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Impact of the clinical nurse specialist role for the myeloproliferative neoplasm program: Part Two – The team and patient care experiences

by Verna Cheung, Melanie Powis, Jaime O. Claudio, Greg Lindberg, Andrea Arruda, Cristina Emanuele, Taylor Nye, Marta B. Davidson, Aniket Bankar, Hassan Sibai, Vikas Gupta, and Dawn Maze

ABSTRACT

Myeloproliferative neoplasms (MPN) are a group of rare clonal disorders of hematopoietic progenitor cells associated with disease-related symptoms, thrombotic events, and risk of transformation to acute myeloid leukemia (Tefferi, 2021). Their relative rarity and complexity of care led to the establishment of the MPN program at the Princess Margaret (PM) Cancer Centre, Toronto, Canada. The MPN program utilizes a shared-care model wherein partnering with local hematologists (shared-care partners) ensures that patients have access to a MPN specialist while continuing to receive care close to home. The clinical nurse specialist (CNS) role was implemented in late 2016 to support not only the shared-care model, but also to triage new patient referrals, and support consultation and follow-up. Although the CNS role has been part of the healthcare system since the 1940s, the role and its impact remain unclear at times to the inter-disciplinary team. This paper describes the process and results in evaluating the CNS role's impact in the MPN program through using a multi-method approach. In this Part II of a series, the focus is on discussing the team and patient care experience with having a CNS as part of the care team.

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INTRODUCTION

The conceptualization of the clinical nurse specialist (CNS) role began in the 1940s and appeared in nursing practice and healthcare sectors in Canada and internationally (United States & United Kingdom) in the 1960s (Canadian Nurses Association [CNA], 2012; Cheung et al., 2022). Over the years the healthcare sector has continued to utilize this role to meet the needs of different programs and patient populations due to the uniqueness and flexibility of the CNS role. However, due to this uniqueness and flexibility, the role is often confused with other advanced practice nursing (APN) roles (Cheung et al., 2022; Mitchell et al., 2017; Pollard et al., 2010). There is also a paucity of papers that holistically evaluate the impact of the CNS role.

In this part two of a series, we will provide a brief overview of the CNS role and the methodology we used [see detail of methodology discussed in Part One (Cheung et al., 2025)], followed by a discussion of the qualitative outcomes of evaluating the impact of the CNS role in the myeloproliferative neoplasm (MPN) program. This discussion includes the internal and external team experience and patient care experience. Lastly, how the CNS role in the MPN program practices according to competencies outlined by the CNA (2019) will be described.

BACKGROUND

The CNS role appeared in practice in the healthcare sector in the 1940s and has been well discussed and compared to other APN roles in the literature (Cancer Care Ontario [CCO], 2018a, 2018b; Cheung et al., 2022; CNA, 2012; Dempsey et al., 2016; Kerr et al., 2021; Kilpatrick et al., 2014a, 2014b; Lincoln, 2000; Mitchell et al., 2017; Morgan & Tarbi, 2016; Pollard et al., 2010). The CNS role has been described in the literature in terms of cost-effectiveness (Kilpatrick, DiCenso et al., 2014; Kilpatrick, Kaasalainen et al., 2014b; Pollard et al., 2010) and effectiveness in addressing care needs or gaps to a patient population (Cheung et al., 2021; Cook et al., 2019; Mitchell et al., 2017; Morgan & Tarbi, 2016; Visser et al., 2015). Timeliness of triage and cost-savings were also reported with the role in Part One of this series (Cheung et al., 2024).

As an initial step in understanding the impact of the CNS role from the standpoint of the team and patient care experience, a review of the literature regarding the CNS role and role impact was conducted through MEDLINE, PubMed, ProQuest, CINAHL, and Google Scholar, using key words: clinical nurse specialist, advance practice nurse, patient outcome, patient care, role impact, and role perception. The

timeframe was limited to between 2000 and 2022. The search was limited to articles written in English that were available in full text. Duplicate abstracts and articles with full-text not accessible were omitted. Abstraction resulted in 96 articles. Each article was reviewed to ensure it included 1) a focus on the CNS or advanced practice nursing role, and 2) patients' or teams' perception of the role. A total of 21 articles met the inclusion criteria.

