

Reflections on the care of the chronically ill

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Abstract

A significant amount of any family physician's time is spent caring for patients with chronic illnesses. Six principles which can aide this caring process are continuity of care, understanding on the part of doctors and patients, participation of patients and their families in their own care, modification of lifestyle, facilitation of adherence to treatment, and a standard management framework. Personal reflections on these principles are shared. (*SA Fam Pract* 2003;45(1):6-8)

INTRODUCTION

Most of the patients I see in my current practice are suffering from chronic diseases such as hypertension, diabetes mellitus, asthma, epilepsy, schizophrenia, HIV, etc. I recently moved from a remote rural area where the shorter life expectancy and more traditional lifestyle mean that chronic diseases are less common, to practice in a peri-urban and semi-rural context, where people apparently live longer and suffer more from diseases of affluence. This has caused me to reflect on the care of such patients, and to revisit the principles of "caring for chronically ill people", elucidated by Fehrsen¹.

A recent edition of the British Medical Journal focussed on the needs of patients with chronic illness. One editorial noted that impaired physician-patient partnerships limit outcomes from chronic diseases.² Another argues that outcomes depend on two types of shared care at primary care level, viz. patient involvement in management and decision-making on the one hand, and specialist involvement to ensure the necessary expertise and guideline-based practice on the other.³ At the same time, the WHO is arguing that many health care providers are poorly trained and

equipped to manage chronic illnesses effectively and is thus advocating systemic strategies to improve clinical care and outcomes for such illnesses.⁴ Chronic disease management programmes are described which require an efficient and well-funded health care system with adequate multidisciplinary staffing.^{5,6}

While not denying the need for an improved health care system and fully supporting the need for innovative and multidisciplinary strategies in the management of chronic illnesses, I believe there is much we can do as primary care doctors despite the chaos within which we often work. Of course, this should not stop us from being agents of change in our role as patient advocates, both at the micro-level in terms of drug supply and availability, equipment, protocols, referral systems, etc, as well as at the macro-level, in terms of the politics and economics of health care delivery.

A number of principles in the ongoing management of patients with chronic illnesses have increasingly shown themselves to be significant to me, and these are elucidated below, in the hope that they will stimulate further thought around this important issue. I believe that trained family physicians

should possess the unique expertise to practice using these kinds of principles.

CONTINUITY

Continuity of care is undoubtedly the single most important factor in ensuring quality of care. This is where Fehrsen also started¹. Previously, I thought that continuity of record (in the form of patient-retained notes) is sufficient, but have come to understand that this, though better than nothing, is limited. The advantages that come from the development of a meaningful relationship, based on trust and openness, between doctor (or nurse) and patient are significant. As much as I seek to be meticulous in my notes, the nuances of patient's wishes and fears, their struggles and insecurities, their families and their contexts, etc, are too many to put on paper and all have a major influence on their care.

I cannot explain why patients who have been seeing me and have been controlled in terms of their particular illness, sometimes go out of control when I no longer see them regularly, while still taking the same medication. I can only assume that this is related to the issue of continuity of relationship.

The principle is important enough

that doctors working in the public sector, who often claim it is not possible to achieve (though many do achieve it) would more profitably spend time and energy making sure this continuity is feasible in their context than any other action in terms of the chronic diseases. I think also that this issue goes beyond the simple doctor-patient continuity to the continuity of the relationship between the doctor and the nurse (and other team members) and to nurse-patient continuity. We need to find ways to address all of these.

UNDERSTANDING

Understanding covers a number of issues – the patient's understanding of his/her illness and its treatment, as well as the doctor's understanding of the patient and his/her conduct.

When new patients are referred to me by nursing colleagues because they are not controlled, or referred to me from a hospital to continue follow-up, I make it a habit to ask what they know of their illness, why it is being treated and what they can do about it. I am constantly shocked by how little patients know of the things that I believe are important for managing their illness (remembering that they usually know much more about things they feel are important.) We fail in this both because we do not see the value in explanations and because we do not know how to talk to our patients in ways that they will understand us.

Again and again I observe students at undergraduate and postgraduate level giving the most rudimentary explanations of problems to patients. Many patients have probably "been told" but the cursory manner and the use of medical jargon have prevented them from hearing. Testing medical students on their ability to explain a Pap smear to a lay person, or listening to doctors on phone-in radio programmes, makes me realise why so few patients understand us.

At the same time I am aware that the best of explanations will not bring understanding if there is information overload, denial, cultural barriers, etc, which stand in the way of my patient really listening to me, and thus I seek to reinforce and check out my explanations on subsequent visits.

I am convinced it is worth every moment of our precious time that we spend on explaining a patient's disease to him/her, in clear and simple (but not simplistic) terms that s/he can understand, together with details of possible complications, reasons for treating and aims of treatment. I am also brought up sharp by patients themselves who on follow up ask about side effects of treatment I did not mention – that too is part of our responsibility.

At the same time we need to understand our patients in terms of their fears and expectations, their constraints and challenges. To expect a patient who has to walk for a full day to get to a clinic to come every fortnight because her BP is not controlled is ludicrous – yet instances like that are very common. We are quick to condemn patients for non-compliance and for defaulting but slow to understand their limitations, very normal human limitations. I always feel humbled by patients who, when I enquire why they did not return on the date given, apologise and say they were collecting their pension! I then apologise for booking them for a return visit on a pension day, assuring them I would also choose pension over treatment. Making a comprehensive assessment, which includes understanding the individual and contextual aspects of the problem, is thus vital.

