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Survey of Consumer Informatics for Palliation and Hospice Care

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Abstract

Context—Palliation in patient care is under-utilized in part because many patients have insufficient knowledge about this management option. Information technology can improve awareness by providing access to numerous sources of trustworthy information.

Evidence Acquisition—To estimate what a patient interested in palliation might find online, online resources were searched in July 2010, using terms relevant to palliation. PubMed was searched for publications relevant to discussed topics.

Evidence Synthesis—Search engines returned vast numbers of hits, and identifying trustworthy sites was difficult. Products judged as trustworthy were classified as information, decision tool, or extended interaction tool. Sites with useful educational material were relatively plentiful; decision guides and interactive tools were much rarer. Available consumer informatics did not address well some terminal illnesses, and some subpopulations such as children, nor was there sufficient attention to literacy levels or principles of instructional design. Online or published information about usage numbers, effectiveness, and cost/benefit considerations was scant. Many sectors, including commercial, government, healthcare, research, and wellness/advocacy groups, have created consumer informatics for palliation.

Conclusions—Online information about palliation is available, although identifying trustworthy sources can be problematic. General information sites are relatively plentiful, but more tools for decision making, and interaction would increase value of web resources. More attention to literacy levels, instructional principles, and needs of special populations would improve products. Research to measure usage of such tools, ability to influence behavior, and cost/benefit issues is needed.

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Context

How the healthcare system manages patients with deadly illnesses has huge consequences for the patient, the patient's family, and the economics of the healthcare system. Palliation, sometimes as an adjunct to attempts to cure, sometimes as an alternate approach to care when cure seems out of reach, is receiving increasing attention as a patient management approach that focuses on quality of life and relief of suffering rather than on eradication of the disease.¹

Many believe that palliation is under-utilized in the U.S.; causes of under-utilization are multiple, but among them is lack of awareness by patients and some physicians of the potential benefits of palliation.² Further, when terminal patients are kept in-hospital for intensive care until death, the potential benefits of hospice care for maximizing quality of life are not realized. In an era in which information technology is greatly enhancing the ability of healthcare consumers to become informed, consumer informatics for palliation could substantially increase sophistication about the value of this type of care.

EVIDENCE ACQUISITION

To obtain an estimate of what consumer informatics could be discovered on the web by a computer-literate patient interested in palliation, online resources were searched using key terms associated with the concept of palliation. In addition, some products were suggested by the authors. Palliation applications found are discussed with respect to sources and types of product, instructional design, coverage for special patient populations, attention to literacy requirements, ease of locating trustworthy sites, extent of usage, and cost/benefit considerations. Suggestions for future directions are made.

DEFINITIONS AND CURRENT STATUS OF PALLIATION

An NIH Conference statement concluded, "There has been a lack of definitional clarity related to several concepts and terms, such as palliative care, end-of-life care, and hospice care. Too often these terms are used interchangeably..."³ Within the overall concept of palliation, "palliative care", "hospice care", and "end-of-life care" are not synonyms. Palliative care is often provided concurrently with treatment intended to halt or reverse disease and may be instituted long before death is imminent. The concept of palliation also includes hospice care, which, in the U.S., is a special form of palliative care provided during the latter stages of an illness and is not associated with any further attempts to cure. End-of-life care is not necessarily palliative; it can take place in hospital or home setting as well as in a hospice.

Ambiguity persists in part because quality of life issues and relief of suffering are interwoven with healthcare in almost all its stages. However, lack of agreement about the meaning of relevant terms hinders the conversation among health professionals, patients, caregiving organizations, and payers about the position of palliation within the healthcare system.