Perception of the CNS role by the interdisciplinary team

In terms of role perception, some articles explored how the interdisciplinary team viewed the CNS role, and other articles discussed how the advanced practice nurses (CNS or Nurse Practitioner [NP]) viewed their own role, role impact, and workload. Overall, the CNS role was viewed positively by the interdisciplinary team, specifically how the role enhances communication and information shared across the team, and how the CNS role can be involved in all the trajectories of the patient's care (Cheung et al., 2021; Cook et al., 2019; Kerr et al., 2021). Although training physicians felt the CNS role was helpful, they also reported that, at times, the CNS role impeded their learning opportunities. For example, missed education opportunities may have occurred as some patients were seen exclusively by the CNS (Eaton et al., 2019b). Cook et al., (2019), also identified the concern that team members would rely overly on the CNS role.

Perception of the CNS role by patients

Patients' perceptions of their care are essential in understanding the value and deficiencies in the CNS role. Although Hoffman et al.'s (2019) study was based on a NP-led clinic, the patients in general were satisfied with the care they received and felt that, with an NP involved in their care, they had an increased understanding of their health conditions. Similarly, in Borland et al. (2014) and Pollard et al. (2010), both patients and caregivers reported that having a CNS involved in their care improved their understanding of their diagnosis and treatment. Patients have also reported the access or timeliness to care was improved with having a CNS involved in their care (Borland et al., 2014; Kim, 2011). Improvements in continuity of care, satisfaction, and trust have also been reported when a CNS is involved in patients' care (Beaver et al., 2010; Droog et al., 2014; Moore & McQuestion, 2012; Pollard et al., 2010; Visser et al., 2015).

Current definition of a CNS

The CNA defines the CNS as a master's prepared registered nurse with advanced nursing knowledge, skills, and clinical expertise in making complex decisions to support and meet the health needs of the patients and their families (CNA, 2019). The CNA recognizes both the CNS and NP role as APN roles; however, possessing graduate-level education alone does not necessarily denote an APN designation. An APN has a specialty practice and ability to work autonomously, applying advanced expertise in assessment, judgment, and skills using theoretical, ethical, and empirical foundations to improve outcomes and initiatives (CNA, 2019).

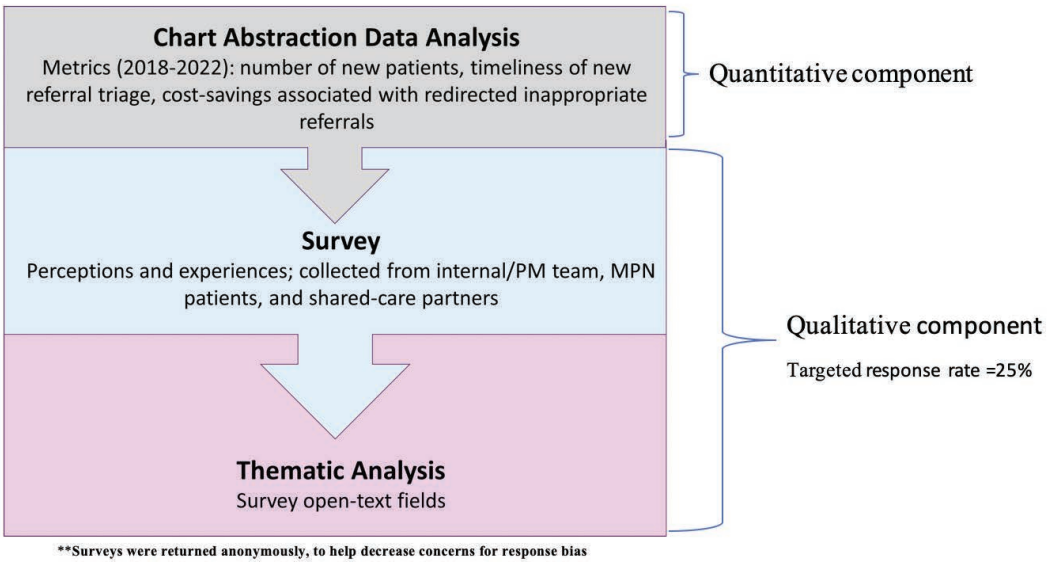
The CNA (2019) also outlines six core competencies of advanced practice nursing, which encompasses the CNS role: 1) direct comprehensive care, 2) consultation and collaboration, 3) research, 4) education, 5) optimizing health systems, and 6) leadership. In this paper we will highlight how the CNS role in the MPN program day-to-day practice encompasses all six competencies.

