WHAT IS THE ADVANCE CARE PLAN? WE ARE NOT IMMORTAL!

AUGUST 13, 2020

- Dr. Joan Berzoff
- Ms. Jenny Kitsen

INTRODUCTION: OUR PURPOSE

- To describe the current state of renal social work advance care planning
- To share the educational content developed for social workers to take leadership in advance care planning
- To discuss challenges encountered in ACP in the time of covid
- To make implementation recommendations for ACP for social workers in the field

WHAT DO WE KNOW?

- Kidney disease is a life limiting, multifaceted chronic illness
- ~600,000 patients are on dialysis in the US
- 5 Year mortality rate is 35.8%
- Yet advance Care Planning rarely takes place in dialysis clinics

REVIEW OF THE LITERATURE
END OF LIFE DISCUSSIONS DO NOT ROUTINELY TAKE PLACE IN NEPHROLOGY

- Few renal patients know of advance care planning (Lim, et.al, 2016; Luckett, et al, 2017)
- Patients fear discussing end of life care with their nephrologists (Moss, 2003)
- Patients, families and staff avoid difficult conversations
- There is a complicated trajectory of co- morbid conditions which impedes end of life care planning (Wachterman, 2017)
- Unexamined cultural and spiritual beliefs erode trust between patients and caregivers (Barclay, et al, 2007)
- Social workers are not supported to do advance care planning (Weisenfluh, et al, 2006)
- Social workers are not trained in schools of social work for advance care planning (Weisenfluh and Cskai, 2013; Murty et al, 2015)

OTHER BARRIERS TO SOCIAL WORK LEADERSHIP IN ADVANCE CARE PLANNING

- Time is in short supply (Merghi and Browne, 2016)
- Lack of private space
- Lack of any integrated advance care planning between healthcare providers, such as: nursing homes, emergency rooms, and inpatient facilities (Wachterman, 2017)

OUR RESEARCH ON ADVANCE CARE PLANNING

- Patient Centered Outcomes Research Institute (PCORI) Grant
- Three- year study, with 18 study sites, in New Mexico and New England
- Goals of the study were to increase end of life planning and hospice referrals
- Social workers would be trained to lead the advance care planning process

THE SAMPLE

- The interdisciplinary research team recruited 125 patients and families from Massachusetts and New Mexico
  - Patient populations were predominately White, Puerto Rican, and African American in Massachusetts. In New Mexico, they were largely Mexican and Native American
- Patient criteria: patients were at high risk for dying in the next 6 months
- 86% of patients enrolled in the study elected to know their prognosis

PCORI STUDY RESULTS

- **Overall, clinic level hospice usage did not vary significantly between pre-intervention and post-intervention periods. (Average rate 25%**
- **Examination of participants that died during the course of the study, 48 stopped dialysis prior to death and 43 percent received hospice services**
- **Enrolled participants with follow-up**
- **The patient sample (N= 125), median age 70, 51 percent male, 12% African American, 14 percent Native American,4 percent white and 37 % reported Hispanic ethnicity**

75 % completed health care proxy

63 % completed MOLST/POLST Life sustaining orders

OUR PART OF THE STUDY ASKED WHAT SOCIAL WORKERS NEED TO KNOW TO PROVIDE ACP

- Using data gathered from two patient advisory groups, focus groups with social workers and with nephrologists, the following training goals were developed:
  - Become better advocates for patients within organizational cultures
  - Practice with greater attention to cultural and spiritual differences
  - Become more knowledgeable about legal and ethical issues: advance directives, living wills, surrogacy, conflicts of interest
  - Learn to break bad news, while communicating hope
  - Increase skills in working with individuals and families
  - Be more adept at addressing countertransference, resistances, compassion fatigue and burnout
  - More effectively assess and address structural barriers and team conflicts in end of life care in nephrology

CONTENT OF THE TRAINING PROGRAM

- Developed an eight -hour didactic training offered by videoconferencing to all 17 social workers in both regions

Faculty were interdisciplinary: a palliative care doctor, five social workers, a lawyer

Four training modules were developed

- Advance practice and communicating bad news
- Leadership skills
- Cultural and Spiritual Issues
- Legal and Ethical Issues