For patients in the late stages of life, palliation must consider social, cultural, legal issues as well as patient management choices. The information required and the choices to be made touch on a host of topics:

- Hospice and other care options
- Clinical management decisions
- Autonomy

- Legal and financial considerations (Advance Directives, Wills, Power of Attorney, debts)
- Funeral and burial arrangements
- Relationships with family and friends
- Psychological issues
- Religious and ethical concerns

Not all of these are conventionally considered aspects of palliation, but they all represent issues of concern, and accordingly, are appropriate targets for informatics tools. Symptom control lies at the heart of palliative care, but attention must also be directed at emotional support, spiritual support, comfort, social support, and interpersonal relationships and communication. Particularly important for those making decisions at this stage of patient care is the need to preserve dignity.⁴ Friends and family members caring for the patient should also be aware that the stress of providing palliation may affect their own health by such phenomena as declining immune function⁵ or “the care giving boomerang”, which refers to the surprising increase in mortality among family members tending to the terminally ill.⁶

EVIDENCE SYNTHESIS

Resources hat Inform

Information per se can be highly useful and is available via the Internet. Information-rich sites are maintained by advocacy organizations, government sources, and healthcare professional groups. Some commercial sites also offer some free information. Popular general health information sites such as AARP and WebMD return a scattershot of documents when asked about “hospice” or “end-of-life” in the site search engines; if one trawls the hits, some useful material can be found.

General resources provide useful information, but may not cover the terminal situation for specific diseases, although disease-specific information can be crucial (e.g., kidney failure, late-stage obstructive pulmonary disease, and terminal cancer have different effects on the patient). Palliative care for patients with devastated minds is particularly complex; a family member recently described the painful issues that arose in caring for an elderly demented patient with a pacemaker that physicians refused to shut off despite a valid advance directive.⁷ Consumer-friendly information can, however, be found for many (but not all) specific terminal conditions.

National organizations devoted to a specific disease could be helpful to patients by offering palliation information but not all do so (e.g., neither the American Diabetes Association nor the American Heart Association includes information about palliation on otherwise richly informative websites).

Resources Designed to Guide Decisions

Although information itself can help rational decision making, decision support usually refers to informatics tools that go a step beyond just furnishing information. Patients must make choices, and merely reading large amounts of information may overwhelm ability to analyze and act. Decision support tools are designed to help a human make decisions when knowledge is incomplete or uncertain. At present, most decision support tools and the federal interest in decision support are aimed primarily at professionals.

A few sites do provide decision support for consumers. The nonprofit Foundation for Informed Medical Decision Making (<http://www.fimdm.org/about.php>) has been creating audiovisual decision aids since 1989, primarily in DVD form. The Foundation is now expanding into interactive web-based decision tools which usually include three elements: describing the reasonable options; showing interviews with patients to illustrate different perspectives; and empowering the patient to share decision making with healthcare providers.

Tools offered cover a variety of preference-sensitive decisions, such as various surgical procedures, and the management of several chronic conditions. For palliation, the Foundation has a decision aid about advance directives, and another for decision making in the setting of advanced illness. A program on metastatic breast cancer addresses palliative care issues. A pilot clinical trial incorporating end-of-life decision aids into hospital-based palliative care service was recently completed. Nine “demonstration” clinical sites are working with the Foundation to learn how to use decision aids in routine clinical care.

Although decision support tools for consumers are rare, some are available.⁸ The Ottawa Hospital Research Institute has a valuable site dedicated to helping patients make “tough” healthcare decisions but does not address palliation and hospice (<http://decisionaid/ohri.ca/about.html>). A few other sites, including some general information sites, also include some elements of decision support, but more development in decision support for palliation is needed. Palliative care requires a number of difficult decisions by patients who may be confused and frightened and consumer informatics has great potential for helping.

