

ORIGINAL RESEARCH

Important, misunderstood, and challenging: a qualitative study of nurses' and allied health professionals' perceptions of implementing self-management for patients with COPD

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Background: In light of the growing burden of COPD, there is increasing focus on the role of self-management for this population. Currently, self-management varies widely. Little is known either about nurses' and allied health professionals' (AHPs') understanding and provision of self-management in clinical practice. This study explores nurses' and AHPs' understanding and implementation of supported COPD self-management within routine clinical practice.

Materials and methods: Nurses and AHPs participated in face-to-face semistructured interviews to explore their understanding and provision of COPD self-management, as well as their perceptions of the challenges to providing such care. Purposive sampling was used to select participants from a range of professions working within primary, community, and secondary care settings. Three researchers independently analyzed each transcript using a thematic approach. Results: A total of 14 participants were interviewed. Nurses and AHPs viewed self-management as an important aspect of COPD care, but often misunderstood what it involved, leading to variation in practice. A number of challenges to supporting self-management were identified, which related to lack of time, lack of insight regarding training needs, and assumptions regarding patients' perceived self-management abilities.

Conclusion: Nurses and AHPs delivering self-management require clear guidance, training in the use of effective self-management skills, and education that challenges their preconceptions regarding patients. The design of health care services also needs to consider the practical barriers to COPD self-management support for the implementation of such interventions to be successful.

Keywords: self-management, COPD, qualitative, interviews, nurses, allied health professionals

Introduction

Background

COPD is a global health issue and the fourth-leading cause of death worldwide, with morbidity and mortality predicted to rise in coming years.¹⁻⁴ COPD exacerbations can result in increased health care utilization and significant burden to the individual.4-6 Self-management has been defined as the systematic provision of supportive interventions designed to increase patients' skills in decision making, problem solving, utilizing resources, and taking action. 1,7-10 Self-management is an integral part of good practice models in chronic disease management, as it seeks to enhance patient confidence, health, and well-being while reducing health care utilization. 11-18 In light of the growing burden of COPD, there is increasing focus

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on the role of self-management within this population, enhanced by a growing body of evidence advocating its benefits; however, the precise format and structure of self-management is inconsistent. ^{4,6,19–23}

Heterogeneity exists between COPD self-management interventions, and there is a lack of guidance on what components form essential prerequisites. This may create confusion for patients, nurses, and allied health professionals (AHPs), and consequently some self-management studies report little impact or negative outcomes. 1,5,24-26,27 The delivery of self-management requires a skilled and knowledgeable practitioner to best enable collaborative working and the acquisition of skills by the patient. 28,29 Confidence in this practitioner has been shown to be important in COPD care, but there has been little focus on the role of the nurses and AHPs in the implementation of self-management for COPD. 28

Challenges to self-management

The chronic care model highlights that self-management implementation requires investment in professional development, yet there is a lack of specialist training and education available specifically for COPD. 9,11,30 This absence leaves self-management support very dependent upon nurses' and AHPs' existing perceptions and knowledge.31 Although these perceptions have been described across other chronic disease groups, to our knowledge only one small survey study has been conducted with nurses working with COPD patients. 7-9,14,16,28-30,32-36 This study highlights a wide variety of definitions of self-management, as well as a number of limitations to self-management delivery.³⁶ No in-depth qualitative studies have specifically explored nurses' and AHPs' understanding of self-management for COPD or their perceptions of the challenges to providing such care. Given that COPD follows an uncertain disease trajectory, and that patients can feel guilty about the often self-inflicted nature of the disease and embarrassed about symptoms, such a study is particularly timely. 28,29,37-39

The purpose of this study was to explore nurses' and AHPs' understanding of self-management for COPD, as well as their perceptions of the challenges to providing such care. Understanding these views is an important step toward enhancing COPD self-management implementation and training.

Materials and methods Ethical approval and consent

The study was approved by the Local Research Ethics Committee, University Hospitals of Leicester Research and Development Department, Leicestershire, Northamptonshire and Rutland Primary Care Research Alliance, and the West Midlands South Comprehensive Local Research Network (07/H0408/114). All participants gave written informed consent.

A qualitative methodology utilizing a phenomenological approach was employed, as the aim of this study was to explore the lived experience of nurses' and AHPs' supporting COPD self-management and their perceptions of the challenges to providing such care.

