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What do people need?

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The key question addressed in this Chapter is “What do people need?”, with “people” here meaning those who live with a rheumatic or musculoskeletal disease. The word “patient” is avoided at this point as not all of the problems or solutions identified are medical in nature. Many are personal, societal and/or environmental. The lead authors are all people who not only live with a rheumatic or musculoskeletal disease, but who are experienced “patient representatives”. Therefore, their insights here stem from a combination of personal and collective experiences and views. Although from different continents, the authors identify a range of common barriers to social participation and optimum management of these conditions, such as late diagnosis, stigma and access to care. However, several solutions are common across these regions too, such as the need for supported self-management and greater public awareness of the impact of these diseases.

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Introduction

Neil Betteridge, UK.

This chapter, through its constituent parts from Africa, America, Asia and Europe, addresses issues that might traditionally be described as “unmet patient need” in rheumatic and musculoskeletal diseases (RMDs). Some of the terminologies used here, however, are less medically framed than those reflecting the 21st-Century reality that many people with chronic conditions do not wish to be defined by their disease. As I have heard said several times: “I am a patient when I am in the clinic, around 1% of the time; and a person (with an RMD) the other 99% of my life”.

So, progressive medical culture has moved from “See the patient, not just the disease” to “See the person, not just the patient”. This development is far more than a form of political correctness, it is utterly practical. Healthcare systems can only deliver optimal and sustainable care at scale by supporting the individuals who use it in a holistic way, addressing what matters to patients and not contenting itself with improvements only in disease activity and/or function (welcome though such improvements are!). In fact, many of the needs highlighted, such as stigma and the design of the built environment, require societal and not just clinical solutions.

Several of the contributors to this chapter are not trained professionally to write articles for medical journals, but instead provide specific insights that many clinical publications may omit: a first-hand, and a collective view on what it is that people with RMDs need to be better supported to live how they wish. To make choices that most others take for granted, such as pursuing higher education, obtaining – and retaining – a paid job, having a family, accessing sports and leisure facilities, and generally enjoying full participation in society.

Through their connections and involvement with national and regional organisations that exist to support people with RMDs – NGOs, charities, online networks, etc. – the authors are able to highlight issues of common, and not just personal, concern. Despite the distances spanned between Canada, Kenya, Cyprus and the Philippines – and the sometimes correspondingly huge variations in socio-economic factors – many of these issues are fundamentally similar. In particular, what emerges as a thread running across the separate contributions is the need to translate the theory of “patient empowerment” into widespread practice, whatever and wherever the setting is.

The good news is that, as part of the wider “patient movement” internationally, advocates, such as our authors here, have been able to educate each other and, subsequently, healthcare professionals about the nature of empowerment. When I was appointed CEO of Arthritis Care in the UK around 15 years ago, for example, I was fortunate to be able to solicit organisational commitment to the notion that everything we did should be to promote empowerment. Providing peer support, self-management courses, telephone and online support from trained counsellors, and delivering evidence-based, clinician approved patient information in lay language helped people to take more control of their lives, not just their disease. While advocating for change at the policy level created not just “better weather” but also a better environment for people with RMDs and those who provide care for them.

Later, during my 8 years as Vice-President of EULAR, representing People with Arthritis and Rheumatism Europe (PARE) (the network of organisations across Europe acting for, and usually run by, people with RMDs), developments took place, which further promoted patient involvement in practical ways. Adopting the slogan “Nothing about us without us”, the European patient movement in RMDs helped EULAR to establish exciting new programmes such as the Patient Research Partners network, training people with RMDs to be effective contributors to discussions on all aspects of medical research. The patient voice was also instrumental in establishing a strong public affairs function at EULAR, providing education and training for patient advocates as well as Health Care Providers (HCPs), which has raised the profile of RMDs at both national and EU levels.

However, at the individual level, one thing people certainly need across the world is support to self-manage. Usually this is inexpensive but highly effective, involving the timely provision of relevant information tailored to the individual, or signposting to where they can find further high-quality information commensurate with their health literacy and activation measures. Access to a healthcare professional to discuss aspects of their learning is, however, a critical and oft neglected part of this support process. The piece in this chapter from Kenya celebrates the impact of the first self-

management courses run in the country several years ago. However, it also laments the fact that the majority of the population do not have access to such support on an ongoing basis because the intervention is not considered a priority. It is for reasons such as this that the suggestion made from this Chapter towards the research agenda is that more evidence is needed to determine the efficacy and value of structured self-management support for people with RMDs.

