Communicating "cure" to pediatric oncology patients: A mixed methods study

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Running head: Communicating "Cure" in Pediatric Oncology

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Abbreviations:

CNS	Central nervous system
SCCR	Swiss Childhood Cancer Registry
SCCSS	Swiss Childhood Cancer Survivor Study

Abstract

Background: Uncertainty about cure puts childhood cancer survivors at risk of mental distress. We asked survivors if they had been told they had been cured and investigated associated factors.

Procedure: We used nationwide registry data and a questionnaire survey for ≥5-year survivors of childhood cancer (n=301), followed by online focus groups with a purposive sample of Swiss pediatric oncologists (n=17). Discussions were coded by investigators using thematic analysis.

Results: Overall, 235 among 301 survivors (78%, 95% confidence interval 73–83%) reported having been told they were cured. The proportion was 89% (81–97%) among lymphoma and 84% (77–91%) among leukemia survivors, but only 49% (33–65%) among central nervous system tumor survivors. Pediatric oncologists acknowledged that telling survivors they are cured may reassure them that their cancer lies behind them. However, many refrained from telling all patients. Reasons included: the possibility of late effects (cure disrupted by a continued need for follow-up care) or late relapse (uncertainty of biological cure), case-by-case strategies (use of "cure" according to individual factors), and reluctance (substitution of noncommittal terms for "cure"; waiting for the patient to raise the topic).

Conclusions: Not all physicians tell survivors they have been cured; their choices depend on the cancer type and risk of late effects.

Introduction

More than 80% of childhood cancer patients currently survive at least 5 years after diagnosis.[1] Patients are transitioned to a survivorship clinic typically 1 to 5 years after treatment.[2] The word "cure" has a central meaning in this process: Besides its biological meaning (permanent remission), this term has also a psychosocial meaning (the belief one has left cancer behind).[3] While waiting to learn whether remission is permanent, patients must cope with uncertainty, which can cause mental distress.[4] For childhood cancer survivors, this fear of recurrence has been called 'Damocles' syndrome'.[5,6]

In general, scientific studies do not mention cure but report survival and remission. Nevertheless, some studies have raised the concept of cure. Since the mid-20th century, the content of conversations on cure have evolved: the first success stories of chemo- and radiotherapy let physicians dream of a cure; later, those not believing in cures were to be condemned, and cure became a major goal (Supplementary Figure S1).[7,8] Cure has been defined as the recovery from the original cancer,[9,10] i.e., physicians discussing the cancer-related prognosis with children and parents as a likelihood or hope of cure.[10,11]

As stated in the Erice statement, written by physicians, survivors, psychologists, nurses and epidemiologists in 2007 and updated in 2018, pediatric oncologists can use the term "cure" in discussions with childhood cancer survivors regardless of remaining uncertainty caused by the type of cancer they had, or existing or potential late effects of treatment.[12,13] This uncertainty includes some remaining risk of relapse, but also excess morbidity and death.[14,15] Late effects can begin decades after the end of treatment and include physical [16,17] or psychological and social problems.[18,19] By age 50, 96% of childhood cancer survivors have had a severe to life-threatening chronic condition.[20] Reassuring cancer patients they are cured while making sure they understand the need to continue follow-up care because of the potential for late effects is a delicate balance.

It is unclear whether pediatricians commonly tell childhood cancer survivors they are cured. To find out, we undertook a mixed-methods study.

Methods

Study design

We followed a sequential explanatory study design (Supplementary Figure S2) that used quantitative methods followed by qualitative methods.[21] We first conducted a quantitative analysis to determine the proportion of childhood cancer survivors who are told by their physicians that they have been cured, and which factors determine whether this is done. We then conducted a qualitative analysis to examine the underlying reasons and the experiences of physicians in detail. To do so, we combined registry data and closed-ended questions in a questionnaire to survivors with online focus group online focus group discussions among pediatric oncologists.

Quantitative methods

Study population

Since 1976, the Swiss Childhood Cancer Registry (SCCR) has collected data on all children in Switzerland diagnosed with leukemia, lymphoma, central nervous system (CNS) tumors, malignant solid tumors, or Langerhans cell histiocytosis.[22] The Swiss Childhood Cancer Survivor Study (SCCSS) is a questionnaire study of all 5-year survivors which includes baseline and follow-up questionnaires. The follow-up questionnaire was sent to a subsample 3 years after the baseline questionnaire.[23] Eligibility criteria for the follow-up questionnaire were: diagnosis of childhood cancer in Switzerland after 1990, <16 years of age at diagnosis, having survived ≥5 years after diagnosis, >18 years of age at the time of the study, and having replied to the baseline questionnaire. Eligible survivors received the questionnaire with a prepaid return envelope. Non-responders received a second questionnaire two months later. The questionnaire was available in German and French.

The outcome of interest

The follow-up questionnaire contained the question: "Have you ever been told you were cured?" Respondents who said yes were then asked who told them and when.

Explanatory factors

We sought to determine which of the following explanatory factors were associated with the message of cure: age at survey, age at diagnosis, year of diagnosis, sex, language region (German, French/Italian), type of cancer (according to the International Classification of Childhood Cancer, 3rd Edition),[24] radiotherapy (no radiotherapy, body and limb irradiation, cranio-spinal irradiation), relapse of original cancer (no/yes), and type of clinic (university or regional clinic). Information on those factors came from the registry. In addition, we used data from the SCCSS baseline questionnaire: presence of late effects (self-reported; no/yes) and migration background (those without Swiss citizenship since birth, not born in Switzerland, or having at least one non-Swiss citizen parent; no/yes), and from the SCCSS follow-up questionnaire: education (primary [compulsory schooling only]; secondary [including vocational training, teachers', technical and commercial schools]; and tertiary [including university and university of applied sciences]).

Analysis

We determined the proportions of survivors described as "cured" and stratified by all listed explanatory factors. We compared the proportions using Chi-squared tests. Reporting of the quantitative part of this study follows STROBE guidelines (Supplementary Document 2).

Since 2004, all patients and their families give informed consent at the time of cancer diagnosis for their data to be included in the SCCR and used for research. Patients who had been diagnosed in the early years of the registry received the information retrospectively and could object to their inclusion in the registry (right of veto). This procedure was decided by the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research when granting the general cancer registry permission to the SCCR, and was endorsed by the ethics committee of the canton of Bern (KEK-BE: 166/2014).

Qualitative methods

Source of data

We conducted online focus groups to which we invited all pediatric oncologists in Switzerland. Using the official online directory of physicians in Switzerland (http://www.doctorfmh.ch/), we retrieved information on their medical specialty, preferred language, and year of graduation from medical school and sent them an e-mail with a short description of the study and a link to an internet forum where the online focus groups took place.

The forum was developed by the Netherlands Institute for Health Services Research in Utrecht. It allowed asynchronous discussions, i.e. reading and writing of contributions at any time, 24 hours a day, for a period of one month. Each participant and the moderator (S.E.) received a unique login name and password to access the forum. The confidentiality of contributions was secured by anonymized login names and SSL cryptography. Using a homogenous, purposive sampling technique, we split the physicians into two German-speaking forums according to their year of graduation (before 1991 and from 1991 onward).[25,26] We conducted an online focus group with physicians in the French- and Italian-speaking part of Switzerland, but only three participated. Therefore, we considered their discussion unrepresentative. We provide the anonymized transcript of this online focus group in Supplementary Document 3.

