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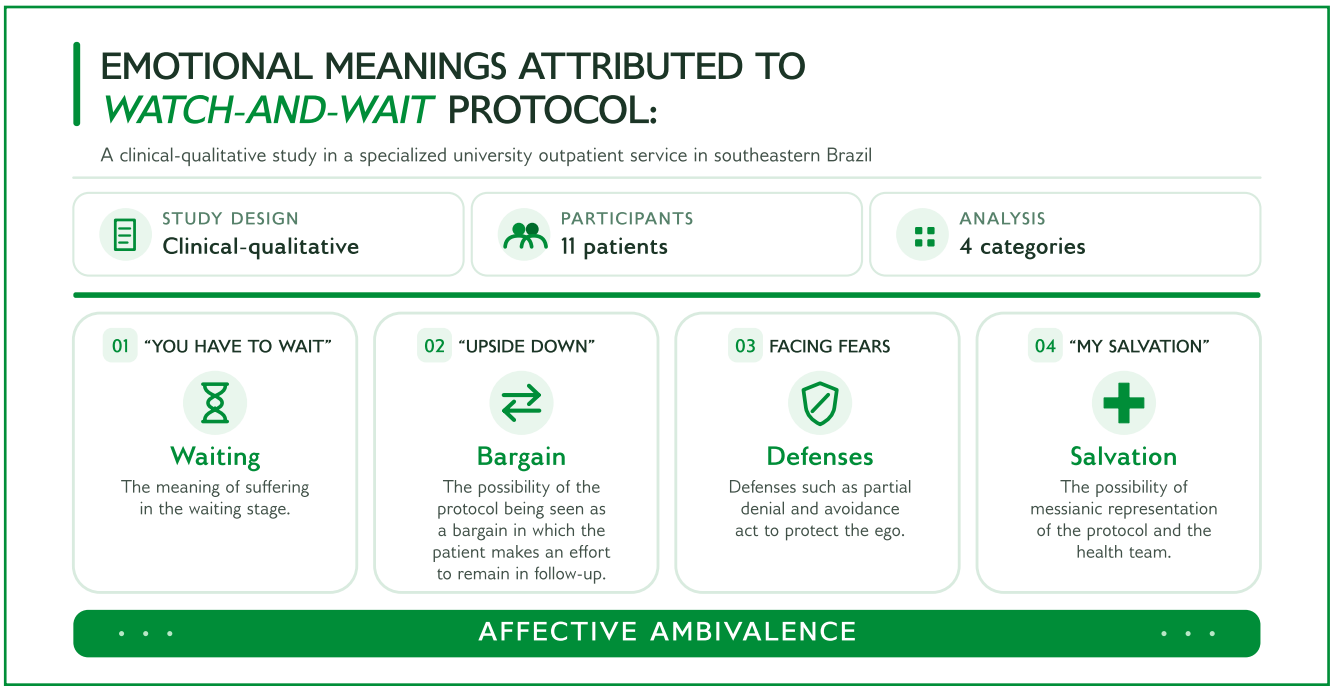
ORIGINAL ARTICLE

Emotional meanings attributed to the watch-and-wait protocol: a clinical-qualitative study in a university specialized outpatient service in southeastern Brazil

VISUAL ABSTRACT



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ARTICLE HIGHLIGHTS

- Patients on the "watch-and-wait" protocol experience ambivalent feelings: hope and relief at avoiding surgery and distress, fear, and uncertainty.
- Waiting is perceived as emotional distress, marked by the fear of tumor regrowth and the possibility of unwanted surgery in the future.
- The protocol can be seen as a "salvation" because it preserves autonomy and offers an alternative to surgery, generating feelings of gratitude toward the healthcare team.
- Psychosocial support is essential for addressing patients' distress and strengthening their coping abilities during clinical follow-up.

CENTRAL MESSAGE

The watch-and-wait (W&W) protocol is a non-surgical strategy for patients with locally advanced colorectal cancer who achieve complete clinical response (CCR) after neoadjuvant chemoradiotherapy. Patients who meet the follow-up criteria continue to undergo rigorous monitoring exams on an outpatient basis every two months in the first year, every three months in the second year, every six months from the third to the fifth year, and annually after five years. We hypothesize that patients on this protocol experience significant psychological distress, driven by the constant uncertainty of the waiting period and the persistent fear of tumor regrowth. Understanding what patients think about their health and disease processes allows us to grasp the emotional meanings that organize and structure their lives in the face of a diagnosis.

