

Further reflections on chronic illness care

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Abstract

There are seven key principles in the care of patients with chronic illnesses which are fundamental in offering an appropriate service and adequate care for these patients. These are the principles that should underlie the setting up and management of any primary health care service endeavouring to treat patients with chronic illness. They determine how one understands the care of such patients and how to organise a service or practice. These principles are discussed in this article and will provide both the right mindset and the right organisational approach for effective chronic illness care.

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INTRODUCTION

A few years ago I wrote a reflective piece on the care of patients with chronic illnesses¹. Subsequent to that I have been asked to teach undergraduate medical students and postgraduate family medicine students on the subject of the care of chronic illness. I was also asked by the Faculty of Health Sciences at the University of the Witwatersrand to suggest a model for chronic illness care. As a result of that I further reflected on the management of patients with chronic illness, and have developed a framework for this which I believe helps students to approach topics in a systematic way. However, more importantly, I believe this is a practical framework that we, in practice, can use on an ongoing basis.

Chronic illnesses have been defined in a number of different ways. Most commonly they have been considered to comprise the non-communicable diseases like heart disease, hypertension, diabetes, asthma and epilepsy. However, increasingly there are communicable diseases that are fitting within the framework of chronic illnesses; the most notable of these is HIV/AIDS. Chronic illnesses can be broadly defined as health problems that require ongoing management over a period of years or decades², or more specifically as illnesses that last longer than 3 months and are not self-limiting³. However one defines them they are characterised in terms of similar demands that they place on patients themselves, on the families of patients, on the health care system and, importantly as well, on the socioeconomic system of a country over time.

It is also true that chronic illnesses are increasing throughout the world, because of changing lifestyles, as well as an ageing global population associated with greater longevity⁴. Of particular significance, the proportion of the global burden of disease represented by chronic illnesses in developing countries is increasing very rapidly. Despite major advances in knowledge of treatment of major chronic illnesses, many patients – perhaps most – are not receiving optimal care⁴.

It has been argued that managing chronic illnesses is conceptually different from managing acute illnesses and requires a new paradigm incorporating a completely different approach to the doctor-patient relationship⁵. Managing chronic illness care based on treatment of acute illness has been likened to scratching one's right leg when one's left leg is itchy - it is doing something and may even seem like the right thing, but it does not solve the problem⁶.

There is increasing awareness that similar strategies can be used in the treatment of most chronic illnesses, as recognised by the WHO², with the development of chronic disease management as an important component of health care⁷. Good chronic disease management is an unfolding process, necessitating both patients and doctors to change their roles⁸. Certainly all chronic conditions need a preventative focus in management as well as a maintenance focus.

Very significantly I believe chronic conditions present a major challenge to the efficiency and effectiveness of the health care system which can and

should be judged on how well these are managed. Sadly evidence from around the world suggests that chronic illnesses are generally managed poorly and that health care providers are inadequately trained to manage chronic illnesses effectively⁴. Furthermore, classic hospital-based medical student training does not provide adequate exposure to the ongoing care of patients with these illnesses⁸, which is why it is important this topic is addressed.

KEY PRINCIPLES IN CHRONIC ILLNESS CARE

There are seven key principles in the care of patients with chronic illnesses which I have identified as fundamental to offering an appropriate service and adequate care for these patients. These are the principles that should underlie the setting up and management of any primary health care service endeavouring to treat patients with chronic illness. They determine how we understand the care of such patients and how to organise our service or practice. In other words, they provide both the right mindset and the right organisational approach for effective chronic illness care.

Many of these principles are embodied in the implementation of the antiretroviral drug rollout programme by the National Department of Health. Unfortunately a major opportunity was lost, in planning this vertical programme, to transform the care of all chronic illnesses at primary care level. The health care delivery system we are part of needs fundamental change to ensure these principles can be implemented. It is however possible to achieve this within the public health sector.

