

REVIEW

Health systems and the management of chronic diseases: lessons from Type 1 diabetes



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Practice Points

- Type 1 diabetes is a useful tracer condition in looking at chronic diseases in health systems.
- The management of chronic diseases is one of the largest challenges that health systems throughout the world face.
- Health systems are currently organized for acute care and not chronic conditions.
- Diabetes care requires an integrated approach, with the person with diabetes, the family and community being involved in care as most of the time diabetes is managed outside of the health system.
- Currently health systems fail to meet the needs of people with chronic disease as they do not address nonclinical aspects appropriately.
- Care for chronic diseases needs to be tailored to each individual.

SUMMARY Type 1 diabetes is a good example of a chronic noncommunicable disease and some have even suggested that it may be used as a ‘tracer’ condition. Chronic noncommunicable diseases are the leading challenge that health systems throughout the world currently face and a shift is needed at different levels of the health system to manage these conditions effectively. However, Type 1 diabetes like most chronic noncommunicable diseases is managed outside the health system, and therefore a larger perspective than purely medical care is needed. This is also required as any chronic disease changes the individual’s perspective and their needs in managing their condition on a daily basis. The purpose of this review is to present a health systems’ perspective on the management of diabetes and chronic conditions. In presenting this perspective the review aims to highlight that although the individual is included in the Innovative Care for Chronic Conditions Framework, current literature fails to address the individual’s experience and how the health system only plays a small role in their overall care.

The management of Type 1 diabetes requires an integrated approach, with the person with diabetes, the family and community being involved in care, which is common to all chronic noncommunicable diseases (CNCDs) [1,101]. Chronic diseases (CDs) are defined as diseases that have

a long duration, generally progress slowly and do not have a cure [2,3,102]. Some CDs are communicable, such as AIDS and tuberculosis (TB). Noncommunicable diseases (NCDs) are those diseases that cannot be transmitted from person to person [102]. CNCDs are the leading cause of

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worldwide mortality with the main causes being cardiovascular disease, cancer, chronic lung disease and diabetes [1]. In 2005, all CDs accounted for 72% of the total global burden of disease in the population aged 30 years and older [4]. In the USA, it is estimated that 100 million people have at least one CD and managing these diseases accounts for 75% of national health expenditure [5].

Approximately 80% of deaths from CDs now occur in low- and middle-income countries [6]. Death rates in these countries, in contrast to high-income settings, are highest in middle-aged people who are the most economically active segment of the population [6]. These countries are now facing the double burden of disease with an increasing number of people suffering from NCDs such as hypertension, stroke, coronary heart disease and diabetes, in parallel to the challenges of communicable diseases such as AIDS, TB and malaria [1,7]. In Tanzania, Setel *et al.* regrouped diseases, whether they were acute or chronic, to reflect their care needs [8]. It was found that 86% of disability-adjusted life years (DALYs) were attributable to CDs. Another study from South Africa found that the need for chronic care has increased more than the need for acute care [9].

Many health systems are not currently organized for the long-term care of individuals, but rather acute care [10,103]. The management of CDs requires a more integrated health system than that needed for one-off acute care with regular availability of drugs, laboratory facilities, data collection tools, a trained healthcare team and educated and empowered patients [11,103]. Type 1 diabetes is an interesting example of a CNCD in that it requires strict management of different aspects of life (medicines, diet and so on) as well as being managed for the most part outside the formal health system.

Type 1 diabetes as a 'tracer condition'

Kessner *et al.* were the first to use the concept of tracers with regards to health systems [12]. They used this concept in a similar way as radioactive tracers are used by healthcare workers to see how different organs work. They then applied this idea to health systems, with certain conditions being used as tracers on how a health system worked. They stated that tracers needed to be distinct and identifiable health problems and were required to show how particular parts of the health system work together to provide

healthcare. Tracers measure both the processes and outcomes of care.

