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Original Experimental

Liv Nyhave Andersen, Kristian Lyndrup Kristensen, Clara Margrethe Howell, Michael Skovdal Rathleff, Kirsten Fonager and Kristian Damgaard Lyng*

What matters to people with chronic musculoskeletal pain consulting general practice? Comparing research priorities across different sectors

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Abstract

Objectives: Chronic musculoskeletal pain (CMP) is a common condition, often consulted in general practice. Our previous study identified research priorities among people with CMP using a broad recruitment strategy. It is unclear whether these research priorities reflect specific settings, including the population in general practice. Potential dissimilarities may have important implications for future research. Therefore, the study aims to explore potential differences between the previously established research priorities compared to priorities of people with CMP consulting general practice.

Methods: Eighty-eight people living with CMP (51 females/37 males) from four regions of Denmark were recruited when they consulted their general practitioner. Participants were presented to an online survey and asked to prioritise predefined research themes (n=14) and research questions (n=38). The prioritisations were summarised into a Top-10 research priorities and compared the Top-10 from our previous study.

Results: Treatment (n=57), diagnosis (n=46), cross-sectoral management (n=39) and influence on daily life (n=39) were the most selected research themes. The most prioritised research questions regarded the effectiveness of treatments and cross-sectoral management, improving diagnostic approaches and how pain affects the individuals' mental state. Four out of ten research questions aligned with our previous Top-10.

Conclusions: Our study identified several differences in research priorities between people living with CMP from the general population and from general practice. These findings highlight the needs for investigating how different settings influence research prioritisation. This adds important knowledge for researchers and policymakers focusing on future research within the management of CMP.

Keywords: participatory research; chronic musculoskeletal pain; general practice

Introduction

According to the *Global Burden of Disease* study from 2017, musculoskeletal conditions have an increasing prevalence, affecting approximately 1.7 billion people worldwide [1, 2]. Chronic musculoskeletal pain (CMP) is defined as pain arising from musculoskeletal structures (e.g., muscles, bones, joints or tendons) that persists or recurs for longer than three months [3]. Living with CMP has a negative effect

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***Corresponding author: Kristian Damgaard Lyng**, Department of Health Science and Technology, Faculty of Medicine, Aalborg University, Selma Lagerløfsvej 249, 9260 Gistrup, Aalborg, Denmark; and Department of Clinical Medicine, Center for General Practice at Aalborg University, Aalborg University, Aalborg, Denmark, Phone: +45 30 66 94 39, E-mail: klyng@dcm.aau.dk
Liv Nyhave Andersen and Michael Skovdal Rathleff
Department of Health Science and Technology, Faculty of Medicine, Aalborg University, Aalborg, Denmark; and Department of Clinical Medicine, Center for General Practice at Aalborg University, Aalborg University, Aalborg, Denmark, E-mail: lnan19@student.aau.dk (L.N. Andersen), misr@hst.aau.dk (M.S. Rathleff)
Kristian Lyndrup Kristensen and Clara Margrethe Howell, Department of Health Science and Technology, Faculty of Medicine, Aalborg University, Aalborg, Denmark, E-mail: klkr19@student.aau.dk (K.L. Kristensen), chowel19@student.aau.dk (C.M. Howell)
Kirsten Fonager, Department of Clinical Medicine, Faculty of Medicine, Aalborg University, Aalborg, Denmark; and Department of Social Medicine, Aalborg University Hospital, Aalborg, Denmark, E-mail: k.fonager@rn.dk

on people and increases the risk of depression, anxiety, loneliness, functional limitations, loss of independence and quality of life [4–6]. A recent report from the Danish Ministry of Health developed a national plan of action to improve the management of people living with chronic pain through different initiatives, one focusing on improved patient involvement in research [7] and complying with the international increased focus on patient involvement in research [8, 9]. Involving people living with disabilities in research and setting priorities ensures the appropriateness and relevance of research topics, empowers stakeholders, and improves end-user recruitment and dissemination of results [10–12]. In our recent study, we attempted to investigate the research questions that were most important to people living with CMP, their relatives, and healthcare professionals (n=1,130) [13]. To this date, no gold standard within priority-setting studies is available, and the current methods often have multiple limitations [14]. Thus, we recruited participants broadly, in a manner similar to previous priority-setting exercises, through personal networks, patient organisations, and social media. This ensured a large sample size, but it is unclear if these priorities are relevant to all patients currently seeking care due to CMP. As the general practitioner is the first point of contact for many consultations due to CMP, we were interested in understanding whether the broad research priorities for people living with CMP also aligned with care-seeking in general practice. Therefore, the aim of this study was to investigate which research themes and questions were selected most frequently, which research questions were the ten most important, and to identify potential differences with previously established prioritised research questions.

