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Using Patient-Reported Outcomes (PROs) in Clinical Practice

Patient-reported outcomes (PROs), broadly defined, comprise information from patients about a health condition and its management. Such outcomes can include health-related quality of life (HRQoL), patient satisfaction with treatment, adherence to medical regimens and other elements of health care and its end results. They have been assessed for at least 4 decades. In the early years, these applications were largely used in national surveys, especially in the United States. Beginning in the mid-1970s and thereafter, PROs have been applied more vigorously in research on both clinical and policy questions. Over the past 20 years or so, instrument developers and users have explored extending applications to clinical practice, raising numerous questions and potential barriers.

At the heart of the debate lie 3 issues:

1. Will clinicians come to accept PRO measures?
2. Will they use them in daily practice in ambulatory or hospital settings?
3. Will such measures demonstrably enhance the very outcomes they are supposed to assess?

There are instances where different applications of PROs in clinical practice have been evaluated although the use of PROs in clinical practice has proven to be a complex intervention. Their use has the potential to influence both how clinicians care for their patients as well as patient's experience of this care and their consequent health outcomes.

Most research to date has focused on their use in the context of the individual clinician-patient interaction. Patients complete a PRO at some point prior to their consultation and this information is then fed back to the clinicians. Early research focused on the use of PROs as screening instruments to improve clinician's ability to detect depression and anxiety in primary care populations. Later research has explored their use in the ongoing monitoring of patient's condition, with completion of PROs by patients and feedback to clinicians occurring on several occasions. This research has examined their use as a means of facilitating discussion between clinicians and patients about the impact of symptoms on HRQoL. PROs have also been used as needs assessment instruments, to inform the development of care plans tailored to the individual patient as a means of improving the extent to which patient's needs are met.

In the clinical practice, HRQoL measures can be collected to evaluate baseline status and monitor progress over time. These measures can be used to indicate whether a course of action has led to improvement or not. Without simply having the HRQoL information, clinicians need to know what to do with it. HRQoL measures are of greatest value when the information they provide can be translated into clinical action. For example, condition-targeted measures may be preferred by clinicians be-

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cause they provide information that may be perceived to be more actionable than generic measures. Resource guides are needed to provide clinicians with options of interventions that are worth considering for a patient with less than optimal HRQoL.

In order to be useful for clinical applications, PROs need to be reliable, valid and provide actionable information for clinicians. Because much of clinical work is targeted at individual patients, measures that are tailored to the individual may be most valuable. Item response theory (IRT) can be helpful in providing the mechanics for choosing the most informative item for each individual. IRT provides the basis for reduced administrative burden while maximizing information.

Once a decision has been made to collect PROs in clinical practice, and their intent application have been considered, the attention needs to turn to the logistics of collecting them. There is a plethora of potential methods of administering PROs in clinical practice These include face-to-face interviews and questionnaires which can be used in settings like ours and touch-screen computers, 'smart-pen' tablets and automated telephone interviews which are being increasingly used in developed countries. The choice is more dependent on the ability to provide appropriate support for the various options, cost issues and most importantly the reasons why PROs are being collected. Questions such as 'do PROs need to be immediately available to the health care providers?', 'do the PRO data need to be connected to other clinical or demographic data?', 'what is the technological sophistication of the patients?' will influence the choice of the most appropriate method of PRO application.

Considerable amount of attention needs to be given to the appropriate level of support for the successful collection and usefulness of these data. A dedicated individual is required to inform the patient of the rationale and logistical issues, direct them to the method chosen, answer questions and try to ensure compliance. If adequate resources are not dedicated, the data obtained will be incomplete and almost certainly be biased towards healthier/more compliant patients, thus resulting in misleading information about the patients' real health status.

In addition to the logistical barriers, the awareness of the purpose of PRO collection, the 'buy-in' and attitudinal barriers need to be carefully considered. Why is this information being collected, and how will it potentially affect the health care provider, are particular issues that require careful attention. Although some surveys of clinicians indicate favourable attitudes towards PRO information, there are clearly views to the contrary, and this may especially be an issue for collection of patient satisfaction data.

Formal PRO measurement may seem strange to clinicians since they routinely obtain PROs (although not defined as such) from their patients. However, the clinicians often focus on objective measures at the expense of evaluating patient HRQoL and satisfaction. However, these measures do not provide a complete picture, most of the time. For example, a person on an ACE inhibitor may note an improvement in her/his blood pressure but develop a cough (replacing an asymptomatic condition with a side effect of treatment); the patient's experience is an important element of the clinical evaluation.

