ORIGINAL ARTICLE

Clinical Nursing WILEY

The preferences of people with asthma or chronic obstructive pulmonary disease for self-management support: A qualitative descriptive study

Selena O'Connell PhD, BA, Postdoctoral Researcher Vera J. C. McCarthy PhD, PGDipT&LHE, MA, BSc(Hons), DipHE, RGN, Lecturer¹ Michelle Queally PhD, MSc, BBS, Lecturer² | Eileen Savage PhD, MEd, BNS, RGN, RSCN, Professor Emeritus¹

Correspondence

Selena O'Connell, School of Nursing & Midwifery, University College Cork, Cork,

Email: selena.oconnell@ucc.ie

Funding information

This study was financially supported by doctoral funding from the Programme for Health Service Improvement, Health Service Executive (HSE)

Abstract

Aims and objectives: The aim of this study was to explore and describe the selfmanagement support (SMS) preferences of adults with asthma and/or chronic obstructive pulmonary disease (COPD).

Background: Self-management support interventions have had beneficial outcomes for people with asthma and people with COPD, though challenges remain in their implementation. Increased understanding of the support preferences of people with asthma/COPD can help inform the development of future interventions to address patients' preferences.

Design: A qualitative descriptive design was used.

Methods: Semi-structured focus group and individual interviews were conducted with 20 adult participants who had asthma and/or COPD in Ireland. Qualitative content analysis was used to analyse interviews. The SRQR reporting guideline was used. Results: Three themes were identified. Support accessibility included having access to routine and unscheduled support from healthcare professionals with specialist knowledge. Consultation content described the need for comprehensive and person-centred support. The person-provider relationship described the value of healthcare professionals acknowledging patient concerns, noted as a challenge for people with asthma, and continuity in relationships over time.

Conclusions: Routine support for people with asthma/COPD needs to be comprehensive in addressing the individual patient's challenges. Access to timely advice during exacerbations was a priority for people with asthma/COPD, suggesting that flexible access to services as well as routine review may be optimal for supporting selfmanagement of asthma/COPD. Feeling listened to regarding symptoms experienced may be of intrinsic value to people with asthma/COPD.

Relevance to clinical practice: The study emphasises the importance of continued training in communications skills for healthcare professionals supporting people with

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. Journal of Clinical Nursing published by John Wiley & Sons Ltd.

¹School of Nursing & Midwifery, University College Cork, Cork, Ireland

²Department of Enterprise and Technology, Galway Mayo Institute of Technology, Galway, Ireland

asthma/COPD, particularly acknowledging the patient's concerns in the context of symptom changes/flare-up. A respiratory nurse specialist was valued as being a care coordinator who could support routine management as well as managing exacerbations, having specialist knowledge and knowing the patient over time.

KEYWORDS

asthma, chronic obstructive pulmonary disease, patient preferences, qualitative descriptive, self-management support

1 | INTRODUCTION

Globally, chronic respiratory diseases such as asthma and chronic obstructive pulmonary disease (COPD) adversely affect quality of life and account for a large proportion of hospitalisations and mortalities (Ampon et al., 2005; Miravitlles & Ribera, 2017; World Health Organisation, 2019). Supporting people with chronic disease in the process of self-management is a key strategy to reduce this burden (Bodenheimer et al., 2002). Self-management involves individuals, living with a chronic disease, actively managing physical, social and emotional well-being within the context of their daily lives (Miller et al., 2015). Self-management support (SMS) is considered effective as a multi-level approach to facilitating self-management that involves a healthcare professional (HCP) and patient partnership at the clinical level that in turn is supported by resources, training and systems at the organisational level (Kawi, 2012). Interventions to enhance self-management for both asthma and COPD have had positive outcomes including improved health-related quality of life, symptom reduction as well as reduced hospitalisation rates (Lenferink et al., 2017; Pinnock et al., 2017; Zwerink et al., 2014).

However, there remain challenges in delivering SMS as part of routine care which may curtail the benefit of these interventions at the population level (Entwistle, Cribb, & Owens, 2018; Grady & Gough, 2014). The reach of interventions and extent to which patients engage with recommended self-management practices are two such challenges. Interventions such as Pulmonary Rehabilitation programmes, commonly delivered in group sessions to people with COPD, have been found to reach limited numbers of the target population (Bolton et al., 2013; Jones et al., 2014). A qualitative synthesis found that participation in COPD support programmes was influenced by many factors including patient perceptions that the programme would be unhelpful; unsuitable; and challenges in accessing the programme (Sohanpal et al., 2015). There are also SMS interventions in which many participants do not enact the recommended self-management behaviours. For example, a randomised controlled trial of an SMS intervention for people with COPD did not significantly reduce hospital admissions overall. However, an exploratory analysis found that participants who made appropriate treatment changes (42% participants classified as successful selfmanagers through reviewing diary records) had lower hospital admissions (Bucknall et al., 2012). This research suggests that there are challenges for people with chronic respiratory disease in engaging with recommended self-management behaviours and potential challenges in the acceptability of SMS.

What does this paper contribute to the wider global community?

- This study purposively explores the preferences of people with asthma/chronic obstructive pulmonary disease (COPD) regarding support in managing their illnesses to shed further light on support priorities from the patient perspective.
- People with asthma/COPD value timely advice on managing symptoms of exacerbation as well as support for self-management on a routine basis.
- People with asthma/COPD value when healthcare professionals listen to and acknowledge their concerns and know them over time.