Methods

This study is reported using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) and Consensus-Based Checklist for Reporting of Survey Studies (CROSS) [15, 16]. This study is based on previous results investigating the most important research questions for CMP, in cooperation with patients, their relatives, clinicians, and researchers, using a modified James Lind Alliance Priority Setting Partnership (JLA-PSP) framework [17]. Data were collected and managed using the secure web-based software platform Research Electronic Data Capture (REDCap) software hosted at Aalborg University [18, 19]. Due to the non-interventional nature of the study, it was exempt from full ethical approval by the North Denmark Ethical Committee. Oral information about participation in the study was provided to the participants in accordance with the Declaration of Helsinki. Written informed consent was obtained before data collection. Data can be made available upon request to the corresponding author.

Design

The study was designed as a quantitative cross-sectional survey that included 59 questions covering eligibility (n=3), demographics (n=4), research themes (n=14), and research questions (n=38). The survey was based on the research questions identified from the interim phase of the previous study by Lyng et al. The development of the survey consisted of four steps:

- Rephrasing and sorting of original research questions [13]
- Design/Layout
- User test (think-aloud)
- Final reiteration

First, we obtained the original research questions (n=38) in Danish, the original language, which was simplified into layman terms to make the survey simpler and more understandable (Supplementary file 1). The research questions were collated into 14 themes to make the survey more manageable for participants (Supplementary file 1). The original research questions were rephrased and sorted iteratively until a uniform consensus within the group was achieved. The survey was designed to contain a series of demographic questions and 14 predefined main themes. Here, the participants were given the opportunity to choose the themes of most relevance and filter out the least relevant research questions. Based on the selected themes most relevant to the participant, subsequent research questions were presented to the participant, who then had to choose the research questions that were most important to themselves. Lastly, the survey was designed to assign a rank to the selected research questions from most to least important (0–10, 0=least important and 10=most important) to conduct a list of the most important research questions. The structure of the survey is illustrated in Figure 1. Think-aloud tests were used to ensure 1) that the research questions were paraphrased correctly and 2) test the designed survey for setup, usability, and face validity. Eight participants from various backgrounds (two people living with CMP, two researchers within CMP, and five healthcare practitioners) participated in the think-aloud testing, and feedback was implemented in the survey for final reiteration. See Supplementary file 1 for the final survey.

Participants

Participants were considered eligible for participation if they were 18 years or above and fulfilled the criteria of the

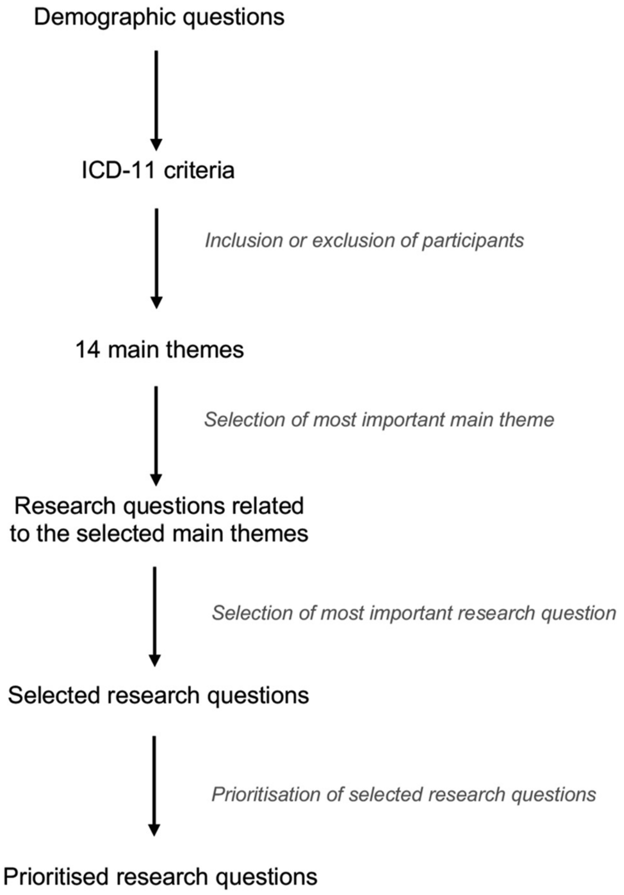

Figure 1: Flowchart of questionnaire.