Data of interest

Physicians were asked to study the main result of the quantitative analysis provided in the forum (proportion of survivors who were told

they had been cured; overall and by diagnostic groups). In the main thread of the forum, they were encouraged to comment on these data, react to each other's contributions, and suggest what might explain why a childhood cancer survivor was or was not told he or she was cured. Two marginal threads were available to initiate discussions, share examples of conversations about cure, and mention published or institutional guidelines or statements on communicating cure, including the Erice statement.[13] In this study, we did not differentiate between the three threads, as many physicians submitted all their contributions in only one of the threads. The moderator interacted with participants, by asking follow-up questions and clarifying participants' views.

Analysis

We interpreted the physicians' answers using a thematic analysis framework: Coding the text was a hybrid of a deductive *a priori* template of codes (from quantitative results) and data-driven inductive codes (adding new/explaining factors).[27] Two investigators (S.E. and C.D.) coded the transcripts independently. In discussions, disagreements were resolved, and data categorized into themes. Discussions of online focus groups were copied verbatim from the forum, and S.E. and C.D. translated them from German to English. An interpreter independently checked the translations for accuracy. Direct quotations give evidence of both typical views and of the diversity of views obtained.

All participants in the online focus group discussions agreed to take part in the study. A jurisdictional inquiry to the ethics committee confirmed their non-involvement as the need to obtain formal approval was waived.

Results

Information from survivors (quantitative data)

Of 754 eligible childhood cancer survivors, 710 could be contacted and 322 (45%) returned the follow-up questionnaire (Figure 1). Average age of participants was 9 years at diagnosis and 21 years at the time of the survey (Table 1). Compared with non-participants, more participants were female (57 vs. 42%) and reported suffering from late effects (42 vs. 34%).

Seventy-eight percent (235/301, 95% confidence interval 73 to 83%) reported that they had been told they were cured. This differed by diagnosis and was 89% (81–97%) in lymphoma survivors, 84% (77–91%) in leukemia survivors, 76% (58–94%) in renal tumor survivors, 67% (48–86%) in bone tumor survivors, and 49% (33–65%) in CNS tumor survivors (Table 2). Survivors who had been given the message of cure were generally younger at diagnosis, further from diagnosis, French- or Italian-speaking, had experienced no relapse, and had secondary education. Year of diagnosis, sex, radiotherapy, type of clinic, presence of late effects, and migration background were not associated with the message of cure. Survivors had received the message of cure a median 6 years after diagnosis (interquartile range 5–8 years, overall range 0–16 years).

Information from physicians (qualitative data)

Of 51 (37 German-speaking) eligible physicians, 42 (31) could be contacted and 20 (17) participated (Figure 2). More participants were male compared with non-participants (65% vs. 50%); there was no difference in age.

The participating physicians highlighted the following objective and subjective factors to explain which survivors had been told they were cured. These factors are summarized here, and additional points can be found in Supplementary Document 4. Published statements on communicating cure, including the Erice statement, and guidelines were widely unknown to the pediatric oncologists, and therefore did not explain why certain survivors had been told they were cured.

Helping survivors finish the cancer story – All pediatric oncologists acknowledged that telling survivors that they are cured may help them "finish the cancer story". Some suggested that the message of cure can lower the level of anxiety in survivors. Having been cured was

viewed as patients' goal and motivation for undergoing taxing therapy (quotations in Supplementary Document 5). No participant mentioned that the message had a negative effect or had to be reconsidered later.

Late effects – Many physicians did not tell all survivors that they had been cured because of existing or potential late effects, especially when these effects were severe. They also feared that patients who were told they were cured could have less understanding of the need for continued follow-up care. As a divergent view, one physician told survivors about cure irrespective of late effects.

Late relapse – The diminishing risk of relapse was an important factor for using the term "cure". Sometimes, the opposite was true: Physicians did not talk about cure because they wanted to be honest when considering the small long-term risk of a recurrence.

Case-by-case use – Some physicians said that they followed a case-by-case approach, using the term "cure" depending on individual factors related to patients and environment. These factors included, for instance, the type of disease and parents' communication style. One physician mentioned that this complexity renders any communication guidelines useless.

Reluctance – Many physicians were reluctant to use the term "cure" and so used noncommittal terms and expressions, waiting until patients specifically raised the topic. Two physicians remained passive and assumed that an early discussion of cure, e.g. during treatment, would be sufficient and remembered by patients and their relatives later on. Some physicians did not exhibit reluctance around the term and actively used it because they felt it was expected by survivors and parents.

Helping physicians resolve cognitive dissonance – One important underlying reason for physician's communication choices was not based on patients' needs. Instead, some physicians resolved their own cognitive dissonance between wanting to help patients and their families get past the illness and wanting to be scientifically correct, i.e., acknowledging that the risk of relapse, secondary tumors or late effects remains present lifelong, even if it becomes smaller as time passes.

Discussion

We found that three-quarters of survivors had been told they had been cured. The questionnaire study showed an association of communicating cure with cancer type, younger age at diagnosis, longer time since diagnosis, language region, no relapse, and secondary education. Online focus group discussions among physicians explored underlying factors to be late effects, late relapse, case-by-case decision making, and reluctance to use the term cure.

We combined a quantitative and a qualitative approach to account for the complexity of the topic, following the advice that different methods employed should allow different insights to tell the reader something new.[28]

Focus groups were particularly suited for studying physicians' attitudes and experiences in terms of communicating cure. They allowed a shift from personal, self-centered explanations to structural ones, e.g. most participants did not use "I"-statements, but instead discussed why "pediatric oncologists" used the term cure. The group setting might have helped those who felt they had nothing to say to engage in discussions generated by the moderator and other participants.

The use of asynchronous online focus groups had some distinct advantages compared with face-to-face focus groups. [29] First, this approach reached pediatric oncologists who have little spare time, and for this reason are often unwilling to travel to attend a face-to-face focus group. [30,31] Second, online focus groups allow participants time to elaborate their contribution before submitting it. This helps avoiding impulsive responses which may block the discussion. Furthermore, the virtual anonymous setting allowed participants to freely express their opinion without feeling judged. We carefully employed the thematic analysis to avoid de-contextualization of physicians' words.

Only one former study empirically studied the actual use of the term cure in practice.[24] Miller reported that 81% of adult oncology clinicians in Boston (physicians, nurse practitioners, physician's assistants) were hesitant to tell patients they had been cured, similar to our findings among Swiss pediatric oncologists. Furthermore, in Miller's study, clinicians reported that patients were hesitant to ask whether they were cured.[24] We did not assess this question, but our finding that physicians are sometime reluctant to speak about cure would be of particular importance in a context where patients have to raise this topic themselves. A study with survivors of adolescent and young adult cancer showed that the fear of recurrence is highly prevalent in this population; the authors suggest the identification of underlying communication processes.[4] Sharing with these patients that they are considered cured may help address this fear.

Pediatric oncologists might have passed the "peak" of believing in and communicating cure, because their knowledge of the late effects of treatment [16,17,32] and late recurrence of the original cancer [15,33] has increased over the last decades. Among other underlying reasons, late effects were cited in the current study by physicians who did not tell survivors that they have been cured, especially younger physicians. This could explain why those diagnosed after 1995 were less likely to receive the message of cure than those diagnosed before. In general, younger physicians were more elaborate in their contributions of different underlying reasons, in contrast to clear cut views of older physicians. This could be related to inexperienced physicians who discuss "how it could/should be" and experienced physicians who convey their way of communicating cure.

