



Vulnerable Populations and End of Life Care in Montgomery County



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In general, end of life services are grossly underutilized.¹ Out of the 2,416,425 individuals who died in the United States in 2001, it is estimated that only 775,000, or 32%, were enrolled in hospice care.² In Montgomery County, out of the 5,462 deaths that occurred in 2001 only 1,470, or about 27% of individuals, were enrolled in hospice care.³ This underutilization can be linked to a number of factors to include: unfamiliarity with end of life services; reluctance of medical professionals to refer patients to end of life services; and difficulty discussing death due to our cultural fear of dying.

For minorities, which tend to make up a high percentage of vulnerable populations, enrollment in end of life care is even lower.⁴ Nationwide for the year 2000, only 18% of all hospice patients were minorities.⁵ Mirroring the national trend, of the 12,057 hospice patients served in Maryland in 2001, only 18% were minorities.⁶ For vulnerable populations, additional barriers to accessing end of life care may include: cost of care; lack of insurance; lack of a permanent residence; distrust of the medical system; and language and cultural barriers.

In Montgomery County, vulnerable populations are sizeable. There are 1,200 homeless on any given day with 4,500 individuals experiencing homelessness over the year.⁷ From 2001 to 2003, homelessness has increased 10.9%.⁸ Maryland is the 12th largest state in the nation for undocumented immigrants, and approximately 15,104 undocumented immigrants reside in Montgomery County.⁹ The uninsured population is large and continues to grow. According to the Maryland Health Care Commission, 16% of Maryland citizens were uninsured in 2001-2002, and the Primary Care Coalition of Montgomery County estimates that between 80,000 to 100,000 individuals are uninsured in Montgomery County.¹⁰ Undocumented immigrants make up 30% of all uninsured, while 62% of undocumented immigrants are uninsured.¹¹ And 47,024 Montgomery County residents live below the poverty level.¹²

Sanctuary for the Dying conducted a needs assessment to examine knowledge, access, and utilization of end of life services by vulnerable populations in Montgomery County. This needs assessment took place during the second half of 2003 and early 2004. Thirty-five service providers were contacted and twenty-eight responded.¹³ The format of the survey was primarily telephone interviews.

The goal of the needs assessment was threefold. The first goal was to determine how familiar service providers, who act as information and referral sources for their clients, were with end of life services. The second goal was to determine if there were gaps or barriers to end of life services for vulnerable populations. The third goal was to determine if vulnerable populations were accessing end of life services.

Service Provider Familiarity with End of Life Services

Many of the service providers interviewed were unfamiliar with end of life services and/or the process in which to get a client enrolled in end of life care. For example, one service provider was surprised to learn that hospice services could be provided in a patient's home and that Medicaid and Medicare covered hospice services.

When asked "Where do you refer your clients if they are terminally ill?," 58% of the service providers did not identify hospice or palliative care programs as a resource and 11% of this group did not have any idea on where to refer their clients. As one service provider commented, "I don't know what services are out there for my clients (who are dying)." Of the service providers who did not know about hospice and palliative care, all of them wanted to know more about end of life services and how to refer their clients to these providers.

Services identified other than hospice and palliative care programs for end of life care were: nursing homes (32%); Adult Protective Services, other county services, and community clinics such as Mobile Med, CCI or Mercy Clinic (21%); and emergency rooms or hospitals (16%).¹⁴

Gaps and Barriers in End of Life Services

Service providers who had referred clients to hospice and palliative care programs were generally satisfied with the services. However, sometimes these providers were not able to admit their client to hospice due to unavailability of inpatient beds. Service providers commented that wait lists for inpatient beds is common and that another inpatient facility in the county would be useful. Fifty percent of the responding hospices supported this need when they agreed that it would be helpful to their organization if more inpatient beds for end of life care were available in the county.

Other concerns expressed by service providers varied widely. The largest concern, expressed by 31% of the respondents, had to do with cost of, and insurance coverage for, end of life services for their clients. The next largest concern, expressed by 23% of service providers, was clients being able to receive culture and language appropriate services. Other concerns included: homeless shelters not being able to handle medical cases; loss of recuperative care beds in shelters; no one to advocate for those with out family members; vulnerable populations not knowing how to access end of life services; waiting lists for services, and not knowing what services were available or how to refer a client to end of life services.

Hospice service providers saw many of the same issues as barriers. They reported clients lacking insurance, a dearth of information for vulnerable populations about end of life services, and language/cultural issues as barriers. In addition, hospices identified reimbursement as a problem. Fifty percent of the responding hospices cited having difficulty with Medicaid eligibility requirements. Other issues with reimbursement include: length of time it takes to qualify a patient for Medicaid; the varying amount of assistance from nursing homes in helping to qualify patients for Medicaid; and the rise in the number of undocumented immigrant patients who are not eligible for Medicaid. Hospices also have concerns about their services being under funded and the current six-month limitation on hospice services.

Referrals to hospice programs were also noted as an obstacle. Examples include: medical providers not talking about hospices services until there is an acute crisis or not discussing hospice care at all; Medicaid managed care organizations may be less likely to refer to hospices, and people don't want to talk about death and therefore don't know what services are available.

Other unsolicited comments about gaps and barriers to end of life services for vulnerable populations included:

- Clients need a different setting than a hospital in which to die
- People who don't have a permanent home need a place where they can die in peace
- Developing trust in each community is mandatory before end of life services will be utilized
- The importance of educating clients about end of life services
- Difficulty of accessing end of life services if there is not a family member involved.