They established six criteria for tracers. In order of importance these are:

- The condition used as a tracer should have a measurable impact on the patient and treatment of this condition should also influence outcomes;
- A tracer condition should be well defined and easily diagnosed;
- The prevalence of the diseases should be significant enough to allow for adequate data collection;
- The progression of the disease should vary with varying use of the health system;
- Medical/clinical management of the condition should be well defined in at least one of the following areas: prevention, diagnosis, treatment or rehabilitation;
- Non-medical aspects of the condition should be known as well as the epidemiology.

The suitability of Type 1 diabetes with regards to these six criteria is detailed in [Table 1](#).

Nolte *et al.* in applying this concept developed a mortality-to-incidence ratio for 29 industrialized countries using published data on diabetes incidence and mortality [13]. They used the mortality/incidence ratio as a crude indicator of 'case fatality' and thus the overall quality of healthcare. This measure was used to identify differences in the performance of health systems. Work in resource-poor settings has found a link between health system factors and life-expectancy for Type 1 diabetes and diabetes-related mortality [14,104–109]. A wide variation was found across countries highlighting that differences in the provision of care for people with diabetes had an impact on outcomes of people with Type 1 diabetes. In parallel, in the USA improvements in care for people with Type 1 diabetes have shown that life expectancy for people with Type 1 diabetes has improved by 15 years between 1965 and 1980 in parallel to life expectancy for the overall US population only improving by 1 year [15]. The difference between life expectancy for the general US population and someone with Type 1 diabetes is now only 4 years. Diabetes is argued to be a good tracer as it shows the ability of a health system to respond to CDs and that the tools and approach from a health system perspective to the management of CDs are similar.

Table 1. The suitability of Type 1 diabetes as a 'tracer' condition.

Criteria for 'tracer' condition based on Kessner <i>et al.</i> [12]	Factor related to Type 1 diabetes
Condition should have a measurable impact on the patient Treatment of this condition should also influence outcomes	Type 1 diabetes has a clear impact on the individual Without insulin the person will die Any failure within the health system in managing Type 1 diabetes will immediately have an impact on the individual
Well defined and easily diagnosed condition	Type 1 diabetes is clearly defined clinically with specific diagnostic criteria
Prevalence of the diseases should be significant enough to allow for adequate data collection	This is the case in some populations, but not all. However, each population no matter where should have at least some people with Type 1 diabetes
Progression of the disease should vary with varying use of the health system	Progression and development of complications is directly linked to use of the health system
Medical/clinical management of the condition should be well defined in at least one of the following areas: ▪ Prevention ▪ Diagnosis ▪ Treatment ▪ Rehabilitation	Type 1 diabetes qualifies in the following areas: ▪ Diagnosis ▪ Treatment
Non-medical aspects of the condition should be known as well as the epidemiology	These are known and clearly described in the literature. Epidemiology in most settings is known. In others where it is unknown, predictions exist as Type 1 diabetes is present to varying degrees in all populations

Health systems & the management of CNCD: what needs to be provided

A health system as defined by the WHO is all "activities whose primary purpose is to promote, restore and maintain health" [110]. This definition includes not only the formal health services, but also traditional healers and all use of medicines. Health systems have three main objectives according to the WHO [110]:

- Improving the health of the populations they serve;
- Responding to people's expectations;
- Providing financial protection against the costs of ill-health.

Stronger health systems are needed to achieve better health for populations [16]. For people with CNCDs, the aim of the health system is to prevent complications and the negative physical and psychosocial impact the disease may have on the individual [2]. As CDs are now the leading cause of death in the world, health systems need a 'paradigm shift' from an acute to a chronic care model [1,17,101,111]. Nolte and McKee state that the management of CDs is one of the largest challenges that health systems throughout the world currently face and that each system needs to find a locally adapted solution [10]. The management of all CDs has common factors mainly linked to the fact that care needs to be provided over a long period of time, which requires the input from a multidisciplinary

team of healthcare workers, access to medicines and diagnostic tools, patient empowerment and the coordination of different elements of the health system [18]. The key principles for the management of CDs are [19,101]:

- The development of a treatment partnership between healthcare worker and patient to support self-management;
- Focus on the individual's main concerns;
- Use of the '5 As': assess, advise, agree, assist and arrange;
- Promotion of patient self-management;
- Organization of healthcare delivery and proactive follow-up;
- Involvement of 'expert patients', peer educators and support staff;
- Linkage between the patient and the community;
- Utilization of written information, such as, registers, treatment plans and so on, and written information for the patients to use for monitoring, reminders and so on;
- Use of a clinical team;
- Assurance of continuity of care.

Despite medical advances in the clinical treatment of most CDs, the benefits have not impacted the outcomes for people with these conditions sometimes because they are not

adapted [19,20]. This so-called ‘quality gap’ is due to the [21]:

- Increased burden of CDs leading to higher demand for health services;
- Complex nature of the scientific and technological advances that have taken place and the ability to adapt these to clinical practice;
- Poor organization of the system, which is unable to adapt to these changes.

Health systems do not work in isolation of the other sociopolitical elements of a given country, and therefore different models of health systems exist [22,110,112–114]. Functions of health systems are: procurement and supply of medicines, disposables and equipment, healthcare workers in sufficient numbers and with the right skills for the given population and disease burden, sustainable financing and healthcare costs that do not overburden the poor and have a financial, budgetary and regulatory framework [112,113].

In trying to achieve these aims, health systems need to provide six key elements [112]:

- Service delivery: presence of safe and quality healthcare and facilities and infrastructure;
- Healthcare workforce;
- Information: research, surveillance systems and so on;
- Medical products, vaccines and technologies;
- Financing;
- Leadership and governance: sometimes called ‘stewardship’, is the role that the government plays in engaging other national actors that impact health [22,110].

Another key element of a health system is responsiveness, with the health system needing to respond to the expectations people have. The needs of people with CDs “should be promptly attended to, without long delays in waiting for diagnosis and treatment – not only for better health outcomes but also to respect the value of people’s time and to reduce their anxiety” [110].

In order to address this, Wagner *et al.* developed the Chronic Care Model (CCM) [20], which was further expanded by the WHO into the Innovative Care for Chronic Conditions Framework (ICCCF) [103]. The elements this model describes for the effective management of CDs are [19]:

- Use of plans and protocols;
- Reorganization of the delivery of care to focus on patient needs, such as:
 - More time spent with patient;
 - Different resources, such as education and health professionals, such as dieticians, made available;
 - Integrated follow-up.
- Need to focus on informational needs and the need for behavior change of patients;
- Access to other specialities when needed;
- Use of information systems.

The WHO framework in [Figure 1](#), shows the inputs necessary to move health systems away from an acute model to one that can address the issue of CDs.

The model above describes the necessary elements that need to be present in order to provide patients with the best level of care for their CD, be it Type 1 diabetes or HIV/AIDS. Included in this model are three levels [103].

Micro: the patient interaction – this includes patients and their families, a motivated healthcare team and informed communities. These three elements work together to ensure care for the individual in the health system, but most importantly at home and in the community [23]. Lewis and Dixon [24] and Bodenheimer *et al.* [5] have described this as ‘three overlapping galaxies’ needed to effectively deliver chronic care. The individual needs to care for themselves by adhering to medicines and lifestyle. Healthcare workers need to provide care and take a multidisciplinary approach to care. Society needs to create healthy environments and remove social and cultural barriers to individual lifestyle choices. However, as detailed by Vallis [25] barriers exist at these three levels.

Meso: healthcare organization and community – this element includes healthcare workers’ skills, the mix of health personnel cadres present, patient follow-up, information systems and tools for patient self-management and self-care. In addition to the health system, the community plays a complementary role to the health system providing support, addressing stigma, resources and additional services.