Resources that Facilitate Interaction Between Patient and Healthcare Team

Yet more complex, but perhaps of greatest value are informatics tools that interact with a patient over time and offer both information and decision guidance. Value has been demonstrated in a small number of pioneer applications, usually by academicians working in a research environment. Information technology (*IT*) *becomes a member of the healthcare team* (e.g., technology in late-stage lung cancer is a feature of the Comprehensive Health Enhancement Support System [CHESSTM] program).^{9, 10}

Accessed through a home computer, CHESS monitors user health status, guides users to information and support, assists in health decisions and teaches coping skills. An enhanced system [CHESS + clinician report (CR)] communicates patient and partner information to the palliative care team. CHESS provides information, social support, decision making, and problem-solving tools, personalized for the patient. Self-determination theory, which is concerned with the motivation behind the choices that people make themselves without any external influence and interference, has been utilized in the design.¹¹ In a controlled trial, CHESS + CR improved survival in advanced cancer over standard care.⁹ Further research and development of CHESS-type tools should be encouraged. Useful interactive informatics tools for cardiac patients and for neonates exist but have not focused on palliation.^{12,13}

HOW SOPHISTICATED IS INSTRUCTIONAL DESIGN OF CURRENT CONSUMER INFORMATICS TOOLS?

Multimedia

YouTube contains nothing but multimedia and is not often helpful. The site returns a number of videos if asked for palliation, hospice, or advance directive, for example, but most are a record of personal experience rather than general instructional material.

Few existing informatics tools for palliation take advantage of such multimedia tools as graphics, color, images. Most web pages are text with links to more text. There are a few exceptions. Healthmark Multimedia, a company that bases its offerings on evidence-based material, makes heavy use of multimedia and instructional principles. It provides interactive tools that enable users to apply new information directly to a personal situation. Palliation is not the chief focus but a program on advance directive is available now, and more relevant material is in preparation. Healthmark products are made for CD-ROM but can be converted to web use. An excerpt from the website illustrates the aim of the developer: "COPD: Living My Best Life® ...includes activities to store medical information, learn self-management skills, reflect on issues related to living well with a chronic condition, prepare advance directives, communicate with doctors and loved ones, and make informed medical decisions." Tools can be purchased from the company.

Presenting Information as a Teachable Moment

Web information on palliation is usually reasonably clear, but few products found appeared to present the information in a manner designed to facilitate learning. Informatics tools might be much more effective if principles derived from cognitive theories about effective teaching were applied when the material is created.¹⁴

SPECIAL PATIENT POPULATIONS NEED TAILORED CONSUMER INFORMATICS TOOLS

Palliation information useful for the general population may be ill adapted to such special patient sets as children, patients with mental disorders, and people from cultures with mores substantially different from conventional American values.

Pediatrics exemplifies such special requirements. More than 50,000 children die each year in the U.S. It is self-evident that information needs in such situations are different than for adults. Particularly for children, a switch from the common perception that sees palliation as a final stage to a more comprehensive view in which palliation is included in the care plan from the beginning could transform management.

Palliation for children must recognize a number of special issues. The family's information needs include options for hospice care, pain management, emotional and spiritual support, explanations appropriate for a child, handling of grief by parents and siblings, how to interact with professional staff.

Books on palliation for children are available, but consumer informatics is not common, and when available, is often focused on a single issue, such as handling grief. A few useful sources exist,^{15,16,17} but not enough. Because of the poignancy of serious illness in children and the complexity of the issues involved, there is no field of medicine with a greater need for more consumer informatics about palliation than in pediatrics. Decision support and interactive tools could have important impact. Many professionals who care for children would also benefit from greater awareness of what palliation can do.¹⁸

CONSUMER INFORMATICS TOOLS FOR PALLIATION NEED TO BE COMPREHENSIBLE

More use of multimedia will come along, but reading with comprehension will remain key if consumers are to benefit. Limited health literacy is common and can have numerous causes including inter alia, personal limitation, poor language facility, and lack of education. In addition, the clinical context of end-of-life decision making can reduce health literacy for

most patients, and particularly so for the elderly, no matter how sophisticated their reading skills when healthy.

Palliation informatics sensitive to the needs of those who read with difficulty is almost nonexistent. More attention to the varying literacy levels of the population is essential for a diverse society. Large segments of the population, it is clear, would encounter some difficulty in reading the material on most of the sites listed in this paper.¹⁹ Comic books work best for some situations, perhaps demonstrating value of multimedia as well as simplification of presentation.²⁰ Excellent guides to health literacy are available from the DHHS^{21,22} and one hopes that future products will incorporate the DHHS principles.

