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Improving Communication in Adolescent Cancer Care: A Multiperspective Study

Stefan Essig, MD, PhD,[1,2,3] **Claudia Steiner,** dipl. phil. II,[4] **Claudia E. Kuehni,** MD,[1] **Heidemarie Weber,** PhD,[5] **and Alexander Kiss,** MD[4]*

Background. Professionals treating adolescents with cancer must communicate well with them and their parents. Evidence suggests that the communication needs of this population are rarely met. Skills training can improve professional communication, but has been criticized for not being based on the experience of the participants in the clinical encounter. We took a multiperspective approach, drawing on perspectives of former adolescents with cancer, patients' parents, physicians, and nurses with the aim to provide suggestions for improvement in communication in adolescent cancer care. ***Methods.*** Adolescent cancer survivors (n = 16), parents (n = 8), pediatric oncologists (n = 12), and pediatric oncology nurses (n = 18) participated in 11 focus groups. They discussed their experiences communicating with each other. Transcripts were analyzed by thematic analysis. ***Results.*** We identified themes within the following sections: (1) The framework in which professionals communicate with adolescents with cancer (regression in a time of detachment, adolescents' perception and knowledge of illness, cognitive versus legal maturity, "lost in transition" between pediatric and adult oncology); (2) communication difficulties between professionals and patients and parents (professionals and patients/parents identified the other party as the source of difficulties), and (3) effective professional communication (there was some overlap on how doctors and nurses should communicate, along with substantially different expectations for the two professions). ***Conclusions.*** The framework within which professionals communicate, the different perspectives on the factors that make communication difficult, and the different expectations regarding good communication by doctors and nurses should be considered when communication skills training courses are developed for professionals who work in adolescent oncology. Pediatr Blood Cancer 2016;63:1423–1430. © 2016 Wiley Periodicals, Inc.

Key words: adolescent cancer; physician communication challenges; qualitative research

INTRODUCTION

Adolescents with cancer are no longer children, but not yet adults. They have specific needs when they communicate with professionals.[1–3] Many adolescents find communication with adults, especially parents, difficult. Ordinary communication problems are exacerbated for adolescents with cancer, who must confront a life-threatening disease, adhere to strict treatment regimens, and deal with the consequences of therapy including changes to their physical appearance. Health care professionals who do not communicate well with adolescents during the transition from pediatric to adult medicine may aggravate the situation, especially when the patient is not clear on clinical competencies and processes.[4,5] Adolescents want to understand their medical condition, be involved in the decision making, be treated respectfully, maintain hope, and feel supported in a trustful relationship.[6–8]

Professionals often do not communicate well with adolescents.[9–14] Adolescents' specific needs such as infertility risks and semen cryopreservation[9,10] are seldom addressed. Professionals have been reported to underestimate the breath of the adolescents' communication needs[11] and adolescents and their parents have claimed that professionals should disclose information more openly and involve them in shared decision making.[12,13] Poor communication can lead to treatment refusal, noncompliance, and abandonment.[14–16]

Those professionals who focus on adolescents are rarely trained to communicate with them.[17] The American consensus statement on continuing education promotes communication skills[18] and specifically addresses training for professionals in pediatric and adult oncology, but not for adolescents. When communication guidelines exist, they are often based on experts' values and not on an assessment of the experience of all individuals in the clinical encounter.[19,20] Training can improve professional communication skills in oncology,[21] but it must be based on training guidelines that take adolescent and parental needs into account, as well as those of health care workers. Studies conducted thus far have tended to focus on either adolescents or parents,[13,22] or on health care professionals.[23,24]

We were asked to develop the content for communication skill training in adolescent oncology in Switzerland. Taking previous criticisms into account, we took a multiperspective approach, including all the parties involved in the clinical experience of adolescent cancer patients to assess communication needs. We did not restrict communication assessment to a specific topic of a clinical encounter and rather than focusing on deficit-oriented findings, we aimed to include positive encounters too. We thus wanted to find out what communication situations former adolescents with cancer, patients' parents, physicians, and nurses had encountered, to compare their perspectives on both effective and ineffective communication practices, and suggest ways to improve communication.