PERSPECTIVES

Understanding the feelings and meanings associated with waiting for patients under the watch-and-wait (W&W) protocol allows us to reflect on the implications of that choice. Therefore, it is possible to develop strategies to minimize discomfort and emotional distress. In light of this study's findings, we reflect on the ambivalence of meanings. Positive meanings include wanting to remain in follow-up for as long as possible and the healthcare team toward whom patients express feelings of gratitude and messianic expectations of salvation. And conflicting negative meanings of suffering. We suggest future research to understand the emotional meanings reported by healthcare professionals who care for patients under the W&W protocol.

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ORIGINAL ARTICLE

Emotional meanings attributed to the watch-and-wait protocol: a clinical-qualitative study in a university specialized outpatient service in southeastern Brazil

Significados emocionais atribuídos ao protocolo 'watch-and-wait': um estudo clínico-qualitativo em um Serviço ambulatorial universitário especializado no sudeste do Brasil

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ABSTRACT

Background: Understanding how people symbolize their illness and treatment and how they cope with it is important for healthcare teams and families. Meaning is a fundamental part of the human experience. It can act as a tool for progress or an obstacle. This is the case of expectant approaches, such as the watch-and-wait protocol, in which people wait and face uncertainty. This protocol is an organ-preservation strategy, in which eligible patients undergo rigorous follow-up and do not undergo surgery immediately after the neoadjuvant chemoradiotherapy stage. **Aims:** To understand the symbolism attributed to the watch-and-wait protocol for patients with locally advanced low rectal cancer. **Methods:** A clinical-qualitative study with semi-structured interviews with in-depth open questions and field notes. Sampling was purposive and limited because of information theoretical saturation. Data analysis included seven steps of clinical-qualitative content analysis, interpreted from the psychodynamic framework of medical and health psychology. **Results:** Four categories were selected: 1. "You have to wait", which discusses anxiety and distress as a form of suffering; 2. "Upside down", which addresses the fact that the protocol can be seen as a bargain; 3. "Facing fears", which talks about defensiveness as a way to cope with distress; and 4. "My salvation", which discusses the possibility of considering the protocol a messianic alternative. **Conclusions:** Patients undergoing clinical oncological follow-up attribute conflicting meanings to the 'watch-and-wait' protocol. Positive meanings of salvation because it offers an alternative to surgery and a bargain to postpone surgery as long as possible, and negative meanings of suffering because of the uncertainty that causes distress.

Headings: Watchful Waiting. Symbolism. Qualitative Research. Neoadjuvant Therapy. Rectal Neoplasms.

RESUMO

Racional: Saber o que as pessoas simbolizam sobre sua doença e processo de tratamento e como lidam com isso é importante para as equipes de saúde e famílias, pois o significado é estrutural para a vida humana e pode ajudar ou se tornar uma barreira nessas relações. Esse é particularmente o caso em abordagens expectantes, como observar e esperar, em que as pessoas precisam aguardar e lidar com a incerteza. Trata-se de uma estratégia de preservação de órgãos, em que pacientes elegíveis podem ser submetidos a um acompanhamento rigoroso e não operados imediatamente após a fase de quimiorradioterapia neoadjuvante. **Objetivos:** Compreender o simbolismo atribuído ao protocolo de observação e espera para pacientes com câncer retal localmente avançado. **Métodos:** Estudo clínico-qualitativo com entrevistas semiestruturadas com perguntas abertas aprofundadas e notas de campo. A amostragem é proposital e fechada devido à saturação teórica das informações. A técnica de análise de dados utiliza sete etapas da Análise de Conteúdo Clínico-Qualitativa, interpretadas a partir do quadro psicodinâmico da psicologia médica e da saúde. **Resultados:** Quatro categorias foram selecionadas: 1. "Você tem que esperar", discussão sobre angústias e ansiedades significadas como sofrimento; 2. "De cabeça para baixo", a possível simbolização do protocolo como uma barganha; 3. "Diante dos medos", defesas ativadas para lidar com a angústia; 4; "Minha salvação", discute a possibilidade de representação messiânica da estratégia. **Conclusões:** Pacientes em acompanhamento oncológico clínico apresentam representações conflitantes sobre o protocolo 'watch-and-wait', significados positivos de salvação, por oferecer uma alternativa à cirurgia e representar uma estratégia para adiá-la o máximo possível; e significados negativos de sofrimento, devido à incerteza que gera angústia.

