

Does patient experience of multimorbidity predict self-management and health outcomes in a prospective study in primary care?

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Abstract

Background. There is a need to better understand the mechanisms which lead to poor outcomes in patients with multimorbidity, especially those factors that might be amenable to intervention.

Objective. This research aims to explore what factors predict self-management behaviour and health outcomes in patients with multimorbidity in primary care in the UK.

Methods. A prospective study design was used. Questionnaires were mailed out to 1460 patients with multimorbidity. Patients were asked to complete a range of self-report measures including measures of multimorbidity, measures of their experience of multimorbidity and service delivery and outcomes (three measures of self-management: behaviours, Self-monitoring and Insight and medication adherence; and a measure of self-reported health).

Results. In total, 36% ($n = 499$) of patients responded to the baseline survey and 80% of those respondents completed follow-up. Self-management behaviour at 4 months was predicted by illness perceptions around the consequences of individual conditions. Self-monitoring and Insight at 4 months was predicted by patient experience of 'Hassles' in health services. Self-reported medication adherence at 4 months was predicted by health status, Self-monitoring and Insight and 'Hassles' in health services. Perceived health status at 4 months was predicted by age and patient experience of multimorbidity.

Conclusions. This research shows that different factors, particularly around patients' experiences of health care and control over their treatment, impact on various types of self-management. Patient experience of multimorbidity was not a critical predictor of self-management but did predict health status in the short term. The findings can help to develop and target interventions that might improve outcomes in patients with multimorbidity.

Key words. Co-existent conditions, health services, primary health care, prospective studies, self-care, self-report.

Introduction

Multimorbidity is a common label for the co-existence of two or more long-term health conditions within the same individual (1).

Multimorbidity is common and represents a major part of the workload of primary care (2). Patients with multiple conditions are particularly prone to poor outcomes, such as reduced quality of life (3), but there is less consensus over the exact mechanisms

underlying those poor outcomes. Identifying mechanisms that can be modified by health service interventions may improve outcomes for patients.

One possible mechanism is barriers to self-management. Self-management has been defined as 'the care taken by individuals towards their own health and well-being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional, psychological and physical needs; to care for their long-term condition; and to prevent further illness or accidents' (4). Although self-management is increasingly seen as critical to the delivery of effective care for long-term conditions, achieving effective self-management is a significant challenge for patients with multimorbidity. Patients have to manage complex treatment regimens and face decisions about priorities among self-management tasks for different conditions (5). Some of the variation in self-management behaviour among those with multimorbidity may represent variation in patient experience of living with multimorbidity. Current delivery of health services is often poorly matched to the needs of patients with multimorbidity (6).

Patient 'illness perceptions' may be critical to the patient experience of multimorbidity. Illness perceptions are beliefs about the cause, nature and management of illness, which enable patients to make sense of their conditions and respond appropriately (7). Most work on illness perceptions has explored single conditions (8), although there is developing interest in patient experience of multimorbidity (9). Developments in this field have been hindered by the lack of a valid and reliable measure of illness perceptions in multimorbidity which could be used alongside traditional illness perceptions scales such as the Illness Perceptions Questionnaire (IPQ) (10). We have described the development and initial validation of a novel measure of patient experience of multimorbidity (MULTIPLEs) (11), which captures the patient experience of multimorbidity along 5 dimensions (see Methods section).

This paper aims to explore what factors predict self-management behaviour and health outcomes in patients with multimorbidity in primary care, with a focus on patient experience of their health care, illness perceptions around single conditions and patient experience of multimorbidity. Identification of such factors may provide suitable targets for tailored interventions.

Methods

To explore predictors of outcomes in patients with multimorbidity, we conducted a prospective study. Patients with multimorbidity were identified from the disease registers of four large general practices in Greater Manchester. We selected patients who had any combinations of the following diagnoses: chronic obstructive pulmonary disease, coronary heart disease, diabetes, osteoarthritis and depression. These conditions were chosen as they relate to our existing research programmes, exhibit different symptoms, demand different self-management and clinical care and are dealt with differently by current incentive systems in UK general practice. Patients with terminal illness, or with severe and enduring mental health problems, were excluded.

Once identified, questionnaires were mailed out by the GP surgeries, with reminders 1 month later. Estimating a response rate of ~40%, we aimed to send out 1500 surveys to achieve a final sample size of 600 to provide a sufficient case to variable ratio for regression modelling. Four months later, follow-up questionnaires were sent to responders to the baseline questionnaire who provided contact details.

