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Aging with Cerebral Palsy: A Consumer's Perspective

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Objectives

1. To illustrate the necessity of an holistic approach to addressing the changing health care needs of adults with Cerebral Palsy.
2. To show the necessity of dealing honestly and creatively with the intimacy/sexuality concerns of older adults with Cerebral Palsy.

Background

Until roughly ten years ago, Cerebral Palsy (CP) in adults was generally thought to be a static disability. That is, the symptoms associated with it (spasticity, tense muscle spasms, lack of muscle tone) were assumed not to degenerate over time (The Roundtable on Aging and Cerebral Palsy, 1997). Therefore, the health care profession neglected to undertake research in the area of aging with CP. The vast majority of work was done with young children where progress can often be made. As adults with CP moved more and more into mainstream society, however, we began to experience physical and psychological changes that we believed could not be explained by aging alone. Aging and Cerebral Palsy seemed to interact in unanticipated ways.

In 1995, a ground-breaking study by Turk, Overeynder, and Janicki (1995) confirmed what middle aged and older adults with CP had long known. The study provided impressive support for the thesis that "aging often brings difficult physical problems for a person with Cerebral Palsy," in the words of the 1997 Roundtable on Aging and Cerebral Palsy. Much of what was believed to be known about the clinical state of adults with Cerebral Palsy was thrown out the window.

Compounding the likely increase in medical problems with advancing years is the fact that persons with severe CP are difficult to examine due to spasticity and speech impairments, thus requiring more of an examiner's time. Furthermore, managed care and third party payer incentives encourage less time with patients, rather than the greater time that someone with CP may need. Medicare and Medicaid, federal insurance programs serving large numbers of people with disabilities, recognize this need for more time with individuals with CP and have started reimbursing practitioners more for these patients. (For more background on the federal government's response to this issue, see Quality First, Government Printing Office, 1998.) Another issue is that medical professionals sometimes link an obvious speech impairment to an imagined cognitive impairment. This assumption can end up frustrating both parties and has the

potential to compromise the results of the examination. In fact, more than two-thirds of adults with CP have no cognitive impairments.

People with severe Cerebral Palsy mature physically at the same age as other young people; but for a variety of reasons, largely environmental, we reach social developmental milestones (e.g., dating, intimacy) later, sometimes much later, than the norm. We also face some challenges in this area that are unique to persons with severe disabilities. Those of us with severe spasticity often have difficulty relaxing our muscles during intimate moments, and, at least in males, the medications taken to control spasticity sometimes have an adverse effect on sexual functioning. These medications include Diazepam, Baclofen, and, to a lesser extent, Dantrium. All of this can mean that professionals dealing with aging adults with CP may well face issues with which they are not familiar, and may bring misconceptions to these encounters as well. Yet, failure to deal with these issues is grossly unfair to their patients. "Low tech" assistive technology, such as lower wheelchair chair sides, can sometimes be of help in this area. After all, the hopes, needs, and interests of adults with CP are the same hopes, needs, and interests as their counterparts without CP.

Case Study

Steve is a 39-year-old computer programmer who uses a power wheelchair because of severe quadriplegic Cerebral Palsy. He also has a significant speech impairment. Most people, if they are patient, however, can pick up his speech patterns after being around him for a period of time. Up until a few months ago, he classified himself as one of the "stable disabled," so stable in fact, that he often forgot that he has a disability for weeks at a time.

If there is one thing that Steve is (and has been) dissatisfied about, it is the lack of romance in his life. He has, and has had, a large number of friends who are women, but only one girl-friend, Sarah, who moved out of state a year ago. He has become increasingly concerned about this throughout the last year, even though he has been very busy with Y2K problems around the small college where he works. His brief experience with Sarah (who has a mild disability) convinced Steve of two things: 1) he wants another woman in his life, and 2) unless this woman has no disability and/or is very strong, they will face logistical problems few lovers ever think about. For example, trying to hug Sarah from his wheelchair while she was seated at an angle from him took a fair amount of planning, and anything further would probably have required the help of a personal assistant. Of course, having a third party present may be awkward for some.

In the last few months Steve has noticed some excess movement and increased spasticity in his right side, especially his right arm. Additionally, he has noticed an increase in his need to void. The immediate effect of this has been to slow down his productivity on the job. His supervisor has tried to be sympathetic, but both men realize that Steve is getting further and further behind. Staying later to catch up is not a viable option; the paratransit that takes him home stops running at 7 p.m.

Steve made an appointment with his primary care physician to discuss these issues. Unfortunately, on the day of his appointment, Beth, the office nurse with whom Steve has by far the most contact, was absent, and it was clear that Dr. Haywood was in a hurry. Dr. Haywood elected to go for two quick

solutions: 1) for the spasticity, a doubling of his prescribed dose of Baclofen; and 2) for the possible bladder problem, referral to the urologist in the building, Dr. Adams. Had Beth been there, she would have suggested that Steve be seen by Dr. Miller, another urologist in the area. Beth knows that Dr. Miller has a son with Muscular Dystrophy, and would likely be better prepared to examine someone with a disability.

A week later, Dr. Adams performed the necessary tests with great difficulty. His diagnosis was a spastic bladder. ("At least my bladder is consistent with the rest of my body," Steve thought to himself.) Dr. Adams prescribed Oxybutynin (the combination of Baclofen and Oxybutynin can sometimes have a dehydrating effect, but that is beyond the scope of this case study). He was visibly shocked when Steve asks if this medication has any effect on sexual functioning. Dr. Adams gets this type of question every day, but he had not expected this from a person with a severe disability.

Back on the job, Steve was much less spastic, but his energy level was way down. With the increase in Baclofen, he had traded one problem for another.

Conclusion

Aging with a lifelong disability, in general, and aging with Cerebral Palsy in particular, is a new area for most medical and human service professionals. With the growth of this population, however, the challenges raised cannot be ignored. As with all populations, professionals serve best when they employ an holistic approach.

Study Questions

1. What health-related problems might a person with Cerebral Palsy face as he or she ages?
2. How might we encourage physicians to learn more about the care needed by persons with severe disabilities?
3. What are some common misconceptions about Cerebral Palsy and about persons who age with CP?

References

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The Professional/Consumer Advocacy Council

The statewide Professional/ Consumer Advocacy Council (PCAC) works to improve the quality of life of Virginians with lifelong, developmental disabilities. Formed in 1994 as an element of the federally-funded Partners III Project on aging with developmental disabilities, the PCAC advocates for policy changes, systems improvements, and increased public awareness so that individuals with lifelong disabilities can grow older meaningfully.

The PCAC's membership includes persons with developmental disabilities, family caregivers, community-based service providers, researchers, educators, and others. The PCAC helped conceptualize the Virginia Caregivers Grant Fund and has co-sponsored educational seminars, a day-long exhibition of assistive technology, and a conference on aging with Cerebral Palsy.

For further information please contact the Virginia Center on Aging at (804) 828-1525.