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Review

Treatment burden and ability to work

Treatment burden can adversely affect patient functioning and wellbeing, including their ability work. Workers with multimorbidity, such as ageing, are disproportionately affected and their number is set to rise as the workforce ages. Complex treatment regimens and their sequalae can be a barrier to a successful return to work or even incompatible with work demands. Enlightened employers will seek to accommodate the burden of treatment by implementing reasonable adjustments. However, where the employer is unable or unwilling to accommodate such adjustments, the result may be loss of employment, with often devastating consequences to the worker's physical and emotional health and wellbeing.

Collaborative action in three key settings: the healthcare system, the workplace and the state can help reduce barriers, thereby enabling working-age people with chronic health conditions or disabilities remain in, and benefit from, employment.

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Educational aims

- To raise awareness on how treatment burden can adversely affect health, work and societal outcomes in working age people.
- To promote good practice in relation to managing treatment burden in healthcare and work settings, so that working age people with chronic health conditions or disabilities can remain in and benefit from work.

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Treatment burden can adversely affect ability work in working age people, mainly those will multimorbidity and the ageing. Shared decision making and adjustments in the workplace are crucial to help these workers continue to remain in and benefit from work. https://bit.ly/35UoqUj

What is treatment burden?

The concept of "treatment burden" refers to the workload of healthcare and its impact on patient functioning and wellbeing [1]. The concept emerged from the realisation that rising standards of care, available treatments and clinical guidelines for optimal management of medical conditions could result in overwhelmed patients and caregivers [2].

The workload of healthcare is wide-ranging and encompasses all demands in a patient's life arising from health-related activities. This can include scheduling and attending appointments (*e.g.* visits to health professionals, diagnostic investigations, laboratory tests), obtaining prescriptions and taking medications, making lifestyle changes, such as diet and exercise, self-monitoring (*e.g.* peak flow or glucose measurements) and looking after medical equipment (*e.g.* cleaning a nebuliser or a continuous positive airway pressure machine), understanding and managing underlying health conditions and care. Depending on the health insurance system of the patient's country of residence, healthcare may be associated with a heavy administrative workload, including the payment of bills [3].

For example, the UK's National Institute for Health and Care Excellence (NICE) 2018 guideline on the management of COPD [4] recommends the following interventions for adults with stable COPD: smoking cessation; inhaled therapy and training in its use; spacer cleaning; clinical review at least annually; vaccination; and exercise and pulmonary rehabilitation. To facilitate holistic care and better clinical outcomes, the guidance recommends the offer of physiotherapy, nutritional support, management of anxiety and depression, and relaxation techniques. Whereas the above undoubtedly contribute to optimal clinical outcomes as part of a holistic care package, the cumulative burden of the above therapeutic interventions can be considerable.

The updated 2018 NICE guideline makes reference to treatment burden and makes recommendation aimed at its reduction. For example, it recommends minimising the number and type of inhaled medication as far as possible. It also alerts people to the commitment required to access treatment, such as pulmonary rehabilitation. However, it does not explicitly quantify the workload and potential effect on a patient's life associated with enacting its recommendations.

Who is affected by treatment burden?

The burden of treatment is dependent on individual and socioeconomic factors (including healthcare resources). It does not affect all patients equally even in the case of patients with the same medical condition [2]. It disproportionately affects patients with complex health needs, chronic health conditions and multimorbidities, such as the ageing.

Multimorbidity is defined as the coexistence of two or more long-term medical conditions or diseases [5]. People are increasingly living with more than one chronic medical conditions and this trend is expected to continue [6]. Among people of working age, those mostly affected by multimorbidity include young adults with serious congenital or acquired impairments [7]; those from disadvantaged socioeconomic backgrounds [8]; and the ageing workforce.

The rise in the proportion of older workers is a reflection of demographic and societal changes. As the populations have grown older, government policies in developed countries have encouraged workers to remain in employment for longer [9]. Many older people have opted to work for longer out of necessity or choice. Studies have consistently shown increasing prevalence of multimorbidity with increasing age, which is estimated to affect up to 95% of the population aged 65 years and above [10]. Moreover, increasing age is the main factor driving multimorbidity in high-income countries. High rates of multimorbidity have been reported among working age populations in numerous countries [11].

