



**North American Association of Christians in Social Work (NACSW)**  
PO Box 121; Botsford, CT 06404 \*\*\* Phone/Fax (tollfree): 888.426.4712  
Email: [info@nacsww.org](mailto:info@nacsww.org) \*\*\* Website: <http://www.nacsww.org>

*“A Vital Christian Presence in Social Work”*

## **HELPING RURAL COMMUNITIES IDENTIFY RESOURCES FOR THE TERMINALLY ILL**

**J. P. Burnham  
Lea Drawdy  
Elizabeth Pierson**

**Presented at:  
NACSW Convention 2005  
October, 2005  
Grand Rapids, Michigan**

*This workshop provides practical information on how to advocate for quality spiritual, emotional and medical care for the terminally ill in rural communities. It explains in step-by-step format how to implement informational programs, using student social work projects that assist families, clergy and physicians in finding resources.*

In rural communities, spiritual, emotional and medical support for the terminally ill is a major concern. While in urban areas hospice has provided quality end-of-life care for several million Americans, rural communities remain greatly underserved. In their study, Virnig, Moscovice, Durham & Casey, found that the rates of hospice care before death were negatively correlated with the degree of rurality. Also they found that Medicare beneficiaries who lived in rural areas are less likely to receive hospice than those in urban areas. (2004).

Awareness of the potential effect of hospice services on both the welfare of patients and their families is limited. National surveys and studies have shown that alternative approaches are infrequently discussed among doctors, patients and families (Merson, Bradley, 2002). Even after rural patients are in a hospice program, when compared to urban patients, differences in the types of medications given, in psychosocial support, and spiritual care were found.

This workshop will provide practical information on the ways social work students can establish community partnering with local health services, and assist in improving end-of-life care for rural populations. Methods for educating different groups such as clergy and physicians on family needs and resources will be discussed. Procedures on how social work students can implement community education will be covered.

### **Project Steps**

Students in a social work macro practice class were asked to select a social problem, develop an advocacy plan and implement it in the community. Two students identified barriers to end-of-life services in local (northeast Tennessee) rural communities. Then, in coordination with local health care agencies, they developed and began implementation of an educational program to increase community awareness on how hospice can help those with terminal illnesses.

The social work students developed their program by following the “IMAGINE” model, a step-by-step intervention process outlined by Kirst-Ashman and Hull (2001). This paradigm serves as a guide for initiating and implementing macro change. The acronym IMAGINE represents seven steps: “I”: start with an innovative idea; “M”: muster support and formulate an action system; “A”: identify assets; “G”: specify goals, objectives and action steps; “I”: implement the plan; “N”: neutralize opposition; “E”: evaluate progress (Kirst-Ashman & Hull, 2001, p.199).

The first step in the IMAGINE process is to identify a project, or an idea. Two members of the class had an interest in identifying resources for terminally ill persons who live in rural areas. One of them was volunteering with a hospice at the time.

Mustering support and information from others is the second step in the model. One informative source was the National Hospice and Palliative Care Organization web site. It provided a tremendous amount of information and studies on hospice services. Another source of support was attained by opening lines of communication with the administrator of a local hospice in which the student volunteered. He was more helpful than administrators of other area hospices who did not know the students. This emphasized the importance of using networks and mutual acquaintances to introduce the

students to their potential support systems. Another good source of information was a thanatology professor at East Tennessee University.

Because clergy are normally among the most respected and influential people in small rural communities, they were also contacted. They provided support and community contact while the students, in return, provided information on resources available to terminally ill patients and families.

Another support system was the local Rural Medicine Program at East Tennessee State University. They suggested tips on how to approach the health care workers and physicians in rural areas. They could be of significant assistance in setting up future seminars for community residents and doctors.

In the next step, assets, (resources and advantages) were determined. One student had a working knowledge of hospice from her volunteer work. She had the opportunity to both observe and participate with palliative care procedures. Also, her one-to one time with patients gave her personal insight into what issues patients face in terms of end-of-life care they were receiving.

The other student was an asset because of her strong computer skills. She used them to research information and to build a web page. She established an on-line support group for friends and family providing care for hospice patients so those caregivers could have an outlet to discuss issues and concerns. The difference in ages and cultures between the two students also provided insight neither would have alone.

Being students in the BSW program at the university provided a large number of people with whom to network and who could serve as resources. Several faculty have experience working with the terminally ill and their families, and offered practical suggestions.

