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REGULAR ARTICLE

Physicians working in oncology identified challenges and factors that facilitated communication with families when children could not be cured

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Abstract

Aim: We explored physicians' experiences of communicating with families when their child had cancer and a cure was no longer an option, by focusing on barriers and facilitating factors.

Methods: Physicians from the six cancer centres in Sweden took part in focus group discussions between December 2017 and May 2018, and the data were analysed using qualitative content analysis. Focus groups enabled us to gather individual and shared perspectives.

Results: The 35 physicians (20 male) had a mean age of 47 (range 31-74) and a mean of 11 years' experience in oncology, ranging from under one year to 43 years. They reported communication challenges when a cure was not possible, namely: emotional and mental drain, lack of mutual understanding and uncertainty about communication skills. They also reported facilitating factors: flexibility in complex conversations, the child's position in the conversations, continuity and trusting relationships, support from colleagues and having discussed the potentially life-threatening nature of cancer from the very start of treatment.

Conclusion: Training to overcome communication issues could support the early integration of palliative care.

KEYWORDS

challenges, childhood cancer, communication, paediatric oncology, palliative care

1 | INTRODUCTION

Communication is a crucial part of the interaction between health-care professionals and families, especially when a child is seriously ill. Good quality communication is vital during this distressing time, as physicians need to make families aware of their child's prognosis and ensure that they receive adequate support.¹ Clear, empathetic

information is needed, as the family's emotional distress can affect how information is received.² The family needs continuous information during this period, so they can prepare for the future, prioritise and make realistic decisions.³ It is also important that shared medical decision-making is possible, which includes the patients as well as the family and clinicians. Research has shown that children and young people with advanced cancer are both willing and able to

take part in complex decision-making regarding medical treatment and the care process.^{4,5} However, paediatric physicians have found communication challenging when it comes to providing information about disease recurrence and, or, the transition to palliative care,⁶ especially with young patients and their families.^{7,8} At the same time, studies have shown that parents with an ill child have reported communication problems with healthcare professionals. For example, the way that they deliver bad news has been perceived as uncaring.⁹ The children themselves want honest information that is communicated with hope and given to them and their parents at the same time.¹⁰ The need for communication training has been described,¹¹ but there is a knowledge gap about the best way to help healthcare professionals to prepare for end-of-life discussions in paediatric care. Every year, approximately 300 children are diagnosed with cancer in Sweden and receive treatment at one of the six oncology centres included in this study. Most of these children survive the disease. However, the physicians who are caring for the one in eight who do not survive,¹² have to tell the patients and families that a cure is not possible and prepare them for palliative care. Paediatric palliative care provides interdisciplinary care that supports the quality of life for both the child and the family. It focuses on relieving suffering and pain, as well as addressing physical, social, psychosocial and spiritual and existential needs. It starts at the time of diagnosis and continues regardless of whether the child receives treatment for the disease.¹³ Studies have shown that families are not satisfied with communication and that physicians find communication difficult. That is why it is important to learn more about how to overcome communication barriers, support successful communication, improve the communication process and facilitate shared decision-making. Therefore, the aim of this study was to explore the experiences of physicians working in paediatric oncology when they were communicating with the families that a cure was no longer an option. We specifically wanted to focus on barriers and facilitating factors.

2 | MATERIAL AND METHODS

In this qualitative study, focus group discussions¹⁴ were conducted between December 2017 and May 2018 with physicians from all six paediatric oncology centres in Sweden. There was one focus group at each centre. We chose to hold focus group interviews as we wanted to facilitate engaged and rich discussions, where both individual and shared perspectives were discussed.¹⁴ The interviews were conducted with the help of a semi-structured interview guide (Appendix S1) and they took place in a separate room at the clinic. A purposive sample was used to achieve the nationwide representation of physicians from all six paediatric cancer centres in Sweden. The initial contact was with the physician manager at each centre, who received verbal and written information about the study. They forwarded the written information, including the researchers' contact details, to their fellow physicians and then discussed the study at one of their meetings. If any of the eligible

