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RESEARCH

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FAMILY MANAGEMENT OF THE CHILD WAITING FOR AN ORGAN TRANSPLANT

*Manejo familiar da criança que espera por um transplante de órgãos**Manejo familiar del niño en espera de un trasplante de órganos***Hellen Angélica Ruiz¹** **Ana Márcia Chiaradia Mendes Castillo²** **Lucía Silva³** **Daniela Fernanda dos Santos Alves⁴** 

ABSTRACT

Objective: to understand the family management experiences of children awaiting solid organ transplantation according to the Family Management Style Framework. **Method:** a qualitative study was conducted using the aforementioned framework as a theoretical model. Interviews were conducted remotely with nine family members of children awaiting organ transplantation. Data were analyzed using a hybrid thematic analysis model. **Results:** families define this phase as oscillating between fear of transplantation, organ rejection and the possibility of dying on the waiting list, and hope for an improvement in the clinical condition. **Conclusion:** identifying the needs of the family waiting for transplantation allows the health professional to implement interventions.

DESCRIPTORS: Family; Transplantation; Pediatric nursing; Child;

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RESUMO

Objetivo: conhecer a experiência de manejo familiar da criança à espera de um transplante de órgãos sólidos de acordo com o Modelo de estilos de manejo familiar. **Método:** foi realizado um estudo qualitativo que utilizou o modelo supracitado como referencial teórico. Foram aplicadas entrevistas, de forma remota, a nove familiares de crianças que aguardavam por um transplante de órgãos. Os dados foram analisados através do modelo híbrido de análise temática. **Resultados:** as famílias definem que essa fase oscila entre o medo do transplante, da rejeição do órgão e possibilidade de morte em fila de espera, e a esperança na melhora do quadro clínico. **Considerações finais:** identificar as necessidades da família que aguarda por um transplante possibilita ao profissional de saúde implementar intervenções.

DESCRITORES: Família; Transplante; Enfermagem pediátrica; Criança;

RESUMEN

Objetivos: comprender la experiencia de gestión familiar de niños en espera de trasplante de órgano sólido de acuerdo con el Modelo de Estilos de Gestión Familiar. **Método:** se realizó un estudio cualitativo utilizando como marco teórico el modelo antes mencionado. Las entrevistas se realizaron de forma remota con nueve familiares de niños que esperaban un trasplante de órgano. Los datos se analizaron utilizando el modelo de análisis temático híbrido. **Resultados:** las familias definen que esta fase oscila entre el miedo al trasplante, el rechazo del órgano y la posibilidad de muerte en lista de espera, y la esperanza de mejora del cuadro clínico. **Consideraciones finales:** identificar las necesidades de la familia en espera de un trasplante permite al profesional de la salud implementar intervenciones.

DESCRIPTORES: Familia; Trasplante; Enfermería pediátrica; Niño.

INTRODUCTION

In the family context, the news of a child's chronic illness has painful repercussions and emotional consequences for all the family members.¹ Transplantation is an alternative for progressive and degenerative diseases of vital organs, but the need for it can create a mixture of emotions in the family, such as fear, uncertainty, anxiety, and hope for the child's recovery.²

The transplant process does not begin with the surgical act, but goes through phases - discovering the need for the transplant, waiting for it, receiving it, and living with it. Each phase can generate changes in family dynamics that require specific monitoring and professional intervention.³⁻⁴ The literature indicates the existence of two crisis phases, represented by knowing the need for transplantation and receiving the transplant, both characterized by imbalance in the family due to the adjustments that are more intense in these periods.³⁻⁴

The phase of waiting for transplantation, also called pre-transplantation, defined from the moment the patient knows the need for this intervention⁵, is characterized by waiting, during which the child and the family experience different feelings and changes, such as anxiety, doubts, fear and depression, which can be aggravated by financial difficulties and changes in family dynamics.¹ Of all the phases, the pre-transplantation phase is described by family members as the phase of greatest stress and uncertainty, compared to "living with a time bomb".⁵

O The increase in the mortality rate of children waiting for organ transplantation affects families, and the possibility of a child's death creates a sense of despair among family

members.⁶⁻⁷ According to official data from the Brazilian Association of Organ Transplantation (ABTO), in 2022, 286 children were added to the waiting list for transplantation, bringing the total number of children in the waiting list to 1,249; of these, 26 died while waiting for an organ in the first half of that year.⁸

