



The Need for Information and Support among First-degree Relatives of Patients with Breast Cancer What Do We Know?

Meme Kanseri Olan Hastaların Birinci Dereceden Akrabalarının Bilgi ve Destek Gereksinimi: Ne Biliyoruz?

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ABSTRACT

Objective: Since first-degree female relatives (FDFRs) of women with breast cancer (BC) also have a high risk of developing BC, providing them information and support is important and this should not be overlooked. The purpose of the study is to determine the needs of primary relatives of women with BC in Turkey for information and support.

Methods: This article is a descriptive research. A total of 199 volunteer relatives of patients with BC were reached and interviewed by nurses in a university hospital's oncology clinic. They completed the Information and Support Needs Questionnaire. Parametric, non parametric, and multiple regression tests were used in statistical analysis.

Results: In the study, a statistically significant difference was observed between the information and support needs and demographics of FDFRs ($p<0.05$). The rate of information need was higher among those who had a risk of BC and who practiced protective behaviors regularly. And also the rate of unmet support need was higher among those who had a risk of BC and who did not practice protective behaviors ($p<0.05$). The need for information and support is increasing in the FDFRs of women with BC whose diagnosis time prolonged.

Conclusion: This study showed that FDFRs of patients with BC needed information and psychosocial support. Nurses should have an important role in communicating with relatives of patients with BC.

Keywords: Breast cancer, information and supports, primary relatives, nursing

ÖZ

Amaç: Meme kanseri (MK) olan kadınların birinci derece kadın akrabaları da (BDKA) MK'ye yakalanma konusunda yüksek risk potansiyeli taşıdıkları için onlara bilgi ve destek sağlamak önemlidir ve onlar göz ardı edilmemelidir. Bu çalışmanın amacı, Türkiye'deki MK'li kadınların BDKA'nın bilgi ve destek ihtiyaçlarının belirlenmesidir.

Yöntemler: Bu makale tanımlayıcı bir araştırmadır. Toplamda 199 gönüllü akrabaya hastalar aracılığıyla ulaşılmış ve bu akrabalarla bir üniversite hastanesinin onkoloji kliniğinde çalışan hemşireler görüşme yapmıştır. Katılımcılar Bilgi ve Destek Gereksinimleri Ölçeği-Türkçe Formu'nu doldurdu. İstatistiksel analizde parametrik, non-parametrik ve çoklu regresyon testleri kullanıldı.

Bulgular: Çalışmada BDKA'nın demografik özellikleri ile bilgi ve destek ihtiyaçları arasında istatistiksel olarak anlamlı bir fark saptandı ($p<0,05$). MK riski taşıyan ve düzenli koruyucu davranışlar sergileyenlerde bilgi ihtiyacı oranı daha yüksekti. Ayrıca MK riski taşıyan ve koruyucu davranışlar uygulamayanlarda karşılanmamış destek ihtiyacı oranı daha yüksekti ($p<0,05$). Teşhis süresi uzamış olan MK'li kadınların BDKA'nın bilgi ve destek ihtiyacı artmaktadır.

Sonuç: Bu çalışma, meme kanseri hastalarının BDKA'nın bilgi ve psikososyal destek ihtiyacı olduğunu göstermiştir. Sağlık hizmetinde görev alan hemşireler, MK'li hastaların BDKA ile iletişimde önemli bir role sahip olmalıdır.

Anahtar Sözcükler: Meme kanseri, bilgi ve destek, birinci derece akraba, hemşirelik

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Introduction

Breast cancer (BC) in the world and in Turkey, is the most common cancer in women (1,2) BC affects about 2 million women every year in the world and is the leading cause of cancer-related deaths in women. In the WHO 2018 data, it was reported that approximately 627 thousand women died due to BC, and this rate constitutes 15% of all cancer-related deaths. BC rates in developed countries continue to increase as all over the world (1).

One of the most important risk factors of BC especially in is the history of BC in the first degree female relatives (FDFRs), especially in mothers, sisters or daughters (3). BC due to genetic predisposition is seen in one-ninth and 5-10% of women with BC in FDFRs. Genes that increase BC risk are BRCA1 and BRCA2 (4-6).

