Perceptions and experiences of care providers as clients of NaviCare/SoinsNavi: a patient navigation centre for children and youth with complex care needs

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ABSTRACT

Objective NaviCare/SoinsNavi is a bilingual patient navigation centre for children and youth 25 years of age or younger with complex care needs in New Brunswick. This research-based centre employs two bilingual patient navigators, one a registered nurse and the other a lay navigator, who assist children/youth, family members and the care team by facilitating more convenient and integrated care using a personalised family-centred approach. The purpose of this study was to explore the perceptions and experiences of care providers who use NaviCare/SoinsNavi. This study builds on ongoing research exploring the experiences of children/youth and their families who are clients of NaviCare/SoinsNavi.

Methods Interviews were conducted with 10 care providers (n=10) from various sectors including social support services (n=6), primary care (n=2), mental health services (n=1) and acute care (n=1).

Results Qualitative interviews were conducted and five themes related to the participants’ perceptions and experiences with NaviCare/SoinsNavi emerged, including : (1) trusted source, (2) connector, (3) capacity builder, (4) partner and (5) time saver. The overall impression of NaviCare/SoinsNavi was positive in the service’s ability to help support care providers and streamline the care they provide to their clients.

Conclusions It is within every healthcare provider’s scope of practice to provide navigational support to essential programmes and services; however, due to limitations in time, resources and capacity, services such as NaviCare/SoinsNavi can be used to help close gaps in care that exists for children/youth with complex care needs and their families.

INTRODUCTION

Children and youth with complex care needs require different healthcare services than the average population.1 It has been observed that both the amount and variation of healthcare services has increased in this particular population creating a need for a high degree of coordinated care.2 Evidence has shown that these individuals and their families have better outcomes if they have access to integrated care.2 Patient navigation is an approach to improve integration of care. Patient navigation helps clients find their way through fragmented services and programmes across sectors.1
NaviCare/SoinsNavi is an example of a patient navigation centre for children and youth with complex care needs. Paediatric complex care needs can be defined as ‘multidimensional health and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis’ (Brenner et al, p1647).3 NaviCare/SoinsNavi is a research-based patient navigation centre in Canada that supports clients by finding and improving access to services, resources, and funding improving care coordination; and facilitating transitions in care, such as the transition from paediatric to adult care for children and youth up to the age of 25.11 NaviCare/SoinsNavi uses a family-centred model to help establish goals of care with clients to meet service needs.11 The centre employs two bilingual patient navigators, one a registered nurse and the other a lay navigator who connect with clients through self-referral via phone, email or Facebook Messenger.11

Patient navigation programmes can contribute to decreasing fragmentation, improving access and promoting integrated care across disciplines for individuals across the lifespan.1–3,5 NaviCare/SoinsNavi provides additional value in comparison to most other patient navigation programmes by providing service to not only patients and their families, but also the care team.1 Patient navigators are able to work with members of the care team to help find resolution to unmet needs and problem solve to overcome identified barriers.1 NaviCare/SoinsNavi has been in operation for two and half years and has served more than 160 families and care providers.1 The purpose of this study was to explore the perceptions and experiences of care providers who use NaviCare/SoinsNavi.

METHODS
A qualitative descriptive design was used to explore care providers’ perceptions and experiences working with NaviCare/SoinsNavi.

Sample
All care providers who were clients of NaviCare/SoinsNavi from October 2018 to August 2019 with closed cases were contacted and invited to participate in this study via email. Although many care providers shared they had used NaviCare/SoinsNavi at other occasions outside of the sampling time period this measurement was not included in our study. Of the 22 care providers who were initially contacted, ten care providers agreed to participate in the study and provided informed consent. No honorarium was given to participate. In the context of our study, the term ‘client’ was used interchangeably to include care providers who were served by NaviCare/SoinsNavi and patients and their families being served by care providers, as both were receiving services.

Data collection
Semistructured interviews lasting 30–45 min were conducted by the lead investigator, who was not part of the NaviCare/SoinsNavi team. Interviews took place either in person, over the phone or through video conferencing. The interview guide (see online supplemental appendix A), addressed questions regarding the following outcomes: satisfaction, knowledge and experience with coordination, integration and continuity of care.

