

PATIENTS' EXPERIENCES OF POSTOPERATIVE INFORMATION AFTER OESOPHAGEAL OR GASTRIC CANCER SURGERY - An interview study

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Målsättning

Att med Klinisk Patientnära Forskning, verka för och underlätta arbetet med patientsäkerhet, och samtidigt bereda väg för en bättre vetenskaplig förståelse och vetenskaplig förankring i den verksamhetsförlagda utbildningen för sjuksköterskestudenter. Metodiken förenar högskolans tre primära uppgifter, forskning, utbildning och samverkan.



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Sammanfattning

Bakgrund

Studier om postoperativ information efter kirurgi på grund av gastrointestinal cancer är begränsade. Patienter som genomgår esofagektomier och gastrektomier pga cancer står inför en omfattande förändring gällande såväl fysiska som psykiska funktioner. Förändringarna som cancersjukdomen och operationen medför har konstaterats påverka återhämtningen vilket motiverar att information är speciellt betydelsefull för patientgruppen.

Syfte

Syftet var att undersöka hur patienter som opererats för esofagus- eller ventrikelcancer upplevde den postoperativa informationen inför och efter utskrivning från sjukhus.

Metod

En empirisk intervjustudie med kvalitativ ansats har genomförts. Semistrukturerade intervjuer genomfördes med elva patienter 3-12 månader efter utskrivning efter operation pga. esofagus- eller ventrikelcancer. Intervjuerna har spelats in, transkriberats och sedan analyserats med latent innehållsanalys.

Resultat

Resultatet påvisade att patienterna överlag hade positiva upplevelser av sin vård och behandling med undantag för den postoperativa informationen som ansågs otillfredsställande. Resultatet visade att informationen kan delas in i tre betydelsefulla områden; *"Förberedande information inför utskrivning"*, *"Kombination av informationskällor och -tillfällen"* och *"Information om framtiden"*. Utifrån dessa områden identifierades att patienterna ser informationen som ett nödvändigt verktyg för att hantera livet efter operationen och att utebliven information hämmar återhämtningen och resulterar i känslor av ensamhet och maktlöshet. Varje del av informationen är betydelsefull för den totala upplevelsen och patienterna beskrev att tillfredsställande information gav dem möjlighet att ha realistiska förväntningar på sin återhämtning.

Konklusion

Den postoperativa informationen är viktig eftersom den har betydelse för upplevelsen av återhämtning.

Nyckelord: Esofaguscancer, ventrikelcancer, upplevelser, operation, postoperativ, information.

ABSTRACT

Objective: The aim of the study was to describe how patients who have undergone surgery due to oesophageal or gastric cancer experience the postoperative information before and after discharge from hospital.

Methods: Eleven patients were interviewed. Interviews were tape-recorded, transcribed and latent content analysed.

Results: Even though the patients describe being satisfied with the care at the hospital, many patients experienced the postoperative information as partly insufficient. Postoperative information helped patients experience control in their daily life, made them feel secure in the new life situation and confident about the future. The patients described needing information from several different sources at the hospital and after discharge.

Conclusion: Information is fundamental to enable patients to manage their new life situation. It is a challenge for health care professionals to both standardise the postoperative information and individualise the information according to the needs of each individual. Studies are needed of implementation of an information program enabling patients to feel in control, secure and confident about the future.

Keywords: Experience, gastric cancer, nursing, oesophageal cancer, postoperative information, surgery.

Introduction

Studies have shown that patients regard postoperative information important but insufficient [1]. Information to patients in surgical care is necessary for giving the patients a possibility to take an active part in their postoperative care [2, 3].

The surgical procedure with respect to cancer in oesophagus, cardia and/or in ventricle is one of the most advanced and strenuous surgical procedures followed by a high complication frequency of 30 to 50 per cent [4]. Even though there has been an improvement in the prognosis during the later years the mortality rate within 30 days after surgery is still about five per cent [5]. As oesophagus and cardia cancer have a lot in common and require comparable treatment, they are labelled "oesophagus cancer" in this study [4].

