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Study protocol for Care cOORDInatioN And sympTom managEment (COORDINATE) programme: a feasibility study

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ABSTRACT

Introduction Sustainable approaches to support care coordination and symptom management needs of critically ill adults living with multimorbidity are needed to combat the challenges and complexity that multimorbidity presents. The study aims to test the feasibility of the Care cOORDInatioN And sympTom managEment (COORDINATE) intervention to improve health outcomes of adults living with multimorbidity.

Methods and analysis A multicomponent nurse-driven intervention was developed using experience-based co-design and human-centred design. Inclusion criteria include (1) age 55 years and older, (2) admitted to an intermediate care unit, (3) presence of two or more chronic health conditions and (4) signed informed consent. Data collection will occur at baseline (time of recruitment predischarge) and 6 weeks and 3 months following hospital discharge. Outcome of interest from this feasibility study is to evaluate the financial, technical and logistic feasibility of a full-scale study including data collection and protocol adherence. Additionally, Cohen's d effect sizes for the change in outcomes over time will be computed to establish power calculations required for a full-scale study. The protocol was prepared in accordance with Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) checklist.

Ethics and dissemination The study has been reviewed and approved by the Institutional Review Board of Johns Hopkins Medical Institutions. Given the success of this feasibility study, the potential for the COORDINATE intervention to decrease the symptom burden and improve participant quality of life among critically ill people with multimorbidity will be tested in a full-scale study, and findings will be actively disseminated.

Trial registration number NCT05985044.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study aims to test the feasibility of the Care cOORDInatioN And sympTom managEment (COORDINATE) intervention to establish power calculation.
⇒ The innovation in this intervention is embedded in the heterogeneity of the population, the locus of care, the use of participatory approaches for intervention development and the need for transitional and supportive care strategies for multimorbidity management which is increasingly a characteristic of healthcare delivery.
⇒ As a single-arm feasibility study, assumptions on the effectiveness of the COORDINATE intervention on outcomes will be limited and contextual.
⇒ The intervention was developed and will be implemented at a single site, and additional work will be needed to understand the context of care and implement intervention within other communities.

INTRODUCTION

Multimorbidity is common and is the coexistence of two or more chronic conditions in the same individual.[1] These individuals live with a higher symptom burden and accelerated functional decline that affects quality of life,[2–4] which can lead to higher caregiver strain and burden.[5] In the USA only, the prevalence of multimorbidity is estimated to be 50% for individuals under 65 years of age, 62% for those aged 65–74 years, 75.5% for those aged 75–84 and 81.5% for those 85 years and older.[4 6] With the population ageing, advances in medical care, and increased longevity, the prevalence of multimorbidity is expected to increase globally.[7] With this comes a rise in the utilisation of healthcare and costs of care.[6 8 9] People with multimorbidity create a particular challenge to care coordination, because they require more holistic person-centred approaches that balance many competing priorities, needs and goals.[10] Moreover, most healthcare specialties are configured around single diseases and organs. Hospitalisation can be a window of opportunity to initiate interventions to promote recovery, resilience and care coordination, decrease symptom burden and in turn enhance quality of life.

Intermediate care units (IMCUs), also known as high dependency units (HDUs), are widely used to care for critically ill patients

requiring more intensive monitoring or nursing care than is provided on hospital acute care wards but who do not have intensive care needs (such as advanced airway management or mechanical ventilation).[11] Half of the patients admitted to intermediate care have multimorbidity[11 12] and have higher symptom burden. Preliminary data suggest intermediate care patients do not necessarily access comprehensive care services because of the organ-centred arrangement of programmes (eg, chronic heart failure, chronic obstructive airway disease and chronic renal failure). Further, individuals living with multimorbidity are not often categorised into single disease-specific categories such as cardiac, respiratory and gastrointestinal because of multiple comorbid conditions and symptoms and have a greater potential for complications, including worse overall management of chronic disease needs.[13] Although the challenges of efficiently and effectively managing care among those with multimorbidity have been recognised, the complexity of the care coordination and possible strategies to help manage these issues are not well identified. Hence, person-centred interventions focused on care coordination and symptom management by empowering patients to interact effectively with the complex care system could be a promising method for improving the health outcomes of critically ill patients living with multimorbidity.

