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Policy, system and service design influence on healthcare inequities for people with end-of-life chronic obstructive airways disease, their support people and health professionals

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Abstract

Background People with end-of-life chronic obstructive pulmonary disease (COPD) experience debilitating physical limitations, with a high mortality rate. Our research has shown health system design and delivery leads to inequitable outcomes. Enabling people with end-of-life COPD, their support people, and health professionals to partner in setting the agenda for resource allocation may inform health service improvement.

Design Qualitative methodology utilising focus groups including patients, family, friends, informal support people, health care workers and professionals.

Methods The analysis, utilising critical theory and Actor-Network theory, positioned people with severe COPD, their support people and health professionals as experts in end-of-life care. Analyses triangulated these perspectives, and were reviewed by the research investigators and an expert reference group.

Results Participants ($n=74$) in seven focus groups reported their experiences of inequity within the healthcare system. Equity was an overarching phenomenon identified by participants, with three specific themes being described: policy design, system design, and service design.

Conclusion Experiences of patients, their support people and health professionals as experts in end-of-life COPD care can inform health systems and health service design to address current inequities in funding and delivery of care for end-of-life COPD.

Keywords Chronic obstructive pulmonary disease, Healthcare network, Quality healthcare, Healthcare systems, Equity

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Background

Chronic obstructive pulmonary disease is a common global long-term condition with an unpredictable trajectory and progressive disability [1]. People with end-of-life COPD experience worsening exacerbations over time, requiring hospital admissions, increased community services and escalating primary care input [2]. Integration of these services is incomplete, causing fragmentation and gaps in care [3]. National and regional governments are generally responsible for the design of healthcare policies to achieve optimal health outcomes [4]. The healthcare system is accountable for service design. Health systems and services are governed and designed without effective partnerships with consumers and health professionals [5]. These policy and system designs suggest that inequity is not inadvertent.

The underlying causes of health inequity arise from economic, social, environmental and structural disparities that promote avoidable and unjust differences in outcomes between groups [6]. The effect of systemic biases and structural inequities in policies and organisations culminates in the design of services for a dominant group in society [7]. People with end-of-life COPD experience a healthcare system over which they have little influence [5]. This lack of contribution to the very system mandated to care for them leads to the continuation of high-quality care for those privileged by health system and service design. Demonstrable improvements in health inequity may require a multi-disciplinary, multi-sector effort endorsed by relevant government ministries to shift [8].

In 2022, the Aotearoa New Zealand government announced major health reforms, moving 20 district health boards into one centralised entity (Te Whatu Ora-Health New Zealand). One of the priorities of this new entity includes creating a simpler and more co-ordinated health system for the whole population [9]. We conducted our study prior to the reforms, thereby evaluating the previous structure, with an opportunity to inform the new system. The purpose of this paper was to explore the health system experiences and perceptions of care for people with end-of-life COPD, their support people and health professionals.

Methods

We utilised qualitative methods and focus groups to position people with end-of-life COPD, their support people and health professionals as expert partners in end-of-life healthcare. The full methodology of this study is published elsewhere [10]. Qualitative methodologies enable researchers to report on differences between best clinical practice and the lived experience of those receiving healthcare [11]. The research team utilised critical theory as a framework to explore the power imbalances

in the healthcare network for people with severe COPD, their support people and health professionals [12]. Actor-network theory was also used to understand the different actors involved in the network and how they connect with one another. This theory purports that the way actors behave and the outcomes produced is caused by encounters with one another. Understanding these connections can inform quality improvements at different levels in the health system [13].

The research team comprised a palliative care physician, a nephrologist with palliative care expertise, a respiratory physician and an Indigenous academic psychologist, all with experience with qualitative methodologies. The nephrologist and psychologist had previous experience with Actor-Network theory and critical theory employed to analyse the data. We utilised the consolidated criteria for reporting qualitative research (COREQ) guidelines [14] and the consolidated criteria for strengthening reporting of health research involving Indigenous Peoples (CONSIDER) [15] checklist to inform study design. A broadly experienced advisory group, including Māori and Pacific representation and healthcare delivery, provided governance to the project at the design and evaluation stages.

