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Sociocultural Factors Shaping Technology Usage:

Fulfilling the Promise

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The widespread underuse and abandonment of adaptive devices is a critical issue for medicine, research, and technology development, as well as consumers and their families. It poses basic financial and ethical dilemmas. For example, competing mandates must be balanced in quality assurance between dispensing devices based on individual need, and accountability for the public costs if a device is likely to be used only a short time. The significance of these issues grows as new federal legislations direct the delivery of adaptive device technologies and as more people with disabilities from disease and injury survive to later life due to improved medical care.

Our century's bright promise of medical-technology solutions to physical impairments is not yet fulfilled because our knowledge of how to implement them in individual cases remains at a more primitive stage. How can we wed the scientific advances with insights into people's utilization of these advances?

This article focuses on the concerns voiced by users. It identifies the cultural and individual factors that contribute to the nonuse of adaptive devices, with an emphasis on later life. Culture refers to shared beliefs, values, sentiment, and expectations; these are internalized during socialization and instill powerful motivations and dispositions that shape how people interpret the meaning of events and objects in their lives. The article first provides an overview of the topic, describes cultural and personal dimensions shaping perceptions of devices, illustrates these with cases from a study of aging polio survivors, and, lastly, offers some practical directions.

BACKGROUND AND SIGNIFICANCE

As a backdrop to the cases illustrating cultural dimensions of noncompliance, the significant need for adaptive devices as related to the rising numbers, changing traits, and age profile of people with disabilities, and rates of compliance is outlined below.

Disability

A universal phenomena with no respect for gender, income, politics, or nationality, preceded the dawn of civilization. Archaeologists document chronic disease impairments (e.g., arthritis) and long-term survival with congenital and accident-related deformities including loss of limbs and sight¹. Today, permanent impairments arise from birth defects, injury, disease, and environmental factors. Temporary impairments occur at all ages due to injury, transient illnesses, pregnancy, climate, or accidents.² The WHO (World Health Organization) estimates that over 10% of the world's population is physically disabled.³ The number of persons with lifelong or newly acquired impairments is rising sharply due to

medical advances and demographic factors. In the United States estimates range upward from 43 million.⁴ There are 5.3 million newly disabled elderly who live in the community.⁵

Life Span

The life span for mobility impaired people (e.g., from spinal cord injury, cerebral palsy, and polio) who number over 2.5 million is now on par with the general population.⁶ The rising numbers of older disabled persons means more people are at risk for multiple chronic impairments. Today's costs of \$42 billion⁷ for their care may triple by the year 2018.⁸ The National Institute on Aging notes that while medicine and technology now enable people to live longer with multiple impairments, service delivery and quality of life issues remain unanswered.^{9,10}

Late Life

Geriatric rehabilitation is no longer an oxymoron;¹¹ positive outcomes from exercise and training are achievable.^{12,13} We are now in the fourth decade of the scientific management of impairments. People aging with disabilities prompted specialists to shift from earlier static models of primary disability to dynamic models of secondary disabilities and chronic conditions.^{14–16} Prior decades focused on survival and post-trauma rehabilitation. Today's frontiers include quality of life after initial rehabilitation, maximizing self-direction and autonomy, and improving professional curricula. The need is clear: How are we doing?

Compliance

Low rates of compliance to adaptive device prescriptions are part of the well-noted general problem of noncompliance to medical recommendations regarding, for example, treatments for obesity, hypertension, substance abuse, or high-risk health behaviors. Even when benefits to the user are unambiguous (e.g., prostheses, portable ventilators) surveys show the high rates of discarding adaptive equipment soon after it is medically prescribed,^{17,18} nonuse,¹⁵ or underutilization.^{19–21} Estimates among the elderly range from 50% to 60%.^{18,17,22} Specialized training programs report higher rates of usage, roughly 78%.¹⁸ These surveys indicate that a better understanding of the perceptions of individual users should be a priority.^{23–25}

