The use of formal and informal knowledge sources in patients' treatment decisions in secondary stroke prevention: qualitative study

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Abstract

Background There is robust empirical evidence to support clinical decision making in secondary stroke prevention after transient ischaemic attack (TIA) or recovered stroke. However, little attention has been paid to patients' utilization of this evidence in coming to decisions about their treatment choices.

Objective To examine the use of formal and informal knowledge by patients in making decisions about carotid endarterectomy (CEA) and medical treatment after TIA/recovered stroke.

Setting and participants Twenty participants were recruited from an outpatient vascular surgical assessment clinic in England. Ten were receiving medical treatment alone, and 10 were undergoing CEA after TIA or recovered stroke.

Method Twenty-eight in-depth qualitative interviews were conducted. An iterative approach was used whereby emergent themes were further explored in later interviews. Interviews were audio-taped, transcribed and coded.

Results Participants gathered and utilized several types of knowledge in the process of making treatment decisions: Empirical knowledge (e.g. clinical trial findings); Pathophysiologic findings (e.g. results of clinical investigations); Experiential knowledge (e.g. personal experience of stroke); Goals and values (e.g. potential impact on family); System features (e.g. apparent urgency of treatment).

Conclusions In addition to formal evidence, patients use other sources of informal or 'non-evidentiary' knowledge to support their decisions about treatment after TIA or recovered stroke. To enable evidence-based patient choice, health professionals need to appreciate the diverse types of evidence which patients use, to help them to access relevant and high-quality evidence, to balance evidence from different sources and to make choices which are congruent with their values and expectations.

Introduction

After transient ischaemic attack (TIA), amaurosis fugax, or recovered stroke, medical or surgical treatment can reduce the patient's future risk of stroke. For those with severe (>70%) stenosis of the ipsilateral internal carotid artery (ICA), stroke risk is significantly lower after surgical carotid endarterectomy (CEA) than with best medical treatment (BMT) alone.^{1,2} BMT confers a 3-year stroke/death risk of 16.8%, while CEA reduces this risk to 2.8%, but with an additional post-operative 30-day stroke/death risk of 7.5%.¹ This evidence has been validated by systematic review,³ has been incorporated in national clinical guidelines⁴ and is supported by a recent review comparing CEA with endovascular treatment.⁵ The timing of intervention is important, because patients' risk of subsequent stroke is highest early after a first event. Recently, services have been developed within the British National Health Service to improve the timeliness and quality of care after TIA.⁶

Patients having CEA are described as 'symptomatic' by virtue of having had a recent TIA or recovered stroke but are usually symptom free at the time of surgery. Stroke or death may follow the operation, yet the majority of patients having medical treatment alone will not experience these consequences.¹ There is no certainty of benefit or harm with either option. The patient's dilemma is whether to undergo urgent surgery which carries an immediate risk of precipitating a stroke, yet which will not completely eradicate the risk of future stroke. Alternatively, they may opt for non-surgical management (BMT) and live with a long-term higher risk of stroke.⁷ Although robust evidence supports CEA for patients who meet certain clinical and radiological criteria, it is impossible to predict which patients will have a stroke, and so the decision to have surgery must take into account patient's values and preferences about the risks involved.

Evidence-based health care (EBHC), defined as 'the integration of best research evidence with clinical expertise and patient values',⁸ is based

on the principle of a hierarchy of evidence.⁹ Criticism has been levelled at EBHC for its insufficient emphasis on patients' autonomy in making decisions about their health, because patients' and practitioners' treatment preferences may differ.¹⁰ Patients' preferences, the expert judgement of the practitioner and the best evidence available must be combined in making decisions about health care,¹¹ especially in situations where outcomes are uncertain.¹² This has led to the reconceptualization of EBHC as evidence-based patient choice (EBPC)^{13,14} also referred to as shared decision making. It has been argued that research evidence is only one part of wider typologies of knowledge, including empirical evidence; experiential evidence; pathophysiologic rationale; patient's goals and values; and system features,^{15,16} or alternatively: research, clinical experience, patient experience and information from the local context.¹⁷ Such typologies are implicitly geared towards providing a framework for clinicians' decisions, but may also be useful to shed light on the processes used by patients in coming to decisions about treatment options. Patient decision aids have also been developed for many clinical situations,^{18,19} though not for carotid endarterectomy. However, such standardized approaches to EBPC are not sufficient to ensure good practice.²⁰

