Disability counts—or does it?

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The relative neglect of research into post-injury disability must be addressed

When it comes to post-injury disability, the disparity between acknowledged need for epidemiologic data and apparent investigative effort is remarkable.^{1–3} Defining the nature of a health problem is the first step in its ultimate management.⁴ A recent issue of *Epidemiologic Reviews* highlighted the importance of garnering the full spectrum of evidence that can help decision makers, the media, and the public appreciate the impact of injuries.⁵ Yet robust information about non-fatal consequences of injury—particularly disability—was acknowledged as an unmet challenge for epidemiologists. What may account for this?

The answer may lie in the fact that in contrast to well established approaches addressing aetiological questions relating to injury,⁶ the discourse on appropriate methods to investigate post-injury disability is complex and unresolved. A recently published textbook concludes the field is diverse, inconsistent, and lacks depth.⁷

The reasons for this situation are not hard to find. Twenty five years ago, an essay on the theory of knowledge noted “The more a science deals with humanity, the less highly resolved it is, and the less its truths are susceptible of cogent proof”.⁸ This is a particularly apt description of disability—a construct defined not only by the specific impairments or functional limitations that individuals may experience, but also by the difficulties created by the institutional practices and societal values of the communities in which they live.⁹ Many issues complicate the capture of these nuances using an epidemiological approach. As one editor notes: “Although a definition of disability that would yield a precise count (either you’re in or you’re out) would appease our desire for precision and quantification, we would in the process lose an important component of this public policy: the understanding that disability itself is not always precise and perfectly quantifiable ... Let us remember that the world of disability is dynamic: it can differ from one day to the next and varies according to the person and the situation.”¹⁰

Although seldom acknowledged, the perspective represented adds to the complexity. Individual self-perception, the responses of caregivers or health providers, and indicators of interest to insurers or program administrators, are all relevant outcomes depending on the object of enquiry. As reviewed by DeJong, however, “outcome measures arise, as do the values implicit in them, from a particular social, professional, and economic context”.¹¹ Therefore, significant qualitative and quantitative differences in the burden of disability viewed from differing perspectives are no surprise.^{11–16}

The interaction between disability and self-perceived quality of life is another source of contention. Some researchers suggest there is incontrovertible evidence of “a disability paradox” (representing the good or excellent quality of life reported by many people with serious and persistent disabilities).¹⁷ Others contend this is a reality of the lived experience, and suggest the notion of a paradox is an externally defined fallacy.^{18, 19} However, both factions agree on an issue central to this argument—that is, the nature of humans to accommodate and cope with change, a process described by Oliver Sacks as “the least discussed, the least understood, the most mysterious of phenomena”.²⁰

Arguably the most revealing debate surrounds the topic of disability adjusted life years (DALYs). Although this metric coined by the World Bank and the World Health Organisation^{3, 21} helped launch injury and violence prevention into the global public health and policy agenda as never before, the approach to disability weighting generated intense scrutiny and considerable disquiet.^{22–24} Some critics view the implication that the lives of disabled people have less value than those without disabilities as unethical and counter to the principles inherent in the Declaration of Human Rights and the goals of the Global Burden of Disease Project.²²

Notwithstanding all of the above, the relative neglect of research into post-injury disability is inexcusable. The scant epidemiologic evidence denies

the opportunity to inform and adequately resource interventions that can prevent disability and its antecedent causes (for example, road crashes). It also limits the political will to change the environments that perpetuate disablement. Imperfect methodologies have not prevented the field from addressing other issues that are similarly unresolved. For example, morbidity is a complex phenomenon involving the occurrence, severity, and duration of an infinite number and combinations of physical and mental conditions. Yet a global item to summarize the experience—self-rated health—is commonly included in population surveys. Its ability to predict outcomes such as death and institutionalisation is equivalent to or greater than that achieved by many multi-item measures.^{25–27}

Measuring disability with parsimony should be viewed as a goal, not a barrier.²⁸ Simple (not complex) measures can be incorporated in population surveys and used in focused research.²⁹ Ellen MacKenzie (who recently joined the editorial board of *Injury Prevention*) and others provide useful frameworks based on existing instruments.^{7, 9, 30–32} At the same time, the priorities articulated by the Institute of Medicine must be addressed.³¹ That is, strengthen the science by developing and validating tools that can measure and predict disability and other relevant outcomes; investigate critical physical, psychosocial, and environmental factors in the enabling-disabling process; and implement effective linkages between research and practice that will involve consumers, assure quality, and enhance service delivery.

There is much to learn about the differing perspectives of disability, whether these represent “objective” measures or subjective judgements. Even more needs to be learned about perspectives rarely represented, such as the voices of children, the underinsured, and other disadvantaged groups. Above all, simple, realistic, and context appropriate approaches to address the vast gap in data in low and middle income countries (which account for an estimated 90% of DALYs lost due to injury worldwide) are long overdue.³²

In conclusion, let us acknowledge the maxim “not everything that counts can be counted, and not everything that can be counted counts”. But let us not forget that disability counts, and not counting—using the best means available—denies the opportunity to steer organisational will and resources to manage a health and societal problem affecting millions each year. As injury researchers, we must rise to this challenge and

not let the excuses of conceptual disputes and imperfect tools deter us from investigating the nature and determinants of post-injury disability.

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