Education & Training Curriculum on Multiple Chronic Conditions (MCC)

Strategies & tools to support healthcare professionals caring for people living with MCC.

Module 1

Person- and Family-Centered Care

Full citations for this presentation appear in the notes section of the slides.

Slide 1 Speaker Notes

This is the first module of the HHS Education & Training Curriculum on Multiple Chronic Conditions (MCC) —a six-module curriculum designed for academic faculty, educators and trainers to inform healthcare professionals caring for persons living with multiple chronic conditions. Based on the MCC Education and Training Framework *(http://www.hhs.gov/ash/initiatives/mcc/education-and-training/index.html),* these modules provide knowledge and tools healthcare professionals can use as they improve quality of care of persons living with MCC.

Terminology used throughout this presentation:

- Multiple chronic conditions (MCC) is defined many ways in the literature and in practice. For the purposes of this presentation, MCC is defined as a person with two or more concurrent chronic conditions. Other similar terms used are complex patient, multimorbidity and comorbidity for this population.
- "Persons living with multiple chronic conditions" (PLWMCC) is used instead of "patient" to place greater emphasis on the individual being at the center of care.

Each module contains a PowerPoint® slide presentation that can used as part of the MCC curriculum series or independently as an introduction to the concepts of Person- and Family-Centered Care for healthcare professionals new to this material. The presentation can be saved, modified, and used in your presentations with healthcare professionals at any stage of education (undergraduate, graduate or continuing education). The notes in the presentation will help guide your talking points during the presentations.

Visit http://www.hhs.gov/ash/initiatives/mcc/education-and-training/index.html to download this and other modules—and to access helpful tools and resources.

Suggested citation:

U.S. Department of Health and Human Services. Multiple Chronic Conditions Initiative. Education and Training Curriculum on Multiple Chronic Conditions. Washington, DC. June 2015.

Learning objectives for this module

After completing this module, you will be able to:

- Communicate the benefits of Person- and Family-Centered Care (PERS) for persons living with multiple chronic conditions (PLWMCC)
- Apply PERS care strategies with PLWMCC

Slide 2 Speaker Notes

This module of the MCC Curriculum, “Person- and Family-Centered Care” provides you with:

1. an overview of person- and family-centered care as an effective mechanism for healthcare professionals to help people manage their multiple chronic conditions and
2. practical strategies and resources for integrating person- and family-centered care into your practice.

Overview of contents in this module

- Investing in persons living with multiple chronic conditions (PLWMCC) using Person- and Family-Centered Care (PERS)
- What makes PERS effective?
- Incorporating PERS for PLWMCC into practice

Slide 3 Speaker Notes

This module is divided into three sections that describe various person- and family-centered care strategies to help you incorporate person- and family-centered care into your practice. Links to useful resources that further support identified strategies are also included.

Section 1

Investing in PLWMCC using PERS

Slide 4 Speaker Notes

This section defines person- and family- centered care (PERS), identifies key PER competencies to care for persons living with multiple chronic conditions (PLWMCC) and presents the benefits of PERS with PLWMCC.

Person- and Family-Centered Care (PERS)

Definition:

Care that involves persons living with multiple chronic conditions (PLWMCC) and their families in every decision, and that empowers them to be partners in their own care.

Slide 5 Speaker Notes

While similar definitions exist using similar names, we are defining “Person- and Family-Centered Care” as care that involves persons living with multiple chronic conditions and their families in every decision, and that empowers them to be partners in their own care. [1] This definition recognizes the critical role patients/PLWMCC and their families play in optimizing the health of persons living with multiple chronic conditions.

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[1] Institute of Medicine (US). Committee on Quality of Health Care in America. (2001). Crossing the quality chasm: A new health system for the 21st century. National Academy Press.

PERS Competencies

1. Participate with PLWMCC and their families and caregivers in identifying and prioritizing their preferences when developing a care plan.

2. Include life context and social and cultural determinants of health when negotiating goals and plans of care with PLWMCC.

3. Assist PLWMCC in reaching their identified lifestyle, management and treatment goals.

Slide 6 Speaker Notes

Here are five competencies for Person- and Family-Centered Care (PERS) needed to appropriately provide care to PLWMCC. The underpinning concepts that support these competencies are discussed in greater detail in this presentation.