This study was conducted in Canterbury, a large district of Aotearoa New Zealand in the South Island. The Canterbury region was selected as the research team was based in this area, with strong links to the community and secondary services. Healthcare in Aotearoa New Zealand is largely delivered in the public sector, with primary care and community-based care subsidised by the government. In Aotearoa New Zealand, about 72% identify as NZ European, 17% as the Indigenous population (Māori), and almost 7% identify as Pacific peoples [16, 17].

For several months before recruitment commenced, AL built relationships with a variety of relevant social community groups, organisations and different providers. Māori and Pacific health professionals were instrumental in identifying participants from their communities and were invited to participate in these groups as is cultural custom. Other participants were recruited through COPD support groups and health professionals. A bereavement group was driven by community request. Health professional participants who deliver care to people with severe COPD were recruited through the research teams' networks and communication with department leaders.

The focus groups were held in either community settings or in the hospital, depending on preference. Table 1 outlines the composition of each group.

Māori and Pacific researchers led the focus groups within their community to support cultural safety within the groups and enabled discussions in preferred

Table 1 Composition of the seven focus groups

No. of groups	Composition
2	Non-Māori/Non-Pacific community focus groups for peoples with end-of-life COPD and their support people .
1	Māori community focus group for Māori peoples with end-of-life COPD, their support people and a health professional .
1	Pacific community focus group for Pacific peoples with severe COPD, their support people and health professionals .
1	group of bereaved support people requested an opportunity to form a specific focus group
2	focus groups involved community and hospital-based health professionals (health professionals) , including allied health professionals, aged residential care carers, primary care practitioners, and respiratory specialists.

languages. The remaining focus groups were led by AL, a palliative care physician, assisted by appropriate co-facilitators. Each focus group commenced with the sharing of a diagram from a systematic review of the existing healthcare networks for people with end-of-life COPD [5]. The diagram set the research context for the participants, enabling patients and their support people and health professionals to provide reflections, critique and considerations of the diagram and their interactions with health systems and services. (Suppl One) The semi-structured interview schedule helped facilitate participant conversation. (Suppl Two) The focus group discussions were audio-recorded and transcribed, with translation of the languages completed by the facilitators.

Multiple coding cycles were undertaken to analyse the data. AL categorised the data linked to each interview question utilising the deductive analysis method of structural coding [18]. These structural codes were then aligned with critical theory and Actor-Network theory to reveal five codes: the context of participants, disconnection in the network, healthcare environment, integration and the expert voice. Within this first cycle, a further analysis was undertaken using descriptive methods to

define and refine specific codes of data. Three descriptive codes were defined as: system, patient/support person landscape and health providers landscape. The second coding cycle utilised pattern coding to focus on relationships between codes. Pattern coding was performed a second time to organise categories into larger themes with a focus on equity for people with severe COPD. Three further codes were revealed: social positioning, political positioning and organisational positioning. After finalising the coding, all subsequent analysis was triangulated among the research team.

This dataset has been analysed utilising critical theory and Actor-Network theory frameworks. Consequently three distinct models of care were proposed by viewing the analysis through different lenses. The first model of care centred on how to deliver high-quality care at the individual and organisational level. This has been published elsewhere [19]. The second model of care explored recommendations towards systems and governance of healthcare delivery [20]. This final analysis of the data utilised an equity lens to report the systematic differences in social resources, the drivers that impact health environments within organisations, and political systemic drivers of healthcare.

Results

Seventy-four participants in seven focus groups reported their experiences of end-of-life COPD healthcare delivery (Table 2). Three main themes describing the need for equity within the healthcare system included: policy design, system design and service design. Subthemes were also identified within each of the main themes and will be further extrapolated on within this section.

Policy design

Policy design was defined within the analysis as the act of governments identifying current issues and formulating steps required to achieve optimal and equitable outcomes. People with end-of-life COPD, their support

Table 2 Characteristics of participants in the seven focus groups

Focus Group	Participants	Patients	Support People	Health professionals
1.	Non-Māori, non-Pacific patients and support people	8	3	0
2.	Non-Māori, non-Pacific patients and support people	10	2	0
3.	Māori patients and support people and health professionals	5	1	1
4.	Pacific patients and support people and health professionals	1	3	5
5.	Bereaved carers		5	
6.	Community-based health professionals			14 Nursing $n=7$ Medical $n=4$ Allied Health $n=3$
7.	Hospital-based health professionals			16 Nursing $n=4$ Medical $n=8$ Allied Health $n=4$

people and health professionals described how current policies and healthcare contracts perpetuated the inconsistent delivery of services leading directly to inequity in health outcomes. The analysis identified three sub-themes: funding prioritisation, political prioritisation and COPD prioritisation.

