



To what extent do pre-discharge tests of competence predict later performance at home in elderly patients, and what factors are influential?

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Summary

Title and duration

To what extent do pre discharge tests of competence predict later performance at home in elderly patients, and what factors are influential? 01/01/1999 to 30/06/2000.

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Main research questions

1. Can pre-discharge Barthel Activities of Daily Living scores be used to predict the functional performance of elderly people 6 weeks after discharge from hospital?
2. What other factors are relevant to the prediction of functional performance of elderly people in the home after discharge from hospital?
3. What are the key domains of importance to patients, carers and relatives regarding discharge from hospital?

Methods and sample size

A multi-centre descriptive study of elderly patients at five hospitals within the East Kent Health Authority region: Nunnery Fields Hospital in Canterbury, Royal Victoria Hospital in Folkestone, Buckland Hospital in Dover, Queen Elisabeth the Queen Mother Hospital in Margate and William Harvey Hospital in Ashford.

To assess the Barthel ADL index as a means of predicting later functional performance after discharge (research question 1), a comparison was made between the Barthel scores of patients just before discharge from hospital and the same patients' scores six weeks later. Functional performance was also measured, in the latter case using an extended ADL questionnaire. To inquire into the other factors which may act as predictors to functional performance (research question 2), a range of descriptive data were collected on patients prior to discharge. These included: age, sex, details of social support, reason for admission, other pathologies, and psychological variables including: anxiety, depression and perceived personal control. These variables were then considered in the light of the functional performance of patients six weeks after discharge from hospital. 104 patients took part in this section of the study; 59 from Nunnery, 24 from Royal Victoria, and 21 from Queen Elisabeth.

In tandem with the above, a series of semi-structured interviews and focus groups were held with patients, their carers and with members of the multidisciplinary team, including: occupational therapists, physiotherapists, speech and language therapists, nurses, social workers and consultants. Data from these interviews were used to uncover domains of importance key to each party regarding the discharge process, and in particular to examine the ways in which the discharge process can fail patients, ways in which the process can be improved, and its most and least appreciated aspects (research question 3). In total, 14

patients, 4 carers and 3 consultants were interviewed. In addition, 3 patient and 4 health professional focus groups were conducted.

Problems

The number of patients recruited into the first part of the study (assessing the Barthel ADL) index, was fewer than anticipated for a variety of reasons. In two of the hospitals, Royal Victoria and Queen Elisabeth, a large proportion of very frail or cognitively impaired patients resulted in a decreased number suitable for inclusion into the study. At Royal Victoria, this was exacerbated by a slow throughout of patients due to changes in joint assessment process, difficulties in finding places for patients in residential and nursing homes, and the closure of one 21 bed unit.

Findings

Mean Barthel score on discharge was 16.1. Six weeks later this had risen to 17.0. These means were significantly different, $p = 0.011$ (Wilcoxon). Pre-discharge Barthel scores were also highly correlated with both week 6 Barthel scores, $p = 0.01$ (Spearman) and week 6 extended ADL scores, $p = 0.01$ (Spearman). Three categories of disability were identified from pre-discharge Barthel scores: SEVERE, Barthel = 0-11; MODERATE, Barthel = 12-16; MILD, Barthel = 17-20. These categories corresponded to abilities within key self-care domains. A clear relationship between pre-discharge disability category and week 6 extended ADL score was identified, with SEVERE patients scoring most poorly and MILD patients scoring the highest. The differences between the extended ADL scores of patients in each category were highly significant, $p = 0.005$ and $p = 0.001$ (Mann-Whitney).

Conclusions

Pre-discharge Barthel scores may be used to predict ADL performance after discharge in general terms and to a limited degree. This predictive ability also extends into the wider domains covered within an extended ADL instrument. Relationships identified between patients' ADL and extended ADL scores and how well they thought they were managing suggests that the domains assessed are relevant to this population.

Experienced teams with good communication between members is crucial to successful discharges. Good communication is essential for the smooth transfer of support from hospital to community. Nurses appointed to bridge the gap as Liaison nurses and Discharge co-ordinators could improve communication and ensure a smoother transfer. If, but only if, current levels of therapy in hospital could be maintained many patients would like to go home earlier. Most patients wanted more information, and a greater sensitivity to individual patient needs should help to ensure patients receive the information they want. Both formal and informal ways of giving information are needed and it seems important, when talking to patients, to check that they have heard and understand what is said. Listening to the patient and allowing or even facilitating patient decision-making would be appreciated by many patients.

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1. Introduction

Discharge from hospital and returning home, especially after a long stay, can be a difficult time for elderly patients and their relatives. Though hospital and community authorities aim to provide a 'seamless service', this is often difficult to achieve. Carey and Posavac (1982) found that support for patients once home was often unplanned and haphazard.

Most studies looking at post discharge outcomes have tended to follow up patients discharged from hospital over periods of six months or more, (Granger et al. 1992, Legh Smith et al 1986, Henley et al 1985). We were more interested in the time period around the discharge itself firstly to find whether assessment prior to discharge predicted functioning at home after six weeks and secondly to examine the process of discharge from the different perspectives of those involved. Patients are usually assessed prior to discharge from hospital to decide whether they are ready to manage in their home circumstances and follow the diagrammatic representation in Figure 1 below:

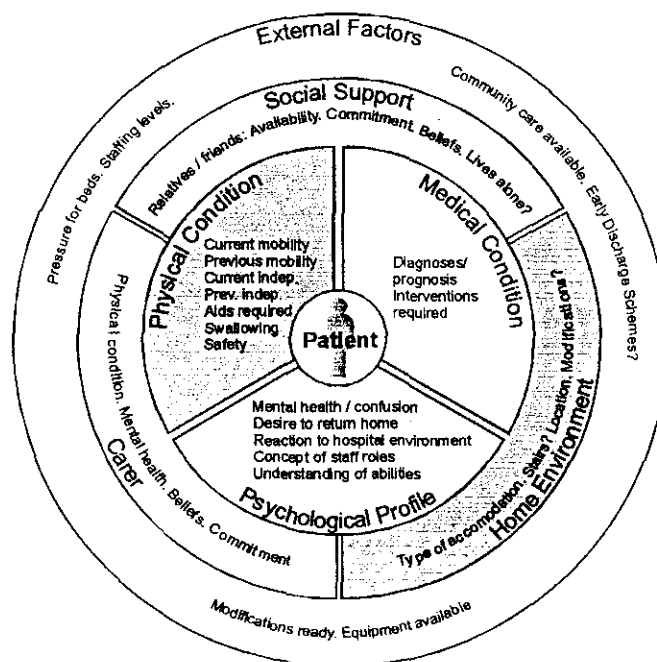


Figure 1. Factors Considered in Discharge Planning

However, little is known about the extent to which tests before discharge accurately predict how patients will manage at home. There is clearly an opportunity for potential problems in the handover from medical to social services. Hakim and Bakheit (1998) found that early liaison between rehabilitation and social services could reduce what they termed the unnecessary length of hospital stay. However what is necessary or desirable may well be different from different viewpoints, and this is what we sought to discover. More in depth information from patients, therapists, their carers and health professionals should provide insights which enable identification of factors which facilitate successful discharges and which mitigate against them.

There were two arms to the study. In the first the relationships between pre discharge assessments and post discharge performance were examined. In the second interviews and focus groups were undertaken with patients and their carers, and with health professionals involved in the discharge process to explore differing perspectives and to identify strengths, weaknesses, and ways to improve service for patients.

2. Barthel as a predictor of later performance

2.1 Design

A descriptive study whose aim was to assess the predictive ability of the Barthel assessment for post discharge level of activity. Objectives were to conduct a pre-discharge Barthel assessment, followed by a repeat assessment 6 weeks post-discharge, which would include both the Barthel and an Extended ADL. Figure 2 provides a schematic of the study procedure.

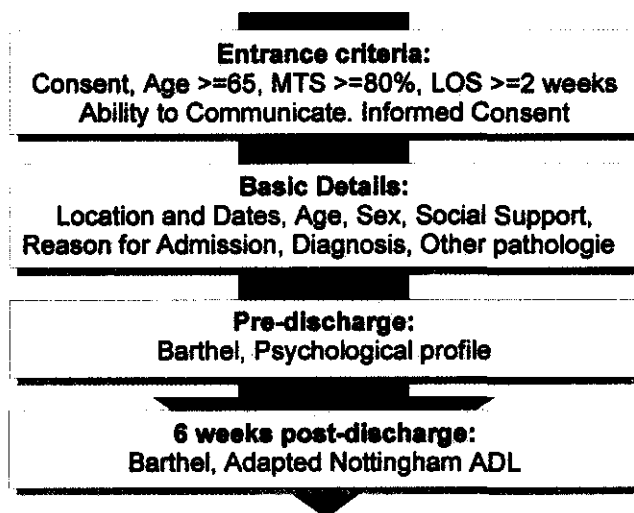


Figure 2. Study Procedure

2.2 Subjects

Patients from hospitals within East Kent Health Authority NHS Trust were recruited into the study. Table 1 lists each hospital and the number of patients recruited. Patients were selected from both acute and post-acute rehabilitation wards.

<i>Hospital</i>	<i>Number of patients recruited</i>
Nunnery Fields Hospital, Canterbury	59 (56.7%)
Royal Victoria Hospital, Folkestone	24 (23.1%)
Queen Elisabeth Hospital, Margate	21 (20.2%)
Total	104 (100%)

Table 1. Recruitment Locations

Selection was made according to the following entrance criteria:

- Age of 65 +
- Expected length of stay (LOS) of 2 weeks +
- Expected discharge to home or residential care
- Mental test score (MTS) of 80% +
- The ability to communicate verbally.

Patients unable to communicate verbally or those with confusion were excluded as assessments were conducted via direct interview. An arbitrary minimum length of stay of 2 weeks was imposed in order to exclude short-stay patients who were expected to quickly

regain previous levels of activity. Patients whose expected discharge destination was nursing care were excluded as this study aimed to focus on patients in an independent or semi-independent environment.

