Healthcare systems and chronic kidney disease: putting the patient in control

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ABSTRACT

Today, health policy seems to be on the top of governments’ agendas around the world. Healthcare systems are challenged by a number of phenomena happening on a global scale; these trends include demographic change in terms of an ageing population, an increase in chronic disease, patients having higher expectations on healthcare delivery and above all a major pressure on public finances to slow increasing healthcare expenditures. Such developments are forcing policy-makers to reform healthcare systems. First, there is a tendency towards decentralization of responsibilities. Second, governments are moving towards reimbursement schemes rewarding good outcomes and performance. Third, great importance is being attributed to transparency and accountability, and to introduce competition in healthcare. Fourth, attention is being shifted from simple treatment of a disease towards preventive initiatives, in a more holistic approach to health. Finally, healthcare policy-makers are recognizing the importance of empowering patients to give them control over decisions regarding their own health. These dynamics can be observed in chronic kidney disease, the management of which is a huge economic burden to healthcare systems globally, and which represents a good example of a field where important changes can be witnessed in therapy, technology, delivery and financing.

Keywords: CKD, dialysis, health policy

INTRODUCTION

One might ask what countries like the USA, the richest economy in today’s world, and Sierra Leone, one of the most impoverished countries in Africa, might have in common. Considering health, Sierra Leone’s average life expectancy of 57 years stacks up poorly against the US’s 78 [1]. Yet, these two countries are quite similar in one aspect: the success of their political leaders will be judged to a great extent by the impact of the healthcare reforms they try to implement during their time in office. The importance of healthcare is in fact valid for many countries around the world, be it Saudi Arabia or Australia, Britain or Brazil, Germany or Italy. Despite being so different, and having such diverse healthcare systems, in each of these economies healthcare seems to be rising to the top of the political agenda.

The reason is easy to explain: in fact, healthcare systems are under a great amount of pressure and are facing bigger challenges than ever before. This pressure is forcing radical reforms (see Figure 1). A new model of healthcare is being born, which will emerge—at least in developed countries—during this generation. It will focus more on prevention rather than just treatment; more on quality than quantity; and most importantly, individual patients will have more power and more control over the healthcare that they receive. This will result in a specific focus by governments on the major issue of chronic disease, and the possibility of home-based and self-administered therapies. In this context, the model of chronic kidney disease (CKD) and renal replacement therapy (RRT) by dialysis represents a good example of the need for radical change in the standard of care.

TRENDS IN HEALTHCARE DELIVERY

Demographic change

Regardless of the country and healthcare system, there are four main trends changing healthcare delivery. The first major...
trend is related to demographic change. It is common knowledge that our societies are ageing decade by decade [2]. In fact, by 2050 a good percentage of citizens in the developed world will be over 60 years of age: about a third in the UK, more than a third in Germany and Italy, and even more in Spain [3]. However, this will not be the same old age we have been dealing with so far. More old people will be living with more comorbidities than ever before. This will require more seamless care from a system that now looks fragmented rather than cohesive. These elderly generations will also have a different attitude; they will be less likely to tolerate a system of care that tells them what to do; rather, they will want to tell it what to do for them. We would most probably prefer to live out the end of our lives in our own homes, cared by people we love and love us, rather than in institutions. Using the CKD parallel, the dialysis population is becoming older, with more elderly patients initiating RRT. In fact, in most developed countries a significant fraction of patients requiring RRT are now over 70 years of age [4].

The evolution of illness

A second big trend is the changing pattern of illness. The healthcare challenge of the last century was about tackling infectious diseases, a battle which is still to be won in developing countries. In the developed world, the next century will present a rising tide of chronic disease. The worldwide diabetes prevalence among adults will grow by nearly 25% in the next 20 years [5]. In the UK, for example, obesity rates have risen sharply over the last 25 years [6]. This is not only a compromise with respect to the quality of life, but is also driving up cost. At the moment, close to four out of every five pounds spent on Britain’s healthcare goes into treating the consequences of chronic disease [7]. By 2020, 157 million of citizens in the USA are predicted to have more than one chronic disorder, with 81 million having multiple conditions [8]. As a recent study points out [9], this increase in multimorbidity imposes a relevant additional cost on patient care budgets, and cannot be addressed in the same perspective as single diseases are dealt with. These dynamics are changing the entire health debate: it used to be about the state of a nation’s healthcare system, now it is becoming about the state of a nation’s health.

The focus is shifting from treatment to prevention, and policy is moving from in-hospital treatment towards community-based care [10], and as telemedicine and telecare evolve, it will eventually move into people’s homes.

