



## Cancer Putting Parenthood to the Test: Evaluation of the Needs and Difficulties Faced by Healthcare Professionals in an Oncology Department

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### Abstract

**Introduction:** Adults suffering from cancer not only face their own anxieties but also parental worries concerning their children's future, particularly in psychological terms. For healthcare professionals, listening to these worries and supporting these patients can add to professional difficulties, potentially culminating in indirect traumas such as burnouts.

**Method:** The purpose of this study is to identify the needs and difficulties of oncological healthcare professionals in supporting their patients concerns about parenthood. We have carried out a joint descriptive analysis of semi-structured interviews held with the healthcare professionals from a Gastro-Intestinal Oncology team.

**Results:** This study sheds light on the difficulties encountered by healthcare professionals in approaching the psychological impact of the disease on their patient's children with them, and particularly in deciding the most appropriate type of information to provide. The lack of subject knowledge is raised. Theoretical training requirements as well as interprofessional dialogue are endorsed.

**Conclusion:** This work is designed as a preliminary study leading to the creation of subject-specific training tools to help oncology healthcare professionals deal with this problem which is unclear and under-estimated at the present time.

**Keywords:** Oncology; Parenting; Healthcare professionals; Cancer; Training

### Introduction

Healthcare professionals are at risk of occupational stress and burnout [1]. Recent studies highlighted a 49% burnout rate among doctors in France [2]. Oncology nurses appear to be most affected by stress and burnout [3]. This particular discipline involves the management of complex diseases with poor prognosis and contact with patients potentially suffering severe pain and anxiety, as they face imminent death [4]. Moreover, oncology is a specialist area plagued in particular by a shortage of nurses, thus contributing significantly to increased dissatisfaction, stress, burnout and a desire to leave the profession [5].

Adult cancer patients not only have to cope with the diagnosis and treatment of their disease coupled with their own end-of-life anxiety about cancer, but also with their concerns about their children's future. The term "parenthood" first appeared in 1959 [6] but was used primarily by specialists up until the 1990s. In 2011, in France, the Comité National de Soutien à la Parentalité (CNSP) (French National Parenting Support Committee) published a definition: "Parenthood refers to all the ways of being and experiencing being a parent [...] It qualifies the relationship between an adult and a child, regardless of the family structure in which this occurs, in an attempt to ensure the child's care, development and education [...]. It is part of the social and educational environment in which the family and the child live". When a parent is diagnosed with cancer, the family dynamics and parenthood can be compromised. Questions arise about the psychological impact of their illness on the children and how best to inform children of what is happening.

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As far as healthcare professionals are concerned, counseling and managing their patients' parental concerns can pose professional difficulties, adding to the stress already associated with the specific psychological and medical needs [7] of the patients themselves. To date, few studies have addressed the needs of oncology staff when exposed to young adults with children. Yet medical and paramedical teams in oncology departments directly encounter concerns and questions about parenthood from patients who have children and teenagers. Ultimately, one of the harmful reactions of this particular exposure may be an increase in indirect trauma leading to burnout in particular.

The training of healthcare staff appears to be a key factor in meeting patients' needs.

We were asked about this subject by staff at the Gastrointestinal Oncology Unit at Rangueil University Hospital Centre (Toulouse) following issues raised by their healthcare professionals following discussions with patients who are parents of children and teenagers. Healthcare professionals in the unit regularly refer to difficulties, a feeling of powerlessness and even professional exhaustion when dealing with patients' concerns and preoccupations surrounding parenthood.

This department has 15 day hospital places and 6 weekday hospital beds. It treated approximately 4,700 in-patients in 2017, including 3,990 "chemotherapy admissions". All gastrointestinal system cancers are treated. This unit also has a clinical research role with numerous clinical trials in the pipeline and a regional referral role, receiving the most complex cases, particularly those involving the youngest patients.

We then considered a project to create and disseminate interactive on-line training or a Small Private Online Course (SPOC) to improve the knowledge and working conditions of healthcare professionals. Prior to devising this training tool, we considered it essential to collect the needs and difficulties of healthcare staff surrounding this issue. This study is a preliminary evaluation of the PAROLE project (Pour Aider à Retrouver en Oncologie la Liberté d'Expression – to help restore the freedom of expression in oncology).