Data analysis
The data from the semistructured interviews were recorded, transcribed and analysed using the six steps of inductive thematic analysis devised by Braun and Clarke.6 Trustworthiness was achieved through independent consensus coding with four authors, all with diverse backgrounds (medicine, occupational therapy, nursing and sociology). Interview transcripts were revisited to ensure no new themes emerged from the data and relationships between codes were determined with the use of concept mapping and further discussion with the research team.

RESULTS
Study participants shared their perceptions and experiences with NaviCare/SoinsNavi, including the patient navigator, and the impact that the centre had on their role as a care provider. Participants included 10 care providers (n=10) from various sectors, including social support services (n=6), primary care (n=2), mental health services (n=1) and acute care (n=1). All care providers had their requests addressed by the patient navigator. To protect anonymity, the specific roles within each sector could not be identified; however, NaviCare/SoinsNavi provides services to any care provider who supports children and families with complex care needs (eg, social worker, doctor, case manager, psychologist, pharmacist). Table 1 summarises the demographics and reasons care providers sought support from NaviCare/SoinsNavi.

Despite the representation of care providers across diverse settings who presented with a variety of different needs, five themes emerged from the interviews to illustrate care providers’ experiences with NaviCare/SoinsNavi. Figure 1 highlights each of the five themes. Table 2 provides illustrative quotes for each theme.

Trusted source
Care providers had a strong positive impression both from working with the patient navigator and from NaviCare/SoinsNavi’s reputation in the community as being a trusted source of information. Due to this level of trust, care providers felt that they could allow the patient navigator to take a role in supporting their clients (table 2, theme 1A).

The patient navigator’s knowledge base and ability to act as an advocate further reinforced the image of NaviCare/SoinsNavi as a trusted source of information (table 2, theme 1B). This sense of trust contributed to feelings of reassurance from the care providers that they could rely on NaviCare/SoinsNavi in areas that they may have struggled with (table 2, theme 1C).
The feelings of trust that were shared by the care providers were further reinforced by their likelihood of using the centre again in the future. Most care providers noted that they would choose to use NaviCare/SoinsNavi in the future.

**Connector**
NaviCare/SoinsNavi was seen as a resource to help care providers connect to services and consequently network with other care providers. As a result, this helped care providers piece together the different levels of care needed to support children/youth with complex care needs and their families (table 2, theme 2A).

Participants reported that NaviCare/SoinsNavi served as a bridge between care providers and resources they were in need of. The patient navigator connected care providers from different sectors to better support their care of children/youth with complex care needs (table 2, theme 2B).

This concept of NaviCare/SoinsNavi serving as a ‘gate-opener’ for care providers alludes to the idea that it has helped care providers overcome the obstacles that they often face in dealing with children/youth with complex care needs. Connecting to services and consequently networking with other healthcare providers for some care providers has been difficult in the past. NaviCare/SoinsNavi was able to initiate connections to resources that may have been otherwise challenging.

**Capacity builder**
Among many care providers, NaviCare/SoinsNavi was identified as being instrumental in helping to gain insight and knowledge in areas they did not have expertise in (eg, medically specific knowledge). As a result, these care providers noted they gained a new level of expertise, which helped to increase their own personal capacity to support clients in the future (table 2, theme 3A).

The knowledge provided by NaviCare/SoinsNavi helped care providers feel more comfortable in areas where they may not have the direct knowledge or expertise. In this regard, the centre helped to facilitate

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**Table 1** Care provider demographics and support received from NaviCare/SoinsNavi

