



Social determinants of advanced chronic respiratory interventions: a scoping review

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This scoping review suggests that there is limited reporting of social determinants of health, pulmonary rehabilitation, singing for lung health and multicomponent palliative care interventions for people with advanced chronic respiratory conditions. <https://bit.ly/46udRVH>

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Abstract

Introduction Income, education, occupation, social class, sex and race/ethnicity are essential social determinants of health (SDH). Reporting of SDH when testing complex interventions for people with advanced chronic respiratory diseases or how they impact accessibility, engagement and effectiveness within sub-populations is unclear.

Aims and methods This scoping review examined reporting of SDH in pulmonary rehabilitation (PR), singing for lung health (SLH) and multicomponent palliative care interventions (MPCI). Reporting of SDH was assessed from studies from PubMed and three systematic reviews.

Results Eight SLH, 35 MPCI and 351 PR studies were included. Sex was most reported (PR: n=331, 94.3%; SLH: n=6, 75.0%; MPCI: n=31, 88.6%), while social class was only mentioned in one PR study (n=1, 0.3%). 18 PR studies (5.1%), two SLH studies (25.0%) and three MPCI studies (8.6%) reported no SDH. Included studies were predominantly from high-income countries (304 PR studies from 26 countries, six SLH studies from two countries and all the MPCI studies from 12 countries), published from 2000 to 2022 with reporting in PR progressively increasing.

Conclusion Reporting of SDH is limited. Consequently, impacts of these social barriers on engagement in clinical trials or whether the complex interventions are effective universally or within certain sub-populations is unclear.

Introduction

Social determinants of health (SDH) refer to the structural, social and economic factors that shape the distribution of health and illness within populations. These include factors such as income, education, occupation, housing and access to healthcare, as well as broader societal factors such as discrimination and poverty [1].

SDH are beyond the control of most individuals and have powerful influences on the experience of healthcare. Low income, unemployment and poor housing and education have been recognised as underlying conditions that negatively influence population health and disease outcomes through multiple risk factors [2]. Advanced chronic respiratory diseases (CRD), such as COPD and interstitial lung disease (ILD) are no exception. People living in lower income and socioeconomically disadvantaged communities are at a higher risk for developing COPD and ILD, which can be attributed to greater exposure to environmental risk factors such as biomass fuel use, smoking tobacco, lack of access to affordable healthcare and limited access to education and information about managing CRD [2]. The World Health Organization (WHO) Commission on SDH acknowledges the racial discrimination endured by indigenous groups globally and their experiences of disadvantaged social positions with health indicators inferior to



those of nonindigenous populations [3]. Specific attention to these SDH is crucial to decreasing disparities in the design of affordable, accessible and effective interventions [2]. Alongside improving health outcomes for people with advanced CRD, addressing SDH is also critical for understanding and ensuring the generalisability of clinical trial results to the targeted population. Recognition of SDH can determine selection, participation and adherence of people with advanced CRD from lower socioeconomic backgrounds to inform implementation of interventions.

COPD is the third leading cause of death globally, responsible for 3.23 million deaths in 2019 and the global prevalence is estimated to be 10.3% [4, 5]. Approximately 90% of COPD deaths were in those under 70 years of age living in low- and middle-income countries [5]. People with advanced CRD are often disabled by chronic breathlessness, fatigue and other symptoms, which not only reduce their quality of life but also impact those around them [6]. Social isolation and financial impoverishment are often both risk factors and consequences of chronic disease for both patients and their carers [6]. An increased prevalence of CRD among those from lower socioeconomic status presents a major challenge as disadvantaged populations often face increased barriers to accessing healthcare services and medications for disease management [2].

