

RESEARCH

Open Access



# A mixed methods process evaluation of a collaborative outpatient palliative care clinic for patients with end-stage liver disease

Grace Warmels<sup>1,2,3,6\*</sup>, Aria Wills<sup>1</sup>, Adrianna Bruni<sup>2,3</sup>, Leila Cohen<sup>2,3</sup>, Erin Kelly<sup>2,3</sup>, James Downar<sup>1,3</sup>, Arpan A. Patel<sup>4</sup>, Greg Dargavel<sup>7</sup>, Shreya Rauthu<sup>7</sup> and Sarina R. Isenberg<sup>1,3,5</sup>

## Abstract

**Background** Patients with end-stage liver disease (ESLD) have significant symptoms and limited prognosis, yet receive less palliative care (PC) than patients with cancer. The optimal outpatient PC model for patients with ESLD remains unclear.

**Objective** We used process evaluation methodology to evaluate a novel PC clinic for patients with ESLD in Ottawa, Canada.

**Design** We conducted a convergent parallel mixed methods study, informed by a logic model and process evaluation framework co-designed with a caregiver partner. Qualitative inputs included semi-structured interviews conducted with patients, family caregivers, as well as PC and hepatology clinicians, and analyzed using applied thematic analysis. Quantitative inputs included data collected through a retrospective chart review, analyzing healthcare utilization up to six months before and after consultation.

**Participants** Interviews conducted with eight healthcare providers (HCPs) and 13 patients and caregivers. Chart review performed for 46 patients seen in the clinic between October 2020 and June 2023.

**Intervention** An outpatient PC hepatology collaboration clinic, led by specialist PC physicians.

**Approach** Qualitative and quantitative data were analyzed independently and then triangulated for overall interpretation.

**Key results** The evaluation demonstrated the achievement of the outcomes in the logic model and process evaluation domains. Interviews highlighted high satisfaction among HCPs, patients, and caregivers, and effective collaboration between the PC and hepatology teams. Perceived barriers include the burden of in-person appointments. Quantitative results indicated decreased acute healthcare utilization in the six months following PC consultation compared to the six months prior. Over 50% of the deceased patients died outside of the hospital.

\*Correspondence:

Grace Warmels  
gwarmels@toh.ca

Full list of author information is available at the end of the article



© The Author(s) 2025. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

**Conclusion** The early outpatient PC clinic provides high-quality, collaborative care for patients with ESLD; study findings suggest an association with reduced acute healthcare utilization and increased likelihood of death occurring outside the hospital. This model represents a promising approach for PC in ESLD and other non-malignant illnesses.

**Keywords** End-stage liver disease, Palliative care, Mixed methods, Process evaluation, Cirrhosis

## Introduction

Palliative care (PC) is a discipline of medicine aimed at optimizing the quality of life of patients with serious illnesses by addressing physical and psychosocial symptoms [1, 2]. Previous research has shown that receipt of PC is associated with improved quality of life and decreased symptom burden [3–5]. Although the benefits of PC are well-recognized, levels of PC involvement differ considerably between patient groups depending on their underlying life-limiting disease [6]. Specifically, patients dying from organ failure have reduced PC involvement and lower quality PC compared to patients dying from cancer [2, 6] despite having a similar prevalence of burdensome symptoms [7].

End-stage liver disease (ESLD) is one type of organ failure with significant morbidity and mortality [8], and represents the 10th leading cause of death in Canada [9]. Furthermore, patients with ESLD experience burdensome symptoms including pain, nausea, shortness of breath, and poor appetite [8]. Caregivers of patients with ESLD experience substantial burden similar to caregivers of patients with advanced cancer [10].

Given the limited prognosis and significant symptom burden associated with ESLD, patients with this condition and their caregivers are likely to benefit from PC involvement [11–13]; however, most patients with ESLD do not access PC. In Canadian studies, only 5–11% of people with ESLD were seen by a PC specialist prior to death, while people dying of cancer are four times more likely to receive PC, with earlier initiation than those dying of organ failure [8, 14–17]. To address this inequity in PC access, in 2020 we created a novel collaborative clinic at The Ottawa Hospital (TOH) in Ottawa, Canada, called the Palliative Support in Advanced Illness (Pal-SAIL) clinic. This model is novel within the Canadian context. Since the establishment of our clinic, two international groups have published studies in 2023 describing comparable outpatient collaborative hepatology-PC models [18, 19].

With the well-recognized need for novel means of early PC provision to patients with ESLD, we completed a process evaluation of the Pal-SAIL clinic to determine whether it is a successful model of outpatient PC for organ failure. To achieve this aim, we developed a logic model and process evaluation plan, leveraging a mixed methods approach to assess the achievement of the logic model outcomes.

## Methods

### Description of the Pal-SAIL clinic

The Pal-SAIL clinic was established in September 2020 at TOH in Ottawa, Canada with the mandate to provide early outpatient specialist PC to patients with ESLD (as well as patients with end-stage kidney disease on dialysis, the outcomes of which are reported separately). TOH is an urban academic hospital network, serving 1.2 million people across eastern Ontario. Physician and hospital services in Canada are universal and publicly funded. Prior to the initiation of the Pal-SAIL clinic, there was no established mechanism for patients with ESLD to access outpatient PC in Ottawa unless they were in the final days or weeks of life. The clinic was created through (1) identifying the community need, (2) identifying a champion within the department of hepatology, (3) developing referral criteria, (4) securing resources such as clinic space and physician time.

Care in the Pal-SAIL clinic is exclusively provided by specialist PC physicians, who collaborate closely with hepatologists, who continue to follow the patients concurrently for medical management of their ESLD. The clinic uses standardized referral criteria based on disease severity, symptoms, and social complexity (Appendix A). Patients considering transplant were not excluded. The clinic operates one half-day per week. Although virtual appointments are offered in exceptional circumstances, patients are seen in the outpatient hepatology clinic. The shared space allows for in-person collaborative case discussions between PC and hepatology, and joint visits when needed. The regional hepatology clinic comprises four hepatologists and two nurses who treat approximately 13,500 patients annually, with cirrhosis representing the most common diagnosis.

The Pal-SAIL clinic aims to achieve its mandate in three main ways, including: (1) assisting with the management of symptoms related to ESLD, (2) facilitating complex goals of care discussions, and (3) helping with future planning in the context of ESLD.

### Models of care

#### *Consultative model*

From September 2020–December 2022, the Pal-SAIL clinic employed a consultative model, where PC physicians assessed patients monthly and provided recommendations to the hepatologists. Notably, without full-time coverage, the PC physicians were not routinely

available to address issues that arose outside of the monthly clinic.

### **Full-time shared care model**

In January 2023, the Pal-SAIL clinic adopted a full-time shared care model, in which a PC physician assessed patients in clinic weekly and was available by phone Monday-Friday, 8 am-4 pm for urgent issues. PC physicians can see patients more frequently with this model, prescribe medications directly, and address issues arising between scheduled appointments.

### **Methodological approach**

To evaluate the performance of the clinic, we conducted a convergent parallel mixed methods study informed by the Saunders, Evans, and Joshi process evaluation framework [20]. We developed assessment criteria based on the recommended domains of a clinic logic model and process evaluation plan [20].

The research team co-designed the logic model of the Pal-SAIL clinic through four virtual meetings with our caregiver partner with lived experience (GD). We developed individual components of the logic model aligned with guidance from the Kellogg Evaluation Guide [21], including inputs, activities, outputs, immediate outcomes, intermediate outcomes, and long-term outcomes (See Fig. 1).

We developed a process evaluation plan, outlining questions related to the recommended domains (i.e., fidelity, reach, recruitment, context, and participant experience) that acted as overarching criteria for evaluation of the clinic, which we mapped to the logic model to inform ideal delivery of the clinic. Saunders, Evans, and Joshi's definitions of process evaluation domains [20] – Fidelity: the extent to which intervention was implemented as planned; Participant experience: participant satisfaction with program, interactions with staff; Reach: proportion of the intended priority audience that participates in the intervention; includes documentation of barriers to participation; Recruitment: procedures used to approach and attract participants at individual levels; includes maintenance of participant involvement in intervention; Context: aspects of the environment that may influence intervention implementation or study outcomes. We employed chart review and qualitative interviews with healthcare providers (HCPs), patients, and caregivers as our data sources.