Macro: policy level – this level addresses leadership and advocacy influencing decision-makers on addressing the challenge of CDs. A

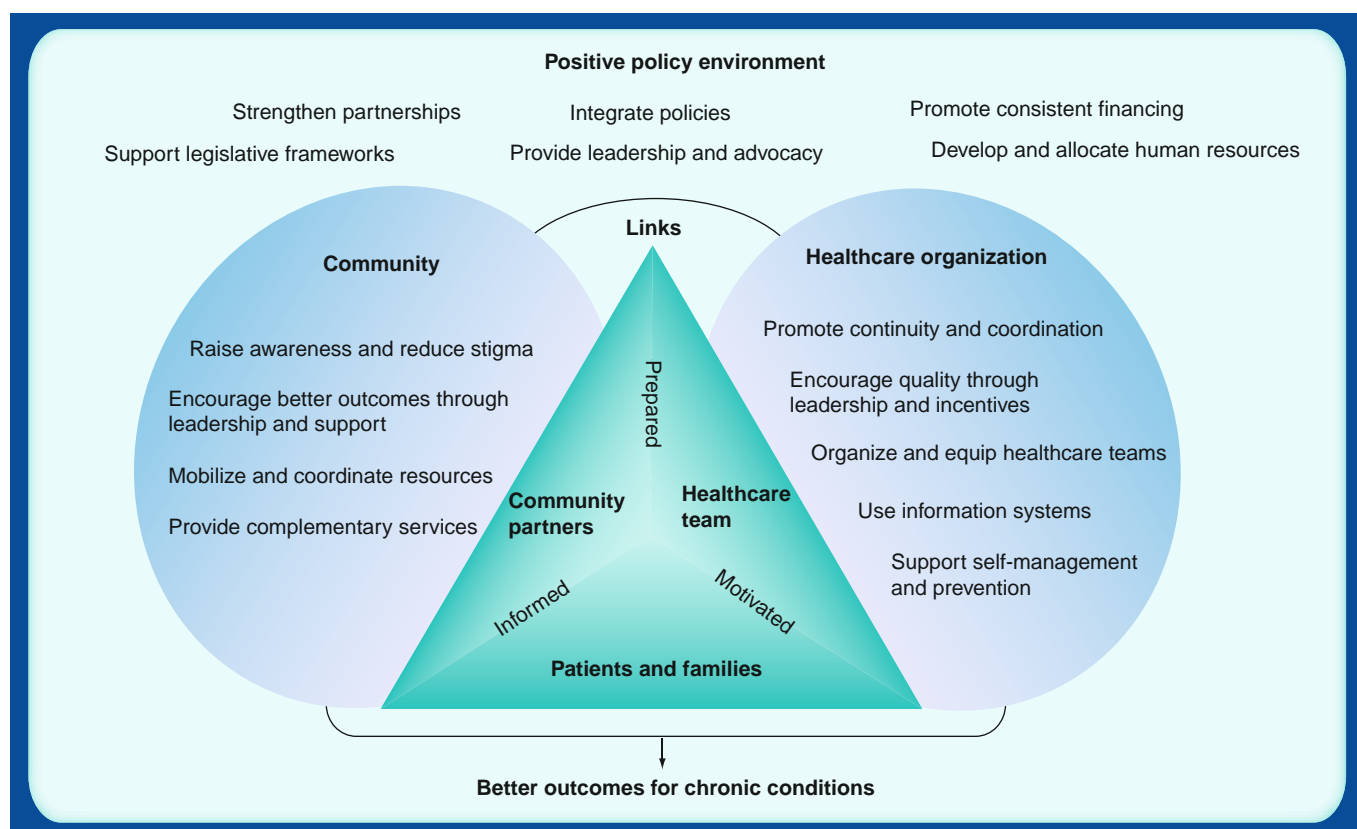


Figure 1. WHO framework on Innovative Care for Chronic Conditions [103].

cross-cutting view of policies is also necessary in that policies affecting people with CDs do not only fall within the area of health. This also needs to be linked to legislation and how this is developed. These policies and legislation also need to ensure proper resource allocation (human and financial) to address NCDs. In addition, policy makers need to be active in developing partnerships to address the challenges of CDs.

