

**Deficits in psycho-oncological care among Turkish immigrant women with breast cancer in  
Germany – an interview study.**

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**Abstract**

**Objective:** Aim of this study was to assess appraisal and utilization of psycho-oncological care of Turkish female breast cancer patients in Germany. The presented results are part of a larger study about care of female German and Turkish cancer patients in Germany (4B-study).

**Methods:** In this qualitative study semi-structured face to face interviews were conducted with Turkish breast cancer patients in Germany. Interviews were transcribed and analyzed in Turkish by two Turkish speaking researchers via content analysis using MAXQDA qualitative analysis software (version 11). Results were discussed among a bilingual research team. Selected citations were translated.

**Results:** Turkish patients showed a great need for support, particularly emotional and informational support. However, the available psycho-oncological care was rarely used due to lack of information, prejudice, language and cultural barriers. A missing belief in effectiveness of psycho-oncological care was also noted.

**Conclusions:** According to this study, psycho-oncological services do not adequately correspond to the needs of Turkish breast cancer patients. If confirmed in more extensive studies, these findings call for the development of migrant-sensitive approaches and therapeutic action to provide ease to cancer patients. Additionally, prejudice against psycho-oncological care needs to be reduced in the Turkish community.

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## Introduction

In 2016, 18.6 million persons with migration background (22.5%) lived in Germany of which the Turkish migrants form one of the biggest group, with 2.8 million persons<sup>1</sup>. Breast cancer is the most common cancer among women in Germany<sup>2</sup>. So far, breast cancer risks of Turkish women have been estimated to be lower than those of women of Western European origin<sup>3</sup>. Even though lower risks for breast cancer among Turkish female migrants of the first generation compared to the non-migrated female population have been observed in Germany this risk advantage disappears in the following generations<sup>4</sup>. In the next years, the number of older Turkish migrants in Germany will increase substantially and hence the number of Turkish migrant women with breast cancer.

The diagnosis of cancer evokes emotional and psychological reactions which are mostly part of the normal coping process after diagnosis<sup>5</sup>. However, a considerable part of patients develops psychological disorders. It is estimated that 21 to 43% of cancer patients are diagnosed with one or more psychological comorbidities<sup>6-10</sup>. The most common psychological comorbidities are adjustment and anxiety disorders and depression<sup>5</sup>. The proportion of psychological comorbidities differs vastly among studies. According to a systematic review, the 4-week prevalence of anxiety disorders is 14%, 11% for affective disorders including depression, and 8% for adjustment disorders among all cancer patients in Germany<sup>11,12</sup>. Studies with information about migration status are missing. Studies from Turkey report higher rates of anxiety disorders (62%-80%) and depressive symptoms (81%-88%) among female cancer patients<sup>13,14</sup>. Although these results should be interpreted cautiously, they might indicate that women with a Turkish migration background have other preconditions for coping with a severe illness such as breast cancer as compared to women from Western cultures. For example, medical doctors and family members in Turkey and other Eastern and Southern European countries often do not disclose the cancer diagnosis to the patient<sup>15,16</sup>. This custom also highlights the role of the family in the treatment process which differs from the role of the family of German cancer patients.

In Germany, psycho-oncological care is already well established in some hospitals, especially in certified

breast centers (CBC) where psycho-oncological care is mandatorily offered<sup>17</sup>. Studies on psycho-oncological care for patients with a migration background are largely missing except for a recent study by Zeissig et al. where no differences in utilization of psychosocial care were detected when comparing cancer patients from different ethnic origins<sup>18</sup>. In Australia, Butow and colleagues identified language and cultural barriers leading to unmet informational, emotional and support needs among Chinese, Greek and Arabic speaking migrants in the oncologic setting<sup>19-21</sup>.

This article reports selected results from a larger qualitative study (4B-study) investigating perceptions of breast cancer and expectations towards medical and psycho-oncological care among female German and Turkish breast cancer patients as well as healthy women. The aim of this paper is to describe need, utilization and appraisal of psycho-oncological care by Turkish female breast cancer patients in Germany.