Developing a goal and objectives was the next step. Educating families, health care workers and clergy about hospice services and how they are focused on quality end-of life care was identified as the primary goal. According to Friedman, Harwood & Shields (2002), educating the people about hospice empowers them to request information from their doctors. The students made copies of opinion and testimonial articles on how the quality of life was improved after patients accepted hospice services.

One such article stated that depression in caregivers whose family member was enrolled in hospice for longer period of times had less depression than those with members enrolled for brief enrollments (Chentsova-Dutton et al, 2002) Specific objectives on meeting the goal were formulated.

One of the most helpful activities at this point is the creation of a PERT chart. This provided an excellent way to track progress toward the goal. Action steps and the person responsible were delineated. Dates and progress notes were recorded. The chart provided both visual direction, and a formative evaluation of progress for the project.

Implementation is the fifth step in the IMAGINE model. A survey was distributed to members of a university thanatology class. The purpose of the survey was to determine how much the class knew about hospice. It showed that the group had only limited information and not all of that was correct. An educational presentation on hospice care was then designed to cover the respondent's lack of knowledge and to address concerns they had mentioned on the survey. Because community training programs increase care, (Ferrell, Borneman, 2002), other groups in the community were contacted and several more educational lectures were planned.

Implementation also took place by the development of a brochure that provided information and listed the national hospice website. Local hospice information was not included in order to avoid the impression of being an agent of any specific hospice agency. The brochure is a resource that can be placed in doctor's offices and other public locations. It is especially useful to those who do not have access to the internet or are not comfortable using a computer.

Another idea that was acted upon was the creation of a Yahoo internet group for caregivers in the northeast Tennessee area. Files were uploaded to the site with information important to anyone learning about hospice care or for those already receiving support. There is information pertaining to talking about death and dying, communicating with the patients wishes, hospice facts, how to get quality care, and even a file where members can post their own stories. There are also links added to the site for added information and resources. This website, while in its fledgling stage, has the potential to help numerous caregivers as an on-line support group resource. To achieve this, students in the next semester need to continue and develop it further.

Kirst-Ashman & Hull (2001) list the sixth step as neutralizing opposition to the project. We found that this is not a linear step, but one that has to be infused throughout the entire process, starting with the mustering of support.

One situation that challenged the ability to neutralize opposition was the tendency of hospices, as separate organizations, to overcome turf-based fears. One method used to counter this attitude was to use common acquaintances to introduce the students and letting the hospice administrators and employees get to know them. Another tactic was to refer to hospice at the national level in the brochures, lectures and website so no appearance of favoritism toward one agency over another would be given. Not mentioning specific agencies by name also bypassed the red tape that was associated with administrative and insurance regulations.

A prevalent issue that needed to be neutralized was the stigma that hospice can have with some people. The Terry Shiavo case did some damage to the reputation of hospice care. Because of this, many people view hospice as a place where patients will be euthanized. Education and testimonials are the best way to counter this belief.

The last step is evaluation of the project. A formative tool is pre- and post-surveys of persons attending lectures or seminars on hospice care is one method of evaluation. As mentioned previously, the PERT chart also served as an evaluation tool. Because this is the first semester of implementation, a summative evaluation is not yet available.

### **Conclusion**

Quality of end-of- life care in rural communities is in dire need of improvement. This project by social work students begins a program that will provide resources for patients and families in northeast Tennessee. Following a recognized step-by-step macro method for social change has laid a foundation for future students and professionals to build upon.

## References

- Chentsova-Dutton, Y., Shucter, S., Hutchin, S., Staruse, L. Burns, K., Dun, L., Miller, M., & Zisook, S. (2002). Depression and grief reactions in hospice caregivers: From pre-death to one year afterwards. *Journal of Affective Disorders, 69*, 53-60.
- Ferrell, B. R., Borneman, T. (2002). Community implementation of home care palliative care education. *Cancer Practice, 10*, 20-27.
- Friedman, Betsy T., Harwood, M.K., & Shields, M. (2002). Barriers and enablers to hospice referrals: An expert overview. *Journal of Palliative Medicine, 5*, 73-84.
- Kirst-Ashman, K.K., Hull, G. H. (2001). *Generalist practice with organizations and communities*. Belmont, CA: Wadsworth/Thompson Learning.
- Merson, M., Bradley, E. H. (2005). Enhancing awareness of hospice through PAL. *Hospice Institute for Education, Training and Research*. Retrieved April 6, 2005 from <http://www.hospice.com>.
- Virnig, B. A., Moscovice, I. S., Durham, S. B., & Casey, M. M. (2004). Do rural elders have limited access to Medicare hospice services? *Journal of American Geriatrics Society, 52*, 731-735.