Funding prioritisation

Funding prioritisation was defined in the analysis as the ways in which funding models drive priorities within the health budget. People with end-of-life COPD, their support people and health professional participants discussed their perception of where current funding is prioritised and how it differed from where they would recommend that funding be directed. Participants under the age of 65 years with end-of-life COPD had limited access to equipment and services available compared to those in the older age group. Funding for end-of-life COPD ensured services were delivered effectively to the older person, who had no dependants and had supportive family who were no longer working. The funding age limit impeded the delivery of care to patient participants whose support people had work responsibilities, and who were ineligible for subsidised care. This increased financial and social stress for these families and reduced access to health services.

We couldn't get access to anything before then because he was under 65 and there was too much paperwork. That was the response. (FG 5 Bereaved support person)

Health professional participants reported that the current focus for funding modelling was on the physical state and age of the person with COPD, and did not include their social and emotional needs. Health professional participants described the lack of recognition by funders that frailty and disability are not exclusively associated with age. Health professional participants described the challenges they faced when transition points between goals of care of a person with COPD had not been reviewed. This often led to significant limitations for patient with end-of-life COPD to access medical services, and negatively affected their mental and emotional health. Participants with end-of-life COPD required funding to be more personalised and accessible earlier in the disease trajectory to prevent illness exacerbations and reduce disabilities.

there's always debate over what is their FEV1 before you start considering that they're end-of-life.

At the moment it's 65.

Yeah, I know, but there are also variables within that. So, I think there needs to be some fluidity in that middle ground that's to do with... (FG6, Community HP)

Allied health professional participants also discussed the emphasis funding models placed on the biomedical paradigm over other models of care. Participants discussed the need for more consistent allied health support and availability to focus on the holistic care of a person with severe COPD.

Political prioritisation

Political prioritisation was defined in the analysis as the need to prioritise the visibility of COPD within the government, healthcare system and community. Support people participants discussed the difficulties they encountered with the lack of visibility of organisations dedicated to providing education and services to those with severe COPD. Participants had seen physical buildings with signage about cancer, diabetes and heart disease but not COPD. This led to feelings of isolation, and a lack of explicit support, resources and structures.

I think it needs to be changed. Those things where you have that disease. You've got for cancer, you've got the cancer society. I know you've got Can Breathe but Can Breathe, not once in all of the time with my brother ever, ever come to see my brother. Not once did they ever come in and offer this that and the other. No services whatsoever did CanBreathe do. Now, I figured Can Breathe was okay, yes their part of the lung thing but I had no idea what Can Breathe did which is really sad.

I've never heard of them until now. I've never heard of them (FG5, bereaved carer)

Māori health professional participants discussed how their services were not always visible to other services in the health system, with the constant need to explain the types of services they deliver. Māori health professional participants also reported difficulties in identifying further referrals options to clinical and culturally appropriate services for Māori. Non-Māori health professional participants reported being unaware of the capacity and capability of Māori services within the regional health sector.

I know that for girls, the RNs, when they ring whoever, "Who are you? What are you?" It's about being visible in the community and it's quite hard. So, we don't have those access. We just have to keep going and pushing until we do get something. (FG3, Māori HP)

People with end-of-life COPD, their support people and health professional participants all discussed a focus on community-led, and government supported, education, health promotion and patient-centred care. Participants with end-of-life COPD described the perceived inequity of the profile of services for diabetes, cancer and heart disease compared with the lack of awareness of COPD. This lack of visibility led directly to people not accessing services and perpetuated the stigma of COPD being self-inflicted.

I've got two friends that are very, very severe with COPD and they don't have any community services. And they go to their doctors. They've never ever heard of Can Breathe. They've never heard of palliative. They've never heard of any of these services. I mean not palliative, respiratory rehabilitation. They've never ever been there, never ever heard of it and they're in stage 4. They're sitting at their home and they're Māori. (FG3, Māori patient)

Participants with end-of-life COPD and their support people required health education in addition to smoking cessation and prevention. These participants wished to prioritise instruction and support on how to manage established COPD.

