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Days at home: an outcome measure in studies of specialist services providing care for older people

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Days at home: an outcome measure in studies of specialist services providing care for elderly people

Summary

It can be difficult to decide if a service for frail older people is successful, or which of several alternative services is best. Mortality may be high. Avoiding death may not be possible, nor a high priority for the service, but we would not want to deliberately increase mortality. Services may aim to relieve symptoms, promote function and quality of life, but these things are not always easy to measure, and cannot be measured for someone who has died. Services try to avoid care home placement, and it is generally seen as a poor outcome, but may be the best solution in some cases.

Surveys of older people suggest that remaining at home is highly valued, and government policy promotes this. The ability of a service to get someone home from hospital, and support them there, without readmission, is attractive as a summary outcome. It should be relatively easy to measure, and provides a proxy for both length and quality of survival. The time frame will vary with the service. Reporting a proportion of days spent at home can standardise the measure.

We discuss the basis and use of days at home as an outcome measurer in health and social care research.





Introduction

A common problem in designing research studies into services for older people, particularly those who are likely to be in the last months or years of their lives, is to find an outcome measure that adequately reflects their problems and is sensitive to interventions.

Currently used outcome measures for complex services for older people

Some services for older people aim to reduce mortality. If this is the only objective, then death rates provide a simple and straightforward outcome measure. However, few services would solely aim to reduce mortality, and most would wish to improve aspects of the service users' health. Indeed, in this context, a service that extended longevity but at the expense of an unacceptable quality of life would not be seen as desirable. It follows that mortality alone is an inadequate outcome measure.

Some services for older people aim to reduce institutionalisation. This is in accordance with health and social policy, and is supported by some evidence from patients with hip fracture or stroke who indicate that they would rather be dead than live in a care home^{1,2}. Measuring institutionalisation rates alone is also insufficient, as these could be reduced by increased mortality, better health, or denial of appropriate requests for care home placement, or influenced by economic factors such as local availability or cost. Hence, such rates are hard to interpret.

Some services might aim to reduce either mortality or institutionalisation, and this combined end point has proved useful in meta-analyses of stroke units trials³. Using this combined end-point, a bad outcome is either death or institutionalisation, to avoid any possible trade-off between the two. So a good outcome is being neither dead or in an institution - in other words, at home.





Similar to this, a service might aim to reduce either mortality or dependency (for example, measured using the modified Rankin Scale). Dependency in this context often dichotomised, with a cut-point between Rankin score 2 (being unable to carry out all previous activities, but able to look after own affairs without assistance) and score 3 (requiring some help, but being able to walk without assistance). This outcome is popular in studies of intervention after a stroke, such as thrombolysis, where there is the possibility that reduced dependency may have to be traded-off against increased mortality⁴. Clearly being alive and independent is preferable to being dead or dependent, and for interventions working at the level of pathology or impairment this is useful. A more severe dependency threshold is sometimes used (e.g. intracranial haemorrhage trials⁵, hemispherectomy trials⁷). Being a relatively crude categorisation, using the modified Rankin scale requires very large numbers of trial participants to give sufficient statistical power. Moreover, this measure also fails to take into account some of the broader aims of healthcare such as rehabilitation, where greater attention to the environment, social care, patients and carers views, decision making and psychological adjustment may result in the successful return home of people despite dependency. In fact, for almost all levels of disability, at all ages, there are more people supported in their own homes than there are in care homes⁷.

Days at home

A further development of this idea would be to count the number of days spent either dead or in an institution in a period of follow up, and the number of days not dead or in an institution. This could be used to create a continuous variable "days at home". Alternatively, a proportion could be calculated. Such a variable would be more sensitive to change than a categorical outcome, and would enable more powerful statistical analyses to be performed.

Being at home would seem to be a reasonably acceptable indicator of success of many services, and so increasing the number (or proportion) of days spent at home would be a potentially valid outcome measure. However, days not spent dead or in a long term





care institution might not be spent at home: people could be having other “bad” outcomes such as being in hospital, or in other health care facilities such as intermediate care, or in respite care. Thus a further refinement of this concept would be to create a composite of the bad outcomes: death, being in a health care facility (hospital or intermediate care), or a social care facility (respite or long term care).

We intend to use “days at home” as an outcome measure in the MCOP studies⁸. Days at home (DAH) would be calculated as follows:

DAH = (total days of follow up) – (days dead) – (days in hospital, including readmissions) – (days in intermediate care facilities) – (days in a long term care placement) – (days of overnight care in respite care)

For people who enter our studies from care homes, a slightly different calculation would be made:

DAH = (total days of follow up) – (days dead) – (days in hospital, including readmissions) – (days in intermediate care facilities) – (days in a new long term care placement at higher levels of dependency).

Limitations

There are a number of assumptions and potential disadvantages of using days at home, so defined.

- 1 Strictly speaking, DAH are not necessarily days at home: people could be on holiday (presumably still a good outcome), or with friends or families (which could be a good outcome, if by choice, or a bad outcome, if unwanted and due to infirmity). More work is needed to examine the extent to which this occurs and whether it reduces the validity of DAH as a meaningful outcome measure from the patient’s perspective.