What are the consequences of treatment burden?

The burden of treatment can adversely affect patient quality of life in terms of time and effort diverted from other meaningful life activities, such as family time, leisure, study and work. Patients and their family and social support network often have to shoulder the workload over extended periods, often over a lifetime [3].

Non-adherence to treatment is more common in overburdened patients who will often opt out of their treatments after balancing the perceived benefits against the investment required in terms of time, energy and cost. This non-adherence results in wasted resources, more encounters with the healthcare system and treating professions, more prescribing and worse patient outcomes [2]

For working age people, treatment burden can affect ability to work and may even result in job loss. The changing work landscape in the past decade has resulted in work factors augmenting the impact of ill-health or its treatment on employment. The number of shift workers and people working unsociable hours has increased. More people work remotely, on zero-hour or short-term contracts. Job security or full-time contracts can no longer be taken for granted during and their working lifetime workers may work in a variety of roles, in a full-time or part-time capacity at different stages. These factors render subgroups of workers particularly vulnerable to job loss.

What is ability to work?

Ability to work, or workability, is the ability of workers to perform their jobs taking into account specific work demands, individual health conditions and mental health resources [12]. Workability differs from workers' ability, which refers to competence to do the job.

Workability is a multifactorial concept dependent on individual, work and societal factors. Although its core is health and functional capacity, it is also dependent on individual skills, values, attitudes and motivation, as well as work [13]. The Faculty of Occupational Medicine's "Position Paper on Age and Employment" [12] describes workability as a function of: health and functional capacities (physical, mental, social); education and competence; values and attitudes; motivation; work demands; work community and management; and work environment.

Recent years have seen a shift in mindset away from "disability" and toward "workability", with a more person-focussed approach aimed at fitting the task to the person rather than *vice versa*.

Why is work important?

Work has a positive impact on health and every person of working age has the right to work safely.

Work is an integral part of most people's adult lives. The benefits of work are multifaceted and extend beyond improving physical and mental health outcomes. Work provides social status, social networks and allows for participation in society. It gives a means of structuring time, activity and involvement [14]. It provides money and other resources needed for material wellbeing. It builds confidence and self-esteem and gives a sense of identity and purpose in life. Work need not necessarily be for financial gain: people derive great non-financial benefits from voluntary or charitable work. The right to work is embedded in in Article 23 of the United Nations Declaration of Human Rights, which states that "everyone has a right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment".

In contrast with the benefits that work brings to individuals, their families and communities, worklessness and unemployment are associated with poor health and, by extension, societal outcomes. The adverse health effects of worklessness include poorer general health, for example due to hypertension and hypercholesterolaemia; poorer mental health; higher medical consultation, medication usage and hospital admission rates; higher mortality, mainly because of cardiovascular disease, lung disease and suicide; and reduced life expectancy because of the aforementioned factors. Health inequalities caused by worklessness and unemployment persist, even after adjusting for social class, poverty, age and pre-existing morbidity [15]. Worklessness and the problems it brings are now recognised as an important public health issue [16].

Importantly, re-employment of those without work leads to improvement in health and well-being. Additionally, placement in work improves health and social status of people who are sick or disabled [14].

How can treatment burden affect ability to work?

Ill-health is a common factor adversely affecting workability. When assessing medical fitness to work, loss of function and any resulting disability are often more important than the medical condition itself. The individual's condition should be assessed in functional terms and in the context of their specific job requirements, especially when the desired outcome is remaining in or returning to gainful work. Whereas treatment may benefit the patient in terms of clinical outcomes, treatment burden may result in loss of function and worsen outcomes in terms of workability.

The concepts of impairment, disability and handicap, as defined in World Health Organization's classification of Impairments, Disabilities and Handicaps [17], can be used to illustrate how treatment burden can affect workability:

Impairment is the loss or abnormality of psychological, physiological or anatomical structure or function. For example, the introduction of a tight insulin regimen to improve the glycaemic control of a patient with type 2 diabetes can result in temporary cognitive impairment due to hypoglycaemia.

A disability is defined as any restriction or lack of ability (due to an impairment) in performing an activity in the manner or within the range considered normal for a human being. Therefore, a given disability may be the result of a variety of impairments. For example, the disability of sudden incapacitation may be the result of hypoglycaemia due insulin or orthostatic hypotension due to antihypertensive agents.

