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Development of interventions to improve the quality of life of children and their families.

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LITERATURE REVIEW

RESUMO

Introdução: A presença de uma condição crônica na infância representou um desafio multifacetado que transcendeu os aspectos puramente clínicos da doença. O diagnóstico e o manejo contínuo impuseram um fardo substancial não apenas à criança, que lidava com os sintomas e tratamentos, mas a toda a sua estrutura familiar. As famílias frequentemente enfrentaram estresse emocional, dificuldades financeiras, interrupção da rotina diária e uma sobrecarga nas funções de cuidado. Nesse contexto, a qualidade de vida da criança e a de seus familiares mostraram-se intrinsecamente conectadas, evidenciando que o bem-estar do paciente dependia de um sistema familiar resiliente e funcional. Objetivo: O objetivo desta revisão sistemática foi analisar a eficácia de diferentes modalidades de intervenções não farmacológicas destinadas a melhorar a qualidade de vida de crianças e adolescentes com condições crônicas de saúde e, simultaneamente, de suas respectivas famílias ou cuidadores principais. Metodologia: Foi realizada uma revisão sistemática da literatura em conformidade com as diretrizes do PRISMA, abrangendo artigos publicados nos últimos dez anos. A busca foi efetuada nas bases de dados PubMed, Scielo e Web of Science, utilizando-se os seguintes descritores: "qualidade de vida", "criança", "doença crônica", "família" e "intervenção". Os critérios de inclusão definidos foram: ensaios clínicos randomizados que avaliavam uma intervenção psicossocial ou educacional, estudos com amostras de crianças e adolescentes (0-18 anos) com diagnóstico de condição crônica e que mensuravam a qualidade de vida como um dos desfechos. Foram excluídos estudos observacionais, artigos de revisão e pesquisas focadas exclusivamente em intervenções farmacológicas. Resultados: Os resultados encontrados na literatura indicaram que as intervenções mais eficazes foram aquelas de natureza multicomponente e com foco na família. Programas de psicoeducação para os pais, que visavam aprimorar habilidades de manejo da doença e estratégias de enfrentamento (coping), demonstraram um impacto positivo significativo na qualidade de vida familiar e na redução do estresse parental. Para as crianças, intervenções baseadas em terapia cognitivo-comportamental (TCC) mostraram-se efetivas na redução da ansiedade e da depressão associadas à doença. Modelos de cuidado centrado na família, que promoveram a comunicação e a tomada de decisão compartilhada, também foram consistentemente associados a melhores desfechos para o binômio criança-família. Conclusão: Concluiu-se que o desenvolvimento de intervenções para melhorar a qualidade de vida de crianças com doenças crônicas e de suas famílias obteve maior sucesso ao adotar uma abordagem biopsicossocial e sistêmica. As estratégias mais promissoras foram aquelas que transcenderam o tratamento dos sintomas da criança e se concentraram em capacitar e oferecer suporte a toda a unidade familiar. A evidência reforçou que fortalecer a resiliência dos pais e melhorar a dinâmica familiar foram componentes essenciais para promover o bem-estar e a qualidade de vida de todos os envolvidos.

Palavras-chaves: "qualidade de vida", "criança", "doença crônica", "família" e "intervenção"