Key notes

- We focused on how 35 physicians working at Sweden's six cancer centres communicated with families when their child had terminal cancer.
- The communication challenges were emotional and mental drain, lack of mutual understanding and uncertainty about communication skills.
- Facilitating factors included flexibility in complex conversations, the child's position in the conversations, continuity and trusting relationships, support from colleagues and discussing the possibility of dying at the start of treatment.

physicians at the centre were interested in participating, a focus group discussion was scheduled. All physicians who worked at one of these centres, and were available at the time of the focus group, were eligible for inclusion. They were invited to participate irrespective of the length of their working experience and whether they worked part-time or full-time. The focus groups were led by two of the authors (CU and ML). They started by giving the participants detailed verbal information about the study and emphasising that participation was voluntary. The participants were then asked to discuss the conversations they had had with families when they informed them that a cure was no longer an option. Each focus group lasted between 60 and 90 minutes. A focus group interview guide was used (Appendix S1).

2.1 | Data analysis

The collected data were analysed using qualitative content analysis.¹⁵ The tape-recorded focus groups were transcribed verbatim, put into a Word document and read by three of the authors (CU, UK and ML). The initial overall impressions of the whole text were discussed by the authors, then the first and last authors (CU and ML) began to identify the meaning units that were relevant to the aim of the study. The meaning units were moved to a separate document and then coded by the first author with short descriptive codes. The first author continued the analytical process by grouping the codes into subcategories and categories based on their similarities. All categories were discussed by the authors and checked against the meaning units to ensure that they retained the original meaning throughout the process. The analysis was complete when all the authors had approved the final result.

2.2 | Ethical considerations

The study was approved by the appropriate Regional Ethical Research Committee (Dnr. 09-022M, 2014-216-32M, 2017-224-32M). Written, informed consent was obtained from all participants after

they had received information about the study and been given the opportunity to ask questions.

3 | RESULTS

Of the 59 eligible physicians who were invited to take part in the study, 35 (20 men) agreed to participate. There was an average of six participants per care centre: three, four, five and seven each from four centres and eight from two centres. They had a mean age of 47 (range 31-74 years) and a mean of 11 years (6 months to 43 years) experience of working in paediatric oncology. Their experiences of communication when a cure was no longer an option fell into two categories: barriers and facilitating factors (Table 1). These are summarised in the text and more detailed quotes can be found in Appendix S2. In general, the 26 physicians whose working experience exceeded three years spoke more and provided richer descriptions than their nine less-experienced colleagues.

3.1 | Communication challenges when a cure was not possible

The physicians described communication as an emotional and mental drain when a cure was no longer possible. They carefully considered the impact of everything they said to the parents because they knew they were emotionally distressed and needed information to be repeated a number of times. Communication was particularly demanding and challenging when the patient was a teenager, as they could suddenly ask questions in a very straightforward and brutally honest way. For example, the physicians described how teenagers planned their own funerals and how some children or teenagers suddenly started to talk about death, which often seemed to surprise their parents. The physicians stated that it was important to respond to the child's cues and answer their questions as honestly as possible. Teenagers sometimes reacted by becoming anxious about death and having panic attacks, which the physicians found emotionally challenging and mentally draining. They compared conversations with teenagers and younger children and said that the

younger children often had their own ideas about death, without really understanding it. However, these children sometimes asked questions about dying, which confirmed to the physicians that it was important to inform children about their prognosis and not just their parents. The physicians described how children who as young as nine years of age sometimes asked direct questions about whether they were going to die, which the physicians tried to answer honestly.