The need for further critical discussion on what constitutes appropriate support for self-management has been raised (Entwistle, Cribb. & Owens, 2018). These researchers encourage a broader focus on understanding what matters to people living with chronic disease rather than on disease control. Eliciting patients' perspectives and values may help to enhance the acceptability of interventions (Araújo-Soares et al., 2019). Qualitative and quantitative studies have offered insights into the preferences of people with asthma and COPD. Adults with asthma have differed in having preferences for active, collaborative or passive roles in treatment decision-making (Caress et al., 2002, 2005). The communication skills of the HCP and the patient-professional relationship were identified as facilitators of participation (Caress et al., 2005). A gualitative synthesis of studies on SMS from the perspectives of adults with asthma/COPD found that their preferences included having prompt and easy access to a HCP, a collaborative relationship with a HCP over time and tailored support content including education and psychological support (O'Connell et al., 2019). However, few of the studies reviewed related to asthma and they mainly evaluated participants' experiences of specific interventions rather than purposively exploring preferences for SMS, prior to intervention development (O'Connell et al., 2019).

Further research is needed to explore the SMS components of greatest value from the perspectives of people with asthma/COPD. This may help enhance the acceptability of interventions and thus increase potential for implementation and positive impact. There is commonality between asthma and COPD in that management of

symptoms needs to address shortness of breath, chest tightness, wheeze and cough and some people present with asthma-COPD overlap (Global Initative for Asthma [GINA], 2019; Global Initative for Chronic Obstructive Lung Disease [GOLD], 2019). There are commonalities in the self-management behaviours these groups engage in such as use of inhalers, management of triggers and flareups and smoking cessation (GINA, 2019; GOLD, 2019). Furthermore, specialist respiratory HCPs support people with asthma and with COPD. However, the clinical profile of these chronic respiratory diseases differs with COPD having a later onset and typically affecting older adults while asthma can affect people of any age and can first occur in childhood (GINA, 2019; GOLD, 2019). Furthermore, symptoms of COPD are persistent and progressive over time while asthma is characterised by symptom episodes that are often reversible (Postma et al., 2014). These differences may have implications for support preferences for people affected by these conditions. While self-management has benefitted from both generic and disease-specific approaches to research (van Houtum et al., 2015), the study of asthma and COPD together is aimed to shed light on common and disease-specific preferences.

The aim of this study was to explore and describe the SMS preferences of people with asthma and/or COPD in Ireland. This study will be used to inform the design of a discrete choice experiment to measure the relative preferences for features of support from the perspectives of people with asthma or COPD.

2 | METHODS

2.1 | Study design

A qualitative descriptive design was used for this study (Bradshaw et al., 2017; Sandelowski, 2010). This design provides a rich description of participants' experiences of a phenomena in easily understood language (Bradshaw et al., 2017). Qualitative description takes a naturalistic perspective where reality is seen as the subjective experience of the participants as well as the interpretation of the researcher (Bradshaw et al., 2017). The Standards for Reporting Qualitative Research (SRQR; Appendix S1) were used to guide reporting (O'Brien et al., 2014). The study was approved by the Social Research Ethics Committee, University College Cork, and participants provided written informed consent prior to participation.

2.2 | Participants and recruitment

The inclusion criteria were adults (over 18 years) with a self-reported diagnosis of asthma, COPD or both. Twenty adults participated of whom nine had asthma, ten had COPD and one had both asthma and COPD. The aim was to recruit a sample who represented people with characteristics that may influence perspectives on SMS such as severity of condition, length of diagnosis and rural/urban living (Patton, 2015). To achieve this, the sample was recruited through

TABLE 1 Topic guide content for semi-structured interviews and focus groups

Experience of managing chronic illness

Support received in managing illness

Support desired to manage illness

Most important elements of support

Ways in which health service can improve support

Nature of support needs

Nature of support provider

Nature of support relationship

Support accessibility

two national support organisations for asthma and COPD in Ireland and by using electronic and in-person strategies. Methods of recruitment through the national organisations involved sharing a study advertisement through social and electronic communication media as well as providing information in-person at sessions run by the organisations. Data collection was ceased when no new codes were identified through additional interviews (Hennink et al., 2016).

2.3 | Data collection

Eight individual interviews and two focus group interviews (range of three to nine participants per group) were conducted from February-June of 2019. Individual interviews explored SMS preferences in greater depth to shed light on the individual contexts which shaped preferences while focus group interviews were used to generate discussion on a range of ideas relating to SMS and to understand convergent and divergent preferences across participants (Dilshad & Latif, 2013). Use of individual and group interviews also provided greater opportunities for participation for people who may have a preference for one of these methods (Lambert & Loiselle, 2008). Interviews were conducted by the first author (SOC), who was not previously known to participants. For focus groups, a second researcher took notes on the discussion and non-verbal reactions. The researcher sought to develop rapport with participants through information exchange prior to interview and expressing empathy during the interview (Bradshaw et al., 2017). Individual interviews lasted 20-40 min while focus groups interviews lasted 50-80 min. Participants took part in either an individual or a focus group interview, based on their preferences and availability.

A topic guide (Table 1) with open-ended questions based on a recent synthesis of international literature (O'Connell et al., 2019) was used (see full topic guide in Appendix S2). A semi-structured approach was used with flexibility to probe further into participants' responses. The topic guide was piloted with the first two participants whose data were included in the analysis. Data collection and analysis were carried out concurrently. An iterative approach was used akin to previous qualitative research for developing a discrete choice experiment (Coast et al., 2012; Coast & Horrocks, 2007). The final focus group interview and last three individual interviews

additionally sought participants' perspectives on features that had arisen from analysis of previous interviews as well as using the topic guide. Demographic information was collected before beginning the interview/focus group for the purpose of describing the sample.

