

# Rehabilitation Outcome Measures

Emma K. Stokes



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藏书章



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### Dedication

This book is dedicated to my parents, John and Margaret Stokes, whose ever present love, support, encouragement and belief in all my endeavours is the constant that brings them to fruition.

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A book written by one author is rarely the work of just that one individual.

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'... when you can measure what you are speaking about, and express it in numbers, you know something about it; but when you cannot measure it, when you cannot express it in numbers, your knowledge is of a meagre and unsatisfactory kind; it may be the beginning of knowledge, but you have scarcely in your thoughts advanced to the state of Science, whatever the matter may be.'

(Lord Kelvin, PLA, Vol. 1, Electrical Units of Measurement, 1883-05-03)

I find it hard to believe there was a time when measurement of observed performance of activity or of the impact of a disorder on patients/clients was not routinely quantified but I recall the early 1990s when this was the case; indeed for a small number of practitioners this is still the case. However, for the majority, standardized outcome measures have become an integral part of day-to-day practice.

For many individual practitioners, it is the prevailing measurement instruments in the service where he/she works which remain an integral part of practice and exposure to new versions and new instruments or outcome measures may be limited. This book takes five domains within rehabilitation and

reviews a number of outcome measurement offerings. It does not make recommendations but reports what has been published to date so that the reader can make up his/her own mind.

Placing the systematic use of outcome measurement in clinical decision-making into a professional context illustrates how far we have come; nonetheless barriers to the use of outcome measures seem to be similar in all countries where such evaluation has been reported.

This book is mindful that readers may wish to explore for *new* instruments and outcome measures, which is why the chapters in Section 1 and 2 are included. Linking Chapter 2 in Section 1 with the tables in the relevant chapters in Section 3 and a review of the measures in Section 4 will, I hope, aid in the selection of new outcome measures in rehabilitation.

Instructions are included, where described, for each measurement instrument, nevertheless, in my experience, developers of instruments are very willing to answer questions about their application and the primary reference for each instrument will provide contact details. Web links are also provided so that readers can stay up-to-date with the developments in outcome measures as newer versions emerge.

Emma K. Stokes 2010

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# Section 1

#### Outcome measurement in context

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This section introduces to you the developments in the use of outcome measurement in physiotherapy practice. This section is included to provide you with a context for where practice has come from, demonstrating the organic and responsive nature of practice internationally. It shows the similarity of experiences within different healthcare settings. It describes the International Classification of Functioning, Disability and Health (ICF) and how this can provide an

internationally recognized taxonomy for describing health and health-related states. Links are provided to the World Confederation for Physical Therapy and its activities, which aim to inform the global physiotherapy community about ICF developments. Finally, this section provides some practical information about how you might go about choosing a new, or reviewing an existing, outcome measurement in your practice.

# Outcome measurement and practice

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#### Introduction

In the past two decades, the focus of many healthcare policies and initiatives has been associated with the increased desire for both accountability and quality in healthcare (Kane 1997). The delivery of quality healthcare requires information on both the appropriateness of the intervention or management and its effectiveness. Kane (1994) suggests that appropriateness is informed by 'clear evidence of efficacy ... under a specified situation' and effectiveness requires the measurement of outcome - the two terms, he believes are not synonymous. Liebenson & Yeomans (1997) suggest that quality is demonstrated by improved outcomes and the utilization of evidence-based intervention. Bury & Mead (1998) employ the premise that clinical effectiveness encompasses evidence-based practice (EBP), and suggest that clinical effectiveness requires the consideration of evidence in the context of external environmental and organizational influences. These represent just a fraction of the definitions used to illustrate a variety of terms employed in the language of healthcare evaluation. By defining each of these terms individually, the relationship between them may be fractured and it does not reflect the place of each and all in day-to-day clinical practice. Figure 1.1 illustrates the dynamic relationship that may exist between clinical effectiveness, evidence-based practice, clinical guidelines, outcomes research and the systematic use of standardized outcome measurement (sSOM).

#### Chapter outline

This chapter briefly considers the outcomes movement, evidence-based practice and clinical effectiveness in physiotherapy as a means of providing a context for the main review of outcome measurement in physiotherapy practice. This review considers the practice of standardized outcome measurement (SOM), the barriers reported to the systematic use of standardized outcome measures and the role of professional organizations in promoting and supporting sSOM.