METHODS AND ANALYSIS

Trial design and purpose

The paper discusses the rationale and design of a single-arm pilot feasibility study of a nurse-driven multicomponent intervention, Care cOORDInatioN And sympTom managEment (COORDINATE), to improve health outcomes among patients living with multimorbidity. The programme includes five individualised, synchronous sessions for patients conducted in person (visit 1) and followed by phone calls (visits 2–5) over 6 weeks. The COORDINATE intervention was developed using experience-based co-design (EBCD) and human-centred design (HCD). The EBCD and HCD methodologies facilitated the person-centred approach of intervention components by considering the needs and preferences of patients, family caregivers and healthcare providers in improving health outcomes when living with multimorbidity. The innovation in this intervention is embedded in the heterogeneity of the population, the locus of care and the need for transitional and supportive care strategies for multimorbidity management. The study flow process followed to help identify, develop and pilot test the COORDINATE intervention is summarised in figure 1.

The purpose of this feasibility study is to evaluate the financial, technical and administrative or logistic feasibility of a full-scale study including issues of data collection and protocol adherence. Additionally, an initial effect size of the COORDINATE intervention will be evaluated to establish the power calculations required for a full-scale study. The protocol is prepared in accordance with Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) guidelines.[14]

Sample and setting

Patients will be eligible to participate if they meet the following criteria: (1) aged 55 years and older, (2) have two or more chronic health conditions identified in the electronic medical record and (3) are willing to provide informed consent. Patients will be excluded if they cannot speak English or have a documented cognitive impairment that would prevent them from participating. Patients will be approached in the IMCU of an academic teaching hospital while they are in-patient before discharge.

Intervention development with patient and public involvement

The study used participatory approaches, EBCD and HCD, to develop a multimorbidity management COORDINATE programme. Participatory approaches to service improvements are effective methods for addressing gaps in knowledge and informing the next step with the involvement as well as exploration of experiences and needs of stakeholders.[15] Increasing evidence suggests that user, patient and public, partnership in the intervention development not only improves its quality focus and effectiveness but also leads to the improvement in outcomes, safety, quality and cost.[15] Hence, the use of EBCD and HCD methodology helped capture and understand the end users' need and design the COORDINATE intervention.

Use of experience-based co-design (EBCD)

EBCD is an innovative participatory research methodology for collaboratively exploring and using individual experiences/emotions of patients, family members and healthcare providers for a more holistic understanding of needs.[16 17] EBCD is an effective means for understanding how to make the best use of data about patient experience to improve the quality of care and culture of health services to cocreate feasible and acceptable interventions.[18] Preliminary work for this study followed a six-stage process (table 1) of EBCD and worked with patients living with multimorbidity, their family caregivers and healthcare professionals through iterative rounds of data collection, analysis, validation and development of strategies to address challenges in multimorbidity care delivery processes. The process started with the preparation for the study (Stage 1) followed by the narrative interviews (Stages 2 and 3) to understand the disease trajectories in the context of multimorbidity and identify improvement priorities for multimorbidity management with patients, family caregivers and healthcare providers. The co-design part (Stages 4 and 5) of the process was the innovative aspect of validating needs and identifying improvement priorities for the multimorbidity management programme. All the inputs from the interviews and co-design events were analysed and summarised[19] as a multimorbidity management toolkit and disseminated