Case studies were created so that throughout the day, social workers met in small groups to integrate theoretical content into practice

ADVANCED PRACTICE SKILLS

- Social workers viewed a video that the team developed on breaking bad news with renal patients and families
- While a face to face meeting may not be possible due to COVID, telehealth and zoom platforms can and should be used
- Social workers were trained to lead difficult conversations, elicit patient and family wishes, engage in follow up , take leadership
- Social workers were encouraged to discuss transference/countertransference experiences and their own resistances
- Social workers explored their own countertransference, compassion fatigue, and burnout

CULTURAL AND SPIRITUAL ISSUES

- Spiritual assessment is crucial
- Cultural and racial misunderstanding and lack of trust leads to non-disclosure
- Power imbalances based in race and ethnicity can be barriers
- Techniques for bridging cultural divides
- Special emphasis on Latina, Hispanic, and Native American Tribes and on joint decision making with families

LEGAL AND ETHICAL ISSUES

- Informed Consent, Living Wills, Surrogacy
- Beneficence and autonomy which may conflict with different cultural groups
- Decisional capacity
- Ethical decision making

ACP INTERVENTION TOOL: PATIENT / FAMILY MEETING

- Patient awareness of disease status
- Acknowledge prognosis course
- Explore life goals/tasks
- Offer EOL resources
- Confirm with patient her understanding of what was discussed
- Clarify next steps
- *https://www.youtube.com/watch?v=ZeaD8tP_0Co*

TAKE AWAYS FROM FAMILY/PATIENT MEETINGS

- Don't make ACP an add on!

  Be aware that autonomy is a western cultural construct

  Be willing to discuss poor prognoses and death

  ACP is not an intellectual task

- It involves approaching vulnerable patients/families with empathy and skill

- (O' Halloran, et al., 2019)

WHAT DID WE LEARN?

- High turnover of social workers
  - started with 17 social workers
  - ultimately had to train 23 social workers and one nurse manager
- Diverse levels of ESRD work experience
- Regional differences in social workers' readiness to be leaders
- Regional differences in peer support
- Unrealistically high caseloads
- Structural barriers to advance care planning along the disease trajectory

STRUCTURAL BARRIERS TO ADVANCE CARE PLANNING IN DIALYSIS

- Social workers lacked time, with caseloads of 150 patients, to engage in difficult conversations and in systematic follow up
- Social workers were critical of a business model that governs care and leads to following the letter of the law on advance care planning but not the spirit
- There is a lack of coordination across multiple providers leading to fragmentation of care
- Corporate cultures do not acknowledge the key role of the social worker in advance care planning
- Discomfort of some nephrologists in discussing prognosis

WHAT DID SOCIAL WORKERS WANT?

- More opportunities to process difficult feelings in the work
- To continue to discuss the dilemma of balancing hope with reality
- A place to talk about self care and their own feelings
- Social workers cited a lack of knowledge about biological issues
- Social workers wanted their nephrologists involved in the training
- Social workers evaluated themselves as highly competent on cultural and spiritual issues but saw the need for ongoing self reflection as crucial

WHAT MUST SOCIAL WORKERS DO?

- Work to take leadership in difficult conversations
- Create conditions for interprofessional leadership
- Promote collaboration
- Assess structural barriers
- Advocate for patient values and goals

IN THE TIME OF COVID

- Create models for ACP that address medical/emotional transitions
- Avoid or reduce crisis mode life decisions
- Acknowledge and creatively manage how social workers' roles have changed
- Discuss the dialysis life journey and that acute death is omnipresent
- Covid intensive treatment: what does the patient want?
- Be aware of anticipatory grief

- What changes have you seen?