2.4 Data analysis

The interviews and focus groups were audio-recorded and transcribed. Participants were anonymised through pseudo-names. Data were analysed using qualitative content analysis (Bengtsson, 2016). This process began with data familiarisation followed by inductive coding based on the manifest content of the data. The transcripts were re-read to ensure that data pertaining to the aim had been coded (Bengtsson, 2016). Codes were grouped into categories and subsequently categories were further grouped into themes. Negative or deviant cases were examined. Coding was primarily carried out by the first author (SOC) and a sample of interviews was cross-checked by two other authors (ES and VMc). NVivo software, Version 11 (QSR International Pty Ltd., 2015) was used to support

TABLE 2 Demographic characteristics of participants, mean (SD) or n (%)

Characteristic	n = 20
Age, years	57.26 (14.81)
Gender	
Male	2 (10%)
Female	18 (90%)
Living arrangements	
Living alone	3 (15%)
Living with a partner/family	16 (80%)
Living in shared accommodation	1 (5%)
Length of asthma diagnosis (years)	25.38 (13.31)
Length of COPD diagnosis (years)	9.39 (8.28)
Presence of other chronic illness	12 (60%)

TABLE 3 Themes and categories

Themes	Categories
Support accessibility	Accessing support in acute phases of illness
	Accessing scheduled support
	Accessing HCPs with specialist knowledge
Consultation content	Comprehensive person-centred support
	Information provision
	An action plan
Person-provider relationship	Listening to the patient's account
	Continuity and integration

data management and an audit trail was kept of the analysis process. The analysis was written up by the first author and reviewed by all contributing authors.

3 | RESULTS

Demographic characteristics of the 20 participants are presented in Table 2. The sample was predominantly female (n = 18), with a mean age of 57.26 (SD = 14.81). There was variation in the living arrangements and length of diagnoses of participants. Twelve (60%) reported having another chronic illness. Three themes were identified from the data: support accessibility, consultation content and person–provider relationship (Table 3).

3.1 | Support accessibility

3.1.1 | Accessing support in acute phases of illness

Participants' accounts highlighted the importance of quick and timely access to services when experiencing exacerbations of their condition, that is, changes in their symptoms ranging from mild to severe. When experiencing a change in symptoms that required additional support, participants preferred to consult with a HCP within 1 or 2 days. As a first point of contact, for many participants, there was a preference for being able to phone a HCP. Others were happy with text or email to check with a HCP regarding self-managed treatment changes in response to symptoms. Participant accounts indicated a preference for having a 'second opinion'/consultation regarding what actions to take as well as support in reducing panic experienced in relation to breathing difficulties, often mentioning an 'asthma nurse' or 'respiratory nurse' for this role:

No she'll just ring you and she'll know. She'll ask you a few questions, but I think especially if you're really out of breath, she'll get you to kind of calm down a bit and she'd be able to work from there and suggest whether you'd need to go into A&E.

(Maureen)

Some participants described delaying making contact with their HCP due to fears of being hospitalised; perceptions that HCPs are busy; that they would be wasting HCP time; or might be perceived to be dramatic by their HCP and others around them. The cost of accessing services was also a deterrent for participants. However, some noted that they had access to a medical card through which most healthcare services are provided free of charge in Ireland. This encouraged early help-seeking: 'I found [medical card] an amazing help because I'm able to go down to my GP before I get ill... and she'll sort me out' (Lucy). Participants suggested that asthma and COPD should be recognised as part of the national long-term illnesses scheme so that medications are subsidised by government.

3.1.2 | Accessing scheduled support

Participants' accounts indicated that having regular scheduled reviews was important to identify changes and discuss management of their condition. In terms of frequency, participants believed that biannual reviews would be more appropriate than an annual review which had been previously experienced. A pattern in the data was that people who experienced greater severity of symptoms had a preference for more frequent reviews such as every three months. A small number of participants suggested having a scheduled local service that was available close to home in their local town to avoid travelling long journeys and spending full days attending appointments. As commented by one rural-living participant, it would be good 'to know that there is a specialist nurse who will meet up locally however many times a year as possible. To know that is there. I don't have to travel very far' (Eleanor).

3.1.3 | Accessing HCPs with specialist knowledge

The primary providers of support for participants in this study were general practitioners (GPs), specialist respiratory nurses and consultants. Other providers of support included practice nurses (based in GP surgeries), pharmacists, physiotherapists, peers and family members. While participants appreciated HCPs with both generalist and specialist remits, many participants valued their HCP having specialist knowledge of their condition. This could include HCPs with a formal respiratory specialist role as well as GPs who acquire additional knowledge relating to managing asthma or COPD. It was considered that GPs or practice nurses without specialist knowledge may not take concerns as seriously. Some participants valued support through the combined care of their GP and respiratory specialists. However, other participants noted barriers to accessing specialist HCPs including lack of awareness of services; lack of referral from primary to secondary care; and waiting lists for appointments to see specialists.

So I felt like even if you could meet someone on a bit more of a specialist level, whether it was a nurse specialist or a consultant, someone to just talk about how I was coping and the fact that I wasn't and what more could I do.

(Michelle)

3.2 | Consultation content

3.2.1 | Comprehensive person-centred support

Participants valued a comprehensive person-centred consultation about their asthma/COPD during which they had sufficient time with their HCP to address a number of important areas of management. Participants acknowledged the importance of reviewing

and adjusting prescriptions. However, many participants spoke of their frustration when checking prescriptions was the main focus of the consultation without attention to managing other aspects of their health. The topics of side effects, constraints on daily life and the emotional impact were most commonly identified as important for discussion. Additionally, participants expanded upon individual challenges requiring personalised support such as managing comorbidities and managing their conditions in the context of exercise. Assistance in managing triggers including allergies and seasonal influences was highly valued especially by people with asthma:

So I felt that he really wanted to get to the actual root of the problem which is important I think rather than just like having prescription on top of prescription and not dealing with the underlying causes and triggers.

