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We need to embrace new pastoral care settings with passion, vision

If you work in a healthcare setting, what is your percentage of patient touches? Ninety percent? Seventy percent? Sixty-five? Forty? What percentage? How many patient touches are now NOT in the acute care setting? As I listen to members and to leaders in healthcare, whatever the percentage is, it is growing steadily and in some places rapidly.

As we know, in the past spiritual care was predominantly provided in hospitals. Some of the new settings most mentioned now include: outpatient and ambulatory care clinics, physician offices, and home healthcare. What does this mean for our chaplaincy profession? If healthcare is holistic, treating body, mind, spirit, then we will need to be in these new settings. However, will we embrace the new settings we will need to serve with passion and vision, or will we be hesitant and reluctant? Do we feel prepared and equipped, or are we uncertain as to what they will require of us? Do we find ourselves saying, “I didn’t sign up for this”?

The first goal of the NACC’s new Strategic Plan 2012-2017 is: To educate and support association members for the future of professional chaplaincy, and the first objective of this goal is Provide formation and resources for chaplains to be effective ministers and leaders, especially in emerging settings and health care systems (both Catholic and other) and across the continuum of care. It’s clear that our NACC members and leaders see defining, prioritizing, identifying competencies for, and providing learning opportunities about these emerging settings as the top priority for us. As one member stated, “we are proactive in learning about and presenting ourselves as key providers in these settings, or we will not be needed in the future – chaplaincy as we know it will end.”

Over the past months, I have been appreciative to the co-planners of the Catholic Health East (CHE) webinars, as they have decided to devote many of the 2012-14 webinars to exploring spiritual care in diverse non-acute settings. I am also grateful to the early sharing of approaches and learnings of Mercy Health System out of St. Louis where more than 90 percent of their patient touches is in non-acute settings, so they are exploring vigorously how to provide spiritual care in those new settings with new spiritual care models. Our NACC members of Mercy, Julie Jones, executive director, mission and ministry, and Dorothy Sandoval, director of pastoral services, St. John’s Mercy Health System in Springfield, MO, presented an innovative forum on “A New Model of Pastoral Care: Expanding into the Clinic Setting,” at the Catholic Health Association of the United States (CHAUSA) Assembly this past June. You can access their presentation here. I urge you to read it to learn about how they are planning to integrate pastoral care into clinic settings, the overall approach, and the lessons they are learning in the process. (www.chausa.org/2012_Handouts.aspx)

What I hear most from leaders and members is that we ALL need to share with one another what we are doing and discovering in these new settings. What is the methodology we are using to assess the spiritual care needs in those settings? How are we partnering with clinicians, managers, physicians, nurses, etc., to develop a referral system and presence/service delivery? What are some of the models that are developing? What service modalities are being tried? How is this service being billed? What new competencies are you discovering as you do this work that you and all of us need to be prepared for? How should NACC prepare and support our members for these new venues?

In this and the next issue of Vision, articles by members are devoted to this type of sharing. The authors have been willing to offer their reflections. We hope it will stimulate you to also consider sharing in writing either for Vision or NACC Now about what you or your hospital/system is doing to begin responding to the
need for spiritual care outside of acute care settings.

We invite, encourage, even implore you pioneers in the field to let us know what you are doing and what you are discovering in providing this chaplaincy “outside the walls,” as one member put it.

I look forward to hearing from you!

David Lichter, DMin
Executive Director
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E-chaplaincy helps chaplains reach beyond hospital walls

By Kenneth Potzman, BCC, Laura Keep, and Julie M. Jones

The grief of losing a loved one, anxiety after receiving a frightening medical diagnosis, worries over caring for an aging parent – these aren’t necessarily medical problems but they are certainly spiritual ones. Now in St. Louis, MO, Mercy Hospital patients and co-workers have an additional place to turn when they need spiritual care alongside physical care. It’s called e-chaplaincy, and it allows patients and their families to reach out to chaplains for prayer and support via e-mail.

Mercy designed e-chaplaincy to make sure patients outside the hospital setting, as well as co-workers working within Mercy St. Louis, have spiritual support at their convenience – whether that be the person who is up at 3 a.m. worrying or the co-worker who is unable to break away from work to schedule an appointment or call a chaplain.

One e-chaplaincy request came from a woman who is the full-time caregiver for her husband who suffers from Alzheimer’s disease. Late one night she was sitting in her kitchen very distressed and felt an intense desire to reconnect with her faith. Her Mercy physician recognized her need for spiritual support and suggested she contact a chaplain through mercy.net. The chaplain was able to connect the woman with resources so she could get some respite from her caregiving responsibilities. In addition, he offered prayer and helped get her in touch with the parish in her area. Later, the woman reported back to her e-chaplain that she had joined the parish and was going through its Rite of Christian Initiation for Adults (RCIA) program.

So how did the idea of e-chaplaincy come about? It grew from an initiative at Mercy Hospital St. Louis to enhance communication between a chaplain and parents of infants in the neonatal intensive care unit. The chaplain found that e-mail was a non-intrusive way to reach out to parents who were unavailable to visit during the day. The response to these e-mail sessions was so positive that a plan was launched to extend e-chaplaincy throughout Mercy including to patients in Mercy clinics. Today, requests come in daily from individuals of all ages – as young as 15 and as old as 91.

Ken Potzman, director of pastoral services at Mercy Hospital St. Louis, where Mercy conducted an extensive year-long pilot of e-chaplaincy, reports a surprising finding: “It’s amazing to me how many people say they could never talk about these things face-to face. People say it’s much easier to reach out over the Internet. It seems to be where our society as a whole is going with social networking. And if that’s the case, we need to extend our reach beyond the walls of the hospital to provide spiritual care where people are most comfortable.”

One example of the anonymity of e-chaplaincy came from a young man who was addicted to drugs for almost 10 years. He realized what his addiction was doing to his family, especially his children and parents, but couldn’t bear to talk to anyone face to face. After reading an article about the pilot program at Mercy Hospital St. Louis, he decided to give it a try. After numerous e-mails back and forth offering encouragement, affirmation and prayer, as well as practical information about support groups and community resources, the man sought professional help. He later reported he had been clean for almost six months.

E-chaplaincy supports Mercy’s larger mission to ensure pastoral care extends beyond hospital walls. For example, e-chaplaincy allows physicians a way to refer patients to e-chaplains as a follow-up to routine
office visits.

Since March 2012, all 38,000 co-workers can contact an e-chaplain through Mercy’s Intranet site. This summer e-chaplaincy was introduced externally to patients in all Mercy communities in Arkansas, Kansas, Missouri and Oklahoma – through Mercy’s Internet site and patient portal where patients contact their physicians, schedule appointments and see test results. Patients are then able to correspond via e-mail or request a phone call.

Some of the issues chaplains are addressing from a spiritual and emotional perspective include grief/loss, relationship issues, loneliness, stress, managing change, life balance, spirituality and growth, coping with health issues and finding a support group.

E-chaplaincy is not a professional counseling service. Instead, one of Mercy’s trained chaplains offers practical advice at times of change and challenge, a listening ear, and prayer and support. There are 12 trained e-chaplains across Mercy with plans to expand the service as needed.

Each e-chaplain is selected by the pastoral services leader in a service area, based on the chaplain’s interest and abilities. In order to become recognized as an e-chaplain at Mercy, the chaplain needs to demonstrate the following skills: be comfortable with electronic media and have concise communication skills as well as solid analytical skills.

E-chaplaincy offers easy access to chaplain services that ultimately impacts more patients than ever.