EOL CONVERSATIONS AND ACP

- Have always been needed and seen as necessary in dialysis clinics
- But are often overlooked or even ignored until the last minute when a medical crisis occurs
- Covid has changed that because we the practitioners and the clients are always at risk for a medical crisis from an unpredictable virus
- Hence we need to be even more honest, and vigilant about facing and planning for unknown future life and death events
- Covid underscores the importance for advance care planning to take place

CHALLENGES IN THE TIME OF COVID

- ACP discussions during dialysis close to impossible with masks and six feet of social distancing

Patients and staff have increased anxiety, emotions, anticipatory grief

Time consuming efforts in reaching patients by phone or telehealth for assessment

Physical discomfort wearing PPE

Hard to hear patients 6 feet away or for them to hear us

COVID

- We are concerned for kidney patients after reviewing the results of a targeted flash survey conducted by the AAKP showing 78% of patients viewed themselves as vulnerable to the coronavirus; and 84% indicated that their medical team had yet to discuss the disease with them, let alone how to protect themselves from contracting COVID-19.

WHAT CAN REALISTICALLY BE DONE TO IMPLEMENT ACP?

- Discuss with Medical Director your ideas of fostering better communication about ACP
- If that is difficult, start with clinic administrator or nurse manager
- Frame the conversations with patients that ACP is a journey over time and that the social worker will provide care and support as medical conditons change over time
- Do periodic assessments with patients by asking them about their self awareness of the disease status, prognosis, and treatment options
- Have conversations about life goals and what is important to still accomplish or fulfill

IMPLEMENTATION SUGGESTIONS

- Increase telehealth communication
- Provide ACP self assessment tools
- Use isolation room for private discussions
- Employ community resources: ie. Ministers, rabbis, iman, visiting nurses,

WHAT CAN REALISTICALLY BE DONE

- Listen for patient's concern for family members
- Listen for patient's level of suffering
- Listen for death anxiety
- Listen for fears of becoming a burden

EMOTIONAL CHALLENGES FOR THE SOCIAL WORKER

- Sometimes the social worker becomes the container for the patient's of family's ambivalence
- Sometimes the social worker hears about and vicariously experiences the patient's and family's fear/ trauma or loss
- Sometimes the cumulative weight of so many sick patients can lead the social worker to feel anger, aversion,or sorrow
- When you feel these, they can be an empathic window into what the patient, or caregiver may be feeling
- Sometimes there is nothing you can do, no way to fix a patient's worries or anxieties
- Sometimes we simply hold the patient/ hold the family

BEING PRESENT

- Its simply hard to stay present
- In dialysis clinics there is a culture of life, but there is also the reality of planning for death
- ACP can revive your own past losses or fears about your own mortality
- What do you do to take care of yourself?

SELF CARE

- It is just hard to stay engaged with people in psychological, spiritual or physical discomfort
- Cumulative grief leads to compassion fatigue
- We need to engage in "relentless self care" (Rezenbrink, 2004)
- This includes supervision, peer learning, debriefing with doctors, or nurses or chaplains
- Staying connected to good colleagues to name feelings, assess institutions, advocate together, create or participate in formal networks of professionals
- Have courage!

RECOMMENDATIONS

- End of life care training needs to occur routinely at the Masters level, at the clinic level and at the corporate level
- Corporations need to train social workers in end of life care management at the beginning of their renal careers
- Social workers should receive ongoing advance care planning training at regional and national meetings

RECOMMENDATIONS

- Renal palliative care for social work needs to be recognized
- Social workers need to be encouraged to form peer support groups to address balancing patient hope with reality, explore feelings and resistances, discuss cultural and spiritual issues, share resources, deal with legal and ethical issues and differentiate their own wishes from those of their patients
- Time for self reflection is a key element to the work
- Social workers need to be helped to advocate for more training and more realistic caseloads

RECOMMENDATIONS

- Ideally social workers know about legal issues, cultural and spiritual issues, countertransference, knowledge of the disease trajectory, leadership in inter-professional work
- Social workers should have multiple methods to becoming leaders utilizing didactic and peer support groups
- Social work schools must pick up the mantle of providing education in palliative care to all students since the two universals we can all count on are being born and dying

CONCLUSION

- There need to be cultural, behavioral and structural changes in dialysis clinics that honor patient and family preferences in ACP
- Social workers are key team members hold knowledge about legal, ethical, spiritual and psychosocial issues
- They need to hold and inquire about the patient and family's changing goals of care throughout the process of dialysis
- They have the duty and responsibility to help patients and families through the disease trajectory, asking and re-asking, while supporting patients' and families' resilience and strengths

