Survey results of different populations vary considerably with regard to preference for home as the location of death. A 2000 systematic review of studies found that, overall, the majority of the general population as well as patients and caregivers would prefer to die at home, but the findings varied considerably by study, with the percentage of people preferring to die at home ranging from 25% to 100%. There can be profound shifts in patient and caregiver preference for location of death as the illness progresses. Hinton found that the preference for a home death changed from 90% initially to 50% as death approached.

Regardless of the ultimate preference for location of death, it is generally agreed that most people would prefer to stay at home as long as possible. Data from the U.S. National Hospice and Palliative Care Organization reveal that in 2008, 95.9% of hospice patient care days were spent at home. A primary goal of home palliative care providers should be to provide pain and symptom management that is comparable to the care received on an inpatient unit while striving to maintain the patient at home as long as possible if that is the patient’s wish.

**Clinician Competencies**

With most clinicians receiving little exposure to home visits in their training and even fewer receiving exposure to home palliative care visits, a number of skills and competencies for those providing care at home must be highlighted.
THINKING AHEAD

A critical element in keeping end-of-life patients at home and out of the emergency room is the capacity to anticipate what crises a given patient may encounter, especially over the next 24 to 48 hours. In an inpatient facility, staff, supplies, and medication are available and readily accessible. For patients at home, it may take hours for a nurse or physician to attend to the patient and even longer to arrange for special supplies and medications. This may be particularly problematic at night or on the weekend. A basic task of the clinician providing care at home is to inform the patient and caregivers about what might occur in the near term of the next few days. For many people, “forewarned is forearmed.” With appropriate education, caregivers will be able to implement appropriate interventions if they have been adequately prepared. The home care clinician is responsible for ensuring that the necessary medications and supplies are in the home. The items that it is possible to have on hand are fewer than in the in-patient setting. However, hospice palliative care providers in many areas have developed emergency medication and supply kits. These kits typically contain the supplies necessary to deal with the common palliative care emergencies. The kit may be placed in the home either at the time of first visit or when the team feels it is appropriate. In the event of a crisis, caregivers can be instructed to open the box and access the necessary medications. Other providers have taken a more focused approach and will order medications and supplies to have on hand that are specific to a given patient’s needs. An extreme example of this is the patient at risk for sudden airway obstruction who wishes to stay at home to die. The family and patient should be fully informed as to what to expect if the patient develops signs of airway obstruction. A common approach in this situation would be to insert a subcutaneous line to allow for parenteral access and have preloaded syringes of an opioid and sedative on hand. Caregivers can be taught how to administer a “stat” dose of the appropriate medication while telephoning for further direction or awaiting a member of the home hospice palliative care team.

MANAGING WITH LIMITED ACCESS TO DIAGNOSTIC INTERVENTIONS

A hallmark of modern medicine is easy access to laboratory tests and diagnostic imaging. The clinician providing home hospice/palliative care must learn to cope with limited access to these modalities. Bloodwork at home may be available, but it may only be on a delayed basis. Mobile radiography and ultrasound may not be available or practicable at all in many jurisdictions. Given the frail state of most patients at this stage of their illness, careful consideration must be given before deciding to transport someone for tests. As a result, the home hospice/palliative care clinician must be comfortable with a certain degree of diagnostic uncertainty when confronted with an acute or unexpected situation. In these situations, one should be reminded of the dictums from training; history, history, history and common things are common. In some situations, time will tell the tale. Initially, it may be hard to determine on the basis of a history and physical alone if the house-bound ovarian cancer patient with abdominal pain and no bowel movement for 5 days is constipated or obstructed. The clinician would not want to give laxatives to a patient who is obstructed. Similarly one could worsen the condition of the constipated patient by implementing a treatment algorithm for bowel obstruction. Symptom progression over time may help one sort out this diagnostic dilemma without
having to transport the patient for an x-ray examination. Clinicians should openly discuss the issue of diagnostic uncertainty with the patient and family as part of the consent for your recommendations. There will be patients who are prepared to accept a certain amount of uncertainty if it means they do not have to make a trip for tests. Others may push themselves in an extreme fashion to have a specific test performed to know “exactly what is going on.” Regardless of their inclination, patients and their families will generally be very understanding of the limitations imposed by the circumstances and will appreciate your careful consideration of their situation.

