

## **Patient Experience Journal**

Volume 7 | Issue 3 Article 8

2020

# Patient reported experience of inpatient rehabilitation in Australia

Jacquelin T. Capell

Australian Health Services Research Institute, University of Wollongong, Wollongong NSW Australia, jcapell@uow.edu.au

#### Tara Alexander

Australian Health Services Research Institute, University of Wollongong, Wollongong NSW Australia, hurst@uow.edu.au

## Julie Pryor

University of Sydney, Sydney, NSW, Australia, julie.pryor@royalrehab.com.au

#### Murray Fisher

University of Sydney, Sydney, NSW, Australia, murray.fisher@sydney.edu.au

Follow this and additional works at: https://pxjournal.org/journal



Part of the Health Services Research Commons, and the Rehabilitation and Therapy Commons

## **Recommended Citation**

Capell, Jacquelin T.; Alexander, Tara; Pryor, Julie; and Fisher, Murray (2020) "Patient reported experience of inpatient rehabilitation in Australia," Patient Experience Journal: Vol. 7: Iss. 3, Article 8. DOI: 10.35680/2372-0247.1424

This Research is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

## Patient reported experience of inpatient rehabilitation in Australia

## **Cover Page Footnote**

Acknowledgments: We thank the 20 participating inpatient rehabilitation facilities, their project champions and patients for their voluntary participation in this study. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (http://bit.ly/ExperienceFramework). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX\_PtFamComm Declaration of conflicting interests The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. Funding The author(s) disclose receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by the Medibank Health Research Fund [2014-066].

#### Research

# Patient reported experience of inpatient rehabilitation in Australia

Jacquelin T. Capell, Australasian Rehabilitation Outcomes Centre, Australian Health Services Research Institute, University of Wollongong, jcapell@uow.edu.au

Tara Alexander, Australasian Rehabilitation Outcomes Centre, Australian Health Services Research Institute, University of Wollongong, hurst@uow.edu.au

Julie Pryor, Royal Rehab & Susan Wakil School of Nursing and Midwifery, University of Sydney, julie.pryor@royalrehab.com.au

Murray Fisher, Susan Wakil School of Nursing and Midwifery, University of Sydney & Royal Rehab, Murray. Fisher @sydney.edu.au

#### **Abstract**

While the value of patient reported experience is increasingly acknowledged, the measurement of rehabilitation-specific patient reported experiences is an area that is yet to attract a lot of attention. The aim of this study was to examine the patient-reported experience of person-centred inpatient rehabilitation. The study consisted of a multi-site cross sectional survey using the 33-item modified Client Centred Rehabilitation Questionnaire (CCRQ). A total of 408 participants were recruited from 20 inpatient rehabilitation facilities across Australia. Participants were in the final days of their inpatient rehabilitation episode when approached to complete the paper based modified CCRQ. Nineteen of the 33 items had an 80% or greater proportion of positive responses ('agree', 'strongly agree'). The items belonging to the Family Involvement and Support subscale had the lowest proportion of positive responses (range 57.1%-82.4%), the highest proportion of 'does not apply' responses (range 10.0%-23.0%) and the largest variability in positive responses across all 33 items. The three negatively worded items (items 2 and 33 in the Client-centred Education subscale and item 7 from the Continuity/Co-ordination subscale) demonstrated the greatest proportions of negative responses (range 44.6%-65.7%). The breadth of the modified CCRQ items enables identification of service gaps as seen from the patient's perspective. Identification of such gaps allows rehabilitation services to plan actions to improve the quality of services provided.

### **Keywords**

Patient experience, inpatient rehabilitation, patient-centred care, measurement, questionnaire

#### Introduction

Internationally there is growing recognition of the importance of patient-reported perspectives as part of the whole evidence base for high quality patient care.¹ This type of evidence commonly takes the form of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). In contrast to PROMs which commonly ask patients their views about their health status and symptoms and their management¹ PREMs seek information about the processes of care²; they tell us about patient experience in relation to expectations about what matters to them.

"Rehabilitation care is care in which the primary clinical purpose or treatment goal is improvement in the functioning of a patient with an impairment, activity limitation or participation restriction due to a health condition. Rehabilitation requires that the patient is capable of actively participating in their care" (METeOR

ID 491557, AIHW, 2015).<sup>3</sup> Although there is debate internationally around the precise meaning of patient-centred care<sup>4,5,6</sup> the concept has become increasingly used in the context of rehabilitation. A number of different concepts are embedded in the term including interactions and treatment which are respectful of the person and their context, which adopt an individualised and holistic approach and which actively engage the person in decision making about matters which are important to them.<sup>7</sup>

While the value of patient reported experience across a broad range of medical conditions is increasingly acknowledged internationally, the measurement of rehabilitation-specific patient reported experiences is an area that is yet to attract a lot of attention. Several factors may contribute to this. One may be a preference for the use of a single organisation wide tool, a decision which may be informed by a limited appreciation of how differences in the requirements for active patient participation between acute and rehabilitation care can impact patient experience. Another may be lack of

information about which aspects of patient experience to include in a rehabilitation-specific PREM.