Women at risk who have BC in FDFRs may experience mental problems such as psychological distress, anxiety and fear (7,8). Approximately 7% of women who are diagnosed as having BC are younger than 40 years of age (9). Based on the rapidly increasing incidence between 25 to 40 years of age, e.g., when a woman is diagnosed as having BC in her 30s, her FDFR should be aware that they may develop BC nearly 8 to 10 years earlier than her diagnosis age (10). While BC was seen in 4.9% of women aged 15-24 years in our country, it was seen in 33.7% of the age group of 25-49 years. Moreover, 45% of women who were diagnosed as having BC were between the ages of 50-69 years and 40% of them were between the ages of 25-49 years (2). Accordingly, it is important to provide guidance on this issue to primary relatives to bring awareness with respect to early screening tests, a healthy lifestyle, and psychosocial support for women in their 20s.

After a cancer diagnosis, some family members already have a high awareness comparable to that of patients with cancer so that they can make healthy lifestyle changes, while some of them do not (11). FDFRs need to be motivated by the possibility of a cancer diagnosis so that they can make healthy lifestyle changes and participate in screening programs rather than experience the challenges that may occur when these changes are not made (12,13).

This study aimed to determine the FDFRs of women with BC information and support needs in Turkey. We are also looking for answers to the following questions: What is the effect of having a hereditary risk for BC and the development status of protective behaviors on information and support needs? What are the effects of socio-demographic features on information and support needs?

Methods

Design

First-degree female relatives (mother, sisters and daughters) were reached for a cross-sectional, descriptive and non-experimental study through patients (n=199) who were under treatment for BC and participated in a survey. The survey sample was calculated using a sample size calculations formula with 95% confidence intervals.

Participants

Nurses of the university hospital interviewed the volunteering patients in the oncology clinic of Pamukkale University Hospital in Turkey. After approval was obtained from the Ethics Committee, a total of 199 FDFRs agreed to participate and signed the informed consent before completion of the surveys. Women over 18 years of age and not previously diagnosed as having BC were included in the study. Data were collected through a Demographic Questionnaire, the ISNQ and the BRAC tools.

Instruments

Demographic Questionnaire

We administered a structured questionnaire that included questions on the following: education, age, number of live births, kinship relations, marital status, biopsy status, menopausal status, breastfeeding, perceived risk of BC. In addition to the potential cancer risk, the respondents were evaluated through a description of their perceived state: "Yes, I am at risk", "No, I am not at risk" or "I do not know".

The Information and Support Needs Questionnaire (ISNQ)

This questionnaire was developed by Chalmers et al. (14) to understand the information and support needs of women who had a family history of BC. This questionnaire is composed of two scales: 1- The importance scale, which contains 18 informational and 11 support items, is evaluated according to a four-point Likert-type scale (4- very important, 1- not important at all); 2- The needs met scale contains twenty-nine items that address whether needs are met, (1 -not met at all to 4- met fully). The Turkish validity and reliability study of the scale was conducted by Aslan and Ceber (15).

BCRA-Breast Cancer Risk Assessment Tool

This interactive tool was developed by Gail et al. (16) to determine the risk factors for the development of BC in women within the next five-year period of their lives and during their lifetimes. BRCA is used in risk calculation for women aged 35 and over. This tool is useful for the estimation of women with a lifetime risk of BC $\geq 20\%$ (17). Moreover, an estimated 5-year BC risk $\geq 1.67\%$ is considered high (18).

Statistical Analysis

Independent Samples t-test, Mann-Whitney U test, Kruskal-Wallis test or one-way ANOVA were used for continuous variables. Multiple logistic regression analysis was used to see the effect of dependent variables on information and support scores. $P < 0.05$ was considered significant in all statistical tests.

Results

The 199 women were FDFRs of patients with breast cancer: 125 were mothers (62.8%), 53 were sisters (26.6%), and 21 were daughters (10.6%). The mean age was 34.48 ± 10.14 years (minimum: 18; maximum: 58) (Table 1).