Lack of mutual understanding was also an issue. The physicians found it challenging when one or both of the parents had a different perspective about their child's condition to the physicians and they did not accept that it was time to end curative treatment and focus on palliative care. When one or both of the parents disagreed with the physician about how to move forward, the physicians tried to minimise that polarisation by discussing the medical indications. The physicians said that the professional team found it difficult when the parents took a child to a foreign country for alternative treatment after they were told that their child could not be cured. Challenging situations also arose when healthcare staff were anxious and upset, but the family had not yet been informed. According to the physicians, these staff were concerned that the child was receiving unnecessary painful treatment and that the child might suddenly deteriorate without the family having the chance to prepare. The physicians said that they made an effort to inform the care staff about their thoughts on the situation and their communication plans. They also wanted to be fully certain that all options had been explored and well prepared before talking to the family about ending curative treating and moving to palliative care.

The physicians also talked about their uncertainty about their communication skills. All the physicians emphasised the need for communication training in how to deliver bad news, but the only one said they followed a specific end-of-life communication manual or guideline. Concerns were expressed that overly formalised and narrowly structured conversations might hinder more open discussions with families. However, the physicians did note that standardising conversations might make it easier to determine what had been agreed. They described how they carefully prepared for family conversations where they would deliver difficult information about changing from curative to palliative care. The physicians felt that they probably talked too much during such conversations and provided too much information at once, even if they knew that the families could take it all in. They also said that sometimes they postponed decisions to move from curative treatment to palliative care and communicate this decision to the family, despite knowing that the child could not be cured. One of the most difficult aspects of conducting a conversation on ending curative treatment was how to conclude the conversation and when to leave the room. The physicians said it was difficult, but important, to stay quietly in the room after they had delivered the bad news. Sometimes they left the parents alone in the room for a while before returning to answer any questions that might have arisen. They found that some families discussed the future and death openly, while other families did not want to talk to them

TABLE 1 Categories and subcategories

Categories	Subcategories
Communication challenges when a cure was not possible	Emotional and mental drain
	Lack of mutual understanding
	Uncertainty about communication skills
Facilitating factors when a cure was not possible	Flexibility in complex conversations
	The child's position in the conversations
	Continuity and a trustful relationship
	Support from colleagues
	Having initially discussed cancer as a life-threatening disease

about what to expect. The physicians said that they did not usually offer to help the parents talk to their child, but they would step in if the family asked for help.

3.2 | Facilitating factors when a cure was not possible

The physicians said they tried to be flexible about how they initiated complex conversations about the fact that a cure was no longer an option and the information that they provided. Most conversations began with them describing the child's first medical treatment and then evaluating every medical step that had been taken through to the present day. The physicians said it helped both them and the family if a nurse or a counsellor who knew the family well was present during the conversation. They described how they tried to adapt the information to each family and this sometimes started by listening to what the family already knew. They also tried to include siblings and other important family members in these important discussions, depending on the parents' wishes.

The child's position in these conversations was also important. Whether or not the parents felt that it was appropriate for the child to be presented during this discussion depended on the child's age and the overall situation. Younger children were sometimes present for a short while. Sometimes the child participated in a second conversation after an initial one between the clinician and the parents. Talking to the parents first was considered crucial, as it gave them time to take in the information and react without the child seeing. The physicians said that the children listened attentively to what they were saying to the parents and how the information was communicated. Sometimes the children were angry with the physician for upsetting their parents by giving them bad news. The physicians felt it was best for the children to receive information that was specially adapted for their age and to participate in the conversation to some degree. They also believed that it would be worse for the child not to receive information or have the opportunity to ask questions and to be left alone with their imagination. They also said that many of the children already knew what was going to happen.

Continuity and trustful relationship were discussed. The physicians considered that continuity in care facilitated a trusting relationship between them and the families, which, in turn, facilitated complex discussions about moving from curative treatment to palliative care. The quality of the communication was affected by whether or not the parents knew and trusted their physician. The physicians felt that communication was more successful if the physician who broke the news that a cure was no longer an option was the same physician who had followed the family throughout the child's illness. This was important because they knew what care had been provided, what medical decisions had been made and how the family had previously reacted to, and coped with, situations. The physicians said they had great support from colleagues and learned by observing more experienced colleagues, who were role models, before conducting difficult conversations on their own. They prepared for difficult conversations with their fellow physicians, as the professional team

evaluated the child's medical treatments and jointly discussed and agreed the next step before, and after, discussions with the family. The timing of conversations about the fact that a cure was no longer an option was not determined by just the physician.