In a similar vein, more than one of our contributors highlight the vital role of the specialist nurse, for example, who may be the person best placed to support the individual in their often significant life adjustments with their RMD. As the perspective from Canada here reminds us, "Left to navigate healthcare independently, a patient's care may be fragmented, resulting in feelings of disappointment, disempowerment and/or depression".

Which is not to imply that changes in healthcare systems generally, and clinician behaviour specifically, can provide everything that people need. It cannot. So while increasing the number of rheumatologists in the Philippines so that it exceeds 200 would be welcome and very helpful, it would not as a single measure solve problems addressed elsewhere in this piece such as late diagnosis. Readers of this journal will not need re-telling that early intervention remains critical for people with RMDs, but the factors involved go further than obvious issues such as waiting lists and poor rates of GP referral. As the essay from Cyprus concedes: "The problem of late diagnosis can be due to the behaviour of the patient as well as to barriers in health systems", which means we are, once again, brought back to low social awareness of how to approach RMDs, and even stigma, whereby people may not believe it appropriate to seek medical support for joint issues. It seems people take the health of their cats, dogs and even their cars more seriously than they do their own musculoskeletal health when it comes to seeking solutions early after the onset of mobility problems.

I hope you agree that the following sections of this chapter offer fascinating and insightful glimpses of life with RMDs in locations that are as diverse as the challenges are comparable.

What people need in North America

Connie Camilleri (lead author), Linda Stoyanoff, Deborah Kopansky-Giles, Canada.

It is now widely evidenced that musculoskeletal disorders (MSDs) are the leading cause of disability worldwide and can be a significant threat to healthy ageing [1–3]. Pain, disability, employment status, mental well-being, social networks and medication dependence are all challenges to living well with MSDs [4]. The high prevalence of this chronic health problem speaks to the need to raise awareness about, and priority for, the burden that MSDs place on individuals, their families and communities as well as local, provincial and national health systems.

Policy makers and clinicians need to implement strategies and policies within their healthcare systems to provide "integrated, person-centred models of MSD care" in a timely manner [2]. Barrier-free, accessible and adequately funded programmes need to be made available to all patients regardless of age or socioeconomic status. Additionally, empowering people to self-manage and advocate for the care they require is important to ensure their mobility, strength and functionality are maintained throughout their lives.

This article intends to describe common challenges experienced by people living with MSDs from the time of early diagnosis to receiving treatment, the role of multimodal therapy, interdisciplinary care and the need for patients to learn and practise self-management interventions (SMIs) as coping strategies. Regardless of an individual's health literacy and socioeconomic background, there continue to be significant challenges to optimal MSD care no matter where they live. As such, there is an ongoing need to increase resource visibility, access and funding to MSD programming.

Common challenges while living with MSDs

MSD patients often have better outcomes when treated by a multidisciplinary team, but such services are not widely available or known [5]. Literature suggests that primary care physicians may have low confidence in their ability to diagnose, treat or properly refer this patient population, resulting in delayed diagnosis, overuse of diagnostic imaging, unsuitable referrals to specialised care

and inappropriate medication prescriptions [6]. As a result, patients may feel ignored, uninformed or misunderstood and may not receive appropriate, effective or timely treatment from the time of initial presentation for care [7]. Left to navigate healthcare independently, a patient's care may be fragmented, resulting in feelings of disappointment, disempowerment and/or depression [5,8].

In Canada, services for government-funded MSD programmes often require a referral to see a specialist, or enrolment in a specific programme. As is often the case, wait times for an initial specialist consultation can be months after injury, leaving the need to self-manage pain, often without being provided with tools, resources or coping strategies. Though online resources and mobile applications are freely available, they are usually not personalised or tailored to the individual's needs and it is often difficult for people to determine what resources are credible and beneficial to help manage their specific presentation [9]. Inappropriate stratification or diagnoses at the outset and long wait times can, in fact, lead to unsafe practices such as medication misuse to manage pain [4,7]. As an example, the current opioid crisis in North America is reflective of a fragmented health system, where narcotic-based pain management (considered largely ineffective for MSD chronic pain management) has been widely used to manage pain, rather than evidence-based approaches with proven efficacy [10].