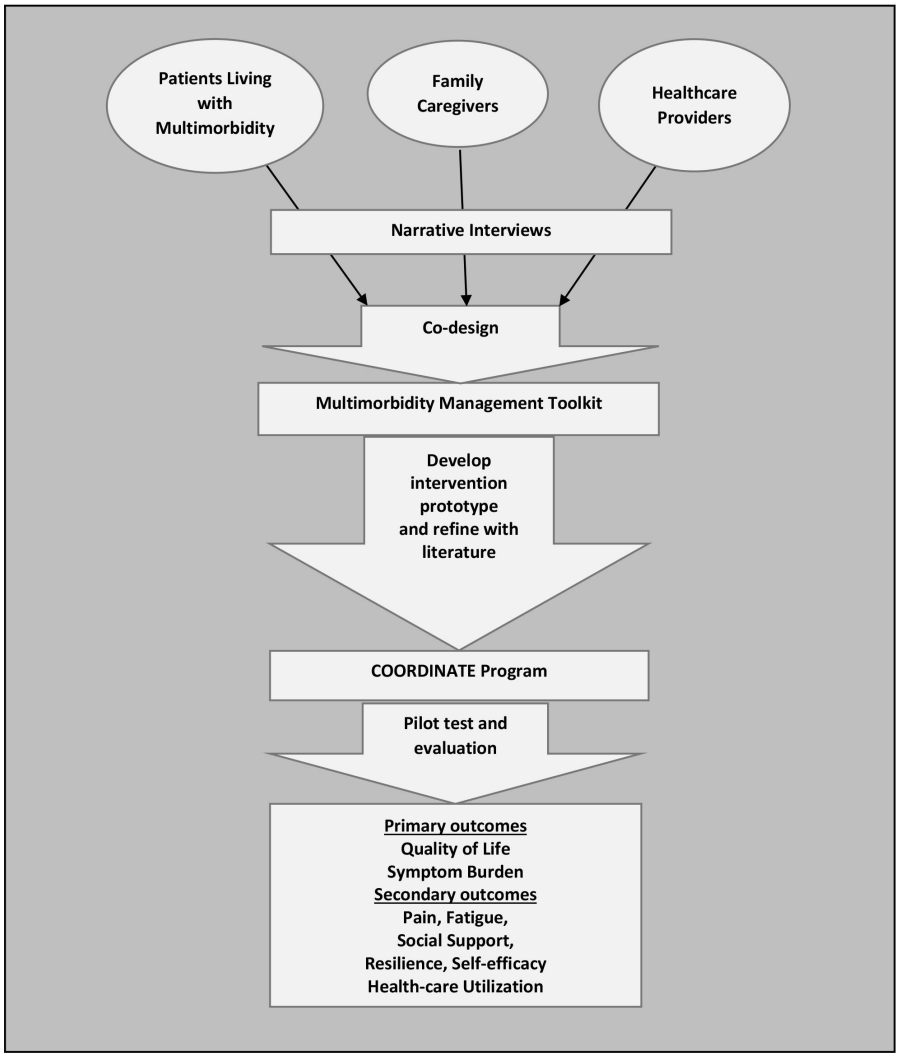

Figure 1 Study flow diagram.

to the stakeholders (Stage 6). Rigorous appraisals and details of the EBCD process have been published, and an online toolkit was available to guide this work.[20]

Use of human-centred design (HCD)

The use of HCD in this project complemented the EBCD process. HCD is a person-first, collaborative process used to understand and define problems, identify opportunities, generate ideas and make tools that support positive change.[21] This process prioritises end users' and important stakeholders' needs, values and lived experiences. Human-centred methods such as storytelling, journey mapping, priority ranking and intervention prototyping were used to identify end users' needs and preferences and design the intervention's components. Storytelling is a narrative tool that is currently used in a diverse range of fields to elicit personal narratives that capture experiences, processes and contexts.[22] Individual narrative interviews in Stages 2 and 3 of EBCD process followed a storytelling approach of HCD to help identify what were the good and bad experiences of study participants when living with and caring for patients with multimorbidity. The co-design event used the journey map and priority ranking exercise with the participants. The patient experience journey mapping is known to use for a better understanding of patients' journey with a phenomenon, their pain points and successes.[23] The journey mapping activity helped validate and identify improvement priorities for multimorbidity management. The ranking exercise was valuable to understand the priority of improvement strategies.

