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Article

Clinical practices for communicating the diagnosis in pediatric oncology: a systematic review

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ABSTRACT

Communication of diagnosis in chronic disease has been little studied in pediatric oncology. Clinical practices for disclosure are mainly carried out at the end of life, not at the onset of the disease, and there does not seem to be clarity on how to communicate to families. *Objective:* to understand the current communication practices of diagnosis in children and young people with oncologic disease. *Method:* systematic review according to PRISMA guidelines. *Results:* A total of 17 studies were obtained that met the inclusion criteria. Two protocols for communicating the diagnosis were identified and several recommendations were found for disclosure according to the patient's age, the right to be informed, and the importance of involving the family. *Discussion:* validated communication practices are required that respond to the mental health needs in pediatric oncology, considering the culture and environment of patients and their families, and other barriers to effective communication.

Prácticas clínicas de comunicación del diagnóstico en oncología pediátrica: una revisión sistemática

RESUMEN

La comunicación del diagnóstico en enfermedades crónicas ha sido poco estudiada en oncología pediátrica. Las prácticas clínicas para la revelación son al final de la vida, pero poco al inicio de la enfermedad, por lo que no parece haber claridad sobre cómo comunicar a las familias. *Objetivo:* conocer cuáles son las prácticas de comunicación del diagnóstico en niños y jóvenes con enfermedad oncológica. *Método:* revisión sistemática según lineamientos PRISMA. *Resultados:* se encontraron 17 estudios que cumplieran con los criterios de inclusión. Se identificaron dos protocolos para comunicar el diagnóstico y varias recomendaciones para hacer la revelación según la edad del paciente, el derecho a estar informado y la importancia de involucrar a la familia. *Discusión:* se requieren prácticas de comunicación validadas que respondan a las necesidades de salud mental en oncología pediátrica, que incluyan la cultura y contexto de paciente y familia, así como las barreras que dificultan la comunicación.

Palabras clave:

Revelación de la verdad
Oncología
Barreras de comunicación
Psicooncología
Revisión sistemática

Cancer is a public health problem that has psychological, affective, and social effects that interfere in the quality of life of the patient and their family and, therefore, throughout the oncological disease feelings may emerge of vulnerability, sadness, fear, depression, anxiety, panic, and social isolation that are also present in childhood cancer (Martínez, et al., 2012, cited in Pozo et al., 2015). In minors these symptoms can be more complex due to the situation of physical, emotional, and family dependence in which they find themselves.

Childhood cancer involves patients, family/caregivers, and healthcare professionals, and therefore the way the diagnosis is communicated is important. This is considered a key clinical skill in the field of oncology; it is a dialogue where information is provided in a satisfactory way and none of the agents are restricted from expressing opinions, questions, or concerns. The way this is done has a positive or negative impact on coping with the disease (Arraras et al., 2017).

In this communication, the patient and their relatives or caregivers should know all the aspects related to the disease (Moro et al., 2014). It is recognized as one of the main elements of the support offered to patients so that they can improve their experience of symptoms, emotional functioning, quality of life, and treatment of the disease (Arraras et al., 2017). With minors it is limited by their parents or caregivers, because they are the ones who decide what they want to say to their children. Sometimes, they prefer to omit aspects related to the disease or simply not tell the truth, a phenomenon known as conspiracy of silence, which refers to the “implicit or explicit agreement by family members, caregivers, or professionals to alter the information provided to the patient in order to hide the diagnosis or prognosis” (Barbero, 2006, p. 23).

At the moment of revealing the diagnosis, the professional must be realistic, and maintain the parents’ or caregivers’ hope by identifying their concerns in order to resolve them and by trying to dispel myths about the disease and its prognosis, as well as providing control tools and resources that facilitate the understanding of the information. After they are clear about the information they have been given and it is sufficient, the process of communication with the patient begins, which should be agreed together with the child, his or her family, and the professional in charge (Lorenzo & Cormenzana, 2012). For effective communication it is suggested that it should: (a) include verbal and non-verbal expression of both positive and negative thoughts and feelings, (b) incorporate active listening to questions from the patient related to the illness, (c) answer only what the child asks without going beyond what they want to know, always in terms of the truth and acknowledging what is uncertain (Lascar et al., 2013).

