Increasing outcome measure completion in adult patients with a traumatic brain injury: Ideas from the research literature and evaluation of service change

Craig Peak, Daniela Di Basilio & Lorraine King

The use of Patient Reported Outcome Measures (PROMs) is increasingly important in clinical practice. Within the Department of Clinical Neuropsychology at Salford Royal Hospital they are used routinely to collect information on the overall physical, psychological and social adjustment of patients with a traumatic brain injury (TBI). In an attempt to increase PROMs completion rates, we implemented two major changes, reducing the number of PROMs completed and changing the collection method. We critically evaluated the influence that these changes have had on PROMs completion rates and discussed the potential barriers in PROMs completion rates in TBI patients, together with reflections for future improvements of the PROMs used and their administration methods.

PATIENT-REPORTED outcome measures (PROMs) are self-reported standardised measures of a patient's health status, generally including questions about mental health symptoms (e.g. anxiety/depression), quality of life and work and social adjustment (Greenhalgh et al., 2005). The distinctive characteristic of PROMs is that they assess patients' own views of their symptoms, symptom-related limitations and overall perceived quality of life. Consequently, they are particularly effective in obtaining information about subjective events in patients such as the severity of pain or an increase in anxiety symptoms (Gwaltney et al., 2008). As they directly reflect patients' perspectives on these dimensions, PROMs assume particular relevance when the patients' symptoms, overall functioning and quality of life are areas of concern (Frost et al., 2007). Moreover, they are effective measures of the limitations patients might experience due to their symptoms, and can enable comparisons of health status at different times (Black, 2013; Boyce et al., 2014).

As Black (2013) highlights, there are different ways in which PROMs are used to improve the quality of care offered to patients in the UK. First, PROMs support clinical decision-making about treatment options. For example, the feedback from PROMs might indicate suitability for psychological therapy, the need for further tests, a change in treatment, or referral on to other services (Greenhalgh et al., 2005). Second, regular assessment of the patients' condition provides valuable information about the experience and management of long-term medical conditions. Third, PROMs are included in the NHS outcomes framework, used by the NHS Commissioning Board and Clinical Commissioning Groups to assess the overall quality of service and care. Devlin and Appleby (2010) have stated that NHS service providers are under increasing pressure to evaluate the quality of the services offered, and this is likely compounded by the considerable slowing in Department of Health growth in recent years (King's Fund, 2018). PROMs can offer a valid contribution to the measurement of patient experience, and effectiveness of services as they reflect patients' experience of their symptoms and subsequent effects on the quality of life (Devlin & Appleby, 2010; Raleigh & Foot, 2010).

Barriers and facilitators of PROMs completion

The process of collecting completed PROMs data at specified time points can be difficult (Triplet et al., 2017). A national postal survey study using PROMs to measure quality of life in cancer survivors reported a satisfactory completion rate of 63.3 per cent (Downing et al., 2015). In the NHS national PROMs programme, impressive response rates for hip and knee replacement surgery have been achieved (76 per cent and 73.6 per cent respectively), with the report adding that response rates have remained stable at around 75 per cent since 2011/2012 (NHS Digital, 2018). A cohort study of patients with a long-term condition, including asthma, chronic obstructive pulmonary disease, diabetes, epilepsy, heart failure or stroke found PROMs rates as low as 38.4 per cent (at baseline) and as high as 71.5 per cent (completed within follow-up appointments with their GP; Peters et al., 2014). No study to our knowledge has investigated PROMs completion rates in an adult TBI population.

It has been widely identified and agreed that patients who are older, non-white or more economically disadvantaged are less likely to complete PROMs (Hutchings et al., 2013; Kopp et al., 2003; Trauer, 2004). The presence of one or more physical health issues (e.g. heart disease or cancer), mental health issues (e.g. substance abuse or psychosis) and cognitive limitations have also been suggested to impact on the ability to complete outcome measures (Schamber et al., 2013; Wild et al., 2001). Further to this, Green (2018) identified client concerns regarding confidentiality and who has access to their data as barriers to PROMs completion. Patient difficulties in summarising experiences and the use of seemingly generic, non-personal questions were also highlighted as factor impeding completion rates (Green, 2018). Others such factors include language or cultural barriers (Gayet-Ageron et al., 2011; Schouten et al., 2007), illiteracy (Pignone et al., 2005), missed appointments and lack of time during face-to-face consultations (Triplet et al., 2017).