Studies point to the need for family assessment and intervention in the pre-transplant period.⁹ When these interventions are carried out, the child's psychological adjustment is facilitated, leading to positive coping with the other stages. However, if the health care team does not adequately support the psychological and social conditions of the parents, this can have negative consequences, such as increased pre-transplant infant mortality, higher risk of late graft rejection, and extended hospitalization time.⁹

Understanding this family's experience of coping with transplantation can help guide the development of specific interventions. The Family Management Style Framework (FMSF)¹⁰ can be used to assess how the family responds to the chronic illness of a member.

The term "family management style" is used to refer to a consistent pattern of the family unit's response to a particular health condition. The term "management" reinforces the focus on the behavioral component of the family response.¹⁰ Family management can be defined as "the role of the family in actively responding to the illness and various health care situations."¹⁰

The FMSF assesses the family's response through three conceptual components: definition of the situation, management behaviors, and perceived consequences.¹⁰ The definition of the situation component refers to the meanings that the

family assigns to the management experience. The management behaviors include the principles adopted by the family members in the different situations imposed by the chronic disease, while the perceived consequences are the real or expected results of the family in the daily management of the disease, which shape the behaviors and, consequently, influence the definition of the situation.¹⁰

Given these needs, and considering the FMSF as a useful tool in the study of family management, the study aims to answer the following question "What is the experience of family management of the child waiting for solid organ transplantation?"

Thus, this study aims to understand the experience of family management of children waiting for solid organ transplantation in the light of the FMSF.¹⁰

MÉTODOS

Study type

Given the objective and nature of the research problem, the qualitative approach was chosen for this study. The FMSF was used as the theoretical framework.¹⁰

Study site

This study was conducted remotely. The principal investigator joined virtual support groups for transplant recipients and their families and posted announcements inviting for participation. The groups were selected based on the profile of the participants according to the objective of the study.

The inclusion of the researcher in the groups was done with the consent of the administrators of these communities. The purpose of the publications was to explain the aim of the research and the opportunity for families to participate. Those interested in participating responded to the publication and scheduled an interview.

Sampling

Sampling was carried out using the snowball sampling technique¹¹ with the virtual support groups as a channel for people awaiting or having undergone transplantation and their family members.

The number of participants was not defined in advance¹² and data collection was stopped when saturation occurred, i.e., when only repetition of existing data appeared without adding relevant information.¹²

Inclusion criteria

Families of children aged 12 years or younger who were waiting for a solid organ transplant were eligible for the study. Families whose children were awaiting a second transplant were excluded - a specific condition that was not evaluated in this study.

Study participants

Nine participants (one father and eight mothers) from eight families were interviewed. The participants ranged in age from

22 to 38 years, the children ranged in age from 4 months to 5 years, the average time they knew of the need for transplantation was 1 year and 6 months, and five children were waiting for heart transplantation, two for kidney transplantation, and one for lung transplantation. Two family members withdrew from participation after consenting, and one family did not meet eligibility criteria. Nine participants (one father and eight mothers) from eight families were interviewed. The participants ranged in age from 22 to 38 years, the children ranged in age from 4 months to 5 years, the average time they knew of the need for transplantation was 1 year and 6 months, and five children were waiting for heart transplantation, two for kidney transplantation, and one for lung transplantation. Two family members withdrew from participation after consenting, and one family did not meet eligibility criteria.

The Interviews

Interviews were conducted remotely via telephone and/or video call. All resources used for the interview were conducted in a protected space to ensure privacy and to protect the identity of the interviewee. It was clarified that the interview would be recorded and conducted via video call (Google Meet, ZOOM and/or Skype) or telephone call, according to the interviewee's preference.

The interview consisted of two parts in a single session. The first part was conducted with questions to identify the child and the family, and the second part consisted of open-ended questions, based on the FMSF¹⁰, to access the three dimensions of the theoretical model adopted (definition of the situation, management behavior and perceived consequences).