Pediatric oncologists might also lack the necessary skills to communicate cure. Adequate communication skills are a fundamental capability of physicians in oncology, but other studies have detailed the struggle of physicians with difficult communication tasks in general,[34,35] for instance with explaining randomization in childhood cancer trials [36] and cross-cultural negotiations.[37]

Our results can inform communication strategies of health care professionals. Long-term follow-up care provides regular opportunities for conversations on cure. Physicians might benefit from regular team discussions on cure, as one participant suggested, that prepare for the discussion with the survivor. Additionally, essential skills for communicating cure might be trainable. However, results from online focus groups also indicate that conversations on cure are complex. Furthermore, the Erice statement, promoting the message of cure,[12] was widely unknown to the pediatric oncologists in the online focus groups. For all these reasons, the role of statements and guidelines remains unclear and their further development would be challenging.

Our study cannot represent all of the intricacies of physicians' communication of cure. In particular, the closed-ended question assessing the message of cure is a simplification and cannot replace more in-depth studies. Some survivors were probably told they were cured but did not remember being told this. This could be for many reasons – the oncologist used another wording, the patient simply forgot, or other reasons. However, survivors who remembered having been told by a physician that they were cured had, on average, been diagnosed at earlier dates and at a younger age than those who did not. The participation rate of survivors was low; however, the sample appeared to be fairly representative, with the exception that responders were more likely to be female and have prevalent self-assessed late effects. This study was performed with survivors and physicians in Switzerland; results might differ in other countries.

Providing the quantitative results from the survivors to the physicians rather than simply discussing about the concept of communicating cure to survivors might have biased the results. Only a few physicians did not contribute their own ideas, limiting themselves to agreeing with previous contributions. Unfortunately, we could only include German-speaking physicians in the analysis; there might have been cultural reasons for the low number of French-speaking physicians participating in the online focus groups.

We suggest evaluating survivors' views and expectations on what kind of communication about cure suits them best. It is unclear if late effects should be considered when discussing cure. Telling a patient after the end of treatment that he or she has been cured might be a fundamental step to reduce emotional distress allowing survivors to achieve well-being, which is an important pillar of future cancer care.[38] Adequately powered studies should adjust for confounding in a multivariable analysis clarifying potential risk factors for not receiving the message of cure. The degree of emotional distress among childhood cancer survivors should be further studied. As far as we know, the link between not communicating cure and mental distress – for example, due to fear of recurrence – seems plausible, but has never been investigated. In this context, it will be important to use valid instruments to assess the outcome.[39,40] If the link is confirmed, it might be advisable to compare the effectiveness of a simple communication of cure with more complex strategies, such as psychological counseling, in designing interventions.

In conclusion, we unfolded some of the biological and psychological motivations behind individual styles of communicating cure. The proportion of patients who had been told they were cured depended on the type of cancer, likelihood of late effects and on the attitude of the physicians towards the concept of cure.

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References

1. Gatta G, Botta L, Rossi S, Aareleid T, Bielska-Lasota M, Clavel J, Dimitrova N, Jakab Z, Kaatsch P, Lacour B. Childhood cancer survival in Europe 1999–2007: results of EUROCARE-5—a population-based study. Lancet Oncol 2014:15(1):35-47.
2. Oeffinger KC, Argenbright KE, Levitt GA, McCabe MS, Anderson PR, Berry E, Maher J, Merrill J, Wollins DS. Models of cancer survivorship health care: moving forward. Am Soc Clin Oncol Educ Book 2014:4:205-213.
3. Van Eys J. The truly cured child: The new challenge in pediatric cancer care: University Park Press; 1977.
4. Shay LA, Carpentier MY, Vernon SW. Prevalence and correlates of fear of recurrence among adolescent and young adult versus older adult post-treatment cancer survivors. Support Care Cancer 2016:24(11):4689-4696.
5. Koocher GP, John EOM. The Damocles syndrome: Psychosocial consequences of surviving childhood cancer: McGraw-Hill New York; 1981.
6. Butow PN, Turner J, Gilchrist J, Sharpe L, Smith AB, Fardell JE, Tesson S, O'Connell R, Girgis A, Gebski VJ, Asher R, Mihalopoulos C, Bell ML, Zola KG, Beith J, Thewes B. Randomized Trial of ConquerFear: A Novel, Theoretically Based Psychosocial Intervention for Fear of Cancer Recurrence. J Clin Oncol 2017:35(36):4066-4077.
7. Barnes E. Caring and curing: paediatric cancer services since 1960. Eur J Cancer Care 2005:14(4):373-380.
8. Prasad V. Use of the Word "Cure" in the Oncology Literature. Am J Hosp Palliat Me 2014:1049909114524477.
9. Hill DL, Miller V, Walter JK, Carroll KW, Morrison WE, Munson DA, Kang TI, Hinds PS, Feudtner C. Regoaling: a conceptual model of how parents of children with serious illness change medical care goals. BMC Palliat Care 2014:13(1):9.
10. Mack JW, Cook EF, Wolfe J, Grier HE, Cleary PD, Weeks JC. Understanding of Prognosis Among Parents of Children With Cancer: Parental Optimism and the Parent-Physician Interaction. J Clin Oncol 2007:25(11):1357-1362.
11. Sisk BA, Mack JW, Ashworth R, DuBois J. Communication in pediatric oncology: State of the field and research agenda. Pediatr Blood Cancer 2018:65(1):e26727.
12. Haupt R, Spinetta JJ, Ban I, Barr RD, Beck JD, Byrne J, Calaminus G, Coenen E, Chesler M, D'Angio GJ, Eiser C, Feldges A, Gibson F, Lackner H, Masera G, Massimo L, Magyarosy E, Otten J, Reaman G, Valsecchi MG, Veerman AJ, Penn A, Thorvildsen A, van den Bos C, Jankovic M. Long term survivors of childhood cancer: cure and care. The Erice statement. Eur J Cancer 2007:43(12):1778-1780.
13. Jankovic M, Haupt R, Spinetta JJ, Beck JD, Byrne J, Calaminus G, Lackner H, Biondi A, Oeffinger K, Hudson M, Skinner R, Reaman G, van der Pal H, Kremer L, den Hartogh J, Michel G, Frey E, Bardi E, Hawkins M, Rizvi K, Terenziani M, Valsecchi MG, Bode G, Jenney M, de Vathaire F, Garwicz S, Levitt GA, Grabow D, Kuehni CE, Schrappe M, Hjorth L, participants in P. Long-term survivors of childhood cancer: cure and care-the Erice Statement (2006) revised after 10 years (2016). J Cancer Surviv 2018.
14. Robison LL, Hudson MM. Survivors of childhood and adolescent cancer: life-long risks and responsibilities. Nature Reviews Cancer 2014:14(1):61-70.
15. Schindler M, Spycher BD, Ammann RA, Ansari M, Michel G, Kuehni CE, for the Swiss Paediatric Oncology G. Cause-specific long-term mortality in survivors of childhood cancer in Switzerland: A population-based study. Int J Cancer 2016:139(2):322-333.
16. Armstrong GT, Liu Q, Yasui Y, Neglia JP, Leisenring W, Robison LL, Mertens AC. Late mortality among 5-year survivors of childhood cancer: a summary from the Childhood Cancer Survivor Study. J Clin Oncol 2009:27(14):2328.
17. Mulrooney DA, Yeazel MW, Kawashima T, Mertens AC, Mitby P, Stovall M, Donaldson SS, Green DM, Sklar CA, Robison LL. Cardiac outcomes in a cohort of adult survivors of childhood and adolescent cancer: retrospective analysis of the Childhood Cancer Survivor Study cohort. BMJ 2009:339.
18. Michel G, Rebholz CE, von der Weid NX, Bergstraesser E, Kuehni CE. Psychological distress in adult survivors of childhood cancer: the Swiss Childhood Cancer Survivor study. J Clin Oncol 2010:28(10):1740-1748.
19. Barrera M, Shaw AK, Speechley KN, Maunsell E, Pogany L. Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. Cancer 2005:104(8):1751-1760.
20. Bhakta N, Liu Q, Ness KK, Baassiri M, Eissa H, Yeo F, Chemaitilly W, Ehrhardt MJ, Bass J, Bishop MW. The cumulative burden of surviving childhood cancer: an initial report from the St Jude Lifetime Cohort Study (SJLIFE). Lancet 2017:390(10112):2569-2582.

