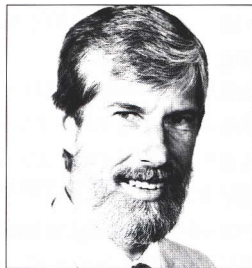


Caring for chronically ill people



Curriculum Vitae

Prof Sam Fehrsen is Head of the Department of Family Medicine (Medunsa) and President of the SA Academy of Family Practice. He is a graduate of the University of Cape Town and worked in mission hospitals in the Transkei for 10 years and the Student Health Service at the University of Pretoria before taking up his present post in 1977. For many years Sam was President of the Transkei and Ciskei Research Society and still has a strong interest in medical missions and giving a high standard of care to underserved areas. He is currently the Convenor of the Task Group of the Academy on Quality Improvement in Family Medicine. Sam is also Chairman of the Christian Medical Fellowship of South Africa and takes great interest in building his understanding of science and religion, as well as how to integrate faith and work. He has several publications to his credit; they range from healing to nutrition, to tuberculosis and the requirements for training in Family Medicine.

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Summary

Modern medicine and technology go to great lengths and great costs to diagnose disease, to manage acute illness or to put people together after major trauma. Medicine has still to show that it can be as sophisticated and dedicated when it has to respond to chronic illness which needs continued care. It is more difficult as it is never as urgent, yet equally important. With a better understanding (by health team and patient) of where a chronic disease comes from and where it is going, medical teams can deliver care of excellence also to chronically ill people. A few practical strategies are discussed which make a difference if implemented in a better organised practice or clinic; and the impersonal, fragmented, ineffectual and expensive treatment can become personal, continuing, comprehensive, shared care for our chronically ill patients.

Introduction

Much of the care available to people, especially those with chronic illnesses is impersonal, fragmentary and episodic. This kind of care is ineffectual and generates unnecessary expense and hardship. Our medical system is good at coming to a diagnosis. It is less effective in giving ongoing care for people who need continued help.

To do better we need to be more organised and develop systems that will make possible an effective ongoing commitment to the patient.

I want to discuss some strategies that can make a difference to people under our care.

We need to organise positively in order that people with a chronic ailment can experience shared care which is personal, has continuity and is compre-

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hensive. This cannot happen without a fair degree of organisation and review of how we practice on an ongoing basis. We need to be organised and disciplined personally and as a practice or health team if we are to achieve the above goals.

Aim

The patient and all those involved in the care should have the same overall aim. The family doctor as the coordinating care giver needs to develop realistic shared aims with the patient. Ideally this shared care will be aiming at a cure, most often it is rather for improvement and control of the disease and at the other end of the spectrum, the agreement is to provide palliate or terminal care. This mutual aim may be developed over several consultations and needs to be reviewed from time to time. It should be clearly recorded for others who share in the care to participate in this agreement.

Organising for continuity and personal care

Care given continuously by the same person is seen by many as the ideal.¹ To achieve this is often difficult. A good appointment system ensuring as far as possible that patients see the same doctor or nurse makes personal care more likely. Through building a relationship over time, individual care gets a chance to become personal. It is in the context of a personal relationship that trust develops. When there is trust the deeper levels of information about the person and her context becomes available for both the doctor and patient to look at. With a fuller understanding of the person and his context the assessment of the problem is enriched and the therapeutic possibilities multiplied.

An orderly and legible record system is a further requisite for continuity. We need to retain information in a readily available form so that thinking and

investigations are not repeatedly started all over again. Whether you work with a card system, a patient retained record or the most sophisticated computerised medical record system, the most important element to introduce is a master problem list and an ongoing medications list. Placed where it can always be seen at a glance helps the record to contribute to continuity in a very simple way. To further extend the usefulness of the record, flow sheets can be constructed for various diseases. Perhaps better still, a patient specific flow sheet can be made. More about this in the next section.

Achieving comprehensivity

A person with a chronic illness is in a complex situation that cannot be addressed by means of a narrow focus on the disease only. It is likely that a series of events lead to the illness. The disease influences people at home and work and they influence the illness. It is therefore imperative that we come to a comprehensive understanding of the situation and make a broader and also a more specific plan than we are generally used to, for better success.² To achieve better results we need to come to a shared understanding of the disease, the person who has the disease and the context in which they find themselves. If we do this we can move on to reaching a shared action plan that goes beyond a general protocol to a specific personalised plan for this person and context.