Policy-makers are beginning to recognize that chronic disease is a permanent fixture of people’s lives; hence, it is beyond the reach of episodic care and instead requires a permanent relationship with the healthcare system. However, it does not end here. If you have a chronic disease, such as diabetes or arthritis, the lifestyle you lead, the exercise you take, the food you eat, all have a direct bearing on your health and ultimately on the healthcare you receive. The question now is how to convert patients from being passive recipients of care, in a system that tends to deny the empowerment of their responsibility, to instead make them active and responsible individuals, who have a greater say over their own health. Again, the example of CKD fits perfectly into a model of prevention, with the possibility to create remission/regression clinics that could be managed by telecare. At the same time, the patient may become a protagonist in the management of the disease, once well instructed and appropriately monitored. The same could be true for congestive heart failure, where a good programme of weight control, blood pressure measurement, sodium intake modulation and biomarker (like B-type natriuretic peptide) monitoring could help prevent several hospitalizations and re-admission for shortness of breath. Portable or wearable technologies for extracorporeal fluid removal could be envisaged to avoid frequent admission to relieve congestion [11].

Patients’ expectations

The third trend that must be addressed is patients’ expectations. People today are more aware and more inquisitive. They expect choice, and they want quality. One piece of evidence about this phenomenon is the result from Pew Research in the USA [12], which asked how many Americans use the internet before visiting their primary care physicians: it was 5 in 10. This number rose to 8 in 10 after they had been to the doctor. This fact tells us that we live in a world where deference is down, but expectations are up. The challenge is to find new ways of harnessing patients’ modern desire for information.
and control, so they can help manage their own conditions. In the case of CKD, peritoneal dialysis (PD) and home haemodialysis (HD) represent good options as home-based and self-administered therapies. However, PD as well as home HD have some limitations, and new forms of portable/wearable dialysis should be explored to allow the expansion of home dialysis programmes.

**Spending cuts**

The fourth and perhaps most important trend is about money. Across the developed world during the last four or five decades, profound increases in healthcare expenditure have not been matched by corresponding increases in economic growth. Governments have simply been spending more than they have been earning. If there is any silver lining to a global financial crisis, it is the ending of this unsustainable surge in healthcare expenditures. This is true not just for the UK, Greece, Italy or Spain, but also for wealthier countries like Germany and Sweden. The problem is that while resources might slow, pressures will not. Policy makers will need to reap more out of what they sow. In this setting, RRT, once viewed as a high-tech treatment, is now considered a commodity therapy. However, while the cost of a single dialysis treatment has progressively decreased over time, the number of prevalent and incident patients is continuously growing [13]. Thus, the burden of CKD represents a challenge in global health, an area that cannot be neglected; changes of policies together with less expensive programmes are needed [13, 14].

**Reforming healthcare**

No country is a stranger to the aforementioned trends. They can be found in different parts of the world in different ways. Their combined effect is to challenge the old assumption that the only way to improve healthcare performance is by continual increases in healthcare investments. A new Holy Grail of global healthcare policy is emerging. The search is on for how to achieve better clinical outcomes, not at higher cost, but lower. This new train of thought is affecting both healthcare payers and healthcare providers.

**Decentralization of responsibilities**

In light of what governments and insurance funds are doing across the world, some major reform directions are emerging. The first development that is now becoming evident is a tendency by policy makers to shift control from centralized to localized. This may not seem apparent in many cases. In the USA, President Obama’s reforms are making the government a more active component of the healthcare system. In Spain, the government is centralizing procurement activity, while in the United Kingdom successive administrations have set more standards and targets at the central level. Despite these initiatives, politicians and policy makers are beginning to realize that self-sustaining improvement in healthcare performance cannot be driven from the top down, but must rather be pushed from the bottom up. If politicians nationalize responsibilities, they take them away from the very people who should be in charge of them: the clinicians and the managers in the healthcare delivery business. This is why many countries are actually devising strategies to delegate power instead of retaining it in the centre. A good example is that of Australia, where the government is creating local hospital networks, in order to shift responsibilities from federal and state government to the hands of local hospitals. In the UK, National Health Service hospitals were effectively denationalized during Tony Blair’s government by converting them into foundation hospitals, which have greater autonomy and are free from political control. Although this move was controversial, the results were interesting; when performance league tables were published, most of the best-performing English hospitals – both in terms of quality and efficiency – were foundation trusts [15]. In this regard, autonomy seems to bring about desirable effects. In the future, a successful healthcare organization will be the one that seizes the opportunity that is given by autonomy, and develops the mind-set of shaping the future rather than having the future shaped. In the CKD context, large dialysis organizations have made important steps towards improvement of quality and standardization of care [16]. The management of CKD is becoming ‘glocal’, which means that patient care is delivered by a single dialysis centre, but built on a platform of quality with standards set by a large dialysis provider. Results are very encouraging, and several governments have applied this model, where a bundled care—often including activities such as drug management, laboratory services, vascular access management, etc., in addition to the dialysis treatment itself—is granted in exchange of a fixed reimbursement.