METHODS

This work was a quality improvement (QI) project to evaluate holistically the impact of the MPN CNS role using a multi-method approach (Figure 1). In a previous article, the quantitative component of this work was described, which demonstrated that the CNS role resulted in timeliness of triaging new referrals and the cost-savings associated with re-directing inappropriate referrals (Cheung et al., 2024). In

Figure 1

Method for evaluating CNS role impact to patient care and MPN program



this article, the focus is on the team members' and patients' experiences with having a CNS as part of the care team. In terms of qualitative methodology, a reflexive/inductive thematic analysis approach was utilized, along with investigator triangulation, of the written comments received from the surveys (Braun & Clarke, 2006). For this project, a QI waiver was granted by the QI committee at Princess Margaret (PM) Cancer Centre to allow for data collection and publishing this work.

The internal and external team

For this article, the internal team refers to the MPN interdisciplinary team at PM. The PM MPN team has a total of 38 team members (five MPN staff physicians, 11 full-time point-of-care nurses in ambulatory clinic, eight clinical trials nurses, four research team members, four administrative support staff, and eight clinical fellows). The target response rate (RR) was 25%, or 10 surveys completed (Fincham, 2008).

The external teams consist of community hematologists (shared-care partners). The PM MPN program collaborates with 59 shared-care partners; therefore, the target RR was 25% (Fincham, 2008), or 15 surveys completed.

Two separate surveys with seven questions each were developed. One was for the internal team and one for the external teams. Each survey included a free-text comment field after each question and a field for any additional feedback or comments at the end of the survey.

Internal and External teams were sent an electronic survey via SurveyMonkey. Completion of the survey was voluntary.

The patients

Patients' perceptions of the CNS role within in the MPN team were captured using a survey consisting of seven multiple-choice questions. Questions referred to the patients' care experience provided by the MPN CNS. A free-text comment section was included for any additional comments.

The MPN program actively sees about 334 patients on an annual basis. The aim for survey return was at least 25% RR (Fincham, 2008), equivalent to 84 completed patient surveys. Accrual occurred over one year. The survey was voluntary, which was made clear in written format on the survey, and its purpose verbally explained to the patients. The survey was introduced to the patients at the end of their visit by either the CNS or an MPN team member. Paper versions were made available for patients to complete and return to a drop off box at the clinic front desk for anonymity. A recruitment log with the patient's last name and medical record number was kept on a separate excel file, to help avoid approaching the same patient more than once regarding survey completion.

Inclusion criteria

- Confirmed MPN diagnosis
- At least three MPN clinic visits in 12 months for new MPN patients, or at least two visits per 12 months for patients being followed in MPN clinic for more than one year

Exclusion criteria

- MPN patients in clinical trials
- Non-English-speaking patients

RESULTS AND DISCUSSION

Shared-care partners' experience with working with a CNS

A total of 15 surveys were returned from our shared-care partners, meeting the 25% RR. Overall responses were positive regarding the experience of shared-care partners with having a CNS as part of the team and involved in patient care. However, some shared-care partners commented that they were unclear about the CNS role and role function. Share-care partners also requested that the CNS provide educational support to the nursing members of their respective teams. In addition, they requested patient education materials to be shared and the CNS role and function be made more visible as a point of contact for their teams (Figure 2A).