Similarly, the communicative interaction with the child should include three aspects that make up the therapeutic triad: warmth, honesty, and empathy, aspects that allow the child to feel confident to interact. In order to do this, their cognitive characteristics and previous experiences must be known in order to use terms that are comprehensible to the child during the conversation (Lascar et al., 2013), in which it is essential to tell the patient the truth so that as he or she understands the illness, he/she initiates an active role in the disease process. The success

of the discussions derives from the professional’s communication skills in adapting the information to the chronological age and cognitive-emotional maturity of the patient (Arraras et al., 2017).

Communicating a discouraging diagnosis is considered a complex practice for the health professional, since the affective and emotional components involve a break in the expectations of the patient and his or her family and/or caregivers (Bascuñán, 2013). When the diagnosis is given, a series of important changes occur in the child’s life, affecting their physical, psychological, and emotional dimensions, so the communication of the diagnosis is the first part of the treatment (Puerto & Gamba, 2015).

Both children and parents show initial responses related to overwhelm and disbelief, which leads them to ask questions about the etiology of the illness in order to understand their child’s current health condition (Bueno & Marín de la Torre, 2008). Parents are often unprepared to receive the news, therefore, at the time of disclosure, psychological support should be provided to avoid reactions that convey feelings of fear and worry to the child (Lorenzo & Cormenzana, 2012).

According to Bueno & Marín de la Torre (2008) there are three phases that family members experience when they learn of the diagnosis: the *first phase* (short duration) refers to the uncontrolled search for information about the diagnosis, and it arises as a control strategy regarding the disease, seeking help and support; however, other parents resort to coping mechanisms such as emotional isolation, avoidance, and denial. In the *second phase* (variable duration) different emotional and behavioral manifestations are presented by parents and/or caregivers such as anxiety, anger, guilt, or depression. In the *third phase* (longer duration) there is acceptance of the diagnosis, and another challenge begins in terms of treatment and prognosis.

In order to understand the practices of diagnosis disclosure, the objective of this research was to identify the existing health interventions for the communication of diagnosis in the pediatric oncology population. Three questions were posed: What are the practices used to communicate diagnosis in the pediatric oncology population, what are the most common elements used in these practices, and what are the reasons given by researchers for using these practices for diagnosis disclosure. Therefore, a systematic review was carried out to answer these questions that may be of interest to professionals in psychology and other health areas.

Method

Search strategy.

This review was carried out following the PRISMA method (Fig 1). The systematic search was carried out in the databases Science Direct, PubMed, APA PsycArticles, Biblioteca Virtual en Salud, ProQuest Central, and Scopus, with no limit on the year of publication or country of the study, and with a cut-off date of October 30, 2020.

The search algorithm used was ((“Truth disclosure” OR “Health communication”) AND (Neoplasm OR “Oncological disease”) NOT “Palliative Care” NOT “Breast Neoplasm” NOT “Fertility Preservation”). Terms were normalized via DeCS and MeSH.

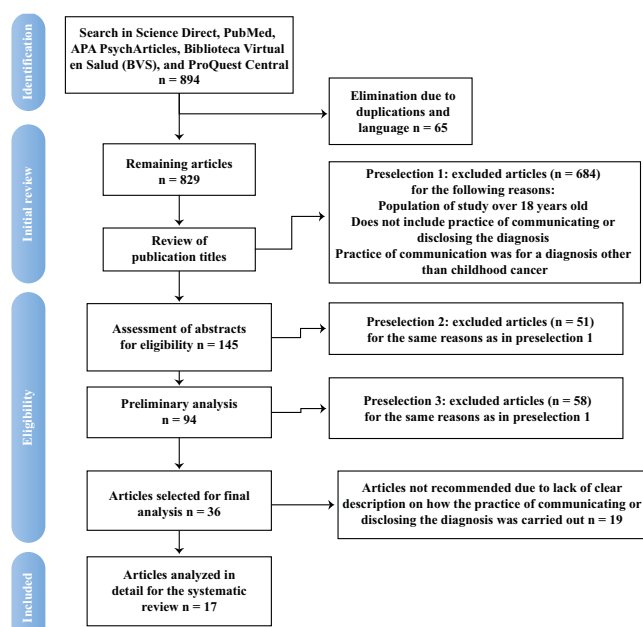


Figure 1.
PRISMA flow chart.

