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Application of Life Care Planning Principles for the Individual with HCV

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Introduction

John X is a 52-year-old Caucasian male who worked as a medical technician and phlebotomist at a large medical center. He acquired hepatitis C virus (HCV) as a result of a needle stick following drawing blood from a confused and disoriented patient. Twelve weeks following the needle stick, John X demonstrated anti-HCV antibodies in his blood. He began to experience fatigue, loss of appetite, weight loss and elevated liver enzymes. A diagnosis of chronic hepatitis C infection was made by treating physicians. The condition was determined to be a workers' compensation case, with benefits due as prescribed by law, in his state of residence.

Initial referral of this case was for assessment and recommendations for current and long-term health care needs. The attending physician is a well-known heptologist who has outlined a clear treatment plan for medications. The focus in this case was to determine care needs and associated costs related to the impact of antiviral therapy which causes toxicity and association complications for health and well-being. Utilizing life care planning principles, the case example included at the end of this article shows an alternate format for displaying information relative to recommended interventions, expected outcomes and associated costs for care.

Mr. X was a "non-responder" to initial antiviral treatment of Interferon and Ribavirin. At referral, he was receiving re-treatment with Pegylated Interferon, Ribavirin and a clinical trial drug, Thymosin. Medical diagnoses for John X, based upon comprehensive review of records and direct communication with treating physicians, are:

1. Hepatitis C – chronic infection
2. Cirrhosis
3. Depression related to antiviral therapy
4. Encephalopathy due to antiviral therapy
5. Chronic pain due to antiviral therapy
6. Sicca Syndrome (deterioration of teeth due to use of interferon)

An in-home assessment of Mr. X was completed. His wife was the primary provider of information due to Mr. X's extreme fatigue level. A usual day was described, including the "ebb and flow" of severe, acute side effects following each weekly injection of the prescribed

Outcome

Based upon review of medical records, communication with treating physicians, assessment and research regarding HCV, eight conclusions regarding care were developed. Consistent with life care planning principles, it was imperative to focus on the client's care needs. In this example, a nursing diagnosis approach was utilized and the information displayed in a format similar to the life care plan format. The eight conclusions defined issues regarding interventions. Defining characteristics clarified Mr. X's status and supported the conclusion statements. Current interventions and recommended interventions were presented with anticipated outcomes as a result of the interventions. Costs specific to the geographical area were identified, with a resource/reference list specifying literature and research support.

The tables included in this study were presented by the requesting insurance company to the treating physician for review and confirmation of agreement with recommendations. As a result, recommended interventions have been implemented and quality of life has improved for the client and his wife/caregiver.

Implications

The major principles of life care planning – comprehensive needs assessment, research and data analysis – may be used to describe needs for individuals with chronic health problems such as HCV. In this case study, the described application of life care planning principles resulted in implementation of additional services to the individual to promote the health of his primary caregiver and to improve his quality of life. Additionally, the approved services have resulted in an increase in the existing support system; specifically, information regarding costs for liver transplantation has assisted the workers' compensation carrier to establish more accurate reserves. By applying life care planning principles for individuals with chronic conditions, one can achieve positive case management outcomes. The attached case example represents an alternate format for displaying information included in a life care plan within the areas of recommended services, purpose of need and costs associated with the service.

antiviral medication. Due to the treatment regimen, Mr. X experiences severe fatigue, weakness and intermittent confusion. Sleep disturbance is described, including disruptive dreams, which cause him to rise from the bed without help, resulting in repeated falls. Mr. X describes depression to the point that on some days he is able only to sit and weep.

Functionally, Mr. X's skills are described as follows:

Self-Care: Mr. X requires assistance for bathing and ambulation up and down stairs. Meals must be prepared for him. Assistance with personal hygiene is necessary due to persistent and violent vomiting and diarrhea. Dehydration is a clear health problem and must be monitored by his caregiver, Mrs. X.