(Patricia)

3.2.2 | Information provision

Many participants indicated a need for greater information such as an explanation of their condition; potential side effects of treatments; alternative treatments and the potential serious impact of asthma or COPD. One participant described the difficulty of getting information on side effects of treatments:

You know, there's no give and take where they could sit you down and explain it to you. Or even get the respiratory nurse to go through it with you.

(Angela)

Some participants described anxiety associated with looking up information online. Participants valued when HCPs would verbally explain the information rather than relying solely on leaflets.

3.2.3 | An action plan

Participants also sought further information on: 'the possible progression of the condition; what are maybe red flags to watch out for; maybe when you should kind of seek help' (Alice). While few participants used the term 'action plan', participants' accounts consistently indicated a preference for being aware of what steps to take when symptoms change or deteriorate. Some participants valued this as being a written document developed with the HCP that helped to identify symptom levels and associated actions. Participants differed in their preferences for having a written plan in the case of day-to-day management with many feeling this was not necessary.

Now my new asthma nurse actually sat down and ... she wrote it all out so on my chart so it's impossible not to understand: here is normal let's say and then

she said if I get into this territory, here's what I do and if I get into this territory here's what I do.

(Aileen)

3.3 | Person-provider relationship

3.3.1 | Listening to the patient's account

Participants' accounts indicated a preference for having input into consultations with their HCPs and referred to the importance of being listened to. In practical terms, this involved the HCP giving the person time to talk and provide their perspective: 'you know, listened, not just cutting in' (Eleanor). Feeling listened to also involved a sense of empathy from HCPs. Many participants valued HCPs who tried to appreciate their situation and concerns, saying: 'I see where you're coming from' (Mary). While participants acknowledged that they needed assistance in identifying their symptoms and the appropriate response, many participants considered it important that their knowledge of their own body and changes be taken seriously by HCPs. This was particularly the case for people with asthma who described a perception among HCPs and the wider public that 'it's only asthma':

The other thing I suppose is that you do know your own body, so I'd like to be kind of believed if you're coming saying that you're feeling unwell. That you'd feel that was acknowledged and validated and that person believed you.

(Michelle)

There were disparities in participants' accounts of the value of tests and scans conducted by HCPs such as 'listening to [the] chest', peak flow measures, breathing tests and chest scans. Many participants perceived physical measures of health to be informative in terms of planning treatment, to help alleviate symptoms and provided reassurance to them about their current health. However, some participants believed measures such as peak flow did not fully represent their experience of their illness: 'I always seem to score well and yet I'm in bits' (Mandy). Participants' comments indicated a desire for HCPs to respond to their experience of changes in their body even if physical tests did not indicate problems: 'I find the doctor doesn't always listen to me because I'm not wheezing at that point and my peak flow is fine but I can feel the difference' (Aileen).

3.3.2 | Continuity and integration

Participants valued continuity in the support received for managing their health. This was predominantly discussed in terms of GPs in primary care though it was also mentioned in terms of specialist services. They explained that from the patient perspective, it was tiresome to have to go through one's history with a new HCP on each visit and it was believed that seeing the same HCP would save time. Patients valued HCPs knowing about their illness, their individual triggers and treatment regimens as well as knowing them individually as a person. They believed this knowledge assisted in selecting the most beneficial treatment options.

I've been to different GPs and some of them wouldn't – they wouldn't really tell you anything. Now she's [GP] not an asthmatic herself but she's just – well she knows me. She knows my asthma. She knows, you know, what works for me and what doesn't work for me.

(Danielle)

Participants sought someone who would oversee their treatment whom they could contact regarding their asthma or COPD: 'one point of contact' (Aileen); a 'liaison' (Trish); someone who 'joins the dots to see how you're doing' (Angela). Participants valued a service in which there was communication between the different HCPs who support them in managing their health, such that HCPs would be made aware of changes in treatment advised by other providers. This was highlighted across primary and specialist settings, particularly for participants who also had other chronic conditions. Participants identified the potential benefit of a shared health record into which various professionals could input, potentially in electronic form, which does not currently exist in Ireland.

4 | DISCUSSION

This research explored the SMS preferences of people with asthma/COPD, extending the literature regarding the features of support that are most valued and accepted from the perspectives of service users. This exploratory study found that people with asthma/COPD placed emphasis on communication with their HCPs and valued HCPs listening fully to their concerns. Concurring with other studies, people with asthma/COPD reported dissatisfaction with paternalistic relationships with their HCPs characterised by a lack of opportunity to recount their experiences, input into decisions or ask questions (Hannane et al., 2019; Lingner et al., 2017; O'Connell et al., 2019). Being believed was a particular concern for people with asthma in this study who felt they were sometimes not taken seriously when presenting with symptoms they were worried about. While inadequate listening to the patient's experience has the potential to contribute to sub-optimal treatments to manage exacerbations, people with breathlessness also experience injustice when their experiential knowledge is not taken into account (Hutchinson et al., 2018). This finding also resonates with Self-Determination Theory where relatedness, that is feelings of being respected and understood, is considered a basic psychological need which in turn influences the mental health of the individual (Deci & Ryan, 2000; Ng et al., 2012). Furthermore,

it is suggested that the HCPs lack of responsiveness may not only affect the management of a specific episode but may also lead to disengaged coping over time and lower help-seeking (Hutchinson et al., 2018). In addition to enhancing communication skills, training initiatives for HCPs should emphasise the importance of communication, particularly listening to and acknowledging the patient's concerns and experiences, through drawing on evidence such as this study.