Another consequence to the lack of available MSD programming is the financial burden placed on a person seeking different therapeutic approaches, many of which may not be funded through government or employee insurance plans. As patients age and enter retirement, fixed income and lack of extended benefits become more challenging to fund care provided outside of government-funded services to achieve health maintenance. While many jurisdictions, such as Canada, have "universal health care", the packages of healthcare services actually funded within the model are limited, and also determined at a provincial level. Different provinces opt to cover different healthcare services and, also, at differing levels of coverage. While access to primary, specialised or emergency care is usually covered under Canadian government plans, many healthcare providers who effectively manage MSDs are usually not funded (physiotherapy, chiropractic, acupuncturists, osteopathy, etc.), resulting in inequitable access to evidence-based care that heavily relies on an individual's ability to pay for the services.

People with chronic MSDs often exhibit social isolation and loneliness [11]. A bi-directional relationship exists between social isolation and MSDs, whereby unmanaged pain can lead to reduced activity levels, self-isolating behaviour and loneliness which, in turn, can exacerbate pain perception [11]. While injuries occurring within the workplace can force individuals to change their line of work, these sudden and/or forced career changes can lead to mental health conditions such as depression, and limit social interactions and/or self-managing activities such as physical therapy or support groups [11,12]. Interventions that take a biopsychosocial approach to MSD pain management – and can improve symptoms while promoting social participation and engagement – are more strongly recommended and should be adopted to prevent further complications and health decline [11].

Moving forward

MSDs can affect multiple facets of daily living. The goal of treatment for patients with such chronic conditions is to "continue life as normally as possible, while accepting that there may never be a cure" [13]. This cannot be attained without adequate programme funding, resource awareness and standardisation of the intake, referral and care process. Optimising care requires the right patient accessing the right provider at the right time for the right condition at the right cost. Fragmented care, commonly seen in both developed and developing countries, limits care optimisation and patient health outcomes [14]. This proposes challenges at all levels – for patients, providers, healthcare facilities and health systems.

For example, to reduce the burden of low back pain (LBP) in Ontario, the Ministry of Health and Long-Term Care (MOHLTC) undertook a 3-year pilot study to evaluate the Inter-professional Spine Assessment and Education Clinic (ISAEC) implementation within three of its regions. The clinic's priority was to provide rapid access to LBP screening and assessment, combined with education and self-management strategies for patients and providers [15]. These clinics aimed to offer a more integrated and co-ordinated approach to addressing LBP, tailored to individual needs. Primary care practitioners were provided with education and training to initially screen patients and a decision-tree for

determining which individuals required further assessment. Chiropractors and physiotherapists were educated to become advanced practitioners in this area and provided initial assessment and management decisions based on a triage protocol.

These providers arranged for diagnostic imaging if indicated and facilitated prompt referral to specialists where needed. This programme utilised a centralised multidisciplinary treatment team, whereby continuous and co-ordinated care was facilitated. The results from the ISAEC programme have been found to be excellent. There were significant reductions in unnecessary specialist referrals (reducing appointment wait times from the usual 6 months to 2–4 weeks), the use of diagnostic imaging (a cost saving of \$24 m annually when extrapolated across Ontario), good health outcomes with reduced need of surgical interventions, and high satisfaction from patients and providers [16]. Subsequently, the ISAEC programme has been scaled up with Rapid Access Centres created across the province to help patients with back pain.

While these clinics are now more widely available to patients in Ontario, further funding and policy change is required for programme expansion both federally and globally. In the meantime, toolkits similar to those used in joint replacement surgeries can be useful within the context of MSDs to improve intake and access to care, better inform patients and define flow throughout the healthcare continuum [17]. These toolkits can be made available at primary healthcare provider offices and other common points of patient contact, to speed the time from initial diagnosis to consultation to treatment.