I believe that if these principles – 7 C's – are introduced as a standard approach and our patients are managed on an ongoing basis according to them, we can make a significant impact on their care. We can consider them the **7 habits of highly effective carers**.

1. Commitment

Commitment is the fundamental principle which underlies all the rest – it is the foundation of care. It is no coincidence that McWhinney's first principle of family medicine is that of commitment to the person, a commitment that is not defined by either the nature of the illness or by a particular field of knowledge⁹. It is vital that we understand, within any strategies we may develop for tackling diseases and systems of care for particular illnesses, that caring for a patient as a person – with all that this means – is central. This commitment to a person enables the doctor and patient to establish a trusting relationship. There is a reciprocity of commitment implied in this – the doctor commits him or herself to the person who is a patient, with the expectation of a commitment in return.

Part of that commitment, on the doctor's part, is to empower patients to enter fully and autonomously into the relationship, through providing knowledge and enabling them to be partners in their own care. I will return to this in due course.

Ideally, this commitment should not be shown by the individual doctor-carer alone, but it should be shared by other health professionals within the same practice or service, and indeed by the management of the health facility, so that the service is structured in a way that both facilitates and demonstrates that commitment to people. The system needs to serve the person visibly, thus being an environment of "people caring for people"¹⁰.

The remaining 6 C's are practical principles arising from this commitment.

2. Continuity

Commitment draws a doctor into continuity, which is the single most important factor in managing care, as I have previously highlighted¹. This has been described as a continuous healing relationship¹¹ and as active, sustained follow-up³. The basis of continuity is commitment to relationship – the relationship between the doctor and the patient that develops over time as they both get to know each other, based on mutual trust and understanding. It is essential for the kind of ongoing care that is required. It may be possible to have some continuity without commitment, but commitment naturally creates continuity.

Care cannot simply be a technical ex-

ercise but must take into account the individual needs, concerns, aspirations and the context of a patient. In seeking to find appropriate management for the patient, and assisting a patient in terms of changes that they need to make, the trust arising from this relationship provides an essential basis - without this patients will often not be convinced of the need to change.

It is often the case that a doctor is convinced of the need to change the drugs that a patient is on, sometimes radically. However, if the patient has been on these drugs for many years and cannot see the need to change, if there is not trust in the relationship it will be very difficult for this change to be made.

Continuity implies an active and sustained follow up of patients with chronic illnesses and an ongoing support of them. Patients with chronic illness require regular assessment to determine whether any complications are developing and to assess particular risk to the patient; again continuity of care is essential for this to happen.

It may be difficult to convince managers who are not health professionals (or in my experience, even one's own medical colleagues), of the value of continuity. At the very least if managers are not convinced of the fundamental importance of relationship in care, a utilitarian argument can be made for continuity. There is no doubt that continuity of care can save time and money. When patients are seen constantly by new providers, investigations are often repeated unnecessarily which increases the cost per patient. Also the provider takes much more time talking to a patient and reading through previous notes to understand what is going on, thus taking longer per consultation. On the other hand where there is continuity, there is an ongoing management plan and the carer can focus on the critical issues that need to be addressed in the particular consultation and make sure that previous matters are followed up. This can only lead to an improvement in efficiency and effectiveness.

3. Collaboration

Collaboration is required on a number of different levels. Primarily, and most importantly, collaboration is between the doctor and the patient. This should be an element of every consultation with every patient¹². One of the major things that distinguishes chronic illness care is the need to involve the patient in their own management and for the patient in fact to be seen as the primary caregiver – this is the major paradigm shift that needs to take place, and for which our medical training equips us poorly.

In order to do this we need to work together with the patient to enable self care to happen, empowering them to care for themselves. Firstly this involves a process of setting targets together in terms of management so that the doctor and patient jointly come to a decision as to what is being aimed at and what is realistic. A part of this is setting goals for the patient to work towards in terms of changing life style and other self care behaviour. There should be a joint planning process around anything that needs to be done. This should be seen as a process of establishing a kind of shared contract between doctor and patient, setting out the roles and responsibilities of each. Jointly setting goals and developing action plans to meet mutually-agreed targets are proven beneficial steps in managing chronic illness³. What can be very helpful for both the doctor and the patient is to have a shared picture in mind which encapsulates the goal; for example, a picture of a healthy active grandparent surrounded by happy grandchildren gives both something positive to aim for (Dr Beverley Schweitzer, personal communication).