There are also factors that have been identified as facilitators of patient responses to PROMs. For example, PROMs completion rates are likely to increase if the patients are aware of the relevance of completion and if they perceive that their data will be used confidentially and in accordance with ethical regulations (Nakash et al., 2006; Nelson et al., 2004; Rendell et al., 2007). The severity of symptoms also appears to be a salient factor, as completion rates have been reported in patients with more severe conditions (Royal College of Obstetricians and Gynaecologists, 2012). This might be due to the prolonged engagement with services in more severe conditions, which provides both more opportunities to complete PROMs and increased familiarity and/or affinity with services.

According to Edwards et al. (2002), response rates also tend to be higher if questionnaires are relatively short; if a follow-up appointment is planned; and if patients who did not respond are provided with a second copy of the questionnaire. Some studies (e.g. Allenby et al., 2002, Bliven et al., 2001) have also indicated that computer-based PROMs have higher rates of completion compared with both paper-and-pencil and interviewer-administered measures. Finally, having completed PROMs previously and receiving follow-up reminder emails, both increase completion rates (Patel et al., 2015; Triplet et al., 2017).

Study rationale and aims

As is evident from the preceding review, PROMs are being increasingly used in different healthcare contexts to measure the quality of services provided (Black et al., 2016; Malhotra et al., 2016) and to identify patients' health goals and formulate treatment decisions (Van Der Wees et al., 2014). They are also relevant to inform comparative effectiveness research, therefore guiding clinical practice and service development (Ahmed et al., 2012; Selby et al., 2012). As such, it is important to monitor PROMs completion rates in different clinical populations and identify which factors might promote or hinder their completion.

With this in mind, we reviewed PROMs completion rates in patients accessing our TBI service, compared them with published completion rates in other populations, and assessed the difference in completion rates following two changes implemented in attempt to increase response rates. This paper aimed to contribute to the existing debates on the use of PROMs and, in particular, on the possible barriers and facilitators to completing these measures in an adult TBI population. We also wish to share our experiences to stimulate discussion with other professionals about how to improve completion rates in TBI patients.

Methods

Data collection

Data were collected from an electronic patient record system that routinely recorded demographic and clinical information and from a TBI service database that captured PROMs completion rates. Data were collected over three 12 month time periods. Data from group 1 spanned the period 19 October 2015 to 18 October 2016, group 2 from 19 October 2016 to 18 October 2017, and group 3 from 1 December 2017 to 31 November 2018. Those in group 1 were asked to complete six PROMS, as follows:

- Generalised anxiety disorder 7 (GAD-7; Spitzer et al., 2006), designed to assess the severity of generalised anxiety.
- Patient health questionnaire 9 (PHQ-9; Kroenke et al., 2001), designed to assess depression severity.
- Work and social adjustment scale (WSAS; Mundt et al., 2002), designed to assess and monitor perceived functional impairment resulting from the TBI covering work, home, social, private leisure and interpersonal domains.
- A locally created TBI checklist which identifies previously existing and new post-TBI symptoms such as seizures, memory difficulties, pain, etc.
- European brain injury questionnaire self-rating form (EBIQ; Teasdale et al., 1997)
- European brain injury questionnaire relative-rating form (Teasdale et al., 1997).

Patients in group 2 were asked to complete an abbreviated PROMs battery, with the EBIQ self and relative-rating forms omitted due to them being considered lengthy at around 66 items each. Patients in group 3 completed the same battery as group 2, but prepaid return envelopes were sent out with PROMs at the post-intervention time point in an attempt to increase post-intervention response rates.