Thus, the aim of this study is to collect and analyze the feelings of oncology staff regarding the topic of parenthood in patients in their care, assuming that the identification of mutual difficulties could lead to the demand for specific training and support.

## Method

### Development of an interview grid

This study was conducted using a semi-structured interview grid. Adopting a multi-step process, LZ, MT and FC devised a semi-structured interview grid to broach the topic of parenthood in cancer patients. This was based on a literature review [8] and preliminary discussions with nurses in the Gastrointestinal Oncology Unit. These documents were validated by the multidisciplinary team involved in the PAROLE project, following analysis and correction.

The finalized interview grid starts with six socio-demographic items about the interviewee: Age, gender, occupation, and length of time in the oncology department, number of children and their ages. It is then divided into four specific sections: Confirmation of the disease, unfavorable clinical course of the disease, psychological impact on the child and needs of the healthcare professionals. Each

specific section consists of open and closed questions.

We chose to focus our attention on situations where an unfavorable clinical prognosis has been given (recurrence, disease advance, and palliative care) in view of the greater frequency of these situations in the Oncology Department in which the study is taking place. In addition, healthcare professionals report more concerns and questions from patients at this stage in the disease.

An English version of the interview is available from the corresponding author.

### Study population

The interviews were conducted with staff making up the Gastrointestinal Oncology Team at Toulouse University Hospital. We included all medical, paramedical and voluntary support staff.

### Interview procedure

The interviews were conducted individually between May 15<sup>th</sup> and September 6<sup>th</sup>, 2018 by MT in the Gastrointestinal Oncology Department of Rangueil University Hospital in Toulouse. Appointments were made in advance during a meeting with each study participant. An office was allocated for each interview and the participant was informed of the approximate duration. All interviews were recorded with the informed consent of the participants. In accordance with French legislation, no ethical approval was required for this anonymous interview-based study.

### Statistical analysis

Simple descriptive quantitative analysis was applied to the socio-demographic data and the closed questions in the interview grid.

The data from the semi-structured interviews were analyzed using text analysis software: IRaMuTeQ version 7.2 (Interface for Multidimensional Analysis of Texts and Questionnaires). An automated textual analysis was carried out, which "aimed to identify the regularities, specificities and correlations of the graphic forms in a body of text", with recognition of the grammatical categories of words and expressions according to active (common nouns, verbs, etc.) and additional (function words) elements. Data collection is based on the recording and transcription of interviews in their entirety to reflect the subjects' viewpoints. We used three types of analysis proposed by the IRaMuTeQ software: statistical analysis based on lexicometry, word cloud analysis and similarity analysis. The data was used anonymously.

## Results

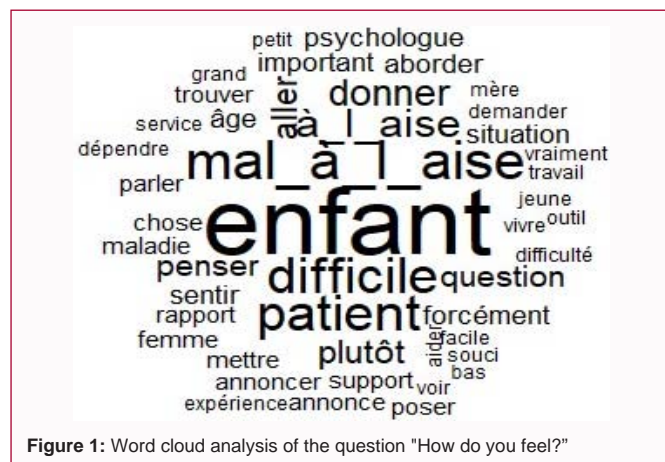
### Characteristics of respondents

Of the 36 members of the Gastro-intestinal Oncology Team (physicians, paramedics and healthcare assistants), 34 took part in this study, i.e. a response rate of 94.4%. The average length of the interviews was 28 min.