Table 1 Stages of experience-based co-design methodology

Stage 1	Project preparation and relationship building
Stage 2	Interview patients and family members
Stage 3	Interview healthcare providers and other stakeholders
Stage 4	Co-design event
Stage 5	Co-design working group
Stage 6	Celebration

Findings from the interviews, co-design events and components of the multimorbidity management toolkit developed from EBCD were analysed using the intervention prototype methodology. Key challenges and recommendations from the early work were grouped into key themes. Then the ideas under each theme were mapped based on their importance and feasibility and identified as intervention components. Evidence-supporting intervention components were also explored to help identify interventions to which these components were used that could be adapted for this population. Key findings from this work identified five improvement priorities: communication, patient-provider relationship, caregiver support, availability of resources for symptom/disease assessment and management and care coordination, and follow-up care.[19] Through an extensive process of EBCD, HCD and evidence evaluation, the final identified COORDINATE intervention components include need assessment, question prompt list, goals discussion, and symptom assessment and tracking.

Intervention components

The intervention consists of four main components: (1) needs assessment, (2) question prompt list, (3) goals discussion and (4) symptom assessment and tracking (online supplemental file 1). A summary of intervention components and the rationale for choosing these components with literature is presented in table 2. The interventionist will guide the individual patient through the first few months of discharge. In contrast to a patient navigator model where the role is more facilitative, in this programme, the intervention seeks to empower and coach the individual on a journey commensurate with their needs.

Participant timeline: intervention journey

The intervention will start with the enrolment of a patient living with multimorbidity. The intervention consists of one in-person predischarge visit by the study team and four follow-up telephone calls (at 48hour, 1-week, 4-week and 6-week postdischarge). The sequence of intervention events and timing of the intervention components is presented in figure 2. Participants' eligibility will be examined at the time of recruitment.

Table 2 Intervention component and evidence basis for component selection

Intervention component	Evidence basis/rational for component
Needs assessment Guided interaction and priority ranking (cord sorting activity) is done each visit focusing on the domains identified as the key improvement priorities from intervention development work. The domains used were patient-provider relationship, communication, availability of resources, caregiver support, care coordination and follow-up care and others—what matters the most	► Need assessment has been identified as one of the key features of multimorbidity models of care studies to identify participants competing needs and develop individualised care plans[24] ► Involving patients in assessment and encouraging them to identify and prioritise their needs is a person-centred approach that builds rapport and increases participation[25]
Question prompt list *Based on the needs identified, tailored question prompt list is developed together with the patients. The tailored question is a tool to empower patients to improve patient-provider relationship, communication skills, shared decision-making as well as convey their need and preferences related to need for resources, caregiver support, care coordination and follow-up care*	► Question prompt list has been identified as a simple and inexpensive communication tool to improve patient-provider relationship, patient engagement, care coordination and shared decision-making[26–28] ► Question prompt list has been extensively used among individuals with chronic conditions but focused to specific disease/condition; evidence focused among people with multimorbidity are limited[29]
Goals discussion *Goals discussion/check-in activity is done each visit to set goals and develop Specific, Measurable, Achievable, Relevant, and Time-bound (SMART) objectives with action plans together with patients focused on behaviour change. Goals discussion/check-in is based on the needs identified*	► Goal discussion drives behaviour change by encouraging participants to identify need and prioritise them.[30] SMART goals provide a framework to goal by addressing important questions and setting specific objectives[31] ► The discussion/check-in of goals and action plans with the interventionist can help reinforce the personal commitment and found to be successful in trials[32]
Symptom assessment and tracking *Regular symptom assessment tool, Edmonton Symptom Assessment Scale (ESAS), is used for symptom assessment and tracking. Participants were encouraged to track their symptom and use this to communicate their need with care providers. Symptom assessment tools and pen and diary was provided to track patients' experiences, symptoms and reflections for the intervention components*	► Assessing and tracking symptom with validated tool provides snapshot/overview of individual health and concern which could be used by patients for self-management and providers to identify and develop care plans as well as promote care coordination and adherence[33] ► ESAS is a validated tool for symptom assessment that allows simple and rapid documentation of multiple patient-reported symptoms and has been used among diverse participants with chronic diseases in both clinical practice and research[34]

