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UNIVERSITY OF
PITTSBURGH
School of Nursing



Penn Medicine

Symposium: Identifying Symptom Clusters in Chronic Illness

20 July 2018

Symposium Organizer: Maya N. Clark-Cutaia, PhD, ACNP-BC, RN

SUPPORT & DISCLOSURES

Sodium-Restricted Diets and Symptoms in End-Stage Renal Disease: A Randomized Controlled Trial NIH-1K23NR015058
(Clark-Cutaia)

The authors/presenters have disclosed they have no significant relationships with, or financial interest pertaining to the work presented.

BACKGROUND & SIGNIFICANCE

- Estimated 40 million deaths attributed to chronic illness annually
 - 70% of the overall 56 million deaths per year worldwide
- 17.7 million deaths secondary to cardiovascular disease (CVD), chronic respiratory disease, cancer, or diabetes
- About half of the United States (US) population (117 million) have ≥ 1 chronic illness
- 1 in 4 American Adults have 2 or more chronic illnesses
- Physical and emotional symptoms are among the primary manifestations of chronic

BACKGROUND & SIGNIFICANCE

- Symptom burden has a strong inverse relationship with quality of life, and is likely to affect a patient's objective and subjective functioning and well-being
- 1 in 4 American Adults have 2 or more chronic illnesses
- Multi-morbidity incidence is increasing globally, resulting in an increase prevalence of the occurrence of solitary and concurrent symptoms.
- Symptom clusters are defined as three or more concurrent and related symptoms.
- Identification of symptom clusters in chronic illness may inform the development of symptom cluster management interventions.

PURPOSE OF SYMPOSIUM

- Identify symptom clusters in chronic illness patient populations
 - breast cancer, end stage renal disease (ESRD), head and neck cancer, heart failure
- Dialogue between panel and audience regarding challenges in symptom management
- Explore new directions for nursing care, management symptom, and nursing research of symptom clusters in chronic illness

SYMPOSIUM OBJECTIVES

- 1) Obtain knowledge in symptom clusters.
- 2) Showcase symptom clusters across diverse chronic illness patient populations.
- 3) Discuss new directions for nursing care, the management of symptoms, and research in symptom clusters in chronic illness.



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Symptom Clusters in Hemodialysis

Maya N. Clark-Cutaia, PhD, ACNP-BC, RN

Mei Fu, PhD, RN, FAAN

Marilyn S. Sommers, PhD, RN, FAAN

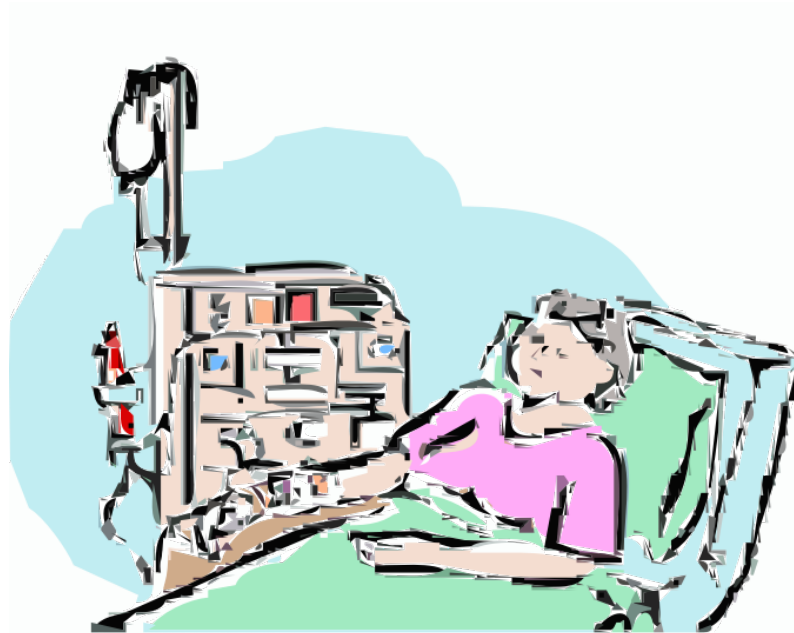
Raymond R. Townsend, MD

Gary Yu, DrPh



Objectives

- 1) Describe the mechanism of symptoms in HD patients
- 2) Identify symptoms experienced in HD.
- 3) Discuss symptom clusters identified in a sample of HD patients.