Additional supporting information can be found in the supporting information tab for this article.

Abbreviation: FG, focus group

[1]Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland; [2]Institute of Primary and Community Care, Lucerne, Switzerland; [3]Swiss Paraplegic Research, Nottwil, Switzerland; [4]Division of Internal Medicine, Department of Psychosomatic Medicine, University Hospital Basel, Basel, Switzerland; [5]Quality Management, University Hospital Basel, Basel, Switzerland

This article expresses views of former adolescent cancer patients, patients' parents, physicians and nurses.

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*Correspondence to: Alexander Kiss, Division of Internal Medicine, Department of Psychosomatic Medicine, University Hospital Basel, Hebelstrasse 2, 4031 Basel, Switzerland.
E-mail: Alexander.Kiss@usb.ch

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METHODS

Study Design

Our inquiry was exploratory, and the amount of existing data was minimal, so we adopted a qualitative study design. We conducted focus groups (FGs) to explore different perspectives on communicating with adolescents who have cancer. We capitalized on group interaction[25] to explore participants' experiences and needs. Participants were encouraged to introduce and discuss relevant points, to listen to different perspectives, and to exchange and elaborate ideas. We anticipated group interaction would show us the extent of consensus and diversity among participants and groups, and allow participants to compare experiences and views.[26] The Ethics Commission of Basel approved all study procedures, and participants gave written consent prior to participation.

Participant Recruitment

To maximize cultural diversity within German-speaking Europe, doctors and nurses were recruited by A. K. and H. W. by contacting pediatric oncology clinics in Switzerland, Germany, and Austria. Senior medical and nursing staff then invited other staff members to participate. We purposively sampled to achieve the greatest variety of age, experience, and gender by requesting this when contacting senior staff. Health professionals could participate if they had at least 6 months experience in pediatric oncology. FGs included doctors only, nurses only, and health care teams of both doctors and nurses. We used separate and mixed groups to create safe spaces for sharing experiences and criticisms. We continued to recruit new participants until our analysis showed that we had achieved data saturation.

We also held FGs with former adolescent cancer patients and parents of adolescent cancer survivors. SE contacted and invited them to participate through patient/parent organizations. Patients had to be over 18 years, diagnosed with cancer between the ages of 13 and 19 years, and disease free for at least a year to be included in survivor FGs. Parents could participate in parent FGs if their children had been diagnosed with cancer between 13 and 19 years of age.

We offered parents and former patients 50 Swiss francs to cover time and travel costs. At their request, the money was donated entirely to parent/patient organizations.

Conducting the FGs

A. K., a medical doctor with previous experience with FGs, qualitative research, and communication skills training,[27–30] facilitated all FGs except those for nurses alone, which were facilitated by a former nurse (H. W.). S. E., an MD PhD student, was introduced to A.K.'s FGs as an observer. FGs were held at the workplace for the convenience of health professionals. FGs with parents were held in neutral spaces rented for the purpose. FGs with former patients were held at the "Waldpiraten-Camp" in Heidelberg (D), which is designed to meet the needs of former child or teenage cancer patients. None of the FG participants were former patients or patients ' parents of the group facilitator.

