Barriers and Facilitators to Accessing Symptom Support by Patients from Culturally and Linguistically Diverse Backgrounds (CLEAR-ACCESS)

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28th ANNUAL CONGRESS • 17-19 JUNE 2026
Perth Convention and Exhibition Centre

Disclosures

Funding received from the VCCC Alliance and MSD

Background

- Advances in cancer treatment have led to complex treatment regimens and prolonged periods on systemic anti-cancer therapy (SACT).
- This has resulted in an increased burden of patients to monitor, manage and report symptoms that arise.
- Timely access and management of treatment related side effects, which often requires unscheduled care, is one of the challenges that continues.

Background

- In Victoria, symptom support is often provided by Symptom and Urgent Review Clinics (SURCs) and via access to specialist cancer nursing care through Clinical Nurse Consultants (CNCs).

Background

- Australian studies show CALD patients have a higher rate of ED presentations and unplanned admissions
- A retrospective cohort study found that migrants born in a country where the official language is other than English had higher mean numbers of unplanned admissions and longer cumulative lengths of stay than non-CALD patients (Scanlon et al, 2023)
- Dufton et al (2019) identified that being born within Australia but not having English as a primary preferred language was the only sociodemographic factor associated with increased risk of ED

Aims

This study aimed to explore

1. The experiences of CALD patients and their carers in accessing symptom support (CNCs and SURCs)
2. More general perspectives of barriers and enablers to healthcare from CALD community representatives and;
3. Healthcare professionals' perspectives on CALD patients and carers accessing symptom support

Methods

- Qualitative exploratory study
- Semi-structured interviews and focus groups
- Participants' experiences of accessing symptom support were explored using Levesque's framework for patient-centred access to healthcare (2013) to understand how these experiences aligned with different dimensions of healthcare access.

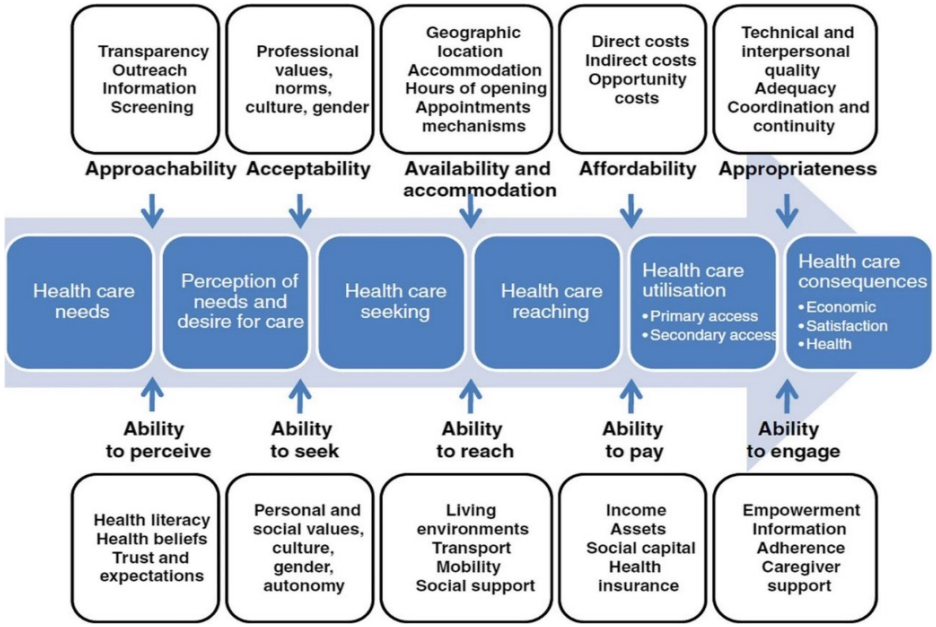

Figure 1. Levesque's framework for patient-centred access to healthcare (2013)

Setting

- Two Victorian Australian cancer centres, Austin Health and Peter MacCallum Cancer Centre (patients, carers and HCPs)
- The Ethnic Communities Council of Victoria (ECCV), the state's peak representative body for Victoria's culturally and linguistically diverse, migrant and refugee communities.
- Patients and carers from a CALD background were defined by country of birth i.e. born in Vietnam, China, Greece or an Arabic-speaking country or with a primary preferred language of Arabic, Vietnamese, Greek or Mandarin. These represent the largest proportion of people requiring interpreting services at the study sites .

