REVISTA DA ESCOLA DE ENFERMAGEM DA USP
JOURNAL OF SCHOOL OF NURSING · UNIVERSITY OF SÃO PAULO

REVIEW

DOI: https://doi.org/10.1590/1980-220X-REEUSP-2021-0153

Communication of HIV diagnosis in proper time: scoping review*

Comunicação do diagnóstico de HIV em tempo oportuno: revisão de escopo

Comunicación oportuna del diagnóstico de VIH: revisión de alcance

How to cite this article:
Cremonese L, Padoin SMM, Paula CC. Communication of HIV diagnosis in proper time: scoping review. Rev Esc Enferm USP. 2021;55:e20210153. https://doi.org/10.1590/1980-220X-REEUSP-2021-0153

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* Extracted from the doctoral thesis "Comunicação do diagnóstico de infecção pelo HIV em pediatria: revisão de escopo", Programa de Pós-Graduação em Enfermagem, Universidade Federal de Santa Maria, Santa Maria, 2020.

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ABSTRACT

Objective: To map how the communication of the HIV infection diagnosis occurs in pediatrics. **Method:** Scoping review of the 64 original articles. We selected research papers in Portuguese, English, or Spanish, with the participants: child, adolescent, relative/family, and/or health professional from 2011–2020. We accessed the following sources: PubMed, CINAHL, Scopus, WoS, ASSIA, PsycINFO, ERIC, Sociological Abstracts, Edubase, LILACS, BDENF, and IndexPsi. **Results:** Regarding the population, it was evident to us that the relative must be the sender of the diagnosis with the professionals' support; regarding the reasons for the communication, the child maturity, expressed by questions, the necessity of therapy adherence, abilities to communicate and the right of knowing the diagnosis must be considered. The communication channel is centered on materials that promote comprehension, quantity, and quality of information. That indicated an interactive process. Regarding the effects, they are beneficial when the communication occurs at a proper time. **Conclusion:** Communication must occur through a process that includes professional support to the relatives/family, development of abilities to evaluate the appropriate moment, and the monitoring effect.

DESCRIPTORS

HIV; Communication; Child Health; Adolescent Health; Review.

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Received: 04/14/2021
Approved: 09/08/2021

INTRODUCTION

Communication has as objective the transmission and recuperation of information between people. To that end, it involves elements: the sender, represented by someone that sends the message; the receiver, who receives the information; the message, that addresses the content or the information communicated; the communication channel, the medium used, and characteristics of the adopted manners to the transmission of ideas; context, that considers the aspects of the life of the people involved before the communication happens; the effects, that are the repercussions after the communication[1].

When the communication is inserted in the field of health, it may be considered bad or difficult news to be transmitted. This communicative process causes sadness, anguish, grief, or other negative feelings related to the health prognosis[2]. The complexity for pediatric communication is in the necessity to align the family demands with the child or adolescent's, besides requiring an interpersonal relationship to establish professional support. Such necessity indicates that the preparation of everyone involved is essential[3].

The diagnosis communication is a medical attribution that involves a multi-professional team that needs to embrace, guide, support, and promote full care[4–5]. The way of communicating must be honest, empathic, and objective, aiming to enhance better effects in the child or adolescent, family, and professionals[6].

In situations where the diagnosis communication is the HIV infection, the complexity of the communicative process increases, considering the stigma and, at times, the diagnosis of other family members[7]. Hence, it requires a plan that begins in the establishment of the diagnosis of this infection and implies in the communication to the family and their preparation[8] to communicate, preferably in childhood, with professional support[9], and remain in monitoring[10]. However, the relatives/family postpone the decision of communicating, and that occurs mostly in adolescence, but we recommend that the communicative process occurs from childhood, which may guarantee for the child the right of knowing their diagnosis[11].

In the World Health Organization's guidelines, there is a recommendation of additional research because professionals need the support of politics and guidelines based on evidence about when, how, and in which conditions children must be informed about their HIV diagnosis[11]. This support may positively imply the competence of health professionals in supporting families in communication. Meeting the World Health Organization recommendation, and to confirm the necessity of developing the present review, we carried out a previous search in the following sources Cochrane, JBI, PROSPERO, and PUBMED, and we identified a review about tools to assist in the communication of the HIV diagnosis for children[12]. Thus, the objective of this review is to map how the communication of the diagnosis of HIV infection in pediatrics occurs.

METHOD

Study Design

Scoping review (ScR) study guided according to the JBI[13] guidelines, an international health research organization based on evidence, that guides the systematic reviews with a wide and inclusive approach of evidence, with a diversity of questions and study designs. To start we established a question of revision structure by the acronym composed by participants, concept, and context (PCC) that constituted in: How does the communication of the HIV infection diagnosis occur for children and adolescents? The review protocol was not published.

For the quality and transparency of the writing of this article, we followed the guidelines of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)[14] checklist.

Eligibility Criteria

For the eligibility criteria, We followed the PCC acronym structure, for the participants, we selected studies with children until nine years old and adolescents from 10 to 19 years old[15] infected with HIV in childhood, health professionals or relatives/family (regardless of the conceptual determination utilized in the primary study, family or relative). Regarding the concept, the criteria were studies that approached the communication of the HIV infection diagnosis. Moreover, regarding the context (location) in which the communication occurred, there was no delimitation aiming to allow the mapping of elements and the different scenarios, such as in the hospital, outpatient, and home environment.

The review considered studies from primary research, with quantitative outlines including experimental, descriptive, and observational studies reporting any quantitative data that could be included in the review and/or qualitative, including phenomenology, data-based theory, ethnography, participative and qualitative description. The included languages in this review were Portuguese, English, or Spanish. The time frame utilized was 2011, considering that the HIV Communication Guide for Children until 12 years old was published that year[11].

Data Collection

For the data collection, we develop a three-step[13] research strategy. The first consisted in mapping the terms according to the PCC acronym, in which we mapped the descriptors/words in the population that contemplated the participants in the communicative process in pediatrics: children, adolescents, health professionals, and family. The mapping regarding the context indicated that the topic articles did not use terms that informed the location of the communication, neither the descriptors nor the words (title, abstract), thus they did not integrate the strategy in order not to limit it. Such terms were utilized to develop a

full strategy of research for PUBMED and adapted to the following database:

("caregivers"[Title/Abstract] OR "caregivers of children"[Title/Abstract]) OR "family"[Title/Abstract]) OR "families"[Title/Abstract]) OR "parents"[Title/Abstract]) OR "children"[Title/Abstract]) OR "child"[Title/Abstract]) OR "pediatrics"[Title/Abstract]) OR "infant"[Title/Abstract]) OR "preschool"[Title/Abstract]) OR "pre-school"[Title/Abstract]) OR "newborn"[Title/Abstract]) OR "parents"[MeSH Terms]) OR "child"[MeSH Terms]) OR "child, preschool"[MeSH Terms]) OR "infant"[MeSH Terms]) OR "pediatrics"[MeSH Terms]) OR "caregivers"[MeSH Terms]) OR "family"[MeSH Terms] OR "paediatric"[Title/Abstract])) AND ("hiv"[Title/Abstract] OR "human immunodeficiency virus"[Title/Abstract]) OR "aids"[Title/Abstract]) OR "hiv/aids"[Title/Abstract]) OR "acquired immune deficiency syndrome"[Title/Abstract]) OR "acquired immunodeficiency syndrome"[Title/Abstract]) OR "hiv"[MeSH Terms]) OR "acquired immunodeficiency syndrome"[MeSH Terms]) OR "infectious disease transmission, vertical"[MeSH Terms]) OR "hiv seropositivity"[MeSH Terms]) OR "hiv infections"[MeSH Terms]) AND ("truth disclosure"[Title/Abstract] OR "disclosure of diagnosis"[Title/Abstract]) OR "self disclosure"[Title/Abstract]) OR "disclosure communication"[Title/Abstract]) OR "disclosure concept"[Title/Abstract]) OR "communication source"[Title/Abstract]) OR "communication barrier"[Title/Abstract]) OR "patient provider communication"[Title/Abstract]) OR "truth telling"[Title/Abstract]) OR "bad news"[Title/Abstract]) OR "truth disclosure"[MeSH Terms]) OR "self disclosure"[MeSH Terms]) OR "communication barriers"[MeSH Terms])

The second step was the search for a database, which occurred in May 2020. The third step refers to the exam of the reference list of the included articles for the additional studies selection.

The information sources were MEDLINE/PubMed, CINAHL/EBSCO, Web of Science Core Collection/Clarivate Analytics, Applied Social Sciences Index and Abstracts – ASSIA/ ProQuest, PsycINFO/APA, ERIC/ProQuest, Sociological Abstracts/ProQuest, Edubase/UNICAMP e LILACS/BVS, BDENF/BVS, and IndexPsi/BVS.

We developed the process to select the studies and extract the evidence of the recovered articles in double-mode independently, with disagreements being decided by the third reviewer. It was not necessary to contact the authors to recover any additional information. We developed the selection by reading the titles and the abstracts, followed by the full-text reading of the articles and the reference list checked of each one of the included studies.

For data extraction, we used a standard form developed by the team of reviewers and previously tested. We organized the mapping in a synoptic chart containing the following information: author, year, country, objective, delineation, and study population. For the result extraction, we utilized sender, receiver, context, message, channel, effects, noise, and failure. For this article, we opted to approach the elements of Lasswell's[1] communication process model, which is when the communication diagnosis happens. Hence, the elements of noise and failure that prevent communication were not explored in this article.

We used Mendeley software for the management of references. We did not carry out a critical evaluation of the individual evidence sources of the recovered articles, because this type of review does not require such evaluation[13].

Analysis and Processing of Data

For data manipulation and synthesis, we grouped the results throughout the elements of Lasswell's[1] communication process model. We represented with figures the situations when the communication happened considering the sender and the receivers. Hence, we called situation 1, when the sender was the familiar and the receiver the child/adolescent. Situation 2 occurred when the senders were a relative/family and the health professional, and the receiver the child/adolescent. And situation 3 happened when the sender was the health professional and the receiver the child/adolescent. We organized these situations and the other communication elements in figures and presented them narratively. The discussion presents convergences of the mapping evidence and interconnected the extension of available evidence with the analytical framework of the communicative process[1] and with the guidelines for the communication of the HIV diagnosis for children. The description of the contribution of the review for the health field, the gaps of knowledge related to the mapping concept projected potential implications for the investigation.

RESULTS

Our search strategy located 1450 articles, of which we selected 70 articles for full-text reading, and we included 64 for the analysis (Figure 1). We excluded six articles, three with a description of an intervention proposal, one with a description of intervention implementation, and two because we did not have access to the full-text, even after contacting the authors.

Most studies were carried out in the African continent, which may have been influenced by the world HIV index because these indexes are higher in this continent and constitute a public health problem. The participants of the study were a total of 10,147 adolescents (10,32%), 664 health professionals (6,54%), and 555 children (5,46%). There is a gap in studies that include a population of children; this data indicates the diagnosis communication as delayed once the studies included more adolescents. We highlight that children have the right to know their diagnosis; they represent a lower percentage of participants in the studies, which indicates evidence of the communicative process being sustained the majority of the time, in the perception of the relatives/family and health professionals (Chart 1). Regarding the

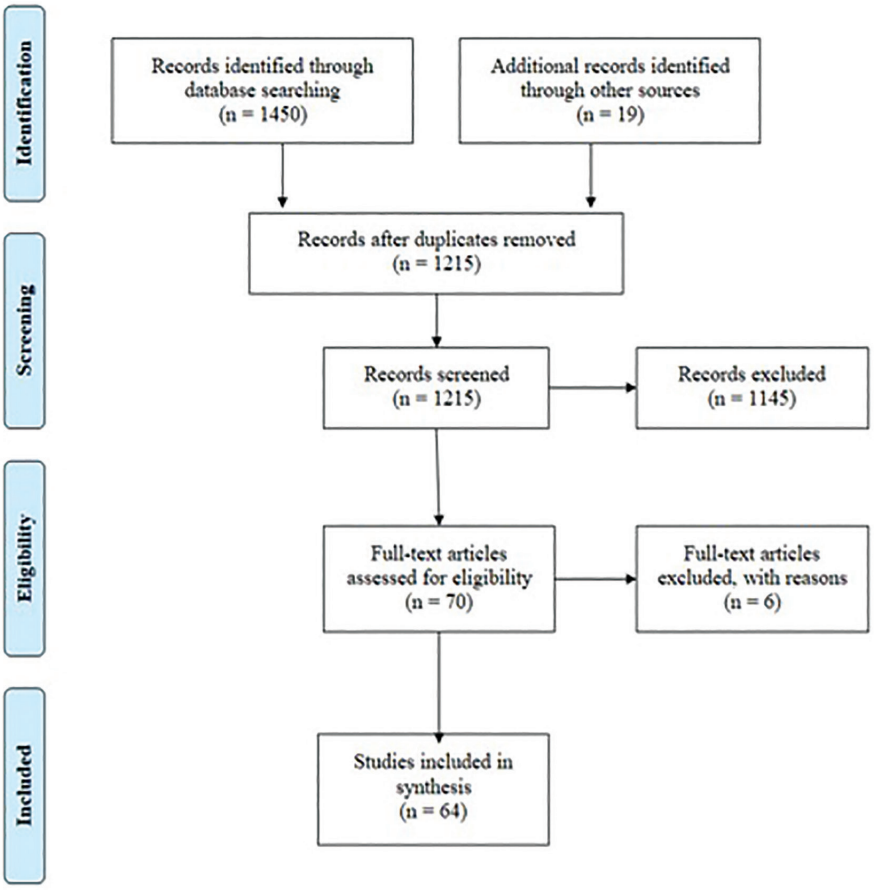

Figure 1 – Flow chart according to the PRISMA Extension for Scoping Reviews (PRISMAScR)[14] – Santa Maria, RS, Brasil, 2020.

Chart 1 – Characterization of the primary studies included in the review in chronological order of publication – Santa Maria, RS, Brasil, 2020.

