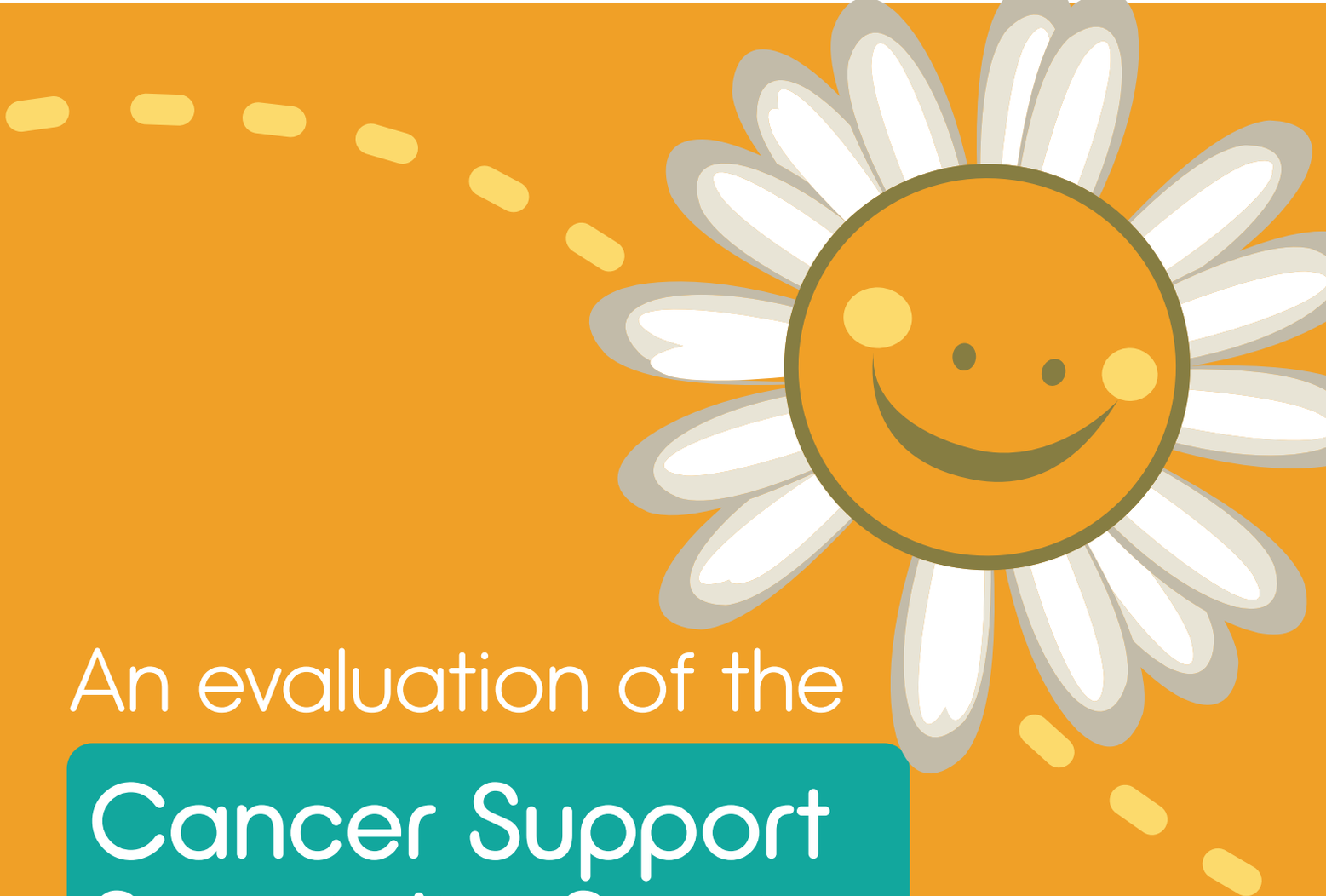

An evaluation of the Cancer Support Specialist Service in Children's Health Ireland

commissioned by Katie Nugent Fund at Children's Health Foundation

cancer fund for children

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

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Executive Summary

Introduction

There has been increasing recognition of the psychological impact of a cancer diagnosis not just on the child, but on the entire family and the wider community. The onset of childhood cancer is sudden and unexpected, and the effect on the family unit can be enormous as they embark on a major life transition. Families of children with cancer have a high level of psychosocial needs due to the many challenges they may face during their child's cancer journey. However, previous research, including phase one of the Katie Nugent research project, indicates that the current healthcare system does not always meet these needs.

In response to this, Cancer Support Specialist Service is being introduced as a partnership between the Katie Nugent Fund at Children's Health Foundation, Children's Health Ireland at Crumlin and the Cancer Fund for Children to provide informal psychosocial support to families of children with cancer. During the period of introduction of the service, five cancer support specialist roles were appointed throughout the Republic of Ireland, providing support to families in St. John's Ward in Children's Health Ireland at Crumlin and in the community in Leinster, Munster, the midlands, and Connaught.

The aim of the study was to explore the implementation and impact of the Cancer Support Specialist Service from the perspective of the key stakeholders involved.

Objectives

The objectives were to:

1. Describe the impact of the Cancer Support Specialist Service on the families that were supported by the service.
2. Ascertain if, and how, the Cancer Support Specialist Service impacted the multidisciplinary team in the oncology service.
3. Describe the Cancer Support Specialist Service model as it evolves over the implementation period, including barriers and enablers to implementation and sustainability.
4. Provide recommendations on the future development of this service.

Research design

Data were collected using semi-structured one-to-one interviews with members of the multidisciplinary team, cancer support specialists and family members, and a member of the steering group. In total, 31 participants (23 MDT members, including four CSSs, a member of the steering group, and eight family members) contributed to 34 interviews (two of the CSSs and a member of the steering group interviewed on two occasions). Data were analysed using both thematic analysis and a framework analysis approach.

Key findings

Impact of the Cancer Support Specialist Service on families:

- Parents felt valued by the focus of the Cancer Support Specialists on their support needs beyond the medical needs of their child, and found the provision of relational support, the presence and time given to them by the role holders, to be a comfort and form of companionship, reporting that it eased in some way the childhood cancer journey.
- Cancer Support Specialists indirectly supported parents by providing respite through their support and engagement of children with cancer and their siblings, giving parents time to focus on self-care activities. Parents mentioned the relief they felt to have someone engage their children when they were otherwise exhausted.
- Parents reported the positive impact that support from the Cancer Support Specialists, in the form of trips outside the home, games and play, had on their children's enjoyment and mood.
- Parents reported that the volume of information to take in from the initial diagnosis and throughout the childhood cancer experience was at times overwhelming. The Cancer Support Specialists assisted in this process through providing information incrementally over time to allow for improved assimilation. The Cancer Support Specialists also relieved parents of the burden of having to seek out information about available supports and services by assisting with service-navigation.
- Cancer Support Specialists developed strong rapports with families, to the degree that Cancer Support Specialists often mediated communication between the multidisciplinary team and families when families felt too overwhelmed to approach the multidisciplinary team.

- The informal nature of the Cancer Support Specialist roles provided parents with a sense of normality, as they could discuss issues, chat and vent with someone who was outside of the context of the medically oriented \ multidisciplinary team. While Cancer Support Specialists provided the companionship of friends and family, there was no expectation of reciprocation or need to protect the role holders as can occur when discussing potentially distressing matters with family and friends.

Impact of the Cancer Support Specialist Service on the multidisciplinary team:

- The Cancer Support Specialist Service augmented the multidisciplinary team's provision of informal support to families, enabling the multidisciplinary team to focus on performing the clinical component of their roles while being assured that families' informal psychosocial needs were being met.
- The flexible provision of support to families in the evenings and at weekends was particularly welcomed by the multidisciplinary team as it filled gaps in support at these times.
- The multidisciplinary team welcomed the immediacy of access families had to the services of the Cancer Support Specialists.

Determinants to the implementation, integration and sustainability of the Cancer Support Specialist Service:

- The co-ordination of communication in the implementation process was an initial challenge to the implementation of the Cancer Support Specialist Service.
- The extensive engagement of stakeholders was a key enabler to the implementation process.
- The flexible design of the Cancer Support Specialist roles was integral to their successful integration, enabling role holders to respond to the informal psychosocial support needs of children with cancer and their families flexibly and adaptively.
- Role holder's personal characteristics enhanced their ability to provide this support. The flexible design of the roles posed an initial challenge to their integration due to the broad job description which led to concerns about new role holder's performing what were perceived to be discipline specific tasks. The willingness of the funding charities and first role holder to adapt the role descriptions to better fit the workplace infrastructure was important in resolving many of these challenges.

Limitations

When interpreting the findings, the following study limitations require consideration:

- The findings are based on a non-probability sample of participants.
- The small number of parents involved and a risk that parents who were most satisfied with the Cancer Support Specialist Service had a greater incentive to participate. In addition, despite reassurance of confidentiality parents may have worried about critiquing a service that they needed and continued to use.
- The interviews were conducted within six months of people taking up the Cancer Support Specialist role; had the roles been longer in place other impacts on families and multidisciplinary team members may have become apparent.
- Parents were interviewed at a very stressful and emotional time in their lives and that may have influenced their recall of issues.
- There was a risk that parents who expressed their satisfaction with the level of support provided by the Cancer Support Specialist Service were presented with recruitment materials more frequently than parents who did not express their satisfaction.
- While members of the multidisciplinary team interviewed were able to provide detailed commentary on the ward-based Cancer Support Specialist role, their knowledge of the Cancer Support Specialist roles within the community was more limited, therefore they were not in a position to provide the same level of commentary on impact.

Recommendations

In light of the findings and limitations, the following recommendations are proposed:

- In consultation with key stakeholders, consideration be given to the development of a specific strategic plan for the next five years. This could include:
  - How the Cancer Support Specialist Service could be developed, sustained and integrated into the National Cancer Control Programme.
  - How to promote and communicate the value of the Cancer Support Specialist roles within Children's Health Ireland, and wider community services.
- To maintain the positive outcomes reported by participants and minimise the potential of burnout and compassion fatigue, thus ensuring retention of the Cancer Support Specialists, there is a need for ongoing review of supports currently available, including the peer support and mandatory supervision to ensure they meet the needs of the Cancer Support Specialists. There is also a need to explore the development of a lone worker policy.

- In view of concerns expressed by parents about the void left when the Cancer Support Specialist Service was no longer available to them, there is a need to consider how to taper the Cancer Support Specialist Service support in the context of what supports are available for families once the Cancer Support Specialist completes their term of service with families.
- Consideration needs to be given as to how to maintain the Cancer Support Specialist Service at times of extended leave and annual leave to ensure an equitable and accessible service to all families across the cancer trajectory.
- Bearing in mind that the evaluation was conducted in the early phase of the implementation of the Cancer Support Specialist Service, it may be helpful to conduct a further evaluation after the service has been in place for a longer period of time. This would capture the long-term impact on families, multidisciplinary team members, community services, and the Cancer Support Specialist role holders themselves. A subsequent evaluation could also include the impact of any additional roles not included in the current study and capture the retrospective perspectives of family members whose child has finished treatment and are no longer availing of the Cancer Support Specialist Service.

Chapter 1

Evaluation in context

Introduction

Annually in the Republic of Ireland, there are, on average, 200 children up to the age of 16 diagnosed with cancer. Between 2011 and 2020, an average of 191 cancers were diagnosed per year in children aged 0-15 years; a further 178 cases were diagnosed per year in adolescent and young adults (16-24 years), giving a total of 369 cases of cancer diagnosed per year in 0–24-year-olds (National Cancer Registry, 2023). Survival rates in childhood cancer are constantly improving with the majority of children now surviving beyond five years. Though mortality rates in children's oncology have declined, childhood cancer treatments have become increasingly complex; as a result, families are more frequently faced with lengthy treatment plans, with harsher and long-term side effects being more common (Chrapek, 2016; Lewandowska, 2022b).

This report focuses on the evaluation of the implementation, integration and sustainability of a Cancer Support Specialist Service (CSSS) to provide informal psychosocial support to families of children diagnosed with cancer. To set this evaluation in context, included in this chapter are a brief review of the impact of childhood cancer on the child and their family, the importance of supporting the family through the cancer journey, the background and context to this evaluation, and the development of the CSSS.

Childhood cancer and the family

There has been increasing recognition of the psychological impact of a cancer diagnosis not just on the patient, but on the entire family and the wider community (Greally et al., 2023). The onset of childhood cancer is sudden and unexpected, and the effect on the family unit is enormous as they embark on a major life transition (Bretones Nieto et al., 2022). Childhood cancer has been described as 'an abnormal event that reorganizes family life' (Lewandowska, 2022a, p. 9). In addition to the profound changes caused by the disease, childhood cancer poses significant challenges to the emotional well-being of affected families. It not only causes extreme distress (Pierce et al., 2017), uncertainty, fear, and anxiety, but it can act as a destabilising force on family life (Lewandowska, 2022b). As family life is disrupted, the dynamics of the family are altered, and the whole family 'falls ill' as they struggle to adapt to a new reality (Melguizo-Garín et al., 2021).

Not surprisingly, this sudden and unexpected change in the family functioning can cause significant distress for all family members as caring for a child with cancer is an emotionally exhausting task, causing physical, mental, social, and economic well-being to decline (Toledano-Toledano & Luna, 2020). After diagnosis, parents find themselves with multiple caregiving demands such as treatment and home care while maintaining pre-existing competing demands. In addition, parents have to cope with many challenges during their child's cancer journey such as side effects caused by treatment, and life-threatening situations, including experiencing the death of other patients (Chrapek, 2016). Financial problems and challenges in maintaining professional life can give rise to emotional problems (Carlsson et al., 2019; Chrapek, 2016).

As a result, parents of children with cancer have a high level of needs, including psychosocial, emotional, physical, informational, financial, educational, communication, and spiritual needs (Aziza et al., 2019; Cheng et al., 2022; Lewandowska, 2022a; Nicklin et al., 2022). In addition, a recent systematic review indicated that the psycho-social needs of children and adolescents include a need for normality, the maintenance of hope, feelings of competence and independence (Carbonell et al., 2021). Further needs of families, children and adolescents include the provision of universal psychosocial support, such as support in navigating charities, community based services, and psycho-oncology services (Delemere et al., 2023), as well as support to develop coping skills (O'Rourke et al., 2019). However previous research, including phase one of the Katie Nugent research, indicated that the current healthcare system does not always meet these needs (Carlsson et al., 2019; Cheng et al., 2022; Lewandowska, 2022a). As children exist in the context of families, interventions that mitigate the impact of cancer on children and families are important (Brand et al., 2017).

Supporting families through the cancer journey

The role of Cancer Support Specialist (CSS) is relatively unique in healthcare with few mentions in the research literature. A scoping review conducted to develop context on similar roles and the determinants of their implementation, integration, and sustainability (Fulham-McQuillan et al, under review) enabled the conceptualisation of the category of informal psychosocial support roles within which the CSS roles can be placed.

The implementation of informal psychosocial support roles has been proposed in international healthcare systems to fill gaps caused by the fragmentation of care between hospital and community care (Hughes et al., 2020; Rosengren et al., 2023), and gaps within the provision of care to individual patients (Hughes et al., 2020; Willis, 2015). These roles are thought to improve the provision of holistic, integrated care to patients (Ilinca et al., 2018) and to meet the psychosocial support needs of not only patients but their families (Ventegodt et al., 2016).

This extension of care to the family is particularly needed in the context of childhood cancer due to the well documented impacts of childhood cancer on the family such as disruptions to family dynamics, including the relationships between siblings of cancer patients and their parents (Borrescio-Higa & Valdés, 2022). Children with cancer often experience negative feelings such as depression, discouragement, irritability, and disimproved social lives (Borrescio-Higa & Valdés, 2022), while parents may experience anxiety, probable post-traumatic stress disorder (Venunathan et al., 2021) and psychological distress (Michel et al., 2020). Psychosocial support can reduce distress, improve coping mechanisms and maintain psychological wellbeing (Koumarianou et al., 2021; Marques et al., 2018). As such, a model of Care for Psycho-Oncology services for Children, Adolescents and Young Adults (CAYA) with Cancer was launched by the National Cancer Control Programme (NCCP) and Children's Health Ireland (CHI) at Crumlin in May 2023 (Greally et al., 2023). The primary aim of the Model of Care is to provide a blueprint for the provision of psychosocial and psychological support services for CAYA with cancer over the lifetime of the current National Cancer Strategy (2017-2026). This model of care highlights the importance of providing a universal level of psychosocial care or support to all families entering the care system as a preventative practice (Greally et al., 2023). A universal model of support recognises that while families experience extreme distress and anxiety, the majority are resilient. In this context, what families need is ongoing information, comfort, and support to mobilize their own inner resources.