Use of End of Life Services by Vulnerable Populations

Because Sanctuary for the Dying is a new organization with limited resources, a client survey could not be performed. Obviously, speaking directly with clients who would need end of life services would provide a much more detailed and accurate picture of whether they are using and/or have information about end of life services in the county. In addition, statistics regarding end of life service use by vulnerable populations could not be found during the needs assessment.

We can surmise that due to the barriers and lack of knowledge discussed earlier, significant portions of vulnerable populations are not accessing end of life services. When surveyed, hospice service providers support this theory. When hospices were questioned if vulnerable populations were accessing their services, 75% of the respondents said no. Reasons included that hospice is underutilized in general, individuals may be concerned about costs, there may be language and cultural barriers, and members of these groups may not normally seek services.

Where do vulnerable populations go for end of life care? While there is no hard data available, the answer may be the local emergency room. Sixteen percent of service providers indicated that they would refer their clients to ERs for an emergency or end of life care, and it should be noted that hospices get a number of their referrals from hospitals and ERs. Moreover, the rate for ER usage for Medicaid enrollees and the uninsured are two to three times higher than for those with private insurance.¹⁵ The Project HOPE report on emergency room usage in Maryland comments "The higher rates of ED use in Maryland seen for racial minorities, Medicaid enrollees, and the uninsured suggest that ERs serve as an important source of care for disenfranchised and vulnerable groups."¹⁶ Further studies need to be done to determine what percentage of individuals who make up vulnerable populations use the ER for their end of life care.

Next Steps

After completing the needs assessment, it became apparent that the majority of service providers and their clients are not aware of end of life services in Montgomery County. Therefore it was determined by Sanctuary for the Dying that the first need to be addressed is to educate service

providers and their clients about existing end of life services. To accomplish this, SFTD will create two brochures with information about end of life services in Montgomery County. The first brochure will be for service providers and the second brochure will be for clients. The brochure for clients will be language and culture appropriate. Currently, SFTD plans to offer client brochures in English, Spanish, Chinese and Korean. Other languages will be produced as resources allow.

As more individuals who constitute vulnerable populations are educated about end of life services, the amount of uncompensated care for end of life service providers will most likely increase. This could place a burden on end of life service providers who are already concerned about reimbursement and funding issues. Therefore, the second need identified by Sanctuary for the Dying is to work with end of life service providers in the county to determine the best way to serve vulnerable populations without diminishing their organization's capacity and resources. SFTD will facilitate a gathering of end of life services providers to discuss the best way to address this problem.

Conclusion

This needs assessment has been a good first step in determining familiarity with end of life resources by service providers and their clients, as well as gaps and barriers to end of life care for vulnerable populations. Continued research is needed to better quantify the usage of end of life services by vulnerable populations, as well as to increase knowledge of where these populations currently seek end of life care.

Sanctuary for the Dying would like to thank all the participants in the survey, as well as the organizations that helped to gather statistical information. For more information regarding Sanctuary for the Dying or this document, please contact Sara Collins at 240-450-0520 or sara@sftd.org.

Endnotes

- ¹ End of life services in this survey were defined as hospice and palliative care programs.
- ² “Access to Hospice Care: Expanding Boundaries, Overcoming Barriers, Jennings, et. al., Special Supplement March-April Hasting Center Report, p. S11 and “Fast Stats A to Z, Death/Mortality,” The National Center for Health Statistics, www.cdc.gov/nchs/fastats/deaths.htm.
- ³ Maryland Vital Statistics Annual Report 2001, Vital Statistics Administration, Maryland Department of Health and Mental Hygiene and Hospice Network of Maryland.
- ⁴ Vulnerable populations are defined here as homeless, undocumented immigrants, low income, and uninsured.
- ⁵ “Access to Hospice Care: Expanding Boundaries, Overcoming Barriers, Jennings, et. al., Special Supplement March-April Hasting Center Report, p. S39.
- ⁶ Hospice Network of Maryland submitted testimony and graphs in support of SB 177.
- ⁷ “Homeless in Montgomery County 2002: Beginning to End, Montgomery County Coalition for the Homeless, www.mcch.net.
- ⁸ “Homeless Enumeration for the Washington Metropolitan Region 2003,” The Homeless Services Planning and Coordinating Committee, Metropolitan Washington Council of Governments, May 2003, p. 2.
- ⁹ “A Magnet for Illegal Immigrants: Surge in Undocumented Population Swamps Area Providers” Mary Beth Sheridan and Peter Whoriskey, Washington Post, March 27, 2001, Page A01 and Montgomery County Latino Health Initiative.
- ¹⁰ “Health Insurance Coverage in Maryland through 2002” Maryland Health Care Commission, www.mhcc.state.md.us and Primary Care Coalition of Montgomery County.
- ¹¹ “Health Insurance Coverage in Maryland through 2002” Maryland Health Care Commission, www.mhcc.state.md.us.
- ¹² U.S. Census 2000, Sample Demographic Profiles, Table DP-3.
- ¹³ Respondents included eight shelters, three departments of Health and Human Services, six community based organizations, four hospices, four clinics and three hospitals.
- ¹⁴ These numbers will add up to more than 100% because some service providers identified multiple sources for referral.
- ¹⁵ “Emergency Department Use in Maryland: A Profile of Use, Visits, and Ambulance Diversions,” The Project HOPE Center for Health Affairs, February 2003, p. iv.
- ¹⁶ “Emergency Department Use in Maryland: A Profile of Use, Visits, and Ambulance Diversions,” The Project HOPE Center for Health Affairs, February 2003, p. v.