For all groups, pre-intervention PROMs were sent in the post with an initial appointment letter requesting that patients complete the enclosed confidential questionnaires and bring them to their first appointment, both to assist with their care, and to help us to improve the service. If these were not returned, the clinician did not generally complete them along with the client in the first appointment. For groups 1 and 2, post-intervention PROMs were sent in the post on discharge with patients being asked to complete these and return them at their own cost. As stated, for group 3 this procedure was changed to add a pre-paid envelope. No reminders were sent to prompt completion if these were not returned.

Results

The TBI service offered 530 patients an initial appointment over the three 12-month time periods. At the time of writing, 33 patients were in receipt of ongoing treatment, so data from 180 patients in group 3 were analysed instead of the 213 seen during this period. This gave an overall sample size of 497 patients. Table 1 below provides a summary of these patients' attendance and PROMs completion rates.

In total, 139 patients were offered an appointment but either did not attend or cancelled on two consecutive occasions and were discharged from the service as per the local attendance policy. This group hence completed no PROMs. Across the three time points, 62 patients attended initial session(s) but later stopped attending without notice, and hence did not complete post-intervention PROMs. Within this cate-

Table 1: Summary of attendance rates and PROM completion rates across three time periods. Note that percentages relate to the *N* per section, not the overall sample.

		Group 1 (Six PROMs)	Group 2 (Four PROMs)	Group 3 (Four PROMs + pre-paid envelope)
Patients offered an initial appointment	*N*	169	148	180
	Discharged before seen	41 (24.26%)	65 (43.92%)	33 (18.33%)
Attended initially but did not complete pathway	*N*	23	20	19
	Pre-PROMs completed	6 (26.09%)	3 (15%)	2 (10.53%)
Completed pathway	*N*	105	63	127
	Pre-PROMs completed	27 (25.71%)	21 (33.33%)	38 (29.69%)
	Post-PROMs completed	1 (0.95%)	4 (6.35%)	9 (7.03%)

gory, 11 patients (17.74 per cent) completed pre-intervention PROMs.

Of the 105 patients in group 1 who completed the service pathway and underwent a planned discharge, 25.71 per cent ($N = 27$) completed the longer pre-intervention PROM battery. Of these 105 patients, only 1 (0.95 per cent) returned the post-intervention PROMs sent by post. Reducing the PROM battery for the 63 patients in group 2 increased the pre-intervention PROMs completion rate to 33.33 per cent ($N = 21$) and post-intervention PROMs completion rate to 6.35 per cent ($N = 4$). Of the 127 patients who completed the pathway in Group 3, 29.69 per cent ($N = 38$) returned the initial PROMs, and 7.03 per cent ($N = 9$) returned the PROMs after discharge.

Discussion

This evaluation assessed PROM completion rates before and after implemented changes in an outpatient neuropsychology department assessing and treating adults with a TBI. The PROMs administration method and length were considered along with possible factors that may impact a person's ability and willingness to complete these measures if they have sustained a TBI. Completion rates were evaluated to identify potential issues arising in light of low completion rates and the impact this may have on services, along with further service development recommendations.

Completion rates increased slightly in groups 2 and 3 for both pre- and post-intervention time points when compared to group 1. The increased rates observed could be attributed to the shortening of the PROMs battery, although they could of course represent random variation. These findings are in keeping with Edwards et al.'s (2002) systematic review on the factors positively influencing response rates in postal questionnaires, highlighting the relatively short length of questionnaires as a factor that may predict higher responses. Despite these small potential increases, response rates are considerably lower than those found in other health care settings previously discussed, which ranged from 38.4 per cent (Peters et al., 2014) to 76 per cent (NHS Digital, 2018). One potential reason for the lower response rates in our sample relative to these other

