Special Article:

Validation of a postal version of the Northwick Park Dependency Score (NPDS)

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Key-words:

Rehabilitation nursing, needs assessment, outcome and process assessment

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Prepared in 2006, this article was presented at local and regional meetings but never formally published

Abstract

Aim:

To develop a postal version of the Northwick Park Dependency Score (NPDS), suitable for self-completion by informal carers, and to evaluate this alongside the original NPDS, administered by telephone interview.

Design:

Repeated measures design. Comparison of agreement between the two versions

Participants:

Carers (n=50) of adults (aged 16–65) with acquired brain injury (ABI), were recruited in the course of a large nationally-based study of carer experiences. A positive sampling strategy ensured client representation across a range of dependencies (Total NPDS score 0-59) and underlying diagnoses - stroke (28%), trauma (30%), encephalitis (28%) and other ABI (14%)).

Methods:

The postal version has the same structure as the original NPDS, but changes in language and phrasing. The two versions were administered in counter-balanced order, a median 26 days (IQR 11-68) apart.

Results:

On item-by-item analysis, absolute agreement ranged from 48-100%. Quadratic-weighted Cohen's Kappa scores (Basic Care Needs subscale only) were 0.45 – 0.91. Strong correlations in total NPDS score (Spearman rho 0.84 p<0.001) between the two version were reflected in the estimated weekly care hours (rho 0.85, p<0.001) and care costs (rho 0.61, p<0.001). However, lower estimated care costs (Wilcoxon p=0.001) on the postal version arose from under-rating of safety awareness and frequent night-time interventions in certain cases.

Conclusions:

In this small sample, the postal NPDS provided roughly equivalent estimations of dependency to the original version, but under-estimated care costs in some individuals. Further study using the revised version is now warranted in larger and more diverse populations.

Background

A reliable measure of nursing dependency has several important functions in a rehabilitation service. It may be used pre-admission to plan an appropriate case-mix in relation to available staffing; to monitor gains in independence in the course of a rehabilitation programme; and to identify care needs, and so facilitate discharge planning[1, 2].

The Northwick Park Dependency Score (NPDS) is an ordinal scale which was developed to measure nursing dependency in rehabilitation settings.[2] Unlike other measures of nursing dependency developed for more acute settings[3, 4], it takes account of the extra time which may be needed to supervise patients with poor safety awareness, or to stand back and encourage patients to undertake self-care tasks for themselves.

Furthermore, the NPDS has been designed to evaluate the full spectrum of dependency and to be sensitive to small changes, particularly for those patients with very heavy care needs, who frequently fall beneath the floor of global disability measures such as the Functional Independence Measure (FIM)[5] or the Barthel Index[6].

An algorithm has been developed by which to translate the NPDS into the Northwick Park Care Needs Assessment (NPCNA)[7]. The NPCNA provides a direct assessment of care needs in the community, including an estimation of weekly care hours, the type of care package that would be required and the approximate weekly cost of providing that care. Both the NPDS and the NPCNA been subject to evaluation[2, 7, 8] and a recent survey of rehabilitation physicians in the UK has demonstrated increasing uptake of these tools for routine use in clinical practice[9].

The tool has further application in long-term community follow-up to demonstrate the stability of gains in independence and reduced care costs after discharge from rehabilitation.

- Postal questionnaires provide a practical and inexpensive route to gathering such follow-up information.
- However, in its current form, the NPDS is designed to be completed by a nurse or other care professional and is written in a language that assumes a level of professional nursing knowledge. Although it has been used in studies involving telephone interviews[10], the NPDS is not currently suitable for application for postal surveys in the community, where the majority of respondents would be non-professional carers or family members,

The purpose of the current study was therefore to develop an adapted postal version of the NPDS which is suitable for self-completion by informal carers and family members, and to evaluate this alongside the original NPDS administered by telephone in a cohort of carers who look after adults with acquired brain injury at home in the community.

Methods

Development of the postal version of the NPDS

The NPDS[2] is constructed on two subscales:

- A Basic Care Needs subscale contains 12 items
    - each rated on an ordinal scale of up to 0-5 (total range 0-65)
- A Special Nursing Needs subscale contains 7 items
    - each rated dichotomously at 0 or 5, (total range 0-35)

A short set of further questions under five headings is added to apply the algorithm which coverts the NPDS to the NPCNA.