This model highlights that for the shift from acute to chronic care, health systems need to adopt the following eight key steps in developing a health system capable of managing CNCDs.

■ Support a paradigm shift

Health systems in low- and middle-income countries are now facing a 'double burden' of disease, due to changes in epidemiology and aging populations. In parallel, some high-income countries have failed to address CDs appropriately. The paradigm shift needs to take health systems that are currently organized around acute care and design them to manage CDs [20]. In order to tackle these CDs, health system strengthening is necessary in order to ensure continued

monitoring of the patient and a continuum of testing, medicines and care.

■ Manage the political environment

In order for an effective health system to be put into place that can manage CDs, a suitable policy environment needs to be in place. This environment encompasses the individual with a CD, their family, healthcare providers and the community as a whole. This policy environment is responsible for legislation, leadership, policy integration, partnerships, financing and the allocation of human resources.

■ Build integrated healthcare

For appropriate management of CNCDs an integrated health system needs to be in place. Each level of the health system has a role to play in care, and thus certain material and human resources need to be present. Also a certain level of organization and coordination between different levels of the health system and different sectors within the same institution (inpatient and outpatient services, pharmacy, laboratory and so on) need to be in place for patient management and referral. Guidelines need to be developed

and used as well as data to ensure efficient and effective care [19,20,115].

■ Align sectoral policies for health

For effective management of CDs, other policies need to be aligned with those impacting on health. One such example of addressing the multisectoral approach to create a favorable policy environment for people with diabetes was trying to remove any taxes on materials used by people with diabetes [115]. Another example of this is described by Ham – one of the requirements for the successful management of CDs in a health system is universal coverage and that care should be free at the point of use ensuring that cost is not a barrier to care [26].

■ Use healthcare professionals more effectively

The transition from acute to chronic care poses a challenge to healthcare professionals [27]. One of the challenges with this is that the onus of care is placed on the individual. Using healthcare workers effectively ensures that the patient benefits from a higher level of care. Issues of training, rational use and availability of appropriate healthcare workers is needed [19]. The health system needs to be better organized overall as well as on a facility level basis with teams of healthcare workers involved in care [18,19,115]. There is a lack of time and also division of roles that different healthcare workers can play in addressing the different needs a person with a CD has [5]. In managing CDs, Greenhalgh describes how the healthcare worker's role switches from being an expert and instructing and deciding for their patient, to being a guide in supporting, advising and helping their patient manage their condition [23].

■ Center care on the patient & family

The health system may provide the majority of aspects that a person with a CD requires; however, the burden of care falls on the individual and their family as the majority of the time spent managing a CD is taken outside of the health system [28]. Issues around patient education and empowerment need to be addressed [18,19,115]. Patients need to be informed and take an active role in their care so that the interactions they have with healthcare workers are more 'productive' [18]. This places a large onus on education of both the individual and their family. The health system, therefore, needs to not only provide medical care, but also the means to improve

the individual's knowledge and self-management skills with people with CDs and their families required "to play a fully informed role in their care" [28].

■ Support patients in their communities

The issue of coping with a CD versus managing it is seen as important and peer support plays a vital role in helping with this [23]. It is therefore necessary for the community to mobilize resources to meet the needs of people with CDs [18,19,115]. The main community involvement in diabetes care, for example, is through diabetes associations. Involvement of other community members such as local government officials, community leaders, village chiefs or elders, as well as traditional healers, is important [2,29].

■ Emphasize prevention

Primary, secondary and tertiary prevention of CNCDS is necessary. Ham states that this is a key element to managing CDs in a health system [26]. As CNCDS cannot be cured the health system has to focus on trying to improve outcomes and quality of life (QoL) [28]. However, the responsibility of care is on the individual, and therefore the healthcare worker and health system need to provide the necessary environment and tools that allow the individual to do this [3,28].

