Faculty of psychology and educational sciences

Academic year 2016-2018

How do cancer patients in a non-curative setting experience psychological help during their treatment?

Thesis to obtain the certificate of the education of ‘psycho-oncology’ by Nele Kerkhofs

Promotor: An Lievrouw

Co-promotor: Ellen De Loore

ABSTRACT

Goal: The goal of this research is investigating the need for and value of psychological support during treatment among patients who suffer from non-curative cancer. Through a questionnaire we get to know how patients have experienced psychological help during treatment, making it possible to improve the approach of psychological support in our and other hospitals.

Methods: We used two kinds of analyses, qualitative (Nvivo 11.4.2) and quantitative (SPSS 20). The questionnaire contained questions that could be answered with simply yes or no, but extra information was asked through open questionnaires to collect as much information as possible. Doing so we wanted to know exactly how patients have experienced psychological help during treatment. To make sure patients felt safe to also share negative experiences we decided to analyse the answers in an anonymous way.

Results: Even though we asked specifically for things patients had missed or experienced as less pleasant during psychological follow-ups, little negative reactions were expressed. On the contrary patients were very positive about the approach of psychologists in our hospital. More specifically, the number of follow-ups they had been given was significantly linked with their positivity about the approach as well as the virtue and the support they had felt. Even though patients admit they wouldn't have asked for psychological support, they benefited from it and almost all patients would advise this kind of help to fellow sufferers. Our study also showed that patients hadn't felt much impediments or taboo about talking to a psychologist. On the contrary, they received positive reactions from their environment that this kind of support was being offered.

Conclusions: Overall we can conclude that following-up patients in a pro-active way is the best approach for psychologists. Patients don't expect this kind of help and wouldn't have asked for it themselves, but they seem to benefit from it. As psychologists we can only hope the positive evolution about little taboo felt will continue in the future, so patients will find the courage to ask for help when needed and not offered anyway. Not only offering psychological help seems to be important, but psychologists should be given the chance to meet patients on a regular basis since the support and virtue felt increase substantially.

INTRODUCTION

Background

Throughout the years more and more attention has gone to the psychological support of cancer patients during treatment. In 2009 the Belgian government set up a National Cancer plan in which they gave hospitals extra financial resources to employ social workers, nurses and psychologists to offer cancer patients the support they needed during a very emotional period in their lives. But do patients experience this support as actually helpful? As an onco-psychologist I asked myself this question several times. Having to make a thesis as a part of the education onco-psychology was the ideal opportunity to do research about it.

In literature little could be found about how patients experienced psychological help during treatment, but a lot of research has been done about the effects of this kind of help on the well-being of patients. Azuero C., Allen, Kvale, Azuero A. and Parmelee (2014) found that among patients who met criteria for moderate depression or anxiety, half of them did not access available psychology services. Factors that enabled patients to receive psychological help were the strongest determinant. The strongest enabling factor was offering psychological help without patients asking. There was no significant link found between need for psychology services and the actual use of these services. Azuero et al (2014) advised future research to focus on care models that optimize enabling strategies to enhance access to psychological help and examine patient-reported barriers to receiving this care.
Epstein and Morrison (2012) concluded in their research that the ability and efficacy of integrating symptom control, communication and quality care delivery early and often into the care of cancer patients and their families leads to an improvement in their quality and length of life. It underlines the importance of a team that works together efficiently.
Lurati et al. (2010) specifically evaluated the effectiveness of an early psychotherapeutic intervention (POI) in newly diagnosed cancer patients. They concluded that an early POI significantly reduces patients' psychiatric symptoms and the risk of a negative evolution of pathological situations in those patients who are motivated and express a need for psychological help. This study underscores the importance of meeting patients' needs in an early stage in order to reduce the occurrence of psychiatric disturbances.

The last few decades attention for palliative care is growing. It is playing a vital role in the oncology population as cancer is detected earlier and its treatments improve. Because of this evolution a few researchers focused their research on psychological support given to the palliative population. In Western Australia, White, D'Abrew, Katris, O'Connor and Emery (2012) concluded that a substantial minority of cancer patients reported unmet needs. When they did report them, it was primarily in the psychological, physical and daily living domains. White et al. (2012) found their conclusion consistent

with conclusions they found in literature, namely that unmet needs in cancer patients is highest on the psychological domain.

Brazil et al. (2009) examined whether services in Ontario, Canada, met the supportive care needs of palliative cancer patients and their families. They concluded, just like White et al. (2012) that the most frequently reported unmet supportive care need was psychological/social support. Many respondents felt that palliative care services were not available when needed. These respondents suggested better exchange of patient information on palliative care patients' social/psychological status within and between programs and staff.

In their literature review Adams E., Boulton M. and Watson E. (2009) have been looking for the extent to which information needs of partners and family members of cancer patients had been addressed. They concluded that partners and family members more likely had unmet needs for information about supportive care than for medical information. Apparently it's not only the patients themselves who experience a lack of information about psychological/social support, but also their relatives.

Baker et al. (2013) came to a more differentiated conclusion in their research. They investigated the readiness of patients to address emotional needs up to eighteen months following a diagnosis of breast, lung or prostate cancer. Patients early in the cancer trajectory, who had not yet been engaged in chemotherapy or radiotherapy, valued knowing that support was available, but did not want to use it. Conversely, patients engaged in treatment readily acknowledged their emotional needs and welcomed help to address these. Psychological intervention might be less appropriate in early stages than at a later time.

Yael, Young, Rachael and Robert (2014) researched whether unmet palliative care needs are associated with an interest in palliative care services among patients with advanced cancer receiving ongoing oncology care. Unmet palliative care needs appeared to be related to psychological distress and symptoms and a higher perceived need for subspecialty palliative care services, but not to the likelihood of requesting palliative care services. They also concluded that willingness to receive palliative care was high if the oncologist recommended it.

Pasacreta and Pickett (1998) examined the consequences when palliative care needs were met. Individual, sociocultural, medical and family factors influenced psychosocial issues faced by patients and their family. Supportive psychotherapeutic measures appeared to help minimize distress, enhance feelings of control and improve quality of life.

