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The Fuelbox “Young Next of Kin”—A Mixed-Methods Study on the Development and Piloting of a Communication Tool for Adolescents Coping With Parental Cancer or Death

KEY WORDS

Adolescents
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Background: Adolescents’ ability to cope with parental cancer and death is largely dependent on information and open communication, but parents and professionals often feel uncertain in such circumstances. **Objectives:** To develop and pilot a communication tool to enhance communication with adolescents living with or having lost a parent with cancer. **Methods:** A Fuelbox was developed in a 4-phased process including adolescents and professionals and piloted by 51 participants (adolescents, parents, and professionals) over 4 months. Using a mixed-methods study with a convergent design, data were collected via a questionnaire and interviews and were then merged. **Results:** The final “Young Next of Kin” Fuelbox consisted of 8 topics and 176 questions. Participants used the Fuelbox in different contexts, utilizing a variety of approaches. The participants found that it covered significant topics and questions important to adolescents’ situation. The Fuelbox was considered a very useful and beneficial tool to promote communication with adolescents, given that users maintain awareness of voluntary participation, confidentiality, preparedness, time, and safe frames. **Conclusion:** The Fuelbox “Young Next of Kin” seems to be a flexible and accessible communication tool in private and professional settings to enhance communication with adolescents living with or having lost a parent with cancer. As the Fuelbox is diagnosis-neutral in nature, it may be transferable to other populations and

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settings. **Implications for Clinical Practice:** The Fuelbox is a flexible, accessible, and useful tool for communication between adolescents and parents, and adolescents and healthcare professionals in specialist and primary healthcare settings.

Parental cancer affects the entire family, especially adolescents.¹ How adolescents cope depends largely on parental coping, family function, information, and open communication. However, both parents and healthcare professionals are often fearful and uncertain about what, when, and how to communicate with these adolescents.² Consequently, this article focuses on the development and piloting of a communication tool, the “Young Next of Kin” Fuelbox, to facilitate open communication between parents and adolescents, as well as adolescents and professionals.

■ Background

On a worldwide basis, it is estimated that 7% to 14% of cancer patients have children younger than 18 years.^{3–5} This highlights the fact that a considerable number of families and children are impacted by parental cancer and death. Research documents that parental cancer may severely harm parents’ quality of life and physical and psychological health,^{6–9} impairing their parenting capacity and their ability to meet their children’s needs.^{10–14} How children are affected depends on the child’s age, prior experiences, level of maturity, parent’s cancer prognosis and treatment impact, and changes in family routines and everyday life.^{15,16} Adolescents are especially at risk of having problems as they are in a vulnerable, developmental phase of life.¹⁷ Even while concerned with their own situation and feeling empathy for their parents, adolescents tend to keep their thoughts, emotions, and concerns to themselves, and they have difficulty putting issues into words, without help.^{18–21} Exacerbating this situation, parents tend to hold back information and restrict communication to protect their children.²² Parents frequently underestimate their child’s worries and anxieties.²³ As communication is the primary process through which adolescents receive information and psychosocial support, limited or lacking communication may lead to mental distress, depression, anxiety, internalizing problems, and posttraumatic stress symptoms.^{24–27} In contrast, open communication may promote effective coping and security, reduce anxiety and psychological distress, and improve school performance.^{18,28–32}

Even though the need for information and open communication about parental cancer is crucial, this is largely an unmet need of adolescents.^{33,34} They need honesty and openness in family communication and want to talk with healthcare professionals about their parents’ illness, but they want this under their own control.^{35,36} Research and clinical practice show that parents often feel insecure about what, when, and how to communicate with adolescents.²² Consequently, parents ask for help and guidance from healthcare professionals, but this is not routinely offered.^{37,38} In Norway, healthcare professionals are obliged by law to ensure that children get information and follow-up when parents or siblings are seriously ill or have died.³⁹ However, here too, research indicates that professionals feel insecure and that

they are lacking in competence related to having such conversations with children.^{36,37,40}

Several interventions for increasing family function and communication have proven to be effective, but these are criticized for their lack of flexible structure and accessibility, unsuitability in meeting the children’s need, or not being routinely provided.^{41,42} A review by Ellis et al³² concludes that interventions designed to support communication between parents and health professionals and enhance children’s ability to comfortably share emotions and normalize their experiences are needed.

Different measures have been used in promoting conversations, for example, Conversation Starter Kit. However, this is primarily designed to be used in discussions of advanced care planning of elderly.⁴³ Another increasingly used tool to generate open conversations related, for example, to work, schools, and couples, is the Fuelbox (eg, <https://Fuelbox.no/>). A Fuelbox contains questions designed to be conversation starters. It focuses on specific topics and accompanying cards with open questions, where the aim is to initiate open communication and create presence, understanding, trust, and belonging. We have found no research on Fuelboxes, and no Fuelbox is developed to target adolescents living with parental illness. However, this may be a flexible and easily available tool for promoting communication between adolescents, parents, and healthcare professionals and thus prevent psychosocial impairment in adolescents.