The clinicians insist that the content of the PROs should vary by clinical venue (inpatient vs. outpatient); especially clinic vs. primary care) and purpose (disease-specific symptoms and functioning or a general assessment of wellbeing/ satisfaction). The following example explains this argument. Patients come to a heart clinic for treatment of their heart failure. Because the primary goal of these clinics is the improvement of the heart failure, a fairly specific PRO tool can be used to help the clinician monitor the patient. In a primary care clinic, the patient often arrives with an undifferentiated problem (i.e. no diagnosis yet) or with a set of co-morbidities (e.g. heart failure, chronic lung disease, and diabetes mellitus). This complexity limits the use of a single standardized PRO tool and forces the clinician to attend to these issues through the normal course of care.

The clinicians have long argued that for PROs to be useful, they have to be clinically relevant. The outcome must affect the process of care, either by assisting in the diagnostic process or by assisting in management (by monitoring treatment effectiveness or side effects). In addition, they argue that one must also know how the patient values that outcome (i.e. how the outcome affects the patient's life).

It has been the position of various clinician organizations that PROs can be used in clinical practice at 2 levels. At the patient level, they provide data regarding how patients experience their diseases, thus allowing the clinician to better help each patient manage their conditions and promoting shared decision-making. At the clinic level, the clinician may identify a common patient concern that suggests a more systematic (instead of individual) approach.

Many experts in the field of outcomes research are of the opinion that future studies to integrate PROs into routine clinical practice should concentrate on outcomes for which there is management of proven value (rather than on broad goals such as improvement of HRQoL), use a design that may detect an increase in the proportion of patients who benefit (rather than in group means) and evaluate whether the short-term benefits of braod interventions from using PROs can be sustained.

This article was based on the proceedings of the Conference on Patient-Reported Outcomes in Clinical Practice organized by the International Society for Quality of Life Research on 24-26 June 2007 in Budapest, Hungary.

Table 1: Vaccine-preventable Diseases & AFP

16th - 22nd June 2007 (25th Week)

Disease	No. of Cases by Province								Number of cases during current week in 2007	Number of cases during same week in 2006	Total number of cases to date in 2007	Total number of cases to date in 2006	Difference between the number of cases to date between 2007 & 2006
	W	C	S	NE	NW	NC	U	Sab					
Acute Flaccid Paralysis	00	02 KD=2	00	01 BT=1	00	00	01 BD=1	00	04	01	46	61	-24.6%
Diphtheria	00	00	00	00	00	00	00	00	00	00	00	00	00.0%
Measles	00	01 NE=1	00	00	00	00	00	01 KG=1	02	00	38	15	+153.3%
Tetanus	00	00	00	00	00	00	00	00	00	00	17	31	-45.2%
Whooping Cough	00	00	01 GL=1	01 VA=1	00	00	00	00	02	02	21	49	-57.1%
Tuberculosis	94	05	02	15	00	04	00	00	120	150	4820	5057	-4.7%

Table 2: Diseases under Special Surveillance

16th - 22nd June 2007 (25th Week)

Disease	No. of Cases by Province								Number of cases during current week in 2007	Number of cases during same week in 2006	Total number of cases to date in 2007	Total number of cases to date in 2006	Difference between the number of cases to date between 2007 & 2006
	W	C	S	NE	NW	NC	U	Sab					
DF/DHF*	61	04	04	05	15	10	01	18	118	140	2290	4616	-50.4%
Encephalitis	00	00	01 MT=1	00	00	00	00	00	01	03	113	71	+59.2%
Human Rabies	01 GM=1	00	00	00	00	00	00	00	01	01	32	30	+6.7%

Table 3: Newly Introduced Notifiable Diseases

16th - 22nd June 2007 (25th Week)

Disease	No. of Cases by Province								Number of cases during current week in 2007	Total number of cases to date in 2007
	W	C	S	NE	NW	NC	U	Sab		
Chickenpox	10	04	10	05	08	04	03	13	57	1800
Meningitis	06 GM=2 KL=4	00	05 GL=1 HB=3 MT=1	00	01 PU=1	01 PO=1	05 BD=5	12 RP=7 KG=12	37	123
Mumps	10	02	02	02	03	02	00	02	23	717

*__DF / DHF__ refers to Dengue Fever / Dengue Haemorrhagic Fever.
__NA__= Not Available.

Sources:

Weekly Return of Communicable Diseases:
Diphtheria, Measles, Tetanus, Whooping Cough, Human Rabies, Dengue Haemorrhagic Fever, Japanese Encephalitis, Chickenpox, Meningitis, Mumps.

Special Surveillance:
Acute Flaccid Paralysis.

National Control Program for Tuberculosis and Chest Diseases:
Tuberculosis.

Details by districts are given in Table 5.

Provinces: W=Western, C=Central, S=Southern, NE=North & East, NC=North Central, NW=North Western, U=Uva, Sab=Sabaragamuwa.