All respondents were female, with an average age of 41 (26 to 56). The majority of this population were nurses (n=13; 38.2%), physicians (n=8; 23.5%) and healthcare assistants (n=7; 20.6%). Six people (17.6%) had another role (psychologist, dietician, social worker, sophrologist, socio-aesthetician, reflexologist). On average, the participants had been working in the Oncology Unit for 8 years, including 4 years in the Gastrointestinal Oncology Department of Toulouse University Hospital Centre. Most of these 34 individuals were parents (n=25; 73.5%) with an average of 1.8 children per

**Table 1:** Socio-demographic and occupational characteristics of participants (n=34).

	n (%)
<b>Gender</b>	
Women	34 (100)
Men	0 (0)
<b>Profession</b>	
Nurse	13 (38.2)
Doctor	8 (23.5)
Healthcare assistant	7 (20.6)
Psychologist	1 (2.9)
Dietician	1 (2.9)
Social worker	1 (2.9)
Sophrologist	1 (2.9)
Socio-Aesthetician	1 (2.9)
Reflexologist	1 (2.9)
<b>Length of service</b>	
<10 years	7 (20.6)
10-20 years	15 (44.1)
>20 years	8 (23.5)
Unanswered	4 (11.8)
<b>Seniority in oncology</b>	
<10 years	15 (44.1)
10-20 years	14 (41.2)
>20 years	1 (2.9)
Unanswered	4 (11.8)
<b>Seniority in the Gastrointestinal Oncology Department</b>	
<10 years	27 (79.4)
10-20 years	0 (0)
>20 years	0 (0)
Unanswered	7 (20.6)
<b>Parents</b>	
Yes	25 (73.5)
No	9 (26.5)



**Figure 1:** Word cloud analysis of the question "How do you feel?"

healthcare professional. The average age of the children was 11.5 years (Table 1).

**Theme A: Disease diagnosis**

Half (n=17, 50%) of the healthcare professionals interviewed broached the subject of informing children about the disease with their patients. Healthcare professionals who did not spontaneously address this issue (n=17, 50%) do not wish to pursue the questions and prefer patients to inquire of their own accord. 58.8% (n=20) of the healthcare professionals stated that they were asked directly about this topic by patients. When this question is raised with patients (on the initiative of the healthcare professional or the patient), the majority of healthcare professionals feel "ill at ease" (Figure 1).

Healthcare professionals then ranked four actions from most helpful (rank 1) to least helpful (rank 4) in terms of when the disease was diagnosed. For 54.8% (n=17) of them, referral to a child

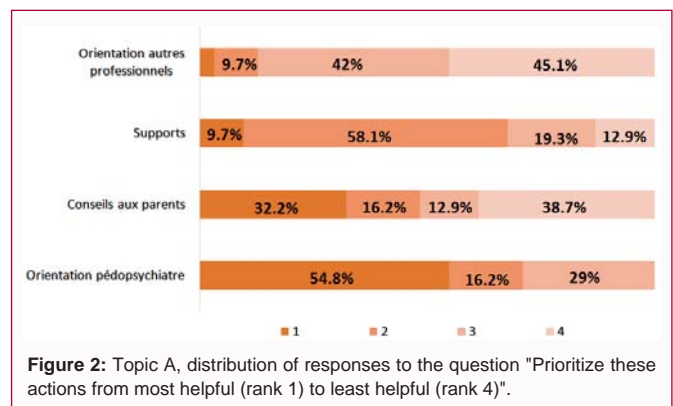
psychiatrist would be the most helpful option for their patients (Figure 2).

The main difficulties expressed by healthcare professionals when handling these situations are a lack of knowledge about the child's understanding of the disease, age-appropriate terminology and also lack of knowledge about the parent-child relationship. The nature of this relationship, they said, would influence the way in which children are told about the disease and the advice that healthcare professionals could give their patients.