Country/Year	Objective	Sample
Ethiopia/2012[16]	To explore the knowledge, attitude, practices, and barriers perceived by parents/guardians regarding the announcement of the HIV status of the children under their care.	172 f
Brazil/2012[17]	To present the participation of caregivers in the strategy building for the HIV communication to HIV positive children as well as to discuss the interventions that contributed to the overcoming of difficulties that commonly prevent relatives/family to accept this process.	23 f, 18 c
South Africa/2012[18]	To identify beliefs about the communication of the HIV diagnosis for HIV infected children among caregivers, health care providers, and children who are knowledgeable of their diagnosis.	51 f, 24 p, 05 c
South Africa/2012[19]	To examine the barriers of caregivers to communicate the HIV diagnosis for their children.	25 f
South Africa/2012[20]	To determine the caregivers' reasons for the communication or not of the HIV diagnosis for children undergoing ART, and determine the perception of caregivers about the reaction.	149 f
Ivory Coast, Mali, and Senegal/2012[21]	To evaluate the effect of the announcement of HIV status in the care retention since the beginning of ART among HIV-infected children of 10 years old or older.	650 c/a
Ethiopia/2012[22]	To evaluate the magnitude and the factor for the communication of the HIV status among infected children.	428 f
Botswana e Tanzania/2012[23]	To comprehend and identify ways between the communication of the HIV status, the ART, and the psychological well-being of the children, including in the own perspective of the adolescents.	05 p, 28 a
Brazil/2013[24]	To present how a childish story contributes to unleashing a conversation with children regarding their treatment.	05 c, 05 f
Kenya/2013[25]	To determine communication relations of the HIV status for children, and determine the attitudes, practices, barriers regarding the announcement of this cohort.	271 f
Italy/2013[26]	To work with small groups of caregivers and discuss common problems and feelings to develop self-confidence competence in family and patients so that the parents and their children effectively manage their own health.	17 f (GI:10, GC:7)
South Africa/2013[27]	To explore the perspectives of a health team and experiences about communication practices.	23 p

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Country/Year	Objective	Sample
South Africa/2013[28]	To determine the characteristics of caregivers of pediatric patients with HIV, to estimate the prevalence and the moment of communication of HIV among these patients, and evaluate the associated factors to the status communication.	286 f
Ethiopia/2013[29]	To evaluate the barriers/factors of caregivers in the announcement of the HIV status of their children and determine the associated factors to the communication to children undergoing HAART.	231 f
South Africa/2014[30]	To examine the Theory of Reasoned Action predictors of announcement of the serological status for children with HIV.	100 f
Uganda/2014[31]	To examine caregivers' perception regarding the concept of communication before that, their motivation to communicate or postpone it and their intentions of short and long term for the communication for HIV infected children.	40 f
South Africa/2014[32]	To examine health professionals' opinions about the exposure of HIV-infected children and determine their role in the announcement for those who access ART.	206 p
Tanzania/2014[33]	To explore the associated factors to the communication of the HIV status for children infected by the HIV that are attended at the Kilimanjaro Christian Medical Center.	211 f, 211 c/a, 25 p
Thailand/2014[34]	To report the rate of HIV announcement among Thai children/adolescents, interviewing their caregivers, to determine if the announcement had an impact or correlation in the ART adherence or immunology and virological results.	260 c/a
Kenya/2014[35]	To describe the prevalence of communication and associated factors in a cohort of HIV-infected children and adolescents.	792 c, a, f
Zambia/2014[36]	To describe barriers for the announcement of HIV; report the factors that influence adolescents to decide to announce the HIV diagnosis to others and the impact of that announcement.	53 a, 24 p, 21 f
Malawi/2014[37]	Explore potential factors that challenge parents/guardians to communicate the HIV status to the perinatally infected child.	20 f
Tailandia/2014[38]	To determine the associated factors to the caregiver's readiness in communicating the HIV status to their child.	273 f
Zimbabwe/2014[39]	To comprehend how the perinatally infected adolescents learn the HIV status and their preferences for the communication process.	31 a, 15 p
Botswana/2014[40]	To report the caregivers' perceptions about the communication and their experiences with infected children that attend an HIV pediatric clinic in a rural district.	20 f
Uganda/2015[41]	To examine the prevalence, reasons for the communication or not, and associated factors to the complete announcement of HIV among children.	302 f
South Africa/2015[42]	To evaluate the efficiency of the infant communication intervention.	35 p, 46 f
Uganda/2015[43]	To determine the rate of communication of HIV by parents/guardians to their children and factors that affect the communication.	174 f, 20 c/a, 10 p
Ethiopia/2015[44]	To identify the predictors that facilitate the communication of the HIV status for children and adolescents and the reasons for not communicating.	177 c/a
Kenya/2015[45]	To understand how the social factors mold communication of HIV to children from the perspective of the caregivers and the children.	61 f, 23 c/a
Brazil/2015[46]	To comprehend the meaning of the HIV diagnosis revelation for the adolescent.	12 a
Ghana/2015[47]	To present the knowledge and beliefs of the caregivers of HIV infected-children that did not have their status revealed.	298 f (GI: 131 GC: 167)
South Africa/2015[48]	To examine the associations between adolescents' knowledge about the HIV-positive status and the adherence to the ART.	684 a
Zambia/2015[49]	To explore the facilitators, barriers, and processes of communication of the HIV status for adolescents by their caregivers.	30 f
South Africa/2015[50]	To establish if the announcement of HIV occurred, how the process was developed, the reasons for not communicating, and the effect on the understanding of the child about their own disease and adherence.	n: 100 f, 27 c/a
Tanzania/2015[51]	To evaluate the determinants and processes of announcement of the HIV status for children from 4 to 17 years old.	334 f
Ghana/2015[52]	To comprehend the benefits of communicating about HIV for children and adolescents infected in the caregivers' perception, and evaluate the nature of the support during the process of communication in the perspective of the health professionals and caregivers.	118 f
Uganda/2015[53]	To explore the experiences of communicating with adolescents infected by HIV.	38 a
Uganda/2016[54]	To identify the tendencies related to the announcement of the age, how caregivers prepare themselves and prepare the child for the process of communication, how this process occurs, and the challenges.	28 f
India/2016[55]	To evaluate the rate of communication of HIV status, understand the experiences after the communication, and study the impact of social desirability among children.	24 c/a