Among some populations, such as polio survivors, compliance is doubly vexing, including over-functioning and underfunctioning. Clinicians report difficulty getting survivors to rely more on adaptive equipment (e.g., substituting a wheel-chair for braces and crutches) or moderating activity to preserve diminishing capacities. Peach and Olejnik report stabilized or improved functioning among compliers but declines among noncompliers.²⁶

Noncompliance has broad consequences. The consequences of nonuse of needed devices include "excess disability" to individuals,¹² excess personal and societal financial costs, and inefficient use of finite health care staff and resources. A great need exists for improved knowledge about the interface between objective and subjective assessments of need or acceptability. Despite the advances in science, technology, and manufacturing, the full benefits of these advances are thwarted by inadequate understandings of the factors shaping the use of these devices.¹⁷

CULTURAL AND INDIVIDUAL CONTEXTS OF TECHNOLOGY ABANDONMENT

Consumers voice discontent about the devices and the cultural meaning of being a device user. Many focus on the basic operation and aesthetics of the devices. For example, they complain about inadequate design, functioning, lack of visual or tactile appeal, instructions about how to use devices, discomfort, difficulty in integrating into personally meaningful daily routines, and the need to make personal alterations to fit individual variations.^{23,27,22} Clearly, the familiar complaints about poor design can be resolved through feedback to manufacturers and practitioners. Equally important are complaints about the *cultural and social implications to the person consequent from using a device*.

Cultural and psychosocial contexts of device use remain understudied compared to device design and dispensing. The importance of this aspect is underscored by qualitative research on the impact of life-style and culture on the rehabilitation process and the use of equipment.^{28–31,25} These studies show a dynamic interaction between several aspects of the consumers life. These factors include, differences in device acceptability due to users' age-related normative psychological and physical capacities, life cycle stage, and family life stage.^{30,24} Further, disability itself is suggested to produce negative emotional effects that influence motivation.³² Clinicians and manufacturers need better control for these diversities among consumers. An example of psychological differences are the coping strategies of elderly compared to younger adults. Gerontologists suggest elderly people tend to cope with adversity or stress more by *secondary coping strategies* (accommodating themselves to the conditions or mentally reinterpreting the stressor as being less problematic), than by *primary coping strategies* (e.g., attacking the cause of distress).³³

The *social and personal stigma* (denigrating labels and treatment) ascribed to people who are visibly different or deviate from norms for behavior and appearance^{30,34} is a major factor in decisions to use devices. The desire to avoid social stigma and to preserve one's self-esteem and prestige as a whole capable person by maintaining independent functioning is a powerful motivation. That is, in the equation of why a device is not used, the consumer's own sense of the *social consequences* of using a device in the wider community and in daily life may be the denominator, while the need for adaptive tools as evaluated in the clinic may be the numerator.

For example, the development of portable ventilators offered ventilator-dependent home-bound polio survivors enormous liberties in freedom to travel outside the home. Tellingly, survivors often chose not to adopt the new technology that allowed independent mobility because they wanted to avoid becoming more visibly impaired, despite the big gains in social life outside the home.¹⁵ Instead they chose to alter their lifestyle and dramatically compromise opportunities for social interactions. Clearly, concerns with social marginality and transitions pervade users' interpretations. Such "motivational" factors are not inherent traits of the assistive device or the physical impairment, but derive from the social contexts of their usage.³⁵ Even medication taking by disabled elderly may be governed by the degree to which the patient feels more stigmatized or dependent by following the prescribed regimen.³⁴

Conflicting cultural goals and expectations arise since people participate in multiple groups or institutional settings, each with its own shared culture and expectations. These may add conflicting social messages which increase reluctance to use adaptive equipment. For example, the goals and perceptions of the consumer diverge from those of the health professional, or again, able-bodied people in the wider community pass judgments based on physical perfection and independent functioning in contrast to patients and their therapist whose goals are to achieve incremental rehabilitation goals.¹³ Becker & Kaufman report that the meanings of successes experienced by the consumer and their family and the therapists are not shared by the community.²⁹ For example, after stroke, regaining mobility with adaptive devices is a major step, but in the eyes of people on the street the client is still defined by their impairments, not rehabilitation success.

