CHOICE: Choosing Health Options In Chronic Care Emergencies

Elspeth Guthrie,¹* Cara Afzal,^{2,3} Claire Blakeley,^{2,4} Amy Blakemore,^{4,5} Rachel Byford,⁶ Elizabeth Camacho,^{4,7} Tom Chan,⁶ Carolyn Chew-Graham,⁸ Linda Davies,⁷ Simon de Lusignan,⁵ Chris Dickens,^{9,10} Jessica Drinkwater,¹¹ Graham Dunn,^{4,12} Cheryl Hunter,¹³ Mark Joy,¹⁴ Navneet Kapur,^{4,15} Susanne Langer,¹⁶ Karina Lovell,^{4,17} Jackie Macklin,¹⁸ Kevin Mackway-Jones,^{4,19} Dionysios Ntais,^{4,7} Peter Salmon,²⁰ Barbara Tomenson^{4,12} and Jennifer Watson^{2,4}

- ¹Leeds Institute of Health Sciences, University of Leeds, Leeds, UK
- ²Manchester Mental Health and Social Care Trust, Manchester Royal Infirmary, Manchester, UK
- ³Greater Manchester Academic Health Science Network (GM AHSN), Manchester, UK
- ⁴Manchester Academic Health Science Centre, Manchester, UK
- ⁵Centre for Primary Care, Institute of Population Health, University of Manchester, Manchester, UK
- ⁶Department of Health Care Management and Policy, University of Surrey, Guildford, UK
- ⁷Centre for Health Economics, Institute for Population Health, University of Manchester, Manchester, UK
- ⁸Research Institute, Primary Care and Health Sciences, Keele University, Keele, UK
- ⁹Institute of Health Research, Medical School, University of Exeter, Exeter, UK
- ¹⁰Peninsula Collaboration for Leadership in Health Research and Care (PenCLAHRC), University of Exeter, Exeter, UK
- ¹¹Leeds Institute of Health Sciences, University of Leeds, Leeds, UK
- ¹²Centre for Biostatistics, Institute of Population Health, University of Manchester, Manchester, UK
- ¹³Health Services Research Unit, Nuffield Department of Population Health, University of Oxford, Oxford, UK
- ¹⁴Faculty of Science, Engineering and Computing, Kingston University, London, UK
- ¹⁵Institute of Brain, Behaviour and Mental Health, University of Manchester, Manchester, UK
- ¹⁶Department of Psychology, Manchester Metropolitan University, Manchester, UK

 ¹⁷School of Nursing, Midwifery and Social Work, University of Manchester, Manchester, UK
¹⁸Royal Free Foundation Trust, London, UK
¹⁹Central Manchester University Hospitals NHS Foundation Trust, Manchester, UK
²⁰Department of Psychological Sciences, University of Liverpool, Liverpool, UK

*Corresponding author e.a.guthrie@leeds.ac.uk

Declared competing interests of authors: Simon de Lusignan has received funding from Eli Lilly and GlaxoSmithKline (GSK) Biologicals. Funding has also been received from the Department of Health for the National Evaluation of Improving Access to Psychological Therapies (IAPT). Elspeth Guthrie reports grants from the National Institute for Health Research (NIHR) during the conduct of the study. Karina Lovell reports grants from NIHR, the National Institute of Mental Health (NIMH) and Arthritis Research UK during the conduct of the study. Chris Dickens reports grants from NIHR during the conduct of the study. Linda Davies reports grants from the NIHR, Medical Research Council, Economic and Social Research Council, Macmillan, Cancer Research UK, Arthritis Research UK and Central Manchester University Hospitals NHS Foundation Trust (CMFT) during the conduct of this study. Peter Salmon reports grants from Marie Curie Cancer Care, the Liverpool Institute of Health Inequalities Research, Merseycare NHS Trust, Royal Liverpool and Broadgreen Hospitals NHS Trust, the Economic and Social Research Council, and the Medical Research Council during the conduct of the study. Navneet Kapur reports other research funding from NIHR, the Department of Health and the Healthcare Quality Improvement Partnership during the conduct of the study. He was not in receipt of any industry funding. He was involved in National Institute for Health and Care Excellence guidelines and Department of Health (England) advisory groups on suicidal behaviour unrelated to the conduct of the current study.

Disclaimer: The views and opinions expressed herein are those of the authors and do not necessarily reflect those of the National Institute for Health Research Public Health Research programme or the Department of Health.

Published July 2017 DOI: 10.3310/pgfar05130

Scientific summary

Choosing Health Options In Chronic Care Emergencies Programme Grants for Applied Research 2017; Vol. 5: No. 13 DOI: 10.3310/pgfar05130

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

Over 70% of the health-care budget in England is spent on the care of people with long-term conditions (LTCs). Reducing unscheduled care has become a priority for the NHS, and there is a drive to reduce unscheduled care use and emergency admissions to hospitals of those people with LTCs who can be managed in the community.