**New incentives**

The second policy change, not only in America and Europe but in Asia as well, is about incentives. We are witnessing a turn away from paying providers for who they are to instead paying them for what they actually deliver. ‘You know what you’re spending and you know what you’re getting’ is an attitude that can be taken for granted to most walks of life, but so far to a limited extent in healthcare. Annualized increases and block contracts have been commonplace, belittling the focus on outputs and outcomes. However, this is changing, the fiscal pressure governments are facing is forcing them to be more vigilant about spending and instead focus on the return of the money they invest. This is why the concept of ‘pay for performance’ has been introduced and reward systems have been implemented in country after country; although such systems may indeed present some limitations – especially when anchored to guidelines that may not reflect best practices in older, multimorbid patients [17, 18] – they are still a powerful tool to encourage good performance. In the United Kingdom, a separation between care-commissioning and care-providing institutions was introduced. The very presence of a local organization responsible for buying care forced healthcare providers to channel their attention towards earning money, rather than just assuming they can spend it. Such policies go hand-in-hand with the challenge of measurability and accountability. It is easy to reward a hospital for carrying out more activity, since it is easy to measure; but the critical question is: ‘Can
we reward a hospital or a health unit not for doing more, but for achieving more, i.e. for improving the outcomes patients actually receive?’. This is the direction healthcare systems are heading towards. The healthcare system that puts quality and efficiency at the heart of everything it strives for will be a successful one. An interesting model could be a CKD programme in which the use of PD versus HD is brought from the European average of 12% to a new local level of for instance 40%. Assuming a pool of 100 incident patients in one year, 40 patients instead of 12 will be placed on PD. Assuming a conservative savings estimate of 10 000 Euros per patient per year, the final saving will amount to 280 000 Euro/year. Given the same clinical outcome, should not this hospital be rewarded?

Transparency

The third issue is that of transparency. The traditional healthcare system tended to be closed and kept things to itself, but in a world of Twitter and Wikileaks there are no secrets anymore. A decade ago, cardiothoracic surgeons in the United Kingdom were encouraged to publish data about risk-adjusted mortality [19], so that also patients and not just clinicians were aware of their performance. Ten years later, the society representing those surgeons publishes these figures on an annual basis [20]. Once the genie is out of the bottle, there is no putting it back: we are moving towards a world of accountability and total transparency.

Due to the increased pressure on governments to balance the books, policy makers are resorting to various forms of openness, with the aim of bringing competition into public healthcare systems. Examples of this trend are abundant. In the Netherlands, health insurance funds now compete for patients. Poland has recently proposed to earmark 10% of all state hospital beds for private use. Even in social democratic Sweden, in Stockholm the biggest public–private partnership in Europe is currently being constructed involving the Karolinska Institute [21]. In the UK, a system was introduced in which private and public providers were sitting alongside each other. The results, although controversial, were extremely interesting: where there was a private provider challenging public institutions instead of having a simple public monopoly, productivity rose, waiting times fell and mortality rates improved. It is sometimes believed that competition and markets do not work in healthcare; the above example proves that—when properly regulated and managed—they indeed can. In dialysis, public registries are available and have started to provide transparent data, even when not prompted by government authorities: as an example, the UK Renal Registry has been devoting significant effort to the disclosure of relevant outcome measures—such as survival—for the RRT population [22]. Patients no longer accept being treated in centres providing suboptimal care. A continuous search for adequate care is paramount for the patients and their families.

From treatment to prevention

A fourth reform trend that is evolving worldwide is the redefinition of the scope of healthcare. The new idea of healthcare goes beyond treatment of sick people, to also include the improvement of overall health. The rising tide of chronic disease is forcing public policy-makers to address issues such as alcohol, drugs and obesity. In countries as different as Finland, Ireland, Britain and France, governments are now running major public education programmes relating to diet and exercise, as well as health and well-being awareness campaigns. In the long term, we might witness a revolution in the way healthcare is delivered; there could be a paradigm shift from detecting and treating illness to predicting and preventing ill health. That may be many decades off, but the need is already apparent to offer a greater variety and quality of preventive care services. For example, currently <4% of every dollar spent on healthcare in the USA goes on preventive and public-health measures [8]. With respect to renal care, as the worldwide rise in the number of patients with CKD is threatening to reach epidemic proportions over the next decade, a global change in the approach to CKD from treatment to prevention is imperative, especially in low- and middle-income countries lacking resources for RRT [13, 23, 24].