Descritores: Conduta Expectante. Simbolismo. Pesquisa Qualitativa. Terapia Neoadjuvante. Neoplasias Retais.

INTRODUCTION

Knowing what patients think about their health and illness processes allows us to understand the emotional meanings that organize and structure their lives in the face of a diagnosis. In particular, patients with a worrying disease who are followed under the "watch-and-wait" (W&W) protocol report anxiety, distress, uncertainty, and fear. These feelings can interfere with patient management, requiring healthcare teams to adjust their expectations and accept them[1,17].

Pennings et al.[21] presented findings on the general aspects addressed in interviews, ranging from emotional to physical symptoms. The first category of analysis by these authors listed aspects associated with anxiety, such as fear of the disease, surgery, or stoma; apprehension surrounding diagnostic exams; and embarrassment and depressive feelings.

Van der Valk et al.[28], in a study on the perceptions of patients and their physicians about different treatment strategies for locally advanced rectal cancer, reported that avoiding sur-

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gery with a permanent stoma was considered by patients to be more important than having two more years of survival in a hypothetical situation. The physicians interviewed showed great concern about disease recurrence. This demonstrates the importance of the physician-patient relationship in adjusting expectations associated with treatment choice.

The W&W protocol is a non-surgical strategy for patients with locally advanced colorectal cancer who achieve complete clinical response (CRR) after neoadjuvant chemoradiotherapy[13,20]. Patients who meet the follow-up criteria continue to undergo rigorous monitoring tests. In the outpatient clinic where this study was carried out, tests are performed every two months in the first year, every three months in the second year, every six months from the third to the fifth years, and annually after five years[18].

However, patients become at risk of local recurrence or metastasis after a few years of follow-up. According to a multicenter study[6] with patients on a W&W protocol, 74.3% of patients achieved a three-year actuarial survival rate without local recurrence. This number dropped to 72.1% of patients at five years. Another study shows that metastases are less common, with approximately 10% expected three years after the decision to follow up[24].

A study by Renehan et al.[22] revealed that survival rates of patients undergoing conventional treatment methods, not W&W, and patients undergoing monitored follow-up do not differ significantly, but stoma-free survival is longer among patients on W&W.

The hypothesis is that the W&W protocol causes suffering as patients live with the wait and the uncertainty of having an unwanted surgical procedure.

METHODS

This was a clinical-qualitative study described by Turato[27]. The clinical-qualitative method (CQM) is a structured form of qualitative research that seeks to interpret the meanings attributed by patients, healthcare professionals, or family members in clinical settings to their experiences of the health-disease process.

Data collection

Data were collected via a semi-structured interview script with in-depth open questions[7] and field notes on feelings and behaviors that emerged from the relationship between the interviewer and the interviewee. Also, nonverbal and paraverbal expressions were used to interpret data, along with the meanings learned from the interviews[3].

The triggering question was: "Could you tell me what it is like for you to be followed under this protocol and what it was like when the physician told you about this strategy?" and the follow-up questions were: "According to the protocol, you have to wait while undergoing tests. What is it like for you?", "According to the protocol, if there is any sign of disease recurrence, surgery is the next step. How do you feel about it?", and "Could you tell me what you think about colostomy?"

Data were collected from October 2022 to October 2023 through single, uninterrupted interviews conducted in a private room immediately following patients' routine medical consultations. All interviews were conducted by the first author—a female psycho-oncologist trained in the role-playing research interview technique—who had no prior relationship with the participants. Participants were approached on the day and at the location of their regularly scheduled follow-up appointments. Sampling was intentional and sequential.