Secondly, self care involves promoting a healthy lifestyle to the patient in order to prevent the progression of the disease and complications. I will return to this below.

Thirdly, self care requires a focus on adherence to treatment which is the responsibility of the patient but requires the support, understanding and ongoing monitoring of the doctor. This is not about compliance, which implies a patient yielding to and obeying a doctor's orders¹³, but rather about a patient understanding and carrying out a management plan that has been mutually agreed upon in collaboration with the doctor. This is embodied in the concept of shared decision-making or concordance¹⁴ – another "C" word!

Patients can also play an important role in the monitoring of key indicators and should be given tools to do so, such as home blood pressure monitors, home glucometers (or at least dipsticks), peak flow meters, etc so that they can be involved in assessing their own progress in relation to their illness. Finally patients also need assistance in taking responsibility for managing the effects on their function, ensuring minimal handicap as a result of any disabling complications that may arise.

Collaboration is about assisting our patients to design personalised self-management plans, and creating relationships with them that are free of judgement and blame⁶. It is about partnership, not only because patients deserve to be partners in their own

health care, but also because it leads to more effective and efficient delivery of health care¹⁵.

Collaboration goes beyond the individual patient. Every chronic illness will have an impact on the patient's family. The support and involvement of the family are thus critical. Research suggests that families affect the outcomes of patients with chronic illness both through the direct effect of the family's emotional climate on the patient's physiologic systems, and through the effect of family members' responses to the disease and its management on self-care behaviour¹⁶. Sufficient evidence already exists to support family-based approaches to chronic disease management¹⁶. The family physician should thus be involved with the family, engaging them too in the process of care and ensuring their collaboration in this important joint venture.

In addition, collaboration with other patients who have the same condition can serve an important function whether this is informally (one on one), or through support groups, be they local or national. Just as the patient is a primary care giver so fellow sufferers become a group of care givers who are supporting each other. There is good evidence that group interventions supporting self care are effective in a number of chronic conditions⁴.

Other members of the health care team are obviously important too in terms of collaboration. It is vital to work in concert and in collaboration with any of the team members that are necessary for the management of a particular condition, be they nurse educators, dieticians, physio and occupational therapists, social workers, etc. Team care has been shown repeatedly to be an effective intervention in chronic disease management¹⁷. The team can support the full range of interventions discussed here. Community resource agencies may form an important component of the broader health care team.

4. Comprehension

Probably the single most significant gift that we can give to a patient with chronic illness to enable them to care adequately for themselves and to live positively is the knowledge that will enable them to have a full understanding of the illness, of its possible complications and of its management. It is worthwhile spending time on this because it will save time in the long run as the patient becomes a true collaborator in the process of his or her care. A range of tools can be used for this in terms of information leaflets, computer programmes, specific patient education courses, videos, etc, as well as the involvement of other team mem-

bers as mentioned above.

Evidence demonstrates that patients who know more achieve better outcomes^{8,18}. Furthermore, knowledge that enables self-management can reduce hospitalisation and costs¹⁸ – certainly this has been demonstrated in respect of diabetes, hypertension and asthma¹⁹, where the evidence of improvement in outcomes is also clear²⁰. This approach goes beyond simply providing patients with information and technical skills, to teaching problem-solving skills,¹⁸ and allowing patients to feel more in control of their problems.

