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‘Managing patient involvement’: provider perspectives on diabetes decision-making

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Abstract

Background Most studies of shared decision-making focus on acute treatment or screening decision-making encounters, yet a significant proportion of primary care is concerned with managing patients with chronic disease.

Aim To investigate provider perspectives on the role of patient involvement in chronic disease decision-making.

Design A qualitative, grounded theory study of patient involvement in diabetes care planning.

Setting and participants Interviews were conducted with 29 providers (19 general practitioners, eight allied health providers, and two endocrinologists) who participated in diabetes care planning.

Results Providers described a conflict between their responsibilities to deliver evidence-based diabetes care and to respect patients’ rights to make decisions. While all were concerned with providing best possible diabetes care, they differed in the emphasis they placed on ‘treating to target’ or practicing ‘personalized care’. Those preferring to ‘treat to target’ were more assertive, while ‘personalized care’ meant being more accepting of the patient’s priorities. Providers sought to manage patient involvement in decision-making according to their objectives. ‘Treating to target’ meant involving patients where necessary to tailor care to their needs and abilities, but limiting patient involvement in decisions about the overall agenda. ‘Personalized care’ meant involving patients to tailor care to patient preference.

Discussion and conclusions Respecting a patient’s autonomy and delivering high-quality diabetes care are important to providers. At times it may not be possible to do both, so a careful balance is required. Involving patients in decision-making may be a means to this end, rather than an end in itself.

Introduction

It has been more than 10 years since the first theoretical models for shared medical decision-making (SDM) were proposed,[1–3] and in that time, the notion of patient involvement in medical decision-making has achieved widespread acceptance as an important component of high-quality care. The research emphasis has shifted from making a case for patient involvement toward developing better ways of measuring whether patients are involved,[4,5] and supporting patient involvement using decision aids.[6] Yet, there remain a number of basic problems and questions.

The first is that most SDM models were not tailored to account for the routine chronic disease decision-making that makes up a significant proportion of primary care. Charles *et al.*'s SDM principles were derived specifically in the context of treatment decision-making for women with early breast cancer – a life-threatening disease where several valid treatment options exist. Their principles also assumed that the patient had accepted their diagnosis and that they were meeting with a physician for the purpose of choosing a treatment option.[1] Yet, many patients with common chronic diseases like diabetes will not necessarily see it as a priority and will consult with their general practitioners (GPs) for any number of reasons. It is not clear how existing SDM models should apply in this case.

Second, a feature of most models of SDM is the concept of mutual deliberation. Yet, Charles *et al.* provide little detail on how mutual deliberation should occur, beyond stating that 'the defining characteristic of deliberation in the SDM model is its interactional nature' and that both parties should exchange information about their preferences.[7] What they do not describe in detail is how the physician should weigh the patient's preferences against their own when deciding whether they can endorse them. Yet, it is this weighing up of preferences and values that is both the essence and the challenge of a SDM process.

Third, most studies of SDM are conducted in the context of clinical equipoise, where there is no single 'correct' medical decision.[8] Yet, for many chronic disease management decisions, there is greater certainty as to what the 'correct' medical decision would be. Also, studies have generally been interested in major treatment decisions, where it is typically the provider who implements the treatment, and the treatments once implemented are irreversible. This in turn has implications for how decisions need to be made in order for the patient to be truly involved.[1] Yet, in managing patients with chronic disease, there is often little urgency, it is typically the patient who is responsible for implementing the treatment, and decisions are often reversible. For example, should the dose of a cholesterol-lowering medication be increased, or should another few months of diet modification be tried? In other words, many of the assumptions of SDM cannot be made in the context of caring for patients with chronic disease.

Indeed, it is only relatively recently that theoretical papers have attempted to modify and adapt the principles of SDM for the context of primary care[9] and chronic disease care.[10] Murray *et al.* emphasized the importance of first agreeing on the agenda for the consultation before embarking upon a SDM approach, thus addressing an aforementioned problem of the original Charles *et al.*'s model.[9] Both they and Montori *et al.* also acknowledged that there should be a greater emphasis on establishing a 'partnership relationship' between patients and their providers, in addition to the usual steps of a SDM process.[9,10] Yet, in both cases, their approach has been to add stages to the existing SDM model, rather than speculate whether a 'partnership relationship' may affect the need for, or the shape of a SDM process altogether.