Inclusion and exclusion criteria.

We selected published articles of any type, even if the research was not exclusively about diagnostic disclosure, whose participants were under 18 years of age, their parents, or caregivers. The language was English and Spanish. Studies where the diagnosis communication was for diagnoses other than childhood cancer were excluded.

Selection of studies.

A group of 5 research assistants and 2 researchers carried out the filtering of articles by title and abstract. A first round of elimination was done in duplicate and based on the exclusion criteria, which reduced the sample to 145. With the second and third round of elimination for not meeting the inclusion criteria, 36 studies were selected in recommendation for the preliminary analysis, of which 17 were left for the final analysis. All three phases were conducted in order to reduce human error as much as possible.

Data extraction.

Two teams were formed, each with a principal investigator and two/three research assistants. Each team reviewed the full text of the articles in the final analysis, thus ensuring independent extraction and adequate inter-observer reliability.

Results

The AtlasTi tool was used to carry out the data analysis. It began with a file containing all the textual information extracted from the 17 units of analysis and, subsequently, the coding and categorization of the product of the analysis was carried out. The process underwent the following phases: (a) extraction of quotations (significant fragments of information), (b) open coding

(list of quotations in codes), and (c) construction of groups of codes (categories). Prior to the analysis, aspects of the scientific production were identified.

The years of publication of the articles were: 1983 (1), 1991 (1), 2008 (1), 2010 (1), 2014 (1), 2015 (1), 2016 (7), and 2017 (4). The study types were as follows: original articles (11), case reports (3), reflection articles (2), and literature reviews (1). Also, 7 studies were conducted in the United States, 2 in India, and the rest in Spain, Norway, Romania, Iran, Egypt, Germany, Brazil, and Sweden. Regarding language, most of the articles (94.1%) were published in English, and the rest in Spanish (5.8%). The database in which the most articles were retrieved was Lilacs (8), followed by PubMed (5), ProQuest (2), and Scopus (2). In terms of disclosure practices, the following were identified: verbal communication and protocols.

Type of approach for the communication of the diagnosis. Seven codes were established that were grouped into two categories: verbal communication and protocols. Verbal communication should be based on objectivity, control of emotions, and empathy, adjusting to the moment in which denial is manifested by the agents (Afonso & Minayo, 2017). This should be done over multiple encounters through which information is provided about the process, the disease, and the current prognosis, taking into account the quality of the information and the sensitivity of the health professionals when communicating (Sisk et al., 2017). Badarau et al. (2015) state that this will only be effective if it responds to the needs of the patients, the family and/or caregivers, and the health professional (El Malla et al., 2017).

In terms of protocols, we found SPIKES, a step-by-step guide on how to adapt the communication of the diagnosis in oncology patients with strong emotions. It determines the technical-medical procedures necessary for the care of a specific health situation (Korsvold et al., 2016). We also found the protocol of *intervención psicológica en diagnóstico reciente y tratamiento de pacientes oncológicos infantiles* [psychological intervention in recent diagnosis and treatment of child cancer patients], which is performed in the early stages of the disease, investigating the adaptation of the family to the diagnosis and medical treatment (Arenas et al., 2016).