I would think across the board education, [...] They do a lot of advertising and that, and more so now and rightfully so on mental health and suicide and that sort of thing, [...] Well, it is the same sort of message where they need to come across for the education, like put somebody walking down the road [...] and somebody that's got COPD and say can you spot the difference. Don't judge a book by its cover. (FG1, Patient)

Pacific participants reported that churches, Pacific radio stations and community-led craft groups were the best modalities for reaching their community with health promotion messages and education.

COPD prioritisation

COPD Prioritisation was defined in the analysis as the desire for a strategic vision for COPD services utilising partnership, Te Tiriti O Waitangi (national treaty between Māori and the British Crown) principles, and

audit cycles of evaluation and feedback. Health professional participants discussed the need for a strategic vision with a government-led respiratory strategy, which could empower organisations to work within a national framework. The national consumer group for chronic lung conditions in Aotearoa New Zealand had developed an inclusive strategy without political input.

Māori patients with end-of-life COPD, support people and health professional participants discussed the requirement for appropriate partnerships through representation on strategy groups. Similarly, Pacific participants also wanted to be included, acknowledging that the Pacific community includes several countries with different cultural identities. Pacific participants with end-of-life COPD also described their expectation that an illness prevention strategy would focus on the whole person.

Māori people with end-of-life COPD and their support people participants desired to have policies related to education, health, and housing aligned with the Treaty of Waitangi (Te Tiriti O Waitangi), which would require partnership with Māori political structures and which would improve health outcomes for Māori.

why doesn't someone just turn around and say, "Okay, why don't we come together and say what we need, let's see what systems we need to go in to get that," because I believe whānau (extended family) should be at the forefront of this. Whānau should be sitting there. Any of these decisions and every part of that should have a whānau that suffers from COPD because they know the answers. [...] People that suffer or have been through it know the answers because they're the ones that will know (FG3, Māori patient)

Health professional participants discussed the need for policies to follow evidence of efficacy with feedback loops through audit and evaluation tools. New projects or initiatives put in place without audit and evaluation mechanisms meant that outcomes were not being measured. The lack of measurement led to a missed opportunity to focus on quality improvement.

System design

Social inequity in the healthcare system within the analysis was defined as systematic differences in the health status of people relative to differential exposures to risk factors. Participants discussed key drivers that perpetuate poor health outcomes, including lack of provision of transport, funding to attend healthcare consultations and management, appropriate housing options, help with activities of daily living, and culturally competent services. The analysis identified three sub-themes: ableist, financial subsidisation and social capital.

Ableist

Ableist was defined in the analysis as a healthcare system that perpetuated inequities through designing services for people with physical, financial, and social resources to access care. Participants with end-of-life COPD and their support people stated that accessing care required utilising public transport to attend GP visits, support groups and pulmonary rehabilitation. Public transport was frequently not available at the right time or schedule. Patients with COPD have significant physical limitations and had experienced public transport systems poorly designed to meet their needs. Public transportation was not free, leading to inequitable care delivery to families with fewer financial resources. Participants had experienced some charitable organisations historically offering appropriate and low-cost transport alternatives. These ceased without other solutions available.

They had a Red Cross van that came, gold coin donation which was awesome. I'd organise that when I couldn't get him there but they stopped it, pulled the pin. I said, 'how are these people meant to come to this pulmonary rehab that is so important to them, yet they can't drive. When it's raining, they can't go on the bus, cos they can't walk to the bus stop.' (FG5, Bereaved carer)

Financial subsidisation

Financial subsidisation was defined in the analysis as the requirement for people with end-of-life COPD and their support people to financially subsidise social and healthcare services to enable access to appropriate care. Participants reported that government departments did not deliver access to services, financial assistance and clear decision-making to participants with end-of-life COPD and their support people. Social services seemed to have little understanding of the complexity and needs of people with severe COPD. Participants perceived that government institutions were siloed and failed to deliver integrated care. This increased stress, isolation, and dependence on families, who were already at their physical, social and financial limits. Pacific participants described their communities' challenges with governmental bureaucracy to access financial aid. Patients and support people commented that they had to rely on family members or non-government organisations for financial support as government services were unresponsive and inflexible.

Health professional participants explained that funding for equipment like wheelchairs or handrails was not provided, which had a more significant impact on patients with fewer financial resources. Attendance at general practice care was not subsidised sufficiently, leading to

attendance at emergency departments to enable care delivery to participants with end of life COPD, their support people and health professionals.

