

Mobile application prototype on educational content for home care of liver transplantation recipients

Protótipo de aplicativo móvel sobre conteúdo educativo para cuidados domiciliares de receptores de transplante hepático

Prototipo de aplicación móvil sobre contenido educativo para cuidados domiciliarios de receptores de trasplante hepático

Neide da Silva Knhis¹  <https://orcid.org/0000-0003-0639-2829>

Laísa Fischer Wachholz¹  <https://orcid.org/0000-0001-9841-9798>

Aline Lima Pestana Magalhães¹  <https://orcid.org/0000-0001-8564-7468>

Daniela Couto Carvalho Barra¹  <https://orcid.org/0000-0003-4560-7706>

Karina Dal Sasso Mendes²  <https://orcid.org/0000-0003-3349-2075>

Keyla Cristine do Nascimento¹  <https://orcid.org/0000-0003-4157-2809>

Sibebe Maria Schuantes Paim³  <https://orcid.org/0000-0003-4249-9148>

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Corresponding author

Laísa Fischer Wachholz
E-mail: laisafischer@gmail.com

Associate Editor (Peer review process):

Bartira de Aguiar Roza
(<https://orcid.org/0000-0002-6445-6846>)
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brasil.

Abstract

Objective: To develop and validate the educational content of a mobile application prototype for managing home care of liver transplantation recipients.

Methods: This is a methodological study for content development and validity, prepared in three steps: (1) integrative literature review; (2) qualitative study through semi-structured interview with a multidisciplinary liver transplantation team and patients who underwent this transplantation; and (3) content validity through the Delphi technique, with the participation of experts with expertise in the subject and liver transplantation recipients.

Results: In total, 14 original articles met the inclusion criteria and indicate care aimed at the use of medications, glycemia control and care with possible complications. In the qualitative study, six units of meaning extracted from the interviews with 20 patients and 13 professionals from the team were formed. Information consolidation allowed to format the application initial screen and six tabs of home care units. Content validity presented an overall mean of validity index of 0.94 for patients and 0.84 for professionals in all items.

Conclusion: The content developed and validated allows managing home care of patients undergoing liver transplantation, which will help to improve patient and graft survival rates, given the life changes necessary for the maintenance of the new transplanted organ.

Resumo

Objetivo: Desenvolver e validar o conteúdo educativo de um protótipo de aplicativo móvel para gestão dos cuidados domiciliares de receptores de transplante hepático.

Métodos: Estudo metodológico para o desenvolvimento e validação de conteúdo, elaborado em três etapas: (1) revisão integrativa da literatura, (2) estudo qualitativo por meio de entrevista semiestruturada com equipe multiprofissional do transplante hepático e pacientes que foram submetidos a esse transplante e (3) validação de conteúdo por meio da técnica Delphi, com a participação de juízes com expertise na temática e receptores de transplante hepático.

Resultados: No total, 14 artigos originais atenderam aos critérios de inclusão e apontam cuidados voltados ao uso de medicamentos, controle da glicemia e cuidados com possíveis intercorrências e complicações. No estudo qualitativo, formou-se seis unidades de significados extraídas das entrevistas com 20 pacientes e 13 profissionais da equipe. A consolidação das informações permitiu formatar a tela inicial do aplicativo e seis abas de unidades de cuidados domiciliares. A validação de conteúdo apresentou média geral do índice de validade de 0,94 dos pacientes e 0,84 dos profissionais em todos os itens.

Conclusão: O conteúdo desenvolvido e validado permite a gestão de cuidados domiciliares de pacientes submetidos ao transplante hepático, que contribuirá para melhorar as taxas de sobrevida do paciente e do enxerto, diante das mudanças de vida necessárias para manutenção do novo órgão transplantado.

¹Universidade Federal de Santa Catarina, Florianópolis, SC, Brazil.

²Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo, Ribeirão Preto, SP, Brazil.

³Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil.

Conflicts of interest: nothing to declare.

Resumen

Objetivo: Desarrollar y validar el contenido educativo de un prototipo de aplicación móvil para la gestión de los cuidados domiciliarios de receptores de trasplante hepático.