Elements of the practices found for disclosing the diagnosis. These were identified based on 8 codes and 4 categories: the needs of the family and/or caregivers and patients, the content of the information when communicating a diagnosis, the intervention or information to be taken into account when performing the treatment, and previous aspects to be taken into account before making the disclosure. It has been found that communication in pediatric oncology includes the understanding of expressions and control of emotions, bioethical issues that require sensitivity, serenity, and truth regarding the end of life (Afonso & Minayo, 2017) (Fig. 2). It was also identified that children want to receive honest and direct information while maintaining hope, receiving the information at the same time as their parents and/or caregivers, but also for it to be able to be understood according to their age (Jalmsell et al., 2016). Empathy is important for promoting comfort, trust, and hope throughout the course of the illness (Afonso & Minayo, 2017).

It is necessary to take into account the meaning and value of the information in order for the child to better understand and respond to parental expectations (Landry-Dattée et al., 2016).

Information that is essential to the patient should be disclosed in the best possible narrative (Gupta et al., 2010) as the patient has the right to receive information to discuss the benefits, risks, and costs of appropriate treatment (Sisk et al., 2016). It is also necessary to constantly assess the child's informational needs at regular intervals to monitor the child's readiness and to guarantee their participation in the process (Levenson et al., 1983) (Fig. 2).

With regard to diagnostic information, patients prefer early and direct disclosure by health professionals, as this allows them to understand the severity of the disease and to make informed decisions about treatment (Rao et al., 2016). Professionals recommend open and objective communication, providing the information with an "air of optimism" (Badarau et al., 2015). The professional should have competence, warmth, and interest, listening skills, patience and acceptance, tolerance for the expression of emotion, sensitivity to moods, as well as good clinical judgement and appropriate use of language (Zieber & Frieber, 2008). Disclosure should be as comprehensive and transparent as possible to increase the parents' hope and the trust in the professional (Sisk et al., 2017).

In terms of the pre-disclosure aspects, age is an important factor, as communication in pediatric oncology is ethically challenging when patients are young (Petersen et al., 2017). Parents consider that there is a limited cognitive capacity in children, so they assume that they will not understand the disease, the diagnosis, or the treatment (Clafin & Barbarin, 1991) (Fig 3).

Preparation for diagnostic disclosure is important because good communication with the patient is a responsibility of health care professionals that facilitates both adherence to treatment and cooperation when patients undergo medical procedures (Arenas et al., 2016). The parent-child relationship is also important, as disagreement between the two parties produces circumstances that hinder the patient's resources to cope with the disease; this explains why some adolescents need more support and reassurance at the beginning, although they may also take a more active role as their strengths and skills develop in the process (Levenson et al., 1983).

