End-of-Life Care in a Medical Respite Setting: Circle the City's Experience

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Overview

- Medical scenarios, care requirements
- Meeting holistic needs
- Implications for the medical respite program (e.g. space, staffing)
- Implications for the medical respite community (i.e. patients, staff and volunteers)
- Grief and loss

Introduction

Began with a unique relationship with a large non-profit hospice

Circle the City Patient Cohort

- 33 hospice patients between 10/12-4/15
- Of those, 7 remained at Circle the City until death, 10 were transferred to hospice in-patient units prior to their death, 12 were discharged to housing with hospice support, 2 left AMA, 2 currently admitted.
- Range in age from 35 to 91
- 27 males, 6 females

Terminal Diagnoses

- Cancer: 13 (40%)
- End-stage Liver Disease: 8 (24%)
- COPD: 4 (12%)
- CHF: 4 (12%)
- Pulmonary Hypertension: 2 (6%)
- End-stage Renal Disease: 1 (3%)
- Debility: 1 (3%)

Program has to adapt to change in goals

- The medical goal becomes comfort
- Spoken/unspoken acknowledgement in some cases that housing after Circle the City will not be necessary
- Rather than looking forward to regaining health and acquiring housing, we help patients with closure

Medical Needs

- Pain control
- Ease of breathing
- Freedom from seizures, bleeding, offensive odor
- ability to think clearly, carry on meaningful conversations with family or friends
- maintaining enough functional capacity to continue doing the things that bring enjoyment (e.g. eating, smoking, being outside, shopping)

Pain Control

Medical staff become familiar with

- Use of long-acting and immediate-acting opiates, varying both choice of drug and formulation
- Accurate conversion between opiates and use of ranges for prn orders
- Treatment of different kinds of pain with non-opiates such as Tylenol, NSAID's, tricyclics, gabapentin, local anasthetics
- Art of adjusting opiates to achieve good pain control in patients with prior opiate addictions

Other medical issues

- Attention to treatment of anxiety and depression is important. No need to avoid use of benzodiazepines, especially as end-of-life nears
- Steroids used frequently. Help with bone pain, decreasing symptoms when brain involvement exists, appetite stimulation.
- Avoid labs and needles whenever possible. Some patients may require drainage of pleural or abdominal fluid repeatedly for comfort. If so, consider placement of drains that allow painless simple procedures at the bedside

Terminal Delirium

- May include severe agitation, trying to get out of bed, struggling with caregivers
- In some cases can be managed with oral meds (benzodiazepines, haloperidol). If so, meds given approximately every hour
- In some cases requires injectable meds. To avoid repeated needlesticks, may use maintenance of IV or subcutaneous access
- This is when families (and Circle the City) use in-patient hospice units.

Challenges with management of wounds

- Particularly cancer patients will present challenges with wound care. Want to avoid odor, maintain appearance as possible.
- Hospice nurses able to help medical respite staff with specialized techniques (e.g. metronidazole or fabric softener sheets in dressing to control odor, cat litter containers under the bed)

Implications for the Medical Respite Program

Does my space allow for the care of hospice patients in a dignified environment which does not provide undue stress on other patients?

Do I have, or can I provide (through affiliations or volunteers) the staff needed to provide the amount of care these patients need?

Space requirements

- Must have some ability for private environment. This may be just for last days of life, or may (depending on diagnosis) be required for more extended care.
- Required for dignity of hospice patient, but also to avoid emotional stress on other patients sharing space

Staffing

- In the beginning, Circle the City had no licensed staff at night. As hospice patients began to request to stay with us through their last days of life, we realized that if that were to happen we needed a nurse at bedside for constant care. Our hospice partner was able to provide that nurse only sporadically. Alternatives became transfer to hospice inpatient units or round-the-clock nursing.
- Circle the City started round-the-clock nursing in the fall of 2014, made possible by a grant written specifically for the support of hospice patients at end-of-life.

Holistic Care

- Importance of availability of mental health support
- Need for getting to know each patient's personal and family history, how to offer emotional and spiritual support in journey toward closure
- Ability to offer multiple ways of self-expression (art, music, pet therapy, creative writing, gardening, spa days, etc.)

Implications for the Medical Respite Community

- Community forms among the patients. Has been good to allow stronger patients to help sicker ones.
- Need to give patients a chance to say goodbye at right time.
- Staff and volunteers become dependable, kind presence in lives of patients nearing death, frequently much like family. While it is important to help everyone maintain good boundaries, it is a valuable time in the life of the program for helping staff understand the impact of their work

Grief and Loss

Have seen the need for grief and loss support for both staff and patients.