The eight Picker Principles of Patient-Centered Care were developed in the USA in the early 1990s<sup>8</sup> using focus groups comprising recently discharged patients, family members, physicians and non-physician hospital staff, and a review of pertinent literature. Providing a useful starting point for considering the broad aspects of treatment which patients might find important these are:

- Respect for patients' values, preferences and expressed needs
- 2. Coordination and integration of care
- 3. Information, communication and education
- 4. Physical comfort
- 5. Emotional support and alleviation of fear and anxiety
- 6. Involvement of family and friends
- 7. Transition and continuity
- 8. Access to care

Aligning closely with the Picker principles but focusing specifically on rehabilitation, Cott<sup>9</sup> used a literature review and focus groups consisting of adults with chronic disabling conditions, such as stroke, arthritis, total joint replacement and spinal cord injury, to explore the components of rehabilitation which they thought were important from the client's perspective. The components identified were then grouped into seven domains:

- 1. Participation in decision making and goal setting
- Client-centred education (information is timely and appropriate)
- Evaluation of outcomes from the client's perspective, not just the perspective of rehabilitation professionals
- 4. Family involvement and support
- 5. Emotional support
- 6. Coordination and continuity
- 7. Physical comfort (recognition and management of pain)

This work informed development of the 33-item Client-Centre Rehabilitation Questionnaire (CCRQ). This rehabilitation-specific patient experience measure has seven sub-scales: decision-making; education; outcome evaluation; family involvement; emotional support; physical comfort; and continuity/co-ordination. A recent examination of an opportunist sample of 13 more recent qualitative studies involving rehabilitation inpatients found continuing support for the seven subscales and the items within. 11

The psychometric properties of a modified CCRQ in an Australian population were previously reported.<sup>12</sup> The aim of this study was to examine the patient-reported experience of person-centred inpatient rehabilitation.

#### Methods

#### Design and participants

The project consisted of a multi-site prospective cohort study using data from a self-report questionnaire based on the CCRQ and completed at discharge by inpatients from Australian rehabilitation services that were members of the Australasian Rehabilitation Outcomes Centre (AROC). Full ethical approval was gained from the Joint University of Wollongong/Illawarra Shoalhaven Local Health District Health and Human Research Ethics Committee (HREC). Local HREC and site-specific approvals were gained from the relevant governing bodies of the participating organisations.

Participants were recruited from 20 inpatient rehabilitation facilities. Facilities were purposively selected to provide a range of impairments treated, size of service (large and small), location (state as well as metropolitan and rural), and type of facility (public and private as well as generalist and specialist services). Once a service was signed up to the project every eligible rehabilitation inpatient in the final days of their episode was invited to participate in the project.

An employee from each of the participating facilities was identified to champion the project at their service and was responsible for recruitment of patients. This employee provided interested patients with an envelope containing the questionnaire, Participant Information Sheet and a prepaid return envelope as per the study protocol.

The duration of the data collection period for each facility ranged from one to three months between September and December 2015.

#### The instrument

The questionnaire contained the 33 item modified CCRQ (Cott et al 2006 with minor modifications<sup>10</sup>; see Fisher et al 2020 for details<sup>12</sup>), a self-report closed response questionnaire consisting of 7 subscales: Decision-making (6 items), Education (5 items), Outcome evaluation (4 items), Family involvement (5 items), Emotional support (4 items), Continuity/coordination (5 items), and Physical comfort (4 items). The six response options for each item ranged from 'strongly agree' (1) to 'strongly disagree' (5) and 'does not apply' (DNA). The questionnaire included three negatively worded items (2, 7 and 33). The items and subscales are shown in Appendix 1. The questionnaire was available in English only.

#### Data analysis

As questionnaires were returned the data were entered into MS Excel 2016. Basic descriptive analysis was conducted over the de-identified data to summarise the demographic data and item responses. Analysis of item level responses focussed on counts and proportion. The responses "did