Ultimately this is about an understanding of whose illness it is. It is not mine; it is my patient's. He needs enough information and understanding to enable him to look after himself adequately and maximise his own care, whereas I need enough understanding to support him in that process. And the patient, of course, remains the expert when it comes to his state of being.

PARTICIPATION

By participation I mean the participation of the patient, his family, other health workers and fellow sufferers in the process of care.

Part of giving control to the patient as described above is involving the patient fully in the management of his own illness, a goal I aim for but often fall for short of. It is a struggle with both my own attitudes and those ingrained in my patients by years of

contact with the system. Full participation of the patient allows for the possibility of shared care between the patient and the doctor.

As family physicians our teaching has been to include the family in care. Often in my day-to-day work this does not seem necessary or appropriate but it is almost always appropriate and important in the management of patients with chronic diseases. Families can give support with taking medication and other practical details. Changes in diet best involve everyone in the family who eats together – and in our patriarchal society there is limited value in explaining a good diet to a man who never goes near the kitchen! Of course at a psychological level the care and support of a family make a big difference.

Participation of other health care workers as and when needed should also be considered, be they nurses, rehabilitation workers, dieticians, social workers or psychologists. In my own experience, apart from nurses, access to other team members is often limited, but where it is possible, participating together in the care of a patient is enriching – for me as well as my patient. Where management is shared with a nursing colleague (typically a PHC nurse in a clinic), I find it useful when I can establish a common understanding of treatment aims and the roles we each have to play.

Finally, the participation of other patients who suffer the same illness, by way of support groups, can be a very positive tool in the care of such patients.

LIFESTYLE MODIFICATION

I have touched on this issue. There is not a single chronic illness (perhaps not a single illness?) in which changes in lifestyle are not a significant factor. This may mean, for example, avoidance of precipitating factors in asthma, diet and exercise in diabetes and hypertension, dealing with stress in epilepsy and depression, dealing with smoking and alcohol habits in almost every illness.

Every time a chronically ill patient visits it is worthwhile reinforcing some aspect of this – while avoiding the lecturing mode we so often slip into. I seek to note what aspect I have touched

on at each visit to ensure coverage of all the important issues over time – repeatedly. As part of this I will often negotiate aims with my patients, for example to decrease from 15 to 10 cigarettes per day, or from 3 to 2 teaspoons of sugar in tea, which I record and check on.

Information sheets, support groups, specifically trained health educators and allied health professionals are all important as part of the process of assisting patients with lifestyle issues.

ADHERENCE

Adherence to treatment is one of the issues that we know very well – usually from a negative perspective, with concepts such as “defaulting” and “non-compliance” (both very doctor-centred terms). What do we do to improve adherence? Obviously ensuring full understanding on the part of the patient about the treatment, when and how to take it, the actions and side effects of the different drugs, etc, are all vital. Also too I think setting realistic goals and preventing false expectations (of cure) are important. We can also assist by rational prescribing: give as few drugs as possible and try to ensure they are taken at the same times of the day. Having seen how one of my own highly educated parents struggled to remember to take all his medication because they had to be taken, variously, daily, on alternate days, twice daily, thrice daily and twice a week, I am convinced we can do more to help our patients in this.

We can also relieve patients and ourselves of a lot of time and effort by getting out of the mindset that every patient with a chronic illness needs to

be seen every month. For example, there is no reason for someone with asthma, diabetes or hypertension, which is well controlled, to be seen every month by a doctor, or even by a nurse. By arranging a few months supply of treatment or repeat prescriptions, we make adherence much easier. It may mean fewer consultation fees in private practice – but it also may save the medical aid from running out, a constant problem that brings patients to my doorstep. In public practice it requires some changes in *modus operandi* and a reliable pharmaceutical supply.

In terms of follow-up visits, I try to avoid the common practice of saying, “come back in one month” or, worse, “come back when your tablets run out”. I give a specific return date, negotiated with the patient, and find this markedly improves timely returns.

Part of supporting adherence which I confess I have not achieved, is to have a system of identifying patients who do not return for follow-up and contacting them to ensure they either return or get treatment elsewhere.

STANDARD MANAGEMENT

Evidence-based management sets out standards for most chronic illnesses, which provide clear, stepwise guidelines for the treatment of these illnesses. It behoves us to keep these clearly in mind and to stick to them regardless of the advertising or the newest agents our local pharmaceutical representatives are pushing. In my opinion, it simplifies management to have such clear guidelines in mind at all times – it reduces the amount of brainwork required of me.

As part of that, flow charts or other uniform record systems help to ensure that we check regularly all the aspects that need to be checked in following up such patients e.g. examination of fundi 6 monthly in diabetic and hypertensive patients, urinalysis every 3 months in patients with hypertension, peak expiratory flow rate measurement every visit in asthmatics, etc. “We need to retain information in a readily available form so that thinking and investigations are not repeatedly started all over again.”¹

CONCLUSION

I do not claim to have discovered anything new, but these principles which I have reflected on have helped me to improve the quality of care for chronically ill patients in my practice population – and remain a goal for which I myself am still striving in optimising care. □

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