Background & Significance

- Symptom burden in HD is substantial and has a tremendous negative impact on all aspects of quality of life¹⁻¹¹
- In ESRD, the nephron is non-functioning, resulting in an accumulation of solutes, wastes, and fluid in the blood
- Volume expansion results in symptoms such as shortness of breath, cognitive impairment, nausea, anorexia, fatigue, weakness and edema⁵⁰
- Electrolyte and waste accumulation cause symptoms pain, cramps, hypotension, restless legs and thirst



Background & Significance

- Inability to eliminate nitrogenous wastes (urea) causes skin disorders; gastrointestinal and neurologic symptoms such as nausea, anorexia, constipation, neuropathy of the extremities, mobility issues, pruritus; and sexual dysfunction
- The intermittent nature of HD ultrafiltration results in frequent fluid shifts and rapid changes in serum osmolarity during sessions¹⁹
 - As a result, patients may experience hypotension, fatigue, insomnia, chest pain, cramping in lower extremities, nausea and headaches



Background & Significance

- Symptoms may be so debilitating that HD sessions must be prematurely discontinued due to ultrafiltration intolerance, or patients may skip sessions to avoid them all together, resulting in an exacerbation of symptoms related to solute (sodium), volume, and waste accumulation
- Symptom science is a relatively new area of inquiry for the hemodialysis patient population





Purpose & Conceptual Framework

- The purpose of this analysis was to explore symptom clusters among patients receiving maintenance hemodialysis
- A physiological conceptual framework based on the pathophysiology of ESRD and its symptoms guided the study development and methodology



Study Aims

Therefore the aims of the study were to:

- 1) Identify symptom clusters in HD patients
- 2) Assess the association of symptom clusters on quality of life, emergency department visit and hospitalization



Design & Methods

- Sodium-Restricted Diets and Symptoms in End-Stage Renal Disease: A Randomized Controlled Trial (NIH-1K23NR015058)
 - A three-group, double blinded, randomized controlled trial with a sample of 42 HD patients
 - Participants were randomized three levels of sodium intake (ambient [CG], 1.5G, and 2.4G)
- Cross-sectional study focused on data collected prior to intervention phase of the study



Setting and Sample

- Patients were recruited from an urban, academic, tertiary acute care center
- Forty-four participants enrolled, 2 withdrawals due to illness: total of 42 participants



POS-S RENAL – PATIENT COMPLETION

Below is a list of symptoms, which you may or may not have experienced. Please put a tick in the box to show how you feel each of these symptoms has affected you and how you been feeling over the past week.

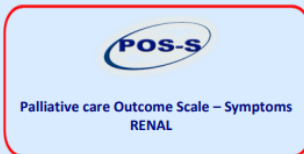
	Not at all No effect	Slightly but not bothered to be rid of it	Moderately limits some activity or concentration	Severely activities or concentration markedly affected	Overwhelmingly unable to think of anything else
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mouth problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drowsiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless legs or difficulty keeping legs still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other symptoms:					
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which symptom has affected you the most? _____

Which symptom has improved the most? _____

Measures

- Palliative Care Outcome Scale (POS-S Renal)



NAME: _____

PATIENT NUMBER: _____



Analyses

- Factor analysis was conducted via SPSS v. 23
 - Principal components analysis
 - Varimax rotation