Table 1. Participant characteristics

| Participant characteristic                 | Responses | Percentage  |  |  |  |  |
|--|-----------|-------------|--|--|--|--|
| Sex  |           |             |  |  |  |  |
| Female                                     | 249       | 61.0%       |  |  |  |  |
| Male                                       | 158       | 38.7%       |  |  |  |  |
|  | (missing  | on 1 form)  |  |  |  |  |
| Reason for rehabilitation (impairment)     |           |             |  |  |  |  |
| Orthopaedic replacements                   | 149       | 36.5%       |  |  |  |  |
| Orthopaedic fractures                      | 41        | 10.0%       |  |  |  |  |
| Other orthopaedic surgery                  | 41        | 10.0%       |  |  |  |  |
| Deconditioning following a medical illness | 35        | 8.6%        |  |  |  |  |
| Stroke                                     | 24        | 5.9%        |  |  |  |  |
| Amputation of a limb                       | 21        | 5.1%        |  |  |  |  |
| Brain dysfunction                          | 19        | 4.7%        |  |  |  |  |
| Neurological conditions                    | 17        | 4.2%        |  |  |  |  |
| Deconditioning following surgery           | 16        | 3.9%        |  |  |  |  |
| Spinal cord dysfunction                    | 15        | 3.7%        |  |  |  |  |
| All other impairments                      | 28        | 6.9%        |  |  |  |  |
|  | (missing  | on 2 forms) |  |  |  |  |
| Age at start of study                      |           |             |  |  |  |  |
| <40  | 16        | 3.9%        |  |  |  |  |
| 40s  | 20        | 4.9%        |  |  |  |  |
| 50-54                                      | 24        | 5.9%        |  |  |  |  |
| 55-59                                      | 35        | 8.6%        |  |  |  |  |
| 60-64                                      | 36        | 8.8%        |  |  |  |  |
| 65-69                                      | 56        | 13.7%       |  |  |  |  |
| 70-74                                      | 56        | 13.7%       |  |  |  |  |
| 75-79                                      | 66        | 16.2%       |  |  |  |  |
| 80-84                                      | 41        | 10.0%       |  |  |  |  |
| 85-89                                      | 41        | 10.0%       |  |  |  |  |
| 90s  | 16        | 3.9%        |  |  |  |  |
|  | (missing  | on 1 form)  |  |  |  |  |

not answer" and "does not apply" were used to assess how well surveys were completed and if the items were relevant. In this analysis the response values of the three negatively worded questions were not recoded to the equivalent of the positively worded questions.

## Results

A total of 408 questionnaires were returned during the study period of which most were from female participants. Median age was 71 years (range 19-99), with half of all respondents aged 61-79 years). Just over half of all reasons for rehabilitation were for orthopaedic conditions. Table 1 provides the distribution for all reasons for rehabilitation (impairment) along with sex and age at the start of the study.

Most items on all returned surveys had a valid response, with 76.8% of respondents completing all 33 items.

Table 2 (see Appendix 2) presents the responses with items grouped by subscale. The response rate per item ranged from 93.1% for item 2 (T had difficulty getting the

health care information I needed') to 98.5% for items 9 ('The rehabilitation staff took my individual needs into consideration when planning my care') and 13 ('I was treated with respect and dignity'). The five items in the Family Involvement subscale (4 'My family/friends were given the support that they needed by the rehabilitation staff), 12 ('My family/friends were given the information that they wanted when they needed it), 17 ('My family/friends received information to assist in providing care for me at home'), 23 ('My family and friends were treated with respect'), and 27 ('My family/friends were involved in my rehabilitation as much as I wanted') returned some of the highest completion rates (95.3%-97.3%). The three negatively worded items (2, 7, 33) returned some of the lowest completion rates (93.1%-94.6%).

All items relating to the Family Involvement subscale (4, 12, 17, 23, 27) returned very high DNA response rates (23.0%, 23.0%, 23.0%, 10.0% and 22.8% respectively). The three negatively worded items (2, 7 and 33) also had higher rates of DNA responses than other non-family subscale items (6.9%, 5.1% and 8.3%, respectively). Only

four items that were neither Family Involvement subscale items nor negatively worded had DNA recorded in more than 5% of responses. These were items 10 (9.1%) (I was given adequate information about support services in the community'), 14 (7.1%) (I had adequate time for rest and sleep'), 29 (5.1%) (I was told what to expect when I got home') and 31 (8.1%) (My emotional needs (worries, fears, anxieties) were recognized and taken seriously by the rehabilitation staff').

Figure 1 (see Appendix 3) shows the distribution of responses for individual items grouped by subscale. For the three negatively worded items (2, 7 and 33) 'strongly disagree' and 'disagree' were considered as positive responses. The three negative items (2, 7, 33) demonstrated the greatest proportions of negative responses, 65.7%, 46.8% and 44.6% respectively. Items 7 and 33 also show the highest proportion of neutral responses (17.2% and 21.6%). The highest proportion of positive responses (89.5% or more) was shown for items 5 (The rehabilitation staff treated me as a person instead of just another case'), 8 ('My physical pain was controlled as well as possible'), 9 ('The rehabilitation staff took my individual needs into consideration when planning my care'), 13 ('I was treated with respect and dignity'), 15 ('My treatment needs, priorities and goals were important to the rehabilitation staff') and 30 ('Rehabilitation staff tried to ensure my comfort').

The Family Involvement subscale items 27, 17, 4 and 12 returned the lowest positive rates when compared to all items (57.1%, 58.1%, 60.1% and 61.2% respectively) due to the high proportion of DNA responses in this subscale. After excluding DNA responses, the family involvement items had positive rates similar to the other subscales.