The mean age of the sample was 82.2 years with a standard deviation of 7.0 and a 95% confidence interval from 80.1 to 83.6 years. The minimum age was 65 and the maximum 96. Of the sample, 71 (68.3%) were female and 33 (31.7%) male. Considering social circumstances, 65 (62.5%) of the sample were widowed, 31 (29.8%) married and 8 (7.7%) single. 63 (60.6%) lived alone, 29 (27.9%) with a spouse, 9 (8.7%) with a relative and 3 (2.9%) with someone else. Patients were admitted with a variety of diagnoses. Table 2 gives patients by diagnostic category.

<i>Diagnosis</i>	<i>Number of patients</i>
Musculo-skeletal	45 (43.3%)
CVA	25 (24.0%)
Infection	15 (14.4%)
Cardiac	6 (5.8%)
Other	13 (12.5%)
Total	104 (100%)

Table 2. Diagnosis

2.3 Materials

The assessment instrument under scrutiny was the 10 item Barthel (Mahoney & Barthel, 1965). The Barthel index has demonstrated reliability (Richards et al., 2000) and was chosen in spite of its known ceiling effect and the inclusion of items measuring both impairment and disability, due to its widespread use within East Kent and elsewhere. The scale comprises the following sections: bowels, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stairs and bathing (Appendix 1). Each item is scored between 0 and 3, with a maximum possible score of 20. Inter-rater reliability within the specific domains of this study was also measured by repeating the assessment on a sub-sample of patients ($n = 11$) using different assessors. A highly significant correlation (Spearman, $p = 0.01$, $r = 0.992$, 95% confidence interval from 0.97 to 1.00) was found between the two sets of scores.

The Barthel scale covers a limited range of functional activity and has a known ceiling effect. Hence, in conjunction with the Barthel, an extended ADL assessment was performed 6 weeks post discharge in order to obtain a more comprehensive picture of performance at home. The assessment chosen was an adapted version of the Nottingham Extended ADL (Nouri & Lincoln, 1987) (Appendix 2). The Nottingham Extended ADL comprises 21 items covering a range of activity broadly categorised into: mobility, kitchen, domestic tasks and leisure activities, and was chosen because of its ease of application and relevance to everyday activity. Items are scored according to the patient's current level of activity for each item, with: "not at all" = 0, "with help" = 1, "alone with difficulty" = 2 and "alone easily" = 3.

The form was adapted in order to simplify assessments and to reduce assessment time. For the adapted form, pilot work was undertaken to ascertain which items could be either combined or removed from the assessment with minimal loss of breadth. The resultant form was reduced to 16 items within the same general categories. For ease of completion, the distinction between "with difficulty" and "easily" was also removed. Items on the adapted

form were hence scored between 0 and 2, with a score of 2 representing "without help" (Appendix 3).

The content validity of the Adapted ADL was measured by conducting the standard and adapted assessments in immediate succession on a sub-sample of 10 patients. Scoring each form as above, a highly significant correlation (Spearman, $p = 0.01$, $r = 0.982$, 95% confidence interval from 0.92 to 1.00) was found between the two sets of scores. Inter-rater reliability was measured by repeating the adapted form on a sub-sample of 10 patients using different assessors. Again, a highly significant correlation (Spearman, $p = 0.01$, $r = 0.970$, 95% confidence interval from 0.87 to 0.99) was found between the two sets of scores.

In order to increase the form's sensitivity to the variability in performance of this age group, a distinction was made between "*can't do*" and "*doesn't do*", enabling items which the subject did not normally undertake to be discarded from the assessment and a "total relevant score" to be calculated. Finally, in an attempt to monitor the change in activity level between 'before' and 'after' hospital respectively, subjects were also asked to recall levels of activity before their most recent stay in hospital with a corresponding score recorded in a separate section on the form.

Psychological data were also recorded. In previous research, mood state and perceived control have been shown to affect performance, e.g. Partridge et al., 1989. Mood state was assessed using the using the 14 item Hospital Anxiety and Depression (HAD) scale (Zigmond and Snaith, 1983). Perceived personal control was measured using the 9 item Recovery Locus of Control (RLOC) scale (Partridge et al., 1989).

2.4 Procedures

A Research Therapist (RT) was appointed at each participating hospital to recruit patients and to collect the data. The RTs were overseen by a Research Co-ordinator (RC) who was responsible for ensuring that assessment practices were consistent across the sites. Prior to commencing data collection, pilot work was undertaken at each hospital in developing the Adapted ADL assessment and training the RTs in its use. The RTs were also instructed in conducting the HAD and RLOC questionnaires. (All RTs were senior physiotherapists and were fully conversant with the Barthel assessment.)

Patients were asked for signed, informed consent, and those who passed the entrance criteria were recruited into the study. Patients were selected from a variety of acute wards as well as stroke rehabilitation units. On recruitment, basic details were recorded from medical notes, namely: name and hospital number, location, dates of admission, referral and expected discharge, age, sex, reason for admission and main diagnosis, other pathologies, mental test score, communication and social support details.

Recruitment was generally conducted immediately prior to discharge, in which case the Barthel assessment was conducted at the same time. The Barthel score was obtained through interview with the patient rather than observation, and cross-checked by referring to nursing staff where necessary. The Pre-discharge Barthel assessment was accompanied by the psychological assessment comprising the RLOC and HAD questionnaires. In instances where recruitment was not conducted immediately prior to discharge or when discharge was re-scheduled, discharge dates were monitored by the RTs and patients were assessed at the appropriate time. All patients were assessed within 3 days of discharge. In cases where

discharge was prolonged after an assessment, patients were reassessed and the previous assessment scores discarded.

Discharge dates were recorded by the RTs, and patients were reminded of their participation in the study after 4 weeks by letter. Patients were reassessed after 6 weeks, with the assessment coinciding with existing day hospital visits where possible. In cases where the patient was either unable or unwilling to travel to hospital, assessments were conducted in the patients' homes. The 6 week post-discharge assessment comprised a repeat of the Barthel assessment and the Adapted Nottingham ADL questionnaire.

Basic details forms were photocopied and returned to the University of Kent, Centre for Health Services Studies, where the information was transferred to database by the RC. This information was also used by the RC to track patients through the study and ensure that all assessment were conducted on schedule. The RC made regular visits to each hospital to cross-check the progress of patients in the study, and to collect assessment forms for transfer to database. Regular reliability sessions were also held at each hospital between the RC and RTs in order to maintain consistency and measure the inter-rater reliability of the Barthel and ADL assessments.

2.5 Results

2.5.1 Characteristics at Discharge

The mean Barthel score for the whole sample was 16.1 ($n = 104$) with a standard deviation of 3.1 and a 95% confidence interval from 15.5 to 16.7. Minimum and maximum scores were 5 and 20 respectively. Figure 3 shows the number of patients with each Barthel score at discharge. (No patients were discharged with a Barthel score of less than 5.)

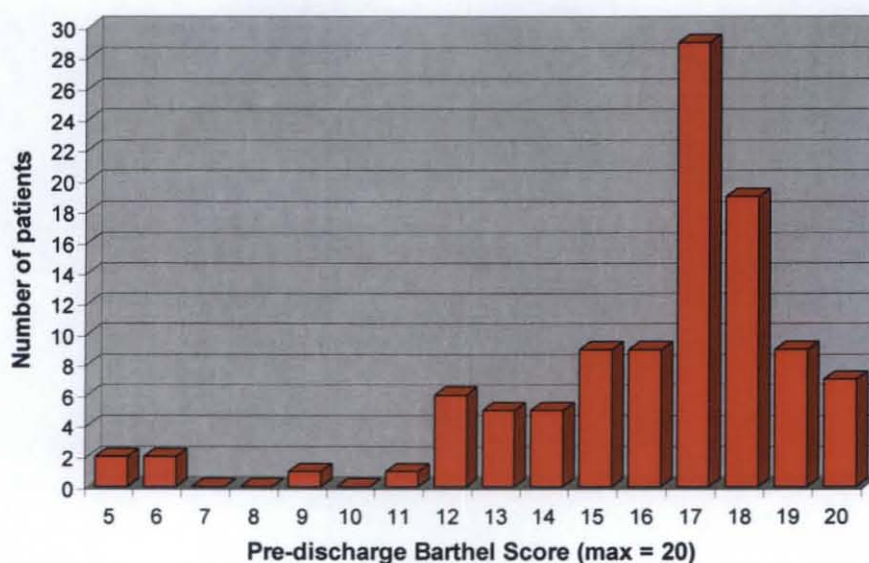


Figure 3. Barthel Scores: Distribution

From the individual pre-discharge Barthel scores, three clear categories of disability were identified; these were named "Severe", "Moderate" and "Mild" respectively, and are summarised as follows: Severe patients required help with most of feeding, grooming, toilet use, dressing and transferring. They were wheelchair dependent and were unable to use either

stairs or bath ($n = 6$). Moderate patients were independent in feeding and toilet use, but required some help with grooming, dressing, transferring and mobility. They were unable to use either stairs or bath ($n = 34$). Mild patients were independent in all areas except stairs and bathing ($n = 64$). The Barthel score ranges for each category were: Severe = 0-11, Moderate = 12-16, Mild = 17-20, and are also visible within Figure 3. Table 3 gives the specific criteria for each category.

Category	SEVERE $n = 6$	MODERATE $n = 34$	MILD $n = 64$
Barthel scores	0 - 11	12 - 16	17 - 20
Feeding, toilet	<i>Some help</i>	<i>Independent</i>	<i>Independent</i>
Grooming, dressing	<i>Some help</i>	<i>Some help</i>	<i>Independent</i>
Transfer, mobility	<i>Wheelchair dep.</i>	<i>Some help</i>	<i>Independent</i>
Stairs and bathing	<i>Unable</i>	<i>Unable</i>	<i>Some help</i>
Bowels and Bladder	<i>No specific characteristics</i>		

Table 3. Categories of Disability

Levels of anxiety and depression, measured using the HAD scale (Zigmond and Snaith, 1983), are shown in Figure 4. The authors suggest scores of 8 or more on each of the anxiety and depression indices to be abnormal. The figure shows the percentages of patients classified in this way.