Background and context to the evaluation

CHI at Crumlin is the national treatment centre for children with cancer in Ireland and was the site for phase one of the Katie Nugent Fund at Children's Health Foundation research. During phase one the support needs of parents of children with a cancer diagnosis who were receiving, or had received care, from the oncology service in CHI at Crumlin was explored. Although parents valued the support offered by members of the multidisciplinary team (MDT), those involved in phase one clearly identified the imperative for additional supports as they navigate the journey of childhood cancer. Parents expressed a wish for additional social, emotional, practical and informational support. In addition to identifying many elements which would help and support their child and their families, during their cancer journey, parents also identified the need for 'someone' who would not be as busy with clinical commitments to provide more informal day to day support. While the provision of informal psychosocial support is part of the role of all staff working in paediatric oncology (Datta et al., 2019), the literature also indicates that informal psychosocial support is not always provided proactively (Scialla et al., 2018). In addition, the time burdens of members of the MDT (Murali & Banerjee, 2018), general understaffing in paediatric oncology (Seguin et al., 2022) and understaffing of formal psychosocial support providers (Besani et al., 2021; Jones et al., 2018; Scialla et al., 2018) can hinder the ability to provide informal support (Wiener et al., 2015). It was in response to this need that the CSSS was conceived and introduced into the oncology service in CHI.

The development of the CSSS

The CSSS is being introduced as a partnership between the Katie Nugent Fund at Children's Health Foundation, CHI at Crumlin and Cancer Fund for Children (CFFC)[1]. In addition, to implement a service based on the recommendations from phase one of the Katie Nugent research, the partnership aims to ensure through the CSSS that families across Ireland have the opportunity to avail of the informal support needed, through both hospital and community-based CSSs and the development of a Daisy Lodge, a dedicated therapeutic short break facility for those aged 0-24 diagnosed with cancer and their families, in the Republic of Ireland. This support would complement the current and long-standing supports that already exist in the cancer services.

The implementation of the CSSS progressed in **four stages**. (See figure 1 for timeline of implementation).

The **first stage** of the CSSS was the appointment of a CSS in St John's ward in CHI at Crumlin in February 2022. Prior to its implementation, the CSS role underwent several iterations as the role was adapted for an optimum fit within the work infrastructure of St John's Ward to ensure that the role would provide more informal support, time and presence with families. The role and job description were designed to be non-professionally affiliated with the overriding emphasis being the delivery of timely/informal and free practical and social support to the families of inpatients on St. John's ward and when needed those attending the National Children's Cancer Service (NCCS) as day patients.

1 Cancer Fund for Children is an all-Ireland charity providing emotional support to children diagnosed with cancer, and their families. Please see www.cancerfundforchildren.com for more information.

The job description also outlines how as an active member of the Psychosocial MDT the person is responsible for:

- Supporting families during their time in Haematology/Oncology through informal individual, social and emotional support, with planned group opportunities for young people and parents where appropriate, and to improve peer connection and reduce isolation.
- Providing informal one to one and group activities in the hospital setting (parents and/or children).
- Contributing to the design and implementation of programmes to support transition, both in age/development and stages of the cancer pathway.
- Developing age-appropriate methods for involving children, young people and parents in the development and evaluation of services.
- Identifying, through the MDT, families that may be in need of support and relaying all direct support offered at each shift following check in and update with the nursing manager.

The **second stage** of the implementation of the CSSS commenced with the appointment of an Ireland-wide community team of CSS roles. While the first ward-based CSS was designed to work primarily with parents, the community-based CSS roles were asked to primarily work with children with cancer and their siblings. The first of these roles was appointed in February 2023 to provide support to families in Connaught. This role was followed with the appointment of three further community CSS roles in July 2023. These three roles extended support to families in the community in Leinster, Munster and the midlands.

The **third stage** of the CSSS will be the appointment of a Youth Support CSS role based in CHI at Crumlin to provide support for adolescents and young adults (AYA) with a plan to extend this across the AYA Cancer Service network in St. James Hospital, Cork University Hospital and Galway University Hospital.

The **fourth stage** of the CSSS will be the completion and opening of Daisy Lodge in Cong in Co. Mayo, Republic of Ireland. While this facility is still in development, the current CSS role holders refer families to the Daisy Lodge facility in County Down, Northern Ireland (see figure 2 for the approximate geographic locations of the CSS roles).

Figure 1 Timeline of the CSSSs' Implementation

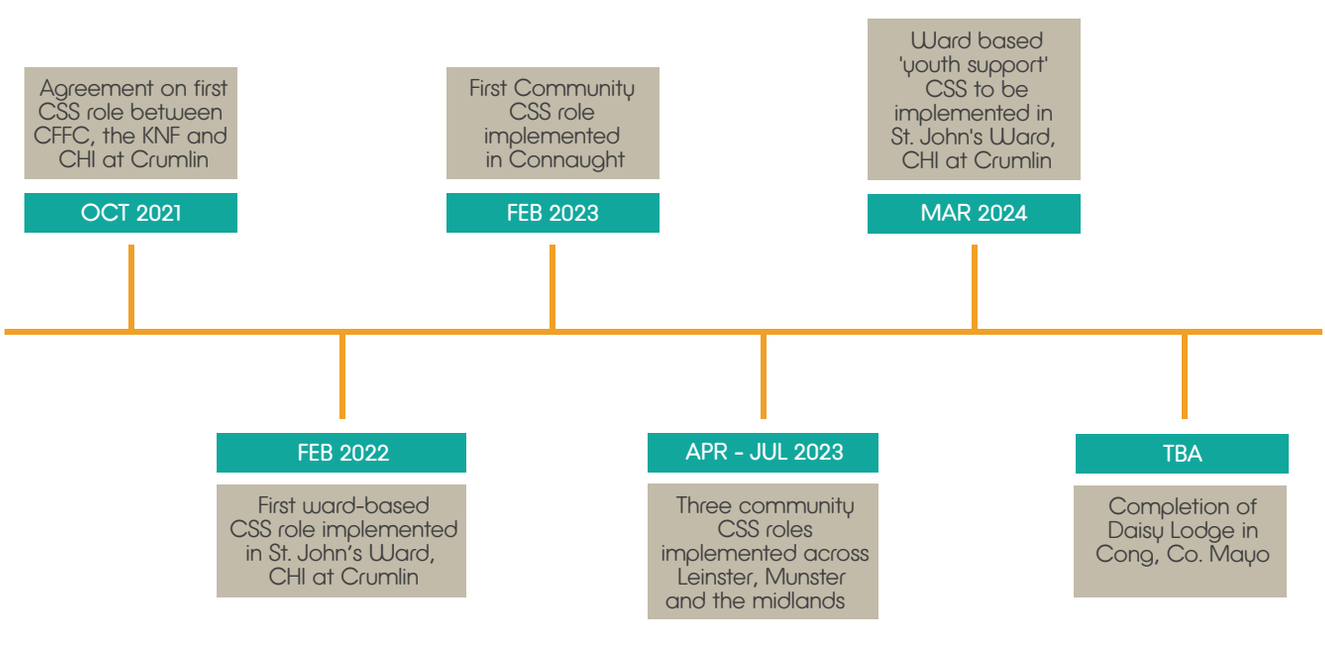
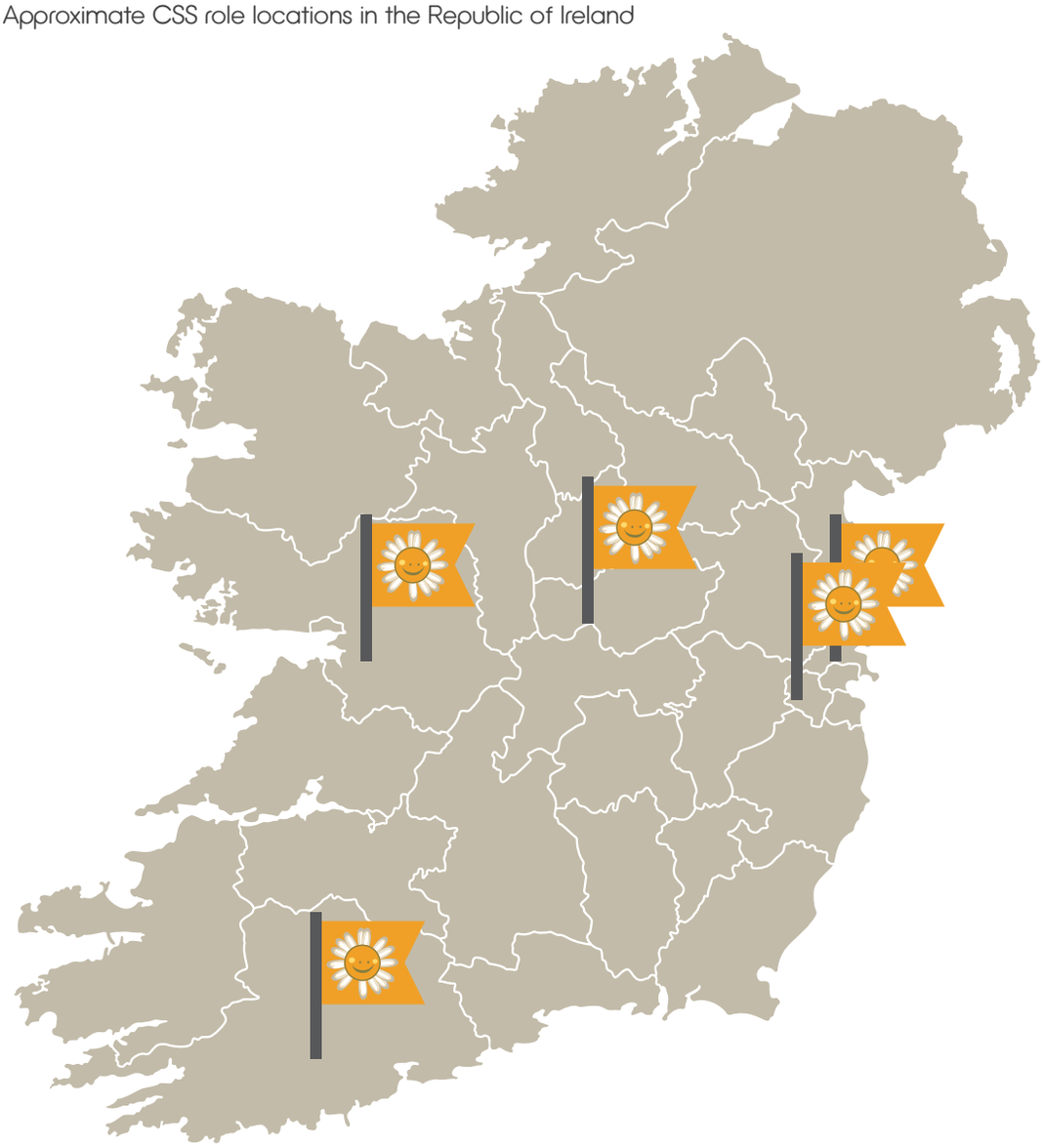


Figure 2 Approximate CSS role locations in the Republic of Ireland



Profile of the role holders

While the job description for each CSS role shares the primary duty of providing informal support, the context of each CSS role necessarily amplifies and de-amplifies aspects of the role resulting in slightly differing job descriptions. In addition, the background of each role holder differs, as do some other demographics. The profiles of CSS role holders at the time of writing can be seen in table 1.

Table 1 Profile of the current CSS role holders

Gender	Current CSS Roles	Professional Background
Female 4 Male 1	Ward-based CSS 1 Community CSS 4	Social work 2 Nursing 2 Play therapy 1

Chapter 2

Research methods

Introduction

In this chapter, the aim and objectives of the study are described, along with the data collection methods, recruitment and detail of the approach to data analysis. This chapter also contains information on participant profiles, ethical considerations and study quality.

Aim of the study

The aim of the study was to explore the implementation and impact of a CSSS within the oncology service in CHI at Crumlin from the perspective of the key stakeholders involved.

Objectives

The objectives were to:

1. Describe the impact of the CSSS on the families that were supported by the service.
2. Ascertain if, and how, the CSSS impacted the MDT in the oncology service.
3. Describe the CSSS model as it evolves over the implementation period, including barriers and enablers to implementation and sustainability.
4. Provide recommendations on the future development of this service.

Study sites

The study was conducted in the oncology services in CHI at Crumlin and in the community areas where the CSSs are geographically located around the country.

Inclusion criteria

To participate in the study people had to be either a CSS, a member of the MDT associated with the oncology services in CHI at Crumlin, be involved in the implementation of the new service or role, or be a family member in receipt of, or have received support from, a CSS.

Access

Permission to access the site was granted by the Director of Nursing in CHI at Crumlin.

Data collection methods

Data were collected using interviews with key stakeholders. Semi-structured one-to-one interviews, informed by an interview guide, were used to collect data from members of the MDT, CSSs, family members and a member of the steering group. An interview guide was developed by the research team which included questions about the introduction and impact of the CSSS, as well as questions on barriers and enablers to implementation. The interview guide was tailored for each cohort. While the interview guide informed the interviews the interviewer had the autonomy to explore relevant areas that may arise during the interview, allowing for greater understanding of the research topic (Adeoye-Olatunde & Olenik, 2021). Participants had the option of a face-to-face interview, a telephone or online interview. It was originally intended to interview children as part of this evaluation, however no parent consented to having their child interviewed. Parents did complete the 'Pediatric Cancer Quality of Life Inventory' (by proxy) (Varni et al., 1998). However due to the small number of parents participating this data will not be reported.

The recruitment of participants required the assistance of gatekeepers: a specific requirement of the approving ethics committees. Hence several people acted as gatekeepers. The Clinical Nurse Manager three (CNM3) in St. John's Ward who was the gatekeeper for the MDT (excluding the nurses) emailed participant information leaflets and consent forms to the MDT via an internal email which comprised a list of all of the members of the MDT on St. John's Ward.

As the CNM3 was the manager for the nursing team, she did not function as a gatekeeper for nurses. Nurses were recruited through posters advertising the study, which contained contact details for the research team and a QR code linking to a participant information leaflet and consent form hosted on the Qualtrics website (www.qualtrics.com).

Key steering group members involved in the implementation were invited to participate by email from a member of the research team. These interviews were used to provide context on the development of the CSS roles within the CSSS.

Parents/guardians who accessed the support of the ward-based CSS received a standardised information leaflet about the study from the CSS. This directed them to the research team if they wished to participate. The CSS informed parents/guardians of the voluntary nature of the research but did not discuss the research with the parents. The CSS did not know which, if any, parents participated in the research. If the parents/guardians had any queries about participating in the research for which they wanted local nursing advice, they were directed to the Nursing Shift Leader on duty, and if they had further questions, they were directed to the Nursing Manager of the Oncology Services. This is in line with the normal procedures within the Haematology Oncology Service in CHI at Crumlin for addressing queries or concerns, and to ensure that questions can be responded to in a timely manner, e.g., out of hours.

Parents/guardians who were interested in participating in the study had the opportunity to contact the research team with any questions they had about the research prior to consenting to be interviewed. A member of the research team emailed interested parents/guardians a link to a Participant Information Leaflet and consent form hosted on the Qualtrics website (www.qualtrics.com). Parents had at least 14 days to peruse the information before participating in any interview.

The recruitment of parents/guardians was understandably challenging. Six months after the implementation of a community-based CSS, another round of parent/guardian recruitment was conducted. The community-based CSS was the gatekeeper for parents/guardians referred to their service. This time information packs including a participant information leaflet and a consent form with prepaid envelopes addressed to the research team were given directly to parents by the community-based CSS. Although the CSS informed parents/guardians of the voluntary nature of the research they did not discuss the research with the parents. Parents/guardians interested in participating were requested to post their consent form directly to the research team.

Profile of participants

In total 31 participants (23 MDT members including CSSs and a member of the steering group, and eight family members) contributed to the evaluation which involved 34 interviews in total, as three people were interviewed more than once (see table 2). Of the 13 family members who consented to be involved, nine were interviewed. One family member interview was not used to inform the evaluation as it did not provide information on the CSS role. Finding a suitable time to interview family members was a challenge due to multiple competing demands of caring for their child with cancer and several of the interviews were rescheduled a number of times.

In total 29 MDT members consented to participate, however six did not reply when contacted for interview. Within the group interviewed several disciplines were represented, including Nurses, Social Workers, Consultant Oncologists, Dieticians, Psychologists, and a member of the steering group. All four of the CSSs who expressed an interest and consented to participate were interviewed.

The interviews were conducted both online and face-to-face. Two participants chose to be interviewed face-to-face, two chose to be interviewed by telephone and 27 participants chose to be interviewed online. Recruitment of all stakeholder groups was an ongoing process from Oct 2022 - Dec 2023 due to a staffing crisis and patient care priorities in CHI at Crumlin. Interviews lasted between 30 and 90 minutes and were conducted by three members of the team.