Eligibility

Target recruitment was five participants per CALD group.

- Aged ≥ 18 years
- Currently receiving or had completed SACT for a solid tumour
- A prognosis of more than 12 months at time of recruitment
- Any level of English proficiency
- Carers were eligible if they had a care recipient who met the CALD criteria listed above
- Carers were eligible to participate even if their care recipient was not a study participant
- Patients and carers did not need to have accessed symptom support to be eligible.

Data collection and analysis

- Data were collected between January 2024 and March 2026
- Focus groups and interviews were conducted in participants' preferred language where possible
- Accredited interpreters were engaged when a bilingual research assistant was not available for the relevant language or where additional language support was required.
- All sessions were audio-recorded, transcribed verbatim, and translated into English by bilingual RAs
- Data were analysed using Braun and Clarke's six-phase approach to reflexive thematic analysis.

Results

153 participants were screened for eligibility, with 41 participants participating in interviews or focus groups

- 23 patients
- 7 caregivers
- 7 community representatives
- 4 healthcare professionals

Preferred languages among patients and carers were Arabic (20%, n=6/30), English (10%, n=3/30), Greek (10%, n=3/30), Mandarin (27%, n=8/30), Vietnamese (33%, n=10/30) .

Results

- Most patients and carers had not accessed symptom support services (63%, n=19/30) and the ED (60%, n=18/30)
- 57% reported seeing their GP for treatment related side-effects (n=17/30).
- Most participants reported having a GP who speaks their language (87%, n = 26/30).
- Four HCPs participated (interpreter n=1, medical oncologist n=1, CNC n=1, GP n=1).

Results

- Focus groups were conducted with:
  - 3 with Mandarin-speaking patients/carers
  - 2 with Vietnamese-speaking patients/carers
  - 1 with Arabic-speaking patients/carers.
  - 1 focus group was held with each of the Mandarin and Vietnamese community groups.
- Participants unable to join focus groups were interviewed.

Themes

Four themes were developed, with between 2-3 subthemes.

01

Family are a bridge to symptom support

02

Knowing where to go and how to ask for help enables access

03

When accessing symptom support felt difficult, patients delayed help-seeking

04

Trusted relationships supported confidence to engage and access symptom support

Theme 1

- Central role of family members in brokering access to symptom support
- Family are both enablers and barriers to access.

Theme 1. Family are a bridge to symptom support

1.1. Family members act as interpreters, navigators & information brokers

1.2. Family availability shaped whether and when care was accessed

1.3. Avoiding burden delayed symptom reporting

Theme 1

"Everyone, when they're sick, the first person they discuss it with is definitely not a doctor. It's definitely discussed with family members first." Mandarin community focus-group participant

Theme 1. Family are a bridge to symptom support

- 1.1. Family members act as interpreters, navigators & information brokers
- 1.2. Family availability shaped whether and when care was accessed
- 1.3. Avoiding burden delayed symptom reporting

Theme 1

“Whenever he had any side effects, he would call me, obviously, because that makes sense, and I could help him, but you know, there were two times when he couldn't get through to me, and so he went to the emergency department instead.” Vietnamese community group participant

Theme 1. Family are a bridge to symptom support

- 1.1. Family members act as interpreters, navigators & information brokers
- 1.2. Family availability shaped whether and when care was accessed
- 1.3. Avoiding burden delayed symptom reporting

Theme 1

“Sometimes he doesn’t say or keeps it to himself because it’s an hour's drive. We try to deal with it as much as we can.” Arabic-speaking caregiver

Theme 1. Family are a bridge to symptom support

- 1.1. Family members act as interpreters, navigators & information brokers
- 1.2. Family availability shaped whether and when care was accessed
- 1.3. Avoiding burden delayed symptom reporting

Theme 2

- Knowing that support exists
- Understanding when support should be used
- Able to explain symptoms in a way that could be understood

