VIEWPOINT
Tailoring Telemedicine to End-of-life Needs
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End-of-life care service needs vary enormously according to patients' circumstances; and meeting these needs using conventional care services can be trying. According to published findings by researchers in the Dartmouth Atlas of Healthcare, oftentimes hospice and end-of-life care service delivery is based not on medical concerns but on provider preferences (i.e., logistics and consequent difficulties). Telehealth tools and services (that is, healthcare tools and services that have communications features) may have the potential to bridge the problem of access to desired care, however.

Tele-tools and Services for End-of-life Care
There is a growing range of telecommunications-ready tools that can help to ameliorate some trying situations at end of life. Starting with the very ordinary household telephone and broadening out to full-scale telehealth workstations and to smart housing devices or entirely wired rooms are some possibilities for extending care. However, few if any telehealthcare tools are designed specifically for end-of-life patient needs. The challenge for practitioners is therefore two-fold.

1. The tools must be identified, first of all, and their features and capabilities scrutinized by physicians so that they can be used correctly and effectively with end of life patients.
To this end, "Tomorrow's Tools," a segment of the Last Acts Web site which is devoted to issues in end of life care, can be a helpful start [1]. Each quarterly installment of "Tomorrow's Tools" features a topical emphasis with a targeted, annotated bibliography, details about new technologies in the "Today's Toolbox" segment, and comments from a panel of recognized experts on potential uses and value of the topic at hand. The February 2001 topic is "Smart Houses: New Ways to Get Patients the Care They Want." Earlier topics have included "Machines that Talk ... and Talk Back;" "Video 2000;" and "Self Care ... Now!?"

Telecommunications-ready or other communications tools that have been focused on to date in "Tomorrow's Tools" include: pre-programmed infusion pumps to deliver pain medication and for hydration and other patient needs. Another range of tools is video technologies that deliver medical directives from any number of clinicians, or for purposes of providing information, solace, and reminders using a show-and-tell approach. Using video, there can be an immediacy of contact - even if the clinician is off site - which is not possible with conventional care to address

end-of-life patients' individual needs. However, as noted by Stephen Spann, MD, who uses video technology for teaching purposes, presenters must learn about video technology's capabilities to use it productively and effectively. Doing so will help physicians to overcome two significant barriers: distance, and infrequent or inadequate communications [2].

2. The second challenging task is matching the appropriate tool with specific patient need or needs.
While end-of-life care patients are as diverse as the population in general, certain qualities are distinctive. They are more fragile, yet the majority wish to spend their last days not in hospitals but in their own homes. If the patients are out of the institutional setting, then there is all the more reason for physicians to locate tools that can ease their patients' transitions at the end of life, ones that are usable by the patients and their family caregivers as well as by home care/hospice nurses. The value: new tools can help physicians to communicate more often and as-needed with end-of-life patients in alternate care settings.

Among the decisions to be made when trying to match tools with patient needs is patient attitude toward using new tools. According to Chris Frank, MD, who manages rehabilitative care in a palliative care unit, independence and the need for self care are important considerations for some patients even at the end of life [3]. Dr. Frank says: Loss of control is one of the most challenging consequences of illness for many people. This is true when considering decisions about medical care, living situations, and extent of treatment, and it is also a major issue for people in the more day-to-day aspects of life. When people need to rely on others for activities of daily living, it commonly causes distress and depression. Most people strive for independence throughout their lives, and independence may be an even more important issue for dying patients. Self-care routines become important since they provide a way for the individual, often in collaboration with their caregivers, to dictate what is important to them in their daily living. It offers autonomy as well as predictability which increases the chances that they feel in control [4]. Enabling patients to continue somewhat with their familiar routines, as well as they are able, may be one of the key features of value of new tools introduced at the end of life.

"Smart" or pre-programmed sensors and other electronic tools can assist in achieving this end. Take a very common consideration at end of life, incontinence and possible ensuing difficulties with bedsores. It is currently possible to program blankets, mattresses, and other mainstays of the patient's bedside with higher tech tools that can time and sense the need to alert patients to empty their bladders and/or alert them or their caregivers to turn the patient or otherwise change position [5]. Beepers, phone calls, and other telecommunications tools used for this commonplace application provide patients at the end of life with increased communications (and ultimately, greater comfort) as and when needed.

Conclusions

A significant problem with introducing technologies in end of life care is the perceived reticence (by physicians, nurses, and patients) toward using high technologies in this highest touch of all care delivery scenarios. Key to the technologies' acceptance is physicians' ensuring that the selected tools are appropriate for use by end-of-life care patients and their family caregivers, and that patient needs can be addressed by means that will extend access to, not replace, hands-on clinical care [6]. Once we're over that hurdle of accepting the idea of technology's use at end of life, it will be an important step for physicians to become involved in development and design of focused tele-tools to ensure usability and that needs are met. To do so, physicians should take the initiative and work with device manufacturers to educate them about end of life patient needs.

References

1. Last Acts is a Web site dedicated to improving care at the end of life, and is sponsored by the Robert Wood Johnson Foundation (http://www.lastacts.org/).
2. Spann SJ. Two-way interactive videoconferencing: why bother? *Fam Med*. 1998;30(7):513-514.
3. Frank C. Personal correspondence with the author, Nov. 13, 2000.
4. Frank C, Hobbs NR, Stewart GI. Rehabilitation on palliative care units: case discussion. *J Palliat Care*. 1998;14(2):50-53.
5. Smart housing developments for possible end-of-life care applications are discussed on the Smart House installment of "Tomorrow's Tools"and for general healthcare applications Potential uses of smart devices with the frail and elderly are discussed in Kinsella, A. "The smart house: taking the same tele-garden path," at: http://tie.telemed.org/homehealth/kinsella6_FT.asp.
6. A range of tools is identified and profiled in Kinsella A. *Home Telehealth in the 21st Century: A Resource Book about Improved Care Services That Work*. Kensington, MD: Information For Tomorrow; 2000.

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