Table 2 Profile of participants in the study

	Number	Discipline/Role/Location	Other relevant information
MDT members	Expressed an interest 29 Participated in interviews 23	Nurses, Social Workers, Consultant Oncologists, Dieticians, Psychologists, Steering group members (19), CSSs (4, hospital 1, community 3)	Interviews completed 26 as 3 MDT members were interviewed twice
Family members	Expressed interest/ consented 13 Participated in interview 8	Mother 7 Father 1	Parents of: 13-year-old girl 16-year-old girl 16-year-old girl 2-year-old boy 2-year-old boy 14-year-old boy 13-year-old boy 16-year-old boy

Data analysis

All interviews were recorded with the permission of participants and transcribed using a transcription service. Prior to analysis, all interviews were cleaned of identifying information, checked for accuracy and uploaded to the data management programme NVivo Enterprise (qualitative data analysis software package) which enabled the management and analysis of the interview data. Data were analysed using a framework analysis approach (King, 2012). King (2012) suggests three approaches to the development of a coding framework which are either based: on a subset of the data; on a predefined theoretical position; or a 'half-way approach' using a combination of some initial predetermined codes and flexibility to refine and develop new codes as the analysis progresses. To answer research objectives one and two, the impact of the role on families and MDT, the third approach was used. Initially a subset of the data (three interviews) were coded by the research team, subsequent to this the team came together to discuss and agree the codes generated. These codes were then used as a framework for the remainder of the analysis with the flexibility to adapt or generate new codes as required (King, 2012). As the analysis unfolded some codes were merged, and others renamed to reflect the theme being discussed.

To answer objective three, the determinants to implementation (barriers and enablers), analysis was informed by the updated Consolidation Framework for Implementation Research (CFIR) (Damschroder et al., 2022) framework. Interview data was coded according to the five domains of this framework, namely: i) the innovation domain; ii) the outer domain; iii) the inner domain; iv) the individual domain; and (v) the implementation process. Once the first level coding using the five domains was complete for all interviews, data coded to each domain was further analysed and coded as either a barrier or enabler to the implementation or sustainability of the CSS role.

One researcher coded the interviews from the MDT while another coded interviews with parents/guardians and a steering group member. The overall team came together at regular intervals to review the coding process and address issues in relation to interpretation of data or the need to merge codes or generate new codes. The findings of all the analysis were then triangulated (Carter et al., 2014) to develop a more comprehensive understanding of the CSSS model, the impact of the CSSS and determinants to its introduction, including how it evolved over its implementation. In order to contextualise the role and provide supplementary data on the CSSS model, the CSS roles and their scope, and the evolution of the CSSS model, key documents were also analysed. Following a request to stakeholders to provide any documents relevant to the development of the CSSS, and the CSS roles, the following documents were reviewed: the job descriptions; information relating to the roll out of support for families impacted by childhood cancer by CFFC in the Republic of Ireland; and the mission of CFFC. Following analysis, the following themes were identified: Impact of the CSSS on families and children; Impact of the CSSS on the MDT; Contextual and mediating factors that influence the implementation and integration of the CSSS; and Visions for the future of the CSSS (See figure 3). These are reported in further detail in chapters three, four, five and six.

Figure 3 Themes identified following analysis

Ethics

Permission was granted to access the site by the Director of Nursing in CHI and ethical approval was granted by the CHI Research Ethics Committee (REC-046-21) and by the Faculty Research Ethics Committee, Trinity College Dublin (Ref: 220603). The study was also reviewed, and approval was granted by the Data Protection Officer in Trinity College Dublin and CHI. A joint data controller agreement was signed between Trinity College Dublin, CHI, the KNF and CFFC. All project team members completed GDPR training provided by Trinity College Dublin. Obtaining informed consent and assent, maintaining confidentiality and anonymity, and participants' rights were all respected throughout the project.

Informed consent was obtained from all study participants. Written information about the study and the nature of each individual's involvement in the study was given to all potential participants. All potential participants were informed of their right to refuse to participate and their right to withdraw from the study at any time. Parents/guardians were informed that neither refusal nor withdrawal would result in any negative consequences to care they or their child received. Members of the MDT were also made aware that should they choose not to participate in the research or if they withdrew from the study, this would not have any impact on their role within the hospital and that this would not be reported by the research team. All participants had at least 14 days to peruse the information before participating in any interview.

The study details and information about the nature of the participant's involvement were reiterated when the interviews were being arranged and at the beginning of the interview. All participants signed a written consent form prior to the interview. People appointed to the CSS roles were aware at the time of their appointment that the research was being conducted. They were also made aware that their appointment was not contingent on them participating in the study. The CSSs informed parents/guardians about the study and did not know which, if any, parents participated in the research. Similarly, the gatekeeper who sent out emails did not know if people read the email as the read function was disabled and they were not aware who participated.

As the study involved interviewing parents at a very stressful and emotional time in their lives, every care was taken to ensure they were not distressed further by a request to participate. It was reiterated to parents at the start of the interviews that interviews could be terminated at any point.

All data files were anonymised, password protected and stored in accordance with the Data Protection (Amendment) Act 2003. To ensure anonymity, participants' identities or any other personal information given during the interviews was anonymised through the use of pseudonyms or by removing identifying information. Data from the interviews were transcribed by an external company, the company of choice for the School of Nursing and Midwifery, Trinity College Dublin. The company is familiar with the process of dealing with confidential information and executed a confidentiality agreement. To de-identify interview transcripts, each transcript was assigned a unique code made up of the cohort group, and participant number (e.g., PP2 for the second parent to be interviewed).

To minimise the risk of inadvertently identifying the CSSs or other team members, when reporting quotes, their discipline or any other designation will not be described; they will be referred to as MDT1, MDT2 etc. In data that arose from a second interview it is designated as interview two using the following: (ii). Data from parent are identified as PP1, PP2 etc.

Rigor and quality

To ensure rigor and reduce inter-rater variability across the data analysis in the interview data analyses, two researchers independently coded 10% (n=3) of the other's interview data. The codes generated by each coder were compared and discussed as a team with the aim of challenging perceptions, ideas and assumptions regarding the data and to help develop a more comprehensive and in-depth understanding of the experiences of the introduction and impact of the CSSS (Tracy, 2010). The use of the CIFR framework also aided transparency and helped reduce inter-rater variability in relation to the analysis on determinants to implementation. In addition, a clear audit trail of the research process is articulated, and evidence in the form of extensive quotes is used to support interpretations.

Chapter 3

Impact of the CSSS on the families and children

Introduction

Being told your child has cancer is one of the most distressing experiences that parents can have (Carlsson et al., 2019). Receiving a diagnosis causes enormous changes and challenges, triggering an array of emotions ranging from shock and sadness to fears and anxiety about survival and concerns about impact of treatment on the child, including sickness and pain (Kästel & Enskär, 2013; Lewandowska, 2022a). In addition, as the illness and treatment trajectory is not a linear process but one that is marked by periods of uncertainty, parents can find themselves experiencing grief and shock at different times during the childhood cancer journey. It takes a great deal of energy for the whole family to adjust to the disruption caused by childhood cancer (Kästel & Enskär, 2013). Parents also worry about how to communicate the diagnosis to the child as well as how to communicate with other children within the family (Kenny et al., 2021). Lewandowska (2022b, p1) describes the term 'collective patient' and 'family pain' indicating that the entire family of the ill child is affected by the child's illness.

Parents can find navigating the healthcare system and interactions with healthcare staff challenging both during the time of diagnosis and later during treatments as parents are expected to process large amounts of medical and other types of information (Melguizo-Garín et al., 2023; Salvador et al., 2019a). Childhood cancer is an unexpected diagnosis in many cases, and it causes deep upset and upheaval in a family and for many the disruption caused by a childhood cancer diagnosis can last for some time (Salvador et al., 2019b).

Though the mortality rates in childhood cancer have declined the impact of childhood cancer on a family has not reduced. Providing adequate supportive care to families enhances families' experiences of childhood and contributes to alleviating some of the illness-induced stress associated with childhood cancer. The focus on this chapter, the first findings chapter, is on the impact the CSSS had on families.

Following analysis of the interviews the following themes in relation to the impact on families were identified:

- Relational Support
- Informational Support
- Mediation Support-Bridging the Gap
- Navigational Support
- Respite Support for Parents (including practical support such as small errands)
- Support to Siblings

Relational support

Support is an exchange of help provided by one person to another (Melguizo-Garín et al., 2023) and the theme relational support refers to the unconditional, flexible support parents received from the CSSS. Parents reported overwhelmingly on the positive impact of the relational support offered by the CSSs. Words such as 'fantastic', 'amazing, 'willing' 'caring' and 'the rock' permeated the interviews. Parents valued the idea of having the CSS that was solely there to support them in their journey and was summed up by parents as 'just being there'. Parents reported that the CSS presence and support offered made their journey with childhood cancer much easier:

> "... I don't know how I can put it into words, to be honest, it's very hard but (the CSS) make(s) a difficult journey much easier." (PP4)

> "I just think it's a fantastic service because we went in there and our heads were spinning and you know we didn't, I've never had come across anything like this before never mind in my own family. And just to have (the CSS) there (they were) the rock, that's all I have to say on the matter, (they are) a rock that was there." (PP1)

This importance of this support was affirmed by members of the MDT:

> "... (the CSSS) is indispensable... the emotional support and shoulder (the CSS) provides to the patients and families when (they are) there, I simply don't think they would get if (the CSS was not there)." (MDT14)

The informal nature of the CSS presence, whether in hospital or the community not only provided great support as parents journeyed through the healthcare system, but the very fact that the person did not have to rush off to deal with other issues offered comfort at a time of enormous upheaval in a families' life:

> "I think it just brought a bit of lightness to the day, you know, knowing that there's someone that you can just kind of sit and have a chat (with)and they don't have to run off to somebody else and, you know, So I think it's just that kind of personal touch, which is really important, you know....As in we could go off and have a coffee and kind of a more relaxed chat I suppose (the CSS) really (were not) being pulled in all directions." (PP5)

> "... the big thing is probably the emotional support... you know even though you mightn't use it. You know it's there if you need to use it. I think that's really good..." (PP7)

> "I could see how (the CSS) was supporting people emotionally as well. (the CSS) was there for parents. I have seen it in action because... we were living on the ward practically and to see how (the CSS) dealt with other families and even just to be there silently at the door for them if they needed when things were tough..." (PP1)

The complexity of childhood cancer treatments requires long periods of hospitalisation and isolation from family and friends. The isolation can also continue when they return home with their sick child. Parents welcomed and valued the presence and informal 'check-ins' by the CSS whether it was in the hospital or family home:

> "It's amazing, I have to say also I know (the CSS) obviously come(s) for the kids and everything you know it's obviously for the kids but it's just nice to have someone just to check in too." (PP2)

The very action of accessing support can be demanding for parents so the 'ready availability' of the CSS was a key benefit. Parents emphasised how the CSS was proactive in offering help as opposed to leaving it up to the parents to request assistance:

> "And how can we support you, you know, what can we do for you today or is there anyone in the family that we can support, you know, it's those questions that other people just don't have the time to ask you or..." (PP5)

> "... without fail every time (the CSS) comes the first thing (they)'ll ask is how am I. How are we all? And the last thing when (the CSS)'s leaving is there anything that you need or anything that you want like you know it's obviously for the kids but it's just nice to have someone just to check in too." (PP2)

> "(the CSS) is there so I don't have to pick up the phone, I don't have to, (the CSS) just arrives and (they) just, you know, (they have) a great manner and (they) get(s) it." (PP4)

For some parents, who didn't want what they described as 'counselling' the informal nature and approach of the comfort and support offered by the CSSS was important. As parents felt they could chat in a 'normal' way, and not have to feel they were in a formal therapy context:

> "... and not necessarily counselling, but just to have a chat with somebody who kind of gets it, you know." (PP6)

> "... it's been able to just talk about what we are going through in a normal, informal way, informal definitely 100% better for us." (PP2)

As the journey through childhood cancer causes emotional turmoil, parents also spoke of the value of the informal support at times of immense emotional distress. Again, it appeared that the opportunity to have an informal conversation at these times is what parents wanted and valued:

> "(The CSS) was there for me when we nearly lost (name of child with cancer) and (they) really, really calming and helpful and you know I didn't know what to do. So I don't know what we'd do without her either." (PP8)

> "you're having a really difficult day... I wouldn't very often have those days but (the CSS) recognised when I did and kind of said, you know, what's going on and I was able to tell her." (PP5)

The well-timed provision of the support was also an important factor for parents. It was not only having a supportive person who knew when and how to be present with the family, but parents also valued that the CSSs had the sensitivity and intuition to know when to withdraw:

> "And if (the CSS) needed to be in your face (the CSS) was in your face, if (the CSS) needed to be in the background (the CSS) was in the background." (PP1)

> "Oh yeah, like I said (the CSS) was always there and (the CSS) knew when to come into you and (the CSS) knew when not to intrude. Very intuitive." (PP4).

While parents valued what they called the 'personal' and 'informal touch' they were also aware of the value that the CSSs skill and knowledge brought to the role. The benefit of the CSSs having a knowledge and understanding of oncology services was welcomed:

> "And it's nice as well because (the CSS) has a clinical background I can chat to (The CSS) as well, do you know what I mean? (The CSS) understands what I'm talking about, you know, to depths that other people don't. So, if I'm telling (the CSS) he's (child) going through X, Y or Z, (the CSS) just knows." (PP6)

> "Like I said already we are very practical people but (the CSS) dealt with us in a practical level. Whereas I saw other parents there would be very emotional. And (the CSS) was able to deal with them accordingly as well, as was needed." (PP4)

> "I suppose it's someone very experienced as well who gets what you're going through, you know, they've met enough families." (PP5)

Although the CSS role was not aligned to a discipline and was an informal support role, parents spoke of feeling free to bounce ideas and discuss issues in a space that was still confidential.

> "One of the earlier discussions I had with (the CSS) was just coping mentally myself and not being able to work..., I needed to know how to address, maybe ideas about how to address things with my own work and I could bounce ideas with (the CSS) in a confidential way." (PP4)

Some of the parents also spoke of the importance of having someone outside the context of family for support, as with the CSS they didn't need to explain or discuss details of their child's illness; as the CSS immediately understood. In addition, parents felt that with families or friends they would be asked questions and expected to tell and retell the details of their child's illness, whereas with the CSS there was no expectation of reciprocity in the support offered. In addition, parents felt they could talk to the CSS and unlike with family and friends they did not have to worry about protecting the CSS from the emotional pain and trauma that they were going through:

> "...I can just say this or that, and (the CSS) knows all about it, you know? You don't like... a normal person that has no background in this, you know? They're like "And what's that then?" and "What's that then?" and then sometimes you don't even bother saying stuff because they won't have a clue and you're tired of explaining." (PP6)

> "Someone to talk to when you mightn't want to, you get sick of ringing your family, I think your family is sick listening to you, you know, (laughs), you don't wanna be the bringer of bad news all the time and it's nice to have someone that can just listen, you know." (PP4)

Informational support

The parents also reported positively on the informational support they received from CSSs. The CSS was aware of how to navigate systems, knew what services were available and provided that information to parents in an ongoing manner. In addition to relieving parents of the burden of having to seek out information, the ongoing nature of information provision gave families time to process and assimilate the information given:

> "There was informational support, stuff like that letting you know what's going on, what supports are available. Like for example the wig, you know, where to get the wig and what supports like grants or services are available for that. We heard about Daisy Lodge...And (the CSS) had put us down on that, we haven't been able to avail of it yet. All that sort of stuff." (PP3)

> "I think the other thing that (the CSS), you know, on a really practical level, it's (the CSS's) information sharing has been invaluable." (PP4)

The CSS shared information voluntarily on a variety of issues ranging from who is who within the MDT, services available such as Daisy Lodge, charities, financial grants available to information on parking:

> "Everything from the Irish Cancer Society to Aoibheann's Pink Tie, the wigs, everything, everything in that yellow pack that we have. That yellow book (the CSS) was very involved with it and very on top, (the CSS) had all the information and (the CSS) knew what was needed and we didn't even know what was involved you know." (PP1)

> "... letting you know what's going on, what supports are available. Like for example the wig, you know, where to get the wig and what supports like grants or services are available for that. All that sort of stuff." (PP3)

> "... the role is very well resourced with beautiful booklets and resources... patients and families can have these hard copies of lots of information and resources, which I think is really helpful. And the direct links to the facility, Daisy Lodge, is great and referring patients in there." (MDT3)

The very fact that the CSS knew this information also relieved parents of the burden of having to worry about where they would access information as the CSSs became the point of contact if they had questions. As a result of knowing this, parents felt enabled to concentrate on caring for their sick child:

> "I didn't have to think about anything. I didn't have to worry about anything. All I had to do was look after my child." (PP1)

> "So, you know you kind of feel like you wouldn't want to be, do you know kind of nearly looking for things, or asking for things." (PP7)

In the context of information support, the timely availability of information was also reported by parents to be of help:

> "... families going in there need all the support they can get in the first few days... I think any support that you can give to parents on the first week because there's so much happens, just so much to take in, and navigate really is the word I'd use. Trying to navigate your way around everything, I mean... even like parking." (PP3)

Mediation support-bridging the gap

The theme mediation support refers to the manner in which the CSS was a conduit between the family and the wider healthcare system. In this context the CSS facilitated communication between the family and members of the MDT, especially at critical times in the child's cancer journey:

> "... you're having a really difficult day and you're really worried about your child and like I wouldn't very often have those days but (the CSS) recognized when I did and kind of said, you know, 'what's going on?' and I was able to tell (the CSS) and then (the CSS) was able to, I suppose I didn't have the strength to do it (talk to the MDT) myself... (the CSS) kind of stepped in a couple of times when we were very worried or having a very difficult day and felt like we couldn't kind of communicate what was going on to the consultant because they're so busy and (the CSS) kind of would have stepped in a few times... made those conversations happen for us, which I don't think they would have without (the CSS) because, the way you're kind of almost, you're not fearful of the (MDT) but... you understand how precious their time is and that there's so many children to look after and you don't wanna be a burden on people." (PP5)

At other times the CSS was the conduit for conversations with the various charities or supports in the community:

> "And (the CSS) is there you hear about all of these charities, it's very difficult to pick up a phone and go through, I'm only even able to kind of verbalize 'my son has cancer' very recently, without bursting into tears." (PP4)

> "And they don't even have to be involved in it they are simply a conduit or a link to all the other support and that happens all the time." (MDT19)

Members of the MDT also reflected on the benefit of the CSS supporting families in communicating at difficult junctures in their child's illness. They recognised that because of the more informal relationship parents have with the CSS, family members may find it easier to open up and tell them things that they would not tell a member of the formal MDT. This was viewed as important in enabling conversations to happen about things that might otherwise be left unsaid or unexplored:

> "It was really, really good because you know it allows us to understand better as well. You know sometimes they will tell the cancer support specialist things that they won't necessarily tell me." (MDT14)

"(The CSS) really facilitated the conversation being productive, both from a family and medical perspective, because (the CSS) knew the family... knew where they were coming from, (the CSS) knew what their priorities were and as a doctor I knew what my medial priorities were, but (the CSS) helped those two things to merge in a really, really positive way in a very difficult situation." (MDT18)

The role of the CSS in providing feedback to the MDT about how things were going for the family was also noted as an important component of enhancing continuity of care and communication from the MDT:

"(The CSS) is really good at feeding back to us... Sometimes when you don't hear from people you think that they're getting on great. And that can be a bit of a red flag that people aren't coping that well. They're trying to avoid communication with you. And they're sort of families that I would refer to the community support, or the cancer support worker. And then (the CSS) would bring back... actually it's not going great for them... maybe they could check in with you... it might be worth giving them a phone call. And that's really good for us because you feel like the parents are ready to have that conversation then, do you know." (MDT12)

Members of the MDT also recognised that the CSS was critical in supporting family members to develop confidence to communicate with the MDT and to seek out more formal support if needed:

"And I think the third thing which is a big benefit, it (the role) supports families indirectly in that confidence in communication." (MDT19)

"Because they (the CSS) know what is going on and I think that (the CSS) kind of is like that but is able to actually provide support, guide families in the direction to formal supports. So, they kind of almost they bridge the gap between the clinical and that the families." (MDT16)

Navigational support

There were several comments from families about the benefit of the navigational support received from the CSSs. Navigational support consisted of help with navigating and guiding parents and families through the hospitalisation experience. While members of the MDT may have explained things to families, the CSS was often the person who was present to translate that information into digestible chunks in a manner and at a pace that family members could take in:

"Naturally enough we didn't know what to expect at first. But (the CSS) kind of sat with us and (the CSS) explained everything and went through an awful lot with us... we didn't know about the centre realistically. We didn't know what supports were there or what we would need or wouldn't need. And (the CSS) just guided us through the whole lot..." (PP1)

"I mean some things which we've been able to avail of, other things that are in the pipeline and under discussion... like Daisy Lodge, he's just been really too ill to do stuff like that." (PP3)

"(The CSS) is just excellent at signposting and recognising what people need." (MDT18)

Parents commented on the amount of information that they had to become acquainted with following their child's cancer diagnosis, including available supports. As family's income can decrease and expenses can also increase at this time, the CSSs role was critical in guiding parents in how to navigate the information:

"(The CSS) has that information and like there's a lot of charities connected with cancer and specifically children's cancer. When you're in the middle of it, as we are now, from a time space, from a head space and from a logistical space, it's very hard to see the wood from the trees, you know." (PP4)

> "She contacted Aoibheann's Pink Tie, and she asked them for practical support for me. She got them to send me out vouchers, which was amazing because obviously my social worker hadn't done that. And considering we were... our original was travelling every ten days for chemo, and then to Galway once a week, so that's forty minutes. So that was amazing..." (PP6)

In addition to navigating the amount of information, the CSS also supported families to navigate the process involved in applying for grants, contacting charities, services and grant applications:

> "And trying to organise then... even with the volunteers from Barrettstown to come in... just to do things with (child with cancer's name). (The CSS) was kind of coordinating all that in the background if (they) thought somebody needed something, if someone needed an extra little bit... the other services, information, a little bit. Aoibheann's Pink Tie they would have been emailing us and once they had our email address and all the rest of it and offering their services. But I think the fact that the CSS was the face of it, you know it was easier than dealing with emails or phone calls. (The CSS) was there just in the ward." (PP1)

The willingness of the CSS to proactively find out relevant information for families that they couldn't find elsewhere was also important to families. One parent spoke of the difficulty her daughter had when her eye lashes fell out because of treatment and how the CSS navigated her to YouTube clips to help and support her:

> "But her eyebrows and her eye lashes were starting to fall out and that was freaking her out more than her hair. So, I was like, Jeez I don't even know how to go, because I went into a salon going you know she is able to get stuff on. They were terrified thinking, oh no she got chemo that really we can't do anything with her... I emailed... (the CSS) going is there any chance you'd have (a) clue of anything that you know to help her. And (the CSS) found... direct YouTube videos and different things... and sent them which was really helpful." (PP7)

Respite support for parents

The uncertainty around childhood cancer can result in parents being reluctant or unable to make any time for themselves. The theme of respite support refers to the support offered to parents that enabled them to take time for themselves to engage in self-care activities, such as having space and time for themselves. The respite support came in many forms, tailored to the individuals needs and varied from family to family. For example, within the hospital system the CSS was described as someone that would make time to take the parent for a coffee or create space for the parent to go for a walk, or if needed do a small shopping errand:

> "... know (the CSS) was around if we needed (the CSS) and if we needed (the CSS), (they) always kind of made time for me, you know, go for a coffee or get out of the hospital even, get some air with (them)." (PP5)

> "... even in terms of lifts... I'd be reluctant to look, ask for help... when we've loads of friends and everything around... When I know there's (CSSs) people who can (help)... I think it's really important. I think it's important that they're there for people who definitely use them...." (PP7)

The CSSs supported and engaged with the siblings of the child with cancer within the home. Parents spoke of how this helped to refocus attention on siblings who may not have received enough attention over the course of their other child's treatment. It also relieved the pressure parents felt to be playing and interacting with their child/children when they were emotionally and cognitively exhausted:

> "(The CSS)is here to support the girls, but in turn with... supporting the girls (the CSS) is supporting me... the last while has been intense treatment, and like my head isn't there to do activities with them. Even the beautiful book (the CSS) gave them, the Invisible String, and (the CSS) went through it all with them and left that there for us as a family. By (the CSS) supporting them, it is inadvertently hugely supporting me." (PP6)

"... as regards what support the cancer nurse specialist (the CSS) gives me. I get a break, a massive break." (PP2)

"(The CSS) might come out and you know maybe go for a walk with the girls. Or have a chat with them... I think it'll be really good for the other two. Because you feel like you've ignored your other children for the last (few) months." (PP7)

Respite support also came in the form of organising activities for the children or organising time away such as in Daisy Lodge. The fact that the CSS took the time to organise these activities also provided respite for parents, as it relieved them of the tasks associated with organising:

"So today like was just a lazy day and (the CSS) came and I got a rest and they got to have their activities, and nobody had to go anywhere." (PP6)

"... we did have a break to Daisy Lodge and (the CSS) would have kind of organized that for us." (PP5)

"... in terms of resources... I mean I mentioned Daisy Lodge and things like that and, you know, there's things that come (the CSS') way, like there was a zoo trip that we were able to do, it's just kind of nice things close by. I've no capacity to be arranging things (laughs), at the moment." (PP4)

The fact that the CSS visited the family home was an important aspect of respite, as it meant that the parent didn't have to organise childcare or take the children anywhere, which frequently adds to the difficulties parents experience in accessing time for themselves:

"Yeah, so I think that's (coming to the house) just the icing on the cake. It's just fantastic that, like that now today I could just be in chill out, and (the CSS) came and I get a rest and the kids didn't have to be loaded in a car to go anywhere to get this emotional support or do activities..." (PP6)

Support to siblings

Siblings of a child diagnosed with cancer can face challenges as the focus of the family turns towards the medical and emotional support needs of the child with cancer. Parents mentioned the importance of the CSS connecting with all family members:

"Well again, supporting us around the whole family, you know, checking in on the whole family and what we need as a family." (PP5)

In the context of supporting the whole family, the support offered to siblings to ameliorate the challenges they encounter was really welcomed. The parents spoke of how the CSS made space for children to play and process their own emotions through the various activities that the CSS engages in:

"... (the CSS) does very beneficial activities with them (siblings and child with cancer) ... (the CSS) came there now there today and they did calm boxes and all that type of stuff... So, if they wanted to talk about their feelings they can. Because sometimes I find with kids as well, a complete stranger, they might open up easier to them than to us, or to aunts or to uncles..." (PP6)

"... we had (the CSS) out to the house. And it just really meant the world to the Children." (PP8)

The sensitive developmentally appropriate activities engaged in with the siblings, as well as the warm supportive approach adopted by the CSS, was highly valued by the parents:

> '(The CSS) comes every few weeks and oh my gosh, my children absolutely adore (them). They love (the CSS), they talk openly with (the CSS) as if (the CSS has) been here all our lives... my little boy like I said isn't even two so obviously he wouldn't be I suppose as involved in the stuff but he, oh my gosh the minute (the CSS) comes in he runs to (them) and he is with them all the time." (PP2)

The fact that the CSS offered opportunities for distraction for their child as well as taking a future orientation was also welcomed by parents. Moments of joy and positivity were welcomed by the parents:

> "(The CSS) would be chatting about things that he wants to do after treatment and (the CSS) (would) be very encouraging to him, like he wants to write a book and he'd be telling (the CSS) and (the CSS) (would) be giving him tips..." (PP5)

> "... although we meet (CSS) in the hospital, (the CSS) helps us more so with the stuff at home, not from an OT perspective, not from, but more just, just bringing joy." (PP4)

The transition into survivorship can poses challenges when curative treatment is finished. As the CSSS is available to families in the community for a limited time period, parents also spoke about the void that would be left when the CSSS was no longer available to them, which they felt was going to be difficult to fill:

> "... I don't know what we are going to do when we don't have our specialist, (the CSS) has just been invaluable..." (PP2)

> "Because they feel like they're losing out on their little lives. But (the CSS) was really great for (child with cancer's name) you know and then for (name of child with cancer) as well. I mean they actually miss (the CSS) now, they really miss (the CSS)... (the CSS) really made a 100% difference to the two of them." (PP8)

Discussion

Relational support is a frequently reported support need of parents in the literature (Cheng et al., 2022; Dwarswaard et al., 2016; Lewandowska, 2022a). Findings indicate that the CSSS added to the pre-existing services already available in the oncology services and enhanced the care provided to families through the provision of flexible, generic informal support. This support was positively appraised by the parents as it met many of their needs and assisted them in navigating the difficulties of childhood cancer. The additional relational support provided by the CSSS was especially appreciated by parents as it expanded the care beyond the medical needs of their children to encompass the family unit; this was reported by parents to be a comfort and a source of companionship. The informality of this support provided parents with the opportunity to chat informally and discuss their experiences outside of a medical or formal therapy context, allowing for a sense of normality for which parents expressed a strong need.

The provision of adequate informational support to families is an important need that is not always met (Cheng et al., 2022; Hashimoto et al., 2023; Nicklin et al., 2022). The CSSS's ability to provide parents with timely and appropriate information about available supports/services was said by parents to relieve them of the burden of having to seek out information and allow them to concentrate on caring for their child. In addition, the CSSS supported families in navigating the various charities and available services and supports. This is particularly important as it has been found that while many supports are often available for families of children with cancer, the lack of connectivity among these supports can make them challenging for families to successfully navigate, while the administrative burden can be a further source of distress (Delemere et al., 2023).

The strong rapport between CSS role holders and families resulted in improved communication to the extent that the CSSs often bridged gaps in communication between the MDT and families. This improved communication was also reported in a UK study of interprofessional care co-ordinators who worked within MDTs (Bridges et al., 2003) and support workers in community mental health teams (CMHT) who more readily formed stronger bonds with clients due to clients finding them less intimidating than professional members of the CMHT (Wilberforce et al., 2017). A challenge common to new informal psychosocial provider roles is role holder's lack of skills to navigate the boundaries of this rapport with patients, sometimes leading to the development of dependency (Procter et al., 2022). However, the healthcare backgrounds of the CSSs in this study are likely to provide them with the necessary skills to manage the boundaries of their relationships with families.

Although the provision of support to siblings is associated with improved psychosocial adaptation it can often be neglected (Sloper, 2000; Wawrzynski et al., 2021). Parents appreciated the provision of support to siblings as some were concerned that they had somewhat neglected siblings of the child with cancer. The provision of support to siblings enabled them to work through their complex emotions and introduced moments of levity in their lives. In addition, this form of support, including the presence of the CSS within the home, gave parents the time to consider engaging in self-care, as it relieved them of the pressure of having to engage their children when feeling emotionally and cognitively exhausted.

Chapter 4

Impact of the CSSS on the multi-disciplinary team members (MDT)

Introduction

Increasing childhood cancer survival rates and longer treatment times (Erdmann et al., 2021) due to newer treatments have led to a greater emphasis on the holistic nature of oncology care which includes the provision of psycho-social support to children and their families throughout the cancer journey (Wiener et al., 2015). Increasing survival rates and longer treatment times have also resulted in expanding roles for all healthcare staff working in paediatric oncology, irrespective of discipline (Challinor, 2023; Cummings et al., 2018). Traditionally nurses were the members of the MDT who most frequently developed the longest and most intense relationships with patients (Zarenti et al., 2021), however the increased time demands of the clinical component of nurses in paediatric oncology can result in nurses not having sufficient time for the provision of psychosocial care and the time for greater development of therapeutic relationships with patients (Chan et al., 2019; McCloskey & Taggart, 2010). While the literature is sparse in relation to other disciplines, increasing demands also affect the time other disciplines have to spend with families, stretching formal psychosocial support services, which ultimately result in increased waiting times.

Increased time demands can also be attributed to staff shortages (Murali & Banerjee, 2018; Zarenti et al., 2021). Indeed, retention of staff is an ongoing concern in the Irish healthcare system with high turnover rates (Fleming et al., 2022), and high rates of emigration (Brugha et al., 2021; Humphries et al., 2017). The ongoing global shortage of healthcare staff (Aluttis et al., 2014) exacerbated by the COVID-19 pandemic also resulted in an increase in turnover (Frogner & Dill, 2022), which in turn has impacted outcomes in adult and paediatric oncology internationally, including in Ireland (Seguin et al., 2022). Understaffing in oncology settings is a recurring issue in the literature particularly due to barriers in recruitment and retention including concerns about the emotional difficulty of the role and issues such as burnout (Challinor, 2023). In addition to increased workloads, and time pressures, a recent systematic review indicated that juggling multiple caring personas including providing medical and emotional care are risk factors for burnout (Zarenti et al., 2021). Although the CSS role is not aligned with a discipline, they are a member of the MDT. Hence this chapter focuses on the MDT perspective on the impact of the role.