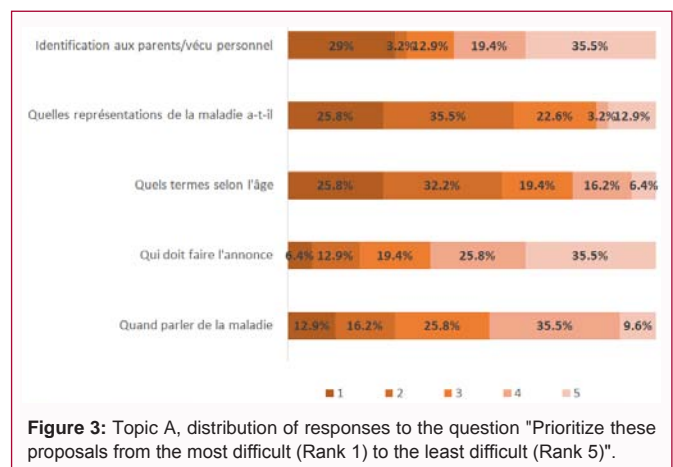
Participants then ranked five proposals from the most difficult (rank 1) to the least difficult (rank 5) based on their opinion. The item "Identification with parents, personal experience that makes this topic difficult for you" was considered the most difficult in 29% of cases (n=9) and, conversely, the least difficult for 35.5% of subjects (n=11) (Figure 3).

**Theme B: Unfavorable clinical course**

In this context, only 29.4% (n=10) of healthcare professionals spontaneously discussed with their patients the information to be given to the children. Questions about the clinical course of the disease and prognosis are already difficult to discuss with patients, and questions raised by children are not deemed a priority in the time spent with their patients. 61.8% of the participants (n=21) stated that they were directly questioned by patients about the information to be given to their children regarding the unfavorable clinical course of the disease. When this question is raised with patients (on the initiative of the healthcare professional or the patient), the majority of healthcare professionals feel "ill at ease" and in "a difficult situation". They then routinely suggest referral to a professional such as a psychologist



**Figure 2:** Topic A, distribution of responses to the question "Prioritize these actions from most helpful (rank 1) to least helpful (rank 4)".



**Figure 3:** Topic A, distribution of responses to the question "Prioritize these proposals from the most difficult (Rank 1) to the least difficult (Rank 5)".