I believe that one line explanations of chronic illness are not only unhelpful but can actually be detrimental in management. The description of diabetes mellitus as "sugar disease" distorts the picture of what the illness is actually about so that instead of focusing on the broader carbohydrate and fat metabolism and the consequences of dysfunction in this regard the patient focuses only on a single foodstuff and will never comprehend all the measures that need to be taken, and certainly not be able to solve problems in self care. If a patient is not fully aware of the possible complications of the disease, how will he/she understand the management plan and the need to take ongoing medication? For it is true that in most chronic illnesses we treat largely to prevent complications arising from or progression of the disease. In this regard it is important to ask the question, whose illness is it? As long as we consider the illness ours in some way, we will not give to our patients the tools they need to manage their illnesses; patients need help to own and take responsibility for their illnesses. To assist in this, we cannot do better than to read and reflect on the Michael Balint classic *The Doctor, his Patient and the Illness*²¹.

Comprehension, however, goes further than the patient's understanding. It also requires the clinician's understanding of his or her patient. In order to manage patients appropriately we need to understand clearly what their aspirations, their needs, their fears and their concerns are. If we do not address these adequately, then any attempt at management is doomed to be unsuccessful.

5. Change

In any chronic illness, change is required. At the very least, patients will have to change in terms of starting to take treatment on a regular basis. More significantly, however, every chronic condition requires lifestyle modification. This should not be seen as an extra, helpful adjunct but actually as basic

core to living with a chronic illness. It is the extent to which we are convinced of this and demonstrate this conviction to patients, which makes a difference. I believe that in many instances even when we know that patients require drugs, we should refrain from prescribing these drugs as long as possible to emphasise the importance of changing. We need to use all the well known tools in terms of educating patients and principles of motivation in order to assist in this process. Modification is vital for promoting optimal health in our patients, for preventing complications and for assisting the adaptation to impairment.

Our attitude, however, is important; the process should be based on the collaborative model. We need to free patients to change, based on what matters most to them, rather than pushing them to change to please us. A range of behavioural techniques have been described for assisting patients with improving their self-care, such as step-wise goal setting, self-monitoring, social support, individualised care, etc. but all are based on a patient's readiness for self-care.³

We also need to be involved in facilitating change in the help seeking behaviour of our patients, as we should be doing in every consultation if we follow the four tasks of Stott and Davis.²² Patients need to understand when they do need to see a clinician but also, as they develop knowledge and responsibility and they are able to control the illness for themselves, when they do not need to see a clinician. There should be times when they can in fact continue for months at a time on maintenance treatment without having to see a doctor or other primary care provider. There is no reason why a patient needs to see a clinician on a monthly basis when they are well controlled. This could be extended to three or six months, depending on their condition. In private practice this is relatively easy to organise. Although the system does not make it easy in the public service, there are various ways to make it happen, such as through repeat scripts. It is again worth the effort to convince managers and pharmacists in particular of the efficiency and cost effectiveness of using such measures appropriately. It does however imply a patient who knows when they need help and has been educated to seek help in between appointments if conditions change.

6. Clinical Guidelines

With the plethora of evidence-based practice guidelines that are available, standard treatment approaches exist for every chronic illness. Although we

are very clever as doctors, we do not need to invent a management approach from scratch but can follow existing, well worked-out management plans. At primary care level it is important to leave the experimentation with new drugs and wonder cures to research clinicians in controlled environments and to stick to the standard tried-and-tested approaches – especially because of the disparities that often exist between results reported in trials and those obtained in routine clinical practice.²³

For every chronic illness there are stepwise management guidelines which assist in decision making. Obviously there needs to be individualisation which is why we are needed as clinicians, responding to the social, emotional and physical context of the patient. It cannot simply be a mechanical process. There needs to be a balance in the patient encounter between evidence and intuition, a dynamic interaction between protocol-driven care and individual patient characteristics²³. Our understanding of the patient, referred to above, allows us to individualise the treatment plan for that patient as well as to work in collaboration with them to see what is most appropriate.