PM MPN team's perception and experience with working with a CNS

A total of 19 surveys were returned from the internal team, reaching 50% RR. Overall responses were positive. The respondents confirmed that having a CNS involved on the team helps to promote improved continuity of care, patient safety, and decreasing team workload (Figure 2B**)**. Comparing the findings of the shared-care partners to the internal team, the internal team seemed to have a better understanding of the CNS role. Like the shared-care partner team, the internal team also requested that the CNS provide educational support related to the field of MPN for nursing staff.

Overall, the responses from both the internal team and shared-care partners to working with the MPN CNS, and the CNS role, were positive. Ninety-three percent of shared-care partners were comfortable with the CNS being part of the care team and felt the role fostered communication across the teams. The internal team had a better understanding of the MPN CNS role and felt that the CNS role contributed to patient safety (94.7%), continuity of care (100%) and decreased the team's workload (89.5%; Figure 2A and 2B).

Amongst the internal and shared-care partner teams a total of 21 additional comments were received through the survey (N = 5 from external, N = 16 from internal team). Investigator triangulation was utilized for the data analysis to help reduce bias from one investigator and improve validity (Fusch et al., 2018). The investigators were the first, second and senior authors of this paper.

The comments were positive overall with three common themes related to the CNS role identified: (1) supporting communications and collaboration, (2) being a resource to the team, and (3) request for knowledge sharing. Within the theme of communication and collaboration, both shared-care partners and the internal team respondents perceived the CNS was a point of contact, and a liaison between the shared-care partners and the internal team. There was continuity of care and consistent communication when the CNS was involved, and timeliness to the communication that was appreciated by both the internal team and shared-care partners (Figure 3).

The MPN team also acknowledged the added value of the advanced nursing knowledge and scope of practice of the CNS role; and the CNS's ability to address a number of the complex patient needs (e.g., advocacy, education, etc.) that may not

Figure 2A

Shared-care partners' summary of responses

2A Shared-care partner summary of responses – overall RR of 25% (n = 15/59)		N = 15, (%)
Are you comfortable with the CNS being involved in your patient's care?	Very comfortable	14 (93.3%)
	Somewhat comfortable	1 (6.7%)
	Not comfortable	-
	Other	-
How could the CNS further support shared-care, and MPN patients (can select 1 or more)	Provide education support to our nurses	8 (53.3%)
	Share patient education material to our nurses for health-teaching purpose	8 (53.3%)
	Provide us with updated information regarding clinical trials	10 (66.7%)
	Other	2 (13.3%)
What is your understanding of the CNS role in the MPN team? (Multiple selection question)	I don't know	4 (26.7%)
	They triage new patient referrals	6 (40%)
	See new consults and follow-up MPN patients	8 (53.3%)
	Schedule patent appointments	1 (6.7%)
	They ensure plan of care is communicated between local team and PM MPN team	11 (73.3%)
	Provide patient and family education regarding diagnosis, treatment, and symptom management	11 (73.3%)
	Ensure bloodwork, diagnostic test are entered at PM	7 (46.7%)
	They ease the workload of the physician team	10 (66.7%)
	Other	1 (6.7%)

Note. Detailed data available in supplementary section.

Figure 2B

Internal teams' summary of responses – detailed data available in supplementary section