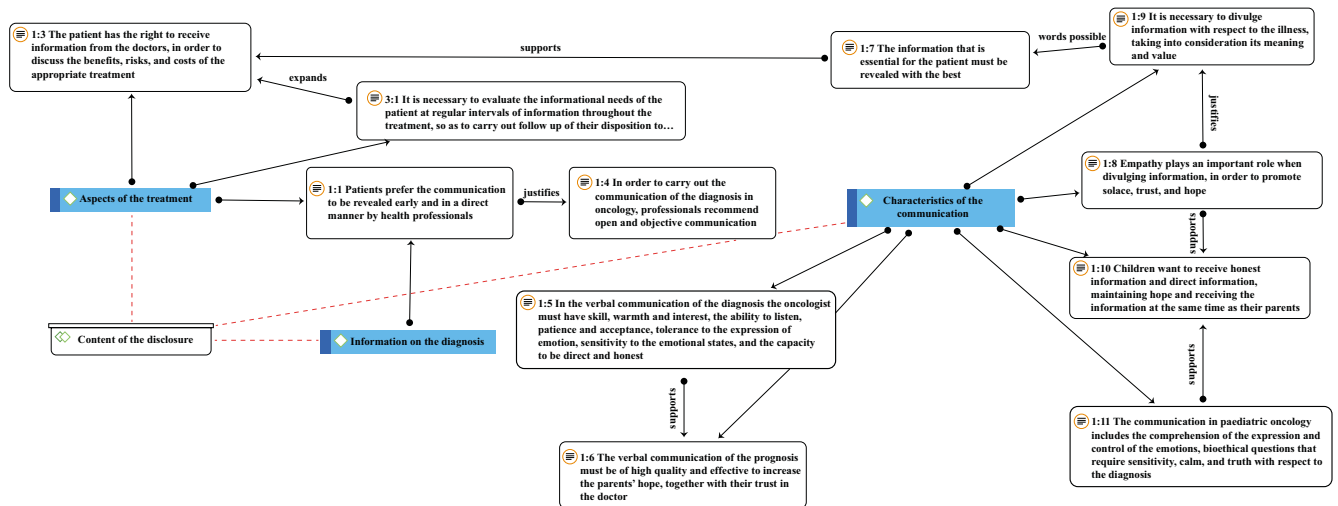


Figure 2.
Disclosure Content.

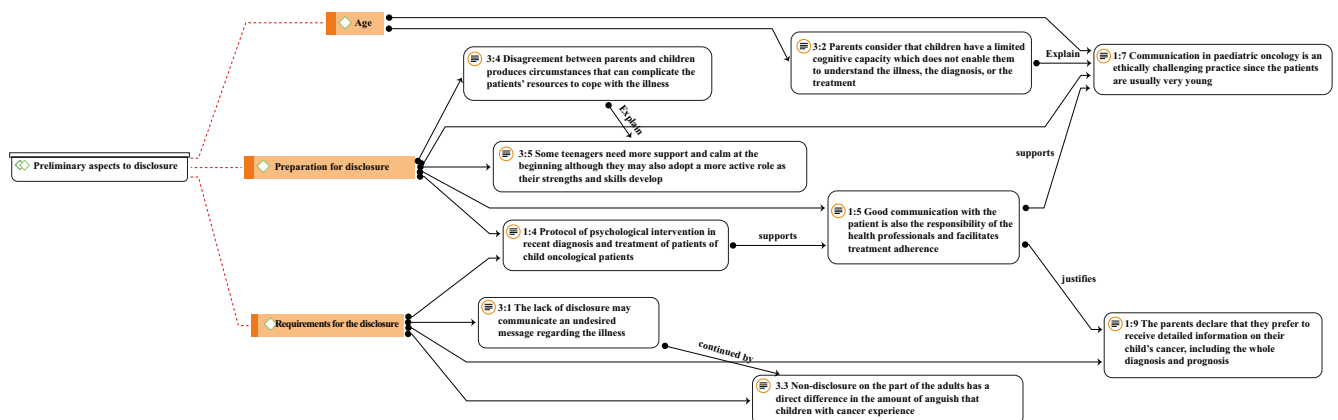


Figure 3.
Preliminary Aspects of Diagnostic Disclosure.

It is of utmost importance for the process to identify the existing needs of parents when communicating, since they express a preference for receiving detailed information about their children's cancer, including the diagnosis and prognosis of the disease, as they consider this information significant and relevant in decision-making (Ilowite, 2017). Additionally, communication of the diagnosis is considered necessary in its entirety, as failure by adults to communicate means greater distress for children, leading them to receive an unwanted message of the disease, such as that it is toxic, dangerous, and cannot be talked about openly (Clafin & Barbarin, 1991).

In this review we also found the protocol of *intervención psicológica en diagnóstico reciente y tratamiento de pacientes oncológicos infantiles* [psychological intervention in recent diagnosis and treatment of childhood oncology patients] by Arenas (2016). This proposes 5 steps: (a) an initial interview with the health professional, (b) the first contact with the family, (c) the first contact with the child or adolescent patient, (d) an interview with the parents, and (e) multiple meetings with the patient. In addition to this, the SPIKES protocol by Korsvold et al. (2016) was also identified, which has a 6-step guide for communicating bad news: (S), Setting up the initial interview, determining the patient's Perception of their condition (P), subsequently Inviting the patient, (I) providing Knowledge and information (K), responding to the patient's Emotions with empathy (E), and explaining the treatment Strategy and providing a Summary (S).