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Country/Year	Objective	Sample
Tanzania/2016[56]	To explore health professionals' experience in the communication of HIV status for infected children.	20 p
Brazil/2016[57]	To understand the adolescent existential movement in front of HIV diagnosis revelation experience.	12 a
Brazil/2016[58]	To unravel the family perception about the HIV diagnosis infection revealed to the child/adolescent that lives with the infection.	12 f
Nigeria/2016[59]	To determine the prevalence, age, and main agent of communication among children undergoing ART, barriers, and facilitators and between communication and health results.	110 f
Brazil/2016[60]	To collectively build a guide for the monitoring of the revealing process of the HIV diagnosis for children and adolescents in specialized service.	7 p
Ghana/2017[61]	To determine the prevalence and barriers to the communication of the HIV status for infected children and adolescents.	118 f
Zambia/2017[62]	To examine the scenario of the communication of HIV for adolescents, their impacts, and suggestions of better communication practices.	190 a
South Africa/2017[63]	To identify socio-demographic and clinical factors associated with the complete announcement.	550 c
Uganda/2017[64]	To examine why and how caregivers decide to communicate the HIV status, as well as explore their feelings and dilemmas.	16 f
Peru/2018[65]	To explore the perception and experiences of children and caregivers about the knowledge of their disease, ART, medical service and the communication to the child; approaches for communication by professionals, advantages and disadvantages; approaches with communication for children policies.	14 c/a, 14 f, 6 p
Ghana/2018[66]	To identify the family factors associated with the non-communication of the HIV status of the children and adolescents undergoing ART.	103 f
Brazil/2018[67]	To unravel the experience of HIV revelation to children under 13 years old for their relatives/family.	8 f
India/2018[68]	To examine the rate of communication of HIV infection in a sample of infected children in the state of Karnataka, their reaction to the learning of their HIV status, and the reasons and barriers to the communication from the point of view of their caregivers.	233 f
Malawi/2018[69]	To evaluate health professionals' perspective and practice of communicating the HIV status to children from 6 to 12 years old.	170 p
Uganda/2018[70]	To explore how the caregivers of children from 7 to 12 years old with HIV perceive and interact with the video.	36 f
India/2018[71]	To estimate the proportion of children to which they were told their HIV status and describe the pattern of communication among children that visit a district center of ART.	185 f
Ethiopia/2018[72]	To evaluate the prevalence of the communication of HIV status for infected children and associated factors among relatives/family.	200 f
Kenya/2018[73]	To describe the experiences of service providers using tablet computers for counseling regarding the communication of children infected with HIV and their caregivers, with additional perspectives of adolescents.	21 p
South Africa/2018[74]	To describe the perceptions of the health workers about the pediatric announcement of HIV, explore communication practices; describe the health professionals' point of view about their role and responsibility in the process of communication.	73 p
New Guinea/2018[75]	To determine the practices of communication of HIV, and evaluate if an increase of the communication education model, as recommended by the WHO, would increase the children's knowledge about their condition and would improve ART adherence.	138 c/a
Zambia/2018[76]	To describe the situation of communicating HIV among rural children and examine the sociodemographic factors that promote it.	79 c/a, 50 f
Namibia/2018[77]	To evaluate the facilitation of the cartoon book in the overcoming of specific barriers to the pediatric announcement of HIV.	64 f, 35 p
Ghana/2019[78]	To explore the narratives experienced by children and adolescents in the communication moment of the HIV diagnosis.	30 c/a
Malawi/2019[79]	To evaluate the socio-demographic, clinical, and psychosocial factors associated with the decisions of the primary caregivers of communicating about HIV to the children from 6 to 12 years old.	429 f

GI: intervention group; GC: control group; F: relatives/family; C: children; A: adolescents; P: health professionals.

setting for the communication to happen, studies indicated the health center (6,25%) and house (4,68%) in the rest of the articles we did not find this information. The relatives/family consider that the communication must be private and in a quiet place (1,57%).

Regarding the **sender** of the communication of HIV diagnosis infection for the child, the mapping results revealed that the relative is the one that must communicate to the child with professional support (Figure 2).

We also mapped the evidence of the **context** of the communication that involved results of the child's maturity evaluation, the necessity of therapy adherence, support, and abilities to communicate, besides the right of knowing the diagnosis (Figure 3).

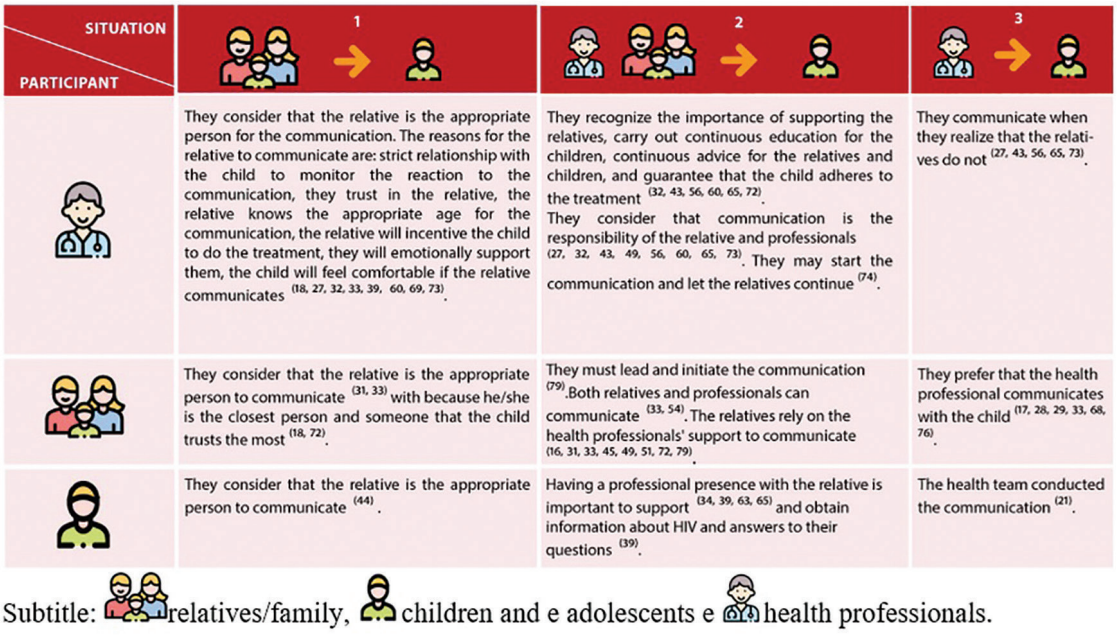

Figure 2 – Sender and receiver of the diagnosis communication of the HIV infection for children and adolescents – Santa Maria, RS, Brazil, 2020.