All the interviews were conducted at an outpatient clinic for patients with extraperitoneal rectal cancer at a Brazilian university hospital, which is a national reference in the treatment of colorectal cancer. The interviews were recorded and transcribed in full by a transcriber trained in the transcription technique[3,27]. Validation took place at meetings of the Clinical-Qualitative Research Laboratory (LPCQ) research group. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used[26].

Data analysis

Data were analyzed and categorized after reading and listening to capture hidden meanings in metaphors, analogies, silences, expressions of emotion (crying, laughter, speech intonations), and lapses that denote content pertinent to the research objective. Data were processed using the Clinical-Qualitative Content Analysis (CQCA) technique, which is based on the Seven Steps of Faria-Schützer et al.[5]. The theoretical framework of the CQM is based on psychodynamic concepts according to Brenner[2] and is associated with the emotional relationships among patients, their illnesses[17], clinical teams[1], their families, and their social circles. Furthermore, we used concepts discussed by Kübler-Ross[15] regarding the phases of mourning.

Inclusion criteria

- Patients with six months or more of protocol follow-up;
- Over 18 years;
- Being monitored at the university diagnostic center;
- Referred by the clinical team for an interview;
- Patients physically, emotionally, and intellectually able to answer the interview according to the physician in charge of the service;
- Patients who signed the Informed Consent Form (ICF) before the interview.

Saturation criteria

The CQM uses the theoretical saturation concept, as defined by Fontanella et al.[8,9], to limit the sample. Each category is saturated after checking that the interview content was sufficiently elucidated to support discussion and that there were no new topics to be further discussed.

Unicamp Research Ethics Committee approved this project under No. 5.642.416 19/09/2022.

RESULTS

The sample was saturated with 11 participants aged between 52 and 77 years. Although conducted in depth, the interviews lasted an average of 14 minutes and provided rich material to explore. Two people refused to take part in the interviews. In floating rereading, we defined categories based on participants' speech interpretation, considering their nuclei of meaning.

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Category 1: "You have to wait"

This category addresses the meaning of suffering during the waiting stage. We can see divergences between the chronological time stipulated by the protocol and the emotional time experienced by patients.

"(...) you can't jump ahead (laughs), you have to wait, while you wait you get a bit nervous, but we go ahead." (E5)

"Anxious? I say I'm anxious to see the end of the treatment, to see if I'm doing well, if I'm calm—to hear that from them.." (E9)

The distress and anxiety captured from the speech clippings prompt us to reflect on the meaning of suffering during the waiting stage attributed to the W&W protocol. Even though patients are duly instructed on these stages and on the chronological time required in each one, uncertainty about the surgical procedure they want to avoid can direct psychic time to the future, when uncertainty would no longer be present.

"(...) so the risk of surgery is imminent, it may be that one day I have to undergo surgery, we hope not (...) (E10)

"(...) I'm just waiting for the monitoring period to stop, for someone to come and say that everything is fine." (E3)

Watching and waiting provoke ambivalent feelings. These feelings are associated with the need for safety, as careful examinations will show healthcare professionals whether CCR is being maintained. However, at the same time, patients fear relapsing.

Waiting means that the surgery will not be carried out immediately. This is desired by patients who fear surgery, as well as by healthcare teams, allowing time for physical recovery after the stages and time to elaborate fantasies and fears associated with the risk of having a stoma. Nevertheless, waiting leaves patients feeling powerless and uncertain, which can be distressing.

Category 2: "Upside down"

This category discusses the possibility of the protocol being seen as a bargain in which the patient tries to remain in follow-up and thus avoid surgery.

"That's why I'll do anything. If the doctor tells me to turn upside down and walk upside down to avoid [surgery], I'll do it to try to get away from it [surgery] (...) (E1)

Turning upside down and walking upside down represent a great effort, a major change, something that requires a sacrificial effort to avoid, or even postpone, surgery and its consequences.

"If they say that a procedure is more painful than the one I'm going through, I'll still do it." (E6)

When facing the distress of waiting and the fear and consequent realization of the surgical procedure, patients can see waiting as a sacrifice to obtain what they want: to remain in follow-up and not undergo surgery.

