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STUDY PROTOCOLS

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Musculoskeletal impairments after critical illness: A protocol for a qualitative study of the experiences of patients, family and health care professionals

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Abstract

Background: Survivors of critical care are at risk of long-term disability from musculoskeletal (MSK) impairments. These can have a biopsychosocial impact on the patient and their families with a reduction in health-related quality of life, increased health care utilization, caregiving roles and associated psychological distress.

Aims: To understand the experiences of patients living with MSK impairments following critical illness, and family and health care professionals supporting them, to inform the development of a future intervention to improve MSK health following critical illness.

Study Design: A four-site qualitative case study approach will be taken, with each of the four hospital sites and associated community services representing a case site. We will conduct semi-structured interviews with 10–15 patients/family members and 10–15 health care professionals about their experiences of MSK impairment following critical illness. Interviews will be audio recorded, transcribed verbatim and analysed using reflexive thematic analysis within a descriptive phenomenological approach. Alongside interview data, analysis of publicly available policy documentation, patient-facing materials and information from service leads at the four sites will be conducted. Discourse analysis will be used for this case study documentation.

Results: This protocol describes a qualitative study exploring the experiences of patients living with MSK impairments following critical illness, and the family and health care professionals supporting them.

Relevance to Clinical Practice: Data analysis will illuminate their experiences and enable data richness to contribute to the qualitative body of evidence of intensive care unit (ICU) survivors. These findings will inform the development of a complex intervention for MSK rehabilitation after critical illness.

KEYWORDS
critical care, experiences, musculoskeletal, post hospital, rehabilitation

1 | BACKGROUND

Advances in health care have led to an increased number of patients who are older, more frail and multimorbid being admitted to intensive care units (ICUs) and surviving. Many patients experience high acuity and require periods of ventilation and organ support. During this time, patients experience periods of enforced bed rest, with muscle atrophy being up to 2% per day in the first week.[1] These factors may contribute to long-term functional musculoskeletal (MSK) impairments such as decreased exercise tolerance, loss of muscle strength, chronic pain and shoulder impairment.[2] These impairments have the potential to translate into a long-term reduction in health-related quality of life, unemployment and increased health care utilization for up to 5 years.[3,4]

Beyond physical impairments following critical care, commonly there is a psychosocial impact. For patients, they may experience anxiety, depression or post-traumatic stress disorder, which may negatively influence their confidence, motivation and re-engagement in social activities.[5] The caregiving role provided by family members may be negatively impacted by financial considerations and a shared psychosocial impact.[6]

Despite the risk of long-term disability, there is no consensus on treatment interventions to deliver MSK rehabilitation following critical illness. Post-ICU studies to date have failed to demonstrate an improvement in physical function but are limited by a single intervention design.[7] Only 17% of ICU follow-up clinics employ a physiotherapist contributing to inconsistent accessibility of expertise in the management of MSK problems.[8] To date, qualitative research has largely focused on the transition of care following ICU and factors to support reintegration into the community setting.[9,10] One retrospective study explored perceptions of an exercise programme following discharge home after critical illness and highlighted that the supervised element of group exercise was considered valuable.[11] To our knowledge, there has been no qualitative exploration of patients following critical illness specifically with MSK impairments, and therefore, how they would like to see or engage in their respective post-ICU rehabilitation.

Qualitative research is fundamental to understanding the perceptions and experiences of the key stakeholders to enhance the person-centred development of an intervention. Given the constraints of the current health climate, it is important to prospectively explore the identified problem and contribute to informing the development of a complex intervention through qualitative work.[12]

What is known about the topic

- Survivors of critical illness are at risk of long-term disability from musculoskeletal (MSK) impairments.
- In addition to physical problems, the impact of post-intensive care syndrome can lead to complex interactions between patients and families across mental and social health.
- Qualitative research has largely focused on the transition of care following intensive care unit and factors to support reintegration into the community.