Design and setting

Face-to-face semistructured interviews lasting 35–90 minutes were used to explore participants' views in depth. The interview schedule included open-ended questions and probes, the development of which was informed by a thorough literature review and the research team's experience of supporting self-management. Example interview questions are included in Figure 1. Initial interviews acted as pilots. Interviews were conducted in a private setting within the participants' workplace by a research physiotherapist (VLJW) who was unknown to the participants, to allow them to speak freely.

Sample

A convenience sample of nurses and AHPs (physiotherapists and an occupational therapist) from primary, community, and secondary care settings were recruited via National Health Service (NHS) primary care trust websites, poster advertisements, and mail-outs to practice managers. These participants were all currently or recently (within the last year) working with COPD patients, and might reasonably have been supporting them with self-management as part of their role. Neither primary nor secondary care physicians were included in the study sample, because they are unlikely to deliver structured self-management interventions in a UK health care setting.

Can you tell me a little about what you do for patients with COPD that you have contact with?

What do you understand by the term "self-management"?

Do you think self-management is important for patients with COPD? If yes, in what ways? If not, why not?

How well do you think you currently help patients to self-manage their COPD? What do you do to help this? Any difficulties in doing this?

Do you feel there are any barriers for patients to adopt self-management strategies?

Figure I Example questions from the interview schedule.

From a pool of interested nurses and AHPs, purposeful nonprobability sampling was utilized to select participants with a wide diversity of views, using a variety of different criteria (Table 1). Sampling occurred until data saturation was achieved, ie, no new insights or information were gathered.⁴⁰

Data analysis

All data were audio-recorded and professionally transcribed verbatim. Field notes were also subject to analysis. NVivo software (version 9; QSR International, Doncaster, VIC, Australia) was used to manage all data.

Thematic analysis was selected as the means of data analysis, because it allows for the systematic organization of data and enables explicit and implicit constructs within the participants' accounts to be linked into comprehensive a account that encapsulates participants' experiences. This is of particular relevance to qualitative work that may help to inform policy and practice development.⁴¹

Three researchers who were AHPs with extensive experience in self-management, COPD, and qualitative research (HMLY, SLH, and LDA) independently familiarized themselves with the data and generated initial codes inductively from the data and identified themes. These themes were reviewed and defined collectively by the whole research team, who moved back and forth between stages as new themes emerged and relationships were recognized. Reliability was ensured through continuous discussion about the data with the wider multidisciplinary research team. Consensus meetings were utilized to ensure agreement over emergent themes.

Table I Participant characteristics (n=14)

Women, n (%)	14 (100)
Ethnicity, n (%)	
White British	13 (93)
African Caribbean	I (7)
Profession, n (%)	
Physiotherapist	3 (21)
Respiratory research nurse	3 (21)
Practice nurse	3 (21)
Community respiratory nurse	2 (16)
Respiratory nurse	I (7)
Nurse practitioner	I (7)
Occupational therapist	I (7)
Grade, n (%)	
Specialized	10 (71)
Highly specialized	4 (29)
Missing information	I (7)
Years of NHS experience, mean (SD)	18.88 (10.31)
Years of respiratory care experience, mean (SD)	7.53 (5.31)

Abbreviations: NHS, National Health Service; SD, standard deviation.

Results

A total of 35 nurses and AHPs received information regarding the study. Fourteen agreed to participate, from a group of 18 who initially expressed interest. Of the four who did not take part, two were unable to attend and two were not eligible for the study. Participant characteristics are summarized in Table 1. None of the participants had undertaken specific self-management training with respect to COPD.

Emergent themes

Analysis of the data resulted in two larger themes representing nurses' and AHPs' understanding and delivery of self-management and perceived challenges to supporting self-management. These are described further with relevant subthemes: 1) understanding and delivery of self-management (education, behavior change, collaboration, other skills), and 2) challenges and barriers to self-management (time, experience, patients).

Nurses and allied health professionals' understanding and delivery of supported self-management: misunderstood and variable

All nurses and AHPs recognized the importance of selfmanagement in the care of their patients, as it primarily allowed them to utilize their limited time effectively. Despite this, it was clear that there were misunderstandings regarding self-management, and participants gave a wide spectrum of different definitions.

