

# Scottish School of Primary Care

GP Clusters

**Briefing**

**Paper 11**



# Treatment Burden

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## Collaborative Quality Improvement in General Practice Clusters

This paper is the eleventh in a series that relates to areas of quality and safety on which general practice clusters could usefully focus improvement activity. Each paper summarises research, guidelines and other evidence about areas of care which can be improved, and improvement methods and interventions.

### Treatment Burden

Treatment burden describes the self-care management demands that are imposed by health care systems, upon those with chronic illness. In view of changing population demographics, and the rise in the prevalence of chronic illness and multimorbidity, the issue of treatment burden is a subject that warrants attention. Treatment burden has been identified as being a consequence of either the workload of healthcare or a result of care deficiencies. The effects of treatment burden will vary depending on the capacity of an individual and their wider support network to cope with any given burden of treatment. This paper describes the literature on treatment burden and explains why treatment burden should be considered a new barometer of quality of care. It will conclude with recommendations for steps that should be considered to minimize treatment burden and provide care that is maximally supportive.

### The Problem

Changing population demographics and lifestyles together with advances in science and technology have led to improved treatments for those with chronic illness, including therapies that aid recovery and prevent further disease. This means that the prevalence of chronic illness and multimorbidity, the presence of two or more long term conditions, has been increasing<sup>1</sup>. Alongside these epidemiological changes there has been an increased investment in specialist care and a growing range of therapeutic options, and an increase in the prescribing of polypharmacy. This has resulted in increasing burden of treatment demands placed on patients and their caregivers as they are required to

follow regimes set by healthcare professionals and to navigate increasingly complex and fragmented healthcare systems<sup>2,3</sup>. Poor coordination across sectors, for example, primary and secondary care and health and social care, also adds to the experienced treatment burden<sup>4,5</sup>.

Treatment burden is defined as the workload of healthcare for patients and the effect of this on their wellbeing<sup>2,4-7</sup> and this can be challenging<sup>8</sup> for patients and caregivers. Excessive treatment burden can lead to negative outcomes such as reduced quality of life, non-adherence, less effective treatment and wasted resources<sup>2,3</sup>. Individuals may vary in their capacity to cope with a given treatment burden. Those who are less well educated, have low health literacy, are cognitively impaired, do not speak the local language, who have sensory and physical challenges, or who lack good social support are less likely to be able to cope with any given treatment burden<sup>2,6,9</sup>. Furthermore, even those who have none of these difficulties can struggle because they are 'time poor' with busy jobs and family schedules to juggle. Treatment burden is also being increased by the growing tendency to shift management responsibilities from healthcare systems and professionals to patients and their caregivers. Many aspects of treatment burden are also likely to be worsened by guidelines and policies set by governing bodies as well as the organisation of health services, making this a significant problem for patients and their caregivers that could be amenable to change through further research and alterations in our approach to the delivery of healthcare<sup>10</sup>.

Treatment burden has been defined as having four dimensions which are: 1) Sense making work, that is the effort needed to gain an understanding of treatments and planning care; 2) Engagement work, the work of interacting with others including health professionals, family and others; 3) Enacting work, which includes the practical day-to-day activities needed to operationalise self-management such as managing polypharmacy, enduring treatment side effects, undertaking lifestyle or self-monitoring activities; and 4) Reflecting work, which includes the work of adjusting therapies and decision making relating to whether to continue with therapies or not<sup>4,5,11</sup> (Table 1).

**Table 1. Examples of Treatment Burden and Capacity Issues**

	Treatment Burden Examples	Patient Capacity Issue Examples
<b>Sense making</b>	Needing to gather information about a condition	Cognitive difficulties
<b>Engaging with others</b>	Organising prescriptions on the phone	Speech impairments/Non English speaker
<b>Enacting treatments</b>	Attending multiple appointments	Lack of transport or money to pay for transport
<b>Reflecting</b>	Monitoring progress	Lack of family support



Measures need to be developed and validated to assess treatment burden and to address more than just treatment side effects. Equally, we need to gain a better understanding of the key factors that affect an individual's, or their wider support network, to cope with any given treatment burden<sup>2,6</sup>.