#### The outcomes movement

In the late 1980s, Relman described the outcomes movement as the 'third revolution in medical care' (Relman 1988). In his opinion, the *Era of Expansion* came after the Second World War and continued

An individual patient/client presents to a physiotherapist (PT). The PT completes a full baseline assessment and set of appropriate outcome measurements. The PT then reviews the findings and outlines a proposed course of action, using the current version of clinical guidelines which is primarily based on professional consensus and which is appropriate to the clinical findings, and the preferences of the patient. At the following appointments, the PT re-evaluates the patient using standardized outcome measurement instruments, which demonstrate that the patient is improving. This is consistent with the reports of the patient. At the end of this period of intervention, the data (clinical, psychosocial, demographic characteristics, treatment, measured outcomes) gathered by the PT are entered into a database where, with the patients consent, it is used as part of a large formal outcomes study. This information along with that generated by other forms of research such as randomised controlled trials may form the basis of the evidence used to inform the development of clinical guidelines.



Figure 1.1 • The dynamic relationship that may exist between clinical effectiveness, evidence-based practice, clinical guidelines, outcomes research and the systematic use of standardized outcome measurement (sSOM).

until the late 1960s. This was followed by the Era of Cost Containment. He suggested that the third stage was the Era of Assessment and Accountability. The origins of this era are not completely clear (Kane 1997) but it is likely that a number of factors contributed. Large variations in the delivery of service, coupled with increasing expenditure, prompted questions about whether differences in outcome existed. With increasing amounts of national budgets being spent on healthcare, decisions about healthcare expenditure required information about the relative effectiveness of interventions and services, with a view to minimizing unnecessary expenditure - cost containment within the context of preserving quality of care. Managed care, with industrial accountability and productivity models, generated a revised way of thinking. Globally, the healthcare system had become a competitive marketplace. Individuals, insurance companies, health maintenance organizations, national health services and individual governments are all purchasers of healthcare. Market decisions are informed by outcomes of care (Epstein 1990, Jette 1995, Enderby & Kew 1995, Kane 1997. Hammond 2000, Beattie 2001).

Epstein (1990) described the three-fold effect of the outcomes movement on assessing outcomes. The emergence of a value placed on outcomes information had a subsequent impact on the way information is collected and stored. In some healthcare systems, large computerized databases are used to inform billing and reimbursement; while the presence of desktop computers in many departments and services has led to local analysis of data. This large-scale collection of data can be used to inform outcomes research and thus expand the existing knowledge base, working in tandem with the results of randomized controlled trials. The range of outcomes measured is broader. If health, as defined by the World Health Organization (1948): 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity', has become more measurable because of the development of well-constructed and evaluated measurement instruments (McDowell 2006), the outcomes movement has influenced the way that these outcome measures are used to inform practice and decision-making (Epstein 1990, Kane 1997).

#### Evidence-based practice

Evidence-based practice became the buzzword of the 1990s (Bury & Mead 1998), albeit that the origin of the concept is at least 150 years old (Sackett et al 1991); its emergence fuelled by increasing research activity and the desire to bring findings into practice and supported by published formats that made the information more accessible and advances in information technology. In physiotherapy, a long tradition of research does not exist, and a critical mass is still only emerging in some areas of practice and not present at all in others (Twomey 1996, Parry 1997). A number of factors have been cited as potential contributors to explain why some areas of healthcare do not have supporting evidence derived from research (Appleby et al 1995, Bury & Mead 1998):

- · Difficulties in designing studies
- Difficulty in removing an intervention, which through custom and practice is now accepted, to perform a clinical trial
- · Existing research that is of poor quality
- Randomized controlled trials not always appropriate to specific areas of healthcare
- Inadequate attention paid to the costeffectiveness of interventions
- · Failure to disseminate research findings.

