



Is there a choice when a sibling is ill? Experiences of children and adolescents who donated stem cells to a sibling

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ABSTRACT

Purpose: When healthy children/adolescents are potential stem cell donors to a sibling, ethical questions arise due to reduced autonomy and dependency on their family. This study aimed to explore the experiences of children/adolescents in Sweden who donated stem cells to a severely ill sibling.

Method: Semi-structured interviews were conducted with thirteen donors, aged 6–17 years at the time of the donation, all with surviving siblings. The interviews were transcribed verbatim and analysed using qualitative content analysis.

Result: The main category in this study was *The presumed 'choice' when a sibling is ill*. The experience included being *Proud without an actual choice*, highlights that the donors were proud to contribute, and perceptions of a request without a choice. *Focusing on the ill sibling and the outcomes* reveals that they were worried and protected the sibling, and downplayed the importance of their own effort. They experienced a *Need of support and information*, which derived from receiving information without communication about what they really needed to know, but also the importance of support through play and talk.

Conclusion: The donation involves the young donor in the care, implying an opportunity to bring the family back together. They have no real choice, when their sibling is ill and the lack of information about possible alternatives indicate that there was no option to decline. There is also a need to focus on the experiences of young donors whose siblings died after the transplantation.

1. Introduction

Developments and progress within hematopoietic stem cell transplantation (HSCT) have made this treatment option available for a wider range of diseases, which implies increased number of transplants as well as children surviving cancer and haematological diseases (Duarte et al., 2019; Passweg et al., 2016; Svenberg et al., 2016).

Over half of the children below the age of 18 who have undergone HSCT had stem cells donated from a related donor, usually a sibling (Styczynski, 2018). Human leukocyte antigen (HLA)-matched siblings are considered the preferred stem cell source to achieve the best

outcome, and there is a 30% chance that a sibling will be a donor match (Kakourou et al., 2017; Yakoub-Agha et al., 2006). HSCT may involve risks for the recipient, such as treatment-related complications and side effects, but also the risk of dying from treatment (Cupit et al., 2016; Duarte et al., 2019; Ljungman et al., 2010; Svenberg et al., 2016). The stem cell collection is considered safe for a young donor (Pulsipher et al., 2006; Styczynski, 2018; Styczynski et al., 2012). However, previous studies from adult donors suggest that the donation process can pose a risk to the donor's health and it cannot be guaranteed that the ill sibling will be cured of their illness (Halter et al., 2009; Kisch et al., 2015; Miller et al., 2008).

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When a child falls ill, the parents' attention is naturally directed towards the ill child while healthy siblings often feel lonely and left out (Løkkeberg et al., 2020; Murray, 2002; Nolbris and Hellström, 2005; Sloper, 2000). The healthy siblings may experience moods of fear and jealousy (Løkkeberg et al., 2020), adjustment difficulties, depression, anxiety and social isolation, but they may also assume the role of a caregiver (Murray, 1998, 2002; Nolbris et al., 2007; Nolbris and Hellström, 2005; Wiener et al., 2008; Woodgate, 2006). Healthy siblings of a seriously ill child have been identified as the most emotionally neglected of family members (Murray, 1998), and they have expressed a need to be part of the care and to help the ill sibling (Eilertsen et al., 2018; Toft et al., 2019; Woodgate, 2006).

Swedish studies on adult stem cell donors describe that donors feel an obligation to donate when asked to do so, and emphasize the need to reduce influence from relatives and healthcare professionals (HCPs) on the sibling's decision to donate (Kisch et al., 2013, 2015). Studies from USA describe the same phenomenon among paediatric stem cell donors (Hoag et al., 2019; MacLeod et al., 2003; Packman et al., 2004). A lack of knowledge and involvement among potential paediatric donors might contribute to concerns about the transplantation process and painful procedures as well as a decreased sense of trust and autonomy (Packman et al., 2004). A Brazilian study showed that paediatric donors hide their emotions and thoughts of loneliness and responsibility for the transplant outcome in order to relieve the parents and the ill sibling (de Oliveira-Cardoso et al., 2010). Positive consequences were also shown after the paediatric donation, as closer relationships within the family (Wiener et al., 2007b, 2008) and a broadened view of the world (MacLeod et al., 2003).

