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Evidence-based medicine and patient choice: the case of heart failure care

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Abstract

The implementation of evidence-based medicine, and policies aimed at increasing user involvement in healthcare decisions, are central planks of contemporary English health policy. Yet they are potentially in conflict. This study used qualitative methods to explore in depth how clinicians working in the field of heart failure resolve this conflict. Qualitative semi-structured interviews were carried out with health professionals who were currently caring for patients with heart failure, and observations were conducted at one dedicated heart failure clinic in northern England. The data demonstrate that, whilst clinicians acknowledged at interview that patient ideas and preferences should be an important part of treatment decisions, the widespread acceptance of the evidence-based clinical protocol for heart failure among the clinic doctors significantly influenced the content and style of the consultation. In conclusion, evidence based medicine was used here to buttress professional authority, and seemed to provide an additional barrier to the adoption of patient-centred clinical practice.

Introduction

The implementation of 'evidence-based medicine' (EBM), and public and patient 'involvement' in health care decisions are both central planks of contemporary English health policy, each supported by a regulatory and other institutions (1). In the case of EBM these include the National Institute for Health and Clinical

Excellence (NICE), charged with producing authoritative guidelines (2), and National Service Frameworks, setting out both clinical and service models that practitioners are expected to follow (3). In the case of *patient* involvement, Patient Advice and Liaison Services, and (more recently) Local Involvement Networks are mandated to provide a patient voice in both health and social care services (<http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/PatientAndPublicinvolvement/index.htm>, accessed Dec 2007). Yet when patient preferences do not coincide with research evidence, these two policies may be in conflict (4). It is not inevitable that such potential conflict will be actualised; the 'critical appraisal' approach envisaged by the academic pioneers of EBM stresses that research evidence should be interpreted according to both judgements about its applicability to the individual, and the patient's own preferences (5). However, the institutional interpretation of EBM in the NHS seems to be nearer to what Harrison (1) has termed 'scientific-bureaucratic medicine' (SBM), in which research evidence is to be implemented primarily via essentially algorithmic 'clinical guidelines', which embody 'the best' management of a particular condition. Examples of this approach include NICE's technology appraisals and production of authoritative clinical guidelines, and the 'Quality and Outcomes Framework' of the 2004 General Medical Services contract, which rewards general practitioners (GPs) financially for treating patients according to (largely) evidence-based guidelines (6). Much critical commentary on this institutionalisation of evidence has focused upon possible denial of desired treatment (as in much-publicised cases of drugs for multiple

sclerosis, breast cancer, dementia and macular degeneration) but it is logically possible that the reverse might occur, with patients receiving undesired treatment.

There is a considerable literature that explores the involvement of patients in decision making about treatment (7, 8), with particular emphasis on how this can be achieved (9). However, there has been less exploration of how this laudable aim can be achieved within the paradigm of SBM, which embodies a set of assumptions about 'the best' treatment for particular conditions. What evidence there is in this area suggests that clinicians struggle to reconcile the demands of the two approaches (10).

This paper addresses empirically the question of how patients' treatment preferences are handled by clinicians working in heart failure care, where the scientific evidence has led to a standard treatment protocol, but where also the trajectory of the condition is highly uncertain, and quality of life may be as badly affected by treatment as by symptoms. In the first part of the study, the attitudes of specialist doctors and nurses working in the field to the management of heart failure were explored, with particular emphasis on patient choice and involvement in decisions. In the second part of the study, observation was undertaken in heart failure clinics in order to gain a more detailed understanding of whether and how the issues explored in the interviews surrounding patients' involvement in decision making were manifest in the actual working practices of doctors.