Independent variables

Multimorbidity

Patients self-reported their existing long-term conditions from a list based on a published scale, which captures both the presence of conditions and their impact (12). Due to expected underreporting of mental health diagnoses, we also used the Hospital Anxiety and Depression Scale (HADS) to measure symptoms of depression and anxiety (13). The HADS consists of 7 items addressing depression and 7 addressing anxiety on 4-point scales and can provide independent scores for anxiety and depression or a combined overall score of psychological morbidity.

Illness perceptions

The Brief Illness Perceptions Questionnaire (B-IPQ) (14) is a 9-item scale that measures illness perceptions around single conditions. The scale has demonstrated reliability and validity, including prediction of functioning and health care utilization (14). We asked patients to complete a Brief IPQ for each of our core long-term conditions (between 1 and 5). For the current analyses, we only used data on the condition that patient reported had the greatest personal impact, and we restricted analysis to items 1 (consequences), 3 (personal control) and 4 (treatment control), which are the optimal predictors of outcome (9).

The Multimorbidity Illness Perceptions Scale (MULTIPLEs) was used to measure patient experience of multimorbidity (see <http://bit.do/multiples>) (11). MULTIPLEs consists of 22 items scored on a range from 0 to 5, with items relating to 5 domains (perceived causal links between conditions, burden of treatment, emotional impacts, activity restriction and the need to prioritize different conditions). In an earlier validation study, we applied Rasch analysis and demonstrated that the constituent MULTIPLEs scales are reliable, unidimensional and fit the Rasch model (11). The scale showed reasonable test-retest reliability and a summary score across all domains (representing the overall impact of multimorbidity on patient experience) showed excellent fit to the Rasch model and was used in the current study.

Patient experience of service delivery

We used the Patient Assessment of Chronic Illness Care (PACIC) to measure patient experience of service delivery and organization of care for long-term conditions (15). PACIC includes 20 items based around 5 subscales: patient activation, delivery system design, goal setting/tailoring, problem-solving and follow-up/coordination. Each item is rated on a 5-point scale and subscale and total scores are based on average scores across items (15).

We also used the Health Care System Hassles scale (16), a 16-item scale rating the difficulties patients face in their encounters with the health care system. Patients are asked to rate the degree to which problems impact on their care such as 'Lack of information about why I have been referred to a specialist'. All items are scored on a 5-point scale. The measure has demonstrated good face validity and reliability and patients with multimorbidity report higher scores (16).

Dependent variables

Self-management

We measured three different indices of self-management. Attitudes and beliefs are important mediators of the benefits of self-management support (17) and we used the self-monitoring and insight scale from the Health Education Impact Questionnaire (heiQ). The scale consists of 7 items on a 6-point scale. The heiQ has demonstrated

preliminary evidence of construct validity (18). The Self-monitoring and Insight scale (defined as ‘the individuals’ ability to monitor their condition, and their physical and or emotional responses that leads to insight and appropriate action/s to self-management’) (18) mapped well on to the definition of self-management discussed earlier (4).

We measured self-reported self-management behaviour using single-item scales which asked respondents to report on the number of days per week that they engaged in healthy and unhealthy behaviours (eating fruit and vegetables, eating red meat, exercise, alcohol and smoking) (19). We categorized patients according to whether they performed these activities >4 days per week as this identifies a moderate level of adherence. We report the number of activities performed >4 days per week (0–5).

We also measured self-report medication adherence using the Modified Morisky Scale (20). The scale consists of 6 items, with dichotomous ‘yes’ or ‘no’ response. Three items measure forgetfulness and carelessness (indicative of motivation) and 3 items measure whether patients stop taking medications and if they understand the long-term benefits of therapy (indicative of knowledge).

Health outcomes

Given the range of conditions included in the study, we measured general health using the Medical Outcomes Study instrument (21), which assesses self-rated health on a 5-point scale (rated from 1 ‘poor’ to 5 ‘excellent’).

Demographic characteristics

We collected data on: age, gender, ethnicity, work situation and deprivation. Ethnicity was measured using the categories in the UK census but was categorized as ‘White’ and ‘ethnic minority’ for analysis. Deprivation was rated using the Indices for Multiple Deprivation (IMD) (22) taken from postcodes and arranged into quintiles.

Analysis

Multivariate linear regression (using SPSS v20) was used to explore baseline patient characteristics that predicted each outcome at 4 months.

We calculated correlations between all baseline independent variables and outcomes to identify candidate variables for the regressions. Variables that were significantly correlated ($P < 0.05$) with the outcome measures were entered into the multivariate regressions. We also forced demographic (gender, age, deprivation) and clinical (number of conditions, health status, HADS) variables into the multivariate model even if they were not significantly correlated with the outcomes.