This article discusses the types of knowledge affecting patients' treatment choices after TIA or recovered stroke. The aims of the study were to examine the use of evidence by patients who were making decisions about CEA and medical treatment and to identify whether the hegemony of 'gold standard' evidence was congruent with the factors which, in practice, influenced patients' decisions. For the purposes of this article, we have adopted a practical-operational definition of 'evidence', focusing on its perceived relevance, applicability or generalizability to a specific context, rather than its quality.²¹ If we define evidence as any form of knowledge that is relevant to an individual patient and decision-making context, the knowledge which is deemed to constitute 'evidence' will be unique to each patient and decision.

Methods

This study was part of a wider qualitative enquiry into people's experiences of the impact of TIA and recovered stroke. The themes discussed in this article emerged early in data collection and were subsequently expanded during further data collection and analysis.

Participants were identified by purposive sampling while attending a vascular surgical assessment clinic in the north-west of England. All participants had experienced a recent TIA or fully recovered stroke, had completed any necessary investigations including a carotid duplex scan and had come to a decision about their treatment plan (whether CEA or BMT alone). Semistructured interviews were conducted 1–2 weeks pre-operatively for surgical patients, and then approximately 4 weeks after surgery, with the exception of one female participant who sustained a perioperative stroke. Patients who were having BMT were interviewed typically 2–3 weeks after recruitment. An interview guide was used, with questions relating to risk, information and decision making (Table 1). An iterative approach was employed in which further questions and discussion at the first or subsequent interviews were derived from participants' responses. Interviews lasted from 15 to 53 min. They were conducted in the participant's own home and were audiotaped, fully transcribed and coded. Emerging themes were explored in later interviews, using the constant comparative method of grounded theory.²² Analysis was undertaken firstly by conducting an overall and line-by-line reading of the interview text, and open coding of content. Second-level coding was then undertaken to identify and cluster themes from these initial codes. Recruitment was completed after 28 interviews with 20 participants in total, when no significant new themes were emerging.

Local research ethics approval was obtained. A particular concern was the need for the researcher to avoid influencing participant' decisions. Therefore, recruitment was undertaken only once a definite treatment plan had been agreed. Potential participants were initially

Table 1 Interview guide

Introduction:
I would like to talk to you today about your feelings about the possible treatments which have been considered by you and the medical staff to reduce your likelihood of having a stroke.
If you do not understand a particular question or prefer not to answer, just let me know.
1. To go back to the beginning – how was the problem first noticed?
2. What did the doctor/surgeon tell you about your chances of having a stroke?
3. What were your feelings about this?
4. What was the most difficult aspect of this situation for you?
5. What information were you given about the situation?
6. When did you get this information?
7. Who gave you this information?
8. Was this information adequate?
9. How would you have liked the information to have been given?
10. How did you and the doctors/surgeons come to a decision about your treatment?
11. At what point was this decision made?
12. How did you feel about this decision at the time?
13. How do you feel about this decision now?
14. Are there any other areas we have not discussed that concern you?

identified by a member of the clinical team. They were then given further information about the study, and written informed consent was obtained by the researcher (JG).

Results

Twenty participants were recruited, 10 having CEA and 10 having BMT. Mean age was 70.2 years (range 50–82 years); 13 were men and seven women. Sixteen had experienced transient ischaemic attack (symptoms lasting <24 h), of whom six had amaurosis fugax and 10 had sensorimotor TIA. The remaining four participants had experienced a stroke but had fully recovered. Three further potential participants were approached but not interviewed: two declined to take part and one died of coronary artery disease shortly after recruitment.