<table>
<thead>
<tr>
<th>Care provider setting</th>
<th>Support provided by NaviCare/SoinsNavi/the patient navigator</th>
<th>Context of support provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute care</td>
<td>Testing and screening</td>
<td>Investigated options for psychological assessment</td>
</tr>
<tr>
<td>Social support services</td>
<td>Community services and programmes</td>
<td>Inquired about recreational options for their client with complex care needs (eg, summer camps)</td>
</tr>
<tr>
<td>Social support services</td>
<td>Testing and screening</td>
<td>Inquired about the availability of testing for a rare genetic disorder</td>
</tr>
<tr>
<td>Social support services</td>
<td>Education and networking</td>
<td>Provided opportunity to connect with local paediatricians to help them address the complex care needs of children/youth who are adopted</td>
</tr>
<tr>
<td>Social support services</td>
<td>Medical services and programmes</td>
<td>Helped explore the medical side of the needs and services required for a client with complex care needs</td>
</tr>
<tr>
<td>Mental health services</td>
<td>Medical services and programmes</td>
<td>Inquired about receiving more information on their client’s Fetal Alcohol Spectrum Disorder diagnosis</td>
</tr>
<tr>
<td>Social support services</td>
<td>Community services and programmes</td>
<td>Desired information regarding daycare funding for a child with complex care needs</td>
</tr>
<tr>
<td>Primary care</td>
<td>Medical services and programmes</td>
<td>Inquired to get access to a medication that was not available in Canada through Health Canada for a client in their care</td>
</tr>
<tr>
<td>Primary care</td>
<td>Community services and programmes</td>
<td>Collaborated with patient navigator to help update existing resources, information, and questionnaires for the families that they work with</td>
</tr>
<tr>
<td>Social support services</td>
<td>Community services and programmes</td>
<td>Worked with patient navigator to get information about services regarding daycare</td>
</tr>
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**Figure 1** Themes of the perceptions and experience of care providers as clients of NaviCare/SoinsNavi.
knowledge transfer of services to help care providers serve clients in the future.

**Partner**

Care providers noted that it was nice to feel like they had additional support from NaviCare/SoinsNavi to help their clients. This was valued more so when care providers experienced difficulty finding answers for their clients. Care providers found it comforting to know that the patient navigator was available to help them and that they did not have to troubleshoot on their own (table 2, theme 4A).

Care providers also shared that they valued not feeling alone. They saw NaviCare/SoinsNavi as a partner who supported them within their scope of practice. This partnership not only provided a sense of support, but it made care providers feel that they too could support the patient navigator in helping them understand the needs of their client (table 2, theme 4B). The care providers valued the support from the patient navigator and the sense of partnership when helping clients.

**Time saver**

A recurring theme that was seen included the importance of timeliness in responding to the care provider requests by the patient navigator within a few business days. The timeliness of the patient navigator’s response made the care provider feel supported and many valued the follow-up communication after the initial request had been made (table 2, theme 5A).

The timeliness of the patient navigator’s response, in conjunction with frequent check-ins and communication, created a high level of efficiency for care providers. Care providers noted that when they are faced with a client with needs beyond their capacity, it is comforting to have NaviCare/SoinsNavi as a resource to help them navigate through the healthcare system. Care providers noted that they felt reassured knowing that the patient navigator could do all the ‘groundwork’ in fulfilling their request, which helped them save time and streamline the care that they in turn, provide to their client.

**DISCUSSION**

The themes reflect how NaviCare/SoinsNavi has positively impacted care provider experiences to deliver integrated care. This is congruent with other studies where patient navigation has been shown to connect patients and caregivers to resources; streamline care; facilitate transitions in care; and provide education, advocacy and support. The perceptions and experiences shared in this study demonstrate how this approach can assist care providers when caring for children/youth with complex care needs.

This study expands on the current body of literature which focuses primarily on the impact of patient

<table>
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<tr>
<th>Theme</th>
<th>Care provider response</th>
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<tr>
<td>1. Trusted source</td>
<td>A. “They were able to let me stand back a bit because the NaviCare worker was such a strong knowledge base and advocate in her own right. That I could kind of step back a bit and go okay you guys got this. You call me when you need me. You guys are doing your thing. So that was helpful.”</td>
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<td></td>
<td>B. “...a trusted source of information that will have the answers”.</td>
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<tr>
<td></td>
<td>C. “It allowed me to step away from the area that I really wasn’t comfortable with, where I didn’t feel that I had expertise in. So it does really help me in my work.”</td>
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<td>2. Connector</td>
<td>A. “I just think it is a fantastic resource that has been needed for many years and I’m glad to see it here. It’s wonderful for families. It’s wonderful for care providers. It’s wonderful for those who work with each other connecting a whole bunch of mystery boxes. For us the fact that we were able to talk to the doctors it seemed like the great unknown. The fact that they could do this for us was amazing. And they wanted to hear from us and we wouldn’t have even known that.”</td>
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<tr>
<td></td>
<td>B. “Because giving me the resources, giving me the information about the resources has helped me to help my families...I don’t see NaviCare as a barrier, I see NaviCare as the gate-opening.”</td>
</tr>
<tr>
<td>3. Capacity builder</td>
<td>A. “I know a little bit more about the medical system and so I don’t have to run to NaviCare for every little thing, but I also feel if like something comes out we can reach out and get a response right away. So I feel way more comfortable when addressing any medical side of things because either I know the next step or I know who to reach out to.”</td>
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<td>4. Partner</td>
<td>A. “I do service and system navigation in general for patients, but sometimes if someone comes to me with something that I have never tackled before... it’s just really nice to have that resource.”</td>
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<td></td>
<td>B. “So to have someone reach out to me as much as I am reaching out to them felt wonderful because I didn’t feel like I was alone...(…)it seems like a partnership. It’s not one sided. Just overall to continue to co-support people I think that’s very important to have that relationship.”</td>
</tr>
<tr>
<td>5. Time saver</td>
<td>A. “To have that follow-up has been extremely helpful...(…)it doesn’t always happen. So to have someone reach out to me as much as I am reaching out to them felt wonderful.”</td>
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navigation on patients and families and demonstrates that there is overlap in the experiences with patient navigation for caregivers of children/youth with complex care needs. NaviCare/SoinsNavi helped provide care providers with comprehensive and integrated care in circumstances where care was perceived as difficult. The support and assurance represented in the theme partner was comparable to sentiments shared by caregivers in a previous NaviCare/SoinsNavi study. This could suggest that when dealing with this vulnerable patient population, the presence of a patient navigator helps to ease the transitions of care and provides valued reassurance for care providers and caregivers alike.