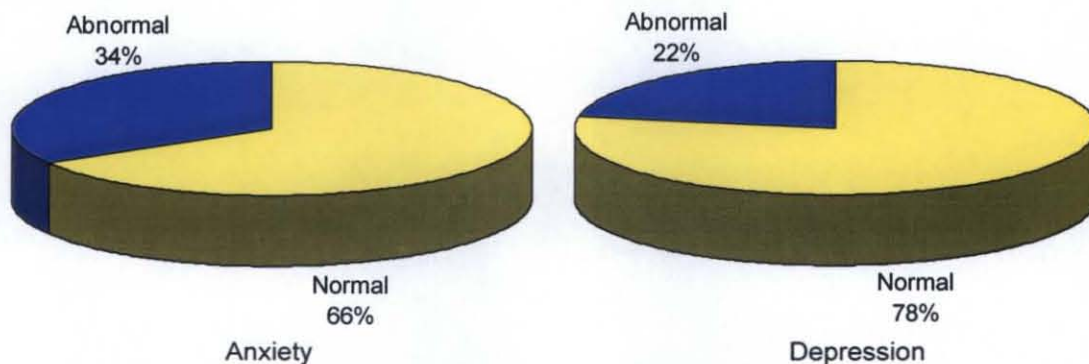


Figure 4. Anxiety and Depression

Classifying patients by initial severity, mean anxiety scores were: Severe: 5.7, 95% confidence interval 2.3 to 9.0, Moderate: 6.0, 95% confidence interval 4.6 to 7.5, Mild: 5.8, 95% confidence interval 4.8 to 6.8. Differences between these values were not significant, and there was no apparent relationship between anxiety and initial severity. Mean depression scores for the three categories were - Severe: 8.3, 95% confidence interval 2.8 to 13.9, Moderate: 5.9, 95% confidence interval 4.6 to 7.2, Mild: 4.6, 95% confidence interval 3.9 to 5.3. These results could suggest a relationship between severity and depression, with a higher level of disability being associated with a higher level of depression. Individual depression scores were correlated with pre-discharge Barthel (Spearman, $p = 0.5$, $r = -0.23$, 95% confidence interval from -0.41 to -0.04) and the difference between the mean depression scores of Severe and Moderate patients was significant at a low level (t-test, $p = 0.2$, difference between means = 2.4, 95% confidence interval from -1.2 to 6.0).

Perceived personal control was measured pre-discharge using the RLOC scale (Partridge et al., 1989). The scale measures the degree to which subjects feel that control of their recovery is in their own hands, or is in the hands of others. Scores range between 9 and 45, with the latter score reflecting the highest possible belief in personal control. The mean RLOC score for the whole sample was 35.5 with a standard deviation of 3.8 ($n = 104$) and 95% confidence interval from 34.8 to 36.3. Minimum and maximum scores were 21 and 45 respectively.

Mean RLOC scores for patients classified by initial severity were - Severe: 31.6, 95% confidence interval from 26.8 to 36.4, Moderate: 35.8, 95% confidence interval from 34.1 to 37.5, Mild 35.4, 95% confidence interval from 34.4 to 36.4. These data could suggest a relationship between severity and perceived control, with a higher level of disability being associated with a lower level of perceived control. The difference between the RLOC scores of Severe and Moderate patients was significant (t-test, $p = 0.1$, difference between means = 4.2, 95% confidence interval from -0.4 to 8.8).

Of the basic details collected, there were no significant differences in characteristics between patients in the three severity groups. However, perhaps worthy of note was a slightly higher mean age for patients in the Severe group (84.1 compared with 82.2 for Moderate). The difference between means was 1.9 years with a 95% confidence interval from -4.3 to 8.2 years. A significant difference was found in length of stay, with a difference between the mean length of stay for Moderate and Mild patients of 10.9 days, 95% confidence interval from 1.4 to 20.4 days, $p = 0.05$ (t-test).

2.5.2 Change in Performance after 6 Weeks

Patients were reassessed 6 weeks after discharge from hospital. Where possible assessments coincided with existing day hospital visits, or were conducted in patients' own homes where unwilling to travel. As it was not always possible to perform the assessment on the due date, some variation in the time period between assessments was unavoidable. In practice, the mean period of time between discharge and the assessment was 44.0 days ($n = 78$) with a standard deviation of 9.9 days and a 95% confidence interval from 42.1 to 46.6 days. There were three outliers, with time periods of 33, 72 and 103 days respectively.

The mean Barthel score for the whole sample at 6 weeks post discharge was 17.0 ($n = 78$) with a standard deviation of 2.7 and a 95% confidence interval from 16.4 to 17.6. Minimum and maximum scores were 7 and 20 respectively. Of the 26 patients who were not followed up, reasons included refusal, admission to nursing homes and death. The mean difference between pre-discharge and week 6 Barthel scores was 0.7 with a 95% confidence interval from 0.2 to 1.1. Week 6 Barthel scores were significantly different to the pre-discharge scores (Wilcoxon, $p = 0.011$) and highly correlated with them (Spearman, $p = 0.01$, $r = 0.55$, 95% confidence interval from 0.37 to 0.69). The correlation between scores is illustrated in Figure 5, which shows individual pre-discharge Barthel scores plotted against week 6 scores. In the figure, it can be clearly seen that, in general, those with poor scores pre-discharge also scored poorly 6 weeks later. A quadratic regression line is also included in the chart. From this it can be inferred that, whilst scores improved during the six week interval, this improvement was smaller for patients with higher initial scores; this is likely to be a result of the Barthel's ceiling effect.

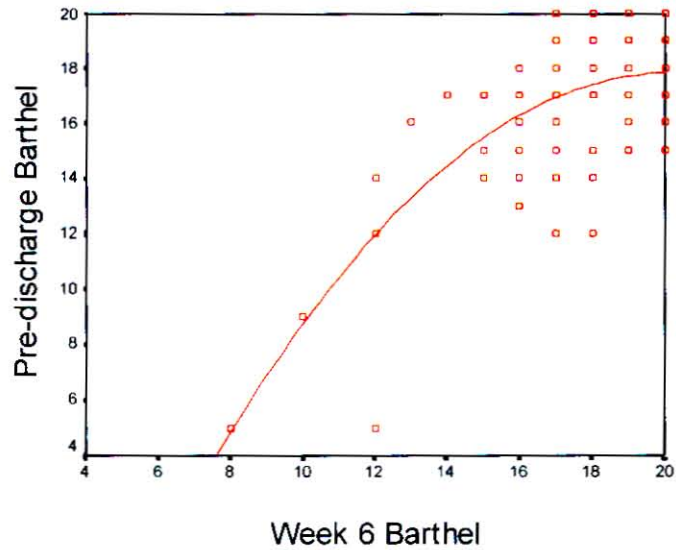


Figure 5. Pre-discharge and Week 6 Barthel Scores

In the previous section, a classification of patients according to initial severity was made. Applying these same categories to patients' Barthel scores 6 weeks post discharge, a picture can be obtained of the number of patients remaining in the same category, those whose performance improved, and those who deteriorated. Figure 6 illustrates. In the figure, each bar is labelled with the initial category on top and the final category underneath. Note that no patients improved from an initial classification of Severe to a week 6 classification of Mild. Neither did any patients with initial classifications of either Mild or Moderate deteriorate to Severe at week 6.

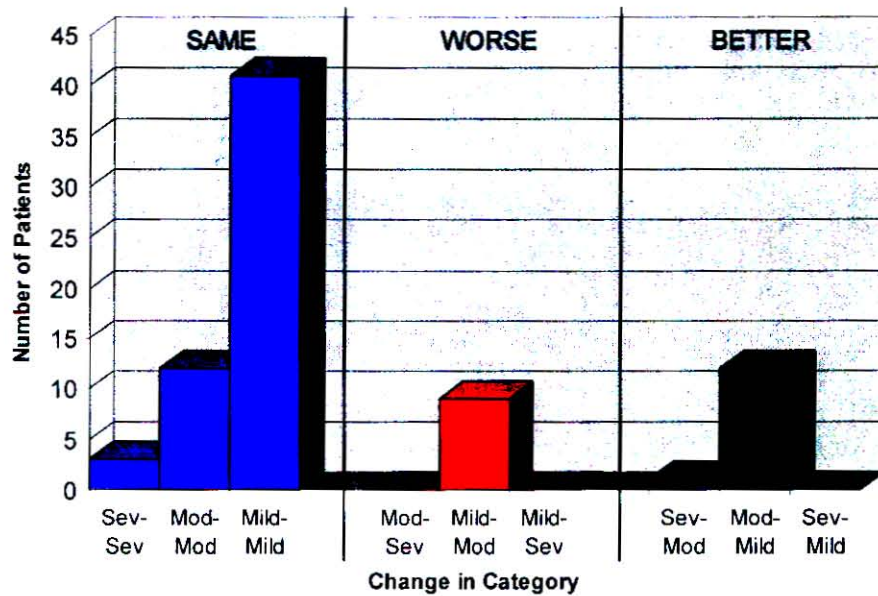


Figure 6. Change in Category of Severity

In general there were no noticeable differences between the basic details or psychological characteristics of the patients who remained the same, improved or deteriorated, although patients in the 'deteriorated' category did have a higher anxiety index than the others (deteriorated = 6.8, same = 6.0, improved = 5.1) These mean scores were not significantly different.