Results

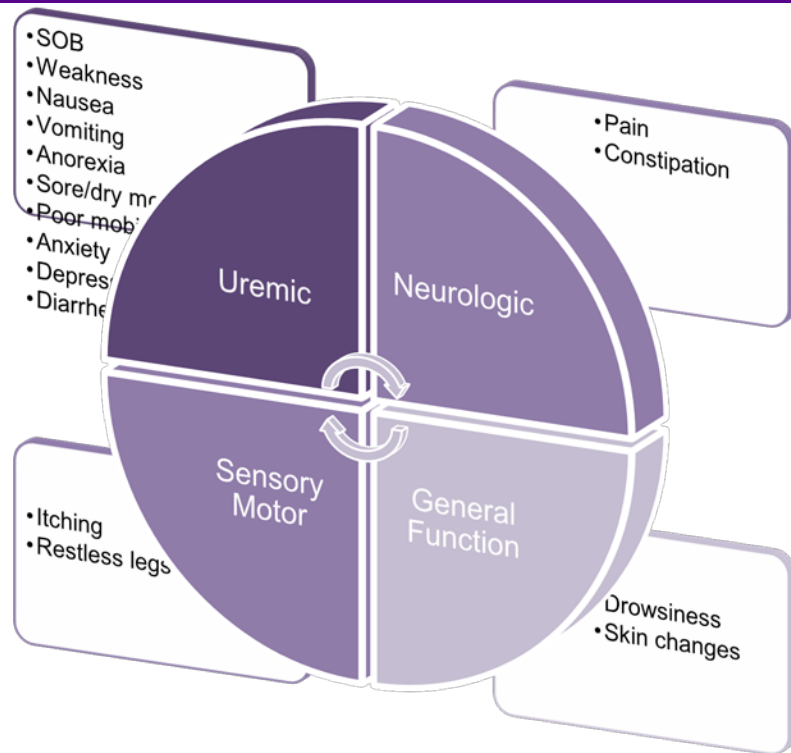
Table 1. Sample Descriptive Statistics

Variable	N(%)
Race/Ethnicity	
African American, Black, African, Afro Caribbean: Not of Hispanic Origin	34 (85.0)
White, Caucasian: Not of Hispanic Origin	2 (5.0)
Native American, Indian, Alaskan Native	1 (2.5)
Other	3 (7.5)
Etiology	
Hypertension	18 (45.0)
Diabetes	9 (22.5)
Other	13 (32.5)
Gender	
Female	19 (47.5)
Male	21 (52.5)
Age	
≤55	18 (45.0)
56-70	17 (42.5)
>71	5 (12.5)



Results

- No statistically significant difference in symptom scores among any of the predictors
- Four symptom clusters emerged from the cluster analyses
 - Uremic/emotional manifestations
 - Neurologic manifestations
 - Sensory motor processing disorder manifestations
 - General function manifestations





Results

Symptom Items	Weekly Average	High	Low	3 Day Average	High	Low
Pain	55.0%	83.7%	30.5%	45.0%	82.6%	17.3%
Shortness of Breath	40.0%	65.6%	18.1%	35.0%	70.8%	8.7%
Weakness	70.0%	100.0%	44.4%	72.5%	100.0%	52.3%
Nausea	22.5%	48.8%	0.0%	20.0%	41.3%	4.3%
Vomiting	20.0%	38.0%	4.6%	15.0%	29.5%	4.3%
Anorexia	42.5%	60.1%	27.4%	40.0%	53.2%	30.3%
Constipation	25.0%	33.1%	18.1%	27.5%	47.3%	13.0%
Dry Mouth	12.5%	27.1%	0.0%	12.5%	23.6%	4.3%
Drowsiness	32.5%	50.1%	17.4%	22.5%	41.3%	8.7%
Mobility	27.5%	50.1%	8.2%	32.5%	70.8%	4.3%
Itching	62.5%	78.3%	49.0%	50.0%	70.5%	35.0%
Insomnia	60.0%	94.5%	30.5%	52.5%	94.0%	22.0%
Restless Legs	47.5%	65.6%	32.0%	37.5%	58.6%	22.0%
Anxiety	37.5%	76.0%	4.6%	37.5%	82.3%	4.6%
Depression	30.0%	65.1%	0.0%	22.5%	46.8%	4.6%
Skin	35.0%	65.1%	9.3%	22.5%	41.3%	8.7%
Diarrhea	17.5%	27.1%	9.3%	17.5%	29.5%	8.7%
Average Number of Symptoms	6.37	10.29	3.03	5.62	9.84	2.53
%	100%	45%	55%	100%	43%	57%
N	40	18	22	40	17	23