Timely access to HCP advice when managing exacerbations was a valued support from the perspectives of people with asthma or COPD in this study. There has been debate regarding the amount of responsibility that is acceptable to people with asthma/COPD in managing symptom changes (Lingner et al., 2017). It is suggested that exacerbation-related self-management may not be possible for all individuals (Korpershoek et al., 2016). Participants in this study valued reassurance from a HCP regarding actions to take when managing symptom changes. The theory of symptom self-management highlights that many variables influence this process including perceived selfefficacy which can be facilitated by direct mastery experiences as well as verbal persuasion (Hoffman, 2013). Scheduled support which builds skills in identifying and managing exacerbations was valued in the current study. However, unscheduled access to support in managing exacerbations was also valued. Interventions including both unscheduled and scheduled support have led to a reduction in severe exacerbations for COPD and asthma (Alí et al., 2019; Jain et al., 2014). Future research should further clarify the effectiveness and cost-effectiveness of unscheduled support in asthma and COPD. The current study also identified that cost of consultations and medications affects access and could delay help-seeking. This finding underscores the importance of implementing plans for universal healthcare in Ireland, with care free at the point of delivery, as outlined in the Slaintecare policy to ensure that cost does not deter timely help-seeking (Burke et al., 2018; Oireachtas Committee on the Future of Healthcare, 2017).

The findings on the importance of continuity of care, in addition to accessibility and provider relationships, reflect the healthcare system facilitators of self-management in the Self- and Family Management Framework (Grey et al., 2015; Schulman-Green et al., 2016). The findings here indicated preferences for continuity in providers and having a single point of contact with services akin to the role of a case manager, as reported in previous literature (Schulman-Green et al., 2016). HCPs with specialist knowledge of asthma/COPD such as a respiratory nurse were valued as a point of contact. In addition, support from different providers was acceptable once adequate communication existed between providers such that HCPs had up-to-date information on the patient's health and treatment. A shared health record was suggested to facilitate communication between HCPs similar to another recent study with people with asthma (Hannane et al., 2019). Electronic records which facilitate information exchange across primary and secondary care HCPs have been proposed in the Irish Health Service (Health Service Executive, 2015). While studies from patient perspectives, including those with COPD, indicate the positive impact of electronic records

on information continuity, challenges are reported from the provider perspective (Waibel et al., 2015, 2016). Further research is needed to enhance the features of these electronic record systems and their implementation.

This study also highlighted the need for SMS to address a range of challenges which can arise for people living with asthma or COPD. There was an emphasis on problem-solving challenges which impact on daily life including managing triggers of exacerbations, side effects of treatments, emotional well-being and comorbidities which have been indicated in other recent studies from the perspectives of people with asthma/COPD (Gardener et al., 2018; Hannane et al., 2019; Lingner et al., 2017). This finding aligns with recent critical perspectives which advocate a 'person-centred' approach to SMS and a focus on helping people to live well with their chronic conditions rather than manage their conditions well (Entwistle, Cribb, & Owens, 2018; Morgan et al., 2017). This approach requires an understanding about what matters generally for the population of interest (Entwistle, Cribb, & Owens, 2018) and the current study contributes to this literature in relation to people with asthma/COPD. However, at the practice level, this requires assessing what individuals with chronic illness want to achieve so that SMS can be aligned with their personal goals (Entwistle, Cribb, & Owens, 2018). Studies from the HCP perspective identify many practical and ethical challenges in achieving this such as patient goals being at odds with biomedical targets (Entwistle, Cribb, Watt, et al., 2018; Franklin et al., 2019). Further research is needed to establish consensus on how personcentred approaches can be incorporated in practice and how the quality of SMS should be assessed (Owens et al., 2017).

4.1 | Limitations

A limitation of the study is that participants were predominately female so it is not clear if these findings are indicative of the preferences of males with asthma/COPD given previously noted gender differences in perceptions of dyspnoea, asthma control and healthcare seeking (Chhabra & Chhabra, 2011; Thompson et al., 2016). In addition, the perspectives are those of people in Ireland and thus caution is needed in considering the relevance of the findings to other countries because of differences in the organisation of health services. While plans for reform are underway (Burke et al., 2018; Oireachtas Committee on the Future of Healthcare, 2017), the Irish health system has a predominantly hospital centric model of support for chronic disease, out-of-pocket costs for those who do not qualify for a medical/GP visit card and inequities in access to healthcare across public and private systems (Darker et al., 2015).

5 | CONCLUSION

This study has identified that people with asthma or COPD value comprehensive person-centred support, specialist knowledge,

continuity with providers, integration between providers and for HCPs to listen and respond to their concerns during contacts. The study finds that communication between patient and provider was an important element of support, particularly the HCP listening to the patient's experiences. People with asthma and COPD desire ease of access to support for managing asthma and COPD, particularly in the context of managing exacerbations. While this study has identified many preferable features of support, further research is needed to provide information on the relative importance of service features from the patient perspective to inform the prioritisation of features for future implementation.

6 | RELEVANCE TO CLINICAL PRACTICE

The many nuanced elements of self-management identified in this study indicate that individualised approaches to SMS are key and that where group approaches are being taken, there needs to be an emphasis on assisting people with their individual challenges and applying relevant problem-solving or coping skills. This study suggests that training for HCPs who support people with asthma or COPD needs to place a greater emphasis on communication skills, particularly in active listening to patients concerns and acknowledging these concerns. HCPs need to be aware that clinical measures do not always align with a patients' subjective experience (Lingner et al., 2017). From a service delivery perspective, there is a need to ensure access to support and advice when people experience early indicators of acute exacerbation. The findings suggest that contact with a known provider with specialist knowledge of asthma/COPD is preferable. A respiratory nurse specialist was valued as a point of contact for both review of management and advice in managing symptoms of a flare-up. Systems which allow sharing of information across HCPs such as shared electronic records are needed to facilitate continuity across HCPs involved in support; this is particularly true for Ireland where electronic health records are underdeveloped compared to other countries (Health Service Executive, 2016).

