



Brief Report

Towards Universal Eye Health: Hospital-based disability-disaggregated data collection in Takeo province, Cambodia



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ABSTRACT

Background: Universal access and equity are salient principles of the World Health Organization global action plan 'Towards Universal Eye Health'. However, collection of disability-disaggregated data to measure access to eye hospitals in low- and middle income countries, including referral to rehabilitative services, are not routinely integrated into Health Management Information Systems.

Objective: This report presents secondary-data analysis of disability-disaggregated data collection that was introduced at a tertiary eye hospital in a rural province in Cambodia.

Methods: A modified version of the Washington Group Short Set of Questions was used to count the number of eye patients with self-reported difficulties. The number of referrals of patients with unavoidable visual impairment to low vision services as well as referral to rehabilitative services was also counted.

Results: From 2011 to 2016, out of 182,327 patients overall 4981 (2.7%; 95% CI 2.66–2.81) reported difficulties with hearing, moving or communicating in addition to visual or other eye-related problems. Most of the difficulties were reported in the age group of patients aged 50 years and older (89.8% [95% CI 88.9–90.6]). All together 901 (0.5%; 95% CI 0.46–0.53) patients were treated at the low vision unit and 652 (0.36%; 95% CI 0.33–0.39) patients were referred to rehabilitation services. The number of referrals to rehabilitation declined annually from the year 2013–2016.

Conclusions: Patients with self-reported impairments constitute a significant proportion of the eye hospital's population. A modified version of the Washington Group Short Set of Questions enabled routine disability-disaggregated data collection but resulted also in possible under-reporting of difficulties.

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The seminal World Report on Disability highlighted that “people with disabilities encounter a range of barriers when they attempt to access health care services”.^{1,2} Disability-disaggregated data that informs health service providers about the access of people with disabilities to health services is still elusive, particularly in low and middle income countries (LMICs). People with disabilities were therefore suggested to be categorized as an “unrecognized health disparity population”.^{3,4}

Disability status is slowly gaining attention in programs focusing

on the reduction of avoidable visual impairment in LMICs^{5–12} but it is still not yet common to monitor inequity related to disability in regional or national eye health programs.¹³

Blindness and visual impairment are closely associated with age and it is conceivable that a significant proportion of eye patients present not only with disabling visual impairment, but also other age-related acquired disabilities.¹⁴ A recent cross-sectional survey from Telanga State, India, suggested for instance that a significant number of people with visual impairment had also either a moderate/severe hearing or physical impairment (25% respectively 15%).¹⁵ The identification of people with multiple impairments and measurement of their access to health services are imperative for the reduction of disability-related barriers.¹⁶ The WHO defined therefore universal access and equity as important cross-cutting principles of its global

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action plan 'Universal Eye Health' (2014–2019).¹⁷

In the lower-middle income country Cambodia, multiple barriers impair the access to health services for people with disabilities as well.¹⁸ Findings from a cross-sectional KAP (knowledge, attitudes, practices) eye health survey suggested that participants with a self-reported disability were more likely to be unable to travel to eye health services on their own, compared to participants without disability (81 versus 64%, $p < 0.001$).¹⁹ Also, referral pathways for patients with unavoidable visual impairment from medical eye health to low vision services and rehabilitation or educational institutions were suggested to be insufficient.²⁰

In Cambodia, the monitoring of programs focusing on improved accessibility of eye health services is impaired by a lack of disability-disaggregated data. The integration of "indicators for measuring disability responses"²¹ into Cambodia's monitoring and evaluation system is part of the 'National Disability Strategic Plan 2014–2018'. This is however challenging in the eye health sector because of its "lack of [a] standardized eye health monitoring system".²⁰

The Caritas Takeo Eye Hospital (CTEH) is one of the main teaching eye hospitals, located in the rural province Takeo in southern Cambodia.²² Takeo had a population of 923,000 in the year 2013 with 16.0% aged 50 years and older.²³ The life expectancy was estimated to be 68.5 years in 2015.^{24,25} The disability prevalence of 6.5% in Takeo province was estimated to be much higher compared to the national average of 2.06%. Almost 2% of women with disabilities in Takeo province reported multiple disabilities.²⁶