I'm not very impressed with my doctor at the moment. They charge you \$47 every time you go so you're a bit reluctant to go. And then when you have to go you've got to pay that. (FG2 Patient)

Social capital

Social capital was defined in the analysis as the ways in which adequate healthcare delivery for end-of-life COPD was reliant on the personal networks and resources available to patient participants and their support people.

Participants discussed that suitable housing with adequate insulation, and temperature control to keep people well, and prevent hospital admission, was not considered in care plans and, therefore, only available to those privileged with social capital.

Housing is another thing. Someone that has COPD, they cannot just live in any state or any housing. It cannot be below 17 degrees. You've got to have double glazing and it's not being picky, but it's the things, cos without those things, their hospital and their exacerbation is more and more...(FG5, bereaved carer)

People with COPD and their support people were required to repeatedly change accommodations which affected their social networks and support people. Pacific participants described the stress of living in a house away from family members and the toll it took on the health of the person with COPD. Pacific health professionals reported the absence of advocates and navigators for their community to enable appropriate housing and that they provided these roles.

we have someone who can navigate our people through private rentals and things.

Basically, just trying to be an advocate for them so that they are provided with the essentials of food, accommodation, shelter and house. (FG4, Pacific health professional)

Participants discussed how health services did not deliver help with daily living activities and health professionals reported they could not provide such services satisfactorily due to underfunding. Participants identified that a lack of home-based support impacted people without

financial and social resources substantially more than others. The lack of funding provided in the current health system to support personal care and domestic assistance in the home negatively impacted peoples' ability to stay at home, particularly when the services required their financial contribution and subsidisation.

They can't have a wheelchair unless [...] (FG2 Community Health professional 1)

Certain criteria. (Facilitator)

Yeah, criteria and we can't get them.

Yeah. They can only get a wheelchair if they need it for mobility [around the house- interjection] inside the house. (Community Health professional 2)

so they're stuck because they can't walk because they get short of breath?

It affects their ability to access services including like their GP or their pharmacist.

And it also impacts massively on their mental health because a lot of them are feeling down anyway and then now they can't get out of the house and sit in the sun because they can't walk that far.

Service design

Service design was defined in the analysis as how an organisation or team designs services that perpetuate inequities in care delivery to groups in the community. Service delivery efficiency and effectiveness was impacted by drivers within organisations and service providers that disproportionately affect the health environment. Participants outlined how an organisation's focus, the way they work and the rules they impose disrupt service delivery. Subthemes included: exclusion from care, inflexible service delivery and culturally unsafe care.

Excluded from care

Excluded from care was defined by the analysis as barriers to high-quality end-of-life care due to inadequate service design. The health system excluded support people and participants with end-of-life COPD from high-quality care and a lack of service delivery. These participants described sensing the irritation of health professionals regarding a past history of smoking as the cause of this particular illness, the belief that their health disabilities were self-inflicted and, therefore, were undeserving of their time. Participants discussed how the health system was designed to be unwelcoming to people with end of life COPD who continue to smoke. This reduced attendance for consultations and opportunities to receive support. These participants described the stigma they experienced within the health system, which led to increased frustration and stress.

I also feel that you feel like it's a smoker's disease and so, you're like a leper. If you've got cancer, oh my god, you poor thing, you've got cancer. My god, you've got COPD, you smoke, it's your own fault and that's what I really... that's how I feel the health system... you almost feel like when we went into hospital just that one time, they'd go, 'are you still smoking?' and he; go, 'yes,' and they'd go... you feel like they're just rolling their eyes.

It's like there's a big red cross or something inside you. (FG5, bereaved carer)

The age of the person with end-of-life COPD also was discussed by support people participants. Those in the younger age groups described organisations that did not understand their specific requirements, especially related to carer responsibilities for dependants. The participants experienced a rigid healthcare system, which groups all people with COPD together and delivers healthcare based on the diagnostic label.

I also 100% hand on heart believe possibly, not necessarily and I don't know your husband but I 100% believe with the age difference, your husband 86 and [...] was 44. He didn't expect. [...] He was not accepted. He had a 10 year old daughter. He had an 11 year old son and an 18 year old son. [...]

