

Change in treatment burden among people with multimorbidity: a follow-up survey

Abstract

Background

Treatment burden is the workload of being a patient and its impact on wellbeing. Little is known about change in treatment burden over time for people with multimorbidity.

Aim

To quantify change in treatment burden, determine factors associated with this change, and evaluate a revised single-item measure for high treatment burden in older adults with multimorbidity.

Design and setting

A 2.5-year follow-up of a cross-sectional postal survey via six general practices in Dorset, England.

Method

GP practices identified participants of the baseline survey. Data on treatment burden (measured using the Multimorbidity Treatment Burden Questionnaire; MTBQ), sociodemographics, clinical variables, health literacy and financial resource were collected. Change in treatment burden was described, and associations assessed using regression models. Diagnostic test performance metrics evaluated the single-item measure relative to the MTBQ.

Results

301 participants were recruited (77.6% response rate). Overall, there was a 2.6% increase in treatment burden. 98 (32.6%) and 53 (17.6%) participants experienced an increase and decrease, respectively, in treatment burden category. An increase in treatment burden was associated with having more than five long-term conditions (β :8.26 (95% CI: 4.20 to 12.32) and living >10 minutes (vs. \leq 10 minutes) from the GP ($a\beta$:3.88 (95% CI: 1.32 to 6.43)), particularly for participants with limited health literacy (mean difference: $a\beta$:9.59 (95% CI: 2.17 to 17.00)). The single-item measure performed moderately- sensitivity: 56.5%; specificity: 92.5%.

Conclusion

Treatment burden changes over time. Improving access to primary care, particularly for those living further away from services, and enhancing health literacy, may mitigate increases in burden.

Keywords: Multimorbidity; epidemiology; General practice; Patient-centered care; Patient reported outcome measures; Self-management.

How this fits in

- The extent to which treatment burden changes over time and which groups of people are likely to experience increases or decreases in treatment burden is not known.
- This study identified that a third of older adults with multimorbidity experienced an increase in treatment burden category (overall 9% moving to the 'high' treatment burden category), and that living more than 10 minutes away from their GP – particularly for those with limited health literacy - was associated with an increase in treatment burden.
- Improving patient access to primary care services and enhancing health literacy may help to mitigate increases in treatment burden.
- Our revised single-item measure performed moderately, suggesting a brief measure of treatment burden consisting of more than one item may be required for use in practice.

Introduction

Treatment burden is the effort required of patients to look after their health and the impact this has on their functioning and wellbeing. [1-4] Taking and managing multiple medications, organising healthcare appointments, monitoring health, performing self-care, and modifying lifestyle contribute to this workload. [3] This workload may be substantially increased for people with multiple long-term conditions (LTCs), potentially outweighing their capacity to manage their health. [5] High treatment burden may be associated with poor adherence to treatment, poorer clinical outcomes, and healthcare inefficiency. [6-9] Given the increasing prevalence of multimorbidity, it is important for health services to be organised in ways that reduce treatment burden and improve quality of life for patients and carers. [10,11]

Recently, changes to health-care delivery have been implemented to improve services for patients. [12-14] Following a major review of the National Health Service (NHS), Integrated Care Systems (ICS) are endeavouring to align primary and specialist care, physical and mental health services, and health with social care. [15] Treatment burden may therefore have decreased over time as a result of improved access to healthcare for some patients, but no population-level quantitative studies have assessed changes in treatment burden, making it impossible to assess the impact of health system change on this patient-centred metric. Furthermore, it is not clear which patient groups are more likely to experience an increase or decrease in treatment burden. Although previous studies have identified patient characteristics associated with high treatment burden [16-17], it is not clear whether these factors also influence change in treatment burden. This understanding could help predict patient trajectories and the planning of future interventions and healthcare delivery, to better meet patient needs and reduce avoidable treatment burden.

At the individual (patient-clinician) level, reductions in treatment burden may be achieved by discussing with patients how best to optimise care. [10,18,19] However, there is currently no swift and accurate method to assess treatment burden during clinical encounters. We previously explored the performance of a novel single-item measure of patient-perceived treatment burden and found that it performed moderately, suggesting further development was needed before such a measure can be adopted in practice. [17]

This study therefore aimed to quantify change in treatment burden over time and determine factors associated with this change in older adults with multimorbidity. We also revised the single-item treatment burden measure and evaluated its performance.