Theme 2. Knowing where to go and how to ask for help enables access

2.1. Limited awareness of symptom support pathways prevents access

2.2. Language and medical terminology limited confidence to seek help and therefore access

Theme 2

“She asked why I didn’t call the hospital. I said I didn’t get any number. I thought that once it became too severe, I would just go into the emergency.” Vietnamese-speaking patient

Theme 2. Knowing where to go and how to ask for help enables access

2.1. Limited awareness of symptom support pathways prevents access

2.2. Language and medical terminology limited confidence to seek help and therefore access

Theme 2

"Well, for him to contact them himself, it would be a huge barrier… he probably wouldn't be able to describe his symptoms… the message might get lost in translation." Greek-speaking caregiver

Theme 2. Knowing where to go and how to ask for help enables access

2.1. Limited awareness of symptom support pathways prevents access

2.2. Language and medical terminology limited confidence to seek help and therefore access

Theme 3

- Decisions to access support were shaped by perceived effort, timeliness and responsiveness

Theme 3. When accessing symptom support felt difficult, patients delayed help-seeking

- 3.1. Practical access barriers made accessing symptom support feel burdensome
- 3.2. Delays and fragmented pathways reduced willingness to seek help
- 3.3. Responsiveness and ease of access encouraged use

Theme 3

"And I think I don't go to the hospital promptly because I think the process is a bit… to me it's still a bit of a hassle, a bit long." Mandarin-speaking patient

Theme 3. When accessing symptom support felt difficult, patients delayed help-seeking

- 3.1. Practical access barriers made accessing symptom support feel burdensome
- 3.2. Delays and fragmented pathways reduced willingness to seek help
- 3.3. Responsiveness and ease of access encouraged use

Theme 3

"Because if I had called in, I would have to wait for interpreter, taking a long time, and I would feel hesitant. So, I would rather lie down and put up with that. I had been in that situation."

Vietnamese-speaking patient

Theme 3. When accessing symptom support felt difficult, patients delayed help-seeking

- 3.1. Practical access barriers made accessing symptom support feel burdensome
- 3.2. Delays and fragmented pathways reduced willingness to seek help
- 3.3. Responsiveness and ease of access encouraged use

Theme 3

“I trust them. Every time I contact them, I get an answer immediately. They would ask the doctor right away and then get back to me.” Vietnamese-speaking patient

Theme 3. When accessing symptom support felt difficult, patients delayed help-seeking

- 3.1. Practical access barriers made accessing symptom support feel burdensome
- 3.2. Delays and fragmented pathways reduced willingness to seek help
- 3.3. Responsiveness and ease of access encouraged use

Theme 4

- Confidence to engage with and access care was based on trust, language, cultural understanding and time to listen

Theme 4. Trusted relationships supported confidence to engage and access symptom support

4.1. Shared language and cultural understanding enabled help-seeking

4.2. Trusted clinicians helped patients engage with care

Theme 4

“If they know that there is an access point there that can speak their language, they'll be a lot more comfortable… they'll tell you everything it is that they're feeling.” Vietnamese community focus-group participant

Theme 4. Trusted relationships supported confidence to engage and access symptom support

4.1. Shared language and cultural understanding enabled help-seeking

4.2. Trusted clinicians helped patients engage with care

Theme 4

"They said, actually we Chinese people are accustomed to "enduring (忍)". You may have a great mental capacity for enduring, but your body may not be able to tolerate that level […] . So they advised me not to endure it." Mandarin-speaking participant (patient)

Theme 4. Trusted relationships supported confidence to engage and access symptom support

4.1. Shared language and cultural understanding enabled help-seeking

4.2. Trusted clinicians helped patients engage with care

Summary

- Access was influenced by **characteristics of services** and **abilities of patients and carers to recognize, reach and engage** with care
- **Families played a central role** as enablers and barriers to accessing care
- A key barrier was **awareness of symptom support**, often delivered in information dense, busy clinical settings
- Barriers are compounded by language barriers

Summary

- A key enabler to access was **trust built on effective communication and responsiveness**
- Patients felt most confident discussing symptoms with a GP who **shared their language and culture**

Future work

This work is being used to inform future research ADVANCE-ACCESS which aims to co-design interventions to improve access to symptom support in these cohorts.

Take home message

CALD patients and carers experience complex, intersecting barriers and enablers to accessing symptom support. Language compounds barriers.