The competencies are:

PERS 1. Participate with PLWMCC and their families and caregivers in identifying and prioritizing their preferences when developing a care plan.

PERS 2. Include the life context and social and cultural determinants of health of PLWMCC when negotiating goals and plans of care with PLWMCC.

PERS 3. Assist PLWMCC in reaching their identified lifestyle, management and treatment goals.

PERS Competencies (Continued)

4 Provide care that is responsive to the preferences, needs and values of PLWMCC.

5 Provide care that is focused on the desired outcome(s) of PLWMCC.

6 Assist PLWMCC, as needed, with coordination of financial resources to optimize quality of care.

Slide 7 Speaker Notes

PERS 4. Provide care that is respectful of and responsive to the preferences, needs and values of PLWMCC.

PERS 5. Provide care that is focused on the desired outcome(s) of PLWMCC.

PERS 6. Assist PLWMCC, as needed, with coordination of financial resources to optimize quality of care.

Reasons for using PERS with PLWMCC

Person- and family-centered care involves respecting the values, needs and preferences of PLWMCC.

- Develops a stronger sense of independence and satisfaction in PLWMCC.
- Increases PLWMCC's trust in the healthcare system which may motivate adherence and actions that lead to better health outcomes.
- Aids families and caregivers in providing informal care and psychological support to PLWMCC.

Slide 8 Speaker Notes

Person- and family-centered care involves respecting the values, needs, and preferences of PLWMCC and applying the best evidence toward a shared goal of optimal health and quality of life.[1]

Person- and family-centered care is critical when caring for people living with multiple chronic conditions (PLWMCC) because it:

- develops a stronger sense of independence and satisfaction in PLWMCC[2];
- increases PLWMCC's trust in the healthcare system, which may motivate adherence and actions that lead to better healthcare outcomes[3]; and
- aids families and caregivers in providing informal care and psychosocial support to PLWMCC.

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[1] Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A.,… & Sunnerhagen, K. S. (2011). Person-centered care--ready for prime time. Eur J Cardiovasc Nurs, 10(4), 248-251.

[2] Lee, Y. Y., & Lin, J. L. (2010). Do patient autonomy preferences matter? Linking patient-centered care to patient-physician relationships and health outcomes. Soc Sci Med, 71(10), 1811-1818.

[3] Venetis, M. K., Robinson, J. D., Turkiewicz, K. L., & Allen, M. (2009). An evidence base for patient-centered cancer care: a meta-analysis of studies of observed communication between cancer specialists and their patients. Patient Educ Couns, 77(3), 379-383

Section 2

What makes PERS effective?

Slide 9 Speaker Notes

In this section “What makes person- and family-centered care (PERS) effective,” key principles, strategies and challenges of PERS will be discussed.

Healthcare Partnerships

Effective partnerships include clinicians working with PLWMCC, their families, and caregivers to achieve mutually agreed upon outcomes.

Slide 10 Speaker Notes

It is helpful for healthcare professionals to regard the patient-provider relationship as a partnership in which persons living with MCC (PLWMCC) are the focal point. An effective partnership consists of clinicians working in concert with PLWMCC, families and caregivers to achieve mutually agreed-upon outcomes.

Healthcare professionals can foster effective partnerships by:

- Clarifying the role of PLWMCC as part of the interprofessional care team;
- Supporting shared and personalized decision making;
- Enhancing communication among care team partners.

Not all PLWMCC are well informed about their medical conditions and how best to manage them. Clinicians, PLWMCC and their families working together help to develop skills and confidence in decision making when it comes to self-managing conditions [1].

[1] Okun, S., Schoebaum, S.C., Andrews, D., Chidambaran, P., Chollette, V., …& Henderson, D. (2014). Patients and Health Care Teams Forging Effective Partnerships Discussion paper. Washington, DC: Institute of Medicine.

A Care Plan

Change the conversation…

from *"What is the matter?"*

to

"What matters to you?"