Less attention is given to how devices succeed or fail to enhance a consumer's quality of life and personal values and goals;^{19,36} the view is to generalized global and normative ideals of enabling "independence" and autonomy. A further grievance commonly voiced by consumers is that manufacturers do not give adequate attention to hygienic or aesthetic aspects of devices which essentially become a part of the person who uses them. Consumers interpret that lack of concern as a social message that people with disabilities are not worth much attention or are undeserving and incapable of "beauty."

Ethnic factors may significantly alter responses to visible deformities and technology use and thus are relevant to professionals and manufacturers. For example, ethnic differences are recognized to shape the nature and course of responses to pain and bereavement. Some ethnic groups place a high value on stoic acceptance, others traditionally complain eloquently.^{37,38} Also, ethnic groups hold varying expectations for how an expert clinician should act. Outcome studies show, for example, better results with German-American families when clinicians assume authoritarian impersonal practice styles, while Latin-Americans require an informal and personal approach.³⁹ Thus, we need better knowledge of the familial and ethnic heritages that make consumers underreport or over-report pain and problems, or demonstrate better outcomes with an authoritarian or a nonauthoritarian clinical practice style.

In one situation regarding mobility impairments, the failure of health care teams working among the Navajo to enlist people into a screening and treatment program for a prevalent congenital hip deformity is instructive. Due to the Navajo's social acceptance of the condition, despite the pain, limited mobility, and daily functioning experienced by many with congenital hip deformities, they do not define it as a disability or stigmata and so would not seek treatment.⁴⁰ Ethnic and cultural definitions influence how people experience and treat health conditions.

Overall, the cultural patterning of consumers' concerns, and their own beliefs about treatment efficacy and outcome must enter into the equation in addition to objective knowledge about impairments and therapy. Patient's explanatory models typically differ from the clinicians'. The criteria central to medical and technological classifications of disease and diagnoses are not found to be the features people themselves use to categorize diseases or plan behaviors.⁴¹

Cultural life course and personal biography shape device abandonment at a more individual level than the cultural- and social-system levels. Each consumer's unique lifetime or personal biography within the normative life course gives them a perspective and set of themes that shapes the focus of attention, health appraisals, and experience.^{24,25} The life course refers to the culturally defined normative script of expected stages and transitions of the socially defined person. Each stage in the normative life course from childhood, to work and marriage, and retirement, is accompanied by a set of psychosocial developmental tasks (e.g., socialization, individuation, maturation). The cultural life course provides a shared timetable for evaluating how "on-time"⁴² life events are from birth to death.⁴³ For example, some polio survivors with the new late-effect symptoms describe their condition as "aging early" because the state of their body does not match the culturally defined life course stage. Consumers interpret the recommendation to utilize devices in the context of their life course stage, developmental tasks, as well as the wider sociocultural meaning of its use. They ask if the functional gains are offset by the losses of being more visibly different, less "independent," the appropriateness of it to their life course stage, and the impact on their self-image and personal biography.

To summarize, the key point of this article paper is that users appraise and experience adaptive equipment as being situated within objective and subjective social, cultural, and lifetime contexts. It would be short-sighted to treat the question of device acceptance as if it is independent from the social consequences and individual concerns for the user; adaptive equipment does not exist in a vacuum.

Two Case Illustrations

Two cases will illustrate the sociocultural and individual factors identified above. These are drawn from in-depth anthropological case studies of the interpretation and management of disabilities by aging polio survivors.

Example One: Sociocultural Meanings and Consequences

Ms. Klein uses a wheelchair to get around the high-rise apartment building for seniors, part of a multilevel of care geriatric center. This feisty 72-year-old relies on a wheelchair, but gets around on leg braces and crutches in her apartment. She has used mobility aids all her adult years. Other residents give her a lot of flak for being there with a wheelchair; they expect that wheelchair users ought to be in the nursing home building. The sight of the chair distresses them. Further, she is unique in not being frail or feeble (physically or cognitively) and in not having an attendant help her dress, eat, and manage daily activities; residents confined to chairs generally cannot fend for themselves. The facility's rules make her continued residence in the apartment towers conditional on her ability to walk on crutches in and out of the dining hall for daily meals without the chair. Thus, the stability of her condition and her lifelong reliance on the device are demeaned, overshadowed by both the institutional regulations and the social attitudes in her community.