The aim of this study was to investigate provider perspectives on the role of patient involvement in medical decision-making in the context of ongoing provider–patient relationships during the routine care of a common chronic condition.

Methods

Context

Diabetes was chosen as it is a condition that is common in primary care and involves many small and large decisions about monitoring and management. While decisions may be informed by good evidence, patients often have comorbidities that make the application of evidence-informed guidelines more complex. Moreover, patients may have strong preferences about diabetes management as it involves lifestyle modification and often rigorous medication regimes, and successful management is almost entirely reliant on the patient for its implementation.

To examine diabetes decision-making, interviews were conducted with providers involved in a process called care planning. In Australia, GPs are encouraged to prepare written care plans for patients with chronic and complex medical conditions. These plans are used to document the various problems and needs of the patient, the goals of treatment, and the tasks that will be carried out to achieve these goals. The care planning process is designed to include the participation of all providers involved in the patient's care, and it requires providers to gain the patient's agreement about the goals and tasks of care. Hence, care planning provided a concrete example of decision-making in practice, and one in which the patient had a potential role, even if the extent to which patients are genuinely involved in care planning remains unclear.[11]

Design

The study was conducted using grounded theory methodology, which provides a means for understanding processes like diabetes care planning from the perspectives of the people who are involved.[12] In using this methodology, the researcher does not start with a preconceived model for how decisions ought to be made, nor do they seek to discover the extent to which participants adhere to any particular model. Instead, the aim is to allow participants to describe their experience of care planning and decision-making in their own terms and to use these accounts to develop an explanatory process.

Sampling

Initial sampling was purposeful, aiming to include GPs, diabetes-related allied health providers (AHPs), and endocrinologists from a range of settings to provide different perspectives on the care planning process. Subsequent sampling was guided by ongoing analysis and theory development and continued until saturation of the major concepts was achieved.

The first technique was to 'minimize differences' by recruiting similar people, increasing the possibility of collecting a lot of similar data on a given category, and helping the researcher identify important differences in attitudes or behaviors between similar participants.[13] The second technique was to recruit people who would maximize differences in comparison with other participants. For example, in early AHP interviews, 'professional credibility' emerged as a concept relevant to their involvement in decision-making. The first five AHPs interviewed all worked in close contact with GPs. Therefore, subsequent sampling of AHPs deliberately sought those working separately from GPs. This resulted in the discovery that it was not where AHPs worked that mattered, so much as that they differed in their perceived influence in patient care decisions, which in turn influenced the degree to which they felt responsible for the patient's health outcomes.

Twenty-nine providers participated (19 GPs, eight AHPs, and two endocrinologists). Fourteen worked in urban areas, with seven in solo practice and twelve in group practices. They had a range of clinical experience. The AHPs included four diabetes educators, three dietitians, and a podiatrist. Three worked in private practice colocated with GPs, while the remainder worked in public practice. The endocrinologists both worked in a combination of private and public practice.

Data collection

Data were collected by in-depth interviews. All interviews were conducted by TS who is a GP and researcher. Initially, providers were asked to describe in detail the most recent care plan they developed for a patient with diabetes. They were also asked to talk about how they made decisions and in particular about patient involvement. Such questions were reserved until participants had already talked about their main concerns. Subsequent interviews became more focused, with the aim of clarifying emerging concepts or comparing along selected dimensions.[12] Interviews with providers lasted an average of 37 min (range 20–60 min).

Analysis

Each interview was tape-recorded and fully transcribed, with all information that could personally identify the participants removed during transcription. All the interview transcripts and field notes were entered into N-Vivo qualitative software for data analysis.[14] TS was primarily responsible for coding. As a GP, he entered the study with his own ideas, beliefs, and practices regarding patient involvement in decision-making. Being a GP was in some respects an advantage, as it enhanced theoretical sensitivity to the providers' concerns. It was important, however, to be on guard against the temptation to impose preconceived ideas or theories on the data. Rigorous application of open coding, constant comparison, and memo-writing was necessary. TS also met with SM and LK on multiple occasions to simultaneously code sections of interviews to increase sensitivity to concepts in the data and to refine the emerging coding framework.