Métodos: Estudio metodológico para el desarrollo y validación de contenido, elaborado en tres etapas: (1) revisión integradora de la literatura, (2) estudio cualitativo por medio de entrevista semiestructurada con un equipo multiprofesional de trasplante hepático y pacientes que se sometieron a ese trasplante y (3) validación de contenido por medio de la técnica Delphi, con la participación de jueces con dominio en la temática y receptores de trasplante hepático.

Resultados: En total, 14 artículos originales atendieron los criterios de inclusión y señalan cuidados orientados hacia el uso de medicamentos, control de glucemia y cuidados con posibles alteraciones y complicaciones. En el estudio cualitativo, se formaron seis unidades de significados extraídas de las entrevistas con 20 pacientes y 13 profesionales del equipo. La consolidación de la información permitió formatear la pantalla inicial de la aplicación y seis pestañas de unidades de cuidados domiciliarios. La validación de contenido presentó un promedio general del índice de validez del 0,94 de los pacientes y del 0,84 de los profesionales en todos los ítems.

Conclusión: El contenido desarrollado y validado permite la gestión de cuidados domiciliarios de pacientes sometidos a trasplante hepático, lo que contribuirá para mejorar los índices de sobrevida del paciente y del injerto, ante los cambios de vida necesarios para el mantenimiento del nuevo órgano trasplantado.

Introduction

Liver transplantation (LTx) is considered an effective therapeutic advance in liver failure treatment, which has been improved over the years. However, home care management and monitoring of patients undergoing LTx is still fragile, representing an important knowledge gap.^(1,2)

It is noteworthy that it is at home that patients, along with their support network, are faced with the susceptibility of adverse events, problems and complications. Upon returning home after hospital discharge, they are faced with the responsibility, commitment and need to compliance with treatment and implement the care plan assigned to them, even in the face of limitations, doubts and insecurities.⁽²⁾

Compliance with treatment is linked to the imposition of daily drug therapy, mostly immunosuppressants, corticosteroids, insulin and others, in addition to care related to body and home hygiene, daily control such as temperature, urine output, blood pressure, weight and blood glucose, among others.⁽²⁻⁴⁾ In this scenario, care technologies, namely mobile applications (apps), arise to subsidize and assist patients and family members in conducting specific health care at home, as well as to inform how each activity can be developed on a daily basis.⁽⁵⁻⁷⁾

Evidence from literature indicates that the use of mobile apps can support home care management and health education regarding the correct and safe use of medications (dosage, schedule, drug interactions, most common side effects); monitor vital signs; indicate major changes (hyperglyce-

mia, hyperthermia, signs of infection and warning signs for other comorbidities); improve communication between health and patient services, treatment and self-care.⁽⁵⁻⁷⁾ Apps have the potential to positively impact treatment support by proposing real-time information related to patients' health needs at home. These technologies help patients and health staff monitor important data recorded and checked daily by patients at home, clarifying doubts, providing greater safety and lower risk for adverse events.^(7,8)

Considering the relevance of using mobile apps nowadays, the objective is to develop and validate the educational content of mobile app prototype for home care management of LTx recipients.

Methods

This is a methodological study, which aimed to develop and validate the educational content for a mobile app prototype, being carried out in three steps (Figure 1), at a teaching hospital in southern Brazil, which is a reference for LTx. It is worth mentioning that the proposal of this study was to present the content development and validity that will make up a prototype of a mobile app. Throughout the method steps, the readers will have the step-by-step development and validity of themes, topics and contents that will compose the mobile app prototype. Figure 1 clarifies each step for prototype content elaboration and validity.

Regarding the first step, an integrative literature review sought evidence on home care for patients

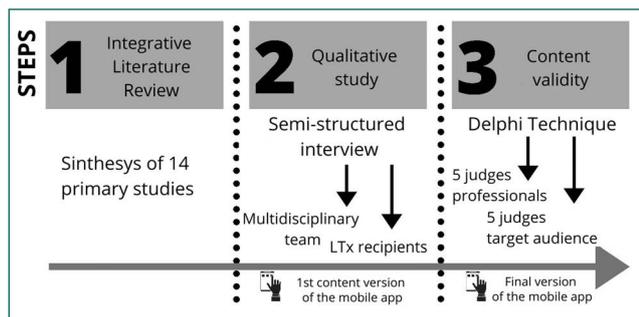


Figure 1. Development steps of mobile application prototype for home care management of liver transplantation recipients

submitted to LTx, conducted in six phases according to the research protocol performed: (1) theme identification and hypothesis and research question selection; (2) selection criteria establishments and literature search; (3) definition of the information to be extracted from the selected studies; (4) assessment of included studies; (5) interpretation of results; and (6) review presentation.⁽⁹⁾