### **Participants & recruitment**

We conducted a retrospective chart review of all patients who received an initial consultation with Pal-SAIL between October 1, 2020, and June 30, 2023, capturing patients from the initiation of the clinic until commencing chart review.

We recruited individuals who were involved in the Pal-SAIL clinic, including HCPs from the hepatology and PC teams, as well as patients and caregivers who received care from the clinic. Eligible HCPs had provided care to at least three patients seen by the Pal-SAIL clinic; eligible patients had at least two interactions with the Pal-SAIL clinic and family caregivers had documented direct contact (in-person or by telephone) with a Pal-SAIL physician regarding the associated patient. All participants were required to have fluency in English, be of age  $\geq 18$ , with capacity to provide informed consent. We required a minimum number of interactions to facilitate the patient and caregiver's capacity to distinguish Pal-SAIL from other PC services. We included bereaved caregivers of patients seen in the clinic, as well as patients and caregivers who opted to participate in dyad interviews.

Convenience sampling was used to recruit interview participants. A recruitment email was sent to the all members of the hepatology division and allied health team, which included the research coordinator's (RC) contact information. Furthermore, Pal-SAIL physicians identified patients who were attending their third appointment with the clinic, informed them about the study and obtained consent to be contacted by the RC. Eligible bereaved caregivers were contacted by phone by the Pal-SAIL physicians, who provided study information and obtained consent to be contacted. The RC contacted all potential participants and obtain informed consent for participation.

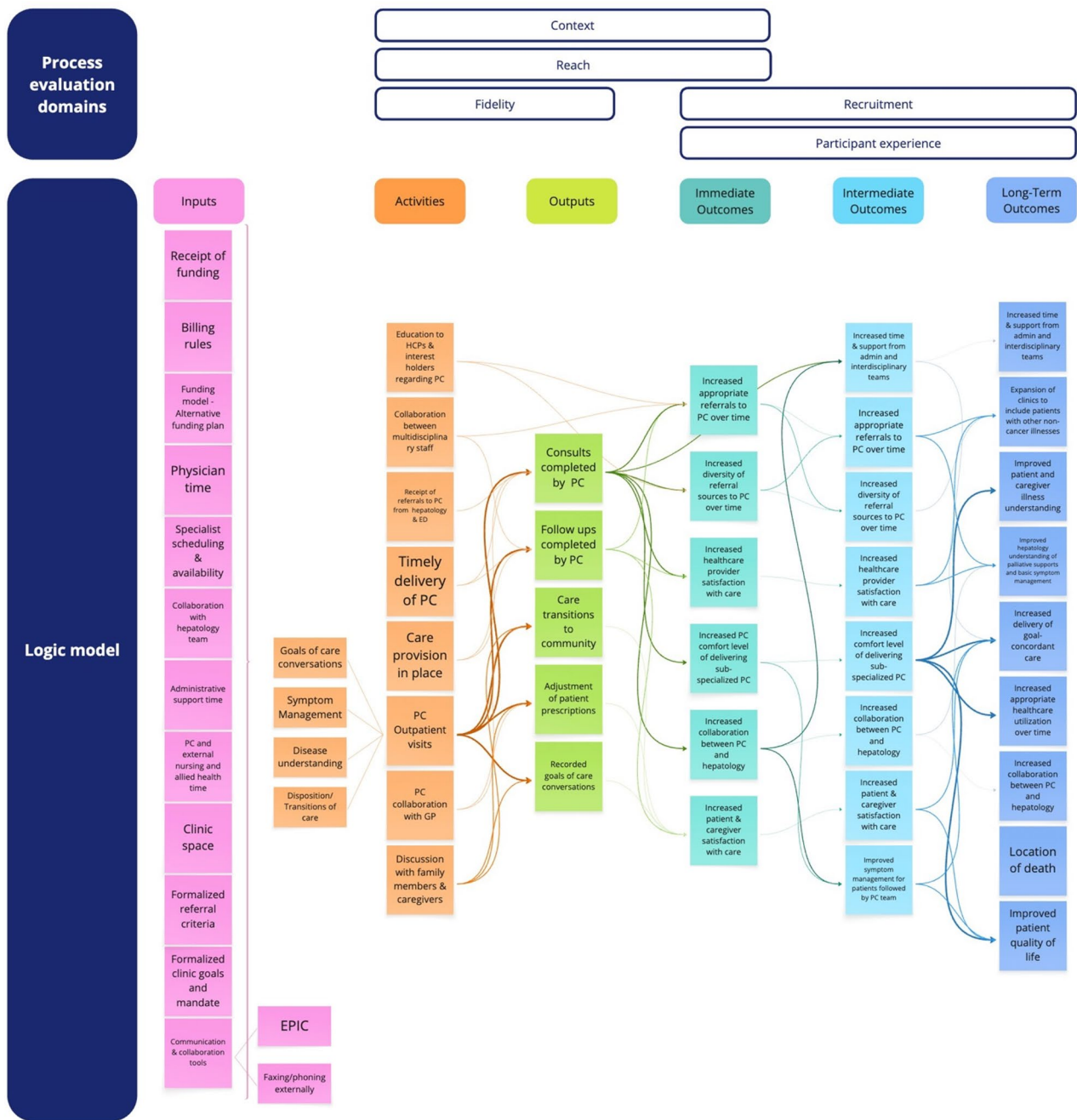
### **Data collection**

Chart reviews and interviews were conducted simultaneously. Ethics approval was received from the Ottawa Health Science Network Research Ethics Board (Protocol ID: 20230227-01 H) and the Bruyère Research Ethics Board (REB Number: M16-23-020).

#### **Data collection: chart review**

In collaboration with the Ottawa Methods Centre, we developed an online database and a case report form. The core study team (GW, SI, AB, LC and AW) developed the quantitative outputs based on the logic model components. From July 2023-January 2024, GW, AB, and LC abstracted data from patients' electronic medical records at TOH. We included patient data from six months pre-consult to six months post-consult or death. GW reviewed 5% of the completed case report forms to ensure data accuracy.

Reviewers abstracted patients' sociodemographic and clinical characteristics including the patients' Palliative Performance Scale (PPS) [22, 23], validated symptom assessment scale [24], goals of care designation, and symptom management medications, as well as outcomes of Pal-SAIL care informed by the logic model, including



**Fig. 1** Process evaluation domains and logic model of the Pal-SAIL clinic

the number of consultations and follow-up appointments. We included patients’ healthcare utilization, including frequency of emergency department visits, hospitalizations, and length of stay during admission. Goals of care data was collected based on the following clinical hospital code status categories: (1) full resuscitation, (2) no cardiopulmonary resuscitation (CPR), but admission to intensive care unit (ICU), (3) no ICU admission but full medical management, (4) comfort care [25]. Regarding the alignment of care with goals during admission, we

defined goal-consistent care as having documented inpatient goals of care at an equal or less intensive level than those documented during robust discussion at Pal-SAIL consultation. All data points captured in the chart review are presented in Appendix B.

**Data collection: interviews**

Semi-structured interviews were conducted with the eligible patients, caregivers, and HCPs. The interview guides were developed by SI, informed by the logic model

and process evaluation domains, and reviewed by AB, GW, LC, and AW (see Appendix C & Appendix D). AW and SI conducted the interviews remotely by videoconference or by telephone. The interviews were conducted prospectively between August 2023 and January 2024. AW interviewed the Pal-SAIL PC physicians (GW, AB, LC) to elucidate their experiences with development and expansion of the clinic. The Pal-SAIL physicians also co-authored this paper. All interviews were audio-recorded, and Home Row Inc. transcribed audio recordings into verbatim transcripts for analysis.

### Data analysis & interpretation

We analyzed the quantitative and qualitative data independently and subsequently triangulated the findings using convergent parallel design to form an overall interpretation.

#### Data analysis: chart review

We descriptively analyzed patient demographics, care processes, and outcomes using R [26] to calculate medians and interquartile ranges (IQRs) for continuous variables and proportions for categorical variables. Patients' healthcare utilization was compared pre- and post-Pal-SAIL consultation using Wilcoxon signed-rank tests to determine significance ( $\alpha = 0.05$ ).