Patient participation

The final—and perhaps most significant—change that is taking place is related to the patient’s individual participation in healthcare. Policy-makers are grappling with the idea of moving patients towards being active participants and not passive recipients. The booming prevalence of chronic disease challenges the very paradigm of how healthcare has been delivered over the last few decades, where the clinician prescribes and the patient just receives. For instance, if one suffers from diabetes, his/her behaviour—what he/she does, his/her exercise habits, lifestyle and diet—has a huge bearing on outcomes. Hence, it is vital to include the patient in the decision-making process rather than keeping him/her outside, ultimately shifting healthcare practices towards a patient-centred approach. One way this new paradigm is being implemented is by offering patients more choice. In the UK, a new system has been introduced, which allows patients to choose the hospital rather than vice versa [25]. In some cases, if patients feel that it is convenient and safe, they would prefer home-based to clinic-based treatment. Taking this view into account, it is of key importance to broaden the availability of technologies that allow for this to happen. In any case, even if patients are treated in a clinic, they want to be given the choice of how care is provided and what services they will receive. As the baby boomer generation grows old and falls into our demographic catchment, they are going to demand precise services, be it online entertainment, wireless Internet, pedicures or manicures in dialysis clinics. If the focus right now is to give patients the choice, the real challenge is how we give patients the control. A number of successful evaluations have been carried out in the UK and the USA about patients being offered their own personal budget to allocate, rather than being offered a standard menu of services [26]. Two remarkable things seem to happen; firstly, the level of satisfaction increases, since the patient feels more in control. Secondly, public expenditure falls, since clinicians seem to be somewhat less conservative than patients when it comes to spending public money on healthcare services.
Based on the above mentioned considerations, the case of CKD constitutes a perfect example of how healthcare systems can be driven towards a new paradigm, characterized by decentralization, transparency, accountability and patient-centred care. Figure 2 depicts a potential integrated approach to the management of kidney disease in a holistic perspective. In the early phases of CKD, diagnosis and early referral at home are quintessential elements for an accurate staging of the disease and the prevention of complications. In fact, patients can be referred to the hospital only when specific clinical assessment and management of acute complications are required; episodes of acute on chronic kidney disease should be managed in hospital for the potential of jeopardizing patient stability and preservation of residual renal function. In a later phase, other conditions moving care from home to the hospital may be limited to pre-dialysis care, such as adjustment of pharmacological therapy or access preparation. When the patient is addressed to haemodialysis, hospital-based events are prevalent due to the very nature of the therapy; home care may only concern dietary regime and pharmacological therapy. On the other hand, different options are available today—or appearing on the horizon. PD is the prototype of a home-based RRT, with minimum access to hospital care only when complications occur. The same is probably true for home dialysis, either performed daily or with other schedules. As in PD, the patient is empowered and put in full control of the therapy; this process of self-assessment can also be assisted by telemedicine or other forms of support such as a programme of regular home visits performed by a specialized nursing team (ref. in press in this issue of NDT). Adopting a longer-term perspective, new avenues can be envisaged, such as wearable solutions for kidney replacement. This ultimate technology – as well as implantable devices – is under evaluation and represents a promise for the future of decentralized, patient-centred treatment [27].

**FIGURE 2:** Holistic approach to CKD based on the integration of hospital care and home care.
The crunch in healthcare expenditure and the dramatic changes in demography, illness and expectations are unequivocally pointing in one direction: a new form of accountability in healthcare. Not to politicians, not to healthcare providers or professionals, but to the patients. In the end, it is their health. In the future, in kidney disease as well as in other fields of healthcare, we will witness a major redistribution of power and control to patients, and with it, the responsibility of how they look after themselves, their health, and their healthcare.

CONFLICT OF INTEREST STATEMENT

A.M. is a Board Member of Diaverum Sweden AB and used to be Secretary of State for Health, the United Kingdom, 1999–2003.

(See related article by Methven and Caskey. Putting the patient first: should we nudge them or shove them? Nephrol Dial Transplant 2014; 29: 941–943.)

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