21. Clark VLP, Creswell JW. Designing and Conducting Mixed Methods Research: Sage Publications, Inc; 2010.
22. Michel G, von der Weid N, Zwahlen M, Adam M, Rebholz CE, Kuehni C. The Swiss Childhood Cancer Registry: rationale, organisation and results for the years 2001-2005. Swiss Med Wkly 2007:137(35-36):502.
23. Kuehni CE, Rueegg CS, Michel G, Rebholz CE, Strippoli M-PF, Niggli FK, Egger M, von der Weid NX. Cohort profile: The Swiss childhood cancer survivor study. Int J Epidemiol 2011.
24. Miller K, Abraham JH, Rhodes L, Roberts R. Use of the Word "Cure" in Oncology. J Oncol Pract 2013:9(4):e136-e140.
25. Barbour RS. Doing focus groups: Sage; 2009.
26. Kitzinger J. Qualitative research: introducing focus groups. BMJ 1995:311(7000):299.
27. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. International Journal of Qualitative Methods 2006:5(1):80-92.
28. Diekroger EA. The power of qualitative research. Pediatrics 2014:134(4):e933-934.
29. Gaiser T. Online focus groups. The Sage Handbook of Online Research Methods London/Beverly Hills 2008:290-306.
30. Tates K, Zwaanswijk M, Otten R, van Dulmen S, Hoogerbrugge PM, Kamps WA, Bensing JM. Online focus groups as a tool to collect data in hard-to-include populations: examples from paediatric oncology. BMC Med Res Methodol 2009:9:15.
31. Zwaanswijk M, Tates K, van Dulmen S, Hoogerbrugge PM, Kamps WA, Bensing JM. Young patients', parents', and survivors' communication preferences in paediatric oncology: results of online focus groups. BMC Pediatr 2007:7:35.
32. Bhatia S, Meadows AT. Long‐term follow‐up of childhood cancer survivors: future directions for clinical care and research. Pediatr Blood Cancer 2005:46(2):143-148.
33. Schindler M, Mitter V, Bergstraesser E, Gumy Pause F, Michel G, Kuehni CE. Death certificate notifications in the Swiss Childhood Cancer Registry: assessing completeness and registration procedures. Swiss Med Wkly 2015:145:w14225.
34. Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. Pediatr Blood Cancer 2016:63(8):1423-1430.
35. Back AL, Arnold RM, Baile WF, Tulsky JA, Fryer-Edwards K. Approaching Difficult Communication Tasks in Oncology. CA-Cancer J Clin 2009:55(3):164-177.
36. Kodish E, Eder M, Noll RB, Ruccione K, Lange B, Angiolillo A, Pentz R, Zyzanski S, Siminoff LA, Drotar D. Communication of randomization in childhood leukemia trials. Jama 2004:291(4):470-475.
37. Surbone A. Cultural aspects of communication in cancer care. Support Care Cancer 2008:16(3):235-240.
38. Bultz BD, Carlson LE. Emotional distress: the sixth vital sign-future directions in cancer care. Psychooncology 2006:15(2):93-95.
39. Thewes B, Butow P, Zachariae R, Christensen S, Simard S, Gotay C. Fear of cancer recurrence: a systematic literature review of self‐report measures. Psychooncology 2012:21(6):571-587.
40. Simonelli LE, Siegel SD, Duffy NM. Fear of cancer recurrence: a theoretical review and its relevance for clinical presentation and management. Psychooncology 2017:26(10):1444-1454.

Legends

FIGURE 1 Participants in the Swiss Childhood Cancer Survivor Study

FIGURE 2 Participants in the online focus groups

TABLE 1 Characteristics of questionnaire non-participants and participants. Values are numbers (percentages)

TABLE 2 Number and proportion of survivors reporting that they were told that they had been cured

TABLE 1 Characteristics of questionnaire non-participants and participants. Values are numbers (percentages)

Characteristic	Participants (n=301)	Non-participants (n=409)	p
Age at time of study (years)			.538
- <25	179 (59)	233 (57)	
Age at diagnosis (years)			.732
- <5	72 (24)	106 (26)	
- 5-9	90 (30)	130 (32)	
- ≥10	139 (46)	172 (42)	
Year of diagnosis			.447
- <1995	141 (47)	204 (50)	
Sex			<.001
- Men	130 (43)	236 (58)	
Language region			.877
- German	226 (75)	305 (75)	
Type of cancer			.639
- Leukemia	105 (35)	131 (32)	
- Lymphoma	56 (19)	84 (20)	
- CNS tumor	37 (12)	64 (16)	
- Renal tumor	21 (7)	19 (5)	
- Bone tumor	21 (7)	24 (6)	
- Langerhans cell histiocytosis	13 (4)	20 (5)	
- Other types	48 (16)	67 (16)	
Radiotherapy			.244
- No radiotherapy	182 (60)	260 (64)	
- Body and limp irradiation	73 (24)	84 (21)	
- Cranio-spinal irradiation	46 (15)	65 (15)	
History of relapse			.260
- Yes	35 (12)	37 (9)	
Type of treatment clinic			.590
- University clinic	226 (75)	294 (72)	
- Regional clinic	75 (25)	115 (28)	
Prevalent late effects (self-assessed)			.028
- Yes	124 (42)	132 (34)	
Migration background			.535
- Yes	24 (8)	38 (9)	
Education			.190
- Primary	63 (21)	77 (19)	
- Secondary	165 (56)	269 (66)	
- Tertiary	67 (23)	63 (15)	

TABLE 2 Proportion of survivors reporting that they were told that they had been cured, by sociodemographic and clinical characteristics

Characteristic	N	%	95% CI[a]	p
Overall	235	78	73-83	
Age at study (years)				.379
- <25	138	77	71-83	
- ≥25	97	79	72-86	
Age at diagnosis (years)				.048
- <5	59	81	72-90	
- 5-9	71	79	71-87	
- ≥10	103	74	67-81	
Year of diagnosis				.050
- <1995	114	81	75-88	
- ≥1995	119	74	67-81	
Sex				.889
- Men	101	78	71-85	
- Women	134	78	72-84	
Language region				.002
- German	167	74	68-80	
- French/Italian	68	91	85-97	
Type of cancer				<.001
- Leukemia	88	84	77-91	
- Lymphoma	50	89	81-97	
- CNS tumor	18	49	33-65	
- Renal tumor	16	76	58-94	
- Bone tumor	14	67	48-86	
- Langerhans cell histiocytosis	12	92	77-107	
- Other types	37	77	66-90	
Radiotherapy				.247
- No radiotherapy	147	81	75-87	
- Body and limb irradiation	56	77	67-85	
- Cranio-spinal irradiation	32	70	57-83	
History of relapse				.006
- No	214	80	75-85	
- Yes	21	60	44-75	
Type of treatment clinic				.617
- University clinic	178	79	73-85	
- Regional clinic	57	76	66-86	