#### Data analysis: qualitative interviews

We conducted a thematic analysis of the interview transcripts [27, 28]. AW drafted the initial codebook inductively based on experience as a primary interviewer and deductively based on domains of the logic model and process evaluation plan. GW, AB, LC, and SI reviewed interview transcripts along with the codebook, which was revised collaboratively.

We coded the interview transcripts using a qualitative analysis software (MAXQDA). Following best practices of thematic analysis [29, 30], the team (GW, SI, AB, AW, SR) conducted group coding of two transcripts, followed by consensus coding of two transcripts to ensure alignment of coder understanding and consistent application. GW, AW, and SR conducted double coding of the remaining transcripts. The Pal-SAIL physicians' transcripts were divided amongst separate team members for coding. GW and AW compared patterns across the codes and categorized the qualitative findings into broader concepts according to the logic model. SI and AB reviewed the qualitative concepts for consistency with the transcripts.

#### Triangulation

Informed by the approach of Creswell and Plano Clark [31], we identified key content represented in both sets of findings and compared and synthesized the results into a table (Table 1). We identified patterns of concordance

and unique dimensions across both sets of findings, and narratively summarized the data according to our interpretations to provide a nuanced and comprehensive perspective on clinic care delivery.

### Results

We included 46 patients who received Pal-SAIL consultations between October 1, 2020, and June 30, 2023, in the chart review (Appendix E). The majority of patients were male ( $n = 29$ , 63.0%) with a median age of 73 years (IQR:68,81). The main causes of ESLD were alcohol-associated liver disease ( $n = 11$ , 23.9%) and viral hepatitis ( $n = 7$ , 15.2%). All patients presented with decompensated cirrhosis at consultation (100.0%). The median Edmonton Symptom Assessment System (ESAS) scores at consultation were highest for symptoms of tiredness (median = 7, IQR:3,8) and appetite (median = 5, IQR:2,7).

We conducted interviews with eight HCPs (Appendix F), four patients, and nine caregivers (Table 2) who met the inclusion criteria. Four patient/caregiver dyads were interviewed together. Most HCPs were between the ages of 19–44 ( $n = 7$ , 87.5%) and all identified as women (100.0%), who lived in an urban (i.e., population > 10,000) setting (100.0%). One provider identified as a visible minority (12.5%). Three PC physicians from the Pal-SAIL team were interviewed (37.5%), alongside four hepatologists (50.0%), and one registered nurse (12.5%). Patients and caregivers ( $n = 13$ ) were largely between the ages of 65–74 ( $n = 5$ , 38.5%) and 75–84 ( $n = 4$ , 30.8%), and most identified as women ( $n = 8$ , 61.5%) and lived in an urban setting ( $n = 10$ , 77.0%). Of the total caregivers ( $n = 9$ , 67.7%), seven were spouses/partners of patients (77.8%) while two were children (22.2%). Most caregivers were designated medical decision makers for patients ( $n = 7$ , 77.8%).

The logic model is composed of: Activities, Outputs, Immediate Outcomes, Intermediate Outcomes and Long-term Outcomes (Fig. 1).

#### Inputs

Inputs are described in the clinic description in the Methods section.

#### Activities

Activities of the logic model, such as the completion of in-person consultations and education, were achieved. Generally, patients felt they were referred to Pal-SAIL at an appropriate time. However, prior to initiating the full-time model (September 2020–December 2022), approximately half of the patients seen died or had a terminal admission prior to their scheduled follow-up. The percentage of incomplete consultations stayed similar through both models, although patients more frequently

**Table 1** Triangulation of quantitative and qualitative data according to the logic model

| Logic model component  | Quantitative data  | Qualitative theme                        | Qualitative data |
|--|--|--|------------------|
| Inputs   |  |  |                  |
| Funding  |  | Description                              |                  |
| Physician time   |  | Description                              |                  |
| Specialist scheduling & availability   |  | Description                              |                  |
| Administrative support time  |  | Description                              |                  |
| Collaboration with hepatology  |  | Description                              |                  |
| Billing rules  |  | Description                              |                  |
| Funding model  |  | Description                              |                  |
| Detailed and formalized referral criteria  |  | Description                              |                  |
| Formalized clinic goals and mandate  |  | Description                              |                  |
| Communication and collaboration tools (EPIC & fax/phone)                         |  | Description                              |                  |
| Activities   |  |  |                  |
| Receipt of referrals to PC from diverse sources                                  | Number of referrals<br>Referring provider<br>Reason for referral   |  |                  |
| Provision of PC consult & follow ups   | Number of consults deemed appropriate<br>Future planning addressed<br>Goals of care addressed<br>Symptom management addressed<br>• Symptoms addressed (pain, non-pain) |  |                  |
| Timely delivery of PC  | Time from referral to consult  |  |                  |
| Provision of care in place   | Method of consult provision (in-person, phone/video)   |  |                  |
| Collaboration between multidisciplinary staff                                    |  | Interviews – quotes referencing activity |                  |
| PC collaboration with primary care provider                                      |  | Interviews – quotes referencing activity |                  |
| Education to HCPs & stakeholders regarding PC                                    |  | Interviews – quotes referencing activity |                  |
| Discussion with family members & caregivers                                      |  | Interviews – quotes referencing activity |                  |
| Provision of PC consult & follow ups: Disease understanding addressed at consult |  | Interviews – quotes referencing activity |                  |
| Outputs  |  |  |                  |
| Completed consults by PC   | Number of completed consults   |  |                  |
| Care transitions to community  | Number of care transitions to community  |  |                  |
| Recorded goals of care conversations   | Goals of care following PC consult   |  |                  |
| Adjustment of patient prescriptions  | Medication started or adjusted at initial PC consult by PC MD (non-opioid, opioid)<br>Total non-opioid adjustments at initial consult (broken down by medication)      |  |                  |
| Completed follow ups by PC   | Number of patients with $\geq 1$ Follow up<br>In-person vs. phone/video  |  |                  |
| Immediate outcomes   |  |  |                  |

**Table 1** (continued)

| Logic model component   | Quantitative data   | Qualitative theme  | Qualitative data   |
|---|---|--|--|
| Increased appropriate referrals to PC over time                 | Appropriate referrals by year                                   |  |  |
| Increased diversity of referral sources to PC over time         | Referral sources by year  |  |  |
| Increased HCP satisfaction with PC                              |   | Theme: Pal-SAIL Hepatology fills an existing care gap  | <ul style="list-style-type: none"> <li>· Early outpatient PC was not previously accessible</li> <li>· Sub-specialized PC decreases out of scope workload for hepatologists in providing patients with activities of clinic mandate: <ul style="list-style-type: none"> <li>o Symptom mgmt</li> <li>o Future planning &amp; goals of care</li> <li>o Coordination of community care</li> </ul> </li> <li>· Benefit of extended appointment time</li> </ul>  |
| Increased PC comfort level of delivering sub-specialized PC     |   | Theme: Pal-SAIL Hepatology promotes patient-centred care   |  |
|   |   | Theme: Pal-SAIL Hepatology collaborates & communicates effectively with Hepatologists, patients & caregivers | <ul style="list-style-type: none"> <li>· Hepatologists trust PC has high understanding of complications of cirrhosis, and how to manage</li> </ul>   |
| Increased collaboration between PC and hepatology               |   | Theme: Pal-SAIL Hepatology collaborates & communicates effectively with Hepatologists, patients & caregivers | <ul style="list-style-type: none"> <li>· Accessibility of Pal-SAIL to hepatologists</li> <li>· Reciprocal education</li> </ul>   |
| Increased patient & caregiver satisfaction with care            |   | Theme: Pal-SAIL Hepatology fills an existing care gap  | <ul style="list-style-type: none"> <li>· Patients described benefit from PC aligned with clinic mandate: <ul style="list-style-type: none"> <li>o Symptom mgmt</li> <li>o Future planning &amp; goals of care</li> <li>o Filled role of coordinator amongst different providers</li> </ul> </li> <li>· Accessibility of Pal-SAIL to patients &amp; caregivers</li> <li>· Caregiver needs for information and support were met</li> <li>· Nuanced goals of care and future planning discussions well received</li> <li>· Pal-SAIL provides holistic care and emotional support</li> <li>· Despite initial hesitancy, patients and caregivers felt that PC was a positive experience</li> <li>· Confusion distinguishing Pal-SAIL from other services</li> </ul> |
|   |   | Theme: Pal-SAIL Hepatology collaborates & communicates effectively with Hepatologists, patients & caregivers |  |
|   |   | Theme: Pal-SAIL Hepatology promotes patient-centred care   |  |
|   |   | Theme: Pal-SAIL Hepatology builds on PC identity & patient perception  |  |
|   |   | Theme: Pal-SAIL Hepatology sees patients 'in person', which may represent an important barrier               |  |
| Intermediate outcomes   |   |  |  |
| Improved symptom management for PC patients                     |   | Theme: Pal-SAIL Hepatology fills an existing care gap  | <ul style="list-style-type: none"> <li>· Sub-specialized PC decreases out of scope workload for hepatologists in providing patients with activities of clinic mandate: <ul style="list-style-type: none"> <li>o Symptom mgmt</li> </ul> </li> <li>· Mixed perceptions of value of early PC (too early, not symptomatic)</li> </ul>   |
|   |   | Theme: Pal-SAIL Hepatology builds on PC identity & patient perception  |  |
| Increased time & support from admin and interdisciplinary teams |   | Theme: Pal-SAIL Hepatology's future development is limited by resources and physician time                   | <ul style="list-style-type: none"> <li>· Limited by interdisciplinary support</li> <li>· Limited by admin hurdles</li> </ul>   |
| Long-term outcomes  |   |  |  |
| Increased delivery of goal-consistent care                      | Goal consistence at hospital admission subsequent to PC consult |  |  |