In addition, specific factors in physiotherapy relate to the development of the profession, its historical placement under the auspices and protection of the medical profession (Roberts 1994, Parry 1995) and its lack of professional autonomy. In the UK, the profession grew out of the establishment of the Incorporated Society of Trained Masseuses in 1894 (Barclay 1994), which was later to become the Chartered Society of Physiotherapy. The practice of its members could only occur under doctor's orders. It was only in 1977 in the UK that physiotherapists finally gained professional autonomy and became first-contact practitioners. This occurred in the 1980s in other countries (Turner 2001). Prior to this there was a requirement for a referral from a medical practitioner, who also prescribed the treatment. The development of educational programmes for physiotherapy occurred in a non-uniform manner internationally. The USA had the first graduate programme (Moore 1995) in the 1920s, South Africa, Canada and Australia in the 1940s, 1950s and 1970s, respectively (Turner 2001). Despite the changes in the professional role, the emergence of a body of

graduates with research skills and equipped for the responsibility of autonomous practice and the drive for EBP in healthcare services, the use of research findings to inform the choice of treatment techniques is limited in physiotherapy (Turner 2001, Pomeroy & Tallis 2000). The factors that physiotherapists/ physical therapists (PTs) use to inform treatment choice have been cited as original professional education, attendance at continuing professional development (CPD) courses, previous experience with a client or peer suggestion (Turner et al 1996, 1999, Carr et al 1994, Nilsson & Nordholm 1992). There is no mandate that requires the profession of physiotherapy to demonstrate efficacy of an intervention prior to its inclusion in an undergraduate course of study, or indeed in the area of continuing professional development (Stratford 1999). Often, in practice decisions are made on the basis of 'personal observations, precedence and consensus' (Parry 1997).

Across all aspects of healthcare, EBP initiatives, driven by the desire for creating greater consistency in the provision of services, have resulted in demands for and the development of Clinical Guidelines. This has presented and continues to present a challenge to many areas in healthcare provision, where a large body of evidence does not exist to support interventions and where professional consensus is hard to reach (Kane 1997, Stratford 1999). This is especially the case in physiotherapy because our research tradition is short but also because many 'higher' forms of research suggest that some physiotherapy interventions are ineffective or selectively effective (Stratford 1999, Pomeroy & Tallis 2000). Nevertheless, clinical guidelines exist in areas such as the management of osteoporosis, stress incontinence and soft tissue injury (CSP 1998, 1999, 2001b).

## The use of outcome measures in practice

Significant challenges facing the physiotherapy profession with the emergence of the outcomes movement were the absence of an agreed framework for measurement and the absence of an ethos of using standardized measurement instruments. With respect to the latter, this chapter reviews the use of systematic outcomes measurement in physiotherapy practice under the following headings:

 The extent to which SOMs are employed in physiotherapy and related rehabilitation practice and the profile of this practice

- The attitudes towards use and the barriers identified by PTs in hindering the use of SOMs
- The role of professional organizations policy in promoting the use of SOM.

The information for the review in this chapter was obtained from a number of sources including a review of the published literature (Medline, CIHAHL and AMED).

Two methods are reported in the literature for the investigation of the extent to which standardized outcome measures are used in physiotherapy practice and rehabilitation: (1) survey instruments using self-report and (2) retrospective chart retrieval or chart audit. The first such reported work in physiotherapy was undertaken in 1992; a task force commissioned by the Canadian Physiotherapy Association and Health Canada completed a national survey, using a stratified random sample that examined the use of client outcome measures by PTs. The definition of an outcome measure was a 'published measurement scale'. The sample included individual practitioners and PT managers and was a random sample (n = 309) from a list of licensed therapists, with a response rate of approximately 80% (Mayo et al 1993, Cole et al 1995). The findings suggested that the use of standardized outcome measures was limited - 50% reported using the measures, but only 20% were able to identify one 'published measurement scale'. At the same time (the study was published 3 years after its completion), Chesson et al (1996) conducted a similar survey of PTs and occupational therapists (OTs) in Scotland. The survey participants were PT and OT managers in hospital and community-based departments. There was a 79% PT response, with only 44% of PT departments reporting to be using at least one standardized outcome measure, many of whom had only introduced the practice in the 1990s. Low rates of usage were reported in some regions suggesting the influence of local policy and SOMs more commonly used in the speciality of rehabilitation of older people than other specialities. Both studies suggested that the use of SOMs was emerging in physiotherapy practice. A pan-European review of the use of outcome measures was completed in 1998 (Torenbeek et al 2001). Using a postal questionnaire, 581 rehabilitation facilities in Germany, Ireland, Italy, Austria and the Netherlands were surveyed about a number of aspects of outcome measurement. The overall response rate was only 17.5% but the results are consistent the findings of the previous two surveys; the authors concluded that, in the area of rehabilitation post stroke and for low back pain, systematic use of SOM is not yet common practice. The results identified that many of the measures used were 'neither published nor validated'. In a review of 182 rehabilitation centres in the UK, Turner-Stokes (1997) also noted that 77% of the centres represented by the respondents used at least one SOM. Stokes & O'Neill (1999, 2009) completed two surveys of practice in Ireland of physiotherapists working with older people and noted an increase in the use of SOMs in this area of practice over a period of 5 years from 1998 to 2003.