Since the year 2008 the hospital has implemented a multi-pronged approach to more comprehensive and inclusive eye health services. The physical accessibility of the hospital was improved and the collaboration with a local community-based rehabilitation (CBR) organization was intensified by organizing joint community-based outreach services and mutual referral of patients. A low vision unit within the CTEH was implemented and four experienced eye health nurses were trained in providing low vision services, long-term support and training for patients with permanent visual impairment. The unit and the referral links to community-based rehabilitation services and special schools for children with visual impairment were essential in improving the services for children and adults with disabilities at the CTEH.²⁷ Routine disability-disaggregated data collection was integrated in the CTEH's Health Management Information System (HMIS) as clinical audit in order to estimate the rate of patients with self-reported temporary or permanent impairment presenting at the hospital and who might benefit from provision of assistive devices and/or referral to further services.⁸

The purpose of this report is to discuss the results of the disability-disaggregated data collection as clinical audit at the CTEH from the year 2011 until 2016, including referrals to rehabilitative and low vision services.

Methods

In the year 2011 a modified version of the 'Washington Group Short Set (WGSS) of Questions on Disability'²⁸ was integrated into the HMIS and the routine paper-based patient files. The original questions were shortened in order to enable their application in a busy tertiary eye hospital with on average 150 to 200 patients daily. The questions and answers were translated into Khmer by administrative staff of the CTEH with excellent command of Khmer and English (Table 1). Additional translations were not provided because speakers of indigenous languages constitute only 2.3% of the overall Cambodian population.²³

Patients of all age groups presenting at the out-patient department (OPD) were asked to self-report difficulties with hearing, moving or communicating/understanding additional to their visual or other eye-related problems. Proxy respondents (for example, parents or caretaker) were asked to answer the questions in case of children or adults who were unable to reply, but this was not specifically marked in the HMIS. It was possible to report multiple difficulties. Questions about visual difficulties were part of the routine management of all patients and data regarding visual impairment are not included in this report. The WGSS questions four and five (difficulties with 'remembering' and 'washing all over') were deemed to be too sensitive to be routinely asked in a hospital within the socio-cultural context of rural Cambodia. The questions were asked verbally by administrative staff during the routine registration process and the answers were entered into the HMIS immediately. Eye health nurses and ophthalmologists could mark previously unreported difficulties in the patient files later if they became obvious during the medical examination. Instead of the WGSS ordinal response options (no/some/a lot of difficulties/cannot do at all) a binary option (yes/no) was introduced in order to reduce the amount of time needed for the responses. Additional assistance to facilitate communication with patients with specific difficulties was not available, for example with patients using sign language. There was no clinical verification of any reported additional impairment. A clause that would enable the separation of permanent or temporary difficulties was also not introduced.²⁹ Inception training on the use of the questions was conducted in 2011.

Additional to the WGSS questions the staff documented referral to a CBR organization for those patients with unavoidable visual as well as other impairments, who could potentially benefit from rehabilitative services. Referrals to further medical treatment were documented in the patient files but not counted and analyzed separately.

Administrative staff conducted simple monthly analysis of the data by extracting them from the HMIS and copying into an Excel file. The data were categorized into four age groups. The age group of people aged 50 years and older was truncated because of the

Table 1
Adjusted Washington Group Short Set questions and answers (English and Khmer version).

1	Do you have difficulty with hearing? Yes/No តើអ្នកមានការពិបាកក្នុងការស្តាប់ឬទេ? បាទ/ទេ
2	Do you have difficulty moving (walking or climbing steps)? Yes/No តើអ្នកពិបាកក្នុងការលាស់ទីឬទេ(ដើរ ឡើងកាំជណ្តើរ)? បាទ/ទេ
3	Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? Yes/No ដោយប្រើភាសាប្រពៃណីធម្មតា តើអ្នកមានការពិបាកក្នុងការទំនាក់ទំនងឬទេ? ឧទាហរណ៍ការយល់ដឹងឬត្រូវបានយល់ដឹង? បាទ/ទេ

Table 2

Number of patients with a single self-reported difficulty additional to visual problems from 2011 to 2016 (exact phrasing of screening questions see Table 1).