■ Objectives and Research Questions

The overall aim of this study was to increase knowledge and enhance communication with adolescents living with or having lost a parent with cancer by developing and piloting the “Young Next of Kin” Fuelbox. More specifically, we aimed to answer the following research questions:

1. Which topics and questions are important and relevant for adolescents to open communication about their challenges?
2. How do adolescents, parents, and healthcare professionals use the Fuelbox?
3. How do adolescents, parents, and healthcare professionals evaluate the content and usefulness of the Fuelbox?
4. How do adolescents, parents, and healthcare professionals experience to use the Fuelbox?

■ Methods

Development of the Fuelbox

Initially, a letter of intent was signed with Fuel It AS, with a separate license agreement related to the rights to use Fuelbox’s trademark, design, and concept. The idea behind developing this Fuelbox was to design questions that could initiate conversations

that may help, develop, and strengthen adolescents between 13 and 19 years of age living with the consequences of serious illness and/or death of a parent. Consequently, the Fuelbox could be used by parents to open a dialogue with their children or by professionals in meeting adolescents living with parental cancer (eg, healthcare providers, school nurses, social workers), as well as by young people in groups. The Fuelbox was initiated by Cancer Care Rogaland and developed in 4 phases:

1. In the first phase, a project group was established, led by the second author. This group consisted of 5 interdisciplinary professionals (nurse, cancer nurses, family therapist) with a high level of competence and lengthy clinical experience within the field, as well as 20 adolescents living with, or having lost, a parent with cancer. The adolescents were recruited from 2 adolescent groups. During 7 workshops within the project group and 1 workshop with the adolescents' parents, a preliminary proposal of 11 topics and 223 questions for the Fuelbox were developed.
2. In phase 2, the preliminary topics and questions were sent to a reference group of 8 individuals consisting of user representatives, a psychologist, a public health nurse, a family therapist, a teacher, and ill and healthy parents—all with competence and experience with adolescents and parental cancer. Next, a 1-day workshop was arranged with the project and the reference groups for the purpose of revising the topics and questions. First, the participants were divided into 4 groups, where all the topics and questions were reviewed and discussed. Important issues were to connect each question to a specific topic, merge similar questions, and safeguard open-ended and diagnosis-neutral questions relevant for adolescents' situation. Then, the results from each group were presented and discussed in plenary, following which some topics and questions were omitted, reformulated, and added until consensus was reached on 8 topics and 223 questions.
3. In phase 3, the revised topics and questions were returned to the reference group and to the first author and a specialist in clinical psychology for a final quality assessment and comments. Additionally, 2 groups of adolescents, led by experienced healthcare professionals, tried out the Fuelbox. In this phase, only minor changes (spelling check, formulation) were made to the questions.
4. In phase 4, the last revision of the Fuelbox was based on comments from the reference group, the 2 experts, and input from Fuel It AS, finally agreeing on 8 topics and 176 questions.

■ Research Design

In piloting the Fuelbox, a mixed-methods study with a convergent research design was conducted. In this design, qualitative and quantitative data are collected simultaneously, analyzed separately, and then merged.⁴⁴ This design draws on the strengths and minimizes the weaknesses of each method and may therefore yield a more complete and nuanced understanding of the topic under study.

Eligibility Criteria, Recruitment, and Participants

The pilot study included 3 groups to pilot the Fuelbox over a period of 4 months. Eligibility criteria were as follows: (1) adolescents: (a) between 13 and 19 years of age and (b) living with or having lost a parent to cancer; (2) parents: (a) parenting adolescent(s) and (b) living with cancer or living with or having lost a partner with cancer; (3) professionals: (a) working in the primary or

secondary healthcare system or schools and (b) meeting adolescents living with or having lost a parent with cancer as part of their work. All participants were recruited by purposive sampling via Cancer Care Rogaland.

Of the 62 invited participants, 51 participants (82.3%) accepted the invitation and piloted the Fuelbox. Those who declined the invitation were professionals who did not work with adolescents. The final sample consisted of 37 females and 14 males, where 26 (51%) were adolescents, 13 (25.5%) were parents, and 12 (23.5%) were professionals (cancer nurses, nurses, social worker, family therapists, school nurses). Twenty of the family members (42.6%) lived with parental cancer, 15 (31.9%) had lost a parent or partner in cancer, and 12 (25.5%) worked with adolescents. An overview of the participants' background data is shown in Table 1.

Data Collection

Immediately after the 4-month piloting, quantitative and qualitative data were collected. Quantitative data were collected via a questionnaire with 23 questions developed for this study. This included questions about background variables, the use of the Fuelbox, the relevance of the topics and questions, and experienced benefits. Answer options ranged from not at all, some, quite a bit, and very much, as well as yes/no and scale variables.

Qualitative data were collected by focus group interviews. Two participants were unable to take part in the scheduled focus group interviews and were offered individual interviews instead. Based on a convenient sample of the total sample who had piloted the Fuelbox and completed the quantitative measures (26 adolescents, 13 parents, and 12 healthcare professionals), the following interviews were conducted: (1) adolescents: 2 focus group interviews and 1 individual interview (n = 17), 5 male and 12 females, aged 13 to 19 years, living with or having lost a parent with cancer; (2) parents: 2 focus group interviews and 1 individual interview (n = 8), consisting of 3 males and 5 females, including healthy and ill parents; (3) professionals: 2 focus group interviews (n = 7), all females, 6 nurses and 1 social worker working in the primary or specialist healthcare system and primary school.