To provide more detail, the characteristics of patients who became unable to perform key functions within the Barthel assessment were singled out ($n = 6$). The Barthel items under consideration are: grooming, toilet use, feeding, transfer, mobility and dressing. These patients had a mean age of 84.0 years with a standard deviation of 7.5 and a 95% confidence interval from 76.2 to 91.9 years; 2 were male and 4 female; 4 lived alone and 2 did not. The mean length of stay in hospital of these patients was 45.7 days with a standard deviation of 20.4 and a 95% confidence interval from 24.2 to 67.1 days. Perceived control in this group was low, with a mean score of 33.2, standard deviation of 2.2 and a 95% confidence interval from 30.8 to 35.5. Mean anxiety and depression scores were 7.5 (standard deviation 4.1, 95% confidence interval from 3.2 to 11.8) and 6.7 (standard deviation 3.2, 95% confidence interval from 3.3 to 10.0) respectively, which are borderline abnormal.

Of the ADL items assessed, 'bathing' and 'using stairs' were the two most likely to cause anomalous results. In the case of bathing, patients in hospital were not permitted to bath independently and were hence scored as unable. In the case of stairs, a large proportion of patients, 28 (35%), did not have stairs at home. As the Barthel scale does not differentiate between 'cannot' and 'does not' and assessments were conducted verbally, these patients were scored as unable at week 6. Tests for correlations and significance were therefore repeated, discounting these items from the Barthel and Extended ADL scales. The only differences in the results obtained were: (1) a reduction in the confidence level of the correlation between pre-discharge and week 6 Barthel, from $p = 0.01$ to $p = 0.05$; (2) no correlation between pre-discharge Barthel and depression scores (previously $p = 0.5$).

2.5.3 Extended ADL performance

The Extended ADL included a range of items extraneous to the Barthel scale, and including: meal preparation, housework, mobility indoors and outdoors, using private transport, gardening and social activities (Appendix 3). Scoring is described in section 2.3, with maximum and minimum permissible scores ranging between zero and 32, a higher score reflecting a greater degree of functional independence. The mean week 6 ADL score was 19.0 ($n = 80$) with a standard deviation of 4.5 and a 95% confidence interval from 18.0 to 20.0. Minimum and maximum scores were 6 and 29 respectively. Week 6 Extended ADL was highly correlated with pre-discharge Barthel scores (Spearman, $p = 0.01$, $r = 0.62$, 95% confidence interval from 0.46 to 0.74), and also significantly different to them (Wilcoxon, $p = 0.01$).

Considering the ADL results of patients classified at discharge into the Severe, Moderate and Mild categories described earlier, there appears a relationship between initial severity and week 6 Extended ADL, with patients in the Severe category scoring a mean of 10.3, 95% confidence interval from 5.5 to 15.0 ($n = 4$) for their ADL, those in the Moderate category scoring a mean of 17.3, 95% confidence interval from 15.8 to 18.3 ($n = 25$), and those in the Mild category scoring a mean of 20.6, 95% confidence interval from 19.5 to 21.7 ($n = 51$). These scores were significantly different (Mann-Whitney, $p = 0.005$ for Severe and Moderate, and Mann-Whitney, $p = 0.001$ for Moderate and Mild respectively). Figure 7 illustrates.

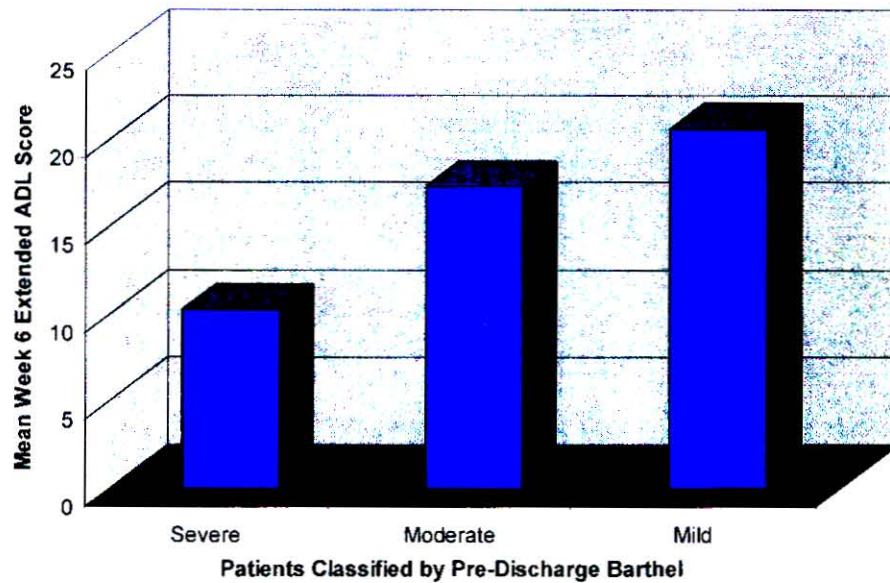


Figure 7. Mean ADL Scores by Initial Severity

The adapted ADL form makes a distinction between patients who could not do items, and patients who do not do items for other reasons, e.g. have never learnt to drive, do not have a garden, do not have stairs at home, etc. This enabled the data to be examined in terms of the proportion of patients who became unable to perform functions as a result of their physical condition. Considering individual ADL items, no patients classified pre-discharge as Severe were independent (able to do without help) at week 6 in any of: cleaning the house, dressing, toilet use, bathing, mobility indoors or outdoors, stairs, using or driving a car, gardening, social activities or their specified favourite pastime. Figure 8 shows the percentage of patients classified pre-discharge as Moderate and Mild who were able to independently complete each ADL item at week 6. The percentages given are in terms of the total numbers of patients for whom each function was relevant. (Severe patients have been excluded from the figure due to the small number in this group ($n = 4$)).

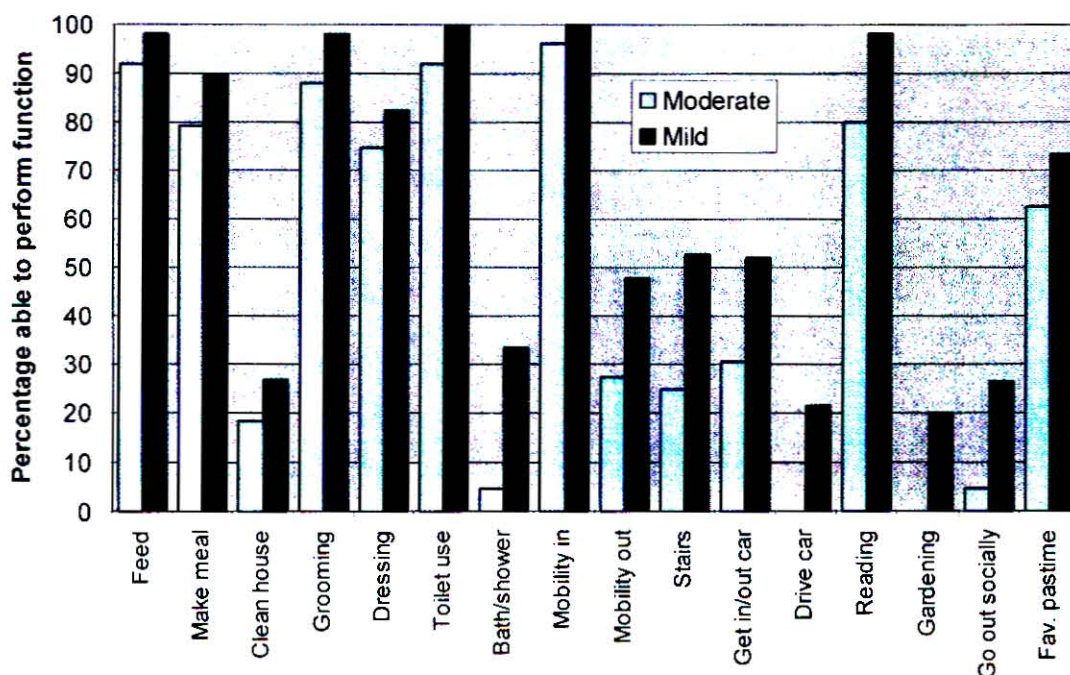


Figure 8. Percentage of Patients unable to Complete ADL items

2.5.4 Patients' perceptions of managing at home

During their week 6 assessments, patients were also asked how well they were managing, according to: "Very well", "Well", "Quite well", "Not very well" or "Not well at all". As one might expect, of the patients classified pre-discharge as Mild, the most common response was "Very well", whilst the most common response of the Moderate patients was "Well". Little can be inferred from the responses of the Severe group as only three were obtained (two of these responded with "Well" and one with "Quite well").

When categorising patients according to their response to the 'managing' question, a relationship emerges between the mean week 6 Barthel and extended ADL scores of patients in each response category, with the scores of patients responding "Not well at all" being the lowest and those of patients responding "Very well" the highest (Figure 9). Differences between these means were not significant.