- Serves as a living document
- Elaborates goals, strategies and processes for optimizing care and health
- Prioritizes activities based on PLWMCC's preferences and severity of health conditions
- Incorporates shared decision making
- Includes integrated care by the interprofessional team

Slide 11 Speaker Notes

Care plans have shown benefits for persons living with multiple chronic conditions (PLWMCC) of all ages from pediatrics[1] to adults[2]. PLWMCC must be involved in creating care plans. Not all PLWMCC in this group will have the ability to review, understand, provide input and agree to a care plan because of their conditions affecting their cognitive abilities. For PLWMCC who are children or have cognitive impairments (i.e., dementia or Alzheimer's), their designated family member or POA (Power of Attorney) should be highly involved in their care plan.

A care plan elaborates on the goals, strategies, and processes for optimizing care and health. Ideally, a care plan serves as a living document that is comprehensive and expected to change over time. It should be individualized, taking into account the PLWMCC'S preferences (taking into consideration that men and women with MCC may have different needs) and severity of health conditions. In addition to clinicians and PLWMCC (their families and caregivers), the care plan should be accessible to all members of the interprofessional team to ensure integrated care across settings and healthcare systems[2]. Care plans should be regularly reviewed and revised as goals change and health milestones are met.

In practice, multiple care plans exist but they should be integrated over time and also across diverse clinicians within their respective health systems[3] to improve efficiency and reduce fragmentation within the healthcare system.

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[1] Quigley L., Lacombe-Duncan A., Adams S., Hepburn C.M., & Cohen E. (2014). A qualitative analysis of information sharing for children with medical complexity within and across health care organizations. *BMC Health Services Research*.14:283-294

[2] Mercer T., Bae J., Velazquez M., Thomas S,. & Setji N. (Published online Apr 9, 2015). The highest utilizers of care: Individualized care plans to coordinate care, improve healthcare service utilization, and reduce costs at an academic tertiary care center. *J Hospital Medicine*. Retrieved April 20, 2015 from http://www.ncbi.nlm.nih.gov/pubmed/25854685

[3] Miller, D., Steele Gray, C., Kuluski, K., & Cott, C. (Published online October 30, 2014). Patient-Centered Care and Patient-Reported Measures: Let's Look Before We Leap. *Patient*. Retrieved February 20, 2015 from http://www.ncbi.nlm.nih.gov/pubmed/25354873

Things to Consider when Creating Care Plans for PLWMCC

Barriers for Clinicians

- Limited time to address all PLWMCC needs during an office visit
- Lack of time to communicate/consult with the interprofessional team
- Medication non-adherence of PLWMCC

Challenges for PLWMCC

- Difficulty prioritizing conditions, especially when tradeoffs of the treatments are not clearly explained or understood
- Difficulty managing multiple medications

Slide 12 Speaker Notes

Many barriers and challenges exist when caring for people living with multiple chronic conditions (PLWMCC), depending on the number of conditions and medications, they have to manage. Additionally, healthcare professionals may be uncertain about the potential benefits and harms of specific treatments due to the lack of evidence on MCC in clinical guidelines and other evidence-based practices.

Some barriers clinicians may experience when creating care plans for PLWMCC include:

1. Need for ample time to communicate/consult with an interprofessional team (e.g., cardiologist for heart disease, endocrinologist for diabetes)[1]
2. Lack of clinician time to address all PLWMCC needs during an office visit. Clinicians have a limited amount of time and are unable to address all of the needs and health concerns of someone with multiple chronic conditions during one office visit.
3. Lapses in medication adherence by PLWMCC.

PLWMCC may experience the following challenges when a care plan is developed and implemented:

1. PLWMCC may be confused about which conditions to prioritize when clinicians do not provide a clear explanation of the trade-offs among treatments. Treatment burden can result in poorer adherence to prescribed treatments and self-care[2].
2. PLWMCC typically have multiple medications that can be difficult to manage. Balancing multiple medications may reduce drug benefits and add harms, burdens and side effects[3].

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[1] Bolster, D., & Manias, E. (2010). Person-centered interactions between nurses and patients during medication activities in an acute hospital setting: qualitative observation and interview study. *Int J Nurs Stud, 47*(2), 154-165.