Same disease but different set of needs. (FG5, bereaved carer)

Community-based health professional participants working with non-government organisations highlighted attempts to build connections with other sectors of the healthcare system, which had met with resistance to collaborate on behalf of this COPD population. This lack of willingness to work together had increased feelings of frustration. However, health professional and support people participants working as volunteers in providing support to people with end of life COPD were successful in building connections with willing organisations.

Our organisation they work really hard outside normal working hours and they take the exercise and that to the community. So, they are actually, you're actually delivering exercise programmes to over a hundred aren't you (FG4, Pacific HP).

Participants with end-of-life COPD described the inclusive nature of respiratory support groups and the difference these had made in their lives. These participants were aware many people in the community with this condition were not aware of these support groups and wanted to discuss ways to improve access to ensure people were not falling through gaps in the system.

Inflexible service delivery

Inflexible service delivery was defined in the analysis as the rigid service designs for people with end-of-life COPD that did not deliver personalised care. Participants with end-of-life COPD, their support people and health professionals discussed that health services did not provide equipment and services due to service rules and funding criteria. In addition, health and social organisations applied different criteria to the same person depending on the setting. For example, in the hospital, people with end-of-life COPD were provided with a shower stool, but this was generally not provided at home unless certain criteria were met. Basic equipment items enabled people with severe respiratory illnesses to perform activities of daily living at home.

Yeah well he got the stool and that when he was in the hospital. But now he's been discharged he gets nothing. (FG2, Support person)

Health professional participants reported that referrals enacted by organisations in a timely way also aided people with end-of-life COPD and their support people to be provided with high-quality care. These referrals occurred more frequently when the person with end-of-life COPD was over a certain age, as age-related policies and procedures define the pathway. Support people participants reported that individual health professionals who understood the health system and the way it worked could

provide beneficial advice and were proactive for future planning. These participants revealed that health professional practices could address health delivery inequities.

We had the social worker, a lovely social worker through the DHB said to me, 'tick every box, [patient name], tick every box, even if you don't want it, you'll need it eventually and then when you go to ask for that, you might not get it cos they have to start again with the paperwork. Tick them all. I ticked them all and I needed all and they there for when I wanted them. (FG1, bereaved carer)

Māori health professional participants described the inadequate funding to their healthcare organisations to provide inclusive services with a small workforce. Māori participants expressed a preference for home services and felt outcomes would ultimately be better for the whole community.

That's the problem with Māori eh, we like to be in a setting that's not clinical, you haven't got the receptionist in. That sounds horrible, but that's the matter of the fact is we like our whānau (extended family) situation, eh?

Yes, we do. And we seem to talk much better.

We do. We're freer to speak our minds within that. (FG3, Māori patient)

Pacific participants with end of life COPD, their support people and health professionals described the lack of Pacific health care workers provided in both the community setting and by hospitals. This workforce issue directly affected the engagement with, and knowledge of, available end-of-life care services.

I believe that's just felt like there's a lot of blocks that they put up. And it's always once you have reached so they'll put you at a level and once you get the paperwork to achieve that level then they take it up higher. Or they make it unobtainable to the people. It comes to the point where the Pacific people just get so sick of being knocked back and then they just go, "Screw it," and just go to family go to extended and that's where everybody else has to come in. (FG 5, Pacific support person)

Health professional participants reported difficulties with after-hours care for people prone to exacerbations. These participants believed that organisations that prioritised the documentation of advance care planning and acute care plans for people with COPD lead to better decision-making by services providing after-hours options. Non-government organisations, especially those providing targeted care to those with life-limiting illness, were seen as more responsive to the requirements of people with COPD. Health professionals referred to these organisations or programmes as soon as possible to bypass some of the blocks encountered in other parts of the system. This had the potential to lead to inequities for those people with end of life COPD not known to those services.

I think through Nurse Maude (Non-government organisation) it's great because you refer and then they are onto it straightaway. But through the public system so if they're not palliative yet, they haven't been given that palliative, we can't access Nurse Maude, so we have to go through public and it's a mission (FG7, Hospital health professional)

Culturally unsafe care

Culturally unsafe care was defined in the analysis as health service design that excludes the patient experience to define and improve the quality of care, including healthcare services reflecting on how the power that they hold affects the ways they deliver care. Health professional participants believed a diverse and culturally-competent workforce within services and organisations would help Indigenous and Pacific communities feel safe and confident in the health system. Connecting people with end-of-life COPD and their support people with workers from their own communities was seen as vital for high quality care and better outcomes. Māori health care teams did exist in the hospital system, albeit thinly spread. However there was no Pacific health support team in the hospital setting.