The treatment of advanced CRD typically involves a combination of different interventions. Pharmacological therapies, such as bronchodilators and antifibrotics, may be delivered in conjunction with rehabilitation [6], and other complex interventions aimed at addressing the various physical, psychological and social factors that contribute to the development and management of the disease [7]. Multidisciplinary services also work with respiratory and palliative care teams to offer patients pulmonary rehabilitation (PR) [8], which is the most evidence-based intervention for improving breathlessness, exercise capacity and health status [9]. Despite achieving comparable clinical outcomes, people living with COPD in the most socioeconomically deprived areas are less likely to complete PR compared to those living in least deprived areas [9]. In New Zealand, those with Māori ethnicity and Pacific Islanders have lower completion rates compared to those with European ancestry [10]. However, it is difficult to measure completion rates in other published cohorts such as the United Kingdom [11] given the lack of reporting of the demographics of people with COPD, as well as the impact of ethno-cultural factors on referrals attendance and completion of PR [12]. Progress in increasing PR uptake and completion has been hindered by the limited reporting of ethnicity and other characteristics associated with health-related disparities such as sexual orientation, sex identity and intersex status [13]. Supporting PR access in diverse communities by recognising the influence of multiple, interacting spheres on health equity is an area that has received very limited attention in data collection [14].

Community-based symptom-directed care such as singing for lung health (SLH) programmes have recently emerged as a novel approach to improve the health-related quality of life of people with advanced CRD through improving capacity to cope with breathlessness [15]. Experienced singing teachers teach breathing and posture techniques in conjunction with group singing activities during the classes, which have been perceived as fun and sociable [15]. Due to the novel nature of the intervention, there has been limited and consideration of SDH contributing to uptake and participation. Multicomponent palliative care interventions (MPCI), which aim to deliver palliative care together with disease-directed care over the last years of life, have also been developed for people with advanced CRD and their carers [6, 7]. However, there remains inconsistent provision of these advanced lung disease clinics and specialist breathlessness services that have been pioneered within palliative care [16]. Reporting on the SDH across complex advanced CRD interventions is important for identifying and addressing disparities, as well as ensuring that interventions are culturally appropriate and responsive to the needs of the community. The WHO Commission on SDH developed a conceptual framework for action on the SDH [3]. This study aimed to utilise this framework to assess the extent of reporting and active consideration of SDH across PR, SLH and MPCI interventions for people with advanced CRD.

Methods

Health researchers have widely used scoping reviews to address broad research questions by mapping evidence from a variety of resources, which allows for examination of practice, policy, research and the identification of gaps [17]. This review was conducted and reported according to PRISMA Extension for Scoping Reviews: Checklist and Explanation [18] and guided by the methodological framework proposed by ARKSEY and O'MALLEY [19], which comprises five stages: 1) identifying the research question, 2) identifying the relevant studies, 3) study selection, 4) charting the data and 5) collating, summarising and reporting the results. This scoping review was undertaken to examine the extent, range and nature regarding how SDH are reported and actively considered across PR, SLH and MPCI interventions for people with advanced CRD and to identify gaps in the existing literature.

Design and search strategy

PubMed was searched for the latest systematic reviews regarding PR, SLH and MPCCI interventions for people with advanced CRD in August 2022. The following systematic reviews were identified and then updated with additional studies found in PubMed using the search strategy implemented by the authors, alongside additional terms to include people with ILD (appendix 1):

- “Pulmonary rehabilitation outcomes in individuals with chronic obstructive pulmonary disease: a systematic review” by SOUTO-MIRANDA *et al.* [20]
- “Singing for adults with chronic obstructive pulmonary disease (COPD)” by McNAMARA *et al.* [21]
- “Effectiveness and implementation of palliative care interventions for patients with chronic obstructive pulmonary disease: a systematic review” by BROESE *et al.* [7].

Eligibility criteria

Published randomised controlled trials, controlled trials, mixed methods and cohort studies that enrolled adults with a diagnosis of COPD or ILD were included. Duplicate studies, case reports, commentaries, conference abstracts, literature reviews or documents describing the outcomes of research studies or other primary data were excluded. L.L. screened titles and abstracts, and full-text reviews were conducted against the stated eligibility criteria.

Data extraction and analysis

Study characteristics including the author, organisation, year, country and title were extracted. For studies of PR, SLH and MPCCI, each social determinant was examined and categorised dichotomously as present or absent. The categorisation of the reported social determinants across the included studies were performed by L.L. with discussion with J.P. and N.S. J.P. is a palliative care physician and researcher, N.S. is a respiratory physician and researcher, and L.L. is a PhD student. To strengthen the rigour of the research, each member of the team contributed their previous experiences and expertise to the group discussions.