What this paper adds

- This protocol encompasses a methodological framework to explore the experiences of patients following critical care specifically with their MSK impairments.
- Beyond patients, this protocol will explore the experiences of their families and health care professionals providing support or respective service provision.
- The study findings will contribute to patient-centred care by informing the development of a complex intervention for MSK rehabilitation after critical illness.

2 | AIMS AND OBJECTIVES

The primary aim of this study is to gain an in-depth understanding of the experiences of patients living with MSK impairments following critical illness and inform future intervention development. The study also aims to explore the lived experiences of patient's families and health care professionals.

3 | DESIGN AND METHODS

3.1 | Study design

This qualitative study uses a descriptive phenomenological approach, through a case study design across four hospital trusts and respective localities. Data collection will include undertaking semi-structured interviews and documentary analysis with patients living with MSK

impairments following critical illness, and family and health care professionals supporting them.

The word phenomenon stems from the Greek 'phanein' meaning 'bringing' to light.[13] The phenomenological approach encompasses lived experiences and accordingly illuminates them.[14] This will enable an in-depth understanding of all the key stakeholders. These experiences will be viewed as a whole for the phenomena rather than as individual experiences.

The case study methodology allows for the exploration of a phenomenon through a variety of lenses (e.g., interviews) to illustrate multiple facets. Cases can be defined by a group of people, process or institution and therefore allowing for an in-depth exploration.[15]

3.2 | Study setting and study participants

3.2.1 | Study setting

This qualitative study will be conducted across four UK NHS trusts and their respective local community services. These services include ICU follow-up services comprising clinics and associated therapy services, post-ICU rehabilitation or community teams. With respect to the case study methodology, each trust and respective locality are bound together as an entity of investigation.

3.2.2 | Study participants

Participants will be purposively sampled to enable a range of individuals to illuminate their experiences of the phenomenon of interest, specifically their experiences of living or supporting MSK impairments following critical illness.[16]

3.2.3 | Eligibility criteria

Patient participants, family members and health care professionals will be sourced from a multicentre cohort study (MSK-ICU), which is aiming to quantitatively evaluate the MSK health state of ICU survivors,[17] 6 months after they were admitted to ICU.

Patients

Patients (aged 18 or above) are eligible for this qualitative study if they are identified in the MSK-ICU cohort study as having a severe MSK problem. This is defined as a Musculoskeletal Health Questionnaire (MSK-HQ) Score of 35 or less.[18] Patient participants will be interviewed between 6 and 9 months after admission to ICU.

Patient participants who are judged to lack capacity at the time of consent as defined by the Mental Capacity Act (2005) or who refuse consent will be excluded. Patient participants who are unable to communicate in English over the telephone for 20 min will be excluded.

Family members

Adult family members (aged 18 or above) will be invited to participate in the qualitative study if the patient participant scores 35 or less on the MSK-HQ and they have had regular contact with the participant from the outset of the injury or illness. Family members will be invited following assent from the patient participant. Family members will be interviewed between 6 and 9 months following their relative's admission to ICU. By illuminating the family perspective, this contributes an additional lens of the support needs required by the patient participant and recognizes the impact on the family following critical illness.

Family members who are judged to lack capacity at the time of consent as defined by the Mental Capacity Act (2005) or who refuse consent will be excluded. Family participants who are unable to communicate in English over the telephone for 20 min will be excluded. Those employed in a professional caring capacity will be excluded.

Health care professionals

Health care professionals may include allied health professionals, nurses, intensivists, medics or psychiatrists. Those working in either follow-up services including clinics or associated therapy services, post-ICU rehabilitation services or community services providing rehabilitation for ICU survivors from the four UK NHS trusts will be invited to participate. Health care professionals will be eligible if they either signpost or refer within a clinic setting to allied health professionals or deliver rehabilitation services. Health care professionals who are in principle and willing to engage following receipt of the participant information sheet (PIS) from the service leads' emails will email the research team.

Health care professionals working outside of the listed services will be excluded.

3.2.4 | Recruitment process

Patients and family members

Patient participants and family members will be invited to participate in this study at the initial MSK-ICU telephone call or a further convenient telephone call. The PIS will be verbally discussed by the researcher (EK) and then an electronic copy will be emailed, or a written copy will be sent to interested parties.