Individualisation however should not be an excuse for throwing the accepted guidelines out of the window. Significant improvements in care have occurred in a wide range of chronic illnesses when health care providers follow clinical guidelines.²⁰

7. Capture of Information

Lastly record keeping, or clinical information systems⁴, is critically important. The problem orientated medical record (POMR) should be the basis for the notes that we keep on our patients. In the Faculty of Health Sciences of the University of the Witwatersrand, we have expanded the traditional SOAP model for the POMR to SOA₃P₄. In this record, A₃ is a reminder of the 3-stage or biopsychosocial assessment that we should be making for every patient²⁴. The P₄ reminds us of the four tasks in the consultation which need to be addressed in the management plan²².

A postgraduate student recently said to me that these are important things for us to think about, but surely we should not write them down. My response was, why not? Indeed I will often write down the full A₃ and P₄ in very brief note form as it is an important way for me of keeping track of what I have covered with the patient and what are the important issues that I need to continue to address.

In addition to the problem orientated medical record however I believe that a very simple tool can make a major differ-

ence to our care, namely the flow chart. A simple card or sheet of paper with columns on it, on which we record the issues that we are regularly checking in our patients, can provide us at a glance with a summary of the progress, control etc of a patient. Thus for a hypertensive patient I might have columns for BP, weight, urine dipsticks and blood tests such as a urea and electrolytes, or in a diabetic I might have similar columns with the addition of blood glucose level, HBA_{1c}, eye checking, ECG, etc. Some of these are filled in at every visit and thus a clear record of what is happening is kept. Others only need to be done every six to twelve months but the empty spaces in the columns show me when these need to be repeated and reminds me to deal with them. For every chronic illness we can establish our own set of columns for the indicators that we want to monitor. Monitoring may be a complex process and requires a good strategy – including issues such as choice of measurements, targets, intervals, etc – but is an essential part of the management of chronic conditions²⁵.

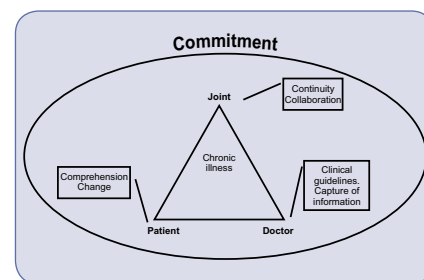
An important task within capturing information is follow up of patients because we need to be recording when, where and for what purpose we are going to be seeing our patients again. Documenting the follow up process is a critical element of their management.

The information we capture must be utilised both in terms of individual patients – for ongoing care and follow up – and for the population of chronically ill patients and patients at risk. In other words, it must allow not only for efficient access to patient notes but also for the possibility of population-based preventive interventions.

Accountability for the Seven C's

I find it helpful to think about who has primary accountability for the different principles in this process. Ultimately the clinicians and the health service need to make sure it happens but the bulk of the responsibility lies with either the clinician or the patient or both. (See diagram 1) According to this, the clinician is primarily accountable for following clinical guidelines and for ensuring adequate capture of information. The patient, given the tools by the clinician, is responsible for ensuring s/he fully understands and comprehends the illness and what it comprises and also for modifying behaviour, to live appropriately with and even control the illness. Then there is joint accountability: this is comprised of the collaboration I have discussed, which is about a partnership between both parties, and also continuity, which I believe is a joint responsibil-

Diagram 1: Accountability for the Principles of Chronic Illness



ity as the clinician must make it possible and the patient value it enough to keep coming back to that clinician; McWhinney⁹ in fact describes it as a mutual commitment. This all takes place within the context of the commitment to the person that I described as fundamental to all these principles.

MANAGING CHRONIC ILLNESS

How then do we apply these principles in the management of the individual patient in a consultation? I find the approach of the World Health Organisation in the Integrated Management of Adolescent and Adult Illness Programme (IMAI)²⁶ to be very helpful. They suggest five A's for every consultation. Because this is clearly laid out in their module on general principles of good chronic care of the IMAI programme, I will not go into detail but only highlight the key areas, to illustrate how the principles mentioned above can all be applied directly in the consultation.