Coding and analysis of the data identified that participants utilized several distinct types of

Table 2 Typology of knowledge¹⁶ applied to types of knowledge used by participants in making decisions after TIA or recovered stroke

Empirical	Randomised trial findings Comprehension and recall of trial findings Reformulation of trial data
Pathophysiologic	Clinical examination Investigation results Percentage stenosis of internal carotid artery Carotid plaque morphology
Experiential	Knowledge of impact of stroke Personal experience of TIA/ recovered stroke Personal experience of treatment for other conditions Instinct
Goals and values	Quality of life Current health status Potential impact of stroke on family
System features	Reputation and track record of health practitioners and institution Implicit seriousness and urgency Uniformity of information and advice

knowledge in coming to a decision about medical and surgical treatment. These are summarized in Table 2.

Empirical evidence

Participants had not had access to detailed scientific literature relating to the risks of surgical and medical treatment for symptomatic carotid stenosis but had been advised by the clinician of the relative risks of treatment options, using figures derived from this literature. Typically, patients with >70% ICA stenosis had been advised of a 5% perioperative stroke risk with CEA, and 1% per year risk thereafter, versus a 20% 3-year risk of stroke with BMT. Those with lower grades of stenosis had a lower risk of stroke with BMT, but would have much the same perioperative risk of stroke. However, the way that the risks were presented to them meant that for many participants:

in the end there was no decision (Male, age 50, preoperative).

They understood that making the 'wrong' decision had potentially serious consequences, if it were to lead to, for example, a perioperative stroke. The emotional context of this apparently straightforward decision was complex.

The perceived magnitude of the risk of CEA could change over time, sometimes dominating their thoughts, at other times being diminished. One participant likened this change in risk magnitude to maximizing or minimizing 'windows' on a computer screen:

That 5% (surgical risk) became a great big bubble, it was like 'Windows' on Microsoft, I could open this one and this would pop up, or that would pop up, and all these questions had to be asked and ... what happens if I do have this operation and I came out with having a stroke ... so it was quite a big 5%...it blows up, magnifies up into something really horrendous...but (after talking to the surgeon), the information was all collated and formulated into a package that I could understand...and then this 5% started to diminish to an acceptable fear rate of 5%. (Male, age 50, preoperative).

Many participants had an inaccurate recall of the risks of treatment options. The risk of having a stroke without surgery was often overestimated or thought of as a certainty. This affected their feelings about this potential outcome:

if somebody tells you there's a 50% chance of having a stroke (without surgery) that's in your mind all the time (Female, age 64, postoperative.) (Actual 3-year stroke risk without surgery was 16.8%).

Participants based their decisions on a comparison of the relative risks, rather than on absolute risks:

I felt that the risk of having the operation far outweighed the risk of having another attack within 12 months (Male, age 50, preoperative).

you're damned if you do and damned if you don't, I'd have a stroke if I didn't have surgery, and I might have the stroke under the operation (Female, age 67, preoperative)

Participants often recalled the quoted surgical stroke risk of 5%, yet might still have considered surgery if the risks of surgical and non-surgical treatment were similar:

(JG: If you had a friend who was in the same situation what would you say to them?) I would advise to go ahead with it...I would say it's just not worth the worry (of not having surgery)' ... (JG: how high would that (surgical) risk have to be before you start thinking, oh, it's not worth having it?) 'Oh well, if somebody says that it's going to be a 20–25% chance that it won't work then I'd have to take some time...I might turn round and say I'd toss the coin and I'll take a chance. (Male, age 69, postoperative).

Participants believed that they benefited from surgery by reducing their overall stroke risk and the associated long-term anxiety. However, surgery compressed the bulk of the remaining risk into the immediate perioperative period. This increased their anxiety about their short-term risk:

if somebody said to you 'right, there's a 5% chance I'm going to kill you in the next 10 minutes'... that would (make me) ... apprehensive (male, age 50, preoperative - referring to perioperative risks).

The fact that randomized trials of the intervention had been conducted was an indicator of the safety of CEA, irrespective of participants' understanding of the methods and outcomes of the research:

the operation has been tested, and so is safe (Female, age 64, postoperative).