There were two types of coding. Substantive codes were used to conceptualize the empirical substance of the research (diabetes care planning), while theoretical codes were then used to conceptualize how the substantive codes related to one another. Analysis was by constant comparison, according to the principles of grounded theory methodology described by Glaser and Strauss.[13]

To illustrate, 'doing the right thing' and 'resolving agenda mismatch' emerged as major categories in provider interviews. Providers gave different interpretations of what it meant to be 'doing the right thing', and these interpretations were found to influence their approach to diabetes care planning and decision-making. A number of other categories could be seen as conditions that influenced how providers defined 'doing the right thing', as well as the extent to which this concern influenced their practice. 'Resolving agenda mismatch' became an important process in 'doing the right thing'. For some providers, 'resolving agenda mismatch' meant 'taking control to assert their agenda', while for others it meant 'relinquishing control and privileging the patient's preferences'. Eventually, 'managing patient involvement to do the right thing' emerged as the main explanatory process for providers' behavior.

Ethics approval

Participants gave written informed consent, consistent with the ethics approval granted by the University of New South Wales and Sydney South West Area Health Service Human Research Ethics Committees.

Results

This section will describe two key findings that have important implications for understanding patient involvement in diabetes decision-making:

1. That providers were strongly motivated by a sense of responsibility for their patients ('doing the right thing'), but that they had different views and beliefs about what constituted best possible care;
2. That they sought to actively *manage* the patient's involvement in decision-making according to what they hoped to achieve.

Doing the right thing

The providers said that their main concern in care planning for patients with diabetes was to make sure they were helping patients achieve the best possible outcomes in the best possible way, described by several as 'doing the right thing'. Yet, there were distinct differences in how providers talked about what it meant to be doing the right thing, and in particular in the differing emphasis, they placed on the two professional responsibilities of beneficence (influencing patients for good) and respecting their patient's rights to make decisions.

Some providers emphasized the importance of achieving ideal biomedical outcomes, an approach that will be referred to as 'treating to target'. These providers acknowledged that there was potential for flexibility in the application of guidelines and that involving patients in decisions was itself an important consideration in trying to deliver quality care. However, they believed it was *more* caring to insist upon treating a patient's diabetes to targets than to respect any patient's preference not to and that they should therefore try to persuade patients to accept their advice. A justification for being persuasive was that while patients may not agree with their recommendations in the short term, they would in the long term.

These providers accepted that many patients would not achieve ideal targets; yet, despite having realistic expectations they still felt it was important to push for ideal targets.

GP02

> Some of my patients are never going to achieve a haemoglobin A1c of less than seven percent either, but it's important to talk about why we would be looking at that as a target.

That is, providers justified the 'treating to target' approach by the rhetoric of 'being idealistic'. There was no virtue in being realistic, but rather a sense that when patients did not reach ideal targets it represented something of a failure, albeit one that was often beyond the provider's control. Their main responsibility was to do whatever was necessary to minimize the possibility of achieving less than ideal outcomes.

GP07

> I don't negotiate. I tell them quite simply 'look, you have a condition such-and-such and such-and-such. If we don't do the right thing by you, and if you don't do the right thing by yourself, the chances of you having so-and-so and so-and-so bluntly are this, that and the other'.

These providers believed a good (and professionally responsible) provider was one with the ability and desire to try to change a patient's priorities and preferences, rather than one who simply respected their priorities when they differed and did not try to change them. This was justifiable on the basis that patients with diabetes were always able to exercise choice, because they themselves were responsible for implementing the treatments.

GP07

> … with the patients we just can't force them to do anything .

By comparison, other providers gave accounts in which they appeared to prioritize the responsibility to respect the patient's right to decide over their responsibility to achieve ideal biomedical outcomes. These providers emphasized the personalized nature of their approach to patient care and described best possible care as determined by the patient's *preferences* as well as needs. They tended to criticize providers who practiced a 'treating to target' approach for taking too little account of the patient. Yet, although these providers made ethical claims about the importance of 'personalized care,' in describing what they did, they typically focused on the practical advantages of this approach. As AlliedHealth01 puts it, 'you've got to be realistic.' 'Treating to target' was fundamentally problematic because it was unrealistic, and not simply because it could be seen as paternalistic.