(...) I have to follow the instructions. In this case, I follow the instructions. I'm not a rebellious patient. I try to do everything right, even if I'm upset, even if I'm distressed. I can't talk about it anymore. (E1)

Trying to follow instructions and medical advice, even at the cost of suffering, demonstrates that the patient is willing to obey and sacrifice to remain in follow-up, which can be understood as a bargain.

Category 3: "Facing fears"

During the interview, when reflecting on the possibilities (to undergo surgery or not) of the follow-up period, interviewees showed signs of defensiveness, including partial denial and avoidance. Despite being less elaborate, defensiveness protects the ego from a potential rupture caused by major distress.

"(...) I don't expect [having a stoma], I don't imagine it, I don't imagine this possibility. Let's face it, if I have to, I'll face it at the right moment" (E3)

"I put it in my head that I wasn't going to do it [the surgery]!" (E2)

The fears reported are fears of the surgery, of the possibility of having a stoma and its consequences, and also of recurrence.

"I believe that my (cancer) won't come back (laughs)" (E6)

We also identified manic defenses in accelerated speech, laughter that expresses bewilderment, and slight irritability. These paraverbal elements in the interviews demonstrate mood elevation to make up for the discomfort caused by confronting the fears that emerged during the interview.

Category 4: "My salvation"

This category addresses the possibility of the protocol being considered messianic[1]. The treatment center and the healthcare team offer patients an alternative seen as something that can "save" their lives or avoid the suffering caused by the idea of undergoing surgery.

"Follow-up was my salvation!" (E2)

The W&W protocol, restricted to large health centers and state-of-the-art care units, offers the possibility of avoiding something feared. It is not common in most public or private healthcare services in Brazil. This leads people to seek out these places because they believe it will offer them invaluable benefits, generating messianic expectations.

"(...) We asked God to call someone who wasn't going to recommend surgery, to give me a chance... and then, well, Unicamp called me" (...). (E1)

A feeling of gratitude toward the institution and the healthcare team permeates the physician-patient relationship. Also,

[1]A messianic representation is understood as an attribution of messianic meaning, i.e., something or someone - a messiah - who will eliminate suffering and promote a new, virtuous, and just order[19].

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we can observe an expectation that the wish to avoid surgery will be fulfilled, and this may represent a form of autonomy.

> *"I'm very grateful, very grateful for this treatment [crying with a broken voice], I feel honored, for me it's a gift from God" (...)*

DISCUSSION

The different symbolic constructions of the experiences of patients followed under the W&W protocol are ambivalent. They are positive insofar as they are presented as an alternative for eligible patients, i.e., a chance to choose standard treatment, with autonomy somewhat preserved. Choosing the protocol is based on fear of the consequences of a surgery that cannot be completely ruled out.

Patients may see the protocol as a "salvation", a messianic alternative, a protective expectation, since it offers the possibility of choice and autonomy, which contrasts with the lack of control experienced when patients realize they have a life-threatening illness. This choice allows patients to avoid, at least a priori, something undesirable, in this case, surgery and its consequences. For these people, their relationship with the healthcare team is permeated by feelings of gratitude, but also by expectations that will need to be adjusted over the course of treatment, since dealing with uncertainty can lead to feelings of distress.

In this sense, it is worth thinking about a consent form for treatment adherence, where information could be given about the possibility of increased anxiety and distress during follow-up, providing places where patients could seek psychological and/or psychiatric care if necessary.

The protocol is also considered a bargain. According to Kübler-Ross[15], this is a stage in the process of dealing with anticipatory grief, an attempt to gain more time for something the patient wishes to avoid: death, or in this case, surgery. For some of the patients interviewed, surgery seems to be more threatening or painful than death. Patients may see the protocol as an opportunity to avoid or postpone the suffering they believe would result from tumor resection surgery. Therefore, they feel compelled to do something (follow medical advice, adhere to follow-up by undergoing tests, and attend medical appointments). They also endure the distress of waiting to remain in follow-up, which may favor treatment adherence.

However, follow-up visits can be emotionally conflicting. For some patients, hearing from doctors about their health condition, at least temporarily, eases their uncertainties and distress. For others, follow-up visits can surface the fear of hearing from doctors that they will no longer be able to remain on the protocol. This requires healthcare professionals to be sensitive and attentive and find the best way to provide this information.