In addition to returning the highest response rates of DNA, at a subscale level the Family Involvement items demonstrated the highest variability in positive response. The range across this subscale was 25.3%, from 57.1% (item 27 'My family/friends were involved in my rehabilitation as much as I wanted') to 82.4% (item 23 'My family and friends were treated with respect'). The ranges in positive responses to the items across the other subscales, excluding the negatively worded items, were 'Emotional support' 20.4%, 'Client participation in decision making' 18.4%, 'Continuity/coordination' 17.9%, 'Client centred education' 15.7%, 'Outcomes evaluation from client's perspective' 5.7% and 'Physical comfort' 1.9%.

Aside from the Family involvement items, the lowest positive responses were for items 29 ('I was told what to expect when I got home'), 25 ('Treatment choices were fully explained to me'), 10 ('I was given adequate information about support services in the community'), 1 ('The rehabilitation staff and I decided together what

would help me'), 24 ('I know who to contact if I have problems following discharge') and 31 ('My emotional needs (worries, fears, anxieties) were recognized and taken seriously by the rehabilitation staff') at 70.8%, 71.8%, 72.3%, 72.6%, 74% and 74.3% respectively.

More than 86% of patients positively responded to the items reflecting scheduling and care planning items 6 ('The rehabilitation staff tried to accommodate my needs when scheduling my therapy'), 9 ('The rehabilitation staff took my individual needs into consideration when planning my care') and 15 ('My treatment needs, priorities and goals were important to the rehabilitation staff'). Close to 87% responded positively to item 20 ('I was encouraged to participate in setting my goals').

In terms of rehabilitation continuity and coordination almost 90% of patients indicated that their therapists, nurses and doctors worked well together (item 32). Almost 81% reported that 'I knew who to contact if I had problems or questions during my rehabilitation program' (item 18).

#### Discussion

As part of service evaluation, the inclusion of the patient's perspective contributes valuable information to assist rehabilitation services in understanding how well they are performing. The value of a questionnaire designed to collect patient reported experience about whether rehabilitation services are patient-centred relies on the extent to which the questionnaire items adequately reflect the components of care which are important to patients. The original CCRQ<sup>10</sup> was developed as a result of a research process incorporating a systematic literature review, input from patients and professionals and psychometric testing. Subsequently, the face validity of the CCRQ items was confirmed via focus groups conducted in the Australian inpatient rehabilitation setting. <sup>12</sup>

Overall, the high level of positive responses ('agree', 'strongly agree') to the positively worded items across the questionnaire used in this study suggests that participants generally found their rehabilitation to be patient-centred. Conversely, across the three negatively worded items the relatively higher levels of disagreement than agreement also indicate that the rehabilitation service received was patient-centred.

Despite the generally positive responses, the variability in item level responses provides specific information which could be utilised to inform service improvements. Collaborative goal setting has long been regarded as central to the rehabilitation process. <sup>13,14</sup> However, in practice the extent to which goal-setting is patient-centred has been observed to vary considerably between clinicians, with a number of factors identified as impacting on the

process including the quality and effectiveness of the patient-clinician collaboration, clinician self-awareness and the organisational and resource constraints in which the goal setting occurred.<sup>15</sup> Participants in this study were highly positive about the goal-setting experience (close to 90%), but less so about whether treatment choices were fully explained to them (79%) or decisions about what would help them were made in collaboration with the rehabilitation staff (73%).

The components of the Family Involvement subscale explored whether the family was involved to the extent desired by the person participating in rehabilitation. This subscale showed the highest proportion of DNA responses suggesting that the care provided was personcentred, since not every person undergoing rehabilitation needs or wants their family involved in their treatment and treatment decisions. 16,17

The proportion of positive responses to the two items about preparedness for transition from the inpatient rehabilitation setting to the community (74% for item 24 and 70.8% for item 29) suggest some room for improvement in service provision. This may to some extent be influenced by variations in need between patients. For example, for patients with impairments that result in living with a long-term condition continuity of care is a critical component of a successful transition. <sup>9,18,19</sup> This includes providing patients with sufficient information about how to navigate community care and access community services once discharged from rehabilitation. Nonetheless, it is ideal for all patient to feel prepared for life in the real world following inpatient rehabilitation.

Taken as a whole, the breadth of the modified CCRQ items enables identification of service gaps as seen from the patient's perspective. Identification of such gaps allows services to plan actions to improve the quality of services provided. This might include working towards the genuine inclusion of patients as partners in their care and the implementation of interventions to promote patient-centred care,<sup>20</sup> for example by strengthening patient-centred communication, shared decision making and goal setting.

The ultimate value of any rehabilitation-specific patient experience questionnaire lies in its ability to collect information about what matters to patients. The CCRQ was developed in collaboration with patients <sup>9,10</sup> and while more than a decade has passed since then a recent literature review<sup>11</sup> found continuing support for the seven subscales and the items within, indicating that these components remain relevant to rehabilitation patients. However, with the passage of time there may be other aspects of rehabilitation which have become important to patients and which have not yet been incorporated into

measures. The growth in the number of publications about person-centred rehabilitation from 2000 to 2017<sup>5</sup> suggest that a review of the key components of person-centred rehabilitation is now overdue.