Focus groups were arranged in quiet environments in Cancer Care Rogaland's offices in Stavanger and Haugesund. The interviews were based on a semistructured interview guide, conducted by the first author and comoderated by the second author. The questions targeted the participants' use of the Fuelbox, their evaluation of the content, and perceived usefulness, allowing participants to freely reflect and raise additional topics (Appendix 1). Both the focus groups and the individual interviews lasted approximately 1 hour each. All interviews were audiotaped and transcribed verbatim omitting identifiable characteristics.

Data Analysis

The quantitative data were coded and verified using SPSS version 22 (IBM, Armonk, New York). Descriptive statistics (mean, SD, or percentages) were used to describe the background variables and scale variables related to the use of the Fuelbox.

Table 1 • Demographic Characteristics of the Sample (N = 51)

	Adolescents		Parents		Professionals	
	n (%)	Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)
Total	26		13		12	
Gender						
Female	18 (69)		7 (54)		12 (100)	
Male	8 (31)		6 (46)		0 (0)	
Age		18 (7.7)		46.7 (4.5)		45.6 (7.9)
Current occupation						
Pupil	17 (65.4)					
Student	5 (19.2)					
Worker	1 (3.8)		12 (92.3)		12 (100)	
Unemployed/sick leave	3 (11.5)		1 (7.7)			
Actual situation						
Living with parental cancer	12 (46.2)		8 (61.5)			
Lost a parent/partner to cancer	12 (46.2)		3 (23.1)		12 (100)	
Working with adolescents	1 (3.8)					
Months living with parental/partner cancer		23.1 (17.3)		37.4 (39.7)		

Abbreviations: N, total sample; n, number of subgroups.

Kruskal-Wallis test was used to explore the differences between scale variables based on group affiliations.⁴⁵ Here, $P < .05$ was set as the significance level. For nominal variables, the 4-point scales were dichotomized and presented as percentages (not at all/some and quite a bit/very much).

The qualitative data were analyzed by using Systematic Text Condensation's 4 steps.⁴⁶ First, the authors read the interviews separately to obtain a total impression. Then, the total impression was discussed, and 4 preliminary themes were agreed on: "Used in different contexts and settings," "Relevant and actual topics and questions," "Frames for use are needed," and "High perceived usefulness." Second, all interviews were reread, and units of meaning were extracted by each author and then discussed. Here, 6 meaning units or codes were agreed upon: "Context used in," "Ways of using the Fuelbox," "Suitability of topics," "Relevance of questions," "Attentiveness and frames for use," and "Perceived benefit." Then, all interviews were coded in relation to these meaning units by using NVivo software (NVivo - QSR International). Third, the content of each code was condensed into groups and subgroups in an analytic spiral between the content of the identified codes, the researchers, and their preunderstandings. Through this analytic process, 3 main themes were identified (see Results). The 3 finalized themes were defined and described, and validating quotes identified in step 4. All findings were discussed throughout the analysis process, and consensus was reached for all interpretations. (For an overview of the qualitative analysis, see Appendix 2.)

Merging the data is the third step in the analysis of a convergent design.⁴⁴ In this process, all qualitative and quantitative data were examined and structured. First, we integrated the quantitative and qualitative results in a joint document. Then, we identified content areas that were represented in both data sets. These content areas were closely compared, looking for similarities and contrasts as convergences and divergences may provide a more complete understanding of the data.⁴⁴ Finally, we synthesized the results and developed a table presenting the merged results (see Results).

Ethics

The Western Regional Committee of Research approved the study (31712). All participants received written and oral information when receiving the Fuelbox, whereby all provided written consent.

Results

The Final Content of the Fuelbox

Focusing on the first research question, the final version of the Fuelbox consisted of 8 topics linked to adolescents' ordinary everyday life, as well as related to parental illness and death. Twenty-two questions were connected to each topic, in total 176 separate questions. All questions were open formulated, encouraging participants to talk and reflect. Although the Fuelbox was developed based on adolescents living with or having lost a parent with cancer, the questions were diagnosis-neutral in nature. An overview of the topics and examples of questions related to each topic is outlined in Table 2. A brief instruction followed the Fuelbox, stating its usability in different settings and different ways of administering the topic and questions.

The Participants' Use of the Fuelbox

Answering the second research question, the results showed that the participants used the Fuelbox in different contexts. Eighteen (36%) of the participants had used it in an adolescent group led by healthcare professionals, 21 (44%) had used the box at home, whereas 10 (20%) had used it in a professional setting. Some of the adolescents had used the Fuelbox both at home and in a group setting. On average, the participants had used the Fuelbox 10 times, covered 4 topics and 8 questions, and spent 0.7 hour each time. No significant differences between the groups were found regarding use of the Fuelbox (Table 3).

Table 2 • Content of the Fuelbox “Young Next of Kin”

	Topics	Related Questions	Examples of Questions
1	A bit of everything	22	What gets you in a good mood? How do you feel when you get up in the morning?
2	Me and my everyday life	22	What is a perfect day for you? What has changed the most for you because of the disease?
3	Thoughts and feelings	22	What is it like for you to take friends home? What makes you scared?
4	Family and friends	22	What is the best thing about your family? How do you take care of yourself?
5	Opinions, attitudes, and values	22	What are you most grateful for in your life? When are you most proud of yourself?
6	Past, present, and future	22	What are you concerned about the future? Has anything changed due to illness/death?
7	Living with illness in the family	22	How do you protect each other in the family? How do family members react differently to the illness?
8	To you who have lost a loved one	22	What do you miss the most about the person you have lost? How do you want other people to react when you tell them about the loss?