Prevalent late effects (self-assessed)				.131
- No	141	82	76-88	
- Yes	92	74	66-82	
Migration background				.711
- No (Swiss)	216	78	73-83	
- Yes	18	75	58-92	
Education				.042
- Primary	43	68	52-84	
- Secondary	137	83	76-90	
- Tertiary	50	74	59-89	

[a]95% Confidence Interval

FIGURE 1 Participants in the Swiss Childhood Cancer Survivor Study

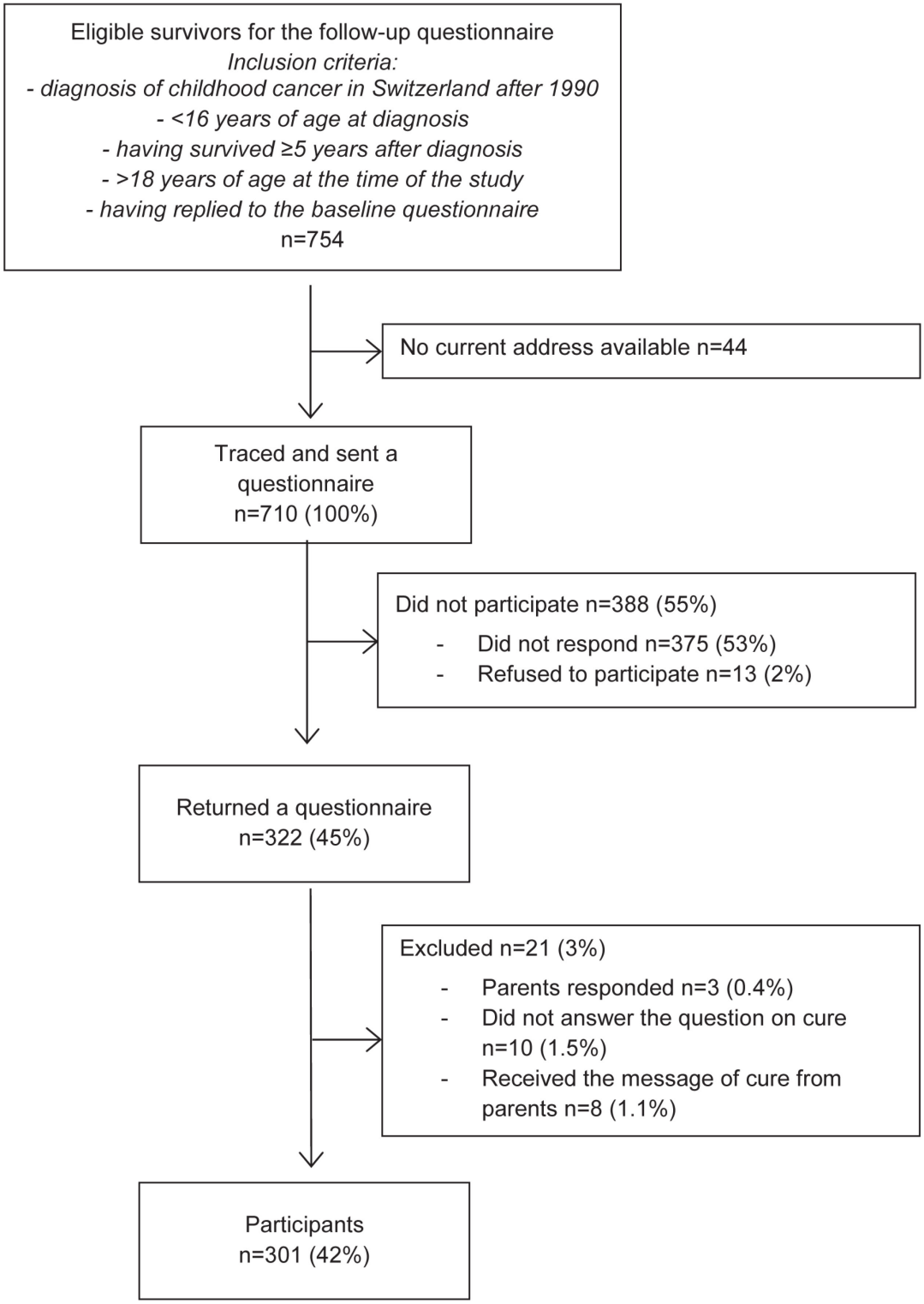
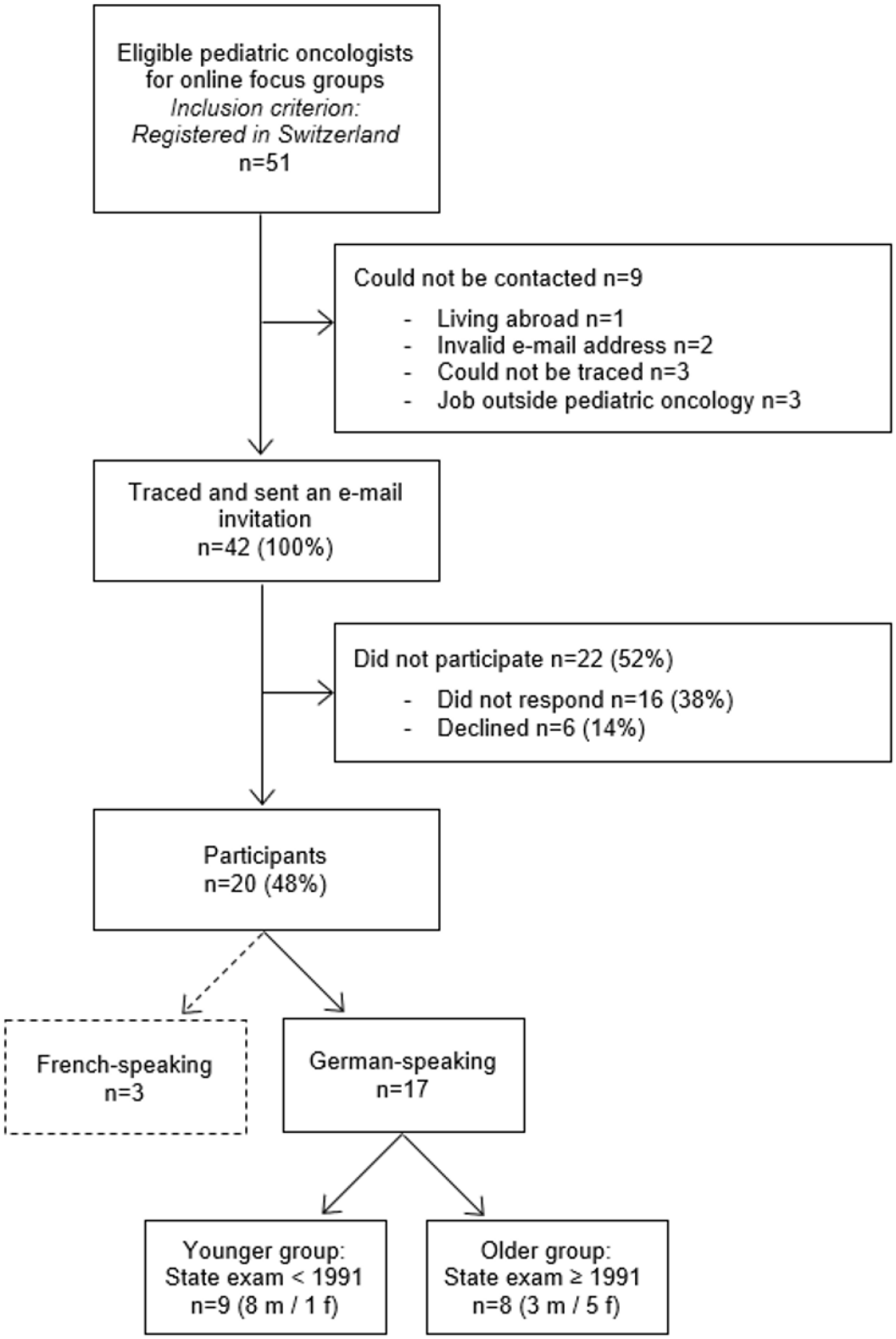