Policy, programme funding and operational changes take time to implement. SMIs to complement the formal healthcare that patients receive are essential. Well-informed healthcare providers, operating within a connected and accessible health system, are required to assist and empower people with MSDs to be the managers and co-creators of their care. Support groups, interest groups, and readily accessible and credible information must be promoted at the time of injury to help manage an upward battle with a lifelong musculoskeletal condition.

What people need in Asia

Josef de Guzman, Philippines.

Psoriatic arthritis: a prelude

Psoriasis is a chronic, non-communicable, painful, disfiguring and disabling disease for which there is no cure and with great negative impact on patients' quality of life (QoL). Skin lesions are localised or generalised, mostly symmetrical, sharply demarcated, red papules and plaques, and usually covered with white or silver scales. Lesions cause itching, stinging and pain [18].

Psoriatic arthritis (PsA) is a chronic, inflammatory disease of the joints and the places where tendons and ligaments connect to bone. The immune system creates inflammation that can lead to swelling, pain, fatigue and stiffness in the joints. About 30% of people with psoriasis will develop this painful and disfiguring condition [19].

Lack of data

There are very few studies on the incidence of psoriasis and/or PsA, which makes reliable data very difficult to find. For now, we use the extrapolated prevalence assigned to us by key opinion leaders (KOLs), which is 1–2% of the population in a tropical setting. Using this estimate, there should be between 315,000 and 630,000 Filipinos with PsA, if we accept that there are between 1,050,000 and 2,100,000 people with psoriasis among the 105,000,000 Filipinos.

There are fewer than 200 rheumatologists in the country. So, if all PsA patients surfaced at the same time to seek rheumatologist support, our doctors would simply be overwhelmed.

In reality, only a fraction of patients will seek medical consultations as clinics, physician fees and medicines are out of reach for the majority of patients. In the Philippines, psoriatic patients must pay 100% of the out-of-pocket expenses when seeking medical attention. As a result, patients are discouraged from seeking the right medical treatment and resort to self-medication, seek alternative

and non-medical treatments, or simply endure the pain, hoping that time will eventually ease their suffering.

No scare, won't care

If your condition is not scary enough to contaminate the whole population, there is a big possibility that your government will not consider this as a priority. This is the sentiment that most patients with chronic, non-communicable diseases (NCD) feel in my country – that QoL, missed opportunities and the physical pain that goes with the disease are all widely neglected. In a country whose economy is in “survival mode”, patients with NCDs are most likely to be seen as low priority in the national health system. With the advent of the COVID-19 pandemic, other patients like me can become further “victimized” and seen as even less of a priority.

Access to medicines and other treatment is the prime challenge, meaning patients do not always seek medical help, for example, availability of affordable drugs like methotrexate is a significant problem. The prices of the more modern and effective biologics mean that they are simply out of reach for most patients.

As a patient support and advocacy group, Psoriasis Philippines (PsorPhil) has been pleading with our Department of Health to include more drugs, including biologics, into the National Formulary. We have been pushing them to come up with a national policy for our disease. Presently, we are one of the many countries in Asia-Pacific, where out-of-pocket expenditures for our treatment are a standard.

I can only envy our neighbouring countries where Universal Health Coverage (UHC) has already been put in place and is serving patients. This doesn't seem like it will be happening soon in my country looking at current government priorities.

Left to fend for ourselves

Without access to affordable treatments and medicines due to the absence of a national policy for our disease, we are left to survive on our own. Physically exhausted and emotionally depleted, we do not have a choice but to negotiate with local government units – from provincial down to the municipal level – hoping that they will invest in patients and buy our medicines by drafting local health policies for our patients. Together with the Philippine Rheumatology Association (PRA) and Philippine Dermatological Society (PDS), we bring the Caravan of Hope to train health workers in the rural areas about our disease, to augment the fewer than 200 rheumatologists caring for the estimated 105 million Filipinos with psoriatic disease.

Early diagnosis for patients is ideal. The sooner patients seek medical consultation, the easier it is for the doctors and patients to co-manage the disease. But with the prevailing conditions, patients often only see their doctors when their pain is already unbearable and symptoms have reached the irreversible stage. In partnership with PRA and PDS, we conduct a free Skin and Joint clinic in areas where we engage the Local Government Units and train their doctors.