## Materials and Methods

### *Participant recruitment and data collection*

We sampled female breast cancer patients whose mother language is Turkish. The patients were recruited at two different stages in their treatment process. Inclusion criteria for the first stage were that the patient should be diagnosed with breast cancer for the first time and the time of diagnosis should not be longer than 3 months prior to enrollment. For the second stage, patients were included while they were in the rehabilitation process after having completed the initial treatment.

Potential Turkish participants were contacted at one CBC and one rehabilitation clinic in Germany. In the CBC, participants were recruited by a case manager. German or Turkish informational material was provided. Interested patients signed consent to be contacted by phone for further information and eventually to make an appointment for an interview at a place of choice. Interviews were done by one female Turkish research team member (YYA, PhD) experienced in qualitative methodology. Only one participant could be recruited in the CBC (n=1) over the time span of 12 months. In the rehabilitation clinic, a medical doctor recruited eligible participants. German or Turkish informational material was given and when the patient was willing to participate,

an appointment was arranged during the patient's stay. The interviews took place in the clinic (n=5).

As indicated, recruitment via medical centers turned out to be inefficient. Hence, a different recruitment strategy was applied. Further Turkish participants were recruited using key persons in social networks<sup>22</sup>. Here, key persons in the Turkish communities were a leader of a self-help group, an organizer of a neighborhood initiative, and a Turkish medical doctor. Study information and informed consent with contact data was handed out by the key persons to female Turkish persons known to have or have had breast cancer. The inclusion criteria to classify participants into first stage and second stage patients (1<sup>st</sup> diagnosis, time of diagnosis < 3 months or being in the rehabilitation process) were abandoned. The women could either contact the researcher (YYA) directly or provide a phone number. The interviews took place mostly at the participants' home or in the context of neighborhood initiative meetings (n=12).

Before the interviews took place, potential participants received full study information, and written informed consent was obtained. We used semi-structured face-to-face interviews focusing on several topics such as illness perceptions, treatment expectations and psycho-oncological care. The semi-structured guideline was developed in German language by an interdisciplinary team including researchers from various fields, i.e. pedagogy, health sciences, and one breast cancer patient. Questions related to psycho-oncology cover need, knowledge, utilization, content, attitude and appraisal of psycho-oncological care. After finalization, the guideline was translated and pretested in Turkish language with one Turkish breast cancer patient who had terminated cancer treatment. Minor adaptations such as rearrangement of questions and words were made. Socio-demographic data were recorded before or after the interview in a separate sheet. Field notes were marked in a postscript. Information about non-responder was not obtainable as potential participants were approached indirectly via key persons. During one interview a relative was present as requested by the participant. All other interviews were conducted without other persons being present.

This study was approved by the ethics committee of the Medical Council of Westphalia-Lippe and the

Medical School of the University of Münster, and by the ethics committee of the University of Bremen.

### *Analysis*

Interviews were audio-taped and transcribed in Turkish. Transcripts were anonymized during transcription. For the analysis, we applied the method of qualitative content analysis according to Mayring<sup>23</sup>. The method allows to work deductive as well as inductive and thereby to assess all issues related to our research questions. We entered MS Word 2010 files of transcribed interview into MAXQDA qualitative analysis software (version 11)<sup>24</sup> which facilitates the categorization and the organization of codes and categories. Overall, four researchers (LS, YYA, YG, FKE) were involved in the categorization process of whom two Turkish-speaking researchers (YYA, YG) categorized the Turkish interviews. During the categorization process the four researchers discussed and unified the categories regularly in order to simplify the comparison between all participants.

Finally, three researchers (LS, YYA, YG) discussed meanings of unclear text passages, as well as resemblances and variations of Turkish and German participants in regular analysis team meetings. Only selected citations were translated. For this paper, Turkish citations were translated from German into English and rechecked with the Turkish original citations.

### **Results**

Overall, we conducted 18 interviews with Turkish breast cancer patients between February 2013 and February 2014. On average, the duration of the interviews was 45 minutes.

Table 1 summarizes the demographic information. Participants had been diagnosed 3 months to 2.6 years before the interview. The age range was 30 to 73 years (median 53.5 years). Overall, the educational level was rather low: More than half of the Turkish participants (11 of 18) had either no education or an educational level of elementary school. Almost all participants were married (16 of 18) and had zero to five children; the majority had three or more children. Most of the participants have been living in Germany for a long time (range 5 to 43 years, median 36.5 years). As the recruitment of Turkish participants who were recently diagnosed failed, results are reported irrespective of the time of diagnosis.