FIGURE 2 Participants in the online focus groups



Supplementary Documents

Supplementary Document 1: Collaborators

The following members of the Swiss Pediatric Oncology Group are non-author contributors: Prof. Dr. med. R. Ammann, Bern; Prof. Dr.med. M. Ansari, Geneva; Prof. Dr. med. M. Beck Popovic, Lausanne; Dr. med. P. Brazzola, Bellinzona; Dr. med. J. Greiner, St. Gallen; Prof. Dr. med. M. Grotzer, Zürich; Dr. med. H. Hengartner, St. Gallen; Prof. Dr. med. T. Kuehne, Basel; Prof. Dr. med. F. Niggli, Zürich; Prof. Dr. med. J. Rössler, Bern; Dr. med. F. Schilling, Lucerne; Dr. med. K. Scheinemann, Aarau; Prof. Dr. med. N. von der Weid, Basel.

Supplementary Document 2: STROBE Statement — checklist

	Item No	Recommendation	Reported on manuscript page
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	4
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	8

Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6
		(*b*) Describe any methods used to examine subgroups and interactions	-
		(*c*) Explain how missing data were addressed	-
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	-
		(*e*) Describe any sensitivity analyses	-
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	Figure 2
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	Table 1
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	-
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	9
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	-
		Cross-sectional study—Report numbers of outcome events or summary measures	-
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	9

		(*b*) Report category boundaries when continuous variables were categorized	-
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
Generalisability	21	Discuss the generalisability (external validity) of the study results	13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Supplementary Document 3: Transcript of French-speaking online focus group

a) Original

Forum thread A

Premier sujet: Souvenirs de conversations au sujet de la guérison

Vous avez tous acquis une formation spécialisée en oncologie pédiatrique. Une conversation particulière entre vous et un patient(e) ou les parents de celui-ci (celle-ci) concernant la « guérison du cancer » vous est-elle restée en mémoire ? Veuillez s'il vous plaît nous décrire cette conversation. Pour quelle raison pensez-vous que cette conversation vous soit restée ? Deux remarques : vous pouvez sans autre intervenir pour d'autres conversations et discuter de la situation. Vous pouvez également nous faire part de plusieurs situations.

Participant Physician #F1:

Ces discussions sur le thème de la guérison sont certainement moins fréquentes et standardisées que les discussions "obligatoires" elles sur le diagnostic et le traitement, au moment de la découverte de la maladie.

Je me souviens de plusieurs d'entre elles chez des patients avec LLA ou Hodkgin ou NHL, où le mot "guérison" ou la phrase "maintenant on peut considérer que tu es guéri(e)" a été utilisé. J'ai ensuite toujours précisé qu'il s'agissait là de la guérison oncologique ("le cancer ne va plus revenir") et qu'on a parlé ensuite des effets à long-terme possibles, y.c. les 2e cancers, surtout dans la maladie de Hodgkin (cancer du sein surtout, évent. de la thyroïde) et des mesures de dépistage précoce, même s'il reste des débats à ce sujet (quelle est la meilleure méthode pour le dépistage précoce, p.ex.)

Ces discussions me sont restées, car elles montrent qu'au fond, pour ces patients-là, l'histoire n'est pas vraiment terminée, même s'ils sont oncologiquement guéris, sont parvenus à l'âge adulte et ne viendront plus en consultation chez nous.

Modératrice:

Traduction:

Je n'ai aucun souvenir d'une conversation en particuler. J'ai pris notes de toutes les discussions auxquelles j'ai participé.

Participant Physician #F2:

Nessun ricordo di una conversazione in particolare. Di ogni conversazione alla quale ho assistito ho tratto degli spunti

Forum thread B

Deuxième sujet: Fréquence et moment du faire part de la guérison

Veuillez considérez les informations de fond (bouton).

Comment interprétez-vous ces informations ? Quelles sont, selon vous, les raisons qui poussent un oncologue pédiatre à annoncer au patient qu'il est guéri ? Quelles sont, selon vous, les raisons qui poussent un oncologue pédiatre à ne pas annoncer au patient qu'il est guéri ?

Participant Physician #F3

La question ne peut pas se répondre en 5min par écrit. En résumé, tout dépends de la pathologie sous jacente et de quels tratement l'enfant a reu. En fonctions de cela, l'enfant pourrait être guéri mais avec des toxicité donc guérisson??? Les effets secondaire peuvent encore survenir plus tard, deuxième cancer....

Participant Physician #F1

Fréquence : comme je le disais en discutant la question 1, le thème de la guérison est abordé moins systématiquement; je dirais dans env. 50% des cas. On sait que c'est un thème difficile, des rechutes tardives (jusqu'à 10 ans post-Dx initial) sont théoriquement toujours possibles, donc le médecin a une certaine retenue. On hésite, on ne veut pas se faire traiter de menteur par son patient plus tard.

Il est clair qu'il est plus facile (plus sûr) de parler de guérison dans certains diagnostics : Hodgkin, Burkitt, tumeur cérébrale bénigne opérée (ex. astrocytome pilocytique de la fosse postérieure) que dans d'autres (tumeur cérébrale maligne, neuroblastome métastatique, autres tumeurs métastatiques, etc.). Si le risque d'avoir des effets tardifs est grand (p.e.x médulloblastome), le médecin aura aussi moins tendance à parler de guérison que s'il est failble (LLA).

Le moment de l'annonce d'une guérison se situe qq part entre 5 et 10 ans après le Dx initial, ceci peut varier en fonction de celui-ci et de certains autres facteurs, également selon la "psychologie" du patient ou des ses parents et de la relation construite au cours des années entre le médecin et son malade/sa famille.

Modératrice:

Traduction

"Ce n'est pas un cas qu'on attend plus de 5 ans pour dire à un patient s'il est guéri. La plupart de rechutes surviennent durant cette période. Normalment on a aussi plus de rechutes pour les tumeur du système nerveux. Dans les cas pour lesquelles le prognostic est plus pessimiste (tumeur du système nerveux, sarcomes) on ne communique si fréquemment la guérison.

Participant Physician #F2:

Non stupisce il fatto che in media si aspetti più di 5 anni per dire al paziente che é guarito. Di solito la maggior parte delle recidive avviene in questo periodo. Normale anche che nei tumori del SNC vi é più reticenza.