At Mercy Hospital St. Louis in St. Louis, MO, Kenneth Potzman is regional director, pastoral service; Laura Keep works in media relations; and Julie M. Jones is executive director, mission and ministry.
Pastoral care in clinic settings poses challenges

Lack of privacy, short visits among hurdles chaplains face

By Marika H. Hull, MDiv, BCC; Sister Fatima Simas, SSD, MA, BCC; Daniel Sullivan, BCC; Sister Carole-Marie Mello, OP, BSN, MA, BCC

Clinic chaplaincy differs in important ways from hospital ministry. In this collaborative article, we would like to present some of the challenges we have observed in our ministries in clinic settings. Our group has experience in medical oncology, radiation oncology, pain clinic and gero-psyche outpatient services. The three biggest challenges are that the patient visits are short, the visits in a clinic are more “public,” and it can be more difficult to engage with patients, doctors, and nurses because of the focused and time-limited nature of the treatment. Each type of clinic has its own constellation of needs and ethical issues, and each type of clinic requires a different way of approaching and connecting with patients.

Overall, the lack of privacy is the biggest hurdle the chaplain has to address in the clinic setting. This makes it harder for the chaplain to connect with patients and to identify those who might benefit from a chaplain visit. In hospital settings, the patients are usually visited in their rooms. There is some privacy, especially if it is a private room, and the patient is in a hospital gown, waiting for, and expecting services. The clinic patient is ambulatory, and the clinic visit is a planned part of their day, rather than an acute care situation. The patients’ first stop is registration, then the waiting room, which is very public and often crowded. Once the patients are in the treatment rooms the nurses are busy delivering and monitoring treatments. The opportunity for a visit is fairly brief once treatment has started.

In medical oncology at Saint Anne’s Hospital in Fall River, MA, there are only a few private or semi-private infusion rooms. The main treatment room does not provide easily for privacy. A curtain can be drawn for visual privacy, but audio privacy can be a challenge, especially with elderly patients, many of whom have hearing deficits. A chaplain must think ahead about positioning in regard to where the patient is sitting to have an effective visit, knowing that there are others around, and within earshot. When a patient is visibly distressed, drawing the curtain around their chair, or calling in the chaplain can be embarrassing and cause the patient to feel vulnerable. In cases of distress, it might be better to move the patient to a private consulting room to speak with the chaplain, although this is not always possible, and often not advisable so as not to embarrass the patient.

In the clinic setting, short visits are the general rule. A chaplain can easily do a social visit, provide religious articles or reading, or briefly acknowledge some difficulties. Longer visits can be quite problematic. The patient can feel embarrassed by the lack of privacy, and the chaplain’s visit may interfere with the frequent monitoring necessary by nursing staff. Many times, just a walk-through and a friendly hello can remind patients and their families that spiritual care is an important dimension of their treatment, and that a chaplain is available for them to talk to.

In addition to privacy and short visits, interfacing with the staff and referrals pose a challenge in the clinic. The clinic is a busy place and nurses are pressed to administer treatments to many people. In the clinic setting, nurses and physicians are focused and often more rushed than on the inpatient floors. They do not often have the time to spend a few minutes speaking to the chaplain as they might on the hospital floors because they have so many patients to attend to. Also, the nurses and physicians are not as inclined to make referrals to the chaplain as they would in inpatient units. There are too many patients to attend to. In addition, the staff may feel that a referral to the chaplain signals a failure of medical
attention and treatment. The most successful referrals in our practice have been through the nutritionists and social workers. Occasionally, our volunteers and administrative staff also have called a chaplain to provide support for a patient that they have noticed is distressed.

Depending on the type of clinic, the style of the visit has to be re-examined and re-imagined. Radiation oncology poses special challenges because the patient is in and out very quickly. There is little or no time to visit. If the chaplain visits while the patient is waiting to be called to meet with the doctor or nurse, the patient may become anxious and worry that they may miss their turn for the treatment or consult, and then have to wait longer to be seen. In settings like radiation oncology, the chaplain may only have the opportunity to greet the patient or express a few words of encouragement.

Over the years, beginning with the ministry of the Dominican Sisters of the Presentation, patients in our medical oncology clinic have been given the opportunity to receive the Eucharist in the clinic. Different chaplains use varied approaches to identify patients who would like to receive. Some chaplains ask each patient, while others make a general announcement that Communion is available for those who would like to receive. Bringing the Eucharist to the clinic is a big support to many patients, especially to daily communicants who cannot attend Mass on treatment days. We are now in the process of thinking about how to provide the Sacrament of the Sick for clinic patients. The greatest challenge is how to do this without intruding on patients who are not disposed to receive the Sacrament or non-Catholics sitting nearby.

In summary, we have shared some general observations, and named some of the challenges we have observed in our clinic ministries. We hope this article will contribute to an ongoing dialogue about the types of strategies and programs that help chaplains to create, innovate, and improve ministry to clinics.

The chaplains who collaborated on this article in addition to their in-patient duties are assigned to clinic and outpatient settings at Saint Anne’s Hospital in Fall River, MA. Sister Carole-Marie Mello is the senior member of the group with nearly 35 years of experience in Medical Oncology and Outpatient Gero-psyche.

Related articles in this issue

Clinic chaplaincy means building relationships, little by little
(begins on next page)
Clinic chaplaincy means building relationships, little by little

By Marika H. Hull, MDiv, BCC; Sister Fatima Simas, SSD, MA, BCC; Daniel Sullivan, BCC; Sister Carole-Marie Mello, OP, BSN, MA, BCC

One of the greatest benefits of clinic ministry at St. Anne’s Hospital in Fall River, MA, is that the chaplain gets a chance to build relationships over a period of time, little by little. Often, clinic patients are admitted to the hospital, and the clinic chaplain becomes part of their inpatient care quite naturally. We also offer short-term counseling for patients who are referred to us, or request this service.

Among the clinics connected to St. Anne’s, the pain clinic is often where the chaplain is most welcome. Patients in pain are eager for the soothing balm of presence and prayer. The chaplain’s presence is a source of hope and strength, and in the pain clinic, a short visit with prayer is very often well received. Although this is also true in other clinic settings, it must be done with discretion and awareness of the public setting.

An effective way of connecting with patients and providing support is with supplemental programs. Linking to these programs provides us with ways to innovate and discover and explore new models of ministry. In the medical and radiation oncology clinics, spiritual care partners with the clinic outreach coordinator. Our clinics provide outreach in the form of scrap-booking, book clubs, yoga, as well as presentations on nutrition and fitness for patients in treatment for, or recovering from different types of cancer. By partnering with the outreach coordinator, the chaplain can provide some very effective and non-intrusive ways of providing spiritual support in the clinic. Spiritual care also sponsors coffee hours and holiday celebrations to help patients and their families keep in mind the spirit, mind, and body connections.

In our radiation oncology center, there is a group called “Life Part Two.” This group of cancer survivors meets on a weekly basis. The members are fairly regular, but the group is open and membership changes frequently. The group is informal and the members decide on the topics. The chaplain is a regular member of this group and provides emotional and spiritual support. The chaplain meets regularly with the social worker, and together they make assessments of the needs and styles of the patients. There is also a prostate cancer survivor group that has met for several years. Spiritual care partners with the social worker who directs this group as the needs and opportunities arise. From time to time, the chaplain is invited to give workshops and didactics on spirituality.

In the last few years, we have developed a successful retreat program for oncology patients that we now hold twice a year. The program was started several years ago by partnering with social work to provide a “field trip” to the Dominican Sisters convent. This has now developed into a one-day weekend retreat program for up to 20 cancer patients. We have a theme and a speaker. There is a liturgy during which the priest administers the Sacrament of the Sick. Yoga and chair massage are available and there is an opportunity to walk the labyrinth. The retreat is popular with our cancer patients.