Mental health is also a huge issue in our community, as depression can severely affect so many people with NCDs like us, even driving some to suicide. We have crafted a PsorCoach Programme that empowers patients to lead other patients by having them trained by different medical doctors, psychiatrists, life coaches, and other pertinent professionals to equip them with knowledge on how to guide newly diagnosed patients in their lonely journey. For the past six years, we have produced 100 PsorCoaches that have served over 5000 patients. Our youth chapter brings our advocacy to the school campuses to address the stigma of the disease.

To help address these issues of stigma, isolation and depression, we have organised social meetings for members via monthly meet-ups in most of our 49 chapters all over the country. We also stage annual national events like the patient summit, patient leaders' summit and other programmes. These are aimed at improving not only the patients' knowledge of the disease but also elevating their QoL by educating them on how to navigate government institutions and offices to seek help for their medical conditions that require financial resources.

Our Facebook fan page, a public site where our organisation can easily be accessed, is run by over 30 trained volunteer patients who are equipped to answer queries from patients almost instantly. This page has been dispensing psoriasis articles and information to help the community increase its

appreciation of the disease. We also have a private group exclusive to patients only, where everyone is free to share his or her thoughts, challenges, aspirations and hopes without any prejudice or judgement from other members. By necessity, this is a moderated group as we discourage self-medication that can put the patient at unnecessary risk. While modern technology has enabled us to reach our target audience, there is a big part of society which does not have access to the internet yet.

Our cry for inclusion

Discrimination is still very real to us in settings ranging from schools, public places to workplaces. Children are still being bullied in school because of their condition and we are still being denied access to certain forms of transport and public facilities. Finding a job is still a challenge for us as we compete with other applicants without medical conditions. If you are lucky and get hired for a job, you constantly worry and hope that you never flare because, as soon as your employer notices that you miss your work occasionally due to your condition, you are in danger of losing your job.

For over five years, we have been fighting to be included in the "Persons with a Disability" (PWD) sector. As a PWD ID holder, people are accorded a 20% discount and zero rate VAT for medicine purchases. But this will only work for those who have money to spend. Right now, we are pushing for social pensions, especially for the most marginalised members.

Over the years, we have managed to endure our pains, public ridicule and exclusion. We keep our hopes alive as long as we have a community and doctors who walk with us in this lonely and challenging journey.

What people need in Europe

Souzi Makri, Cyprus.

Rheumatic and musculoskeletal diseases (RMDs) affect a large proportion of the population, namely about 25% of the overall European population (about 120 m). It is estimated that the direct cost of RMDs is as high as 2% of the European GDP. Thus, RMDs cause a large utilisation of health resources in Europe and the total burden amounts to 240 billion euro per year. RMDs are the most prevalent occupational diseases in Europe, representing 38% of all occupational conditions [20]. Moreover, 60% of all sickness absences and 60% of all permanent incapacity are also due to RMDs [21].

The high cost of rheumatic diseases to society lends great significance to the fact that the early diagnosis greatly reduces the burden. Data show that still, today, the diagnosis is often not timely.

The problem of late diagnosis can be due to the behaviour of the patient as well as systemic barriers in health systems. What we see in southern Europe, and through our work with patient organisations across the region, is that many people still believe that RMDs mostly affect older people. Owing to those misplaced beliefs, prospective patients may ignore their symptoms and do not self-refer to a doctor early enough.

Late referral by the GP and long waiting lists in secondary care can also cause diagnostic delays and late start of treatment. Unsurprisingly, the delay in the start of appropriate treatment can delay or jeopardise the opportunity to achieve remission in inflammatory forms of arthritis. For example, in Cyprus where a new national health system has recently been implemented, rheumatologists have long waiting lists (4–5 months), a factor that can lead to delays in diagnosis and cause late start of treatment. Delayed remission can cause avoidable absences from work, lower productivity, more doctor visits, more pain and depressive mood, leading to a vicious circle of symptoms and thus more pressure on health systems and societies.