### Can Treatment Burden Be Reduced?

It is important to be clear that not all treatment burden can be avoided and many treatments ameliorate symptoms or improve outcomes. So, polypharmacy may be necessary to reduce the risk of disease exacerbations or to improve quality of life. Equally, self-monitoring activities or clinical investigations may be important to maintain wellbeing. However, disease-centred rather than person-centred approaches together with fragmentation of care often means that clinical guidelines are applied to patients without the necessary consideration of their individual context and the patient's own goals and personal priorities at any given point in time. It has been suggested that 'minimally disruptive medicine'<sup>3</sup>, an approach to care that prioritises patient preferences, takes account of personal circumstances, and aims to lessen the health care work patients have to do, is the solution. Such an approach prioritises person rather than disease-centred care and emphasises the importance of effectively coordinated care. Enhancing capacity to cope with treatment burden should also be an important target as there is emerging evidence that interventions that enhance capacity for self care can have benefits for healthcare systems, for example, through decreasing hospital readmissions<sup>12</sup>. Those interventions that improved capacity took a broad approach to helping the individual and did not focus purely on addressing healthcare surveillance or intensity of treatment<sup>12</sup>.

Treatment burden can be reduced and patient experiences transformed; however achievement of this will require a concerted effort in four areas:

- Clinical Guidelines should be amended to take account of comorbidity and multimorbidity. These need to inform clinicians on how best to deal with polypharmacy, for example which medications to prioritise in cases of drug interactions<sup>3,13</sup>. Although there are a vast number of potential combinations of comorbidity, there are a number of chronic conditions like chronic obstructive pulmonary disease, diabetes and heart failure that commonly co-occur. There is a need to fund research to enhance understanding of such issues and to develop guidelines to clarify how best to treat such individuals<sup>3,14,15</sup>.
- Co-ordination of care – Primary care will clearly have an important role going forward, as it is ideally placed to have a key role in enhancing care coordination for those with multimorbidity. Ensuring that primary care clinicians are incentivised to promote holistic care rather than merely achieving clinical targets will be an important advance<sup>3,14,15</sup>.
- Putting patients first – at present health care systems are designed to ensure smooth running rather than prioritising adaptation to better suit patient priorities and requirements. Patients need to have a greater role in decision making about their care and their perspectives need to be given greater priority<sup>3,14,15</sup>.
- Finally, as outlined above there is a need for better tools to assess treatment burden and help identify those who are most risk of being overburdened<sup>3</sup>.

### Implementation in real-life NHS practice

The findings from this programme of work can be translated into a number of key actions for NHS policy makers and clinicians. Information has been gained about different aspects of treatment burden and patient capacity and potential interventions to address these issues will be discussed in turn. There is not one simple solution to these problems but rather here we provide an overview of a roadmap to lessen burdensome healthcare.

### Co-morbidity/Multimorbidity

Multimorbidity and co-morbidity have been shown to be extremely common in the population of Scotland and the numbers of morbidities suffered high<sup>1,10,16-18</sup>. This has implications for the design of both health services and clinical guidelines which currently under appreciate co-morbidity and remain disease rather than person focussed. Type and number of morbidities suffered are likely to influence healthcare workload, capacity and care provision. Those who have more conditions to manage simultaneously are more likely to suffer ill health and socioeconomic deprivation, and individuals will have access to different services dependent on their condition<sup>1</sup>. Partly due to these high rates of co-morbidity, polypharmacy is also common, increasing the risk of adverse events<sup>19</sup>. Clinical guidelines should be amended to inform clinicians on how best to deal with polypharmacy, for example, which medications to prioritise in cases of drug interaction. When clinical guidelines cannot adequately address these issues then 'invention and adaptation' will be necessary<sup>14</sup>.