The databases were defined: Scopus, Latin American and Caribbean Literature on Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE), consulted through PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), BDENF, Web of Science and the Scientific Electronic Library Online (SciELO) virtual library. The search strategy, carried out by one of the researchers in January 2019, was elaborated with descriptors “Liver transplantation” and “Hospital Discharge” in all databases in the same format.

Primary studies published between 2014 and 2019, in Portuguese, English and Spanish, were included. Theses, dissertations, letters, editorials, as well as studies that did not address the theme of interest, were excluded. To collect the information from the studies, a spreadsheet was elaborated containing title, author, journal, country, objective, methodological design, care recommendations for LTx discharge and types of evidence.

In the second step, a qualitative study was carried out with the LTx multidisciplinary team (physicians, nurses, pharmacists, nutritionists, physiotherapists, social workers and psychologists) and LTx recipients to learn about the health care provided by patients at home.

Professionals from the multidisciplinary team who worked in the care of LTx for at least 12 months and patients submitted to LTx between 2011 and 2019 were included. The period in question was defined considering that the said institution of study started its activities in 2011. As for the period of 2019, it was the cut-off to start collecting information in early 2020. All patients submitted to LTx at the institution where the research was developed, who underwent outpatient follow-up with this team during the data collection period, were included. Professionals who did not work at hospital discharge and in home care management, in addition to patients who did not undergo transplantation in the state of Santa Catarina and patients under eighteen years of age, were excluded. The research sample was intentional non-probabilistic, because we sought to interview patients who underwent transplantation with a survival time of one year, three years and five years, seeking to identify, with greater complexity, home care in the context of LTx over time. The interviews were closed when the researchers observed data saturation in the information. Thus, 13 health professionals and 20 patients were included.

Data collection was performed from March to May 2020, through semi-structured interviews, with five questions related to the profile of participants and five subjective questions, in order to know the health care to be performed by patients at home, as well as the contents or themes that this public considers important for the mobile app. The interviews were conducted by the researchers themselves, recorded, transcribed and validated by participants. Next, content analysis was performed, according to the thematic modality, following three steps: pre-analysis, material exploration with coding, treatment of results obtained and interpretation.⁽¹⁰⁾

The information obtained in the first and second steps formed the first version of the mobile app content. To consolidate this information, two researchers with more than 20 years of experience in the theme and two professionals of care practice with more than 10 years of experience with LTx

participated. This version was submitted to validity by judges.

And finally, the third step, composed of content validity through the Delphi technique. This technique did not define the exact number of judges, there is only one recommendation that is greater than three.^(11,12) For this, there was the participation of two groups of judges (team of professionals and LTx recipients), whose inclusion criteria were: for the team - to be part of the LTx multidisciplinary team, to have experience in the subject for five years, current or later performance in the care related to the moment of hospital discharge, in addition to having previous experience in content validity; for recipients - having performed LTx for more than a year, being up to date with outpatient care and having been discharged from the hospital with the support of the LTx team.

The judges judged the content of each item and sub-item, considering clarity of language, text content, item coherence, the item relationship with each category and important aspects of managing home care for patients undergoing LTx. For each item and subitem, a Likert-type scale was used. The results of each item and subitem were inserted into a Microsoft Excel® spreadsheet, and the Content Validity Index (CVI) was calculated. The value equal to or greater than 0.80 for each item of the CVI was considered valid. Scores below 0.80 were reviewed and revalidated. It is noteworthy that in the present study, all items had a CVI greater than 0.8 and agreement greater than 80%.

The research followed Resolution 466/2012 and its complementary ones from the Brazilian National Health Council/Ministry of Health, which provides for Regulatory Guidelines and Norms for Research Involving Human Beings, and was approved by the Research Ethics Committee according to protocol 1,575,457 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 54900716.8.0000.0121.