On the other hand, because of uncertainty, waiting can give the W&W protocol negative meanings: suffering and distress. In psychoanalytic theory, two opposing concepts of distress exist: automatic distress, a reaction to a traumatic situation or its reproduction, and signal distress that triggers the reaction experienced in a traumatic situation but in a diminished form, initiating an egoic defensiveness[16].

Automatic distress may be triggered by the diagnosis of locally advanced rectal cancer, as it is a life-threatening disease. Conversely, signal distress may be manifested at follow-up visits, when patients are faced with the reality, denied or avoided, of the need for monitoring and the risk of tumor recurrence.

Patients can also blame their uncomfortable feelings of anxiety and distress on the healthcare team as if they had caused them. This can hinder the physician-patient relationship and treatment. Empathetic listening and team discussions with psychosocial professionals can help understand this and create coping strategies. This can be done using Balint group models or by including a psychosocial professional in case discussions.

Waiting interrupts action by paralyzing the subject, according to Minkowski 1965 apud Costa and Medeiros[4]. From this phenomenological perspective, all waiting is distressing and "provokes a near-death sensation". Waiting inverts the direction of time, and the future is directed toward the subject. This highlights how a patient's internal psychological time can differ from the protocol chronological timeline.

The findings on anxiety and distress discussed in this study are in line with those of Pennings et al.[21] and Rittenmeyer et al.[23]. Their studies address uncertainty, fear, and anxiety as emotions present in patients treated with watchful waiting strategies.

Choosing follow-up is crossed by fear, whether of real death in the experience of anticipatory mourning[10] when diagnosed with a potentially fatal disease, or of symbolic death, since the stoma can directly interfere with the way the subject sees themselves and relates to other people, affecting their identity[25].

To cope with distress, patients used less elaborate defenses[11,12], such as denial[2], avoidance[11], and even manic defenses. According to Klein[14], these are primitive defenses people use when they feel their ego threatened by major distress. In an omnipotent way, they try to control the feeling of losing something valued by denying its importance and triumphing over the suffering to come. Defensiveness was also seen in the aforementioned paraverbal elements during the interviews when patients were trying to cope with distress. This is believed to have significantly influenced the length of the interviews.

We suggest approaches that can accommodate suffering and distress, such as group meetings with W&W patients so they can talk freely about their fears and emotional coping difficulties during the waiting stage. These meetings should be a moment of catharsis and should be led by a psychotherapist who would help patients with mental organization.

Healthcare teams that communicate compassionately with patients can favor the expression of feelings, doubts, anxieties, and needs, which can be accepted and validated. This would help create coping strategies and strengthen the physician-patient bond.

CONCLUSIONS

In view of the above, we reflect on the ambivalence of meanings: positive meanings, including patients who want to remain in follow-up as long as possible, a feeling of gratitude toward the healthcare team, and messianic expectations of salvation. On the other hand, negative meanings include suffering, which can also be attributed to the relationship with the healthcare team, contradicting the initial hypothesis.

Despite waiting distress being perceived as suffering, patients also attribute positive meanings to the protocol, such as salvation and autonomy.

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Understanding W&W protocol patients' feelings and meanings makes it possible to reflect on the implications of this choice. Consequently, strategies can be created to minimize discomfort and emotional suffering.

We suggest future research to understand the emotional meanings reported by healthcare professionals who provide care to patients under the W&W protocol.

AUTHORS' CONTRIBUTION

Suedt MR: Conceptualization, Investigation, Methodology, Data analysis, Writing – original article, Literature review. Silva SA: Data analysis. Santos CG: Data analysis. Ponce-de-Leon JR: Data analysis. Silva FS: Data analysis. Carvalheira JBC: Conceptualization. Martinez CAR: Conceptualization. Turato ER: Conceptualization, Methodology, Data analysis.

Data Availability Statement

The datasets generated and/or analyzed during the current study are available from the corresponding author upon reasonable request. The information regarding the investigation, methodology, and data analysis of the article is archived under the responsibility of the authors.

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