published observations could concern the nature of the condition and severity of the TBI, as TBI patients experience a range of cognitive deficits depending on the location and severity of damage (Draper & Ponsford, 2008). Deficits following a TBI have been found in a wide range of cognitive domains; for example, but not limited to, executive functioning, reduced speed of information processing (Fleminger, 2008; O'Jile, 2006), attention (Hopkins et. al., 2005; Mathias, 2007), memory (Bigler, 2007; Fleminger, 2008; Palacios et al., 2012), and language comprehension (see Rowley et al., 2017). As a result, damage resulting from a TBI may impact a person's ability to complete and return PROMs as requested as they may forget to do this due to memory difficulties, disengage due to attentional difficulties, or struggle to understand the wording of PROMs if completing these independently and unsupported. It would be interesting to investigate the relationship between reasons for non-completion and TBI location. Future research could also analyse specific reasons why TBI patients might find it challenging to complete PROMs and potential ways to overcome these barriers to PROMs completion.

As previously discussed, the administration methods used to collect PROMs data have been found to impact completion rates. The current data set relied on patients independently completing PROMs outside the appointment and returning them in a prepaid envelope. Post-intervention PROMs completion rates increased only marginally (from 6.35 per cent to 7.03 per cent) when a prepaid envelope was provided. Individual services will need to balance whether any intervention which can increase accessibility and engagement with services (albeit only slightly) is worthwhile, given pressures on services to cut costs.

One possible method of improving completion rates could be to allow patients to complete PROMs online, rather than having to post paper measures. Studies on electronically based PROMs have shown that online administration can result in high completion rates (Howell et al., 2017; Malhotra et al., 2016) particularly when email reminders are sent (Triplet et al., 2017). However, Dommeyer et al. (2004) and Ogier (2005) found higher face-to-face paper based completion rates of 75 per cent and 65 per cent, compared to online rates of 43 per cent and 30 per cent respectively in student survey studies. Gaining consent to digitalise PROMs may be difficult due to copyright law, and raises additional concerns regarding information governance and data protection. Services would also need to consider the cost of the infrastructure needed to provide an electronically based PROMs completion option which would require tablets or computer terminals in waiting and clinic rooms.

Face-to-face interactions would offer an alternative to digitalising PROMs and would likely be more valid, as cognitive difficulties could be managed through appropriate adjustments to help understanding and engagement. A face-to-face administration method would also allow scope to overcome the aforementioned barriers to completion as demographic variables; language ability, confidentiality concerns and cultural relevance can be considered. Whilst completing PROMs in a face-to-face session may be a therapeutic process and provide useful observation assessment information, it incurs greater costs and can take time away from other assessment and intervention activities.

Information obtained from PROMs can: guide treatment decisions (Greenhalgh et al., 2005); increase understanding of experiences and the management of long-term health conditions; help patients to recognise their own improvements (Nordal, 2012); and assess the overall quality of services and care (King's Fund, 2018). Having low PROMs completion rates is therefore concerning, as this information is not routinely gathered and monitored for all patients accessing the service. Low completion rates will also impact the validity of information being collected, particularly when considering commissioning decisions, as it does not provide valid representation of the service and its outcomes.

Concluding remarks

We plan to complete further projects to investigate the factors underlying low PROMs completion rates in the TBI population and implement future interventions aimed at increasing completion rates. The team also plan to discuss the potential ways of overcoming barriers to completing PROMs with patients accessing our TBI service in the future. We welcome any information from other clinical neuropsychologists working in TBI services about their PROMs completion rates and/or interventions that may have helped with this. We also welcome any interest in collaborating in our future work.

Craig Peak
Assistant Psychologist, Department of Clinical Neuropsychology, Salford Royal Hospital; Craig.Peak@gmmh.nhs.uk
Daniela Di Basilio
Lecturer in Psychology, Faculty of Health Psychology and Social Care, Manchester Metropolitan University, Manchester; D.Di-Basilio@mmu.ac.uk
Lorraine King
Clinical Neuropsychologist, Department of Clinical Neuropsychology, Salford Royal Hospital, Salford; Lorraine.King@srft.nhs.uk

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