Method

Survey design and sample

This was a 2.5-year follow-up study of a cross-sectional survey on treatment burden in 835 older adults (55 years and older) with multimorbidity in Dorset, England. [17] The follow-up survey was planned prior to the COVID-19 pandemic and implementation of ICS in Dorset. The follow-up postal survey, conducted between August-December 2021, was sent to people who had participated in the baseline survey and consented (at baseline) to receiving a follow-up survey. Inclusion criteria for the baseline survey are presented in Box 1.

Follow-up recruitment, invitation and response

All eight GP practices participating in the baseline study were asked to identify patients who responded to the baseline survey and consented to receiving the follow-up survey. Six of the eight practices were able to participate. Practices manually screened these participants for the same exclusion criteria as at baseline, excluding those who now met these criteria. Practices then posted survey packs to eligible patients. Recruitment and invitation processes were similar to the baseline survey, which were described in full elsewhere. [17,20]

Data collection

Treatment burden outcome measure

Treatment burden was measured using the 10-item Multimorbidity Treatment Burden Questionnaire (MTBQ). [21] The MTBQ was validated in a similar population and is a concise, easy to use measure that asks questions about difficulty with medication, healthcare appointments, and lifestyle changes. [21] Possible responses to each item on the MTBQ are: 0 (not difficult/does not apply), 1 (a little difficult), 2 (quite difficult), 3 (very difficult) and 4 (extremely difficult). For patients completing five or more items, a global score is then calculated by multiplying the average item score by 25 to yield a score ranging from 0-100. Treatment burden was also categorised to none (global score of 0), low (>0 and <10), medium (≥ 10 and <22), or high (≥ 22). A revised single-item tool which asked: "Have you felt overstretched by everything you've had to do to manage your health in the last month (e.g., taking medicines, getting prescriptions, attending appointments)?" to which participants could respond 'yes' or 'no' was also included. This measure emerged from focus group discussions with patient and public contributors with lived experiences of multimorbidity (Box 2). [17]

Independent variables

Data on number of prescribed regular medications and dosing frequency, specific LTCs (based on survey inclusion criteria), mode and travel time to healthcare, recent (within the previous six months) emergency attendances and admissions, outpatient appointments, and GP appointments were collected. Perceived level of difficulty in meeting financial costs of healthcare was assessed on a 5-point Likert scale ranging from 'not difficult/not applicable' to 'extremely difficult'. Perceived frequency of needing help to read health-related written material was assessed using the Single Item Literacy Screener (SILS), measured on a 5-point Likert scale and categorised into 'not limited' ('never' or 'rarely') or 'limited' ('sometimes', 'often', 'always').[22]

Sociodemographic data included age (as a continuous variable), sex (male/female), marital status (married or in a civil partnership, single [never married or in a civil partnership], divorced or dissolved civil partnership, widowed). Home ownership (homeowner/non-homeowner) and education level (in three categories) were also included as indicators of socioeconomic status. Survey data underwent manual database input by the first author with careful rechecking to minimise risk of input errors.

Statistical analysis

The maximum available sample was, to some extent, determined by sample size of the baseline survey.[17] A sample size calculation using nQuery version 7.0 indicated that 154 patients were needed to detect the minimum possible change in treatment burden as measured by the MTBQ (1 point in the MTBQ raw score).[20]

Descriptive statistics compared the number, proportions, and characteristics of participants reporting 'none', 'low', 'medium' and 'high' levels of treatment burden (at follow-up) and change in global score and treatment burden categories over time. Characteristics of participants who experienced an increase in treatment burden category and those who did not were compared using t-tests (for normally distributed variables) and chi-square tests (for categorical variables). Similar comparisons were made for those who experienced a decrease in treatment burden category. Univariable and multivariable mixed regression models (including GP practice (as a random effect)) assessed associations with change in treatment burden and baseline characteristics of participants. We first fitted a linear mixed model regressing change in treatment burden (as a continuous outcome) on baseline patient characteristics and adjusted for clustering at GP practice (as a random effect). This model was repeated additionally adjusting for potential confounders (age, sex, marital status), treatment burden category at baseline, and any variables that were found to be significant in univariable models. A limited number of potential two-way interactions were also considered

between travel time for healthcare and home ownership, financial difficulty and health literacy - as effects may vary across these groups. These potential interactions were considered one at a time, as additions to the otherwise final, fully adjusted, model.