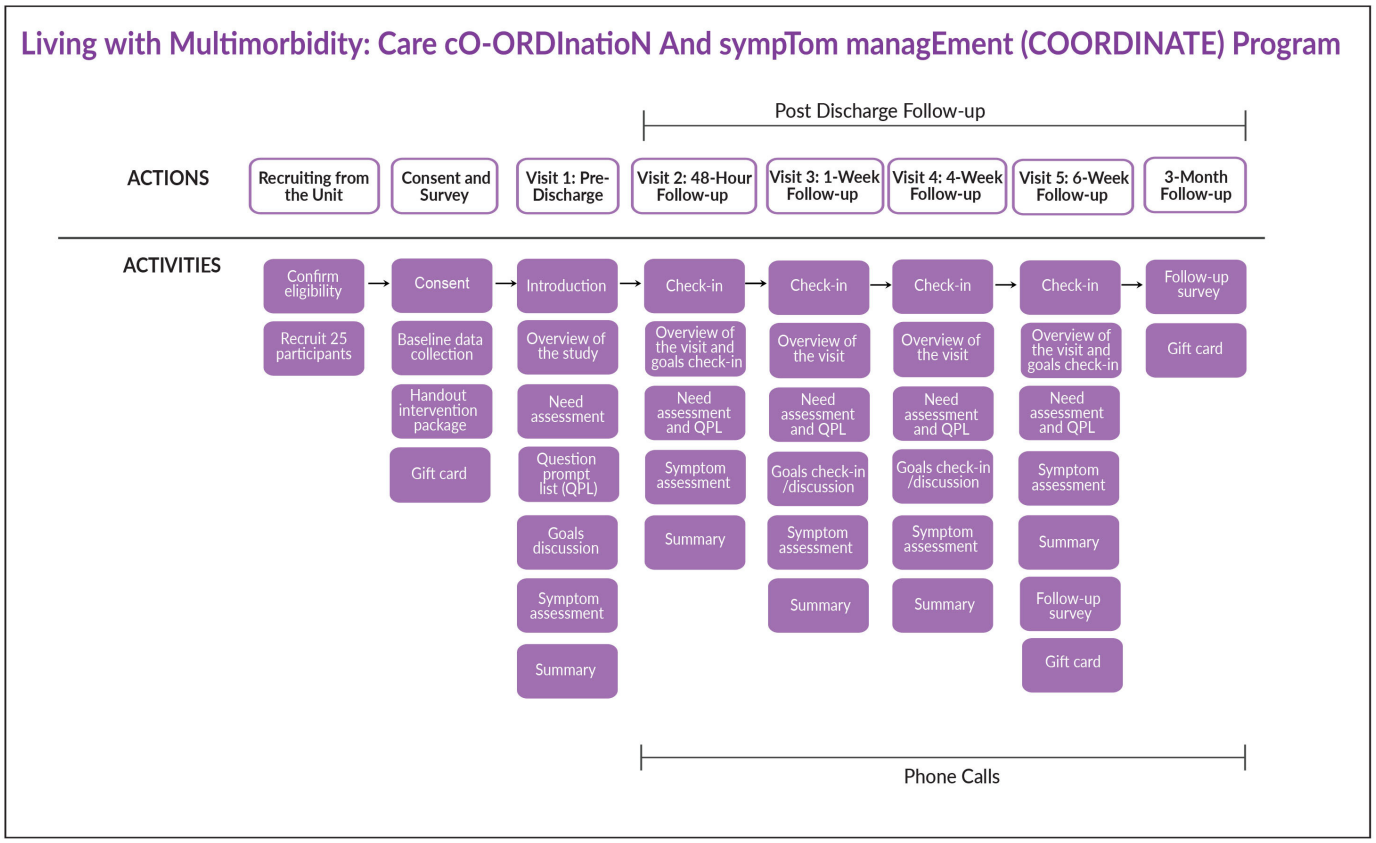

Figure 2 Intervention journey.

Outcomes

The outcomes of interest for this feasibility study are to evaluate the financial, technical and administrative or logistic feasibility of a full-scale study including issues of data collection, questionnaire use and protocol adherence. Additionally, to establish power calculations required for a full-scale study using primary outcome variables of full-scale study. The primary outcomes for the full-scale study include quality of life and symptom burden, and secondary outcomes include pain, fatigue, social support, resilience, self-efficacy and healthcare utilisation (emergency visits, hospitalisations and critical care admissions). The list of outcomes with measures that will be used for data collection is identified in table 3. A follow-up survey at the end of intervention implementation (6-week follow-up) includes items on the intervention's satisfaction and acceptability/feasibility among study participants.

Sample size

As a pilot feasibility study, the analyses will likely not have adequate power to detect significant differences in outcomes. Hence, effect sizes, rather than statistical significance, will be examined for evidence of the effectiveness of the intervention with a target sample size of 25.

Recruitment

Prospective-consecutive participants meeting eligibility criteria will be approached for the study using convenience and purposive sampling from the IMCU.

Table 3 Outcomes and measurements

Outcomes	Measures	Items (n)	Cronbach's alpha
Symptom burden	Edmonton Symptom Assessment System (ESAS)[35]	10	0.79[34]
Quality of life	BRICS NINR Short Form Survey (SF-36)	36	≥0.7 (36)[36]
Pain	BRICS NINR PROMIS SF v1.0- Pain Intensity 3a	3	0.83 to 0.93[37 38]
Fatigue	BRICS NINR PROMIS SF v1.0- Fatigue 6a	6	0.7 to 0.86[38 39]
Social Support	ENRICHD Social Support Inventory (ESSI)	7	0.88[40]