Heart Failure

Heart failure is the end point of a number of disease processes which damage the capacity of the heart muscle to contract, causing breathlessness, fatigue and fluid retention (11). It is most commonly caused by previous myocardial infarction (heart attack), but other causes include long-standing hypertension, congenital heart defects, viral infection and substance misuse. Heart failure is the only major cardiovascular condition with increasing prevalence, incidence and mortality in the UK (12). Quality of life in chronic heart failure is often poor, with symptoms such as breathlessness and fatigue difficult to control. Life is usually shortened, with one review reporting a five year survival rate of about 40% (13). Heart failure is sometimes classified symptomatically according to the New York Heart Association stages, with stage 1 being classed as mild and stage 4 severe. However, the trajectory of the condition is often unpredictable, and a patient's clinical condition may improve as well as deteriorate, and death may occur suddenly. In recent years studies have demonstrated that drugs such as ace-inhibitors and beta-blockers can improve both symptoms and life expectancy. However, these drugs frequently cause side-effects, including cough, tiredness, dizziness, cold hands and feet and 'heaviness' in the legs on exercise. Research has shown that heart failure patients experience poor care, especially in its end-stages, in comparison with cancer patients (14). It also suggests that patients are poorly-informed about the condition and its treatment (15). The last decade has seen rapid growth in specialist heart failure clinics and the creation of new heart failure specialist nursing posts, and NICE has published an evidence-based clinical guideline for the treatment of

chronic heart failure, primarily with ace-inhibitors, beta-blockers and diuretics, though the guideline does acknowledge that some patients may be unable to tolerate these drugs. The guideline also suggests that patients should be fully informed about their condition, and that treatment decisions should be made in partnership (11).

The following sections respectively describe our study methods, report interview data and observations, and discuss our findings.

Methods

Approval was obtained from a local Research Ethics Committee and the appropriate 'locality' and hospital Trust clearance secured. All data were collected by the first author. The interview sample was selected from lists of hospital consultants and specialist heart failure nurses obtained from the relevant NHS Trusts. Respondents were selected purposively from 10 separate hospitals in northern England, including regional and district general hospitals, so that interviews would reflect a cross-section of opinions and practice styles. Following initial interviews, a 'snowball' approach to recruitment was adopted in which respondents provided contact details of clinicians with a special interest in heart failure. From a total of 23 cardiologists and specialist nurses contacted, 8 cardiologists (all male, 5 consultants, 3 registrars) and 10 nurses (3 male, 7 female) agreed to participate. Interviews were audio-recorded (with permission) and transcribed verbatim. Interviews were qualitative and semi-structured, based on a

topic guide that included: clinicians' beliefs about communication with patients; how treatment decisions are reached; perceptions of any standard protocol for managing heart failure; and the extent of any inter-disciplinary consensus on heart failure care.

Patients for the observation study were recruited from a large NHS heart failure clinic in one of the 10 hospitals from which staff were recruited for the interviews. Four research registrars in cardiology took turns in the outpatient clinic, supported by two specialist heart failure nurses. The patient list was obtained before each clinic and both new and follow up patients over the age of 18 years were approached for permission to observe. One was excluded due to impaired cognitive capacity. All patients had had their diagnosis confirmed by echocardiogram. Twenty-four patient/ cardiologist consultations and sixteen nurse/ patient consultations were observed and audio-recorded and field notes taken on: age, marital status, social class, disease stage and co-morbidities of patients; 'body language', demeanour, and consultation style of the participants. Notes of informal conversations with medical and nursing staff were also made. Although all our patients were diagnosed with 'heart failure' (left ventricular dysfunction), disease severity was variable.

Data analysis employed the 'constant comparison' method, where themes emerging from the interviews and observations were compared systematically (16). Interview and consultation transcripts, in addition to field notes, were coded using

Atlas-ti, and classified into categories and sub-categories. Data were analysed through the identification of patterns, meanings and relationships emerging from the interviews. Memos outlining emerging ideas were written throughout the data collection, and coded excerpts were compared and contrasted within the context of the entire transcript, and subsequently the entire data set of relevant codes.

Participants' identities are anonymised, and italics used to highlight key points. The data and interpretations were discussed with a medically qualified colleague with experience of managing patients with heart failure (KC). Quotations and consultation excerpts were chosen as typical representations of the data.