Cognition: Mr. X has short-term memory problems and has impulse control deficits. These cognitive issues result from antiviral therapy toxicity.

Communication: Mr. X is able to express himself verbally, but may respond inappropriately during conversation. He is able to read, but cannot remember what he has read.

Behavior: Mr. X cannot be left alone due to memory deficits. Due to impulse control deficits and extreme weakness, he may not realize his mobility limits and become injured.

Mobility: Mr. X is unable to drive due to weakness, fatigue and memory deficits. He is able to ambulate short distances and requires physical assistance to ascend and descend stairs.

Elimination: Mr. X has ongoing diarrhea due to antiviral therapy. Hydration is an ongoing goal for care. Of note, he has lost 80 pounds since therapy initiation.

Safety: Mr. X is at risk for injury due to weakness and cognitive deficits.

Community Re-entry: Mr. X is isolated from social interaction due to weakness, vomiting and other expected side effects of therapy.

Medications were reviewed and a drug interaction study completed. Questions regarding medications were addressed to treating physicians.

Psychosocial Issues

Mr. and Mrs. X were married six months prior to his diagnosis. She is her husband's only caregiver. Mrs. X administers all medications, observes and records his responses, assists him with all hygiene and assists him during acute episodes. The couple is well aware of the course of treatment and the potential for a liver transplant. Mrs. X appeared fatigue during the assessment interview and stated she has been prescribed an antidepressant. The couple note little support from family.

Mr. X's education and work history were reviewed. His fragile health status prevents him from participating in work activity at any level. His wife has left full-time employment to provide care to her husband.

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #1: Mr. X is experiencing chronic pain with associated disruptive effects, which require ongoing intervention.			
Defining Characteristics	**Interventions**	**Outcome**	**Cost**
Mr. X demonstrates verbal or observed evidence of restlessness, depression, changes in sleep patterns and altered ability to continue previous activities	Use of pain control: currently prescribed Propoxyphene – use of alternate drugs is limited, due to potential liver damage. Monitored pain management – wife currently completes. Explore non-pharmacological techniques to promote pain relief. **RECOMMENDED INTERVENTIONS** 1. Counseling to include relaxation, guided imagery, hypnosis. 2. Massage therapy to promote circulation and skin maintenance. 3. Psychiatric care to prescribe medications and monitor treatment; prescribed by Dr. XYZ.	Pain control Expect weekly sessions during continued Interferon therapy. Expect weekly sessions during continued Interferon therapy. Expect weekly-biweekly sessions during continued Interferon therapy.	Current total medication costs per month are $7,000. $125 / hr. $85 / hr. $125 / hr.

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #2: Mr. X is experiencing activity intolerance/fatigue affecting endurance, self-care and the ability to carry out environmental management (maintaining a safe, immediate environment).			
Defining Characteristics	**Interventions**	**Outcome**	**Cost**
Mr. X has insufficient physiological and psychological energy to endure or complete required or desired daily activities.	Self-Care Assistance Mrs. X currently provides assistance with ambulation, bathing, hygiene, dressing, grooming, toileting, balance, medication administration. Home Maintenance Assistance Mrs. X currently provides all environmental management, including housekeeping, food preparation, laundry, lawn care. **RECOMMENDED INTERVENTIONS** Home Health Services RN assessment, care giving, medication administration: 15 hours per week (Note: Mrs. X provides current services 24 hours daily: CNA care is $22/ hr.) Housekeeping (2 hrs/ week) Lawn Care (1 / week)	Activity Tolerance Monitor status; prevent complications; provide respite periods for caregiver. Relieve caregiver stress Relieve caregiver stress	*$528 / day, if 24-hour care provided by CNA ($22 / hr. is current agency rate)* $50 / hr. $65 / hr. $35-60 / wk.