Generalised logistic mixed regression models were then fitted to assess associations with the binary outcomes of an increase (vs. no change or a decrease) or decrease (vs. no change or an increase) in treatment burden. These models included GP practice as a random effect and additional adjusting variables in a similar style to the linear mixed models.

Sensitivity, specificity, positive predictive value, negative predictive value, and positive and negative likelihood ratios were calculated to evaluate the single-item tool relative to the MTBQ. A receiver operating characteristic curve was also plotted and the area under the curve (AUC) estimated to evaluate the ability of the single-item measure to discriminate between high and non-high treatment burden.

Analyses were conducted in STATA v15.

Results

Study population

A total of 525 potentially eligible patients were identified, and practices posted out 388 survey packs, after excluding 137 patients who met exclusion criteria (Figure 1). Survey response rate was 77.6%, with 301 participants returning completed surveys and consent forms (Figure 1).

The mean (SD) age was 74.4 (8.0) years (Table 1). Most were of white ethnicity (n=299, 99.7%), female (n=172, 57.1%), retired (n=265, 88.0%), married (n=190, 63.1%) and owned their home (n=251, 84.0%). Many participants (n=130, 43.2%) reported medium (n=84, 27.9%) or high (n=46, 15.3%) treatment burden at baseline.

Characteristics of study participants were similar to those of the invited sample (Table 1 and Supplementary Table 1).

Change in treatment burden

Overall, there was a mean (SD) increase of 2.6 (11.2) points in treatment burden global score at 2.5-year follow-up. One hundred and fifty one people (50.3%) experienced a change in treatment burden category, with 32.6% (n=98) and 17.6% (n=53) experiencing an increase and decrease, respectively. Twenty-seven (9.0%) participants moved from a lower category to 'high' treatment burden. Figure 2 presents a matrix of the dynamics of treatment burden in our study sample. A higher proportion of those experiencing an increase in treatment burden category were older (aged

75+) and reported being ex-smokers, homeowners, with more than three LTCs and prescribed more than three medications (although differences were not statistically significant). A lower proportion of those experiencing a decrease in treatment burden category were female and lived alone. A higher proportion experiencing a decrease in treatment burden category were employed and lived less than or up to 10 minutes from their GP (although differences were not statistically significant). Supplementary Table 2 and Supplementary Figure 1 present characteristics of participants that experienced change in treatment burden category.

Associations with change in treatment burden

Univariable regression models indicated that high treatment burden category (compared to no burden) at baseline was associated with a decrease in treatment burden global score (as a continuous outcome measure), β : -4.85 (95% CI: -8.80 to -0.91, where β is the effect of one unit change in a predictor on a one unit increase in global score change)- those with high treatment burden at baseline being less likely to experience an increase in treatment burden (Table 2). Having > five LTCs (β : 5.89 (95% CI: 1.98 to 9.80) and living >10 minutes from the GP (β : 3.89 (95% CI: 1.27 to 6.52) were associated with an increase in treatment burden. Associations with change in treatment burden remained significant after adjusting for age, sex, marital status, time to GP, number of LTCs and baseline treatment burden category: β : -7.00 (95% CI: -11.04 to -2.96), β : 8.26 (95% CI: 4.20 to 12.32) and β : 3.88 (95% CI: 1.32 to 6.43) for high treatment burden category, number of LTCs and time to GP, respectively. The remaining variables were not significantly associated with change in treatment burden. The only significant univariable association with change in treatment burden category was that those in baseline medium treatment burden MTBQ category were less likely to increase category (vs. those in the no burden category, odds ratio 0.37, 95% CI: 0.19 to 0.71, $p=0.003$) (Supplementary Table 3).

Additional linear mixed regression models indicated higher travel time to GP was more strongly associated with an increase in treatment burden value for participants with limited health literacy compared to those with higher literacy; mean difference: β :10.41 (95% CI: 2.85-17.96) and β : 9.59 (95% CI: 2.17 to 17.00), in unadjusted and adjusted models, respectively.

Single-item measure

A response of 'yes' to the single-item measure had a sensitivity of 56.5%, specificity of 92.5%, positive predictive value of 66.0% and negative predictive value of 89.2%. Positive likelihood ratio

was 7.59 (95% CI: 4.59 to 12.52) and negative likelihood ratio was 0.47 (95% CI: 0.34 to 0.65). The AUC was 0.74 (95% CI: 0.68-0.81).