In gero-psyche, a re-motivation and spirituality group helps depressed patients think about the positive aspects of their life and helps to engage them with others. We often add music or feature a musician to play as part of the session. The chaplain leads the group, charts the progress of the patients, and interfaces with the social work staff.

Ethical and justice issues are increasingly an important part of our practice and vary according to the type of clinic practice. In each clinic setting, we are called to provide guidance to staff and to support our
patients with compassion and in light of church teaching. In medical and radiation oncology, we are called to be knowledgeable about addressing reproductive issues, as well as conflicts that arise when patients request or refuse particular treatments. Issues regarding chemotherapy and radiation for patients of childbearing age and pregnant women are particularly pressing. The licensing requirements for physicians and social workers demand that they provide education and guidance that may be in conflict with church teaching.

In the pain clinic, patients may insist on more relief, while the clinicians have well-founded concerns about dependency and addiction. In the gero-psyche setting, there are issues of autonomy and competency. Just as in in-patient settings, the clinic is subject to scarcity of resources, uneven availability of drugs, and breakdowns of machinery, which interrupt or interfere with the ability of the staff to provide the treatment patients need.

We hope the pastoral care opportunities we mention in this article will contribute to dialogue about new models of chaplaincy. We encourage our chaplain colleagues to share their experiences with reaching out to patients in outpatient settings.

*The authors are chaplains at Saint Anne’s Hospital in Fall River, MA.*

**Related articles in this issue**

Pastoral care in clinic settings poses challenges  (pg. 5)
New model of chaplaincy takes chaplain into patient’s home

By Laurie Hansen Cardona
Vision editor

While not many physicians make home visits these days, chaplains with Community Care, Inc., in Wisconsin do so all the time, as do the other members of their interdisciplinary teams.

In fact, they visit Community Care members wherever they are, whether at home, in an assisted living facility, in an adult day care center, or in the hospital. The chaplains are members of interdisciplinary teams that likely include a physician, nurse, social worker, advanced disease support technician, physical therapist, occupational therapist, dietitian, nursing assistant, recreational assistant and driver.

At Community Care, each member of the team is important, said Karen Nehls, chaplain at Milwaukee-based Community Care until she recently retired. Ms. Nehls led a workshop at the NACC National Conference during which she introduced members of her interdisciplinary team and members explained their roles on the team and how Community Care works.

She said that when the teams were first established, they met daily. “As we grew, meetings became less often.” Now team members communicate regularly by team notes and charting, by e-mail messages and phone calls. At meetings, team members “are purposeful” in their discussions, she said.

According to Ms. Nehls, the chaplain’s role at Community Care has been to be “listener, teacher, advocate, facilitator, role model, bridge, and giver of unconditional love” by being “present, available, responsive” and making bridges between members, family and staff.

She noted during the workshop that Community Care is a private, non-profit agency that receives government funding and is designed to enable elderly and disabled adults to remain independent through case management services and the provision of affordable in-home and community-based services. In Wisconsin, Community Care has 11 interdisciplinary teams that operate in six counties.

Toni Kesler, a nurse practitioner who is the manager of palliative care and advanced disease support, said that Community Care offers three programs that provide care to its members. One of these programs, called PACE, the Program for All-Inclusive Care for the Elderly, was based on a successful model first developed in San Francisco’s Chinatown.

Ms. Kesler said the Chinatown program was “well received” because of its success at providing members needed health and social services without requiring them to leave their homes. “We’re the fourth replication site,” she noted. To be eligible for PACE, members must be 55 or older, live in Milwaukee or Waukesha counties, meet financial and functionality requirements and be enrolled in Medicare, if eligible. A Community Care staff physician becomes the member’s primary doctor.

A second Community Care program, called Partnership, allows members to select a doctor from Community Care’s network of community-based physicians. The interdisciplinary team members work with the member and his or her family. To be eligible, an individual must be at least 18, live in certain Wisconsin counties, meet financial requirements, and be eligible for Medicaid.

A third program, titled Family Care Program, provides long-term care services that make independent
living possible for older adults and adults with disabilities. This program offers home health, personal care, therapy and other long-term care services.

At Community Care, a chaplain may be involved in a case “from home to hospice, from enrollment to death,” said Ms. Kesler. She said in some cases a chaplain gets involved with a member by helping after a spouse dies.

Getting a chaplain on the interdisciplinary team at Community Care wasn’t a given when the organization began in Wisconsin, said Ms. Kesler. She said chaplaincy involvement began after a request for Bible study by members. The request was met, but there was staff conflict. Some said it wasn’t appropriate for a government-funded operation to provide this kind of religious option, Ms. Kesler said.

But today that’s ancient history. Ms. Nehls was employed as a Community Care chaplain in 2002, team members came to rely on her, and an Advanced Disease Support Team was established, Ms. Kesler said. Two full-time chaplains now are part of the team and their efforts are “readily accepted,” she noted. They are frequently involved in palliative care with members as well as play an important role on Community Care’s Ethics Committee.

Tiffany Kather, Community Care nurse practitioner, noted that at Community Care the triggers for chaplain referral include:

- End-of-life/palliative care needs.
- Sudden unexpected death.
- A member who is depressed, lonely or anxious.
- A caregiver who is stressed and in need of support.
- Death of a loved one, role change, change in health, or a new diagnosis.
- A member who is unwilling to accept mental health or psychiatric services.
- A member who has significant mental health needs.
- A member who values participating in religious services, but is unable to attend due to physical limitations.

The chaplain contributes to the interdisciplinary team by providing “a non-medical perspective in difficult situations,” said the nurse practitioner. She added that the chaplain offers bereavement support to all team members in need of support, whether due to work-related duress or personal loss.

Ms. Kather noted that Ms. Nehls, as chaplain, brought “a sense of peace and calm to a situation.” She said she supported “the team as much as the members.”

Dr. Marilyn Sincaban, medical director of Community Care, commented that in her view it is critical for all members of the team to recognize the value of spirituality in healthcare.

She said that religious practice or lack of it can affect medical decision making; lead to spiritual struggles, which impacts outcomes; result in beliefs that conflict with medical care; and negatively impact disease detection and compliance.

Bill Leon, Community Care social worker on the interdisciplinary team, commented that when members make religious or spiritual observations, it’s helpful to “be intentional about discerning if chaplain referral is warranted” and get permission from the member.

He noted that sometimes if discussions with members require greater depth, “a chaplain can open an important door.”
Mr. Leon added that when working with persons with advanced dementia, it’s a good idea to query family members about childhood background. Information provided, such as prayers, songs, rituals, Scripture, may trigger a need to link to the chaplain, he said.

At the workshop, Ms. Nehls read and distributed four case studies of Community Care members. They can be found at:

- Case Study: Ann’s story (p. 13)
- Case Study: Jane’s story (p. 15)
- Case Study: John’s story (p. 17)
- Case Study: Robert’s story (p. 19)

See also the article "This chaplain follows her patients wherever they go" by Lisa Gilvary, a chaplain for Community Care (p. 21)
Staying the Course: Ann’s Story

Ann was an 89-year-old Catholic woman who had several strokes. She had told staff that she did not want heroic measures, but after a devastating stroke, her daughter opted for full code status and artificial feeding. She made this change because she felt her mother was too demented at the time to make that type of decision. Ann ended up with a permanent trach, vent and feeding tube.

The daughter, who had been estranged from her mother, said to her, “Look at all I have done for you so you can live. Are you happy?” When Ann said “yes,” her daughter took it as an affirmation that her mother wanted all of the life-extending treatments.