Locating Useful Informatics for Palliation

Finding information on the web is easy but bewildering. Entering “palliation” as a search term in popular search engines returns hundreds of thousands of results. Identifying trustworthy sites is a challenge; authoritative resources are interspersed among personal anecdotes, sites selling remedies or advice, speculative theorists, and jargon-heavy material intended for professionals. Most consumers are not familiar with the criteria that have been established for evaluating trustworthiness of health information on the web.²³ Google™ and other popular search engines could immensely increase their usefulness in providing access to health information if they were willing to provide some special label to sites believed to be of high quality according to generally acceptable criteria.

Inspections of the applications identified for this paper strongly suggests that consumers looking for worthwhile information would be well advised to start with sites developed by federal agencies, associations dedicated to palliation/hospice issues, or health professional organizations. However, some excellent resources are available in the commercial sector or developed by researchers. Decision guides and interactive tools are much harder to find than descriptions and explanations. A “consumer informatics” clearing house, recently established by a consortium of distinguished government organizations, involves stakeholders from various sectors— commercial IT, government, health care, education and research, advocacy, and may prove to be an excellent first stop for patients and family looking for reliable help (<http://informaticsforconsumerhealth.org/>).

ARE CONSUMER INFORMATICS TOOLS FOR PALLIATION USED, AND DO THEY MAKE A DIFFERENCE?

The extent to which consumer informatics resources are actually consulted by the public is not known. A few sites make usage metrics available, but it would be helpful to have more information about how many patients seek out such information and whether the numbers are growing.

Whether consumer informatics tools actually help the user remains an open question. However, the belief that informatics can educate, relieve anxiety, change behavior, and guide decisions is not entirely a speculation. Although controlled trials to study effectiveness of consumer material for palliation have not been published, a recent review of randomized clinical trials and other studies of the effectiveness of consumer informatics in a variety of health areas concluded “Despite study heterogeneity, quality variability, and some data paucity, available literature suggests that select ... applications may effectively engage consumers, enhance traditional clinical interventions, and improve both intermediate and clinical health outcomes.”²⁴ More research is needed to identify what aspects/components of a consumer informatics application are effective in influencing behavior.

Cost/benefit considerations for informatics tools are important but have not often been measured. Money is required for research and development, dissemination, and maintenance; such costs will need to be justified by application benefits. Some benefits have been demonstrated (e.g., substantial cost-saving decreases in hospital length-of-stay have been demonstrated for CHESS in HIV/AIDS).²⁵ Of greater import for reducing healthcare expenses is the potential of consumer informatics to increase use of palliative care and hospice. A member of the WHO Collaborating Centre for Public Health Palliative Care Programmes reported savings of 8 million Euros in 2005 in a regional public palliative care program in Catalonia.²⁶

Conclusion

For those who know where to look and how to judge quality, information technology can provide much useful general information and a few more focused informatics tools relevant to palliation. Challenges remain for those who develop consumer informatics resources:

- Improve accessibility to trustworthy sources and tools on the web. Search engines, now largely indiscriminate, could help by labeling healthcare sites that meet acceptable criteria for quality of information...
- Tailor applications for diverse populations with attention to age, disease, culture and literacy
- Help consumers to act on the information they are given by developing more informatics decision tools that provide personalized guidance for selecting among palliation options.
- Expand research and development of tools that exploit the potential of information technology to provide ongoing interaction between patient and professionals as care is given.
- Increase use of multimedia to leverage the ability of graphics, images, colors to improve comprehension and retention.
- Incorporate effective instructional principles in the design of informatics applications
- Evaluate consumer informatics offerings to determine what elements are most effective in teaching and in influencing behavior.
- Direct more attention to education of professionals, whose understanding and acceptance of palliation and hospice care is sometimes below the level needed for palliation to be used most effectively.
- Provide tools that educate consumers about ways and means of judging quality of information found on websites.