In casi dove la prognosi é più incerta (tumori cerebrali, sarcomi) é possibile che si sia meno propensi a dare la notizia di guarigione.

Forum thread C

Troisième sujet : Directives pour la communication de la guérison

Est-ce que vous connaissez des directives (provenant d'une clinique, de votre formation continue ou de publications) concernant le faire part d'une guérison ? Est-ce que vous vous y tenez ? Si oui, pourquoi ? Si non, pourquoi pas ?

Participant Physician #F3:

Non je ne connais pas de directives dans ce domaine. Je ne penses pas que cela soit très utile d'en avoir. A mon sesn le plus important est que les médecins aient une excellenet formation dans l'annonce des nouvelles, l'empathies.

Participant Physician #F1:

Je n'en connais pas non plus et je pense que c'est impossible et probablement inutile d'en produire. Pour le malade et sa famille, cette annonce d'une guérison de la maladie est certainement importante et très attendue; d'autre part, eux-mêmes savent souvent très bien qu'il ne s'agit souvent pas d'une guérison complète et qu'un suivi sera nécessaire, parfois toute la vie. Pour le médecin, parler de guérison, c'est prendre un risque : celui de se tromper ou d'induire en erreur son patient, ce qui est évidemment difficile à vivre. Donc, on hésite souvent.

L'important, c'est le dialogue ouvert et le plus clair possible. Annoncer la guérison du cancer, oui, très probable, après une dizaine d'années sans rechute; mais avoir le courage aussi de parler d'effets à long-terme potentiels, de recommander un suivi lorsque c'est nécessaire et ici, suivre les recommandations existantes. En fait, continuer la stratégie bien connue en oncologie de l'information ouverte, du consentement éclairé (ici au suivi à long-terme quand il est nécessaire ou recommandé).

Modératrice:

Traduction du participant Physician #F2

Je ne connais aucune directive pour communiquer la guérison à un patient.

Participant Physician #F2:

Non sono a conoscenza di direttive che indichino come informare un paziente sul fatto di essere guarito.

b) English

Forum thread A

First Topic: Memories of conversations about healing

You all have specialized training in pediatric oncology. Is there a special conversation between you and a patient or his / her parents about the "cancer cure" in your memory? Please describe this conversation to us. Why do you think this conversation has stayed with you? Two remarks: you can not intervene for other conversations and discuss the situation. You can also tell us about several situations.

Participant Physician #F1:

These discussions on the theme of healing are certainly less frequent and standardized than the "mandatory" discussions on diagnosis and treatment at the time of the discovery of the disease.

I remember several of them with patients with LLA or Hodkgin's or NHL, where the word "cure" or the phrase "now we can consider that you are cured" has been used. I always said that this was the oncological cure ("the cancer will not come back") and then we talked about possible long-term effects, including 2nd cancers, especially in Hodgkin's disease (especially breast cancer, thyroid event) and early detection measures, although there is still debate about it (e.g. what is the best method for early detection)

These discussions have stayed with me, because they show that basically, for these patients, the story is not really over, even if they are oncologically cured, have reached adulthood and will not consult with us anymore.

Moderator:

Translation:

I have no memory of a particular conversation. I took notes of all the discussions I participated in.

Participant Physician #F2:

Nessun ricordo di una conversazione in particolare. Di ogni conversazione alla quale ho assistito ho tratto degli spunti

Forum thread B

Second topic: Frequency and timing of sharing healing

Please consider the background information (button).

How do you interpret this information? What do you think are the reasons for a pediatric oncologist to tell the patient that he is cured? What do you think are the reasons for a pediatric oncologist not to tell the patient that he is cured?

Participant Physician #F3

The question can not be answered in 5 minutes in writing. In summary, everything depends on the underlying pathology and what treatment the child received. In these terms, the child could be cured but with toxicities, so cured??? Side effects may still occur later, a second cancer....

Participant Physician #F1

Frequency: As I said while discussing Question 1, the theme of healing is addressed less systematically; I would say in approximately 50% of the cases. We know that this is a difficult theme, late relapses (up to 10 years post-initial Dx) are theoretically always possible, so the doctor has some restraint. We hesitate, we do not want to be called a liar by our patient later.

It is clear that it is easier (safer) to talk about cure in certain diagnoses: Hodgkin, Burkitt, operated benign brain tumor (e.g. pilocytic astrocytoma of the posterior fossa) than in others (malignant brain tumor, metastatic neuroblastoma, other metastatic tumors, etc.). If the risk of having late effects is high (e.g. medulloblastoma), the physician will also be less likely to talk about healing than if he is weak (ALL).

The timing of the announcement of a cure is somewhere between 5 and 10 years after the initial Dx, this may vary depending on it and certain other factors, also depending on the "psychology" of the patient or his parents and the relationship built over the years between the doctor and his patient / family.

Moderator:

Translation

"It is not a case that we wait more than 5 years to tell a patient if he is cured. Most relapses occur during this time. Normally we also have more relapses for tumors of the nervous system. In cases where the prognosis is more pessimistic (tumor of the nervous system, sarcomas), a cure is not so frequently communicated.

Forum thread C

Third topic: Guidelines for communicating the cure

Do you know any guidelines (from a clinic, continuing education or publications) about sharing a cure? Do you stick to it? If so, why? If not, why not?

Participant Physician #F3:

No, I do not know any guidelines in this area. I don't think it's very useful to have any. In my opinion, the most important thing is that doctors have excellent training in news announcements and empathy.

Participant Physician #F1:

I don't know of any either, and I think it's impossible and probably useless to create. For the patient and his family, this announcement of a cure for the disease is certainly important and much awaited; on the other hand, they themselves often know very well that it is often not a complete cure and that a follow-up will be necessary, sometimes lifelong. For the doctor, to speak of a cure is to take a risk: to be mistaken or to mislead the patient, which is obviously difficult to live with. So, we often hesitate.

The important thing is the clearest and most open dialogue possible. Announce the cure of the cancer, yes, very likely, after ten years without relapse; but also have the courage to talk about potential long-term effects, to recommend follow-up when necessary, and follow the existing recommendations. In fact, continue the well-known strategy in oncology of open information, informed consent (here at long-term follow-up when it is needed or recommended).

Moderator:

Participant Physician # F2 Translation

I do not know of any directive to communicate healing to a patient.

Supplementary Document 4: Additional results

- Timing

Many physicians told the patients that they were cured after a specific period of time had passed after diagnosis or end of therapy, most commonly five years after the end of therapy. Others chose a more flexible approach:

> "Situation: Routine follow-up visit five years after the end of therapy with, at this point in time, routine statement that the child is now 'cured' according to the official definition because a relapse is highly unlikely." (Physician #8, male, older group)

> "In fact, it is important for parents if I tell them that they can consider their child to having been cured three to five years - depending on diagnosis - after the end of therapy." (Physician #3, male, older group)

> "The moment for younger children is clearly the end of therapy. […] Older children are more able to abstract that it is not over at the end [of therapy] but that one can only call it "cured" later." (Physician #10, female, younger group)

- Embedding of conversation on cure in clinical practice

Only one physician mentioned how the conversation on cure is embedded in clinical practice:

> "Always one colleague in continuing education and mostly a nurse have to attend the discussion. Formal education on this topic takes place in a lecture and once per year in staff training. The nurse has to report the conversation in the regular rapport and note it in the journal in written form. And in the weekly rapport with the entire staff, the conversation has to be mentioned and discussed." (Physician #1, male, older group)

- Reactions of patients and parents

Those physicians who used the term cure, reported that parents and patients were relieved when they received the message of having been cured. Some physicians reported that parents and patients eagerly awaited the message; others seemed to have considered to having been cured already before their physician told them:

> "You can feel the parents' relief in those moments, even if not too much is being said about it [cure]." (Physician #3, male, older group)

> "Usually, [the message of cure] triggers a great happiness. The time of waiting is over at last." (Physician #8, male, older group)

- Misclassification

Two participants raised the concern that the survivors may have forgotten about the message of cure and that they classified themselves as being cured ignoring the exact question in the questionnaire.