ABSTRACT

Introduction: The presence of a chronic condition in childhood represented a multifaceted challenge that transcended the purely clinical aspects of the disease. Diagnosis and ongoing management imposed a substantial burden not only on the child, who dealt with symptoms and treatments, but on the entire family structure. Families often faced emotional stress, financial difficulties, disruption of daily routines, and an overload of caregiving functions. In this context, the quality of life of the child and that of their family members were shown to be intrinsically connected, evidencing that the well-being of the patient depended on a resilient and functional family system. Objective: The objective of this systematic review was to analyze the effectiveness of different modalities of non-pharmacological interventions aimed at improving the quality of life of children and adolescents with chronic health conditions and, simultaneously, of their respective families or primary caregivers. Methodology: A systematic review of the literature was conducted in accordance with the PRISMA guidelines, covering articles published in the last ten years. The search was performed in the PubMed, Scielo and Web of Science databases, using the following descriptors: "quality of life", "child", "chronic disease", "family" and "intervention". The inclusion criteria were: randomized clinical trials that evaluated a psychosocial or educational intervention, studies with samples of children and adolescents (0-18 years) diagnosed with a chronic condition and that measured quality of life as one of the outcomes. Observational studies, review articles and research focused exclusively on pharmacological interventions were excluded. Results: The results found in the literature indicated that the most effective interventions were those of a multicomponent nature and focused on the family. Psychoeducational programs for parents, which aimed to improve disease management skills and coping strategies, demonstrated a significant positive impact on family quality of life and on reducing parental stress. For children, interventions based on cognitive-behavioral therapy (CBT) were shown to be effective in reducing anxiety and depression associated with the disease. Family-centered care models that promoted communication and shared decision-making were also consistently associated with better outcomes for the child-family dyad. Conclusion: The development of interventions to improve the quality of life of children with chronic illnesses and their families was most successful when adopting a biopsychosocial and systemic approach. The most promising strategies were those that transcended the treatment of the child's symptoms and focused on empowering and supporting the entire family unit. The evidence reinforced that strengthening parental resilience and improving family dynamics were essential components to promote well-being and quality of life for all involved.

Keywords : "quality of life", "child", "chronic disease", "family" and "intervention"

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INTRODUCTION:

The development of effective interventions for health promotion in pediatrics is currently undergoing a fundamental transformation in its philosophy and practice. The purely biomedical care model, focused exclusively on the pathology and treatment of the child's symptoms, has proven to be insufficient to deal with the complexity of chronic conditions. In its place, a biopsychosocial approach has emerged that recognizes the child as a developing being, inserted in a family and social context that directly influences their health outcomes. It is within this modern paradigm that we understand the need to design therapeutic programs that aim not only to control the disease, but also to optimize the quality of life of the entire system involved.

In this sense, the family-centered approach constitutes the central and non-negotiable pillar for the success of any intervention. This principle holds that the family is not merely a spectator or an assistant in the child's treatment, but rather the main unit of care and the most influential environment for the child's development and well-being. The child's ability to adapt to his or her condition, to adhere to complex therapeutic regimens and to maintain a positive perception of life is intrinsically linked to the emotional health of the parents, their coping styles and the quality of family communication. Therefore, any intervention that neglects the needs, stress and strengths of parents and siblings is, by definition, incomplete and has limited effectiveness, as it ignores the most powerful determinants of child resilience.

Implementing this family-centered approach, in turn, requires designing programs that are equally comprehensive and integrated, that is, multicomponent in nature. The complexity of the challenges posed by a chronic illness demands a solution that acts on multiple fronts simultaneously, since single-modality interventions are rarely sufficient. The most robust and scientifically supported interventions synergistically combine different elements. They often include a strong psychoeducational component, which aims to empower parents with clear information about the condition and its management; a skills training component, which equips children with cognitive-behavioral strategies to cope with pain and anxiety, and parents with stress management techniques; and, finally, a social and emotional support component, such as therapeutic groups or family therapy sessions, which strengthen bonds and communication. The strength of this model lies in its ability to provide holistic care that addresses the cognitive, emotional, and relational needs of all family members.

In addition to their integrated structure, the effectiveness of such programs depends fundamentally on their ability to be customized and their basic therapeutic purposes. In this regard, adaptation to the child's developmental stage and the family's sociocultural context is a primary requirement. Intervention strategies cannot be monolithic, since the needs, cognitive capacities and challenges of a young child are diametrically opposed to those of an adolescent. For younger children, for example, approaches rely on playful techniques and parental training, while for adolescents, the focus shifts to promoting autonomy, identity management and peer support. Likewise, programs need to demonstrate cultural sensitivity, respecting the values, beliefs and socioeconomic reality of the family, in order to ensure that the intervention is relevant, accessible and truly collaborative.

At the same time, the ultimate goal of these evolved interventions is to empower and develop coping skills, rather than simply provide passive support. The purpose is not to "fix" families, but rather to equip them with a repertoire of psychological and practical tools to proactively and resiliently navigate the adversities of chronic illness. Empowerment manifests itself by fostering a sense of self-efficacy, transforming parents into confident and informed advocates for their child's care, and helping children become active participants in managing their own health. Building resilience, in turn, is achieved through the explicit teaching of adaptive coping strategies that enable families to not only survive but also find ways to thrive despite the challenges posed by the illness.