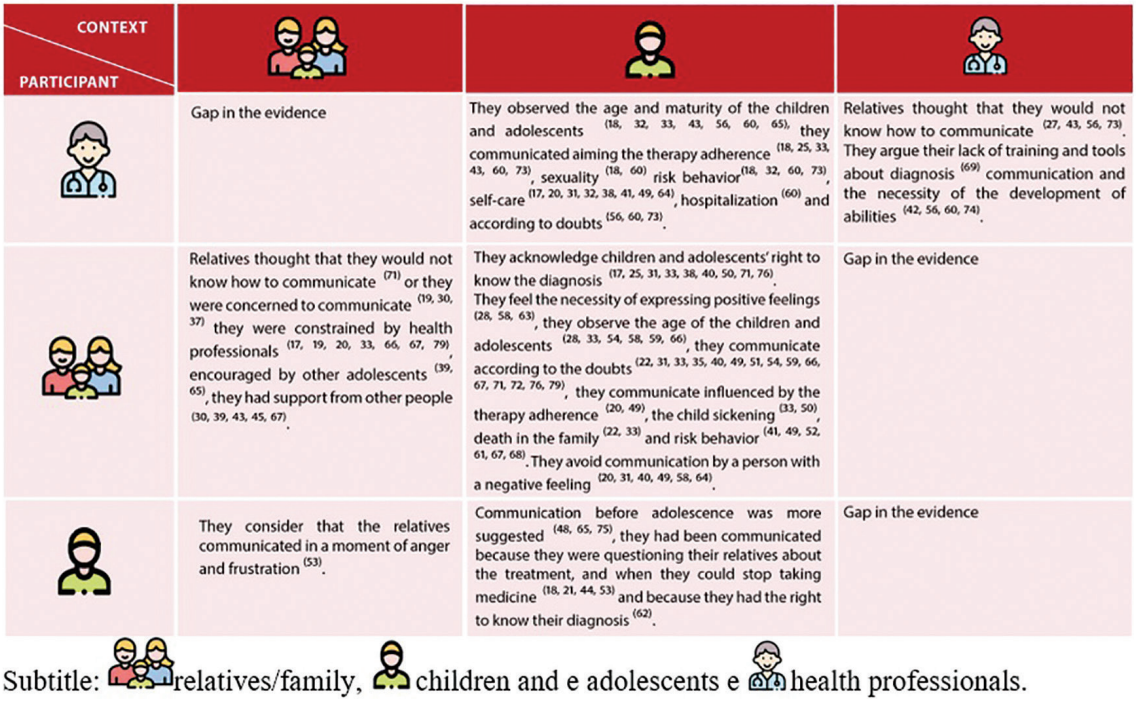

Figure 3 – Context of the diagnosis communication of HIV infection for children and adolescents – Santa Maria, RS, Brazil, 2020.

Regarding the **effect** of the communication, most of the repercussions were beneficial and, the majority of the feelings are present among adolescents (Figure 4).

DISCUSSION

The extension of available mapped evidence in this scoping review has indicated that the announcement of HIV diagnosis at childhood occurs as a communicative process, converging with the theoretical framework used in this study for the extraction and analysis of data[1], and with the global guideline about the HIV revelation advice for children until 12 years old[11]. This guideline sustains that communication is a process and not an isolated act, it may occur during a period of time, in the course of several moments, in distinct environments, with different people, and in response to new events (for instance, the death from a family member)[11]. The international recommendation recognizes that the ideal communication is the prepared one, promoting health and

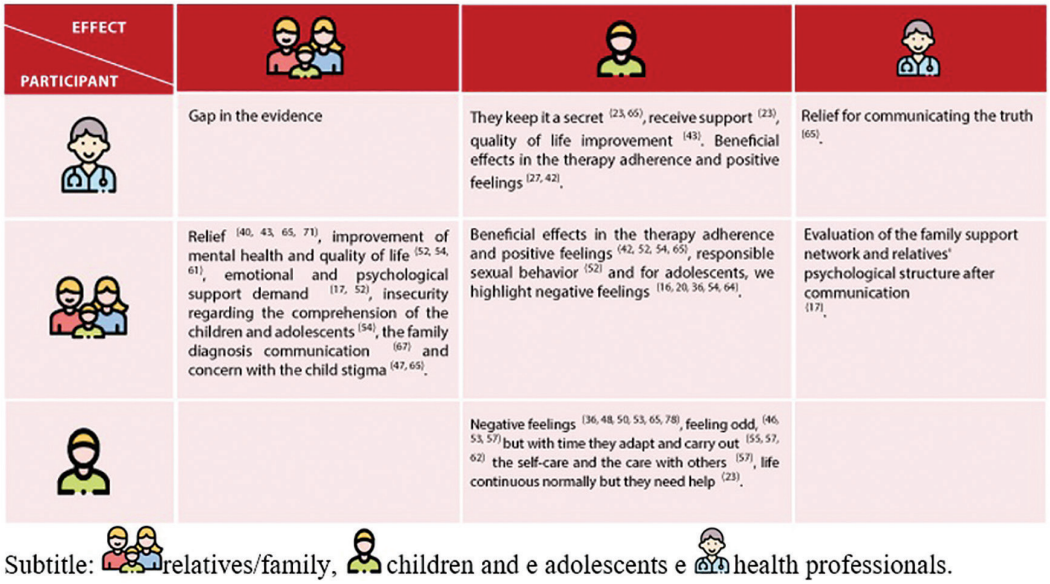

Figure 4 – Effects of the diagnosis communication of the HIV infection for children and adolescents – Santa Maria, RS, Brazil, 2020.

age-appropriate, that occurs in a support and empowerment environment, and that is treated according to the complexity of the situation[80]. What is contemplated in the Brazilian therapeutic guideline for the handling of HIV infections in children and adolescents that registers the diagnostic revelation is a process that requires the engagement of everyone that participates in the care, relatives, and multidisciplinary team. In addition, it recommends individualization, starting as soon as possible, and to assure the protection and preservation of the child's exposure[81].

In this communicative process, the **sender** is the person that communicates the HIV diagnosis to the child. In this study, it became clear that there is a convergence between the perception of relatives/family, health professionals, and the child once they express that the relative is the one that should communicate to the child. And that the bond with the child is fundamental, independent, of who communicates. We highlight that, according to the communicative process framework, for the communication to occur, an interaction between at least two people is fundamental, that is, someone will communicate something to the other person, and this person will decode the message to make sense. This decoding is what allows the comprehension of what was said[1].

Professionals argue that the family protagonism is important and justify it by the everyday interaction and due to the trust relationship with the child to evaluate the appropriate moment, monitor the reaction to the communication, support/comfort in emotional aspects, encourage treatment[18,27,32–33,39,60,69,73]. The reasons indicated by the relatives/family converge with those expressed by the professionals and reinforce that nobody knows more than them, which is positive for their children[18,31,33,72,79]. The children also understand that the relative is someone that must communicate[44].

Another convergence among the perceptions of relatives/family, professionals, and child is the importance of the professional. This support involves preparation, monitoring of the process, and availability to the emotional and rientational demands, increasing the probability of relatives/family communicating with the child and he/she feeling safe and explained. Thus, the co-responsibility in the communicative process strengthens it to be carried out at an appropriate moment, avoiding late communication[33,49,56,60,65]. The children indicate that professional presence is important to answer questions regarding the routine aspects and how to live with the diagnosis[34,39,63,65].

However, there are situations where the relatives/family postpone the communication and do not communicate, for instance, when they are concerned about questioning and being blamed for the HIV transmission[17,28,29,33,68,76], which may damage the emission and decoding of the message[1]. Although the announcement must occur in a supportive environment that ideally includes well-informed parents and professionals, some parents may decide that the professional takes this responsibility[81–82].

Relatives/family that discussed the communication of the HIV diagnosis with health professionals presented a higher probability of communicating[33,45]. In the interrelationship with the guideline[11], the recommendation is that the decision regarding who will communicate to the child must be oriented by the intention to promote the well-being of the child and the quality of the relationship between the child and the parents/guardians.

The importance of the support involves the preparation evaluation of those engaged in this communication process[16,31,33,51,79]. For instance, being prepared for the emotional demands, such as insecurity, sadness, clarifying the child's doubts[27,32,43,49,56,60,65,72,73]. For the professionals, the support can imply assuming the leadership in the

communicative process because they have noticed that the main difficulty of the relatives/family is not knowing how to start the communication[74].

