

Caring for the Caregiver (and Improving the Client's Quality of Life) Through Appropriate Use of Technology; but ... Only if the Needed Information is Available and Accessible!

Charles J. Robinson, D.Sc., P.E., Fellow IEEE

Abstract – For those with a terminal illness, the ability to maintain a reasonably good Quality of Life (QoL) is important. One key to this is to be able to carry out oneself or via a caregiver Activities of Daily Living (ADLs). Simple to complex assistive technology exists in the rehabilitation field to help with these ADLs and their use is termed iADL (instrumented ADL). Finding appropriate, adequate and cost-effective iADLs is difficult even for rehab professionals, who are not often involved in hospice situations because of the short-term need. So the consumer and caregiver need access to information about what might be available, and then to a way to acquire the needed device in a cost-effective manner.

I. INTRODUCTION

As professionals in our various fields, we all have access to information that is not necessarily readily available to the public. We often review such material as we prepare to teach a class, develop a product, write proposals and do research. So it might seem reasonable that crises in our personal life that by happenstance draw upon the collective wisdom that we have amassed might be more easily handled by us than by others without this in-depth knowledge. This is most evident in the health care field, where an understanding of medical terms and standards and practice of care can greatly aid one who is thrust into a role as a primary caregiver. Alas, but it would be that simple!

I am a rehabilitation engineering specialist and a neuroscientist. I have taught many rehabilitation courses and have had high level oversight of a number of comprehensive centers in the USA that provide assistive technology assessment and services. And I have spent much time on VA Hospital wards and services that treat and/or house our disabled veterans. I was the founding Editor of the IEEE Transactions on Rehabilitation Engineering and my wife was its Managing Editor for a number of years. Even with that background, it still was difficult for both of us to find the appropriate technology to use as she slowly succumbed over 2.5 years to the spreading paralysis of Lou Gehrig's disease (ALS). Just as we would find a technology to solve a problem, we would get at best 3 months use of that solution before we had to find or invent another one.

Robinson is Director of the Center for Rehabilitation Engineering, Science and Technology, Clarkson University, Potsdam, NY 13699, USA; Senior Rehab Research Career Scientist, Research Service, VA Health Care System, Syracuse, NY 13210, USA; and Adjunct Professor, Dept of Physical Medicine and Rehabilitation, SUNY Upstate Medical University, Syracuse, NY, 13210, USA <c.robinson@ieee.org>. The views expressed here are his alone and are not to be taken as reflecting those of his employers.

The author thanks personnel of Hospice and Palliative Care of St. Lawrence County, the ALS Clinic at SUNY-Upstate, and the Syracuse MDA. This abstract is based on a talk given to Hospice in April 2009.

Both of us often commented that we could not image how others without this type of extensive background knowledge could possibly find and handle the changing technology needed to deal with progressive neuromuscular (and other) diseases like this. Certainly there are clinical specialists well trained in selected aspects of assistive technology, and they do provide valuable support. But we found no comprehensive solutions even from comprehensive centers because most focused on the client (as is indeed needed), while putting little effort into training the ordinary supporting people that need to provide day-to-day care in their homes in real time. In other words, the care needed to be provided to the *caregiver* with respect to how the technology works and options available down the line were lacking, and strikingly so in a very rural area like ours in far upstate New York State.

Caregivers can be spouse, family, hospice staff, aide and friends. In an ideal world, duties are shared. Palliative and End-of-Life care is stressful for caregivers, and Quality of Life issues are important to both clients and caregivers. Can technology help relieve the caregiver's burden?

As the focus of this Accessibility conference is to identify needs and propose solutions, I, with the indulgence of all, will illustrate these needs from personal experience. The items being discussed fall under the rubric of *quality of life*, which gets so little political attention when compared to issues involving the saving or extending of life. As such, I will deal with "*informed*" technology choices that we together made over the last 2.5 years of her life.

II. METHODOLOGY

A. Needs Assessment and Truly *Informed* Decisions

How do you maintain a quality of life for an active someone who is slowly becoming totally paralyzed? Singing in choral groups, cantoring in church, talking to our children on the phone, teaching, cooking and grand-mothering were of great value to her — and some have no technological substitute. So, with client involvement, the question should be "*What do you need to do and want to (be able to) do?*" Such questions presuppose that a) the client has a means to communicate that information, and b) does not hold back because they assumed that they cannot perform some task. It becomes a question of a "dis-ability" rather than a disability.

Once a need or want is determined, one then has to find out whether there is enough residual function left to carry out the task in a modified way with retraining, or whether a technological solution should be sought. Simple to complex rehabilitation (or assistive) technology often exists as aids to enhanced quality of life. But finding appropriate solutions within a price range is difficult, even for a professional.