2B Internal team summary of responses - overall RR 50% (n = 19/38)		N = 19, (%)
What do you think are the current responsibilities of the CNS role? (Multiple selection question)	Triage new patient referral	15 (78.9%)
	See new consults and follow-up MPN patients	19 (100%)
	Schedule patient appointments	11 (57.9%)
	Connect patients with local hematologist	12 (63.2%)
	Communicate with local hematologist	17 (89.5%)
	Provide patient and family education regarding diagnosis, treatment and symptom management	18 (94.7%)
	Create education material	9 (47.3%)
	Educate fellows, residents, nurses, and new hire staff	8 (42.1%)
	Ensure bloodwork, diagnostic tests are all entered	14 (73.7%)
	I don't know what they do	-
	Other	-
The CNS role helps to decrease workload?	Almost always	14 (73.7%)
	Usually	3 (15.8%)
	Sometimes	1 (5.3%)
	Rarely	-
	Almost Never	-
	Other	-
The CNS role contributes to continuity of care for patients?	Almost always	17 (89.5%)
	Usually	2 (10.5%)
	Sometimes	-
	Rarely	-
	Almost Never	-
	Other	-
The CNS role contributes to safe patient care?	Almost always	16 (84.2%)
	Usually	2 (10.5%)
	Sometimes	-
	Rarely	-
	Almost Never	-
	Other	-
The CNS role contributes to fellow/ resident/nurses learning?	Almost always	7 (36.8%)
	Usually	7 (36.8%)
	Sometimes	3 (15.8%)
	Rarely	-
	Almost Never	-
	Other	2 (10.5%)

Note. Detailed data available in supplementary section.

have been addressed without the role. The CNS role was also thought to be valuable and applicable to other disease sites within oncology (Figure 3).

The findings in this QI project are aligned with the literature, in that the CNS role was found to reduce team workload, foster communication, and be a point of contact for the team (Cook et al., 2019; Eaton, O'Meara et al., 2019; Stahlke Wall & Rawson, 2016). These attributes contribute to a positive team environment. Of note, most studies only explored internal team feedback; however the uniqueness of this QI project was that it included feedback from both internal and external teams. This inclusion underscored its impact of the CNS role and provided added insight into the value of how the CNS role can extend beyond the walls of an organization and foster collaborations across organizations.

Patients' perception and care experience with having a CNS involved in their care

Amongst the 334 MPN patients who are actively followed in the program, a total of 139 patient surveys were completed (RR of 41.6% for the program). Of note, 144 surveys were distributed directly to patients in the clinic, therefore this return rate is 96.5%, (N = 139/144). Overall patients' feedback was positive. Ninety-eight percent of patients were aware a CNS was involved in their care (N = 137/139). Patients expressed trusting the advice and care the CNS provided (N = 136/139, 97.8% strongly agree/agree), and 97.1% of patients were also satisfied with the care the CNS provided (N = 135/139, strongly agree/agree; Figure 4).

All patients' comments were carefully reviewed to identify common themes, with the thematic analysis conducted through investigator triangulation.