> "Interpretation of background information [quantitative results]: I think the healthier and 'better-feeling' the children feel after the end of therapy the more they think of themselves as being 'cured'. Therefore, the lower proportion of cure in bone and brain tumours than in leukaemia and lymphoma is not that surprising." (Physician #3, male, older group)

> "If the background information [quantitative results] says that 78% were told to be cured, this can be correct in their memory but does not have to be in accordance with the facts except if they received the message in written form." (Physician #5, male, older group)

> "Doctors and patients probably define the term 'cure' differently (remaining disease-free vs. freedom of all tumour- and therapy-related bio-psycho-social health limitations). The numbers probably present a mixture of both concepts." (Physician #13, male, younger group)

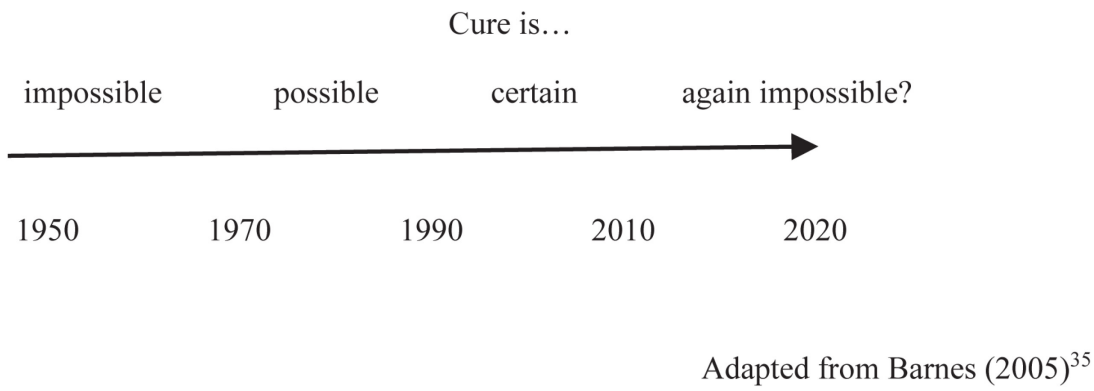
Supplementary Document 5: Quotes from physicians' online focus groups

Topic	Quotes
Helping survivors finish the cancer story	"They finally get the chance to leave cancer behind." (Physician #3, male, older group)
	"Perhaps, the patients do not address the topic of cure out of fear." (Physician #12, female, younger group)
	"One reason for telling patients they are cured is to help them to lead as normal a life as possible without fear." (Physician #13, male, younger group)
	"For me, the topic of cure is of great importance when in contact with patients, and because I realized over the years how important it is for children. […] It is important to talk about cure. Otherwise, a child will not understand the meaning of having undergone this nearly unbearable therapy." (Physician #10, female, younger group)
Late effects	"[reason for] Not telling: if problems after the end of oncological therapy predominate in such a way that the cure from the oncological disease is no longer in the foreground, for example, independent living is no longer possible, or the daily routine is full of pain or disability." (Physician #16, female, younger group)
	"Talking about cure would imply that follow-up care is not needed. However, this is not going to happen and parents feel that." (Physician #15, female, younger group)
	"It is tricky to talk about cure in pediatric oncology given the possible late effects. […] If you talk about cure, patients and their relatives will have difficulty in understanding why continued follow-up care is necessary even after five years from treatment end." (Physician #5, male, older group)
	"For me, late effects do not necessarily speak against talking about cure. That's why the small proportion [who remembered the message of having been cured] in bone tumor survivors especially surprised me." (Physician #10, female, younger group)
Late relapse	"Wishful thinking/optimism of a professional, his evaluation that it is more useful to ignore the very small probability of a relapse or the risk for future late effects than being statistically correct and mention every contingency no matter how unlikely." (Physician #13, male, younger group)

	"Possible reasons not to tell him/her that he/she is cured: The effort to be honest/correct knowing that there is still the possibility of a relapse." (Physician #13, male, younger group)
	"The proportions of those informed that they were cured pretty much resemble the survival probabilities of the respective cancer types." (Physician #1, male, older group)
Case-by-case decisions	"I do not have a standard approach, but choose my message individually and adapt it to the disease, the questions asked, and the parents' communication style." (Physician #17, male, younger group)
	"The message of cure depends on the disease and respective situation." (Physician #3, male, older group)
	"How do you want to set up guidelines for a situation that is determined by so many factors and also changes at least from year to year? That should be a wasted effort." (Physician #5, male, older group)
Reluctance	"I try to respond to the patients' questions." (Physician #16, female, younger group)
	"I always tried to avoid the word cure. I said, for example, that the child was doing fine after finishing the treatment and that we hoped it would remain that way." (Physician #5, male, older group)
	"The term cure means the process of constitution or reconstitution of physical and mental integrity out of a burden or disease. In medicine, cure means the reconstitution of health and achievement of the original state. Therefore, it is fundamentally impossible to talk about cure in oncology, but instead about long-term survival and remission, with or without late effects." (Physician #14, female, younger group)
	"The conversation during or at the end of the treatment includes the statement that one can assume cure after a period of 5 years. The patient or parents have already received the information and one assumes that it does not have to be repeated, especially because parents can remember it very well and do not need further information." (Physician #2, female, older group)
	"Many parents and patients ask directly whether they are cured at a certain point in time." (Physician #11, male, younger group)
	"I can remember one mother who has regularly asked whether her child is cured since the end of therapy (3 years ago, acute lymphoblastic leukemia) and really wants to know when this is." (Physician #12, female, younger group)

Helping physicians resolve cognitive dissonance	"Possible reasons not to tell him/her that he/she is cured: The effort to be honest/correct knowing that there is still the possibility of a relapse." (Physician #13, male, younger group) "Relatively soon after the rise in survival rates in the 1970s, we realized that it is delicate to speak of cure in pediatric oncology in view of the possible late effects. I therefore tried to avoid the word "healing" and said in each case, for example, that it was gratifying that the child was now well again despite discontinuation of therapy and that we hoped that this would now remain so." (Physician #5, male, older group) "Reason to not communicate the healing could be one's own insecurity, possibly late consequences, which give the feeling that the patient is actually not healthy or actually that it is a non-healable tumour or even a benign tumour/residual tumour which persists and is observed." (Physician #12, female, younger group) "Perhaps, they talk about cure in order to reassure over-anxious survivors or their relatives or to express that the patient can now again do anything of the same age. The more experienced an oncologist, the more cautious he will be: who knows what the future holds?" (Physician #5, male, older group) "And I certify the child's health. However, health is not the same as cured and parents rarely ask whether the child is "cured"." (Physician #15, female, younger group)

Supplementary Figure 1



Adapted from Barnes (2005)[35]

Supplementary Figure 2