When the information and support needs of the study group were evaluated, the five most significant items were determined to be; information about ways that could help decrease the suffering of relatives with BC (3.60±0.82), information about the treatments of BC (e.g., radiation, chemotherapy, side effects) (3.59±0.75), information about the emotional reactions of women who were newly diagnosed as having BC (3.58±0.78), information about how to support relatives during their experience with BC (3.57±0.79) and information on and a demonstration of a BC examination (3.54±0.81). The five most important items within the “needs met” scale were; information about the treatments of BC (e.g., radiation, chemotherapy, side effects) (2.96±1.06), information about the causes of BC (2.86±1.03), information on and a demonstration of BC examination (2.83±1.05), information about how to support relatives during their experience with BC (2.82±1.00), and information about the emotional reactions of women who were newly diagnosed as having BC (2.81±1.02) (Table 1).

When the importance of information and support needs of FDFRs was evaluated based on their socio-demographic characteristics, it was found that FDFRs who were aged 40 years or older had higher information needs than the other two groups (p=0.032). Those who were widowed and divorced had a greater need for information than single FDFRs (0.042), and those who were graduates of elementary school had a greater need for information than those who were graduates of middle school (p=0.022). Unemployed FDFRs had a greater need than employed FDFRs (p=0.002), and menopausal women had a greater need than women who were not in menopause (p=0.000). The differences between groups were found to be statistically significant (Table 1).

When needs met were evaluated based on the socio-demographic characteristics of FDFRs, it was found that support needs were not met among the 31-40 year-old group compared with the other age groups (p=0.000) and among the relatives with secondary education (p=0.028) and higher education (p=0.018) groups compared with the relatives with the primary education group. The differences between these groups were statistically significant, but no statistically significant differences were observed between the other variables and the importance and needs met (p>0.05) (Table 1).

When the status of FDFRs was evaluated with respect to their risk for BC and the adoption of preventive behavior, it was determined that the need for information was higher among those whose mothers had cancer than in those whose sisters had cancer (p=0.000). The need was also higher in those who were diagnosed after 40 years of age compared with those who were diagnosed before 40 years of age (p=0.042) and in those whose duration of diagnosis was more than one year compared with those whose duration was less than one year (p=0.033). The need for information was also higher in those who had education/information about BC than in those who did not (p=0.003) and in those who performed breast self-examinations than in those who did not (p=0.005). Finally, the need was higher in those who underwent mammography than in those who did

not (p=0.038), in those who underwent a breast examination by a healthcare professional (e.g., doctor, nurse, midwife) than in those who did not (p=0.002) and in those who stated that “presence of BC among my relatives creates a risk for me” than in those who stated “I do not know” (p=0.003). These differences were found to be statistically significant (Table 2).

When the status of FDFRs was evaluated with respect to their risk of BC and the adoption of preventive behavior, and when their effects on needs met were examined, it was found that support needs were not met among the women whose duration of diagnosis was less than one year compared with those whose duration of diagnosis was more than one year (p=0.001). Support needs were also not met in those who performed breast self-examinations compared with those who did not (p=0.001)

Table 1. Socio-demographic characteristics of the study group and their information and support needs

	Importance n=199	Needs met n=199	P value
Age group			
18-30 (69)	3.26 (0.82)	2.78 (0.77)	IN:0.005 SN:0.000
31-40 (67)	3.17 (0.87)	2.14 (0.74)	
40 or over (63)	3.59 (0.51)	2.77 (0.99)	
Marital status			
Single (64)	3.17 (0.80)	2.62 (0.82)	IN:0.042 SN:0.517
Widowed/divorced (135)	3.41 (0.74)	2.54 (0.92)	
Education level			
Primary (10)	3.85 (0.23)	3.32 (1.08)	IN:0.002 SN:0.025
Secondary (93)	3.17 (0.88)	2.56 (0.76)	
University (96)	3.43 (0.66)	2.52 (0.95)	
Work status			
Housewife (88)	3.53 (0.49)	2.51 (0.88)	IN:0.002 SN:0.391
Outside work (111)	3.18 (0.91)	2.62 (0.89)	
Income status			
Low (40)	3.20 (0.78)	2.36 (0.83)	IN:0.094 SN:0.141
Middle (123)	3.33 (0.82)	2.70 (0.86)	
High (36)	3.52 (0.53)	2.36 (0.98)	
Status of live birth			
Yes (127)	3.36 (0.76)	2.60 (0.92)	IN:0.502 SN:0.419
No (72)	3.29 (0.79)	2.50 (0.83)	
Biopsy history			
Yes (13)	3.56 (0.28)	3.05 (0.44)	IN:0.948 SN:0.078
No (186)	3.32 (0.79)	2.53 (0.90)	
Menopause			
Yes (29)	3.74 (0.36)	2.87 (1.12)	IN:0.000 SN:0.065
No (170)	3.27 (0.80)	2.51 (0.84)	
Breastfeeding			
Yes (124)	3.35 (0.77)	2.64 (0.91)	IN:0.766 SN:0.149
No (75)	3.31 (0.78)	2.45 (0.85)	