Many participants spoke of referral to pulmonary rehabilitation (PR) when asked about the self-management support that they provided to COPD patients. Participants described how supporting self-management was not always integral to their daily practice, and thus referral to PR became an alternative. See Table 2 for example quotations. Two practice nurses expressed deep frustration at not being able to directly address patients' self-management needs, while others had actively taken steps to allow them to assist with supporting self-management within the constraints of their role.

Education

Perceptions of the delivery of self-management in practice also varied. All nurses and AHPs considered education to be a key element, and felt that their patient's knowledge was directly related to accurate symptom interpretation and speedier engagement with health care services. Education was delivered to patients verbally, and aimed primarily to encourage compliance, particularly in relation to medications

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Table 2 Exemplar quotati	ions from interviews regarding	Table 2 Exemplar quotations from interviews regarding nurses' and AHPs' understanding of self-management and its importance
Theme	Subtheme	Participant quotation
Understanding of self-management	Importance	It's a chronic condition that's not going to go away. The more control they have over the disease, then the better they'll feel in themselves, and it can obviously reduce hospital admissions and reliance on health services. It's empowering for them
)	Misunderstanding	it gives them more of a voice (physiotherapist) Participant definitions of SM range from: Patients being able to manage themselves in the community without having to speak to or be
		involved with a health professional (occupational therapist) To Fool management more partiaged from the procession than the procession for this of the partiaged for the part
		ro. Isen-management, means parents ram me necessar y knowrege and skins to be agie to cope with their disease [wine] sun having advice and treatment when needed (physiotherapist)
		I do nurse-led COPD clinics. I follow the NICE guidelines, so inhalers so I talk to them about pulmonary rehabilitation and get them
		referred if they're willing \dots (practice nurse)
		I have to send them away to the stop-smoking service, rather than dealing with it myself. I just get down to the nitty-gritty, then I have
		to send them away, so they go off the boil. If I could deal with that myself, that would be a big help (practice nurse)
Abbreviations: AHPs, allied hear	Abbreviations: AHPs, allied health professionals; SM, self-management; NICE,	NICE, National Institute for Health and Care Excellence.

and exacerbation management. See Table 3 for example quotations.

Behavior change

Nurses and AHPs described feeling powerless to address the behavior change they viewed as another key part of self-management. Some participants assumed that increased knowledge via the provision of facts and information would automatically encourage health-behavior change. Participants felt that it was difficult to assess a patient's readiness to change. Most were hesitant about approaching patients they viewed as resistant or ambivalent. They struggled to identify management strategies for these patients and to assess whether these were effective. Only one professional was using motivational interviewing, a patient-centered counseling approach to enhance motivation to change and explore ambivalence. 42,43 See Table 3 for example quotations.

Collaboration

Three participants described working collaboratively with their patients, which was primarily achieved by developing a rapport. They believed this rapport encouraged honesty and helped the professional to tailor their support. Despite this, the majority of the nurses and AHPs still set the agenda for their consultations, provided patients with solutions to their problems (as perceived by the professional), and "gave" them self-management skills. See Table 3 for example quotations.

Other self-management skills

To a much lesser extent, participants described using other self-management techniques in practice. Goal setting was considered valuable in helping motivate and encourage patients, yet nurses in particular were unfamiliar with structured goal setting. Only three participants felt it important to help patients access and utilize other health care resources. Action planning for acute exacerbation was similarly underutilized, although participants were aware of the potential benefits of these plans. See Table 3 for example quotations.

Challenges and barriers to supported self-management

Time

The greatest perceived challenge to the provision of selfmanagement support to COPD patients in practice was lack of time, exacerbated by the need to prioritize other tasks. Other activities, particularly achieving the Quality and Outcomes