Ann’s life then became a series of trips from the nursing home to the hospital. Her hospitalizations were due to sepsis, continued decline, dislodged feeding tube, infections, bleeding and inconsistent feedings. The staff at both the nursing home and the hospital believed that Ann was suffering and frightened. They appealed to Community Care staff to convince the daughter to change the course of treatment to palliative. The daughter would not listen to CC team members or any of the consultants that spoke with her. This went on for several years. Only when Ann developed untreatable bleeding with sepsis did the daughter allow her to be removed from the vent.

Ann and her daughter’s journey took them to multiple hospitals and nursing homes. The daughter actually “fired” staff, including physicians, hospital staff and nursing home staff. Chaplains and the Advanced Disease Support Team were allowed to continue to visit, however, and were the only consistent part of the support.

The Community Care team that cared for Ann was emotionally drained. Every conversation with her daughter produced frustration. She spoke of how much she loved her mother and wanted to do the best for her, but the staff felt that the treatments she insisted upon were actually causing more suffering for her mother.

Our team members did not feel successful because they were never able to persuade the daughter to discontinue treatment. However, we were successful in that we stayed the course and remained on the journey with Ann and her daughter, no matter where it took us.

**Referral:** from Community Care team for acute change of condition and possible end-of-life care
(Subsequent referral was for assisting with daughter’s decisions)

**Challenges:**

- Daughter did not acknowledge Ann’s wishes for end-of-life care that had been expressed to chaplain
- Daughter reacted strongly to any suggestion regarding allowing her mother a natural death.
- Daughter expressed strongly that any attempt to end tube feedings or remove the vent was an attempt to kill her mother.
- Allowed visits and phone calls by chaplains, but would not speak of end of life
- Daughter would request a new doctor, new nursing home and hospital as soon as anyone suggested that
treatment provided was causing more suffering for her mother or was inappropriate

Daughter lost trust with medical staff

Daughter would not respond to phone messages or attend meetings with team

**Opportunities (Role of Chaplain)**

Pastoral presence for Ann, daughter and team

Offer spiritual support to daughter by being present and listening to her concerns

Maintain communication with daughter by calling after each visit with Ann

Attempt to gain confidence/trust of daughter

Stay on the journey with daughter; chaplains shared visits to keep a constant presence and due to frequent moves

Offered unconditional love for Ann’s daughter, affirming her even when we did not agree with her

**Lessons learned:**

We don’t always feel like we won

We did our best

We did not give up

Ongoing spiritual support for staff, including chaplains, is extremely important

Importance of total team support for each other

We learned to support and affirm even when we disagreed with family member’s decisions
Calm Amid the Storm: Jane’s Story

Jane was 67 years old when she entered our program. Jane was homebound with multiple serious diagnoses, including diabetes, stroke and heart condition. She lived at home with her husband who was her main caregiver. They had a strong belief that God would heal Jane and that God did not need help from the medical profession. As a result they would not follow Jane’s diabetic diet restrictions. Her husband would adjust her medication, withholding her Lasix if she complained about going to the bathroom too often, or reducing her dose of insulin if he felt it was too much.

Jane’s health continued to decline and she had multiple hospitalizations, including one during which she had a near death experience. This affirmed their trust that God would heal her because he had already brought her back once! Her declining health caused them to move to assisted living and then with family members who could help because she did not want to go to a nursing home. They continued to dream and hope for her recovery.

The journey became very difficult when Jane had a massive stroke and needed to change to another hospital. She spent three months in an acute care facility. They continued to look for cures, hoping to wean her from the vent. Jane’s husband slept in his car so he would be near her. He got angry at the medical staff because he felt Jane’s care wasn’t good enough and she wasn’t improving. He himself considered suicide because he could not think of life without her. Eventually the family allowed Jane to be transferred to a nursing home. Her husband again was extremely demanding and angry at staff.

It took time, loving presence, and listening to continue this journey with Jane and her husband. Both Community Care chaplains were involved due to the change of counties and intense need for spiritual care for Jane, husband, family and staff.

Gradually, her husband could see Jane would not recover. His tone changed from anger to requesting care for comfort and a peaceful death. The environment became one of music, prayer and peaceful visits with family.

Referral:

from entire Community Care team to offer spiritual support to Jane and her family, as well as assistance and support to the team.

Challenges:

Noncompliance with medical treatment

Lack of trust in medicine

Trusting God to heal Jane through family interventions

Frustrated team

Opportunities (Role of Chaplain)

Assist in encouraging compliance with medical treatment
Offer spiritual support to meet Jane’s faith needs

Offer spiritual support to caregiver

Assist family to reframe hope as Jane continued to decline

Continuity of spiritual support for Jane, husband and family as she moved to a different county and two different care teams.

**Lessons learned:**

Never give up!

Value of calming presence

Open to change

Continuity of chaplains’ role to maintain spiritual support as Jane changed teams and counties for her care
Bridging: John’s Story

John was an 82-year-old divorced male living in an apartment in northern Wisconsin. Medical diagnoses included stage IV colorectal cancer, a significant open wound, and a host of other health issues. His daughter decided to move him to an assisted living facility in the Milwaukee area so that he could be closer to her. Their relationship had been strained for years and she saw this as an opportunity for them to reconcile.

Instead of moving to assisted living, however, John ended up in a nursing home, because his health declined rapidly. His daughter started to feel guilty, wondering if his decline in health was due to the move. She became critical of the care being provided and lost trust in the nursing home staff as well as the Community Care team.

John’s daughter was alone in making decisions for his care. Her brothers refused to come. Eventually the daughter accepted support from the Community Care chaplain, who remained during John’s ER stay and continued to provide support via daily visits and phone calls, assisting her in clarifying her questions.

In John’s final days, he was discharged from Community Care to a formal hospice agency. Our chaplain continued to minister to them to bridge this transition. The time was short, and our chaplain had one good conversation with John during which he shared how much he loved his daughter and trusted her, and how grateful he was that she had moved him close to her so that she could take care of him. The chaplain was able to tell the daughter these things, so that when her father was actively dying she could be present to him and help him have a peaceful death.

Referral:

from Community Care team through social worker when it became apparent that John was physically declining and daughter’s increased anxieties indicated a need for more support.

Challenges:

Member very new to Team

Health declined rapidly after member joined our program

Daughter and father had strained relationship for several years

Daughter was very anxious to do the best for her father

Daughter’s guilt regarding father’s decline in health after the move

Daughter’s dissatisfaction with care

Opportunity (Role of Chaplain):

Provide opportunity for reconciliation between John and his daughter

Provide spiritual support for John as he entered his end-of-life journey
Provide spiritual support for daughter as she tried to provide the best care for her father

Be a pastoral presence at team meetings with daughter when she was anxious

Be a pastoral presence with daughter at father’s bedside

Encourage daughter to be present to her father and express her feelings of love and forgiveness

Be a bridge between daughter and CC team and nursing home staff when daughter was distrusting

Lessons learned

Importance of exchange of information between chaplain and Community Care team to maintain continuity of spiritual support

Importance of pastoral presence to member, family and team

Importance of being open to the journey and opportunities that may present themselves only once

Importance of early referral and immediate response by chaplain
Smooth Road: Robert’s Story

Robert originally enrolled in 1988 with his wife, who suffered from Alzheimer’s disease. Robert was very devoted to his wife. Although he had several physical disabilities due to strokes, he took care of her at home for as long as he could. When she went to a nursing home, he visited her every day.

In 2005, the Community Care chaplain received a referral to provide end-of-life care to Robert’s wife. The chaplain was present when Robert was called to the nursing home at the time of his wife’s death. The chaplain remained with Robert, sharing prayers of commendation at the bedside, walking home with him, listening to his stories about his wife, looking at pictures. She helped arrange a memorial service in Robert’s apartment building.