**Table 1** (continued)

| Logic model component  | Quantitative data   | Qualitative theme  | Qualitative data   |
|--|---|--|--|
| Increased appropriate healthcare utilization                             | Total healthcare utilization pre & post PC consult<br>Frequency of ED visits pre & post PC consult<br>Frequency of hospitalizations pre & post PC consult<br>Length of stay in hospital pre & post PC consult |  |  |
| Increased deaths in preferred location                                   | Location of PC patient death  |  |  |
| Improved hepatology understanding of PC supports and basic symptom mgmt. | Reasons for referral to PC clinic   | Theme: Pal-SAIL Hepatology builds on PC identity & patient perception  | · Benefit from clear referral criteria   |
| Expansion of clinics to include other non-cancer illnesses               |   | Theme: Pal-SAIL Hepatology's future development is limited by resources and physician time                   | · Financial sustainability<br>· Limited by clinic space<br>· Limited by interdisciplinary support<br>· Limited by admin hurdles<br>· Challenges in expanding home paracentesis |
| Improved patient & caregiver illness understanding                       |   | Theme: Pal-SAIL Hepatology collaborates & communicates effectively with Hepatologists, patients & caregivers | · Improved understanding of illness and feeling more prepared for progression  |

died prior to their first appointment in the part-time consultative model, as detailed in Table 3.

The Pal-SAIL clinic received 70 referrals from September 2020-June 2023 and completed 46 consultations (65.7%). Referrals were most frequently from hepatologists ( $n=43$ , 93.5%), with some from inpatient internal medicine ( $n=3$ , 6.5%). The median time from referral to consultation was 19 days. Of initial consultations, 73.9% were completed in-person. Reasons for referral included: future planning and disposition (47.8%); goals of care discussion (67.4%); symptom management (76.1%); and others (2.1%). Referrers were able to select multiple reasons for the cause of the referral. Issues addressed during the initial consultation are detailed in Table 4.

PC physicians demonstrated high levels of collaboration with patient care teams (including family physicians, hepatologists, etc.), and provided education to the hepatology team to improve their primary PC skills.

*"I think we often act as a hub for people who have a lot of different providers [...] to try to make them feel that they have a bit more cohesive care and enable better communication between all members of the care teams." (PCHCP21).*

*"I almost don't look at [Pal-SAIL] now as a separate entity; it's a part of the package. It seems to fit together well." (LPT11).*

*"We have the same intentions, and we walk together; we are on the same page, supporting each other's decisions and recommendations." (LHCP19).*

*"If I just have a general question about any sort of [PC] issues, [Pal-SAIL are] really helpful to help me navigate, even if it's not somebody that I necessarily need to refer to this clinic." (LHCP03).*

### Outputs

Outputs from the clinic comprised documented clinical decisions, including goals of care discussion and medication adjustments (see Table 5). After initial PC consultation, patients' documented goals of care were most often full code (32.6%) or medical management only (30.4%). PC-relevant medications were initiated/adjusted at the time of consultation in 25 (54.3%) patients; non-opioid medications were initiated/adjusted more frequently (68.0%) than opioid medications (32.0%). Sixteen patients (35.5%) were ultimately transitioned to receive home-based PC in the community. Twenty-two (47.8%) patients seen in consultation received subsequent follow-up appointments with the PC team. Anecdotally, hospital admission or death often precluded follow-up.

### Immediate outcomes

Immediate outcomes included impressions of the clinic, and the how the clinic's participants interacted. The number of appropriate referrals to Pal-SAIL and the diversity of referral sources increased over time (Fig. 2).

Hepatologists reported that the Pal-SAIL clinic met the previously unmet needs of their patients.

*"Prior to the clinic, we [hepatologists] could see that our patients weren't doing well. We were having*

**Table 2** Demographic characteristics of patient & caregiver participants in qualitative interviews

| Characteristic (n [%])                               | N = 13     |
|--|------------|
| Age  |            |
| 45–54  | 3 (23.1%)  |
| 55–64  | 1 (7.7%)   |
| 65–74  | 5 (38.5%)  |
| 75–84  | 4 (30.8%)  |
| Gender   |            |
| Man  | 5 (38.5%)  |
| Woman  | 8 (61.5%)  |
| Area of residence                                    |            |
| Rural  | 3 (23.1%)  |
| Urban  | 10 (77.0%) |
| Participant role                                     |            |
| Caregiver  | 9 (66.7%)  |
| Patient  | 4 (30.8%)  |
| Caregiver relationship to patient                    | N = 9      |
| Child  | 2 (22.2%)  |
| Spouse/Partner                                       | 7 (77.8%)  |
| Caregiver status as patient's medical decision maker |            |
| No   | 2 (22.2%)  |
| Yes  | 7 (77.8%)  |
| Patient comorbidities                                |            |
| Acute kidney injury                                  | 1 (25.0%)  |
| Asthma/Chronic obstructive pulmonary disease         | 2 (50.0%)  |
| Chronic kidney disease                               | 1 (25.0%)  |
| Cirrhosis  | 4 (100.0%) |
| Depression   | 2 (50.0%)  |
| Diabetes   | 2 (50.0%)  |
| Heart failure  | 1 (25.0%)  |
| Hypertension   | 1 (25.0%)  |
| Myocardial infarction                                | 1 (25.0%)  |
| Treated cancer                                       | 1 (25.0%)  |

**Table 3** Activities of Pal-SAIL clinic across clinic models

| Logic model component                        | Consultative model (January 2020–December 2022) | Full-time shared-care model (January–June 2023) | Total      |
|--|---|---|------------|
| Receipt of referrals <sup>a</sup>            | 46 (65.7%)                                      | 24 (34.2%)                                      | 70         |
| Complete consults                            | 30 (65.2%)                                      | 16 (66.6%)                                      | 46 (65.7%) |
| Incomplete consults                          | 16 (34.8%)                                      | 8 (33.3%)                                       | 24 (34.3%) |
| Declined to consult                          | 2 (12.5%)                                       | 4 (50.0%)                                       |            |
| Died prior                                   | 11 (68.8%)                                      | 1 (12.5%)                                       |            |
| Transitioned to other appropriate PC service | 3 (18.8%)                                       | 3 (37.5%)                                       |            |