The following changes were made to the original NPDS in order to make it suitable for self-completion by carers:

- The general layout was changed for clarity
- Clinical terminology was replaced by lay language
- The item descriptors and instructions were re-formatted as questions. For example, the descriptor *"Mobility: Give most usual method of mobility around bay (hospital) or indoors (home))"* was changed to *"How much help does he/she need to get around indoors?"*
- An item in the Special Nursing Needs section regarding 'MRSA Screening/isolation' was removed due to its irrelevance in the community setting. Instead, it was replaced by an item regarding the application of therapeutic splints or braces by a trained carer.

Apart from this one item, the structure of the postal NPDS was unchanged from the original version and the total scale remains on a range of 0-100.

Participants

The evaluation of validity was undertaken as part of a large nationally-based project, funded by a grant from the Department of Health Research and Development Fund to investigate the experiences of people who care for someone with an acquired brain injury (ABI)[11].

The participants for this larger study were recruited through a large regional rehabilitation service in North-west London, and through voluntary organisations including Headway and the Encephalitis Society.

- Letters were sent out widely to people registered with these organisations, explaining the purpose of the study and inviting the participation of carers who spend at least several hours a day caring for an adult (aged 16–65) with an acquired brain injury.
- Respondents were contacted by telephone to explain the details of the study and were then sent a questionnaire pack, which included, among other questionnaires, the postal version of the NPDS and the Barthel Index.

For the purpose of this validation, a convenience sample was selected from the main study cohort.

A positive sampling strategy was adopted to ensure representation:

a) across the range of dependencies which are usually seen in patients discharged from rehabilitation services (ie approximately 0-40) and
b) across the range of underlying diagnoses (stroke, trauma and encephalitis).

Consent for this study was obtained separately during the explanatory telephone call, since it involved an additional telephone interview to administer the original NPDS by telephone.

Ethics permission was obtained from the Local Research Ethics Committee (Harrow) permission was in relation to the individuals recruited through the NHS service, but was not required for individuals recruited through the voluntary organisations.

Using a repeated measures design, consenting carers were asked to complete:

a) the adapted NPDS via postal questionnaire *and*
b) the original NPDS, administered by telephone interview in the style normally adopted by nursing staff.

The two questionnaires were delivered in counterbalanced order.

To minimise recall bias a gap of at least one-week was left in between administration of each questionnaire.

Data analysis

NPDS data from the two versions were entered separately into the purpose-designed computer programme to compute the NPCNA estimations of total weekly care hours and approximate weekly cost of care. Association between the total NPDS score for the two versions was tested using Spearman rank correlations. Similarly NPCNA estimations of weekly care hours and costs.

Any systematic bias between the two methods was tested for using Wilcoxon Sign Rank tests.

Item by item agreement between the original and postal NPDS was tested using quadratic-weighted Cohen's Kappa statistics for the Basic Care Needs Subscale.

Kappas could not be computed for the Special Nursing Needs subscale because of a preponderance of zero scores, so only % absolute agreement is given for those items.

Results

The demographics of the study population are given in Table 1.

Table 1 The demographics of the client population (n=50)

Age	Mean 48.5 (SD 13.6) years
Male: female ratio	32:18
Time since injury	Median 6 (IQR 3-11) years
Cause of brain injury:	
Stroke	14 (28%)
Trauma	15 (30%)
Encephalitis	14 (28%)
Other (Hypoxia, tumour)	7 (14%)
Carer relationship to client	
Spouse or partner	32 (64%)
Parent	16 (32%)
Sibling	1 (2%)
Friend	1 (2%)

23 (46%) respondents completed the postal questionnaire first, and 27 the original version first.

The median time lag between telephone interview and receipt of the postal version was 68 days (IQR 58-84) in those who received the postal version first, compared with only 15 days (IQR 9-22) in those who were interviewed first.

- Time lag appeared to be a particular problem when the postal questionnaire was completed first, because carers were sometimes difficult to get hold of on the telephone, often necessitating several phone calls before a successful interview could be completed.
- However, despite their longer time lag, the former group did not show any larger discrepancy in NPDS scores between their two different ratings, than the latter group (Mann Whitney Z -.73, p=0.46).

The relationship between total NPDS and subscale scores for the postal and original version is shown in Table 2, and scattergrams are shown in Figures 1 and 2.

Correlations between the two methods were highly significant (p<0.001) for the NPDS and both its subscales, as well as for the derived NPCNA estimations of weekly care hours and costs.