A handicap is a disadvantage for a given individual, resulting from a disability or impairment, that limits or prevents the fulfilment of a role that is normal (depending on age, gender, social factors) for that individual. A given disability may produce a range of handicap which is dependent on the individual performing their expected role or activity. For example, the impairment and disability caused by the hypoglycaemic episode is unlikely to cause a serious handicap for a sedentary worker in a well-supported role. In contrast, the same impairment in a professional driver or an emergency worker will result in a profound handicap.

Poorly realised treatment regimens in conjunction with badly designed working conditions

can be more relevant in producing handicap than the condition itself.

Pharmacological treatments require special consideration in terms of their potential impact on ability to work. Medication is normally positive for employment, as it enables the control underlying health conditions, thereby allowing many people of working age, who would otherwise be unable to work safely and effectively, to pursue productive employment. However, the side-effects associated with both short-term and long-term pharmacological treatments can affect ability to work, the risk of harm increasing with polypharmacy. Medication can have affect cognition, psychomotor functions, mobility, manual dexterity, or vision. It can also distract from work tasks by troublesome side-effects, such as gastrointestinal upset, tremor or malaise.

In addition to the side-effect profile of medications and the workload associated with treatment, prescribers need to consider how work factors may affect the effectiveness and safety of pharmacological treatments, but also adherence, where treatment is perceived with work activity. Heavy physical activity, shift work, hot or cold working conditions, transport, safety-critical work, emergency work, lone working, long-distance travel, risk of injury or exposure to hazardous substances are examples of work factors that require additional considerations to ensure that safety and function are not compromised.

Below are some examples of the potential effects of pharmacological treatment on work function and safety:

- Safety-critical work, including emergency work and transport (many safety-critical occupations have developed their industry-specific working standards): caution with treatments that can cause sedation and cognitive impairment (*e.g.* sedative analgesics), or sudden incapacitation (*e.g.* due to hypoglycaemia caused by hypoglycaemic drugs or postural hypotension caused by antihypertensive agents)
- Shift work: the recent years have seen a sharp rise in the number of people working shifts. Shift working is associated with somnolence, which can be enhanced by sedative medications. It can also interfere with the taking of medications at the required time, with the consequence that many employees may deliberately or unintentionally omit doses, thereby affecting the management of the underlying health condition.
- Heavy physical work or work associated with the risk of injury: caution with anticoagulants or other medications that increase the risk of bleeding.
- Extremes of temperature: caution with diuretics (increased risk of dehydration at high temperatures) and beta-blockers (exacerbation of Raynaud's phenomenon and cold intolerance in cold environments).
- Work requiring good manual dexterity: caution required with medications that can cause tremor (*e.g.* tricyclic antidepressants), or extrapyramidal symptoms (*e.g.* typical antipsychotics).
- Work requiring good vision: caution is required with treatments that can cause visual disturbance, (*e.g.* tricyclic antidepressants, chloroquine).
- Noisy work environments: the harmful effects of noise exposure may be enhanced with ototoxic agents, such as gentamycin.
- Potential work exposure to infectious agents, such as Covid-19: caution required with certain agents causing immunosuppression, thereby increasing vulnerability.

To illustrate the above points with an example, a 63-year-old male factory worker with the diagnoses of uncomplicated type 2 diabetes mellitus and hypertension, will typically require at least three pharmacological agents; regular blood tests for glycaemic control as well as monitoring of renal function and medication adverse effects; dietetics appointments; exercise on prescription; monitoring for long-term complications of diabetes; blood pressure monitoring; smoking cessation interventions if relevant. The treatment burden may to include frequent leave from work (paid or unpaid) to attend the above scheduled appointments and adverse effects of medication (*e.g.* hypoglycaemia or orthostatic hypotension) which may affect safe working with machinery. The worker is likely to require disability leave from work, if provision in made in the employer's policy, and placement in less hazardous setting. An additional chronic health condition and its treatment burden, in the context of limited redeployment opportunities or health benefits in his work setting, renders him at risk of loss of employment.