<sup>a</sup>n (%)**Table 4** Activities of Pal-SAIL clinic

| Logic model component                                    |             |
|--|-------------|
| Receipt of referrals <sup>a</sup>                        | N = 70      |
| Referrals seen for PC consult                            | 46 (65.7%)  |
| Consults completed                                       | N = 46      |
| Referring provider <sup>a</sup>                          |             |
| Hepatologist   | 43 (93.5%)  |
| Other: Inpatient internal medicine                       | 3 (6.5%)    |
| Reasons for referral <sup>a</sup>                        |             |
| Future planning/disposition                              | 22 (47.8%)  |
| Goals of care  | 31 (67.4%)  |
| Symptom management                                       | 35 (76.1%)  |
| Other: Emotional support                                 | 1 (2.1%)    |
| Consult deemed appropriate                               | 46 (100.0%) |
| Timely delivery of care                                  |             |
| Time from referral to consult (days) <sup>b</sup>        | 19 (8, 34)  |
| Provision of care in place                               |             |
| Method of consult provision <sup>a</sup>                 |             |
| In-person  | 34 (73.9%)  |
| Phone/video  | 12 (26.1%)  |
| Provision of outpatient PC consult <sup>a</sup>          |             |
| Future planning/disposition addressed at initial consult | 27 (58.7%)  |
| Goals of care addressed at initial consult               | 42 (91.3%)  |
| Symptom management addressed at initial consult          | 27 (58.7%)  |
| Symptoms addressed by PC MD at consult <sup>a</sup>      |             |
| Pain   | 14 (32.6%)  |
| Other symptoms   | 18 (39.1%)  |
| Appetite   | 3 (7.0%)    |
| Changes in cognition                                     | 2 (4.7%)    |
| Depression   | 1 (2.3%)    |
| Drowsiness   | 2 (4.7%)    |
| Itching  | 7 (16.3%)   |
| Muscle cramps  | 1 (2.3%)    |
| Nausea   | 2 (4.7%)    |
| Sexual function  | 1 (2.3%)    |
| Shortness of breath                                      | 4 (9.3%)    |
| Sleep  | 2 (4.7%)    |
| Tiredness  | 5 (11.6%)   |

<sup>a</sup>n (%)<sup>b</sup>Median (IQR)

*challenges just trying to navigate [PC] in the community for our patients. And we were finding that they weren't getting [PC] period. [...] But now I can say when you start to have lots of symptoms, we have this clinic, we can refer you onwards." (LHCP03).*

*"I think it's helpful for patients to feel supported by multiple people, not just me [hepatology HCP]. [Pal-SAIL physicians] help support patients not only with symptoms directly related to their liver disease but also [their other symptoms]. So, I think it's overall just helps improve the quality of life for my patients, the ones that are connected. [...] They've really met my expectations." (LHCP12).*

**Table 5** Outputs of Pal-SAIL clinic

| Logic model component   | N = 46           |
|---|------------------|
| Future planning/disposition <sup>a</sup>  |                  |
| Care transitions to community PC MD/Nurse practitioner                                | 16 (34.8%)       |
| Goals of care following PC consult <sup>a</sup>                                       |                  |
| Full resuscitation  | 15 (32.6%)       |
| No CPR, but admission to intensive care unit (ICU)                                    | 6 (13.0%)        |
| No resuscitation or ICU admission, but full medical management                        | 14 (30.4%)       |
| Treatments focused exclusively on comfort with no goals of life-prolongation          | 5 (10.9%)        |
| Unknown   | 6 (13.0%)        |
| Symptom management <sup>a</sup>   |                  |
| Number of patients with medication started or adjusted at initial PC consult by PC MD | 25 (54.3%)       |
| Non-opioid medications  | 17 (68.0%)       |
| Opioid medications  | 8 (32.0%)        |
| Total non-opioid medication adjustments at initial PC consult by PC MD                | N=22             |
| Anti-depressants (for various indications)  | 2 (9.1%)         |
| Anti-emetics  | 1 (4.5%)         |
| Benzodiazepines   | 1 (4.5%)         |
| Gabapentinoids (for various indications)  | 1 (4.5%)         |
| Laxatives   | 5 (22.7%)        |
| Other <sup>2</sup>  | 12 (54.5%)       |
| Provision of follow ups   |                  |
| Receipt of ≥ 1 follow up visits <sup>a</sup>  | 22 (47.8%)       |
| Median number of in-person follow up visits <sup>b</sup>                              | 2.0 (1.75, 2.25) |
| Median number of phone/video follow up visits <sup>b</sup>                            | 1.0 (1, 3)       |
| Receipt of no follow up visit <sup>a</sup>  | 24* (52.1%)      |

Non-steroidal anti-inflammatory drugs (NSAIDs), topical Camphor/Menthol

<sup>a</sup>n (%)

<sup>b</sup>Acetaminophen, Cholestyramine

HCPs, patients, and caregivers felt satisfied with the care provided by Pal-SAIL physicians.

*“I think that [hepatologists] feel confident [in Pal-SAIL], and that relationship has been really important because they are confident in sending people to us and that we are not going to be the doom and gloom scary people, and that their patients are going to be well [cared for].” (PCHCP13).*

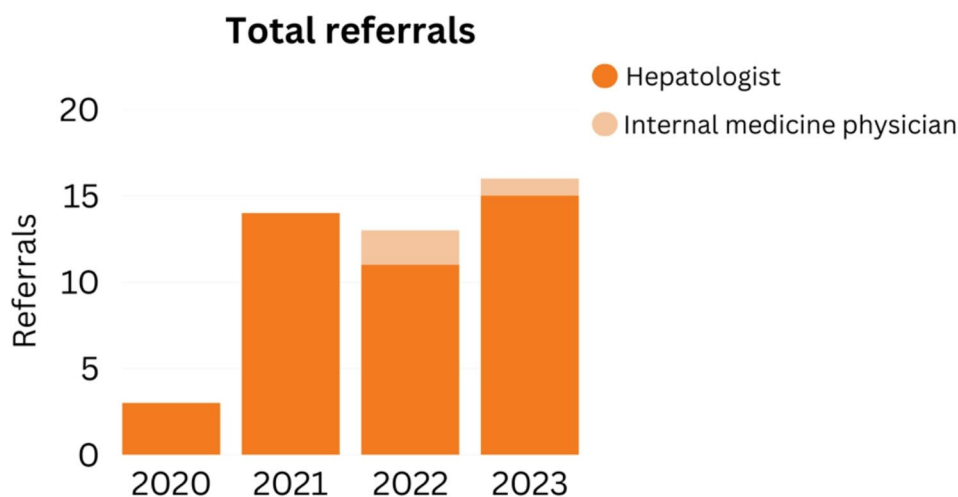
*“I feel really, really well taken care of [...] Just [PAL-SAIL’s] attention and care, honestly. Sometimes they bring me to tears because they’re so nice.” (LPT23).*

*“Some of the discussions and elements that [Patient] had in the progression of his illness, it was difficult, but the [Pal-SAIL] doctors always made us feel like there was hope. Even though he was eventually going to die, they helped us through the whole process. It was difficult at times, but I can’t really say that we had a bad visit. They were always helpful.” (LCG14).*

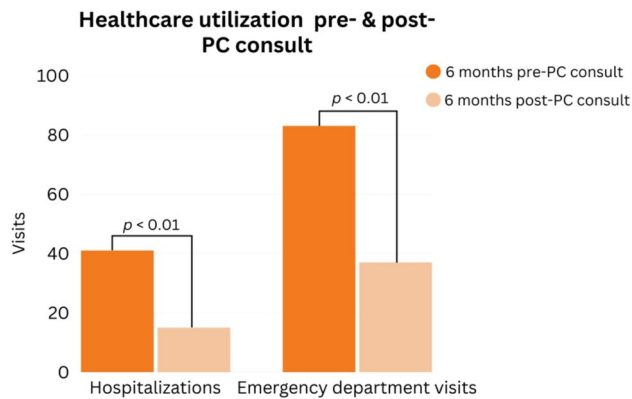
The hepatology team indicated that Pal-SAIL physicians developed expertise in providing sub-specialized hepatology-PC for patients with ESLD and in managing their psychosocial needs and complex symptoms.

*“[Pal-SAIL Physicians] know the complications of the disease. They know how to address them. They know that our patients have other issues rather than just end of life. They have ascites, confusion, constipation, bleeding, so they know what to expect and how to address these issues. It’s not just comfort care.” (LHCP19).*

In some cases, in-person appointments represented a barrier to receiving care due to the burden of travel, especially for patients with functional limitations. Nevertheless, participants felt they were easily able to access the clinic for any reason.