Results

In the integrative review (step 1), 1,169 studies were identified: BDENF (n=3), CINAHL (n=836),

LILACS (n=91), PubMed (n=229), Scopus (n=3), Web of Science (n=7). After applying the inclusion criteria, 14 original studies were obtained for analysis. Regarding the main findings identified in the original studies, recommendations for self-care encouragement are highlighted, with special attention to ensuring that these patients already start educational activities in the hospital environment as soon as they are able to receive information and develop care.⁽¹⁾ Moreover, relevant information was found regarding the importance of patients and caregivers being able to indicate signs and symptoms that may correspond to intercurrents and complications. These same studies reinforce that it is necessary to be clear which way to be followed by them when identifying these changes.^(5-7,13,14)

Regarding the use of medications, there are recommendations that involve the need for patients to know how to identify drugs against rejection, the main side effects, in addition to highlighting the importance of the pharmacist's participation at all times of guidance for this care.⁽¹³⁾ There are recommendations for the use of apps for self-management of care, that is, these studies point to greater tranquility of patients in developing home care considering the use of this care tool.^(5-7,14-16)

In the qualitative study (step 2) the sample consisted of 33 participants, 20 patients and 13 professionals from the multidisciplinary team, including two nurses, two physiotherapists, two psychologists, two nutritionists, two pharmacists, one physician and two social workers. The mean age of professionals was 32.4 years. Regarding patients, the mean age was 55.4 years and the mean transplantation time was 996.5 days.

Professionals considered the following home care: drug regimen, vital sign and blood glucose control, food and hygiene care maintenance. Information from patients showed the need for the app to contain clear and simple data on how to proceed with blood glucose control, use of medication, signs and symptoms of intercurrents and complications, as well as care with house hygiene and cleaning and emotional issues.

To consolidate, define and format the app content, the information obtained was structured based

on the identified needs and with the aim of offering LTx recipients educational content regarding the treatment to be performed at home after LTx. As for the format, the objective was to present data and information sequentially, so that, on the first page of the app, the target audience has access to the topics contained and, by clicking on each of the topics, they have access to educational information related to the desired content.

Consolidation of the first content version is demonstrated in Chart 1, with data from the presentation screen with the proposal of the app prototype content. After clicking “follow”, the second screen appears with six tabs containing the units of meaning. In each of the tabs, it is possible to click and obtain information regarding the care units, with their respective sub-items. Due to the content extension, the medication topic contents will only be displayed when clicking on the second tab.

Five professionals (nurse, psychologist, nutritionist, nutritionist, physiotherapist and pharmacist) participated in content validity (step 3), with a mean time of integration in the LTx multidisciplinary team of three years and eight months, and five patients undergoing LTx, with a mean time of treatment after LTx of four years and two months. There were two rounds for the app content assessment. Regarding the suggestions for changes made by judges, what was most identified as needing adjustments by patients was language. Practically, all suggestions involved transforming the content presentation into simple language using more understandable words, avoiding technical language. Still, there was the suggestion that the explanations be transformed into audiovisual materials, since for them it would be clearer. Regarding the adjustments requested by professionals, there were greater requests regarding the topic of feeding. The suggestions were related to make it clear, besides stressing what can and cannot be ingested by patients after transplantation. Considering that all prototype content items were assessed by all judges, there were many results from the CVI. Thus, we chose to present two tables, due to the extension of contents. The first refers to the topics that were assessed by each judge in each item of the medication topic,

Chart 1. User interface presentation of home screens and drug-related screen

Initial screen	Second screen
Home care management by patients submitted to LTx	Drug care information Food care information Hygiene and cleaning care information Psychosocial care information Daily control information* Disease prevention information
By clicking on the item "Medications"	Information (second screen)
Initial screen: Drug care information	Medications to prevent rejection Access to medications Storage Care questions and observations
Clicking on the item "Food-related care"	Information (second screen)
Initial screen: Food care information	Daily meals Allowed foods Forbidden foods Food preparation Prohibited consumption
By clicking on the item "Hygiene and cleaning care information"	Information (second screen)
Initial screen: Hygiene and cleaning care information	Hygiene and body care Observation Home cleaning and organization Observation
By clicking on the item "Psychosocial care information"	Information (second screen)
Initial screen: Psychosocial care information	Emotional changes Self-esteem Self-care Observation
Clicking on the item "Daily control information"	Vital signs check Blood glucose check Weight check Diuresis measurement
Clicking on the item "Injury prevention information"	Information (second screen)
Initial screen: Disease prevention information	Main complications Main problems