NaviCare/SoinsNavi is seen by care providers as a trusted source of information due to the qualifications and rapport of the patient navigators and the centre’s reputation in the community. Programmes which deal with health and medical issues use patient navigators with professional healthcare qualifications, such as registered nurses, community health workers, and social workers. Lay patient navigators are often seen in programmes that deal with mental health and addiction issues in youth. NaviCare/SoinsNavi is unique in the fact that it employs both a registered nurse and a lay patient navigator to better fit client needs. It has been shown that having diversity in qualification, culture, and ethnicity among patient navigators facilitates a more trusting relationship between navigator and client. When patient navigators were seen as trustworthy, clients were more likely to use the recommended services. When clients saw care providers as a partner, it also helped to build trust and confidence between both parties. Not only is there value in having qualified patient navigators to deal with a variety of inquiries, but the quality of those interactions is greatly influenced by the interpersonal relationship developed between the patient navigator and the care provider.

Most care providers reported feeling more knowledgeable and confident about the healthcare system and the availability of community-based programmes and services. Previous literature has shown that care providers who care for children with complex care needs have demonstrated a limited capacity in terms of skills, time and knowledge of available resources. NaviCare/SoinsNavi increased care providers’ professional capacities through knowledge translation that helped streamline and reduce the time spent per family by care providers. Other patient navigation programmes have also shown how the efficacy of navigators can improve the timeliness of care. Part of this can be explained by the patient navigator’s ability to connect care providers to resources to expand their professional networks and working knowledge. Although timeliness of care was not quantified in this study, this is an area to be explored.

Although many care providers are responsible for helping their clients navigate various systems, this can still be a challenge with the multiple resources that are required for children/youth with complex care to ensure comprehensive care. Integrating care as a whole is challenging as there are evident financial, organisational, and service delivery barriers. The complexity of integrating multiple care domains has made it difficult to coordinate care for care providers and families alike. Parents of children/youth with complex care needs have noted the value in having a point person to coordinate service between different sectors of care, navigate the healthcare system, and advocate on behalf of their child. Patient navigation centres can serve as that unified source of support to decrease fragmentation of care.

It has been seen that the field of primary care lacks interprofessional patient information sharing, which is needed to meet the biopsychosocial needs of patients who are complex. As a result, there is a great need for collaboration and coordination of services both within and outside of primary care to deliver patient-centred care. This includes social and community services which reside outside of the healthcare system. Care providers saw NaviCare/SoinsNavi as a ‘gate opener’ to accessing resources both within and outside of the healthcare sector. Navigation programmes aim to address barriers to interprofessional collaboration by acting as the bridge between multiple sectors and thereby reduce the burden of this responsibility on care providers and the family. By doing so, NaviCare/SoinsNavi is able to provide a family-centred care approach by recognising the different dimensions of care needed for children/youth with complex care needs. Family-centred care models have been shown to increase parent satisfaction, decrease parental stress and improve child outcomes. As patient navigation evolves, it can continue to serve the needs of care providers in not only streamlining, but providing robust integrated care.