**Fig. 2** Immediate & intermediate outcomes: Increased appropriate referrals over time & Increased diversity of referral sources to PC clinic over time



**Fig. 3** Long-term outcome: Increased appropriate healthcare utilization over time

*“I think the main barrier is that they only accept in-person consultations, because we see patients from [further away], and oftentimes they’re elderly and frail, so it makes sense they don’t want to travel.” (LHCP12).*

*“[Attending in-person appointments] was very difficult with [Patient’s] mobility. I actually had to take time off work most times to make sure he could get there.” (LCG20).*

*“There’s never a problem seeing anybody really. We have their numbers and they all say, ‘If you have any problems or any questions, just give us a call!’” (LCG03).*

### Intermediate outcomes

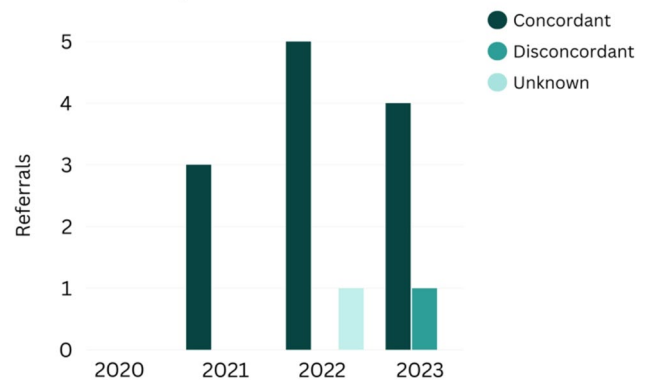
Intermediate outcomes included all immediate outcomes, in addition to benefits from PC and administrative support for the clinic. The clinic received some increased administrative support 2021–2023 but, with continued clinic growth, participants felt that administrative resources remained insufficient.

*“Compared to more well-developed clinics, I think we, the [Pal-SAIL] physicians, do a lot of the administrative stuff. Even though we do have some administrative support, we still take a lot of that on ourselves. So, it can be difficult to imagine how we’ll continue to do that as numbers hopefully continue to grow over time.” (PCHCP22).*

Patients and caregivers felt that care from Pal-SAIL provided symptomatic benefits, which was connected to improved quality of life.

*“[Pal-SAIL physicians are] just being so careful, so gentle, and so thorough with everything. If one of the symptoms is getting out of hand, they will always suggest medication.” (LPT23).*

### Goal concordance at hospital admission subsequent to PC consult



**Fig. 4** Long-term outcome: Increased delivery of goal-consistent care

### Long-term outcomes

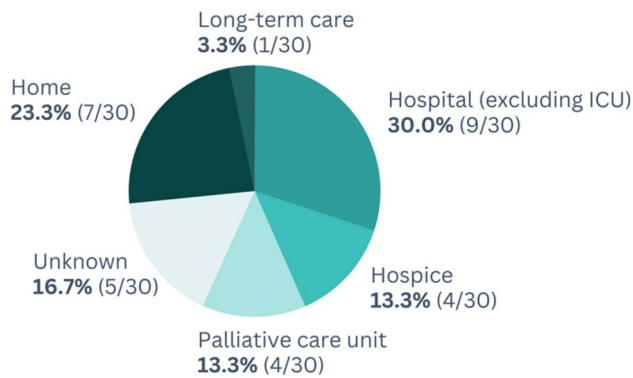
Long-term outcomes included healthcare utilization by Pal-SAIL patients, public perception of PC, and future growth of the clinic.

We examined change in patients’ healthcare utilization before and after Pal-SAIL consultation (see Fig. 3). Per individual who experienced hospitalization, the median (IQR) number of hospitalizations at TOH decreased from 1 (1,2,3) in the six months pre-consultation to 0.5 (0,1) in the six months post-consultation ( $p=0.004$ ). The median length of stay for patients who were hospitalized remained consistent pre- and post-consultation (6.8, IQR:4, 13.5; 6.8, IQR: 5.8, 10,  $p=1.00$ ). During hospitalizations that occurred after the initial Pal-SAIL consultation, documented goals of care were generally consistent with goals discussed at PC consultation (Fig. 4). Median visits to TOH ED decreased from 2 (1,3) in the six months pre-consultation to 1 (1,2) in the six months post-consultation ( $p=0.001$ ). Patients seen by the Pal-SAIL team who died during the study period ( $n=30$ ) most frequently died outside of hospital, including hospice/PC unit (PCU) (8, 26.6%), home (7, 23.3%), long-term care (LTC) (1, 3.3%) (See Fig. 5).

Pal-SAIL physicians developed clear referral criteria for the clinic, provided education to patients and caregivers about the role of PC, and helped dispel common myths. The clinic continued to build on the existing identity and public perception of PC.

*“I think now that we [Pal-SAIL physicians] have a good understanding and provided education with referral criteria, it has become much easier for [HCPs] to identify who is an appropriate patient, and they’ve been doing a very good job.” (PCHCP13).*  
*“Because when you hear ‘palliative’—I’ve been palliative for quite some time, so I just really thought, ‘This is it. They’re just going to let me die.’ But that’s absolutely not what happened, and I’m really happy*

### Location of patient death



**Fig. 5** Long-term outcome: Location of death

about it. The word “palliative” is perceived differently by different people.” (LPT23).

Despite this, some patients/caregivers reported difficulty in differentiating the Pal-SAIL team from other care teams (such as home care, hepatology, or family physicians).

“I don’t know whether that was home care or whether that was [Pal-SAIL] that kind of was directing that [...] I really wasn’t certain at times who was [Pal-SAIL] and who was not.” (LCG17).

While the clinic is now well established, HCPs expressed concern that future growth may be limited by factors such as physical clinic space and physician time.

“I think it’s possible that the volumes will keep increasing, and that, at some point, if [Pal-SAIL] fol-

low all the patients, that might be overwhelming to them.” (LHCP12).

Pal-SAIL physicians aimed to improve patient and caregiver understanding of illness and the potential future complications of ESLD (Fig. 6). When appropriate, Pal-SAIL physicians offer prognostic information to help patients and families make decisions for the duration of their illness.

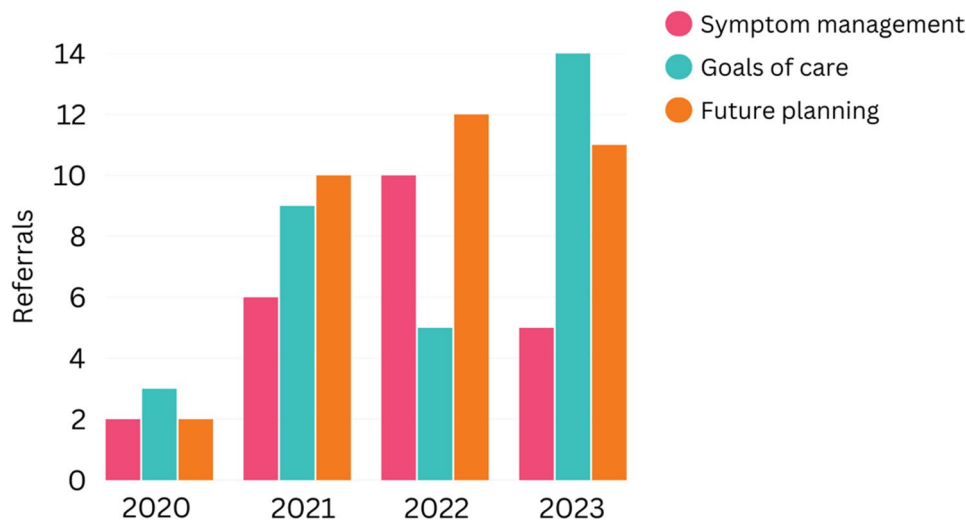
“At the very first appointment, [Pal-SAIL Physician] truly drew graphs for me. ‘Here’s a timeline for somebody with condition A, condition B. [...] We don’t know, but we anticipate the following.’ And so that that was very good for me, and the visual to be able to put it together.” (LCG05).

“[Pal-SAIL] were very thorough in explaining everything to us every time we’d go. Every time he had a different ailment, they would explain everything in detail. Like, possibly six months down the road, this might be happening with your illness, the progression, and so on.” (LCG14).

### Discussion

We completed a process evaluation of the Pal-SAIL clinic, which is a novel clinic providing early outpatient PC to patients with ESLD in Ottawa, Canada. This model was perceived as providing high-quality care to patients with ESLD. Hepatologists reported high collaboration and effective communication with the PC team. Patients and caregivers reported that the Pal-SAIL physicians were accessible, compassionate, and supportive. Triangulated results suggested that referrals to PC occurred at an acceptable point in the illness, may decrease healthcare

### Reasons for referral to PC clinic



**Fig. 6** Long-term outcome: Improved understanding of palliative supports and basic symptom management

utilization related to ED visits and hospitalizations, and may increase the frequency of deaths at home, hospice, or PCU.

#### **Pal-SAIL as a novel model of care**

To our knowledge, this is the first study to describe a collaborative outpatient hepatology-PC clinic in Canada. Two existing studies have described outpatient hepatology-PC collaborations internationally [18, 19]. Van Zyl et al. described a California PC clinic integrated within the hepatology clinic offering joint visits by a PC-trained nurse practitioner and social worker for one half-day per week and found patients receiving integrated PC had more frequent goals of care discussions than those not receiving PC [19]. Like van Zyl et al., our findings show that a large majority of patients seen by PC had goals of care conversations documented, and that these goals were consistently documented longitudinally during subsequent hospital admissions [32]. Unlike the interdisciplinary model described by van Zyl et al., Pal-SAIL currently consists of specialist PC physicians only.

Additionally, HepatoCare is an Australian physician-led collaboration between PC and hepatology that also includes a nurse and pharmacist [18]. Unlike Pal-SAIL, HepatoCare excludes patients being considered for transplant. However, similarly, Kearney et al. reported increased home/PCU deaths and fewer hospitalized days in HepatoCare patients.

Our study adds to the sparse existing literature [18, 19] on early outpatient PC provision for patients with ESLD and highlights the importance of establishing an optimal model for care delivery.

#### **Timing of referrals**

While patients felt that they were referred to PC at an appropriate point in their illness, the quantitative results highlighted a gap in the timing of consultations. During the Pal-SAIL consultative model (prior to January 2023), 24% of the total patients referred died or had a terminal admission prior to their scheduled consultation, suggesting that more availability needed because of the unpredictable nature of ESLD progression. Consequently, Pal-SAIL increased access by initiating a full-time shared-care model (January 2023), where only 4% of total referred patients died prior to the first assessment. As the clinic continues to grow, increased physician time and additional clinic space are needed to optimize flexibility in booking urgent visits.

#### **Healthcare utilization**

While it is generally expected that ED visits and hospitalizations will increase as a patient's illness advances, a notable finding of this study was the reduction in acute care utilization following PC consultation. This decrease

is consistent with the existing literature indicating that PC may reduce the strain on acute healthcare resources for patients with ESLD [18, 33–35]. The accessible and holistic approach of Pal-SAIL may help patients avoid unnecessary hospitalizations and emergency interventions through longitudinal goals of care discussions [32] and by effectively addressing issues such as pain, dyspnea, and other symptoms that prompt acute care utilization.

#### **Place of death**

Many patients desire to die at home or on a PCU, rather than in a hospital [36, 37]. Historically, patients with non-malignant illnesses such as ESLD have faced significant barriers to achieving their preferred place of death, with approximately 80% of such patients dying in hospitals or intensive care units [38]. Our study demonstrated that over 50% of deceased patients who were followed by Pal-SAIL died either at home, in their LTC home, in hospice, or a PCU. This is likely related to the Pal-SAIL team coordinating individualized care, which supports patients in navigating their end-of-life values and preferences.

#### **Implications for practice**

Although Pal-SAIL fills an existing gap, our findings also highlight several areas for improvement. Patients and caregivers noted in-person appointments as a barrier due to the burden of travel and reported difficulty in differentiating the Pal-SAIL team from other relevant care teams. This finding represents an opportunity to increase education and highlight the unique role of the Pal-SAIL clinic. Based on this, Pal-SAIL aims to incorporate virtual care provision when appropriate and provide written materials to increase recognition.

#### **Limitations**

This was a single-center process evaluation study of a novel early PC hepatology clinic. Data regarding ED use and hospitalizations were only gathered from TOH. While healthcare utilization from external hospitals was not captured, TOH is the largest hospital system in the region. The clinic began before the process evaluation was launched, therefore, although we used historical controls where possible, a control group was not feasible for all outcomes. Both the *consultative* and *shared-care* iterations of our model were included in this study due to sample size, which may impact the overall results such as follow-up frequency. The sample size was small, which equally limited the power of the statistical analysis and precluded the ability to control for confounders. The interviews revealed that patients and caregivers could not always distinguish the Pal-SAIL team from other care teams; thus, some interview responses may have been inappropriately attributed to Pal-SAIL.

### Strengths

We used mixed methods for a patient-centered approach, highlighting outcomes that are important to patients/caregivers, and HCPs. Our study team included a caregiver partner who provided us with valuable insights. The novel nature of this study provides useful information regarding the optimization of early outpatient PC models for patients with ESLD and other non-malignant illnesses.

### Conclusion

This study emphasizes the critical role that PC outpatient clinics can play in caring for patients with ESLD. Hepatologists, patients, and caregivers feel that the Pal-SAIL clinic model offers high quality, collaborative, and accessible care. The high proportion of Pal-SAIL patients who died at home/hospice/PCU highlights the positive impact of PC on end-of-life care. These findings support ongoing investment in PC services for ESLD patients. Future research should include a more rigorous and highly powered analysis of the outcomes for patients in this clinic, including differences based on transplant candidacy. As healthcare systems strive to improve care for individuals with all forms of advanced illness, integrating this model for early outpatient non-malignant PC in other centers can enhance patient quality of life and collaborative healthcare delivery.

### Abbreviations

|          |  |
|----------|--|
| CPR      | Cardiopulmonary resuscitation          |
| ESLD     | End-stage liver disease                |
| HCP      | Healthcare provider                    |
| ICU      | Intensive Care Unit                    |
| IQR      | Interquartile range                    |
| LTC      | Long-term care                         |
| NSAIDs   | Non-steroidal anti-inflammatory drugs  |
| Pal-SAIL | Palliative Support in Advanced ILIness |
| PC       | Palliative care                        |
| MD       | Medical Doctor                         |
| PCU      | Palliative care unit                   |
| PPS      | Palliative Performance Scale           |
| RC       | Research coordinator                   |
| TOH      | The Ottawa Hospital                    |

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12904-025-01977-y>.

Supplementary Material 1.

### Authors' contributions

GW, AB, LC and SI conceived of and designed the study. GW, LC, AB, AW and SR gathered the data and interpreted results with SI's supervision. AW and GW wrote the manuscript. Patient partner GD provided guidance on ensuring the lived experience of patients was represented in the study and presentation of results. GW, AW, AB, LC, EK, JD, AP, GD, SR, SI reviewed and approved the final manuscript.

### Funding

This project was funded through The Ottawa Hospital Academic Medical Organization (TOHAMO) innovation grant, and the University of Ottawa Department of Medicine developmental research grant.

### Data availability

The datasets generated and/or analysed during the current study are not publicly available due to privacy or confidentiality restrictions. Any inquiries about data sharing can be sent to the corresponding author.