**Table 1:** Demographics of Turkish study participants with breast cancer (n=18).

<b>Age</b>	Range:	30-73 years
	Median:	53.5 years
<b>Time since diagnosis</b>	Range:	3-44 months
	Median:	12.5 months
<b>Education</b>	None:	3
	Elementary:	8
	High school or higher:	7
<b>Marital status</b>	Married:	16
	Divorced/widowed:	2
	Single:	-
<b>No. of children</b>	0:	1
	1-2:	6
	3 or more:	11
<b>Years lived in Germany</b>	Range:	5-43 years
	Median:	36.5 years

### Need for support

Assuming that a felt need for support builds a basis for patient-driven utilization of psycho-oncological services, statements of participants on a subjective need for support are presented initially.

Turkish participants described numerous worries and anxieties related to their illness, their coping with the disease and the consequences of breast cancer, i.e. cancer recurrence and side effects of cancer treatment. In relation to that, the participants showed a large need for information on breast cancer: Some women were not able to describe their diagnoses and thus worried about what they had to expect, i.e. long term consequences of the disease.

*"I have many questions in mind. Whether this illness can really be bettered or can you die of it. I have big problems, a human wants help."*(ITRR5)

*"I have no information; I don't know anything about it [the disease]."*(ITTR4)

Furthermore, participants worried about the future of their children and coping with the challenges of the everyday life. Some of the participants described a state of depressiveness, i.e. they tried to suppress their illness but did not succeed and, in consequence, felt worse.

*"I don't know what to do. How can I throw away the sorrow in me? I need a lot of support. I want to get strong. I don't want to tell others my worries but still I do. I want to leave this behind and turn over a new leaf."*(ITRR5)

*"I have been suffering since then. I refused to accept my disease. I thought about other things. Now I suffer from depression."*(ITRR1)

Some participants mentioned a need for support in specific phases of the treatment process, i.e. after the surgery.

*"After the surgery I would have wanted someone [to talk to]. I felt such a need."*(ITRR1)

*"I think of it [breast cancer] especially when I am alone at home. It comes to my mind that I am ill. There is no one I can talk to about that."*(ITRA2)

Many statements indicate that they feel alone with their disease and related questions and problems.

Even though for Turkish participants the family has an important function during the treatment process, support from the family was not perceived as positive or sufficient from all participants. Mostly, the family attends to the woman morally, trying to make her forget her disease i.e. by going for a walk or meeting grandchildren. Partners or children go along with the women to consultations and treatments in order to translate between the patient and the medical staff as some participants lacked fluency in the German language. However, also feelings of not being understood or not being taken seriously and fear of stigmatization were described. In addition to that, not wanting to burden the family is an important issue for Turkish participants so that some concerns are not communicated within the family.

*"They take an effort to support me morally and make me feel good."*(ITRR3)

*"You can talk about some issues with family and friends until a certain point and not more."*(ITRA5)

*"I tell my family that they do not take my disease seriously. They say that I have talked enough about it and that I should not think about it anymore. They may think of this as easy. If you do not experience it you do not know what it is like."*(ITRR6)

Some participants also experienced negative or inconsiderate comments in their social environment which led to a social retreat.

*"The reasonable people react normally. Others say: 'Poor she, she will die soon, too bad for her husband.'. My neighbors came to the hospital and said: 'Too bad for your husband, he will be lonely, after you. Tell your sons to let him remarry.'"*(ITRR1)

### Knowledge of psycho-oncological care

Most participants knew the possibility of psycho-oncological care. Sources of information were psycho-oncologists, doctors, relatives (primarily daughters) or written information. Some patients stated that they did not know this offer or got to know about it late in the treatment process.

*"They came when I was in the hospital. I think there was also a psycho-oncologist."*(ITRR3)

*"My physician recommended it. He said that it would be good for me."*(ITRA2)

*"No one came to me."*(ITRR4)

However, the statements of some participants indicate that they did not understand the objective of psycho-oncological care and confounded it with psychiatric treatment. In fact, participants confounded psycho-oncology and psychology in the sense that they only said "psychology" or "psychologist" in any context. Some did not use these words and said "it", "that" or "they" instead, like participants avoided to say "breast cancer". In consequence, psycho-oncological services were perceived only useful for persons with psychiatric disorders.