Both versions showed similar, moderately strong correlations between total NPDS score and the Barthel Index (postal version: Spearman rho 0.77, original version: rho 0.76 – both significant at p<0.001)

Table 2: Associations between NPDS and NPCNA scores for the postal and original version of the NPDS

	Original version Median (IQR)	Postal version Median (IQR)	Correlation	P
NPDS				
Total score	18.5 (12-25) Range 3-59	17 (8-25) Range 0-54	rho 0.84	p<0.001
<u>Subscales:</u>				
Basic Care Needs	15 (8-23)	15 (8-20)	rho 0.89	p<0.001
Special Nursing Needs	5 (0-6)	0 (0-5)	rho 0.37	p<0.01
NPCNA estimations				
Weekly care hours	35 (22-42)	31 (17-38)	rho 0.85	p<0.001
Approximate Weekly cost of care	£1100 (£1095-1574)	£1100 ($366-1100)	rho 0.61	p<0.001

Figure 1: Scatterplot of total NPDS scores

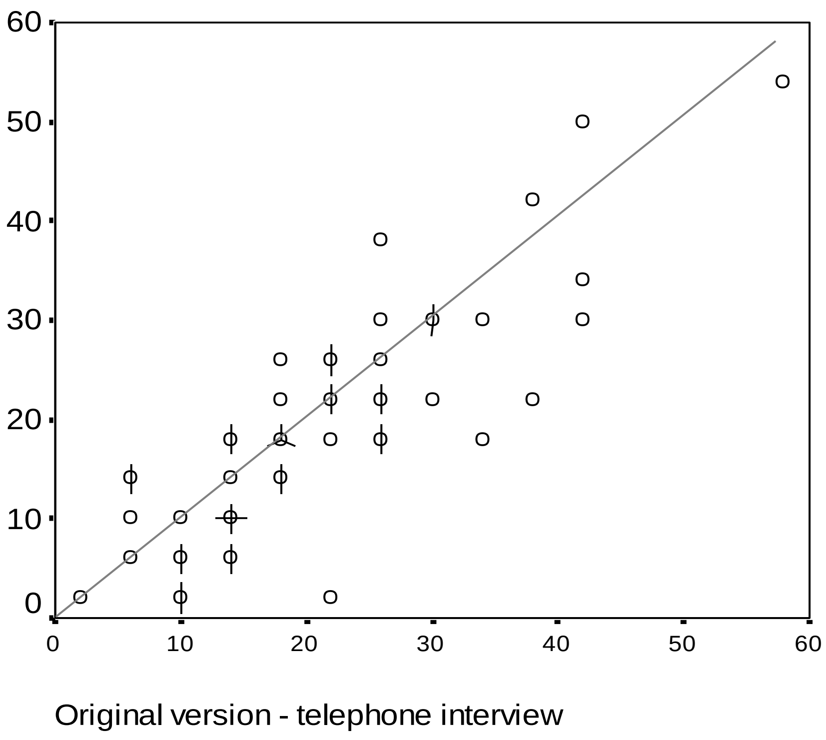


Figure 2a: Scatterplot of estimated weekly care hours

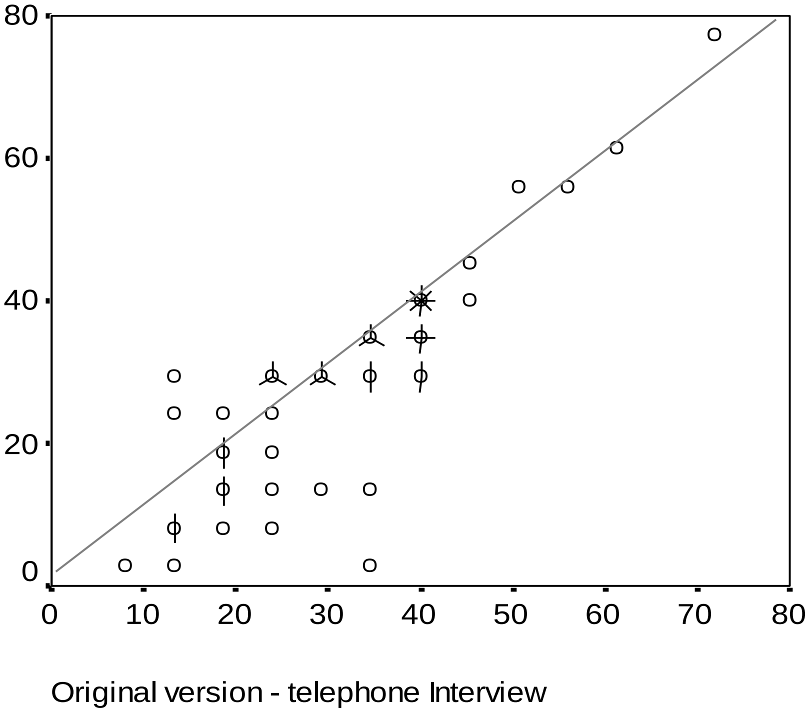
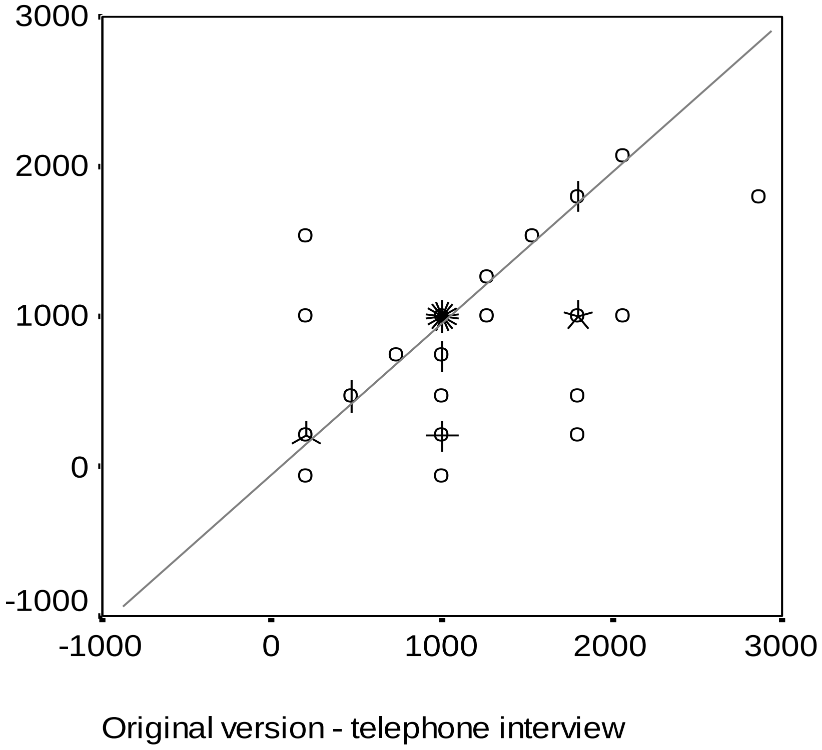


Figure 2b: Scatterplot of estimated weekly care costs



An item-by item analysis of agreement between the two versions is summarised in table 3.

Table 3: Item-by-item analysis for the agreement between the postal and the original version of the NPDS and any significant differences observed

Item	% Agreement	Weighted Kappa	Wilcoxon z score	Adjusted ** significance	Lower rating
Basic care needs					