In their explorative, prospective research Pagliuchi et al. (2011) hypothesized that an early psychological diagnosis followed by adequate suitable and timely interventions could provide significant benefits for them and their families. It might also improve their adherence to the medical treatments and chemotherapy and thus improve the effectiveness of the cures. They concluded that an early psychological intervention could reduce the emotional distress and improve patients' adherence to treatments. Anxiety can rapidly be reduced and the depressive status can be controlled on the long term. Guo et al. (2013) found similar results in their study. The objective was to determine the benefits of psychosocial interventions for cancer patients who received radiotherapy. Patients assigned to the group that received psychological interventions showed significant improvements on

symptoms of depression, on anxiety and health related Quality of Life when compared with the control group. Female patients that received high doses irradiation and adjuvant chemotherapy could even benefit more from psychological interventions. No difference was found between the two groups and survival.

The importance of palliative care gets more and more attention throughout the years and is incontestable. But what is it exactly in psychological care that patients benefit from, how do they experience the approach and interventions of onco-psychologists? Gao, Bennett, Stark, Murray and Higginson (2010) asked themselves a similar question. They wanted to understand how psychological distress changes over the cancer trajectory to target interventions and care. They concluded that assessing psychological distress through survivorship may identify unmet psychological needs and allow targeted psychological support.

We can summarise that Yael et al. (2014), Azuero et al. (2014) and Baker et al. (2013) came to the conclusion that patients who need help don't always ask for it themselves. But if patients are offered help, even without asking, they seem to benefit from it as shown in the research of Epstein and Morrison (2012), Lurati et al. (2010), Pasacreta and Pickett (1998), Pagliuchi et al. (2011) and Guo et al. (2013).

From the literature above we can conclude that unmet needs are the highest in the psychological / social domain. Through the last years a lot of financial support has been assigned to this kind of support in hospitals in Belgium. In our hospital we work in a proactive way by following and supporting every cancer patient during treatment. Doing so, we hope the needs of psychological support will be met. In our study we will examine whether patients have experienced this support as helpful or not.

Literature shows that unmet needs lead to psychological distress and symptoms, and a higher perceived need for palliative care services. On the other hand, when the needs are met, it leads to an improvement in quality of life, length of life, reduced psychiatric symptoms, reduced risk of a negative evolution of pathological situations, minimized stress and enhanced feelings of control. All these studies underline the importance of offering psychological support to cancer patients. Since in our hospital we follow every patient with cancer and we hope their needs are met, we decided not to focus on the effects of met or unmet needs, but more on the content of the support. What did patients experience as helpful, what did they miss during our sessions, would they advise psychological help to other patients,… We also asked patients whether they thought their family members were supported enough during the whole process since the impact on their lives is very significant as well. The answers of patients can be very valuable in the support of future patients because it may lead to a modified approach of offering psychological support.

Azuero et al. (2014) advised future research to examine patient-reported barriers to receiving psychological care. In our study we followed his advice, more specifically we asked patients if they had

felt an impediment when the psychologist came to introduce herself for offering support and if they had experienced any form of taboo about talking to a psychologist during treatment.

METHODS

Participants

Questionnaires were sent to 86 patients in a non-curative setting of which we received 32 replies (response rate 37%), but 4 of them could not be used for various reasons, e.g. the patient was too weak, the patient didn't remember his conversation with the psychologist,… We chose this group because psychologists have the chance to follow them over a long period of time during treatment. The disadvantage of this group appeared to be that some patients were too weak to fill in the questionnaire. All patients are being followed by one of the three onco-psychologists in Sint-Trudo Ziekenhuis in Sint-Truiden, Belgium. The 86 patients selected for this research were all being treated in a palliative setting. It didn't matter whether patients were primarily metastatic or had suffered relapse. We, as onco-psychologists, started selecting patients in May 2017 and went back one year which means that all the non-curative patients we had seen since May 2016 were being sent a questionnaire along with an envelope with stamp to return the questionnaire without any costs involved. On the envelope we wrote the name of the onco-nurse, so she could separate the informed consent from the answered questionnaire. Patients were not informed in advance about the fact they were being sent a questionnaire.

Procedure

In our research we will focus mainly on the way cancer patients experience the psychological support offered to them. Because there is so little research done about this topic we chose to perform a combination of quantitative and qualitative research. We asked questions on which patients could answer with yes or no, and asked to explain why they chose this answer. This way patients could speak freely about their experience. We chose to do this anonymously to encourage patients to express positive and negative experiences. Negative answers might offer us the most information about our approach. The content of the questions were the result of a brainstorm session between the three onco-psychologists. We asked ourselves what might be interesting to know about our approach, to evaluate it and be able to make adjustments in the future to provide better services to our patients.
The questionnaire included a list to ask demographic data as sex, age, diagnoses,… This way we can search links between a certain group of patients and certain needs.
Before sending the questionnaire to patients we consulted the ethics committee in our hospital. They checked whether the questions were appropriate to ask patients and they gave suggestions about the content which were very helpful. Together with the questionnaire we mailed an informed consent to patients to ask their permission to use their data anonymously and their agreement to participate in this study.

Analyses

The yes-no answers to the questions were linked to the demographic data in order to find links between both. For this the statistical program SPSS 20 was used. The data collected through open questions were coded and analysed with Nvivo 11.4.2.

RESULTS

The questionnaire offered to patients contained ten questions which were all processed through qualitative and quantitative analyses. To keep the overview we will start with the quantitative analyses using SPSS 20 and discuss every question individually. We will continue with the qualitative analyses using Nvivo 11.4.2.

Quantitative analyses

*1. What do you think about the **approach** of the psychologists (meeting conversation, coming by at their own initiative, frequency,…)? Circle the number of your choice.*

(Not good) *1 - 2 - 3 - 4 - 5* *(Very good)*

For what reason or which reasons do you chose this number?