Patients undergoing surgery due to oesophageal or gastric cancer are faced with an extensive change, psychosocially, functionally and with respect to activities affecting their well-being and ability to recover after surgery [3]. The changes that the patients suffer from and the influence that these have on recovery indicate that patient information is especially important in this group [6]. It has been established that the postoperative well-being increases if the patient gets preoperative information [2, 7]. In a review by Shuldham [8] it was shown that if the patient has more knowledge, the experience of problems decreases and the recovery after surgery is enhanced. Studies have shown that information is important for patients in a preoperative stage [2, 4, 7]. Some studies [1, 2, 9] focus on patients going through surgery due to benign diseases. Studies of patients who have gone through general surgery cannot fully be transferred to patients who have gone through surgery due to life-threatening diseases such as cancer, due to differences in the psychological situation [1].

Patients discharged from hospital, after general surgery, who have been provided with little/no discharge information tend to be less familiar with handling their state of health after discharge and visit health care more often than other patients. The reason for this is often insecurity [9]. Even though research on preoperative information has shown that the postoperative information is insufficient [1], research focusing on postoperative information is meagre.

There is a need for studies focusing on how patients experience the postoperative information after surgery due to oesophageal or gastric cancer, since studies of patients who have gone through general surgery cannot fully be transferred to patients who have gone through surgery due to life-threatening diseases such as cancer. In addition, preceding this study, no studies were found focusing on the patient's experiences of postoperative information after surgery due to oesophageal or gastric cancer.

Aim of the study

The aim of the study was to describe how patients who have undergone surgery due to oesophageal or gastric cancer experience postoperative information before and after discharge from hospital.

Methods

This study was designed as an empirical interview study with a qualitative methodology. The qualitative methodology aims at capturing a person's understanding of and experiences of his or her lifeworld [10].

Context

Depending on the tumour size and localisation, oesophagectomy (oesophagus is removed), abdominal gastrectomy (the stomach is removed) or oesophagogastrectomy (the stomach and a part of oesophagus are removed) is made. In Sweden, most of these surgical procedures are done at university hospitals. Each year about 60 patients undergo surgery due to cancer in oesophagus or ventricle in the hospital where this study was carried out. The surgical procedure takes about eight hours and the median length of hospital stay is about 21 days.

The patients were provided with oral information in connection to hospital admittance about one week to one day before surgery. This information was provided by the surgeon, anaesthetist, registered nurse and physiotherapist. Besides surgical, anaesthesia and care aspects, the information covered practical preparations at the ward. After surgery the patients got information from the responsible surgeon about the results from surgery. The responsible nurse provided oral information continuously. At the time of the study there were no standardised routines for what and how information should be provided.

Sample

Patients were consecutively included in the study. Inclusion criteria were that the patient had undergone oesophagectomy, abdominal gastrectomy, or oesophagogastrectomy due to malignancy and had his/her place of residence in the region (to avoid geographical difficulties for carrying out the study). He/she also had to manage the Swedish language in speech and writing and had to have been discharged to ordinary living after hospital stay. Patients with cognitive decline, reduced understanding of the language or mental problems, meaning that an interview could not be carried out, were excluded. During the selection procedure two patients were excluded. In total twelve patients were asked for participation in the study and eleven decided to participate (five men and six women) with a mean age of 62 years (range 43-81 years)(Table 1). Content saturation was reached after eight interviews. Thus, the last three interviews were not regarded as contributing with any new information.

Table 1. Description of the respondents, time and place for interview and return visit (after discharge but before interview).

Interview number	Gender	Age	Cohabitation	Surgery	Time (days) to interview		Return visit	Place for interview
					from surgery	from discharge		
1	Male	55	Cohabiting	Oesophagectomy	43	24	No	Home
2	Female	56	Cohabiting	Oesophagectomy	36	20	No	Home
3	Female	43	Cohabiting	Oesophago-gastrectomy	50	18	Yes	Hospital
4	Female	81	Alone	Oesophagectomy	64	36	Yes	Home
5	Male	62	Cohabiting	Oesophagectomy	64	33	Yes	Hospital
6	Female	57	Alone	Oesophagectomy	40	23	No	Hospital
7	Male	63	Cohabiting	Oesophagectomy	50	26	No	Hospital
8	Female	69	Cohabiting	Oesophago-gastrectomy	87	71	Yes	Home
9	Male	60	Cohabiting	Abdominal gastrectomy	37	19	No	Home
10	Male	62	Cohabiting	Abdominal gastrectomy	53	28	No	Hospital
11	Female	76	Cohabiting	Oesophagectomy	50	23	No	Home

Data collection

In order to make sure that the interview guide and the interview set-up was relevant for the aim of the study, two test interviews were done, resulting in small adjustments of the interview guide [10]. These two respondents were also included in the final sample of the study.