Chronic diseases & health systems: the need to focus on the individual's perspective

The individual in managing their diabetes, for example, will only have 2 h with the health system and the remaining 8758 h managing their diabetes at home and in their communities [30]. From the individual's perspective there is a change in all aspects of the individual's lifestyle, adoption of self-management skills, including taking medicines, the need for family involvement and developing coping mechanisms [18,20,31]. In addition, the person has a 'disease without an illness' in that the person clinically has a CD, but does not necessarily feel unwell [32,33].

Currently health systems fail to meet the needs of people with CDs as they do not address non-clinical aspects such as education and psychological support [19,34,35,103]. In addition, healthcare workers often do not address the capacity of the individual to function with their condition and fail to provide all the necessary information and support for psychosocial factors, leading to poor

self-management [20]. This is due to healthcare workers not having enough time, inadequate follow-up and guidelines either lacking or not being properly used [20].

CDs are described by Bury as a 'biographical disruption', where the life of the person and things that they normally take for granted are changed [36]. CDs impact life at home and work, as well as time spent caring for the condition and the socio-economic costs of the condition [36]. This change in 'biography' is described in Figure 2. With an acute condition the change in routine is for a few days, weeks or even months, but once recovered the individual returns to 'normal'. With a CD the definition of 'normal' changes as the person needs to adapt their life to manage this disease. In addition, the person may face a certain amount of stigma because of their condition [34].

The other aspect of the change due to a CD is the view that the person now has of themselves and the views of others. People come to view themselves and be viewed as 'diabetics' or 'asthmatics' and so on [37,38]. They may see themselves or be viewed as unwell even though their condition may not cause them any problem [39]. Despite these labels most CDs are invisible to others and the change is only with the way the individual adapts their lifestyle [39]. This is a change in what people conceive as normal and also an increased awareness of their body and what is wrong [39]. Williams states that in addition to lifestyle changes, pain, suffering and death become a reality for people with a CD and their families [29]. This is an added challenge, especially in children, as CDs and death are usually distant or something that happens to older people [40]. Therefore CDs do not only impact the physical health of people, but also their mental state [40,41].

Children with CDs have many similarities in their life experiences and challenges. Stein and Jessop quote Pless and Pinkerton in that what impacts children and their families more than the disease itself is its chronic nature [40]. Psychosocial aspects are important and healthcare workers need to focus on the individual needs of each child. Williams, in work with adults, also describes different stages that the person diagnosed with a CD goes through [29]. The first stage is 'what is going on here', which leads to an increased attention to things that are happening as a result of the disease. The second aspect discussed is the questioning that follows the onset of a CD. The 'why me', 'why now',

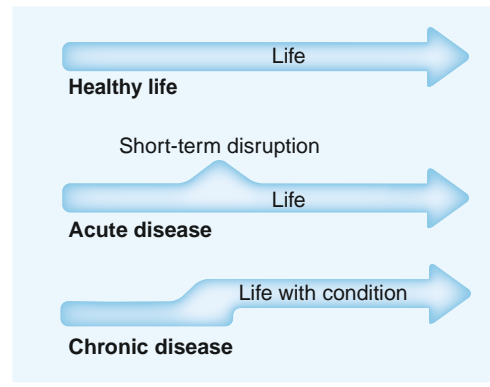


Figure 2. Chronic diseases as a 'biographical disruption'.

Data taken from [36].

'what have I done'. As health professionals cannot provide an explanation to these questions, people with a CD develop their own answers and reasoning for onset of the disease. The last aspect discussed is the 'mobilization of resources' once the person comes to terms with their situation. These can be social, financial, medical and so on. This aspect as discussed by Bury is described as coping as the 'cognitive process' that enables people with a CD to 'tolerate' or 'put up' with the condition they have [36]. Coping is the first stage in a process that leads the individual to adapt their attitudes and way of managing their condition [33]. The last aspect that brings together these other concepts is 'style'. In a sense this is how people package their coping and strategy in the way they behave and interact with society [36].

