The challenge of Multimorbidity in the context of leprosy

C. RUTH BUTLIN*
* DBLM Hospital, Nilphamari, Bangladesh

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Introduction

Multi-morbidity (generally defined as the presence of two or more chronic health conditions simultaneously),\textsuperscript{1–2} is increasingly recognised in the medical literature as a problem both for care providers and for sufferers. However, while there are many discussions about it, there are few studies on which to base recommendations.

The residual morbidity arising from leprosy is one serious long term condition which requires on-going care and attention from both the sufferer and the concerned clinician, but as life progresses people affected by leprosy are also at risk of incurring any of numerous other chronic conditions which in turn need care and attention. In fact they may be at higher risk than same-age members of the community for some conditions, because of the well-known association between illness/disability and socio-economic status.

In many countries guidelines for management of chronic conditions are proliferating, but each addresses one particular condition and they rarely address the issue of adapting guidelines to individuals cases where multiple pathology complicates the clinician’s decision making. This is also true of some international guidelines.\textsuperscript{3} At the same time health services (at least for secondary care) are organised on a disease-specific basis, and except in a few countries (where general practice is recognised as a specialty in its own right) post-graduate training of doctors is largely confined to the narrow boundaries of their chosen specialty with the result that consultants feel uncomfortable handling diseases outside their area of expertise.

This growing problem is affecting leprosy as much as any other field, although in many places more for the leprosy staff trying to manage other conditions with which they are unfamiliar, than for other specialists trying to manage leprosy in their own clinics. Despite World Health Organisation (WHO) encouragement and the acceptance of ‘integration of leprosy into basic health care services’ (with leprosy-related treatment being offered by the same staff at the same place and time as treatment for other medical conditions) as policy in most endemic countries, such full integration is not yet achieved everywhere and ‘reverse integration’\textsuperscript{4} - often pioneered by leprosy organisations - is the next best solution.

Correspondence to: Ruth Butlin, 42 Old Drive, Polegate, East Sussex, BN 26 5ES, UK (e-mail: drbutlin@yahoo.com)
For some combinations of conditions polypharmacy is the biggest challenge, but leprosy-affected people spend only a small proportion of their ‘disease career’ taking regular medication (6–12 months of Multi Drug Therapy, then maybe a few courses of prednisolone over the first 2–5 years after diagnosis), and a much higher proportion of time struggling with self-care for residual morbidity such as nerve function impairment. The ‘burden of self-care’ can become very high if an individual also has other chronic conditions necessitating daily attention, for example diabetic peripheral vascular disease or lymphatic filariasis (as well as leprosy). Some combinations of conditions present the patient with risks of complications which are overlapping (risk may be multiplied rather than additive).

USING GUIDELINES

When medical practitioners attempt to apply several individual guidelines to one patient with multiple conditions, they meet a situation in which every individual recommendation made by a guideline may be rational and evidence based, but the sum of all recommendations in the individual is not. The need to adapt guidelines when a person has more than one condition has been discussed: to help clinicians’ decision-making, it is suggested, guidelines should include a mention of which treatments are least likely to benefit/most likely to harm. There is also a need to improve the evidence base from which guidelines are created by undertaking trials which include as subjects those with at least the most common combinations of conditions, and older people, then examining outcomes in subsets of subjects. The same points were made by Roland who also mentions a need for published guidelines for a few specific combination of conditions. As it will never be feasible to have evidence for every possible combination of conditions, at least disease-specific guidelines could be delivered in a format that is more useful for managing people with Multi-Morbidity and methods developed to facilitate integration and prioritisation of different clinical pathways. Nonetheless, professionals will use personal judgement in the face of uncertainty and the appropriateness of their decisions varies with their individual clinical acumen.

Some attempts have been made to obtain evidence on management of dual morbidity. The combination of physical and mental conditions is particularly challenging. Ackroyd looked at either diabetes or heart disease, with depression. Apart from when it is coincidental comorbidity, depression may result from other long term illness or disability as well as impair one’s ability to manage other conditions. This was recognised by NICE when it published a clinical guideline on depression with other long term conditions.

The value of well-prepared guidelines lies partly in the authors having properly assessed the evidence base, to identify interventions which are not of proven effectiveness even though their usefulness might have seemed self-evident. This prevents burdening patients with unnecessary workload. Sun and Xin studied self-care training sessions for Chronic Obstructive Pulmonary Disease, Irritable Bowel Syndrome and diabetes and concludes that "not all feasible interventions are effective and not all effective interventions are feasible".