DPDHS Divisions: CB=Colombo, GM=Gampaha, KL=Kalutara, KD=Kandy, ML=Matale, NE=Nuwara Eliya, GL=Galle, HB=Hambantota, MT=Matara, JF=Jaffna, KN=Killinochchi, MN=Mannar, VA=Vavuniya, MU=Mullaitivu, BT=Batticaloa, AM=Ampara, TR=Trincomalee, KM=Kalmunai, KR=Kurunegala, PU=Puttalam, AP=Anuradhapura, PO=Polonnaruwa, BD=Badulla, MO=Moneragala, RP=Ratnapura, KG=Kegalle.

Table 4: Laboratory Surveillance of Dengue Fever

16th - 22nd June 2007 (25th Week)

Samples	Number tested	Number positive *	Serotypes				
			D_1	D_2	D_3	D_4	Negative
Number for current week	09	01	00	00	00	00	01
Total number to date in 2007	309	19	00	08	04	00	06

Source: Genetech Molecular Diagnostics & School of Gene Technology, Colombo. * Not all positives are subjected to serotyping.

Table 5: Selected notifiable diseases reported by Medical Officers of Health
16th - 22nd June 2007 (25th Week)

DPDHS Division	Dengue Fever / DHF*		Dysentery		Encephalitis		Enteric Fever		Food Poisoning		Leptos-pirosis		Typhus Fever		Viral Hepatitis		Returns Re-ceived Timely**
	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	%
Colombo	40	617	08	189	00	05	02	39	00	43	02	67	00	01	05	46	**85**
Gampaha	10	258	08	189	00	14	02	40	00	28	01	129	00	08	02	55	**71**
Kalutara	11	160	26	269	00	01	00	30	01	17	01	62	00	01	02	31	**100**
Kandy	04	232	08	153	00	03	00	36	00	07	01	42	02	41	70	1083	**77**
Matale	00	58	06	107	00	05	00	09	00	03	00	22	00	03	01	82	**75**
Nuwara Eliya	00	26	08	153	00	02	01	70	00	366	00	08	00	27	30	186	**100**
Galle	01	51	03	81	00	07	00	08	01	04	00	30	00	18	00	13	**100**
Hambantota	01	29	02	37	00	05	00	16	02	15	00	30	03	28	00	09	**82**
Matara	02	81	09	156	01	08	00	23	00	10	00	108	07	126	02	17	**100**
Jaffna	00	18	00	72	00	02	00	297	00	05	00	00	00	80	00	14	**00**
Kilinochchi	00	01	00	00	00	00	00	03	00	00	00	00	00	02	00	02	**00**
Mannar	00	07	00	11	00	00	04	42	00	00	00	00	00	00	00	05	**75**
Vavuniya	00	10	02	29	00	04	00	11	00	15	00	02	00	00	00	05	**100**
Mullaitivu	00	03	00	09	00	06	00	14	00	00	00	00	00	00	03	00	**60**
Batticaloa	03	61	07	333	00	08	00	14	00	10	00	00	00	22	55	365	**91**
Ampara	01	03	07	58	00	00	00	03	00	00	00	00	00	00	00	15	**43**
Trincomalee	01	41	06	131	00	03	01	14	00	23	00	04	01	04	05	57	**78**
Kurunegala	14	202	11	241	00	02	01	38	04	16	01	16	01	26	00	26	**89**
Puttalam	01	75	03	61	00	10	02	44	00	03	00	15	00	04	00	60	**100**
Anuradhapura	06	61	02	54	00	07	00	17	00	13	00	16	00	17	00	28	**74**
Polonnaruwa	04	40	01	50	00	02	00	05	00	03	02	19	00	00	01	13	**86**
Badulla	01	19	06	318	00	00	03	57	00	08	04	28	04	82	08	139	**73**
Monaragala	00	10	08	179	00	02	01	34	00	10	02	32	01	34	01	19	**90**
Ratnapura	09	113	15	315	00	10	03	39	00	08	02	34	00	10	07	40	**81**
Kegalle	09	114	04	156	00	06	02	29	00	04	03	57	02	15	07	57	**91**
Kalmunai	00	03	06	92	00	01	00	07	00	00	00	00	00	02	02	82	**62**
SRI LANKA	**118**	**2290**	**156**	**3443**	**01**	**113**	**22**	**939**	**08**	**611**	**19**	**721**	**21**	**551**	**201**	**2674**	**80**

Source: Weekly Returns of Communicable Diseases (WRCD).
***Dengue Fever / DHF** refers to Dengue Fever / Dengue Haemorrhagic Fever.
****Timely** refers to returns received on or before 30 June 2007. Total number of reporting units = 290. Number of reporting units data provided for the current week: 232
A = Cases reported during the current week. **B** = Cumulative cases for the year.

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Comments and contributions for publication in the WER Sri Lanka are welcome. However, the editor reserves the right to accept or reject items for publication. All correspondence should be mailed to The Editor, WER Sri Lanka, Epidemiological Unit, P.O. Box 1567, Colombo or sent by E-mail to chepid@sltnet.lk.

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