The Checklist for Reporting Of Survey Studies (CROSS) was completed.[23]

Discussion

Summary

This longitudinal study identified that half our sample of older people with multimorbidity experienced a change in treatment burden category in 2.5 years with 33% and 18% increasing and decreasing respectively. Having more than five LTCs and greater travel time to GP were statistically significantly associated with an increase in treatment burden value (but not category). With regard to travel time to GP, this was particularly the case for participants with limited health literacy. Our single-item treatment burden measure performed moderately, suggesting further development of this measure is still needed.

Strengths and limitations

To the authors' knowledge, this is the first quantitative population-level study to describe change in treatment burden over time in the UK. Key strengths were the use of a validated measure of treatment burden, minimal non-response bias, and the inclusion of geographically dispersed and socioeconomically diverse GP practices, allowing a range of participants to be included.[17]

Furthermore, patient-level follow-up will have reduced unobserved confounding.

However, there were important limitations. Firstly, the follow-up survey was conducted in the wake of the COVID-19 pandemic. This may have resulted in an underestimate in treatment burden change as people may not have been attending as many appointments, either in-person or virtually, or there may have been changes in practice (such as more telephone consultations) that influenced treatment burden. During the pandemic GP consultations in England changed dramatically, with face-to-face appointments decreasing initially (February to April 2020) then increasing substantially by August 2021 with telephone consultations almost trebling.[24] For some, the lack of social support or reduced contact with a health professional may have increased treatment burden. [25-30] Surveys were mailed out at a point of minimal COVID restrictions to try and minimise these effects. Secondly, although exceeding the minimum target sample size, the study may have been underpowered to assess some associations with treatment burden category change and the clinical significance of a single point change in MTBQ global score has not been well established. Thirdly, associations with treatment burden are based on self-reported survey data which may be subject to recall bias and some participants may have interpreted questions differently. Fourthly, we are not

able to make any causal inferences of the associations presented here. Finally, the Dorset population has relatively low levels of deprivation and low ethnic diversity, so findings may not be widely generalisable. Participants who were ineligible to receive the survey (i.e., those excluded by practices) may have had higher treatment burden than those included, resulting in underestimation of high treatment burden.

Comparison with existing literature

The overall increase in treatment burden may be a result of changes in individual factors such as an increased number of LTCs and medications at follow-up. [25] Pandemic factors such as lack of continuity of care, inadequate information and difficulty accessing healthcare may also have contributed to this overall increase. [25-30] Our finding of a positive association between travel time to GP and an increase in treatment burden is consistent with findings from qualitative studies on the time burden associated with travel to healthcare. [31,32] This association was moderated by health literacy, in line with studies suggesting health literacy may be protective against experiencing high treatment burden. [3, 33] Unlike previous cross-sectional treatment burden studies, we found no association between sociodemographic factors and *change* in treatment burden. [17,34]

A recent prospective study in the US evaluated treatment burden trajectories among 396 people (aged 20+) with multimorbidity.[35] The study measured treatment burden at four time points over two years and identified differing patterns of change between treatment burden ‘workload’ and ‘impact’. Workload trajectory was broadly represented in two groups – persistently high and persistently low, while impact had three patterns – consistently high, increasing, and consistently low. Consistently high workload was associated with lower health literacy, lower self-efficacy and higher interpersonal challenges with others, while consistently high impact was associated with more mentally unhealthy days, lower health literacy and higher interpersonal challenges with others. Increasing impact was associated with more physically unhealthy days and higher interpersonal challenges with others.[35] Our study was only able to assess two time points, had an older population and considered a different range of LTCs, and, in contrast to their findings, identified higher number of LTCs as independently associated with increasing treatment burden, and assessed aspects of access to healthcare, of which distance from a GP was independently associated. Some important differences in these studies are summarised in Supplementary Table 4.