1. Assess

There are a number of aspects which should be assessed every time a patient visits a health worker. I find it useful at this point to think of these aspects in terms of another four Cs:

i) Complaints or concerns

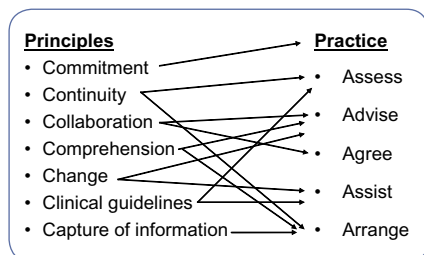
These are the issues that the patient brings to the consultation, either new complaints that have arisen since the previous visit, or ongoing problems that the patient is concerned about. They are important to assess, to ensure that we are meeting the patient's needs and addressing the patient's agenda.

ii) Control

We need to assess the clinical status of the patient in regard to the illness and the extent to which the illness is under control. This involves monitoring by both patient and doctor as discussed above.

iii) Compliance

This is assessing the adherence of the patient to treatment, which should be done in an open and non judgemental way to ensure that the patient is able

Diagram 2: Relating the principles to practice

to express honestly his/her difficulties so that we do not change management unnecessarily. (I use the term compliance advisedly simply because it fits into a mnemonic which makes it easy to remember what we should do; concordance also fits but has a wider connotation than simply medication use, whereas at this point in the consultation the focus is on how patients are coping with disease management, including both self-care and medication use.)

iv) Complications

In every consultation we should be assessing whether there is progression in the disease, whether there are any complications developing and whether there are risks that should be attended to.

These are a measure, to a large extent of the collaboration that exists. The standard used for the assessment is a combination of the patient's self-assessment and objective clinical evaluation, weighed against evidence-based guidelines. All need to be clearly documented.

2. Advise

Our task is to give the key information to the patients about their concerns, their control, their complications and their risks and then to present the management options to the patient in order to allow them to be involved in the decision-making process in the collaborative way discussed above. It is also critical we offer the information and advice patients need in order to care for themselves.

3. Agree

Here we jointly agree on the goals and targets that we are aiming for and on the treatment plan we will be implementing in order to reach those. It is dependent on proper comprehension on the part of the patient and of the doctor.

4. Assist

Our primary role in the management of chronic illness is to assist the patient through the provision of the necessary treatment as per our management plan, through linking the patient to health care team members whose support is needed, and through linking the patient to

people or groups in the community who can be of assistance. We also assist in terms of facilitating particular problem solving that a patient might require.

5. Arrange

Most importantly we need to arrange follow up and the safety net of ongoing care. We should also arrange referral if it is needed. Finally we must arrange that there is a record of the consultation, ideally retained by the patient in addition to a summary kept by us, to assist with the process of continuity and ongoing care discussed above.

This approach to every consultation provides a very useful framework for managing patients with chronic illness. It provides a practical framework within which all the principles of chronic illness care can be applied in the consultation (See diagram 2). One colleague has printed these steps out, laminated that page and stuck it on the wall of his consulting room.

This approach can also be used as a tool for empowerment. I was told that a group of people living with AIDS in Lesotho who, after being taken through this programme, could recite exactly what their caregiver had done or had not done in terms of these five A's and they thus could evaluate the extent to which the consultation had met their needs. Imagine if we could educate all our patients with chronic illnesses to that extent - what a difference it would make to the health care service! I wonder how many of us as clinicians would be open to such an idea or whether we feel too threatened to allow such empowerment.

CONCLUSION

I have presented a framework of principles that can make a radical difference to the way that we manage our patients with chronic illness and more importantly, the way our health system is structured to provide care for such patients. If implemented, I believe it will not only improve the quality of patient care but also the efficiency and effectiveness of care which we all strive for.

While some aspects may be easier to implement in the private health care system, it is also implementable and certainly highly necessary in the public health care system. I long to see our system transformed to meet the challenge of the broad range of chronic illness that our patients are facing, which is often neglected because of the very important focus on HIV/AIDS.

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