The making of such a more comprehensive diagnosis or assessment is more fully explained elsewhere.² In essence we need to describe the illness accurately and record our evidence for making a specific diagnosis which will give other caregivers confidence in continuing with the care. This would exclude a diagnosis of say, "known hypertensive". There are people so labelled who do not have hypertension but have been on treatment for years. Another step towards comprehensivity

Care which is personal, comprehensive and has continuity.

Much of the care for the elderly, is impersonal, fragmented and episodic.

An orderly and legible record system.

An ecomap will help you and your patient to understand the illness and its context in many ways.

An easy-to-see master problems list, as well as an ongoing medications list.

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is to ask what kind of person has this disease. What is her understanding of her illness? What are his feelings about it, his fears? What does he expect to happen and what does he expect from you?

The third component is to ask what context does this person come from and how does this influence her situation? How she influences the context is also important to grasp. As we ask these questions we lay the foundations for an ecological or a systems understanding of the person. In a system there is a multiplicity of helpful ways of understanding and dealing with a problem. It gives us so many more options in management. The main focus for an hypertensive patient may change from drug treatment to working with a difficult family relationship or a work related inadequacy for instance.

A good tool to use to get and work with this information about the context is an ecomap.³ This is basically an annotated family tree drawn up with the help of the patient. This helps to get a picture of the patient within his family, home, work, school, church and recreational context which often opens up the patient's understanding as he makes new connections looking at the ecomap. He might realise for the first time a familial tendency towards the illness he has, or see the strong support system he has around him for the first time. The ecomap helps to get an historical perspective of things. It might help to see how the illness has developed. It might motivate a patient to choose a different life style from a family member of a previous generation with the same problem who had a bad outcome. This is especially so for diabetes mellitus. The patient and family can see that their way of living makes them all vulnerable to this condition. It is then easier to get them to accept changes in eating patterns that will be good for the control of mother's diabetes but also a very effective

means of preventing others who are susceptible, to develop it.

The sharing of the care thus extends from doctor and patient to family and others in the support system as well. A further way in which care is shared is when a generalist as coordinator refers the patient to others outside the immediate primary health team. We need to retain responsibility and avoid that the patient gets hijacked on to a referral merry-go-round. This is costly in more than mere financial terms. If we and the patient see this as sharing of care with a consultant or allied health professional, the other care givers are likely to start understanding this as well.

Flow sheets

To work constructively with this breadth and depth of information, a flow sheet is a most useful tool. Within the broad aims we have set for the overall management with the patient we need to focus on some specific areas and record this in a way that we can visualise our progress. These are: the control of the disease, the complications and the progression of the disease, the monitoring of the toxic and side effects of the management and investigations and any other patient specific issues you have agreed to follow. If we are using a universal flow sheet we can use the columns for patient specific recording and build in prompts such as in our patient with diabetes, to tell us when the next fundoscopy is due. This can be effectively done with the simplest record system but also with very sophisticated computer systems.

With modern technology we go to great lengths to hunt down diseases at great cost. We also go to great trouble in managing acute illness or putting people together after major trauma. Medicine still has to respond with the same sophistication and dedication to the continued care of people with chronic illness. It is more difficult as it

A patient-specific flow sheet will help.

A disease influences people at home and at work; and people at home and at work influence the disease.

The GP needs to retain responsibility and avoid that his patient gets hijacked on to an impersonal referral merry-go-round.

We can deliver excellence also in caring for the chronically ill.

Individual care becomes personal over a period of time.

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is never as urgent though still very important. We need to go beyond the blaming of defaulters and get more organised and disciplined within our practices, clinics and health districts to deliver excellence also in caring for chronically ill people.

If we and our patients share an historical perspective giving us some understanding of where this condition has come from and where it is going, we will be able to respond to it more appropriately. If we further have a more comprehensive, an ecological and person-specific understanding we are helped to make better decisions for

the specific person and circumstances. Patients so managed are likely to have a more satisfactory quality of life as they live with their illness under our care.

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