CONFLICT OF INTEREST

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTIONS

Study design: all authors. Data collection: SOC and VMcC. Data analysis: SOC, VMcC and ES. Final analysis and manuscript: all authors.

DATA AVAILABILITY STATEMENT

The data are not shared to privacy and ethical restrictions.

ORCID

Selena O'Connell https://orcid.org/0000-0003-4563-2944

Vera J. C. McCarthy https://orcid.org/0000-0001-7573-7961

Michelle Queally https://orcid.org/0000-0002-1259-7874

Eileen Savage https://orcid.org/0000-0002-2403-557X

REFERENCES

- Alí, A., Giraldo-Cadavid, L. F., Karpf, E., Quintero, L. A., Aguirre, C. E., Rincón, E., Vejarano, A. I., Perlaza, I., Torres-Duque, C. A., & Casas, A. (2019). Frequency of emergency department visits and hospitalizations due to chronic obstructive pulmonary disease exacerbations in patients included in two models of care. *Biomédica*, 39(4), 748–758. https://doi.org/10.7705/biomedica.4815
- Ampon, R. D., Williamson, M., Correll, P. K., & Marks, G. B. (2005). Impact of asthma on self-reported health status and quality of life: A population based study of Australians aged 18–64. *Thorax*, 60(9), 735–739. https://doi.org/10.1136/thx.2005.040311
- Araújo-Soares, V., Hankonen, N., Presseau, J., Rodrigues, A., & Sniehotta, F. F. (2019). Developing behavior change interventions for self-management in chronic illness: An integrative overview. European Psychologist, 24(1), 7–25. https://doi.org/10.1027/1016-9040/a000330
- Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, 2, 8–14. https://doi.org/10.1016/j.npls.2016.01.001
- Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA-Journal of the American Medical Association*, 288(19), 2469–2475. https://doi.org/10.1001/jama.288.19.2469
- Bolton, C. E., Bevan-Smith, E. F., Blakey, J. D., Crowe, P., Elkin, S. L., Garrod, R., Greening, N. J., Heslop, K., Hull, J. H., Man, W.-C., Morgan, M. D., Proud, D., Roberts, C. M., Sewell, L., Singh, S. J., Walker, P. P., & Walmsley, S. (2013). British Thoracic Society guideline on pulmonary rehabilitation in adults: Accredited by NICE. *Thorax*, 68(Suppl 2), ii1. https://doi.org/10.1136/thoraxjnl-2013-203808
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4, 1–8. https://doi.org/10.1177/2333393617742282
- Bucknall, C. E., Miller, G., Lloyd, S. M., Cleland, J., McCluskey, S., Cotton, M., Stevenson, R. D., Cotton, P., & McConnachie, A. (2012). Glasgow supported self-management trial (GSuST) for patients with moderate to severe COPD: Randomised controlled trial. BMJ (Clinical Research Ed.), 344, e1060. https://doi.org/10.1136/bmj.e1060
- Burke, S., Barry, S., Siersbaek, R., Johnston, B., Ní Fhallúin, M., & Thomas, S. (2018). Sláintecare A ten-year plan to achieve universal health-care in Ireland. *Health Policy*, 122(12), 1278–1282. https://doi.org/10.1016/j.healthpol.2018.05.006
- Caress, A., Beaver, K., Luker, K., Campbell, M., & Woodcock, A. (2005). Involvement in treatment decisions: What do adults with asthma want and what do they get? Results of a cross sectional survey. *Thorax*, 60(3), 199-205. https://doi.org/10.1136/thx.2004.029041
- Caress, A., Luker, K., Woodcock, A., & Beaver, K. (2002). A qualitative exploration of treatment decision-making role preference in adult asthma patients. *Health Expectations*, 5(3), 223–235. https://doi.org/10.1046/j.1369-6513.2002.00181.x
- Chhabra, S. K., & Chhabra, P. (2011). Gender differences in perception of dyspnea, assessment of control, and quality of life in asthma. *Journal of Asthma*, 48(6), 609–615. https://doi.org/10.3109/02770 903.2011.587577
- Coast, J., Al-Janabi, H., Sutton, E. J., Horrocks, S. A., Vosper, A. J., Swancutt, D. R., & Flynn, T. N. (2012). Using qualitative methods for attribute development for discrete choice experiments: Issues and recommendations. *Health Economics*, 21(6), 730–741. https://doi.org/10.1002/hec.1739
- Coast, J., & Horrocks, S. (2007). Developing attributes and levels for discrete choice experiments using qualitative methods. *Journal of Health Servives Research and Policy*, 12(1), 25–30. https://doi.org/10.1258/135581907779497602
- Darker, C., Whiston, L., & O'Shea, B. (2015). Chronic disease management in Ireland: Perspectives from patients and clinical stakeholders