**DELEGATING MEDICAL AND NURSING TASKS TO FAMILY MEMBERS**

Patients and their families are frequently called upon these days to provide complex medical care in the home. It is amazing, at times, to see the care that laypeople with appropriate instruction are able to provide to their loved ones. Family members are routinely taught by hospice providers to accomplish rather advanced skills such as changing wound dressings, changing intravenous bags or even managing central lines, or administering artificial nutrition whether through the intravenous route or through a percutaneous endogastric tube. For patients at the end of life, family members can be enlisted to assess and manage symptoms, administer opioids, and utilize pain pumps. However, it is important that the clinician never assume that all caregivers and family members are up to the task at hand. Although many people are willing and able, a significant number are unwilling or unable to assist with care in this way. It is easy for family members to feel “guilted” into assisting with care that they are uncomfortable providing. Furthermore, once a caregiver has agreed to provide a certain type of care, the hospice palliative care providers must ensure that people are well trained and well educated about the task. For example, family members who are providing opioids when needed for pain at the end of life must be advised of the possibility that they may give a dose of medication and see their love one stop breathing a short while later. Given the common myths about opioids, it is easy to envision this person believing that their action of administering medication had a direct impact on the timing of their loved one’s death. Appropriate counseling about the possibility of there being a “coincidence” in the timing of a dose of medication and the person’s death must be provided before a family member administers a PRN (as needed) or even an RTC (round-the-clock) opioid dose at this point in the illness. Active, hands-on caregiving can be an enormously satisfying experience for some family members, whereas for others it can be extremely stressful and embarrassing. Clinicians providing home palliative care must take the time to assess a given family member’s capacity and willingness to perform various tasks.

**THE INTERDISCIPLINARY TEAM IN THE HOME**

The interdisciplinary team is the cornerstone of palliative care. The role and function of the interdisciplinary team is covered elsewhere in this textbook. However, a few issues regarding the interdisciplinary team in the home setting should be highlighted.

There may be a need for greater fluidity in roles in the home care setting than there is in an inpatient facility. As a result, members of the various disciplines may have to stretch their “comfort zones” and perform tasks that may not be typically part of their discipline. In an institutional setting, the social worker who walks in the
room to find a patient in a pain crisis can go out into the hall to find a nurse to assist. In the home setting, the social worker, as part of the interdisciplinary team, would be expected to be able to assess the situation, assist the patient to take some breakthrough medication, and call the nurse or physician to report in and request follow up. Similarly, a physician performing a home visit to follow up on medication changes from last week may need to counsel the patient’s children when one is enraged that the other is not “pulling their weight.” In this situation, the physician would need to perform some initial family counseling and arrange for follow up with the social worker.

It should be noted that not all home palliative care patients have access to the full range of professionals who, ideally, should make up an interdisciplinary team. Depending on where one lives and how home palliative care services are funded, the interdisciplinary team may be composed of a nurse and a physician. In some instances, the nurse is the only one seeing the patient, with the physician providing orders and medication from afar at the nurse’s recommendation. Under these circumstances, clinicians may really find themselves stretching to fulfill the various roles. For some, this can be extremely rewarding and refreshing as it forces one to “get out of the box” and learn new skills. However, it can also lead to burnout. Clinicians must be mindful of their limits and should create systems of supports both for themselves and their patients. Often, this entails actively recruiting others, such as the patient’s spiritual leader, if they have one, to be a “member” of that patient’s care team. Teams can come together around a given patient and disband at the time of death. Over time, these individuals working in the community may come to know each other and be able to function at an increasingly high level. For their own mental health, the clinician may need to identify a few peers with whom they can discuss cases and vent when necessary. Although most palliative care providers find their work highly rewarding, working in an environment where one is the “lone ranger” may not be conducive to a lengthy career in the field.

**CLINICIANS TAKING CARE OF THEMSELVES ON THE STREETS**

Clinicians need to be cognizant of personal safety when providing home palliative care. Good clinical records on a patient before the initial visit may include sufficient information on the home situation. Working in the community involves a type of risk beyond that experienced by most health care providers who work in facilities. In addition to the angry and occasionally violent patients and families one has to deal with in health care facilities, the home health care worker may have to contend with areas of high crime, aggressive panhandlers, gangs, prostitution, poor driving conditions, and unsafe parking areas as they travel between patients. Exact statistics are hard to come by. A study done in Saskatchewan, Canada, in 1995 showed that nurses working in urban settings experienced twice as many assaults and five times as many threatening situations as their rural counterparts. Become knowledgeable about your organization’s safety policies and procedures and undertake appropriate safety education. Risk minimization strategies should be identified and implemented when relevant. Having two members of the team do a joint visit can be a very effective care intervention while providing a degree of peace of mind for the providers. It is essential that once a risky situation has been identified, a system exists to disseminate this information to the other team members and home health providers who may be involved in providing on-call and after-hours coverage. Some home care services provide escorts for clinicians in some settings. However, one should question
whether a given patient is a candidate for home palliative care if an escort is truly required.