Pathophysiologic evidence

This category encapsulated the participants' understanding and interpretation of their individual clinical situation. All participants had had duplex ultrasound scanning of the carotid arteries to determine the degree of ICA stenosis. The degree of stenosis of an artery is a continuous variable (from 0 to 100%), but in clinical trials and practice, it is treated as ordinal data and is usually reported to be within a specific range (e.g. 50–59%) rather than a precise figure. A stenosis greater than 70% is defined as 'severe', and lesser degrees are classified as 'mild' or 'moderate'. Participants similarly reinterpreted the continuous variable of ICA stenosis, even when they remembered their own

investigation results accurately. Carotid stenosis of < 70% was believed to equate to a negligible or even zero risk of future stroke, while a stenosis of > 70% was more serious:

it's OK, it's 50% (stenosis), so that's it (Male, age 79, BMT).

he (doctor) said it was 50–55% blockage, and that's not too bad...he said up to 80% they're not really too keen on doing surgery (Male, age 64, BMT).

An exception to this pattern was seen with one participant who had several scans on different occasions, with conflicting findings. She clearly understood that higher degrees of stenosis indicated a gradual increase in her stroke risk:

I've had about 3 or 4 scans...so from being like 50–60 (% stenosis) it was going definite 60, and now it's like 65... once it gets to 70 I think it's, the options close...I'll have to have the surgery... I just hope it keeps 65% for a few years...if it (a stroke) happens, it happens (Female, age 75, BMT).

Plaque morphology in the ICA was also believed to be significant:

the other thing that helped to make my mind up is when (the surgeon) commented (that) the restriction in the artery is loose, it's flaky, which is more dangerous than being hardened (Male, age 69, postoperative).

In making decisions about treatment options, participants undertook a process of reframing of the pathophysiologic data. The continuous variable of carotid stenosis was translated into ordinal data, conferring a high, low or zero risk of stroke. Those with severe ICA stenosis usually believed their risk to be greater than their actual 3-year stroke risk without surgery (16.8%). They believed stroke to be very likely or even certain, making surgery worthwhile. By reinterpreting their long-term risk as very high or certain, they resolved the cognitive dissonance^{23,24} of undergoing surgery with no certainty of benefit. Conversely, for those who had moderate ICA stenosis and who did not have surgery, the reframing process implied that their long-term risk of stroke was negligible, despite an actual 3-year risk of stroke of around 10%.

Experiential evidence

Participants' decisions were influenced by personal experiences of having a TIA or recovered stroke, knowledge of the potential impact of stroke and self-appraisal of their general health status. Stroke was seen as a devastating condition:

you hear these horrendous stories about people having strokes and they can't talk, can't walk, so obviously that was a factor (Male, age 50, preoperative).

you look at some of them poor rascals in there (stroke club) who haven't had the choice...I don't think I could live with that, the way some of them are...wheelchair bound and speechless and what have you (Male, age 69, preoperative).

The personal experience of having a TIA or recovered stroke motivated participants to undergo treatment:

(when you have a TIA) you make all sorts of promises, you'll do anything they (health professionals) tell you to do (Male, age 69, BMT).

I might not have been as lucky, if it had been permanent...if it (TIA) had been the big one, if it had left me (disabled) but having that warning, it brought me to ... having the option to have it put right (Male, age 69, preoperative).

With recurrent TIAs, this effect was particularly marked:

I know if I don't have it (CEA) I've no chance. I have too many of these (TIAs) now. (Male, age 81, preoperative).

Participants interpreted the experience of TIA or recovered stroke as a warning sign, a '*wake up call*' (male, age 50, postoperative) and also as evidence of how a more serious stroke might affect them. Others used their previous experiences of treatment for other conditions as an indicator that treatment was likely to be beneficial after their TIA:

the other thing that helped me make my mind up is the fact that I'd had (coronary) angioplasty... I thought to myself that if it does that to my heart ... you've got this carotid artery going in, well if that's blocked, well it's gotta be cleared. (Male, age 69, postoperative).