Results

Descriptive data

Thirty six per cent ($n = 499$) of patients responded to the postal questionnaire, with 13 (2%) excluded because of missing data (>40%). Of the 486 included at baseline, follow-up questionnaires were sent to 480 patients who had provided their contact details. The return rate was 80% ($n = 432$) and 79% ($n = 410$) provided full data for analysis. From the 1460 questionnaires originally sent out, the sample included in the analysis was 28% ($n = 410$). All analyses represent the 410 patients who completed both baseline and follow-up questionnaires.

Participants’ age ranged from 31 from 91 years (mean: 70 ± 10). The majority were from an older age group (51–70 years, $n = 191$

and 71+ years, $n = 203$) with just 16 patients aged ≤ 50 years (see Table 1).

Multivariate analyses

Predictors of Self-monitoring and Insight

Baseline Self-monitoring and Insight predicted scores at follow-up (coefficient: 0.51, SE 0.05). The Health Care System Hassles scale was negatively correlated (coefficient: -0.14 , SE 0.06), indicating that fewer ‘Hassles’ resulted in better Self-monitoring and Insight (see Table 2).

Predictors of self-management behaviours

Self-management behaviour.

Baseline self-management behaviour predicted scores at 4 months (coefficient: 0.46, SE 0.05). Illness perceptions around consequences of the most important individual long-term condition were negatively correlated with self-management behaviours at 4 months (coefficient: -0.04 , SE 0.02) (see Table 3).

Medication adherence.

Baseline medication motivation score predicted motivation at follow-up (coefficient: 0.52, SE 0.04) as did self-report health status (coefficient: -0.12 , SE 0.05) where patients with poorer health status reported better motivation to take their medications at 4 months. Better Self-monitoring and Insight (coefficient: 0.09, SE 0.05) and fewer ‘Hassles’ (coefficient: -0.11 , SE 0.05) also predicted motivation to adhere to medication at 4 months (see Table 4).

Predictors of health status

Baseline self-report health status predicted health status score at follow-up (coefficient: 0.57, SE .05), while younger patients (coefficient: -0.01 , SE .00) and patients who reported less negative experience of multimorbidity (coefficient: -0.10 , SE .04) also reported better health status at 4 months (see Table 5).

Discussion

Our results suggested that different aspects of patient experience of multimorbidity affect different outcomes. The most consistent

Table 1. Sample demographics for patients included in the analysis ($n = 410$)

Demographics	% or $M \pm SD$
Female	50.5%
Age (years)	70 ± 10
White ethnicity	97.5%
No. exemplar conditions	2.2 ± 0.8
COPD	35%
CHD	50%
Depression	41%
Diabetes	45%
Osteoarthritis	53%
Total no. conditions	7.3 ± 3.1
Retired	67%
Index of Multiple Deprivation	27 ± 52^a

^aRange from 3.08 to 78.02, a higher score indicates higher levels of deprivation. Mean score of 27 lies within the 4th quintile (22.73–46.01), indicating moderate/high levels of deprivation. COPD, chronic obstructive pulmonary disease; CHD, coronary heart disease.

Table 2. Analyses of predictors of heiQ Self-monitoring and Insight at 4 months by baseline variables in all participants (*n* = 410)

Independent variable (mean, SD, range or %)	Multivariate analyses		
	<i>B</i>	SE <i>B</i>	β
Gender (48% male)	0.07	0.07	0.04
Age (70 years \pm 10, 31–91)	0.00	0.00	0.01
IMD (2.5 \pm 18, 3.08–78.02)	0.00	0.00	0.01
Number of conditions (7 \pm 3, 2–20)	–0.01	0.01	–0.02
Health status (2 \pm 1, 1–5)	–0.09	0.06	–0.10
Anxiety/depression (HADS) (14 \pm 8, 0–40)	–0.01	0.01	–0.09
Self-monitoring and insight (heiQ) (5 \pm 0.8, 0–10)	0.51	0.05	0.53**
Patient experience of care (PACIC) (2.4 \pm 0.9, 1–5)	–0.01	0.05	–0.01
‘Hassles’ with health care (0.9 \pm 0.8, 0–4)	–0.14	0.06	–0.14**
Illness perceptions – consequences (IPQ) (6 \pm 3, 0–10)	–0.01	0.02	–0.05
Illness perceptions – personal control (IPQ) (5 \pm 3, 0–10)	0.01	0.02	0.02
Illness perceptions – treatment control (IPQ) (7 \pm 3, 0–10)	0.02	0.02	0.07
Patient experience of multimorbidity (MULTIPLEs) (2 \pm 1, 0–5)	0.01	0.05	0.02