[2] Ridgeway, J. L., Egginton, J. S., Tiedje, K., Linzer, M., Boehm, D.,… & Eton, D. T. (2014). Factors that lessen the burden of treatment in complex patients with chronic conditions: a qualitative study. Patient Prefer Adherence, 8, 339-351

[3] Fitzgerald, S. P., & Bean, N. G. (2010). An analysis of the interactions between individual comorbidities and their treatments--implications for guidelines and polypharmacy. J Am Med Dir Assoc, 11(7), 475-484.

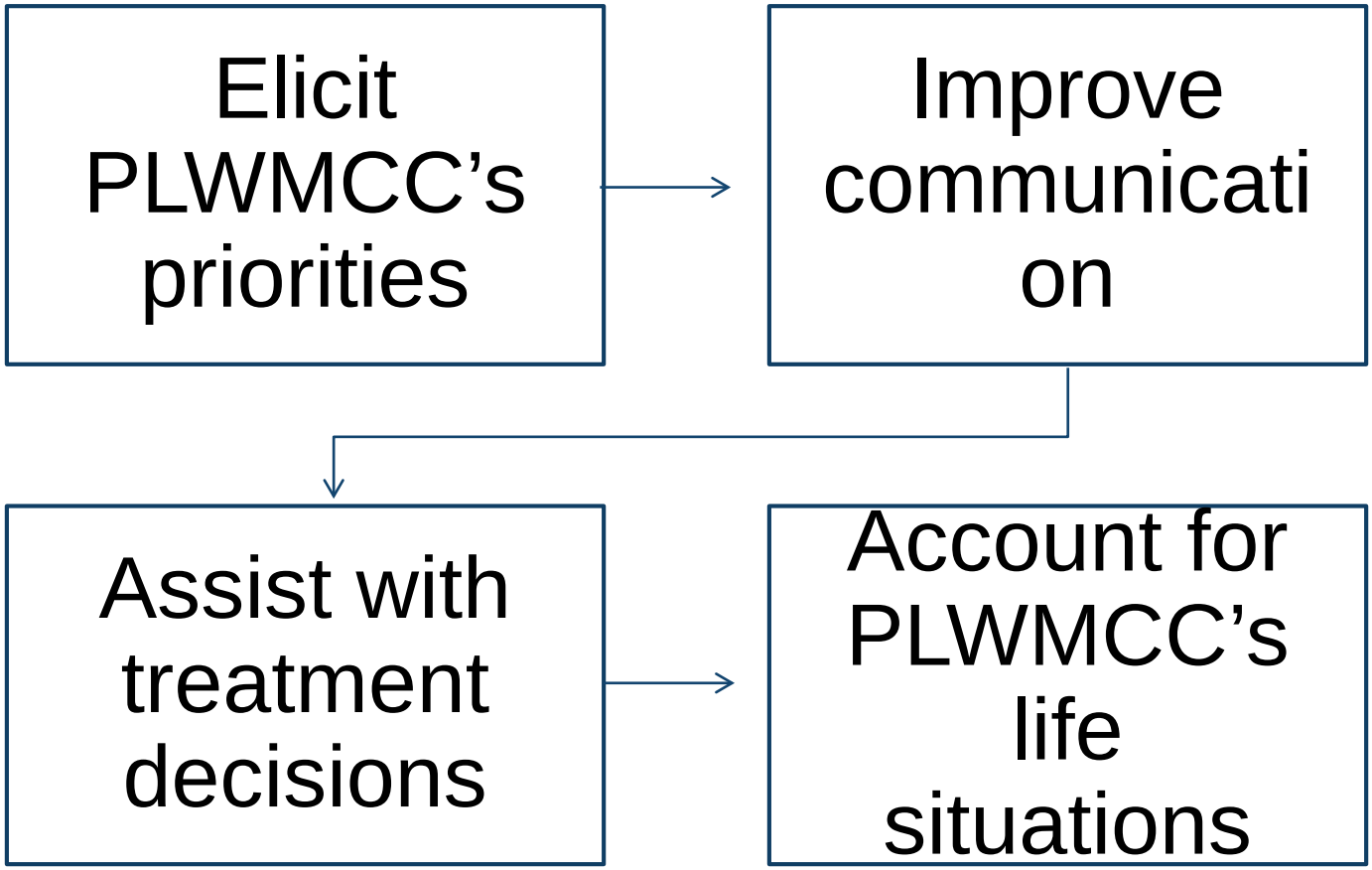
Section 3

Integrating PERS into practice

Slide 13 Speaker Notes

This section, “Integrating PERS into practice” provides effective mechanisms for healthcare professionals to support people in managing their multiple chronic conditions.