#### Strengths and limitations

While the design of this study was strong, the study's limitations are also acknowledged. As the questionnaire was only available in English, participation was restricted to people fluent in English. Neither the wording, length nor the relevance of the modified CCRQ has been tested for people with limited spoken English. Similarly, people with aphasia were not specifically sought to participate in this study. While the views of both these groups may have been captured in some of the returned questionnaire, no data were collected about this. Further research is needed to examine the appropriateness of this and any other rehabilitation patient experience questionnaire for both people with limited English and people with aphasia, as both are represented in the Australian rehabilitation context.

#### Conclusion

To move beyond the rhetoric of patient-centred care to patient-centred care in action, patients must be authentically engaged as partners in their care. To assist this endeavour, the availability of specific and sufficiently detailed information about the aspects of rehabilitation that patients regard as important is central. The modified CCRQ provides a tool which services can use to collect specific information which can be acted upon to improve patient-centred care. The rehabilitation specific focus and level of detail able to be provided by analysis of the modified CCRQ responses could provide insight at the service level into any discrepancy between the clinicians' beliefs that they effectively engage in patient-centred activities, such as goal setting and patient education, and the patients' experiences of these activities.

#### Acknowledgment

We thank the 20 participating inpatient rehabilitation facilities, their project champions, and patients for their voluntary participation in this study.

## Declaration of conflicting interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors disclose receipt of the following financial support for the research, authorship, and/or publication

of this article: This study was supported by the Medibank Health Research Fund [2014-066].

#### References

- Chen J. Integrated Care. Patient reported outcomes measures and patient reported experience measures – a rapid scoping review. Agency for Clinical Innovation, New South Wales. https://www.aci.health.nsw.gov.au/\_\_data/assets/pdf\_file/0009/281979/ACI\_Proms\_Prems\_Report.pdf. 2015. Accessed 20 December 2019.
- Coulter A. Measuring what matters to patients [editorial]. BMJ. 2017;356:j816.
- Australian Institute of Health and Welfare. National Health Data Dictionary: version 16.1. National Health Data Dictionary series. Cat. no. HWI 130. 2015. Canberra: AIHW.
- Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns*. 2016; 99(12): 1923–1939.
- Jesus TS, Bright FA, Pinho CS, Papadimitriou C, Kayes NM, Cott CA. Scoping review of the personcentered literature in adult physical rehabilitation. *Disabil Rehabil*. 2019; DOI: 10.1080/09638288.2019.1668483
- Leplege A, Gzil F, Cammelli M, Lefeve C, Pachoud B, Ville I. Person-centredness: Conceptual and historical perspectives. *Disabil Rehabil*. 2007; 29:20-21, 1555-1565.
- 7. Australian Commission on Safety and Quality in Health Care. Patient centred care: Improving quality and safety through partnerships with patients and consumers. 2011. ACSQHC, Sydney.
- 8. Picker Institute. Picker Principles of Person- Centred Care: https://www.picker.org/about-us/picker-principles-of-person-centred-care/ accessed 18 December 2019.
- 9. Cott CA. Client-centred rehabilitation: client perspectives. *Disabil Rehabil.* 2004; 26 (24) 1411-1422.
- Cott CA, Teare G, McGilton KS, Lineker S. Reliability and construct validity of the client-centred rehabilitation questionnaire. *Disabil Rehabil*. 2006;28 (22) 1387-1397.
- 11. Pryor J & Fisher M. An examination of the CCRQ as a measure of person-centred rehabilitation. *JARNA*. 2019; 22(2):22-26
- 12. Fisher M, Pryor J, Capell J, Alexander T, Simmonds F. The psychometric properties of a modified client-centred rehabilitation questionnaire in an Australian population. *Disabil Rehabil.* 2020; 42(1) 122-129.
- 13. Wade DT. Goal setting in rehabilitation: an overview of what, why and how [editorial]. *Clin Rehabil*. 2009;23: 291–295.

- 14. Wade DT. Forward. In: Siegert RJ and Levack WMM (eds). Rehabilitation goal setting: theory, practice, and evidence. Boca Raton, FL: CRC Press; 2014: vii–ix.
- Cameron LJ, Somerville LM, Naismith CE, Watterson D, Maric V, Lannin NA. A qualitative investigation into the patient-centered goal-setting practices of allied health clinicians working in rehabilitation. *Clin Rehab*. 2018; 32(6) 827–840.
- D'Cruz K, Unsworth C, Roberts K, Morarty J, Turner-Stokes L, Wellington-Boyd A, Matchado J, Lannin NA. Engaging patients with moderate to severe acquired brain injury in goal setting. *Int J Ther Rehabil*. 2016; 23(1): 20–31.
- 17. Pegg PO, Jr, Auerbach SM, Seel RT, Buenaver LF, Kiesler DJ, Plybon LE. The impact of patient-centered information on patients' treatment satisfaction and outcomes in traumatic brain injury rehabilitation. *Rehabil Psychol.* 2005; 50(4):366.
- 18. Lefebvre H, Pelchat D, Swaine B, Gélinas I, Levert MJ. The experiences of individuals with a traumatic brain injury, families, physicians, and health professionals regarding care provided throughout the continuum. Brain Inj. 2005; 19(8):585–597.
- 19. Rotondi AJ, Sinkule J, Balzer K, Harris J, Moldovan R. A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *J Head Trauma Rehabil*. 2007;22(1):14–25.
- Lewin S, Skea Z, Entwistle VA, Zwarenstein M, Dick J. Interventions for providers to promote a patientcentred approach in clinical consultations. *Cochrane Database Syst Rev.* 2001; (4): CD003267. DOI:10.1002/14651858.CD003267.