Reasons for communicating the diagnosis. This was the aspect in which the greatest substantiation was found, i.e., robustness by virtue of the number of citations. Fourteen codes and four categories were defined that revolve around the main actors in the communication process (patients, families, oncologists) and the process itself (Fig. 4).

The patient is the central member since he/she is the one the whole process revolves around and who needs the most understanding and accompaniment from the other agents (parents and/or caregivers and health professionals) at the time of disclosure.

Some patients are less receptive to additional information and rely more on their parents as their sole sources of information at least during the early periods of treatment (Levenson et al., 1983). Because of their developmental stage, they are more likely to exhibit strong emotions (Korsvold et al., 2016, in which a strong desire for involvement of their families and/or caregivers is identified, to receive accurate information about their diagnosis and prognosis in order to feel better prepared to cope with the disease process (Jalmsell et al., 2016). This is supported by the patients' right to be informed. Likewise, such information, while disclosed with complete truthfulness, must be adapted to the age of the child, since the communication of the diagnosis has an effect on the course and completion of the treatment (Sisk et al., 2017).

This right to be informed exposes an important link between communication and the age of the patient, where it is important to consider the patient's age and the language that will be used when communicating, especially when dealing with a minor. However, patients should know that they are not being lied to, but that they will be told only what they want to know (Sisk et al., 2016). This represents an important paradigm shift, as the child goes from knowing nothing to deciding what information they want to know about themselves when they are ready to know it (Petersen et al., 2017). This again highlights the importance of communicating information to the patient for treatment, but also for the health professional-patient-family relationship (Sisk et al., 2016).

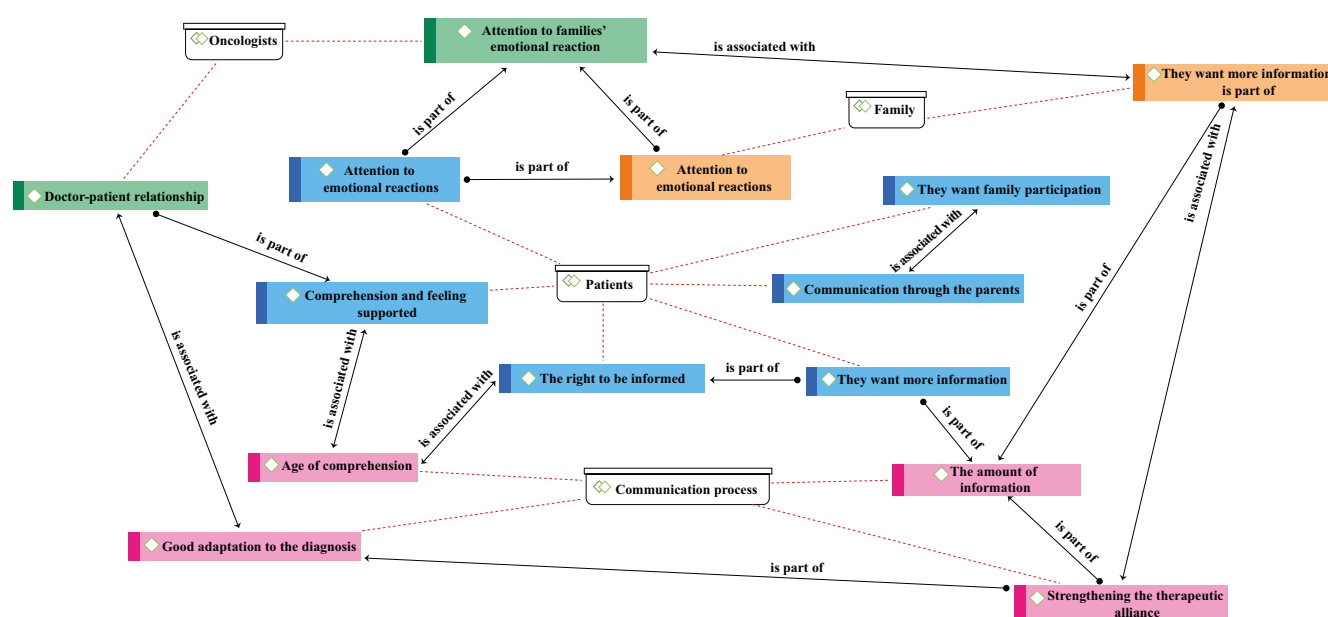


Figure 4.