Robert was able to remain in his apartment with help from Community Care, which provided medical care, assistance with personal care needs, and housekeeping. The social worker and chaplain worked closely together to provide spiritual support and guidance as he grieved the loss of his wife.

Robert was transitioned to a second CC chaplain as our caseloads grew. His first chaplain stayed current with Robert’s case through updates from the social worker and attending team meetings periodically.

Robert adapted well to the new chaplain, but his relationship with the first chaplain remained strong and special. He called her when he decided it was time to bury his wife’s ashes.

This chaplain was contacted immediately when Robert died suddenly in 2011. She was able to be a comfort to Robert’s sister, his only living relative, sharing stories about Robert’s life. The social worker and chaplain worked together to arrange his funeral.

Referral:

from Community Care team for end-of-life care for Robert’s wife and later for bereavement support for Robert.

Lessons learned:

Importance of communication between team members

Ongoing bereavement support

Value of building rapport – available to bury wife’s ashes

Early identification of dying process and earlier referral to offer end-of-life support to family

Challenges:

Referral came when member’s wife was at end of life with end-stage dementia. Chaplain was unable to visit or converse with her due to her advanced dementia.

No immediate family support
Opportunity (Role of Chaplain):

Bereavement support, including bedside support for Robert

Officiating at funeral

Ongoing spiritual support as Robert learned to live his life without his beloved wife

Officiating burial of wife’s ashes when Robert was ready

Shared ministry with social worker

Shared information with team regarding Robert’s interests and concerns

Lessons learned:

Value of early referral

Value of establishing relationships

Value of relationship with team to maintain continuity of care and goals
This chaplain follows her patients wherever they go

By Lisa Floch Gilvary, MA, BCC

I am sitting in the apartment of a 56-year-old woman who has a debilitating disease. She is lying in a hospital bed in her living room. I have just read Psalm 84 and point out that in this psalm, even the sparrows have a home in God's heavenly city.

The woman notes how much she enjoys hearing the birds through her open window. She used to keep finches and canaries, and she used to play with the dogs she helped care for at her son's kennel. "I miss the birds," she says, "and the dogs."

Her voice is barely audible, but I hear the sadness of having to give up these life-affirming experiences as her physical abilities have diminished. We pray that God will be with her and strengthen her, especially on the days when her disease becomes overwhelming, and so ends my monthly visit.

This chaplain visit, along with her medical care, is provided by Community Care Inc., my employer. A non-profit organization founded in 1977 in Milwaukee, WI, Community Care provides all-inclusive care to elderly and disabled people. When patients (or members, as we refer to them) enroll in our program, they entrust their Medicaid and Medicare dollars to us and in return they are cared for by our social workers, nurses, doctors, therapists (OT, PT, recreation, speech, behavioral health), and chaplains. Our personal care workers and home care aides attend to their personal hygiene and housekeeping as needed.

I have worked as a hospital chaplain and through CPE I have experienced chaplaincy at nursing homes and a hospice facility. In my work at Community Care I visit people in all three of these settings, and many more.

I start my day in my office, checking the computerized appointment schedule to see which members will be present at the day center. Some members come to the day center regularly for socialization, physical therapy and nutritious meals. I make a list of the members I need to see. Then I check the e-mails, looking for referrals from social workers, nurses or recreation assistants. These are the staff members who most frequently observe a need for chaplain intervention.

I share the pastoral care of our members with my colleague Chaplain Joyce Lawlor, an ordained Protestant minister. We deal with a population of people who have few resources (our members must be Medicaid eligible). Many of them have had difficult lives – abuse, violence, drug addiction, alcohol abuse, dysfunctional families, lack of resources – along with medical problems such as diabetes, heart disease, kidney failure, dementia, cancer, multiple sclerosis, PTSD. These are the people we visit monthly to hear their stories, affirm them, and share God's love with them.

After prioritizing my visits I hit the road, either figuratively, going upstairs to the day center where the daily gathering of members is in full swing, or literally, traveling to nursing homes, group homes, hospitals, apartment buildings and hospice facilities. Wherever our members go, we follow them. As a result, we are able to form long-term relationships with the members and their families. This becomes invaluable when members begin to fail and we are able to provide loving care and support.

I try to attend one of the interdisciplinary care team meetings each week. There is no hierarchy around this meeting table; social workers, dietitians and chaplains offer pieces of information that are considered
with the same attention as reports provided by the doctors, nurse practitioners and RNs. The team then assembles a unique plan of care for each member.

The interdisciplinary teams respect and utilize the chaplains, thanks to the work of our predecessor, Chaplain Karen Nehls, BCC. Ms. Nehls started the chaplaincy program at Community Care, with the help of our supervisor, Toni Kesler, an advance practice nurse with specialties in gerontology and end-of-life care.

There are two things that I most appreciate about working for Community Care: our team-oriented approach to providing healthcare, and the opportunity to really get to know the people we serve. Chaplains in every healthcare setting have the opportunity to grow close to their patients. In my job, however, I visit people in their homes and get to know their families. I am with them at difficult crossroads, and I assist their healthcare team in determining the best treatment while respecting their wishes. This is a healthcare model that works well for patients and for employees, and I am proud to be a part of it.

*Lisa Floch Gilvary began ministry as a chaplain at Community Care Inc. in Milwaukee, WI, in February.*
PRPII, standards, team building among topics of joint meeting of ITEs, certification commissioners

By Matthias Merges, PhD, and Lindsey Tews, MA

The NACC Interview Team Educators (ITEs) and the NACC Certification Commission held their respective meetings July 11-13 and July 12-14. Parts of two days were dedicated to a joint meeting of the two groups. Everyone involved remained committed to the NACC certification process, to recognizing how and why it works, and to improve other areas. The main topics of discussion were the Presenter’s Report Part II (PRPII), comments on several standards, team building and applicant materials.

Presenter’s Report Part II

The quality and ease of use of the PRPII continue to generate much attention from the national office as well as from the Certification Commission. The two major quality improvement areas identified during the meeting were: congruency of the writing and professionalism of the document. Three process changes were developed and will be implemented for October 2012 interviews.

1. The time window for writing the PRPII will be expanded from 60 to 90 minutes. The first part of the window is available for the interviewer team to facilitate discussion where each team member expresses her or his thinking and the team members begin to formulate the message that they want to deliver to the applicant as well as to the Certification Commission. The intent is to allow time to discuss and process the interview before starting the actual writing. Allowing ample time for discussion that is separate from the writing should alleviate some of the stress that may be associated with completing the PRPII.

2. Two PRPII templates will be available for writing the PRPII. The first will be the template that the NACC has been using and which has the “locked” fields. As is now done, this is the form that will be saved and transmitted to the Certification Commission. A second template will be available for the interview team to use to develop drafts of the PRPII. The fields on this form will not be locked and will have all the MSWord functions, spelling and grammar check in particular, to facilitate the creation of the wording for the Process, Content, and Recommendations sections of the PRPII. When the team is satisfied with the draft copy it then can be “copied and pasted” into the form that will be submitted. Details of the process will be given and demonstrated by each site’s ITEs.

3. The Certification Commission will provide guideline questions to address the congruency issues. For example, “Did the applicant demonstrate competency in the standard being addressed? If yes, how? If not, why?” These questions will be available for the interview team during the writing process and will be part of the education made available by the ITEs during the pre-interview phone calls. The questions also will be on the Draft PRPII template as a visual guide when writing the Draft PRPII.

Comments on several standards

During the last interview cycle there were questions raised about the interpretation of several standards. A summary of the discussion follows.