Work adjustments to accommodate the burden of treatment

Where an employee is unable to remain at work because of the direct effects of the underlying health condition or the burden of its treatment, an enlightened employer will seek to make reasonable adjustments to promote workability. This will often require the input of occupational health professionals, rehabilitation specialists or human resources professionals. Both physical and organisational aspects of the job should be considered.

Examples of adjustments include:

- Flexible working pattern to allow attendance at appointments. Additional provisions may be necessary to support the employee with absences secondary to side-effects of

treatment, for example influenza-like symptoms following interferon infusion; or nausea and malaise following the administration of weekly methotrexate.
- Adjustments to shift patterns, including exemption from night work where necessary.
- Allow additional breaks for the administration of treatment or monitoring (*e.g.* insulin injection or blood glucose monitoring).
- Home working (fully or partially) to allow for implementation of treatment routines.
- Provision of suitable space at work for medication storage and the administration of treatment administration (for example, storage and administration of insulin).
- Provision of work adaptations, safety guards, awareness and training, personal protective equipment to protect against injury.
- Provision of disability leave in line with the employer's policy.
- A flexible approach to sickness absence management for absence due to the underlying health condition or its sequelae.
- Modification of work duties or redeployment to alternative duties where it is not possible to accommodate safe or effective working in the original role.

Recommendations

Reducing treatment burden requires individualised holistic care of the patient, that attends not only to their clinical needs but also the personal, work and social context of their lives. Removing the barrier of treatment burden on workability, while maximising fitness for work and job retention, can be achieved through an integrated approach across three key settings: the healthcare system, the workplace and the state. Healthcare professionals, patient advocacy groups, researchers, employers, policymakers and other stakeholders should work toward the shared goal of enabling working age people remain in and benefit from employment. This will produce the additional benefits of optimising the use of resources, reducing waste, tackle health inequalities caused by the disability employment gap and improve health, work and societal outcomes.

The healthcare system

Patient-centred models of care

The aim of patient-centred models of care, such as minimally disruptive medicine, is to minimise the treatment burden by optimising the workload necessary to achieve patient goals while boosting capacity [3]. Such an approach can greatly improve the care and quality of life for patients. This can be achieved through goal setting, shared decision making, reduction of workload (*e.g.* medicines optimisation, streamlining of appointment schedules and repeat prescriptions), and enhancement of capacity, such as collaboration with community services [18].

Shared decision making is important and should be at the heart of the consultation. Studies suggest that patients assessments of medication importance differ from those of their clinicians [19] and that clinicians do not explore contextual factors that may impact on their patients' health [20]. The aim of shared decision making is to enable health professionals to understand the values, preferences and priorities of their patients, including about demands and desired outcomes related to work, and to help patients make informed decisions about their treatment, which they are then more likely to adhere to. This is particularly important for patients with multimorbidity and for treatments with high workload, who are at high risk of being overwhelmed [2].

Shared decision making is crucial in reducing inappropriate barriers to work. For example, the holistic care needs of a safety-critical worker of shift worker are likely to best served by the use of insulin pump technology and continuous glycaemic monitoring rather than a traditional insulin regimen. Anticoagulation point of care testing and self-monitoring is likely to be the best option for regular therapeutic monitoring of a full-time worker requiring long-term anticoagulation. New and innovative ways of delivering care, for example telemedicine and e-therapies, can greatly reduce the burden of accessing healthcare services. Patients will greatly benefit from good professional advice about the benefits to their health and wellbeing from returning to work and this in turn can guide their life decisions.

Medicines optimisation

It is estimated that about one-third of patients prescribed a new medication for a chronic condition do not take it as prescribed and, in almost half of cases, deliberately so [21]. Patients' unmet needs for information and support, as well as problems taking the medication, have been identified as reasons with this non-adherence [21]. Nonadherence is a sign of failure of the healthcare system to identify overburdened patients who are unable to absorb the work and cost of their treatment [22]. Medicines optimisation is a patient-centred approach to safe and effective medicines use. It is used, for example, in the UK's National Health Service and is achieved through improved collaboration of health and social care practitioners and greater patient engagement.

Inclusion of treatment burden in guidelines

There is a compelling case for the inclusion of treatment burden in clinical practice guidelines [2].

Self-assessment questions

Select one correct answer.