Resilience	Brief Resilience Scale	6	0.91[41]
Self-efficacy	Coping Self-Efficacy	11	0.91[42]
Healthcare Utilisation	Emergency Visits, Hospitalisations and Critical Care Admissions		

Data collection and management

After informed consent (online supplemental material), participants will complete the baseline survey. Data on patient demographics and outcome surveys (table 3) will be collected at the time of recruitment (baseline data), 6-week follow-up and 3-month follow-up. Data will be collected from participants' self-reports and medical records. Reflection of study team members on the financial, technical and administrative feasibility of the intervention implementation will be collected from the principal investigator (PI), interventionists and research assistants involved in recruitment and data collection. The team will prepare a standard intervention protocol with guidance on communication techniques, details of intervention components, and possible/potential questions and scripts to use by interventionists among participants. The team members will audio record intervention and reflections to improve adherence to intervention protocol and implications for bigger trial intervention development. Team members will meet every week to reflect on the project activities and discuss issues of data collection, protocol adherence and questionnaire use.

All study data will be stored in a secure, password-protected and Health Insurance Portability and Accountability Act (HIPPA)-compliant server, and only study team members can access it. These are OneDrive, REDCap and encrypted and password-protected safe desktops. Any hard copies of source data are stored in a locked cabinet in a locked office. The PI will notify the Data Safety Monitoring Committee and the Institutional Review Board (IRB) within 48 hours of becoming aware of any serious adverse event.

