Continuing health care criteria: their use in a specialist disability service

ABSTRACT

Objective: to evaluate the British National Health Service (NHS) criteria for determining eligibility for continuing health care when applied to a population of younger people with severe, usually neurological disability.

Design: an observational study with descriptive analysis of the data.

Setting: the specialist disability service catering to the population of Oxfordshire (560,000).

Subjects: 196 patients in contact with the specialist services in January 1996.

Intervention: senior staff graded the extent to which each patient had one or more of five health and three non-health needs addressed by the service (rated on a scale of 0–3 for each item).

Measures: the Oxfordshire Health Authority guidelines for determining eligibility were used, with an additional three criteria covering non-health needs (social interaction, supporting carers, supporting Social Service care packages).

Results: 196 patients were assessed: 128 (65%) had all health and non-health needs being satisfied by the service; multiple needs were being met in 165 (84%). Only 18 (9%) had no health needs being met. There was no clear-cut separation either between different categories of health need or between health and non-health needs.

Conclusion: the current categories cannot be applied at the level of individual patients without conflict because:

- they are unclear, not being based on any logical, coherent framework
- in almost all patients the needs being met by health services include many non-health needs.

Faced with increasing demands on the health budget, the British government has chosen to define more closely the services available ‘free at point of delivery’. The intention is to transfer responsibility for more services from the centrally funded NHS to social services which are funded locally and are means-tested. To this end, the Department of Health (DoH) promulgated eight areas of continuing health care need (HSG(95)8) defined as being the responsibility of health authorities, with the implication that all else was not. Local purchasers and providers were asked to devise criteria to enact the guidelines.

Oxfordshire Health Authority (OHA) consulted widely with other purchasers (eg social services), providers (eg the community health trust), and the general population (largely through representative organisations), and published a set of guidelines. We were concerned that the areas defined and the resultant guidelines might not be usable or useful in the field of disability and rehabilitation. Using the guidelines, we looked for answers to the following questions:

- how many of our patients receive services for health needs (as defined) and in which areas?
- how many receive them for important but non-health needs (eg social needs)?
- how usable are the criteria?

Method

The study involved Rivermead Rehabilitation Centre (RRC) and Ritchie Russell House (RRH), which together offer a comprehensive specialist disability service to Oxfordshire. They cover the in- and outpatient needs of patients at all stages of their disabling disease from the acute recovery phase to long term support and palliative care, but do not offer any long-term inpatient care (ie for the rest of an individual’s life). Rivermead also offers an inpatient service to other health authorities, but these patients were excluded from this survey. The service has five components:

- inpatient rehabilitation (RRC IP)
- outpatient rehabilitation (RRC OP)
- day care, both at Rivermead (RRC DP) and at Ritchie Russell House (RRH DP)
- inpatient intermittent respite care at Ritchie Russell House (RRH IP).

The central directive dictated eight areas of interest (Table 1). We considered that three areas of health need (D,G,H) did not fall within the remit of our service.

The guidelines for continuing inpatient care (D) seemed to include only patients actually in the intensive care unit, and certainly not patients in active rehabilitation. Community health care (G) is, by definition, not specialist health care delivered by a specialist service. Specialist transport (H) is vitally important to all people with impaired mobility, but it is provided by the ambulance service. Thus, our guidelines for the disability service concerned only five areas (A, B, C, E, F). They were agreed by the OHA and are available on request (see Acknowledgements). For each of the five areas, the extent of need was graded from 0 (no need...
to 3 (great need), but in the analysis only patients graded at 2 or 3 were considered to be in need.

Previous research has shown that attending for day care is the only social interaction outside their family for 80% of patients attending RRH (A Wilson; unpublished observations). The following three additional non-health areas of need were therefore identified:

- an opportunity for social interaction
- some respite for carers
- to support social services’ care packages.