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Variable delivery of self-management	tion	It's for the patient to recognize their symptoms: when they're getting worse, compliance with their medication, knowing about what their
Behavic		condition is, and what it's caused by (practice nurse) We provide them with information, with the leaflets we have. [They include] practical things about managing breathlessness, trying to save their energy, being aware of when they're becoming breathless making sure they're taking their medication (occupational therapist) their energy, being aware of when they're becoming breathless making sure they're taking their medication (occupational therapist) I tend to [give education] one to one, and then I back it up with booklets. I've got one at the moment that I give out. I talk to people about the fact that it covers all the ranges of COPD and you know a lot of the stuff might not apply, so not to get concerned by it. The most important thing is that you actually don't just hand it over; you go through it with them so they understand where the benefits are; otherwise, the risk is it gets taken home and stuck in a drawer somewhere and never used (practice nurse) For patients, education is very generic: we cover everything really. The main things that we look at [are] quality of life and prevention of exacerbations. We obviously talk a lot around inhalers, the benefits that inhalers give, such as preventing exacerbations, why things such as
Behavic		nebulizers aren't always the answer; you know, recognizing exacerbations, managing flare-ups, and knowing when to call upon other people (community respiratory nurse) There's a lot of little handouts we give out, and just the "I've not read it", "Oh, it got covered in water", or "I've lost it", you know, "Oh another leafler", maybe that's not the hest way (nhysintheranist)
	Behavior change	If they understand about their health and what they need to do to improve, that encourages them, doesn't it? (practice nurse) You try and encourage them, you make your recommendations but you can't force people to do things I will give them the information, and I think that's all you can do (occupational therapist) Sometimes, you think [the patient] didn't take anything on board, and then you meet them 12 months later and they say "Oh, by the way, I stopped smoking", or unfortunately, the other extreme is that you keep seeing them in hospital (respiratory nurse) Its hard to judge [how many patients change behavior in relation to smoking]. I feel they take it on when they're sitting next to me – they will
		listen, nod, and agree – but its hard to judge that really (practice nurse) If they haven't done any exercise for a long time, it's quite a big change of mindset, trying to break down that vicious cycle of not wanting to do any exercise 'cos it makes them breathless can be a problem (physiotherapist)
Collabo	Collaboration	I think a lot of the time, the sputum can be addressed quite quickly, and then we get on and discussing the main [things], like activity, health promotion, and support (community respiratory nurse) Giving people strategies to be able to recognize when their disease is changing or if they're becoming unwell with an infection and strategies to deal with that (physiotherapist)
Other skills	· skills	I haven't got experience of setting goals in a structured way but that would be something that [is] part of what we do (community respiratory nurse) No, I don't use an action plan at the moment. I think there is a need for it it would be nice to have something formal that you could send out with them (practice nurse)

Framework indicators, were often prioritized. See Table 4 for example quotations.

Experience

Eleven participants felt that their professional knowledge alone ensured the skills and competence to support COPD patients to self-manage. Consequently, the majority of nurses and AHPs, when this was explored further, were often not consciously aware of any personal learning needs regarding self-management, although the learning needs of more junior staff were identified.

Despite this, three participants identified that greater experience and levels of specialism may create difficulties communicating with patients, and sharing "control" with patients. Another participant outlined some of the self-management advice that she had picked up through her practice, which highlights a lack of standardization in the self-management support and education provided to patients. This has the potential to lead to inconsistent messages provided to patients across health care settings. See Table 4 for example quotations.

Patients

The provision of self-management support in practice was further influenced by participants' assumptions about a patient's ability to self-manage. Older patients were seen as less confident, unmotivated, and having greater potential for cognitive deficits that could impede self-management. Five participants also felt that older patients preferred to defer responsibility for managing their condition to the professional, as well as enjoying the social interaction offered by regular visits to health care services. Older COPD patients were viewed as less likely to regard their symptoms as deviant from the normal aging process, and thus less likely to engage in activities aimed at addressing them.

Self-management was also believed to be culturally less acceptable to patients from ethnic minority backgrounds, and yet participants did not specify what these barriers might entail. Practical issues, such as language barriers, also made collaboration and education more difficult. These assumptions appeared to influence the amount and type of support that these groups of patients were given. See Table 4 for example quotations.