Patients were contacted by phone one to two weeks after discharge from hospital and had the opportunity to decide the time and place for the interview themselves. The interviews were done between three and twelve weeks after discharge and took between 40 and 95 minutes, with an average of about 60 minutes. Six of the interviews were carried out in the patient's own home while the other five were carried out in a calm environment in the hospital [11] (Table 1).

During the interview, the patients were asked to talk about their experiences of postoperative information before and after discharge from the ward. A semi-structured interview guide was used during the interview [10]. The interviews were tape-recorded and transcribed word by word. Data making it possible to identify the person (name, living area and similar) were removed [11] in order to ensure confidentiality. After eight interviews, data was regarded as saturated. However, three further interviews were completed in order to validate that no further variations or any additional information would appear.

Analysis

The texts were analysed with qualitative content analysis [12, 13]. Meaning units in the texts were structured and common themes were looked for. The analysis was latent, aiming at finding underlying meanings in the text [13].

The analysis was divided into four steps according to Burnard [12]. First, the text was read through several times to get an overall understanding. Second, an open coding was conducted, marking paragraphs and noting shorter phrases or words in the margin [12]. Third, the reading continued and was focused on the marked paragraphs and notes that best related to the aim, and meaning units were identified [12, 13]. Fourth, themes and sub-themes were identified. In the fourth step all original text was read through again, controlling that the themes and sub-themes that had emerged through analysis were correct in relation to the original text.

The analysis was done in parallel by the authors in order to avoid individual subjectivity in the analysis and interpretation of the texts [10]. Through the discussions, results were strengthened or rejected.

Ethical considerations

In accordance with the regulations of ethical reviews of research on humans [14], this study has applied and received ethical approval from the ethical board at Kristianstad University College (Dnr ER2005-63). Ethical demands on information, consent and confidentiality were taken into account [15].

Results

Patients requested in specific postoperative information about nutrition, appetite, hunger, weight, mood, pain, drugs, information from former patients, information both in written and orally, information about the future, prognosis, the care chain, contact information to healthcare and about return visits.

Patients who experienced that the postoperative information was in accordance with their needs felt control in their daily life, and were secure and confident about the future. The patients who did not experience satisfying postoperative information described feeling a lack of control, powerlessness and insecurity in their daily life

Table 2. Description of the patients' experiences of postoperative information in themes and sub-themes.

Theme	Sub-theme
To experience control or lack of control in daily life	Empowerment and support to manage change Expectations on recovery
To experience security or insecurity in the new life situation	Availability of information - a precondition for feeling calm and secure Other patients as a trustworthy and strengthening source of information Combining different sources of information and occasions for information – necessary for patient satisfaction
To experience confidence or powerlessness about the future	Planning in relation to disease, care and treatment To be alone with questions about the future

To experience control or lack of control in daily life

Empowerment and support to manage change

The postoperative information was described by patients as a source of power and energy to manage the changes and setbacks that emerged in their daily life after surgery. Patients who experienced that this information was insufficient or lacking described negative feelings such as loneliness, abandonment and powerlessness. When the patients returned home the responsibility to take care of themselves and their own health was transferred from the health care staff to themselves, and this caused worries. How the patients handled changes such as impaired abilities and changes in mood after discharge was described as being dependent to a large extent on what information they had got in hospitals and whether they had access to information also after discharge.

"...I know on beforehand what will happen...how I will feel, I know I will feel sick one day and...I know that I can't run out anyhow the closest month...know that I will not feel hunger...but...the whole time when it happens it is only a confirmation that they were right. I do not get surprised if I feel in a certain way" (Interview 7)

Information prepared patients for what could be expected after discharge, gave them strength to fight and a feeling of security despite the changes that took place. Lack of or insufficient information was described as bringing about feelings of sadness, worries and depression as they interpreted deteriorating abilities and new emerging symptoms as an aggravation of the disease. This in turn drained their energy to continue fighting.