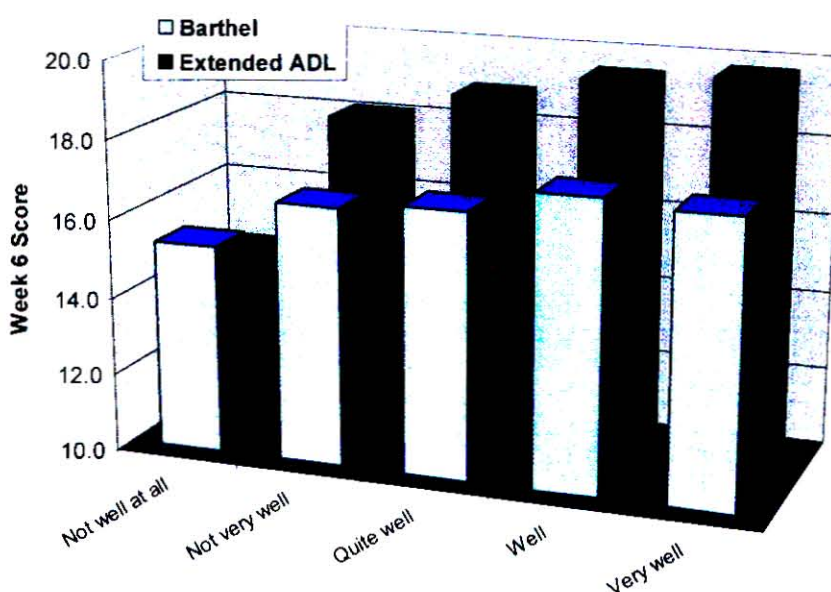


Figure 9. Mean Barthel and Extended ADL scores by 'Managing' Response

2.6 Discussion and conclusions

Three clear categories of functional ability emerged from the individual pre-discharge Barthel scores: Severe, Moderate and Mild, as described in section 2.5.1. These categories were useful in considering ability and change in ability in a context more meaningful than from changes in individual scores alone. Categories were established from the degree of assistance required in key activities, and hence broadly reflected both overall activity and ongoing support required. For example, and referring to Table 3, Mild patients were all capable of independent living given a suitable home environment, e.g. single floor living for those unable to use stairs. Moderate patients required varying degrees of care on a daily basis, with activities such as grooming, dressing and transfers, although being independent in feeding and toilet use, the actual amount of care may be small. In contrast, Severe patients required considerable assistance in most activities, and would hence require support throughout the day.

Six patients (6%) were discharged with a Barthel score which would classify them as Severe, 34 (33%) of patients had a pre-discharge Barthel score of between 12 and 16 and a resultant classification of Moderate, whilst 64 (62%) scored 17 or more and were classified as Mild. Of the information recorded on each patient, there was little to differentiate the categories of patients. However, Severe patients were characterised by a significantly lower level of perceived control (RLOC = 31.6), significantly higher depression score (depression = 8.3), and they were slightly older (84.1 years) (not significant). Mild patients spent significantly shorter periods in hospital than the other patients.

In general, the Barthel score of patients was seen to increase significantly during the 6 weeks immediately after discharge. This may reflect a real change in functional performance, or may partially reflect the restrictions of hospital and the freedoms of living at home. (This increase was not reflected by a change in the number of patients within each category of severity, rather in the mean scores.) The change in Barthel over this period was less pronounced for those patients more independent pre-discharge, although this is likely to be a result of the Barthel's ceiling effect. The correlation of pre and post discharge Barthel scores also implies that those with a higher degree of functional ability retain this after discharge, whilst poorer patients remain so. A small proportion of patients worsened (changed to a more severe category) during the first 6 weeks after discharge. Although no significant characteristics were identified to describe this group, these patients were slightly older than the others (mean age = 82.7), and did have a slightly higher anxiety index (mean anxiety score = 6.8).

Barthel results may have been affected by two factors: (1) the practice of not permitting patients to bath themselves in hospital; and (2) the fact that some patients live in bungalows and did not have the opportunity to use stairs during the 6 week period. In the first instance, some patients may have scored lower during their pre-discharge assessment than would have been the case were they permitted to bath on their own. This, however, would only affect the Mild group as it is unlikely that patients classified as Severe and Moderate on other criteria would be able to bath independently even if permitted. In the second instance, the fact that some patients did not have the opportunity to use stairs may have resulted in lower Barthel scores in some cases at week 6. However, as the extended ADL scoring system does differentiate between 'cannot' and 'does not', data from these assessments were available to estimate the likely impact on the Barthel scores. In practice, 28 out of the 44 patients scored as unable to use stairs on the Barthel scale did not have stairs at all (64%).

Recalling the key question of whether pre-discharge Barthel may be used to predict later performance, a broader measure of performance at home was required. For this purpose, an extended ADL assessment was used and scored as described in section 2.3. Of particular importance was the result that the groups of patients, classified according to their pre-discharge Barthel scores, also scored differently on their week 6 extended ADL assessments; with Severe patients scoring most poorly, Moderate patients with intermediate scores, and Mild patients achieving the best scores (Figure 7). The differences between the scores were all highly significant. Week 6 extended ADL scores were also highly correlated with pre-discharge Barthel scores. This strongly suggests that a Barthel assessment conducted pre-discharge can be used to predict performance after discharge within a considerably wider range of activity.

The classification of patients according to pre-discharge Barthel score had further implications, in that none of the Severe patients could independently perform any of the additional items included within the extended ADL scale, with the exceptions of preparing food and reading. Moderate and Mild patients fared somewhat better, although Moderate

patients en masse were consistently poorer in all of the extended ADL items, with very few able to bath or shower and none able to drive (Figure 8). Items that relatively few patients could perform independently included: cleaning the house, bath or shower, mobility outdoors, stairs, using a car, driving, gardening and going out socially. Items which between three quarters and all of the Moderate and Mild patients could perform independently included: feeding themselves, preparing a meal, grooming, dressing, toilet use, mobility indoors, and reading. Approximately two thirds of Moderate and Mild patients reported that they were still able to undertake their favourite hobby or pastime 6 week after discharge from hospital.

In summary, pre-discharge Barthel scores were shown to be useful in predicting ADL and extended ADL performance at home 6 weeks after discharge in general terms and to a limited extent. For those with a low pre-discharge Barthel score (0 - 11), it is unlikely that these patients would be able to perform any extended ADL activities (except reading) 6 weeks later. For patients with intermediate scores (12 - 16), and high scores (17 - 20), post discharge Barthel scores would remain similar to the pre-discharge levels, and extended ADL scores would be correlated with them. Finally, and recalling the data presented in Figure 9 (the mean Barthel and Extended ADL scores of patients categorised according to their response to the question of how well they thought they were managing), this relationship between ADL scores and perceptions suggests that the patients did consider their performance within domains similar to those actually assessed, strengthening the case for the use of these particular instruments within this context.

The ability to predict patients' performance at home is one of the factors central to a successful discharge. In order to obtain a rounded picture of all the key domains within discharge planning, the experiences and opinions of those involved must be sought.

3. Exploring different perspectives on discharge

3.1 Purpose

To investigate the process of discharge from hospital from the perspective of patients, carers and health professionals to identify those factors which facilitate a smooth discharge and those which mitigate against it.

3.2 Methods

Information was collected through semi-structured interviews with probe questions, and focus groups undertaken with patients, carers, and health professionals involved in the patient's discharge. The interviews and focus groups were tape recorded with the participant's permission, the material transcribed and the content analysed to identify re occurring themes.

Criteria for inclusion was; being over 65 years of age, having been in hospital for at least two weeks prior to discharge, and giving informed consent to take part. The health professionals included physiotherapists, occupational therapists, speech therapists, nurses, doctors and care managers, all were involved in the discharge of elderly patients. Some carers of the patients discharged would also be interviewed

We intended to include all hospitals in the Health Authority which were discharging elderly patients, they were Buckland Hospital Dover, Royal Victoria Hospital Folkestone, Nunnery Fields Hospital Canterbury, the Queen Elisabeth the Queen Mother Hospital Margate and William Harvey Hospital Ashford.

3.3 Materials and Procedure

The purpose of the study was explained to the participants and if permission was given and informed consent obtained, they entered the study. The confidentiality with which the material would be treated was explained, and also the fact that no individual would be identified. All interviews and focus groups were tape recorded with permission from participants. This work would be continued until saturation point was reached, that is when no new themes emerged. The tapes were transcribed and analysed to identify common themes. The aim was to obtain an in depth understanding of the different individual perceptions of the process of discharge.

3.4 Results

In the event all hospitals did not collaborate in the study and only the following hospitals were included; Buckland Dover, Royal Victoria Hospital Folkestone, Nunnery Fields Hospital Canterbury, and Queen Elisabeth the Queen Mother Hospital Margate. There were 14 patient interviews and three patient focus groups, three health professional interviews, four health professional focus groups, and four carer interviews.

3.4.1 Patients and carers

When interviewing, and on initial scrutiny of the data it became evident that discharge from hospital was a different experience depending on the length of the patient's stay in hospital prior to discharge. Most patients after only two or three weeks in hospital reported

few problems, and seemed to make the transition with ease, they often had little to say about the discharge process, and did not perceive it as a potentially or actually troublesome time. However those who had been in hospital for many weeks or months, and particularly those who were going home with new or increased disabilities reported more problems.

The comments and views of patients and carers contained very similar themes and are therefore sometimes considered together here. This is not to say the individual patients and carers necessarily agreed, or shared the same concerns, but this was not the focus of this work.

For those who had a longer hospital stay, especially those with physical disabilities such as stroke, three phases were apparent in the process of discharge where different problems could occur. Initially in the hospital prior to discharge, then the home visit which seemed a potentially challenging time, and finally the first weeks at home. There were however some major themes which occurred at all stages and they will be considered together first.

a. Information

There were a number of interlinked themes which had to do with the patient obtaining information about their condition and about their discharge, they related to the information itself, the way it was given, the form in which it was given; the extent to which patients felt staff listened to their requests for help, and the communication between patients and staff were all important.

The majority of patients said they would like to have detailed information about their condition and its management before they went home. Lack of information was said to be a problem at the time of discharge, both written information and the opportunity to discuss things informally with staff was much appreciated. Carers too spoke of the lack of information as a problem. However there was considerable individual variation in what had happened, what people wanted and what they got. It was generally agreed information was helpful:

'the more information you get the happier you are its as simple as that'

Written information was usually helpful:

'my daughter in law gave me a book which told you what to do, and what not to do when you had had a hip replacement, it was wonderful I don't know what I would have done without it.'

'I got lots of information off the internet, very helpful'

'I would have liked to get hold of a text book and really try to understand my condition'

'if you are hard of hearing its really important[to have it written down, you can't keep asking people to repeat things or they will think you are daft'

'I was given a book and it frightened the life out of me'

The way in which information was presented was important. Patients said they wanted information given in a personal way, to have the time for an informal chat about their discharge home with time to think through possible problem areas.