Psychological comorbidity is high in people with physical LTCs. For example, people with two or more LTCs are seven times more likely to have depression than those who are physically well. Comorbid psychological morbidity in people with LTCs is associated with a range of adverse outcomes, including increased mortality, poorer physical health outcomes, longer stay in hospital, and increased health costs and service utilisation.

The aim of this programme of research was to examine the relationship between psychological morbidity and use of unscheduled care in people with LTCs, and to develop a tailored psychosocial intervention, which would have the potential to reduce use of unscheduled care. We used a mixed-methods approach.

Throughout the programme, we focused on four common exemplar conditions [asthma, coronary heart disease (CHD), chronic obstructive pulmonary disease (COPD) and diabetes] and all the results refer to people with at least one of these four conditions, unless stated otherwise.

The programme was divided into three phases. The first phase involved evidence synthesis. The second phase involved mapping the frequency and pattern of unscheduled care in patients with the four exemplar LTCs over a 12-month period, and the identification of potential red flag markers for patients at risk of using unscheduled care.

Phase 3 involved developing and testing the validity and utility of the red flag markers using current NHS databases. We also developed and evaluated a low-intensity psychosocial intervention for use in primary care with the intention of reducing use of unscheduled care in people with LTCs, and tested this in an exploratory and feasibility cluster randomised controlled trial (RCT).

Phase 1

Objective

To systematically synthesise the current evidence about psychosocial drivers of unscheduled care, and complex interventions that reduce unscheduled care, in patients with LTCs.

Methods

We carried out five systematic reviews. The first two reviews focused on potential psychosocial predictors of unscheduled care and included studies that had assessed the use of unscheduled health care prospectively over a defined time period. The first review focused on depression and the second on anxiety. The third and fourth reviews focused on the evidence base for complex intervention that may reduce unscheduled care use in (a) asthma and (b) COPD. RCTs which had included a measure of unscheduled care as part of the outcome measures were included in reviews 3 and 4. Standard meta-analytic techniques were used to process the data in all of the above four reviews. The fifth review was a synthesis of qualitative studies that had explored reasons why people with LTCs use unscheduled care.

[©] Queen's Printer and Controller of HMSO 2017. This work was produced by Guthrie *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Results

Review 1

Depression was associated with an increased risk of using unscheduled care in patients with LTCs [16 studies; odds ratio (OR) 1.49, 95% confidence interval (CI) 1.35 to 1.64; p < 0.0005].

Review 2

Anxiety was not associated with use of unscheduled care (eight studies; OR 1.078, 95% CI 0.877 to 1.325; p = 0.476).

Review 3

In COPD, the overall combined effect associated with the interventions was a 32% reduction in the use of unscheduled care (32 studies; OR 0.68, 95% CI 0.57 to 0.80).

Review 4

In asthma, complex interventions were associated with a 21% reduction in the use of unscheduled care (33 studies; OR 0.79, 95% CI 0.67 to 0.94).

Review 5

Qualitative work suggested that patients used unscheduled care because of a sense of pressing need, which was linked to their worsening physical health, and a sense of having 'no choice'. Previous experience of health care shaped future use. Emotional, social and cultural factors that could lead to use of unscheduled care remain relatively unexplored in the existing literature.

Conclusions

We found evidence that depression, but not anxiety, is prospectively associated with an increased probability of using unscheduled care in patients with LTCs, but it was unclear from the work carried out whether or not this is mediated via severity of physical illness. We found very few primary care studies, yet primary care is the major arena in which care of LTCs is provided in the UK. We concluded that further work, based in primary care in the UK, is necessary to determine if depression or other psychosocial factors are important predictors of unscheduled care in people with LTCs.

The results from the qualitative review suggest that patients understand differences between services and make informed decisions about when and what type of health care to use, and they see hospitals as places of safety and expertise.

Phase 2 (comprising three studies)

Study 1: longitudinal prospective study in primary care

Objectives

- 1. Derive estimates of the frequency and pattern of unscheduled care in patients with asthma, CHD, COPD and diabetes as examples of common LTCs.
- 2. Develop and validate a 'red flag' system that will identify patients with LTCs who are at risk of becoming frequent users of unscheduled care (phases 2 and 3).

Methods

We conducted a primary-care, prospective cohort study of patients with LTCs aged \geq 18 years to identify predictors of unscheduled care. Patients were identified from Quality and Outcomes Framework (QOF; a pay-for-performance scheme) registers from 10 general practices in Manchester. Participants completed a baseline postal questionnaire and follow-up questionnaire 1 year later. Two measures of outcome were

used: emergency hospital admissions (EHAs) recorded from the general practitioner (GP) records and self-reported use of unscheduled care from questionnaire data. Key factors we examined included physical comorbidity, severity of physical illness, demographic characteristics, prior use of unscheduled care, depression, life stress, and distance to the nearest emergency department (ED).