In some Southern European countries, where specialist care may be concentrated into a small number of locations, long distances may also be a challenge for the individual when needing to visit a rheumatologist.

Lack of priority

In many parts of Europe, the lack of priority for RMDs means resources for treatment can be scarce. For example, in the Romania healthcare system, resources are particularly limited and cannot cover the

cost of treatment for all RMD patients who would benefit from biological therapy. Consequently, Romanian regulatory agencies (Ministry of Health, the National Health Insurance House) have used administrative criteria to regulate the access of RMD patients to biological therapy within a prescription protocol. These regulations are based on efficacy criteria and not on a cost effectiveness study of biologics [22].

The pressure on healthcare systems from late diagnosis can be alleviated by raising awareness of RMDs and their implications for the individual and for societies. A good example of this is the EULAR campaign “Don’t Delay, Connect Today – Time2Work”. This campaign is being widely implemented by European patient organisations across Europe. The aim of the campaign is to promote early and timely diagnosis in order to enable patients to stay or return to work and remain productive members of society.

Therefore, timely start of treatment is a prerequisite for achieving treatment goals including, in some cases remission, the ability to continue working and to have a good quality of life. However, “treatment” does not only comprise pharmacological interventions, but also included complementary ones.

The multidisciplinary team

Owing to the multifaceted nature of RMDs and the number of co-morbidities that these can involve, a multidisciplinary team is essential for ensuring effectiveness in treatment. A team of professionals is thus needed to obtain optimum results in treatment and management of RMDs. The team may include a rheumatology nurse, although sadly this role is non-existent in most Southern European countries. The role of the nurse is vital and complementary to that of the rheumatologist as she/he can devote more time to explain things to the patient in detail – for example, how to take the prescribed medicines, side effects involved, etc. The rheumatology nurse can also help the patient get in touch with the local patient organisation and benefit from the services and expertise offered.

Apart from the rheumatology nurse who may be the first person that the patient meets after consultation with the physician, other specialties might be needed from time to time. Occupational therapy, physiotherapy, psychotherapy and other forms of psychological support are just some of the areas where supplementary help can be provided to the RMD patient. To be able to obtain optimal care, patient organisations largely believe that a rheumatology centre that includes all of the above-mentioned professional areas would be most effective. Governments and healthcare systems would be able to reduce costs if healthcare provision was routinely incorporated into multidisciplinary teams and there was timely access to all relevant healthcare professionals.

Patient associations have a role to play

Additionally, patient associations themselves could enhance patient care further by offering self-management workshops. Through these workshops, patients learn to self-manage the challenges of living with a chronic disease every day, to be adherent to their treatments, to communicate effectively with their healthcare professionals, to exercise safely, to adopt a healthy lifestyle and generally to improve well-being. It is encouraging that more and more organisations, especially across southern Europe in recent years, have patient trainers who can equip people with Rheumatic and musculo-skeletal diseases (RMDs) to self-manage. The aforementioned barrier faced by patients in remote areas can be overcome by online courses and apps, which increasingly serve as a means of delivering patient education.

A further barrier to timely care – and something that can make patients refrain from disclosure of their RMDs (to employers and wider society environment) – is stigma. Unfortunately, this is still a problem across Europe and co-ordinated actions, and relevant campaigns are needed by both the EU and national governments to mitigate the effects.

In conclusion, RMDs are difficult-to-manage conditions and can cause significant deterioration of quality of life. With better access to a specialist and multidisciplinary team of health professionals with a holistic approach to treatment, patients can be supported to overcome stigma and remain independent members of society. Greater patient education is needed to promote early diagnosis, empower patients, and offer them the necessary skills they need to remain active and economically productive.

To this end, solutions need to be found. For example, more public–private initiatives could be encouraged by the EU and national governments, such as the European Patients' Academy (EUPATI) programme which, in recent years, has greatly changed the role of the patient in today's health landscape by training patient leaders to become informed contributors to dialogue on advances in therapeutic options. Such schemes should be seen as investments rather than costs, with payback that could significantly reduce the burden of RMDs across Europe.

What people need in Africa

Lillian Mwaniki, Kenya.