In SPSS 20 we looked for correlations between the answers on this question and demographic data we collected through a short questionnaire. One strong correlation was found, more specifically between the number of follow-ups done by psychologists and the satisfaction about this follow-up ($r = 0.484$). The connection also appeared to be significant ($p = 0.010$). This finding is important and something we should take into account in our day-to-day job. It proves that it takes time to build up a trust band, but that it pays off in the feeling of satisfaction patients have about our help. It also proves that going to patients proactively on a regular basis is a good strategy to follow since patients don't tend to ask for help themselves (see question 2).

*2. Would you have **asked** psychological help **yourself**? Yes/No*
If so, for what reason?
If not, are you satisfied it was offered anyway?

No correlation or significant connection was found between this question and the demographic data, probably because only four of the 28 patients answered that they would have asked for help themselves. No link was found between these four people. But even without the lack of significance between all variables it becomes clear that very few people would ask for psychological help, which is a pity since we will find out later that patients experience this help as very supportive.

*3. Would you **recommend** psychological help to lotteries? Yes/No*
For what reason would you (not) do so?

Only one woman indicated that she wouldn't recommend psychological help to fellow sufferers. She only had one conversation with a psychologist. It's difficult to check significance with only one negative reaction, but the fact that there was only one person out of 29 that wouldn't recommend psychological support shows us that patients appreciate our help and would like us to help others in the same way.

*4. Are there any aspects of the psychological help that you have experienced as **less pleasant**? Yes/No*
Please explain

Only one woman indicated she has experienced one aspect of the psychological support as less pleasant. Again it is impossible to find links between this questions and any demographic data, but the fact that there was only one negative reaction is very stimulating to keep working the same way.

*5. Is there a certain aspect of the psychological help that has specifically done **virtue** to you? Yes/No*
Please explain

Four patients answered this question negatively. All four of them had had their diagnoses less than one year ago. Because of this these patients hadn't received many follow-up conversations. We found a strong connection ($r = -0.429$; $p = 0.023$) between the number of follow-ups and the feeling that psychological help had done virtue to the patient. It might be the case that more follow-up conversations strengthen the feeling of confidentiality which enhances the feeling of virtue. For psychologists in hospitals this finding is very important to take into account if they want to support their patients as good as possible.

*6. Is there something you have **missed** during psychological help?*
Please explain

Only one man reported he had missed something during the psychological follow-up. His explanation will be analysed in the qualitative research.

*7. Did you experience psychological help as **supportive**? Yes/No*
Please explain

A strong connection was found between the number of follow-ups and the feeling that psychological help was experienced as supportive ($r = -0.580$; $p = 0.002$). This underlines again the importance of having conversations with patients on a regular basis. We can imagine it takes time for many people to

feel comfortable with sharing their experiences with someone unknown. The more psychologists pass by, the more the confidence grows and the more patients feel safe to share their personal feelings.

*8. Did enough attention go to your **closest ones** (partner, children, parents,…)? Yes/No*
Please explain

Five patients indicated that too little attention had gone to their closest ones. From these five patients, four had had their diagnoses less than one year ago (r = -0.283). Family doesn't always join patients during treatment, so it is possible that it takes a while before psychologists have the chance to talk to significant others. It's important to keep in mind we should pay attention to the closest ones, also in the first year after diagnoses.

*9. Did you have the feeling you had to exceed an **impediment** to talk to a psychologist? Yes/No*
Can you explain the reason why?

Not one patient answered this question positively, which means no one had the feeling to have to exceed an impediment to talk to one of the psychologists. This might be explained by the fact that psychologists in our hospital visit every patient proactively. They see that psychologists pass by every patient which means they don't get the feeling something is wrong with them on a psychological level. Because every patient answered this question the same way, it's impossible to do any statistical analyses.

*10. Did you have the feeling it was **taboo** to your environment you talked to a psychologist? Yes/No*
What made you feel like that?

Three men indicated to have felt a form of taboo about talking to a psychologist. A correlation could be found between a positive answer and age (r = -0.289). The younger, the less taboo felt.

Correlations	Sex	Year of birth	Marital status	Children	Diploma	Psychological help in past	Time since diagnosis	Number of follow-ups	Type of diagnosis
Approach	-0,046	0,122	-0,013	0,059	0,105	0,235	0,053	**0,484**	0,219
Ask yourself	0,012	-0,091	-0,15	0,204	0,123	0,024	0,035	-0,076	-0,071
Recommend	**0,289**	-0,112	0,087	-0,118	-0,249	**-0,319**	-0,212	**-0,337**	-0,218
Less pleasant	**-0,289**	0,12	**0,549**	0,118	-0,025	**0,319**	-0,091	-0,212	-0,262
Virtue	0,266	-0,217	-0,101	-0,035	-0,075	-0,095	**-0,343**	**-0,429**	-0,145
Missed	0,156	-0,05	-0,083	0,112	**-0,299**	-0,141	0,199	**0,307**	0,204
Supportive	0,134	0,097	-0,156	0,026	0,054	-0,187	-0,267	**-0,58**	-0,183
Closest ones	0,147	0,019	-0,163	0,036	-0,244	-0,195	**-0,283**	-0,098	0,01
Impediment	,	,	,	,	,	,	,	,	,
Taboo	**0,283**	**-0,289**	0,233	-0,109	0,123	0,024	0,035	-0,234	-0,261

Tabel 1 Pearson correlations between the answers on yes/no questions and demographic data

Significance	Sex	Year of birth	Marital status	Children	Diploma	Psychological help in past	Time since diagnosis	Number of follow-ups	Type of diagnosis
Approach	0,417	0,289	0,476	0,395	0,316	0,14	0,405	**0,01**	0,158
Ask yourself	0,479	0,34	0,247	0,175	0,288	0,456	0,436	0,366	0,373
Recommend	**0,096**	0,31	0,351	0,3	0,132	**0,074**	0,171	**0,062**	0,165
Less pleasant	**0,096**	0,297	**0,004**	0,3	0,456	**0,074**	0,343	0,171	0,119
Virtue	0,115	0,167	0,328	0,438	0,371	0,337	**0,059**	**0,023**	0,26
Missed	0,239	0,411	0,354	0,305	**0,083**	0,26	0,181	**0,077**	0,175
Supportive	0,277	0,333	0,244	0,455	0,406	0,206	0,115	**0,002**	0,207
Closest ones	0,252	0,465	0,229	0,435	0,13	0,186	**0,095**	0,329	0,482
Impediment	,	,	,	,	,	,	,	,	,
Taboo	**0,095**	**0,09**	0,142	0,31	0,288	0,456	0,436	0,141	0,114