IN: Information needs, SN: Support needs

Table 2. Protective behavior development in first degree female relatives of patients with breast cancer and their information and support needs

	Importance n=199	Needs met n=196	P value
Family relationship			
Mother (125)	3.43 (0.82)	2.63 (0.91)	IN:0.000 SN:0.168
Sister (53)	3.14 (0.67)	2.35 (0.86)	
Daughter (21)	3.25 (0.61)	2.67 (0.79)	
Age at diagnosis in relatives			
30-40 age (64)	3.17 (0.80)	2.62 (0.82)	IN:0.042
41 age and (135)	3.41 (0.74)	2.54 (0.92)	SN:0.517
Time of diagnosis (month)			
12 and (112)	3.24 (0.93)	2.38 (0.89)	IN:0.033
13 and (87)	3.46 (0.48)	2.79 (0.84)	SN:0.001
Education/information retrieval related on breast cancer and breast self-examination (BSE)			
Received (132)	3.45 (0.60)	2.65 (0.84)	IN:0.003
Not received (67)	3.10 (0.99)	2.39 (0.97)	SN:0.064
Information/instruction request on early diagnosis of breast cancer and BSE			
Willing	3.51 (0.54)	2.67 (0.83)	IN:0.000
Unwilling	3.03 (0.99)	2.40 (0.96)	SN:0.047
BSE			
Performed	3.47 (0.64)	2.75 (0.91)	IN:0.005
Did not perform	3.17 (0.87)	2.34 (0.82)	SN:0.001
Breast examination made by health personnel (doctors, nurses, midwives, etc.)			
Underwent (70)	3.56 (0.46)	2.87 (0.90)	IN:0.002
Did not undergo (129)	3.21 (0.87)	2.40 (0.84)	SN:0.000
Mammography			
Underwent (49)	3.50 (0.54)	2.74 (0.87)	IN:0.038
Did not undergo (150)	3.28 (0.83)	2.50 (0.89)	SN:0.095
Perceived cancer risk since has a primary relative with BC			
Yes (150)	3.48 (0.49)	2.55 (0.90)	IN:0.003 SN:0.326
No (6)	3.27 (0.56)	3.37 (0.00)	
I do not know (43)	2.83 (1.09)	2.56 (0.87)	
Five-year risk			
No (76)	3.49 (0.48)	2.47 (0.77)	IN:0.060
Yes (31)	3.67 (0.42)	2.71 (1.20)	SN:0.318
Lifetime risk			
No (97)	3.53 (0.48)	2.50 (0.94)	IN:0.755
Yes (10)	3.59 (0.32)	2.97 (0.48)	SN:0.164

IN: Information needs, SN: Support needs, BC: Breast cancer, FDFR: First degree female relatives

and in those who did not undergo breast examination by a healthcare professional (e.g., doctor, nurse, midwife) compared with those who did ($p=0.000$). These differences were found to be statistically significant (Table 2).

At the end of the multiple regression analysis in which importance was the dependent variable, the F value of 4,399,

which tested the overall significance of the regression model, and the F statistic, which was calculated as $p=0.000$, were found to be significant. As the duration of BC diagnosis in their relatives increased, importance also increased among FDFRs; it was determined that importance decreased among FDFRs who were not in menopause and whose sisters and daughters were

diagnosed as having cancer. It could be stated that variables such as age, education and age of the relatives at diagnosis did not have a significant effect at the significance level of 0.05 (Table 3).

As a result of the multiple regression analysis using needs met as the dependent variable, the F value of 3,659, which tested the overall significance of the regression model, and the F statistic, which was calculated as $p=0.002$, were found to be significant. As the duration of BC diagnosis increased, needs met also increased. It could be stated that variables such as age, education, degree of kinship and the age of the relatives at diagnosis did not have a significant effect at the significance level of 0.05 (Table 3).