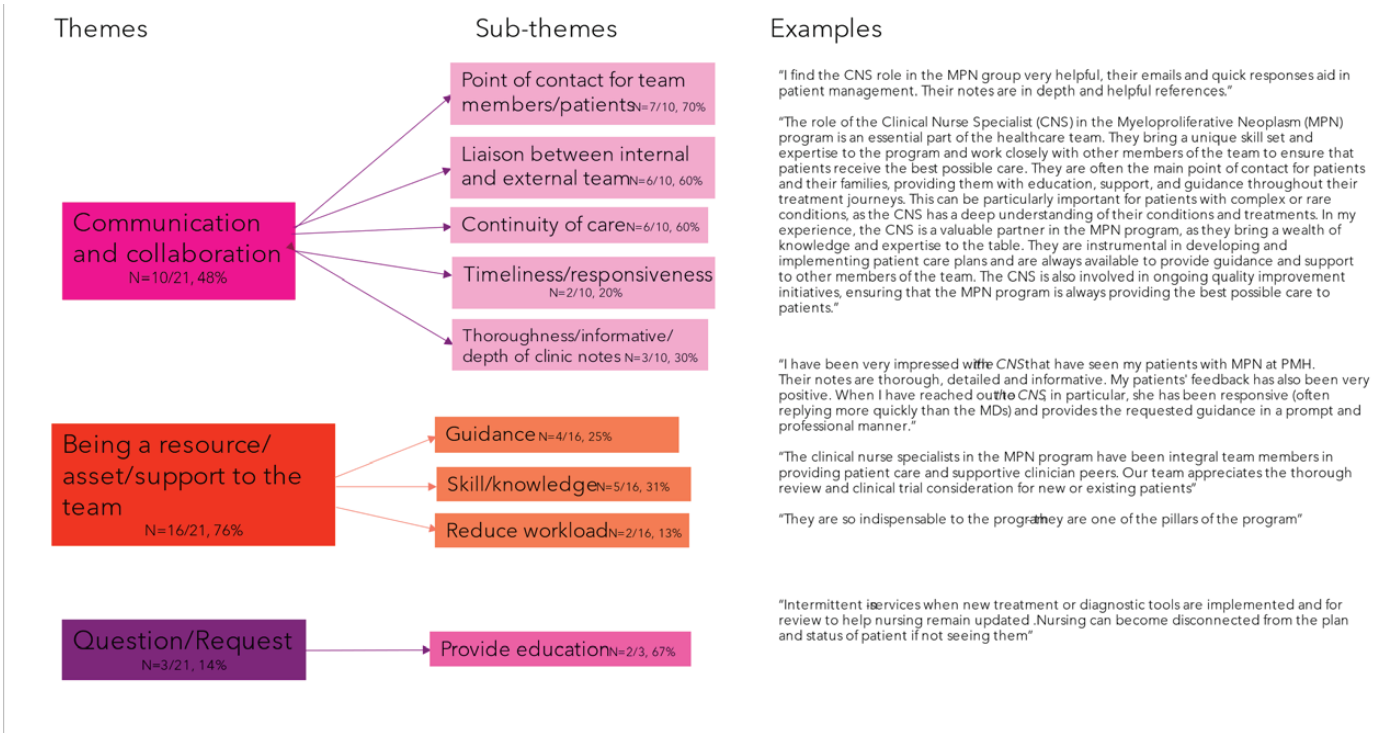
Amongst the 139 complete surveys, 62 surveys provided additional comments. Fifty-six percent (N = 35/62) of the comments expressed a positive patient experience having a CNS involved in their care. This perspective is illustrated in the following patient quote:

> *"I am very happy that I have the CNS as part of my care team. She's been great and I feel that I am in good hands." (Patient#88)*

The thematic analysis revealed three major themes: (1) continuity of care/care coordination, (2) access to information, and (3) counselling and support. Subthemes that stemmed from the three major themes include: patients reported appreciating having a point of contact (N = 28/62) and a sense of improved communication between the PM MPN team and their local hematologist (N = 10/62), which, in turn, allowed them to have confidence in the care they had received (N = 14/62). This perspective is illustrated in the following patient quote:

Figure 3

Thematic Analysis of Internal Team and Shared-Care Partner Team Feedback



"She is providing great counselling regarding any concerns I have; she has been working to connect me to a local hematologist for frequent and additional appointments." (Patient#36)

Within the major themes of access to information (N = 28/62) and counselling support (N = 21/62), patients reported feeling that they had the opportunity to seek clarification, further explanation, and have their concerns addressed through having a CNS involved in their care. Many of the comments within the patients' feedback expressed this appreciation for knowledge sharing and health teaching (N = 19/62) the CNS provided.

"My CNS (name removed) is always extremely patient, empathetic, knowledgeable and very helpful, because I have had the opportunity and privilege of receiving care from her for several years now, I completely trust her and feel I can ask her anything. She is very reassuring and always responds to my questions and concerns in a timely fashion and with very helpful assistance/advice. She is exceptional, and I am deeply grateful to have her on my medical team." (Patient#79)

Through such interactions as illustrated, the CNS has, in turn, instilled a sense of safety (N = 17/62), re-assurance (N = 14/62), and trust for the patients (N = 12/62). This perspective is illustrated in the following patient quotes below:

Figure 4

Summary of Patients' Survey Responses (Response Rate: 139/334; 41.6%) –

N=139/334, 41.6%		
Are you aware a Clinical Nurse Specialist is involved in your care?	Yes	137 (98.6%)
	No	2 (1.4%)
How is the Clinical Nurse Specialist involved in your care? Please select all that apply.	I see them in clinic or speak with them over the phone for follow-up appointments.	136 (97.8%)
	They help ensure my local hematologist/physician is aware of any changes made to my plan of care.	113 (81.3%)
	They help facilitate referrals for additional support on my behalf.	88 (63.3%)
	I contact them for questions related to my symptoms.	73 (52.5%)
	I contact them for questions related to my medications.	59 (42.4%)
	I contact them if I have a concern related to my appointment	53 (38.1%)
	I contact them for health advice related to my MPN	54 (38.8%)
	Other – please specify in comments section below	7 (5%)
I am comfortable with telephone visits involving the Clinical Nurse Specialist	Strongly Agree/Agree	107 (77%)
	Neutral	8 (5.8%)
	Strongly Disagree/Disagree	2 (1.4%)
	Not Applicable	22 (15.8%)
I trust the Clinical Nurse Specialist's advice and care.	Strongly Agree/Agree	136 (97.8%)
	Neutral	2 (1.4%)
	Strongly Disagree/Disagree	1 (0.7%)
	Not Applicable	-
I am satisfied with the care provided by the Clinical Nurse Specialist.	Strongly Agree/Agree	135 (97.1%)
	Neutral	3 (2.2%)
	Strongly Disagree/Disagree	1 (0.7%)
	Not Applicable	-
I would like to continue to be seen by a Clinical Nurse Specialist.	Strongly Agree/Agree	132 (95%)
	Neutral	7 (5%)
	Strongly Disagree/Disagree	-
	Not Applicable	-

Note. Detailed data available in supplementary section

"I appreciate the CNS as she takes time to explain and discuss various aspects of my condition and options/symptoms; she was instrumental in getting the heart clinic involved in my care and bringing to their attention concerns in my care was critical, great asset to the team." (Patient#74)

"I have so much trust and confidence in my CNS (name removed). She follows up with me regarding referrals if they did not give me an appointment. She is always available to respond to my phone calls or give me advice, respecting me and listening to me. I can always talk to her related to my symptoms, medications, or if I disagree, she takes the time to explain to me why it is important I follow the treatment plan." (Patient#25)

The findings from this QI project align with the findings in the published literature on advanced practice nursing roles and their contribution to positive patient experience. This contribution includes outcomes of increased patient understanding of their diagnosis and health (Borland et al., 2014; Hoffman et al., 2019), enhanced timeliness of access in care (Beaver et al., 2010; Kim, 2011), and fostering trust and satisfaction in care the patients received (Droog et al., 2014; Pollard et al., 2010; Visser et al., 2015). Analysis of patients' feedback, collected in this QI project, captured a reduced level of anxiety, an expression of personalized care and an overall sense of positive care experiences that patients receive as a result of having a CNS involved in their care.

Figure 5 provides a diagrammatic illustration of the thematic analysis from the patient's feedback. It is also a reflection that the MPN CNS meets all six CNS core competencies as outlined by the CNA (2019). For instance, through timeliness in triaging, redirecting inappropriate referral, and prioritizing referral based on urgency, this ensures, not only patient safety, but is optimizing the health system. Being a liaison for external interdisciplinary team members is one example of contributing to care coordination and collaboration.