"...it would have calmed me to know some things beforehand, that if you get worried, we know that you will be. That the mood goes up and down, that you can get sad, and that it is ok to get sad, and you may feel that 'oh my god how will this go'...because it is normal, but that...that I didn't know..." (Interview 4).

Expectations on recovery

A precondition for experiencing control over one's life situation was, according to the patients, to have realistic expectations regarding recovery. Knowledge was described as resulting in realistic expectations on health, recovery and life situation after discharge. The expectations that were built up were acting for the patients as a measure of how they managed after surgery. When their own expectations were not fulfilled, they experienced it as a failure.

"...and then it would have been good if he had told me that it often happens that one gets pain and such things...//...but I, I thought that one would get home and it would start to heal and it would be fine..." (Interview 8)

To experience security or insecurity in the new life situation

Availability of information – a prerequisite for feeling calm and secure

Patients who experienced the information after discharge as available described themselves as calm and secure after discharge, unlike those patients who experienced the information as unavailable.

"...there was no one who cared after I left the hospital...so I got a feeling of...then I had to manage it by myself. I had telephone numbers and such, but to find the one I needed in that moment was not easy and...it should be much better I think" (Interview 4)

The "care chain" after discharge from hospital was described by most patients as complicated and difficult to understand. Some patients said that it was difficult to know whom one should contact in different situations, for instance the surgical department, the reception nurse, the outpatient care, the health centre and/or the district nurse.

Patients who had received information in hospital about the ability to contact the reception nurse concerning questions that arose after discharge, described feeling calm and secure in managing by themselves and in the changes that they were faced with after discharge. To see a reception nurse before discharge was wanted, as some patients described it as unpleasant to call someone whom they perceived did not know about their situation.

"...and there I got a good conversation with her (the reception nurse) and clear information about that it was ok to do it. So, that is the conversation that I have had with her, I know where she is..." (Interview 7)

Other patients as a trustworthy and strengthening source of information

As a complement to the postoperative information from the staff, many of the patients wanted information from former patients who had gone through similar procedures. Such information was regarded as especially trustworthy as it was built on the patients' own lived experiences. It was also stated that a patient group could be a forum for meeting others and discussing equivalent experiences. Such a contact could be initiated by the hospital and continued after discharge. If they could gain positive information from other patients this would strengthen their own hope and at the same time result in a feeling of "I'm not alone with this type of problem", something that some patients experienced that they were.

"...If I could get...the other patients' experiences, what problems they have had and how they solved these problems..." (Interview 3)

Combining different information sources and occasions – a precondition for patient satisfaction

According to the patients, a combination of information sources and information occasions is optimal for satisfaction with the postoperative information.

Many patients emphasised the importance of having the opportunity to sit down in peace and quiet with the doctor or the nurse and have a conversation. Many questions were answered during the moments when nurses took their time and sat down for a moment, some patients said. The contact between the staff and the patients was deepened during individual conversations, with the result that the patient could even raise questions of a sensitive character.

"...One Friday NNN came and we sat down.... He had a lot of time and we discussed the whole situation...//...I was really surprised that so much time was devoted to this and did not at all feel that he hurried through it, quite the opposite...it inspired me to feel calm that they gave me that time, I felt important for them...it was really positive..." (Interview 7)

Written information as a complement to the oral information was requested by many of the patients. They emphasised that it was difficult to remember the information they got since there was so much to think about.

The day patients were discharged from hospital returned as an important moment for the postoperative information. Many felt that the discharge day would be the best time for information that would help them in daily life after the hospital stay. The patients wanted a discharge conversation with those who were involved in the admittance (surgeon, anaesthetist, registered nurse and physiotherapist) during which general information about the operation as well as information about the future could be given. The discharge conversation seemed to have a value for the patient, both with respect to information in general and as “closure” after the time at the hospital.

“... ‘yes go home now you are discharged’...and in that moment I did not think about it perhaps...because I was happy to get home and be discharged from there...But then, at home I started to wonder ‘oh Jesus’ I did not get any information at all...”
(Interview 1)

The patients highlighted that it is very important that the postoperative information at the ward does not exclude the availability of information after discharge. Many patients felt insecure when they had returned to their own homes. The questions that arose were experienced as bigger than they actually were, due to the fact that there was no one close by to ask. Not knowing was described as the source of worries, and some patients felt that it would have been positive if a nurse had called them at home so that they could ask questions. Some patients said that someone calling you at home not only means that questions can be answered, but also contributes to feelings of security in the home.