	2011		2012		2013		2014		2015		2016	
	(n/%)		(n/%)		(n/%)		(n/%)		(n/%)		(n/%)	
	M	F	M	F	M	F	M	F	M	F	M	F
OPD	12,328	16,651	12,839	17,046	12,351	16,664	12,765	17,087	13,295	19,341	13,096	18,864
Hearing	302/ 2.4	522/ 3.1	158/ 1.2	276/ 1.6	287/ 2.3	546/ 3.3	178/ 1.4	303/ 1.8	463/ 3.5	519/ 2.7	283/ 2.2	506/ 2.7
Moving	70/ 0.6	34/ 0.2	52/ 0.4	21/ 0.1	38/ 0.3	22/ 0.1	27/ 0.2	7/ 0.04	57/ 0.4	41/ 0.2	32/ 0.2	11/ 0.06
Communi- cation	21/ 0.2	27/ 0.2	47/ 0.4	59/ 0.3	5/ 0.04	2/ 0.01	10/ 0.08	6/ 0.04	11/ 0.08	24/ 0.1	6/ 0.05	8/ 0.04
Referral	68/ 0.6	71/ 0.4	96/ 0.7	99/ 0.6	74/ 0.6	74/ 0.4	48/ 0.4	44/ 0.3	25/ 0.2	31/ 0.2	11/ 0.08	11/ 0.06

OPD: Total number of old and new patients presenting at the out-patient department of the CTEH.

Referral: From CTEH to CBR (community-based rehabilitation services).

young population age structure at Takeo province. New and old patients were not separately analyzed because of the main objective to identify patients with difficulties who might benefit from further management (for instance, a patient reporting difficulties with hearing in one year and temporary difficulties with walking in another year would be counted twice). No additional staff for data collection or analysis was employed. The number of patients who were treated at the low vision unit was retrieved from a separate low vision unit data collection template which was not integrated into the hospital HMIS.

Statistical analysis was performed with Excel, confidence intervals (CI) were calculated with Stats Direct (version 3.1.17).

The research followed the tenets of the Declaration of Helsinki. Secondary clinical audit data that was used for analysis of this report was devoid of any identifying data and Institutional Board Review was waived by the CTEH.

Results

From 2011 to 2016, out of all 182,327 patients presenting at the OPD of the CTEH all together 4981 (2.7%; 95% CI 2.66–2.81) patients reported having difficulties with hearing, mobility or communicating/understanding, additional to their visual or other eye-related problems. The detailed annual sex distribution is shown in Table 2. All together 4343 patients (2.4%; 95% CI 2.3–2.5) reported hearing difficulties, and the rate of female compared to male patients was significantly larger (2.5%; 95% CI 2.4–2.6 versus 2.2%; 95% CI 2.1–2.3). The rate of those reporting difficulties with moving was significantly larger for male patients (0.4%; 95% CI 0.31–0.41 versus 0.13%; 95% CI 0.11–0.15). Overall, 89.8% (95% CI 88.9–90.6) of all difficulties were reported by patients aged 50 years or older. In this age group, the rate was 5.3% (95% CI 5.1–5.4). There were marked differences in the annual number of reported impairments (for instance, 106 patients reported communication difficulties in the year 2012 compared to only 7 patients in the year

2013). In the age group of children (0–14 years) 0.2% (95% CI 0.16–0.29) reported any additional difficulties. Overall, 64 patients reported multiple difficulties with hearing and moving.

The number of patients referred from CTEH to CBR services (overall 652 patients, 0.36%; 95% CI 0.33–0.39) was stable in the first years but plummeted from 2014 onwards (Table 2). From 2011 to 2016, overall 901 (0.5%; 95% CI 0.46–0.53) patients were treated at the low vision unit. The number of treated adult low vision patients decreased annually from 95 in the year 2012 to 19 in the year 2016. This was compensated for by an annually increasing number of children treated at the low vision unit (from 30 children in the year 2011 to 198 in the year 2016). The slightly higher rate of male children with low vision unit was statistically not significant (52.8%; 95% CI 48.5–57.1).