1. Which of the following groups are not disproportionately affected by the burden of treatment?
   a. Older workers
   b. Young workers
   c. Workers with multimorbidity
   d. Workers in safety-critical occupations
2. Sudden incapacitation as a result of medication side-effects is:
   a. An impairment
   b. A disability
   c. A handicap
3. Which of a following types of medication do not adversely affect shift work?
   a. Antiepileptics
   b. Hypoglycaemics
   c. Tricyclic antidepressants
   d. Anticoagulants
4. Which of the following is not a reasonable workplace adjustment?
   a. Dismissal of the employee due to safety concerns
   b. Redeployment on medical grounds
   c. Modification of work duties
   d. Exemption from night shifts

In working age adults, guidelines should also include acceptability and feasibility of implementation of treatment in the work context.

Traditionally, clinical guidelines place the greatest focus on therapeutic interventions that achieve the best clinical outcomes (for example, prolonging survival). Guidelines make no explicit reference to the burden of the recommended treatments or to the potential effects of treatment burden on work outcomes. Inclusion of the above information would help patients make informed decisions about their health and work that are in alignment with their values and priorities and consequently improve adherence and outcomes [2]. This is more so relevant for patients with multimorbidity, where complex treatment regimens are recommended and where work outcomes are important (for example to prevent the loss of employment).

The workplace

Employer training and engagement is key in creating safe and healthy workplaces where people, including those with disabilities and chronic health conditions, can work and thrive. Appropriately trained managers, informed employees and good practice in human resource management can help ensure that valuable skilled employees are not disadvantaged because of their ill-health or disability.

Employers have good reasons to make reasonable adjustments. Making reasonable adjustments to retain an employee who develops a health condition or disability costs much less than recruiting and training new employees. Moreover, enabling an employee to remain at work is therapeutic and carries important health as well as social benefits. Thus, such good employment practice is important both in financial and human terms.

The employer's occupational health service, where available, has a key role to play in supporting affected employees while assisting the employer in making appropriate adjustments. Specialist occupational health input is particularly important in safety-critical work settings where treatment burden has to potential to adversely affect safety. Where access to occupational health advice is unavailable, as is often the case with small-size employers, government-funded schemes, such as "Access to Work" in UK, can provide a much-needed resource. Working age people with significant health issues or disabilities can be supported by government initiatives to support suitable employers in the provision or supported employment or sheltered work.

The state

The state has a significant role to play in raising awareness, shifting attitudes and creating opportunities for working age people with chronic diseases. Action can include developing policy which supports, enables and facilitates work; initiatives to support employers; support in the development of research tools and good practice guidelines. This can be achieved through partnership working with health services, education and training bodies, patient advocacy groups, employers and other stakeholders.

Human rights and equality legislation is important in safeguarding the interests of people of working age who wish to enter or remain in employment. Legislation prohibits discrimination on grounds of health and requires that employers make reasonable adjustments to enable qualifying individuals to enter or remain at work. Disability is determined in functional, rather than medical terms, and may include the effects of treatment (for example, side-effects of medicines). Such legislation is key, as employers tend to be strongly influenced by legal mandate.

Embedding work as an outcome measure

Remaining at work or returning to productive employment is one of the most meaningful objectives of treatment in working-age adults, as well as an important prognostic indicator. However, in practice, traditional health services are focussed on narrow clinical outcomes. The result is that a large proportion of individuals make a good clinical and functional recovery from physical or mental illness only to find themselves excluded from work,

thereby enhancing the health and social inequalities associated with worklessness.

In the recent years, work has gained recognition as an outcome measure for health interventions in people of working age [16]. Explicit policy will assist in raising the profile of work as a health outcome amongst health professionals and embedding work as a health outcome in practice.

Key points

- Treatment burden can result in adverse work outcomes for working age people with chronic health conditions or disabilities.
- Enlightened employers will seek to accommodate or reduce the impact of treatment burden by implementing reasonable workplace adjustments.
- Subgroups of workers are vulnerable to loss of work as a result of their health condition or its treatment, which in turn is detrimental to their physical and mental health.
- Reducing treatment burden requires individualised holistic care of the patient, that attends not only to their clinical needs but also the personal, work and social context of their lives.

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Conflict of interest

A. Trakoli has nothing to disclose.

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Suggested answers

1. b.
2. d.
3. d.
4. a.

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