Health care professionals

Health care professionals who in principle are willing to engage following receipt of the participant information from the service leads' emails will contact the research team.

For both interested patients/family members and health care professionals, an appointment will be booked for a face to face, videoconference with audio recording or telephone interview. Potential participants will be informed that they can cancel the appointment if they no longer want to participate or wish to have more time to consider the information. Informed consent will be gained according to the Declaration of Helsinki (2013) prior to the start of the interview.

The researcher will explain that the participants are free to pause or stop the interview at any time.

4 | DATA COLLECTION

4.1 | Interviews

The process for interviewing patients, family members and health care professionals will be similar. One semi-structured interview will be conducted at a time and location convenient to the participant using either face to face, videoconferencing or by telephone. Participants from the coordinating site will also have the option to be interviewed on the Headington Campus of Oxford Brookes University. It is recognized that a face-to-face interview provides the best opportunity for the researcher to view the nuances and non-verbal cues from participants especially in the discussion of material that participants may find distressing. However, it is important to offer videoconferencing and telephone options to participants who prefer not to engage in a face-to-face conversation, for those who are at risk of digital exclusion, and particularly given the high level of MSK ill health in the patient cohort.[19]

Participant consent will be gained at the time of the interview. If the interview is face to face, written informed consent will be obtained by the researcher (EK or SV). If the interview is via videoconferencing or telephone, the researcher will obtain verbal consent that will be audio recorded separately from the interview recording. The researcher will read through each part of the consent form and request a verbal agreement. The researcher will self-initial each part of the paper consent form and then post it to the participant to be signed and returned.

Each interview will last up to 60 min and will be audio recorded. Following the interview, the participants will be posted or emailed a summary to enable member checking and asked to respond if they have any comments. Return of the data to the participant allows them to check for accuracy and resonance with the data.

The target sample size is 10–15 patient and family participants and 10–15 staff across all four sites. Reflecting the descriptive, phenomenological design of the study, it is not an aim of the study to reach data saturation but to gain information power from the richness of the interviews.[20–22]

Semi-structured topic guides have been developed to elicit the experience of patient participants, family members or health care professionals. This topic guide includes predetermined open-ended questions and prompts to explore particular experiences of a topic and was developed from previous literature. The flexibility of the topic guide provides the opportunity for the interviewer to explore particular responses further.

The initial questions for the patient participants explore their MSK impairments, leading onto the additional questions for patient participants' and family members exploring how they lived or supported the patient with daily activities in and out of the home. Interview questions for health care professionals explore their roles and service provision in providing MSK rehabilitation, engagement and limitations/improvements within and for services.

4.1.1 | Case study documentation

Service leads for four localities will act as gatekeepers for this study and will be approached for information about current service provision in the form of questions. This will also include documentary analysis of policy documentation (hospital and ICU) and patient-facing materials such as information leaflets and educational resources.

5 | DATA ANALYSIS

Interview transcripts will be recorded verbatim, transferred into qualitative analysis software (Nvivo 12) and anonymized during transcript checking. EK, MW, AW and SV will use reflexive thematic analysis to illuminate the lived experiences of patients, adult family members and staff participants from the interviews.

We will undertake reflexive thematic analysis through the development of codes, themes and potential subthemes. Thematic analysis will be undertaken through the six phases outlined by Braun and Clarke[23] to allow for the identification of themes and patterns of meaning across the data. In phase one—familiarization with the data—the research team will listen to and read the transcripts. In phase two, the initial analysis will be undertaken and initial codes developed leading to phase three—generating themes. In phase four, themes will be reviewed advancing to defining them in phase five. Phase six is the summarization of the findings. This will be an iterative process with discussion across the research team as critical friends (MW, AW and SV). One interview will be archived and then analysed at the end as part of referential adequacy to enhance credibility. Pseudonymized quotes will be used in research reports and publications.