Results

A total of 1860 patients completed the baseline questionnaire, 1203 patients completed the follow-up questionnaire and 1415 GP records were checked to record EHAs. Multimorbidity was present in 72% of patients. Sixteen per cent of patients had an emergency admission in the year prior to completing the questionnaire and 17% the year after.

Independent predictors of both EHAs and participant-reported use of unscheduled care were no partner, number of threatening experiences, use of unscheduled care in the baseline year and a Hospital Anxiety and Depression Scale (HADS) score for depression of ≥ 8 . More severe depression (HADS score of ≥ 11) was associated with a twofold risk of use of unscheduled care. The most powerful predictor of future use of unscheduled care was prior use (threefold/fourfold risk). Other predictors for either EHAs or reported use of unscheduled care were severity of illness and multimorbidity.

Costs

Detailed service use data were costed using published national health- and social-care unit costs data and included unscheduled and scheduled care costs. The mean costs for unscheduled care accounted for roughly half of the total cost of health care during the period studied. The total costs for the group of patients as a whole were significantly higher for depressed patients than for non-depressed patients, both for scheduled and unscheduled care. The presence of depression at baseline, maximum severity of LTC and the total costs in the year before baseline were independently associated with increased unscheduled care costs and total costs.

Conclusions

The most powerful predictor of prospective use of unscheduled care was previous use of unscheduled care, but psychosocial factors (having no partner, threatening experiences and depression) were independent predictors in their own right. The costs of unscheduled care used by the patients in the study approximated to half of their total health-care costs. Our findings suggest that a psychosocial intervention may be helpful in reducing use of unscheduled care in people with LTCs and, if so, may also reduce costs.

Qualitative studies 2 and 3

Objective

To identify personal reasons for use of unscheduled care including barriers to access for routine care; patients' motivations; expectations and decision-making processes; influences from families and relevant health-care workers; and factors in routine consultations with health-care practitioners (HCPs) in primary care.

Study 2: why do people use unscheduled care?

Methods

We conducted semistructured interviews with a subset of participants from the longitudinal cohort study and with HCPs across primary and secondary care. Interviews were audio-recorded, transcribed verbatim and analysed using a framework approach.

Results

Twenty-nine HCPs and 50 patients were interviewed. HCPs typically described use of unscheduled care as inevitable for people with LTCs. Patients expressed a reluctance to use unscheduled care and a preference to access routine care. Health-care choices and judgements of need were influenced by previous

© Queen's Printer and Controller of HMSO 2017. This work was produced by Guthrie *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

experiences of services. The potential role that psychosocial factors may play in urgent help-seeking did not arise in the accounts of HCPs or patients.

Conclusions

Use of unscheduled care was influenced by patients' previous experience of care. In order to address use of unscheduled care, HCPs need to be more aware of the different value patients attach to routine and unscheduled services in the context of health crises, and the way they make choices about health care.

Study 3: what happens in routine primary care consultations?

Methods

We audio-recorded primary care consultations for people with LTCs. We used stimulated recall to encourage discussion of consultations during semistructured interviews with patients and HCPs. Using a longitudinal approach, we kept in contact with patients for 3 months, providing them with optional health-care logs to complete when they thought about or decided to seek help, and asking them to discuss their health regularly with a researcher by telephone. After 3 months, patients were invited to participate in a further interview.

Results

Thirty-four patients agreed to take part. Twenty-nine consultations were audio-recorded by HCPs; 10 HCP interviews, and 27 initial and 22 follow-up patient interviews were completed. Reviews predominantly focused on the clinician's agenda, in particular on achieving QOF 'targets', often to the detriment of other aspects of care. Discussion of unscheduled care or crisis management and behaviour change work were rare, with patients positioned as passive recipients of care.

Conclusion

This study suggests that routine reviews tend to have a narrow focus and fail to address patients' needs holistically. Routine reviews present an opportunity to improve LTC management and influence patients' health-care use, but this may require the adoption of a more holistic and patient-centred approach to consultations.

Phase 3 (comprised two studies)

Study 1: revalidation study in primary care

Objective

To validate the research findings from the longitudinal cohort study in phase 2, using routinely collected electronic data.

Methods

We analysed NHS electronic data from two large geographical areas in north London for patients aged \geq 18 years with at least one of the four exemplar LTCs. Potential predictor variables included age, sex, each of the four LTCs, depression and previous use of unscheduled care for a 2-year period before a specified index date. We used two dependent variables: attendances at EDs and EHAs over a 12-month post-index date period.