ICD-11 for chronic primary musculoskeletal pain (i.e., pain in one or more anatomical regions, that had persisted or reoccurred for longer than three months, which was associated with significant emotional distress or significant functional disability and could not be explained by another chronic condition.) [3, 20].

Recruitment

The current study recruited people who met their general practitioner using a purposive and consecutive sampling strategy. To ensure representability, we intended to include a diverse group of participants by selecting general practices in multiple regions of Denmark. The data collection began in March 2022 and ended in October 2022.

Analysis

Descriptive statistics were used to describe the results. The most frequently chosen research themes and questions were then identified. The ten most important research priorities were calculated based on the total number of points based on the assigned value (1–10) from all participants, with ten being the highest points and one the lowest. At last, the Top-10 most important research questions were compared to the Top-10 of our previous study.

Results

Data were collected in seven different general practices representing four regions of Denmark. From here, 88 participants were qualified and completed the survey. Full demographics are presented in Table 1. The results from the survey are represented in regard to the chronological order of the survey as displayed in Figure 1.

Table 1: Demographics of participants.

	n (%)
Age in years	
18–30 years	9 (10.2 %)
31–40 years	17 (19.3 %)
41–50 years	15 (17.0 %)
51–60 years	11 (12.5 %)
61–70 years	15 (17.0 %)
71–80 years	13 (14.8%)
80+ years	8 (9.1%)
Sex	
Female	51 (58 %)
Male	37 (42 %)
Other	0 (0 %)
Do not want to state	0 (0 %)
Region	
Region of Northern Jutland	50 (56.8 %)
Region of Central Denmark	15 (17.0 %)
Region Zealand	17 (19.3 %)
Capital Region	6 (6.8 %)
Ethnicity	
Danish	79 (89.7 %)
Immigrant	3 (3.4 %)
Descendant	3 (3.4 %)
Do not want to state	3 (3.4 %)

The table displays that most participants were 31–40 years old, and the least participants were 18-30 years old or 80+ years old. The majority of participants were represented by women. Half the participants were residents of Region of Northern Jutland, and the other half was distributed across Region of Central Denmark, Region Zealand, and Capital Region. Lastly the participants were predominantly represented by Danes and sparsely represented by immigrants and descendants.

Prioritization of main themes

The selection rate of the 14 main themes by all participants is represented in Figure 2. Of the 14 main themes, the five most chosen themes were *treatment (n=57), diagnosis (n=46), cross-sectoral management (n=39), influence on daily life (n=39)* and *disease mechanism (n=30)*. The least chosen theme by the participants was *inequality in healthcare and stigmatisation (n=8).*

Prioritization of research questions

The selection rate of research questions was determined. For the full list of selection rate of research questions, see Supplementary file 2. Nine out of ten most selected research questions were also represented on the top ten research questions based on the point-based assigned value. The ten most important research questions are represented in Table 2. For the full list of prioritised research questions, see Supplementary file 3.

Comparison between previous PSP

The ten most important research questions were compared to the ten most important research questions from our previous study. Four out of ten research questions were represented on both top-10 lists regarding improved diagnostics, enhanced patient education, effective treatment options and pathogenesis of CMP. Our previous study identified important research questions regarding specialised pain clinics, municipal management, healthcare professionals (HCP) education, cost-effective treatment options and coherent organisational care pathways. This study identified important research questions regarding cross-