Mobility	72%	0.56	-3.64	**<0.001**	Original
Transfers	86%	0.85	-1.13	0.26	
Bladder management	70%	0.69	-0.09	0.93	
Urinary incontinence	58%	0.64	-2.27	0.02	
Bowel Management	76%	0.83	-2.05	0.04	
Faecal incontinence	84%	0.69	-2.53	**0.01**	Original
Washing / grooming	62%	0.66	-0.42	0.67	
Bathing / showering	60%	0.85	-2.60	**0.01**	Postal
Dressing	80%	0.81	-0.26	0.79	
Eating	78%	0.71	-1.60	0.11	
Drinking	78%	0.60	-.71	.0.47	
Enteral feeding	95%	0.91	-1.34	0.18	
Skin pressure relief	91%	0.45	-1.13	0.26	
Safety awareness	54%	0.65	-1.85	0.06	
Communication	66%	0.76	-1.57	0.116	
Behaviour	48%	0.52	-2.6	**0.01**	Postal
Special Nursing Needs subscale*					
Tracheostomy	100%	-	0.00	1.00	
Open wound	92%	-	-1.00	0.32	
>2 night-time interventions	80%	-	-2.53	**0.01**	Postal
Psychological input	76%	-	-0.57	0.56	
Splints	98%	-	-1.00	0.32	
Intercurrent illness	64%	-	-2.83	**0.005**	Postal
One-to-one specialing	88%	-	-0.816	0.41	
Additional questions					
Assistance with stairs	79%				
Meal provision	78%				
Medication	72%				
Qualified nurse / trained carer	96%				
Domestic help	69%				

*Kappas could not be computed

** Level for significance taken at p≤0.01 in view of the large number of tests.

Quadratic-weighted Kappa scores for items in the Basic Care Needs subscale ranged from 0.45 ('moderate agreement' according to Fleiss 1981[12]) to 0.91 ('excellent agreement').