Following the coping phase the next stage is normalization where the CD becomes normal and part of how the person behaves in order to minimize the impact of the condition on their day-to-day life [36]. Finally, the strategy focuses on the actions individuals take and what they do with their condition and the attitudes that they develop. Strategies may be altered and adapted in their interaction and social interactions.

Kay *et al.* argue that there are really two dimensions when looking at chronic care of an individual, the care dimension and the psychosocial dimension [116]. **Box 1** describes the elements of these two dimensions. This table highlights the variety of needs that are required from the health system for the individual to manage their CD and how some of them fall outside the remit of what is traditionally viewed as the health system. Also some of these needs are tangible, in that the health system can provide these. Whereas others

Box 1. Two dimensions of chronic care.**Care dimension**

- Insurance (payment of care)
- Medicines
- Health decision-makers
- Rehabilitation
- Patient associations
- Care providers (home visiting nurses, doctors and so on)
- Patient education
- Academic and professional education
- Health facilities
- Coping and psychological factors
- Tests (i.e., laboratory tests and x-rays)

Psychosocial dimension

- The actual condition the person has
- Medicines
- Religion and belief
- Healthcare workers
- Friends
- Work
- Family
- Schooling
- Lifestyle
- Coping
- Nutrition

Data taken from [116].

could be viewed as needing a process to implement them, or some such as 'religion and belief' could even be viewed as intangible. This is a challenge as healthcare workers only focus on the symptoms of the CD versus the integral person with their condition – that is, the psychosocial dimension [20].

CD management needs to be tailored to the individual including both the care and psychosocial dimensions. Goals need to be set, but for the healthcare workers these are clinical, such as better blood glucose readings, whereas for the individual these are personal, being able to go to a party and eat what they want, partake in physical activity and so on [2]. The terms self-care or self-management are key in the management of CDs as the responsibility of day-to-day care is placed on the individual. Self-care is defined as activities that individuals, families and communities carry out in order to improve health, prevent diseases, limit illness and restore health. Self-care is based on 'lay experience and daily living with a given condition' and includes such aspects as self-diagnosis, self-management, self-medication and self-monitoring [41].

The term self-management was first used to describe the active participation of people with a given condition in their treatment [2]. Self-management addresses both the direct physical aspects of the condition that the person suffers, but also the psychological impact the disease may have. This is seen as a collaborative process between the healthcare worker and patient. Self-management in an ideal world is the individual with a CD being able to take the clinical information they have been given and use their experience to adjust the way they care for themselves [2]. This can be influenced by family and friends, but ultimately self-management leads to goals to be established and the individual using the resources available to them to self-manage their condition. It is important to note that self-management is not just taking medicines, but also adapting to and adapting one's environment to best suit the care of the condition.

Management of chronic diseases: the importance of the individual's needs

In looking at the literature linked to improving health systems for CDs no studies discuss the needs of people with a given condition in improving health systems and very few address the situation outside the developed world. The literature focuses mainly on:

- Theoretical models [3,17,19,24,26,42–46];
- Descriptions of initiatives in specific countries [3,47–54];
- How the CCM has been implemented for specific diseases [55–59];
- The role of different levels of the health system, especially primary care, in the management of CDs [5,60–66];
- The role of nurses [67,68].

As stated by Kralik *et al.* the literature on the management of CDs is focused on the healthcare workers' perspective or outcomes [69]. The outcomes described in the literature are either clinical [56,70–72] or organizational [73–80]. One study by Glasgow *et al.* looked at patients' self-reporting if the care received was in line with the CCM [81]. However, a clear gap in the literature exists in identifying the needs people with a specific CD have and linking this to the organization of care. Ham in a review of the use of the CCM, highlights this gap and states that what is required is to focus the development of health

systems to address CDs based on the needs of the population [26].