*The "Information for daily control" screen refers to care with checking vital signs, weight, measuring diuresis, checking blood glucose, in addition to checking for any changes in the skin, mouth region and genitals.

considering the final averages for professional judges and patients in the second round (Table 1).

Table 2 presents the CVICVI values compiled by patients and staff.

Discussion

The development of content and validity for the mobile app prototype made it possible to identify relevant information related to home care, both in the search for evidence in the literature and in the qualitative study. The educational content of this care technology may help minimize the risk of com-

Table 1. CVI result obtained through the assessment of judges on the topic of medication

Questions assessed by judges			
1. Regarding content	CVI (general)	Mean	Standard deviation
1.1 Information provides clear guidelines according to hospital discharge and return home.	0.86	3.86	0.89
1.2 Texts are written in a clear, simple and objective way.	0.88	3.76	0.83
1.3 Content follows a logical sequence in presentation.	0.89	3.92	0.92
1.4 Information presented for the prototype is in accordance with hospital discharge and home care.	1.00	4.00	0.96
1.5 Information presented is able to promote the continuity of home care.	0.96	3.90	0.92
2. Regarding language	CVI (general)	Mean	Standard deviation
2.1 Language is clear, simple and understandable.	0.88	3.13	0.64
2.2 Language is in agreement with spelling.	0.92	3.88	0.89
2.3 Theme titles are in accordance with care transition.	0.96	3.89	0.92
2.4 There is a sequential language of the information presented.	1.00	4.00	0.99
3. Regarding layout/presentation of prototype content sequence	CVI (general)	Mean	Standard deviation
3.1 It is relevant with the information submitted.	0.94	3.88	0.90
3.2 Topics with information are consistent.	0.92	3.76	0.89
3.3 The number of topics is appropriate.	0.89	3.92	0.92
3.4 Illustration and spacing colors are attractive.	1.00	4.00	0.99
3.5 Illustrations are in accordance.	0.91	3.90	0.93

Table 2. Average CVI of each application prototype topic by professionals and patients

Screens	CVI patient	CVI team	CVI mean
Medication	0.85	0.86	0.85
Food	1.00	0.88	0.94
Cleaning and hygiene	1.00	0.89	0.94
Psychosocial	0.88	0.87	0.87
Daily control	1.00	0.80	0.90
Injury prevention	0.88	0.82	0.85
Overall mean	0.94	0.84	0.89

plications and complications, in addition to mitigating the occurrence of adverse events, promoting better quality of life, preventing the risk of organ loss and recurrent hospitalizations of LTx recipients; since hospital discharge is a complex process that comprises the transition from the hospital environment to the home.⁽¹⁷⁾

Studies point to the need for the organization of hospital discharge, especially in the transition, in care management and in health education. When patients and family members are not safe and able to develop home care, patients may be exposed to risks such as infections, rejection, low treatment compliance, and the risk of depression and reduced autonomy.^(3,4,18)

Another decisive aspect in the prototype mobile app design content was the development of language sequentially, clearly and without technical terms. There is evidence that points to the low level of education of many patients and caregivers, and this characteristic can impact non-compliance with home therapy. In agreement with these findings, other studies emphasize that, among the attributes of a mobile app content, user performance, app effectiveness and characteristics and operator are crucial, and it is prudent that the final product meets the needs of the population that will use it.⁽¹⁹⁻²¹⁾

The data allowed the consolidation of information in care units and subunits, aimed at meeting the main needs identified, both by multidisciplinary team professionals and patients. It is expected that this technology will be of great value for health education, treatment compliance and support in care management.