Results

Prior use of unscheduled care and each of the LTCs were independent predictors of ED attendances and EHAs. The rates of depression were very low in both areas, which suggested problems with identification and recording in GP data systems. Depression was an independent predictor of ED attendances, but not EHAs, which may have been because of the low prevalence of recorded depression.

Discussion

The findings from this study generally supported those from the cohort study in phase 2. The prevalence of recorded depression in the electronic databases was very low, which reduced its potential as a predictor variable.

Study 2: an exploratory and feasibility cluster randomised controlled trial in primary care

Objective

To develop and evaluate an intervention that will reduce/prevent unscheduled care, while maintaining or improving patient benefit, and to use statistical and health economic modelling to estimate the costs and benefits associated with treatment intervention.

Methods

We worked with people with lived experience of chronic disease to develop a patient-centred intervention, and carried out an exploratory cluster RCT to evaluate its acceptability and key parameters for a larger definitive study. We randomised six GP practices to either the intervention or control group. We used COPD as an exemplar LTC. The intervention consisted of two components:

- 1. A practice-level intervention to improve the overall care of patients with COPD, and to improve methods of identifying 'at-risk' patients.
- 2. A targeted patient intervention, delivered by a liaison health worker (LHW) working in the practice, for people with COPD who had psychosocial risk factors for increased use of unscheduled care. This consisted of four sessions of brief low-intensity treatment for depression, coupled with social interventions to help with challenging life experiences arising from the LTC.

The main outcome measure was use of unscheduled care over the 12-month period of the trial.

We used qualitative methods to assess the acceptability of both levels of the intervention.

Results

There was no evidence from either quantitative or qualitative work that the practice-level intervention impacted on use of unscheduled care or was integrated into the practices. The targeted patient intervention was highly acceptable to patients, with good recruitment and retention, very good qualitative feedback and preliminary evidence of reduction in depression and use of unscheduled care (ED attendances) for patients who received it.

Conclusions

Organisational change in primary care is difficult, and challenging, and may require considerable resources and time to produce demonstrable benefits for people with LTCs. A targeted patient intervention delivered by LHWs showed promise in terms of its acceptability to patients.

Research recommendations

In the context of ongoing service change, the programme raises a number of further research questions, summarised here in priority order:

- 1. Can routine primary care consultations for patients with LTCs become more patient centred to facilitate discussion of psychosocial issues that impact on health care, and can these consultations be used to implement behavioural change?
- 2. What are the costs and benefits of a targeted patient intervention to reduce unscheduled care and overall costs for people with LTCs and comorbid depression?

[©] Queen's Printer and Controller of HMSO 2017. This work was produced by Guthrie *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

- 3. Does case-finding for depression in people with LTCs in primary care improve physical and mental health outcomes?
- 4. What is the mechanism whereby depression and other psychosocial factors affect the use of unscheduled care in people with LTCs?
- 5. What is the most appropriate and sensitive primary outcome measure to accurately assess the impact of psychosocial interventions in people with LTCs and co-existing psychosocial problems?

Funding

Funding for this study was provided by the Programme Grants for Applied Research programme of the National Institute for Health Research.

Programme Grants for Applied Research

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the Programme Grants for Applied Research journal

Reports are published in *Programme Grants for Applied Research* (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Programme Grants for Applied Research programme

The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health Research (NIHR), was set up in 2006 to produce independent research findings that will have practical application for the benefit of patients and the NHS in the relatively near future. The Programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director.

The programme is a national response mode funding scheme that aims to provide evidence to improve health outcomes in England through promotion of health, prevention of ill health, and optimal disease management (including safety and quality), with particular emphasis on conditions causing significant disease burden.

For more information about the PGfAR programme please visit the website: http://www.nihr.ac.uk/funding/programme-grants-for-applied-research.htm

This report

The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0707-10162. The contractual start date was in December 2013. The final report began editorial review in May 2015 and was accepted for publication in September 2016. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGfAR or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGfAR programme or the Department of Health.

© Queen's Printer and Controller of HMSO 2017. This work was produced by Guthrie *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Programme Grants for Applied Research Editor-in-Chief

Professor Paul Little Professor of Primary Care Research, University of Southampton, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

NIHR Journals Library Editors

Professor Ken Stein Chair of HTA and EME Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Senior Scientific Advisor, Wessex Institute, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

Dr Catriona McDaid Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Professor of Health Sciences Research, Health and Wellbeing Research Group, University of Winchester, UK

Professor John Norrie Chair in Medical Statistics, University of Edinburgh, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professor of Child Health Research, UCL Institute of Child Health, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Professor Martin Underwood Director, Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of members of the NIHR Journals Library Board: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk