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**Shared decision making after severe stroke- how can we improve patient and family involvement in treatment decisions?**

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***Shared decision making after severe stroke- how can we improve patient and family involvement in treatment decisions?***

***Involving patients and their families in making decisions about the treatments they receive after a severe stroke can help them achieve outcomes that are most acceptable to them. In this article, we offer ideas for improving decision making after stroke, drawing on current evidence in various patient groups and highlighting where further research is needed.***

**Abstract**

People who are well may regard survival with disability as being worse than death. However, this is often not the case when those surviving with disability (e.g. stroke survivors) are asked the same question. Many routine treatments provided after an acute stroke (e.g. feeding via a tube) increase survival, but with disability. Therefore, clinicians need to support patients and families in making informed decisions about the use of these treatments, in a process termed shared decision-making. This is challenging after acute stroke: there is prognostic uncertainty, patients are often too unwell to participate in decision-making, and proxies may not know the patients' expressed wishes (i.e. values). Patients' values also change over time and in different situations. There is limited evidence on successful methods to facilitate this process. Changes targeted at components of shared decision-making (e.g. decision aids to provide information and discussing patient values) increase patient satisfaction. How this influences decision-making is unclear. Presumably, a 'shared decision-making tool' that introduces effective changes at various stages in this process might be helpful after acute stroke. For example, by complementing professional judgement with predictions from prognostic models, clinicians could provide information that is more accurate. Decision aids that are personalised may be helpful. Further qualitative research can provide clinicians with a better understanding of patient values and factors influencing this at different time points after a stroke. The evaluation of this tool in its success to achieve outcomes consistent with patients' values may require more than one clinical trial.

**Main text**

Many people who are well regard survival with severe disability to be worse than death.(1) However, when people with severe disability (.e.g., stroke survivors) are asked whether death is better than severe disability, they usually answer: 'no'.(2) Decision making in the setting of acute stroke is particularly challenging because a severely affected patient may not be able to answer as their previously well self or their disabled future self.

Shared decision-making is a dynamic process in which patients and clinicians share information, express treatment preferences and agree decisions. This is a gold standard in clinical care. Yet there is limited evidence on successful methods to facilitate this process. (3) To date, there are no trials evaluating shared decision-making on treatments after stroke. However, the effect of decision aids on information provision, a step towards shared decision-making, increases patient knowledge and satisfaction in various patient groups including stroke (4).

Sensible decisions are made with knowledge about likely outcomes with different treatment strategies and knowledge about a patient's wishes for the future (i.e. patient values). (5) We know this from studies on patients with multiple sclerosis(6) and in geriatrics.(7)

How information provision and eliciting patient values impacts on decision-making remains unclear.

Ideally, we want to develop a tool that targets several components of the shared decision-making process that is successful in helping patients achieve outcomes in keeping with their values. To do this, we need to understand the challenges to adopting this process after stroke.

Firstly, there is considerable statistical and clinical uncertainty about prognosis after stroke.(8) Providing information that is uncertain may hinder patients and families when making decisions about the appropriateness of treatments.

Secondly, individuals place different values on different outcomes after stroke. This is because different outcomes (e.g. ability to talk, walk) may impact differently on different individuals' quality of life. Many factors can affect this including culture and religion. (9)

Thirdly, it may be difficult to elicit patient values after a stroke, and be certain of the accuracy of previously expressed wishes. This is because, those severely affected from their stroke may have dysphasia or cognitive impairments, preventing them from communicating their values. In these circumstances, clinicians often rely on proxies who may not know the patient's values well. Even where a patient has expressed a previous wish, this may change over time (2) or when faced with the reality. For example, healthy people versus those who survived but were disabled after hemispherectomy had differing views on survival with disability. (1) (2)

There are a number of key decisions about treatments after stroke. Some reduce both mortality and long-term disability such as thrombectomy. (10) However, routine treatments like tube feeding (11) increase the chance of survival with disability. Given that different individuals place different values on different outcomes, it is crucial that patients and families are intimately involved in making decisions about the use of these treatments.

To do this, more guidance is required. Firstly, clinicians need to be able to provide accurate information on prognosis. This may require clinicians to complement their professional judgement with predictions from prognostic models. Existing models that predict outcome after stroke have high specificity for survival or very poor outcome only. (8) Models that predict recovery of functions (e.g. mobility, speech) updated with data on early patient progress (e.g. early infection, continence) could improve accuracy of predictions. (12)

Secondly, decision aids that are personalised could help information provision. In the development of a decision aid for thrombolysis after acute stroke, patients and relatives emphasised that information should be framed positively (e.g. independence rather than dependence). (13) Presenting information in different formats adapted to specific impairments (e.g. aphasia) using visually attractive methods (e.g. coloured charts) also aided clarity and relevance.(13)

Thirdly, clinicians need to gain a better understanding of individual patient's values for possible outcomes after stroke and factors influencing this. By encouraging patients and families to bring agendas to clinical meetings, clinicians have an opportunity to gain insight into factors affecting decision-making. Further qualitative research (e.g. by interviewing stroke survivors and their families over time) can provide an awareness into patient values pre- and post-stroke, changes over time and factors affecting decisions. Although the generalisability of such information is potentially

challenging, the information gained would be invaluable to clinicians discussing appropriateness of treatments after severe stroke.

To summarise, practising shared decision-making on treatments after severe stroke can be challenging. We recommend the development of a tool that incorporates changes at various stages in this process. Evaluation of this may require more than one clinical trial.

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