Following analysis of the interviews with MDT members the following themes were developed which highlight some of the impacts of the CSSS on the MDT:

- Filling the gap of unmet needs for families
- Flexibility in the provision of the service for families
- Immediacy of access for families
- Freeing up time for clinical component of MDT work

Filling the gap of unmet needs for families

MDT members reported positively on the impact of the CSSS on their work. The availability of additional support for families was important to the MDT members as they noted that parents had unmet needs that could in part be met by the CSSS. In their view, the CSS role operated differently to other MDT team members and was outside of the traditional medical orientation of the MDT. In addition, in what they described as an "under resourced" (MDT2) setting, the presence of the CSS role was a welcome addition in meeting the needs of families:

> "The role operates outside of kind of the traditional MDT, so we all have our really specific roles whereas the cancer support specialist is able to kind of provide support I don't know I think for the families in a way that is less medicalised, less clinically orientated." (MDT16)

> "Listening more than anything... popping into a room... getting to know them from day one. Getting to know what's important to them, getting to know.... It was just building a relationship so that people feel safe that they can chat. And then if they can chat then you get to know them. If you get to know them and give them that time and just listen, listen, listen." (MDT17(ii))

The needs of families were emphasised by members of the MDT and having the auxiliary role of the CSS on the ward enabling the further prioritisation of families' multiple needs:

> "...we're not the important people in this, it's the patients and families, but I have to say my day is better when I see (CSS) on the ward because I immediately feel, okay, (the CSS) is here and you just know (they are) going to be with the families who need (the CSS)." (MDT18)

"They're (families) worried about this, they're worried about that. And (the CSS is) able to say, I can help with that, even some of it is very practical support that (they will) give them. Or meeting them and checking they're okay, sometimes it's a phone call. Or then (they) makes sure they go and have a cup of coffee, or you know links in with play and various people to make sure that the mum can actually leave and get a little bit of a break." (MDT9)

The generic nature of the CSS role was welcomed and valued by members of the MDT. Members of the MDT referred to having the CSSS as a relief, because it added another source of support to call on:

"I can say we have a support worker who will be there... in whatever way you want, rather than having a specific label, having a specific job description. This is a person as a generic support worker and I think that's the biggest aspect of it." (MDT19)

"I suppose we all had kind of almost like huge relief in us that there is somebody then that we can call when we don't have anybody else to call..." (MDT6)

"It definitely takes so much pressure off families. I keep coming back to that, it's an extra person, it's a friendly face coming in, even at the weekend sometimes, and I just... think it's good to have that, to build up a rapport with the families." (MDT12)

"The universal level of care is listening and making sure families have all the information they need.... the cancer support specialist is whatever the family needs at that time" (MDT17 (ii))

Flexibility in the provision of the service for families

The flexibility and availability of the CSSS at weekends was noted as a benefit as many services were provided only between Monday and Friday. Weekends are also a time when there are less members of the MDT working. The fact that CSSS was not restricted to a Monday to Friday or nine to five hours ensured that support was provided if families experienced challenges or if a child was in the ICU in the evenings or over the weekend, filling this gap within services:

"... (the CSS) does some weekends and that's been really helpful because you could be leaving a newly diagnosed family or a family of a child that has just relapsed. Or a child in ICU and they don't get much support then over the weekend... They do go up if they have to go to ICU and they're obviously very supportive." (MDT11)

"... we see lots of challenges at weekends. And having that flexibility, ...not being stuck to a nine to four rota ... is a brilliant addition I think." (MDT18)

"Being able to be available at a weekend to be a contact for a family ...perhaps there is an unexpected decline or deterioration. I think that's an amazing resource for people and certainly I think people who have had the support of a cancer support specialist over a weekend have really benefitted from it." (MDT14)

"I think there is a real gap in the service in that like if you look at weekends or evenings or something like that for a support person to actually be present, to be available to parents who need them. Because you know social workers and psychologists... only work kind of 9 to 5, all the other allied health professionals, OTs, physios... only work sort of 9 to 5. And then nurses are quite busy on the ward." (MDT5)

Evenings and weekends were identified as opportune times to provide additional support to families as it provides a greater opportunity to spend time with the wider family members such as siblings and other family member visitors. As there is less clinical based activity focused on the child during these times; it also allows for a quieter, less busy, environment for families to reflect on and address some of their concerns:

> "Whereas at least then if (the CSS) is around and has the capacity to be late and with more flexible hours, (the CSS) is catching parents at different times. If they're juggling, like mum is here during the day, dad comes in in the evening. But he might know more about this, or he might have a worry. It's easier to catch them when there's a bit more leeway in (the CSS') hours." (MDT10)

> "... when the humdrum of the day is settling down, the evenings, the weekend time, siblings come in, visiting people come in, and you've got a much greater out-reach and that's where we need to concentrate." (MDT14)

> "... I think there's some Saturdays covered, which is great... the weekend can be a long time for people. There's less people around and in a way it provides the families with more time as well, because there's less medical things, there's less scans, there's no scans unless someone's unwell. There's time for them to think and reflect and I suppose to open up to people as well." (MDT12)

Immediacy of access for families

The availability of the CSS support and immediacy of access to the CSS, which was partly enabled by having no waiting list was viewed as very beneficial to the care of the families:

> "You can just kind of nab her in the corridor and that has been the case exactly with me... I've referred at least three families, well not referred but have kind of brought to her attention that especially new families. They need a huge, huge amount of supports and then (the CSS) hasn't had any waiting lists like a lot of other services." (MDT16)

> "... really important to meet families as early as possible. You know because they're generally quite shocked. And they're not taking in information. They take in less we reckon about half the information. And then it's liaising with the team. And just kind of picking up little bits of information that might be useful for the team... So, it's listening, listening, listening, getting to know." (MDT17 (i))

The availability of the CSSs and their ability to provide support at the right time for families was also welcomed by MDT members:

> "... (the CSS) will always text so we'll always arrange a day and then (the CSS will) text the week before or whatever and I can always WhatsApp (them) yeah if there's anything... so very, very easy to reach." (PP2)

> "... it's very hard to just get that time that you can sit for half an hour and just listen. So that's been amazing... after leaving here say (the CSS) would go up to ICU for example for a weekend to see families and they are just blown away by that support. And to be honest I kind of feel like they've gotten through it much easier than they might have otherwise, you know." (MDT7)

Freeing up time for clinical component of MDT work

Combining clinical work with family support was spoken of as a challenge for the MDT. Hence clinical work often took precedent over time spent supporting families. A combination of a lack of time or specific training were noted as factors in the ability of the MDT to respond to families adequately:

> "Because I have to go do four hundred and one other things... as much as you want to give them the time. But we're also not hugely, we wouldn't necessarily have a huge amount of training in how to support somebody either...Yea all of that as much as we'd love to be able to do it, there's often the time limitations." (MDT9)

> "Having the time to listen. A lot of us don't have the time and also having the right words in incredibly difficult situations." (MDT16)

Members of the MDT also commented on how the support the CSSS provided to families enabled them to concentrate on the clinical component of their work, while being assured that the needs of families were being met:

> "Where we find the support worker, we might say to them can you sit with mum or dad, while they run out to do something. And that's been great support with us... I'm not talking about their taking over jobs from us. They're actually allowing us a little bit freer to do our nursing jobs. And (it) is a good support in a nice way... a huge support. And I find the person very supportive to nurses..." (MDT4)

> "I know if (the CSSS) is supporting a family I can go in and concentrate on the oncology directed care and the medical piece." (MDT14)

> "... every... component to the MDT is just delighted when we see (the CSSS) on the ward, we know that our day will be better. We know the families' needs are going to be met and I think it allows everyone to stay in their lane..." (MDT18)

Members of the MDT also noted how parents felt a sense of relief when the CSSS was on the ward, and reported that the feedback they received from families on the impact of the CSS was overwhelmingly positive:

> "I find it really hard to have anything negative to say about the service because you know the feedback from families which is the most important indicator of how we are doing actually has been overwhelming positive and you know just having that extra support to lean on... in time of distress of which there are many in a patient's cancer journey." (MDT14)

Discussion

Caring for the family who is experiencing the disruption and distress of childhood cancer requires a coordinated MDT approach (Loh et al., 2023). It is vital that parents' support needs are met during and after their child's cancer treatment (Melguizo-Garín et al., 2023). The MDT members in this study reported positively on the auxiliary impact of the CSSS on their work in providing care to families. It is important to acknowledge that the MDT participants were not in a position to provide the same level of detail on the impact of the community CSS role as they could on the impact of the ward-based role.

An important finding was the perception that the work of the CSSS supported the MDT in caring for families. Members of the MDT mentioned that they did not always have enough time to spend with families and to provide the informal psychosocial support that families required or the required skills to provide this support. Increased treatment times (Erdmann et al., 2021), expanding roles due to increased treatment complexity (Cummings et al., 2018) and challenges in staff retention in paediatric oncology (Challinor, 2023) can result in a lack of time and ability to provide informal psychosocial support. The CSSS's provision of this support allowed the MDT to focus on the technical and medical aspects of care while being assured that families' informal psychosocial needs were being

met. A common benefit of the implementation of informal psychosocial roles within the literature has been to reduce the work burden of healthcare professionals in this way (Bridges et al., 2003; Shelton et al., 2010; Stanmore et al., 2006; Wilberforce et al., 2017).

Meeting the informal psychosocial needs of children and families out of hours including on evenings and weekends was a challenge for the MDT prior to the implementation of the CSSS. Increased accessibility of psycho-oncology services is a recognised need of families of children and adolescents with cancer (Delemere et al., 2023). Many hospital services are not provided on a 7-day model except nursing and medical staff, with many allied health professional services provided Monday to Friday only. The provision of allied health services on weekends is an ongoing debate in health service design, research and policy (NHS, 2013). One participant suggested that these families' needs on weekends could be met with additional staff, however staff shortages in paediatric oncology are an issue both in Ireland and internationally (Seguin et al., 2022). The flexible provision of support to families by the CSSS out of hours, in the evenings and at weekends was particularly welcomed as it filled a gap in care at these times. This is reflected in the literature on the weekend provision of allied health services (O'Brien et al., 2017). Participants noted the presence of the CSSS on the weekend also allowed for greater access to patient's families, which has also been found in the literature (O'Brien et al., 2017). Well timed and immediate support for families during working hours was an additional benefit to the MDT as waiting lists for other services tended to cause some delay in meeting families' needs. The immediacy of access to the CSSS for families reduced unnecessary stress for families' during the cancer journey, as short wait times are associated with improved patient satisfaction (Abbasi-Moghaddam et al., 2019).

Chapter 5

Contextual and mediating factors that influence the implementation and integration of the CSSS

Introduction

Implementing new roles in existing healthcare systems is a complex process which can present a number of challenges (Higgins et al., 2020). These challenges may be compounded within a boundaried health system, when a role is not aligned with a specific discipline. International research indicates that the flexible design of new roles is an enabler to their implementation and integration as it is associated with an improved level of informal psychosocial support provided to patients (Bridges et al., 2003; Cain et al., 2020; Gilburt, 2016; Herber & Johnston, 2013; Manthorpe & Martineau, 2008). Flexible designs however can also present a challenge due to a low level of clarity around the duties and boundaries of new roles leading to tension and conflict with pre-existing MDT members (Cain et al., 2020; McCrae et al., 2008; Wilberforce et al., 2017). A lack of support, supervision, and training specific to new roles can exacerbate both boundary issues, and difficulties in navigating professional relationships with patients (Bennett, 2016; Cain et al., 2020; Huxley et al., 2009; Wilberforce et al., 2017). The body of literature on informal psychosocial support roles is small, and as few studies formally explore challenges and enablers to implementation, there is little research on determinants that influence each stage of the implementation process as outlined in the CFIR (Damschroder et al., 2022).

Following analysis of the interviews with MDT members, CSS role holders, parents and stakeholders the following themes were developed which highlight some of the challenges and enablers to the implementation and integration of the CSSS:

Challenges

- Role clarity and boundaries
- Co-ordinating communication in implementation

Enablers

- Role holder characteristics
- Liminal nature of CSS roles
- Flexible nature of CSS roles
- Willingness of charity and role holder to adapt role descriptions
- Extensive engagement to resolve challenges

Challenges that influence the implementation and integration of the CSSS

The challenges to the implementation were Role clarity and boundaries, and Co-ordinating communication in implementation.

Role clarity and boundaries

At the intervention level, a lack of understanding of the role by some members of the MDT in the early stages of the implementation resulted in their having reservations about the role's integration in the ward. Participants also recognised that introducing any new role is likely to involve territorial challenges, and while the flexible design of the CSS roles was an enabler at the level of the intervention, the integration of new informal and flexible roles into a boundaried health system posed particular challenges. A broad job description was perceived to be necessary to build in flexibility to the roles, however, the broadness of the description was perceived by some members of the MDT as not providing sufficient clarity for the role's boundaries:

> "... there's massive potential and need. But... I suppose the broadness of the job description didn't help." (MDT1)

> "I think everybody was delighted with the extra support and the extra resources and I think that was across the board, but there was some concern about the... boundaries of the role and how do we integrate successfully that type of role in our already complex MDT system." (MDT15)

In the early stages of the implementation of the CSSS, when the role was at its most flexible, there were concerns from some disciplines about the ward-based CSS performing what were perceived to be discipline specific tasks when members of other disciplines were not available to perform these tasks, and perceived insufficient communication when this occurred:

"... now we'd be very happy to have someone else do them but obviously that needs to be agreed and formalized and, you know, everyone needs to be at the table for that. So there's just so much uncertainty and not knowing actually what roles were being done and what pieces of our work were being done sporadically, maybe at a time of crisis, maybe it's when we're not there, but there was no note or no update to say, look, I've just stepped in here and completed this task because there was an urgency or because the mum was upset or for various reasons..." (MDT3)

This occurred in part due to the ward-based role holder having previously held a role in a different discipline within the ward resulting in parents and members of the team not always realising that they had changed roles, and thus expecting the role holder to perform duties associated with their previous role. This initial confusion exacerbated concerns from other disciplines that the boundaries of the role had the potential to blur with the boundaries of their own roles:

"Sometimes... people can still be a little bit confused over roles. And again, it takes people if they've been off for a while and to see (the CSS) who is in post at the moment. You've nearly to remind them, no not in (their) old role. (They are) in this new role. And this new role has a different remit, it's got different boundaries and so we do things differently." (MDT9)

"... I was with... in a round last week just talking about the cases. And... some of the consultants rely on (the CSS) like really too much as well... It's like oh can you do that, yea can you do that." (MDT7)

Some charities and hospitals presented organisational boundary challenges when CSSs in the community engaged with them, such as questioning the role and whether it overlapped aspects of their own organisation's activities:

"There is still some resistance from professionals as to, are (CSS)s stepping on their toes. ... are (CSS)s sort of threatening their role?... And they'll ask very basic questions... Like do parents need to give consent?... There's a mindset of sort of ownership. So, ownership of the family, instead of realising just let that go." (MDT22)

A primary challenge concerned the description of the ward-based CSS role, particularly the use of terminology which was believed by some members of the MDT to be discipline specific such as therapeutic and emotional support. While both terms were removed from the job description, the provision of informal emotional or relational support to families was believed by a number of participants to be a natural aspect of each role within the ward from the MDT to household staff in addition to their stated role duties:

"The most important person on the ward providing emotional support is a lady... who brings the tea... everybody provides emotional support." (MDT17)

"I am talking yes more informal and maybe they would feel more likely and more open to discuss certain things with them as is the case so often with the household teams. Like if you want to find out what is going on with a family talk to the people that are in and out all the time doing nonclinical work." (MDT16)

"...I think COVID has played a huge part as well, but what I have noticed over the last three and a half years, increasingly, the patients and families have looked to me and my colleagues or to the clinical nurse specialists or to the nurses on the ward to try to get that emotional supportive piece because they're just not getting it from everyone else and COVID played a part in that because before the grandparents used to be in..." (MDT18)

"...it's fantastic, obviously our role is supporting as well, but on a more medical base and kind of managing expectations and stuff like that, but we're not counsellors, we're not trained to provide that support..." (MDT12)

Co-ordinating communication in implementation

A challenge in the early phase of the implementation of the CSSS was in coordinating communication and engagement between key decision makers and those in leadership positions. This was a challenge due to general understaffing in the ward, staffing changes within disciplines and differing periods in leave among those on the ward who were championing the CSSS and those who had reservations about how the new service would best integrate into the MDT. These factors may have resulted in a perceived lack of engagement and communication from the perspective of both champions of the CSSS and those who had reservations as the following quotes illustrate:

> "... the role profile was shared with disciplines and... I think got an email back from one of the disciplines with twenty questions. And they were meaty, meaty questions. It must've took me three or four days to respond to them all. And I responded to them all and I've yet to see a response to that email. So, because the team changed and then it moved on." (MDT23)

> "... we had a couple of newer seniors in that area. And so they were aware of it. But I'm not sure that they saw the, particularly the significance... it was a bit of a perfect storm, both (a senior member of the MDT) and (a senior member of the MDT) had been on leave at different periods. So, I suppose I was kind of getting to know about this when it was almost, you know had been advertised..." (MDT1)

This resulted in "a rocky start" (MDT15) for the role, as there was a feeling that not enough engagement had taken place with all members of the MDT, and that some of their concerns had been dismissed. At the time of the earlier interviews, participants in some disciplines believed that more communication was necessary to enable improved integration of the first of the CSS roles:

> "... I would just recommend more communication in terms of how the post could best be used to compliment the services already in place with the professions already in place, that would be my recommendation." (MDT2)

However, by the time of the latter interviews in the study, participants noted that the CSS in the ward had settled into the workplace structure within a psychosocial model of care that follows the NCCP guidelines and the NCCP's Model of Care for the provision of psychosocial and psychological support services for CAYA:

> "... because the universal level of care fits into the model, it suits... it makes perfect sense for continuity... we're very happy to sit under this new psychosocial model of care which falls under the NCCP guidelines for care. And which absolutely includes, the CAYAs model of care... a model which we operate under, which is the preventative model of care for children and family." (MDT17 (ii))

Enablers that influence the implementation and integration of the CSSS

Five enablers were identified that supported the implementation and integration of the CSSS, these were Role holder characteristics, Liminal nature of CSS roles, Flexible nature of CSS roles, Willingness of charity and role holder to adapt role descriptions, and Extensive engagement to resolve challenges.