Tabel 2 Significance between the answers on yes/no questions and demographic data

Qualititative analyses

Even though the questionnaires were taken anonymously to invite patients to also express negative experiences, the number of these negative responses are very low as you can see in Tabel 3. Even specifically asking about things patients have missed or experienced as less pleasant did not lead to much feedback. This might of course be explained by the fact that patients that have filled in the questionnaire are more open to psychological help than those who didn't.

	Number of responses
Approach	27
Ask yourself	14
Recommend	21
Less pleasant	6
Virtue	19
Missed	4
Supportive	17
Closest ones	17
Impediment	16
Taboo	10

Tabel 3 Number of responses on each question

Going through the answers I noticed certain themes came back in different answers. It became possible to categorise all the answers into 5 categories which could be divided in subcategories as can be seen in Tabel 4. By minimising the number of categories it became possible to find stronger links between the answers and demographic data. These links could be found by inserting all the data in Nvivo 11.4.2 and performing certain data-analyses.

Approach	Negative		3
	Positive	Attitude of psychologist	15
		Expectations	12
Experiences	Positive		18
	Disappointing		5
	Role of psychologist	As a person	6
		Psycho-education	6
Significant others	Positive		10
	Negative		4
Impediment	Externally	Positive	8
		Negative	1
	Internally	Positive	8
		Negative	2
Taboo	Externally	Positive	4
		Negative	2
	Internally	Positive	3
		Negative	1

Tabel 4 Number of answers in each category

We made a distinction between externally and internally felt impediment and taboo to be able to find out what was more important. Making the distinction between internally and externally was necessary because many patients felt they were being supported by their families to talk to a psychologist in stead of experiencing any form of taboo. For example:

"Everybody reacted positively."
was categorized as Taboo Externally Positive

"Is in many cases considered as 'not done'."
was categorized as Taboo Externally Negative

"Taboo is exaggerated, but I felt a certain restraint. Ultimately you have to expose yourself towards a stranger, which is not something I do naturally."
Was categorized as Taboo Internally Negative

Not only the number of responses in each category is interesting, even more interesting is to find out which group of patients made which response. For instance: is there a large difference in taboo felt between men and women, or between patients that have had psychological help in the past or not. To find differences between groups of patients we linked the answers to the demographical data as can be found in appendix 1. Below we will discuss interesting results found in each category together with examples of answers that were categorized in this specific group.

Approach

Of all the women that participated in this study, 18% gave negative feedback on the approach of psychologists, compared to only 6% of men.

"She only asked questions."

"I didn't get follow-up."

In contrast to this finding 82% of all women gave positive feedback on the approach of psychologists compared to only 35% of men. Overall more women (15 responses from 11 women) than men (15 responses from 17 men) gave comments on the question about approach.

"A good conversation, which felt supportive."

"You broke the barrier for us."

“Information”

“The psychologist is pleasant to deal with.”

Less difference between men and women could be found about expectations about the approach of psychologists. 47% of men and 36% of women gave a response that could be categorized in this subdivision. Both men and women were surprised by the offer of psychological help during treatment.

“The coming over of psychologists supports you unexpectedly.”

“I would never have asked for it, but I experience it as very positive;”

“The offer was a pleasant surprise.”

No difference in the number of responses in the three subdivisions of approach could be found between patients that have had psychological help in the past or not. Both groups shared the same opinions about psychological help being offered to them.

The aspect that does seem to make a difference in opinion about the approach of psychologists is the number of follow-ups. The less follow-ups, the more responses on the subdivision ‘negative’. On the contrary, the more follow-ups, the more responses in the subdivision ‘positive’. For psychologists in practice this finding is important. It takes a while to build up a professional relationship with your patient before he/she will benefit from it. Even though this result seems to be normal, namely the more follow-ups the more your patient feels supported, it’s very important for the policy in hospitals. Psychologists should be given enough time not only to meet every patient, but also for follow-ups on a regular basis.
Important to notice is that 33% of the patients that only had one conversation with a psychologist responded positively on the fact that psychological help was available.

Experiences

A lot more positive (18) than negative (5) responses were given on the question about the experiences of getting psychological help during treatment, with no difference between men and women. There also was no difference found between patients that have received psychological help in the past or not.

“A pleasant intermezzo during chemo.”

“Help is always welcome.”

“It is nice that someone other than your family or partner comes over to ask how you are really doing.”

Again, a difference was found between patients that have received little versus many follow-ups during treatment. 50% of the patients that had only had one conversation with a psychologist gave a negative comment in the category ‘experience’. In strong contrast to this, 80% of patients that have had more than 4 follow-ups gave a positive response. Again, the importance of performing many follow-ups is underlined. Connecting with this finding it seemed to be that the role of the psychologist was valued more when patients received more follow-ups. 30% of patients that had received more than 4 follow-ups commented on the subdivision ‘role of psychologist’ while only 17 % of patients did so when they had had only one conversation.

No difference could be found in the category ‘experience’ between patients from another year of birth, with another marital status or level of education. The number of responses in each group were similar.

Significant others

Overall ten patients gave positive input about the support given to significant others in contrast to only four negative responses. Women seem to be more positive (55% vs 24%) and less negative than men (9% vs 18%) about the follow-up of significant others.

“The follow-up is interesting for the patient and important others.”

“My daughter has experienced a positive conversation for herself and the grandchildren.”

“We had many questions about the children. How do you let them participate in this story.”

“My son was often present during these conversations which made him accept the situation better.”