- Anticipatory grief session with hospice staff was helpful
- Need to allow patients to say goodbye
- Call community together (staff and patients) to announce when a patient has died, letting patients talk about how they are feeling, what they remember
- Schedule memorial service at the Medical Respite Center. Publicize so that staff, Board, volunteers, former patients can attend. Invite hospice chaplain or minister of the patient's faith to preside, but patients put service together, read, sing, display their art.

Karen's story

41 year old woman with history of breast CA, also cardiomyopathy as a result of chemotherapy. Living with abusive boyfriend, doing meth and alcohol prior to going to the hospital with difficulty breathing. In ER, chest X-Ray showed cancer in ribs and florid CHF (EF 10-15%). Couldn't lay flat for PET scan to assess CA involvement, but discharged to hospice with diagnosis of CHF, and estimate that she only would live weeks. Transferred to Circle the City with her little dog Georgie, a 4 pound Maltipoo, in October of 2013.

- We admitted Karen (and Georgie) directly into a private room with the expectation that her shortness of breath would get worse and she would decompensate quickly.
- To our surprise, her respiratory status and exercise tolerance improved (probably as her clean and sober time increased).
- She did have bony pain from the rib metastases, which was controlled on a combination of opiates and Tylenol. Her cardiac meds were titrated and CHF became compensated.

Getting to know Karen…

Karen's mother had been killed in a car accident when she was 17. Her father was still living, although elderly and frail. He lived in New Jersey, and she also had a loving brother who lived in North Carolina. Karen had been raised in the LDS faith. She had a 19 year old son who lived locally but with whom she had no contact.

- As she began to feel better Karen took part in lots of activities at Circle the City. She had always wanted to play the piano, and volunteer piano teacher Dan began giving her lessons. She learned to make fishtail rubber band bracelets, and loved having gifts to give to the other patients and staff. She made friends easily, and– of course– everybody loved Georgie.

Reconsidering the medical plan…

- In January of 2014 Arizona restored Medicaid to childless adults, and Karen got health insurance coverage. At this time she showed no symptoms of heart failure, and although there had been no repeat testing done, it appeared clinically that her ejection fraction had improved. We had no imaging to know how widely her breast cancer had spread. What if the rib lesion was her only metastasis? What if this beautiful 41 year old woman could, with the aid of some Tamoxifen, have quality life ahead of her? Do we even want to bring the subject up, and instill hope that might be false?

PET scan…

- After a frank discussion of the issues and possibilities, Karen decided she wanted to know.
- PET scan was accomplished in January of 2014, and showed cancer in almost every bone, both lungs, both lobes of the liver, and a suspicious lesion in the brain.
- After tearfully accepting the news, she decided she “still had some living to do.” She signed up for every activity there was, and also to help with whatever chores she could do to help around the facility.

- Karen began to decompensate clinically in late February. Pain control became a challenge, and we transferred her to a hospice in-patient unit for a week in order to convert her large doses of morphine to Methadone which achieved better control.
- One day she began to have double vision and a disconjugate gaze. Steroids were started with great results. She didn't like the weight gain, but the double vision resolved.

- We encouraged her father and brother to come out for a visit, but they didn't sense the urgency of our concerns and postponed the visit. Karen talked with them almost daily.
- Someone came from her LDS ward, but Karen related better to the hospice chaplain, and they talked frequently.
- Georgie stayed in her room with her, and other patients would help take him outside and watch him if Karen needed to rest.

- Karen was only unconscious and bed-bound for the last 48 hours of her life. All meds were stopped with the exception of liquid morphine and lorazepam, administered sublingually every hour or two. A Foley catheter was placed.
- Hospice agreed to provide continuous care in the room (as they would do for a housed patient in the community) “if they had the staff.” Our nurses volunteered to come in and provide the care if it was not available through hospice. It was that important to all of us that Karen be able to die at Circle the City as she wished.

- She experienced terminal delirium for the last three or four hours, and with the addition of liquid haloperidol it was adequately managed.
- She expired at Circle the City on April 17, 2014 with twelve Circle the City staff in the room and Georgie on her bed.
- Her memorial service was held at Circle the City about 2 weeks later. It had to be moved to the dining room to accommodate the crowd of patients, volunteers, Board members and staff who came.

In Conclusion

- The addition of hospice services to a medical respite program requires some capacity of facility and staff, and the partnership of a local hospice, to accommodate the special needs involved.
- However, it seems a natural extension of our expertise to extend compassionate holistic care for those experiencing homelessness all the way to the end of life.
- For Circle the City the need for this service was articulated to us before our doors were even open. In our first two and a half years in operation we have tried to grow and accommodate to meet the need. The process has brought comfort to those we serve and a deep satisfaction to all of us in the organization.