Some aspects of participants' understanding of their clinical problems and their decisions about treatment had an instinctive quality:

you don't need to be told about these things (symptoms) do you, you just feel them, you just know there's something wrong (Male, age 69, BMT).

right at the beginning I felt...that the way we've been (surgery) was the only way to go (Female, age 64, postoperative).

This may have been a product of the clarity of the empirical and pathophysiological evidence. Because this evidence was perceived to be of high quality, it was easy for participants to assimilate it into their decision; in consequence, they felt that the choice was intuitively obvious. Other factors were important in framing the decision which had been made on the basis of the empirical and pathophysiological evidence.

Patients' goals and values

Participants' current health status and quality of life influenced their decisions about treatment choices, particularly in more active or younger individuals:

I'm sure that some people would say...let's not risk having anything (surgery) done (but) not in my case. Not at all, no. Because I've got far too much to lose (Male, age 50, preoperative).

I said I've got to go for it (surgery)...I'm enjoying life and I want it to go on, without having a stroke (Male, age 69, postoperative).

However, one participant who chose not to have CEA, despite having > 70% ICA stenosis, had a fatalistic attitude towards his health:

I wouldn't be here if I had a major stroke. It'd see me off...it could happen to me again...but I'm prepared to take that chance...I've had a good life. Very good life. No worries. (Male, age 79, BMT).

Participants also felt it was important to avoid a stroke because of its potential impact on their family and friends. They recognized that a severe or fatal stroke '*would devastate...my loved ones' lives*' (Male, age 50, preoperative) and sought to involve family members in their decision:

my wife was with me, and she said...I don't want to be losing you yet... she said go ahead and get it done... I insisted on her being there, because...it's as much her loss or gain as mine, so...she helped me make my mind up. (Male, age 69, preoperative).

so that's why I had the operation, I had it because I want my independence (Female, age 58, postoperative).

System features

Participants' decisions were also influenced by their interactions with the health-care system, including the perceived quality of treatment being offered, the implication of seriousness and the uniformity of advice received.

The reputation of the health-care professionals and the hospital helped participants to decide on the best course of treatment and who should undertake it. This reputation was derived from participants' own past experiences or from other sources and contributed to the development of trust. All the responses in this category related to positive reputations, with no reports of negative experiences.

I didn't want to blot his (surgeon's) copybook, he said he hasn't lost anyone (with a fatal perioperative stroke) yet (Male, age 64, preoperative).

as for being in hospital, each time I've been in, they've been very good (Female, age 67, preoperative).

I'm 100% behind what that doctor (GP)'s given me, I really am, 'cause she's very good, actually in that surgery they all are (Male, age 64, BMT).

Some participants also received or actively sought out acquaintances' opinions about the hospital service and clinicians, and the treatment itself:

if you're going to go under the knife, you try and get some homework done on them, and he (surgeon) comes out a shining light (Male age 50, preoperative).

I've heard of different people who have had this operation and it's been successful...it certainly gave me confidence... (Male, age 72, preoperative).

One participant had sought additional information via the internet. His aim was not to seek out alternative views but to recapitulate the information given by the health professionals:

When (surgeon) discovered what it was and he gave me all the information, ... I went through all this again on the internet (JG: what did you find?) Exactly, everything (surgeon) had said to me ... not that I didn't trust him, I trusted him wholeheartedly...I just like to go over it in my mind (Male, age 69, postoperative).

On seeking medical attention, participants had usually received urgent consultations, investigations and treatment. This haste, to them, implied that their medical condition was serious and that treatment was essential:

(I asked) how many months will I wait for this, and he said in a fortnight...they think she's heading for a major stroke, it could happen any time, we want to avoid it, I can see the logic (Female, age 58, preoperative).

they won't give you these things unless it's necessary, because I mean it's costing too much for the national health service to do it, so if they say it, they're saying it because they know that I need it (Male, age 79, BMT).

The speed with which interventions were planned and carried out meant that participants had little opportunity for a lengthy perusal of their options:

he (surgeon) said 'go home and think about it' and I thought what's the point in going home to think about having it done... So I made up my mind then and there within five minutes... (if I'd gone home) I would have thought no, I'll leave it as it is for the time being, which would be a stupid thing to do. But then when he said come in within the fortnight (for operation), well I nearly fell off the chair then... but it was well worth it. (Female, age 71, postoperative).