When the potential donor is a minor, further complexity arises from both an ethical and a legal perspective, as the minor has reduced autonomy and might lack competence or authority to make decisions. The guardian is the one who, according to Swedish law (Swedish Ministry of Justice, 1949), has the right and obligation to make decisions regarding donation, but in this situation they have conflicting loyalties to the child as a potential donor and the seriously ill sibling. There are limited studies exploring the donation process when children/adolescents donate stem cells to their ill siblings (Bauk et al., 2013; Hutt et al., 2015) and studies are lacking in the Nordic context. Increased knowledge and understanding of the minor donors' perception of the decision and donation process is important to be able to develop and optimize the care for the donor and the entire family.

The aim of this study was to explore experiences of children/adolescents in Sweden who donated stem cells to a severely ill sibling.

2. Methods

2.1. Design

In this qualitative study an inductive content analysis was performed to understand and describe the experiences expressed in interviews (Elo and Kyngäs, 2008; Hammersley, 1992; Krippendorff, 2019).

2.2. Setting and recruitment

The participants were recruited from the four paediatric HSCT centres in Sweden. All centres are accredited under European guidelines according to JACIE standards, the European guidelines (European Society for Blood and Marrow Transplantation et al., 2019).

Initially a coordinator (nurse/physician) at each centre was informed about the study as well as the following inclusion criteria for potential participants: children/adolescents below 18 years of age at the time of stem cell donation to a severely ill sibling in Sweden at least one year prior to contact, thus the acute HSCT phase had passed. The coordinator made an initial purposive selection (Endacott and Botti, 2005; Shorten and Moorley, 2014) of who to invite for an interview. The researchers had no insight in this process. If the families accepted, the first author

contacted them to give more information about the study. Altogether, 20 families and donors accepted to be contacted. Three families did not respond to the author's contact attempts by phone or letter, two families declined, and one donor withdrew consent before the interview. Following the oral and written information to parents and children/adolescents and signed consent to participate, the time and place for the interview was determined.

2.3. Data collection

The interviews were conducted face-to-face at a place proposed by the donor, all in the donors' homes except for one interview at the hospital. The interviews were conducted by the first author (n = 12) and a colleague paediatric nurse (n = 2), both with extensive professional experience in paediatric cancer nursing, but not involved in the care of the participants. The fourteen interviews were conducted as semi-structured conversations using an interview guide. The interview guide was created to direct the interviews and conversations towards the research topics, derived from clinical experience. The interview guide still allowed interviews to take unanticipated turns in the conversations by using open ended questions (Ryan et al., 2009). The interview started with open questions about actions before moving on to questions on experiences and feelings (Price, 2002). After the initial warm-up conversation, the donors were asked to tell their stories, with focus on the donation process including information, the decision to consent, and support. One child wished to be accompanied by a silent parent during the interview. The first three interviews were conducted as pilot interviews to evaluate the interview guide. As the guide was not revised afterwards, these interviews were also included in the study. The interviews lasted for 23–58 min and were digitally sound recorded, enabling the interviewer to focus on the conversation.

2.4. Data analysis

The interviews were transcribed verbatim and deidentified by the first author and analysed using qualitative content analysis according to Elo and Kyngäs (2008). The analysis began with the preparation phase, reading the transcribed interviews several times to obtain a sense of the text as a whole. Next step was open coding, using the software for qualitative analysis, NVivo 12 (QRS International). Codes were grouped into sub-categories by comparing incidents with similar or related content/meaning. The sub-categories were kept on a descriptive level, close to the data. Similar or related sub-categories were further grouped into categories on a higher abstraction level. The narratives were used to describe the experiences in the categories. Finally, the overall meaning was generated by abstracting the categories that constitute the main category. The last author read transcribed interviews, coded and compared codes, sub-categories and citations, and discussed the findings with the first author.

2.5. Ethical considerations

Ethical approval was obtained from the Regional Ethical Review Board in Uppsala (211/301) and later amendments from the Ethical Review Authority in Sweden (ref: 2019-00065). Families accepting contact were sent written information and consent forms, including information about the aim of the study, and that participation was voluntary and confidential. Age-adapted information was provided to children 6–12 or 13–18 years old. Some days after sending the letter, the first author called to give verbal information, answer questions and subsequently plan for in-person interviews. Before the interview, written consent was obtained from all children/adolescents and from their parents. All participants were offered psychological consultation, but none accepted the offer.