Clearly, using a wheelchair in this environment implies a very different constellation of meanings. Ms. Klein must constantly assert the uniqueness of her present use of devices from the perspective of her whole lifetime. She must demonstrate to others she is

exceptionally more self-directing and independent than any other wheelchair user on the geriatric center campus.

Apart from these problems device-use creates in her social environment, they also exact a toll on her continued psychological development. She feels strongly about the results of needing several devices and the time they demand.

If I wouldn't be crippled, I know I wanted if I'd come to this age, I would do volunteer work. I would go and help people that are less able than I. And, you know, that bothers me quite a bit because I can't. I feel I'm *useless* right now. Yeah. That's a feeling you get that you're useless because every bit of strength that you have you save for yourself, and you save for yourself to be taking care of yourself longer everyday as the day goes. You know what I mean?

The mounting time and effort demanded just for basic self-care in the face of her failing energy produces the unsavory feelings of being narcissistic, "save for yourself" and "useless." Her negative self-image is reflective of American cultural ideals of independence and autonomy, and the late-life developmental stage of "generativity" (altruistically helping others and nurturing the next generation, avoiding stagnation). Adaptive devices, in the narrow physical view, have enabled this woman to remain independent, but in the wider lived context of her own self-evaluation they require too much time focused on herself, limiting her time and energy for other people and activities. From a developmental perspective she experiences a dilemma. While the devices help her to be independent and autonomous, core cultural values, they simultaneously drain her ability to achieve the later-life developmental stage tasks of generativity, avoiding stagnation and narcissism or excessive self-involvement. Younger adults would be equally concerned with their attractiveness for dating, or ability to keep a job. The impact of these kinds of social and developmental life concerns must be taken into account when working with patients in need of adaptive devices. Another example of the multiple, sometimes conflicting, nature of cultural values is highlighted by Mrs. Carver.

Example Two: Life Course and Biographic Perspectives

Mrs. Carver, in her early fifties, is an insightful direct woman in her second marriage. She told me that a local reporter interviewing her about her polio late effects told her "that's no big deal" upon learning that Mrs. Carver now needed to use a power chair. The reporter asked if Mrs. Carver could refer her to someone else who was, "really bad off."

Mrs. Carver had severe bulbar and spinal polio as a child. The prognosis was, in her words, "lifetime confinement to a wheelchair." The device defined her future permanent state of immobility. In fact, she was discharged in a wheelchair with no push rims, being thought too weak to ever use them.

A theme in her life story narrative was how, by heroic perseverance, she and her family transformed the adaptive devices, objectively embodying the medical prognosis of extreme disability, into transitional objects which were subsequently discarded along with her medically defined destiny and identity. She asserted an individual destiny and achieved able-bodiedness instead of an identity as disabled. At maximal recovery she walked with lower-

leg braces and a cane. The continuing **nonuse** of these was significant to her sense of personal identity and the “normalized” vigorous life-style she led of active employment career and marriages. During the decades of her stable phase she would tell strangers she had broken her leg skiing.

As the stable phase slowly converted into chronic polio, she ignored the changes that included pain, fatigue, and muscle-soreness and spasms. When she did seek medical advice she was told the soreness was a “charley horse,” the fatigue due to a cold or depression. The symptoms were not at that time medically recognized as a syndrome. Finally, she had a catastrophic failure, she collapsed after being unable to climb the one flight of stairs to a friend’s house. Lying there, she cried for over an hour, “hysterical and terrified,” in her words. In retrospect that was the turning point. She rested, recovered; some months later her diverse symptoms were defined as polio late effects.