It was remarkable that 60% of patients without children gave positive feedback about the support given to significant others in contrast to only 30% of the patients with children.

Impediment

Specifically asking about impediments felt towards psychological support only led to three negative responses.

“I didn’t experience any impediments, but maybe the therapist did (about the end of life).”

From the positive responses we could conclude that patients felt they were being encouraged by their environment to benefit from the psychological support offered to them. Again, the increasing number

of follow-ups was related to more positive reactions about impediments felt internally and externally. The more support offered by psychologists, the more positive responses about impediments felt. In contrast to these two patients that responded negatively on impediments felt internally were patients that were given more than four follow-ups. The number of follow-ups couldn't change the fact they were no 'talkers' by nature.

"I am not really a talker."

Taboo

Very little responses were given on the question about taboo. Remarkably only men gave negative responses about this subject. 12% of the male patients felt taboo from their environment about accepting psychological support and 6% of the male patients felt an internal taboo.

"It's a subject which is inadequately known by the bigger mass."

Another remarkable finding is the fact that only patients who live together gave positive responses about taboo felt by the environment. From the ten patients responding this question, only one was single.

DISCUSSION

A few results we found in our study are similar to results we found in literature. First of all different studies showed that patients don't easily ask for psychological help (Baker et al., 2013), even when they suffer from depression and/or anxiety (Azuero et al., 2014). Azuero et al. (2014) suggested for future research to look for strategies to minimize barriers patients feel to ask for this kind of help. In each hospital in Belgium the psychological department can chose their approach to patients according to their own argumentation, more specifically they can chose to talk to each onco-patient proactively or only when patients ask for help themselves. A lot of hospitals chose to minimize the barriers by letting psychologists talk to every patient with an onco-diagnosis. Going to patients proactively makes sure that psychological help is offered to patients with or without their request. During follow-ups, it becomes clear to what extent patients need psychological help and the approach will be adapted to each patient individually. In our study it became clear that many patients gave positive answers to the proactive approach of psychologists in our hospital. It also seems to lead to little responses on threshold and taboo felt towards this kind of support. Patients can see with each other that every patient is being followed-up by a psychologist, which makes it very normal. Only one patient in our study wouldn't advise accepting psychological help to other patients.
Brazil et al. (2009) found that unmet needs are reported the most according to psychosocial support. He advised better exchange of information about psycho-social status within and between teams. As a psychologist in a regional hospital I can only speak for the climate in our hospital, where a lot of attention goes to the psycho-social status of patients, especially within the onco-team. This way other caregivers can take psycho-social vulnerabilities of patients into account during their care.

In his research Epstein et al. (2012) concluded that help offered often and in an early stage led to higher quality of life and it would even extend the lifespan. This is the only research we found which proves that help offered on a regular base is important. In our research this seems to be the most important finding. With increasing number of follow-ups, the satisfaction, virtue and support felt increase, as found in the quantitative research. In the qualitative part of our research we found similar results. With increasing number of follow-ups, the number of positive reactions on 'approach' and 'experience' increase. We can conclude that patients experience more benefits when being followed-up on a regular base. This might be explained by the fact that a relationship of trust gets built by increasing number of follow-ups. Patients dare to open up more and thus experience more benefits.

Both Epstein et al. (2012) and Lurati et al. (2012) found in their research that psychological help offered in an early stage had positive effects on the well-being of patients. In our research we cannot draw any conclusions considering this topic since we always see patients at the same time in their treatment. In practice we feel we sometimes catch up patients too late since the first shock of getting the diagnoses has passed when patients start their treatment. It might be better to talk to them soon after they first hear about their disease. This might be an interesting topic for future research.

Summarised, literature shows us that met needs lead to more quality of life, less psychiatric symptoms, less chance of depression or anxiety, less distress, increased feelings of control, better adherence to treatment,… In contrast to this, unmet needs lead to more psychological distress and higher need of palliative care. Since the answers in our study are much more positive than negative, we hope our pro-active approach leads to the fact that the psychological needs of patients in our hospital are being met. Again we could conclude that the number of follow-ups is the factor that is the most determinative. When the number of follow-ups is rather low, the answers are coloured negatively. Many follow-ups on the other hand lead to more positive answers. The reason why some patients were being less followed-up is because they haven't been in treatment for a long time. We offer every patient the same opportunity to talk to us by passing by on a regular basis. Patients may of course ask not to be followed up by us.

Shortcomings of our research and recommendations for future research

Since every research has its deficiencies, we will now discuss aspects that could have been performed better and we will make suggestions for future research.

In total only 28 of 87 patients responded on our questionnaire. Some results were very clear, but with more participants other results might have been significant as well. The number of patients included was little to begin with because our hospital is regional and thus rather small. It would be meaningful if this study could be carried out in an academic hospital with much more patients.
Patients didn't only give positive comments, but also suggestions for the future. Negative answers were limited, but if we would ask other patients specifically about this negative experience, they would probably agree, for example the need of more privacy during conversations. One negative experience is not much in numbers, but its content might be very valuable for the hospital.

Only half of the patients answered on the open question about significant others. In practice we often notice that patients don't easily bring their children to hospital. Maybe they want to spare their children from confrontation with the hospital, or they have the feeling their support towards the children is sufficient and no help from psychologists is needed. In their research Inada et al. (2016) set up a program (Children's Lives Include Moments of Bravery) in which psychosocial support was provided to children who have parents with cancer. Results showed that attending this program was useful for both children and their parents. For children it was a good opportunity to talk about their feelings with children who went through similar situations. It helped children understand what cancer is and how to cope with their parents in distress.
In Belgium lots of attention and finances go to the psychosocial support of patients going through cancer. Little attention though is provided to their children which feels like a shortcoming. Hopefully programs similar to CLIMB will be set up in the future, but we will probably be confronted with the same issues as the researchers, namely poor publicity about the program, time-consuming,

inadequate funding,… Research about psychosocial support offered to children of patients with cancer seems to be very interesting and necessary for the future.