'I was given written information from the Stroke Association. It was a brochure folded so that you needed two hands to open it. When I finally got it open I found it patronising and condescending'

'what you need to do is to talk things through really well'

'what you really need is an in depth chat to start things off'

'she came and sat on the bed and we had a chat, that was good'

Some patients reflected on why they were not given information, and made suggestions for improvement.

'I don't know whether they hold back because they're afraid people might not understand and might get even more worried'

'its important that perhaps key questions are put to the patient to open them up to speak'

Others felt they would not get information unless they asked for it.

'Well it was really up to me to ask various questions.'

'I think if she [the wife] hadn't insisted it would have been a different story'

Many also wanted information about what to expect from their condition, what could be considered 'normal'

'when I was getting emotional and crying all the time, no one said well that often happens when you've had a stroke'

'they did not tell me to expect so much pain' [after a hip operation].

b Listening

Listening is clearly linked to information giving, as patients seeking information need someone to listen to their fears and worries to be able to give appropriate information. Nobody listens, or has time to listen was an often repeated theme, as was the fact that patients did not know the right questions to ask.

'its not just listening, you don't really know what questions to ask at first'

Many suggested it was the staff's workload that prevented stopped them from listening.

'nurses so terribly busy you don't like to ask and they certainly haven't time to listen'

'Yes they did listen to me but it must have gone in one ear and out the other, they are nodding as if they understand but they don't act on anything you've said'

'the physios were quite nice but they were always in and out, no time to talk'

'I didn't find it easy to talk to the nurses, I wanted a heart to heart really, I had so many problems'

What was valued most was time for a personal informal chat with staff to ask for information and identify potential problem areas.

1. In the ward prior to discharge

In general the main problems at this stage seemed to be related to failures of communication. Many, though not all patients were worried about how they were going to manage, and felt ill prepared.

'I was really worried whether I was going to be able to look after myself, my wife is 70, but I didn't talk to anyone about it. Nobody talked to me about going home either.'

Most patients said they wanted to be part of the discussions about going home

'When they involve you its good'

'the physio came and the OT and told me exactly what to do when we got home'

There was a problem with communication where patients were transferred between hospitals, as about a third of those we interviewed had been.

'the problem is they keep moving you around from hospital to hospital, it was all fixed [the discharge] for one then they moved me again one hospital told me everything, then I came here and there was no preparation '[this patient had been in four hospitals],

' there were a lot of well meaning people who came and left visiting cards, but they did not do anything practical or tell me what was going on'

Many patients found it difficult to cope with uncertainty, particularly when different members of the team did not agree.

'the doctors and therapists disagreed about her coming home, but I think the therapists were right she was so very weak when she first came home'[carer]

'I just had about an hours notice, they needed the bed, I was in a reasonable condition but not really right, the therapists did not think I was ready to go'

'I felt I was being let down, they discussed what they wanted to do with me some said I could go others said not, I was led astray with false information. Things just dragged on'

'in hindsight she should have stayed another 2 weeks[husband]I know the therapists wanted that'

'some wanted to put me in a nursing home some wanted me to come home'

One patient summed it up rather well:

'that's not to say what they decided was wrong it was just wrong for me'

Another problem mentioned was being able to discuss confidential matters privately.

'Its difficult because I am asking them really confidential things, there is nowhere to take people to discuss family issues'

Patients were often worried about their relatives who would be their carers, they also thought that there should be much more involvement of carers from an early stage.

'close relatives can suffer more than the patient'

'the wife wasn't included in anything before I went home'

'they did not involve my wife in anything before I left hospital'

'not a lot [of conversation with the wife] one or two conversations, not much'

'don't think my wife was ever there when they came'

'they did let me practice with her in the hospital the things I would have to do for her when she came home, this was helpful'

Some patients felt powerless, that their wishes were not important.

'they [the professionals] have the power'

'there is a tendency, with the best will in the world, for the professional to know best, sometimes they may know best but for the patient's dignity confidence and well being, it is important for them to promote the patient's self belief, you need confidence to grow, you need to be treated like an adult'

'if they don't dictate to you ..that's good'

'they didn't tell me anything really but I accepted what they said'

'I didn't say a lot to the staff because I accepted their judgement'

2. The home visit

For those who had been in hospital for over four weeks and who had some physical disabilities, most went for a home visit to plan for the move and highlight any possible problem areas. Patients wanted to be involved in planning

'I learned about home visits on the grapevine, no one actually told me till just before the visit'

Two themes emerged strongly which were important to the majority of patients, this was the number of people on the home visit, and the familiarity of the staff with the patient.

'about 5 people came including a student far too many and too noisy it was very upsetting'

'too many people 4 of them I think'

'they were all talking to each other they didn't ask me what I wanted at all'

'it was very rushed, I needed more time to consider things its all so strange after such a long time'

'we had two hours but it wasn't enough'

'there were a lot of people about 8 in all frankly I was overwhelmed, I had clear ideas but they wanted something different'

Similar themes were clearly evident when things went well.

'my OT was great, things started to happen when she got onto it'

'my home visit was a complete success in every way, we had a social occasion which is what it should be'

'I was quite happy about it really, OT and my social workers, they were very good'

'Just two people came and it was successful we had a whole afternoon, I made tea and managed beautifully'

'my own physio and OT came that was fine'

'two people came to see how I could cope, I managed beautifully'

Many patients saw it as a test which they had to pass if they were to be allowed home, this made some very nervous. Others accepted it as necessary.

'dreadful just trying to prove to me I could not manage at home- they were right I admit but they need not have been so brutal about it'

'in this hospital you have to prove to them you are ready to go, I did well, I passed the test so I could go home'

For some patients gadgets and adaptations were thought to be essential by the professionals, but occasionally the patient thought differently. There could be a problem when there was a delay in delivering necessary equipment, and patients saw unnecessary bureaucracy in the supply of aids.

'Its bureaucracy gone mad, the OT can order me a perching stool for toilet purposes but not for the shower!'

Some patients did not want the help offered.

'They arranged for me to have all sorts of things, stair lifts, rails etc. I said no way if you do that you take away all hope'. Now I've been home two weeks and I walk with two sticks and can manage the stairs if I really concentrate so much easier'

'they offered me meals on wheels but I said no I'd go barmy if I had nothing to do'

However some later changed their minds.

'they were understanding and helpful, I said I did not need a rail, they said I did, then later I had to ask for it they were nice and came and fixed it'

3. Back home

Being back home was said to be a traumatic experience by many patients and their relatives. It took time to adjust to being away from the routines of hospital, and perhaps having to adapt to a new lifestyle, about a third of the patients spoke of withdrawal symptoms. Many felt that what they needed was someone to check up on them when they first got home, they also wanted their own wishes to be taken into account.

'you get withdrawal symptoms, I was scared, I was worried, I wasn't prepared for going home'

'nobody bothers no one comes to check up'

'its pretty difficult, I want to be upstairs but they have decided I should be downstairs, I'm squashed in a tiny room, and all my things are upstairs'

'its really friends who give the real help and support, they help you to do what YOU want to do, rather than telling you what to do'

'no nobody has been I do think the nurse or somebody should have been in to check'

'It was horrendous for the first two weeks she was home, I had to get up every two hours to get her on the commode'[carer]

Access to professional support and advice from someone after leaving hospital was clearly an important theme. People providing regular and dependable help were valued.

'knowing I can pick up the phone and get the district nurse is really good'

'district nurses are very good, very very good and regular'

'I don't want to knock the NHS I think its very good but they do fall down about the going home bit, particularly the tables we didn't know what they were for'

'I could keep in touch this was the best thing, they are not abandoning you because he is coming home'[relative]

'they made me feel it was an open book [the advice and help I needed] that can go on for as long as he needs it'

'the staff were there for me and insisted I did not take up too much of their time'

Patients and carers expected support from their General Practitioner once home and valued it highly.

'We have a very good GP, he's most attentive, he came every few days at first, then weekly and now back to once a month'

'withdrawal symptoms were very bad, I got panic attacks, the GP was very good he came round and talked to me, that helped the depression'.

'I had only been home 3 days and my GP was there'

Others reported a different experience and were upset at the lack of GP visits.

'honestly the follow up from the general practice is pretty poor, a month after I got home my neighbour said, hasn't he been yet? and I said no, I think its disgusting'

'I have had no visits from my GP, the follow up from the GP practice was very poor'

'its disgusting no visits[from the GP] at all'

Many patients said how much they appreciated achieving practical goals and being less dependent on others.

'the best thing about being home is doing things for yourself, real progress every day as you do more'

'the best thing is I can get out, go to the shops see people'

'we're positive thinking people, take each day at a time'

'being self reliant again, getting back to doing things for myself'

'being able to cook a hot meal, a roast dinner for myself'

Relatives saw their role as important.

'it was important that he kept his dignity, there were all sorts of practical things where I could still let him take the lead'[wife]

The provision of the community services varied widely. Some had Community Assessment Rehabilitation Teams[CART] and others Early Rehabilitation Stroke Teams [ERST]. There were community services for some patients and a Red Cross visiting team for the first six weeks post discharge. Patients' opinions varied about the usefulness of the different services. There was a common theme about the community teams who visited them at home after discharge. Some patients reported that when different people came each time they often did not really understand them and their problems.

'a team came in who did not know me, different people each day. One kept telling me to walk without a stick, I knew I couldn't but she didn't listen she kept on so much I knew the only way to convince her, was to do it and fall, which I did, luckily I did not hurt myself much'

'the OT said you must get in the bath with a bath board, what ever she says I won't use it, the bath has only a ledge of ¾ of an inch to rest on, just not safe'.

'Well she [OT] thought I could go upstairs, I know I can't because I could barely manage before I went in, she kept saying you can, but I can't .This was difficult she just did not know me atall'.

Many patients felt that the best option was for the hospital staff who really 'knew them' to oversee the transfer from hospital to home. Being confident was the key to managing well, and they said they were only confident with people you know.