Reasons for communicating the diagnosis: oncologists (green), patient (blue), family and/or caregivers (orange) and the communication process (pink).

Limiting information may prevent children's emotional distress, but over time they report experiencing greater distress. Even if it is not directly communicated to them, they know about the illness and its effects, because the symptoms of the illness convey the seriousness of the situation much more powerfully than any words withheld by adults, probably because children pick up on their parents' emotional distress even when parents try to reassure them or make efforts to present a calm demeanor (Clafin & Barbarin, 1991).

The same thing that happens with patients, and their desire to have complete knowledge of the disease process, also happens with the families. The main reason for communicating is the request they make for more information and more meetings throughout the process when their children have a poor prognosis (Sisk et al., 2017). Being kept up-to-date and discussing periodically with the health professional is very useful for them, as they show a preference for being always informed, encouraging immediate self-help in relation to their children's treatments so that in this way they themselves are prepared to participate as much as possible in their own treatment, knowing the implications of their behaviors in the course of the disease (Levenson et al., 1983). If the above is fulfilled, it will be possible to respond to the emotional reactions that the families and/or caregivers have, since they are the ones who know their children best, so they should receive guidance to accompany them throughout the process of the disease (Arenas et al., 2016).

The process of communicating the diagnosis is also relevant in itself from the understanding of the main context of the patient's development and the importance of knowledge of the risk and protective factors of the families and/or caregivers, since this, as well as the family support structure that the child has, will facilitate adaptation to the news of the diagnosis and subsequent treatment. The above determines when it is considered prudent to communicate, how to do it, the ideal level of involvement for all participants in the process, the keys to good communication, and the information that patients want (Arenas et al., 2016). Levenson et al. (1983) also identified arguments for the desirability of an active patient role in personal healthcare, as children who express curiosity about their medical procedures generally exhibit fewer anxious behaviors than children who are less actively involved.

From the perspective of health professionals, it was identified that communicating a diagnosis of cancer leads to complex emotional reactions that must be dealt with at the same time (Korsvold et al., 2016). Health professionals decide to communicate their diagnosis to the patient in a complete and truthful way above the decisions of parents and/or caregivers, since its non-disclosure or partial disclosure has consequences that directly affect the treatment, jeopardizing the parent/caregiver-child and doctor-patient relationship. Communication on the part of health professionals should be done with the aim of obtaining a better adaptation to the diagnosis of both the patient and their relatives or caregivers, thus facilitating a warm relationship, where the professional gains the child's trust and generates confidence while strengthening the therapeutic bonds (Jalmsell et al., 2016). Such communication functions as a facilitator for the professional on the child's understanding of his or her illness, adherence to treatment, satisfaction, and adaptation to the illness (El Malla et

al., 2017). However, this can be affected by aggressive or upset reactions from parents or caregivers at the time of disclosure, which causes professionals to modify the information provided to mitigate these reactions. On the other hand, these reactions can be mitigated through multiple post-diagnostic meetings, which provide greater reassurance to families and/or caregivers.

Discussion

This research aimed to identify existing health interventions for the communication of diagnosis in the child oncology population, and the search for this information was guided by three questions through which the main findings will be presented. Throughout the review and analysis process, the amount of information about disclosure and its practices in the adult population and in different diagnoses, as well as at the end of life, became evident. It showed that there is a limited amount of information on disclosure in the pediatric oncology population, which is why the final phase of the PRISMA method yielded a small number of units of analysis (17 articles).

The analysis carried out allowed us to identify two practices for communicating the diagnosis in the pediatric oncology population. The first, defined as verbal communication and the second related to protocols for the disclosure. Both practices include all the agents in the process in order to carry out the process of communicating the diagnosis.

