Disability-disaggregated data collection: Application of Washington Group Questions in an eye hospital in Paraguay

Manfred Mörchen MD, FEBO, MPH
CBM

Olmedo Zambrano
CBM

Alexander Paéz, Fundación Vision, Paraguay

Paola Salgado, Fundación Vision, Paraguay

David Lewis, CBM
Eye health services and disabilities...

“I do not know if I can do cataract surgery on this patient, he is wheelchair bound…”
Cataract surgeon, urban public hospital low-and middle income country Asia

“...questions about vision are not often asked in hearing clinics, and vice versa”

“Clinicians also need to be alert to depression and hearing loss which will be more common in their patients with visual impairment compared to those without…”
Differential physical and attitudinal barriers exist for patients with disabilities accessing eye health services. It is therefore important to be informed about the number of patients with eye health problems and disabilities. However, counting patients with disabilities is challenging due to, for example, culturally different definitions of disability, underdeveloped hospital-based Health Information Systems and neglect of patient-centered approaches.

We now report key results of a pilot project at the Fundación Visión eye hospital, Paraguay, which aimed to test the Washington Group (WG) questions in the daily routine of a busy satellite eye hospital in a rural area of Paraguay.
Methodology

• Two WG questionnaires were selected as data collecting tools:
  1) The WG Short Set (WG-SS) for patients ≥ 5 years
  2) The WG-ES 3 questionnaire (“Short Set Enhanced”), for patients ≥ 13 years (excluding the “upper body” questions in order to improve feasibility of the data collection,
• The Spanish WG version was translated into Paraguayan Spanish and then into the local language Guarani
• Eye hospital staff (nurses, administrators, and social workers) were trained for one week on the use of the WG questions by trainers with extensive experience in community-based inclusive development in South America. Additional advice was provided by the International Center for Evidence in Disability, London
• Both WG versions were used alternatively from July to September 2018
• We applied the Washington Group cut-off definitions for disability (“cannot do at all” and “having a lot of difficulties”)
• Focus group discussions and interviews with participating staff were conducted in January 2019
Results
Short Set of Questions

- 999 patients (556 female) aged five years and older answered the short version.
- The mean age was 47 years, with the majority from the age groups 50 to 70 years and 10 to 20 years.
- Overall, 27.7% were categorized as having at least one type of disability.
- Most commonly reported were visual difficulties with 16.4%, followed by communication difficulties with 9.6%, remembering difficulties with 5.9% and mobility difficulties with 3.8%.
- The rate of disability increased significantly with age, for example hearing disability increased from 0.9% in the age group 21-50 years to 11.8% in the age group 71 years and older.
- 32% of those categorized as a person with a disability reported multiple disabilities.
Results
Extended Set of Questions

- 501 patients aged 13 years and older answered the extended set
- Indicator 4 patients were categorized as being disabled (for example: “feeling a lot depressed daily”)
- 3.6% were categorized as disabled because of being worried, nervous or anxious (female 3.4%)
- 1.4% were categorized as disabled because of feeling depressed (female 1.2%)
Results

Qualitative findings

- Seven people (five women, two men) from the hospital staff participated in focus-group discussions.

- The hospital staff was overall very positive about the WG questionnaires and considered them as being practical.

- The staff felt that the questionnaires enabled them to know more about disability; they had not expected a high rate of patients with disabilities accessing their services.
Results
Qualitative findings (continued)

- Application of the questions resulted often in longer conversations with the patients: “The flow of patients was not interrupted, but there were patients open to talk, they began to tell you more” or “Applying the questions was like a conversation”

- Some staff members indicated that they needed to be better prepared to deal with emotional reactions of the patients: “One person started crying when I asked the last four questions and I didn't know how to comfort her.”

- It was felt that application of the questions on a daily basis would need more resources: “I would recommend the questionnaire, but something more practical, to shorten it more and make it faster, with more summarized questions”
Conclusions/Recommendations

• WG SS seems to be a feasible tool for periodic disability-disaggregated data collection in a secondary/tertiary eye hospital with a basic and functioning Health Information System, but requires substantial training (especially if mental health questions are being used)

• Daily application required additional administrative and human resources

• Results should inform specific actions to mitigate barriers, for example for patients with communication difficulties, and to improve referral pathways for further medical or rehabilitative services

• Changes over time regarding the rate of patients with disabilities accessing the hospital need to be monitored, for example by periodic short application of the questionnaires once a year

• More integration of the WG questions with other hospital data could be useful (for example, combination with income classification or access to cataract surgeries)