AlliedHealth01

> I mean I'll help anybody, and try to find a way to give them assistance, but sometimes it's very hard and these people have been [diabetic] years and years and years, and they don't want to break habits, they don't want to purchase a blood glucose meter, those sorts of things. You've got to be realistic.

These two approaches of 'treating to target' and 'personalized care' could be seen as two ends of a spectrum, with most providers in this study describing a preferred approach aligned with one or other end. That is, some were *primarily* concerned with treating to target, while others were *primarily* concerned with personalized care. Generally, it was the doctors, and in particular GPs, who saw themselves as ultimately responsible for their patients' health outcomes, and more inclined to want to 'treat to target.' By comparison, AHPs defined themselves by their ability to personalize patient care.

The implications of this are seen in the following excerpt where GP11 tells how a diabetes educator had failed both him and his patient, because presumably by 'being realistic' and respecting the patient's cultural background, the educator had not taken enough responsibility for ensuring that their diabetes control improved.

GP11

> I actually saw an Indonesian fellow with diabetes who had been seeing the diabetes educator for the last 10 years. And he's on insulin, he's only about 50 something years old, and his haemoglobin A1c is always high. And 1 day I sat down and asked him 'look, what rice do you eat?' 'Jasmine rice'. You may or may not be aware, jasmine rice glycaemic index is about 98, basmati is 26. 'And what bread do you eat?' All the wrong things. What have they been doing? I entrust their care to the diabetes educator and they haven't done anything.

A small number of providers appeared to be fairly inflexible in applying their preferred approach, but most described how they took note of other factors when caring for individual patients and that their actual approach involved finding a balance. For example, those who expressed a preference for 'treating to target' tended to apply this for certain types of problems or patients (for example, the young, relatively healthy patient who had not developed irreversible complications) but not others.

GP13

> I think when the patients are younger, the younger diabetic patients we're much more rigorous about their haemoglobin A1cs than the older patients.

Similarly, those providers who said they provided 'personalized care' also indicated that they would modify their approach according to the patient's potential to benefit from ideal care, even if they used slightly different language in describing how. For example, AlliedHealth06 prefers to say that she negotiates (that is, she allows the patient to express their preferences), but says she is 'very encouraging' if a patient was younger or healthier. In other words, she is more assertive in her recommendations for certain patients.

Interviewer

> What about if a patient has just got diabetes, is it different for them, in terms of what you, or how you negotiate, or whether you negotiate?

AlliedHealth06

> I think we can negotiate anyway, but probably be very encouraging for them. Encouraging them to actually stick to what's recommended.

In summary, this section shows that providers often experienced a conflict between the two professional responsibilities of achieving ideal health outcomes for their patients with diabetes and respecting their patient's rights to make decisions. Compromise was often necessary. For those who were determined to 'treat to target', compromise was acceptable, but only with certain conditions, as discussed later. By comparison, for those practicing 'personalized care', compromise was more easily tolerated as a natural component of their preferred approach.

Managing patient involvement

A major problem providers described in trying to manage patients with diabetes was that there was often some disagreement about what the patient's main problems and priorities were, let alone the best way to manage them. Although this was a common issue generally in primary care, it was particularly relevant to diabetes, where patients often had few or no symptoms and most of the treatment aimed to prevent possible complications, yet it often involved substantial and difficult lifestyle change and long-term medication. Indeed, this basic 'agenda mismatch' was so common that providers described the task of aligning agendas as one of their major concerns in caring for patients with diabetes.

Those providers who were more inclined to 'treat to target' described how they would try to align their patient's agenda more persuasively and would at times seek to assert their agenda despite patient resistance (for example by making ultimatums). By comparison, providers preferring 'personalized care' described their approach as encouraging rather than persuasive, and they were more accepting of different priorities and preferences. Yet, even they had limits as to what they would tolerate, as there were very few circumstances where they would not make some attempt to convince unwilling patients to accept diabetes treatment.