Although professionals recognize the relatives/family' autonomy[79] and that they must and can continue the communication process[34], sometimes professionals assume this role[43,56,65,73]. That occurs especially in cases of insufficient therapy adherence[73] and when they realize that these relatives/family do not feel safe, not even with enough knowledge to answer the questions that might appear during the communication of the diagnosis[27,43,56,73]. Professionals recognize that it is necessary to maintain the children's monitoring, especially for the success of the treatment[32,43,56,60,65,72].

The mapped evidence in this scoping review shows a gap of knowledge production regarding the sender element, mainly in the studies about the child perception when the familiar carries out communication. Such a gap may indicate that the theme is surrounded by stigma, it maintains itself restricted to the family, and that support network is limited.

The mapped evidence of the communication **context** refers to the life aspects of the people (senders and receivers) involved[1] that contemplated a group of circumstances, which produced the message they wanted to send: the HIV diagnosis to the child. The evidence converges in the maturity evaluation expressed in the child questions and age, in the necessity of therapy adherence, support, and abilities to communicate.

Regarding the child's maturity, which can be expressed by their questions and age, we reinforce the recommendation of communicating in the appropriate moment, linked with the observed opportunities in everyday life and the health service. For that, professionals recognize that they need to be attentive to the questions and signals that the child may bear the diagnosis and its implications, including the HIV stigma[18,32,56,60,73]. Different countries' recommendations recognize that the communication of the diagnosis for children and adolescents must consider their age and psychosocial maturity as well as the complexity of the family dynamics and the clinical context[81–84]. In a systematic approach, the child's age will serve as a guide, but it is not enough, we must consider the development stages (physical, social, emotional), and the cognitive capacity of the child as the key for communication[80].

Regarding the age to the communication of the diagnosis, health professionals diverge. In some studies, they advocate the age of 5 to 9 years old because of cognitive maturation[18,33,56,65], and in others, they recommend from 10 years old and above[32,33,43]. Professionals recognize that older children (9–11 years old) and adolescents (12 to 17 years old) had a higher probability of being communicated about the diagnosis than younger children (5 to 8 years old)[18]. Despite the lack of agreement, relatives/family and children recognize the right that children have of knowing their diagnosis. This right regards children's access to information and materials destined for the promotion of interests, especially physical and mental health. Hence, the global guideline recommends that children of school age must be informed about the positive HIV status, younger children must know their status gradually to accommodate their cognitive abilities and emotional maturity, preparing them for full communication[11]. The American Academy of Pediatrics recommends that symptomatic children, especially those that require hospitalization, must be informed of their serological status, considering that the probability of them inadvertently learning about their diagnosis in a hospital environment is high[81].

The mapping has traced alerts for the beginning of communication, among them, the sexual awakening in adolescence, being triggers the beginning of affective relationships and sex life[18,60]. Professionals indicated other alerts for the communication, such as the necessity of therapy adherence[18,25,60,73], risk behaviors[18,32,60,73], the necessity of self-care[17,31,32,41,64] to live better[20,38,49], and the hospitalization[60]. The children that were taking medicines[33] for more than 12 months[43] had a higher probability of being communicated.

The alerts of risk behaviors, the necessity of ART adherence, and the sickening converged with the professionals' and family perception for the urgency in communicating, mostly at adolescence. However, for adolescents, communication before adolescence is more indicated[48,65,75]. Adolescents have experienced situations in which their relatives/family have communicated the diagnosis in a moment of anger or frustration because the child was resisting taking the medication[53]. We highlight that knowing the diagnosis only at adolescence demands one more adaptation that could have happened in an appropriate moment assuring the child's right to know about their health condition and face it. The recommendation is that the adolescent must be fully informed about their serological condition for the appropriate decision making, including treatment[81–82]. We must develop the counseling of the adolescent through a healthy process of communication so that they learn to face their chronic condition and manage their health[80].

In the relatives/family' perception, the communication rate significantly increases with the child's age[28,33]. The relatives/family believed it was important to wait until adolescence due to the question of the young[22,33,72,76] regarding the reason for taking medicine and for how long that would be necessary[31,49,71]. They also questioned other aspects about the infection[35,40,66], such as regular medical appointments[51,54,79]; or different routines from family members[59,67]. The risk behavior contributed to the communication of the diagnosis[41,49,61,67–68] that indicated a necessity of orientation regarding healthy sexual practices for prevention of reinfection or transmission[41,52,68]. Other situations that contributed to the communication were insufficient therapy adherence[20,49], the sickening of the child[33,50], or the death of their parents or family members[22,33].

We understand that the communication and comprehension of the message are influenced by the worldview of the sender and receivers, that is, the way they built meaning of the diagnosis and HIV infection can determine the decision of communicating. Hence, the relatives/family have opted to communicate to avoid that they would hear from another

person with a negative perspective[20,31,40,49,58,64] due to the stigma. In the global guideline about the counseling of revelation[11], the stigma is recognized as a barrier for the communication of HIV for children, the involved ones delay their decision of communicating because they fear that the child faces stigma. Thus, there is the recommendation that after full communication, family and health professionals help the children to manage the stigma[11]. The unintended communication of the child may lead to stigmatization, discrimination, or ostracism regarding the child and other family members[81–82]. To decrease the stigma associated with HIV, we must provide the child with proper knowledge about its own condition. This explanation must be separate from the experiences and associations of HIV from adult family members[83].

In the communicative process it is also necessary that, in the absence of adequate support and tolerance of the community, the media and society may contribute to minimizing the stigmatization once they influence people's thinking[1]. Having the necessity of expressing positive feelings, the senders aimed to transmit the confidence to the children and adolescents, saying that they could grow strong[63]. We indicate that the positive vision of the involved regarding the prognostics has contributed to the communication ability once the communication occurs with more frequency as long as the involved improve their knowledge and abilities because it causes trust improvement to carry out quality communication. When professionals feel unprepared[27,43,56,73], they carry out book readings[42], material reviewing in their free time normally outside their work, and discussion with other health professionals[60,73]. They reported having more trust in evaluating the children's aptitude to be communicated about the diagnosis when they received training[42,60,69,74].

Relatives/family showed that they communicated because of the health professionals' encouragement or pressure[17,19-20,33,66-67,79]. Although sometimes, the relatives/family may ask for confidentiality according to what they believe to be the best for their children, the professionals have the responsibility of supporting them towards informed consent[82], actively integrating the communication planning[81]. The parents and guardians need opportunities for trustworthy conversations with health professionals about the benefits of the children knowing about their diagnosis even younger[83].

They need to deal with a series of fears that influence them in their preparation for this communication. They prepare themselves for some questions that the children could ask, such as the origin of how they were infected, and because of that, they need to develop abilities not to transmit a negative perspective[19,30,37,71]. The relatives/family that exchange experiences with other people in the waiting room and a support group had more preparation[43,45,67] because sharing experiences among family members contributed to the empowerment and prepared them to feel confident and capable of communicating the diagnosis to the children or adolescents[67]. The relatives/family that attend health services may have the possibility of knowing positive experiences from other adolescents[39] and receive advice to communicate as soon as possible to the child because the appropriate time entails a better acceptance[65]. We highlight that the strategy of adolescents' volunteer participation in groups or individual appointments enables family members to know the experience from those who have experienced the communicative process and enables the right to know the diagnosis and the communication at an appropriate time.