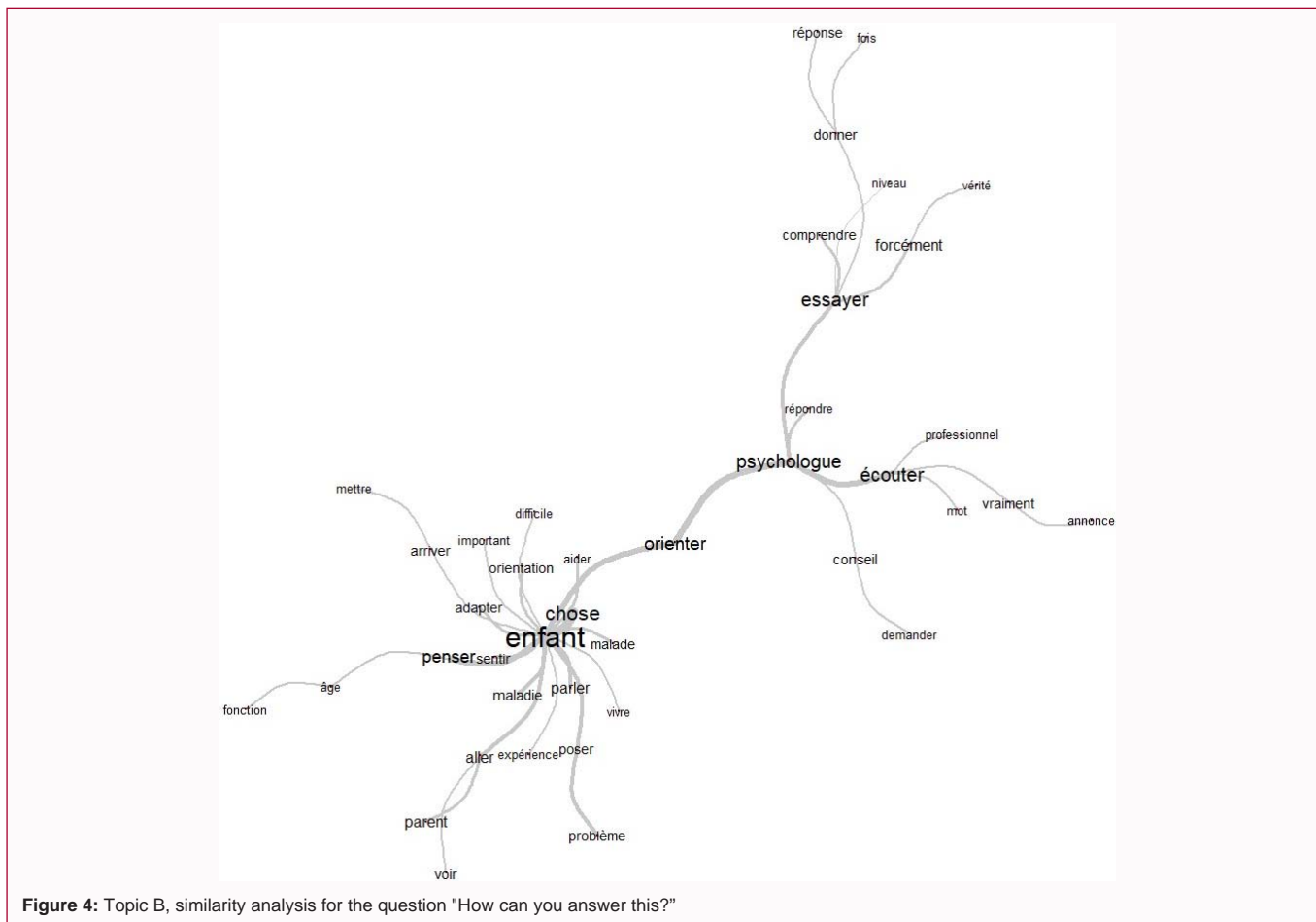


Figure 4: Topic B, similarity analysis for the question "How can you answer this?"

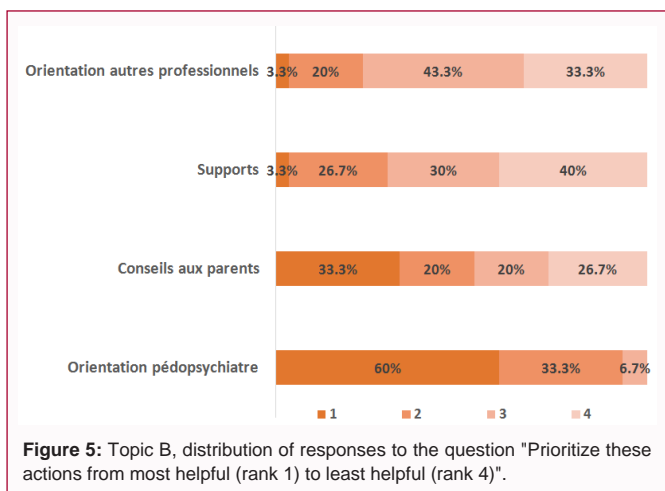


Figure 5: Topic B, distribution of responses to the question "Prioritize these actions from most helpful (rank 1) to least helpful (rank 4)".

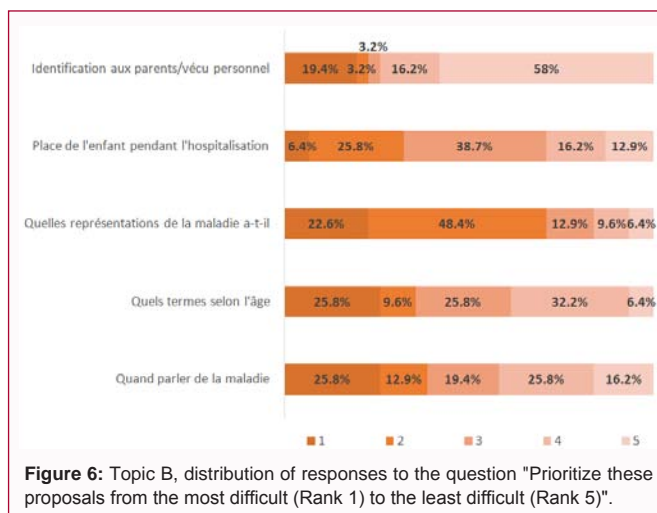


Figure 6: Topic B, distribution of responses to the question "Prioritize these proposals from the most difficult (Rank 1) to the least difficult (Rank 5)".