Discussion

The findings from this study determined the most important issues for the guidance of FDFRs with respect to their BC risk. The risk of the development of cancer was found to be increased 2-fold among the women whose first-degree relatives such as mother, sister or daughter had BC; moreover, the risk was increased 3-4 fold among women with two or more relatives diagnosed as having BC (14,19,20). The importance of the detection of the information and support needs of first-degree relatives of women with BC, and of meeting these needs during primary prevention has been previously reported (14,20-22).

Out of the 29 items of importance that were identified, the five most important subjects that were selected by the participants were: genetic counseling for themselves and their daughters, ways to help decrease the suffering of a relative with BC, treatments for BC, emotional reactions of women who were newly diagnosed as having BC, and side effects of BC treatments. Among the 29 items for needs met that were identified, the five most important items that were chosen by the participants were: treatments for BC, causes of BC, side effects of BC treatments, support for relatives with BC, and frequency of mammographic screening. In agreement with these results, it was understood that the majority of FDFRs in the study group knew that BC was inherited, and they wanted genetic counseling to learn their risk as well as their children's risk. They also wanted to be informed as to how to support their relatives during cancer treatment.

It was also determined that other topics for which information needs were not met were associated with the causes of BC, its treatment, side effects, ways to provide support to relatives and the frequency of mammography procedure. These results showed that FDFRs were aware but that they required a more accurate orientation. Previous studies have shown that FDFRs of patients with BC need information about the causes of breast cancer, diagnostic methods and behaviors that promote health. Another common theme is that their needs for information about the causes of BC, its treatment, side effects, ways to provide support to their relatives and the frequency of mammography have not been met (14,22-25). Nurses may help women understand their risks of BC more accurately by determining and meeting the information needs of FDFRs of patients with BC, providing relief to them through confidence and providing support for their care. FDFRs of patients with BC have a variety of needs. The results of one study indicated that nurses were not always capable of correctly assessing and meeting these needs (26). In Turkey, nurses generally spend their time on routine care in the wards, and no professional oncology nurses exist solely for this purpose. Oncology specialists or liaison-consultant nurses should be trained and employed in clinics as a guide just for these patients and their FDFRs.

In our study, the importance of information and support needs of FDFRs was evaluated based on sociodemographic characteristics, and it was found that the information and support needs were higher in those who were 40 years of age and older, were divorced or widowed, had a lower education level, were unemployed and were in the menopause period. In addition, the support needs were also higher in the middle-aged group (31-40 years of age) and in those who had a middle school education and above. In the literature, few studies have shown the relationship between the information and support needs of FDFRs of women with BC and their sociodemographic characteristics. In one study, Aslan and Ceber (15) reported no significant relationship between sociodemographic characteristics of FDFRs and their requirement for information and support. In our study, the informational support needs of women who were older than 40 years of age, had a low education level and were unemployed were found to be higher. This revealed that these women demonstrated a higher

Table 3. Result of multiple regression analysis when importance and needs met taken as dependent variables

Independent variable	Unstandardized coefficients		T		p	
	IN	SN	IN	SN	IN	SN
Age	.081	-.070	.930	-.725	.353	.470
Education	.062	-.217	.847	-1.949	.398	.053
Status of menopause	-.178	-.364	-2.153	-1.729	.033	.085
Family relationship	-.206	-.075	-2.681	-1.324	.008	.187
Age at diagnosis in relatives	-.121	-.124	-1.654	-.864	.100	.388
Relatives diagnosis time	.208	.504	2.721	3.616	.007	.000

SN: $R^2=0.325$ Adjusted R square :0.077 F=3.659 $p=0.002$
 $SN = 16.193 + .208$ (relatives diagnosis time).
 IN: $R^2=0.350$ Adjusted R square :0.095 F=4.399 $p=0.000$
 $IN = 14.46 + -.178$ (menopause) + $-.206$ (relationship degree) + $.208$ (diagnosis time)

awareness because they had a relative with BC. Moreover, these data suggest that middle-aged women and women who have a higher education level can obtain information more easily, which increases their requirement for support.