Appendix 1. The instrument

| Subscale                     | Item |   |  |  |  |  |  |  |
|------------------------------|------|---|--|--|--|--|--|--|
| S1. Client participation in  | 1    | The rehabilitation staff and I decided together what would help me.   |  |  |  |  |  |  |
| decision-making and goal-    | 6    | The rehabilitation staff tried to accommodate my needs when scheduling my                                       |  |  |  |  |  |  |
| setting                      | 9    | therapy.  The rehabilitation staff took my individual needs into consideration when                             |  |  |  |  |  |  |
|                              | 9    | planning my care.   |  |  |  |  |  |  |
|                              | 15   | My treatment needs, priorities and goals were important to the rehabilitation                                   |  |  |  |  |  |  |
|                              | 20   | staff.  I was encouraged to participate in setting my goals.  |  |  |  |  |  |  |
|                              | 25   | Treatment choices were fully explained to me.   |  |  |  |  |  |  |
| S2. Client-centred education | 2    | I had difficulty getting the health care information I needed.  |  |  |  |  |  |  |
|                              | 10   | I was given adequate information about support services in the community.                                       |  |  |  |  |  |  |
|                              | 21   | I received the information that I needed when I wanted it.  |  |  |  |  |  |  |
|                              | 26   | My therapy program was explained to me in a way that I could understand.  |  |  |  |  |  |  |
|                              |      |   |  |  |  |  |  |  |
|                              | 33   | There were times when I received more information than I was ready for.   |  |  |  |  |  |  |
| S3. Outcomes evaluation      | 3    | I was kept well-informed about my progress in areas that were important to me.                                  |  |  |  |  |  |  |
| from client's perspective    | 11   | I accomplished what I expected in my rehabilitation program.  |  |  |  |  |  |  |
|                              | 16   | The rehabilitation staff and I discussed my progress together and made changes as necessary                     |  |  |  |  |  |  |
|                              | 22   | I learned what I needed to know in order to manage my condition at home.  |  |  |  |  |  |  |
| S4. Family involvement       | 4    | My family/friends were given the support that they needed by the rehabilitation staff.                          |  |  |  |  |  |  |
|                              | 12   | My family/friends were given the information that they wanted when they needed it.                              |  |  |  |  |  |  |
|                              | 17   | My family/friends received information to assist in providing care for me at home.                              |  |  |  |  |  |  |
|                              | 23   | My family and friends were treated with respect.  |  |  |  |  |  |  |
|                              | 27   | My family/friends were involved in my rehabilitation as much as I wanted.                                       |  |  |  |  |  |  |
| S5. Emotional support        | 5    | The rehabilitation staff treated me as a person instead of just another case.                                   |  |  |  |  |  |  |
|                              | 13   | I was treated with respect and dignity.   |  |  |  |  |  |  |
|                              | 28   | I felt comfortable expressing my feelings to rehabilitation staff.  |  |  |  |  |  |  |
|                              | 31   | My emotional needs (worries, fears, anxieties) were recognized and taken seriously by the rehabilitation staff. |  |  |  |  |  |  |
| S6. Physical comfort         | 8    | My physical pain was controlled as well as possible.  |  |  |  |  |  |  |
|                              | 14   | My reports of pain were acknowledged by rehabilitation staff.   |  |  |  |  |  |  |
|                              | 19   | I had adequate time for rest and sleep.   |  |  |  |  |  |  |
|                              | 30   | Rehabilitation staff tried to ensure my comfort.  |  |  |  |  |  |  |
| S7. Continuity/coordination  | 7    | I had to repeat the same information to different rehabilitation staff.   |  |  |  |  |  |  |
|                              | 18   | I knew who to contact if I had problems or questions during my rehabilitation program.                          |  |  |  |  |  |  |
|                              | 24   | I know who to contact if I have problems following discharge.   |  |  |  |  |  |  |
|                              | 29   | I was told what to expect when I got home.  |  |  |  |  |  |  |
|                              | 32   | My therapists, nurses and doctors worked well together.   |  |  |  |  |  |  |