Interview accounts of heart failure treatment

Our interview data indicate that most respondents held two somewhat inconsistent sets of views about the treatment of heart failure. Firstly, respondents expressed the normative concern that the professional 'culture' in cardiology is geared towards active intervention with patients, and that this approach is often inappropriate for a condition such as chronic heart failure, where the benefits of active treatment are relatively limited and possibly outweighed by side-effects:

One of the problems is because heart failure isn't perceived as a terminal condition, is that it then gets treated inappropriately aggressively. So rather than thinking about relieving pain and suffering and breathlessness, there's more sort of well you know "let's get some more diuretics on board. Maybe we could do this or we could put in a balloon pump" rather than standing

back and looking at the overall picture, and thinking that this is all wholly inappropriate. (Dr H, consultant).

In cardiology the culture had been, our job is to save their lives, and if they die in some ways we feel like a failure. (Nurse P, specialist nurse).

This nurse spoke feelingly about both the inappropriate pursuit of active treatment and the failure of doctors to actively engage patients in the decision-making process:

Nurse: Yeah. Nobody dies when they become a cardiac patient.

Cardiologists will try to the very end, the bitter end, and continue to prescribe medication for patients even though they're in the terminal phase of their life

Interviewer: Do you think that a lot of the time the patient's point of view in terms of what they want is not taken into account as much?

Nurse: Oh yes, it's completely ignored. It's always perceived that the doctor knows best, and I don't think they're ever asked what do you want to do? Half of them don't even know they've got heart failure because nobody's ever told them, which is a big thing – if they don't know what they've got then how can anyone make any decisions – we're very good in the medical profession as they know, you need the patient's consent as they need to be fully informed and it's a joke because half of them have got no concept of any of it what they've got...(Nurse T, specialist nurse).

In spite of this apparent awareness of both the need for restraint, at least in the terminal phases of illness, and the need to engage patients in decisions about their treatment, clinicians' descriptions of their practice made it clear that these considerations were less important than following established clinical guidelines:

When I make a diagnosis or confirm heart failure, it's very important that these patients are put on the right treatment, and when I am talking about treatment I am talking about the drugs first. So number two, is to make sure they are on optimum treatment because you know that patients with heart failure if they're not on the right treatment then obviously it has its consequences (Dr A, consultant).

Probably heart failure is not that much....because we have sort of established treatment. It's not that you give one chemotherapy regimen versus another. You can argue [about] say one ace-inhibitor versus some other or trade name or whatever. There is not much argument about these, whether you should be given them or not. ... so this is easier in that way. There's more difficulties about the patient's [compliance] about how they perceive it, how serious the problem is that they really understand. This is very difficult to judge.If you pursue them more and more then probably eighty to ninety percent will agree to whatever medication (Dr G, registrar).

In this extract Dr G seems to be suggesting that patients did not have a legitimate choice to participate in decision-making because the effectiveness of the treatment was well established. He framed the decision-making process as a 'pursuit' of the patient, suggesting that the doctor's main task was to educate the patient about the benefits of drugs and secure consent rather than to deliberate about their pros and cons. Although many nurse specialists stated that they had more time than cardiologists to discuss illness and treatment with patients, in the observed consultations they generally reinforced the cardiologist's recommendation. Many also supported the view that the scope for patient involvement was limited:

Patient participation... is a difficult subject because all they can do is make sure they drink the correct stuff, they keep an eye on their weight, they keep active, and keep taking the tablets. But, as regards treatment options, then there's not many patients that the doctor will say to them you can have a bypass or transplant or we'll leave you as you are; and it's not like cancer in the respect that you actually see something which is going to potentially cure you, because you're going to have this for the duration. So few patients know enough about them to be able to make an informed decision (Nurse P, specialist nurse).