The following is, first, a glimpse of a personal experience as a person living with a musculoskeletal (MSK) condition in Kenya. Second, it captures experience as a patient trained in self-management, who has also trained other patients in self-management.

My journey with an MSK condition

My journey began 21 years ago and happened at a time when there was scant information relating to arthritis in Kenya. MSK conditions were – and, to a large extent, still are – considered as diseases affecting elderly people. Patient education or forums to assist people to understand their condition were also less common then and completely lacking in interior parts of the country. Under these circumstances, most people manifesting with MSK disorders would be seen either by clinical officers, general practitioners, orthopaedic surgeons and/or, in some cases, obtain treatment from herbalists and self-medicate.

My own experience in the early stages of seeking the right diagnosis and treatment for the MSK condition illustrates some common challenges. I received treatment from a doctor whom I understood was a specialist but who, within a few months, had closed their clinic and left without notice. Owing to the severity of my symptoms I sought treatment urgently and was forced to look outside my country. With a confirmed diagnosis and treatment plan, I was referred to a rheumatologist for further follow-up and, eventually, received treatment in Kenya. Today the country has only four rheumatologists and, given the growing population, many MSK patients are still often seen by clinical officers, general practitioners, orthopaedic surgeons and herbalists.

Therefore, people with MSK conditions usually seek conventional medical treatment from these sources – supplemented by physiotherapy support when needed – because the population as a whole lacks awareness that there is more that can be done by way of support. However, over the last two decades, there has been a welcome increase in awareness of the prevalence and impact of MSKs. Initially, this awareness was generated through public lectures and seminars, which importantly included the participation of patient organisations. These groups are run by volunteers and provide patient information which, over time, has promoted a better understanding of MSK conditions. The use of internet services has also enabled metropolitan patients to become more informed about these disorders and available treatments online.

Self-management

The first formal self-management training for MSK patients in Kenya was carried out in 2013 and further refined and delivered in 2015–2016. With a view to cascading this means of support, eligibility criteria for these courses included the willingness of the individuals concerned to go on and be trained as future trainers. The training, which was only possible because of the provision of resources from overseas, was received enthusiastically by the participants, who all reported significant benefits. These included a better understanding of their condition/s, new levels of confidence, better coping skills, increased adherence to treatment and an enhanced understanding between them and their doctors. Some patients, however, had challenges that interfered with full attendance. For some, it was lack of transport to the urban venues, where the courses were held. Other patients would skip a session due to bouts of sickness, while those in paid employment would sometimes not get leave.

Early diagnosis and treatment

While there has been some improvement in accurate and timely diagnosis over recent years, there is still a possibility that today's MSK patients might be misdiagnosed in the sense that specialist skills may be out of reach for people in remote rural areas. The country does not have established data on the number of MSK cases, so it is unclear how big a barrier this is. However, a patient travelling to an urban location for a specialist/rheumatologist appointment will usually allocate a full day, due not only to travel time but also to long waiting hours. For many, this is a deterrent, for others an impossibility.

The high cost of consultation and treatment is also a considerable barrier that might contribute to a missed diagnosis on account of unaffordability, especially for the unemployed. Some patients might obtain access to treatment through their private health insurances, but insurance policies are expensive, which imposes further limitations as to who can access the right treatment at the right time. Aside from the high cost of insurance policies, there are also low limits on the amount that a patient with an MSK can claim for a chronic condition. Priority is given to other non-communicable diseases such as cancer and diabetes, while MSK receives a relatively low budget allocation, even when the impact on the individual may be severe.

Other barriers to better care

Other barriers that hinder access to the right treatment at the right time could be reduced by training more specialists in rheumatology; expanding the skills of all healthcare professionals in the assessment, evaluation, diagnosis and treatment of MSK disorders; reducing the cost of medication; and introducing self-management principles into the medical curriculum taught in universities and colleges, as a complement to the conventional treatment regime. What people really need is for governments to fund the provision of self-management training in different settings across the country. Given that personal mobility will be a factor in enabling people to reach these locations, the engagement of specialist engineers to review the infrastructural and structural gaps in the roads and transport systems is essential to ensure social inclusion. Building regulations also need to be robust, so that patients have easy access to public premises of this kind and are not disabled by the built environment.