Limitations

- Not repeated measures due to exploratory nature
- Primary Study was a feasibility study with minimal power.
- Small convenience sample and the survey consisted of 17 items.
- Some survey items correlated heavily with one another.
- Sampling bias



Conclusions

- Symptom burden is associated with elevated blood pressure, ED visit and hospitalization, as well as length of stay (LOS)
- A larger scale RCT is necessary to further explore clinical relevance of symptom clusters identified as well as impact on morbidity and mortality
- Symptom Cluster research is its infancy in the HD patient population. Further analyses with larger samples are necessary to begin to develop interventions to improve the patient symptom experience



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Thank you.
MC7009@NYU.EDU

References

- 1 Thomas, MC, Moran, J, Forsblom, C, et al. The association between dietary sodium intake, ESRD, and all-cause mortality in patients with type 1 diabetes. *Diabetes Care*. 2011; 34(4): 861-866.
- 2 Clark-Cutaia, M., Sommers, MS., Anderson, E., & Townsend, R. Design of a randomized controlled clinical trial assessing dietary sodium restriction and hemodialysis-related symptom profiles. *Contemporary Clinical Trials Communications*. 2016; 3: 70-73. doi:10.1016/j.conctc.2-16.04.002.
- 3 Brook, RD, Appel, LJ, Rubenfire, M, et al. Beyond medications and diet: alternative approaches to lowering blood pressure: a scientific statement from the American Heart Association. *Hypertension*. 2013; published online before print April 22, 2013, 10.1161/HYP.0b013e318293645f.
- 4 Clark-Cutaia, M, Ren, D, Hoffman, L, Burke, LE, Sevick, MA. Adherence to hemodialysis dietary recommendations: influence of patient characteristics, self-efficacy and perceived barriers. *Journal of Renal Nutrition*. 2014; 24(10): 92-99. DOI: 10.1053/j.jrn.2013.11.007
- 5 Smyth, A, O'Donnell, MJ, Yusuf, S, Clase CM, Teo, KK, Canavan, M, Reddan DN, & Mann JF. Sodium intake and renal outcomes: a systematic review. *Am J Hypertens*. 2014; 10: 1277-84. DOI: 10.1093/ajh/hpt294.
- 6 Kimmel PL, Emont SL, Newmann JM, Danko H, Moss AH. ESRD patient quality of life: Symptoms, spiritual beliefs, psychosocial factors, and ethnicity. *Am J Kidney Dis*. 2003; 42:713–21.
- 7 Merkus MP, Jager KJ, Dekker FW, de Haan RJ, BoeschotenEW, Krediet RT: Physical symptoms and quality of life inpatients on chronic dialysis: Results of The Netherlands Cooperative Study on Adequacy of Dialysis (NECOSAD). *Nephrol Dial Transplant*. 1999; 14: 1163-70.
- 8 Murtagh, FE, Addington-Hall, J, Higginson, IJ. The prevalence of symptoms in end-stage renal disease: A systematic review. *Advances in Chronic Kidney Disease*. 2007; 14(1): 82-99. DOI: 10.1056/j.ackd.2006.10.001.
- 9 Parfrey PS, Vavasour H, Bullock M, Henry S, Harnett JD, Gault MH. Symptoms in end-stage renal disease: Dialysis v transplantation. *Transplant Proc*. 1987; 19: 3407–09.
- 10 Parfrey PS, Vavasour HM, Henry S, Bullock M, Gault MH. Clinical features and severity of nonspecific symptoms in dialysis patients. *Nephron*. 1988; 50: 121–28.
- 11 Parfrey PS, Vavasour H, Bullock M, Henry S, Harnett JD, Gault MH. Development of a health questionnaire specific for end-stage renal disease. *Nephron*. 1989; 52: 20–8.