It was remarkable that no patient answered negatively on the question about having felt an impediment towards receiving psychological help. We should take into account that patients who did feel an impediment towards the visit of a psychologist might have chosen not to fill in the questionnaire. By performing the questionnaire anonymously we tried to avoid this, we tried to invite patients to give us negative feedback, but this might have been not enough to convince them to fill it in.

On the question about taboo the number of answers were limited as well and were more positive than expected. In our research we asked this question after patients had already received psychological support. It might be interesting for future research to ask about taboo felt towards getting psychological help before patients start with treatment. In research with more participants than ours conclusions might be drawn about taboo felt and demographical data like age. It would be interesting, for example, to check if younger patients feel less taboo towards psychological support than older patients.

Overall the feedback given was more positive than negative. We shouldn't be too thrilled about this because it's possible that patients with negative experiences didn't want to do the effort to make time to fill in the questionnaire. Nonetheless patients who filled in our questionnaire have been very open to giving feedback on our approach. The conclusions we have drawn are interesting for our hospital and every hospital where psychologists use the same approach, namely going to patients proactively, without them asking.

The conclusions found in our study seem to be interesting for the approach of psychologists, but we should look at the results in perspective since it only included answers of 28 patients. It would be very interesting to evaluate the work of psychologists in an oncological setting on a larger scale.

After doing this research it would be interesting to ask ourselves what we could change in our approach. First of all it's important to take into account that patients don't easily ask for help themselves. In our hospital we talk to every onco-patient, but we also see patients in other departments when asked by other caregivers. We should stimulate them to request our help when they feel the patient could benefit from it. Working in a proactive way has been proven very worthy and appreciated by the patients, so that will be retained. An aspect that seemed to be very valuable is the number of follow-ups patients receive from the psychologists. This is something we will certainly keep in mind in our daily practice. Finally we received individual input about things patients have missed like lack of privacy during conversations or the feeling that talking about the end of life was not done.
For future research it might be interesting to find out in which stage psychological interventions should be started. Lurati et al. (2010) and Baker et al. (2013) come to different conclusions about this matter. Lurati et al. (2010) strongly advised to see patients in an early stage, while Baker et al. (2013)

concluded from research that psychological interventions are less appropriate in early stages. It would be interesting to complement our questionnaire with a question about timing. Have patients missed our support directly after finding out about the diagnosis or would it have been too soon? In our hospital psychologists usually start seeing patients when the treatment starts, but it might be advisable to start sooner.

It might also be interesting to focus more on the specific interventions made by the psychologist. What do patients experience as helpful or what do they find unnecessary. This research should probably be performed sooner after conversations between patients and psychologists, because patients might forget the specific interventions done by the psychologist.

Another interesting question might be whether there is a difference in experience between patients in a non-curative or a curative setting. Do they have different needs, expectations,… Results from this kind of research might change our approach in practice.

To stay informed about the needs of patients during psychological follow-up and to evaluate our approach it would be very useful to send this questionnaire to patients every once in a while which we intend to do in our hospital.

WORD OF THANKS

I would like to take the opportunity to thank my promotor An Lievrouw and my co-promotor Ellen De Loore for the pleasant cooperation. Their feedback was valuable and always at short notice which made it possible for me to stick to my planning.

I would also like to thank Sint-Trudo Ziekenhuis for giving me the opportunity to follow this education, which has been very meaningful for my daily practice, and my colleagues for supporting me. Of course I cannot forget to thank the patients for making the effort of filling in the questionnaires. Their answers are very valuable to optimize our approach in the future. I would also like to thank the ethics committee for checking my questionnaire and making suggestions to improve it.

Last but not least I would like to thank Cédric Hèle Institute for organizing this education and for supporting us every step of the way.

REFERENCES

Adams E., Boulton M. & Watson E. (2009). The information needs of partners and family members of cancer patients: A systematic literature review. *Patient Education and Counseling*, 77 (2), 179-186.

Azuero C., Allen R. S., Kvale E., Azuero A. & Parmelee P. (2014). Determinants of psychology service utilization in a palliative care outpatient population. *Psycho-Oncology*, 23 (6), 650-657.

Baker P. , Beesley H., Dinwoodie R., Fletcher I., Ablett J., Holcombe C. & Salmon P. (2013). 'You're putting thoughts into my head': a qualitative study of the readiness of patients with breast, lung or prostate cancer to address emotional needs through the first 18 months after diagnosis. *Psycho-Oncology,* 22 (6), 1402-1410.

Brazil K., Bainbridge D., Sussman J., Whelan T., O'Brien M.A. & Pyette N. (2009). Coordination of palliative cancer care in the community: "unfinished business". *Supportive Care in Cancer*, 17 (7), 819-828.

Epstein A.S. & Morrison R.S. (2012). Palliative Oncology: identity, progress and the path ahead. *Annals of Oncology*, 23 (3), 43-48.

Gao W., Bennett M.I., Stark D., Murray S. & Higginson I.J. (2010). Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications. *European Journal of Cancer,* 46 (11), 2036-2044.

Guo Z., Tang H., Li H., Tan S., Feng K., Huang Y., Bu Q & Jiang W. (2013). The benefits of psychosocial interventions for cancer patients undergoing radiotherapy. *Health and Quality of Life Outcomes,* 11 (1).

Inada M., Komatsuzaki K., Kobayashi M., Shimizu A., Kawarai-Lefor A. & Tamba K. (2016). Psychosocial Support Program for Children Who Have Parents with Cancer – Program Significance and Problems for Dissemination in Japan. *Journal of Pain and Symptom Management,* 52 (6), 92.

Lurati C., Riva M., Resega R., Mantica C., Garassino M. C., Sburlati P., La Verde N., Cinquini M., Piva S., Mencacci C. & Farina G. (2012). A mono-institutional prospective study on the effectiveness of a specialist psychotherapeutic intervention (POI) started at the diagnosis of cancer. *Supportive Care in Cancer,* 20 (3), 475-481.