LIMITATIONS

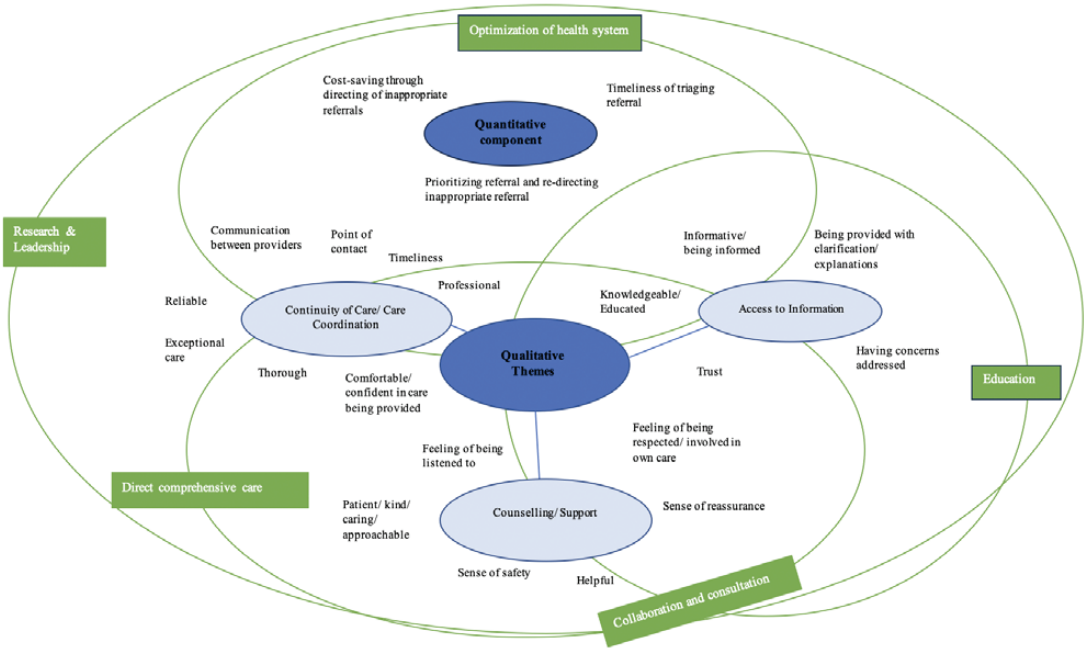
The authors acknowledge the small sample size of this study, and the one facility focus. Despite our team's best efforts to communicate both in written and verbal format to the potential participants that completion of surveys is voluntary, and ensuring all surveys were returned anonymously, there is still the risk of response bias and avoidance of negative feedback. There is also concern for a non-response bias especially from our shared-care partner team, due to lower RR. This raises the question whether there may be a difference of opinion among individuals that responded, compared to those who did not.

FUTURE STEPS

At present, there is communication between the PM team and the referring teams regarding changes in patients' condition to expedite initial appointments. However, being able to reduce waiting time even for non-urgent patients would improve patient access to care and treatment planning. In turn, this could decrease patient anxiety surrounding diagnosis. A topic worth exploring is leveraging digital platforms to build capacity with our shared-care partners.

Figure 5

Diagrammatic Illustration of Qualitative Theme Analysis and Quantitative Component of QI Project in Relation to the Six Core Competencies for Clinical Nurse Specialist Roles



CONCLUSION

This QI project underscores the value of the CNS role in the MPN program. From a program operations perspective, the CNS involvement in the triage process ensures timeliness of specialized care for new patients (Cheung et al., 2025). The redirecting of inappropriate referrals, in turn, is also cost effective in reducing unnecessary tests and inappropriate use of health care resources.

From the qualitative outcomes, based on feedback from both internal and external teams, as well as patients, how the CNS role ensures continuity of care was highlighted. The role is seen as a point of contact for all stakeholders in the shared-care model, translating to a positive team and patient experience. Ultimately, having a CNS as part of the care team contributes to patient safety.

In the current climate where healthcare resources are strained, patients and caregivers are expressing increased frustration in access to care (Patient Ombudsman, 2023) and occupational burnout is being expressed across the healthcare workforce (Duong & Vogel, 2023). In this context the findings from this QI project are valuable. The findings highlight how the CNS role can help to support the healthcare team, improve patient care access, provide personalized care, and have a positive impact on both the healthcare team and patients. This QI project and data collection was completed over the course of one year, which highlights the feasibility of applying such an evaluation process in other settings to evaluate the impact of the CNS role.

CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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The authors confirm that this project was unfunded.

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This project was also presented as a poster abstract at the 35th Canadian Association of Nurses in Oncology (CANO) conference in Niagara Falls, Ontario, Canada, October 20–23, 2023, and the 15th International Congress Myeloproliferative Neoplasm 2023, in Brooklyn, New York, United States, November 2–3, 2023.

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