### Addressing Knowledge Deficits

The published literature has made it clear that patients spend significant time and effort seeking out, cognitively processing and reflecting on information about their management. There is also evidence that the provision of this information by health services is currently inadequate. There is evidence that 1) access to information is inadequate, 2) adequate time is not given for the exchange of information, and 3) the information provided is not easily understood by patients and not tailored to suit their needs<sup>20</sup>. These three factors result in



patients having to expend time and energy researching their management. Enhanced communication during the clinical encounter along with improvement in the provision of information to patients must be addressed by health services, as patients' understanding of the rationale behind therapies and their trust in management plans may influence adherence<sup>21</sup>. Knowledge deficits mean that patients can be ill equipped to plan and organise their care or to develop effective coping strategies. Time is precious in the NHS but, at present, there is often inadequate time to provide all the necessary information and, indeed, many of the complex concepts trying to be communicated, meaning that many people will struggle to fully comprehend the implications of the information shared, especially as we know health literacy issues affect almost half the population<sup>22</sup>. It will therefore be important to consider a range of strategies to enhance patient understanding of the implications of any given illness which will include considering novel strategies. For example, recordings or other records of consultations could be provided, along with clear individualised management plans for every patient in a format comprehensible to them. Improved access, uptake and utilisation of enabling health literacy tools and resources across NHS Scotland would also be important.

Previous research has shown that during the consultation patients are not always forthcoming with their own agendas and therefore eliciting their ideas, concerns and expectations is an important skill for all health professionals<sup>23</sup>. However, there are a number of clinician related and system barriers to improved communication in those with serious illness<sup>24</sup>, so training in these areas should be prioritised by NES and academic centres responsible for health professional education.

### Reconfiguring Services

The organisation of services at both macro and micro levels appears to significantly impact treatment burden<sup>20</sup>. Attending and planning appointments takes considerable time and effort on behalf of the patient, made all the more difficult by poorly organised, fragmented services<sup>4,5,11</sup>. Having multiple appointments to attend can be challenging to remember and practically difficult to enact. A move from disease-centred to more person-centred services would be a good place to begin service reconfiguration. An example of a disease-centred service is the rapid access heart failure services that are designed to rule-in or out a diagnosis of heart failure in someone with breathlessness. As there are many different causes of breathlessness, a negative test for heart failure leaves the patient's problem unresolved and further referrals are often required, delaying diagnosis. Consideration should be given to "breathlessness" clinics which would allow a patient's problem to be addressed rather than just excluding or diagnosing a given disease/illness. A reduction in volume of appointments along with allocation in consultation with the patient would improve attendance. Healthcare systems need to consider how to improve the efficiency of interacting with healthcare from the patient's perspective (e.g. by streamlining administrative hurdles or other barriers to care)<sup>27</sup>.

Polypharmacy can be problematic, as therapies can interact with each other and cause difficulties for patients. This is particularly relevant for patients with multimorbidity who have multiple treatment regimens to deal with simultaneously. Additionally, poor continuity of care along with poor communication across the primary and secondary interface and between health professionals increases the chance of mixed messages on how to optimise therapy which can be extremely challenging for patients. Consequently, there is a need to promote improved communication and timely information sharing between health professionals if the goal of individualised, holistic patient-centred care is to be achieved. If meetings cannot be carried out face-to-face then adequate secure methods of communication such as clinical email systems must be utilised, with confidentiality of patient information considered.

### Supporting Patients

An individual's capacity to cope with their treatments has a huge influence on their experienced treatment burden. Within clinical encounters, greater consideration needs to be given to identifying contextual limitations in individual capacity that may impact self-management and that may be amenable to support or intervention<sup>27</sup>. Those who have to attend multiple appointments should be helped using evidence based strategies such as reminder systems to improve attendance<sup>28</sup>.