The focus of the CCM, ICCCF and CD management in general is stated to be the individual, yet research does not focus on this. Analyzing a health system for CDs poses many challenges. However, using Type 1 diabetes as a ‘tracer’ condition may help in addressing this gap.

Conclusion

Advances in different health system factors have led to large improvements in outcomes for people with Type 1 diabetes. Of course improvements in clinical aspects such as improved healthcare worker training, availability of self-monitoring and patient education have played a role in these improvements. However, given that most of the management of diabetes happens outside of the health system, factors within the person’s daily life must also play an important part. It has been stated that key to proper management of CDs is self-management. The individual needs to adapt different aspects of their lifestyle to include the management of their CD in their routine with the health system facilitating this. Type 1 diabetes provides an almost extreme example of this as someone with Type 1 diabetes needs to constantly adapt their management [82,83]. In the literature for Type 1 diabetes, three concepts using the word ‘self’ play an important role.

Self-efficacy, being capable of carrying out certain tasks that lead to success in certain situations, is key to diabetes management [84]. The first aspects of self-efficacy in diabetes management even for young children are to learn about self-care tasks such as measuring their blood glucose, carbohydrate counting and dosing of insulin.

Self-management puts the onus of disease management on the individual, but it is challenging and requires motivation on the part of the individual [40]. One key element is problem solving, which can be supported by the community and healthcare workers and needs to be linked to the different elements of the CCM.

Self-care is defined as activities that individuals, families and communities carry out in order to improve health, prevent diseases, limit illness and restore health. Self-care is based on “lay experience and daily living with a given condition” and includes aspects such as self-diagnosis, self-management, self-medication and self-monitoring [41].

From the individual’s perspective being diagnosed with a CD means a complete change in the way they lead their lives. The perspective that they have of themselves and the way they are viewed by society changes. People with CDs require both their medical and social needs to be dealt with by the health system.

The literature linked to improving health systems for CDs fails to address the needs of people with a given condition in improving health systems and very few address the situation outside the developed world. The focus is mainly on the theoretical aspect of implementing the CCM or ICCCF or describing the implementation of this model in specific settings or for specific diseases. If outcomes were measured these were either clinical or organizational. Few studies try to identify ways of enhancing aspects of self-efficacy, management and care.

One could argue that in comparison to other CDs Type 1 diabetes is unique in that any failure in the health system or the individual’s self-efficacy, management or care will lead to an immediate impact and that people with Type 1 diabetes know exactly how a specific health action will have an impact on their outcomes. However, very little is known about the management of Type 1 diabetes outside the health system.

Future perspective

As CDs continue to increase throughout the world innovative solutions will need to be found to address these conditions. As health systems are not designed for this long-term care in parallel to people managing these conditions at home, school, work and so on, these environments will need to be included in what we view as part of the health system. Health system research will need to investigate the needs of people managing their CD in these settings and health professionals will have to adapt to this new paradigm where their role in disease management will be less active and need to be adapted to the individual. This tailoring of care will be necessary as each individual is unique, and living in different situations, for example, a young school child versus a professional, and this means that the approach of health professionals and the health system itself will need to change. In addition, the role of the community and other potential providers of medical care or support will need to be investigated, developed and adapted to each setting.

One key element in this is providing education, again tailored to the individual, but also ensuring that the individual is empowered. Empowerment is defined by the knowledge, skills, attitudes and self-awareness that people need to have in order to change their own behavior. For this, people with CDs need to know that a specific health action will have an impact on their outcomes. These outcomes may not only be clinical, for example, improved blood glucose management for someone with diabetes, but also social in that the individual is now able to 'adapt' their diabetes to any activity they want.

In delivering this new model, research will play a key role. The importance of combining clinical, health system and individual research will also be key to ensuring adequate management of these conditions. Clinical research will be needed to develop treatments and their delivery. Health system research will be necessary to optimize the organization of this delivery and finally research into the individual and their needs will be necessary to ensure that the treatment and the way it is delivered is in line with what is expected and

does not create any clinical or social barrier that may impede proper treatment and adherence.

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