FGs lasted approximately 1.5 hr. Each session began with an explanation of the intent and the goals of the research, after which participants granted informed consent. Participants filled out a brief sociodemographic questionnaire before discussion began. Moderators used a brief set of guidelines to guide discussion asking: (1) "Do you remember situations that were difficult in terms of communication?", (2) "Were there times in which communication went well?", (3) "What should doctors do to communicate well?", and (4) "What should nurses do to communicate well?" (with minor differences in phrasing between groups, see Online Appendix brief S1).[31]

Data Analysis

We conducted an inductive thematic analysis[32] to identify the set of themes that best captured the diverse perspectives and experiences of participants using Braun and Clarke's six-phase approach (familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report).[32] We adopted thematic analysis as an essentialist or realist method that reports experiences, meanings, and the reality of participants.[32] FG discussions were audio recorded and transcribed verbatim. A. K. and H. W. independently documented and discussed observations from the FG discussions. They began to analyze transcripts when the first two FGs were transcribed and generated initial codes and potential themes. Their findings were presented and discussed within the research group. Together with the research questions that shaped the guidelines for discussion, these findings determined the initial themes. Two researchers (H. W. and C. S.) then used this framework to independently code the transcripts. When they had differences over coding, they returned to the original data and resolved the question by consensus. Determining the themes was an iterative process: we collected data, analyzed, and discussed it; collected more data; reconsidered our set of codes; and regularly discussed new themes. After all transcripts were coded, we presented our preliminary findings at meetings of adolescent patient survivor groups, and at meetings of health care professionals who work with adolescents with cancer, in order to receive feedback and to corroborate our findings. We used MAXQDA software to manage and code the data.

RESULTS

Sample Characteristics

We conducted 11 FGs, which averaged five participants (range: 2–12), between June 2010 and October 2011. We held two FGs with doctors (Basel [CH] n = 4; Vienna [A] n = 3), three with nurses (Bern [CH] n = 5; St. Gallen [CH] n = 5; Freiburg [D] n = 6), two with health care teams of doctors and nurses (Zurich [CH] n = 5; Lausanne [CH] n = 2), two with survivors in Heidelberg (D) (n = 4 and n = 12), and two with parents (Bern [CH] n = 5; Heidelberg [D] n = 3). Table I summarizes gender, age, years working experience of professionals, and the age at which former patients and parents' children were diagnosed.

Qualitative Findings

We identified themes within three sections shaped by the questions in the FGs.

TABLE I. Characteristics of Participants

Characteristics	Doctors (n = 12)	Nurses (n = 18)	Survivors (n = 16)	Parents (n = 8)
Female	6 (50)	17 (94)	10 (63)	6 (75)
Age at discussion				
Mean (SD)	44 (8.5)	37 (9.4)	27 (4.7)	54.3 (5.3)
Range	31–56	26–57	21–34	45–62
Years in pediatric oncology				
Mean (SD)	13.3 (8.0)	8.3 (8.1)	–	–
Range	1–25	0.5–33	–	–
Mean (SD) age at diagnosis	–	–	15 (3.2)	13.8 (1.0)[a]
Mean (SD) years in treatment	–	–	3.4 (2.3)	4.1 (1.8)[a]
Mean (SD) years since treatment completion			8.6 (4.2)	6.4 (4.1)[a]

[a]Pertains to parents' child with cancer.
Values are numbers (percentages) unless otherwise stated.

(1) The framework in which professionals communicate with adolescents with cancer

All parties agreed that the framework in which communication occurs was unique and specific to adolescents with cancer. This section includes the following themes:

(A) Regression in a time of detachment

Adolescents are detaching from their parents and gaining autonomy. This process may be interrupted by the cancer experience:

> "You can feel the tension between the adolescents and their parents (…) it intensifies with the diagnosis, when the parents take back the parental role and the adolescents are practically forced into a more child-like one. That often leads to conflict." (FG Lausanne, nurse, line 9)

(B) How adolescents perceive and what they know about illness

Adolescents may not perceive and understand their illness the same way as children and adults:

> "I think they still have the feeling they're maybe not quite immortal but even with cancer, they have the feeling it can't be that bad." (FG Basel, doctor, line 47)

(C) Who decides? Discrepancy between cognitive and legal maturity

Normally, parents decide for their children and adults decide for themselves. Decision making for adolescents is less clear-cut. The legal age is 18, but some adolescents have an adult capacity for judgment. Adolescent cancer patients may feel they are mature enough to make their own decisions and disagree with their parents.