I'd like to see a Pasifika (Pacific people), like how they have Hauora Māori in the secondary care system, there should be a Pacific team now because we are seeing high admission rates of Pacific that can be prevented, but we need advocacy within that space. The same out in the community, GPs to be able to feel free to reach out to Pacific workers. Doesn't have to be medical, because sometimes it's social issues that are affecting there. (FG5, Pacific HP)

Pacific participants with end-of-life COPD, their support people and health professionals described the vital importance of spiritual and cultural practices in their

health outcomes. These participants also explained the communal nature of their world views, which did not align with the current health system. This worldview included different perceptions of privacy policies, which appeared to create a barrier to the provision of appropriate care to their communities.

unfortunately, with that, for the greater majority, we have to align ourselves with mainstream services, and unfortunately those mainstream services do not cater to our needs. (FG4, Pacific support person)

Participants reported the need for organisations to have cultural and spiritual competencies as part of their service models. Pacific support people discussed their desire for all healthcare workers to have mandatory Pacific cultural education days. Participants felt it important that healthcare workers understood that the Pacific included nation and region-specific cultures and identities.

There needs to be a lot more services on offer that is culturally competent to Pacific and to understand that we are not just one people, we're a diverse range of people, so acknowledge the diversity within Pasifika (Pacific people). I think in Canterbury itself there's a lot of stereotypes of what we are as a people and it can come down as being racist at the best of times. With that too, I feel that we don't get the best healthcare, and unfortunately for us we're a respectful people, like it's been shown, and we don't question. And so with that, we don't get the best possible care. (FG5, Pacific support person)

Table 3 outlines practical recommendations as suggested by participants in the focus groups. These recommendations provide signposts to policy designers as to how health systems may be delivered in a way that provides high-quality end-of-life care.

Discussion

This study explored the equitable delivery of healthcare and social services to people with end-of-life COPD. The research positioned people with COPD, their support people and health professional as experts, utilising the frameworks of Critical Theory and Actor-Network theory to reveal the dominant socio-political context and power imbalances of the current healthcare delivery. The critical theory framework and analysis enabled people with end-of-life COPD, their support, and health professionals to critique the power and social structures that lead to unjust healthcare delivery disparities. The word 'design' appears in each of the themes and describes how the creation of governmental policies excludes people with COPD and their support people, and generate

Table 3 Recommendations for change from participants from an equity perspective**Recommendations for change from participants****Policy Design****Funding prioritisation**

Fund services based on need, not age or trajectory of a person with end-of-life COPD

Support families/whānau who are performing dual roles of working and supporting

Pivot funding to organisations/sectors who are providing end-of-life care services

Political prioritisation

Development of physically- visible services

Increased awareness of the range of culturally-appropriate services available

Support for ministries to engage meaningfully with each other

Investment in health promotion and management of COPD

Investment in and support for community-led education

COPD prioritisation

Development of a government-endorsed national respiratory strategy

Strategic plan that follows Te Tiriti O Waitangi principles

Strategic plan with adequate Pacific representation

Strategies that follow robust evidence with built-in evaluation mechanisms

System design**Ableist**

Invest in public transport options that are acceptable to people with end-of-life COPD

Support community-based services to provide appropriate transport options

Financial subsidisation

Fund respiratory equipment and GP visits appropriately

Streamline and create culturally-competent processes for accessing financial support

Social capital

Develop processes that house people with end of life COPD near support network

Develop processes that place people with end of life COPD in appropriate houses

Fund high quality and appropriate homecare services

Service design**Excluded from care**

Non-judgemental attitude towards people with end of life COPD

Incentives for organisations willing to work collaboratively with other services

Increased awareness of respiratory support groups

Inflexible service delivery

Consistent access to services across settings for people with end of life COPD

Consistency across health professionals regarding knowledge of health system and proactive planning

Services prioritise advanced care and acute care planning

Adequate funding for a culturally-competent workforce

Culturally unsafe care

Develop a diverse workforce that reflects the Aotearoa New Zealand population

Mandate spiritual and cultural competencies for healthcare services/organisations

Mandate Pacific cultural education days

inequities in the health system, the social system and within service delivery.