1. 303.8 “Communicate effectively orally and in writing.” This standard applies to all applicants. Effective writing in applicant materials and use of English during interpersonal communications such as the applicant certification interview must be demonstrated.
2. 304.9 “Facilitate theological reflection in the practice of pastoral care.” This standard requires demonstration of competency facilitating theological reflection with those to whom the chaplain ministers as well as self-reflection by the chaplain.

3. 305.3 “Articulate an understanding of institutional culture and systems, and systemic relationships.” Demonstration of this standard is required in order to assure that the applicant is capable of projecting a professional image when ministering as a certified NACC chaplain.

Team building

Serving as an interviewer is a ministry of the NACC. During the joint meeting it was noted that more structured communications with the interviewers between interview weekends would be of benefit to interviewers in particular and the NACC in general. The efforts would target connectedness with the hope of building long-term community relationships with all members of the certification team.

Applicant materials

In order to ensure that interviewers receive the applicant materials that have been verified for completeness by the national office, the letter requesting the applicant to mail these materials to the interviewers will contain the phrasing “All materials must be identical to those already sent to the NACC National Office.”

Matthias Merges ministers as a home hospice chaplain and provides bereavement services for VNA Health Care, a community based non-profit operating in Aurora, IL, and surrounding counties. Lindsey R. Tews serves as the NACC administrative specialist/certification in Milwaukee, WI. She also is the NACC staff liaison to the ITEs and Certification Commission.
Music can be powerful tool of the Spirit in pastoral ministry

By James J. Castello, MBA, MA, BCC

I believe that if God has given you the gift of music, you should consider using it at appropriate times in your ministry. God has given all of us many gifts – some we are aware of and use and some we are not aware of and, therefore, are unable to use. I know from personal experience over a 14-year career as a professional chaplain serving in three hospitals and a nursing home that the gift of music can be an incredible healing power to patients, residents, family and staff in certain situations where God’s Spirit is present.

Sensitivity

I have discovered that about one-half of the human creatures God created have been given the gift of music – they are moved by it, are sensitive to it and it rekindles powerful memories in them. The other half does not relate to music, but may be moved by art, stories, or nature. I am a reflection of my mother, who was an amazing and musical person. She had a good voice, could read music (which I can’t), played a flawless piano into her 90s after taking only two years of piano lessons in grade school, and sang throughout her daily routine. My father, on the other hand, would sing a little ditty while washing his car with words that only he knew (“O Roadie O Doe”). Someone once asked him if he played a musical instrument and he replied, “I play the radio.”

When my mother died at 93, we literally sang her into heaven – my family, three nuns praying the rosary, and two priests who came to give her the Sacrament of Anointing. I know she loved it. I also knew when my dear father, Paul Sylvester Castello, was dying three years later, he clearly did not want to hear any music nor did he seem to wish anyone near him when he took the big step into his Lord’s arms. We are all created as unique spiritual beings with special gifts, preferences and desires that should be respected.

Use the gift, but with discernment

We do not have to be professional musicians or have trained voices like Mario Lanza or Kate Smith to use the gift of music in God’s service for healing and comforting the sick. I have a rather average voice that I once sensed God tell me I should use in “small settings,” meaning no large auditoriums. It works rather well in patient’s rooms but not as well on large stages.

I can play piano and guitar by ear since I cannot read music. I only know perhaps 12 guitar chords and generally sing about six songs that seem to work well in my ministry. A few are religious songs – “Amazing Grace,” “Just a Closer Walk with Thee,” “I Walk in the Garden” – but the most powerful ones are secular songs – John Denver’s “Country Roads” and “Annie’s Song,” and the incredible “You Are My Sunshine” (first two verses only). Of these, “Sunshine” is by far the most healing song I have ever used. It is a popular, beloved song not only in the United States, but also around the world. It can be sung as written in English by people who do not speak any English. I was amazed that the family of a Japanese patient, who was dying in our ICU and spoke no English, sang every word with me in English. I believe this simple song is so healing because people hear it as God singing directly to them, “You are MY Sunshine.”

The key to using this incredible gift is to know when to use it and when not to use it. Once I was called to the NICU to try to comfort a Hispanic family that was about to remove life support from their dying infant.
They spoke no English and I spoke no Spanish so what could I do but be present and pray silently. However, the Spirit led me to get my guitar and sing and play softly in the back of the room. When I looked up as I was playing, I noticed the family and the staff were deeply moved by the Spirit as evidenced by their tears.

What I didn’t know at the time was that live music was absolutely forbidden in the NICU. As a result of my decision to play, a music therapist was hired to cover that unit. I actually played and sang with this therapist in the NICU on many occasions after the hire. You just never know where the Spirit of God will lead you.

Another time I was referred to an elderly male patient who was in a coma and dying. I was told this patient loved music and was an avid guitar player so I visited the patient and his family expecting to use music as a means of comfort. I asked the family if I could do so and they initially agreed, but when I returned with my guitar, I was told that the daughter in charge of the situation declined music as a comfort at that time. We need to be vigilant about when music is likely to work and when it won’t. As Michele Le Doux Sakurai, a fellow member of Vision’s Editorial Advisory Panel, once said, “It’s fine to use music and art to ‘enhance our work’ and make our care more effective, but we shouldn’t be ‘seduced by doing’ rather than providing a needed presence.”

Power of music

If we use music in appropriate settings at the right time, it can be immensely healing and helpful to patients, family and staff. A good example was the time I was called into a room of a dying female patient whom I had known for a four-month period, during which time I often had played and sang for her. In the room were her husband, daughter and son-in-law. I sang three songs for them – “Amazing Grace,” “You Are My Sunshine,” and “Country Roads.” At the precise moment I reached the end of the final song (“Country Roads, Take Me Home”), the patient went to her Lord and Savior.

Later that week, the family had asked me to conduct a brief memorial service at the funeral home as the family did not have a church of their own. They specifically asked me to use those three songs in the service. Just before I began the service, the daughter told me that each of the three songs I sang happened to be a favorite of the three people in the room. Praise God, who works in strange and mysterious ways!

On occasion, I would “make the rounds” of the hospital in the evening with a fellow chaplain – a wonderful Jewish rabbi and former businessman who has the gift of harmony. We would visit both Jewish and Christian patients who might respond to our duet. However, the good rabbi felt uncomfortable singing the lyrics to Christian songs, so he would harmonize with “ooohh, ahhhh” while I sang the melody and the words to “Amazing Grace.” I would always tell listeners to focus on him as he had the gift of “tongues.”

One night we were singing in the Psych Ward when a female patient and police officer entered the room. The woman was drawn to us by our music and immediately started to sing in a loud, operatic voice that took us by surprise and was enjoyable. She obviously had a trained voice and basically, blew us away (which was OK). She sang three songs with us at full volume to the delight of the patients and staff on the unit. We did not find out until the next day that this woman had been in the unit for more than one week and had not uttered a word until that moment. The music was able to reach her and draw her out of her shell. Music can be a powerful, life-giving gift in our ministry. If you have this gift, use it for the glory of God.

Jim Castello, of Kennett Square, PA, worked 35 years in executive marketing positions for two global manufacturers before becoming a chaplain in 1998. Mr. Castello is a member of the NACC Board of Directors and a member of the NACC Editorial Advisory Panel.
Narrative Medicine: Recovery of soul through storytelling of the chronically mentally ill

By Bonnie McDougall Olson, MFA, MDiv

Introduction

Stories knit us together and define us; they tell us who we are and who we belong to, and help us imagine who we might be. Jesus’ ministry was centered in the telling of stories, relaying the love and presence of God through parables and encouraging others to follow his witness. We are followers of Christ today because we have found and continue to find ourselves in the Christian story of God with us. Every moment of our life story is an invitation to witness the presence of God with us, to honor our lives as a holy gift, to remember that there is nowhere our life can take us that God is not present (Psalm 139).