'the people you know give you confidence'.

'you build up confidence with the therapist ..so yes continuity over the early weeks at home would be good'

'If you have the physio you know, they know what you are capable of, they know how you think and understand what you are saying'

'my own OT knows what I can and cannot do, she gives me confidence and that's what you really need when you go home'

It was unhelpful to have to wait for equipment which sometimes took weeks to come. Some solved their own problems.

'I went home on Saturday and they started work on the Friday at 4.00pm, though we'd been planning for 6 weeks'

'I needed a ramp, I got in touch with someone and they contacted someone else but nothing got done, over months so I saw this advert in the paper for handyman, he came round gave me an estimate and within a week it was done! Of course I had to pay for it myself'

Patients had different ideas about the extent to which they themselves contributed to the success or otherwise of the transfer from hospital to home. They spoke of their mental attitudes and what motivated them to go home.

'I prepared myself for [going home] both mentally and physically'

'No progress made without self confidence, I had to re gain self reliance, the indifference of the nursing staff here ruined my self esteem'

'mental attitude is all it depends on the individual, 90% is mental attitude'

'my biggest motivation was to get back to work and earn some money'

'my greatest pleasure in life is eating, so I was motivated to get home and cook my own food, we had a taste free diet in hospital'

'the important thing is to be prepared mentally, prepare yourself'

Many patients spoke of the bad effects of 'institutionalisation'. They described this in different ways.

' You lose all initiative you have to do everything when you are told, even go to the loo'

'It really is dreadful because you sit for most of the day doing nothing'

'your self reliance has been taken away, you become institutionalised'

'you are told what to do and when to do it, can't make any decisions for yourself'

For those who had stayed in months rather than weeks there was general agreement that it would be better to go home earlier, but only if the same amount of therapy could be maintained.

'you only start making real progress when you go home and meet real life problems, it's a great boost as you overcome them'

'I only started to make real progress when I got home'

' you can start to get on with your life once you are home'

' goals mean something when you are at home, doing everyday things'

'You have got to learn to manage at home so the sooner the better'

3.4.2 Health professionals

1. Introduction

There was some semantic confusion about terms used by different health professionals and this was explored with the participants. The two main areas of confusion were the terms Case conferences and discharge policies. Case conferences were seen by many as the weekly coming together of the multidisciplinary team to discuss the patient's problems, however it was the term used by others to describe the occasional conference which was only used for a patient who presented with particular problems, where all those involved from the hospital and community came together to discuss possible solutions.

'we have weekly Case Conferences and all discuss the patient's readiness for discharge'

'we have regular interdisciplinary team meetings, we only have a Case conference if there is conflict between the team and family members it's a way of trying to resolve the conflict'

In relation to policies, many people said that they did not have any policies, but went on to describe action plans and procedures that had to be followed by all, which were termed policies by others. Most of the hospitals did have a written hospital discharge policy but it did not appear to be the basis for practice in many. This is hardly surprising as policies we saw were mainly aspirational in character for example: *'To promote the highest possible level of independence from the patient and his/her carers by encouraging self care activities'* and *'discussion and assessment will be initiated at the pre assessment clinic where this service is available'*.

Others were more practical *'The patient and his/her carers will be given the hospital telephone number and the extension numbers of various disciplines prior to discharge'*. Though these overall hospital policies did not appear to be influencing practice, staff talked of departmental policies and procedures which were clearly important in the smooth running of their department. Safety was clearly a key issue, a speech therapist said that the policy and checklist provided in her hospital for stroke patients with swallowing problems was vital in deciding whether it was safe to send a patient home or not.

'when staff change problems can occur because they are not aware of our policy, a classic example is referral to the day hospital, the plan is for the nursing staff to fill this in, but if this doesn't happen....'

'there is a check list that the nurses are meant to tick off to show that everything has been done'

There was general agreement by non medical staff that the doctor had to decide on the medical condition of the patient, unless medically fit a patient could not be considered for discharge. The importance of the assessment process prior to discharge was stressed by nearly all respondents.

'co-ordinated interdisciplinary care is the key, with a detailed assessment to find the underlying diagnosis, care without understanding of the underlying problems leads to disaster'

'once a week systematically we come together, each profession has made their assessment independently and then there is give and take in the discussion and a synthesis is arrived at'

The themes of timing, communication, involvement of the whole team and multidisciplinary team meetings were seen as important. Timing of events and planning ahead was seen as helpful. Rushed discharges because of pressure on beds could cause problems.

'set the dates and then everyone works towards them'

'its worth an extra week to get everything tidied up and make sure its going to work'

'if the therapists want the patient to stay a week longer I usually agree if it seems reasonable'

'pressurized discharges are likely to fail'

In most hospitals there were formal and informal procedures to be followed.

'there needs to be both informal and formal structures for this to work, the ward round and the meeting form the building blocks for the process of discharge, then no one slips through the net'

Good communication between team members was mentioned as crucial by almost everyone. This was seen by some as happening only if structures and an organised process was in place.

'having everyone there including the social worker, who is attached to the ward and knows the patient, is important, if you rely on more distant contact through phone calls etc it doesn't work so well'

Everyone working together was stressed as important, and this involved good communication and liaison between all team members in the hospital and with those in the community .

'for a good discharge everyone must be motivated for it to work, from the patient and carers, all staff involved in the hospital, and in the community the GP district nurse and care manager; if anyone is not motivated they can easily scupper it'

'there can be antagonism if there is not good liaison'

'the community liaison nurse is invaluable particularly when the patient is very dependent'

There was agreement that it was much harder to get a feel for the patient's abilities if there was no team in place. Multidisciplinary teams mostly met on a weekly basis, here it was stressed that as many of the people involved with the patient as possible should be present. In

others these meetings were on the ward after the ward round. In some the consultant or a member of his medical team chaired the meeting, while we were told by others that:

'the team functions whether I am there or not, goes ahead irrespective of my presence if everything else is fine, don't wait for consultant opinion'

'though the buck stops with the doctor in rehabilitation not much input for the doctor, the team should get on and do it I try to encourage them'

The main therapist's themes about pre discharge management were related to practice for independent performance of activities, involving carers and giving the patient confidence to manage well at home.

'I try to get them to have as much independence as possible standing back and letting them do it on their own, practising'

'start them doing everyday things here before they go'

'its all about giving some of them confidence'

'I often spend quite a long time with my patients talking about going home and then follow up with a phone call when they get home, its all about giving them confidence'

'the longer you can spend with the patient the more they are going to talk to you, there is more rapport and then they will tell you the important things'

Involvement of carers was seen as important.

'making sure the carer knows what the patient can do, so they don't jump in and do things for them'

'when relatives are adamant that they are going to take the patient home the carers come along and look after the patient[in the hospital] do the washing and dressing, that's really good because everyone is there'

'The involvement of family and carers is essential, knowing what's going on, being part of the process, defining how far they can go and when they need help'

We asked who made the decision about the patient's discharge. It was generally agreed that the medical team made decisions about the patient's medical fitness for discharge, after that it seemed that in most hospitals the therapists, in conjunction with Care managers, were most influential in deciding when the patient was able to manage and ready to go home.

'we assess and come to a consensus'

Another point of view was:

'the patient really decides if they are well and want to go I would go ahead'

There could be conflict if there was not agreement about the patient's readiness for discharge. Therapists said they often wanted to keep patients in just a little longer than the doctors to make them and their relatives more confident and capable of managing ;

'if we feel we can really do something in an extra week we try to keep them in'

'If they are very dysphasic they need intensive treatment, the only place they can get it is here in hospital, so they'll have to stay a bit longer'

'they can't go home until their swallowing is safe'

'if a patient goes now without any further rehab [no services where she lives]she will lose everything she's gained in here'

'we also have to ask what is their functional ability, what support have they got and have they got a suitable Care Package?'

About lack of consensus therapists had different experiences:

'There is often a discrepancy between what they[the consultants] think and what we think'

'They[the doctors] ask us to do an assessment and we are in the middle of doing that and they decide they[the patient] is fit for discharge'.

Some Consultants said they usually went by the therapist's advice

'I go along with what they say'

If the patient was disabled lived alone or had been in hospital a long time a home visit was often undertaken prior to discharge. The occupational therapist and Care manager seemed those most commonly involved, the physiotherapist went in some instances, and an OT technician where alterations to the house were required. Another reason for a visit might be because staff thought the patient would not be able to manage, and this needed to be clearly demonstrated. Participants recognised that there could be problems with these visits.

'There is a danger sometimes there can be too many people on the home visits, that can be quite intimidating for the patient, so you have got to try to strike a balance'

'must be someone familiar to them, no sense in having a complete stranger'

'you are asking them to do quite a lot in a short space of time, it can be quite exhausting'

'it depends what the patient's capabilities are how long we stay, sometimes I end the visit if I see its becoming too distressing for the patient'

'I think its fair to say many patients aren't asked enough about what they want, but they are often unrealistic, perhaps that's part of having a stroke'

'we also liaise quite closely with the patient about who they want on the home visit, sometimes they don't want their relatives to be there'

Others expressed concern about the current system, and questioned the extent to which it was really patient focussed.

'we are aiming to become more patient focused-working towards it- it is about being aware of what the patient needs, can be really simple, Everything is automatically served here, so you cannot say we are patient focused'

'I think we are getting more institutionalised than ever, because of the massive throughput, and all the rules and regulations'

'the irony is that we think we've moved towards patient empowerment, individualised care, in fact we haven't'

'some patients really want to be in control, its important for them to think they are making the decisions'

*'I think its fair to say the patient is not asked enough about what they want'
'important to establish a one to one rapport with the patient to find what they want, they are often very anxious'*

It was recognised that there could be risky discharges, perhaps where the patient wanted to go home but was quite heavily dependent.