(Figure 4).

Healthcare professionals ranked four actions from most helpful (rank 1) to the least helpful (rank 4) in terms of unfavorable clinical course. Sixty percent (n=18) of healthcare professionals were of the opinion that referral to a child psychiatrist would be the most helpful option for their patients (Figure 5).

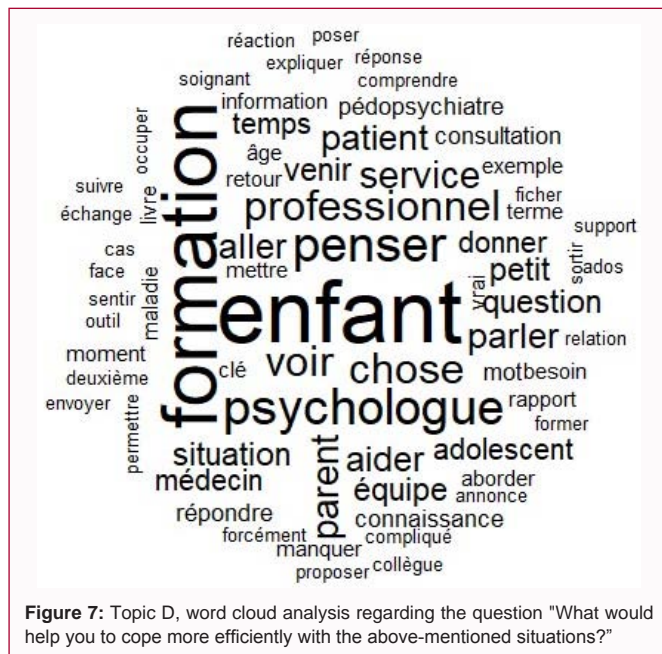
Participants then ranked five proposals from the most difficult (rank 1) to the least difficult (rank 5) based on their opinion. The item "Identification with parents, personal experiences that make this topic difficult for you to talk about" was considered the least difficult

in the context of an unfavorable disease outcome for 58% (n=18) of healthcare professionals (Figure 6).

**Theme C: Psychological impact on the child, when to refer to a specialist**

The majority of participants (n=21; 61.8%) asked patients about their parental concerns and worries. Conversely, 38.2% (n=13) of the healthcare professionals did not broach this topic with their patients. They did not want to draw patients into a discussion, choosing to let the patients address their own concerns themselves when they wished to do so.





Of the healthcare professionals interviewed,  $n=26$  (76.5%) tried to identify signs of children's suffering through discussions with their patients. The  $n=8$  (23.5%) healthcare professionals who did not do so explained that they are not trained for this, and do not possess sufficient pediatric, psychological or psychiatric knowledge.

Some healthcare professionals wait for patients to mention signs of suffering or discomfort in their children before referring them to a specialist. Others prefer to refer them to a psychologist or child psychiatrist from the outset, in order to prevent possible suffering.

#### Theme D: Needs of the healthcare professionals

The need for training is very clear. Many healthcare professionals also want time to talk and chat to each other, under the supervision of a psychologist or child psychiatrist. The option of being able to refer to a child psychiatrist to ask questions and seek help when they need it was also highlighted. The last point addressed by the healthcare professionals was to be better informed about the different professionals with whom consultations can be arranged for their patients' children (Figure 7).

We then asked the participants about the value of interactive on-line training (SPOC) on how to talk to children about the disease and then on the child's understanding of illness and death. 94.1% of the participants ( $n=32$ ) thought that this type of training could help them to gain a better understanding of this subject with their patients. 5.8% ( $n=2$ ) questioned the instrument/tool used (computer).

91.2% of the healthcare professionals interviewed ( $n=31$ ) are in favor of role-playing training.