3. Results

Out of 20 donors who initially agreed to receive more information about the study, 14 agreed to participate in the study. During the interview, one donor was found not to match the inclusion criteria and was thus excluded from this study, resulting in a total of 13 participants. For the participants' characteristics, see Table 1.

3.1. The presumed "choice" when a sibling is ill

The experience of having had a sibling with a life-threatening illness affected the healthy child/adolescent more than the HSCT process itself and it changed their view of life. All participants expressed proudness to be able to donate, and that it felt good to have contributed to their sibling's recovery. They were driven by the love of their siblings and strong family ties, which also implicated that they did not really have a choice. Furthermore, they lacked information about alternative solutions, giving them no option to decline. The categories are presented in Table 2, and subsequently separately presented with donors' quotes in the text to illustrate the results.

3.1.1. Proud without an actual choice

The participants were pleased and proud to contribute to their sibling's recovery. They wished to contribute out of love and family obligation. It was never an option to say no. This category consists of "Proud to contribute" and "Request without a choice".

3.1.1.1. Proud to contribute. All donors described a feeling of pride, increased self-esteem, and inner strength by having contributed to the health of their sibling and having done something important in life, despite the cost of some anxiety and discomfort.

"So yes, you feel more confident and then you feel proud that you have done it. Then you can sit and think that you are a good person instead of a bad person who does nothing."

Female, age 15

"They said he was going to have a transplant and that only about 20% of the sibling's bone marrow would match, and then I really hoped that mine would match with him, then. And then, when they told me it was so, I was very happy that I could finally help him. So, aah ..."

Female, age 11

Table 1
Characteristics of the study participants (n = 13).

	Female	Male	All
Donors, n (%)	7 (54)	6 (46)	13 (100)
Age at donation, median (range)	9 (6–16)	14 (7–17)	11 (6–17)
Age at interview, median (range)	14 (11–19)	20 (10–22)	17 (10–22)
Years from donation at interview, median (range)	4 (2–7)	5 (1–9)	4.5 (1–9)

Table 2
Sub-categories, categories and the main category.

Sub-category	Category	Main Category
Proud to contribute	Proud without an actual choice	The presumed "choice" when a sibling is ill
Request without a choice		
Concerns for the ill sibling, the parents and the outcomes	Focusing on the ill sibling and the outcome	
Downplaying the importance of own effort		
Satisfied with information but lacking understanding	Need of support through information and play	
Support through play and talk		

Everyone ultimately described it as a positive experience, especially when it had proven successful. Their whole life had become "better" because the sibling was healthy, and the family was together again. They would recommend other potential donors to donate, also because it would be selfish not to do so.

"I was very relieved, it felt like, I'm the one who can most likely succeed in, like, helping him, and like, it felt so good that I could actually do something. Because you just sat in the room, like, and looked when he got medication and so on. But now I could kind of, actively help, so that, it was cool, it was wonderful."

Female, age 15

3.1.1.2. Request without a choice. Most participants felt that they had made the choice by themselves, but at the same time they said that "it is not a choice, you just do it". Even if they wanted to donate, it was not a choice situation but a presumed expectation that they would want to do it.

"... but, mom and dad had not matched very much, so it was me. And then there was probably no one else who was very close who could do it."

Female, age 14

One donor describe that he was not asked if he wanted to donate, but that his parents and the HCPs assumed it was no problem, and that he would not mind. Few participants remembered that they were asked whether they wanted to donate. They understood that this was vital for the seriously ill sibling, and thus was not a choice situation.

"Well, (doubtfully) it was just to do it, well, I wanted to do it, of course, to be kind to my brother then, but it was also... you do not have much choice, it has to be done."

Male, age 20

No one expressed coercion, bribery or pressure. Furthermore, they wanted to help their ill sibling to get well because it was hard to be separated from their parents and siblings during the hospital stays. By contributing to the sibling's recovery, the family could be reunited again.

3.1.2. Focusing on the ill sibling and the outcome

The family had lived with the illness of the sibling during a period of time filled with worries; consequently, the ill sibling and parents had enough concerns and the participants avoided complaining about the situation. However, they did worry about the outcomes of the HSCT and much of the experience was related to the positive outcome. This category consists of "Concerns for the ill sibling, the parents and the outcomes" and "Downplaying importance of own effort".