The Participants’ Evaluation of the Content and Usefulness of the Fuelbox

Addressing the third research question, most participants rated the relevance of all the 8 topics as high (Table 4). Parents and professionals rated the topics’ relevance somewhat higher than the adolescents did, except from the topic “thoughts and feelings.” The adolescents also scored the topics “past, present, and future” and “to you who have lost” higher than the parents did. Most participants found that the questions were relevant, well formulated, easy to understand, and well organized into the topics. The participants found no topics or questions they would like to add or omit from the Fuelbox. The majority (75.5%) reported that questions related to thoughts and feelings, living with illness, and death were especially important to focus on. Seventeen percent, mostly adolescents, found that the Fuelbox had made them talk about issues they had never talked about with anyone before.

The majority (82.2%) scored the overall usefulness of the Fuelbox as high (Table 5). In general, parents and professionals scored the usefulness higher than the adolescents did on all variables, except from “made us understand each other better” and “made me feel better.” The parents scored “made us talk easier” as the highest benefit in line with professionals, whereas the professionals also scored “made thoughts and feelings normalized” and “made us talk without an agenda” at the same high level.

Most participants (71.4%) reported that they did not think it was necessary that a professional led Fuelbox conversations or that professional help was needed in the aftermath of such conversations (81%). In total, most participants (88.6%) reported that the Fuelbox was a good tool for communication with adolescents living with, or having lost, a parent with cancer.

The Participant’ Experiences From Using the Fuelbox

Answering the fourth research question, 3 main themes describing the participants’ experiences with using the Fuelbox were illuminated: theme 1: “It may be used in different contexts and different ways,” theme 2: “The topics and questions cover a wide and relevant spectrum,” and theme 3: “A valuable communication tool—given some precautions.” Each of these themes had several facets as elaborated below.

THEME 1: “IT MAY BE USED IN DIFFERENT CONTEXTS AND DIFFERENT WAYS”

The findings showed that the participants had used the Fuelbox in different contexts. The parents had used the box in different settings within the family, mainly in relation to a meal: “We have used it after dinner or supper, when we are gathered around the table before new activities or finished for the evening” (ill mother). The adolescents had also used the box in varied contexts, in the

Table 3 • Participants’ Use of the Fuelbox (N = 51)

Variable	Adolescents		Parents		Professionals		Differences
	n (%)	Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)	P
Variable	26 (100)		13 (100)		12 (100)		
Times used the Fuelbox	26 (100)	8.4 (5.2)	11 (84.6)	12 (9.9)	11 (91.7)	11.9 (19.1)	.343
Topics covered each time	26 (100)	4.9 (2.2)	13 (100)	4.6 (2.1)	11 (91.7)	3.3 (2.3)	.218
Questions covered each time	23 (88.5)	8.3 (7.1)	11 (84.6)	8.6 (6.9)	12 (100)	5.4 (3.5)	.626
Time frame each time, h	25 (96.2)	0.8 (0.5)	11 (84.6)	0.7 (0.6)	12 (100)	0.5 (0.4)	.474

Abbreviations: N, total sample; n, number of subgroups; P, significance level (<.05). Differences measured by Kruskal-Wallis test.

Table 4 • Participants' Evaluation of the Topics' Relevance

Topics	Total (N = 51)		Adolescents (n = 26)		Parents (n = 13)		Professionals (n = 12)	
	Not at All/Some	Quite a Bit/Very Much	Not at All/Some	Quite a Bit/Very Much	Not at All/Some	Quite a Bit/Very Much	Not at All/Some	Quite a Bit/Very Much
1 A bit of everything	20.9	79.1	26.1	73.9	20	80	10	90
2 Me and my everyday life	14.3	85.7	18.2	81.8		100		100
3 Thoughts and feelings	9.3	90.7	8.7	91.3	10	90	10	90
4 Family and friends	4.7	95.3	8.7	91.3		100	0	100
5 Opinions, attitudes, and values	19.0	81.0	30.4	69.6		100	10	90
6 Past, present, and future	16.3	83.7	17.4	82.6	30	70		100
7 Living with illness in the family	16.3	83.7	26.1	73.9		100	10	90
8 To you who have lost	28.6	71.4	30.4	69.6	30	60	20	80

Abbreviations: N, total sample; n, number of subgroups.

family, in group settings, or individually with professionals. However, most adolescents preferred to use it in an adolescent group or together with professionals: “I find it easier to open up here than at home—because here we are the same age and know how it is to have ill parents. My mum and dad do not know how I am. It feels safer, and we go a bit deeper [in the adolescent group]” (adolescent). The professionals had also used the Fuelbox in different contexts, from groups, individually with adolescents and parents, and with adult cancer patients and other professionals.

All participants had used the box several times, although the frequency and the amount of time varied greatly: “Sometimes we have used it every weekday, other times only in weekends. Sometimes, only one card and other times several. Sometimes, we have spent an hour; even more, but other times we are finished after 5 minutes” (ill mother). In most families, the parents took the initiative to use the box, but in others, the adolescents initiated the use. In some families, the parents administered the box, whereas in other families, the adolescents took charge. The professionals seemed to use the box more deliberately both individually and in group sessions: “Sometimes I picked out the card myself, and sometimes I put the box on the table. But I give priority to the topics and cards that I find important to illuminate” (professional).

