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Patient Satisfaction With Centralising Care of Gestational Trophoblastic Disease in Western Australia: A Descriptive Cross-Sectional Evaluation

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ABSTRACT

Introduction: Gestational trophoblastic neoplasia (GTN) is a rare, malignant form of gestational trophoblastic disease (GTD), and international guidelines recommend centralisation of care for best outcomes. The Western Australian Trophoblastic Centre (WATC) was established in 2023 aiming to provide centralised, person-centred care coordinated by a specialist nurse within a multidisciplinary team. This project aimed to describe the patient population and evaluate lived experience and satisfaction in this new model of care.

Methods: An observational descriptive study utilised a review of service data to describe the profile of service users and a cross-sectional survey to collect quantitative and qualitative evaluation data. Data underwent descriptive statistical and content analysis.

Results: The review determined 172 people accessed the WATC from January 2023 to April 2024. The majority were treated for a partial mole (50%) or a complete mole (38%). Sixty-six service users responded to the survey. Descriptive analysis revealed an extremely high level of service satisfaction across all areas of care. The few reports of dissatisfaction related to awareness of psychological and external services and support for family member needs. Survey participants expressed mixed preference for face-to-face and telephone appointments. Within open-ended responses, participants commonly expressed satisfaction with empathetic and supportive care delivered by the specialist nurse, information provision and having access to a contact person through the service. Suggestions for improvement were associated with practical issues, such as parking and logistical challenges in attending appointments, and communication.

Conclusions: Satisfaction with this centralised service model for the management of GTD was extremely high, emphasising the person-centred approach coordinated by a specialist nurse. This evaluation validates service continuation in its current form and supports wider implementation of similar models in other centres for people accessing care for GTD management.

1 | Main Text

Gestational trophoblastic disease (GTD) is a group of diseases that arise from trophoblastic cells, the cells that help an embryo attach to the uterus and form the placenta after fertilisation [1]. GTD affects women of reproductive age; the incidence in Australia is estimated at 1 in 200–1000

pregnancies [2] but varies internationally [3]. The World Health Organization classification divides GTD into two main types: premalignant hydatidiform mole and malignant forms termed gestational trophoblastic neoplasia (GTN) [4]. Hydatidiform moles can be categorised as complete mole, where there is no maternal genetic material present in the ovum, or partial mole, where both parental genetic materials are present but it is insufficient to support foetal development [5]. Patients with GTD have an up to 20% risk of progression to GTN, typically in the form of persistent or invasive mole. Additionally, GTN may present in other forms including gestational choriocarcinoma, placental site trophoblastic tumour and epithelioid trophoblastic tumour. Fortunately, GTN has a high cure rate, approaching 100% [3, 6].

Best practice guidelines released by the European Organisation for the Treatment of Trophoblastic Disease (EOTTD) emphasise that referral to a centralised specialist service is considered best practice for the management of care for patients with GTD and GTN [7]. Published literature supporting the development of centralised GTD/GTN services emphasises the importance of establishing a core multidisciplinary team with clinical expertise in this specialty to achieve the mission of delivering optimal patient-centred care [8–10]. Additionally, published best practice nursing guidelines are available to support nurses to achieve optimal care specific to their roles [11].

Numerous centralised centres for the management of GTD/N have been established across Europe, North America and Brazil [12]. Care provided amongst all reported centres includes consultation and serum hCG monitoring with some also offering centralised pathology and treatment services. Centralisation has resulted in improvement for key clinical indicators, such as accuracy of diagnostic score documentation, contraception counselling, median time from diagnosis to chemotherapy and reducing the number of patients with incomplete follow-up [12].

While this evidence to support the benefit of centralised services in practice is positive, no current literature has examined the perspectives of patients with lived experience of trophoblastic diseases on this model of service. International consensus recommends that cancer care should focus on outcomes that matter to patients [13]. Capturing the perspectives of people with lived experience is important to share insights into care quality [14] and ensure a complete approach to service evaluation. Additionally, in Australia, care evaluation is informed by the principles of consumer-centred, evidence-based and organised care to enhance safety and quality in health care [15].

The Western Australian Trophoblastic Centre (WATC) service commenced in January 2023 to centralise care of trophoblastic diseases for women in Western Australia. In the context of this service model change, this study aimed to evaluate its efficacy through four objectives:

1. Describe characteristics of the patient population receiving care from the WATC;
2. Examine the ways patients navigated their care for GTD;
3. Assess satisfaction with care provided by the WATC; and
4. Identify areas for improvement.

2 | Materials and Methods

2.1 | Design

An observational descriptive study was utilised to evaluate service provision informed by the Australian Safety and Quality Framework for Health Care [16] and the principles of quality improvement and service evaluation [17].

The study comprised two phases [1]: a retrospective review of service users to describe their demographic and diagnostic profile; and [2] a cross-sectional survey to collect quantitative and qualitative evaluation data.

2.2 | Study Setting

A centralised service for the management of people with trophoblastic diseases was established at a major public tertiary women's hospital in Western Australia in January 2023. This service provides care for people across a geographical area of 2.5 million square kilometres ranging from a major metropolitan city to remote regional locations. Before the establishment of this centralised service, patients accessed care through local healthcare services across the state, from clinicians with variable expertise in this specialty area of care. The WATC centralised service is staffed by a multidisciplinary team of clinicians including a coordinating clinical nurse with specialist knowledge and expertise in the care of patients with trophoblastic diseases.

2.3 | Study Population

For Phase One, participants were included in the review if they were aged 17 years or older and attended the service within the 16-month period between service inception in January 2023 and April 2024. For Phase Two, a purposive sample of patients attending the WATC was sought. As the survey and accompanying participation information statement were provided in English, only those proficient in written English were eligible for survey participation.

Before study commencement, workload records revealed that 172 service users received care from the WATC in the 16-month time frame. The retrospective review aimed to include all service users, and the target sample size for the survey was 69, assuming a 40% response rate [18].

2.4 | Recruitment and Data Collection

2.4.1 | Phase One

Patients who received care from the WATC between January 2023 and April 2024 (inclusive) were identified from workload records stored in the hospital's internal patient management system. As only nonidentifiable data routinely collected at the health service were extracted, consent to participate was not required. Data were extracted from service records and entered into a review tool on a Microsoft Excel spreadsheet and were crosschecked by two members of the research team for accuracy. The data collection tool was designed to address objective one of this study. Data included age, postcode, country of birth, language, Aboriginal and/or Torres Strait Islander status and medical condition. Medical record numbers were initially collected to avoid duplication and were later deleted for analysis and reporting.

2.4.2 | Phase Two

The survey tool was developed by the research team who have experience in survey design. The questions were developed to meet the study objectives, guided by the principles of quality improvement and service evaluation [17]. Additionally, questions from the Australian Hospital Patient Experience Question Set were contextually adapted for inclusion [19]. The survey collected data using Likert, multiple choice and open-ended questions to examine how participants received and navigated care, assess their satisfaction with the care provided and identify areas for improvement. The inclusion of both quantitative and qualitative data collection was used to optimise measurement of service quality, enabling patients to focus on what matters most to them [20]. The full survey tool is provided as a supporting file. The survey was administered using REDCap electronic data capture tools hosted at the study site [21, 22].

Patients who were identified as eligible for inclusion in the review were sent an invitation to participate in the survey by email or text message through the hospital's messaging system. The invitation included a link to the participant information statement outlining the purpose of the survey along with confidentiality information, explanation of the voluntary nature of their participation and a survey link. Before survey commencement, participants were required to complete a hurdle question to acknowledge they had read the statement, met the eligibility criteria and consented to participate. No identifying information was collected, and therefore, responses remained anonymous. The survey was piloted with six eligible participants to assess readability and clarity. Minor changes to syntax and formatting were subsequently made before distribution. Their responses were not included in the final analysis. Surveys were collected between May and June 2024.

2.5 | Data Analysis

Phase 1 and 2 quantitative data were uploaded and analysed using descriptive techniques (frequencies and percentages) in SPSS Statistics 24 [23]. Country of birth data were analysed in Microsoft Excel for ease of categorisation into the continent of birth. Missing data were handled using case-wise omission. To maintain anonymity, participant identification numbers (i.e. P1 and P2) were allocated to each survey response and de-identified by replacing any reference to names and places in open-ended responses with pseudonyms.

Qualitative data provided in survey open-ended responses were analysed using inductive content analysis [24, 25] in Microsoft Excel. These steps included [1]: familiarisation with the data [2]; dividing text into meaning unit [3]; condensing meaning unit [4]; formulating codes; and [5] developing categories into the who, what, when and where. Irrelevant responses, such as 'n/a,' were omitted from analysis. These data were independently coded by two members of the research team who participated in regular verbal and written reflexive practice to minimise the influence of internal bias. Codes, categories and category definitions were discussed until consensus was achieved. Categories were chosen as the highest level of abstraction for reporting because responses were brief and did not contain enough latent meaning to support theme development [25].

2.6 | Ethical Considerations

This study complied with Australian standards for responsible and ethical conduct of human research [26, 27], jurisdictional guidance for implementing the Declaration of Helsinki [28]. This project was reviewed by the Women and Newborn Health Service Human Research Ethics Committee and approved by the Quality Improvement Sub-Committee on 13 May 2024 (approval number GEKO50521).

3 | Results

3.1 | Participant Characteristics

In total, the Phase One review included 172 service users, and subsequently, 66 of these people completed the survey. The average age of WATC service users within the review period was 32 years, ranging between 17 and 53 years. Detailed information on the characteristics of the review population and survey respondents can be found in Table 1. Of note, most participants lived in a metropolitan location (review data $n = 147$, 85%; survey data $n = 49$, 74%). Most self-identified their ethnicity as Australian (survey data $n = 48$, 73%) which included Aboriginal Australians and those identifying as mixed-Australian ethnicity (i.e. Asian–Australian and British–Australian) with 10 participants (15%) identifying as other ethnicities including British, Asian, Finnish and New Zealander/Maori. Most participants preferred receiving health information in English (survey data $n = 59$, 89%). The most common type of health condition identified in the review was complete mole ($n = 65$, 38%), followed by partial mole ($n = 52$, 30%). Other rare types of trophoblastic diseases comprised 12% ($n = 21$) of service users and included conditions, such as choriocarcinoma, atypical placental site nodule, placental site trophoblastic tumour, epithelioid trophoblastic tumour and unknown GTD type.

3.2 | Navigating GTD Care

Survey respondents' appointment types and access to chemotherapy treatment and psychological support were measured to examine the ways patients received and navigated their care within the WATC service. Most survey respondents were diagnosed after the inception of the WATC at KEMH, with the majority being diagnosed between July and December 2023 ($n = 18$, 32%) (see Figure 1). Of note is that a category for January–April 2024 was inadvertently not included in the survey after amending the study to include these patients. Therefore, the 20% ($n = 11$) who selected 'I can't remember' may also include people who were diagnosed in this time period for which there was no available category.

Survey respondents indicated they attended, were offered, and preferred a variety of appointment types by the WATC service (Table 2). The most common type of appointment attended with the WATC was by telephone ($n = 45$, 75%), and the least common was video conferencing ($n = 6$, 10%). Approximately half of respondents ($n = 32$, 53%) preferred a face-to-face appointment, followed by a telephone appointment ($n = 26$, 43%), and a small number of respondents ($n = 14$, 23%) had no preference. Of the survey respondents requiring chemotherapy treatment for their condition ($n = 7$, 12%), almost all received their first dose within 2 weeks of being informed this treatment was required ($n = 6$,

TABLE 1 | Characteristics of total population ($n = 172$) and survey respondents ($n = 66$).

Variable measured		Population data *n* (%)	Survey responses *n* (%)
Gender[b]	Female	—	60 (91)
	Missing		6 (9)
Location	Perth Metropolitan	147 (85)	49 (74)
	Rest of Western Australia	22 (13)	11 (17)
	Missing	3 (2)	6 (9)
Self-reported ethnicity[b]	Australian	—	48 (73)
	Other		10 (15)
	Prefer not to say		2 (3)
	Missing		6 (9)
Continent of birth[a]	Oceania	103 (60)	—
	Asia	43 (25)	
	Europe	16 (9)	
	Africa	8 (5)	
	Americas	2 (1)	
Aboriginal and Torres Strait Islander status	Yes—Aboriginal and/or Torres Strait Islander[a]	10 (6)	
	Yes—Aboriginal[b]		2 (3)
	Yes—Torres Strait Islander[b]		1 (2)
	No	162 (94)	57 (86)
	Missing	0	6 (9)
Preferred language for health information[b]	English	—	59 (89)
	Other		1 (2)
	Missing		6 (9)
Interpreter required[a]	Yes	8 (5)	—
	No	162 (94)	
	Missing	2 (1)	
Health condition[a]	Complete mole	65 (38)	—
	Partial mole	52 (30)	
	Possible partial mole	34 (20)	
	Other rare types	21 (12)	

[a]Variable collected in the review dataset only.
[b]Variable collected in the survey dataset only.

86%). Just over half of survey respondents ($n = 37$, 56%) indicated they did not want to access psychological support through the WATC despite this service being available. Eight survey respondents ($n = 12\%$) indicated they would have liked psychological support but did not access it. WATC appointment types, chemotherapy treatment and psychological support access are presented in Table 2.

3.3 | Assessing Satisfaction With Care Provided by the WATC

In the survey, 18 items were used to assess respondents' satisfaction regarding various aspects of their care. Figure 2 demonstrates the level of agreement or disagreement with each of these items. The results indicate that overall, 100% ($n = 65$) of the participants were satisfied with the care provided by the WATC. Items where some level of disagreement with statements existed highlighting potential areas for improvement included: being unaware they had access to support services ($n = 8$, 13%); being unaware of how to access support services ($n = 11$, 17%); and meeting family and/or support people's needs ($n = 4$, 8%). Overall, high levels of satisfaction with all types of staff members were reported, namely doctors ($n = 55$, 95%), nurses ($n = 62$, 100%) and office staff ($n = 56$, 93%). It is acknowledged that these high reported satisfaction levels may have been influenced by response bias and by the distribution of the survey by the clinic nurse, despite the survey being anonymous.

Of the seven participants that required chemotherapy, all agreed on feeling emotionally supported by the chemotherapy staff during their treatment and receiving information regarding possible side effects. Six participants indicated they felt emotionally supported by the WATC staff during chemotherapy with one not answering the question. Six respondents had received information regarding chemotherapy before the medication and were contacted at completion of chemotherapy for follow-up.

In two open-ended questions, participants were asked to identify both what made it easy and what made it hard to make an appointment with the WATC. Twenty-two survey respondents commented on what made it easy to make an appointment, and the responses were grouped into six categories as shown in Table 3. No responses were recorded for the question 'What made it hard to make an appointment?'

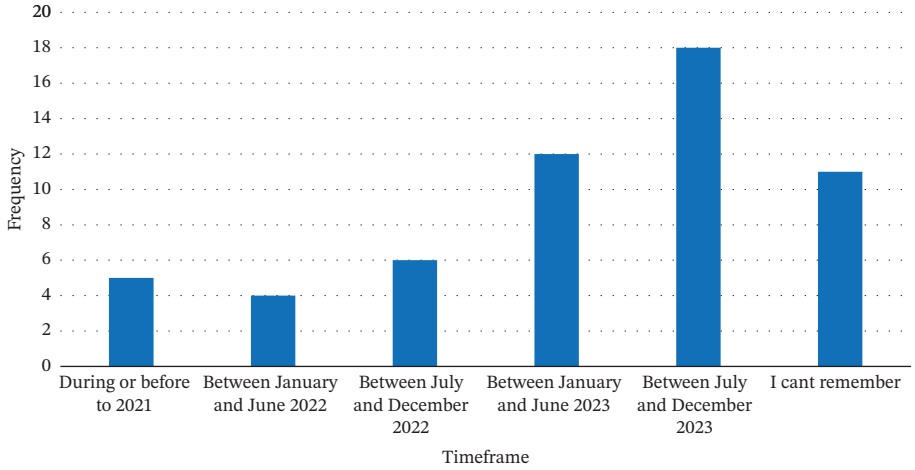

FIGURE 1 | Timeframe of gestational trophoblastic disease (GTD) diagnosis.

3.4 | WATC Service Evaluation and Areas for Improvement

In open-ended survey questions, participants were asked to identify both the best and worst things about their experience with the WATC, as well as to provide suggestions on how the WATC service could improve. Final categories, along with their supporting quotes and how often the category occurred for each, are presented in Table 4.

When relating the best thing about their experience with the WATC service, 46 out of 66 survey respondents provided positive comments

TABLE 2 | WATC appointment types, chemotherapy treatment and psychological support access.

Survey item		Survey responses *n* (%)
What type of appointment did you attend with the WATC?*	Face-to-face	29 (48)
	Telephone	45 (75)
	Video conferencing	6 (10)
Were you offered alternative types of appointments?*	Yes, telephone	21 (35)
	Yes, video	9 (15)
	Yes, face-to-face	19 (32)
	No	14 (23)
	Not sure	17 (28)
What is your preferred type of appointment?*	Face-to-face	32 (53)
	Telephone	26 (43)
	Video conferencing	8 (13)
	No preference	14 (23)
Did you receive chemotherapy?	Yes	7 (12)
	No	53 (88)
Where did you have chemotherapy?	Tertiary women's health service	4 (57)
	Alternate public health service	2 (29)
	Private health service	1 (14)
Time of first dose after being informed chemotherapy was needed	Within 2 weeks	6 (86)
	2–4 weeks	0 (0)
	More than 4 weeks	1 (14)
Did you access psychological support (PS) through WATC?	Yes	9 (14)
	No I did not want PS	37 (56)
	No but I would have liked PS	8 (12)
	No I access PS elsewhere	4 (6)
	I can't remember	3 (4)
	Missing	5 (8)
Was psychological support provided at an appropriate time?	Yes	7 (78)
	No	2 (22)

*More than one response could be selected.

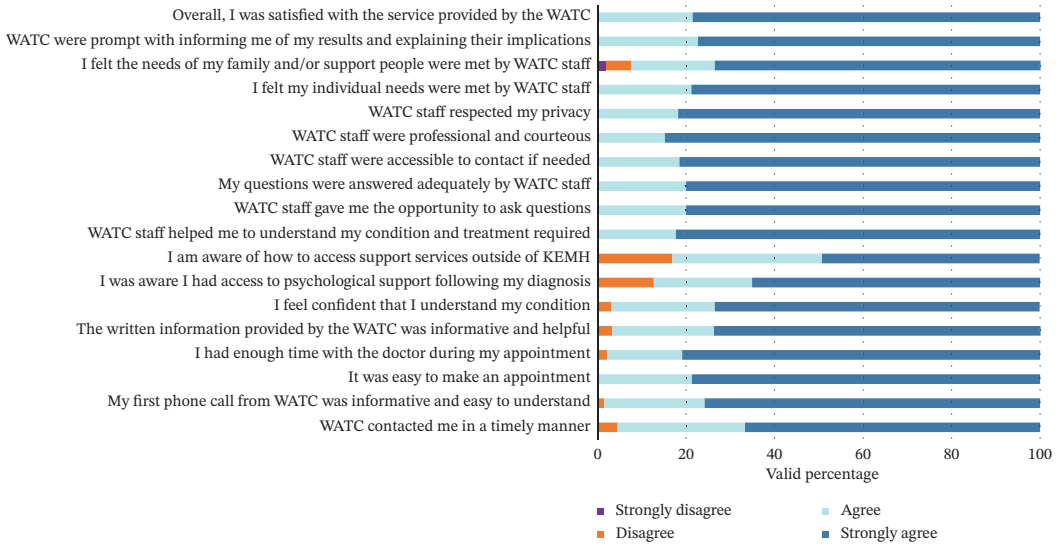

FIGURE 2 | Responses to WATC service satisfaction items (valid percentage).

relating to positive staff attributes, most often relating to the specialist nurse, such as 'compassion and empathy' (P59); a positive communication experience; praising supportive staff; staff being contactable; service efficiency and experiencing personalised care. Furthermore, when asked to comment on the worst thing about the service, 40 respondents provided comments; however, of that number, only ($n = 6$) comments related to a negative experience, such as a lack of parking ($n = 2$) and a negative communication experience ($n = 4$). The remainder ($n = 35$) responded with 'nothing' or provided an answer that did not address the question. For example, 'It wasn't there when I was first diagnosed' (P15), 'Me, I was a mess, the staff were wonderful' (P21), and 'Having to be referred to them in the first place' (P18).

Similarly, of the 24 people who responded to the question asking for service improvement recommendations, 17 provided answers positively praising the service or indicated no recommendations. For example, 'What you do is truly amazing, and I wish for the WATC to maintain the level of care exactly as is' (P10), 'I enjoyed my experience (as much as you can given circumstances) so there was no need for improvement' (P16) and 'You are already doing a great job, keep your good work' (P39). The six remaining suggestions included, more parking, the provision of a home chemotherapy service, empathetic communication training, requesting to be contacted sooner and more family support.

4 | Discussion

This evaluation of a centralised service model for the care of people with GTD in Western Australia was the first of its kind to report on the demographic profile of service users and satisfaction from the perspective of people with lived experience. Survey results revealed an extremely high level of service satisfaction across all measured aspects of care. Qualitative survey data confirmed satisfaction was related to the caring attributes provided by the specialist nurse, positive communication experiences with the team, feeling supported and having access to a contact person, which in this service was the specialist nurse. Areas for improvement related to practical issues and the suggestion of a home chemotherapy service.

4.1 | Implications of a Centralised, Multidisciplinary Service

While no previous literature has reported on evaluation of centralised GTD care from the perspective of service users, one recent study investigated social media post content of people with lived experience of GTN [29]. It was found that women openly shared experiences of their diagnosis, treatment, side effects and challenges during cancer through this channel and suggested that they were seeking practical and psychologically supportive care through sources outside the clinical setting.

It is known that women experiencing pregnancy loss due to GTD experience various psychological impacts, such as anxiety and depression, at similar rates to women experiencing non-GTD-related miscarriage [30]. Factors, such as a lack of partner support and poor education, demonstrated increased risk of psychiatric morbidity [30]. Women registered as having lived experience of GTD in Ireland have indicated their need for psychological support, bereavement counselling and peer support groups [31]. The high levels of satisfaction of our survey participants regarding the provision of care and support suggest that this centralised service model met their physical and psychological needs.

Since the introduction of best practice guidelines supporting GTD service centralisation [7], evidence to support its effectiveness and acceptability continues to emerge. Joyce et al. [31] suggest that a dedicated, centralised service offers the opportunity to improve monitoring compliance. Their survey of 215 women in Ireland revealed that phlebotomy attendance at a noncentralised GTD service was impacted in 26.5% of cases by the need to explain to the healthcare professional why they needed monitoring. Furthermore, centralisation may improve standardised assessment of service users' needs and provide coordinated treatment to reduce negative long-term effects. A study from the Netherlands concluded that women experiencing GTD-related pregnancy loss who are at risk of long-term psychological complaints may be identified through screening tools, such as the Hospital Anxiety and Depression Scale or the Impact of Event Scale as a component of supportive care [32]. Our high

TABLE 3 | Factors that made it easy to make an appointment with the WATC.

Category	Quotes	Count
Person-centred communication	'WATC reached out to make the appointment. I was very grateful of the phone calls and email reminders of my appointments' (P62)	7
Service being contactable	'Ability to touch base with Tabitha* via text' (P31)	6
Staff assistance	'Everyone within the WATC made it so easy to book appointments' (P10)	6
Positive staff attributes	'The staff were kind and understanding' (P21)	5
Organised	'It's organised' (P1)	1
Knowing the staff	'Knowing the person I am dealing with - the clinical nurse and doctor' (P29)	1

*Pseudonym presented.

rates of satisfaction with information provision and the availability of being able to contact a trusted health professional suggest that these outcomes may be prevented through the nurse-coordinated service model and highlight the importance of adequate assessment through a supportive care framework. Further research to investigate standardised assessment of supportive care needs in people with GTN is recommended.

4.2 | Supportive Care and Role of the Nurse

The psychological and emotional impacts of a GTD diagnosis on those with lived experience and their families are widely recognised. A recent systematic review and meta-analysis report significant psychological impacts on patients with GTD, including a 34.9% prevalence of anxiety and 22.2% prevalence of depression [33]. Multidisciplinary care is considered essential to address the emotional aspects of experiencing GTD and is a core component of the model of specialised and centralised GTD care [34]. A recent qualitative study from the Netherlands exploring the psychosocial impacts of GTD experiences highlighted the importance of psychological support delivered by specialised nurses [35]. This study emphasised the importance of personalised care delivered with empathy, also described by the participants in our setting.

While not all diagnoses of GTD progress to the malignant GTN stage, the applicability of a supportive cancer care framework to conceptualise the care provided through an integrated multidisciplinary team of specialists in this context would ensure that the needs of the person with lived experience are emphasised as central to care [36]. Regardless of centralisation status, we recommend that other health services consider how incorporating the principles of supportive care can support women's needs using a multidisciplinary approach to achieve high levels of satisfaction and reduce detrimental outcomes.

In our service, the specialist nurse undertakes a critical role to meet the needs of people with lived experience of GTD pregnancy loss and cancer. This was highlighted in our study as a key factor influencing the high levels of satisfaction with the service. Broadly in gynaecological cancer care, clinical nurse specialists are recognised as a 'central contact' for patients and are critical in the coordination of care [37]. Communication, support, advocacy, knowledge, education, assessment, referral and management are considered key aspects of the specialist nurse role [37]. Clinical nurse specialists in cancer care have also been shown to improve a wide range of patient outcomes including symptom management, psychological support, meeting information needs and patient satisfaction in a cost-effective way [38]. The results from our study provide further evidence supporting patient satisfaction with nurse-led service models. Further qualitative research may offer greater depth of insight into factors affecting patient satisfaction with GTD care and service models.

4.3 | Chemotherapy in the Home

One recommendation identified from the survey data was the option for the provision of chemotherapy treatment for GTN at home, to reduce disruption to other responsibilities. Women undergoing treatment for GTN are often juggling responsibilities, such as work and caring for children. The treatment regimen for GTN typically involves women attending the service for intramuscular injections of methotrexate (a cytotoxic agent) several times over a fortnight for a minimum period of 8 weeks and can continue for many months, until the disease resolves [39]. Apart from the practical inconvenience this causes, the repetitive attendance at the health service may adversely affect psychological outcomes.

Provision of chemotherapy in the home is considered an appropriate care model to complement current care [40, 41]. This approach also encompasses the principles of person-centred supportive care, where the multifaceted needs of the patient are prioritised as central to the care experience [36]. While it is recognised that current robust evidence on safety and cost-effectiveness is lacking, particularly regarding safety in larger populations and intravenous administration, patient acceptability and preference for this model are apparent [42]. Concerns regarding the risk of home chemotherapy infusions are recognised [41]; however, an observational study from Argentina included the administration of intramuscular chemotherapy regimens and reported low incidence of minor adverse events only [40]. We recommend that home-based methotrexate administration is an opportunity for further clinical development and research to optimise person-centred care and improve psychological outcomes.

4.4 | Strengths and Limitations

This observational descriptive study provides perspectives from people with lived experience of a recommended care model, a previously neglected gap in the current literature. A strength of the study is that, as a population descriptive study, data of all service users within the data collection period were captured, offering insight into the characteristics of people with GTD in Western Australia. While the survey sample size of 66 was small, they represented 38% of the eligible population. The use of a nonvalidated survey tool is considered a limitation; however,

TABLE 4 | Categories from qualitative data on service evaluation and areas for improvement.

Category	Quotes	Count
Best thing about WATC experience (n = 46)		
Positive staff attributes	'My wonderful nurse was truly the most amazing person. She was incredibly kind and understanding' (P54)	21
Positive communication experience	'The first phone call was made by Tabitha—she delivered the news and did so incredibly empathetically. she was warm, reassuring and validating of my questions and decisions' (P23)	17
Supportive staff	'Tabitha, my nurse. I felt very well looked after, seen and supported' (P41)	13
Contactable staff	'How easily it was to contact them when I had questions or needed information' (P37)	11
Efficient service	'Receiving results ASAP' (P46)	6
Personalised care	'One of the most comforting aspects of my experience has been the personalised attention I receive' (P10)	1
Worst thing about WATC experience (n = 6)		
Lack of parking	'Parking at the hospital is almost non-existent' (P3)	2
Negative communication experience	'Lack of details of diagnosis and nil understanding of how long I needed blood tests for' (P5)	4
Recommendations for improvement (n = 6)		
More parking	'More car parking spaces' (P31)	2
Provision of a home chemotherapy service	'Potentially have the chemo injections as an at home to minimalise the disruption to everyday life especially if working full time' (P29)	1
More family support	'It was mentioned in the surveys about family support being met but not once was I asked about my family' (P22)	1
Empathetic communication training	'It can be taken lightly or assumed staff know how to communicate, however a reminder or refresher of ways of effective communication face to face or phone conversation plus written would be my suggestion' (P59)	1
To be contacted sooner	'I would have liked to have been contacted sooner by the WATC' (P46)	1

satisfaction items were adapted from a standardised tool recommended in Australia and were considered appropriate for this descriptive study. It is acknowledged that the distribution of the survey tool by the specialist nurse working at the service may have influenced participant responses. Survey participation was anonymous to minimise this limitation. Some variables collected in the first phase (i.e. country of birth and health condition) were not collected in the survey, and so, it is not possible to compare the proportions of representation by participants using these variables. Readers should use caution if attempting to generalise these results to their local context and are encouraged to consider their own population demographics and healthcare system context which may influence service access and outcomes. This study does, however, offer novel insight into the recommended centralised care model for people with GTD, showing that this approach is associated with high levels of satisfaction.

5 | Conclusions

The establishment of a centralised service model for the care of people with trophoblastic diseases in Western Australia followed international best practice guidelines and represented a significant change in practice. This evaluation is the first to contribute experience of service use from the perspective of people with lived experience in the current literature. Satisfaction with the new service model was extremely high, emphasising the person-centred approach coordinated by a specialist nurse. Participants described that satisfaction was related to the caring attributes provided by the specialist nurse, positive communication experiences with the team, feeling supported and having access to a contact person.

We recommend that future evaluation of similar service models include data from the perspectives of service users to ensure that care is meeting their needs. The specialist clinical nurse is valued as a critical member of the team to meet the clinical and supportive care needs of people experiencing GTD. The application of a supportive care framework to care models is encouraged to ensure these principles underpin the service. We recommend that the integration of a home chemotherapy service be pursued as an area for further clinical development and research.

Author Contributions

Natalie Williams: conceptualisation, methodology, investigation, formal analysis, project administration, and roles/writing–original draft. Marion Kember: conceptualisation, investigation, and roles/writing–review/editing. Hayley Fleay: investigation, formal analysis, and roles/writing–original draft. Chloe Hall-Grande: investigation, formal analysis, and roles/writing–original draft. Danelle Ward: roles/writing–review/editing.

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Disclosure

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Research data are not shared.

References

1. Cancer Australia, "Gestational Trophoblastic Disease (GTD)," (2024), https://www.canceraustralia.gov.au/cancer-types/gestational-trophoblastic-disease-gtd.

2. P. Duggan, Y. Leung, D. Neesham, et al., *Management of Gestational Trophoblastic Disease* (The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2017).

3. H. Y. S. Ngan, M. J. Seckl, R. S. Berkowitz, et al., "Update on the Diagnosis and Management of Gestational Trophoblastic Disease," *International Journal of Gynecology & Obstetrics* 143, no. S2 (2018): 79–85, https://doi.org/10.1002/ijgo.12615.

4. J. T. Rabban, "WHO Classification of Gestational Trophoblastic Disease, Pathology of the Placenta," in *Gynecologic Pathology*, ed. S. Stolnicu and R. Ali-Fehmi (Cham: Springer International Publishing, 2023), 647–648.

5. L. Eiriksson, E. Dean, A. Sebastianelli, et al., "Guideline No. 408: Management of Gestational Trophoblastic Diseases," *Journal of Obstetrics and Gynaecology Canada* 43, no. 1 (2020): 91–105, https://doi.org/10.1016/j.jogc.2020.03.001.

6. M. J. P. Seckl, N. J. F. Sebire, and R. S. M. D. Berkowitz, "Gestational Trophoblastic Disease," *Lancet (London, England)* 376, no. 9742 (2010): 717–729, https://doi.org/10.1016/s0140-6736(10)60280-2.

7. C. Lok, N. van Trommel, L. Massuger, et al., "Practical Clinical Guidelines of the EOTTD for Treatment and Referral of Gestational Trophoblastic Disease," *European Journal of Cancer* 130 (2020): 228–240, https://doi.org/10.1016/j.ejca.2020.02.011.

8. J. Coulter, N. van Trommel, and C. Lok, "Ten Steps to Establish a National Centre for Gestational Trophoblastic Disease," *Current Opinion in Oncology* 33, no. 5 (2021): 435–441, https://doi.org/10.1097/cco.0000000000000756.

9. C. Lok and M. Seckl, "Guidelines and Multidisciplinary Care Are Essential to Improve Survival Rates and Quality of Life Globally for Women with Gestational Trophoblastic Disease," *Gynecologic and Obstetric Investigation* 89, no. 3 (2024): 163–165, https://doi.org/10.1159/000539107.

10. N. van Trommel, C. Lok, L. Massuger, and J. Coulter, "25 Establishing New Gestational Trophoblastic Disease (GTD) Centers-a Practical Guide to Set up a New GTD Center: Balancing Between Optimum and Feasibility," *Gestational Trophoblastic Disease*, ed. B. W. Hancock, M. J. Seckl, and R. S. Berkowitz, 5, ed2022.

11. K. Singh, S. Rollins, and J. Ireson, "Gestational Trophoblastic Disease: Best Practice Nursing Guidelines," *Gynecologic and Obstetric Investigation* 89, no. 3 (2023): 1–7, https://doi.org/10.1159/000530570.

12. C. Mitric, K. Yang, G. Bhat, et al., "Gestational Trophoblastic Neoplasia: Does Centralization of Care Impact Clinical Management?" *International Journal of Gynecological Cancer* 33, no. 11 (2023): 1724–1732, https://doi.org/10.1136/ijgc-2023-004526.

13. C. M. Booth, M. Sengar, A. Goodman, et al., "Common Sense Oncology: Outcomes that Matter," *The Lancet Oncology* 24, no. 8 (2023): 833–835, https://doi.org/10.1016/s1470-2045(23)00319-4.

14. D. C. Ferreira, I. Vieira, M. I. Pedro, P. Caldas, and M. Varela, "Patient Satisfaction with Healthcare Services and the Techniques Used for its Assessment: A Systematic Literature Review and a Bibliometric Analysis," *Health Care* 11, no. 5 (2023): 639, https://doi.org/10.3390/healthcare11050639.

15. Australian Commission on Safety and Quality in Health Care [Acsqhc], "National Safety and Quality Health Service Standards," (2021), https://www.safetyandquality.gov.au/publications-and-resources/resource-library/national-safety-and-quality-health-service-standards-second-edition.

16. Australian Commission on Safety and Quality in Health Care [Acsqhc], "Australian Safety and Quality Framework for Health Care," (2010), https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-safety-and-quality-framework-health-care.

17. A. Backhouse and F. Ogunlayi, "Quality Improvement into Practice," *BMJ* 368 (2020): m865, https://doi.org/10.1136/bmj.m865.

18. V. M. Meyer, S. Benjamens, M. E. Moumni, J. F. M. Lange, and R. A. Pol, "Global Overview of Response Rates in Patient and Health Care Professional Surveys in Surgery: A Systematic Review," *Annals of Surgery* 275, no. 1 (2022): e75–e81, https://doi.org/10.1097/sla.0000000000004078.

19. Australian Commission on Safety and Quality in Health Care [Acsqhc], "Australian Hospital Patient Experience Question Set 2023," https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/patient-experience.

20. C. Lees, "Measuring the Patient Experience," *Nurse Researcher* 19, no. 1 (2011): 25–28, https://doi.org/10.7748/nr2011.10.19.1.25.c8768.

21. P. A. Harris, R. Taylor, B. L. Minor, et al., "The Redcap Consortium: Building an International Community of Software Platform Partners," *Journal of Biomedical Informatics* 95 (2019): 103208, https://doi.org/10.1016/j.jbi.2019.103208.

22. P. A. Harris, R. Taylor, R. Thielke, J. Payne, N. Gonzalez, and J. G. Conde, "Research Electronic Data Capture (REDCap)—A metadata-driven Methodology and Workflow Process for Providing Translational Research Informatics Support," *Journal of Biomedical Informatics* 42, no. 2 (2009): 377–381, https://doi.org/10.1016/j.jbi.2008.08.010.

23. *IBM Corp. IBM SPSS Statistics for Windows. 29.0 Ed* (Armonk, NY: IBM Corp, 2023).

24. H.-F. Hsieh and S. E. Shannon, "Three Approaches to Qualitative Content Analysis," *Qualitative Health Research* 15, no. 9 (2005): 1277–1288, https://doi.org/10.1177/1049732305276687.

25. C. Erlingsson and P. Brysiewicz, "A hands-on Guide to Doing Content Analysis," *African journal of emergency medicine* 7, no. 3 (2017): 93–99, https://doi.org/10.1016/j.afjem.2017.08.001.

26. The National Health and Medical Research Council [NHMRC], The Australian Research Council, Universities Australia, "The Australian Code for the Responsible Conduct of Research" (2018).

27. The National Health and Medical Research Council [NHMRC], The Australian Research Council, Universities Australia, "National Statement on Ethical Conduct in Human Research 2023. Canberra2023".

28. World Medical Association, "WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Participants," (2024), https://www.wma.net/policies-post/wma-declaration-of-helsinki/.

29. L. M. Chambers, J. Chalif, and R. Vargas, "Analysis of Patient Experiences with Gestational Trophoblastic Neoplasia Reported on Instagram Social Media," *Gynecologic Oncology* 165, no. 3 (2022): 603–609, https://doi.org/10.1016/j.ygyno.2022.03.029.

30. P. J. Tenório, L. Katz, and M. M. R. Amorim, "Symptoms of Anxiety and Depression in Women with Gestational Trophoblastic Disease Compared to Women Who Had a Miscarriage: A cross-sectional Study," *Journal of Psychosomatic Obstetrics and Gynecology* 44, no. 1 (2023): 2210747.

31. C. M. Joyce, J. Coulter, C. Kenneally, T. V. McCarthy, and K. O'Donoghue, "Experience of Women on the Irish National Gestational Trophoblastic Disease Registry," *European Journal of Obstetrics & Gynecology and Reproductive Biology* 272 (2022): 206–212, https://doi.org/10.1016/j.ejogrb.2022.03.039.

32. L. Blok, Y. Eysbouts, C. A. R. Lok, S. F. P. J. Coppus, F. C. G. J. Sweep, and P. Ottevanger, "Psychological Impact over Time of Women with Pregnancy Loss due to Gestational Trophoblastic Disease Compared with Miscarriage," *International Journal of Gynecological Cancer* 33, no. 12 (2023): 1882–1889, https://doi.org/10.1136/ijgc-2023-004639.

33. C. N. R. Sibarani, S. Salima, G. N. A. Winarno, N. Adrianto, and G. Mangkuliguna, "Prevalence of Depression and Anxiety in Gestational Trophoblastic Disease: A Systematic Review and meta-analysis," *Australasian Psychiatry*, 0, no. 0, 10398562251355145.

34. A. C. G. França, E. M. H. Uberti, K. P. Muller, et al., "Emotional and Clinical Aspects Observed in Women with Gestational Trophoblastic Disease: A Multidisciplinary Action," *Revista Brasileira de Ginecologia e Obstetrícia* 44, no. 4 (2022): 343–351.

35. L. J. Blok, Y. K Eysbouts, S. Bastiaans, F. Sweep, and P. B. Ottevanger, "Evaluation of the Psychosocial Impact and Received Care in Patients with Gestational Trophoblastic Disease-a Qualitative Interview Based Study," *Journal of Psychosomatic Obstetrics and Gynaecology* 46, no. 1 (2025): 2451992, https://doi.org/10.1080/0167482X.2025.2451992.

36. M. Krishnasamy, A. Hyatt, H. Chung, K. Gough, and M. Fitch, "Refocusing Cancer Supportive Care: A Framework for Integrated Cancer Care," *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer* 31, no. 1 (2022): 14, https://doi.org/10.1007/s00520-022-07501-9.

37. O. Cook, M. McIntyre, K. Recoche, and S. Lee, "Our Nurse is the Glue for Our Team-Multidisciplinary Team Members' eEperiences and pPrceptions of the gGnaecological oOcology sSecialist nNrse rRle," *European Journal of Oncology Nursing* 41 (2019): 7–15, https://doi.org/10.1016/j.ejon.2019.05.004.

38. H. Kerr, M. Donovan, and O. McSorley, "Evaluation of the Role of the Clinical Nurse Specialist in Cancer Care: An Integrative Literature Review," *European Journal of Cancer Care* 30, no. 3 (2021): e13415, https://doi.org/10.1111/ecc.13415.

39. Cancer Institute NSW, "Gestational Trophoblastic Disease Low Risk Methotrexate ID:668 v.4 2022," https://www.eviq.org.au/medical-oncology/gynaecological/gestational-trophoblastic-disease/668-gestational-trophoblastic-disease-low-risk-met.

40. J. M. Sanguinetti, D. Martínez, F. Dimase, et al., "Patient Safety and Satisfaction in Home Chemotherapy," *Home Healthcare Nurse* 39, no. 3 (2021).

41. N. R. Handley and J. E. Bekelman, "The Oncology Hospital at Home," *Journal of Clinical Oncology* 37, no. 6 (2019): 448–452, https://doi.org/10.1200/jco.18.01167.

42. L. Grobler, D. O'Connor, D. Rischin, et al., "Delivery of Intravenous Anti-Cancer Therapy at Home Versus in Hospital or Community Settings for Adults with Cancer," *Cochrane Database of Systematic Reviews* no. 4 (2025).

Supporting Information

Additional supporting information can be found online in the Supporting Information section. *(Supporting Information)*

Supporting Information. Survey Tool: Patient Evaluation of Western Australian Trophoblastic Centre Experience.