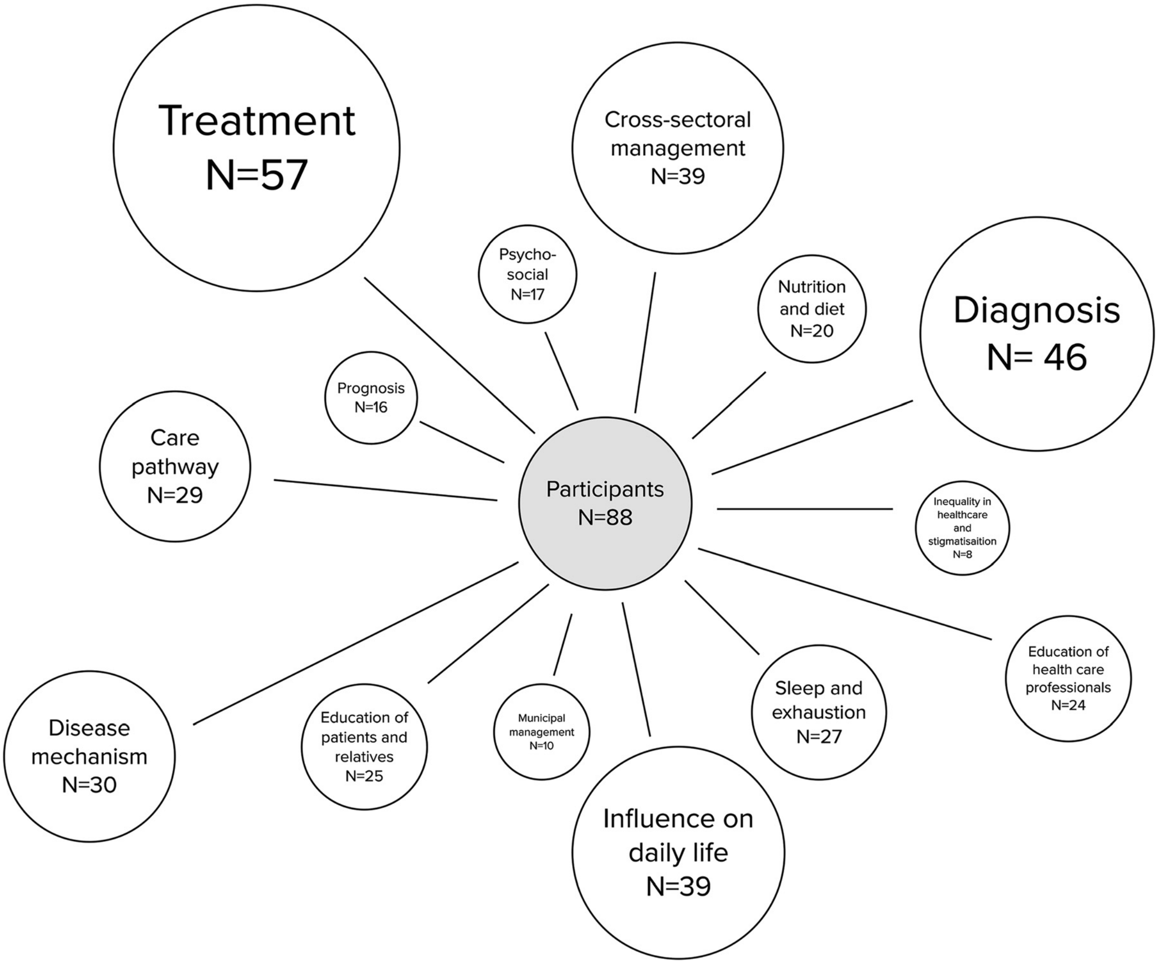

Figure 2: Selection rate of main themes.

Table 2: Ten most important questions in prioritised order.

No.	Research questions
1	What is the most effective treatment for patients with *chronic pain in muscles, bones and joints*?
2	What is the effect of cross-sectoral management of patients with *chronic pain in muscles, bones and joints* have – and can we optimize it?
3	How do we improve diagnostic methods in order to give a diagnosis faster and more accurately?
4	How can we reduce the time before getting a diagnosis while minimizing diagnostic errors?
5	How does *chronic pain in muscles, bones and joints* affect the patient's mental status, thoughts, concentration, and memory, and how can this effect be reduced?
6	What influence does *chronic pain in muscles, bones and joints* have on quality of life and how can it be improved?
7	How can we identify the patients, who are at risk of getting *chronic pain in muscles, bones and joints*, faster?
8	What is the reason someone develops *chronic pain in muscles, bones and joints*, and what increases the risk of it?
9	How can the quality of sleep be improved for patients with *chronic pain in muscles, bones and joints*?
10	How can patients gain more knowledge on their own condition, and become better at handling their own pain?