Retrospective chart retrieval and chart audit were the methods employed by Turner et al (1996, 1999) and Kirkness & Korner-Bitensky (2002). In 1993 in the UK, Turner et al (1996) screened a sample of case notes and included the case notes if pain was on the problem list, being treated or was noted in the initial assessment. A total of 1010 case notes were selected for audit. On initial assessment, 90% of cases presented with pain as a problem, 64% were treated for pain but only 21% actually quantified pain in any way. Reassessment occurred in 73% of cases and in those cases, 94% of cases had pain as a noted problem on reassessment. A total of 63% noted treatment for pain but only 2.5% quantified the pain on reassessment. Similar findings were reported in a later study by Turner et al (1999), in 1994-1996, 1,254 patient records were reviewed from five hospitals to consider the measurement of muscle strength and range of motion in the management of low back pain and after knee replacement surgery. A total of 810 charts met the criteria, i.e. the relevant parameter listed as a problem, in treatment plan, or treated by PT. In 95% of cases treatment for increasing muscle strength (MS) and range of motion (ROM) was documented. Both were initially quantified in approximately 64% of cases, but reassessment only took place in 10% of cases for MS and 30% for ROM. In both of these papers, charts from paediatric wards, patients <14 years, day hospitals for older people and patients aged >85 years were excluded. Nevertheless, the authors still noted that patients aged >55 years were less likely to have pain assessed than younger patients. Pain was measured using a body chart, and the end of range pain. MS was measured using manual muscle testing, limb girth and dynamometry. ROM was measured using goniometry. The attrition in the use of SOM across the period of intervention was noted by Kirkness & Korner-Bitensky (2002) in their investigation of the prevalence of

SOM use by PTs in the management of low back pain. They reviewed 256 randomly selected charts from 40 physiotherapy practice settings in Canada. The prevalence of PTs consistently using standardized outcome measures was low (34%). All but one of the respondents (53 PTs and 265 charts) employed measures of impairment of structures such as pain and range of motion, while one PT used a measure of activity limitation (disability). The authors divided their respondents into 'consistent users' and 'inconsistent users'. Clients of the former received more treatment sessions and were treated over a longer period of time; payment for their services was more likely to come from a hospital source as opposed to a private source or third party source, i.e. insurance company, workers' compensation scheme. The numeric pain rating score was the most commonly noted standardized measure employed, 27% used it at initial assessment but this level of usage dropped over the duration of intervention, with only 4% using it again at discharge. This attrition in the use of SOMs was consistent across all the instruments employed, suggesting that the information obtained was not used to measure change as a result of intervention.

In 2001, the results of a further survey on practice in Canada (completed in 1998) were published (Kay et al 2001). This survey focused on a review of practice following a number of strategic interventions by the Canadian Physiotherapy Association. In addition to general and specific questions on the use of outcome measurement, respondents were asked questions about their sources of information about outcome measurements and their confidence in a variety of situations relating to outcome measurement. In the second survey, respondents were identified as being either staff PTs (n = 69) or professional

practice leaders (PPLs) (n = 20). Direct comparison could be made between the 1992 and 1998 surveys. A total of 41% (n = 58) of staff PTs reported that published measurement scales were used in their department in 1992, this increased by only 2% to 43%, (n = 26) in 1998. A more focused question asked respondents to consider a list of published outcome measures; check if they were familiar with the measure, and if they currently used it. Almost the entire sample reported that they currently used at least one of the outcome measures. The discrepancy between the two answers leading the authors to observe that 'it is difficult to conclude whether or not overall use of client outcome measures has increased since the 1990s'. It is interesting to note that two of the three stroke specific outcome measures reported as being used in 1992, were no longer reported as in use in the 1998 survey, although approximately one in three staff PTs and PPLs reported using the Chedoke McMaster Stroke Assessment Impairment Inventory Scale; an increase of 25%. The Berg Balance Scale was used by 45% of respondents (n = 40), an increase of 28% from 1992.