Procedures for analyzing and processing qualitative data

The interviews were fully transcribed by the researcher in order to deepen the data. The use of the recording helped the researcher to be more attentive to the participants and allowed her to focus on the interview and pay attention to the clarification of the information.

Data analysis was carried out using the hybrid model of thematic analysis, which integrates the deductive approach, based on code models, and the inductive approach, guided by the data.¹³

Ethical aspects

The project complies with CNS/MS Resolution No. 466/12, which deals with research involving human subjects at all stages.¹⁴ The research was submitted to the Ethics Committee in Research of the State University of Campinas (Unicamp), and the data collection was carried out after obtaining a favorable opinion (n° 5.636.628 and CAAE: 59443322.5.0000.5404).

The free and informed consent form (ICF) was sent electronically (by e-mail or messaging application) so that the participant could read it, clarify any doubts and sign it before the interviews began. It should be noted that one consent form was filled in per participant and not per family, i.e. in the case of two participants from the same family, each one filled in their own consent form.

RESULTS

The results are then presented according to the conceptual components defined by the FMSF10, illustrated by the speech of the participating families.

Definition of the situation

In terms of the child's identity, the family members define them as equal to others of the same age in terms of their ability to perform some typical childhood activities.

"She does her activities, we find everything for her to do, she knows how to draw, she knows how to count, we put on videos to stimulate her." (mother G.)

On the other hand, they see their child as different from other children when they recognize the limitations imposed by the disease, whether in the hospital or in the home context.

"But the difference is this: I can't nurture him; he feeds through a tube. I can't breastfeed him like other babies." (mother C.)

The vision of illness is guided by the discovery of a new reality: chronic illness preceded by the need for organ transplantation. Families see this situation influenced by fear, insecurity, and uncertainty about the cause, severity, and prognosis of the disease in the child and in the family.

"We are afraid of immunosuppressants, we are afraid of rejection, and we are afraid of the waiting time, that people still have a very big prejudice, a very big resistance to donating organs." (Mother C.)

The management's attitude is guided by the parents' view of the disease. The search for knowledge and information influenced the parents' view of the consequences of the disease and consequently the management mentality, as some families had more clarity about the decision to transplant and others had more questions about the consequences of transplantation and the prognosis of the disease.

"But then I did a lot of research and they explained to me why and how it should be done and if I didn't do it, what would happen, the pros and cons. And we thought it was the right thing to do and we decided to get on the list." (Mother P.)

Sharing similar beliefs and perspectives about the child and the illness promotes mutuality between parents. However, there are couples in the process of divorce and without mutual support; in these cases, despite the absence of the spouse, the mothers found mutuality with the maternal grandparents - who provided an effective and instrumental support network.

"We are very united! I even thought it would shake us up a bit, that we'd be a little disunited, but I think we're fine, we help each other". (Mother A.)

Management behaviors

The absolute priority is the child, so families organize themselves in such a way that the mother takes full care of the child, giving up her job and putting aside self-care routines. They try to give their children all the typical childhood experiences, despite the limitations caused by the disease.

"Everything we did, even if we made a mistake, we did it with good intentions, we wanted to make things possible for him." (Mother K.)

The prioritization of the child and the illness influenced the management approach and included changes that were deemed necessary - such as moving and adjusting the family routine.

"I had to move to São Paulo because of this problem. I came from Minas Gerais." (Mother N.)

The search for knowledge and information about care and the disease made the approach more flexible, as parents acquired skills to use hospital equipment and felt more confident in managing childcare, allowing them to add other family demands to the dynamics of the home.

"The difficulties are in the sense of not having the technical knowledge. A lot of doubts in the beginning, like how to use the probe, how to deal with it when she loses the probe and then how to position it, you don't have to be afraid, you start to live with it, and you start to understand that it's not a seven-headed beast." (Mother I.)

Perceived consequences

The focus of the family is on the child and the illness in such a way that the healthy siblings end up receiving less attention so that the parents can focus their efforts on the sick child.

"Sometimes I focus too much on F. and forget that I have my other two (daughters)." (mother E.)

The demands of this new context create overload and stress for family members, even leading to health problems.

"So, it has made me very tired, it has made us tired and stressed." (Mother I.)