This research identified the need for flexible funding streams which consider illness severity, trajectory and community networks. This aligns with other studies who have identified that national health systems worldwide have grappled for decades to develop funding models that drive equitable health outcomes for their populations. Over 30 years ago, Brazil embarked on major health reforms encompassing health and social system initiatives, significantly improving health outcomes across

its population [8]. Population and needs-based funding approaches have attempted to prioritise equity for high-risk groups in the community [21]. These needs-based funding models do not guarantee the correct distribution of resources to appropriate population cohorts [22]. However, new funding models such as “value-based” care have been proposed that appear to have underlying principles of flexibility and community engagement in their descriptions [23].

This research also identified support for the development of a National Respiratory Strategy aligned with

Te Tiriti O Waitangi (Treaty of Waitangi) principles endorsed by the government. Development of the strategy would need adequate representation on the working group, with illness prevention and cultural safety to be part of the strategic plan. High-level health strategies that outline priorities and actions for a system or population, have the opportunity to improve the performance of the health system for population groups such as people with end-of-life COPD [24]. This finding aligns with the World Health Organisation recommendation that there is a strong need for monitoring, evaluation and the review of national health strategies to ensure relevant accountability [24]. The aspiration for an operational strategic plan to set the long-term direction for a sector and provide a concrete framework for work programmes, was highlighted within our findings and aligns with current healthcare strategies [25].

Our research findings support the prioritisation of psychological health, social determinants, and cultural domains of health to improve health outcomes. Investment into resource development and design such as appropriate transport options allow people to connect with their community and healthcare team. Policy, system and service design can impact the social determinants of health, defined as the condition within which people live, work, play, worship, and learn, that affects their quality of life [26, 27]. People with physical disability such as those with end-of-life COPD, are particularly impacted by issues with housing, employment and transport [28, 29]. In New Zealand, a research project into home insulation and improved chronic respiratory incidence led to national initiatives to create 'healthy' homes [30]. Increased social support for the older person with COPD positively impacts on the treatment burden [31]. Programmes that include psychological and social support for families of people with severe COPD revealed improvements in coping adjustment to limitations of the condition [32].

Strategies for implementing culturally-competent healthcare at an organisational level included integrating appropriate community health workers, community outreach programmes, and creating support networks. An Australian study of chronic care co-ordination through community health workers in remote Indigenous communities reported improvements in access to health care and improved disease management [33]. National healthcare systems that have meaningfully engaged with their Indigenous population and incorporated their worldview into initiatives have shown better outcomes for people with COPD in these communities [34].

Strengths and limitations

This study was conducted in Aotearoa New Zealand, with a distinctive health system and cultural identity.

Actor-Network theory was utilised to understand the healthcare network for people with end-of-life COPD, and critical theory allowed the research team to better understand the socio-political landscape for this population. Due to this being in one location it is presented like a case study, where generalisability of the findings to other settings will need to be determined by those based in other locations/settings/health systems. The study did triangulate the voices of multiple stakeholders and undertook in-depth analysis to reach a number of practical recommendations to health policy, system and service designers.

Conclusion

People with severe COPD, their support people and health professionals proposed several actionable suggestions for ways equity could be achieved for end-of-life care within the current health system. These proposed healthcare quality improvements could potential have impact on patient outcomes, support people experiences, and health professional job satisfaction.

Abbreviations

COPD	Chronic obstructive pulmonary disease
COREQ	Consolidated criteria for Reporting Qualitative Research checklist
CONSIDER	Consolidated criteria for strengthening reporting of health research involving indigenous people
ANT	Actor-Network theory

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-024-11705-6>.

Supplementary Material 1.
Supplementary Material 2.
Supplementary Material 3.

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Authors' contributions

All authors made substantial contributions to the design of the study, and the analysis of the data. AL and SGP collected data. All authors provided intellectual input into all drafts and approved the submitted version.

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Availability of data and materials

The datasets collected and analysed during the study described are not publicly available due to participants only consenting for the data to be utilised for this research project. Data was included from Indigenous Peoples of Aotearoa New Zealand who retain sovereignty over the information. Please contact author AL if requesting data from this study.

Declarations

Ethics approval and consent to participate

This project has ethical approval from the New Zealand Health and Disability Ethics Committee (20/CEN/114/AM05). Participants provided written and informed consent before participating. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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