CONCLUSION

- End of life care knowledge is limited among renal social workers
- Needed content areas for further training include self reflection, legal and ethical issues and diversity
- Corporate management must support systematic advance care education across regions and levels of experience

REFERENCES

- Berzoff, J., Lucas, G., Deluca, D., Gerbino, S., Browning, D., Foster, Z. & Chachkes, E. (2006). Clinical social work education in palliative and end of life care: Relational approaches for advanced practitioners. *Journal of Social Work in End of Life and Palliative Care,* Vol . (2),
- Berzoff, JJ., Kittsen, J, and Klinginsmith, J. (2019)

Barclay, J.S., Blackhall, L., and Tulsky, J.A. (2007). Communication strategies and cultural issues in the delivery of bad news. *Journal of Palliative Medicine*, Vol. I0, (4) 958-977.Berkman, C., & Stein, G. L. (2017). Palliative and end-of-life care in the masters of social work curriculum. *Palliative & Supportive Care,* 1-9.

- Cervantes, L., Jones, J., Linas, S. & Fischer, S. (2017). Qualitative interviews exploring palliative care perspectives of Latinos for dialysis. *Clinical Journal American Social Nephrology*, 12 (5), 788-798.
- Davison, S. N., & Torgunrud, C. (2007). The creation of an advance care planning process for patients with ESRD. *American Journal of Kidney Diseases: The Official Journal of the National Kidney Foundation, 49*(1), 27-36.
- Huff, M. B., Weisenfluh, S., Murphy, M., & Black, P. J. (2006). End-of-life care and social work education: What do students need to know? *Journal of Gerontological Social Work, 48*(1-2), 219-231.
- Merighi, J.R., & Browne, T. (2015). Nephrology social workers' caseloads and hourly wages in 2014: Findings from the NKF-CNSW professional Practice Survey. *Journal of Nephrology Social Work*, 39 (1), 33-60.
- Mobireek, A., Al-Kassimi, F., Al-Zahrani, K., Al-Shimemeri, A., Al-Damegh, S., Al-Amoudi, O., Al-Eithan, S., Al-Ghamdi, B., & Gamal-Eldin, M. (2008). Information disclosure and decision making, the Middle East versus the Far East and the West. *Journal of Medical Ethics,* 157(3), 328-333.
- Murty, S. A., Sanders, S., & Stensland, M. (2015). End-of-life care as a field of practice in the social work curriculum. *Journal of Social Work in End-of-Life & Palliative Care, 11*(1), 11-26.
- O'Halloran, T, Normaneud, K, Norwood,, Maxkwell, P, Shields, J, Fogarty, D., Murtagh, F, Morton, R. and K. Brazil. (2018, DOI.18.10)Advance care planning with patients to have end stage kidney disease, a systematic realist review, Journal of Pain and Sympotm Management,
- Tulsky, J.A. (2015). Decision aids in serious illness: Moving what works into practice. *JAMA Intern Med,* 175(7), 1221-2.
- Wachterman, S., Lipsitz, S., Marcantino, E., Zhonge, M., Keating, N.L. (2017) End of Life Experiences of Older Adults Dying of End Stage Renal Disease: A comparison with cancer. *Journal of Pain and Symptom Management,* Vol. 54, #2, 789-795.
- Weisenfluh, S., and Csikai, E. (2013). Professional and educational needs of hospice and palliative care social workers. *Social Work in End-of-Life & Palliative Care*, 9, 58–73.
- Weisenfluh,. S. Murphy, M. Black, P., and Huff, M (2006) End of life care social work education. J of Gerontological Social Work, Vol, 48, 1-2, 231-48.

RESOURCES

- www.Kidneysupportivecare.org
- www.cdc.gov/dialysis/coalition
- www.kidney.org
- Coalition for Supportive Care of Kidney Patients www.kidneysupportcare.org
- Center for Disease Control and Prevention www.cd.gov/dialysis/coalition
- Institute for Health Care Improvement: The Conversation Project www.theconversationproject.org
- American Association iof Kidney Patients www.aapk.org
- Your local ESRD network

QUESTIONS?

- Contact information:
  - Jenny Kitsen: jennykitsen@sbcglobal.net
  - Joan Berzoff: jberzoff@smith.edu