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #3: Mr. X is experiencing diarrhea and vomiting which impact fluid balance, hydration and nutritional status.			
Defining Characteristics	**Interventions**	**Outcome**	**Cost**
Mr. X experiences uncontrolled bowel elimination and vomiting.	Physician Monitoring Currently seen twice annually by Dr. XYZ and monthly by Dr. LMN. Laboratory Blood Studies Currently done monthly. Daily Monitoring of Fluid Intake and Output Currently completed by Mrs. X. Provision of Foods and Fluids Currently completed by Mrs. X. **RECOMMENDED INTERVENTIONS** Nutrition Evaluation and Counseling (monthly for 4 months)	Hydration and adequate nutritional intake, fluid, electrolyte balance. Improved hydration/ nutrition	See current charges See current charges $120/hr evaluation $85/hr counseling

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #4: Mr. X is experiencing impaired memory and impulse control which impacts his ability for self-care and socialization.			
Defining Characteristics	**Interventions**	**Outcome**	**Cost**
Mr. X experiences the inability to remember bits of information or behavioral skills which is attributed to encephalopathy.	Surveillance for Safety Mrs. X currently completes this activity. Environmental Management and Cognitive Stimulation Mrs. X currently completes this activity. Fluid/Electrolyte Management Mrs. X currently completes this activity. **RECOMMENDED INTERVENTIONS** See Conclusion 2: Home Care, Housekeeping and Lawn Care	Prevent injury; promote cognition.	

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #5: Mr. X is experiencing sleep pattern disturbance.			
Defining Characteristics	**Interventions**	**Outcome**	**Cost**
Mr. X may sleep for extended periods, however sleep is disrupted by pain, diarrhea, vomiting.	Energy Management; Pain Management; Environmental Management – Comfort; Positioning; Emotional Support All are currently being provided by Mrs. X. **RECOMMENDED INTERVENTIONS** See Conclusion 1 regarding counseling and psychiatric care.	Sleep enhancement	

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #6: Mr. X is experiencing mobility deficits.			
Defining Characteristics	**Interventions**	**Outcome**	**Cost**
Mr. X demonstrates weakness of muscle groups, which limits mobility and exercise	Exercise Therapy; Energy Management; Environmental Management – Safety; Balance All are currently provided by Mrs. X. **RECOMMENDED INTERVENTIONS** Installation of stair railings, both upstairs and down (one time) Installation of elevator (one time) OR Bathroom modification and dining room use as bedroom	Safe ambulation Support during stair climbing Safe transport to upper/ lower levels of home Care in safe environment without stair climbing	 $650-800 $15,000 $8,500

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #7: Due to multiple demands upon Mrs. X for services to her husband, there is risk for significant caregiver role strain.			
Defining Characteristics	**Interventions**	**Outcome**	**Cost**
Mrs. X states vulnerability and difficulty in performing as caregiver to her husband. She demonstrates fatigue and has been prescribed antidepressant medication.	Respite Services See recommendation for home care services. Note: Home care service hours may increase with potential increased care needs for Mr. X. **RECOMMENDED INTERVENTIONS** Counseling services for Mrs. X (weekly during continued treatment of her husband).	Caregiver emotional health Caregiver ability to continue role.	$102 / hr.
Revised 10/02/02 Mrs. X requires therapy for a shoulder injury incurred while assisting her husband.	In-home assistance, 25 hours per week for cleaning and cooking.	Home maintained; nutritional intake maintained.	$13.50 / hr.

CURRENT AND RECOMMENDED SERVICES

CONCLUSION #8: Mr. X may become a candidate for liver transplant.			
Defining Characteristics	**Interventions**	**Outcome**	**Cost[4]**
Mr. X may experience non-response to current therapeutic treatment, resulting in eventual end-stage liver disease.	Organ transplant	Continued life	$200,000 for evaluation, procurement, hospital and physician $9,600 per month (candidacy) $48,400 (follow-up 1st year) $12,800 (immuno suppressants – annually)

[4] Estimated U. S. Averaged Billed Charges per Liver Transplantation – First Year; 07/31/01, provided by UNOS.