Expectations for the future oscillate between fear and hope. Fear of rejection of the transplanted organ and the possibility of death of the child on the waiting list, and hope for success of the transplantation and improvement of the quality of life, or that the child's condition will improve to the point where he or she will be able to maintain the function of the organ and will not need a transplant.

"My husband still has this belief; he still thinks that she can come off the transplant list." (Mother A.)

DISCUSSION

Waiting for transplantation upsets the balance of the entire family system. The nurse must be aware of how the family is trying to restructure itself to meet the demands of the illness to intervene and help them regain balance. In this context, the use of the FMSF¹⁰ - used to guide the collection and analysis of data in this study - provides an understanding of the management experience lived by these families.

The use of the FMSF allowed for an organized understanding of the management experience in the context of waiting for solid organ transplantation and made it possible to think about specific interventions for families focused on their needs.

The duration of living with the chronic disease is an important element of management, as families begin to acquire more autonomy and competence for care.¹⁵

The course of the disease allows the family to obtain opportunities to interact with different elements in the experience, ensuring training and the search for alternatives and strategies to deal with the disease.¹⁵ In this way, time becomes an ally of families to acquire skills and mastery that can lead to more security or control to manage the situation.¹⁵

Therefore, nurses should take advantage of this moment to provide families with forms of training for their management skills. This should be done through education that serves as an opportunity for training and encouragement to seek strategies for living with the disease and providing information to the family means providing a change in perspective on the disease. From the moment parents begin to see the disease in a different way, they begin to adjust the management mentality.¹⁶ As a result, the management mentality is modified and may lead parents to manage the situation in a better way.

For families experiencing the context of waiting for a solid organ, the road to transplantation is fraught with uncertainty. Parents have uncertainties on how long they will be on the waiting list, on the possibility of the child on the waiting list dying, about organ rejection, and about the quality of life after transplantation.

The study emphasizes that one of the resources to face uncertainty is hope, because it gives you the strength to allow yourself to continue fighting and to overcome problems by focusing on the future.¹⁷ As a peculiarity of our families, hope is experienced by parents in two ways: hope that the child will receive the transplant soon, and hope that the child will not need the transplant and will be taken off the waiting list.

Therefore, the study proposes the following suggestions for interventions with families going through this experience: promotion of psychosocial support, through social interaction groups with families facing the same context; activities that increase the family's confidence; emotional and situational coping skills, such as promoting psychological and social support for these families; through actions with a multidisciplinary team; and ensuring that information is made available from reliable sources about the child's situation and the disease.¹⁷

In this study, of the eight families interviewed, two experienced the divorce of the parents after the discovery of the child's disease. In one of them, the marriage did not last because of disagreements about the child's treatment. However, the other families described how the discovery of the chronic disease brought unity and mutual support to the family. Despite the new demands and changes in routines and adaptations that came with the new context, the families affirm that this phase strengthened the couple's mutuality.

However, despite the positive and negative points that permeate changes in conjugality, they are directly related to the child's prognosis, that is, they can increase or decrease according to the evolution of the child's chronic disease.¹⁸ In addition, the experience of chronic disease can extend over a long period of time, causing wear and tear in marital life.¹⁸

In this sense, a study on the resilience of families of hospitalized children describes points that can minimize the impact on the marital relationship and can serve as suggestions for possible interventions with our families, also taking into account the context of a child's chronic illness and changes in family dynamics.¹⁹ First of all, supporting communication between the couple is of paramount importance, since communication, whether verbal or not, influences the marital climate and can have a positive or negative impact on the relationship between the parents.¹⁹

In addition, it is necessary to strengthen empathy between the couple, so that one can put oneself in the other's shoes and begin to understand the other's feelings. Couples should be given the opportunity to share experiences, as this implies a reduction in the impact of the disease on the person and increases the cohesion of the family unit, so that it can achieve resilience and withstand the process.¹⁹

The last point to be discussed is the burden of the family caregiver, since in most cases this burden is borne by only one person,²⁰ and historically this role has been played by the mother.²¹ In a cultural context, a Brazilian study points out that traditionally, domestic care and child-rearing have been obligatory female activities. In this way, the mother's figure is associated with domestic responsibilities, while the father's is associated with financial participation and the labor market.²⁰

In all the families interviewed in this study, the mother was the main caregiver of the sick child. In addition, seven of the participating mothers stopped working to devote themselves exclusively to their children.