Role holder characteristics

At the individual level, the professional backgrounds of the CSS role holders in paediatric healthcare settings were considered by participants including parents, members of the MDT and CSS role holders to be an enabler in implementing the CSSS due to the skillsets they brought to the service. This included having knowledge and understanding of paediatric cancer settings and knowing how to navigate healthcare systems. These skillsets enhanced role holders' familiarity with the local context of the ward and the community setting, increasing the speed of their integration:

> "... because (the CSS) worked on the ward as well I think that's been a huge help. Because (they) know what it's like to be there... it made that transition much easier... Because... it's hard in oncology haematology, it's not easy to be there all the time..." (MDT7)

"... our CSS has massive experience in the area and it's great because (they have) an awful lot of knowledge and also many links to so many services from (their) years working in John's before this." (MDT12)

"...we are blessed with the current support worker having considerable experience in this field..." (MDT19)

Similarly, the role holder's backgrounds allowed for an in-depth understanding of the medical terminology and experiences of parents of paediatric cancer patients, which participants believed enhanced the role holder's abilities to quickly and effectively provide informal support according to each family's circumstances. As previously discussed in chapter three, this meant that the informal support provided by CSSs was at times favoured by parents over that provided by friends as the parent did not have to expend energy explaining details to the CSS about their child's current stage of treatment:

"... it's easier to text (the CSS) back or ring (the CSS) than a friend, because (the CSS) knows... has that clinical... so it's a fast... this is happening," and (the CSS)'s like "Oh right, okay... Whereas I'd be quicker to text (them) back sometimes than a friend.... I don't have to go into mega detail... I just don't have the energy for you today, I'm just... having to explain all this." (PP6)

Members of the MDT and parents noted that the personal characteristics of role holders enhanced their ability to build a rapport with families and provide informal support. These included an innate ability to identify people's needs and priorities, and an ability to meet these, being suited to their position and having a good understanding of children:

"The willingness to work and help families, the kindness, not putting themselves first, not talking about capacity, just willing to help, just a really nice, helpful person." (MDT13)

"... (the CSS) has an incredible, very natural ability to get to the crux of what people want and what their priorities are, exactly what they need, (they are) able to identify that magically... (they) seem to know innately what people want and need and has an incredible ability to make that happen." (MDT18)

"... (they have) an old head on (their) shoulders..., (they are) a nice (person)... just well rounded... very suited to (their) position as well... (they have) a good understanding of children." (MDT11)

Flexible nature of CSS roles

At the level of the intervention, one of the most significant enablers was the flexible design of the CSS roles. This enabled role holders to be responsive and adaptive to the informal support needs of families. This was achieved firstly by ensuring that aspects usually associated with healthcare roles such as statutory requirements, the need to spend time completing documentation and waiting lists could be avoided:

"We don't grind them down with bureaucracy and form filling and statutory requirements. We make it free, so the worker is 90% of the time in front of families. So, it is flexible..." (MDT23)

"... for the majority of our services there's waiting lists and there's no waiting list for this role and this is something the families really like because it's accessible straightaway." (MDT15)

Secondly, members of the MDT emphasised that while each member of the MDT had a clinical agenda in addition to providing informal support to patients and families, the only agenda of the CSS role holders was to support families. Rather than having specific duties, the ward-based role operated under principles which centred around being present with the family, giving them time, and listening rather than asking questions:

"... in one sense this person doesn't have any specific job... come under it. And in another sense, it is very, it has very specific principles. It's like a friendly face going in to talk to the parents... Whereas physically they may not put their arms around a child and family that's what they're doing in a different form. They're sitting with them; they're giving them this listening ear... and taking direction. They're giving probably the parent and child a little bit of maybe control back." (MDT9)

"... we will spend time with the families as medical professionals. To sit in and answer all of their questions. But... you need somebody to sit and listen. And somebody with some level of understanding... I think that's where this role has been really important... sometimes you just need people to either be silent and listen, or to help you process through what nobody should have to process through." (MDT8)

"... a space for the child to be able to talk... to be able to process what they've been going through... I think they really appreciate that it's not forced... (have) had multiple parents say... to (the CSS), are you a counsellor, are you going to be asking like about feelings... and then they're instantly reassured when (it is explained that the CSS') role... is to have fun with them. And to use that space of relationship... for them to open up and talk if they want to, and... have that environment of trust." (MDT22)

This flexibility enabled the CSSs to focus entirely on the families' informal support needs at a universal level of care, including providing navigational, relational, and practical support such as shopping and doing small errands for families to reduce their levels of stress:

"... the universal level of care is... is whatever the family needs. And it's, it can be anything, it can be anything from going out to making a cup of tea. To doing more in-depth work and sitting and listening... Anything that alleviates a little bit of stress. (The CSS) would have on occasions popped into (names shop) and brought in clothes... it's whatever's needed at whatever time. And that's what's lovely about this role." (MDT17 (ii))

The amount of time the ward-based CSS had to spend with families was noted by MDT members as a particular advantage because time was generally in short supply on the ward:

"... having I think the cancer support specialist role because you know primarily a support role, I think they have the time to spend with families that we don't have." (MDT14)

The need for this informal support, particularly in the ward, was said to have increased since the COVID-19 pandemic which resulted in a restriction on extended members of the family, and siblings visiting the ward to limit the spread of COVID-19. This left a gap in the support received by families. Many of the participants mentioned the benefit of the ward-based CSS having the flexibility to make themselves available in the evenings and on weekends. This availability was said to fill a gap in the support needs of families as prior to the introduction of the service there had been no support workers operating at these times:

"The strength is there is a support worker who's able to come at any time of day and night in the hour of greatest need for our patients. I've seen the greatest effect... in the terminal phase of a patient's journey... and bereavement... I've seen that incredibly helpful at antisocial hours, Saturday, Sunday, when we don't have any official support worker or a support service on the ground." (MDT19)

"... the flexibility of the service being available at weekends... Families have the time to kind of catch up and breath after a busy week of doctors in and out every day and investigations and trips to theatre... being... available at a weekend... for a family who you know perhaps there is an unexpected decline or deterioration... I think that's an amazing resource for people and certainly I think people who have had the support of a cancer support specialist over a weekend have really benefitted from it." (MDT14)

"Or the mum has come in from home and she suddenly says to somebody, oh I have a problem. Or I want to come in, but I can't because things often arise at five o'clock in the evening. Whereas at least then if (the CSS) is around and has the capacity to be late and with more flexible hours (the CSS) is catching parents at different times." (MDT10)

Members of the MDT said that while they would like to provide this support, they did not feel they had as much time as the families required due to their ongoing clinical duties in the ward:

"...I think again being able to plug that hole or the gap in the social support piece for parents is really crucial. And sometimes they just need someone to sit with them you know sometimes just to sit and listen, and you know I think parents really need that time to feel listened to and to feel understood. And with the best will in the world, we do it social workers do it, the physios do it, the play therapist do it but we don't always have the time..." (MDT14)

CSSs in the community were enabled by the flexibility of their roles to develop strategies to engage with different categories of patients, from different age groups to genders, and improve their ability to connect with families. When a young adolescent patient did not appear to be responding to one of the CSS's prepared games, the inbuilt flexibility of their role enabled the role holder to engage the patient using a novel technique of testing the different hot chocolates available in the nearby village:

"... I just kind of felt like, (adolescent) just wouldn't talk to me. And I said it to someone, and they gave me a couple of games. You know (the adolescent) had to talk. And then I just said it to the mum one day... I was like look, is it okay if we go and I really felt like we needed to go out of (the house). And the first day I went (they) met at my car when I was parking. (They were) ready to go. And I was like, oh my God and (they) was like a different child. And it's, do you know I find like literally I just said right we're going to do a hot chocolate challenge." (MDT20 (ii))

Liminal nature of CSS roles

A unique strength of the CSS roles, as noted by participants, was that they occupied a liminal space between the formal healthcare provided by the members of MDTs and companionship as provided by family and friends. This was due to the design of the roles in providing informal support, and the focus of the roles on supporting the family. When discussing the CSS role, participants including members of the MDT, CSSs, the steering group member and parents tended to use terms that reflected this liminal space between formal healthcare and informal companionship, and its benefits to families such as friendship, warmth, presence, and feeling valued:

"... this role was definitely about supporting the whole family... and the wider family. How... can a family navigate the experience of hospital and be supported during it. And like a warm introduction to the hospital and a warm hold throughout. So, and not very specific... it was more just to be there." (MDT23)

"I know that there are support specialists in the North... and we had been told about what they did, but I just thought it seemed like a lovely presence to have on the ward." (MDT10)

"... the feedback really early on is the surprise (of) the families that (the CSS is) coming to their house. So firstly, that it's free, so they're not being charged for this. Understanding that (the CSS is) not part of the medical team... that kind of dawns on them, oh so (the CSS is) not part of the medical team. And yet (the CSS is) still coming out here. And then... the penny drops of we can't believe (the CSS) coming all this way just to do this work with us... I think it makes them feel special, it makes them feel valued." (MDT22)

"... having someone who is not like a member of you know the MDT, like I know they do attend the MDT meetings, but they're not seen as an employee of Crumlin... and... they're in their own clothes and... they have a different kind... ID. I think it can be seen as definitely something that's more informal and considered more of a chat. And I think that can really help parents... (MDT4)

As a result of the CSSs occupying this liminal space and spending time with the families, participants noted that they were able to connect with the family on a level beyond that of many members of the MDT. This enabled the CSSs to improve communication between members of the MDT and families to the benefit of both families and the MDT:

> "So, we might think that there's one issue going on with the family. But then (the CSS will) come back and go, actually the reason why they're not turning up was financial. It's not because they don't believe in the treatment, or they don't want their child cured. So, (the CSS) will find out that." (MDT8)

Extensive engagement to resolve challenges

Engagement between primary stakeholders from the KNF, CFFC and a member of the medical team in CHI at Crumlin was an essential enabler in developing the plan for the CSSS. Participants emphasised the extensive engagement of stakeholders and potential collaborators during the implementation process, including those who had expressed reservations with CSSS. The initial agreement and support of senior staff in St. John's Ward was an essential enabler in the implementation process:

> "I think we then we introduced to... a team of real senior (members of a discipline within the ward). A couple of (members of a discipline within the ward) maybe in the February, just before the pandemic hit. And in that meeting basically it was like green light, green light, green light..." (MDT23)

The willingness of champions of the CSSS to work to ensure that the CSSS complimented the work of other disciplines on the ward, combined with the family centred focus of the MDT were further enablers in the implementation process:

> "... let's negotiate and let's negotiate with grace. And let's negotiate with humility. We're the visiting organisation here so we need to make it work... I think we went into every negotiation saying we're here to compliment, let's talk... and I know these people are busy... But that shows you their belief in their work and their genuine love for families... And I have never worked in a clinical environment where people care more about families in my working career... we're happy to do the work because I've nothing but respect for these professionals." (MDT23)

As part of this engagement, there was a need to educate members of the MDT on the duties of the role and how they differed from existing healthcare roles. This was necessary as being a new role in the health system, there was some confusion about what the role entailed:

> "... the first thing we had to do was to have meetings. This role... it's just a new way of working... there is a link person in the hospital. But the line manager for this role is external. And that's the first thing people have to realise... So, it meant, the concerns people have; we had meetings then with the line manager, with the person in the role... just to listen to people's concerns, to iron out their concerns, and see could we address them. And again, reiterate what the role is about, why the role was established. What's the aim of the role and why we're rolling this out?" (MDT9)

> "... what became clear was that education was needed with (members of a discipline on the ward) and saying I understand that this family needs to see (discipline), what I can do is I can advise them where they can get this information, but I can't do it for them because it's the (discipline)'s role and its causing difficulties. And we need to work together, we have to find a way. So, it took almost that year for the (members of a discipline on the ward) particularly and (members of a discipline on the ward) to say ... will you go see that family, I know you can't do this piece, but will you please do that piece..." (MDT17 (i))

The willingness of members of the MDT to engage in negotiations, despite their reservations about the role, was an important enabler. The process of engaging with members of the MDT to integrate the first of the CSS roles was said to have continued for the first year of the role holder's occupancy in the role. While the majority of the MDT members were in support of the role, some continued to have reservations around the specifics of the role:

> "Then the role came in and again I met with (discipline within the ward) ... so there was an awful lot of, with the principle it was around agreeing this. And the role's not this, is it this, no it's not that. And so, there was a bit of toing and froing... I met with (discipline within the ward). I met again... my role became the person in meeting these different disciplines, trying to pave the way, and trying to soften the land along." (MDT23)

> "... in the last few months there's definitely been more effort for trying to kind of integrate, it's still a concern for me, but there's definitely been more effort to get stakeholders around the table." (MDT15)

The implementation of the first and subsequent CSS roles in the community benefited from the negotiations conducted around the first role. In addition to having addressed reservations of some people, there were also procedures in place for subsequent CSSs such as a referral system via the ward-based CSS:

> "... the referrals are the majority are coming from either (the CSS in the ward in Crumlin) or community nurses and the life limiting nurses or AYA nurses." (MDT20 (i))

A further enabler was the CSS role holders in the community's willingness to engage with local hospitals, shared care centres and charities to develop a wider referral network. This experience of developing working relationships and receiving referrals was mostly positive with staff in shared care centres, hospitals, palliative care settings and charities responding positively to the potential for the role holder to provide support to families of their patients:

> "But I suppose how I went about it was I called them first the share care centres... I usually ask to speak to a nurse manager or an CNS. Some of the hospitals don't have a specific CNS... told them who I was, told them what I do. Some of them were so excited... couldn't wait... could you do something with this family, could you do something with this family..." (MDT21)

Willingness of charity and role holder to adapt role descriptions

The CSSS as initially envisioned by CFFC and the KNF necessarily required adaptation for the first of the ward-based roles to best fit within the work infrastructure of the ward and to a lesser extent for the first of the community roles to fit within the community's referral network. The two charities worked with the MDT to address concerns and adapt the ward-based role to find a match between their initial vision for the service and the needs of the ward, further enabling the implementation and integration of the service:

> "... what the role became, what it is now is potentially different where we started... and there is always a point in this which is getting a function and need to be clear about... who we are and what we are. We are not a counselling organisation. We are not a social work organisation. We are not a play therapy organisation, but we are an informal social, emotional support. And we are prepared to be really flexible around that..." (MDT23)

An enabler in this process was the ward-based role holder's understanding of the necessity to adapt the role to the needs of families while ensuring compatibility with the existing formal psycho-social support in the ward. Additionally, champions of the role within the ward assisted in this process of adapting the ward-based role to address concerns about the overlapping of the role's boundaries with those of other disciplines on the ward:

> "And then (we) did have an opportunity to meet with (a senior member of the MDT) who was involved to look at some of the job description and to see if we could tweak it a bit. Because you know there was a bit of concern at the overlap. Because it was quite a broad job description." (MDT1)

Discussion

Five enablers and two challenges to the implementation and integration of the CSSS were identified. Enablers were CSS role holder characteristics, Flexible design of the CSS roles, Liminal nature of the CSS roles, Extensive engagement of key stakeholders and collaborators, and Willingness of the charities and role holder to adapt role descriptions. Challenges were Role clarity and boundaries and Co-ordinating communication in the implementation process. It is again important to acknowledge that the MDT participants were not in a position to provide the same level of detail on impact of the community CSS role as the ward-based role.

A key enabler in this study was the flexible design of the CSS roles which enabled role holders to meet the psychosocial needs of families in a flexible and responsive manner. The flexible design and boundaries of new informal psychosocial provider roles are key determinants which can enable the implementation and integration of these new roles (Bridges et al., 2003; Cain et al., 2020; Gilburt, 2016; Herber & Johnston, 2013; Manthorpe & Martineau, 2008). The flexible and responsive design of the CSS roles was achieved through a broad job description focused on the provision of support to families, and which did not include tasks often associated with healthcare such as requiring the documenting of cases or the use of waiting lists. Members of the MDT spoke of their having clinical agendas which limited their ability to meet the informal support needs of families whereas the CSSs primary agenda was to provide informal psychosocial support to families, and so could spend more time with families than many other members of the MDT.

