

Culturally-appropriate tools are needed to measure childhood outcomes in low- and middle-income countries: A call to action for consistency and collaboration

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The burden of neurodevelopmental, cognitive, behavioural and mental health disorders in children will continue to rise as more newborns and children survive (1). In recognition of this epidemiological transition, the international community is shifting the focus from child survival to child “thrival” with the aim of supporting children to fulfill their developmental potential and promote their well-being. This is encapsulated in the WHO Global Strategy 2016-2030 for mothers, children and adolescents of “survive, thrive and transform”. The new Sustainable Development Goals (SDGs) now include a focus on early child development (SDG 4) in order to address this goal (2). Over the past ten years, funding agencies have spent more on large scale studies to provide evidence on underlying aetiology and epidemiology of these disorders, as well as on interventional research to improve outcomes in these disorders. In doing so, researchers and clinicians in low and middle income countries (LAMIC) require reliable and valid tools to screen, identify and assess children in their local settings.

Most available tools for measuring these outcomes were developed and validated in rich resourced Western, industrialized societies and thus reflect the expectations for children of those cultures (3). Clinicians and researchers cannot assume that translating a Western measure into a local language also transfers its validity, since there are considerable cross-cultural differences in concepts, norms, beliefs and values for children’s behaviour (4, 5). At present there is no single, agreed-upon framework or formal guidance for cross-cultural adaptation and validation. Some tools that are used in LAMIC have been formally adapted on an ad hoc basis, while others have not (6). Normative data from US or UK settings is often used for the tools, but these may have culturally specific items which may or may not be relevant or may be poorly and literally translated (7). Some new tools have been created for LAMIC settings but they are very few in number (6). In order to have culturally robust tools, it is important to take the time and effort to develop appropriate tools. In order to do so, there is a need to invest in more trained personnel (psychologists and developmental paediatricians).

In addition to the problem of how to measure outcomes in LMIC settings, there is the problem of which outcomes to measure. The field is wide and multidisciplinary, and spans disciplines of epidemiology, infectious diseases, nutrition, economics, mental health and education. Many of those conducting studies may not necessarily have expertise in the science of measurement, which makes the choice of tools for these studies narrow and predictable. This makes it particularly difficult to come to a common understanding and framework of what should be being measured, let alone how. Many of the new tools concentrate on measuring child development, with fewer tools validated for use in assessing cognition, behaviour, mental health. This often leads to a “one size fits all” approach (8) which may facilitate some cross-country comparisons, but which may also fail to reflect important culture- and disease-specific outcomes. Organisations such as the World Bank and Gates Foundation have attempted to create repositories of tools (9). The tools in these repositories have however concentrated on the measurement of early child development and cognition rather than the wider agenda of the International Classification of Functioning and Disability (ICF). The latter emphasises functioning, participation and the wider family and community environments as vital aspects which need to be considered in most studies (10). A recent example of this is demonstrated in the follow-up of children affected by congenital Zika. Most researchers are using the Bayley III as their major outcome measure despite the fact that these children are often severely disabled. This may provide only limited information on the functioning of these children whereas more information may be gleaned by assessing adaptive functioning, parent-child interaction and parental well-being. Another example might be the focussing in on specific cognitive assessment of children affected with cerebral malaria without measuring the wider aspects of the impact of this disorder on the child and family (quality of life, participation and school attendance). Potentially, in areas with limited human resource capacity to perform such tests, a screening program with

appropriately developed screening tools may be implemented and those failing such tests evaluated in more detail by the few experts.

Further efforts to incorporate the wider ICF framework and to develop internationally agreed guidelines in the adaptation and validation of tools for different settings are needed. This requires funding capacity to enable better triangulation (with external validation) on the use and adaptation of tools in different settings and an understanding of the use of these outcome measures in multicentre cohort studies. If we can make this effort and have better tools which measure all areas of the ICF framework and which are pertinent to local settings and allow comparison across settings, we will be able to study more robustly the effect of interventions which may treat, support or prevent an increasing number of invisible children who are surviving but who are not thriving. With improvements in medical care, this includes the ever increasing number of children surviving from premature birth, asphyxia, neonatal sepsis, meningitis and emerging viral infections such as congenital Zika and encephalitis. As we move forward into the new millennium, this shift in focus necessitates an increase in capacity, to share expertise and collaborate across diverse global settings not just within the world of early child development, but more broadly within the framework of disability and the ICF. We suggest that the framework of measurement should be consistent to support meta-analysis across settings but that this should be balanced with making sure all tools are culturally appropriate and contextually relevant to ensure validity. Without expertise, funding and capacity building in allied areas (psychology, neurosciences, mental health, therapy based specialities, education and social sciences), the agenda, ideas and ways to progress will be limited. Finally, we need to continue to connect the disability agendas and views from families and stakeholders, to enable us to move forward in a meaningful way into the future.

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Commented [GM1]: Coxsackie?? Or other??

Commented [GM2]: I have now discussed this with the editorial team, and we think that the the call to action in the last paragraph could be made stronger.

Could you expand on the last paragraph, perhaps by highlighting specific priority areas: which areas/domains are particularly understudied or poorly studied because of a lack of measurement tools? Which conditions need the most urgent attention (eg, congenital Zika because of its recent emergence)? It would also be good to briefly discuss the balance between having something global and comparable across countries (a core outcome set) vs something specific to the local/cultural context.