THEME 2: “THE TOPICS AND QUESTIONS COVER A WIDE AND RELEVANT SPECTRUM”

The second main theme focused on the participants' experiences of the topics and questions' content. In general, all participants expressed that the topics and questions were relevant to the

adolescents' situation. Both the parents and professionals found the number of questions impressive, stating that they would not have asked many of these on their own initiative: “The questions were good, and it was useful to get an awareness (...) You get more specific questions you otherwise do not think of” (ill mother). Another crucial factor highlighted by all participants was that adolescents had participated in developing the questions: “And to get questions that adolescents have participated in developing (...). It's not only professionals who created these; they have participated themselves... It's important” (professional). However, both the parents and professionals put emphasis on the importance of the illness-related topics, whereas the adolescents also highly valued the topics related to their everyday life: “It's very beneficial that there is variation... Not all about disease (...) and I find THAT brilliant” (adolescent). None of the participants expressed a need to add or omit any topics or questions. Both the parents and adolescents found some questions more difficult to talk about than others, especially related to the illness- and death-related topics as these involved more feelings: “...I got the question ‘Where are you in 5 years?’ (...) and she [my wife] nodded toward the graveyard, and I envisioned that I will be there then... and then the tears came, and she [my daughter] does not see that every day (...) And then, ‘it's ok,’ I said, ‘these are important things to talk about’” (ill father). Other families deliberately avoided the topic related to loss as they did not find it relevant for their current situation. Even if the adolescents also found the same topics and questions challenging, they stressed that these were still important to talk openly: “I think it's a good thing. I'm not here to be comfortable; I'm here to work through my emotions (...) and I have to feel them” (adolescent).

Table 5 • Participants' Evaluation of the Usefulness of the Fuelbox

Perceived Usefulness	Total (N = 51)		Adolescents (n = 26)		Parents (n = 13)		Professionals (n = 12)	
	Not at All/Some	Quite a Bit/Very Much	Not at All/Some	Quite a Bit/Very Much	Not at All/Some	Quite a Bit/Very Much	Not at All/Some	Quite a Bit/Very Much
	%	%	%	%	%	%	%	%
Made us talk easier	20	80	39.1	60.9	100	100		
Easier to talk about difficult topics	35.6	64.4	52.2	47.8	10	90	16.6	83.3
Made thoughts and feelings more normalized	27.3	72.7	39.1	60.9	33.3	66.7		100
Made us become closer	36.4	63.6	39.1	60.9	33.3	66.7	33.3	66.7
Made us talk about other things than usual	25	75	30.4	69.6	11.1	88.9	25	75
Made us talk about things I have never talked about before	56.1	43.9	47.8	52.2	77.7	22.2	55.6	44.4
Made us understand each other better	22.7	77.3	17.4	82.6	40	60	18.2	81.2
Made me be honest	24.4	75.6	30.4	69.6	10	90	25	75
Made us talk without an agenda	23.3	76.7	39.1	60.9	10	90	0	100
Made us get better acquainted with each other	38.1	61.9	43.5	56.5	44.4	55.6	20	80
Lead to unwanted thoughts and feelings	78.1	21.9	65.2	34.8	88.9	11.1	100	
Made me feel better	35.9	64.1	30.4	69.6	44.4	55.6	42.9	57.2
My overall evaluation of the Fuelbox	17.7	82.2	26.1	73.9	10	90	8.3	91.7

Abbreviations: N, total sample; n, sample of subgroups.

Here, the professionals were in line with the adolescents: "...the Fuelbox asks questions that they have not thought about (...) normalizes some of the usual brooding thoughts (...). I think it's important to bring out emotions (...) I'm not the one who creates these emotions, because they are already inside them... I think that's why they like it—because we dare to touch directly. It can be hurtful, but also very good" (professional).

THEME 3: "A VALUABLE COMMUNICATION TOOL—GIVEN SOME PRECAUTIONS"

The qualitative analysis illuminated that all participants acknowledged the Fuelbox as a useful tool in communication with adolescents. Most important, the adolescents found the box particularly useful to focus on significant topics that they previously had not talked about: "It's been easier for me when we have the Fuelbox. Before, it has been like 'Is there anything you would like to say?' And then nobody says anything (...). But with the questions, then it became more specific. In a way you get to say what you want, but without knowing that you wanted to say it" (adolescent). In families, and especially in the group settings, the adolescents expressed that the Fuelbox had helped them to get to know themselves and each other better, to get

and give support, to share experiences, to ventilate and normalize thoughts and feelings, and practice putting thoughts and emotions into words: "I get to put things into words that I may not have thought about before" (adolescent).