In each of these areas the need was graded 0–3 (as for health needs), with grades 2 and 3 indicating that the service was their major (2) or only (3) opportunity for social interaction outside the family or that the carers or the social services care package would not be sufficient if the service were withdrawn.

In the first two weeks of January 1996 staff at both centres compiled lists of all patients actively involved with the disability service. Active involvement was interpreted as having some contact with, or action from, the service in those two working weeks; at RRH, patients for whom future admissions for respite care had already been booked were included even if there had been no active contact in the preceding two weeks. Patients booked prospectively for outpatient review (eg patients being monitored at two-monthly intervals) were not included.

At a series of meetings attended by senior staff, each patient was graded on the extent of his or her needs in the eight areas (five health and three non-health).

### Results Data

We identified 196 patients. Multiple sclerosis (n = 61), stroke (n = 54), head injury (n = 20), spinal injury (n = 9), spina bifida and hydrocephalus (n = 7), and epilepsy (n = 5) were the most common diagnoses. Six patients had non-neurological diagnoses, and four had primarily psychiatric diagnoses (ie, non-organic disability).

The numbers of patients graded 2 or 3 for the eight areas are shown in Table 2, which cross-tabulates patients who need health or social care in more than one area. For example, 33 of 70 patients graded as needing assessment (need A) were receiving rehabilitation or recovery (B), 15 palliative care (C), 29 respite care (E) and 18 specialist health care support (F); 33 needed opportunities for social interaction, 39 support to carers and in 21 cases we were supporting social services. The single largest area of continuing health care need (129; 66%) was in specialist health input (F). Among non-health needs, providing opportunities for social interaction (a patient benefit) and supporting carers (not a patient benefit) were the two most common.

Table 3 shows that two-thirds of the patients had two or more health needs, and half had two or three non-health needs; only six had none. Additional analysis showed that 128 (65%) of all patients received help for at least one health and one non-health need; 50 (26%) had only health needs being met, and 18 (19%) had only social needs being met.

| Needs* | A | B | C | E | F | Social | Care | SS |
|---|---|---|---|---|---|---|---|---|
| A | 70 | 33 | 15 | 29 | 48 | 33 | 39 | 21 |
| B | 33 | 63 | 3 | 13 | 33 | 22 | 32 | 12 |
| C | 15 | 3 | 22 | 19 | 20 | 15 | 13 | 15 |
| E | 29 | 13 | 19 | 96 | 85 | 68 | 62 | 54 |
| F | 48 | 33 | 20 | 85 | 129 | 79 | 76 | 56 |
| Social | 33 | 22 | 15 | 68 | 79 | 105 | 71 | 3 |
| Care | 39 | 32 | 13 | 62 | 76 | 71 | 106 | 50 |
| SS | 21 | 12 | 11 | 54 | 56 | 53 | 50 | 71 |

*See Table 1 for identification of areas of need.
Social = Need for social interaction.
Care = Need to support carer; care would break down if need not met.
SS = Need to support social services, package would break down if not met.
How the needs were met by different components of the service is shown in Table 4. It is apparent that the non-health needs of Rivermead day patients were predominantly being met but even in this group at least half (12/23) received help for one or more health care need (F). Tables 2–4 strikingly demonstrate the complete mixture of needs being met, with many patients having many of their needs met simultaneously. There is no obvious group where only one need is being met.

Discussion

The classification of the eight areas of needs given by the DoH was a major source of difficulty, because it was unclear and inconsistent. All patients must undergo an assessment (A) before any decision can be made. It is a continuing process which will necessarily involve giving treatments, and will necessarily be repeated. Assessments are not only made by medical and nursing staff but also involve many health and non-health professionals (eg care managers). We included only recent formal assessments by at least one team member from the disability service (which includes expert social workers).

Rehabilitation and recovery (B) could cover everything else. We decided to define it as the giving of treatments, though this is not the general understanding of rehabilitation. (The term ‘recovery’ in the DoH directive is a complete mystery.)