- Implications and recommendations for the Irish healthcare system. Adelaide Health Foundation. http://www.adelaide.ie/wp-content/uploads/2015/04/Chronic-Disease-Management-overview-of-patients-and-clinical-stakeholders-implications-recommendations-for-Irish-healthcare-system-Darker-et-al.-2015.pdf
- Deci, E. L., & Ryan, R. M. (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, 11(4), 227–268. https://doi.org/10.1207/S15327965P LI1104 01
- Dilshad, R. M., & Latif, M. I. (2013). Focus group interview as a tool for qualitative research: An analysis. *Pakistan Journal of Social Sciences* (*PJSS*), 33(1), 191–198. https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=96874 385&site=eds-live
- Entwistle, V. A., Cribb, A., & Owens, J. (2018). Why health and social care support for people with long-term conditions should be oriented towards enabling them to live well. *Health Care Analysis*, 26(1), 48–65. https://doi.org/10.1007/s10728-016-0335-1
- Entwistle, V. A., Cribb, A., Watt, I. S., Skea, Z. C., Owens, J., Morgan, H. M., & Christmas, S. (2018). "The more you know, the more you realise it is really challenging to do": Tensions and uncertainties in person-centred support for people with long-term conditions. *Patient Education and Counseling*, 101(8), 1460–1467. https://doi.org/10.1016/j.pec.2018.03.028
- Franklin, M., Willis, K., Lewis, S., Rogers, A., & Smith, L. (2019). Between knowing and doing person-centredness: A qualitative examination of health professionals' perceptions of roles in self-management support. *Health*, 1363459319889087. 25(3), 339–356. https://doi.org/10.1177/1363459319889087
- Gardener, A. C., Ewing, G., Kuhn, I., & Farquhar, M. (2018). Support needs of patients with COPD: A systematic literature search and narrative review. *International Journal of Chronic Obstructive Pulmonery Disease*, 13, 1021–1035. https://doi.org/10.2147/ copd.s155622
- GINA. (2019). Global strategy for asthma management and prevention. www.ginasthma.org
- GOLD. (2019). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: 2020 report. www.goldcopd.org
- Grady, P. A., & Gough, L. L. (2014). Self-management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health*, 104(8), e25-e31. https://doi.org/10.2105/AJPH.2014.302041
- Grey, M., Schulman-Green, D., Knafl, K., & Reynolds, N. R. (2015). A revised self- and family management framework. *Nursing Outlook*, 63(2), 162–170. https://doi.org/10.1016/j.outlook.2014.10.003
- Hannane, A., Misane, L., Devouasso, G., Colin, C., & Letrilliart, L. (2019). Asthma patients' perception on their care pathway: A qualitative study. NPJ Primary Care Respiratory Medicine, 29(1), 9. https://doi. org/10.1038/s41533-019-0121-2
- Health Service Executive. (2015). Knowledge and information strategy: Delivering the benefits of eHealth in Ireland. https://www.ehealthireland.ie/Knowledge-Information-Plan/Knowledge-and-Information-Plan.pdf
- Health Service Executive. (2016). National electronic health record: Strategic business case. https://www.ehealthireland.ie/Strategic-Programmes/Electronic-Health-Record-EHR-/Progress/National-Business-Case.pdf
- Hennink, M., Kaiser, B., & Marconi, V. (2016). Code saturation versus meaning saturation: How many interviews are enough? *Qualitative Health Research*, 27(4), 591–608. https://doi.org/10.1177/10497 32316665344
- Hoffman, A. J. (2013). Enhancing self-efficacy for optimized patient outcomes through the theory of symptom self-management. *Cancer Nursing*, 36(1), E16–E26. https://doi.org/10.1097/NCC.0b013 e31824a730a

- Hutchinson, A., Barclay-Klingle, N., Galvin, K., & Johnson, M. J. (2018). Living with breathlessness: A systematic literature review and qualitative synthesis. European Respiratory Journal, 51(2), 1–19. https://doi.org/10.1183/13993003.01477-2017
- Jain, V. V., Allison, R., Beck, S. J., Jain, R., Mills, P. K., McCurley, J. W., Van Gundy, K. P., & Peterson, M. W. (2014). Impact of an integrated disease management program in reducing exacerbations in patients with severe asthma and COPD. Respiratory Medicine, 108(12), 1794–1800. https://doi.org/10.1016/j.rmed.2014.09.010
- Jones, S. E., Green, S. A., Clark, A. L., Dickson, M. J., Nolan, A.-M., Moloney, C., Kon, S. S. C., Kamal, F., Godden, J., Howe, C., Bell, D., Fleming, S., Haselden, B. M., & Man, W.-C. (2014). Pulmonary rehabilitation following hospitalisation for acute exacerbation of COPD: Referrals, uptake and adherence. *Thorax*, 69(2), 181–182. https://doi.org/10.1136/thoraxjnl-2013-204227
- Kawi, J. (2012). Self-management support in chronic illness care: A concept analysis. *Research & Theory for Nursing Practice*, 26(2), 108–125. https://doi.org/10.1891/1541-6577.26.2.108
- Korpershoek, Y., Vervoort, S., Nijssen, L., Trappenburg, J., & Schuurmans, M. J. (2016). Factors influencing exacerbation-related self-management in patients with COPD: A qualitative study. International Journal of Chronic Obstructive Pulmonary Disease, 11, 2977–2990. https://doi.org/10.2147/COPD.S116196
- Lambert, S. D., & Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, 62(2), 228–237. https://doi.org/10.1111/j.1365-2648.2007.04559.x
- Lenferink, A., Brusse-Keizer, M., van der Valk, P. D. L. P. M., Frith, P. A., Zwerink, M., Monninkhof, E. M., van der Palen, J., & Effing, T. W. (2017). Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, (8), CD011682. https://doi.org/10.1002/14651858.CD011682. pub2
- Lingner, H., Burger, B., Kardos, P., Criée, C. P., Worth, H., & Hummers-Pradier, E. (2017). What patients really think about asthma guidelines: Barriers to guideline implementation from the patients' perspective. *BMC Pulmonary Medicine*, 17(1), 13. https://doi.org/10.1186/s12890-016-0346-6
- Miller, W. R., Lasiter, S., Ellis, R. B., & Buelow, J. M. (2015). Chronic disease self-management: A hybrid concept analysis. *Nursing Outlook*, 63(2), 154–161. https://doi.org/10.1016/j.outlook.2014.07.005
- Miravitlles, M., & Ribera, A. (2017). Understanding the impact of symptoms on the burden of COPD. *Respiratory Research*, 18(1), 67. https://doi.org/10.1186/s12931-017-0548-3
- Morgan, H. M., Entwistle, V. A., Cribb, A., Christmas, S., Owens, J., Skea, Z. C., & Watt, I. S. (2017). We need to talk about purpose: A critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expectations*, 20(2), 243–259. https://doi.org/10.1111/hex.12453
- Ng, J. Y., Ntoumanis, N., Thøgersen-Ntoumani, C., Deci, E. L., Ryan, R. M., Duda, J. L., & Williams, G. C. (2012). Self-determination theory applied to health contexts: A meta-analysis. *Perspectives on Psychological Science*, 7(4), 325–340. https://doi.org/10.1177/17456 91612447309
- O'Connell, S., McCarthy, V. J. C., & Savage, E. (2019). Self-management support preferences of people with asthma or chronic obstructive pulmonary disease: A systematic review and meta-synthesis of qualitative studies. *Chronic Illness*. 1–23. https://doi.org/10.1177/17423 95319869443
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245–1251. https://doi.org/10.1097/acm.000000000000388