***P* < 0.01.

Table 3. Analyses of predictors of self-help behaviours at 4 months by baseline variables in all participants (*n* = 410)

Independent variable (mean, SD, range or %)	Multivariate analyses		
	<i>B</i>	SE <i>B</i>	β
Gender (48% male)	0.18	0.10	0.08
Age (70 years \pm 10, 31–91)	0.00	0.01	0.02
IMD (2.5 \pm 18, 3.08–78.02)	–0.00	0.00	–0.03
Number of conditions (7 \pm 3, 2–20)	–0.02	0.02	–0.06
Health status (2 \pm 1, 1–5)	0.04	0.08	0.04
Anxiety/depression (HADS) (14 \pm 8, 0–40)	0.00	0.01	0.01
Illness perceptions – consequences (IPQ) (6 \pm 3, 0–10)	–0.04	0.02	–0.13*
Illness perceptions – personal control (IPQ) (5 \pm 3, 0–10)	0.02	0.02	0.04
Self-help behaviours (3 \pm 1, 0–5)	0.46	0.05	0.44**
Patient experience of multimorbidity (MULTIPLEs) (2 \pm 1, 0–5)	0.00	0.06	0.00

P* < 0.05; *P* < 0.01.

predictor of self-management was patient scores on the Health Care System Hassles scale (a measure of the difficulties patients have interacting with the health care system). ‘Hassles’ were negatively correlated with scores on Self-monitoring and Insight of the heiQ questionnaire and self-reported medication adherence.

Patient experience of the burden associated with multimorbidity (based on the MULTIPLEs scale) did not predict self-management but was related to self-reported health status.

Relationships with existing research

An interview-based study (5) which aimed to identify perceived barriers to self-management in patients with comorbidity reported a wide range of barriers including: physical limitations, lack of knowledge, financial constraints, logistics of obtaining care, need for social and emotional support, aggravation of one condition by symptoms or treatment of another, multiple problems with medications and overwhelming effects of dominant individual conditions. Our quantitative study extends this by linking ‘Hassles’ with specific types of self-management behaviour and outcomes.

A number of commentators have suggested that current delivery of care is poorly suited to the needs of patients with multimorbidity,

but the link with patient outcomes has not been definitively demonstrated. Much current work on patient experience of multimorbidity is qualitative (5,23). A previous cross sectional quantitative study of 352 older patients with multimorbidity in the USA found that number of conditions, depression and gender were all significant predictors of health status (24). However, a prospective design has significant advantages, especially when outcomes are self-reported. Ours is one of the first quantitative studies to demonstrate that patient experience of multimorbidity predicts future health status. Our findings are in line with a recent prospective study in the United States showing the impact of burden in predicting mental and physical health outcomes in multimorbidity, although their measure of ‘health care task difficulties’ was more akin to ‘Hassles’ scale (25).

Strengths and limitations

The sample demonstrated a wide range in the number of long-term conditions, involved both deprived to affluent areas, and included respondents aged 31–90 (although the majority were older adults aged 70+). Postal methods allowed us to collect large amounts of information from patients, but this may have contributed to an initial response rate of 36% and inclusion of 28% of those surveyed. This is consistent with other postal surveys in primary care (26), but

Table 4. Analyses of predictors of Morisky Medication Motivations at 4 months by baseline variables in all participants ($n = 410$)

Independent variable (mean, SD, range or %)	Multivariate analyses		
	B	SE B	β
Gender (48% male)	0.119	0.067	0.076
Age (70 years \pm 10, 31–91)	0.005	0.004	0.067
IMD (2.5 \pm 18, 3.08–78.02)	-0.001	0.002	-0.029
Number of conditions (7 \pm 3, 2–20)	-0.017	0.012	-0.070
Health status (2 \pm 1, 1–5)	-0.119	0.051	-0.132*
Anxiety/depression (HADS) (14 \pm 8, 0–40)	-0.004	0.007	-0.038
Illness perceptions – consequences (IPQ) (6 \pm 3, 0–10)	-0.017	0.014	-0.066
Illness perceptions – treatment control (IPQ) (7 \pm 3, 0–10)	0.014	0.012	0.052
Self-help behaviours (3 \pm 1, 0–5)	0.036	0.034	0.047
Self-monitoring and insight (heiQ) (5 \pm 0.8, 0–10)	0.093	0.045	0.100*
Morisky medication motivation (2.5 \pm 0.8, 0–3)	0.522	0.044	0.552**
Morisky medication knowledge (2.5 \pm 0.7, 0–3)	0.041	0.050	0.038
‘Hassles’ with health care (0.9 \pm 0.8, 0–4)	-0.107	0.050	-0.108*
Patient experience of multimorbidity (MULTIPLEs) (2 \pm 1, 0–5)	0.044	0.042	0.068

* $P < 0.05$; ** $P < 0.01$.