This belief has been at the center of my ministry as a chaplain in an inpatient state psychiatric hospital where I strive to recover patient life stories from the overwhelming voice of their illness through a specialized ministry of writing. The study of Narrative Medicine has played an instrumental role in the use of writing and literature in my ministry. Both chaplaincy and Narrative Medicine focus on patient-centered care and the healing potential of storytelling.

Why Writing?

"Whether I shall turn out to be the hero of my own life, or whether that station will be held by anybody else, these pages must show.” Charles Dickens, “David Copperfield”

Chronic Mental illness is an illness of dependency. Patients are dependent upon medication, support and care networks in order to survive. The patient’s recovery is dependent upon his or her insight into such dependence and their ability to structure their lives around such awareness and the limitations of mental illness. The act and process of writing is an independent one in which writers are invited to trust themselves to think through what they will write about, make choices, and then plan how those ideas will take form in words and structure on the page. Writing is an act of empowering patients to trust themselves. A memory is not just recalled but created; a future can be imagined (Frank).

To write one’s story or part of one’s story is to proclaim it worthy to be read or heard by another. The gift of being listened to without judgment or correction is a rare gift, but an especially needed one for those suffering chronic mental illness. Part of our contract as a group is our mutual agreement to participate in active listening to each other’s stories; members are asked not to level moral judgment on what they have heard, but to respond by offering how what they have heard has resonance or raises questions in their own lives. Similar stories, insights or feelings are generated in this way. Empathy and relatedness within the group are fostered and the writers as a result are reminded they are not alone in their life experiences but are among a community of peers who have faced similar challenges and feelings.

The process of writing requires planning, sorting, and organizing one’s thoughts onto paper. Such skills parallel the life skills that are crucially needed to counter the mental confusion and disorganized thinking of those suffering with chronic mental illness.

While the task of writing is the patient’s job, reading, discussion and the writing task needs to be structured in such a way that members will be able to clearly follow the task at hand and feel empowered to achieve it.
in the best way they can. Synthesizing material and reiterating purpose provide a dependable framework and sense of safety for the group and foster a sense of accomplishment for members.

The process of writing facilitates the writer’s metacognition. As writer Joan Didion has said, “I write entirely to find out what I’m thinking, what I’m looking at, what I see and what it means. What I want and what I fear.” Focused, purposeful writing tasks provide an opportunity and structure for patients who have ongoing difficulty organizing their thoughts in a coherent manner. Achieving coherence, even in a small way, is significant for patients suffering from chronic mental illness.

Spiritual themes of grace, forgiveness, gratitude, faith, mercy, etc are not confined to stories of the Bible but present and active in the stories of human experience. These are easily “bracketed” for emphasis and discussion (Patton). Similarly, patients’ stories and experiences provide grist for theological reflection, raising important universal questions such as “Why me?,” or “Is my illness a sign of divine punishment?”

Method

I lead three hour-long spiritual writing groups for inpatients every week. I lead one group on my own, one with a psychologist, and the other with a senior rehabilitation staff member. We form a team; co-leadership provides two leaders that the patients can relate to, preferably of opposite sexes. The different discipline and training of each leader adds variety, insight and depth to the group.

Each weekly writing group has from four to six patients, selected by their interest to be in the group and subject to approval by the treatment team. The groups are considered to be part of the patients’ overall treatment plan, and require approved protocol by the team as well as monthly progress notes that reflect treatment objectives.

The design of the group work is a simple one: the reading and discussion of literature followed by the writing of personal experience as it relates to the reading of the day. Readings vary from Bible and devotional material to excerpts of fiction, non-fiction, and poetry. Readings are kept short to allow for discussion and maximize the time for personal writing by the patients.

Once the reading has been discussed, the patients are given a writing prompt based on the reading of the day. The writing portion of the session varies in approach, asking participants to apply questions or themes of the reading to their personal experience, imagine themselves into the lives of characters, or write their thoughts on a particular theme or idea. Writers then share what they have written with the group and members are invited to apply what they have heard to their own lives as well as to ask questions of the writer to enhance the writer’s own sense of being heard. If a patient does not wish to write he or she is given that option, but I have never had any patients say they didn’t want to write nor to say they didn’t want to read their work aloud.

Examples

Exploration of the biblical story of Jacob wrestling with the angel resulted in patients writing narratives and poems describing their own spiritual wilderness, with one patient transferring the setting of the Jacob story to an urban ghetto. Dylan Thomas’s poem, “Do Not Go Gentle into that Good Night,” provided a venue to write a villanelle about the chronic grief and struggle of mental illness. A short article on the discovery of the Lascaux caves led patients to write stories that they would “leave behind” to tell about themselves. Other times patients have “finished” a story they have read, by projecting themselves into the story and writing their own ending; this was the case in a short vignette, taken from “The Book of Embraces,” by Eduardo Galeano, in which a medical administrator leaves the hospital late Christmas Eve night when he is followed by a young child who looks up and tells the man, “Tell someone I am here.” Many patients, in different groups, wrote of the administrator as God.
Sometimes readings provide natural bridges into discussing unrealistic fears or hoped-for outcomes; a reading of Shel Silverstein’s humorous children’s poem, “Whatif,” about a child’s nighttime worries afforded the patients an opportunity to compose their own poems that listed their night fears. Group discussion followed that raised the inverse of such worries: “What if I don’t get discharged soon?” became a thoughtful discussion of “What if I am discharged soon?”

Lessons from Narrative Medicine

Narrative Medicine seeks to improve the effectiveness of medical care by attending to the whole patient within his or her story of illness. Illness is contextualized within the scope of a patient’s whole life allowing for contiguity with related events in the patient’s life (Charon). By providing patients an opportunity to write their own stories of illness, the patient is empowered to explore how their illness intersects and defines his or her life as a whole. New knowledge about illness becomes accessible as a result and can result in different perspectives and outcomes (Epstein).

Narrative Medicine seeks to recover the voice of the patient that illness has overwhelmed or snuffed out and enables the patient to construct new maps for his or her personal road to recovery. The process of writing provides patients not only with the experience of being the author of their own stories, but also provides them the opportunity to be a witness to how they have navigated their own path (Frank). Writing, unlike speech, records a visible remembrance of the patient’s experience of illness.

The study of narrative teaches that speech and storytelling are never done in isolation but embedded in a co-constructive relationship with those who receive the story. Meaning for the writer or teller of the story comes from a dialogical process with others in community, where assumptions can be tested and new perspectives heard. Similarly, a community of listeners serves as a witness to the patient’s experience, reminding the patient they are not abandoned in their illness.

Other applications

This past spring I published an in-house online journal of some of the writers’ work. (All work appears anonymously to avoid confidentiality issues.) The title of the journal is The Voice Inside, a name one of the patients thought of as a way of expressing the spiritual voice inside of the writers as well as the voice inside the institution. Writing pieces were framed and put on display anonymously in the building as well.

Conclusion

Jesus’ ministry of healing the sick was modeled on a two-fold approach: restoration of the person’s relationship with God and restoration to community. Mental health chaplaincy seeks to do the same. Through my work with patients at an inpatient state psychiatric hospital, I have learned that the stories of the chronically mentally ill are defined by their illness. They are stories that are told by the artifacts of illness: admissions and discharge dates, medications and treatments. These are important markers for recovery from mental illness but do not tell the story of the person’s recovery of soul. My ministry as a chaplain has sought to help those struggling with mental illness to recover their souls through writing their own life stories. I have found that the tools of Narrative Medicine can help pave the way through the stories of illness.