Case study documentation will be collated through description and aggregation of questions and resources. Discourse analysis will be undertaken and include critical discussion among the research team. Discourse analysis interprets human experiences through the narrative of their own experiences and allows for the interpretation of the motivators behind the text.[24]

6 | CREDIBILITY AND TRUSTWORTHINESS

Numerous strategies will be employed during this research study to ensure the credibility and trustworthiness of the data. This is important to ensure there is confidence in the findings of the research, and that it accurately represents the population explored. During and after the interviews and across the development of the study, a reflexive diary will be kept by the lead researcher. Field notes will enable documentation of any non-verbal cues or poignant reflections for example. The

reflexive diary will support researcher's reflection and key decision-making. Triangulation, including the capture of researcher field notes and the reflexive diary, provide further confirmability and credibility to this study, alongside allowing the researcher to demonstrate their positionality within this research.[25] The member checking after the interviews, as described earlier, will provide further credibility.[26]

7 | ETHICS AND DISSEMINATION

This study received ethical approval from the North of Scotland Research Ethics Committee (21/NS/0143) and was approved through a substantial amendment to The MSK-ICU study: version one dated 17th June 2022.

This protocol has been written in relation to Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT)[27] and consolidated criteria for reporting qualitative research (COREQ) checklist.[28]

As described in the PIS, participants may withdraw from the study at any time without giving a reason. If participants withdraw from this study, they will no longer be contacted or have any further data collected but will use the data already collected previously will be utilized.

Findings will be disseminated to local teams, at regional and international conferences, in peer-reviewed journals and through social media. The study will be presented as part of a PhD thesis.

8 | DISCUSSION

The findings of this qualitative study will illuminate the experiences of patients living with MSK impairments following critical illness, family members supporting them on a daily basis and staff delivering rehabilitation services. Through exploring and gaining an in-depth understanding of what is important, meaningful and amenable to patients for their recovery, this will inform the development of patient-centred care. In particular, the time point of patient and family participant interviews at 6–9 months encompasses impairments that are persistent following hospital discharge, and therefore are likely to lead to long-term disability. To our knowledge, this will be the first study exploring this patient population with specific relation to their MSK impairments; recognized as a common and profound impairment following critical illness. This knowledge, alongside the MSK-ICU Study, will inform the development of a complex intervention for MSK rehabilitation after critical illness.[29]

9 | LIMITATIONS

Every effort will be made to maximize our reflexivity and credibility through member checking, yet there are some limitations to this study methodology. Excluding participants who are unable to clearly communicate in English over the phone for 20 min can prevent participation of those for whom English is not their first language or those with communication difficulties over the telephone. This risks limiting research access and diversity. Despite best efforts to ensure a variety of patient presentations, levels of family support, statuses of return to work and employment across respective localities, there is a risk that some population characteristics might not be included. If interviews are conducted over the telephone or via videoconferencing, the subtleness of non-verbal or in-person cues may be missed.

10 | IMPLICATIONS FOR FUTURE PRACTICE

There is a known failure to implement National Institute for Health and Care Excellence guidance (NICE CG83) regarding post hospital discharge critical illness follow-up and rehabilitation.[30] The knowledge from this study will enable a holistic development of interventions beyond the immediate MSK patient treatments, but wider in terms of service delivery and potential health care professional education. This study encompasses knowledge from patients, family members and health care professionals, which will contribute to overcoming the challenges of providing a dedicated service despite the heterogeneity of this patient population and the recognized need for bespoke treatments.

11 | CONCLUSIONS

This protocol describes the methodological process for a qualitative investigation into the MSK impairments of patients following critical illness, alongside their family and health care professionals. The rich insight gained from their experiences and through the case study nature will enable inter- and cross-case analyses for data richness. These findings will inform the development of complex interventions for MSK rehabilitation after critical illness.

AUTHOR CONTRIBUTIONS

EK, OG, MW, SV and AW developed the protocol. EK drafted the manuscript. MW, SV and AW are providing PhD supervision for EK. All authors contributed to and revised the final manuscript.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

ETHICS STATEMENT

Ethical approval has been obtained through the North of Scotland Research Ethics Committee 2 (21/NS/0143).

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