Table 5. Analyses of predictors of health status at 4 months by baseline variables in all participants ($n = 410$)

Independent variable (mean, SD, range or %)	Multivariate analyses		
	B	SE B	β
Gender (48% male)	0.07	0.07	0.04
Age (70 years \pm 10, 31–91)	-0.01	0.00	-0.14**
IMD (2.5 \pm 18, 3.08–78.02)	-0.00	0.00	-0.04
Number of conditions (7 \pm 3, 2–20)	-0.02	0.01	-0.07
Health status (2 \pm 1, 1–5)	0.57	0.05	0.57**
Anxiety/depression (HADS) (14 \pm 8, 0–40)	0.00	0.01	0.00
Illness perceptions – consequences (IPQ) (6 \pm 3, 0–10)	-0.01	0.01	-0.05
Illness perceptions – personal control (IPQ) (5 \pm 3, 0–10)	0.01	0.01	0.04
Illness perceptions – treatment control (IPQ) (7 \pm 3, 0–10)	-0.00	0.01	-0.01
Self-help behaviours (3 \pm 1, 0–5)	0.04	0.05	0.03
Self-monitoring and insight (heiQ) (5 \pm 0.8, 0–10)	0.02	0.03	0.02
Morisky medication knowledge (2.5 \pm 0.7, 0–3)	0.00	0.05	0.00
‘Hassles’ with health care (0.9 \pm 0.8, 0–4)	-0.05	0.05	-0.05
Patient experience of multimorbidity (MULTIPLEs) (2 \pm 1, 0–5)	-0.10	0.04	-0.14*

* $P < 0.05$; ** $P < 0.01$.

does potentially weaken external validity. For example, it is possible that patients with more significant functional impacts of multimorbidity may be less likely to respond. There may be a need to employ a variety of methods to improve response rates such as incentives, data collection at primary care centres and translation of the measures to aid completion among diverse populations.

Our survey used validated scales to provide a comprehensive assessment of patient experience, although we were only able to assess outcomes over 4 months. We did not meet our pre-planned sample size, limiting the precision of our estimates. For recruitment through disease registers, the study focussed on five conditions. However, patient experience of multimorbidity may vary with other combinations of common conditions. The lack of response by patients from ethnic minorities (1.6%, $n = 7$) highlights the need for further work with these groups.

Implications for policy and practice

Our results would suggest that innovations in care delivery are needed to ensure that patients experience fewer ‘Hassles’ and more ‘minimally disruptive care’ (27). Although case managers co-ordinating care may be relevant for some patients, a more comprehensive model

may require redesign of primary care systems to better meet the needs of patients with multiple conditions, as current systems in the UK have generally been designed around single condition pathways in response to incentives (28). However, further work is required to assess which ‘Hassles’ (seeking information, interacting with health care providers, taking medications, accessing health care) most impact on self-management: previous work would suggest potential effects from the logistics of obtaining care (arranging and attending appointments) and poor doctor–patient communication (5,24).

The current results also suggest that significant attention to patient experience of the burden of multimorbidity would be a potential way of impacting on health outcomes. Our measure of patient experience of multimorbidity (MULTIPLEs) did not predict self-management but did predict health status, even when initial health status and age were controlled. This finding must be considered tentative, as this measure is early in the development cycle, but the finding is potentially important. Tailored support and preparation (such as helping patients better manage priorities between conditions and their management or better support for the emotional consequences of multimorbidity) may help improve outcomes.

Conclusions

The impact of patient experience of multimorbidity on self-management and health outcomes requires further research. This study links specific experiences of patients with multimorbidity, with specific types of self-management behaviours: helping patients better navigate health care services or redesigning services for patients with multimorbidity may improve self-monitoring behaviours and medication adherence; patient experiences of the impact of multimorbidity is an important dimension in self-management beyond health status and age. Therefore, tailored preparation helping patients manage priorities and the emotional consequences of multimorbidity may help reduce the impact of multimorbidity; and subjective experience of illness as represented by multimorbidity might be positively influenced by targeted individual support of interventions, so potentially resulting in better quality of life.

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