To experience confidence or powerlessness about the future

Planning in relation to disease, care and treatment

Information that made planning in advance possible was stressed as important and as a factor that affected the life situation after discharge positively.

“...she calls me again within one and a half month to check my weight...and how I feel. It is already taken care of, that I know...so you see I get very good information about what will happen far ahead...one can’t ask for more...” (Interview 5)

The return visit was experienced as an occasion to ask questions, and the information was to a great extent a repetition of what had been said earlier. Many of the patients who had had a return visit experienced it as positive, and some said that they got more and better information at the return visit than he had got before discharge. Despite the information about the coming return visit some patients expressed worries for not knowing what will happen after that. This lack of information was described as frustrating.

“...What will happen now? And then, at the end what will happen when I get home? Thus, I have not got any clear picture of...of return visits, yes that I got...that I will have a return visit after a month, but what happens thereafter...what shall I do then? I didn’t get anything like that...” (Interview 6)

3.3.2. *To be alone with questions about the future*

Most patients described feeling disappointed in the lack of information about the future. Many patients had remaining questions after discharge regarding the prognosis and wondered, can the cancer come back? Many existential questions were raised by the patients and they talked about the necessity of future decisions, for instance about to stop working. According to the patients, the information that could support them in those difficult decisions about the future was lacking. They pointed out that they wanted honest information about the future, i.e. not getting vain hopes.

"...no one has talked about cytotoxic drugs and such things...and if it had been something else they would or...that I must ask as well...But then they would have told me I suppose...or one cannot see that already?..." (Interview 2)

Discussion and conclusion

Discussion

In qualitative studies, the concept of trustworthiness and transferability is often discussed [13, 16]. The choice of data collection method and how it is carried out is of importance for the trustworthiness of the study [13]. The respondents stated that they experienced it as positive to choose the time and place for the interview, as is also shown in the literature [11]. This might have contributed to the fact that only one patient chose not to participate in the study. The analysis of the two test interviews made the interviewee (M.M.) aware of how the questions were asked and what answers could be expected. The test interviews were regarded as responding to the aim of the study and were then included in the study. Even though the data was experienced as saturated after eight interviews another three were conducted. The answers in those later interviews were similar to what had been given in the earlier ones, increasing the trustworthiness of the study. The trustworthiness of the study further increases as the authors have analysed the data together and as the different steps of the analysis have been described [13].

One factor that might have affected the results is that the time from discharge to the date of the interview varied. The respondents' ability to describe their experiences of the postoperative information can have been affected as the memory might have changed over time. According to Christiansson and Loftus [17], persons who have experienced special events or traumatic events often remember these quite well. This is supported by findings from the present study, in which no obvious differences were seen due to how much time had passed between discharge and interview.

Regarding transferability in qualitative studies, Graneheim and Lundman [13] claim that the author can give suggestions regarding transferability to other contexts but that it is the reader's task to determine whether the result is transferable. The authors suggests that the result can be transferred to patients in similar contexts, taking the details in descriptions of the sample, data collection, method of analysis and results into consideration [13]. The variations regarding the information need makes it not possible to totally couple the findings from this study to those studies focusing on patients undergoing surgery due to benign diseases, since patients going through

surgery due to malignancies have other specific needs relating to faith in the future and survival [7].

Patients undergoing surgery due to oesophageal or gastric cancer have in this study been shown to experience the postoperative information as very valuable, but in many cases as insufficient, an experience which is confirmed in other studies focusing on other patient groups [1, 2]. Both patients who are satisfied with the information and those who are not have the same thoughts about what information they would like to receive. Three different areas have been shown to be of importance for the postoperative information: preparatory information before the discharge, the combination of different information sources, and information about the future. Without a combination of the different information areas the patients experience that the information is insufficient, contributing to feelings of loneliness, insecurity and powerlessness after discharge (Figure 1).