In the home context, the parents seem to find the Fuelbox more useful than the adolescents did. Even though some parents initially were skeptical, they perceived several benefits from using the Fuelbox. Primarily, they experienced that the Fuelbox helped them initiate a dialogue with their children: "It is an important gateway, maybe because it was not ME asking the question, it was the BOX. It creates a setting where you can neutralize a bit. (...) [so that it is] not us intruding or nagging (...)" (ill father). Furthermore, the parents expressed that the box had helped them to understand and learn more about their adolescents, especially struggles they were unaware of: "We did not know how much she [daughter] was struggling. There have been things and concerns that we have become aware of (...) that we maybe did wrong. I think it's been very positive!" (ill mother). The parents also stated that because of the box they have talked about difficult topics they had previously deliberately avoided. However, they expressed that bringing up difficult topics that triggered strong emotions made both the parents and the children feel good, relieved, and safe: "It was tough, but it also had

good effects (...) it makes them feel safe (...) It is a superb tool. To take time. You can prevent a lot by using that tool, I think. It prepares the adolescents for situations that we as parents in a crisis could not" (Healthy mother). Family members who had lost a parent also perceived the box as a useful tool:

The professionals shared many of the same experiences about the Fuelbox's usefulness as the parents and adolescents had expressed: "We have got an extra important tool to use in communication, both in groups and individually. I feel that this is something I've been missing" (professional). In addition, the professionals found the Fuelbox very helpful when they followed up adolescents over time and to have a conversation without an agenda. All participants also highlighted that the box could be useful for other groups of families living with parental or sibling illnesses or challenges and for a variety of healthcare professionals and school professionals.

Although all participants expressed that the Fuelbox was a useful and an important communication tool, they—especially the adolescents—emphasized the importance of some precautions when using it. First, the parents stated that the Fuelbox should not be used in the initial phase of a crisis but should be introduced after a while: "No, I do not think you can use it wrongly. But, in the beginning, I had more than enough think about with myself and vomiting... I do not think I would have had the strength to use it. You must, in fact, have some surplus energy..." (ill mother). In contrast, the adolescents expressed that they wanted the box quite early in the illness process: "Maybe it would have been easier to start earlier. Or, perhaps not easier, but we would have gotten the questions as we went along, instead of looking back" (adolescent). Here, the professionals acknowledged that they had a responsibility for when and to whom they should introduce the Fuelbox, as well as how to use the box: "It's important to advise how it should be used (...). I would not have used it in a first conversation; you must get acquainted first. If the parents are in a crisis where they cannot safeguard their adolescents, then you should be careful" (professional). A second precaution, especially expressed by the adolescents and professionals, was related to creating safe frames, time and preparedness when using the box: "It may be emotionally difficult; have some chocolate, tissue paper, pizza—light some candles, sit round a table. I think the situation has to focus on the box, not a football match" (adolescent). A third precaution expressed by everyone, but especially the adolescents, was that using the box and answering questions have to be voluntary: "I do not want to talk about absolutely everything. There is no point in trying to force emotions out of me, because then I only get hostile. You do not want to feel depressed all the time" (adolescent). In line with this, a fourth important precaution was to ensure privacy and confidentiality both in groups and the families. For the adolescents, breach of privacy in the family could be an important cause for withholding thoughts and feelings.

In merging the quantitative and qualitative results, the findings seem to complement each other and give a more comprehensive picture of the participants' experiences with using the Fuelbox. The merged results are compared and displayed in Table 6 and discussed below.

■ Discussion

The wide range of topics and number of questions developed in the Fuelbox underline that parental illness strongly influences all part of adolescents' life. This also underpins that a lot of topics and questions are of relevance and interest for adolescents to talk about. In the following, the main results are discussed.

Useful in Different Context With a Variety of Approaches

An important finding was that the Fuelbox was used in a variety of contexts from within the privacy of families in different life circumstances, to a variety of professional settings. Furthermore, who administered the Fuelbox, and how it was administered, varied greatly, ranging from a random to a very considered choice of questions. Consequently, the Fuelbox seemed to meet the criticisms against previous early family interventions of being highly dependent on professionals and lacking flexibility and accessibility.^{19,32,42} Another significant finding was that the parents welcomed the Fuelbox in the family context, whereas the adolescents preferred to use it in an adolescent group together with peers with similar life conditions and supported by professionals. In line with previous research,^{18,19,21} the adolescents found it more difficult to share their thoughts and emotions openly at home based on empathy for their parents' situation, lack of understanding, previous parental or family conflicts, communication, and respect for privacy. This finding highlights that participation in an adolescent group led by professionals and/or individually followed up by professionals may be important to promote effective coping and decrease distress for adolescents.^{18,30,47} However, as open communication in the family is one of the most important factors for adolescents' coping and psychosocial health,^{16,17,25} communication between parents and adolescents should be promoted and encouraged. Here, the Fuelbox seemed to be an easy and available tool as the box was regularly used over the 4-month period. These results also highlight the importance of communication about the consequences of living with illness in the family as a process over time, and not as a 1-time occurrence.²⁹ However, and in line with previous research,³⁷ the parents may need instructions and advice on how to promote family communication before using the Fuelbox.