This table displays the ten most important research questions selected by participants met in general practice. The top-10 research priorities were identified by assigning selected research questions a value from 1 to 10, ten being the highest points and one being the lowest point.

sectoral management, influence on mental status and quality of life and lastly, sleep quality. The similarities and differences are represented in Table 3.

Discussion

One of the main objectives of research is to resolve the most important challenges experienced by the people that the research revolves around [21]. Several studies have mapped the most important research questions in relation to musculoskeletal pain, however, these studies do not reflect how recruitment setting influences what the most important research question is to resolve [13, 22, 23]. In this study the most frequently selected overarching research themes were treatment, diagnosis, cross-sectoral management, and influence on daily living. The highest prioritised specific research questions were the questions related to 1) finding more effective treatment strategies, 2) investigating the effect of cross-sectoral management, 3) improving diagnostics, 4) investigating how pain influences mental health, 5) improving quality of life and 6) improving sleep quality and lastly 7) improving knowledge on own condition. Interestingly, compared to our previous study, only four out of ten research questions aligned with the previously established top-10. These findings suggest that we need to address the differences across different samples to determine research priorities for future research.

A recent meta-ethnographical study based on over 3,000 people with chronic pain aimed to understand the experience of living with chronic pain, including chronic musculoskeletal pain [24]. In this study, it was highlighted that living with chronic pain should be understood as an iterating journey in which the paining person must learn to reconceptualise their pain in order to improve their conditional state as opposed to understand it as a static condition. Our findings might reflect that the most important priorities depend not only on where the individual is on their healing journey, but also on the link between the setting in which they are situated. The element of temporality in living with chronic pain was also highlighted in a study by Nilsen and Elstad, who interviewed people with pain lasting between 3 and 30 years [25]. This study emphasised how the dynamic and unpredictable experience of living with pain could complicate how clinicians and people with pain communicate and vice versa [25]. These results help us recognise the importance of understanding priorities across different settings and at different times in their pain journey. Furthermore, it demonstrates that it needs to be acknowledged that when pain changes, priorities may follow. Importantly, it needs to be acknowledged that variations in the research priorities found in our study might be contributed to other factors than just setting and conditional state. Compared to our previous study, we observed key differences in gender composition (35 % smaller proportion of women) and age group representation (In Lyng et al. most dominant age group were 51–60-year-olds (36 %) and in this study 31–40-year-olds (19 %) were the most dominant). Due to the small sample size of this study, we were unable to compare research priorities between gender and age. To our knowledge there are no studies that has directly investigated gender or age specific differences in research priorities within CMP, however, individual characteristics are known to differ across gender and age, e.g., pain severity [26, 27], illness perception [28] and health literacy [29], which could influence prioritisation and should be kept in mind in future studies. Another important demographic factor was the underrepresentation of non-Danish ethnicities in both studies (Lyng et al. 3 %, this study 7 %). Recent studies have identified variance in coping mechanisms and pain experience when comparing ethnicities [30, 31], which could impact research question prioritisation and should be investigated in future studies.

Additionally, a Danish study by Mose et al., observed significant differences in care-seeking behaviours across five distinct trajectories, where it was highlighted that high-users of the healthcare system had greater use of pain

Table 3: Comparison of ten most important research questions with Lyng et al.