Encouraging family support means reinforcing reciprocity so that it extends to listening to each other's concerns and feelings, drawing out strengths and resources for support between the couple, which can also extend to other family members, and strengthening the possibility of collaboration in childcare and household chores.¹

CONCLUSION

The study has allowed us to understand the family management of children waiting for solid organ transplantation. Therefore, it is observed that this context is peculiar and requires

understanding on the part of the health professional - so that he can exercise specific interventions for the families who live this experience.

The theoretical model of the FMSF used for this research was unique in terms of knowing the experience of family management, making it possible to go beyond evaluation and direct specific interventions, thus demonstrating that it is a useful framework for care practices.

As recommendations for practice, the empowerment of health professionals in terms of knowledge about the pre-transplantation phase of solid organs, especially in terms of its impact on the child and the family, is encouraged in order to act in this context to support these families. In addition, the professional nurse should be recognized as an important member of the multidisciplinary team in terms of knowing the family's management of the pre-transplantation phase and listing specific and necessary interventions to help families manage and cope with this phase.

Regarding the recommendations for future research, it is suggested to implement education and preparation programs for solid organ transplantation, considering that there is a need to eliminate the doubts and uncertainties of families and to disseminate information from reliable sources - taking into account the specificity of each type of solid organ, such as: use of medications and drug therapies, side effects of implemented therapies, manipulation of hospital equipment at home, warning signs and symptoms of the clinical picture and encouragement of ways to promote typical childhood activities.

It is also recommended to create platforms that offer not only support for coexistence, but also the possibility of obtaining health information from reliable sources and in accessible language.

Thus, as recommendations for teaching, it is suggested to provide professionals and future health professionals with information on the importance of understanding the family, since changes in a single member alter the entire family dynamics and the pre-transplant context outlines peculiarities that are not limited to the individual.

Limitations of the study include the fact that, due to the remote nature of the interviews, only families with Internet access were able to participate.

BIBLIOGRAPHIC REFERENCES

1. Virches A, Miyazaki ET, Dos Santos Junior R, Duca WJ, da Silva Fucuta P, Ferreira da Silva R, et al. Burden, Stress, and Depression in Informal Caregivers of Patients Pre and Post Liver Transplant. *Transplant. proc.* [internet]. 2021[cited 2024 jan 18];53(1). Available from: <https://doi.org/10.1016/j.transproceed.2020.02.072>.
2. Hickner B, Anand A, Godfrey EL, Dunson J, Reul RM, Cotton R, et al. Trends in Survival for Pediatric Transplantation. *Pediatrics.* [internet]. 2022 [cited 2024 jan 18];149(2):e2020049632. Available from: <https://doi.org/10.1542/peds.2021-054099>.
3. Mendes-Castillo AMC, Bousso RS, Ichikawa CR de F, Silva LR. The use of the Family Management Style Framework to evaluate the family management of liver transplantation in adolescence. *Rev. Esc. Enferm. USP.* [Internet]. 2014 [cited 2024 jan 18];48(3). Available from: <https://doi.org/10.1590/S0080-623420140000300007>.
4. Weissheimer G, Mazza V de A, Teodoro FC, Szylit R, Ichikawa CR de F, Schepelski UG de FA. Family Management and socioeconomic situation of children and adolescents with neurological disorders. *Rev. bras. enferm.* [Internet]. 2020 [cited 2024 jan 18];73(4):e20190042. Available from: <https://doi.org/10.1590/0034-7167-2019-0042>.
5. Anthony SJ, Annunziato RA, Fairey E, Kelly VL, So S, Wray J. Waiting for transplant: physical, psychosocial, and nutritional status considerations for pediatric candidates and implications for care. *Pediatr. transplant.* [internet]. 2014 [cited 2024 jan 18];18(5). Available from: <https://doi.org/10.1111/petr.12305>.
6. Deshpande S, Sparks JD, Alsoufi B. Pediatric heart transplantation: Year in review 2020. *J. thorac. cardiovasc. sur.* [internet]. 2021[cited 2024 jan 18];162(2). Available from: <https://doi.org/10.1016/j.jtcvs.2021.04.073>.
7. Avsar M, Petená E, Ius F, Bobylev D, Cvitkovic T, Tsimashok V et al. Pediatric urgent heart transplantation with age or weight mismatched donors: Reducing waiting time by enlarging donor criteria. *J. card. surg.* [internet]. 2021 [cited 2024 jan 18];36(12). Available from: <https://doi.org/10.1111/jocs.16041>.
8. Associação Brasileira de Transplantes de Órgãos (ABTO). Dimensionamento dos transplantes no Brasil e em cada Estado no ano de 2022 [internet]. *Rev. bras. transp.* [acesso em 18 janeiro 2024]. Disponível em: <https://site.abto.org.br/wp-content/uploads/2022/11/rbt-naoassociado.pdf>.
9. Sahin Y, Virit O, Demir B. Depression and Anxiety in parents of children who are candidates for liver transplantation. *Arq. gastroenterol.* [Internet]. 2016 [cited 2024 jan 18];53(1). Available from: <https://doi.org/10.1590/S0004-28032016000100006>.
10. Knafl K, Deatrick J. Further refinement of the family management style framework. *J. fam. nurs.* [Internet].