NEED FOR AWARENESS AMONGST HEALTH WORKERS

It is important for those generalists with overall responsibility for individual patients (rather than for specific diseases) to be aware of their difficult role in balancing ‘benefits and risks of multiple recommended treatments’ since “individual recommendations may be
harmful/burdensome”. Sinnott\textsuperscript{12} who interviewed General Practitioners as to how they cope, coined the word ‘Satisficing’ for what they do when conflicts arise. These clinicians “accept trade-offs between drugs, diseases and recommendations”, and their compromise is to half satisfy and to half suffice. It sounds almost like sacrificing one goal for another.

As it was put in a Royal College of General Practitioners paper “we need to rediscover the essential skill of good judgement- not everything that could be done for a patient with just one problem should be done for patients with lots of problems”.\textsuperscript{1} Another aspect of the ‘good clinical judgement needed’ is the willingness to change management priorities over time in response to evolving conditions.\textsuperscript{7}

Care of a patient with multi-morbidity is often shared between specialists, but needs to be coordinated (preferably by a generalist clinician who is able to offer long term continuity of care). Issues related to management of multi-morbidity are being researched by the “School for advancing generalist expertise” (SAGE).\textsuperscript{13} The wise generalist will attempt to understand the patient’s priorities, helping the less articulate to express their opinions\textsuperscript{6} as well as interpret management plans for them (bringing order into chaos for patients). When one negotiates with patients and carers regarding the goals of treatment, instead of simply using physician-set targets,\textsuperscript{14} one may find they rank social participation and functional status above clinical and health service chosen targets.\textsuperscript{15} This may be particularly true of older people. “Single disease guidelines rarely refer to people with limited life expectancy. . .” Guthrie,\textsuperscript{5} but multiple morbidity may include at least one life-limiting condition, and anyway is more common in the elderly. Guidelines which recommend interventions likely to have delayed or long-term benefits (e.g. reduction in 10 year risk of a complication) are not appropriate to apply in people who – on account of another health condition, or simply their advanced age - are unlikely to survive 10 years.

Polypharmacy presents a real risk (in terms of pharmacological interactions) and practitioners need to focus on ‘medicine optimisation’ and the place for ‘deprescribing’ some long term medications,\textsuperscript{16} not least because handling complex drug regimens demands a lot from the patient: “the burden of the treatment” may be excessive,\textsuperscript{17} or even exceed the expected benefit. For many, having a ‘normal’ daily life and fulfilling perceived social obligations may take priority over control of symptoms or of risks.\textsuperscript{16}

Multi-morbidity may be not the only problem (nor the major problem) in the lives of the patients concerned. Mere survival in a resource-poor situation may be occupying most of their attention,\textsuperscript{18,19} leaving health matters to a lower level of priority. There is an association with lower socioeconomic status: looking at prevalence and type of patients with multi-morbidity, even in the relatively well-provided population of Scotland (1.75 million people in GP), Mercer\textsuperscript{20} found increasing prevalence with age and with deprivation compared with the more affluent. To supplement such cross-sectional data one needs longitudinal studies looking at the progression of the burden over a lifetime.

NEED FOR MONITORING HOW PEOPLE COPE

Empowerment has been described as a “goal in rehabilitation of disabled people which provides tools they need to attain independence and self-determination”.\textsuperscript{21} So called ‘self-care’ is a major tool, but it is not a single entity and responsibility for self-care is not something which can be easily handed to a patient: “(the concept of) self-care involves a spectrum of activity. . . many patients already self-manage. . . . for many others self-care is
a distant aspiration . . . many have a more complex task . . .”. Personalised care planning is at the centre of good management.

If we do not know how to measure empowerment we will not know which methods are best for enhancing it. One systematic review by Bakker & van Brakel\textsuperscript{22} identified 17 questionnaires to assess empowerment in context of disability, but none had been developed/validated in developing countries and there was variation in ‘construct of empowerment’. The most widely used and best validated/tested was the ‘empowerment scale’ (ES) of Rogers;\textsuperscript{23} most scales (including this one) although they had been developed primarily for mental illness seemed to be applicable other disabilities. Bakker pointed out the need for “cultural validation of any tool and to look at equivalence criteria”.

MODELS OF SELF-MANAGEMENT

Self-management which can be defined as “the care taken by individuals towards their own health and wellbeing” includes preventative actions, a healthy life style, satisfying emotional and social needs as well as actually managing the condition in question.\textsuperscript{9}

It is helpful to consider alternative models of self-management which have been developed for various chronic conditions, to see which are most applicable in a multi-morbidity situation. A person-centred collaborative approach (which captures the subjective feelings of loneliness, and of being ‘a burden to others’) is preferred to professionally-owned models of care which rely mostly on objective clinical indicators.\textsuperscript{24} One well-established approach is used by Pain Clinics, which says accepting that pain is part of one’s life and deliberately “taking control”, instead of “giving up” allows one to do things differently and live with the pain, setting realistic goals.