In our study, information needs were found to be higher among those who obtained education/information about BC and breast self-examinations, performed breast self-examinations, underwent breast examination by a healthcare professional, underwent mammography and stated that "having a relative with BC increases my personal risk". It was observed that awareness of FDFRs about early diagnostic methods of BC and its risk factors increased their requirement for information. The literature has primarily addressed the approaches to the early diagnosis of BC in women with a family history of BC. In previous studies, approaches to the early diagnosis of BC in FDFRs have shown differences. In the study by Cohen (27), it was determined that women with a family history of BC were more likely to perform regular breast self-examinations. In their study, Chalmers et al. (20) found no difference between women who did and did not have a family history of BC in terms of compliance to early diagnostic applications. In the study by Norman and Brain (28), it was reported that women with a family history of BC did not undergo regular clinical breast examinations. The reasons for these different diagnostic approaches were due to the inadequacy that the FDFRs felt regarding this subject matter, the lack of sufficient information about clinical breast examinations, their emotional obstacles and their concerns about experiencing BC (29,30). Concerns and fears of FDFRs of patients with BC may increase their tendency to seek more information (15,31,32). In the study by Dincel et al. (33) which evaluated the knowledge of FDFRs about their risk of BC, breast examinations and screening methods and which provided information to women who had certain risk factors, it was found that the needs of women regarding BC could be eliminated by providing information.

In our study, it was determined that the support needs of those whose relatives were diagnosed as having BC after one year, who did not undergo breast self-examinations and did not undergo breast examinations by a healthcare professional, were not met. In parallel to our results regarding information needs, the lack of early diagnostic applications among FDFRs has revealed the requirement for support. During early diagnostic applications, information and support should be provided together. No planned health program has been established for these support needs in our country, and individual approaches of healthcare professionals and support approaches that are accomplished privately are not sufficient.

Study Limitations

In our study, 5-year and lifelong cancer development risks were calculated and no significant difference was found between information and support needs of the ones who did and did not have risk. Rees and Bath (32) postulated that the acceptance of BC risk occurs in three phases. They observed that FDFRs of patients with BC share the experiences of the patient during the first phase. They accept that they are also at risk during the

second phase, and during the third phase, they are completely aware of their risk (32). Researchers who have emphasized that information, support and communication are helpful during this process, have also indicated that information is effective in the correct perception of individual risk, the provision of individual control and minimizing fear (32,34). The lack of any information regarding risk calculations may not affect the level of information and support needs of FDFRs.

In the regression analysis, the increase in the duration of BC diagnosis in their relatives increased the need of FDFRs for information and support, whereas menopause and a BC diagnosis in mothers increased the information needs of FDFRs. In previous studies, no information was found regarding the year of diagnosis of the relative with BC and the needs of FDFRs with respect to information and support. It has been emphasized that women can negatively affect their family members by reflecting their fear and anxiety due to BC; thus, BC should be evaluated as a disease of the family (26). In our study, the duration of BC diagnosis might cause FDFRs to feel anxious about an advanced stage of cancer that cannot be treated.

Conclusion

An issue that should be considered is that relatives do not have the same individual needs as women with BC. Therefore, it is important to learn their special needs. However, it is difficult to reach these relatives. On the other hand, because of the priorities, nurses generally have to take their time to patient care on wards instead of support and talk with patients. For this purpose, oncology programs should be organized to reach primary relatives at risk through women with BC. It is recommended to increase training in primary relatives as much as possible through strategies such as increasing awareness by informing periodically, and planning to diminish unwanted stress-causing situations. The results of our study will guide health professionals working in both clinics and field. A liaison-consultant nurses or oncology nurses should be recruited. It should be make it possible for nurses to understand these needs is so important. We found out that FDFRs of patients with BC needed factual information and psychosocial support. This study supports the establishment of psycho-oncology units in oncology centers.

Ethics

Ethics Committee Approval: Pamukkale University Non-invasive Clinical Research Ethics Committee (date: 06/02/2017/ decision no: 60116787-020/8900).

Informed Consent: A total of 199 FDFRs agreed to participate and signed the informed consent before completion of the surveys.

Peer-review: Externally peer reviewed.

Authorship Contributions

Surgical and Medical Practices: S.Ö., F.Ö., İ.Ö.Ç., S.G.T., Concept: S.Ö., F.Ö., İ.Ö.Ç., S.G.T., Design: S.Ö., F.Ö., İ.Ö.Ç., S.G.T., Data Collection or Processing: S.Ö., F.Ö., İ.Ö.Ç.,

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