Brain Injury as a Chronic Condition: IMPLICATIONS FOR EDUCATION

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Where We Are, Where We Should Be

Education is a dynamic process involving the coordination of students, teachers, information, and timely dissemination. Additional effort is required when attempting to alter prevailing opinions and conventional wisdom, such as changing commonly regarded perceptions of brain injury (BI) as an event to the concept of a chronic condition. This effort is further complicated since basic concepts regarding BI are still incompletely understood within professional fields and by the general public; i.e., many misconceptions prevail. This includes primary issues such as the definition, etiology, treatment/service options, and likely courses of BI. As a result, a multifocal effort is required that identifies those likely to want and benefit from the information, key dissemination groups, available materials, gaps requiring new information, opportunities to influence established training and dissemination venues, and key themes across constituencies.

Special consideration is required in presenting the concept of BI as a chronic condition to help people understand that chronic brain injury (CBI) includes medical challenges as well as social, psychological, vocational, educational, community, cultural, life span, legal and judicial issues. Accordingly, the means to manage life with BI involves multiple systems and perspectives similar to many other chronic disease processes. Thus, stakeholders need information to help balance the negative implications of having such a condition with proactive coping strategies that promote capacity and life quality.

Getting From Here to There

BI involves a multitude of stakeholders. Individuals with BI are one obvious group, but so are family members, friends and others who have historically been involved in that person’s life; people providing services; funders, legislative and advocacy groups who promulgate policy; researchers, teachers, and trainers; product and curricular developers; media groups who disseminate information and the general public. Educating these different groups requires coordinated yet divergent efforts according to the roles, resources, and accessibility of different participants/stakeholders. Seemingly obvious approaches to education may not always be effective or practical.

For example, students would appear to offer a captive audience. Yet they are often overwhelmed with the sheer amount of material they are already expected to master. Consequently it is difficult to add additional material to densely packed curricula. Practicing professionals are synonymous with overextended time commitments, making continuing education difficult enough—let alone transformational training, such as, the reconceptualization of BI as a chronic condition. Other groups offer their own unique challenges, constraints, and opportunities for outreach. For purposes of education strategy, it may be possible to classify diverse participants and stakeholders into the following five categories, each of whom may require their own unique approach.

Pre-service: People involved in their initial training within a given field or position. Revising curricula and training programs can take years and additional material on BI is not always a priority in many medical, educational or allied health training programs. One possible means to influence such training is to become involved in the InterProfessional Educational Collaborative (IPEC) movement. IPEC has been developing nationally as a means for training students in multiple professions to be educated both didactically and clinically as teams. Most experts believe that in order to deliver high-quality, safe, and efficient care, and meet the public’s increasingly complex health care needs, the educational experience must shift from one in which health profession students are educated within “disciplinary specific silos” to one that fosters collaboration, communication, and a transdisciplinary team approach to providing care. Team-based care, which frequently includes patients and their caregivers, is likely to be the “new normal” for care and hence, education should include how best to function as a team member.

In 2010, the IPEC developed core competencies to advance substantive interprofessional learning experiences and help prepare future clinicians for team-based care. With this approach, health-related colleges and university programs create teams, document
cases, and develop various methods to train students. Opportunities exist within this infrastructure to develop training cases based on BI. This method of infusing information to students is the educational wave of the future and holds promise for developing a cadre of students and professionals who understand the complexity of BI from a team perspective.

In medical and other health-related discipline schools, instruction in cultural competency that includes responsiveness and sensitivity to the needs of persons with disabilities is included in the curriculum. Without having to significantly revise the curricular content or method of delivery, existing curricula can emphasize topics in disability management for persons with BI. Similar opportunities exist in schools of regular and special education.

In-service: Training of practicing professionals/people in the field. Established practitioners have to be reached in several different formats. Most disciplines have statutory expectations for continuing education (CE) and a wide range of training venues are already available to deliver these services. Existing CE providers, especially those providing on-site seminars, webinars, conferences and other didactics training experiences, are generally receptive to new and timely information.