Integrating PERS into practice



Slide 14 Speaker Notes

Here are ways you, as healthcare professionals, can integrate person- and family-centered care into your practice.

- Eliciting the priorities of/for people living with multiple chronic conditions
- Improving communication with PLWMCC
- Assisting PLWMCC with their treatment decisions
- Accounting for PLWMCC's life situations.

These four strategies are further described in the next two slides.

Strategies for incorporating PERS into practice

Elicit PLWMCC's priorities

- Document their preferences, beliefs, and values
- Prioritize their preferred health outcomes
- Ensure that PLWMCC and their families and caregivers are engage as a partner in their care
- Reexamine preferences over time especially as health status changes

Improve communication

- Share learning experiences using narrative communication
- Practice instrumental communication
- Use motivational interviewing and shared decision making techniques
- Reduce language barriers

Slide 15 Speaker Notes

Eliciting PLWMCC's (preferences and family health) priorities:

- Document PLWMCC preferences, beliefs, and values, as well as involvement in care and treatment decision-making. Recognize that men and women with MCC may have different needs.
- Ask PLWMCC and families to prioritize their preferred health outcomes, for example:
  - ✓ Living longer,
  - ✓ Alleviating pain,
  - ✓ Maintaining physical function,
  - ✓ Maintaining social function,
  - ✓ Maintaining cognitive function[1].
- Ensure that PLWMCC and their families and caregivers are engage as a partner in their care[2]
- Reexamine preferences of PLWMCC, which may change over time, particularly with health status changes[3].

<u>To learn more about family-centered care, review the following resources:</u>

The Family-Centered Care Assessment Tool for Providers developed by National Center for Family/Professional Partnerships helps providers measure the family-centeredness of health care services. (http://www.fv-ncfpp.org/activities/fcca/)

The National Center for Family/Professional Partnerships provides leadership, technical assistance, peer support, and coordination to advance medical shared decision-making and the practice of family-centered care to healthcare for children and youth with special healthcare needs, their families, professionals, and stakeholders.

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[1] Hartford Institute for Geriatric Nursing and Health Resources and Services Administration (HRSA). (2014). Primary Care of Older Adults Program (PCOA) e-Learning Modules.

[2] Working for quality. Agency for Healthcare Research and Quality. Retrieved from http://www.ahrq.gov/workingforquality/about.htm#priorities.

[3] Miller, D., Steele Gray, C., Kuluski, K., & Cott, C. (2014). Patient-Centered Care and Patient-Reported Measures: Let's Look Before We Leap. Patient

Strategies for incorporating PERS into practice

Assist with treatment decisions

- Recognize when "preference sensitive" decisions need to be made
- Clearly state the expected benefits and harms of treatment options

Account for PLWMCC's life situations

- Design treatment planning and communication that addresses PLWMCC's emotional needs
- Consider PLWMCC's lifestyle and social and cultural determinants of health when recommending and explaining treatment options
- Assist PLWMCC with financial resources, when requested

Slide 16 Speaker Notes

Assist With Treatment Decisions:

- Ensure that PLWMCC are adequately informed about the expected benefits and harms of treatment options.
- Recognize when PLWMCC face "preference-sensitive" decisions, e.g., therapy to improve a condition that makes another condition worse[1]. Furthermore, realize that PLWMCC are likely to grapple with these decisions due to the potential risk of adverse events associated with the treatment options and possible limited benefits.

Account for PLWMCC's Individual Life Situations: Individual situations are important moderators of patient-centered care, e.g., a cancer patient needing emotional support;

- Design treatment planning and communication to target PLWMCC emotional needs[2];
- Consider and weigh PLWMCC factors (age, race, level of family support, community resources)[3] in recommending and explaining treatment options.
- Assist PLWMCC with financial resources, including insurance, qualifications, and choices for durable equipment, when requested.
  *It should be noted that regardless of inpatient/outpatient setting PLWMCC should be made available or resources for Ethics consults, when needed. This can be a frequent problem that can cause disruptions the PLWMCC, their families and caregivers.