The cardiologists seemed to suggest that the clinical consensus on heart failure management obviates the need for patient choice. Rejection of the standard treatment was not viewed as a legitimate choice because the evidence base

favouring intervention is so compelling. Rather, patient empowerment consisted of being given information about the benefits of the drug regime and coming to realise that any side-effects were to be tolerated in return for them:

Absolutely, certainly whenever a patient comes to me and he says “I’m getting dreadful side effects” I say to them, “well the option to stay on these tablets is yours, I’m going to give you the information I know and then you can make a balanced decision as to what you want to do”. So you have all these patients coming in and they’ll say “oh I’ve got a terrible cough, these tablets have destroyed my life, I want to come off them, why am I on them?” and you speak to them and you say “well this is why” and then they all go and they say “oh I think I’ll stay on them”. It’s their choice, I haven’t really done anything. I’m not making them take the tablets. They’re taking the tablets out of their choice, empowered with the knowledge that I’ve given them and I think compliance is much better and then they come back next time and say “please increase these tablets, they’re going to do me good....”
(Dr G, registrar).

Furthermore, this nurse suggests that she finds it difficult to accept that patients might want to refuse a treatment that she believes has clear benefits:

I think in my experience [patients] participate in the respect that they’re informed, but when they start to have views about whether they want to

carry on with things [the medication], not necessarily because they're getting poorly or what have you, that does need to be taken on board. *But it is difficult to take it on board when you know the benefits and the prognosis is quite poor without it.* You have to sort of like take that on board (Sister J, specialist nurse).

Thus these interviews seem to suggest that, despite acknowledging the need to treat heart failure patients holistically, significant barriers exist in the minds of clinicians to the provision of treatment choice. The scientifically-established benefit of beta-blockers and other drugs in terms of extending survival meant that both cardiologists and specialist nurses saw the rational patient as a compliant patient.

Making the case: observations of heart failure treatment decisions

Observations revealed a common pattern in consultation structure. The cardiologist initially recorded the medical history and symptoms, then undertook a physical examination to assess heart function. Finally, the problem was explained and treatment offered. The data presented here concern this final element of the consultation, where the cardiology registrar 'made the case' in favour of treatment. In general, strong emphasis was placed on the treatment option, discouraging patients from exercising choice. Explanation of the clinical problem frequently emphasised that treatment might extend life, perhaps as a means of pre-empting resistance to the treatment recommendation:

Registrar (to new attendee, male, 79): When you look at someone's heart on the scan, you're trying to work out how much blood pumps out every time it beats. So, in your case, if someone did a scan on a normal person, I would expect that every time the heart would pump, it would pump out about 60% of the blood that is in it. In your case that's down to 40%, so we have to ask ourselves why this has happened. When you have a weak heart, it means two things: it means firstly that you don't have as good a quality of life as when you have a strong heart. It means that you don't live as long as if you have a strong heart. So what we want to try and do ideally, we want to try and find out why you have a weak heart and secondly whether we can strengthen it up again. In so doing, we also want to improve your quality of life and try and *improve your length of life*.

In this part of the consultation, the patient was told that he had a weak heart and that people with heart failure had a worse quality of life and a reduced lifespan. The patient did not intervene, and the registrar tried to prepare him for the subsequent treatment recommendation:

Registrar: So the things *you need to do so far* are: you need to cut down on the alcohol intake, you need to slow the heart down, *by giving you the tablets* and we need to give you the tablet to thin your blood and prevent you from having clots. *We also want* to give you some tablets that will strengthen your heart up. So there are lots of tablets to take but I think that with all

these tablets you will feel a lot better and we can *strengthen your heart up as well*. Additionally it is also very important that you stop smoking. As you get older, the effects of relatively bad lifestyle will now start coming to haunt you. The most important thing is that you stop doing the things that probably led to this. One is alcohol, secondly, smoking. I will work on the irregular heartbeat and the *weak heart* and hopefully we should be able to make you feel a bit better.

This part of the consultation took a didactic form; statements such as ‘we also want to give you some tablets’, ‘so the things you need to do’ and ‘so there are lots of tablets to take’ indicate that the clinician was responsible for the treatment decision. The cardiologist did not ask the patient’s views on the recommendation, but instead indicated what ‘needed’ to be done, with the implicit suggestion that not to do so would result in an early death.

As the following transcript shows, previous experience of drug side-effects led some patients to express reservations:

Doctor (to male, 66, attended with spouse): Have you ever been on a beta-blocker tablet?