Health and social care services should prioritise increasing capacity for those with chronic illness through implementation of interventions that strengthen social support systems and improve ability to self-manage. For example, prompt provision of carer services, adaptations to the home and pharmacy delivery services can transfer the home environment into a safe place for discharge into the community after hospitalisation. Importantly, appropriate and timely financial aid in the form of government benefits can also considerably improve capacity, and negates any worry of being unable to pay for essential services such as heating and electricity. For those with a poor social network, adequate signposting to available services can provide social support that is vital, as services are often available that patients do not know exist<sup>27</sup>.

Navigating health and social care services can be very challenging and the most vulnerable fare worst in such circumstances. Missing an appointment can result in discharge from services, even if the fault is at the healthcare end, and more work for patients as they try to renegotiate access. Appointment slots can be provided at short notice resulting in missed appointments or necessitating rescheduling. Accessing the results of investigations can require multiple phone calls or visits. These challenges need addressed.

### Implications for collaborative quality improvement in general practice clusters

The burden of treatment imposed by the delivery of



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health care services should become an important barometer of quality of care for GP clusters<sup>2</sup>. Equally, the level of support provided by health services to maximise patient capacity should be monitored. Effective measures need to be developed and validated that assess the disruptive effects of adhering to treatment regimens for patients, including interferences to their work, family life and/or other obligations. A measure to assess treatment burden has just been developed in the United States<sup>29</sup>. This Patient Experience with Treatment and Self-management (PETS) scale is a patient reported measure of treatment burden and merits testing in Scotland as it appears to be a promising comprehensive measure of treatment burden which may help increase our understanding of the workload of self-management and how it impacts on wellbeing. Patient-centred rather than disease-centred care should be promoted and targets set locally that relate to overall wellbeing rather than individual disease markers. GP clusters have the ability to reduce the burden on patients through making improvements such as better care co-ordination, improved information provision and 'signposting'. Such improvements, along with the implementation of interventions that enhance and support patient capacity, can improve health-related outcomes for those with long term conditions.