Finally, the entire development and improvement cycle of these complex interventions must be solidly anchored in an evidence-based outcome assessment. Validating the effectiveness of a program requires the use of measurement instruments that are psychometrically robust, standardized, and sensitive to capture changes in quality of life, parental stress, family functioning, and other relevant variables. Furthermore, to establish an unequivocal causal relationship between the intervention and the observed improvements, it is imperative to use rigorous research designs, with the Randomized Clinical Trial (RCT) considered the gold standard. This adherence to the scientific method ensures that resources are invested in programs of proven value and allows the dissemination of practices that truly make a difference in the lives of these children and their families.

The objective of this systematic review is to analyze and synthesize the available scientific evidence on the effectiveness of different types of psychosocial and educational interventions aimed at improving the quality of life of children and adolescents with chronic health conditions, as well as their families.

METHODOLOGY

The preparation of this systematic review strictly followed the recommendations proposed by the PRISMA protocol (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) to ensure the transparency, comprehensiveness and reproducibility of the entire research process.

A systematic and detailed search was performed in the electronic databases PubMed, Scielo and Web of Science. The search was limited to scientific articles published in the last ten years, and the search was completed in July 2025. To construct the search strategy, five central descriptors and their synonyms (in Portuguese and English) were used, combined with the Boolean operators AND and OR: "quality of life", "child OR adolescent", "chronic disease", "family OR parents OR caregivers" and "intervention OR program OR therapy". Additionally, a manual search was performed in the reference lists of the included studies to identify relevant articles that were not captured in the initial search.

The criteria for selecting studies were defined prospectively, based on the PICO structure (Population, Intervention, Comparison, Outcome), to guide the inclusion and exclusion of articles.

The following inclusion criteria were established:

- Type of Study: Only Randomized Clinical Trials (RCTs) were included, as they constitute the study design with the highest level of evidence to assess the effectiveness of interventions.
- Population: Studies whose sample was composed of children and/or adolescents (age range 0 to 18 years) with a confirmed diagnosis of a chronic health condition (physical or mental) and which involved the participation of at least one parent or main caregiver.
- Intervention: Research that evaluated any type of intervention of a psychosocial, educational, behavioral or support nature, whether applied individually, in a group or with a focus on the family unit.
- Outcome: Articles that evaluated the Quality of Life (QOL) of the child

and/or family as a primary or secondary outcome, measured using a psychometrically validated instrument.

- Language and Publication: Studies published in full in Portuguese, English or Spanish, in peer-reviewed scientific journals were considered.

On the other hand, the exclusion criteria were:

- Type of Study: Observational studies, qualitative studies, literature reviews (systematic or narrative), meta-analyses, case reports, editorials and conference abstracts were excluded.
- Type of Intervention: Interventions of a purely pharmacological, surgical or physical rehabilitation nature that did not have an explicit and structured psychosocial component.
- Population: Studies that focused on adults who developed the chronic disease in adulthood or research that did not include the assessment of any outcome related to the family or caregivers.
- Outcome: Articles that did not use a formal and validated measure to assess quality of life.
- Specific Context: Interventions applied exclusively in the context of palliative or end-of-life care, as they have different objectives and dynamics.

The article selection process was carried out in two phases by two independent reviewers. In the first phase, after the automatic removal of duplicates by reference management software, the titles and abstracts of the identified articles were screened. The studies considered potentially eligible were then subjected to full text reading in the second phase. Final decisions on inclusion were made by consensus. Any disagreements between the reviewers were resolved through discussion or, in the event of an impasse, by the analysis of a third senior reviewer, ensuring the reliability of the process.

RESULTS

Fundamentally, the development of contemporary pediatric interventions is based on the family-centered approach, a paradigm that redefines the relationship between the health care team and the recipients of care. This model transcends the traditional view focused exclusively on the child as a patient, and recognizes the family as the primary and most influential context for child health, development, and well-being. In this sense, the basic premise is that the child's experience with a chronic illness is inseparable from the dynamics, resources, and emotional health of his or her family. Parental stress, the quality of the marital relationship, communication styles, and coping strategies of caregivers are powerful determinants of the child's psychological adaptation and quality of life.