There were more substantial differences in how providers sought to actually implement diabetes care. The aim for those who were 'treating to target' was to implement care according to guidelines, and they would involve patients *where necessary* to facilitate this, which typically meant tailoring care to the patient's needs and abilities. This did not necessarily mean that patients were involved in making decisions. Note in the following excerpt that GP10 does not suggest she involves the patient in deciding what they should do, but simply gathers specific information from them to come up with a personalized plan.

GP10

> First I ask them about their diet, do they eat, how much exercise they do, and then I tell them what should they do.

These providers would in fact deliberately seek to *limit* patient involvement in care planning to prevent too much deviation from best practice guidelines. The main way in which they were prepared to negotiate with patients was with regard to timeframes.

GP09

> I explain to them 'you've come with these problems, we need to deal with them, we need to have some sort of timeframe. I'd like this timeframe, if you have a different timeframe you can tell me. And then we can put the timeframe. But we need to get somewhere in this whole plan of your blood pressure control, or your diabetic control'.

In other words, in 'treating to target,' patients were involved where necessary in deciding how and when to treat their medical problems, but not *what* problems to treat and *whether* to treat them. Rather, providers limited patient involvement in these aspects of care by controlling the options they were prepared to discuss and endorse.

By comparison, adopting a 'personalized care' approach meant involving patients at all levels of the care plan. The first principle of 'personalized care' was to set realistic, achievable goals, and the best way to ensure that the goals were realistic was to involve patients in setting them in the first place.

AlliedHealth04

> If they're 40 kg overweight there's no use telling them instead of weighing a hundred they should weight 60. You're better off having goals of what can be achieved.

Whereas providers who 'treated to target' would ensure that treatment was tailored to the patient's ability, these providers were more inclined to work 'within what they're prepared to do'. This is subtly but importantly different from tailoring care to the patient's ability. In effect, these providers were tailoring care to the patient's *preferences*. They were not only aware of the patient's readiness to make changes but also more respectful of it (whereas the providers who 'treated to target' were more inclined to insist upon certain treatments regardless of the patient's readiness).

AlliedHealth02

> Well from my perspective you can give them as much information as you can give them but ultimately it's up to them to make the changes themselves. So I think that they become the most important part of the team because they then have the control over how much they do. So working within what they're prepared to do is I think the best way to get results for them.

In other words, the 'personalized care' approach meant soliciting patient involvement in deciding *what* problems to treat and *whether* to treat them, as well as how and when they ought to be treated.

The other way in which providers managed patient involvement, and in doing so to resolve any conflict between their preferred approaches, was by revisiting decisions over time. On some occasions, they might need to be more assertive (for example, when patients were at high risk of imminent complications), and at other times more accepting of the patient's preferences. In doing so, providers would use 'treating to target' and 'personalized care' more like different styles of interaction that varied in degree of assertiveness, rather than as fundamentally different philosophies of patient care.

GP16

> People say to me 'I absolutely don't want to take anything for cholesterol' – then I'll talk about the herbal things, the losing weight, and I show them the exercise, what exercise will do to their HDL (cholesterol). I say 'well let's just go with that first'. It's a learning curve for the patient. I say 'over time we'll check it again. Check it in 6 months, see where your cholesterol's at then'.

Discussion

Providers in this study drew on different ethical principles and different quality care paradigms when justifying their preferred approaches to patient care. Some prioritized the principle of beneficence and the paradigm of evidence-based medicine, focussed on the patient's biomedical problems, and preferred to 'treat to target.' Others prioritized respect for the patient's autonomy and the paradigm of patient-centered care, focussed on the patient's biopsychosocial problems, and preferred 'personalized care'. Each justified their approach by reference to its ethical superiority as the best possible care they were able to offer. Yet, while the providers often described these principles and paradigms as opposites, as they are often described in the literature,[15,16] in practice, the majority described a more flexible approach that drew on both depending on the circumstances. Beauchamp supports this, arguing that there is in fact no pre-eminent bioethical principle, but that 'beneficence provides the primary goal and rationale of medicine and health care, whereas respect for autonomy (along with non-maleficence and justice) sets moral limits on the professional's actions in pursuit of this goal'.[15]

Moreover, regardless of their beliefs about the relative importance of beneficence or respect for autonomy, none of the providers in this study suggested that patients should be involved in diabetes decisions because this would result in *better* care. Instead, they involved patients if they believed it would result in better *implementation* of the care they thought the patient needed – in other words, patient involvement in treatment decisions was motivated by the principle of beneficence. Specifically, providers involved patients where necessary to tailor care, either to the patient's specific needs and abilities (in the case of 'treating to target') or their preferences and readiness to change (in the case of 'personalized care').