> "The patient was 15, (…) and wanted to terminate adjuvant therapy. There were 11 adjuvant chemotherapy cycles following surgery and he didn't want the last 3 or 4. (…) he wasn't of legal age but certainly capable of sound judgment, and as he said, clearly conscious of the consequences (…). So, we have the parents (…) who are legally responsible and ourselves, the treatment team, who clearly disagree with this decision. That's a conflict." (FG Basel, doctor, line 31)

(D) Lost in transition between pediatric and adult oncology

Former adolescent cancer patients were often treated in age-inappropriate pediatric wards, but felt that adult oncology would not have met their needs either:

> "It isn't optimal for adolescents to be in the pediatric ward because (…) there is nothing for them to do and no peers to befriend, but (…) I'd rather be treated like a child than be in adult oncology where no one really takes care of you." (FG Heidelberg, patient, line 60)

(2) Difficulties that professionals, patients, and parents have communicated with each other

Professionals found both patients and parents difficult to communicate with, and the reverse was also true. Table II shows the themes we identified (one quotation each; additional quotations in Online Appendix Table S1). Doctors and nurses found it hard to communicate with adolescents who reacted to their predicament by withdrawing and showing indifference. Professionals found it hard to communicate with adolescent patients when adolescent priorities conflicted with their treatment. Doctors and nurses found it hard to communicate with both patients and parents when their loyalties were torn between the two; when, for example, parents asked physicians to withhold information from their adolescent patient.

Adolescents did not like to be thought of and treated like children. Both adolescents and parents sometimes felt that medical staff did not take them seriously. Adolescents and parents could be overwhelmed by the vast amount of information given them by doctors, but felt that sometimes pertinent information was withheld.

(3) Effective communication by professionals

Doctors, nurses, patients, and parents reported experiences where they felt communication went well, and their expectations

TABLE II. Communication Difficulties: Views From Different Perspectives

Communication is difficult for doctors and nurses when …
• adolescents are indifferent and withdraw *"There are a lot of adolescents who withdraw when they receive the diagnosis, and that can be very difficult (…) you can't treat them without communication, of course. It can be really difficult to reestablish communication, and we have to rely on the help of our professionals, our psychologists because sometimes it really isn't possible for us." (FG Lausanne, doctor, line 27)*
• adolescents have other priorities *"They have other priorities. An adult will turn his life around to do chemotherapy, with adolescents it's the other way around; we have to adapt our chemotherapy to their lives." (FG Basel, doctor, line 51)*
• conflicts of loyalty occur between patients and parents *"… communication is difficult, when for instance, the parents want us to continue treatment and the 15 or 16 year old patient doesn't want to." (FG Basel, doctor, line 37)*
Communication is difficult for patients and parents when …
• professionals do not perceive them as adolescents *"As a 16 year old I wanted to wash myself (…), to go to the bathroom and take a shower. I didn't want them to come with a bucket and rub my back down. It was so unnecessary, (…) inappropriate. At first they wouldn't accept that I said, 'thanks, but I'll do it myself'." (FG Heidelberg, patient, line 159)*
• professionals do not take them seriously *"My worst experience with the personnel was that they didn't take me seriously when I was in pain (…) even my parents said, she's not one to pretend, if she's screaming from pain, then she is in pain (…) it took a really long time for them to give me medication." (FG Heidelberg, patient, 112)*
• professionals give too much information *"… first, you have to listen, and later you understand (…). Sometimes I understood nothing at all and then they asked 'do you have questions?' It's just too much at one time and you're overwhelmed by all the information." (FG Bern, parent, line 154)*
• important information is withheld *"…what really confused me after the operation (…) was that my left leg really hurt and I couldn't understand why my leg was hurting. It turns out they took a piece of the muscle and transplanted it into my head. (…) it was a totally confusing situation." (FG Heidelberg, patient, line 23)*