Covering a Wide Range of Relevant and Important Topics and Questions

Overall, the merged results showed that all participants found all topics relevant and that they targeted adolescents' actual situation. An interesting finding was that the parents and professionals rated most of the topics' relevance somewhat higher than the adolescents did. Supported by previous research,^{18,19,40} an explanation may be that both parents and professionals find it difficult and need help to talk with adolescents about illness issues. The adolescents also underscored the importance of all the topics. An essential finding is that even if both parents and adolescents found it difficult to talk about illness-related issues, the adolescents stressed the importance of these issues higher than the

Table 6 • Merged Findings From the Quantitative and Qualitative Results

	The Use of the Fuelbox	Evaluation of Content of Topics and Questions	Evaluation of Usefulness
The quantitative findings	<ul style="list-style-type: none"> - 36% used the Fuelbox in AGs led by professionals - 44% used it at home - 10% used it at work - On average, the box was used 10 times and covered 4 topics and 8 questions, with 0.7 h spent every time 	<ul style="list-style-type: none"> - All topics evaluated as relevant - Relevant questions, open and well formulated, easy to understand - No topics or questions the participants would like to add or omit - About one-third found illness-related questions difficult to talk about, but most still found these especially important 	<ul style="list-style-type: none"> - High perceived usefulness - Highest perceived benefit <i>Parents:</i> easier to talk adolescents: increased understanding <i>Professionals:</i> talk easier without an agenda/normalized thoughts and feelings - Limited need for professional support during or in aftermath - A good communication tool
The qualitative findings	<p>Theme 1: “It may be used in different contexts and different ways”</p> <ul style="list-style-type: none"> • Used in context: <ul style="list-style-type: none"> <i>Parents:</i> different settings at home. <i>Adolescents:</i> different settings at home, in adolescent groups, and individually with professionals—preferable in adolescents’ groups <i>Professionals:</i> different settings in groups and individually • Used the box regularly, but number and time each time varied • A wide diversity in administering the topics and questions 	<p>Theme 2: “The topics and questions cover a wide and relevant spectrum”</p> <ul style="list-style-type: none"> • All topics experienced as very relevant • A wide range of questions • Parents and professionals especially valued the illness-related questions, whereas adolescents valued all topics • Participants did not want to add or omit any topics or questions 	<p>Theme 3: “A valuable communication tool—given some precautions”</p> <ul style="list-style-type: none"> • Perceived usefulness: <ul style="list-style-type: none"> <i>Adolescents:</i> focus on unspoken topics, increased knowledge of themselves and others, give and get support, ventilate, normalize emotions and thoughts, and put these into words Preferred professional support <i>Parents:</i> initiating dialogue and open communication, increased understanding, focusing on avoided topics <i>Professionals:</i> as above, and very helpful in follow-up, talk without an agenda, learning outcome • Precautions: voluntarily, confidentiality, preparedness, time, and safe frames
The merged findings	The Fuelbox was used in different private and professional contexts with a variety of approaches	The Fuelbox perceived as covering a wide range of relevant and important topics and questions related to the adolescents’ situation	The Fuelbox was perceived as a useful and beneficial communication tool given some precautions

Abbreviation: AG, adolescent group.

parent. This indicates that adolescents want to talk about their situation, but that the initiative must come from parents or professionals. Another key finding was that the adolescents did not constantly want to focus on the illness, as the current situation influenced all areas of their life. This is in line with previous research showing that physical, psychological, and social dimensions of quality of life of these adolescents are highly impaired^{40,48} and that adolescents also need free spaces from illness.¹⁹

Overall, the participants found the questions to be open and well formulated, and no participants found any topics or questions they wanted to add or delete. Consequently, and in line with the recommendations of Ellis et al,³² it seemed that the Fuelbox’s topics and number of questions targeted the adolescents and families’ situation. In this respect, all groups underlined the importance of adolescents’ involvement in the development of the Fuelbox as crucial for credibility and relevance.

A Useful and Beneficial Communication Tool, Given Some Precautions

Overall, the participants evaluated the Fuelbox as a valuable and useful tool in communication with adolescents. The adolescents themselves reported several benefits from using the box, especially

related to increased understanding in the family, and that these conversations made them feel better. This may signify the Fuelbox as an important, flexible, and accessible tool in alleviating psychosocial distress and promoting effective coping for adolescents and enhancing their ability to comfortably share emotions and normalize their experiences.^{30,32}

In general, the parents scored the usefulness of the Fuelbox higher than the adolescents did, where the highest perceived benefit was that it made them talk easier. The qualitative results elaborated that the parents found the Fuelbox as a gate opener for dialogues and increased understanding of the adolescents’ situation and struggles, as well as talking about taboo topics such as death and ventilating feelings. These findings are promising, as they seem to target parents’ insecurity and specific challenges in holding back information and restricting communication, as well as underestimating the negative impact of parental illness on the adolescents.^{23,24}

The professionals expressed that the highest benefits of using the Fuelbox were that it made conversations with adolescents easier, normalized thoughts and feelings, and made them talk without an agenda. Consequently, the Fuelbox may support professionals in fulfilling their legally mandated obligations and be an important tool in preventing their feelings of insecurity, lack of competence,

and hesitance to have open communication.^{19,37,40} Another encouraging finding was that when professionals had used the Fuelbox in their clinical practice, they acknowledged the transfer value of the Fuelbox to other settings and diagnoses, as they had learned that the questions were diagnosis-neutral.

Even though the participants highly valued the Fuelbox, certain precautions were highlighted. These precautions were related to whom and when in the illness trajectory to introduce it, as well as promoting preparedness, voluntary participation, confidentiality and privacy, time, and safe frames. These are important factors to be aware of, especially for healthcare professionals both when using the Fuelbox in professional settings with adolescents themselves and when introducing it to parents and families. Most parents expressed that they did not feel they needed professional support while using the Fuelbox or in the aftermath, whereas both the adolescents and professionals acknowledged that this may be beneficial. This places a responsibility on professionals to screen the situation when introducing the Fuelbox in families, as an example by being present the first time, to introduce it and be a role model, as well as offer follow-up and guidance.