Lyng et al. [11]		**This study**
How can specialised pain clinics support people living with chronic MSK pain compared to usual care-pathways?	1	What is the most effective treatment for patients with *chronic pain in muscles, bones and joints*?
How can we minimise errors in diagnosing people living with chronic MSK pain?	2	What is the effect of cross-sectoral management of patients with *chronic pain in muscles, bones and joints* have – and can we optimise it?
How can patient education be improved in order to make patient more knowledgeable in their own condition?	3	How do we improve diagnostic methods in order to give a diagnosis faster and more accurately?
What is the most effective treatment option(s) for people living with chronic MSK pain?	4	How can we reduce the time before getting a diagnosis while minimizing diagnostic errors?
How can we improve the general level of knowledge chronic MSK pain for clinicians to ensure better management of these people living with chronic MSK pain?	5	How does *chronic pain in muscles, bones and joints* affect the patient's mental status, thoughts, concentration, and memory, and how can this effect be reduced?
How can current care-pathways be improved to ensure a more coherent organisation?	6	What influence does *chronic pain in muscles, bones and joints* have on quality of life and how can it be improved?
How can we ensure that people living with chronic MSK pain receives the same support in the municipalities to avoid stigmatisation and dissatisfaction?	7	How can we identify the patients, who are at risk of getting *chronic pain in muscles, bones, and joints*, faster?
What is the mechanism and which risk factors (e.g., other illness) are associated with developing chronic MSK pain?	8	What is the reason someone develops *chronic pain in muscles, bones, and joints*, and what increases the risk of it?
How can we improve the management that people living with chronic MSK pain receive in the municipalities?	9	How can the quality of sleep be improved for patients with *chronic pain in muscles, bones, and joints*?
What is the most cost-effective treatment to people living with chronic MSK pain?	10	How can patients gain more knowledge on their own condition, and become better at handling their own pain?

This table displays the two top-10 list of the study by Lyng et al. and this study, respectively. The green color highlights the similarities in research priorities between studies. NB: Some of the research priorities in this study have been formulated differently to improve readability.

medication, more invasive treatment contacts and higher depressions scores [32]. In continuation hereof a qualitative follow-up study explored the motives for care-seeking behaviour and found considerable differences; low-users of the healthcare system sought to rule out serious conditions and preferred self-management opposed to high-users of the healthcare systems that expected HCP's to be partners, used both conventional and alternative treatment options, and sought explanation for their pain [33]. The differences in care-seeking behaviour adds on another perspective to the variations in research priorities depending on setting and individual pain characteristics.

Our findings are not without limitations and especially it should be noted that we currently lack a golden standard for end-user driven research, including the gathering of research priorities directly from the end-users. In the last years, several mixed-methods studies, systematic reviews, and realist review studies have investigated how patient and public involvement can be assessed and evaluated [34–39], and even more frameworks have been developed [40]. The role of evaluating the impact and validity of patient and public involvement in research remains heavily debated. Some studies question the current conceptualisation of patient and public involvement and highlight that the purpose of this kind of research is not necessary to determine the benefits and effectiveness but more so to create value in other ways, such as public knowledge, empowerment, and even to reduce the perception of isolation felt by researchers conducting medical research [41–44]. While there are undoubtedly limitations in using patient and public involvement in studies and hence our study too, researchers should acknowledge the continued relevance of patient and public involvement. Furthermore, this study was conducted to test the external validity of our previous study to the population in general practice with a previously established list of future research priorities within CMP. The main limitation of our study was the lack of proper sample size calculation; hence, the results should be interpreted with a certain degree of caution. Additionally, a potential limitation of our study was the lack of data on diagnostic profiles, length of complaints and sociodemographic backgrounds (e.g., specific ethnicity, household income). Knowledge on pain sites, pain duration and sociodemographic background secures better understanding of research prioritisation due to pain characteristics, which should be included in future studies.

To our knowledge, we are the first to conduct this type of study, and it can be speculated whether this was the most appropriate method to test the external validity and priorities across different settings. An alternative method would be to interview people living with CMP to encapsulate their experiences and preferences for future research priorities. This approach would enable the collection of in-depth details regarding what and why of future research priorities, although the sample size would be drastically smaller than what is seen in our study.

Conclusions

This study identified that four out of ten research questions aligned with our previously identified research priorities. This suggests that research priorities may differ depending on the setting, which provides important knowledge for policymakers and future end-user-driven research. Therefore, this study underlines the need for validating end-user-driven research across different settings.

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Research ethics: This study was exempt from full ethical approval by The North Denmark Region Committee on Health Research Ethics due to the design of the study.

Informed consent: Informed consent was collected prior to data collection. All data were stored in accordance with the GDPR law.

Author contributions: All authors made significant contributions to designing the protocol, data collection forms, interpretation of data and manuscript writing. LNA, KLK, CMH and KDL conducted the data collection. All authors have approved the final version of the manuscript.

Competing interests: No authors have any conflicts of interest to declare.

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Data availability: Data can be made available upon request to the corresponding author.

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