of good communication from doctors and nurses. Some of the themes apply to both physicians and nurses, but we also found notable differences between the professions. Tables III and IV identify these themes and identify the group of participants from which they emanated (additional quotations in Online Appendix Tables S2 and S3). According to the participants of the different FGs, doctors and nurses need to be clear and honest with patients. They should also spend enough time with patients and have personal, trustful relationships. Empathy and professional competence can help doctors and nurses communicate effectively. Being able to negotiate with adolescents is helpful, as is taking an interest in an adolescent's world.

FG participants described several components of good communication that relate solely to doctors. Doctors should take adolescents seriously, treat them respectfully, and be loyal to them. Nurses, parents, and patients emphasized that doctors also need to communicate effectively with other professionals. Nurses thought doctors should be good at handling constant disturbances and interruptions during critical conversations with adolescents. When decisions needed to be made, patients and parents thought that, whenever possible, doctors should respect their preferences.

Certain aspects of effective communication only applied to nurses. Doctors, nurses, patients, and parents thought that nurses should be effective go-betweens for doctors and patients. Nurses were expected to spread good humor and cheer, balance professionalism and close relationships with patients, and check whether patients had everything they needed. Nurses felt that they communicated more effectively when they showed respect for adolescent autonomy, and they connected with patients by explaining what they were doing, reading between the lines, and taking advantage of quiet times during the night shift to make personal contact and give massages. Nurses also emphasized their own coping strategies, including patiently enduring a difficult situation, being supported by their teams, and, when all else failed, handing over responsibilities to another team member.

DISCUSSION

This study includes the perspectives of all parties involved in the clinical experience of adolescent cancer patients (patients, parents, physicians, and nurses) to assess their communication with each other. Professionals and patients/parents focused on entirely different themes when they discussed problems with communication. We also found notable differences between physicians and nurses, in terms of what kind of communication was expected of them.

The communication difficulties parents/patients and health care workers identified are similar to situations described in other studies.[23,33–35] Professionals said that adolescents had other priorities and, for example, thought that chemotherapy had to be adapted to fit into their schedule, while adults will adapt their schedules to the treatment. Grinyer[33] described situations in which the priority adolescents put on independence conflicted with the need of professionals to prescribe specific courses of treatment. Conflicts between adolescents and their