- Three items showed less than 60% absolute agreement:
    - *urinary incontinence* was rated more severely in the postal version (z=-2.27, p=0.02)
    - *safety awareness* and *behaviour* were rated more severely on the original version at interview (z=-2.58, p=0.01 and z=-1.8, p=0.06 respectively).

Overall there was a tendency for the postal carer-completed scores to be slightly lower than the interview scores, although this did not reach significance for the unconverted total NPDS scores (Wilcoxon signed rank test z=-1.9, p=0.052).

However, when computed to the NPCNA, weekly care hours and cost of care were significantly lower for the postal version (z=-2.6, p=0.01, and z=-3.3, p=0.001 respectively). Two main contributing factors to this discrepancy appeared to be under-rating on the postal version of *safety awareness* the need for *>2 night-time interventions* (z=-2.5, p=0.01) (see discussion).

Discussion

The study findings provide overall support for the hypothesis that it is feasible to administer the NPDS by postal questionnaire, and that the postal version of the NPDS provides essentially similar information to the original version delivered by telephone interview, especially at the level of the total NPDS score.

However, the agreement is not perfect and there may be two main reasons for this.

1. The long time lag (up to two-and-a-half months) between administration of the two versions could have been a contributory factor, if real change in dependency occurred during that time. Case-by-case exploration identified four cases that did appear to have made real changes in dependency during this delay, but generally the population appeared to be stable with respect to dependency, which is not surprising given the length of time since brain injury (median 6 years).
2. Alternatively, there may be genuine differences in interpretation of the questions in the postal version, compared with interview administration, when a skilled interviewer can probe in more detail to obtain a more accurate picture.

There was an overall trend towards lower scores on the postal version of the NPDS, which led to significantly lower NCPNA estimations of the weekly cost of care. Closer analysis revealed that principal sources of discrepancy were relative under-reporting of a) *safety awareness* and b) of the need for *>2 night-time interventions* on the postal version.

Both of these items add significantly to the need for care. People with poor safety awareness are more likely to need live-in care, and need for more than two night-time interventions identifies a need for *waking night care* in the NPCNA algorithm. These factors add a large additional cost to the weekly care package, hence this made a more noticeable difference when translated into care hours and costs than for the total NPDS.

These and other smaller discrepancies have led to further revisions in wording for the postal version, but in the meantime the potential for under estimation of care needs in these areas should be noted.

There a number of recognised limitations to this study.

- The postal version was evaluated against telephone report rather than face to face interview or direct observation. However, this is the method by which the original NPDS is most frequently applied in routine practice when information is required from a remote source. This allowed inclusion of individuals from a larger national base, as opposed to just those living within easy travelling distance.
- Although the order of administration was counterbalanced, it was not randomised. This was partly for pragmatic reasons given the time-pressures on the main study of which this was a small part. Carers were often busy and unable to speak for long. Hence it was often necessary to take an opportunistic approach. However, our analysis revealed no evidence of systematic bias arising from the order of administration.
- Although the maximum possible NPDS score is 100, the study population clustered in the lower two-thirds of the scale (NPDS 0-59). However, in reality this is the range of scores normally observed for people with neurological disabilities living in the community and tallies with those reported in other studies[2, 10].
- Finally, this is a small study population confined to clients with acquired brain injury. Larger studies across different populations will be required in order to confirm the usefulness of the revised version of the postal NPDS in this and other contexts.

Clinical messages

1. A postal version of the Northwick Park Dependency Score (NPDS) was developed to facilitate remote recording of dependency by family and informal carers in the community
2. The postal version yielded broadly similar results to the original version (administered by telephone interview) for total NPDS scores.
3. A slight trend towards lower NPCNA estimates of dependency through the postal version led to significantly lower estimates of care hours and costs, which particularly reflected care needs for night time interventions and poor safety awareness. Further adjustment has since been made to the postal version.
4. Further studies using the revised version across different populations will be required in order to confirm the usefulness of the postal NPDS in this and other contexts.

Acknowledgements

The authors would like to thank all the carers and clients who gave generously of their time to take part in this study.

Statistical advice was provided by Paul Bassett, Consultant Statistician.

Financial support for the main study was provided through a Department of Health R&D grant (no 030/0059) and support for preparation of this manuscript was kindly provided by the Luff Foundation.

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