- Oireachtas Committee on the Future of Healthcare. (2017). Committee on the future of healthcare Sláintecare report. http://hdl.handle.net/10147/622734
- Owens, J., Entwistle, V. A., Cribb, A., Skea, Z. C., Christmas, S., Morgan, H., & Watt, I. S. (2017). "Was that a success or not a success?": A qualitative study of health professionals' perspectives on support for people with long-term conditions. *BMC Family Practice*, 18(1), 39. https://doi.org/10.1186/s12875-017-0611-7
- Patton, M. Q. (2015). Qualitative research & evaluation methods: Integrating theory and practice: The definitive text of qualitative inquiry frameworks and options. SAGE Publications Inc.
- Pinnock, H., Parke, H. L., Panagioti, M., Daines, L., Pearce, G., Epiphaniou, E., Bower, P., Sheikh, A., Griffiths, C. J., & Taylor, S. J. C. (2017). Systematic meta-review of supported self-management for asthma: A healthcare perspective. *BMC Medicine*, 15(1), 64. https://doi.org/10.1186/s12916-017-0823-7
- Postma, D. S., Reddel, H. K., ten Hacken, N. H., & van den Berge, M. (2014). Asthma and chronic obstructive pulmonary disease: Similarities and differences. *Clinics in Chest Medicine*, 35(1), 143–156. https://doi.org/10.1016/j.ccm.2013.09.010
- QSR International Pty Ltd. (2015). NVivo (released in December 2015). https://www.qsrinternational.com/nvivo-qualitative-data-analy sis-software/home
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77–84. https://doi.org/10.1002/nur.20362
- Schulman-Green, D., Jaser, S. S., Park, C., & Whittemore, R. (2016). A metasynthesis of factors affecting self-management of chronic illness. *Journal of Advanced Nursing*, 72(7), 1469–1489. https://doi.org/10.1111/jan.12902
- Sohanpal, R., Steed, L., Mars, T., & Taylor, S. J. C. (2015). Understanding patient participation behaviour in studies of COPD support programmes such as pulmonary rehabilitation and self-management: A qualitative synthesis with application of theory. NPJ Primary Care Respiratory Medicine, 25, 15054. https://doi.org/10.1038/npjpc rm.2015.54
- Thompson, A. E., Anisimowicz, Y., Miedema, B., Hogg, W., Wodchis, W. P., & Aubrey-Bassler, K. (2016). The influence of gender and other patient characteristics on health care-seeking behaviour: A QUALICOPC study. *BMC Family Practice*, 17(1), 38. https://doi.org/10.1186/s12875-016-0440-0

- van Houtum, L., Rijken, M., Heijmans, M., & Groenewegen, P. (2015). Patient-perceived self-management tasks and support needs of people with chronic illness: Generic or disease specific? *Annals of Behavioral Medicine*, 49(2), 221–229. https://doi.org/10.1007/s1216 0-014-9649-0
- Waibel, S., Vargas, I., Aller, M.-B., Coderch, J., Farré, J., & Vázquez, M. L. (2016). Continuity of clinical management and information across care levels: Perceptions of users of different healthcare areas in the Catalan national health system. BMC Health Services Research, 16(1), 466. https://doi.org/10.1186/s12913-016-1696-8
- Waibel, S., Vargas, I., Aller, M. B., Gusmão, R., Henao, D., & Vázquez, M. L. (2015). The performance of integrated health care networks in continuity of care: A qualitative multiple case study of COPD patients. *International Journal of Integrated Care*, 15, e029. https://doi.org/10.5334/ijic.1527
- World Health Organisation. (2019). Chronic respiratory diseases. https://www.who.int/respiratory/en/
- Zwerink, M., Brusse-Keizer, M., van der Valk, P. D. L. P. M., Zielhuis, G. A., Monninkhof, E. M., van der Palen, J., Frith, P. A., & Effing, T. (2014). Self management for patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, (3), CD002990. https://doi.org/10.1002/14651858.CD002990. pub3

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: O'Connell S, McCarthy VJ, Queally M, Savage E. The preferences of people with asthma or chronic obstructive pulmonary disease for selfmanagement support: A qualitative descriptive study. *J Clin Nurs*. 2021;00:1–10. https://doi.org/10.1111/jocn.15790