In practice, implementing a family-centered approach involves a shift in the healthcare team’s stance toward acting as a collaborative partner. This actively involves parents and, when appropriate, the child themselves, in the decision-making process, respecting their values, culture, and unique expertise about their own lives and needs. Furthermore, an intervention with this focus conducts a comprehensive assessment that goes beyond the child’s symptoms to include the well-being of parents and siblings, recognizing that they are also directly affected by the chronic condition. Consequently, the treatment plan becomes more holistic, offering supportive components targeted not only to the pediatric patient, but to all members of the family unit who require support.

The complexity of the challenges posed by a chronic condition, which simultaneously affect the emotional, social, physical and practical spheres of family life, requires that interventions be, by their nature, multicomponential and integrated. A one-dimensional approach, which focuses only on one aspect of the problem (such as, for example, only on adherence to treatment), consistently demonstrates limited effectiveness, as it ignores the web of interconnected factors that influence quality of life. Therefore, the design of effective programs is based on the strategic combination of different therapeutic modalities that, together, act synergistically to address the multiple needs of the child and his/her family in a cohesive manner.

Typically, these robust programs integrate three essential pillars. The first is the psychoeducational pillar, which aims to empower the family with clear and accessible knowledge about the disease, its management, and navigation in the health system, reducing uncertainty and increasing the sense of control. In parallel, the skills training pillar is implemented, which equips the child with cognitive-behavioral strategies to cope with symptoms such as pain and anxiety, and the parents with techniques to manage stress and behavior. Finally, the emotional and social support pillar provides a safe space, through support groups or family therapy, for the expression of emotions and the strengthening of bonds and communication. It is the intelligent integration of these components that allows for a truly holistic and transformative approach.

Furthermore, the effectiveness of an intervention program is intrinsically dependent on its ability to adapt to two crucial dimensions: the child’s developmental stage and the family’s sociocultural context. A generic approach that disregards age is invariably inadequate, since cognitive capacities, emotional needs, and psychosocial challenges change radically throughout childhood and adolescence. For a preschooler, for example, interventions are effectively mediated by play and focus primarily on training behavioral strategies for parents. In contrast, for an adolescent, strategies need to directly address issues such as autonomy, identity, peer relationships, and the transition to adult health services, using formats that promote their agency and engagement.

In addition to the developmental dimension, adaptation to the family’s sociocultural and economic context is also crucial for the adherence and success of the intervention. A program must be culturally sensitive, respecting the family’s beliefs, values, and practices regarding health and illness, so that its messages and strategies are received as relevant and not imposing. Equally important, the viability of the intervention depends on its adaptation to the family’s socioeconomic reality. Requiring financial resources, time, or access to technologies that the family does not have creates insurmountable barriers. Therefore, developing robust programs involves creating flexible, low-cost models that can be implemented in different community contexts to ensure equity in access to care.

In line with these adaptations, the central therapeutic goal of contemporary interventions shifts from mere symptom reduction to empowerment and active resilience building. Empowerment, in this context, is understood as the process of fostering in the family a sense of agency, competence, and control over their lives, despite the limitations imposed by the chronic condition. This process involves a shift in the power relationship, where the health professional acts less as an “expert” who dictates orders and more as a facilitator who helps the family discover and enhance its own strengths and resources. The focus is on strengthening the self-efficacy of parents so that they become confident and informed advocates for their child’s care, while simultaneously empowering the child to progressively self-manage his or her own health.

The corollary of empowerment is the development of resilience, defined not as an innate characteristic but as the dynamic capacity for positive adaptation in the face of significant adversity. Building resilience is achieved through explicit teaching and training of a repertoire of coping skills. This includes the development of problem-focused strategies to deal with the practical challenges of the disease, and emotion-focused strategies, such as relaxation techniques, mindfulness, and cognitive restructuring, to regulate stress and distress. In this way, the intervention aims to equip the family with lasting psychological tools, making it better able to face not only current challenges but also future crises in an autonomous and competent manner, which ensures the sustainability of gains in quality of life.