B. Appropriate Technology

Judging what is the appropriate amount of technology is quite complex, and involves scientific, socioeconomic, clinical, cosmetic, engineering, and political issues. Total avoidance of "technology" in rehabilitation devices for a hospice or palliative care client is not warranted. Technical literacy is not high for many, so acceptance is a concern. Training often is an issue. Length of expected use of a specific technology is an unfortunate consideration for hospice clients because of reimbursement issues that arise from the limited availability and mix of funds for assistive technology from government, personal or private sources. Buy-in and understanding are needed from client, family caregiver(s) and hospice caregivers. One should strive to maintain as much independence as possible without burdening the client or the caregiver.

Rehabilitation problems can often be treated with a low-technology solution, with no need to use higher technology. Solutions using "higher" technology might exist for many problems and can provide qualitative/quantitative benefits to some. Yet they can have high initial and maintenance costs that limit availability and desirability. Thus we propose here a minimalistic definition: *Appropriate (rehabilitation) technology to use is that which accomplishes a task adequately given the resources available.*

Adequacy is verified by determining when increasing a solution's technological content results in diminishing gains or increased primary or secondary costs whatever the reason.

C. Searching for Solutions

The ability to carry out Activities of Daily Living (ADLs) greatly influences one's quality of life. The ADLs (or instrumented ADLs [iADLs] if technology is used) involve things like eating, combing hair, putting on shoes, etc. — all the simple things that one does to get through the day. As a rehab specialist, I know that there are huge 500-page catalogs (and their web versions) that list iADLs for every imaginable use. These sites have simple items for aiding communication, but one needs to go to individual vendors and through other specialists (generally Speech-Language Pathologists or SLPs) for the more complex Alternative and Augmentative Communication (ACC) equipment.

Because of the many different sensory, movement, and cognitive aspects to rehabilitation or quality palliative care, ideally specialists in each field would be available for consultation. Indeed this is the case at major rehab centers, and serves as a model for rehabilitation practice. But few clients and caregivers in palliative and hospice care situations have access to, or can afford, such a team setting. How then can those in need find out aides that might be available to them?

III. RESULTS

Perhaps the single greatest shock to me even as a practitioner in the field was the lack of a comprehensive way to find a solution to the particular need at hand, given cost constraints

and the limited projected time of use of any device or gadget that we might want to use. The information was simply not as accessible as it needed to be. The hospice team and I, with the help of many of my rehab colleagues, generally managed to find a cost-effective solution that would work over the limited time scale when it would be effective. But it was a very inefficient process, because solutions generally used in traditional rehabilitation situations where recovery was the aim were not appropriate in a case like ALS. In ALS, the goal is to maintain an ability for as long as possible before it becomes lost, by working with whatever residual functioning is still left. When that function disappears, the search then went on for another means to get the same task done.

A big help in finding solutions was the presence of listservs run by the various consumer advocacy associations (like MDA-ALS). These exist on two levels: ones for professionals to discuss and ask suggestions for a particular problem, and ones for caregivers and clients. But in the end, it comes down to what the local care team (including the significant caregiver) can find with limited time and budget. Some of these organizations have *loan closets*, where one can often find a technological device that can be borrowed for a few months to help with a particular task. These can range from \$100 walkers to \$2000 sling lifts to \$20,000 electric wheelchairs. But supply is catch-as-catch-can.

This poster will discuss the time line that evolved regarding the role of assistive technology in enabling us to continually compensate for my wife's decreasing functional movement. The technology helped us for a while to stay one step ahead of the increasing functional losses caused by ALS. It will also point out critical information and supply bottlenecks in empowering the consumer and caregivers to make critical and rapidly changing decisions about what technology is appropriate (if any) and how to acquire it.

IV. DISCUSSION

Accessibility has many different meanings when applied to an individual client. Traditionally the word applied to the ability to navigate freely through physical space. Its meaning has been extended to refer to navigation through any space, include places like web sites. But accessibility should mean more than just navigation. It can mean that the information needed is collected, assembled and available in one place — such that the information content itself is *accessible*, by whatever route one needs to take to get there (e.g., print or web). Even having the information is not enough! Adequacy and appropriateness then must be judged. One then needs to determine out how to acquire the device [i.e., have physical *access(ibility)*], given cost and other use constraints. Lastly, the device itself then has to be functionally *accessible* (i.e., usable) to the client and caregivers without frustrating them.

REFERENCES

- [1] Beth Witrogen McLeod, AND THOU SHALL HONOR- The caregiver's Companion. ISBN 1-57954-558-0. 445 pp. Rodale, 2002.
- [2] Beth Witrogen McLeod. Caregiving: The Spiritual Journey of Love, Loss, and Renewal, John Wiley and Sons, 1994.