Palliative health care (C) was readily defined as providing patients who have ‘a progressive illness which is no longer curable’, with specialist assessment and treatment ‘to alleviate distressing symptoms’.

Respite health care (E) is the continuation of complex care in a different setting.

Specialist health care support (F) was interpreted as liaising with, advising and generally supporting health and non-health professionals involved in other settings.

The three remaining areas (D, G, H) were not considered to fall within our remit.

The needs of patients vary with time. In this study, we related need to the recent past, but in many patients different needs had existed only shortly beforehand. Moreover, we could predict with reasonable certainty in some patients that their needs would change and increase within the next few weeks or months.

Recommendations

In our study decisions were made quickly by senior staff familiar with the patients. If the NHS is not to be bogged down in more inessential bureaucracy it will be necessary to have criteria that can be easily applied in this way. We studied only younger patients but it is likely that elderly disabled patients will pose the same difficulties.

The main messages from this survey are that the

| Needs met | Health | Non-health | Both |
|-----------|--------|------------|------|
| 0         | 24     | 50         | 6    |
| 1         | 38     | 48         | 25   |
| 2         | 75     | 60         | 34   |
| 3         | 45     | 38         | 37   |
| 4         | 13     | 0          | 36   |
| 5         | 1      | 0          | 38   |
| 6         | 0      | 0          | 16   |
| 7         | 0      | 0          | 4    |

Table 4. Cross-tabulation between needs met and services.

| No. of patients | A | B | C | E | F | Social | Care | SS |
|-----------------|---|---|---|---|---|--------|------|----|
| No. of patients | 70| 63| 22| 96| 129| 105    | 106  | 71 |
| RRC DP          | 23| 2 | 6 | 1 | 5 | 12     | 14   | 17 |
| RRC IP          | 6 | 4 | 4 | 0 | 0 | 3      | 2    | 3  |
| RRC OP          | 47| 32| 40| 1 | 0 | 23     | 9    | 19 |
| RRH DP          | 94| 20| 13| 15| 67| 71     | 68   | 48 |
| RRH IP          | 66| 20| 8 | 12| 58| 54     | 44   | 48 |

*see Table 1 for identification of areas of need

RRC = Rivermead Rehabilitation Centre
RRH = Ritchie Russell House
RRC DP = Outpatient day care
RRH DP = Outpatient day care
RRC IP = Inpatient respite care
SS = Social services

RRC OP = Outpatient rehabilitation treatment
RRH OP = Outpatient day care
RRH IP = Inpatient rehabilitation treatment
needs for continuing health care do not fall neatly into separate categories, and that health needs (as defined) overlap with supposedly non-health needs, such as having opportunities for social interaction, giving carers relief and supporting complex social service support. This survey also shows that patients attending a 'health' service will often be receiving 'non-health' benefits. Consequently, it is unlikely that it will be easy to agree on separating responsibility for patients attending services.

Our main suggestion is that all attempts to divide the needs of individual patients into 'health' and 'non-health' should be abandoned. Instead, health authorities and social services should share budgets. All patients will end up either being means-tested for all services or receive jointly-funded services free. The relative proportions of resources allocated to the service could be determined using a yearly survey such as this one. If separation at the level of individual patients is required, it is vital to use a logically consistent framework. We recommend that this should be based on the World Health Organisation ICIDH model of illness and a rational approach to disability management.

We urge that the directive on separate responsibilities for continuing health care (HSG(95)8) be withdrawn immediately. If such a separation is desired, the criteria should be completely revised in consultation with clinicians who face the reality of making these decisions. As long as the current irrational 'system' with no logic or consistency is used, trouble will inevitably arise. There will be many sterile and bitter arguments about individual patients. Collaborative teamwork will suffer as will patients and, through the waste of resources arguing about responsibility, society will suffer.

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Reference

1 Wade DT. Stroke: rehabilitation and long-term care. Lancet 1992;339:791-3.

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