3.1.2.1. Concerns for the ill sibling, the parents and the outcomes. When the participants witnessed the suffering of the ill sibling and the sad and worried parents, they were concerned and wanted to protect them from further sorrow and burdens. After contributing with the donation, they felt that their own, their parents and their siblings' suffering decreased. They could talk to their parents for support but did not want to burden them. One participant described that he kept everything inside in order to be considerate and not draw attention from the sibling.

"It was difficult for [brothers name], you can't show too much that you do not want, and so on, so you tried to keep it in, and so on".

Female, age 11

They had lived with an ill sibling for a long time and the concerns for the ill sibling were not limited to the HSCT itself, but also included undesirable outcomes of HSCT.

"I understood that he would get my bone marrow, but then I did not know if it would help or not, or what would happen after that. I was

still very frustrated that we did not know what would happen. Because, yes, it is very reasonable that, when your brother becomes so seriously ill, that you want to make sure that he gets well, too. Especially when you do something to help, as well. So I thought that was really hard, not to know."

Male, age 22

"Uhm, yes, but it was a bit like this, if, if the transplant had not worked, it would have felt very hard personally, that I was not good enough, sort of. That it did not work as it was supposed to do."

Male, age 22

In consideration, they avoided reminding the sibling or talking about the difficult time and the side effects of the transplant process. One participant described it as awkward when grandma pointed out how much he had grown, because his brother had stopped growing as a side effect, and was sad about it. Few had spontaneously talked with their ill sibling about the donation afterwards. Most thought there was no reason as it had turned out well. The participants believed that they got away easily at the hospital during the donation procedure compared to their ill sibling.

3.1.2.2. Downplaying the importance of own effort. The participants downplayed the value of their own efforts in relation to their siblings' serious illness and suffering.

"There were so many blood samples, but considering what my brother has to go through, it feels like nothing. It is an easy thing to do."

Male, age 19

They were not worried about themselves during donation but were very concerned about their siblings and whether the treatment would succeed. According to the participants, going through medical procedures during donation was nothing compared to what the sibling had gone through. They felt that their medical procedures went smoothly and that they were well taken care of by the HCPs, nevertheless, some described anxiety, discomfort, and pain during some days. They did not expect anything else, as they wanted the ill sibling to get the very best.

"But it's not me who should have all the attention, either. I understand that it is he who is ill, it is he who should be taken care of. ... but I do not think I have anything to complain about."

Male, age 19

Some were told that they performed a heroic act and some classmates were a little jealous. Those who had received heroic comments dismissed them and did not think they deserved the halo as "it goes without saying".

"So I remember that everyone around was like "Oh, now you've saved your little brother's life", but I was more, like, that it felt so obvious. It wasn't like I ever considered not doing it, so, it didn't feel so very heroic."

Female, age 19

3.1.3. Need of support through information and play

The participants described a need for information through a dialogue, and the importance of support provided by different people, especially their parents. The sub-categories "Satisfied with information but lacking understanding", and "Support through play and talk" formed this category.

3.1.3.1. Satisfied with information but lacking understanding. When the ill siblings were diagnosed, the participants were informed by their parents. The participants could not recall that HCPs informed them directly. The parents explained to them, and they also understood from the parents' reactions (e.g. crying) that it was something very serious,

but they were not able to fully understand it.

"Then they said he had leukaemia. I did not understand what it was, I was 11 [years old]. Because I did not know. Eh, and then, yes, my parents, they got really sad and started crying, and I understood from their reaction that it was something serious. Eh, although I still did not know anything, so I was sitting quietly in a corner and wondered - what happened now?"

Male, age 21

Some participants immediately searched for information on survival rates online.

Most participants received the information that they had been found to be suitable as a donor, from a parent. They were informed that they were the best option as a donor. Few knew that there were alternative stem cell donors for the ill sibling, and some did not remember being informed, while others had a vague memory of it. Not everybody understood what made them match as donors, and speculations varied from "being of the same sex" and "we have the same parents" to "lottery".

Participants said that they were well informed about the donation procedure, but still, later in the interview, they described that they did not understand what would happen, which made some donors worried and scared. One participant found it strange that his blood samples were needed as it was the sibling who was ill.

"I understood, well, that they would, sort of, take that syringe and that you would give blood to another, kind of, so that you change the blood. I understood that later, so I almost did not understand how it would go then. Otherwise, I knew what it was."