Studies are mostly centered on analyzing children's and family context in the communicative process, which indicates a gap. Hence, we projected potential implications for the studies regarding the professional context. We highlight that knowing the family's life aspects is important to guarantee their protagonism in this process. In addition, knowing the aspects related to professionals enables the support and monitoring in practice based on evidence.

The fact of relatives/family and children expressing the right to know the HIV diagnosis contributed to the communication[17,25,31,33,38,40,50,62,71,76]. South Africa is legally obligated to guarantee that the appropriate communication becomes an integrated component of the comprehensive management of HIV, once that several children's rights and, when opting to not communicate, those children's and adolescents rights are violated instead of preserved[81]. The interdependence between the elements of the communicative process[1] showed that the right to know entails not in the decision of if they are communicating, but how and when they will do it. To recognize this right contributed to the development of the communication and through the choice of the **communication channel**. The channel, which refers to the analysis of mains utilized in the communicative process, includes technology and language[1].

In the communication channel, it was possible to map what the main strategies are to the communication of the diagnosis that the relatives/family and health professionals utilized according to the age group of the children and adolescents. National[81] and international[84] recommendations recognize that strategies must be adequate to the age group and that it respects the child's and adolescent time to think in front of the playful activity chosen and that also to get closer, for instance, physically and crouch to their level. The child must be supported with approaches according to the necessities of their age, with continuous opportunities to have open and honest conversations[82]. These strategies refer to the attitude, the materials, and the quantity and quality of information through time, which indicates a communication being developed with an interactive process in which the combination of strategies enables the comprehension of information. Hence, the relatives/family and the children or adolescents do not need to wait until the next medical appointment to clarify any doubts, also avoiding that they search for information from not reliable sources.

The **communication channel** choice includes the use of adequate educational materials to promote the comprehension of the child, for instance, the use of toys, drawings, videos, and children's books, leaflets, computer tools (social media, sites), and quizzes[56,60,70,73–74] used by health professionals. For example, the playful strategy with toys and drawings in

storytelling when professionals relate the characters and the narrative to the child's condition[56], with a hopeful perspective that approaches the medicines as allies[77], not necessarily naming the HIV[60].

The senders must utilize the materials in a combined way according to the availability of the resource and with the maturity of the receiver. In the scope of the global guideline, children need real information adequate to their understanding. Children suggested the strategy to communicate the parents' diagnosis in advance[25,53], the use of analogies to explain the virus and the medicine[51], and the more interactive processes that may include videos, games, and audiovisual resources to help them understand HIV[65].

For teenagers, however, professionals use the strategy of observing the questions about their medication, frequent visitation to the service, and laboratory test routine highlighting the adherence[73]. Thus, they develop the communication and amplify the information according to the demands expressed by the adolescents[60]. They also use computer tools to mediate the communication[60], for instance, a video with narratives culturally appropriate to share experiences of relatives/family and adolescents mediated by the use of donated tablets[73]. Health professionals also consider it important to offer materials for consultation at home. For that, they deliver information leaflets about the most frequently asked questions[74].

The relatives/family utilized the strategy of talking about their life, the maternal and/or paternal serological condition, and how the child was infected[17,31,54]. The relatives/family' metaphorical discourse included words such as "fight," "army," and "defense," alluding to war in the body, a fight in which the immunological system and the medicine allow the combat and preserve life[67]. Regarding children that did not have the capacity of comprehension due to their maturity or age, the interventions were limited to the elucidation of the virus action mechanisms in the organism, and the importance of the therapy adherence, without naming the diagnosis. The explanations of the virus transmission were introduced according to the curiosity or interest of the child[17,54].

We also highlight that the communication may vary from each culture and each place, depending on the available resources and the wishes and worries of the caregivers. Hence, these resources utilized as communication channels demand adaptation to different geographic areas and resource environments, which project potential implications for the creation of projects, or cultural educational and/or careful technological adaptation for the use of professionals, relatives/family, and the children and adolescents.

Regarding the evaluation of the quantity and quality of the message content, the relatives/family focused on subjects such as HIV transmission, medicine ingestion and evaluated the comprehension of the information they offered. They recognize the importance of clear and honest communication of information with the use of HIV or aids terms[31].

To register which information children and adolescents already knew, health professionals utilized stickers or letters in promptuaries, for example[56]. Having adequate systems of registers maintenance aiming to document the communication journey has a list of recommendations of the best practices for communications in Africa[80]. This converges with the recovered evidence in this study, in which the communication of the diagnosis must occur procedurally[17,31,36,41,54,56,60,66,68,74] and not in an event or a single conversation[80], considering the monitoring before, during, and after[27,42,49,72]. And, also, in India, the recommendation is that such monitoring must be developed by the same professional[84].

We believe that the register of the communicative process is a strategy that may avoid that professionals communicate the diagnosis untimely, besides organizing and promoting the amplification of information through medical appointments. As they pay attention to the quality and quantity of information, the facilitators and professionals strengthen the bond with the child to advance in the communication until they evaluate that the children are ready for full communication. Communication guidelines of Africa indicated that this process must be prepared and appropriated to the age, occur in an environment of support and team capacitation with the necessary knowledge and abilities to facilitate the communication process and attend to the complexity of the situation and in addition make a process of health promotion[80]. However, guidelines recognize that health professionals usually do not have policy support based on evidence about when, how, and under what conditions the child must be informed about their own HIV status or their caregivers'[11].

Regarding the mapping of evidence about the communication **effects**, everyone involved indicated that there are repercussions after the communication of the diagnosis. This effect refers to the message reception emitted and the communication means (how the message was communicated) that implies the comprehension and the reaction of the involved in the communicative process (sender and receiver)[1].

The communication effects in the long term present a tendency to be beneficial in the perception of the children and adolescents[34] when the communication happens at an appropriate time, considering the acceptance of the diagnosis, especially among children[78]. Relatives/family recognize that when the children got to know the diagnosis in the first childhood, they learned very early the issues that elapse from their serological condition and negative feelings, such as fear, anxiety, shame, guilt, they became less relevant when the diagnosis was communicated conveniently[58]. It caused tranquility to know that their relatives/family presented the same diagnosis[53] and that they were born with the virus and that they were not guilty[23]. The United Kingdom recommendation indicates that the health services that attend infected children with HIV need to adopt more proactive approaches to talk about their condition from an early age. This will allow children to assume more active roles in their own care and treatment during its development[83].

The adolescents indicated positive results regarding the improvement in the therapy adherence[65] and the feeling of self-esteem and hope for the future[39,62] even if they kept the diagnosis a secret[45,62,78]. However, some of them had positive experiences when they shared their diagnosis with friends

that they considered reliable, besides positive experiences of confronting stigma at school when they told teachers[23]. However, we also highlight negative reactions such as feeling odd[46,53,57], sometimes denial, confused, sad, revolted, with no hope, with fear, rage, death wishes, and drug use, including concern with the stigma and with the necessity of treatment for the rest of their lives[36,48,50,53,62,65,78]. They were also afraid of developing intimate relationships[62]. They felt frustrated because they grew up with a lie and a secret that was not trusted to them[18,48,53]. But, they ended up adapting to caring for themselves and the others[46,55,62], but they still need help[23].