TABLE III. Effective Communication by Doctors: Views From Different Perspectives

According to …			
d	*n*	*p*[a]	*Doctors' communication is good when they …*
x	*x*	*x*	• **are honest with patients** ***"I'm happy when the doctor is honest with the patient and clearly states his viewpoint, when he states the facts clearly but is prepared to listen to the patient too. …when there is a dialogue between the two and the patient has the opportunity to ask questions …" (FG Freiburg, nurse, line 223)***
x	*x*	*x*	• **take their time** ***"Most of them, with the exception of one doctor, never took any time to just stand still and wait and say …do you have questions or is there anything on your mind? They left so quickly that I couldn't. Except for one doctor, who I continue to see to this day because back then, that's what he did." (FG Heidelberg 2, patient, line 52)***
x	*x*		• take adolescents seriously, treat them respectfully *"take them seriously, I always make it clear that it's about you, not your parents, not us, it's you and the situation you are in with all the worries and problems that go with it (…) I mean that honestly (…) and it does provide a basis for a dialogue." (FG Vienna, doctor, line 46)*
x		*x*	• **have a personal, trustful relationship** ***" …I trusted the doctor who was treating my son and then there was a change (…) the new doctor really had to prove to me that he could relate to my son and was capable. Otherwise I always had the feeling that I had to bear all the responsibility. I had to keep track of the values, the examinations, make sure that things were taken care of …" (FG Heidelberg, parents, line 32)***
	x	*x*	• **have empathy** ***"It's a fine line and a very special situation in which one is very vulnerable …I think it's really important to take the situation into consideration and to have some sensitivity for the person you are dealing with and how much he or she can take …" (FG Bern, parent, line 232)***
	x	*x*	• communicate well between professions *"Where I was, the collaboration between neurosurgery, endocrinology and the oncology department was very good. They coordinated my consultations so that I didn't have to go three times for one thing. It worked really well as long as I was in the pediatric ward (…)." (FG Heidelberg 2, patient, line 68)*
	x	*x*	• **have professional competence and experience** ***"For me it was always important (…) that I had the feeling that the doctor was professionally competent and knew what he was doing." (FG Heidelberg, parent, line 73)***
x			• **negotiate with adolescents** ***"It's relatively frequent with adolescents that we have to reschedule therapy. We're constantly negotiating - when do we start chemotherapy? Can't it be five days later, because I have a party and this and that …That happens a lot, I find, with adolescents and young adults. Negotiate, negotiate, negotiate, one or two beers, we're always negotiating." (FG Basel, doctor, line 41)***
x			• are loyal toward the patients *"Adolescents have the right to a certain amount of confidentiality. That really needs to be respected. You have to make it clear to the parents that they have to accept that too. One has to create an own space for the adolescents. Sometimes that is easy, and sometimes it's a bit more difficult." (FG Lausanne, doctor, line 3)*
x			• **show interest in the adolescents' world** ***"Interest, yes, I would even say a general interest for the lives of today's adolescents, (…) I think that if you know nothing about the internet, about Facebook, about all these things where they are very active, networking, friends via Web (…). I think one has to show interest for their world, for the virtual world too, sometimes they spend more time there than in the real world." (FG Lausanne, doctor, line 80)***
	x		• deal well with disturbance and interruption *"Sometimes it's really crazy but there are doctors that will ask someone to keep their pager and be there for the patient." (FG Freiburg, nurse, line 244)*
		x	• request preferences in the decision making process *"Acknowledge it and react when something isn't working …Take fizzy calcium tablets for example. They can take them for weeks and then at one point it disgusts them to the point where they can't down the 200 ml and prefer to swallow four pills. Things like that need to be taken seriously." (FG Heidelberg, parent, line 136)*

[a]d, doctors; n, nurses; p, patients and parents.
Themes in bold are shared between Tables III and IV.