## Discussion

The purpose of this study was to collect and analyze the feelings of oncology healthcare professionals on the topic of parenthood in relation to the patients in their care, regardless of the clinical course of the disease. The results of this work highlight the difficulties and needs commonly expressed by the various healthcare professionals interviewed.

The difficulties encountered concern the negative emotions

experienced by healthcare professionals when their patients address the subject of parenthood at different stages of the disease. There is a sensation of powerlessness and staff finds it difficult to support patients, particularly when it comes to answering questions. These emotional states exacerbate the stress and exhaustion of the professionals who find themselves in these situations. Healthcare professionals nevertheless try to respond to their patients by giving age-appropriate advice for the children, mostly drawn from their personal experiences. Thus professionals with children are more comfortable in providing this support.

Needs have emerged with a priority demand for training and support. Healthcare professionals are unanimous in their belief that their knowledge of pediatrics is inadequate as they work in adult units. Being better informed would enable them to advise their patients and answer their questions more calmly. Interventions with the children of cancer patients have proved effective [9]. Supporting patients with their parenting skills could promote indirect intervention with their children and an improvement in their physical well-being, which is significantly reduced compared to other children [10].

There are also times for exchange and discussions, supervised by a psychologist or a child psychiatrist, during which everyone can share their experiences in order to feel, supported and assisted in question and answer sessions. Realizing that they are not alone in this situation and that others are experiencing the same problems could alleviate the impact on professionals when faced with their patients' concerns. Empathy, support and training are three factors to protect against burnout [11].

One of the needs expressed concerns the option to refer to a professional to ask questions and seek help. These discussions could facilitate the less routine referral of children to child psychiatrists by allowing them to identify situations warranting this approach.

Healthcare professionals would also like to have closer links with the various psychologists and child psychiatrists who could meet with their patients' children, to give them optimum guidance when necessary.

## Strengths of the Study

To our knowledge, this is the first exploratory work of its kind. In fact, no study has reported implementing a MOOC (Massive Open On-line Course) or a SPOC (Small Private On-line Course) following previous identification of the needs of future learners and by adapting the training content to these needs.

Analysis of the results shows concordance in discussions between the various healthcare professionals interviewed. Indeed, mutual needs and difficulties were highlighted.

The strong participation rate is noteworthy, since 94.4% of the health care staff in the unit in which the study was conducted responded to the semi-structured interview.

## Study Limitations

This work was carried out with healthcare professionals from a single Gastrointestinal Oncology Unit, which limits its general extrapolation to different oncology departments although the diversity of the professions interviewed makes this a representative sample of a large number of healthcare professionals.

The interpretation of the results must be qualified by the small number of subjects, which could reduce the power of our study, even

if the analysis remains valid.

A methodological bias exists due to the interpretative descriptive qualitative analysis. This type of research is not trivialized in a consensual way and there is little written evidence. Access to descriptions of the phenomena is essential for healthcare professionals to understand the situations encountered in a clinical setting.

## Conclusion

The results of this study highlight the difficulties experienced by healthcare professionals in the Gastrointestinal Oncology Department at Rangueil University Hospital Centre (Toulouse) in discussing with patients the psychological impact of the latter's disease on their children as well as the most appropriate information to give the children about the disease. These difficulties are notably due to an inherent lack of knowledge. The needs expressed suggest this line of approach since their priority is the need for training in order to enrich their knowledge about children.

This work is a preliminary study for the implementation of specific training tools intended to assist oncology healthcare professionals in dealing with an issue that is currently unclear or underestimated. The PAROLE project suggests creating and disseminating an interactive on-line training course such as SPOC in order to improve the theoretical knowledge and working conditions of the healthcare professionals. We intend to develop the SPOC content based on the needs and difficulties encountered by healthcare professionals and highlighted in this work to boost the potential efficacy of training. This on-line training will be combined with face-to-face meetings and discussion through simulation sessions.

In the long term, we believe that the PAROLE project will improve the management and quality of life of patients who are parents to children and teenagers by offering them greater support. It will also assist healthcare assistance to cope with real-life settings and working conditions. In this way, we hope to limit stress factors that can lead to burnout and other forms of indirect trauma in healthcare professionals.

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