Our revised single-item measure needs further development, and a single question may not adequately capture the different components of treatment burden. It may be more prone to sociopsychological biases and random error, making it less stable and precise. [36]

Implications for research and practice

This study emphasised further need to consider the factors influencing burden and mitigate them where possible. Factors such as improving access to primary care, particularly for those living further away from services, may reduce treatment burden. This may include further consideration on modes of health service delivery to specifically meet needs of those patients more likely to feel overburdened. [37] Better education or more simplified information may be needed to allow patients to make more adequate choices regarding their healthcare. Our finding that greater travel time to GP services is associated with an increase in treatment burden may be somewhat unexpected given more appointments were delivered virtually during the pandemic. [24,38] Although there would have been some face-to-face appointments, this finding may also indicate that virtual consultations increase burden for some patients. [29, 39] Larger population-level studies are needed to confirm these findings. The impact of health system changes were likely affected by the pandemic and it may not be possible to unpick these issues. Further qualitative research is needed to better understand patients' views of treatment burden post-pandemic and the practical health service barriers and facilitators to managing multimorbidity. Development of a brief measure of treatment burden consisting of more than one item may be needed for use in clinical practice.

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Data availability: Data may be available upon request from the authors.

Competing interests: None declared.

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References

1. Mair FS, May CR. Thinking about the burden of treatment. *BMJ*. 2014;349 doi: 10.1136/bmj.g6680
2. Sav A, King MA, Whitty JA, et al. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expect*. 2015;18(3):312–24. doi: 10.1111/hex.12046
3. Shippee ND, Shah ND, May CR, et al. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *J Clin Epidemiol*. 2012;65(10):1041–51. doi: 10.1016/j.jclinepi.2012.05.005
4. Eton DT, Ramalho de Oliveira D, Egginton JS, 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. doi: 10.2147/PROM.S34681
5. May CR, Eton DT, Boehmer K, et al. Rethinking the patient: using burden of treatment theory to understand the changing dynamics of illness. *BMC Health Serv Res*. 2014;14:281. doi: 10.1186/1472-6963-14-281
6. Pifferi M, Bush A, Di Cicco M, et al. Health-related quality of life and unmet needs in patients with primary ciliary dyskinesia. *Eur Respir J*. 2010;35(4):787–94. doi: 10.1183/09031936.00051509
7. Vijan S, Hayward RA, Ronis DL, et al. Brief report: the burden of diabetes therapy: implications for the design of effective patient-centered treatment regimens. *J Gen Intern Med*. 2005;20(5):479–82. doi: 10.1111/j.1525-1497.2005.0117
8. Ho PM, Rumsfeld JS, Masoudi FA, et al. Effect of medication nonadherence on hospitalization and mortality among patients with diabetes mellitus. *Arch Intern Med*. 2006;166(17):1836–41. doi: 10.1001/archinte.166.17.1836
9. Rasmussen JN, Chong A, Alter DA. Relationship between adherence to evidence-based pharmacotherapy and long-term mortality after acute myocardial infarction. *JAMA*. 2007;297(2):177–86. doi: 10.1001/jama.297.2.177
10. May C, Montori VM, Mair FS. We need minimally disruptive medicine. *BMJ*. 2009. Aug 11;339:b2803. doi: 10.1136/bmj.b2803
11. Abu Dabrh AM, Gallacher K, Boehmer KR, et al. Minimally disruptive medicine: the evidence and conceptual progress supporting a new era of healthcare. *J R Coll Physicians Edinb*. 2015;45(2):114–7. doi: 10.4997/JRCPE.2015.205
12. Collins B. What is Covid-19 revealing about innovation in the NHS? London: King's Fund, 2020. Available: <https://www.kingsfund.org.uk/blog/2020/08/covid-19-innovation-nhs>. [Accessed 24 Jan 2022].
13. Drinkwater C, Wildman J, Moffatt S. Social prescribing. *BMJ* 2019; 364: l1285.
14. NHS England General practice forward view, 2016. Available: <https://www.england.nhs.uk/wp-content/uploads/2016/04/gpfv.pdf>. [Accessed 24 Jan 2022]
15. National Health Service England (NHS). The NHS long term plan - 2019. Available: <https://www.longtermplan.nhs.uk/>. [Accessed 24 January 22].
16. Herzig L, Zeller A, Pasquier J, et al. Factors associated with patients' and GPs' assessment of the burden of treatment in multimorbid patients: a cross-sectional study in primary care. *BMC Fam Pract* 2019; 20(1): 88.
17. Morris JE, Roderick PJ, Harris S, et al. Treatment burden for patients with multimorbidity: cross-sectional study with exploration of a single-item measure. *Br J Gen Pract*. 2021;71(706):e381–e390. doi: 10.3399/BJGP.2020.0883