Appendix 2. Table 2 Modified CCFQ item response rates

|   |      |   | ITEM RESPONSE |                   |     |         |    |         |     |          |     |                      |    |          |    |         |
|---|------|---|---------------|-------------------|-----|---------|----|---------|-----|----------|-----|----------------------|----|----------|----|---------|
| Subscale  | Iten | number and question   |               | Strongly<br>Agree |     | Agree   |    | Neither |     | Disagree |     | Strongly<br>Disagree |    | Does Not |    | Did not |
| Client<br>participation<br>in decision-<br>making and<br>goal-setting | 1    | The rehabilitation staff and I decided together what would help me.   | 132           | (32.4%)           | 164 | (40.2%) | 48 | (11.8%) | 23  | (5.6%)   | 7   | (1.7%)               | 17 | (4.2%)   | 17 | (4.2%)  |
|   | 6    | The rehabilitation staff tried to accommodate my needs when scheduling my therapy.                              | 197           | (48.3%)           | 157 | (38.5%) | 23 | (5.6%)  | 5   | (1.2%)   | 4   | (1.0%)               | 10 | (2.5%)   | 12 | (2.9%)  |
|   | 9    | The rehabilitation staff took my individual needs into consideration when planning my care.                     | 199           | (48.8%)           | 169 | (41.4%) | 19 | (4.7%)  | 9   | (2.2%)   | 1   | (0.2%)               | 5  | (1.2%)   | 6  | (1.5%)  |
|   | 15   | My treatment needs, priorities and goals were important to the rehabilitation staff.                            | 194           | (47.5%)           | 172 | (42.2%) | 20 | (4.9%)  | 9   | (2.2%)   | 1   | (0.2%)               | 4  | (1.0%)   | 8  | (2.0%)  |
|   | 20   | I was encouraged to participate in setting my goals.  | 177           | (43.4%)           | 177 | (43.4%) | 25 | (6.1%)  | 11  | (2.7%)   | 3   | (0.7%)               | 6  | (1.5%)   | 9  | (2.2%)  |
|   | 25   | Treatment choices were fully explained to me.   | 127           | (31.1%)           | 166 | (40.7%) | 49 | (12.0%) | 19  | (4.7%)   | 3   | (0.7%)               | 19 | (4.7%)   | 25 | (6.1%)  |
| Client-centred<br>education   | 2*   | I had difficulty getting the health care information I needed.  | 17            | (4.2%)            | 35  | (8.6%)  | 32 | (7.8%)  | 141 | (34.6%)  | 127 | (31.1%)              | 28 | (6.9%)   | 28 | (6.9%)  |
|   | 10   | I was given adequate information about support services in the community.                                       | 130           | (31.9%)           | 165 | (40.4%) | 38 | (9.3%)  | 23  | (5.6%)   | 7   | (1.7%)               | 37 | (9.1%)   | 8  | (2.0%)  |
|   | 21   | I received the information that I needed when I wanted it.  | 156           | (38.2%)           | 195 | (47.8%) | 35 | (8.6%)  | 8   | (2.0%)   | 2   | (0.5%)               | 5  | (1.2%)   | 7  | (1.7%)  |
|   | 26   | My therapy program was explained to me in a way that I could understand.  | 162           | (39.7%)           | 197 | (48.3%) | 22 | (5.4%)  | 7   | (1.7%)   | 2   | (0.5%)               | 3  | (0.7%)   | 15 | (3.7%)  |
|   | 33*  | There were times when I received more information than I was ready for.   | 18            | (4.4%)            | 64  | (15.7%) | 88 | (21.6%) | 124 | (30.4%)  | 58  | (14.2%)              | 34 | (8.3%)   | 22 | (5.4%)  |
| Outcomes<br>evaluation<br>from client's<br>perspective                | 3    | I was kept well-informed about my progress in areas that were important to me.                                  | 166           | (40.7%)           | 177 | (43.4%) | 27 | (6.6%)  | 13  | (3.2%)   | 6   | (1.5%)               | 6  | (1.5%)   | 13 | (3.2%)  |
|   | 11   | I accomplished what I expected in my rehabilitation program.  | 153           | (37.5%)           | 184 | (45.1%) | 45 | (11.0%) | 9   | (2.2%)   | 2   | (0.5%)               | 3  | (0.7%)   | 12 | (2.9%)  |
|   | 16   | The rehabilitation staff and I discussed my progress together and made changes as necessary                     | 151           | (37.0%)           | 169 | (41.4%) | 45 | (11.0%) | 18  | (4.4%)   | 1   | (0.2%)               | 11 | (2.7%)   | 13 | (3.2%)  |
|   | 22   | I learned what I needed to know in order to manage my condition at home.  | 158           | (38.7%)           | 184 | (45.1%) | 32 | (7.8%)  | 8   | (2.0%)   | 2   | (0.5%)               | 9  | (2.2%)   | 15 | (3.7%)  |