Forced to readopt a wheelchair, and all the mobility restrictions it entailed, she found many of her core personal meanings and self-definitions challenged, especially her earlier life achievements and refutations of medically defined destiny. It is important to note that the devices represented a broader sense of loss, not just of physical function, but of a spectrum of cherished patterns of activity, sentiments, and ways of life. Thus, the prescription for use of a new device carries life span personal connotations in addition to the sociocultural labels and meanings. Prospects for future hope and change are now more limited.

Adopting a power chair also reintroduced the prior “destiny” as defined by the medical establishment during the earlier acute phase. Her ability to control her body and social definitions of herself are eroded. The reporter’s remark revoked the social “invisibility” gained through rehabilitation.²⁹ This example also suggests the social contexts continue to minimize the personal experience of loss, not fully validating the extent of the loss experienced, just as her earlier gains were minimized when the community tended to view her disability rather than recovery.

SUMMARY AND IMPLICATIONS

The significance of the underuse and abandonment of adaptive equipment is growing as medicine can now help more people survive severe accidents and disease and as the numbers of elderly grow. It also poses serious policy, financial, and ethical issues beyond this article’s scope. How can providers best balance the competing obligations to provide high quality comprehensive rehabilitation care and equipment, and at the same time attend to the increasingly cost-conscious climate? To what extent can we justify continuing to pay for devices and reimburse health professionals the time to prescribe, train, and monitor patients if better outcomes cannot be achieved?

This article contributed descriptions of some of the factors shaping how users appraise and experience adaptive equipment. The factors it identified include: sociocultural, life course, and personal meanings, and goal conflicts between users, professionals, and the community. These factors clearly show device utilization is a multilayered phenomena extending beyond the mechanics and fit of the devices. A “one size fits all” approach is not effective; clinicians need to tailor their prescription and training practices to the personal, social, family or ethnic

values, interests, and life stage of each individual client. These observations suggest several practical implications.

Clearly, first, device manufacturers can aid in reducing underuse by continuing to improve the comfort, ease of use, and attractiveness of devices. Publication of consumers' ratings of preference may provide an incentive to the industry to make further improvements. Second, greater emphases must be given by researchers and clinicians to processes and outcomes; current practice focuses more on assessing need and dispensing devices. Third, more empirical knowledge is needed about the consumers' perspective, their focal concerns about the devices, and wider concerns about the social consequences of being seen as a device user.

Fourth, curricula and training programs are needed to equip health care providers and device engineers with techniques that enhance their ability to discover and fulfill the consumer's wants and worries, including the cultural and personal values. More effective outcomes should be achieved when providers are trained to respond to a wider range of expressed concerns. For example, after asking if the devices function properly, are comfortable and pleasing to the user, practitioners should address psychosocial issues related to how consumers feel about using the device. That can be done in two ways, by listening and questioning. Providers can be sensitized to listen for themes (repeated statements or topics) about the personal meaning and social consequences of becoming a device user. Listen also for expectations or hopes, often stated as "I wish I could..." Next, ask simple questions such as, "What does it mean to you to need this?" or "Do you think about how you will look now to other people?" can help reveal these topics and guide dialogues.

Users, prospective and current, may need help to explore and modify what device use means to them. Useful results of the talk may be to bring to light unstated worries or conflicts that can be resolved or referred for supportive therapy. Or, the talk may just suggest the need for a simple waiting period while the client does the natural work of sorting out thoughts and emotions.

Fifth, expectations and goals must be clarified. By design, standard procedures for device training should include routine discussions for mediate potential goal and value conflicts in the rehabilitation setting and afterward in the community. In that way value conflicts can be anticipated and addressed as they arise. Meetings should include practitioners, clients, and family. This reinforces the need for a multidisciplinary team approach that allows training and monitoring over time. Ideally, a home visit some time after the device was put into use would offer an informal atmosphere for talking and a chance to observe the devices in actual use after users have really confronted the problems of integrating the devices into their life-style.

To conclude, in order to fulfill the promises of biomedical and technological advances in our century and to improve the quality, not just length of life, requires greater dedication to the processes of implementation of adaptive technology as part of whole persons' lives and greater attention to outcomes. These tasks will require closer collaboration among a range of disciplines and practitioners working in closer concert with consumers and their families.

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Biography

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