18. Eton D, Ridgeway J, Linzer M, et al. Healthcare provider relational quality is associated with better self-management and less treatment burden in people with multiple chronic conditions. *Patient Prefer Adherence* 2017;11:1635–46. doi: 10.2147/PPA.S145942
19. Tran VT, Montori VM, Eton DT, et al. Development and description of measurement properties of an instrument to assess treatment burden among patients with multiple chronic conditions. *BMC Med.* 2012;10:68. doi: 10.1186/1741-7015-10-68
20. Hounkpatin HO, Roderick P, Morris JE, et al. Change in treatment burden among people with multimorbidity: Protocol of a follow up survey and development of efficient measurement tools for primary care. *PLoS One.* 2021;16(11):e0260228.
21. Duncan P, Murphy M, Man MS, et al. Development and validation of the Multimorbidity Treatment Burden Questionnaire (MTBQ). *BMJ Open.* 2018;8(4):e019413. doi: 10.1136/bmjopen-2017-019413
22. Morris NS, MacLean CD, Chew LD, et al. The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Fam Pract.* 2006; 7:21. <https://doi.org/10.1186/1471-2296-7-21>
23. Sharma A, Minh Duc NT, Luu Lam Thang T, et al. A Consensus-Based Checklist for Reporting of Survey Studies (CROSS). *J Gen Intern Med.* 2021;36(10):3179–3187. doi: 10.1007/s11606-021-06737-1.
24. Green MA, McKee M, Katikireddi SV. Remote general practitioner consultations during COVID-19. *Lancet Digit Health.* 2022;4(1):e7. doi: 10.1016/S2589-7500(21)00279-X.
25. Sheehan OC, Leff B, Ritchie CS, et al. A systematic literature review of the assessment of treatment burden experienced by patients and their caregivers. *BMC Geriatr.* 2019; 19:262. <https://doi.org/10.1186/s12877-019-1222-z>
26. Lippiett KA, Richardson A, Myall M, et al. Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research. *BMJ Open.* 2019;9(20):e020515.
27. Gallacher K, May CR, Montori VM, et al. Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *Ann Fam Med.* 2011;9(3):235–43.
28. Rosbach M, Andersen JS. Patient-experienced burden of treatment in patients with multimorbidity – a systematic review of qualitative data. *PLoS One.* 2017;12(6):e0179916.
29. Mair FS, Montori VM, May CR. Digital transformation could increase the burden of treatment on patients. *BMJ.* 2021;375:n2909. doi: 10.1136/bmj.n2909. PMID: 34824093.
30. Anderson J, Walsh J, Anderson M, Burnley R. Patient Satisfaction With Remote Consultations in a Primary Care Setting. *Cureus.* 2021;13(9):e17814. doi:10.7759/cureus.17814
31. Hounkpatin HO, Leydon GM, Veighey K, et al. Patients' and kidney care team's perspectives of treatment burden and capacity in older people with chronic kidney disease: a qualitative study. *BMJ Open.* 2020;10(12):e042548. doi:10.1136/bmjopen-2020-042548
32. Gallacher KI, May CR, Langhorne P, et al. A conceptual model of treatment burden and patient capacity in stroke. *BMC Fam Pract.* 2018; 19: 9. <https://doi.org/10.1186/s12875-017-0691-4>
33. Friis K, Lasgaard M, Pedersen MH, et al. Health literacy, multimorbidity, and patient-perceived treatment burden in individuals with cardiovascular disease. A Danish population-based study. *Patient Educ Couns.* 2019; 102(10): 1932–1938.