DiscussionMain findings

This study is the first to examine nurses' and AHPs' perceptions of self-management specifically in relation to COPD, and our findings have important implications for both the

perceptions of challenges and barriers to supported self-management Table 4 Exemplar quotations from interviews regarding nurses' and AHPs'

Theme	Subtheme	Participant quotation
Challenges and	Time	"There's always the issue in general practice of what we do being managed by the QOF, so I can do the MRC scale because that's part of the QOF
barriers		but what you don't get so much time for is actually addressing the issues that come up" (nurse practitioner)
	Professional	"I've been here for quite a while, so I think obviously you pick up things, don't you? I feel quite confident that I could deliver [self-management] at a
	experience	basic level. I think it's about experience I've had the training I need" (occupational therapist)
	sufficient	"I've got the expertise now because I have done COPD for 12 months. I am more confident" (community respiratory nurse)
		"I don't necessarily feel that the [junior AHP] would have those skills, not because I don't think they could do it, but I think it's a training thing and i
		time" (occupational therapist)
		"I think one of the problems with trying to educate people is when you forget you're coming from a specialist perspective actually a lot of the
		terminology that is second nature to you, a lot of ideas that are second nature are absolutely brand new to patients" (nurse practitioner)
		"Walk up the stairs and come back down, up and down, and to get out for at least 20 minutes walking each day. Breathing exercises as well, I go
		through that with them, deep breathing exercises. I've had some really good results actually with that. It's just what I have picked up myself through
		the years, you know" (practice nurse)
	Patients	"I'm picturing an elderly frail lady [tuts]. I just cannot picture her being motivated to act" (respiratory research nurse)
		"There are some people [whose] visits to the surgery are something of a social occasion, and they enjoy coming in and they like to hand it over
		to you" (nurse practitioner)
		"I think the older generation tend to put things down to age. It becomes an excuse sometimes" (practice nurse)
		"One of the issues was around the ethnic patients and the problems that we used to have [with] cultural issues" (respiratory nurse)
		There's a lack of English language in this area they're just not very keen and I think it's because of the language barrier (practice nurse)

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implementation of self-management within clinical practice and professional education. Although very mixed views about self-management existed, in general it was seen as an important way to utilize limited resources efficiently while empowering patients. There was explicit lack of coherence about how to support self-management, which created variation in practice. There are also a number of practical barriers and professional assumptions that appear to influence self-management implementation negatively.

Self-management is shrouded in confusion for professionals working in clinical practice, and the term is often rather curiously used synonymously with PR. This variation is perhaps unsurprising, given that research designed to evaluate self-management has shown large variation in content, follow-up, and outcome measures used. PR includes patient education, psychological support, and behavior modification designed to enhance self-management, but is distinct in that it also provides opportunities for social interaction and supervised exercise.²⁴ PR is often only offered at the latter stages of COPD, can be resource- and time-intensive, and may not be appropriate or readily available for many patients.^{14,24}

Limitations

Although the interviews provided a great deal of rich data, the study was not without its limitations. The sample of nurses and AHPs recruited for the study were all female, predominantly of white British background. While the sex and ethnicity bias reflects the general trends within the UK health service workforce, we cannot be certain whether the viewpoints of participants in this study would be shared by male participants and those from other ethnic backgrounds. We did not confirm whether participants had in fact received formal training for self-management in any other long-term condition. Interestingly, this was not identified by any participants, suggesting that no relevant training that may have influenced their knowledge and skills in relation to COPD self-management had been received.

Interpretation of findings in relation to previous work

This study demonstrates that increasing patient knowledge was viewed by participants as a key element of self-management, sufficient to ensure behavior change, while other elements were marginalized, due to lack of time, awareness, and professional confidence. Nurses and AHPs have difficulty detaching themselves from traditional health education models that encourage them to provide information

based on their interpretation of the impact of the disease for the patient. 30,32,35,44-47

Delivered alone, such education has little impact upon patient behavior across a spectrum of chronic diseases, including COPD, as it fails to consider patients' self-efficacy and the importance they place upon behavior change. 1,3,18,20,28,29,36,46-48 Self-management support requires nurses and AHPs to regard their expertise as complementary to that of the patients in managing their disease within the context of their life. 4,7,8,10,14,16,24,28,42,43,49-52 Despite this, our study and others highlight that nurses and AHPs often facilitate collaboration solely through the development of a good rapport with the patient. 18 The resultant partnership work is often superficial, as many of the professionals still sought to lead consultations and viewed patients' failure to comply with their advice as evidence of the individuals' inability to self-manage. These assumptions may block patients' attempts to become more autonomous, perpetuating passivity. 13-17,32,33,44,50

This study highlights the fact that the nurses and AHPs base their current self-management practices upon knowledge and skills developed through practice and experience rather than formal training, and that most are not aware of any education needs. This is supported by a study evaluating a self-management training program that concluded that many professionals felt they already possessed the necessary skills and knowledge to deliver self-management support.³⁵ This represents a significant barrier to the delivery of training to nurses and AHPs, as professional experience alone has been found to be insufficient preparation to deliver self-management in other chronic diseases and leads to the selective use of strategies that may be ineffective or inappropriate. 16,18,31,33,52 Structured training forms a standard part of the delivery of some self-management interventions in other long-term conditions (eg, the DESMOND [Diabetes Education and Self Management for Ongoing and Newly Diagnosed] program for diabetes), and a similar approach appears warranted in COPD care.