### Declarations

#### Ethics approval and consent to participate

Ethics approval was received from the Ottawa Health Science Network Research Ethics Board (Protocol ID: 20230227-01H) and the Bruyère Research Ethics Board (REB Number: M16-23-020). The study adheres to the Declaration of Helsinki. Informed consent was obtained from all participants.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

#### Author details

<sup>1</sup>Bruyère Health Research Institute, Ottawa, Canada

<sup>2</sup>Ottawa Hospital Research Institute, Ottawa, Canada

<sup>3</sup>Department of Medicine, University of Ottawa, Ottawa, Canada

<sup>4</sup>VA Greater Los Angeles Healthcare System, California, USA

<sup>5</sup>School of Epidemiology and Public Health, University of Ottawa Ontario Canada, Ottawa, Canada

<sup>6</sup>General Hospital, Palliative Care Room 7462, 501 Smyth Rd, Ottawa, ON K1H 8L6, Canada

<sup>7</sup>Ottawa, Ontario, Canada

Received: 23 September 2025 / Accepted: 10 December 2025

Published online: 19 December 2025

### References

1. Abraham JL. Advances in palliative medicine and end-of-life care. *Annu Rev Med.* 2011;62:187–99. <https://doi.org/10.1146/annurev-med-050509-163946>.
2. Harrison KL, Kotwal AA, Smith AK. Palliative care for patients with noncancer illnesses. *JAMA.* 2020;324(14):1404–5. <https://doi.org/10.1001/jama.2020.15075>.
3. Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet.* 2014;383(9930):1721–30. [https://doi.org/10.1016/S0140-6736\(13\)62416-2](https://doi.org/10.1016/S0140-6736(13)62416-2).
4. Kavalieratos D, Corbelli J, Zhang D, et al. Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *JAMA.* 2016;316(20):2104–14. <https://doi.org/10.1001/jama.2016.16840>.
5. Hui D, Heung Y, Bruera E. Timely palliative care: personalizing the process of referral. *Cancers (Basel).* 2022;14(4):1047. <https://doi.org/10.3390/cancers14041047>.
6. Lau C, Meaney C, Morgan M, Cook R, Zimmermann C, Wentlandt K. Disparities in access to palliative care facilities for patients with and without cancer: a retrospective review. *Palliat Med.* 2021;35(6):1191–201. <https://doi.org/10.1177/02692163211007387>.
7. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage.* 2006;31(1):58–69. <https://doi.org/10.1016/j.jpainsymman.2005.06.007>.
8. Poonja Z, Brisebois A, van Zanten SV, Tandon P, Meeberg G, Karvellas CJ. Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management. *Clin Gastroenterol Hepatol.* 2014;12(4):692–8. <https://doi.org/10.1016/j.cgh.2013.08.027>.
9. Government Of Canada SC. Top 10 leading causes of death. (2019 to 2022). November 27, 2023. Accessed April 17, 2025. <https://www150.statcan.gc.ca/n1/daily-quotidien/231127/t001b-eng.htm>

10. Verma M, Horrow J, Carmody S, Navarro V. Unmet needs and burden of caregivers of patients being evaluated for a liver transplant are similar to those of cancer caregivers. *Am J Hosp Palliat Care*. 2024;41(4):391–7. <https://doi.org/10.1177/10499091231176297>.
11. Rakoski MO, Volk ML. Palliative care for patients with end-stage liver disease: an overview. *Clin Liver Dis (Hoboken)*. 2015;6(1):19–21. <https://doi.org/10.1002/clid.478>.
12. Brown CL, Hammill BG, Qualls LG, Curtis LH, Muir AJ. Significant morbidity and mortality among hospitalized end-stage liver disease patients in Medicare. *J Pain Symptom Manage*. 2016;52(3):412–419.e1. <https://doi.org/10.1016/j.jpainsymman.2016.03.013>.
13. Verma M, Tapper EB, Singal AG, Navarro V. Nonhospice palliative care within the treatment of end-stage liver disease. *Hepatology*. 2020;71(6):2149–59. <https://doi.org/10.1002/hep.31226>.
14. Canadian Institute for Health Information. Access to Palliative Care in Canada, 2023. Ottawa, ON: CIHI; 2023. <https://www.cihi.ca/en/access-to-palliative-care-in-canada>.
15. Rush B, Walley KR, Celi LA, Rajoriya N, Brahmania M. Palliative care access for hospitalized patients with end-stage liver disease across the united States. *Hepatology*. 2017;66(5):1585–91. <https://doi.org/10.1002/hep.29297>.
16. Seow H, Qureshi D, Isenberg SR, Tanuseputro P. Access to palliative care during a terminal hospitalization. *J Palliat Med*. 2020;23(12):1644–8. <https://doi.org/10.1089/jpm.2019.0416>.
17. Quinn KL, Wegier P, Stukel TA, Huang A, Bell CM, Tanuseputro P. Comparison of palliative care delivery in the last year of life between adults with terminal noncancer illness or cancer. *JAMA Netw Open*. 2021;4(3):e210677. <https://doi.org/10.1001/jamanetworkopen.2021.0677>.
18. Kearney A, Tiwari N, Cullen O, et al. Improving palliative and supportive care in advanced cirrhosis: the model of integrated collaborative care. *Intern Med J*. 2023;53(11):1963–71. <https://doi.org/10.1111/imj.16248>.
19. van Zyl C, Storms AD, van Deen W, et al. A pilot study of a palliative care service embedded in a hepatology clinic at a large public hospital. *J Palliat Med*. 2023;26(6):776–83. <https://doi.org/10.1089/jpm.2022.0438>.
20. Saunders RP, Evans MH, Joshi P. Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. *Health Promot Pract*. 2005;6(2):134–47. <https://doi.org/10.1177/152483990473387>.
21. W.K. Kellogg Foundation Logic Model Development Guide. Published online. January 2024. [https://www.naccho.org/uploads/downloadable-resources/Programs/Public-Health-Infrastructure/KelloggLogicModelGuide\\_161122\\_162808.pdf](https://www.naccho.org/uploads/downloadable-resources/Programs/Public-Health-Infrastructure/KelloggLogicModelGuide_161122_162808.pdf)
22. Anderson F, Downing GM, Hill J, Casorlo L, Lerch N. Palliative performance scale (PPS): a new tool. *J Palliat Care*. 1996;12(1):5–11.
23. Downing DGM. Palliative Performance Scale PPSv2.:2.
24. Donlan J, Zeng C, Indriolo T, et al. The Edmonton Symptom Assessment System is a valid, reliable, and responsive tool to assess symptom burden in decompensated cirrhosis. *Hepatol Commun*. 2024;8(4):e0385. <https://doi.org/10.1097/HCG.0000000000000385>.
25. Goals of Care | University of Ottawa Heart Institute. November 10, 2021. Accessed December 7, 2025. <https://www.ottawaheart.ca/patients-and-visitors/tools-and-resources/goals-care>
26. R Foundation for Statistical Computing. R Core Team. (2021). R: A language and environment for statistical computing. Published online 2021. <https://www.R-project.org/>
27. Boyatzis RE. Transforming Qualitative Information: Thematic Analysis and Code Development. Sage Publications, Inc; 1998. p. xvi–184.
28. Guest G, MacQueen KM, Namey EE. Applied Thematic Analysis. Sage; 2012.
29. Braun V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. <https://doi.org/10.1191/1478088706qp0630a>.
30. Braun V, Clark Victoria. Thematic Analysis: A Practical Guide. Sage publications; 2022.
31. Creswell JW, Plano Clark VL. Designing and Conducting Mixed Methods Research. 3rd ed. Sage; 2018.
32. Ernecoff NC, Wessell KL, Bennett AV, Hanson LC. Measuring goal-concordant care in palliative care research. *J Pain Symptom Manage*. 2021;62(3):e305–14. <https://doi.org/10.1016/j.jpainsymman.2021.02.030>.
33. Shehadah A, Yu Naing L, Bapaye J, et al. Early palliative care referral may improve end-of-life care in end-stage liver disease patients: a retrospective analysis from a non-transplant center. *Am J Med Sci*. 2024;367(1):35–40. <https://doi.org/10.1016/j.amjms.2023.10.006>.
34. Ufere NN. Advance care planning and goals of care discussions in advanced liver disease. *Curr Hepatol Rep*. 2021;20(3):77–84. <https://doi.org/10.1007/s1901-021-00565-x>.
35. Sohal A, Chaudhry H, Sharma R, et al. Recent trends in palliative care utilization in patients with decompensated liver disease: 2016–2020 national analysis. *J Palliat Med*. 2024;27(3):335–44. <https://doi.org/10.1089/jpm.2023.0367>.
36. Higginson I, Sen-gupta G. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med*. 2000. <https://doi.org/10.1089/jpm.2000.3.287>.
37. Skorstengaard MH, Neergaard MA, Andreassen P, et al. Preferred place of care and death in terminally ill patients with lung and heart disease compared to cancer patients. *J Palliat Med*. 2017;20(11):1217–24. <https://doi.org/10.1089/jpm.2017.0082>.
38. Kelly EM, James PD, Murthy S, et al. Health care utilization and costs for patients with end-stage liver disease are significantly higher at the end of life compared to those of other decedents. *Clin Gastroenterol Hepatol*. 2019;17(11):2339–2346.e1. <https://doi.org/10.1016/j.cgh.2019.01.046>.

## Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.