Statistical methods for data analysis

Descriptive and exploratory analysis will be used for all study variables. Continuous variables will be described using means and SD or median and interquartile ranges. Categorical variables will be described using frequency and percentages. Cohen's d effect sizes for the change in outcomes over time will be computed. Generalised estimating equations (GEE) will be used to examine the change in primary and secondary outcomes over time. Intervention acceptability and feasibility in financial, technical and logistic aspects will be examined using both qualitative and quantitative data. Qualitative analysis will be conducted from reflection data of study team members recruiting participants, collecting data and delivering the intervention and interview data from selected participants who completed the intervention and left the intervention if agreed to be interviewed. The quantitative data from satisfaction and feasibility items will be descriptively analysed (mean, range, percentages). Further, an evaluation of participant recruitment and retention rates will be performed.

ETHICS AND DISSEMINATION

Ethical approval

The study will be conducted in accordance with the Institutional Review Board of Johns Hopkins University, as well as the approved study protocol (IRB00244792).

Informed consent

A physical as well as a survey using REDCap e-consent will be used to review the consent form and obtain a signature if the participant is interested. The research assistant will review the informed consent with the participants and enough time and opportunities will be provided to ask questions before agreeing to be involved in the study. The participant will be provided with a printed consent form in their intervention package.

Risks and benefits

This trial is developed with deliberate attention towards minimising the risk of harm to participants. There are no physical risks to participants. However, the potential risks of the study include time involvement, fatigue and emotional distress because of the severity of the disease, recall of their experience and the nature of some questions in the survey. All participants are informed about the potential risks of participating during the informed consent process. Participants are allowed to withdraw or stop the study at any time. The research team including the PI and research assistants are and will be registered nurses or graduate nursing students who are experienced in caring for patients living with chronic and complex disease conditions. Any adverse events, unanticipated problems and study deviations will be documented on designated forms and reported within 48 hours, by the PI to the Data Safety Monitoring Committee of the study monitoring entity, PROMOTE centre (Promoting Resilience in Persons with Multiple Chronic Conditions) and IRB. If deemed necessary by the monitoring entity or IRB, study activities will be paused until problems are resolved.

The study procedure will provide an opportunity to discuss and empower patients for care coordination, symptom tracking and symptom management. The pilot test of the intervention is anticipated to reduce symptom burden and improve quality of life. Additionally, the intervention is expected to decrease pain and fatigue, enhance resilience, self-efficacy and social support and reduce healthcare utilisation among participants involved in the study. Participants are compensated for their time and involvement with a $25 gift card given at three time points: baseline, 6-weeks and 3-month follow-up survey completion.

Dissemination

Multiple platforms will be used to disseminate the research findings. This will involve the use of academic media such as peer-reviewed journal articles and presentations at national and international conferences; social media such as Facebook, Instagram, Twitter and LinkedIn; media such as newspapers, radio and television; as well

as community engagement activities such as clinical site events, stakeholder meetings or community forums.

Access to data

Common data will be submitted to NIH Common Data Elements (CDE) Repository. Additional data will be available on request.

Conclusion

The study is being conducted to determine the feasibility of a COORDINATE intervention for patients living with multimorbidity to establish power calculations and evaluate the financial, technical and logistic feasibility of a full-scale study to help improve quality of life and decrease symptom burden. This intervention is novel in its use of EBCD and HCD for its development, focus on individualisation with diverse disease/condition and flexibility of standard intervention components to address the specific person-centred needs of the patients living with multimorbidity.

Twitter David N Hager @davidnhager

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Contributors BK and PD conceptualised the study. BK, SB, DNH, LS, NP, CDH and PMD were involved in the planning of the study. BK is the study's principal investigator and is responsible for conducting the study. SF and CF provided feedback on the planning and conduct of the study. All authors provided their expertise for the intervention development and continuous refinement, critically appraised and approved the reporting in a manuscript, and assumed responsibility for the content of the manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods and analysis section for further details.

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