The Recovery model from mental health suggests one should ‘look beyond mere survival’ and concentrate more on recognising and fostering one’s abilities, interests or dreams, rather than on getting rid of problems. The ‘collaborative care and support planning’ model is based on the idea that it is the people with chronic conditions who are in charge and the primary decision-makers, a health worker’s role is to support them in managing challenges. The ‘Ariadne Principle’ approach\textsuperscript{2} has been developed for identifying realistic treatment goals and preparing individualised management plans taking into account patient preferences.

The cumulative complexity model\textsuperscript{25} describes a patient’s response to being overburdened when the ‘workload’ imposed on him (by being expected to manage all his multi-morbidity) exceeds his capacity to cope. If this situation arises one has to both diminish the treatment demands, and increase the capacity of the person to cope/self-manage, but it should preferably be avoided by anticipatory action.

One suggestion from Hodkinson\textsuperscript{24} for thinking about people with multi-morbidity is to group them into three categories, while realising that over time people shift between groups: (i) those who, while having complex multi-morbidity are functionally fairly independent. (ii) Those who are struggling to maintain independence while receiving some level of regular intervention, or becoming more frail. (iii) Those who are definitely frail, or largely dependent, having been already assessed are currently in receipt of adequate support.

Research is still needed into the methods some patients use successfully, in order to learn from them how best to help those who are not coping well with their multiple prescribed medications.\textsuperscript{16}
APPLICATION TO LEPROSY

One relatively straightforward issue for leprosy clinics is handling co-Incidental, acute, illness (Tb, jaundice, neglected tropical diseases) during chemotherapy or during immune-suppressive/anti-reaction treatment, but not much has been written about opting not to treat new nerve function impairment in some cases, if the patient has other chronic conditions (or is very old) which would mean a disproportionate increase in the attendant risks of adverse effects of steroids. It is more difficult – for the patient as well as the clinician - to handle a second or third long-term condition superimposed on disability related to leprosy, even if he no longer needs medication for his leprosy. Often leprosy staffs do not have the knowledge or skills to advise the patient and in some places the leprosy-affected person either is not welcome when he tries to obtain medical advice/treatment for other conditions at general health services facilities, or he is unable to access the facilities for practical reasons (including transport problems or finances).

Self-care problems may be compounded by other disabilities so that the person – although comprehending and motivated - is physically incapable of carrying out all advice he receives from health workers (blindness plus nerve function impairment prevents daily inspection of limbs) and some attempt has been made to develop an integrated grading system for functional limitation in the presence of leprosy/filariasis comorbidity.

Particular overlap of leprosy with other neglected tropical diseases (NTDs) has been noted: both “often co-exist and often associated with poverty”. There is scope for integration of staff training, and of services (e.g. in-patient care) etc. and also for development of scales which measure ‘ability to cope’ in the face of burdensome self-care regimens for more than one chronic disease. The American Leprosy Missions has recently made available valuable teaching aids for addressing morbidity arising from various NTDs in a coordinated way.

Considering a common non-communicable disease which often co-exists with leprosy, De Bruin & Van Brakel investigated whether health workers were willing to combine self-care teaching for diabetes and for leprosy, by means of a questionnaire. They found a qualified readiness to undertake a joint approach provided certain barriers could be overcome. There have been several surveys assessing prevalence of depression amongst leprosy affected people but fewer studies on management of mental illness in this group. Similarly, the epidemiology of co-existent Tb and leprosy has attracted more attention than the management of these two conditions in the same patient. Many leprosy-affected people live in dire poverty: one needs to heed the fact that poverty itself undermines one’s ability to cope with other problems in life, including illness or disability.

SUMMING UP

Since the current usual definition of multi-morbidity (two or more conditions) includes such a large proportion of the population, and some chronic conditions do not necessitate much daily attention, it may be more helpful (for planning interventions or training of health workers) to narrow it down to the working definition to those with three or more chronic conditions requiring constant attention by the sufferer. That might be residual morbidity from leprosy along with at least two other conditions. Cahill says “the subgroup of patients whose combination of conditions cause them a particular burden are a priority, where management is a challenge for themselves, their clinicians and their carers”. We need to think particularly
about the burdens on older people with residual morbidity from leprosy (i.e. permanent nerve function impairment or other leprosy-related disability), who have one or more other chronic conditions requiring self-care (be it lymphatic filariasis, diabetes, depression, epilepsy or chronic obstructive pulmonary disease) and how these can be tackled in an integrated way.

Finally we must keep in mind that ‘patients are more than the sum of their individual diseases’.33

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