RESPECTING THE PATIENT’S “BAD” DECISION

Health care providers have all, at some point in training or practice, had a patient who has made a decision that is hard to agree with. For instance, we may be deeply troubled by a decision to insist on staying at home to die. Clinicians are often troubled by the 82-year-old widow with congestive heart failure who has no children and no family, lives in a squalid apartment, and insists that she will only leave her home “feet first,” or the 66-year-old bed-bound man with advanced cancer who is being abused and neglected by his alcoholic wife and similarly won’t leave his home to be cared for at an inpatient unit. Patients are well within their legal and ethical right to refuse offers of care, and we must respect their rights to make these decisions as long as they are competent. Caring for patients under these circumstances can exact an emotional toll on the clinician. Case conferences and team meetings should be used to discuss these challenging situations and allow providers an opportunity to share their feelings and frustrations.

System Capacities

In addition to personal skills and competencies, a number of system capacities are necessary for the provision of quality home palliative care.

24/7 ACCESS

Patients can only be maintained at home if they have access to advice and assistance 24/7. Where there is no formal home palliative care program, individual clinicians have been successful at coming together as a call group to provide the necessary coverage. It is difficult to expect that families can care for someone at home if assistance and support are only available from 9 to 5 or from 7 am until 11 pm. Many eventualities can be anticipated and planned for, but there will always be the 3 am phone call from a patient or the family when an unexpected or unforeseen event occurs. Efforts should be made to ensure that the after-hours call system is simple and easily accessed with a timely response. It would be challenging for someone in a crisis to have to handle multiple options on an automated answering service and then have to wait 2 hours for a reply. Creating an easily accessible after-hours network can be extremely difficult, and if it seems unrealistic, home hospice may not be right for that person’s setting.

ACCESS TO PHYSICIANS

Physician involvement in home palliative care varies significantly from country to country and within countries as well. Anecdotally, the degree of physician involvement seems to be influenced by how home palliative care is organized, by reimbursement schemes, and by the local medical culture. In certain areas it is the norm for physicians to provide home visits, whereas in other nearby areas it may be exceedingly rare. Access to a physician has been shown to have a significant impact on end-of-life quality of care. Burge and colleagues, using administrative data from Nova Scotia, Canada, demonstrated an association between a family practice continuity of care index and emergency department visits. Patients experiencing low continuity made 3.9 (rate ratio 3.93; 95% CI = 3.57–4.34) times more emergency
department visits than those experiencing high continuity. Barbera and colleagues, using administrative data sets from Ontario, Canada, showed that a physician house call or a palliative care assessment were associated with decreased odds of emergency department visits, intensive care unit admissions, and chemotherapy in the last 2 weeks of life. These indicators were selected by the study’s authors as measures of poor end-of-life care.

The challenge in many jurisdictions has been how to involve and maintain the involvement of the primary care physician for the patient who requires home palliative care. Barriers to primary care physician involvement have been explored in several studies. Lack of clinical expertise, the challenge of scheduling home visits, poor remuneration, the emotional toll of caring for dying patients, and the lack of resources within the health care system have all been identified as impediments to the provision of home palliative care by primary care physicians.

ACCESS TO PATIENT INFORMATION

Ideally, there should be timely flow of patient information between providers from different organizations and between providers within the same organization. This is particularly problematic for patients being discharged for home palliative care follow-up. For all patients, there are significant deficits in information flow. A 2007 U.S. study found that direct person-to-person communication between hospital physicians and primary care physicians was infrequent (3%–20%). Furthermore, the availability of the discharge summary at the first post-discharge visit was poor (12%–34%), with only modest improvement by 4 weeks (51%–77%). When the discharge summary was available, it was frequently found to be missing key information such as course in hospital, discharge medications, and follow-up plans. The study authors felt that computer-generated summaries with standardized formats might remedy some of the identified deficits.