'At the end of the day its their decision, their choice, its really difficult for us to let go sometimes'

'sometimes we get it wrong, we think they are not safe but they surprise us and do really well'

'of course sometimes they say they can manage, but they can't'

'it requires confidence to allow people to go home in some circumstances'

The availability of post discharge facilities to patients varied considerably between hospitals. One had an early discharge team to look after the patient for the first six weeks. Others were able to refer, if necessary, to a Community Assessment Rehabilitation Team[CART] or an early discharge team[ERST], a community services or to a Day Hospital. This meant that the amount of support in the community differed between geographical areas. Some had community liaison nurses, and a discharge co ordinator.

Some health professionals were aware of the problems experienced by the patient, and tried to arrange post discharge support.

'a big hurdle from hospital to home, if they can jump this then they can manage well'

'if they have lots of help in the first few days then it can gradually tail off, the first few days are crucial'

'an awful gap between hospital and home and no outpatient services here'

'a new service hospital from home run by the Red Cross go in for a visit twice a week for 6 weeks- free and I find it invaluable'

'if the patient is seen to be at risk, then we will get them up to the Day Hospital for a few weeks to keep an eye on them'

'patients can be monitored in the Day hospital for two weeks, maybe a month if we are worried about them'

If no services were available:

'sometimes we give them a telephone number so they know there is someone to contact'

We asked the health professionals what they thought characterised good and poor discharges, and there was considerable agreement between sites and professions.

2. Good discharges

Key factors were seeking the patient's views, working together with them and other members of the team:

'when we go through the assessment process and are happy they are ready to go home'

'when we chat with the patient to identify any problems they envisage, then discuss equipment and a care package'

'it gels when everyone works together'

'when patients go home with a care plan'

'a good experienced team working together, 'everyone motivated to make it work'

3. Problem discharges

There could be many reasons for this and differing perspectives. The problem of bureaucracy was thought by some to be paramount in causing considerable frustration and delay. Problems arose when social services and the multidisciplinary team do not agree about the patient's placement, where this may involve continuing care, and funding coming from different agencies.

'There may be delays of up to two months while the patient's situation is discussed by the multidisciplinary team, then a joint assessment, with therapists and social services, then Social Services Panel, and if there is not

agreement it can go to arbitration. The process may be repeated and eventually the patient goes to the destination originally decided'

'delay is bad for the patient, they become depressed and of course something else may happen to them'

Other reasons included the following:

'very quick discharges no time to prepare'

'when they slip through the net'

'some patients say they are desperate to go home but they won't work with you to achieve it'

'staff shortages so not time to do things properly'

Some patients and carers were described as 'unrealistic' which was said to create a problem.

'he was totally unrealistic'

'the wife kept saying she wanted him home, but when a definite date was given, she panicked and found a reason for delay'

'some people are very unrealistic and you need to take them home for them to realise that'

'some are notoriously unrealistic'

Disagreement between patients and carers was also problematic.

'when the patient and carer don't agree you are walking on egg shells, sometimes the carer is more anxious than the patient'

One care manager commented on a recent problem she found

'I assess them and decide they really need say two hours each day, but now when they have to pay it all themselves [if they are not on state benefit] they feel they cannot afford it and they try to manage without, which isn't always safe'

A number of therapists and nurses commented on the individual and personal nature of the patients' predicament and recognised there could be no overall recipe.

'its about assessing what is relevant to their needs'

' some patients very much want to be In control, its really important to them to be making the decisions'

When timing, communication, or liaison within the multidisciplinary team failed this also created difficulties and could contribute to discharge problems

3.5 Discussion

Some patients were very satisfied with all aspects of their care, others felt constrained to avoid critical comment and only started to talk more freely toward the end of the interview. In the focus groups free discussion enabled patients to express their feelings and sharpened their comments to agree or disagree with others.

It was interesting to note that some of the same themes emerged in some professional and patient reports, each recognising the others perspective. A few health professionals seemed to feel that they were the only ones in touch with reality, describing patients as being 'unrealistic', if the patient's 'reality' did not agree with theirs.

In general the process of discharge was given considerable attention by all those concerned. It was also interesting to note that some were very perceptive in picking up both good points and shortcomings in their services. When patients and carers said they were not given information or consulted this does not necessarily mean they were not given the information as their memory in a stressful situation may have been faulty. This highlights the importance of checking whether information has been understood and remembered. Rapport with the patient and informal one to one chats were seen as important in achieving this. It may be somewhat surprising that these elderly patients spoke of being active in obtaining information from text books and the internet. This may be the way for some people to be helped to get the information they want. Patients did very much want to be asked and listened to, rather than told. Disagreement between staff was a problem for patients and does suggest that a consensus when talking to the patient is important, or perhaps involving them more in the decision process for some patients would be desirable. Many patients felt that they wanted to be able to be more proactive and initiate actions rather than have to rely totally on professional opinion.

Over half the patients felt that the long stay in hospital was not desirable, and some spontaneously mentioned becoming institutionalised. Boredom, the lack of opportunity to make decisions, and the lack of 'goals that mattered' were all mentioned. It was felt that once home the motivation to resume everyday tasks was very strong. However they all felt though they would like to go home earlier they would want the same level of therapy to be maintained. Most patients wanted their own hospital therapists to see them through the immediate transition from hospital to home, as they were familiar with them and their problems. One speech therapist said that the most satisfying aspect of her work was being able to follow her patients into the community and help them manage during the transition period from hospital to home. Though many therapists supported this, others felt this might encourage dependence.

3.6 Conclusions

- Experienced teams with good communication between all members are crucial to successful discharges.
- The smooth transfer of support and services from hospital to community is a key point where good communication is essential. Nurses appointed to bridge the gap as Liaison nurses and Discharge co-ordinators could improve communication and ensure a smoother transfer.

- Most patients wanted more information and more sensitivity to individual patient needs should help to ensure patients receive the information they want.
- Both formal and informal ways of giving information are needed and it seems important that when talking to patients to check that they have heard and understand what is said.
- It may be useful to consider different and innovative ways of delivering information to patients.
- Home visits may be more successful if fewer people, who are familiar with the patient, attend.
- Listening to the patient and allowing, or even facilitating patient decision-making would be appreciated by many patients.
- Many patients would appreciate more involvement in decisions about their own treatment and management.
- Patients found the uncertainty of actual or seeming disagreement between health care professionals about their discharge unsettling.
- If, but only if, current levels of therapy in hospital could be maintained many patients would like to go home earlier. Few patients found the goals of treatment in hospital motivating; only when there were 'real life' every day goals to be achieved did they say they perceived progress.

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Appendix 1. The Barthel Scale

1. *Bowels*

- 0 = Incontinent (or requires enemata)
- 1 = Occasional accident (once a week)
- 2 = Continent

2. *Bladder*

- 0 = Incontinent, or catheterised and unable to manage alone
- 1 = Occasional accident (maximum once per 24 hours)
- 2 = Continent

3. *Grooming*

- 0 = Needs help with personal care
- 1 = Independent face/hair/teeth/shaving (implements provided)

4. *Toilet use*

- 0 = Dependent
- 1 = Needs some help, but can do something alone
- 2 = Independent (on and off, dressing, wiping)

5. *Feeding*

- 0 = Unable
- 1 = Needs some help cutting, spreading butter, etc.
- 2 = Independent

6. *Transfer (bed to chair and back)*

- 0 = Unable, no sitting balance
- 1 = Major help (one or two people, physical), can sit
- 2 = minor help (verbal or physical)
- 3 = Independent

7. *Mobility*

- 0 = Immobile
- 1 = Wheelchair independent, including corners
- 2 = Walks with the help of one person (verbal or physical)
- 3 = Independent (with or without aid)

8. *Dressing*

- 0 = Dependent
- 1 = Needs help but can do about half unaided
- 2 = Independent (including buttons, zips, laces, etc.)

9. *Stairs*

- 0 = Unable
- 1 = Needs help (verbal, physical, carrying aid)
- 2 = Independent

10. *Bathing*

- 0 = Dependent
- 1 = Independent (or in shower)

Appendix 2. The Nottingham Extended ADL

	not at all	with help	alone with difficulty	alone easily
<i>Mobility - Do you:</i>				
Walk around outside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Climb stairs.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get in and out of the car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walk over uneven ground	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cross roads	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel on public transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>In the kitchen - Do you:</i>				
Manage to feed yourself.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Manage to make yourself a hot drink.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Take hot drinks from one room to another.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do the washing up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Make yourself a hot snack.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Domestic tasks - Do you:</i>				
Manage your own money when you are out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wash small items of clothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do your own shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do a full clothes wash	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Leisure activities - Do you:</i>				
Read newspapers or books	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use the telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Write letters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Go out socially	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Manage your own garden.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drive a car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	not at all	with help	alone with difficulty	alone easily

Appendix 3. Adapted Nottingham Extended ADL

	<u>After Hospital</u>				<u>Before Hospital</u>			
	doesn't do	can't do	with help	without help	didn't do	couldn't do	with help	without help
1. Feed yourself	d	c	h	w	d	c	h	w
2. Make a hot drink/meal	d	c	h	w	d	c	h	w
3. Clean the house	d	c	h	w	d	c	h	w
4. Wash face, teeth, hair, shave	d	c	h	w	d	c	h	w
5. Get dressed/undressed	d	c	h	w	d	c	h	w
6. Go to the toilet	d	c	h	w	d	c	h	w
7. Take a bath or shower	d	c	h	w	d	c	h	w
8. Get around inside the house	d	c	h	w	d	c	h	w
9. Get around outdoors	d	c	h	w	d	c	h	w
10. Climb stairs	d	c	h	w	d	c	h	w
11. Get in and out of a car	d	c	h	w	d	c	h	w
12. Drive a car	d	c	h	w	d	c	h	w
13. Read newspapers or books	d	c	h	w	d	c	h	w
14. Do your gardening	d	c	h	w	d	c	h	w
15. Go out socially	d	c	h	w	d	c	h	w
16. Favourite pastime	d	c	h	w	d	c	h	w
(Specify)								