The five most frequently cited measures and the pattern of their use are outlined in Table 1.1. This question was not asked in the 1992 survey; hence no comparison of practice is available. The degree of attrition of use by OMs such as ROM, MS and pain is significantly less than that reported by Turner et al (1996, 1999) and Kirkness & Korner-Bitensky (2002), nevertheless one-third of PTs would still not measure balance, e.g. at both admission and discharge. These results indicate that optimum use of outcome measurements may not be occurring in clinical practice. This is consistent with the results of the section of the survey on the level of confidence in knowledge

Outcome measurement	Current use	At admission	At admission and discharge	More often	
Range of motion	90	90	85	61	
Manual muscle testing	88	92	85	68	
Goal setting	73	95	85	57	
Visual analogue scale pain	57	86	67	61	
Berg Balance Scale	45	83	63	38	

Item	Staff PT		PPL	
	${\sf Mean} \pm {\sf SD}$	Range	$\mathrm{Mean} \pm \mathrm{SD}$	Range
Knowing enough about test construction to develop own measure	$\textbf{27.8} \pm \textbf{22.2}$	0-80	$29.5 \pm 21.4$	0-80
Knowing how to link information to other information	45 ± 24.3	0-90	52 ± 22.4	10-90
Knowing how to compare scores to baseline levels across client groups	51.1 ± 25	0-100	54.8 ± 22.3	10-90
Knowing enough about measurement properties to choose	$58.7 \pm 21$	10-90	$64.5 \pm 20.4$	20-90
Knowing whether suitable measures are available	$\textbf{62.5} \pm \textbf{22.7}$	10-100	$\textbf{73} \pm \textbf{21.7}$	40-100
Knowing what to do with scores	62.9 ± 19.7	10-100	70 ± 22.9	10-90
Overall, knowing what to do with the information obtained	64 ± 21.6	10-100	$\textbf{68.5} \pm \textbf{23.9}$	10-90
Knowing why to measure	$71.5 \pm 20$	10-100	$77.5 \pm 23.4$	10-100
Knowing how to track clients' progress with outcome measures	$73\pm16.2$	20-100	$73\pm22$	10-100
Knowing how to score measures	$73.7 \pm 16.2$	20-100	$75.5 \pm 18.8$	30-90
Knowing what to measure for client groups	$\textbf{73.8} \pm \textbf{15.6}$	20-100	$77.5 \pm 23.1$	0-100
Knowing how to administer OM in standardized manner	74.1 ± 16.3	20-100	75 ± 18.2	30-100
Total Confidence Score (higher score, greater confidence)	65.2 ± 14.2	10-100	68.5 ± 25.9	10-90

about and use of SOMs. Respondents were asked to consider 12 statements and rate their confidence from 0% (not confident) to 100% (completely confident). Table 1.2 is a summary of the results reported. No statistically significant difference was noted between the groups for levels of confidence scores. The least amount of confidence was reported in the areas of measurement properties, linking information, comparing scores across groups and overall, what to do with the results. It would appear that outcome measures are used with confidence, but PTs are less confident or familiar with their broader use in the context of overall evaluation.

## Attitudes and barriers to the use of SOM

Similar barriers to using outcome measures were reported in both Canadian surveys and were:

 Lack of time: reported by 52% staff PTs and 55% PPLs in 1998

- Lack of knowledge about measures: reported by 82% staff PTs and 75% PPLs in 1998
- Limited availability of measures: reported by 51% staff PTs and 50% PPLs in 1998
- Not meeting needs of clients: reported by 33% staff PTs and 60% PPLs in 1998
- Lack of professional consensus on what to use: reported by 27% staff PTs and 15% PPLs in 1998.

In addition to the quantitative survey results, the researchers undertook a series of focus groups to further examine the themes that had emerged following analysis of the survey (Huijbregts et al 2002). The results of this qualitative research methodology were supported by the quantitative survey results. It was observed that while it was accepted that the use of client outcome measures had become intrinsic in physiotherapy practice, consistent application was not uniform; and the utilization of the information gathered in a meaningful way lagged behind the collection of data. In terms of how practice is influenced, the authors noted that it is a combination of an organizational mandate to use standardized measures and