The information disseminated must be validated both professionally and scientifically. A concerted effort towards publishing high quality research, reviews and position papers in both peer-reviewed and professionally circulated journals, as well as in books, can aid this process as publication timelines can be lengthy.

Acknowledging the limited time available for healthcare professionals, venues for knowledge dissemination need to provide accessible information frequently to reinforce and articulate this information. Short pieces in periodicals, mailers, and on-line services can aid this effort. Providing relevant information to professional organizations and professionally-oriented peer support networks via list-serves and other available venues can also aid this process of information dissemination and translation into practice.

Changing practice requires that we go beyond solely disseminating information. Practitioners will practice the way they were trained until convinced otherwise and then the change is incorporated into daily care. The information must be translated to be ready for implementation in order to be carried into practice. For example, the development of guidelines, protocols, electronic applications, and educational handouts for patients may help the practitioner make shifts in thinking and practice.

We need to go beyond the education of those who are already thinking about and treating people with BI. In order to care for BI as a chronic condition we will need to educate more rehabilitation providers and reach out to primary care providers and midlevel providers and to case managers.

General public/society. There are broad arrays of venues for the general public to access information about BI. The internet is one frequently accessed domain that is populated by advocacy organizations, service providers, professional organizations, military and veterans’ organizations, government supported sites, academic organizations, first-hand accounts, chat rooms, list servers, news links, as well as attorney and other marketing sites. Other media outlets, such as, television, radio, newspapers, magazines, and books, are also readily available. The overall accuracy and quality of this information appears to be improving. However, it still may be important to help users interpret the quality, timeliness and accessibility of available information, especially if they are new to the field, or seeking information on complex or debatable topics.

Consumers: People with brain injury and people in their support circles. In addition to information available to the general public, consumers may also receive information from providers and service organizations that is specific to their current and future needs. Providing practitioners with relevant materials that they can distribute to their clients/patients can help and provides the dual benefit of educating the consumer while concurrently teaching or reminding the provider. Accessibility of knowledge is critical as a variety of cognitive and perceptual problems may impair comprehension. Some information may be at an academic or professional level that is too difficult to understand. This is a frequent complaint of consumers and adaptation of such information is critical. Finally, consumers need tools to determine the authenticity and relevance of the information they secure, especially when it relates to treatment or service decisions. In some cases, problems can develop when accurate information is misunderstood. In other cases, inaccurate information can place recipients at risk.

Policy/Funding: People and groups involved in policy, funding or advocating for service provision and models. Groups in this category may include public, private, collaborative and hybrid organizations with a variety of agendas. Some may be involved in developing public policy ranging from local to national levels. Others may be advocating for commensurate funding or categorization of funding – such as, means tests for financial or service qualification. Funding sources such as insurance companies may seek criteria for exclusionary or inclusionary procedures; whereas, legal and advocacy groups may seek information for promoting access to care. Other groups may focus on research agendas, public education or other issues. Regardless of the specific focus, most groups in this category require two types of information: (1) succinct information to form and disseminate the key point of focus, and (2) more in-depth references and annotated material to substantiate the group’s focus and basis for identified needs and recommendations.

The National Injury and Violence Prevention and Control Center at the Centers for Disease Control has an explicit public health mission and now features traumatic BI as one of its three research domains. Its agenda includes identifying the services needs and barriers that restrict access for persons with BI, and identifying the programs that effectively reduce disability and prevent post-injury symptoms and long term effects. This agenda, commensurate with a chronic disease model of BI, exemplifies the kind of community, public health approach necessary to facilitate community reintegration and promote health and well-being following BI.

Summary and Next Steps
There is already a significant amount of information regarding BI. However, additional work is required to incorporate new information from scientific, clinical, philosophical and advocacy perspectives on the implications of BI as a chronic condition. Much like the rungs of a ladder, this may best be approached in four distinct steps though activities in each of these steps can occur concurrently as information becomes available.

1. optimize existing dissemination and knowledge translation materials;
2. adapt conceptually relevant information/material that may not be contextually correct to a CBI model;
3. fill in knowledge gaps where we know we have accurate information but need to create the material;
4. create systems to effectively capture/create new material as the CBI model evolves in response to societal changes.