In the framework of communication, the main actor is the patient, who has the right to receive information regarding their health and disease, taking into account cultural and family factors that may influence the process, and including the adaptation of communication to their cognitive age. For this reason, the health professional assumes the most significant challenge when communicating the diagnosis to both the patient and the family or caregivers, because their use of language is related to the satisfaction of parents regarding the information that they receive about the health status of their children. Likewise, the oncologist must be objective in disclosure, considering the amount of information that may be appropriate for parents or caregivers.

The needs and experiences of parents or caregivers regarding the information received about their children's disease were identified; communication characteristics, diagnostic information, and aspects of treatment are included here as elements of the communicative process in pediatric oncology. The content of the communication should respond to these needs in order to respond to the emotional expressions that arise at the time of disclosure of the diagnosis.

The reasons described for communicating the diagnosis are based on the need to address the emotional reactions of the psychological impact of receiving this news, reactions that both the patient and his or her family manifest during the process of communicating the disease. The purpose is to strengthen the therapeutic alliance, the doctor-patient relationship, and promote adaptation to the diagnosis, fulfilling the right of all patients to be informed about their illness in order to feel understood and supported. The importance of these findings lies in the aspects of communication that, applied with ethics and professionalism, allow a better adherence to the disease and its treatment by all the agents.

Although the literature highlights the importance of meeting these mental health needs in relation to being properly informed about a diagnosis, there is a need for diagnostic communication practices that have empirical evidence of their efficacy and effectiveness. In this systematic review we found few studies worldwide that show how the disclosure is made or which ones are used for these purposes.

One of the limitations of this systematic review is that the search for studies was done in a restricted way, using only standardized terms by thesaurus with which the search algorithm was created; this also excluded terms related to disclosure at other times such as end of life, fertility preservation, and others. This made it difficult to trace research that could be indexed with key terms in natural and non-standardized language. Additionally, the search was limited to databases specialized in health, leaving out meta-search engines or databases from other fields such as social and human sciences, where studies on the topic could have also been found. Another limitation was that original and review articles were included, but postgraduate theses and other types of publications were not.

In the analysis carried out, a category emerged that is not related to the research questions posed, but which exposes an interesting perspective that contributes to the understanding of the communication of the diagnosis: the barriers and preferences of disclosure in pediatric oncology. This category includes family aspects such as education and language, which have a significant impact at the time of disclosure and at the same time imply an adaptation in accordance with these characteristics, which varies between cultures and societies (Ilowite et al., 2017). Likewise, disclosure preferences are oriented towards satisfaction with the information received in terms of quantity and timing of communication.

This indicates that there are other factors to consider that affect the information to be disclosed and that can be key aspects when carrying out or designing practices to communicate the diagnosis in its initial phases. This can prepare health professionals and families or caregivers in this context by removing barriers that prevent adequate health communication.

It is important to mention that although children express the desire for more information, the ethical and legal framework of the process of communicating the diagnosis should be taken into account, since even though the patient may verbally express this need, he or she is a minor and it is his or her parents who are legally responsible for his or her health and safety. Likewise, not having parental approval to communicate any type of information about the process undermines ethical aspects that are actionable and would have legal repercussions for the health professional.

Based on all that has been explained in this section, it is evident that there is a need to design and validate diagnostic communication strategies, particularly in pediatric oncology, to support the health professional in understanding the child (not only in medical aspects but also in their cognitive, affective, family, and social development) and to guide them in the communication process. The aim of these tools is to overcome barriers to disclosure by dispelling fears of stigma and psychological harm to the patient, using appropriate language and facilitating implementation in low-resource settings.

Considering current living conditions and advances in information and communication technologies (ICTs), their application would be timely to reach remote or vulnerable populations whose mental health needs in the context of childhood oncology may not be covered. On many occasions, healthcare services do not respond to the daily dynamics of vulnerable populations, which could be exposed to risk factors associated with emotional stress experienced throughout the disease process.

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