The flexible design of the CSS roles, and informal nature of the support provided, resulted in the CSS roles occupying a liminal space between formal healthcare and informal support as provided by family or friends. This, aligned with the increased time the CSSs spent with families, and the CSS's lack of a medical agenda led to the development of strong rapports with patients and their families. The individual ability to develop a strong rapport is an integral part of new informal psychosocial roles. As such, the personal characteristics of role holders can dictate the role's success (Procter et al., 2022; Sobotka et al., 2022). The CSS role holders' personal characteristics were perceived by both members of the MDT and parents to enhance their ability to quickly and efficiently connect with families and provide support. The backgrounds of role holders in paediatric healthcare provided them with knowledge of paediatric oncology and associated skillsets which similarly enhanced their ability to integrate into the work infrastructure of the ward and the community, and to quickly understand the changing medical circumstances of the children of parents. Introducing a new informal and flexible role to a boundaried health system posed a challenge to implementation and integration in the ward setting. This is reflected in the literature on new informal psychosocial roles (Cain et al., 2020; McCrae et al., 2008; Wilberforce et al., 2017). The broad job description provided a low level of clarity around the CSS roles, resulting in some MDT members misunderstanding the CSS role, and having concerns about the CSS overlapping the boundaries of existing roles in the team. Broad job descriptions for new informal psychosocial provider roles have previously led to concerns about role holders unconsciously breaching the boundaries of existing professional roles, duplicating work, and taking on tasks without having professional accountability leading to tensions between MDT members and the new role holder (Cain et al., 2020; McCrae et al., 2008; Wilberforce et al., 2017). While boundary breaching is often compounded by a lack of training for new roles in the literature (Cain et al., 2020; Wilberforce et al., 2017), this was not the case for the CSSS as the CSS role holders had strong skillsets from their backgrounds in healthcare. These backgrounds however resulted in some MDT members and parents initially expecting the role holders to perform duties associated with their previous healthcare roles, which initially compounded MDT member's concerns of overlapping duties. While this issue was not found in the literature, differing role expectations resulting in new role holders working beyond the boundaries of their roles can occur when MDT members (McCrae et al., 2008; Stanmore & Waterman, 2007) and patients do not receive adequate notification of new roles and their duties (Procter et al., 2022; Smith-Merry et al., 2015; Sutton et al., 2016).

The extensive engagement of stakeholders and potential collaborators and the willingness of the charities and role holder to adapt the ward-based role to match the stated needs of the MDT and fit within the work infrastructure of the ward were important enablers in negotiating the successful implementation of the CSSS. Interestingly, there is little on the engagement process or adaptations in the small body of literature on the implementation of new informal psychosocial provider roles, which may be due to many studies occurring after the implementation of the role. However in one study, which was conducted prior to the new role implementation, engagement with the MDT on the role's job description was associated with a greater appreciation and integration of the role (Rolfe et al., 1999).

While extensive engagement was an enabler, there was some difficulty in co-ordinating communication between key stakeholders due to understaffing in the ward, staffing changes within disciplines and differing periods in leave among those on the ward who were championing the CSSS and those who had reservations about how the new service would best integrate into the MDT. This resulted in a perceived lack of engagement and communication from the perspective of both champions of the CSSS and those who had reservations which may have prolonged the engagement process.

The expansion of the CSSS was enabled firstly by referrals from the first CSS in the ward to new CSSs, and secondly by the engagement of CSSs in the community with local hospitals, shared care centres to develop additional referral pathways. This latter engagement often took the form of educating potential collaborators on their roles, particularly those who may have been concerned about the CSSS breaching the boundaries of their organisations. New informal psychosocial support providers can feel a need to 'sell' their roles when meeting with potential collaborators outside of their immediate team or organisation (Cain et al., 2020; Smith-Merry et al., 2015).

An initial challenge that was resolved by this adaptation was the inclusion of the terms therapeutic and emotional support in the CSS job description, both of which were deemed discipline specific and not appropriate for an informal support provider role. While these terms were removed from the job description, many of the participants believed that the provision of informal emotional support was a necessary aspect of working on the ward from the MDT and household staff, as has been previously recognised in the literature (Datta et al., 2019; Vance et al., 2022).

Chapter 6

Future directions and sustainability

Introduction

While the previous three chapters outlined the impact of the CSSS on families and on the MDT, and enablers and challenges to its implementation and integration, this final results chapter addresses the future of the CSSS including determinants to its sustainability, and participants' visions for its future. Sustainability in this study relates to the sustainability of the CSSS and the role holders that make up the CSSS, and is an important factor in planning the continuation of new interventions (Shelton et al., 2018). Determinants to the sustainability of new informal support roles and new healthcare roles have received less attention in the literature than determinants to their implementation and integration. The research on the sustainability of new roles in healthcare mostly refers to organisational factors (Crespo-Gonzalez et al., 2020; Maxwell et al., 2013a). This research indicates that many of the enablers to the implementation and integration of the CSSS outlined in the previous chapter are likely to positively affect the sustainability of the CSSS such as its gradual implementation, and the flexibility of the roles (Crespo-Gonzalez et al., 2020; Maxwell et al., 2013a). The findings in this chapter refer to sustainability at the individual level and the level of the intervention.

Burnout is a well-documented factor in the sustainability of healthcare roles (Taranu et al., 2022), due to its links with intention to leave and turnover (de Vries et al., 2023). MDT members working in oncology settings are repeatedly exposed to situations with a high emotional load and frequently experience compassion fatigue (Van Mol et al., 2015). This puts them at a high risk of burnout (Macintyre et al., 2022; Murali & Banerjee, 2018). A contributing factor for burnout in nurses is the development of long term relationships with patients (Macintyre et al., 2022). CSS role holders may be similarly at risk of burnout due to the strong rapport they develop with families who are undergoing traumatic events. A further contributing factor to burnout is when the demands of a job exceed a healthcare worker's available resources (de Vries et al., 2023; Meredith et al., 2022).

The informal psychosocial focus of the CSS roles may however be a protective factor against burnout. A recent systematic review found that psychosocial clinicians such as social workers and psychologists in oncology settings were at a lower risk for burnout than their nursing and oncologist colleagues (Morris et al., 2021). This lower risk was attributed to their not experiencing moral distress regarding treatment decisions to the same degree as nurses and oncologists. This lower risk could be attributed to their inbuilt and ongoing clinical supervision/ reflective time that is not a feature of nursing or medicine in paediatrics despite the gravity of situations they continuously deal with. Additional protective factors were having more experiences of patient's recoveries in terms of distress reduction and the development of coping skills. Motivation and the ability to find meaning in work are further factors which can protect against burnout and contribute to the sustainability of healthcare roles (Morris & Bird; Tokarz & Malinowska, 2019).

Following analysis of the interviews with MDT members, CSS role holders, parents and stakeholders the following themes were developed which highlight some of the enablers and challenges to the sustainability of the CSSS, and participants' visions for the future of the service:

- **Sustainability enablers**
  - Role holder's intrinsic motivations to work in the CSS roles
  - Expansion of the CSSS
  - Boundaries for community-based CSS role holders
  - Supervision
- **Sustainability challenges**
  - Initial limited number of CSS roles
  - Wellbeing of role holders
- **Visions for the future of the CSSS**

Enablers to the sustainability of the service

Within the theme of sustainability, four enablers and two challenges to the sustainability of the CSSS were identified. Enablers were the role holder's intrinsic motivation to work in the CSS roles, the expansion of the CSSS, boundaries for community-based CSS role holders and supervision.

Role holder's intrinsic motivations to work in the CSS roles

Each of the CSSs had previously worked in permanent healthcare positions which had come with higher levels of pay than the CSS roles. All role holders mentioned that they were motivated to take on the role of CSS because it aligned closely to their intrinsic motivations to work with and to support families and children. This motivation enhanced the service they provided and enabled the sustainability of the roles:

"... I am very satisfied like I still can't believe that this is my job you know I am someone said to me the other day I found my niche and I am like I think I have because I love all this. I love the craft, I love the mindfulness, I love the support..."

"... this role has given (the CSS) the freedom to, you know... do what (they) want to do and that's just minding kids and families really."

Expansion of the CSSS

A second enabler to the sustainability of the CSSS was the ongoing expansion of the CSSS. In addition to the appointment of community roles during the study, participants anticipated that a planned second ward-based CSS would relieve the workload of the first CSS. It was also expected to extend the provision of informal support to more families:

"... they've advertised the post around the country. I think it'll help (the CSS) hugely... because they can take the stuff in the shared care a bit off (the CSS) ..." (MDT7)

Boundaries for community-based CSS role holders

An enabler for the sustainability of the Community-based CSS role holders was having a boundary on the amount of time spent working with individual families. Participants spoke of families receiving support for two years. There was some variability in the number of visits allocated to families within this time, based on the needs of families:

"... support is for a period of two years. So, for two years they'll be under (the CSSS) umbrella... it's direct work for probably about four to six months... that means going out to families about six to eight times... every three weeks or so... And then... for... the remainder of the two years... (CSSs) just check in with them every month or two. Just a phone call to the parents saying, and then if they need that more intensive support, (the CSSs will) come about out again then..." (MDT21)

Supervision

Some concerns were raised in the early phases of the implementation around supervision for role holders. However, as the implementation progressed mandatory clinical supervision was implemented every six weeks. Participants mentioned the lack of readily accessible peer support in the community in comparison to working in a hospital setting. With the appointment of further community CSS roles across the Republic of Ireland, the community CSS role holders began to hold weekly online peer support sessions, which, at times, included training, and less frequent in-person sessions:

"... a weekly... debrief or check in at the end of the week... (the CSSs) do that... every Friday, (they)... come on to MS Teams and... have a sort of team check in." (MDT21)

Community CSSs also found supervision from their manager in CFFC to be helpful in protecting against some of the challenges that working as a lone worker might pose. One community CSS believed that the level of support available in this role was much greater than that provided in their previous healthcare role. Community CSSs also had the option of seeking external clinical supervision, the costs of which would be covered by CFFC. This was also found to be helpful by those who took it up:

"(CSSs) also get the option of external clinical supervision... with a psychologist or psychotherapist... (CSSs) source that... and... cancer fund for children cover the cost... I think it's important to have that." (MDT22)

Challenges to the sustainability of the service

The challenges to sustainability were the initial limited number of CSS roles and the wellbeing of role holders.

Initial limited number of CSS roles

Many members of the MDT and parents noted that with respect to the sustainability of the CSSS, the main challenge was in the number of role holders appointed to the service, particularly within the ward. At the time of the earlier interviews there was one role holder in the service, with the community CSSs yet to be appointed. The ward-based CSS role holder acknowledged the inability of one role holder to provide support seven days a week. To mitigate the challenge of having one CSS on the ward, the role holder limited their annual leave to one week at a time to ensure shorter gaps in their continuity of care to families. Understandably, despite these efforts, it was perceived that parent's support needs outweighed the ability of the one role holder to provide it. Participants mentioned that this meant that there could not be an equal distribution of the service. One parent mentioned that they felt they were missing out on this support when seeing other families on the ward receiving it:

> "... it's a huge amount of patients to serve as one person so like it's great for the people who are able to access it. But obviously one whole time equivalent is a finite resource it would be great if the support was there that it was able to provide... because sometimes... it's the family that shouts the loudest that gets the services... because... I think sometimes people get missed along the along the edges." (MDT16)

> "... we would like more of them... obviously we only have one at the moment... and while one person in a role can fill lots of gaps there is still lots of gaps." (MDT14)

> "... we'd go in there... I think it was every four weeks or something like that... And then we were in for a week. So really that was the only time we got to see (the CSS), but there's other people then that are going in as day patients, and I'm not too sure if (they) can spread (themselves) around all of them and everybody that's on John's Ward. But any support is absolutely a God send in there." (PP3)

Role holder's wellbeing

A possible challenge to the future of the service as it stood during the time of the interviews was the impact on role holders' wellbeing. A number of participants expressed concerns relating to the role holders' strong commitment to the role and the seriousness of the families' situations that they work with. The first role holder's commitment to the CSS role was perceived as putting them at risk of burning out due to their willingness to work extra hours whenever needed:

> "... you see (them) at night-time coming in at all hours. (They are) there all hours in fairness." (MDT11)

> "... the problem with (the CSS) is (they) will do actually too much... If you said to (them) I need you in at seven o'clock in the morning (they) nearly would. And (they) stay 'till ten o'clock at night. But there's only one of (them). (They would) end up at some point collapsing... and that's not fair either." (MDT10)

> "... it's very hard to give everyone what they need and not get burnt out. Because it's all-consuming work." (MDT7)

> "I suppose then as I said before (they do) seem to be doing a lot of extra work. Because (they are) just so committed to the role. So that you would be worried that how long can that go on and hoping that (they don't) burn out, or get sick..." (MDT6)

Compounding the possible effects of this commitment was the difficult nature of the role. Participants said that as the CSS works with the families of children who are having the most difficulty with their condition, this could take a toll on their wellbeing. The role holder is exposed to, and becomes very familiar with families in the ward undergoing the most difficult circumstances unlike many members of the MDT:

"... I think (their) role is one of the most difficult on the ward. Because (they are) only dealing with the children who are really sick... all of the time. So, you can imagine, (they see) all of the sick children. And all of the really hard cases you know. And I honestly, I mean I don't know myself how I get through it, because it's not easy at times... but like I don't hear all of the stories." (MDT9)

As lone workers, the community CSS role holders faced slightly different challenges. One community-based role holder faced some difficulty with a parent who had expressed anger. The CSS was unsure how to manage if the parent required support in the future. Community CSSs need to travel to appointments with families; some role holders had long journeys to and from family's homes. Another role holder sometimes found themselves missing the social and companionship aspect of working in a ward-like environment:

"I like chats and I like people, so I do. There're definitely times where I miss the colleague part or the banter, or... just being in that vicinity. It's very different to what I was doing previously. But it also has its advantages and like it's kind of swings and roundabouts a little bit... you have those few days of quiet, which I might find a bit tough. And then like the rest of my week is just like go, go, go. Which I'll be like great..." (MDT22)

A further possible challenge was the difficult circumstances of the families that community role holders worked with. As the ward-based CSS often worked with families in the most serious situations on the ward, these were the families that they tended to refer to community-based CSSs:

"...they tend to be sending the like really sort of end of life, like the most serious cases they have." (MDT21)

Vision for the future of the CSSS

Many participants expressed a need to expand the service to ensure that all families in the ward have the opportunity to receive timely informal support from the CSSS, and to protect the ward-based CSS from overworking. By extension, it was perceived that this would also assist in reducing pressure on the MDT in the ward. At the time of the earlier interviews, participants were not aware of the plans to appoint a second ward-based CSS. However, many independently stated that there was a need for the appointment of a second ward-based CSS. Participants also envisioned the need for the provision of a 24/7 CSSS in the ward. On witnessing the benefits of the initial CSS roles, a number of participants expressed a hope for an extension of the service across Ireland with community support so that every family of children with cancer could benefit from the service:

"... it would be that every child with cancer and their family have access to a cancer support specialist who has the expertise to support the family. But also... in collaboration with the MDT so that we can make sure that you know every aspect of their needs is addressed..." (MDT14)

"It would be it would be a lovely thing if it was if there was... a cancer support specialist in each... province or if there were areas so that... they could meet people in the home... if it was more like an outreach kind of a thing where you able to travel to the families that really needed it." (MDT16)

"... even a second same type of role for the ward would be great. Not even that, it would be great if there would be more (CSSs) around the country." (MDT10)

Additional visions for the future of the CSSS were to expand the service to families whose children's health was not in the terminal phase, and to expand across age groups to cover the differing support needs across the stages of childhood:

"... if I was to say a vision of this post. We definitely would need to increase in numbers of support workers we have. We'd need to see them across the age. Because we're in an age of zero to sixteen... So, they've got very different needs... somebody for each... age group. But what you could do is split them into the younger children. And then maybe the younger teens or the older teens, or just put the teens together... you definitely could have somebody for the teens." (MDT9)

Discussion

These findings outline factors that were perceived by participants to influence the future direction of the CSSS. These were developed in two themes, sustainability of the service, and vision for the future of the CSSS. Enablers to the sustainability of the service were the role holder's intrinsic motivations to work in the CSS role, and the expansion of the CSSS. Challenges to the sustainability of the service were the wellbeing of role holders and the initial limited number of CSS roles.

While motivation is an important factor in the sustainability of healthcare roles (Tokarz & Malinowska, 2019), recent research indicates that intrinsic motivation is a greater prediction of employee retention than extrinsic motivators such as high salary levels (Miao et al., 2020). CSS role holders all indicated that their motivation for the CSS roles was intrinsic, that is to work directly with families and for their role to focus on providing support. This suggests a high level of sustainability of the CSSS. A possible challenge in the implementation of new informal roles is the risk that new role holders will take on roles with the aim of using them as a stepping stone to a professional role (McCrae et al., 2008). This challenge did not apply in this study as the CSS role holders had all been previously engaged in permanent professional and pensionable healthcare roles with higher salaries. This may further reflect their intrinsic motivation to take on these new informal roles.