It is noteworthy that the theme “use of medications” emerged in all research steps, therefore, the presence of timely information in the mobile app prototype is important, because it is an essential care in LTx treatment. Medication therapy is necessary for the survival of the transplanted organ and reduction of complications.^(13,22) The study highlights the importance of immunosuppressive therapy, being essential for the success of transplantation.⁽¹³⁾

Another care at home that was fundamental was regarding food. The feeding routine becomes more rigid after transplantation, which makes it difficult for patients to put into practice the information received. Thus, it is necessary that they understand the way food is prepared, which ones they can ingest and food contraindications. Literature shows that primary care with feeding after transplantation minimizes the risk of infection, overweight or low weight, in addition to diseases related to nutrition and metabolism.^(23,24)

With regard to potential complications, interurrences and warning signs, these emerged as useful, necessary and important information, since graft and patient survival are directly related to the prevention, identification and treatment of possible diseases. Such information, with the early iden-

tification of patient and family, enables the health team to be informed about these events.⁽¹⁾

Regarding daily control, this study highlighted the care with body temperature, blood glucose, blood pressure, diuresis and body weight control, and physical activities. In this regard, the information contained in the prototype detailed step by step how patients, family and caregivers should proceed to perform such activities. Through this educational information, these people will be able to develop the required care sequentially, paying attention to hygiene, as well as knowing how to assess whether the result obtained should be communicated to the health team or not. Regular physical activity emerges as paramount to help keep patients healthy, however it requires medical release for its onset.^(25,26)

Strict blood glucose control is an indispensable care to avoid complications, mainly due to the use of corticosteroids in the initial phase of immunosuppression. Patients need to be trained to use the glucometer as well as interpret the results. Studies have shown that glycemic monitoring, at predefined times and the correct interpretation of results, can prevent the worsening of a clinical picture,⁽³⁾ besides favoring the maintenance of body weight and performing protection against metabolic syndromes.⁽²⁷⁾ It is also considered that changes in glycemic level can decrease graft and patient survival,^(1,28) so it is essential that patients understand and perform the technique properly.

In relation to social, emotional and self-esteem issues, decreased libido (due to clinical condition and use of immunosuppressants), social isolation and return to work, was pointed out by practically all patients participating in the research. Literature also showed psychological and behavioral alterations.^(29,30) Thus, the mobile app prototype presented themes, such as signs of irritability, anxiety, fear and information on how to establish a support network to interact, the importance of sleeping at least eight hours a day, among others, to assist in these aspects. Education and health promotion of issues involving psychological and social issues after transplantation are important to support these people at home.⁽²⁹⁾

The study brought essential aspects for structuring the content, encompassing the care evidenced by the literature along with the guidelines provided by professionals, in addition to analyzing the needs faced by the patients themselves. It is noteworthy that the prototype validity obtained satisfactory CVI values and provided an opportunity to improve the information, with judges' contributions. Other apps already validated demonstrate the effectiveness in treatment of patients in other areas, being considered an effective strategy to encourage self-care and minimize complications in peripheral arterial diseases,⁽³¹⁾ asthma and allergic rhinitis⁽³²⁾ and in orthognathic surgery.⁽³³⁾ It is pointed out that, in the LTx scenario, there are few apps developed internationally,^(34,35) while in the national context, it has not been identified.

Among the methodological limitations, it is highlighted that there is a need to carry out a usability test in order to assess user interaction with the mobile app interfaces, as well as satisfaction with the information received. Furthermore, it is highlighted the difficulty in identifying apps aimed at transplants for home care management that could support the study.

Conclusion

The study describes a prototype content development and validity of an educational mobile app aimed at managing home care for LTx recipients. It was possible, therefore, to validate the mobile app prototype content with patients and multidisciplinary team based on the demands identified by literature review and qualitative research, systematizing the information sequentially and clearly. The tool developed seeks to ensure greater home care management for patients and caregivers in order to improve patient and graft survival rates in the face of so many life changes caused after LTx. The next step will be to assess, over time, the impact of this technology in preventing complications related to surgical treatment, as well as assessing the impact on transplantation recipients' quality of life.

Collaborations

Knhis NS, Wachholz LF, Magalhães ALP, Barra DCC, Mendes KDS, Nascimento KC and Paim SMS contributed to study design, data analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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