Patient: I was maybe years ago. I think it was for anxiety he gave me. I don’t know.

Dr: OK.

Patient: I enjoyed very bad side effects from...

Dr: What was that?

Patient: In fingers and in my toes, freezing cold. Pins and needles.

Dr: OK. The beta-blockers we use these days are much better than...

Patient: You're talking 10 years ago.

Dr: They're much better than those ones, and it'll certainly be worth a try to put you on that tablet at a very tiny dose and see how you get on, because as I say that's a tablet when somebody's got, *when somebody's heart doesn't pump well*, that's one of the tablets that's *proven* to help you *live longer* and help you breathe much better. So *what we'll do*, we'll chase up these breathing tests but we'll give you a dose of a one of the beta-blocker tablets and what we tend to do in these situations is start people off on just a very, very tiniest dose which is about 1.25 mg and see how you get on with that, and we'll probably give that to you now while you're in the waiting area.

This patient expressed concerns about his previous experience of beta-blockers. The doctor, however, reassured him that the drugs had improved, quickly stating that it would be advisable to accept the treatment and, without waiting for a response, continued to present the reasons for recommending treatment. The use of the term 'proven' illustrates a reference to the scientific basis of the advice. The sentence, 'that's one of the tablets that's proven to help you live longer' also serves to demonstrate the potentially life threatening nature of the condition and the risk of

death if the treatment is refused. Finally, to reassure the patient about the limited risk of side effects, the doctor twice emphasises the 'very tiny' dose.

In the following consultation excerpt the registrar adopted a similar approach:

Registrar (to female, 73 years, married, attended alone): As you know, the problem that you were seeing [other doctor] for was that the heart doesn't pump as well as it might.

Patient: That's right.

Dr: And, that's the cause of your breathlessness. What we are trying to do is to get you on the right mixture of tablets that will help the heart to pump a bit better, and try and get you feeling a bit better as well. There's a couple of drugs that in heart failure are *proven* to be particularly useful. One of them is the class of drugs that [Eprosartan] is part of, and that's a good tablet to be on. Another tablet that has shown to be very helpful in heart failure are the beta-blocker tablets, so things like [Sotalol] and that sort of thing. That's the main reason that [other doctor] has suggested that we see you here, because we can perhaps get you started on a different type of one of those, and a very miniscule dose, and then gradually build it up and see how you get on with it. Probably the reason three years ago you were saying the local GP suggested that you shouldn't be on the beta-blocker then was three years ago we thought beta-blockers weren't that good for heart failure, but *since then we know from big studies that people who have a bit of heart*

failure take beta-blockers, and they live longer, they get [breathless] less frequently, and on the whole it's a very beneficial tablet to be on. So that's why we'd be keen to start you off on that if you would be willing?

Patient: Can I just say – the only reason I'm hesitating is because I've had so much problems with tablets and side effects, that I'm a bit hesitant about swapping them because these seem to be...

Dr: Understandably, I mean I certainly wouldn't say we'd be taking you off any of the tablets that you're currently on, it would be in addition to those, and the sort of dose of... The reason people go for certain types of beta-blockers only that we use for this purpose, is because they are beta-blockers that can be started off with really, really tiny doses. We would normally give people – starting doses probably a fifth of the normal doses that you would even start people on for other things, and so the likelihood of side affects is small, and the likelihood of problems is small. I guess the other aspect of it is if the tablet doesn't suit you then we just stop it.

As in the previous excerpt, the registrar does not wait for the patient to finish, interrupting her concerns with an even more specific account of how small the dose will be. The scientific basis of the treatment recommendation is further emphasised by reference to 'big studies', with again the implied message that not to go along with the recommendation will shorten her life.

In summary, when patients sought to express concern about medication, cardiologists avoided any discussion of pros and cons, simply reiterating the research evidence in varying degrees of detail, and stressing the small dosage and consequent improbability of side-effects, alongside the implicit threat that not to comply would result in early death. Within the consultations we observed, significant clinical uncertainties remained hidden from patients. In no instances was the staging of the condition discussed, nor were patients provided with an estimated probability of life expectancy, remission or relapse.