Sharing information among the home palliative care providers may be even more of a challenge. Patients generally have a chart in the home that can be utilized when the clinician is in the home. However, not infrequently, patient contacts may occur by phone. This information will at best then only be updated in the home chart at the next visit. Furthermore, the chart in the home is of no help to the on-call clinician who gets called after hours for a patient that the clinician may not be personally following. Many palliative care programs have implemented electronic medical records to address these gaps in information sharing. Systems now allow remote access such that a provider can log on to the network and access a given patient’s chart at all hours. Recently, a patient with amyotrophic lateral sclerosis suffered a choking episode and was taken to the emergency department unconscious after the panicked caregiver called 911. The patient’s power of attorney had yet to arrive. The emergency physician contacted the palliative care program as a decision was required about intubation. The on-call clinician was able to log into the patient’s chart and advise the emergency physician that the patient did not want to be intubated. Comfort measures were instituted and the patient was returned home based on her previously stated wish to die at home. Her family was able to be with her at home when she died 24 hours later.

Electronic medical records are very costly and there are significant challenges associated with their implementation. However, they can be exceedingly valuable from a patient care perspective as long as the appropriate information is being entered into the system in a timely fashion.
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SUPPLIES, MEDICATION, AND EQUIPMENT

Access to supplies, medication, and equipment also varies from location to location, depending on care organization and funding. It is a necessary system capacity feature that patients being cared for at home have timely access to the necessary medications, equipment, and supplies to ensure that they can be adequately cared for at home.

Predictors of a Home Death

A number of factors are predictive of a patient staying at home to die. Highly significant are the patient’s stated preference to die at home and the presence of a caregiver. These two factors were significant in studies from a number of different countries. In an effort to better understand variation in place of death in the United States, Gruneir and colleagues conducted a systematic review and multilevel analysis in which they linked death certificates with county and state data. Their findings indicate that Americans who are white have greater access to resources and social support, and Americans who have cancer are more likely to die at home. The multilevel analysis revealed that minority status and lower educational attainment increase the probability of death in hospital. Nursing home deaths were associated with a higher density of nursing home beds and a higher state Medicaid payment rate. As can be seen, both individual level characteristics and health care system characteristics impact the rate of home deaths.

Home Palliative Care Is Not for Everyone

Although a home death is an extremely rewarding and enriching experience that lessens the pain of loss for many families, for others it can be a highly stressful and negative experience. Home palliative care clinicians may sometimes need to help families relieve themselves of the burden of a promise to their loved one to care for them at home by encouraging the patient to consider other options. Perhaps the most challenging scenario is when the patient is no longer able to make decisions for himself, but he did indicate his prior wish to be cared for at home, and the family is not coping. In this situation, the substitute decision maker has to decide whether to respect the patient’s wishes to stay at home or acknowledge that the family is unable to manage and authorize an admission to an inpatient unit. The home palliative care team must help the decision maker consider immediate needs against the prospect of guilt from a broken promise down the road. There is little in the literature that provides guidance on this question. For some, the prospect of long-term regret is such a concern that they may elect to tough it out for a few more days or weeks. For others, the immediate stress will overcome a hypothetical concern of regret in the future.

Clinicians must be aware of their own biases and beliefs and be careful not to inject them into the decision-making process. Injecting our own biases and beliefs can be extremely damaging, as is illustrated in this quote of an interview of a health care provider from a Canadian ethnographic study examining the social context of home-based palliative caregiving.

I remember one family I worked with, and they wanted their loved one admitted [to the hospital]. They asked me, “What would you do if it was your father?” And I said, “Well, I’ll tell you what I did when it was my mother. I took a leave of
absence and I just stayed with her.” And they just looked one to the other and said, “Oh, we can’t afford to do that.” And I said, “I couldn’t afford not to.”

Home palliative care is not for all clinicians either. Most palliative care clinicians find their work to be extremely rewarding and professionally fulfilling. However, for some, providing frequent palliative care can exact an emotional toll. Providers must be conscious of their own personal tolerance to being exposed to significant suffering on a daily basis. Working with supportive and caring colleagues is a key element to a long career in the field.

**PEARLS**

- Do think ahead and prepare patients and their families for anticipatable events.
- Be cautious of your own safety.
- Accept and manage the challenge of diagnostic uncertainty in the home.

**PITFALLS**

- Failing to acknowledge and recognize when the work is taking an emotional toll on you.

**Summary**

There are many unique challenges to providing home palliative care. A home palliative care clinician must be aware of the unique competencies required of the individual as well as the vagaries of the health care system he or she is practicing in. In many countries, there is still much work to be done to achieve the necessary system capacities. Although a home death may not be the wish of all palliative care patients and their families, care at home will compose a significant portion of most hospice patients. For those who do wish to die at home, high quality care with appropriate resources to support the patient and family should be the objective of the palliative care team and the health care system.

**References**