## References

- Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B: Epidemiology of Multimorbidity and Implications for Health Care, Research, and Medical Education: a Cross-Sectional Study. *Lancet* 2012, 380: 37-43.
- Mair FS, May CR: Thinking about the burden of treatment. *BMJ* 2014, 349: g6680.
- May C, Montori VM, Mair FS: We need minimally disruptive medicine. *BMJ* 2009, 339: b2803.
- Gallacher K, Morrison D, Jani B, Macdonald S, May CR, Montori VM et al.: Uncovering Treatment Burden as a Key Concept for Stroke Care: A Systematic Review of Qualitative Research. *PLoS Med* 2013, 10: 10.1371/journal.pmed.1001473.
- Gallacher K, May C, Montori VM, Mair FS: Understanding Treatment Burden in Chronic Heart Failure Patients. A Qualitative Study. *Ann Fam Med* 2011, 9: 235-243.
- May CR, Eton DT, Boehmer K, Gallacher K, Hunt K, Macdonald S et al.: Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Serv Res* 2014, 14: 281.
- Eton DT, Ramalho-de Oliveira D, Egginton JS, Ridgeway JL, Odell L, May CR et al.: Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Relat Outcome Meas* 2012, 3: 39-49.
- Sav A, Kendall E, McMillan SS, Kelly F, Whitty JA, King MA, Wheeler AJ. 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia. *Health and Social Care in the Community* 2013; 21 (6):665-674.
- Shippee ND, Shah ND, May CR, Mair FS, Montori VM: Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *J Clin Epidemiol* 2012, 65: 1041-1051.
- Gallacher KI, Batty GD, McLean G, Mercer SW, Guthrie B, May CR et al.: Stroke, multimorbidity and polypharmacy in a nationally representative sample of 1,424,378 patients in Scotland: implications for treatment burden. *BMC Med* 2014, 12: 151.
- Jani B, Blane D, Browne S, Montori VM, May CR, Shippee ND et al.: Identifying treatment burden as an important concept for end of life care in those with advanced heart failure. *Curr Opin Support Palliat Care* 2013, 7: 3-7
- Leppin AL, et al. Preventing 30-day hospital readmissions. *JAMA Internal Medicine* 2014; 174(7):1095-1107.
- Guthrie B, Payne K, Alderson P, McMurdo MET, Mercer SW: Adapting clinical guidelines to take account of multimorbidity. *BMJ* 2012, 345: e6341.
- Abu Dabrh, A.M., Gallacher, K., Boehmer, K.R., Hargraves, I.G., and Mair, F.S. (2015) Minimally disruptive medicine: the evidence and conceptual progress supporting a new era of healthcare. *Journal of the Royal College of Physicians of Edinburgh*, 45(2), pp. 114-117. (doi:10.4997/JRCPE.2015.205)
- Stewart S, Riegel B, Boyd C, Ahamed Y, Thompson DR, Burrell LM et al. Establishing a pragmatic framework to optimise health outcomes in heart failure and multimorbidity (ARISE-HF): A multidisciplinary position statement. *International Journal of Cardiology* 2016; 212:1-10.
- Agur, K., Morrison, D., and Mercer, S. (2016) The epidemiology of multimorbidity in chronic respiratory conditions. *Primary Care Respiratory Journal*, (Accepted for Publication)
- Simpson, R. J., McLean, G., Guthrie, B., Mair, F., and Mercer, S. W. (2014) Physical and mental health comorbidity is common in people with multiple sclerosis: nationally representative cross-sectional population database analysis. *BMC Neurology*, 14(128), (doi:10.1186/1471-2377-14-128)
- Smith, D. J., Court, H., McLean, G., Martin, D., Langan Martin, J., Guthrie, B., Gunn, J., and Mercer, S. W. (2014) Depression and multimorbidity: cross-sectional study of 1,751,841 patients in primary care. *Journal of Clinical Psychiatry*, 75(11), pp. 1202-1208. (doi:10.4088/JCP.14m09147) (PMID:25470083)
- Calderon-Larranaga A, Poblador-Plou B, Gonzalez-Rubio F, Gimeno-Feliu LA, Abad-Diez JM, Prados-Torres A: Multimorbidity, polypharmacy, referrals, and adverse drug events: are we doing things well? *Br J Gen Pract* 2012, 62: e821-e826.
- Browne, S., Macdonald, S., May, C., Macleod, U., and Mair, F. Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLoS ONE* 2014;9(3):e93288.
- Chambers JA, O'Carroll RE, Hamilton B, Whittaker J, Johnstone M, Sudlow C et al.: Adherence to medication in stroke survivors: A qualitative comparison of low and high adherers. *Br J Health Psychol* 2010, 16: 592-609.
- Making it Easy. A Health Literacy Action Plan for Scotland. NHS Scotland 2014. Scottish Government. <http://www.gov.scot/resource/0045/00451263.pdf>
- Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N: Patients' unvoiced agendas in general practice consultations: qualitative study. *BMJ* 2000, 320: 1246.
- Lakin, JR, Block SD, Billings J et al. Improving Communication About Serious Illness in Primary Care. *JAMA Internal Medicine* 2016 Published online July 11, 2016. doi:10.1001/jamainternmed.2016.3212
- Benz M: The first year of rehabilitation after a stroke - from two perspectives. *Scand J Caring Sci* 2003, 17: 215-222.
- Kaldjian LC, Curtis AE, Shinkunas LA, Cannon KT. Goals of Care Toward the End of Life: A Structured Literature Review. *Am J Hosp Palliat Care* December/January 2009 vol. 25 no. 6 501-511.
- Shippee ND, Allen SV, Leppin AL, May CR, Montori VM. Attaining minimally disruptive medicine: context, challenges and a roadmap for implementation. *J R Coll Physicians Edinb* 2015;45:18-22.
- Macharia WM LG: An overview of interventions to improve compliance with appointment keeping for medical services. *JAMA* 1992, 267: 1813-1817.
- Eton DE, Yost KJ, Lai JS et al. Development and validation of the Patient Experience with Treatment and Self-management (PETS): a patient reported measure of treatment burden. *Qual Life Res* 2016.