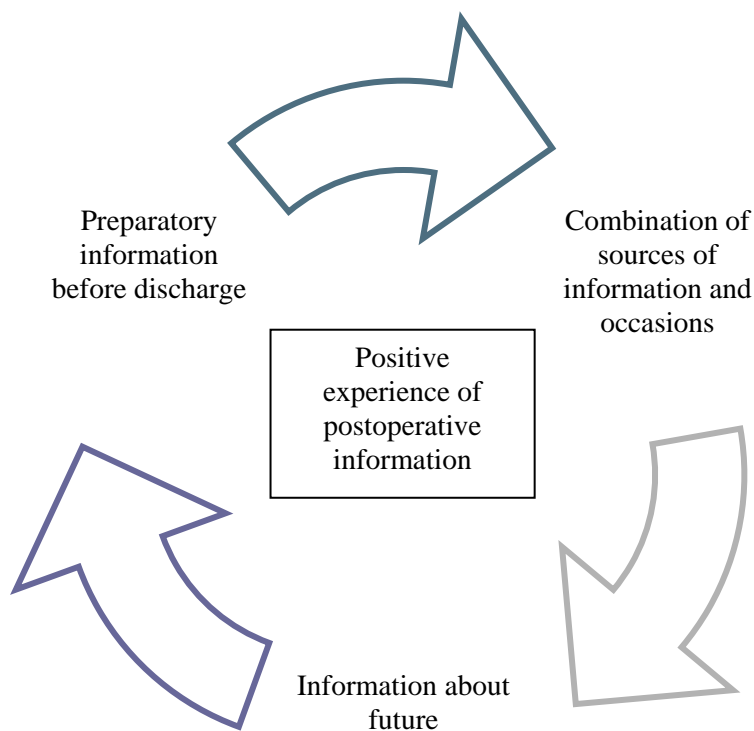


Figure 1. Interaction between some important parts in the postoperative information.

Other results [18, 19] highlight the importance of providing information about the potential problems and complications that can emerge after discharge and that might have an impact on daily life. Studies have shown that patients who feel that they have been provided with the information they need to a lesser extent experienced problems after discharge [18] and that information is necessary if the patients are to experience control over their life situation after discharge [20], supporting the results of this study.

Patients who go through upper gastrointestinal cancer surgery have a protracted postoperative course with remaining symptoms a long time after surgery [21]. Olsson [21] highlights that it is important that the nursing personnel have knowledge about

the patients' experiences and remaining symptoms during the recovery period, for instance pain and nutritional problems, as this has been shown to be of importance for the patients' quality of life. This study shows that when patients experience that they have received satisfying postoperative information and have access to information also after discharge, their feelings of security and safety increase. A prerequisite for patients receiving the information is, as also Olsson [21] states, that the staff has good knowledge, not only about what relates to the workplace but also about how patients feel after discharge.

Most of the patients who had got information about the reception nurse experienced the contact as positive and felt safe in knowing that they could contact her if they had any questions. Some of the patients who not had been provided with information about the reception nurse asked for someone who they could contact when needed. This result is supported by Viklund et al. [6], and shows that the contact nurse is important for patients undergoing upper gastrointestinal cancer surgery in order for them to feel secure in their situation.

To carry on conversations with other patients who have gone through similar surgery was pointed out as an opportunity to get advice and help from someone who has been in a similar situation. That no group discussions and no contacts with other patients were offered was seen as a shortcoming of the postoperative information. Other studies [3, 22, 23] have also shown that patients who have cancer ask for and experience it as positive to meet other patients in similar situations. Adamsen [22] describes the same thing as in this study, namely that conversations with and information from other patients can strengthen the patient to move on. Olsson [3] states that patients themselves like to share their thoughts and feelings about for instance survival, as is also described by patients in this study.

Already in 1986 Engström [24] described in a thesis that dissatisfaction with information was a common problem among patients in health care. Many studies have been published since then within the area of patient information and education. Even though information to patients has been highlighted during many years, there is still today many studies concluding that shortcomings exists.

Conclusion

It is known that postoperative information is experienced as important by the patient and that it affects the postoperative course. This study establishes that postoperative information is of great importance for patients undergoing oesophageal or ventricular cancer in order to feel safe and experience control in their situation after discharge. An improvement in postoperative information can possibly contribute to patients experiencing themselves as more safe after discharge and thereby feeling control over their life situation. At the same time they can look towards the future with confidence instead of as a time of feeling abandoned, worried and fearful.

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