Support from colleagues helped them to ensure that the medical information was clear and accurate and that they were prepared for what they would say. In addition, they maintained contact with national and international paediatric physicians to make sure they had not missed any possible treatment. They said they prepared what to say beforehand and which care plan they would suggest going forward. The physicians often initiated the conversation by looking back through every treatment and medical step that had been taken along the way, eventually arriving at the present.

The physicians said that previous conversations about cancer being a potentially deadly disease helped to pave the way for discussions about a terminal prognosis. For example, some said that no treatment plan was 100% successful when they discussed the first medical treatment. While they felt this was a difficult balance, they considered it was important to talk about the possibility of death from the start, because this was the worst fear for most parents. They found that the parents were not taken completely by surprise when a cure turned out to be impossible if death had been mentioned at the outset. The physicians emphasised that although the curative treatment was ending, it was crucial to suggest a firm care plan going forward, as this it often gave the parents something to focus on. They could then shift their focus from a possible cure to other aspects, such as supporting their child's quality of life.

4 | DISCUSSION

In this study, physicians from all six paediatric oncology centres in Sweden discussed their experiences of communicating with families when a cure was no longer possible. The physicians described the challenges that created barriers to effective communication: emotional and mental drain, lack of mutual understanding and uncertainty in communication skills. These barriers have also been described in previous studies.^{6,7} However, the study also revealed a number of facilitating factors: flexibility in complex conversations, the child's position in the conversations, continuity in trustful relationships, support from colleagues and having initially discussed cancer as a life-threatening disease. These facilitating factors were important as they ensured that conversations about ending curative treatment were not postponed, causing families to miss out on palliative care that they would have benefited from.¹⁶

The physicians told us that flexibility and trustful relationships with the family facilitated complex and distressing conversations. This was in line with a study by Sisk et al, who emphasised that effective communication must be tailored to the family, the child's illness and the overall situation.¹⁷ However, our findings indicate that the physicians' desire to provide comprehensive information sometimes overshadowed their attempts to be flexible, although flexibility was recognised as a facilitating factor. These are important

results because too much attention on the physician means that the sole focus will be on providing information and not two-way communication and shared decision-making with the patients and their families. The results of our study highlight how difficult it may be to implement facilitating factors in practice, such as balancing clear information with being flexible and promoting hope. Promoting hope is an important part of communication, as it has been shown to help decrease psychological distress.¹⁸ Our results show that suggesting a concrete plan for going forward may promote hope for aspects other than a cure, such as minimal suffering. The facts that the physicians in our study told patients and families that a cure was no longer an option must be considered a positive one for medical care in general, because in the past bad news was often withheld from patients because physicians wanted to protect and not cause harm.¹⁷ Alternative strategies for achieving effective communication, such as active listening and responding to emotions,¹⁹ may be difficult to apply without training. It is possible that physicians who have received training could initiate discussions more often, by listening to what the parents and child know and how they perceive the child's situation, before moving on from there.

The physicians in our study wanted communication training, especially with regard to situations that they found particularly challenging, such as delivering bad news and communicating with teenagers. They also saw a need for flexible communication and were worried about becoming overly constrained by standardised communication guides. This indicates a need for clarity about the best way to use communication guidelines, while still being able to adapt the information and cater for each family's unique needs. It is important to consider this since healthcare professionals must be able to understand the family's values, hopes and fears in order to guide them further.²⁰ Communication training for professionals has been suggested as a way to increase teenagers' involvement in treatment and care decisions.^{21,22} The fact that the physicians were open to communication training is important, as it may help them to balance how they provide information. Studies have shown that providing too much information at any one time should be avoided so that physicians do not overload the parents when they are emotionally distressed.²³ In addition, patients who received explicit information about their prognosis said that they interpreted the communication as less compassionate.²⁴ It has been reported that a lack of communication training can cause uncertainty about what to say and how, but can also lead to overconfidence.²⁵ The physicians in our study wanted to be fully prepared and certain of the prognosis before initiating a discussion with the family, but ways to communicate uncertainty could be addressed in training in order to support family discussions. The present study revealed that one facilitating factor for learning communication skills was support from colleagues and learning from role models, including observing more experienced colleagues. Although learning from role models is important, this could risk delaying progress if it was the only strategy used for training physicians to deal with challenging communication. Weaver et al suggested that children and adolescents with cancer, and their families, should receive early integrated access to family-centred