McGuire *et al.* describe very similar results from interviewing physicians in the United States. Although their physicians often stressed the importance of involving patients out of respect for autonomy, the researchers found that:

> They engaged patients in decision-making largely because they hoped it would result in better health

> outcomes, believing that involving patients in decision-making promotes trust and honesty that leads to better diagnosis and care.[17]

Differences between provider approaches were not simply rhetorical. The more the provider felt personally responsible for the patient's actual health outcomes, the more likely they were to want to 'treat to target,' and the more prepared they were to try to assert their agenda. 'Treating to target' meant involving patients only in certain types of decisions.

These results suggest that the responsibility to provide 'ideal' care according to guidelines is a powerful influence on provider behavior and cannot be easily overlooked in also trying to respect patients' rights to make decisions. Resolving this conflict may at times mean accepting a less than ideal approach, but may also mean revisiting a decision over time, and trying to move the patient toward adopting a more ideal management plan. The key to quality chronic disease care may therefore not be to involve a patient in every decision, but rather to ensure that patients are both well cared for and respected. It might therefore be improper to judge the quality of chronic disease decision-making simply according to the principles of SDM. Moreover, the patient themselves becomes an important judge of quality, as they can only say whether they feel sufficiently respected *and* cared for.

The providers in this study were focussed on delivering best possible care, not on making individual decisions in a particular way. This study suggests that in considering routine primary care of chronic disease, the emphasis may need to move away from the ethics of decision-making *per se* toward a more nuanced view of the ethics of the provider–patient relationship. Medical decision-making is only one aspect of the relationship between patients and their providers, albeit a central one. What matters is not simply whether patients are involved in making specific decisions, but whether the provider is responsive to the patient and succeeds in providing appropriate care and respect.

Conclusion

This study has shown that providers are deliberately trying to manage patient involvement in diabetes decision-making in an attempt to balance competing professional responsibilities. This is driven by their concern to deliver the best possible care while maintaining a respectful relationship – an outcome that does not give primacy to one ethical principle or to a particular decision-making style. Instead, patient-centered communication and SDM may be seen as means to this end, rather than an end in themselves. As Epstein notes, 'the teaching of communication goes beyond technique; there are always important philosophical and moral issues'.[18] If the main ethical justification for SDM is to protect the patient's autonomy, then context is relevant. It is no surprise that most SDM research has been in the context of clinical equipoise, where by definition the principle of beneficence offers little assistance in decision-making. There are also practical implications for information sharing and deliberation if patients and providers are meeting on a single occasion to make an important treatment decision. Here, the specific stages of SDM as described by Charles *et al.*[7] may be necessary to promote genuine SDM. Yet, they may be less important when making chronic disease decisions in the context of a long-term relationship when it is the patient who implements the decision. Here, patients inevitably play a role in decision-making. Communication between providers and patients around these decisions may therefore have different purposes, such as to educate, encourage, warn, or persuade.

There are efforts to measure quality in primary care, which typically focus on the degree to which providers adhere to evidence-based guidelines in delivery of care and the extent to which patients achieve target biomedical outcomes.[19] This study suggests that there will be circumstances when high-quality respectful care will not equate to 'ideal' clinical care and will not lead to improvement in patient health outcomes. This needs careful consideration if providers are to be judged on the quality of care they deliver.

The broader question of what weight should be given to the delivery of best possible 'respectful care' in comparison with high-quality technical care is essentially an ethical one and may yet require a closer understanding of the relationship between interpersonal and technical quality. Does higher-quality interpersonal care lead to more agreement between patients and providers, and better patient health outcomes? To best answer questions such as this, future efforts should be directed toward developing reliable measures of respectful care.

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