TABLE IV. Effective Communication by Nurses: Views From Different Perspectives

According to …			
d	*n*	*p*	*Nurses' communication is good when they …*
x	x	x	• **have a personal, trustful relationship** ***"It's what all people do, first you have to build up trust and find out how the other person ticks, and I don't think that you can expect more. Both parties need to get to know each other, the nurses and the patients." (FG Freiburg, nurse, line 132)***
x	x	x	• **have empathy** ***"that they show they are empathetic, (…) that they have the capacity to put themselves in the adolescent's situation and to think, well, if I were in that bed now, how would I be, how would I feel (…) For me, empathy is pretty fundamental." (FG Lausanne, doctor, line 109)***
x	x	x	• **show interest in adolescents' world** ***"I had to explain everything to my parents (…) because they didn't speak German and didn't understand the doctors. What was really positive was that in both the oncological ward and the stem cell transplant center the nurses and the social workers started learning words in Turkish …" (FG Heidelberg 2, patient, line 82)***
x	x	x	• **are calm and flexible, willing to negotiate** ***"Well sometimes they also turned a blind eye, with watching tv for instance, or some other treat - the adolescents could negotiate a little independence now and then." (FG Bern parents, parent, line 186)***
x	x	x	• are the go-between *"Communication between the patient and the nurse can probably be called "good," when the nurses learn things that the doctors don't (…) Sometimes patients ask if they are going to die. It's really exceptional that they ask the treating doctor. But they'll ask the nurse." (FG Zurich, doctor, line 97)*
x	x		• **are honest with the patients** ***With adolescents, you're much better off if you tell them honestly and from the very start what the situation is. Talk to them openly and honestly, don't try to mislead them and never, ever lie to them, but always tell them how it really is. (FG Bern, nurse, line 99)***
	x	x	• spread humor and cheer *"And the best thing was, when the nurses stopped by to joke around, when things weren't so terribly serious." (FG Heidelberg 2, patient, line 112)*
x			• **have professional competence and experience** ***"I think that a certain amount of experience is important. It's more difficult at the beginning, which is why I feel that lectures, symposiums or meetings and seminaries on communication are important when you're young and inexperienced, because there they have the opportunity to learn and to try things out." (FG Lausanne, doctor, line 109)***
x			• maintain the appropriate proximity/distance *"Situations come to mind, where I had the feeling that the nurses and patients were speaking to each other in a very relaxed and friendly style, which can still be absolutely professional. I think that it is important for adolescent patients to have partners with whom they can communicate casually (…) and still be respectful. I don't believe the two are necessarily exclusive." (FG Zurich, doctor, line 109)*
		x	• **take their time** ***"When I arrived, she really took her time (…) She explained everything to me and also let me ask lots of questions. I immediately felt that I was in good hands." (FG Heidelberg 1, patient, line 167)***
		x	• check to see what is needed *"I was there for a bone marrow biopsy and the nurse was great (…) she immediately came by to see what I needed and it was great that she did." (FG Heidelberg 2, patient, line 123)*
	x		• respect the adolescents autonomy *"that one includes them in the decision making and respects their self-determination and really asks them directly what it is they what and how." (FG Lausanne, nurse, line 68)*
	x		• seek to establish contact *"During the day there is much too much distraction for a conversation that is over 5 minutes long. (…).If I want to have a conversation with an adolescent, I much prefer the night hours." (FG Freiburg, nurse, line 80)*
	x		• have coping strategies *"That's why we're a team, so I can ask the others their views or tell them that I have difficulties dealing with the parents or that the child is just too difficult for me right now. Then someone can give me a tip or simply help me out." (FG Freiburg, nurse, line 193).*

d, doctors; n, nurses; p, patients and parents.
Themes in bold are shared between Tables III and IV.

parents, over who has the right to make decisions, have been described as distressing and ethically challenging for professionals, especially when professionals feel one party is in the right.[34,35] It is difficult for professionals to negotiate between an adolescent's need for information and a parent's wish to withhold information to "protect" their child. This is one of the key competencies for health professionals who work with adolescents who have cancer.[23]

Adolescents felt it was difficult when they were addressed age inappropriately, or were not taken seriously. Both are issues of respect and contribute substantially to high-quality patient-centered cancer care.[36] Parents found communication difficult when they received too much information at one time, but some adolescents found it difficult if important information was withheld. Most adolescents want detailed, but easy to understand, information on cancer treatment and diagnosis, so they can participate in the decision-making processes.[12] Some professionals tend to prioritize "protection" over the information needs of adolescents by the routine use of nondisclosure.[37] Former adolescent study patients said they felt neglected in discussions because doctors decided what they thought was in their best interest without seeking their consent.[38]

We confirm and expand existing knowledge about the ways doctors and nurses can communicate effectively. Like Forsey and colleagues, we found that doctors and nurses relied on each other to communicate well with adolescents and their parents.[39] When Forsey compared the accounts of doctors and nurses, describing how they provide emotional care for parents of children with acute lymphoblastic leukemia, their descriptions were markedly different. Doctors reassured parents through ongoing clinical care, explaining the potentially curative nature of treatment. Nurses relied on psychological skills and explicitly discussed the emotions of parents with them, providing reassurance. All parties thought that doctors should communicate clearly and honestly and take their time to listen. Information sharing and clear communication are top priorities for patients.[11,12] No group of participants thought it important that doctors deal with the emotions of patients, which corresponds with the results of a recent study on parents of children with cancer: most parents did not want to discuss their feelings with the oncologist, despite guidelines that encourage oncologists to engage patients in discussion about their emotions.[19] Our multiperspective data show that good communication by nurses overlaps with the therapeutic alliance, the collaborative bond between provider and patient (and in our case parent), characterized by trust and respect.[40,41] Nurses focus on building a strong relationship with adolescent patients and their parents, rather than on imparting information. Unlike doctors, they do not focus on mastering a specific set of communication skills.