Discussion

Our interview data provide accounts of their practice by health professionals working in heart failure care that reflect the policy tension between EBM and patient participation. On the one hand there is a view that chronic heart failure patients ought not to be treated too aggressively, so that it is legitimate to accept concerns about side-effects as grounds for declining treatment. On the other hand, there is a view that the evidence in favour of treatment is so compelling that patient participation in decision-making can only occur at the margins. Our observational data show that, in the consulting room, this tension is resolved in favour of EBM, with the doctors using a variety of techniques to persuade patients to accept treatment.

There is an extensive literature that explores the issue of patient participation in treatment decisions. In the late 1990s there was a concerted effort to persuade

medical professionals to move away from the idea of 'compliance' with medication towards one that was labelled 'concordance' (18). The essence of this 'new paradigm' was that patient's concerns should be central to the decision-making process, with associated acceptance of the right to decline beneficial interventions (19). This approach found some favour amongst doctors (20), chiming with the notion of 'patient-centred practice' (21), and research has been undertaken to investigate how this can be achieved in practice (9). However, our observations in heart failure clinics suggests that, in this setting at least, clinicians are more concerned to persuade and cajole their patients than to engage them in any meaningful discussion. In a detailed ethnographic exploration of work in a hospital diabetic clinic, Lutfey (17) explored the different approaches used by clinicians to persuade patients to adopt both medication and lifestyle changes. Amongst other styles of practice she describes 'salesmen' and 'policemen', the latter of whom tended to threaten their patients with the consequences of non-compliance. Our data illustrate doctors adopting both of these personae in order to obtain agreement.

There are a number of possible explanations for this. Firstly, as reflected in our interviews, there is a 'life-saving' culture in the speciality of cardiology, and a preoccupation with technical issues, that can detract from patient participation in treatment decisions (22, 23, 24). Secondly, our data suggests that the 'scientific' nature of EBM may act to limit the degree to which doctors solicit patient involvement in decision-making. References to 'big studies' and treatment being

'proven' to work were used to persuade patients to take treatment and to pre-empt resistance. Katz (25) argues that the existence of clinical guidelines might lead doctors into a situation of 'over-certainty', thereby constraining patient autonomy, and Loughlin (26) draws attention to the 'rhetorical force of certainty' in the continual use of the word 'quality' to describe innovations introduced under the banner of EBM. Specialist clinicians with a solid grounding in research evidence may naturally seek to apply that evidence to patients even though, strictly speaking, probabilities from population-based research cannot be transferred to individual members of that population (27).

Of course, it should not be concluded that easy solutions exist to these problems. As discussed earlier, heart failure is a condition that is uncertain in its course, making it difficult to clearly identify when a patient's condition moves from being 'chronic' (with a life expectancy of years) to being actively terminal (which is usually regarded as having a life expectancy of six months or less). It is possible that the clinicians observed here were in part reflecting this uncertainty. However, it was noticeable that, whilst the doctors did take a history and perform an examination to assess the stage of the disease, this assessment did not appear to influence the conduct of the rest of the consultation, which was, in general, fairly standardised. This suggests that, whatever the clinical stage, the presumption is always in favour of active treatment. Furthermore, whilst it might seem that an approach that shares decision making in the consultation would be ideal, the literature discussing 'concordance' suggests no simple way in which this can be achieved in practice

(28), and some commentators have suggested that the whole concept is in fact a sham, with the explicit coercive nature of 'compliance' replaced by implicit or concealed coercion in 'concordance' (29). At the very least, however, our evidence seems to suggest that, alongside the other difficulties associated with introducing truly patient-centred practice, the danger that EBM might push practitioners towards adopting a more doctor-centred style should be borne in mind. If patient autonomy is important, those involved in the care of patients with heart failure should at least be aware of the issues we raise here, and some attempt be made to temper the 'certainty' that seems to be generated by the collection of evidence from randomised controlled trials into algorithmic guidelines.

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