palliative care, to minimise the burden of symptoms and provide preventative bereavement care for the families.²⁶ If palliative care was integrated with oncology care, it could gradually move into focus if needed, which would probably make communication easier when a cure was not possible. Our results indicate that overcoming communication barriers could support the integration of palliative care throughout the illness trajectory. Continuity was identified as another facilitating factor. Continuity of contact enabled relationships with the family, which in turn, was perceived to facilitate the successful communication of even distressing information. The physicians thought continuity was not just important for the family. It was also important for them as physicians because it helped them to feel more secure in communicating with the family if the family recognised and remembered them. Fostering relationships has been reported to be one of the core functions of communication between clinicians, patients and their parents.¹⁹ However, good intentions about achieving continuity should not lead to family conversations being postponed if the physician is unavailable. In our study, all the physicians at the clinic continuously discussed all the children and jointly evaluated their treatments. This strategy may have made it easier to avoid unnecessary delays if the physician in charge of that particular child's treatment was not available and a colleague had to step in and conduct difficult conversations.

Our results indicate that physicians have a unique opportunity to support family members when they need to communicate with each other. The physicians stepped in when a family asked for their support in communicating information about the disease and the situation to their child, but the physicians did not initiate this action themselves. Taking a more proactive stance, by asking families if they needed help to communicate difficult information about their child's cancer could provide families who do not ask for help with greater support. It is extremely stressful and distressing for both siblings²⁷ and parents when a child has cancer.² Communication is a key way of achieving optimal cancer care.²⁸ Sisk and Mack pointed out that few interventions have focused on improving prognostic communication.²⁹ They suggested that one way to improve communication about prognostic information in paediatric oncology was to focus on the purpose and process, where purpose was the will to communicate and the process was the ability to communicate.²⁹ It is important to consider the facilitating factors found in our study on how to overcome barriers when designing future interventions that focus on communication when a cure is no longer an option. Sisk and Mack emphasised that there is a need to prioritise addressing the purpose in order to enhance prognostic communication in paediatric oncology care.²⁹ With the exception of early discussions about cancer as a potentially life-threatening disease, the facilitating factors in our study tended to focus on the process.

Although this study was limited by the fact that only 59% of all the physicians working part-time or full-time in the six cancer centres took part, the qualitative approach contributed to our in-depth understanding of the complexities concerning prognostic communication in paediatric oncology. The study was sufficiently broad to cover the physicians' perspectives and experiences at a national

level and included all the Swedish paediatric oncology centres. A strength of our study was the fact that it was nationwide and that this contributed to our knowledge, regardless of clinic. Despite this, it was not our intention to produce generalisable findings, as our aim was to contribute to a better understanding of the communication between physicians and families when a cure was no longer an option.

5 | CONCLUSION

The findings of this study showed that, despite the challenges that the physicians faced when they communicated with the families of seriously ill children, there were also facilitating factors. These included the importance of physicians being aware of what the patients and families wanted and how they had dealt with the different stages of the disease so far. This knowledge enabled them to communicate effectively with them. Developing training to overcome communication issues could support the early integration of palliative care. In addition, knowing that palliative care could be part of their child's treatment if a cure was not possible would probably support continuous, flexible and trustful relationships with the family.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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