FG participants differed in their descriptions of and expectations about good communication. Only doctors felt that mastering the skill of negotiating with adolescents improved their ability to communicate, or that showing an interest in the adolescent's world and being loyal toward them (rather than to their parents) improved the quality of communication. Nurses identified more aspects of good communication in their profession, including respect for adolescent autonomy and using diverse strategies to establish and maintain contact, including nonverbal communication. Nurses often described behaviors that amount to coping strategies, which were very important to the nurses. We list them because they were very important to the nurses. These strategies included simply staying with parents and sharing their sadness or helplessness with them, or finding a more appropriate person to take over.

Our findings may be useful for those who design communication skill training for professionals who care for adolescents with cancer, and the parents of these adolescents. Most Pediatric Hematology/Oncology fellows have had little or no communication skills training, even though the Accreditation Council for Graduate Medical Education established communication as a core competency for physicians-in-training.[17] Most training is for either doctors or nurses; only a minority of training is interprofessional.[42] A systematic review showed that the evidence for an effect of training is weak and needs further assessment.[43] Given our results, it may be appropriate to establish separate goals for teaching effective communication for doctors and nurses. Professionals, and adolescents and their parents, have very different problems with communication. All perspectives should be incorporated into skills training specific to adolescent oncology. According to the American and European Societies of Clinical/Medical Oncology Global Curriculum, training has to be learner centered, use role play and structured feedback, and should be conducted in small groups by trained facilitators.[44] Following these guidelines, our themes and quotations can be used in training sessions to:

(1) illustrate the communication challenges in adolescent oncology and what kind of communication approaches are helpful or not with this age group;
(2) fuel the discussion with case studies;
(3) script role plays with genuine content.

We should also evaluate if established techniques in clinical practice, such as the HEEADSSS assessment,[45] have an effect in those areas that we describe as difficult. Furthermore, the promotion of specific environments for adolescent oncology, especially adolescent and young adult services, could help to set the stage for successful communication.

The major strength of this study is that it included the perspectives of doctors, nurses, patients, and parents on how to best communicate with adolescents with cancer. It contributes to a better understanding of communication needs in the underresearched field of adolescent oncology.

Since our findings are based on a small German-speaking sample, they might not be generalizable. We cannot exclude volunteer bias in participating survivors and parents, since patient/parent organizations helped us find participants. Male survivors and fathers are underrepresented. The patient–physician interaction and professional education may have changed since the former patients in our FGs were diagnosed with cancer. We preferred long-term survivors as participants to protect participants from being too "involved" but possibly causing long-term memory bias. Although all FG sessions began with an introduction explaining the intent and goals of the research, the first question on communication difficulties may have biased the participant's responses to be more negative than they would have been had we begun with an open-ended question. We cannot rule out that the powerful status of the physician leading many of the discussions may have created a bias. We barely addressed

the common triadic (adolescent, parent, health professional) nature of communication with adolescents and their parents. We did not focus on individual perspectives on specific interactions between an adolescent or parent with a professional. We hope future studies, with different designs, explore these complex interactions in more detail.[46]

Professionals have a substantially different perspective than adolescent cancer survivors and parents on the factors that make communication between them difficult. Despite some agreement on what constitutes good communication by doctors and nurses, they have different goals when they communicate with patients and parents. These differences should be taken into account when communication skills training courses are developed for professionals who work in adolescent oncology.

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