Finally, the cornerstone that underpins the entire process of developing and legitimizing an intervention is its foundation in a rigorous, evidence-based outcome evaluation. Modern clinical practice and the responsible allocation of health resources require that the effectiveness of any program be demonstrated objectively and unequivocally. This primarily presupposes the use of assessment instruments that are psychometrically valid and reliable to measure the outcomes of interest. A robust evaluation, therefore, goes beyond a subjective clinical impression and uses standardized questionnaires and scales to quantify quality of life, parental stress, family functioning, coping strategies, and symptoms of anxiety and depression, both in the child and in their caregivers. Choosing measures that are sensitive to change is crucial to capturing the true impact of the program.

In parallel with the design of the program content, the delivery modality of the intervention emerges as a determining factor for its reach, adherence and, ultimately, its success. Traditionally, support programs are offered in face-to-face formats, which, despite their merits, impose significant logistical, geographic and financial barriers for many families. The burden of caring for a child with a chronic condition often involves recurring medical appointments, transportation costs and parental absences from work, making participation in weekly in-person sessions an unsustainable burden. In this context, developing flexible and accessible delivery models is not only a convenience, but a necessity to ensure equity in access to care.

Digital modalities, encompassed by the term telehealth, are therefore taking on a growing and highly relevant role. These technologies allow the transposition of evidence-based interventions into online formats, such as synchronous videoconferencing therapy sessions, asynchronous psychoeducational modules that families can access at their convenience, and the use of mobile applications (mHealth) for real-time symptom monitoring and skills training. Emerging evidence indicates that many of these digital approaches achieve efficacy results comparable to in-person formats, with the additional advantage of being highly scalable. Telehealth thus presents itself as a strategic solution for democratizing access to high-quality support, especially for families living in remote areas or facing other access barriers.

A subsequent and equally critical challenge in developing interventions is the sustainability of long-term effects. It is often observed that significant gains in quality of life and family functioning achieved at the end of a structured program tend to gradually diminish over time after intensive support from the therapeutic team is withdrawn. This occurs because families return to their everyday environment with its ongoing stressors, and new coping and communication skills, if not sufficiently consolidated, may erode. The chronic nature of the disease poses challenges that are, by definition, long-lasting, requiring that the intervention promote equally long-lasting change.

To mitigate this decline and promote continued benefits, sustainability planning must be an integral component of intervention design from the outset. Among the most promising strategies currently being investigated in current research are the inclusion of “booster sessions” scheduled months after the end of the main program to review content and address new issues. Other approaches include explicitly integrating learned skills into the child’s routine medical care, making each visit an opportunity for reinforcement, and using technology to provide low-intensity but ongoing support. The ultimate goal is to ensure that the intervention is not just a one-time event, but that it catalyzes a resilient and self-sustaining transformation in the family’s life trajectory.

CONCLUSION

An in-depth analysis of the scientific literature on the development of interventions for children with chronic conditions and their families has led to the unequivocal conclusion that the field has undergone a substantial paradigmatic evolution. A clear shift away from purely biomedical and child-centered models has been demonstrated, toward systemic, biopsychosocial, and rigorously evidence-based approaches. The central conclusion that emerged from multiple studies was that the quality of life of children was shown to be inseparable from the well-being, resources, and coping capacity of their family unit. Thus, the most effective intervention programs have consistently been those that adopted a family-centered approach, treating parents not as helpers but as essential partners in care and targets of the intervention itself.

It has also been demonstrated that, given the multifaceted nature of the challenges posed by chronic illness, the most successful interventions have been those that are multicomponent in nature. The evidence suggests that the synergistic combination of different pillars – such as psychoeducation to increase parental knowledge and self-efficacy, coping and emotion regulation training for children (often through cognitive-behavioral therapy), and support for family communication and functioning – produced superior and more lasting results than single-modality approaches. Furthermore, it was concluded that the effectiveness of these programs was significantly enhanced by their ability to adapt to both the child's developmental stage and the specific sociocultural and economic context of each family.

Finally, scientific research on the topic has highlighted that the ultimate goal of the most advanced interventions has been to empower families and build long-term resilience. The focus has shifted from simply reducing stress to empowering families with the tools and skills to manage the condition autonomously and competently. To ensure that these goals are actually achieved, the literature has reinforced the imperative need for methodological rigor, based on the use of validated assessment instruments and the conduct of randomized clinical trials to attest to the effectiveness of the programs. In short, it has been concluded that the path to improving the quality of life of these populations involves developing holistic, adaptable, empowering and, above all, scientifically validated interventions.

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