In contrast, if they experienced any delays in consultation and treatment, they interpreted this to mean that the problem was not considered to be urgent:

I got a head scan quite quickly, and then on the morning that I was due to see him they rang me up and said due to unforeseen circumstances he can't see you today... and it was quite a while after that

before... they made another appointment... and we both thought well it can't be that serious, otherwise they'd have wanted me back (Male, age 78, BMT).

Participants also expressed reciprocity. They felt that if health professionals were taking the situation seriously, the patient should do likewise:

Once people have made the effort to do tests on you and give people results, I feel...I should do something and go ahead (Male, age 50, preoperative).

The uniformity of advice and information from diverse health professionals helped to clarify participants' decisions:

everything that was done from the information given to me and... all the personalities that I met...their positive attitude helped me confirm that we had made the right decision (Male, age 50, postoperative).

More or less everybody's on the same plane...getting reassurance throughout is very good actually, right from the start...there's nobody throwing a spanner in the works, along the line (Male, age 69, preoperative).

If there had been a dissenting voice amongst the professionals, this would put the decision more firmly in the hands of the patient:

if there was a conflict, I'd be somewhere in the middle, and that would have to be a layman's decision (Male, age 64, BMT).

If a stroke were to occur, the timing and location were important. Those who had CEA believed that having a stroke while at home would be worse than having one post-operatively in the 'safer' hospital environment:

well I wouldn't like to be here and have one (a stroke) on my own...and the (adult) children to come in and find me (Female, age 58, preoperative).

the way I looked at it was, at least if I have a stroke during the operation, I'm in somewhere where it can be dealt with...I'd have got treatment immediately...and also I stood a better chance, if treatment is there immediately, I'm only assuming this...if I'm going to have a stroke let's have it in there... I'm safer there (hospital) (Male, age 69, postoperative).

Discussion

The participants in our study had a superficial and often inaccurate awareness of the robust empirical and pathophysiologic evidence base of secondary stroke prevention. Instead, they utilized other types of knowledge, including experiential evidence, personal goals and values, and system features. This included the following: their experiences and beliefs about stroke, personal experiences of TIA, personal health beliefs and experiences, instinct, reputation of the health-care team, implicit seriousness and consistency of information.

This is the first study to report the ways in which patients use 'evidence' in making decisions about treatment options after TIA or recovered stroke. The sample recruited was fairly representative of the population of TIA and stroke survivors in terms of age and sex distribution. Participation was high among those approached to take part, minimizing sampling bias. The use of in-depth interviews, with patients who were currently or recently faced with the real life situation being studied, enhanced validity and minimized recall bias.

This study has a number of important limitations. Participants were drawn from a single health-care setting, and all consulted the same vascular surgeon, although a number of different primary and secondary care health professionals were also involved in participants' care. This limits the generalizability of the study. Second interviews with participants having BMT, as well as those having CEA, could have been conducted to identify any changes in their appraisal of the evidence base over time. The study was based on interviews alone. Observational data from consultations would have allowed comparison of the evidence discussed by patients and health professionals with that used in participants' eventual decisions. For ethical reasons, we conducted interviews only after participants had come to a formal decision about treatment. Participants may have therefore portrayed a post hoc rationalization of their decisions, rather than discussing the factors

relevant to the decision at the time they actually made it.

The presentation of detailed and accurate scientific data about the risks and benefits of treatment options may have limited relevance to patients' treatment choices after a TIA or recovered stroke. Even where treatment is expected to confer no benefit at all in terms of mortality or morbidity, some patients may still prefer an active treatment option, as has been previously found with patients with breast cancer.²⁵ The provision of additional written and verbal information about CEA has been found to have no effect on patients' understanding of the procedure and its risks and complications, or on patients' levels of anxiety.²⁶ Furthermore, it is known that the provision of more detailed information and options can overwhelm people's information-processing capabilities, and results in them resorting to strategies of simplification that may overlook much of the information and can lead to poorer decisions.²⁷ Other researchers have found that patients' recall of post-operative stroke risk relating to CEA is generally poor.^{24,28} The malleability of accurately recalled risks (such as the quoted 5% stroke/death rate after CEA) has also been noted in a study of thrombolysis for acute stroke, in which a 2% mortality risk was seen as small, yet also highly significant.²⁹