Rev. Bonnie McDougall Olson, a chaplain at Creedmoor Psychiatric Center in Queens, NY, is enrolled in the Master’s Program in Narrative Medicine at Columbia University. She is a fellow of the American Association of University Women and gratefully acknowledges the association’s support of her work and research.
References


At first I am afraid.

I hear a small voice and wait outside your tired garden hoping you invite me in but you do not.

The walls are concrete reinforced by steel so thick so high no sun no wind no rain would dare enter here.

So I wait pacing circling searching for an opening any crack where I might catch a glimpse of you inside.

Then I see it near my feet barely enough space for a hand to reach through and touch something, anything on the other side.

Yet even on knees I can’t reach you so I lie down belly to earth and call,

“Are you in there?” Silence.
“Are you in there?” Echo of my own voice answers.

So, I reach into darkness arm outstretched as far as it can reach hand open groping air hoping waiting for something anything to touch me on the other side.

I hope and wait until at last you say, “I’m here,” your hand grasps mine a touch sublime so utterly divine I start to shed my human skin.

Smaller smaller I become til I can walk head high right through that crack and straight into your cold damp garden too dark still for me to see.

Together hand-in-hand we stand

in mud and slop glass shards old ashes burnt human remains buried where not even a pig would dare to tread.

“This is my home,” you say, “and welcome to it.”
“Thank you,” I say, “for letting me in.”
“Shall we walk?” you ask still holding on. “Why not?” say I, still holding on.

Together holding on we slog we trudge through muck so deep it covers knees— we stumble and bleed til both of us are covered in mud blood and ashes.

“Are you ok?” “I’m not,” I say, still holding on and wondering, “Can I go on?” Will this ever end? Can I really be your friend?” And then, we stop, you see, because I struggle.
Then reaching down
you scoop
up ground
and place
two handfuls
where I frown
and by the hand
you lead
me now
toward sound
of running
water.

You
push me down
then lift me up
three times
immerse
my face
in oil
or is it
blood
or tears
or sweat
from all
our years
of toil?

“Open,”
you say,
and I comply
but it
takes time
you know
for eyes
to see
when light
is new.

And what
I see
I can’t
believe—
rising sun
bluest sky
my walls
have tumbled
to the ground
and birds
are singing
all around.

The grass
is green
so we lie down
to rest
to feel
the soft caress
of earth
to simply be
ourselves
in silence
together
still holding on
as I get
to know you
better.

We talk
and talk
til day
is night
and finally
when the time
is right
you let me go
you send me on
you wave
until I’m out
of sight—

and now I walk
now I see
now I know
you saved
my life
and I
am not afraid.

David Orr, who resides with his family in Lynchburg, VA, wrote this poem for the worship service celebrating “graduation” of his CPE intern group at the University of Virginia in March. He was completing his first unit of CPE, which he called a profound experience. In Mr. Orr’s words, “The poem addresses how deep encounters, deep relating, transforms us and makes more of our journeys.” Mr. Orr received his master’s degree in theological studies in May 2011 from Washington Theological Union.
Book Review: *Medical Ethics*


By Father James F. Buryska, STL, BCC

This fourth edition of Boyle and O’Rourke’s book is exactly what the title says it is: a compendium of sources of teaching pertaining to medical ethics in the Roman Catholic tradition. As such, it is an important resource for anyone involved in the application of medical ethics – as a clinician, teacher, ethicist or member of an institutional ethics committee.

The organization of the book is straightforward. A comparatively brief (29 page) introductory section (“Understanding Church Teaching”) sets out the basic concepts that underpin and guide Catholic moral teaching: person; community; health and sickness; sexuality; moral principles such as double effect and cooperation; concepts such as subsidiarity, solidarity and justice that also ground Catholic social teaching. The reader need not be deceived by the brevity of the introduction; by itself it is worth the price of the book, foundational for everything that follows – a succinct primer in principles of Catholic moral discernment. A short section explaining and differentiating various levels of teaching is particularly helpful.

The balance of the book (“Specific Teachings of the Church”) consists of 75 topical sections, alphabetically arranged, which collectively address most ethical issues encountered in medical practice. Each of these sections typically includes one or several documents pertinent to the topic at hand; each documentary quotation is identified with its source reference and date. Occasionally – I imagine to avoid repetition – documents are cross-referenced as necessary. The topics range from the medically predictable (“Abortion,” “Research on Human Subjects,” “Withholding and Withdrawing Life Support”) to the unnervingly timely (“Health Care Reform,” “Government Mandates”) to the somewhat surprising (“Guidelines for Evaluating Reiki as an Alternative Therapy”). Apart from the arrangement by topic, each document stands on its own; wisely – I believe – the authors have refrained from adding explanation or commentary.

In my view, one of this volume’s most valuable contributions to the broader field of healthcare ethics is its willingness to move beyond strictly clinical applications (what we used to call “medico-moral issues”) into the institutional and public policy spheres: sections on “Care for the Poor,” “Labor and Management Relations” and “Right to Health Care” bring the resources of the Catholic social teaching tradition to bear on urgent health issues of today, and help remind Catholics in the United States that our own healthcare delivery, funding and governance assumptions are not the only conceivable ones, and perhaps not the most ethical ones. It is also a reminder that the Catholic Church has a long and robust tradition of addressing social and political matters.

In summary, if you are a clinician, a CPE supervisor, a teacher of medical ethics or a participant in an institutional ethics committee, and if you want or need insight into the sources from which specific Catholic teachings or positions on healthcare ethics are drawn, this book will make an excellent addition to your bookshelf.

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Book Review: *The Best Care Possible*


By John Gillman, PhD, BCC

Already well known to many in our field from his ground-breaking work, "Dying Well" (1997), and by his regular appearances as a keynote speaker for annual meetings of chaplain associations, Ira Byock makes an impassioned plea in "The Best Care Possible" for a radical re-thinking and restructuring of our healthcare system.

The 10 chapters in his book are divided into five parts: the best care possible, life-and-death decisions, palliative care – completing the therapeutic continuum, real doctoring for the 21st century, and transforming medicine and society. His mantra for patients is to offer them "the best possible care," which he currently aspires to in his role as palliative care physician at Dartmouth-Hitchcock Medical Center in New Hampshire.

Evoking a wide range of emotions and provocative thinking about our current system, the stories that fill his narrative leave two impressions. The first is that Dr. Byock deeply cares for his patients shown, for example, by his commitment to earn trust and build a relationship before doing a medical assessment. I was particularly inspired by the caring presence he offered to 15-year-old Sharon, suffering from cystic fibrosis, who was known as the "Prince of Darkness" on the pediatric ward. Sometimes on Saturdays Dr. Byock would take this socially withdrawn teenager to a pet store where she would be "brimming with the energy of youth." Using narrative charting in the progress notes, he wrote extensively about their interaction, her mood, and relationship with family members and her fighting spirit.

The second impression is Dr. Byock’s appreciation for the spiritual. He speaks about the hospital chaplain, who is involved extensively in some of the cases. Though he himself does not claim to be religious, he has learned from dying people that "human life is inherently spiritual." He has developed a daily practice of meditating for 20 minutes, finding this to be "the single most important thing I could do to prepare for each day" (p. 191). From his own Jewish tradition he has a profound reverence for life: "we toast L’chaim! (To Life!)." He also aspires to love his patients, for "love is, after all, the primal impetus and sustaining force of all the caring professionals" (p. 284).

I highly recommend this book for physicians, chaplains, and others, especially those involved in palliative and end-of-life care. Those interested in analysis of our current healthcare system, what works and what does not, will find the author’s perceptions in the last three chapters helpful. My only critique is that Dr. Byock, while he does make several concrete recommendations (e.g., extending the hospice eligibility period), does not lay out his vision for a comprehensive transformation of end-of-life care as it now functions.

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