■ Study Strengths and Limitations

To our knowledge, this is the first study of the development and evaluation of a communication tool to enhance communication with adolescents living with or having lost a parent to cancer. A major study strength is the 3-fold user involvement from development to evaluation of the Fuelbox, involving especially the adolescents themselves. Another strength is the use of mixed-methods study with convergent research, where quantitative and qualitative data are collected, and the findings are presented in a joint display. This approach enhances the study's validity and reliability, as it combines the strengths of each design, thereby offsetting their weaknesses.⁴⁴ A relatively small sample size, maybe biased toward self-selection, the lack of a control group, an overrepresentation of females, a limited intervention period of 4 months, no baseline findings, and the use of a self-developed questionnaire may represent study limitations affecting the generalizability of the results. Further studies with larger samples and control groups, as well as other samples and contexts, are warranted.

■ Conclusions and Implications for Clinical Practice

The final version of the Fuelbox “Young Next of Kin” contained 8 topics and 176 questions. The merged results showed that the Fuelbox was helpful in different private and professional contexts and with a variety of approaches. The participants expressed that it covered a wide range of relevant and important topics and questions related to the adolescents' situation. Adolescents, parents, and professionals perceived the Fuelbox as a flexible, accessible, and beneficial communication tool. Important safeguards when implementing the Fuelbox outside a research setting were related to voluntary participation, confidentiality, preparedness,

time, and safe frames. Consequently, following these precautions, the Fuelbox “Young Next of Kin” may be an important tool for parents and cancer nurses in specialist and primary healthcare settings in opening up communication with adolescents. As the Fuelbox is diagnosis-neutral, it may be transferable to other populations and settings.

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Appendix 1: Semistructured Interview Guide for the Qualitative Interviews

Main Questions	Additional Questions if Necessary
<p>The use of the Fuelbox Can you first tell me how you have used the Fuelbox?</p>	<ul style="list-style-type: none"> - Situations? - With whom? - Times used?
<p>The topics The box are divided into the 8 topics of (1) “A bit of everything,” (2) “Me and my everyday life,” (3) “Thoughts and feelings,” (4) “Family and friends,” (5) “Opinions, attitudes, and values,” (6) “Past, present, and future,” (7) “Living with illness in the family,” and (8) “To you who have lost.” Can you please tell me how relevant you found these topics and what experiences you have made with these?</p>	<ul style="list-style-type: none"> - Which topics are most/least relevant? - Topics to be added? - Especially difficult/useful topics?
<p>The questions The box consists of 176 questions in total. Based on your current experiences of using this box, can you please tell me how you experienced to use these questions as a baseline for a conversation?</p>	<ul style="list-style-type: none"> - Number of questions used? - Formulation of questions? - Difficult or problematic questions? - Questions to be deleted? - Questions to be added?
<p>Perceived usefulness Based on your current experiences, can you please tell me how you perceive the usefulness or effect of using the Fuelbox?</p>	<ul style="list-style-type: none"> - Experienced usefulness—what? - Perceived importance for open communication - Examples? - Specific groups or situations?
<p>Recommendations for eventual change and use of the Fuelbox Based on your experiences, do you have any suggestions or input to the use of the Fuelbox?</p>	<ul style="list-style-type: none"> - Recommendations to others? - Who may benefit? - How to introduce it? - Specific time points in the cancer trajectory?
<p>Ending Is there anything else you would like to add that I have not considered before we close this interview?</p>	

Appendix 2: Overview of the Qualitative Data Analyses using Systematic Text Condensation

Step 1	Step 2			Step 3	Step 4
Total Impression: From Chaos to Themes	Identifying and Sorting Meaning Units: From Themes to Codes			Condensation: From Code to Meaning	Synthesizing: From Condensation to Descriptions and Concepts
Process: (a) The authors read the transcribed interviews separately (b) Discussed the total impression to consensus of preliminary themes	Process: (a) The authors coded the data separately (b) Discussed the codes to consensus within the codes			Process: (a) The authors analyzed the contents separately (b) Several discussions to consensus	Process: (b) The authors discussed the findings against the transcribed interviews (c) Each author found direct statements to elucidate units of meaning and discussed to consensus
Identified preliminary themes: Fuelbox used in different contexts and different ways Relevant and actual topics and questions Frames for use are needed High perceived usefulness	Identified meaning units:			Identified meaning: Theme 1: “The Fuelbox is functional in different contexts and in different ways” Theme 2: “The topics and questions range wide, highly matching adolescents’ concerns” Theme 3: “A valuable tool in communication with adolescents living with parental cancer—given some precautions”	Synthesizing: Summarized findings and presenting direct statements for illustrating the identified meaning
	Code	Source	References		
	Contexts used in	8	88		
	Ways of using the Fuelbox	8	86		
	Suitability of topics	8	56		
	Relevance of questions	8	120		
	Attentiveness and frames for use	8	142		
	Perceived benefit	8	150		

Code: identified meaning units; source, number of interviews talking about the code (n = 8); references, number of quotes related to the code.