While the use of decision aids may help to structure patients' decisions and help ensure that formal sources of evidence are taken into account, patients' unique goals and values, and their use of informal knowledge, may be overlooked. The extent to which different types of formal and informal knowledge are used, and the use of structured decision aids, are themselves matters for individual preference.

The literature of EBHC is mostly based on a hegemony of evidence from experimental research and systematic review. While some research studies are, of course, more robust than others, the unquestioning application of the hierarchy of evidence to clinical practice has been widely criticized. Some have suggested that the clinical acumen of professional judgement is not a lesser form of evidence when compared

with the 'gold standard' of the RCT, but is a qualitatively different form of evidence,^{16,30} which should not be ranked in terms of the hierarchical scale of EBHC. It has also been argued that the integration of 'non-evidentiary' forms of knowledge (such as clinical expertise and judgement) into clinical decision making undermines the whole epistemological stance of EBHC.¹⁶ Other authors have sought to reformulate 'evidence' to incorporate other forms of knowledge.³¹ Similarly, patients might regard other sources of information about their proposed treatment (for example, a friend's health-care experience; their personal health beliefs; or their judgement of the trustworthiness of clinicians or health-care institutions), as evidence which they have personally '*derived from a variety of sources that has been subjected to testing and has been found credible*'.³¹ The available 'gold standard' evidence is framed and evaluated in relation to its coherence with evidence from informal sources.

Conclusions

Evidence-based health care and its better understanding by patients are cornerstones of shared decision making. However, patients use many types of evidence in coming to decisions about treatment and judge validity by an informal, and usually tacit, evaluation of trustworthiness. This is based on such factors as their previous experiences, lay acquaintances' advice and uniformity of professionals' advice. When the available empirical evidence is robust, these measures might be used partly as a means of wresting back some control over the decision in a situation in which they feel powerless.

These findings go beyond simply incorporating the patient's values and preferences in EBHC, towards an alternative hierarchy of evidence applicable to shared decision making. The trustworthiness of the proposed treatment, conveyed by scientific or informal measures, is perhaps the most important 'evidence'. The framing of recommendations, in the context of the patient's symptoms and in the seriousness conveyed to them, is also important. Stroke risk

reduction can confer additional benefits in the reduction in uncertainty and anxiety about future strokes. However, it is likely that this anxiety is itself exacerbated or even generated by the haste and complexity of investigations and interventions.

Patients appear to adopt an instinctive, heuristic approach to making decisions about treatment options after TIA or recovered stroke. Having made a decision, they then engage in post hoc rationalization, drawing evidence from a wide variety of sources, to validate their decision. Patients' decisions about treatment options after TIA or recovered stroke incorporate non-evidentiary knowledge including experiential knowledge, goals and values, and system features. Even where robust evidence exists for an intervention, patients reinterpret this with varying degrees of accuracy. In this light, the utility of decision aids which aim to give patients a clearer understanding of the scientific data is limited and may even be counterproductive. Treatment adherence and acceptability may be enhanced by reframing the scientific evidence into forms which respect and incorporate patients' experiences, goals and values. System features, such as ease of access, timeliness, consistency of professional advice and (where applicable) financial cost, are also a source of 'evidence' for patient decision making and must reflect the goals of evidence-based clinical guidelines.

We suggest that although robust empirical and pathophysiologic evidence influence patients' decisions about treatment after TIA or recovered stroke, their decisions are also based partly on other, non-evidentiary knowledge sources.

Health professionals need to appreciate the diverse sources of knowledge which patients use, to help them to access relevant and high-quality evidence, to balance evidence from different sources and to make choices which are congruent with their values and expectations.

Conflicts of interest

We declare that there are no conflicts of interest.

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