| Family  | 4    | My family/friends were given the support that they needed by the rehabilitation staff.                          | 112           | (27.5%)           | 133 | (32.6%) | 44 | (10.8%) | 6   | (1.5%)   | 5   | (1.2%)               | 94 | (23.0%)  | 14 | (3.4%)  |
| involvement   | 12   | My family/friends were given the information that they wanted when they needed it.                              | 96            | (23.5%)           | 154 | (37.7%) | 38 | (9.3%)  | 12  | (2.9%)   | 3   | (0.7%)               | 94 | (23.0%)  | 11 | (2.7%)  |
|   | 17   | My family/friends received information to assist in providing care for me at home.                              | 97            | (23.8%)           | 140 | (34.3%) | 40 | (9.8%)  | 23  | (5.6%)   | 1   | (0.2%)               | 94 | (23.0%)  | 13 | (3.2%)  |
|   | 23   | My family and friends were treated with respect.  | 170           | (41.7%)           | 166 | (40.7%) | 16 | (3.9%)  | 1   | (0.2%)   | 0   | (0.0%)               | 41 | (10.0%)  | 14 | (3.4%)  |
|   | 27   | My family/friends were involved in my rehabilitation as much as I wanted.                                       | 95            | (23.3%)           | 138 | (33.8%) | 50 | (12.3%) | 11  | (2.7%)   | 2   | (0.5%)               | 93 | (22.8%)  | 19 | (4.7%)  |
| Emotional<br>support  | 5    | The rehabilitation staff treated me as a person instead of just another case.                                   | 240           | (58.8%)           | 139 | (34.1%) | 8  | (2.0%)  | 3   | (0.7%)   | 6   | (1.5%)               | 2  | (0.5%)   | 10 | (2.5%)  |
|   | 13   | I was treated with respect and dignity.   | 254           | (62.3%)           | 132 | (32.4%) | 11 | (2.7%)  | 4   | (1.0%)   | 0   | (0.0%)               | 1  | (0.2%)   | 6  | (1.5%)  |
|   | 28   | I felt comfortable expressing my feelings to rehabilitation staff.  | 176           | (43.1%)           | 186 | (45.6%) | 19 | (4.7%)  | 12  | (2.9%)   | 1   | (0.2%)               | 2  | (0.5%)   | 12 | (2.9%)  |
|   | 31   | My emotional needs (worries, fears, anxieties) were recognized and taken seriously by the rehabilitation staff. | 152           | (37.3%)           | 151 | (37.0%) | 37 | (9.1%)  | 16  | (3.9%)   | 3   | (0.7%)               | 33 | (8.1%)   | 16 | (3.9%)  |
| Physical<br>comfort   | 8    | My physical pain was controlled as well as possible.  | 195           | (47.8%)           | 171 | (41.9%) | 6  | (1.5%)  | 4   | (1.0%)   | 3   | (0.7%)               | 20 | (4.9%)   | 9  | (2.2%)  |
|   | 19   | My reports of pain were acknowledged by rehabilitation staff.   | 186           | (45.6%)           | 178 | (43.6%) | 20 | (4.9%)  | 14  | (3.4%)   | 2   | (0.5%)               | 0  | (0.0%)   | 8  | (2.0%)  |
|   | 14   | I had adequate time for rest and sleep.   | 199           | (48.8%)           | 163 | (40.0%) | 8  | (2.0%)  | 2   | (0.5%)   | 0   | (0.0%)               | 29 | (7.1%)   | 7  | (1.7%)  |
|   | 30   | Rehabilitation staff tried to ensure my comfort.  | 184           | (45.1%)           | 186 | (45.6%) | 13 | (3.2%)  | 3   | (0.7%)   | 1   | (0.2%)               | 3  | (0.7%)   | 18 | (4.4%)  |
| Continuity / coordination   | 7*   | I had to repeat the same information to different rehabilitation staff.   | 24            | (5.9%)            | 79  | (19.4%) | 70 | (17.2%) | 113 | (27.7%)  | 78  | (19.1%)              | 21 | (5.1%)   | 23 | (5.6%)  |
|   | 18   | I knew who to contact if I had problems or questions during my rehabilitation program.                          | 144           | (35.3%)           | 186 | (45.6%) | 38 | (9.3%)  | 15  | (3.7%)   | 8   | (2.0%)               | 8  | (2.0%)   | 9  | (2.2%)  |
|   | 24   | I know who to contact if I have problems following discharge.   | 134           | (32.8%)           | 168 | (41.2%) | 31 | (7.6%)  | 29  | (7.1%)   | 12  | (2.9%)               | 12 | (2.9%)   | 22 | (5.4%)  |
|   | 29   | I was told what to expect when I got home.  | 124           | (30.4%)           | 165 | (40.4%) | 49 | (12.0%) | 22  | (5.4%)   | 5   | (1.2%)               | 21 | (5.1%)   | 22 |         |
|   | 32   | My therapists, nurses and doctors worked well together.   | 195           | (47.8%)           | 167 | (40.9%) | 21 | (5.1%)  | 10  | (2.5%)   | 1   | (0.2%)               | 2  | (0.5%)   | 12 | (2.9%)  |

<sup>\*</sup>Denotes negatively worded items