*"Persons who have mental problems should go there, shouldn't they? If they have this illness, depression, they should go there."* (ITRR8)

#### Utilization of psycho-oncology

Turkish participants did not clearly state whether or not they used the option of psycho-oncology. Still, it seems that most of the participants had at least one initial contact to a psycho-oncologist but then refused further care due to various reasons. One participant did not get the information of psycho-oncological care which she regretted. Most often, Turkish breast cancer patients stated that due to language and cultural barriers they could not take advantage of psycho-oncological care. Some participants only speak broken German so that they cannot express their feelings and worries and vice versa do not understand the psycho-oncologist properly.

*"The person who comes to me will only speak German. If I do not understand him properly, just listen and do not understand, this makes no sense."* (ITRR4)

*"We tried to talk about half an hour, we could not go on because we could not communicate, because the conversation stayed superficial, we could not get any deeper."* (ITRA6)

Even those participants who speak German have their doubts about communicating with German psycho-oncologists as the cultural norms and values differ vastly, i.e. the role of the family. Some participants give examples which show that the advice given by a German psycho-oncologists or previously attended psychologists does not fit to the real world of Turkish breast cancer patients.

*"A German would not understand my culture. This is why I do not want to go to a German [psycho-oncologist]."* (ITRR3)

*"I understand German just like Turkish. Still there are differences. There are other customs."* (ITRR8)

*"I talked to a psychologist here [in the rehabilitation clinic]. She said that I should feel at ease, that I should unwind. I cannot do so. I think of my home. I think of my children."* (ITRR8)

*"She gave me relaxation music. I have no use for that."* (ITRA2)

Some women did not see the need for psycho-oncological help or did not want to talk about breast cancer as it would upset them and make them re-experience their suffering from breast cancer. Nevertheless, some women said that if they had felt such a need, they would have asked to talk to a psycho-oncologist.

*"I told her that I do not want to talk much about it. I do not want to be reminded of it. I try to forget."* (ITRR4)

*"I did not see a need. If I had seen a need I would have gone there."* (ITRR7)

Other participants refused psycho-oncological care because of prejudice or negative attitudes towards psychological care in general. Even though these participants did not state clearly that they have prejudices they found reasons against psycho-oncological care which might indicate that they have a low estimation of psycho(-onco)logical care, i.e. having no time.

*"The person who is faithful does not need such a doctor."* (ITRA4)

*"Many other appointments come."* (ITRR8)

#### Appraisal of psycho-oncological care

Most comments on psycho-oncological care were rather negative except for one participant who appreciated the care she received.

*"I liked that she took care of me."* (ITRR7)

Turkish participants criticized mostly that their expectations were not met or the language and cultural barriers prevented them from effective psycho-oncology. Expectations from Turkish patients were to get help or advice for everyday life, to be relieved from worries and mental suffering, and to get help for coping with breast cancer and its consequences. Considering these unmet expectations, many Turkish patients asked for Turkish psycho(-onco)logists.

*"My expectations were different. The psycho-oncological care you do not render assistance for everyday life."* (ITRR5)

*"I thought that she could help me get rid of the things in my mind. But so far I do not see that help."* (ITRR6)

*"I would be so happy to find a Turkish psychologist and to tell it all and to understand all, too."* (ITRR10)

*"Psychologists are missing; there should be more Turkish psychologists here and overall in Germany. They are really needed."* (ITRR2)

## Discussion

This qualitative study is among the first to explore the need, utilization and attitudes towards psycho-oncology among Turkish breast cancer patients in Germany. While the results are specific to the care context in Germany, we believe that some general lessons regarding psycho-oncology in cancer care for Turkish migrants irrespective of country may be drawn from our findings.

To summarize, Turkish participants showed a need for support, notably informational and emotional support. Turkish participants face barriers which prevent them from psycho-oncological care. First, due to the language barrier the communication between patient and psycho-oncologist is impossible or stays at a superficial level. Second, cultural differences between the patient and the psycho-oncologist might lead to misunderstandings or advice given by the psycho-oncologist which does not fit into the daily life of the patients. Due to negative experiences with psycho(-onco)logical care, some participants did not believe in its effectiveness. Third, some Turkish patients did not understand the objective of psycho-oncology and/or had prejudices in mind. However, few participants showed a high level of suffering and therefore openness towards psychological help in general.