Discussion

A modified and shortened version of the WGSS of questions was integrated into the HMIS of CARITAS Takeo Eye Hospital in order to capture individual-level, disability-disaggregated patient data. This yielded important information about self-reported difficulties additional to eye related problems. From 2011 to 2016, out of 182,327 patients overall 4981 patients reported difficulties with hearing, moving or communication. Significantly more female patients reported difficulties with hearing and more male patients reported difficulties with moving. These findings can be triangulated with the Cambodian inter-censal population survey 2013: In rural Cambodia, more women than men had a hearing disability (11.4 versus 6.5%) whereas more men had a physical disability that restricted moving (43.8 versus 25%).²⁶ It is conceivable that these patients have special needs and face barriers to a comprehensive management of their ophthalmological diseases. Even in high-income countries there is evidence that the needs of the large group of people who are hard of hearing and visually impaired are neglected: "... questions about vision are not often asked in hearing

clinics, and vice versa”.³⁰ The fact that these questions are not asked suggests that medical practitioners might not be aware how many patients with multiple impairments present at eye hospitals and what their specific needs are. Also, there might be augmented barriers to eye health services at the community level for people with additional impairments which emphasizes the importance of counting the number of patients with impairments accessing the hospital.¹⁹

Modification of the WGSS questions

Disability-disaggregated data collection in health systems with very limited financial and human resources is challenging,³¹ especially in countries where “disability as a concept and an identity is not an explicit cultural concept”.³² The audit of disability indicators at the CTEH was introduced with very limited additional resources and with the purpose of developing a “good-enough approach collecting minimal information”.³³ Although any modification of the WGSS questions – especially with an imposed dichotomy – is not recommended,³² it was deemed necessary in order to render additional and potentially time-consuming continuous hospital-based data collection feasible. For instance, the introduction of the unmodified WGSS questions in eye health projects in India was reported to be time-consuming depending on the age of the participants (approximately 5–7 min per patient and up to 15 min for older patients when questions had to be repeated).³⁴ The exclusion of those WGSS questions which were perceived as being too sensitive to be asked routinely in the setting of a rural Cambodian hospital (difficulties with “washing all over” or “remembering”) as well as the binary answer options were therefore important steps to introduce disability-disaggregated data collection at the CTEH. The main purpose of the modification was the aim of developing a sustainable way of data collection which was feasible within the available resources and independent from longer-term external financial and technical support. Qualitative research is needed to explore further aspects such as perception of medical staff towards additional disaggregated data collection. For instance, how did the ophthalmologists at the CTEH perceive the routine audit of disability related data compared to cataract surgical outcome monitoring which might appear as being more relevant to their clinical work?³⁵

The overall results indicate that patients might underreport impairments, for instance because of the binary answer options which could have resulted in the exclusion of patients with only mild difficulties.³⁶ It is also possible that hospital staff did not ask the questions consistently – especially at the busy out-patient registration – which might explain some of the conspicuous differences in the annual rate of reported difficulties as well as the very low number of patients with two or more additional difficulties.

The reasons why only 0.2% (95% CI 0.16–0.29) of all children was reported with additional difficulties need further exploration. Annually, approximately 3900 children aged from 0 to 14 years were examined at the CTEH (personal communication) and it is counterintuitive that there were only very few children with impairments who needed further rehabilitative management.

Disability-disaggregated data and improved patient outcomes

The significant number of patients with additional difficulties presenting at the hospital requires more efforts to mitigate specific barriers. In the past the CTEH strived to remove especially physical barriers (for instance, construction of a ramp, purchasing of wheelchairs, installation of signage with high-contrast letters etc.), whereas the needs of patients with hearing or other impairments

were lesser addressed.³⁷ Particularly, the high number of patients reporting difficulties with hearing asks for efforts to address possible communication barriers, for instance by training of health staff in communicating with patients who are hard of hearing or by exploring options to offer dedicated services together with a sign language translator.^{38,39}

The high number of patients treated at the Low Vision unit is encouraging and enablers for the successful implementation should be explored further.

The declining number of referrals to CBR services at the CTEH from the year 2014 onwards is concerning and warrants exploration of causes. For instance, high workload or negative feedback loops from referred patients might discourage medical staff to continue to refer patients to CBR services.^{20,40}

Cambodia is a state party to the United Nations Convention on the Rights of Persons with Disabilities and has a clear vision to develop an improved data system that considers also disability.²¹ Disability-disaggregated data collection at health institutions in Cambodia could play a pertinent role in the implementation of the National Disability Strategic Plan.

Conflicts of interest

The authors do not have any conflict of interest to declare.

Disclosures

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