Pagliuchi M., Botta C., Martellucci I., Correale P., Fruscoloni G., Celestra A., Basile A. & Maria alle Scotte S. (2011). Early Psychological Intervention in Cancer Patients: Effects on Emotional Distress. *European Journal of Cancer,* 47 (1), 308.

Pasacreta J.V. & Pickett M. (1998). Psychosocial aspects of palliative care. *Seminars in Oncology Nursing,* 14 (2), 110-120.

White K., D'Abrew N., Katris P., O'Connor M. & Emery L. (2012). Mapping the psychosocial and practical support needs of cancer patients in Western Australia. *European Journal of Cancer Care,* 21 (1), 107-116.

Yael S., Young P. S., Rachael M. & Robert M.A. (2014). Do patients with advanced cancer and unmet palliative needs have an interest in receiving palliative care services? *Journal of Palliative Medicine,* 17 (6), 667-672.

APPENDIX

1. Tabel 1: Demographics

Approach												
				Negative			Positive					
		# answers per category	Total # answers	Negative	% relative to # answers	% relative to category	Attitude of Psy	% relative to # answers	% relative to category	Expectations	% relative to # answers	% relative to category
	# Answers			3			15			12		
Sex	Man	17		1	4	6	6	21	35	8	29	47
	Woman	11	28	2	7	18	9	32	82	4	14	36
Year of birth	31-'40	4		1	4	25	2	8	50	1	4	25
	41-'50	10		1	4	10	6	25	60	6	25	60
	51-'60	6		0	0	0	3	13	50	3	13	50
	61-'70	4		0	0	0	2	8	50	1	4	25
	71-'80	0	24	0	0	0	0	0	0	0	0	0
Marital Status	Single	5										
	Living together	22	27									
Children	Yes	23										
	No	5	28									
Diploma	None	2		0	0	0	2	7	100	0	0	0
	Primary School	6		2	7	33	3	11	50	1	4	17
	Secondary School	14		0	0	0	7	25	50	7	25	50
	Higher Ed/University	6	28	1	4	17	3	11	50	4	14	67
Psych. help in past	Yes	8		1	4	13	4	15	50	4	15	50
	No	19	27	2	7	11	10	37	53	8	30	42
Diagnosis since	< 1j ago	14										
	> 1j, < 3j	8										
	> 3j ago	5	27									
Number of follow-ups	1	6		2	7	33	2	7	33	1	4	17
	> 1, <4	11		1	4	9	5	19	45	6	22	55
	> 4	10	27	0	0	0	6	22	60	4	15	40

Experiences (1)									
		# answers per category	Total # answers	Positive	% relative to # answers	% relative to category	Disappointing	% relative to # answers	% relative to category
	# Answers			18			5		
Sex	Man	17		11	39	65	3	11	18
	Woman	11	28	7	25	64	2	7	18
Year of birth	31-'40	4		2	8	0	1	4	25
	41-'50	10		6	25	60	1	4	10
	51-'60	6		4	17	67	2	8	33
	61-'70	4		3	13	75	0	0	0
	71-'80	0	24	0	0	0	0	0	0
Marital Status	Single	5		4	15	80	1	4	20
	Living together	22	27	14	52	64	4	15	18
Chrildren	Yes	23							
	No	5	28						
Diploma	None	2		2	7	100	0	0	0
	Primary School	6		3	11	50	1	4	17
	Secondary School	14		11	39	79	2	7	14
	Higher Ed /University	6	28	2	7	33	2	7	33
Psych. help in past	Yes	8		4	15	50	1	4	13
	No	19	27	13	48	68	4	15	21
Diagnosis since	< 1j ago	14							
	> 1j, < 3j	8							
	> 3j ago	5	27						
Number of follow-ups	1	6		3	11	50	3	11	50
	> 1, <4	11		5	19	45	1	4	9
	> 4	10	27	8	30	80	1	4	10

Experiences (2)									
				Role of psychologist					
		# answers per category	Total # answers	As a person	% relative to # answers	% relative to category	Psycho-education	% relative to # answers	% relative to category
	# Answers			6			6		
Sex	Man	17		3	11	18	4	14	24
	Woman	11	28	3	11	27	2	7	18
Year of birth	31-'40	4		0	0	0	1	4	25
	41-'50	10		3	13	30	1	4	10
	51-'60	6		1	4	17	2	8	33
	61-'70	4		2	8	50	1	4	25
	71-'80	0	24	0	0	0	0	0	0
Marital Status	Single	5		0	0	0	0	0	0
	Living together	22	27	6	22	27	6	22	27
Children	Yes	23							
	No	5	28						
Diploma	None	2		1	4	50	0	0	0
	Primary School	6		1	4	17	3	11	50
	Secondary School	14		3	11	21	1	4	7
	Higher Ed /University	6	28	1	4	17	2	7	33
Psych. help in past	Yes	8		2	7	25	2	7	25
	No	19	27	4	15	21	4	15	21
Diagnosis since	< 1j ago	14							
	> 1j, < 3j	8							
	> 3j ago	5	27						
Number of follow-ups	1	6		1	4	17	1	4	17
	> 1, <4	11		2	7	18	5	19	45
	> 4	10	27	3	11	30	0	0	0

Significant others									
		# answers per category	Total # answers	Positive	% relative to # answers	% relative to category	Negative	% relative to # answers	% relative to category
	# Answers			10			4		
Sex	Man	17		4	14	24	3	11	18
	Woman	11	28	6	21	55	1	4	9
Year of birth	31-'40	4		1	4	25	2	8	50
	41-'50	10		4	17	40	0	0	0
	51-'60	6		2	8	33	0	0	0
	61-'70	4		2	8	50	0	0	0
	71-'80	0	24	0	0	0	0	0	0
Marital Status	Single	5		2	7	40	1	4	20
	Living together	22	27	8	30	36	3	11	14
Children	Yes	23		7	25	30	3	11	13
	No	5	28	3	11	60	1	4	20
Diploma	None	2		1	4	50	0	0	0
	Primary School	6		1	4	17	2	7	33
	Secondary School	14		6	21	43	0	0	0
	Higher Ed /University	6	28	2	7	33	2	7	33
Psych. help in past	Yes	8		2	7	25	1	4	13
	No	19	27	7	26	37	3	11	16