34. Pedersen MH, Larsen FB, Lasgaard M, et al. Patient-perceived treatment burden. The first study in a general population – Denmark 2017. *Eur J Public Health*. 2018; 284. <https://doi.org/10.1093/eurpub/cky214.070>
35. Eton DT, Anderson RT, St. Sauver JL, et al. Longitudinal trajectories of treatment burden: A prospective survey study of adults living with multiple chronic conditions in the midwestern United States. *Journal of Multimorbidity and Comorbidity* 2022;12:1-14. doi:10.1177/26335565221081291
36. Bowling A. Just one question: If one question works, why ask several? *J Epidemiol Community Health*. 2005;59(5):342-345. doi:10.1136/jech.2004.021204
37. Murphy J, Elliot M, Ravindrarajah R, et al. Investigating the impact of distance on the use of primary care extended hours. *Int J Popul Data Sci*. 2021;6(1):1401. doi: 10.23889/ijpds.v6i1.1401.
38. Gray DP, Sidaway-Lee K, Harding A, et al. Reduction in face-to-face GP consultations. *Br J Gen Pract*. 2020;70(696):328. doi: 10.3399/bjgp20X710849.
39. Shaw S, Wherton J, Vijayaraghavan S, et al. Advantages and limitations of virtual online consultations in a NHS acute trust: the VOCAL mixed-methods study. NIHR Journals Library, Southampton (UK). 2018. PMID: 29939519.

Box 1. Inclusion and exclusion criteria for baseline survey

Inclusion criteria: Patients aged 55 years or over and living at home with three or more of specified LTCs (defined using the Quality and Outcomes Framework (QoF) clinical code clusters and Read codes). : atrial fibrillation, coronary heart disease, heart failure, hypertension, peripheral arterial disease, stroke or transient ischaemic attack, diabetes, asthma, chronic obstructive pulmonary disease, depression, chronic kidney disease, epilepsy, osteoporosis, rheumatoid arthritis, Parkinson's disease, multiple sclerosis, inflammatory bowel disease, coeliac disease, osteoarthritis. Reasons for choosing these conditions are discussed elsewhere. [17] Only one patient per household was eligible to participate. Patients who were living in a care home, receiving palliative care, had a serious mental health diagnosis (psychosis, schizophrenia, bipolar disorder) or dementia, active cancer (recorded in the last three years), expressed a wish not to participate in research, lacked mental capacity to participate in the study, or deemed (by healthcare professionals at the GP practice with sufficient knowledge of the patient) unsuitable to receive the survey were excluded from the study. [17,20]

Box 2. Development of revised single-item treatment burden measure

We explored ways in which our initial treatment burden question based on a number-line ('Please consider the overall effort of looking after your health. On a scale of 0-10, where 0 is no effort and 10 is the highest effort you can imagine, how would you rate the amount of effort you have to put in to manage your health conditions?') could be improved using a 90 minute workshop involving two patient and public contributor members of our Patient and Public Involvement (PPI) team and seven other PPI representatives from the National Institute for Health Research Applied Research Collaboration for Wessex (n=9 in total). We had open discussions about how best a single-item question could be worded to reflect the patient perspective of treatment burden, with guiding questions. This was followed by virtual iteration of the question. The group were then sent three potential questions and asked to rank them by preference. We summed the rankings and selected the question with highest

Figure titles

Figure 1. Survey flowchart: recruitment, invitation, and response.

Figure 2. Variation in treatment burden category status between baseline and follow up

Table 1. Baseline characteristics of follow-up survey responders (n=301)

Characteristic	Number	% of N
Age in years, mean (SD)	74.4 (8.0)	
Age category in years (n=299)		
55 to 59	15	5.0
60 to 64	17	5.7
65 to 69	45	15.1
70 to 74	77	25.8
75 to 79	66	22.1
80 to 84	44	14.7
85 to 89	28	9.4
90 to 94	7	2.3
Sex (n=301)		
Male	129	42.9
Female	172	57.1
Education level (n=291)		
NVQ4/NVQ5/Degree	80	27.5
NVQ3/GCE A Level/4NVQ2/GCE O Level/5NVQ1/CSE other grade	92	31.6
No qualification	118	40.6
Other	1	0.3
Ethnicity (n=300)		
White	299	99.7
Other than White	1	0.3
Marital status (n=301)		
Married or in a partnership	190	63.1
Widowed	69	22.9
Divorced or dissolved partnership	31	10.3
Single	11	3.7
Living situation (n=300)		
Cohabiting	205	68.3
Lives alone	95	31.7
Home ownership (n=299)		
Homeowner	251	84.0
Non-homeowner	48	16.1
Employment status (n=301)		
Retired	265	88.0
Employed	24	7.8
Unemployed	6	2.0
Other	6	2.0
Smoking status (n=301)		
Current smoker	13	4.3
Ex-smoker	154	51.2
Never smoked	134	44.5
Number of long-term conditions (n=301)		
0	6	2.0