LIMITATIONS

While the findings of this study provide valuable insights into the experiences and perceptions of a diverse group of care providers as clients of patient navigation, they cannot be generalised to all patient navigation programmes due to the qualitative nature of this study. This study also had a limited sampling time frame, where only 10 of the 22 care providers who were contacted, were able to participate. Responses were largely dependent on participant recall and recollection, potentially affecting the accuracy of details shared. It is also unknown if the care providers that participated did so solely because their experiences were positive.

While the majority of experiences were positive, one care provider felt that the patient navigator did not understand the needs of the client they were working with. This misunderstanding led to the care provider feeling that the patient navigator had stepped over the boundaries of their role. In the context of this experience, the care provider felt that the patient navigator had done tasks meant exclusively for the care provider (e.g., communication around goals of care). It has been shown that the role
of the patient navigator is defined by the clinical context and the organisational setting.  

Further education on roles and duties for patient navigators on both of these domains can help to better serve care providers. In addition, respecting personal and professional boundaries can prevent future misunderstandings. Although the experience of this care provider was singular, this is an important lesson to be conscious of as patient navigation starts to be used more.

CONCLUSIONS

NaviCare/SoinsNavi provides an approach to help support children/youth with complex care needs, their families and care providers alike, through a patient-centred approach. NaviCare/SoinsNavi is able to support care providers by acting as a partner and trusted source of information to respond to their inquiries and needs. It helps care providers gain access to resources and knowledge to help develop their own personal and professional capacities as care providers. In addition, patient navigators help care providers save time and overcome barriers they experience in trying to help children/youth with complex care needs. Patient navigation programmes can contribute to decreasing fragmentation, improving access, and promoting integrated care across different sectors for individuals across the lifespan. NaviCare/SoinsNavi is unique from other patient navigation programmes in that the centre serves not only patients and their families, but also the care team. Further research will be warranted as to how patient navigation has created a long-term impact on the role of care providers who serve children/youth with complex care needs.

Acknowledgements

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Contributors

NT wrote the first draft of this paper, conducted all key informant interviews and completed data analysis and coding of data. KEL was actively involved in the editorial process and aided in internal validity of the data analysis and coding of data. AL was involved in editing and reviewing final manuscript, and acquisition of funding and ethics review. SD was involved in editing and reviewing final manuscript, consolidating central themes of the paper and acquisition of funding and ethics review. SD is the senior research supervisor and guarantor of this work. All members of the authorship team played a role in the study design and methodology. All authors have read and agreed to the published version of the manuscript.

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Competing interests

None declared.

Patient and public involvement statement

The overall purpose of this study is to evaluate the New Brunswick Navigation Centre for Children with Complex Health Conditions. A qualitative descriptive design was used to explore care providers’ perceptions and experiences working with NaviCare/SoinsNavi. Ethics approval was obtained from the University of New Brunswick, file # 026-2016. Care providers were contacted in the beginning of the research process during a selected sampling time frame to ask if they would be willing to participate in the study. Informal consent was obtained and consent was given via signature of the study’s consent form. The current project is part of a larger four-year study focused on children with complex health conditions and their families. The research question and outcomes were designed to assess the components of the NaviCare/SoinsNavi programme evaluation. Care providers were asked to describe their experiences in using NaviCare/SoinsNavi. All care providers who were clients of NaviCare/SoinsNavi from October 2018 to August 2019 with closed cases were contacted and invited to participate in this study via email. Of the 22 care providers who were initially contacted, ten care providers agreed to participate in the study. Amount of time to conduct key informant interviews was described to all potential participants before confirming consent. Participants were aware of the time required for their participation. They were not asked to assess this burden formally. All results received from this study upon confirmation of publication will be linked to NaviCare/SoinsNavi’s website. Care providers were made aware that when the results were published they could access the information that was received from our website. No patients were involved.

Patient consent for publication

Not applicable.

Ethics approval

This study involves human participants. Ethics approval was obtained from the University of New Brunswick, file # 026-2016. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review

Not commissioned; externally peer reviewed.

Data availability statement

All data relevant to the study are included in the article or uploaded as online supplemental information.

Supplemental material

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Author note

Since completion of this study, NaviCare/SoinsNavi served New Brunswick for one and half more years before the research funding ended and thus the closure of the centre.

REFERENCES


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