Male, age 11

Technical information was provided by HCPs but lacked what they really wanted to know, i.e., how the transplantation would affect the ill sibling and what the potential results would be. Two participants did not understand that the sibling had received an intensive treatment before they received the new stem cells, and were shaken to see their sibling so very ill. They had thought that the sibling would get well as soon as he/she got the new stem cells.

How they would have wanted the information varied. Most donors expressed that information was lacking in advance, and that they wished to be more involved and to understand the process. However, some expressed no need to know everything "you understand it when it happens", while others described incorrectly focused information.

"I learned how it would happen technically. That they should move it to a drip bag and so on. But it isn't that, it's not that interesting when you are ..., oh well ... (laughing) It's more how it goes for me and my brother than it is for you [HCPs] as you move the drip bag like that. So, I think it was a bit, it was good that they tried to include me in the process a bit in a way, but it was a bit wrong focused, maybe."

Male, age 20

Few understood the consequence of a stem cell failure before the donation, while others had not even considered the possibility. Some had discussed this possibility with their parents before the donation and they knew it would not be their fault. The participants did not remember having discussed the topic at all with HCPs.

3.1.3.2. Support through play and talk. Play and talk was important as distraction, it made the hospital stay more bearable and sometimes also provided information. Support came from grandparents, friends, and neighbours, but most importantly from the parents. Support was also provided from HCPs, and participants especially mentioned play therapists and sibling supporters (i.e., employed professional team member for the siblings) as well as the nurse consultant who provided information to teachers and schoolmates. The sibling supporters were considered a positive element at the hospital, a friend to play or do fun things

with. Sibling supporters were also described as a trusted person they could talk to, “the one who can keep a secret”, and could also give information about what was going to happen.

“Then I had a “sibling nurse”, [name], she used to play with me then, and it actually felt good. It was fun anyway.”

Male, age 11

All participants declined the offer to talk with a professional psychologist or social worker.

They preferred to talk with their parents, their healthy siblings, or the sibling supporters.

“But in the beginning, I mostly talked to my [healthy] brother about it. We didn’t understand much, so we talked to each other and tried to make sense of, figure out, what would happen.”

Male, age 20

It felt really good mentally to be able to share it with someone.”

Female, age 16

Because the parents spent a lot of time with the ill sibling in the hospital, the participants were “forced” to become more independent and learn to manage on their own. They were “growing up faster” and learned other sides of life from this experience. Some participants described feeling abandoned by the parents but at the same time they understood why it happened, and accepted that the parents should stay with the ill sibling.

4. Discussion

In this study we explored the experiences of healthy children/adolescents who donated stem cells to their severely ill sibling. The main result was that the participants felt that donating stem cells is *The presumed “choice” when a sibling is ill*. Overall, they were happy to contribute to the recovery of the ill sibling and it also gave them feelings of having done something good.

The participants of the present study were *Proud without an actual choice*. Only a few remembered being asked whether or not they wanted to donate. However, results are based on what the participants remember at the time of the interview and thus may not imply that they were not asked this question.

In the study of MacLeod et al. (2003) donors described experiencing influence, pressure, bribery or coercion to donate from HCPs or caregivers. Other studies also reveal pressure on minor donors from parents and unintentionally from HCPs (Then, 2015), as well as from friends, families and colleagues (Kisch et al., 2015). This kind of pressure was not mentioned by the participants in the present study, but some still experienced an expectation to do it. In the study of adult sibling donors in Sweden (Kisch et al., 2013), HCPs and relatives were found to influence the decision to donate. This resulted in the creation of an information and care model (IC model) for adult family donors (Kisch et al., 2008) to protect and support the donors’ free choice (Kisch et al., 2013). Such a model would also be needed in the paediatric setting where parents make the legal decision, to enable inclusion of the children/adolescents in the decision.

FACT-JACIE international standards have specific requirements for related donors, including children (European Society for Blood and Marrow Transplantation et al., 2019). While variation exists, best practice includes: independent clinicians for donor assessment and care; specific processes for young donors; and donor involvement (to an age-appropriate extent) in the decision-making process (Then et al., 2018).

Even if children do not have full autonomy, it is an ethical problem when their growing autonomy risks being violated (Bartholdson et al., 2015; Swedish Ministry of Justice, 1949; van Walraven et al., 2010). A study on children’s participation in decision-making show that they were not given any options and thus were not involved in treatment

decisions (Coyne et al., 2014). The adolescents were frustrated because they were aware that they did not have real choices as they were not allowed to refuse treatment (Coyne et al., 2014). A previous study showed that donors wanted to make their own decision but they were not always aware of the options (Hoag et al., 2019). Few donors in the present study knew the alternative to using them as the donor. Giving the information that siblings are the best option but not including knowledge about the options might influence the donor’s decision.