Previous qualitative literature has demonstrated how nurses and AHPs use judgments about patients to predict their likely behavior and thus guide patient interactions and care. 53-55 More recent studies have also shown that judgments are also made in relation to patient's ability to self-manage, although this has not previously been demonstrated in COPD. 47 Our work indicates that these extend to the belief that older and ethnic minority patients are less able to undertake self-management. 31,35,45 The assumptions made by nurses and AHPs about what care is appropriate for them may prevent this patient group from receiving appropriate

and tailored support. 4,10,47 Self-management training must additionally address these issues.

A recent Cochrane review indicates clear benefit of self-management interventions, and thus should be internationally endorsed. The trials are heterogeneous, and range from a complex supervised intervention over several months to far-briefer interventions.1 The training of the staff supporting these interventions is rarely described. A rigorous international effort to define the competence of staff to deliver effective self-management may be required. A recent self-management trial was terminated prematurely, because of concerns over a detrimental effect of the intervention; the reasons behind the excess mortality in the intervention group are unclear, the data suggested the intervention had not altered the behaviors of the group, and one might argue that more staff training might be required firstly to identify those participants that might be successful self-managers, as intimated by the study by Bucknall et al.26

Time limitations and the prioritization of other duties are also barriers that frustrate nurses and AHPs trying to support self-management. Similar challenges have been highlighted in other self-management studies, and include practical constraints, such as inflexible health care infrastructures, excessive workload, and lack of privacy and continuity of care. ^{2,13,30,35,36,44,45,51,56} These barriers appear to encourage nurses and AHPs to enforce compliance, make decisions for patients, and offer solutions to their problems, reducing the effectiveness of self-management support. These barriers need to be carefully considered in the design of services and interventions if self-management implementation is to be effective. ¹⁷

Implications for future research, policy, and practice

As the burden of chronic disease grows, the importance of supported self-management is consistently acknowledged, yet the workforce seems ill-prepared to support patients with COPD. There is a need to develop guidance that clarifies how it should be delivered, together with the professional competence and quality-assurance standards that have driven up the quality of self-management support in other chronic diseases, such as diabetes. The requirements to support individuals with COPD to self-manage their disease effectively is irrespective of the mode of delivery. A number of different approaches and technologies have been tested to support self-management in COPD, with disappointing results. ^{26,57,58} We may speculate that more training is required

for the health care practitioner and the individual with COPD to manage the burden of the disease effectively and achieve important lifestyle changes.

Our work also suggests that as well as guidance and training in self-management skills, nurses and AHPs may also benefit from education that challenges the assumptions they may make about patients' abilities to self-manage, and future research should focus upon developing and testing such educational programs.

Conclusion

Self-management is valued by nurses and AHPs and believed to be important, yet there is misunderstanding about what it entails. There were also practical challenges and professional assumptions made about the ability of COPD patients to self-manage, all of which led to further variation in support.

Nurses and AHPs were ill-equipped to support self-management, and there was wide variation described in the self-management support for COPD patients in daily practice. These problems may be addressed by clearer guidance for the implementation of self-management in COPD and professional training that addresses both nurses' and AHPs' skills and challenges their attitudes. Careful thought also needs to be given to the design of existing services so that more time is allowed to accommodate self-management for COPD within primary care where multiple conflicting priorities may exist.

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Author contributions

HMLY carried out the data analysis and data interpretation. SLH and LDA carried out the data analysis and assisted with data interpretation. VLJW conducted the data collection. NH and SJS designed the study and assisted with data interpretation. SJS conceived of the study. All authors assisted in drafting, revising and approving the final manuscript. All authors accept accountability for all aspects of the final manuscript.

Disclosure

The authors report no conflicts of interest in this work.

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