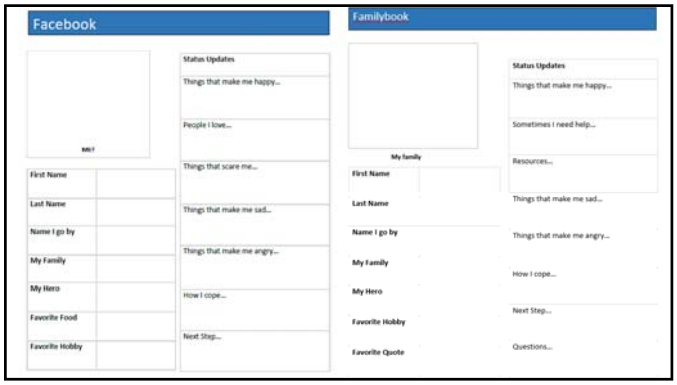
•Whenever possible, first discuss inappropriate or disruptive behavior with the patient (if appropriate) and caregiver felt to be interfering with the patient's care . Then, attempt to engage them in creating scripted responses for staff (verbal and behavioral), with a focus on improving communication and care for the patient.

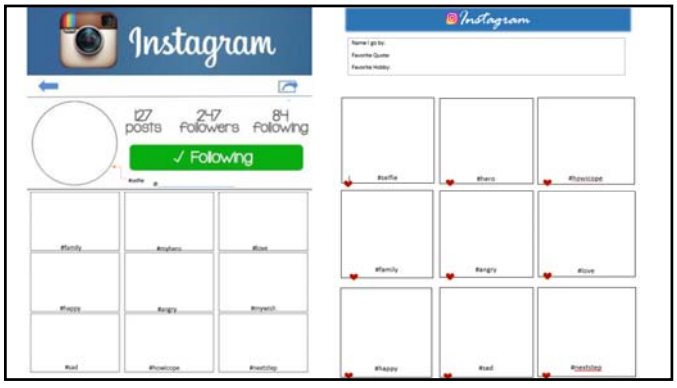
•If not possible to discuss with patient or caregiver, engage affected members of MDT to clearly identify when scripted responses will be used and what these responses will be.

•In both instances, once scripted responses are established, they should be clearly written out, then reviewed with the patient (if appropriate) and caregiver. This is best 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
- Collaborate 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

Mancini J.A., Bowen G.L. (2013) Families and Communities: A Social Organization Theory of Action and Change. In: Peterson G., Bush K. (eds) Handbook of Marriage and the Family. Springer, Boston, MA.

Parent-Child Behavior Contract

This contract between _____ and _____ begins on _____. We agree to look at it again after _____ to see if we need to adjust any details or set new goals.

Goals

Goal 1: _____

Step for success: _____

Step for success: _____

Step for success: _____

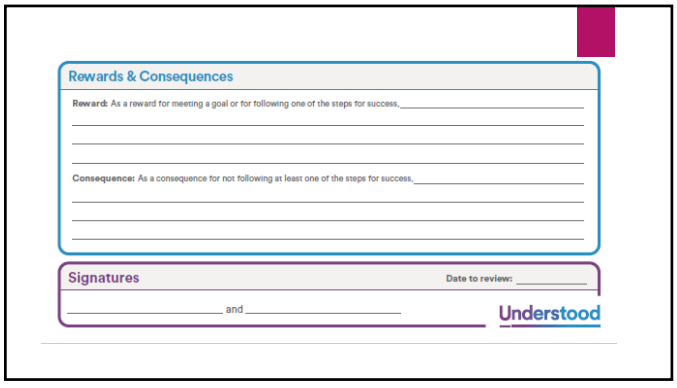
Goal 2: _____

Step for success: _____

Step for success: _____

Step for success: _____

Morin, Amanda. "Understood | For Learning and Attention Issues." *Understood.org*, 2014, www.understood.org/en.



Rewards & Consequences

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

Consequence: As a consequence for not following at least one of the steps for success, _____

Signatures Date to review: _____

_____ and _____

Understood

Example: Behavior Contract

Goal 1: Take medication (oral liquid)

- Steps for success: Will count down from 3 and sip
- 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 refers to a social worker's responsibilities in understanding the relationship between culture and personal identity, recognizing the uniqueness and strengths within varying cultures, and experiencing and studying cultural and ethnic diversity.*

***References:** Allen-Meares, P. (2007). Cultural competence: An ethical requirement. Journal of Ethnic and Cultural Diversity, 16(3/4), 83-92. Guy-Walls, P. (2007). Exploring cultural competence practice in undergraduate social work education. Education, 127(4), 569-580. National Association of Social Workers. (1999). Code of Ethics. Washington, DC: Author. Simmons, C., Diaz, L., Jackson, V., & Takahashi, R. (2008). NASW cultural competence indicators: A new tool for the social work profession. Journal of Ethnic and Cultural Diversity in Social Work, 17(1), 4-20."*

Scenario 2: Diversity

- 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: *Kohli, H.K., & Faul, A.C. (2005). Cross-cultural differences towards diversity issues in attitudes of graduating social work students in India and the United States. International Social Work, 48(6), 809-822. Maidment, J., & Cooper, L. (2002). Acknowledgement of client diversity and oppression in social work student supervision. Social Work Education, 21(4), 399-407."*

Questions and Discussion

References

- Anderson, Craig. (1983). Imagination and expectation: The effect of imagining behavioral scripts on personal influence; Journal of Personality and Social Psychology, 1983. Vol. 4'. No.2. 293-30
- Back, A., Arnold, R., & Tulsky, J. (2009). Mastering Communication with Seriously Ill Patients: Balancing honesty with empathy and hope. New York, NY: Cambridge University Press.
- Eriksson, M., Ghazinour, M. & Hammarström, A. (2018). Different uses of Bronfenbrenner's ecological theory in public mental health research: what is their value for guiding public mental health policy and practice. Social Theory & Health. Retrieved from https://doi.org/10.1057/s41285-018-0065-6
- Farrell, M., & Terry, W. (2016). Communication with Patients, Family and the Health Care Team. State of Washington Medical Quality Assurance Commission. Retrieved May 5, 2018, from https://www.doh.wa.gov/Portals/1/Documents/3000/MD201604CommunicationGuideline.pdf
- Hull, S.K., & Broquet K. (2007). How to Manage Difficult Patient Encounters. American Academy of Family Physicians: Family Practice Medicine, 14 (6). Retrieved from https://www.aafp.org/fpm/2007/0600/p30.html
- Mancini J.A., Bowen G.L. (2013) Families and Communities: A Social Organization Theory of Action and Change. In: Peterson G., Bush K. (eds) Handbook of Marriage and the Family. Springer, Boston, MA.
- National Cancer Institute. (2018). Communication in Cancer Care (PDQ®) Health Professional Version. Retrieved August 21, 2018, from https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/communication-hp-pdq#section/_AboutThis_1
- Nelson, K. 1986. Event knowledge: Structure and function in development, Hillsdale, NJ: Erlbaum.
- Rolland, J. (1994). Families, Illness and Disability: A bio-psychosocial intervention, New York, NY: Ingram Publishers Services US.
- Schank, R.C. & Abelson, R. (1977). Scripts, plans, goals, and understanding. Hillsdale, NJ: Erlbaum.
- Turner, J.C. (2009). The Handbook of Childlife: A guide for pediatric psychosocial care. Springfield, IL: Charles C. Thomas Publisher, LTD.