The vital role of the multidisciplinary team

People with MSK conditions want their support to be provided by a multidisciplinary team, but financial barriers often prevent this. Physiotherapy on a needs-led basis is available, but there are fewer referrals to psychologists, psychiatrists, occupational therapists and chiropractors. Indeed the discipline of chiropractice is not well understood in Kenya, which means that consultations only occur at the patient's own initiative.

In summary then, what people in Kenya need is access to holistic, individualised care. For this to happen, a number of measures need to be taken. The authorities should move to ensure a reduction in the cost of medication; multidisciplinary professional services should be available at a subsidised cost to the individual; the training of healthcare professionals should be adapted to incorporate self-management principles in every individual's treatment plan; and the healthcare team should be inter-consultative to enable a truly holistic, patient-centred approach.

Owing to societal perceptions, MSK patients will sometimes find themselves disadvantaged relative to other members of society and their community. Stigma and discrimination still exist – people with mobility challenges may, for example, not be given equal opportunity or secure reasonable adjustments in employment such as shorter working hours. Additionally, difficulties of access to places of employment, transport systems, entrances into buildings and so on still debar a lot of people from participating fully in society.

Therefore, there is a need for the national government to address these gaps and imbalances – and be sensitive to the needs of people with MSK disorders. Since many MSK challenges relate to

infrastructure and the built environment, the government could close this gap through the appointment of qualified professionals in positions of policy influence. Flexible working hours would also assist the MSK employee to continue in employment. Incentives and support that boost the talent and creativity of people with MSK conditions would give MSK patients a chance to contribute to the national economy. To spearhead reasonable provision for MSK patients, qualified professionals, technicians and engineers with MSK conditions themselves should be considered for deployment in key areas such as road planning, city planning, transport, general planning and design of the buildings.

Conclusion

Against the backdrop of an over-stretched healthcare system in Kenya, what people need most is to see self-management training across all healthcare professionals and governmental support to complement the efficacious treatment of MSKs.

Overall summary – what people need globally

Neil Betteridge, UK.

It is clear from these four “snapshots” delivered by people who are experts in the issue of unmet need in RMDs that what people need does not differ markedly from one region of the world to another. They need timely access to the best available care where they live, but they also need to know what additional support is available to them and how they can access that too.

Healthcare systems may frequently lack the capacity to provide optimal care to everybody living with a rheumatic and musculoskeletal disease (RMD), but very often those people themselves have capacity to do more for themselves if adequately supported.

In the long aftermath of COVID-19, this under-utilisation cannot be allowed to persist, which is why advocates of “empowerment” may find that our time has finally come – a global movement born not out of political correctness, but out of the stark necessity to focus on what works.

Practice points

- Healthcare systems face increasing pressures from demographic changes and latterly the advent of Covid-19, and clinicians should promote cost-effective self-management strategies to support people to better support themselves, for example, by enabling patient information and education; training in lifestyle issues; and referring where appropriate to patient associations, peer groups/self-help, psychological support, and digital resources such as high-quality apps.
- Early diagnosis and timely access to treatment/disease management remains a barrier to better care, not just because of cost but also because of stigma and lack of public awareness of rheumatic and musculoskeletal diseases (RMDs), suggesting that proactive strategies and campaigns such as EULAR's “Don't Delay, Connect Today” initiative are greatly needed to promote earlier intervention and thereby deliver better patient outcomes.
- The role of the multi-disciplinary team is vital and needed for all patients where appropriate, and access to a specialist nurse is considered particularly desirable as part of an overarching self-management strategy to complement clinical care.
- People with RMDs still experience discrimination in daily life, for example, negative assumptions from employers about capacity for a job, so clinical consultations should routinely consider the patient's employment status and wishes, as well as addressing the person's personal and societal needs individually and holistically.

Research agenda

- Evidence is needed to demonstrate the effectiveness of self-management strategies. Anecdotal feedback suggests timely support for individuals with a rheumatic and musculoskeletal disease (RMD) can transform their levels of knowledge and confidence, and thereby their quality of life. Data are needed to identify the nature and extent of personal benefits and how these can contribute to sustainable healthcare systems.

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