- 2003 [cited 2024 jan 22];9(3). Available from: <https://doi.org/10.1177/1074840703255435>.
11. Vinuto J. A amostragem em bola de neve na pesquisa qualitativa: um debate em aberto. *Tematicas*. [internet]. 2014 [acesso em 18 de janeiro 2024];22(44). Disponível em: <https://econtents.bc.unicamp.br/inpec/index.php/tematicas/article/view/10977>.
 12. Boyatzis R. *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks (CA): Sage; 1998.
 13. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *Int. J. qualit. methods*. [internet]. 2006 [cited 2024 jan 18];5(1). Available from: <https://doi.org/10.1177/160940690600500107>.
 14. Ministério da Saúde (BR). Resolução nº466, de 12 de dezembro de 2012. Aprova diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial da União* 12 dez 2012; Seção 1.
 15. Sellmaier C. Physical and Mental Health of Mothers and Fathers Caring for Children with Special Health Care Needs: The Influence of Community Resources. *J. fam.* [internet]. 2022 [cited 2024 jan 18];43(11). Available from: <https://doi.org/10.1177/0192513X211035580>.
 16. Gesteira ECR, Szylit R, Santos MR dos, FariaIchikawa CR de, Oliveira PP de, Silveira EAA. Family management of children who experience sickle cell disease: a qualitative study. *Rev. bras. enferm.* [internet]. 2020 [cited 2024 jan 18];73(4):e20190521. Available from: <https://doi.org/10.1590/0034-7167-2019-0521>.
 17. Saricam H, Meral D, Ahmetoglu E . Examination of hope, intolerance of uncertainty and resilience levels in parents having disabled children. *Global Journal of Psychology Research: New Trends and Issues*. [Internet]. 2020 [cited 2024 jan 18];10(1). Available from: <https://doi.org/10.18844/gjpr.v10i1.4398>.
 18. Bartolo MJ. *Impacto do Coping Diádico no Ajustamento Mútuo conjugal em contexto de Doença Crónica no sistema filial* [Mestrado em Psicologia e Ciências da Educação]. Coimbra (Portugal): Universidade de Coimbra; 2018. Disponível em: <https://hdl.handle.net/10316/85330>.
 19. Pertence L, Kohlsdorf M. Resiliência Familiar no Processo de Hospitalização Infantil. *Perspectivas em Psicologia*. [Internet]. 2020 [acesso em 22 de janeiro 2024];24(1). Disponível em: <https://seer.ufu.br/index.php/perspectivasempsicologia/article/download/58078/30420/247141>.
 20. Toledano-Toledano F, Luna D. The psychosocial profile of family caregivers of children with chronic diseases: a cross-sectional study. *BioPsychoSocial Medicine*. [internet]. 2020 [cited 2024 jan 18];14:29. Available from: <https://doi.org/10.1186/s13030-020-00201-y>.
 21. Wright LM, Leahey M. *Enfermeiras e famílias: guia para avaliação e intervenção na família*. 5ª ed. São Paulo (SP): Roca; 2012.