The participants confirmed that they had received adequate procedure-related information before the donation, but later in the interview told that they still lacked understanding, indicating inadequate information. The shortcomings in the communication with the donors from the present study are in accordance with previous studies (D’Auria et al., 2015; Hoag et al., 2019; MacLeod et al., 2003; Pentz et al., 2014; Wiener et al., 2007a). Moreover, lack of age-appropriate information might increase anxiety before interventions (Gillam et al., 2020). According to the Swedish Patient Act (2014: 821) (Ministry of Social Affairs and The Swedish Parliament, 2014) §3 concerning consent to care, the child’s attitude to the treatment must be clarified as far as possible, in relation to age and maturity. According to the Convention on the Rights of the Child (CRC) (United Nation UN, 1989) children and adolescents have a right to be heard on decisions concerning their life, as competent citizens. According to Article 12, they also have the right to express their views and being taken seriously (United Nation UN, 1989). In this case, the care is directed at a healthy child/adolescent for the sake of an ill sibling, which raises the question of whether even stricter rules should be applied. Making the best decision requires complete, age adapted and correct information. As the participants felt obliged to donate, it is important to inform and discuss options with them prior to HLA typing and to ensure that potential donors are given the informed possibility to decline typing and donation.

According to previous Swedish studies (Eilertsen et al., 2018; Nolbris and Hellström, 2005) the children/adolescents with siblings with cancer mainly received information from parents rather than HCPs. They did not become involved until the late stage of treatment, or, as in this study, when donation was relevant. It is relevant to question whether it is possible for parents to inform their child/the prospective donor in an impartial manner. The Swedish Patient Act (2014: 821) (Ministry of Social Affairs and The Swedish Parliament, 2014) says that all patients have the right to receive individualized information and participate in medical decisions. HCPs are responsible for providing information, adapted to the recipient’s age, maturity, experience and language (Ministry of Social Affairs and The Swedish Parliament, 2014; National Board of Health and Welfare, 2015) and have no right to waive their obligations to the parents. HCPs’ tendency to build partnership with parents at the expense of the children has been identified as an argument for child-rather than family-centred care (Coyne et al., 2016).

We use self-reported retrospective data communicated quite a long time after the experience, with no on-site observation, implicating that results are based solely on the perception of the participants at the time the interviews were performed. However, this might also be seen as a strength of the study as it reflects what characterizes the memories many years after the event itself.

Another limitation of this study is that only participants with positive outcomes were recruited by the coordinators and the results, for example that participants were proud to contribute, seem to be connected to that success.

Previous research has described how guilt diminished positive emotions in cases with a mournful outcome (MacLeod et al., 2003). Therefore, it would be worthwhile to investigate the experiences of young donors after negative outcomes in a Swedish context, to better support and inform a presumptive donor.

5. Conclusion

It is obvious that the donation process enables the young donor to

become involved in the care of the ill sibling and offers an opportunity to bring the family back together. Nevertheless, children/adolescents with a seriously ill sibling have no real choice when there is need for them to donate stem cells. Noteworthy is the lack of information about possible alternatives, indicating that the potential donor actually did not have a true option to decline.

Moreover, the findings highlight the importance of age-appropriate information based on own questions as well as information on available treatment alternatives, to enable the potential donor to make a decision possible to live with regardless of the outcome of the transplant for the sibling. Obviously, there is a need to focus on the experience of young donors whose siblings died after the transplantation.

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CRedit authorship contribution statement

Carina Rinaldo: Conceptualization, Methodology, Validation, Investigation, Resources, Data curation, Formal analysis, Writing – original draft, Writing – review & editing, Visualization, Project administration. **Margaretha Stenmarker:** Resources, Writing – review & editing. **Britt-Marie Frost:** Conceptualization, Resources, Writing – review & editing. **Ingrid Øra:** Resources, Writing – review & editing. **Pernilla Pergert:** Supervision, Funding acquisition, Conceptualization, Methodology, Validation, Resources, Writing – original draft, Writing – review & editing, Project administration.

Declaration of competing interest

The authors have no conflicts of interest to disclose.

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