- 2 DAH does not include any direct health status measurement. People could, potentially, be at home with poor health and quality of life, or in hospital or a care home with good health and quality of life. DAH would not detect such a difference. It would therefore be helpful to have secondary outcome measures of health or quality of life in survivors able to complete them.

- 3 It is not necessarily a bad outcome to be in long term care. In a study of a specialist community service for dementia, we noted that although keeping clients at home was the principal objective at the point of referral, over time a move into long term care was often seen as positive and preferable ⁹.

- 4 Being in hospital or in another health care facility is not necessarily a bad outcome either, if the alternative is to have needs that require such care being left unmet.

- 5 Using DAH as an outcome measure in a trial or as a benchmark could encourage health services to target the outcome measure at the expense of patients' interests. In the extreme, DAH could be maximised by prolonging death at the expense of a quality of life that is unbearable, denying patients hospital and intermediate care from which they could benefit, denying appropriate long term care, and compelling families to attempt to look after patients unwillingly. Using DAH alone, such a service might be seen as superior to one which did not do this.

- 6 More subtly in the trial context, different services could affect different components of the variables that make up DAH. Thus, two services could appear to be equivalent on this measure because they lead to similar DAH, yet they could achieve this differently: one could have high rates of early death and low rates of hospital use, whilst another could have the reverse. Even more subtly, two different services could affect different components of days at home that are omitted from our definition of DAH – for example, two services could have similar DAH and hence would appear to be equivalent, yet one service could lead to more families looking after the patients than the other.





- 7 The degree to which services might actively seek to improve DAH at the expense of what would be seen to be good clinical practice (such as denying hospital care) is uncertain. If this variable were used routinely by the NHS as a performance target, then this possibility would be real (c.f. behaviours used by NHS Trusts to achieve 4 hour wait targets for emergency departments). However, there are already numerous policy directives and targets that shape clinical service organisation and behaviours: there are pressures to reduce length of hospital stay but this might be at the expense of readmission, the use of intermediate care or the use of institutional care – DAH is an outcome measure that enables the global effect of these to be seen.
- 8 Another weakness is that the composite outcome does not lend itself well to attaching costs. Increased DAH might suggest cost savings – but for whom: the acute hospital, adult social care departments? Length of stay in hospital vs. community (driven by current UK health policy) might be used as a secondary outcome, albeit with the loss of power compared to DAH.

Strengths

A defence of this outcome measure, suggested caveats in its use, and further research are discussed below.

- 1 As a broad generalisation for most old people towards the end of their lives, we feel that it is uncontentious that being at home is preferable to being dead, in hospital or in another setting. Toward the end of life all these outcomes are common and real fears for this group of people. An outcome measure of this nature is likely to be easily understood by patients, their families, politicians, commissioners and providers. As a composite outcome it is likely to be more persuasive than any individual component (death, length of stay, etc).
- 2 Measuring health status in older people who are towards the end of their lives is not easy, in some cases impossible, and in other cases difficult to interpret.





Even with great skill and care to overcome communication barriers, many research participants do not have the cognitive capacity to complete health status assessments. In practice, participation in research can be burdensome to many participants and their families who may choose to withdraw from studies after having initially consented. Ethically conducted research must be sensitive to this. A consequence is that there is likely to be significant missing data in ethically conducted research using health status outcome measures. The scientific consequences of this include the possibility of the study being underpowered, or biased. A possible ethical consequence could be undue pressure by researchers on participants to complete outcome questionnaires. DAH is a measure that does not require direct patient contact as it can be drawn from records. DAH should be ascertainable for nearly all people entered into studies, meaning that there will be few missing values.

- 3 Costs relating to DAH are whole system costs and so encourages a broader view of managing frail older patients than costs attributable to individual parts of the system, which might be shifted or played off against each other in the name of 'efficiency'.
- 4 Attempts to manipulate DAH as an outcome measure may not be successful in reality. Discharge home despite severe problems, and in the face of inadequate support, is unlikely to be sustained for long. However, as with many evaluations of complex services, it would be important to include DAH as part of a battery of outcome measures, in order to identify any trade-offs that might be occurring in terms of disability, psychological well-being, and carer strain. Alternatively a parallel qualitative study might be employed.





Further work

Work is required to examine the psychometric properties of DAH, in particular its distribution, to establish how it should be handled in statistical analyses. Further work could also be conducted to investigate patient and family carer perspectives on the assumptions made in using DAH as a measure of good outcome.

Work is also required to ascertain if days at home measured using routine hospital or social services databases is feasible to collect, and if it is accurate. Random date entry errors might be expected and would have the effect of reducing statistical power. More worrying would be non-random (differential) data entry error – for example, deliberate manipulation of hospital length of stay data. This is unlikely, but has happened. Collecting the data from multiple sources multiplies the risk of error (differential or non-differential).

Conclusion

We suggest that DAH is a suitable primary outcome measure for studies of older people using hospital services (including a trial of a specialist unit for people with mental health needs in general hospitals, and a trial of specialist medical input to high risk patients discharged from acute medical units). It is important to examine, as secondary outcomes, the components that are used to calculate it. It is also important to use other measures of health status as secondary outcomes.

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