Treatment burden in multimorbidity

1	27	9.0
2	89	29.6
3	94	31.2
4	51	16.9
5	19	6.3
≥6	15	5.0
Medications prescribed (n=299)		
0 to 3	46	15.4
4 to 6	108	36.1
7 to 9	90	30.1
10 to 14	41	13.7
≥15	14	4.7
Treatment burden category (n=301)		
High	46	15.3
Medium	84	27.9
Low	87	28.9
None	84	27.9
Health literacy (n=300)		
Never	211	70.0
Rarely	53	17.7
Sometimes	23	7.7
Often	8	2.7
Always	5	1.7
Financial difficulty with healthcare (n=298)		
Not difficult or n/a	237	79.5
A little	44	14.8
Quite	10	3.4
Very	7	2.4
Extreme	0	0
Travel time to hospital (n=277)*		
≤1 hour	261	94.2
>1 hour	16	5.8
Travel time to GP (n=297)*		
≤10 minutes	187	63.0
>10 minutes	110	37.0
Number of outpatient appointments in last 6 months (n=273)		
0-2	226	82.8
≥3	47	17.2

* The majority (191, 64%) reported travelling to their GP by car, with 72 (24%), 13 (4%) and 11 (4%) reporting walking, taxi and bus respectively. For travel to hospital these were 207, 71% (car), 12, 4% (walking), 25, 9% (taxi) and 29, 10% (bus).

Table 2. Associations with change in treatment burden global score

	Univariable				Multivariable**			
Characteristic	β^*	95% CI		p-value	β	95% CI		p-value
Age category in years (vs. 55-64)								
65 to 74	0.197	-4.13	4.52	0.93	-1.08	-5.35	3.19	0.620
75 to 84	2.461	-1.92	6.84	0.27	1.70	-2.65	6.05	0.445
≥ 85	4.27	-1.11	9.66	0.12	3.17	-2.33	8.68	0.258
Female (vs. male)	-0.61	-3.14	1.91	0.64	-0.29	-2.87	2.29	0.825
Marital status (vs. married)								
Single	-2.32	-9.00	4.36	0.44	-2.30	-8.75	4.14	0.484
Divorced or dissolved partnership	1.67	-2.53	5.86	0.50	2.07	-2.07	6.22	0.327
Widowed	0.12	-2.97	3.21	0.94	-1.87	-5.22	1.48	0.273
Lives alone (vs. with others)	-0.93	-3.66	1.80	0.50				
Non-homeowner (vs. homeowner)	-2.16	-5.57	1.26	0.22				
Employment status (vs. employed)								
Unemployed	-2.29	-12.15	7.56	0.65				
Retired	2.06	-2.58	6.69	0.39				
Other	-0.48	-10.35	9.40	0.92				
Smoking status (vs. never smoked)								
Ex-smoker	0.94	-1.61	3.49	0.47				
Current smoker	-4.35	-10.64	1.94	0.18				
>5 long-term conditions (vs. ≤ 5)	5.89	1.98	9.80	0.003	8.26	4.20	12.32	<0.001
≥ 7 medications prescribed (vs. <7)	2.48	-0.03	4.98	0.05				
Limited health literacy (vs. not limited)	0.46	-3.40	4.31	0.82				
Some financial difficulty (vs. none)	-0.22	-5.68	5.23	0.94				
≥ 1 hour to hospital (vs. >1 hour)	1.22	-4.61	7.04	0.68				

Treatment burden in multimorbidity

>10 minutes travel time to GP (vs.≤10)	3.89	1.27	6.52	0.004	3.88	1.32	6.43	0.003
≥3 outpatient appointments last 6 months (vs. <3)	-2.55	-5.90	0.79	0.13				
≥3 GP appointments in last 6 months (vs. <3)	-1.44	-3.99	1.10	0.27				
Baseline MTBQ category (vs. no burden)								
Low	-0.82	-4.11	2.46	0.62	-0.67	-3.91	2.56	0.68
Medium	-0.43	-3.75	2.88	0.80	-1.34	-4.62	1.92	0.42
High	-4.85	-8.80	-0.91	0.016	-7.00	-11.04	-2.96	0.001

*β is the effect of one unit change in predictor on a one unit increase in global score change

** Adjusting for age, sex, marital status, travel time to GP, number of LTCs and baseline treatment burden category