In providing care for individuals with MCC, healthcare workers should be aware of the United States' Supreme Court's *Olmstead* decision which states that public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity[4]. As individuals with MCC are at particular risk of institutionalization, the healthcare workforce should focus on caring for individuals with MCC from a community inclusion and integration perspective.

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[1] Ickowicz, E. (2012). Patient-centered care for older adults with multiple chronic conditions: a stepwise approach from the American Geriatrics Society Journal of the American Geriatrics Society 60(10), 1957-1968.
[2] Venetis, M. K., Robinson, J. D., Turkiewicz, K. L., & Allen, M. (2009). An evidence base for patient-centered cancer care: a meta-analysis of studies of observed communication between cancer specialists and their patients. Patient Educ Couns, 77(3), 379-383.
[3] Rocco, N., Scher, K., Basberg, B., Yalamanchi, S., & Baker-Genaw, K. (2011). Patient-centered plan-of-care tool for improving clinical outcomes. Qual Manag Health Care, 20(2), 89-97.
[4] *Olmstead v. L.C.*, 527 U.S.at 607.

Resource for Insurance: Local State Health Insurance Assistance Programs (SHIP) can assist with any insurance, including the marketplace insurance. Visit https://www.shiptacenter.org/ for more information.

PERS Resources

- Primary Care of Older Adults Program e-Learning, Mod 8
  http://consultgerirn.org/uploads/File/PCOA/story.html
- Teaching Principles of Managing Chronic Illness Using a Longitudinal Standardized Patient Case
  www.mededportal.org/publication/7833
- An Interprofessional Approach to Chronic Conditions, Module 5: Caregiver and Family Support in Managing Chronic Conditions http://www.pogoe.org/productid/20651
- HHS MCC Education and Training Repository
  http://www.hhs.gov/ash/initiatives/mcc/educationalresources

Slide 17 Speaker Notes

The following resources may further assist you (healthcare professionals) reinforce and/or apply person- and family-centered care with PLWMCC.

- **Primary Care of Older Adults Program** e-Learning Modules, developed by the Hartford Institute with support from Health Resources and Services Administration, is a series of 10 primary care-focused online learning modules. Module 8 of the series discusses the impact of MCC on healthcare choices; describes ways to incorporate the patient and family as an essential part of the healthcare team; discusses how prognosis influences treatment decisions; and describes how minimizing harm and optimizing benefits can be used to effectively plan care for patients with MCC[1].
- **Teaching Principles of Managing Chronic Illness Using a Longitudinal Standardized Patient Case**, the Jane Henderson case, is a standardized patient vignette to expose first- and second-year medical students to caring for a patient with several chronic illnesses and a complex psychosocial situation. Other health professions might find it a useful tool for group discussions as well.[2]
- **An Interprofessional Approach to Chronic Conditions, Module 5: Caregiver and Family Support in Managing Chronic Conditions** is a 30-minute module that gives healthcare professionals and students an understanding of the caregiver role using an interprofessional approach to care. Intended health profession audiences include: Medicine, Nursing, Social Work, Therapy, Physician Assistant, and Physical Therapy[3].
- **To find more MCC related education and training resources for health professionals, visit the HHS MCC Education and Training Repository at http://www.hhs.gov/ash/initiatives/mcc/educationalresources.**

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[1] Hartford Institute for Geriatric Nursing and Health Resources and Services Administration (HRSA). Primary Care of Older Adults Program (PCOA) e-Learning Modules. Retrieved June 23, 2014 from http://consultgerirn.org/uploads/File/PCOA/story.html

[2] Wamsley, M., Carpenter, L., Chou, C., Wilson, E., Deshpande, M., & Miller, B. (2010). Teaching Principles of Managing Chronic Illness Using a Longitudinal Standardized Patient Case. Retrieved on June 11, 2014 from www.mededportal.org/publication/7833

[3] Borden C., & Waddell-Terry, T. MS (2010). An Interprofessional Approach to Chronic Conditions 5: Caregiver and Family Support in Managing Chronic Conditions. Retrieved on June 12, 2014 from http://www.pogoe.org/productid/20651