This study intended to explore and categorise the reporting of social determinants for PR, SLH and MPCCI to make appropriate recommendations for future work. Therefore, the quality of the studies themselves were not assessed.

Data synthesis

Social determinants reported across the literature were assessed and benchmarked against those proposed by the WHO Commission on SDH conceptual framework [3], which included income, occupation, education, social class, sex and race/ethnicity (table 1).

Results

Study selection and characteristics of included studies

Three SLH studies were extracted and included from McNAMARA *et al.* [21], 23 MPCCI studies from BROESE *et al.* [7] and 267 PR studies from SOUTO-MIRANDA *et al.* [20]. All studies retrieved met the eligibility criteria and were available in full text. After conducting the PubMed searches, an additional five SLH, 12

TABLE 1 Definitions and examples of social determinants of health (SDH) from World Health Organization Commission on SDH framework [3]

SDH	Definitions and examples
Income	Components include the listing of individual/household income, wage earnings, pensions, child support etc. [3]
Education	Measurements as a continuous variable (<i>e.g.</i> years of completed education) or categorical variable (<i>e.g.</i> completion of primary or high school, higher education diplomas, or degrees) [3]
Occupation	The classification of jobs Any indication of employment (<i>e.g.</i> unemployed, retired, informal or illegal jobs) [22]
Social class	Defined according to relations of power, ownership and control over productive resources [3]
Sex	Biologically determined characteristics [23]
Race/ethnicity	Social groups sharing cultural heritage, ancestry and/or selective and arbitrary physical characteristics (<i>e.g.</i> skin colour) The reporting of race/ethnicity followed Krieger’s glossary for social epidemiology [24], which employs a broad and comprehensive definition that encompasses social aspects beyond biological factors

MPCI and 84 PR studies were included in this review (appendices 2–4). All included studies were published between 2000–2022. Of the 351 included PR studies, 304 were from 26 high-income countries, 37 from five upper middle-income countries and 10 from seven lower middle-income countries, in accordance with the World Bank country income classifications [25] (table 2). Six SLH studies were from two high-income countries and two were from two upper-middle income countries. All MPCI studies were from 12 high-income countries (appendices 5–7).

Main findings

Key findings indicate limited reporting of SDH beyond sex. This was consistent across intervention type and country of study (table 3 and appendices 7–9). The most commonly reported social determinant of health across all interventions was sex (PR: n=331, 94.3%; SLH: n=6, 75.0%; MPCI: n=31, 88.6%). Social class was the least commonly reported determinant, appearing in only one PR study (n=1, 0.3%). MPCI (n=11, 31.4%) and PR (n=12, 3.4%) studies more frequently reported race/ethnicity than SLH studies (n=0, 0.0%). 18 PR studies (5.1%), two SLH studies (25.0%) and three MPCI studies (8.6%) reported no SDH (table 3). Mean number of reported SDH per study improved over time, most noticeably for PR studies (figure 1).

TABLE 2 Characteristics of included studies			
	PR studies (n=351)	SLH studies (n=8)	MPCI studies (n=35)
Studies from high-income countries	Australia (n=24) Belgium (n=1) Canada (n=13) Denmark (n=9) Finland (n=1) France (n=29), Germany (n=16) Greece (n=2) Ireland (n=3) Italy (n=23) Japan (n=25) Korea (n=1) New Zealand (n=1) Norway (n=6) Poland (n=3) Portugal (n=6) Romania (n=1) Saudi Arabia (n=2) Spain (n=13) South Korea (n=1) Sweden (n=3) Switzerland (n=4) Taiwan (n=5) Netherlands (n=21) UK (n=62) US (n=29)	Denmark (n=2) UK (n=4)	Australia (n=2) Belgium (n=1) Canada (n=6) Germany (n=2) Italy (n=2) New Zealand (n=1) Sweden (n=1) Singapore (n=1) Switzerland (n=1) Netherlands (n=3) UK (n=5) USA (n=10)
Studies from upper-middle income countries	Brazil (n=4) China (n=16) Colombia (n=1) Thailand (n=3) Turkey (n=13)	Brazil (n=1) China (n=1)	
Studies from lower-middle income countries	Egypt (n=1) India (n=4) Indonesia (n=1) Iran (n=1) Nigeria (n=1) Sri Lanka (n=1) Tunisia (n=1)		
Time period	2000–2022	2009–2022	2003–2022
MPCI: multicomponent palliative care interventions; PR: pulmonary rehabilitation; SLH: singing for lung health.			