These results are somewhat paradoxical. On the one hand, the results clearly show a need notably for emotional and informational support among participants. On the other hand, psycho-oncological care was not used although it – in principle – directly aims to cover the needs the participants expressed. Thus, psycho-oncological care as assessed in our study does not adequately correspond to the needs of Turkish participants yet.

The subsequent claim of the participants for Turkish psycho(-onco)logists is a classical migrant or culture specific intervention and fits into a current discussion on how to deal with culturally diverse patient groups. A different approach is to provide culture-sensitive care within the usual health services, i.e. diversity management<sup>25,26</sup>. Even though evaluation studies are scarce, culture-sensitive interventions are mostly preferred considering practicability and financial feasibility.

Our results suggest changes on both, the provider's and the beneficiary's sites, i.e. by offering culture sensitive psycho-oncology, a better and culture-adapted clarification of the purpose and content of psycho-oncological care as well as actions for a change of mind regarding psychological care in general in the Turkish community.

An earlier study in Germany detected no differences in utilization of psychosocial and informational services between immigrant and non-immigrant cancer survivors<sup>18</sup>. Equally, in our study most of the Turkish participants had at least one contact to a psycho-oncologist. However, Turkish participants did not benefit from psycho-oncological care as it was not used beyond an initial contact partly due to prejudices or a missing belief in the effectiveness of psycho-oncological care. In conclusion, the attitude towards and appreciation of psycho-oncological care is crucial for effective utilization.

Our findings confirm an earlier study<sup>27,28</sup> which showed a less positive attitude towards psychotherapy among young Turkish adults living in Germany compared to young German adults. The sex and the grade of acculturation moderated the attitude<sup>27</sup>. In a systematic review<sup>28</sup>, further determinants of attitude towards seeking psychological help were sociodemographic variables, fluency of the host country language, and psychological attributions of distress. A study on Moroccan and Turkish migrants in the Netherlands stressed the impact of sociodemographic factors rather than ethnicity<sup>29</sup>.

The low level of information about their disease among Turkish breast cancer patients might be due to the low educational level, poor language proficiency, and the cultural habit that the diseased person is not told the truth about his or her disease<sup>15</sup>. Furthermore, the caregivers' attitude, lacks of effort to provide information and of cultural understanding may also contribute to an overall low level of disease knowledge in these patients.

Similar results could be ascertained among Turkish immigrants in Germany with Diabetes mellitus type 2 who showed lower disease knowledge and outcome quality despite more diabetes training compared to a non-immigrant sample of type 2 diabetics<sup>30</sup>. Informational needs on the disease and the health system were also detected in Australian migrant studies which mostly were related to poor proficiency of the language of the host country<sup>20,19</sup>.

This study has some limitations. First, as the results of this study are generated by qualitative interviews this sample does not necessarily reflect Turkish or other migrant female cancer patients in general. Hypotheses derived from this study therefore should be tested in a larger sample. Second, it was not possible to recruit Turkish cancer patients recently diagnosed so that differences in utilization and appraisal of psycho-oncological care at the beginning and the end of the intense cancer treatment could not be compared. We assume that differences exist according to the phase of cancer treatment. For this reason, it is worthwhile that different phases of the treatment course are reflected in future studies. Third, bilingual research projects face the problem of lost information due to translation. The meaning of expressions and underlying social constructs might differ between cultures and thus might be interpreted differently. For example, in this study, Turkish participants wished to 'relax' in the psycho-oncological setting which initially would not be defined as an objective of psycho-oncology. However, this expression might contain more meaning for Turkish participants. A methodology to address this problem is missing but should be developed for future bi- or multilingual health research projects.

## Conclusion

To conclude, valuable information on the situation of Turkish breast cancer patients in Germany could be ascertained which indicates a need for improvement in psycho-oncological care in societies characterized by population diversity. Further studies should test our results, investigate other immigrant populations and if necessary develop and evaluate interventions for better psycho-oncological care of immigrants.

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## Conflict of interest

The authors have declared no conflict of interest.

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