Addressing such challenges is not the responsibility of any one sector; advances will come from commercial developers, government, healthcare professionals, researchers, and Wellness/Advocacy groups working alone or, perhaps more fruitfully, in partnerships.

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Table 1

Examples of sites that offer general information about palliation and end of life

<u>ADVOCACY ORGANIZATIONS</u> <ul style="list-style-type: none"> National Hospice and Palliative Care Organization http://www.nhpco.org/templates/1/homepage.cfm
<u>GOVERNMENT SOURCES</u> <ul style="list-style-type: none"> DHHS http://www.healthfinder.gov/ National Library of Medicine (NLM) http://www.nlm.nih.gov/medlineplus/ National Cancer Institute (NCI) http://www.cancer.gov/cancertopics/coping Agency for Healthcare Research and Quality (AHRQ) http://www.ahrq.gov/
<u>CAREGIVER ORGANIZATIONS AND ACADEMIC MEDICAL CENTERS</u> <ul style="list-style-type: none"> Mayo Clinic http://www.mayoclinic.com/health/cancer/CA00048 Harvard http://www.health.harvard.edu/press_releases/end_of_life_medical_decisions Cleveland Clinic http://my.clevelandclinic.org/services/palliative_medicine/hospice/default.aspx
<u>COMMERCIAL SECTOR</u> <ul style="list-style-type: none"> Hospice Foundation of American http://www.hospicefoundation.org/pages/page.asp?page_id=53382

Table 2

Examples of sites that offer disease-specific guidance for end-of-life

<u>ALZHEIMER'S DISEASE</u>
<ul style="list-style-type: none"> HelpGuide.org http://helpguide.org/elder/alzheimers_disease_dementia_caring_final_stage.htm
<u>CHRONIC OBSTRUCTIVE LUNG DISEASE</u>
<ul style="list-style-type: none"> Canadian Lung Association http://www.lung.ca/diseases-maladies/copd-mpoc/living-vivre/care-soin_e.php
<u>CONGESTIVE HEART FAILURE</u>
<ul style="list-style-type: none"> The Washington Home Center for Palliative Care Studies www.medicaring.org/educate/download/chfbookfinal.pdf
<u>BREAST CANCER</u>
<ul style="list-style-type: none"> Breast Cancer Network of Strength http://www.networkofstrength.org/information/
<u>KIDNEY DISEASE</u>
<ul style="list-style-type: none"> Kidney End-of-Life Coalition http://www.kidneyeol.org/index.htm

Table 3**Consumer informatics that use multimedia**

<p>Sites that Address Palliation</p> <ul style="list-style-type: none"> • HealthMark Multimedia http://www.healthmarkmultimedia.com/default.asp • Compassion and Support <ul style="list-style-type: none"> – http://www.compassionandsupport.org/index.php/resource_directory/compassion_and_support_video_library/public_service_announcements_videos – http://www.healthmarkmultimedia.com/default.asp
<p>Sites that address health issues but not palliation</p> <ul style="list-style-type: none"> • X-Plain Corporation http://www.patient-education.com/main.asp?p=aboutxplain • MedicalView http://www.medicalview.com/ • The A.D.A.M. Multimedia Encyclopedia http://www.adam.com/MutlimediaEncyclopedia.aspx • Agency for Healthcare Research and Quality. http://www.ahrq.gov/news/av.htm • MedlinePlus http://www.nlm.nih.gov/medlineplus/ (addresses palliation but not with multimedia)

Table 4

Factors contributing to decreased cognition and diminution of health literacy

<u>Aging</u> <ul style="list-style-type: none">• Reduced information-processing speed• Greater tendency to be distracted• Reduced capacity to process new information• Reduced capacity to remember new information
<u>Illness</u> <ul style="list-style-type: none">• Stress• Fatigue• Depression• Effects of medication• Additive effects of multiple medical conditions