TABLE 3 Summary of social determinants of health (SDH) reported across interventions

	PR (n=351)	SLH (n=8)	MPCI (n=35)
Number of studies reporting SDH			
Income	8 (2.3%)	1 (12.5%)	4 (11.4%)
Education	35 (10.0%)	2 (25.0%)	8 (22.9%)
Occupation	21 (6.0%)	1 (12.5%)	4 (11.4%)
Social class	1 (0.3%)	0 (0.0%)	0 (0.0%)
Sex	331 (94.3%)	6 (75.0%)	31 (88.6%)
Race/ethnicity	12 (3.4%)	0 (0.0%)	11 (31.4%)
Number of studies reporting no SDH	18 (5.1%)	2 (25.0%)	4 (11.4%)

MPCI: multicomponent palliative care interventions; PR: pulmonary rehabilitation; SLH: singing for lung health.

Discussion

To our knowledge, this is the first study to examine and categorise the presence and absence of social determinants of health across existing complex interventions for people with advanced CRD. Findings of this scoping review reveal a very limited acknowledgement of SDH, which are underpinned by the structural determinants defined in the WHO Commission on SDH conceptual framework: 1) income, 2) education, 3) occupation, 4) social class, 5) sex and 6) race/ethnicity [3]. Complex interventions delivered for people with advanced CRD are individualised, and there is a need for health services internationally to recognise the entire set of SDH consistently. Despite the strength of the evidence and the widespread use of PR around the world, this review revealed that only a small number of studies have considered ethnicity (3.4%) in contrast to those focused on MPCI (31.4%). Findings from this scoping review also highlight the immense need to involve consumers (people with advanced CRD population) from diverse backgrounds in clinical trial recruitment planning and the co-design and implementation of community-based interventions.

While findings reveal differential reporting of SDH across the studies, a key concept emerging from this review is that SDH are currently under-reported and that addressing them is the first hurdle towards understanding the more complex and interacting barriers that underlie them. Inconsistent reporting of SDH across PR, SLH and MPCI interventions may be due to the different purposes of each intervention. This review reveals that MPCI studies typically reported more SDH compared to PR. These findings are consistent with the theoretical framework of person-centred care which underpins many palliative care approaches that aim to deliver long-term holistic care and address patients' physical, psychological, social and spiritual needs [7]. PR programmes, on the other hand, are more medicalised [26] and focus on alleviating symptoms related to physical activity, such as dyspnoea and fatigue, and improving exercise capacity and quality of life [27]. Yet, studies exploring the SDH that impact adherence and completion of these prescribed treatments for people with COPD is scarce due to a lack of socioeconomic data documented in clinical registries and medical records [28]. There also remains a need to actively consider more SDH among SLH studies given the cultural differences in attitudes and responses to singing worldwide.

Findings from this study build on current evidence which indicates that there remains a limited understanding of factors driving known racial and ethnic disparities in pulmonary health outcomes due to the lack of sufficient demographic reporting [29]. Reporting SDH such as race/ethnicity of clinical trial participants can reveal disparities in the efficacy of treatments for minorities with respiratory disease [29]. It is important to note that inequalities due to race/ethnicity are often confounded by other SDH, particularly socioeconomic status. Existing literature emphasises that the relationship and independent impacts of race/ethnicity and socioeconomic status on COPD health outcomes remains poorly understood [30]. There have been recommendations to eliminate disparities in end-of-life care by designing interventions that address the reasons for inequalities by race/ethnicity and socioeconomic status [30]. This review reveals that the reporting of novel interventions such as SLH programmes has similar limitations.