In the initial phase of the CSSS, role holder's intrinsic motivation was further exemplified by strong commitment to provide sufficient support to families despite being the single role holder in the service. The single worker status of CSSs may pose a challenge to the continuity of their services during periods of leave, including annual leave or extended leave for other reasons. Members of the MDT believed that the appointment of a single role holder was a challenge to the service's sustainability due to the imbalance between the number of families requiring support and the ability of role holders to meet their needs. This imbalance allied with the CSSs' strong commitment to the role was believed to put the role holder's wellbeing at risk. It has been recognised in the literature that there is a need to balance new informal role holder's caseloads with role holder's engagement opportunities to ensure sustainability (Smith-Merry et al., 2015). The appointment of new roles during the study, and the planned appointment of more roles increased the CSSS' resources and ability to meet the needs of more families. This is important for the wellbeing of CSSs, as a heavy workload that exceeds workers' ability to meet it is predictive of burnout (de Vries et al., 2023; Meredith et al., 2022). The appointment of further roles may also enable role holders to provide a universal level of care to all families on the ward, including those who appear to be coping well.

A further challenge noted in the literature was new role holder's feeling emotionally drained due to the amount of time they spent on a one to one basis with a small group of patients (Rolfe et al., 1999). This this did not appear to be a factor in this study, perhaps due to the role holder's prior experiences and expertise in healthcare settings. The setting of boundaries on the time spent with families for community CSSs may also be a protective factor against emotional exhaustion.

The lone worker status of the community CSSs was perceived to pose differing challenges to that of the ward-based CSSs such as missing peer interaction from working in a hospital environment. Lone workers are known to be at risk of loneliness and isolation (Patynowska et al., 2023; Procter et al., 2016). An enabler in this aspect was the development of a weekly peer support group that meets remotely and in person. Regular peer support was recommended in a recent study as an intervention to combat the risk of loneliness in community workers (Patynowska et al., 2023). One community CSS role holder discussed uncertainty around how to manage if a parent who had expressed anger in their last meeting required support in the future. A further enabler for the sustainability of the CSSS was the provision of supervision which role holders believed helped to protect against some of the risks of lone working, as did the option to have external supervision which would be paid for by CFFC. Adequate supervision and support for new informal support workers has been noted as enabling the sustainability of new roles by providing role holders with opportunities for discussion and reflection (Hek et al., 2004; Sobotka et al., 2022; Stanmore & Waterman, 2007). Participants' visions for the future of the CSSS were to extend the service with a number of aims: including the provision of 24/7 support in the ward; community support across Ireland; supporting children whose cancer is not in the terminal phase; and expanding support to cover the differing support needs across the stages of childhood.

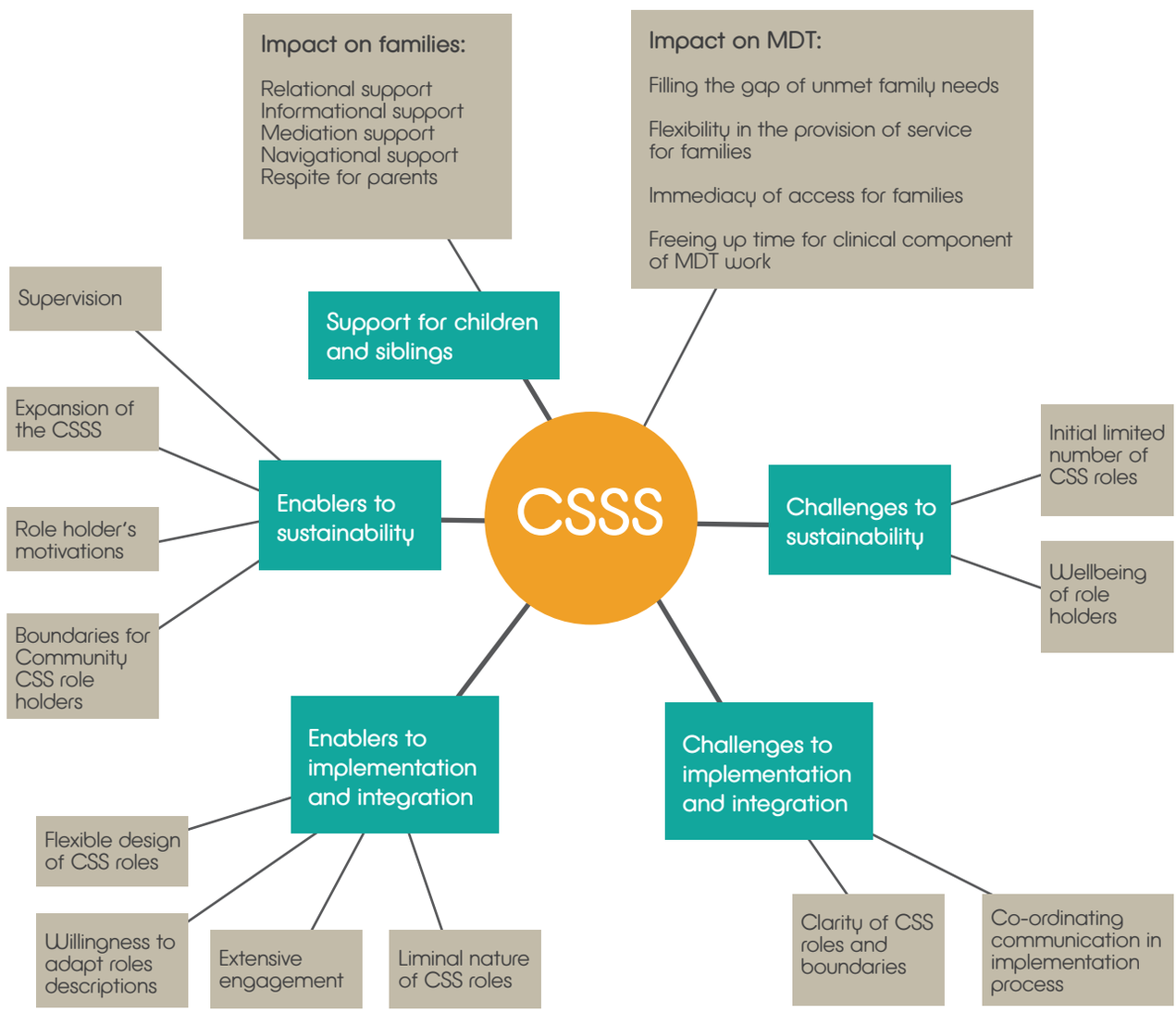
Chapter 7

Synthesis of findings and recommendations

Introduction

This study, phase two of the Katie Nugent research, An Evaluation of the Cancer Support Specialist Service, sought to explore the implementation and impact of a CSSS within the oncology service in CHI at Crumlin from the perspective of the key stakeholders involved. This study used a qualitative design comprised of semi-structured one-to-one interviews with members of the MDT, CSSs, parents of children with cancer, and a member of the steering group of the service. This chapter provides a brief summary of the findings in relation to the impact of the CSSS, and the determinants to its implementation, integration and sustainability. An overview of the key findings can be seen in detail in figure 4. The chapter concludes with a number of recommendations arising from these findings.

Figure 4 Overview of study findings



Synthesis of findings

The findings provide a rich level of detail of the impacts of the CSSS on families and the MDT, and the determinants to the implementation, integration and sustainability of the service. Parents felt valued by the focus of the CSSs on their support needs beyond the medical needs of their child. The provision of relational support through the presence and time provided by the role holders was a comfort and form of companionship to parents, and was said to ease in some way the childhood cancer journey, while meeting their support needs. Relational support is a central need of parents of children with cancer (Cheng et al., 2022; Dwarswaard et al., 2016; Lewandowska, 2022a), and a keystone of psychosocial support (Dwarswaard et al., 2016).

The informal nature of the CSSs support provided parents with a sense of normality, as they could discuss issues, chat and vent with someone who was outside of the context of the medically oriented MDT. An additional value of

this was that while CSSs provided the companionship of friends and family, there was no expectation of reciprocation or need to protect the role holders as can occur when discussing potentially distressing matters with family and friends. A such, the role holders occupied a liminal space between the formal care of the MDT and the informal support of family and friends, allowing for the development of strong rapports with families, resulting in CSSs often mediating communication between the MDT and families when families felt too overwhelmed to approach members of the MDT.

Parents reported that the amount of information to take in from the initial diagnosis and throughout the childhood cancer experience was at times overwhelming. The CSSs assisted in this through providing information gradually over time to allow for improved assimilation. CSSs also assisted parents by proactively navigating and suggesting appropriate supports and services. This relieved parents of the burden of having to seek out information about available supports and services, which can be an additional and unnecessary stressor during the experience of childhood cancer (Delemere et al., 2023). Parents' need for informational support is not always met despite the importance of information to their ability to cope with stress (Cheng et al., 2022; Hashimoto et al., 2023; Nicklin et al., 2022). In addition to directly supporting parents, CSSs indirectly supported parents by providing respite through their support and engagement of children with cancer and their siblings, giving parents time to focus on self-care activities. Parents mentioned the relief they felt to have someone engage their children when they were otherwise exhausted.

As the CSS roles were designed so that role holders would not be constrained by waiting lists, and other administrative duties often associated with healthcare roles, role holders were free to spend more time with families than many other members of the MDT. This further enabled CSSs to provide flexible, adaptive, and accessible support, which was overwhelmingly appreciated by parents.

While there were initial challenges in the implementation process in co-ordinating communication between stakeholders, the extensive engagement of key stakeholders and willingness of the charity and role holder to adapt the role description to avoid what were perceived to be discipline specific terms were key enablers to the implementation of the CSSS. These determinants are under discussed in the literature on new informal psychosocial provider roles, perhaps due to a lack of research conducted during the implementation period.

As frequently found in the international literature on new informal psychosocial support roles (Bridges et al., 2003; Cain et al., 2020; Gilburt, 2016; Herber & Johnston, 2013; Manthorpe & Martineau, 2008), the flexible design of the roles was a central enabler to the integration of the CSSS. This flexible design enabled role holders to fill gaps in the informal psychosocial support provided by the MDT during working hours, and during out of hours, and to respond flexibly and adaptively to the varying support needs of children and families. The personal characteristics of role holders, including their backgrounds in healthcare, enhanced their ability to provide this support (Procter et al., 2022; Sobotka et al., 2022), and the integration of the roles into the MDT.

Members of the MDT valued the CSSS as an auxiliary support that assisted them in meeting the informal support needs of families. MDT members especially welcomed having an extra staff member whose primary agenda was to informally support families, as while many recognised that this was a duty of everyone in the MDT, the primary agendas of MDT members were the clinical component of their roles, resulting in their having less time to provide informal support. It is recognised in the literature that the increasingly complex nature of cancer treatments (Chrapek, 2016; Lewandowska, 2022b), and understaffing in healthcare, including in oncology settings (Seguin et al., 2022), can increase the work burden of MDTs (Murali & Banerjee, 2018). The CSSS enabled MDT members to focus on the clinical component of their roles in the knowledge that families' informal psychosocial needs were being met. This may also have supported staff's wellbeing as an increased workload is a risk factor for burnout in allied health workers (Guveli et al., 2015), oncologists (Murali & Banerjee, 2018), and nurses in oncology settings (Zarenti et al., 2021).

While the flexible design of the CSS roles was an important enabler, it initially acted as a challenge to the integration of the roles due to the lack of clarity that the broad role descriptions provided. This is a common challenge when implementing new informal psychosocial roles (Cain et al., 2020; McCrae et al., 2008; Wilberforce et al., 2017), and led to some concerns about the role holder performing what were perceived to be discipline specific tasks when members of other disciplines were not available to perform these tasks. A blurring of role boundaries frequently occurs between new flexible roles and pre-existing roles in the early stages of implementation (Cain et al., 2020; McCrae et al., 2008; Wilberforce et al., 2017). Additionally, role holders in the community faced initial organisational boundary challenges when some charities and hospitals they engaged with questioned their role and whether it overlapped with aspects of their own organisation's activities.

An enabler of the sustainability of the CSSS, in addition to the gradual implementation (Maxwell et al., 2013b), adaptability and flexibility of the CSS roles (Crespo-Gonzalez et al., 2020), was the role holder's intrinsic motivation to perform the roles. Intrinsic motivation is a strong predictor of employee retention (Miao et al., 2020) and may protect against burnout (Morris & Bird; Tokarz & Malinowska, 2019).

Additionally, as community-based CSSs were lone workers, they faced risks to their wellbeing common to lone workers such as loneliness and isolation (Patynowska et al., 2023; Procter et al., 2016). The provision of boundaries around the time they spent with families, supervision and support by the CFCC, and the development of a weekly peer support group between the CSSs were all enablers against these risks. The provision of supervision and support are noted as enablers to the sustainability of new informal psychosocial provider roles in the literature (Hek et al., 2004; Sobotka et al., 2022; Stanmore & Waterman, 2007).

Participants believed there was a need to expand the number of roles in the service to ensure its sustainability as initially the engagement opportunities of the first CSS were outweighed by the support needs of families on the ward leading to concerns about the role holder's wellbeing. Participants additionally mentioned expanding the service with the aim of broadening the provision of support with 24-7 support in the ward, community support across Ireland, and to provide support to a greater age range of children and adolescents. At the time of these interviews, the expansion of the service beyond the first role holder had yet to take place. As can be seen in figure 1, the expansion of the service section to provide support to families across the country, and to an increased age range is part of the overall implementation plan for the CSSS. This will go some way to fulfilling these visions and improving the balance of each role holder's opportunities for engagement and the needs of children and their families, further protecting role holders and meeting the support needs of more families across the island of Ireland.

Strengths and limitations of the study

When interpreting the findings, the following study strengths and limitations require consideration. Strengths of the study include the diversity of participants involved enhancing the robustness and reliability of the findings. A further strength is the composition of the research team. This was an independent team of researchers, comprised of experienced researchers with a knowledge of both research and children with cancer and their families.

Limitations

When interpreting the findings, the following study limitations require consideration:

- The findings are based on a non-probability sample of participants.
- The small number of parents involved and a risk that parents who were most satisfied with the Cancer Support Specialist Service had a greater incentive to participate. In addition, despite reassurance of confidentiality parents may have worried about critiquing a service that they needed and continued to use.
- The interviews were conducted within 6 months of people taking up the Cancer Support Specialist role; had the roles been longer in place other impacts on families and multidisciplinary team members may have become apparent.
- Parents were interviewed at a very stressful and emotional time in their lives and that may have influenced their recall of issues.
- There was a risk that parents who expressed their satisfaction with the level of support provided by the Cancer Support Specialist Service were presented with recruitment materials more frequently than parents who did not express their satisfaction.
- While members of the multidisciplinary team interviewed were able to provide detailed commentary on the ward-based Cancer Support Specialist role, their knowledge of the Cancer Support Specialist roles within the community was more limited, therefore they were not in a position to provide the same level of commentary on impact.

Recommendations

In light of the findings and limitations, the following recommendations are proposed:

- In consultation with key stakeholders, consideration be given to the development of a specific strategic plan for the next five years. This could include:
    - How the Cancer Support Specialist Service could be developed, sustained and integrated into the National Cancer Control Programme.
    - How to promote and communicate the value of the Cancer Support Specialist roles within Children's Health Ireland, and wider community services.
- To maintain the positive outcomes reported by participants and minimise the potential of burnout and compassion fatigue thus ensuring retention of the Cancer Support Specialists, there is a need for ongoing review of supports currently available, including the peer support and mandatory supervision to ensure they meet the needs of the Cancer Support Specialists. There is also a need to explore the development of a lone worker policy for the Cancer Support Specialists.

- In view of concerns expressed by parents about the void left when the Cancer Support Specialist Service was no longer available to them, there is a need to consider how to taper the Cancer Support Specialist Service support in the context of what supports are available for families once the CSSS completes their term of service with families.
- Consideration needs to be given as to how to maintain the Cancer Support Specialist Service at times of extended leave and annual leave to ensure an equitable and accessible service to all families across the cancer trajectory.
- Bearing in mind that the evaluation was conducted in the early phase of the implementation of the Cancer Support Specialist Service, it may be helpful to conduct a further evaluation after the service has been in place for a longer period of time. This would capture the long-term impact on families, multidisciplinary team members, community services, and the Cancer Support Specialist role holders themselves. A subsequent evaluation could also include the impact of any additional roles not included in the current study and capture the retrospective perspectives of family members whose child has finished treatment and are no longer availing of the Cancer Support Specialist Service.

To conclude this report, the authors would like to take the opportunity to acknowledge the commitment of everyone involved in the successful implementation of the CSSS.

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Notes

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