Impediment (1)									
				Externally					
		# answers per category	Total # answers	Positive	% relative to # answers	% relative to category	Negative	% relative to # answers	% relative to category
	# Answers			8			1		
Sex	Man	17		5	18	29	1	4	6
	Woman	11	28	3	11	27	0	0	0
Year of birth	31-'40	4		1	4	25	0	0	0
	41-'50	10		3	13	30	0	0	0
	51-'60	6		0	0	0	1	4	17
	61-'70	4		3	13	75	0	0	0
	71-'80	0	24	0	0	0	0	0	0
Marital Status	Single	5		2	7	40	0	0	0
	Living together	22	27	6	22	27	1	4	5
Children	Yes	23		5	18	22	1	4	4
	No	5	28	3	11	60	0	0	0
Diploma	None	2		0	0	0	0	0	0
	Primary School	6		2	7	33	0	0	0
	Secondary School	14		5	18	36	0	0	0
	Higher Ed /University	6	28	1	4	17	1	4	17
Psych. help in past	Yes	8		3	11	38	0	0	0
	No	19	27	5	19	26	1	4	5
Diagnosis since	< 1j ago	14		3	11	21	1	4	7
	> 1j, < 3j	8		4	15	50	0	0	0
	> 3j ago	5	27	1	4	20	0	0	0
Number of follow-ups	1	6		1	4	17	1	4	17
	> 1, <4	11		2	7	18	0	0	0
	> 4	10	27	5	19	50	0	0	0

Impediment (2)									
				Internally					
		# answers per category	Total # answers	Positive	% relative to # answers	% relative to category	Negative	% relative to # answers	% relative to category
	# Answers			8			2		
Sex	Man	17		4	14	24	1	4	6
	Woman	11	28	0	0	0	1	4	9
Year of birth	31-'40	4		1	4	25	0	0	0
	41-'50	10		1	4	10	2	8	20
	51-'60	6		3	13	50	0	0	0
	61-'70	4		1	4	25	0	0	0
	71-'80	0	24	0	0	0	0	0	0
Marital Status	Single	5		1	4	20	1	4	20
	Living together	22	27	7	26	32	1	4	5
Children	Yes	23		7	25	30	2	7	9
	No	5	28	1	4	20	0	0	0
Diploma	None	2		1	4	50	0	0	0
	Primary School	6		1	4	17	0	0	0
	Secondary School	14		4	14	29	2	7	14
	Higher Ed /University	6	28	2	7	35	0	0	1
Psych. help in past	Yes	8		2	7	25	1	4	13
	No	19	27	5	19	26	1	4	5
Diagnosis since	< 1j ago	14		4	15	29	0	0	0
	> 1j, < 3j	8		2	7	25	2	7	25
	> 3j ago	5	27	2	7	40	0	0	0
Number of follow-ups	1	6		1	4	17	0	0	0
	> 1, <4	11		4	15	36	0	0	0
	> 4	10	27	3	11	35	2	7	20

Taboo (1)									
				Externally					
		# answers per category	Total # answers	Positive	% relative to # answers	% relative to category	Negative	% relative to # answers	% relative to category
	# Answers			4			2		
Sex	Man	17		2	7	12	2	7	12
	Woman	11	28	2	7	18	0	0	0
Year of birth	31-'40	4		1	4	25	0	0	0
	41-'50	10		1	4	10	1	4	10
	51-'60	6		1	4	17	0	0	0
	61-'70	4		1	4	25	0	0	0
	71-'80	0	24	0	0	0	0	0	0
Marital Status	Single	5		0	0	0	1	4	20
	Living together	22	27	4	15	18	1	4	5
Children	Yes	23		4	14	17	1	4	4
	No	5	28	0	0	0	1	4	20
Diploma	None	2		1	4	50	0	0	0
	Primary School	6		1	4	17	1	4	17
	Secondary School	14		1	4	7	1	4	7
	Higher Ed /University	6	28	1	4	17	0	0	0
Psych. help in past	Yes	8		2	7	25	1	4	13
	No	19	27	2	7	11	1	4	5
Diagnosis since	< 1j ago	14		2	7	14	1	4	7
	> 1j, < 3j	8		0	0	0	1	4	13
	> 3j ago	5	27	2	7	40	0	0	0
Number of follow-ups	1	6		1	4	17	0	0	0
	> 1, <4	11		2	7	18	1	4	9
	> 4	10	27	1	4	10	1	4	10

Taboo (2)									
				Internally					
		# answers per category	Total # answers	Positive	% relative to # answers	% relative to category	Negative	% relative to # answers	% relative to category
	# Answers			3			1		
Sex	Man	17		1	4	6	1	4	6
	Woman	11	28	2	7	18	0	0	0
Year of birth	31-'40	4		0	0	0	0	0	0
	41-'50	10		1	4	10	1	4	10
	51-'60	6		1	4	17	0	0	0
	61-'70	4		1	4	25	0	0	0
	71-'80	0	24	0	0	0	0	0	0
Marital Status	Single	5		0	0	0	0	0	0
	Living together	22	27	3	11	14	1	4	5
Children	Yes	23		2	7	9	1	4	4
	No	5	28	1	4	20	0	0	0
Diploma	None	2		0	0	0	0	0	0
	Primary School	6		0	0	0	0	0	0
	Secondary School	14		3	11	21	1	4	7
	Higher Ed /University	6	28	0	0	0	0	0	0
Psych. help in past	Yes	8		0	0	0	0	0	0
	No	19	27	3	4	16	1	4	5
Diagnosis since	< 1j ago	14		0	7	0	0	0	0
	> 1j, < 3j	8		2	0	25	1	4	13
	> 3j ago	5	27	1	7	20	0	0	0
Number of follow-ups	1	6		0	4	0	0	0	0
	> 1, <4	11		1	0	9	0	0	0
	> 4	10	27	2	11	20	1	4	10