The group participation helped adolescents to feel positive, such as reducing stress in home trouble situations, because it was a place where they had friends and acquired knowledge about HIV[23]. Also, they had support from their relatives/family and health professionals because this support contributed to physical, emotional aspects and well-being in general, relationships promotes, with relatives/family, and information clarifications about HIV transmission, pregnancy, and other topics as they emerged[65]. Religion was also important to give comfort and hope for the cure[23].

Regarding the effect of the feeling, relatives/family expressed relief because they communicated the truth of what once was a secret[40,43,65,71], as well as health professionals[65]. However, there are negative feelings[16,20,36,64], such as insecurity of the relatives/family about the understanding of information by the children, especially about the comprehension of the diagnosis[54] and concern with the stigma[47,65]. At times, they demand psychological and emotional support[17,52]. About the relatives/family, the communication of the diagnosis improved the ambiance with the routine, self-care, therapy adherence, positive feelings, self-esteem, trust[42,52,54,65], mental health[52], and quality of life[61,64]. Also, there is an effect in responsible sexual behavior when the child becomes an adolescent[52].

The mapping of evidence showed that the majority of times, the effects were beneficial for the relatives/family, children, and adolescents, converging with the concern with the stigma and the manifestation of the necessity of support. This result indicates that the communicative process does not end in communication but indicates monitoring. Also because there is evidence of negative effects in the perspective of the family and children, and mostly, the negative feelings are among adolescents, which indicates the necessity of the communication to be at an appropriate time.

The global guideline presents evidence of health benefits (for instance, reduced risk of death and higher adherence to treatment) and little evidence of psychological or emotional damage caused by the revelation of the HIV status to the seropositive children. And they indicate that the immediate emotional reactions dissipate through time and respond to the program interventions. The diagnosis communication, according to researchers and professionals, is not isolated but a step in the process of the adaptation of the child, caregivers, and the community to a disease and to the challenges of life that it represents[11]. The South Africa National Department of Health recognizes that communication guarantees the physical, emotional, cognitive, and social well-being of the child and adolescent and implies treatment benefits in the long term through adherence and retention in the service. Nationally, the therapeutic guideline declares that the benefits of this communication process are to the child, adolescent, and family, as well as the health service and professionals that attend them[81].

Health professionals recommend children and adolescents maintain their diagnosis in the family until they become capable of defending themselves from the stigma[23,65]. They recognize the necessity of supporting the children[23] and that one of the effects of the communication is the life quality improvement[43] with the adherence to therapy[27,42].

Another gap identified in the mapping of this study refers to the effect element of the communicative process generated in the relative population because of the lack of studies in the children's and professionals' perception with this focus. This gap indicates the necessity that they must know the repercussions to qualify the monitoring of the family in the communicative process.

The contribution of the review for the health field indicates convergences and progress of the mapped evidence if compared with those that sustain the guideline, which shows the advance in the knowledge frontier in the 2011–2021 decade, once the referred guideline is from 2011, and was used as a political mark of reference for the time frame in this present scope review. Thus, such mapping offers subsidies for critical reflection of practices and policies, strategy possibilities to be created or adapted for the local context of the communicative process of the HIV diagnosis, ensuring children's right to know at the appropriate time, and even projects potential implications for studies, according to the indicated gaps.

The limitation of this review is in our option of not include terms referring to the adolescent population, once that the mapping descriptors, words, and the strategy elaboration tests of search recovered productions of diagnosis revelation of anti-HIV test in adolescence, in counseling situations pre and post-test, and not of communication of the pediatric diagnosis. We add the complexity of results extraction produced by different research outlines and from distinct cultural and geographic contexts. The time frame, although justified, may be a mapping limitation.

CONCLUSION

The evidence regarding the context of communication sustains that the relative/family is the proper person to tell the child about their diagnosis of HIV infection. This communication must be developed as a process that includes the professionals' and family support, the development of abilities to evaluate the appropriate moment, and the monitoring of effects. In practice, the senders may observe age, maturity, and questioning as signs of opportunity to unleash this process through playful and interactive strategies.

RESUMO

Objetivo: Mapear como acontece a comunicação do diagnóstico de infecção pelo HIV em pediatria. **Método:** Revisão de escopo que selecionou 64 artigos originais, em português, inglês ou espanhol, com os participantes criança, adolescente, familiar e/ou profissional de saúde, no recorte temporal de 2011–2020. Foram acessadas as fontes *PubMed*, *CINAHL*, Scopus, *WoS*, *ASSIA*, *PsycINFO, ERIC, Sociological Abstracts,* Edubase e LILACS, BDENF e IndexPsi. **Resultados:** Quanto à população, ficou evidente que o familiar deve ser o emissor do diagnóstico com apoio dos profissionais; quanto aos motivos para a comunicação, consideram-se a maturidade da criança, expressa por questionamentos, a necessidade de adesão à terapia e de habilidades para comunicar, além do direito de saber do diagnóstico. O canal de comunicação está centrado em materiais que promovem compreensão, quantidade e qualidade das informações, o que indica um processo interativo. Quanto aos efeitos, são benéficos quando a comunicação acontece em tempo oportuno. **Conclusão:** A comunicação deve ocorrer mediante um processo que inclui o apoio dos profissionais aos familiares, o desenvolvimento de habilidades para avaliar o momento oportuno e o acompanhamento dos efeitos.

DESCRIPTORES

HIV; Comunicação; Saúde da Criança; Saúde do Adolescente; Revisão.

RESUMEN

Objetivo: Trazar un mapa sobre la comunicación del diagnóstico de la infección por VIH en pediatría. **Método:** Se trata de una revisión de alcance que seleccionó 64 artículos originales en las fuentes PubMed, CINAHL, Scopus, WoS, ASSIA, PsycINFO, ERIC, Sociological Abstracts, Edubase y LILACS, BDENF e IndexPsi, en portugués, inglés y español, con los participantes infante, adolescente, familia y/o profesional de la salud, bajo el marco temporal 2011–2020. **Resultados:** Con respecto a la población, quedó evidente que el familiar debe ser el vocero del diagnóstico con el apoyo de los profesionales; sobre los motivos de la notificación, se consideró la madurez del niño, expresada mediante el interrogatorio, la necesidad de adherencia a la terapia y las habilidades de comunicación, además del derecho a conocer el diagnóstico. El canal de comunicación se centra en materiales que promueven la comprensión, la cantidad y la calidad de la información, partes de un proceso interactivo. Con relación a los efectos, estos son beneficiosos cuando la notificación se produce en el momento oportuno. **Conclusión:** La comunicación debe llevarse a cabo con el apoyo de los profesionales a los miembros de la familia, con el desarrollo de habilidades para evaluar el momento oportuno y el seguimiento de los efectos.

DESCRITORES

VIH; Comunicación; Salud del Niño; Salud del Adolescente; Revisión.

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Funding

The present work was carried out with the support of the Coordination for the Improvement of Higher Education Personnel – Brazil (CAPES) – Financing code 001.