Despite well-documented disparities due to income, education, occupation, social class, sex and race/ethnicity, results from this review indicate that these determinants remain widely under-reported. Our findings indicate at best that there is insufficient reporting and, at worst, a lack of consultation or consideration in the design of clinical trials and implementation of knowledge to ensure that interventions are accessible and acceptable for the populations most severely impacted by advanced CRD. Findings from this study build on the existing literature which reinforces the need for researchers to consider diversity [31]

Year	Average number of SDH reported		
	PR	SLH	MPCI
2022	1.44	2.50	1.50
2021	1.30	1.00	1.90
2020	1.00	1.00	
2019	1.40	2.00	1.50
2018	1.15		1.33
2017	1.05		0.50
2016	1.31		2.00
2015	1.23		1.00
2014	1.57		1.33
2013	1.15		4.00
2012	1.10	0.00	
2011	0.93		
2010	0.94	0.00	1.00
2009	1.00	1.00	1.00
2008	1.15		
2007	0.90		
2006	1.00		3.00
2005	0.67		
2004	1.13		4.00
2003	1.13		1.67
2002	1.00		
2001	0.80		
2000	0.89		

FIGURE 1 Reporting of social determinants of health (SDH) over time across pulmonary rehabilitation (PR), singing for lung health (SLH) and multicomponent palliative care interventions (MPCI) studies. The colour of each cell represents the number of SDH reported over time in each intervention from most comprehensively reported (green) to least comprehensively reported (red).

and the involvement of affected communities in the co-design of complex interventions. The well-recognised WHO Commission on SDH conceptual framework has evolved from previous models by conceptualising the health system as a social determinant of health. In line with this concept, a culturally safe Australian PR programme, known as the Breathe Easy, Walk Easy, Lungs for Life (BE WELL) programme, is being developed and implemented using participatory action research [32]. It is widely known that accessibility to PR services provided in hospital outpatient departments among First Nations people are hindered by their distrust of the hospital system resulting from a history – past and current – of colonialism, dispossession, and of institutional racism [33]. The BE WELL project aims to deliver effective and culturally safe interventions for COPD by ensuring equity of access for indigenous people through involving First Nations health workers

to co-design the PR programme [32]. Recognition of the cultural identity of participants is crucial in order to facilitate uptake of safe and targeted interventions for people with advanced CRD.

Implications

The findings reveal inconsistent reporting of SDH across PR, SLH and MPCCI interventions. Neglecting or under-reporting SDH could consequently lead to the implementation failure of interventions for people with advanced CRD. Future research involving the design of novel interventions, such as SLH, should be consumer-driven and involve measurements of participant experiences to ensure that the interventions are culturally appropriate and align with the targeted demographics of people with advanced CRD and their carers. Funding for future study interventions could also mandate the standardised collection of SDH to ensure that these factors are addressed during the design and conduct of trials. Further work is also required to revise existing interventions and palliative care models to acknowledge the SDH that impact participant uptake, adherence and completion.

Strengths and limitations

The risk of bias was minimised in this study by conducting the review in accordance with the PRISMA process [18]. Findings provide valuable data regarding the importance of reporting SDH across interventions for people with advanced CRD, which can inform the future implementation of tailored programmes and services that address inequality by meeting the specific needs of different communities.

This scoping review only included studies focusing on people with COPD or ILD, as these CRD have been the greatest focus of research for PR, SLH and MPCCI. Recognising this limitation, further work is required to determine the reporting of SDH across interventions designed for populations with other lung diseases. In keeping with other published examples [34], critical appraisal was not used in this scoping review to assess the quality of studies included. Given the extensive evidence base, particularly for PR studies, future research could involve systematic reviews or meta-analyses to enhance the rigor and quality of reporting.

Conclusions

To address inequalities limiting accessibility and adherence of healthcare interventions more fully, future work should explore and extensively report social determinants of health. Currently, there is an opportunity for novel interventions such as SLH programmes to consider individual patients' cultural needs and person-centred experiences to inform broader expansion and implementation worldwide.

Provenance: Submitted article, peer reviewed.

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