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Therapeutic itineraries of children with the early loss of primary teeth: A qualitative phenomenological study

Research Paper

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ABSTRACT

Background: Children with untreated dental caries tend to have a higher prevalence of early tooth loss, causing physical, psychosocial, and financial impacts on children and their families. The present study aims to understand the therapeutic itineraries of children with the early loss of primary teeth due to caries by analyzing the access to and integrality of care. **Methods**: This was a qualitative phenomenological study. Participants were caregivers, aged 18 years or older, of children up to 12 years of age who attended the University Dental Clinic of a Public University in Southern Brazil. Analysis of medical records and interviews were performed. The saturation criterion defined the sample size (n=44). **Results**: Public and private health services were accessed by families in the search for treatments for children's oral health conditions until they reached the University Dental Clinic. Children experiencing suffering and pain, who had had multiple extractions, and families affected financially and emotionally by the oral health condition of their children highlighted these itineraries. The resilience of these families in overcoming the challenges experienced and their continuous efforts to find solutions for the oral health care of their children were emphasized. Their relations with students and teachers at the University Dental Clinic were also discussed. **Conclusion**: The study showed a range of paths taken by children and their families and suggested weaknesses in ensuring the integrality of care for children in the Brazilian National Health System. Qualitative analysis of the therapeutic itineraries of children's families presented in this study is proposed as a complementary tool for health care. This study has the potential to contribute to the evaluation of health services in the country, strengthening children's oral health.

KEYWORDS

Integrality in Health, Pediatric Dental Care, Qualitative Research, Therapeutic Itinerary

BACKGROUND

In Brazil, implementing a National Universal Health System (SUS) and the National Oral Health Policy has brought advances in terms of Brazilians' needs and rights to health (Paim et al., 2011; Lima, Carvalho & Coeli, 2018; Pucca Júnior et al., 2009). This policy prioritized a health care model organized by lines of care (i.e., child, adolescent, adult, and elderly), involved all levels of complexity and the definition of reference and counter-reference system. With this, there was an increase in access and integrality of oral health actions, as well as funding for oral health teams in primary health care settings (Pucca Júnior et al., 2009; Pucca Júnior et al., 2015).

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Despite advances in health policies, dental caries persists as a serious public health problem and one of the most prevalent chronic diseases in the world (Peres et al., 2019), primarily affecting children from families with low socioeconomic status (Nunes & Perosa, 2017). Data from the last epidemiological survey on oral health in Brazil showed that, at the age of five, a Brazilian child has, on average, the DMFT index (i.e., the sum of decayed teeth, with indicated extraction and filled teeth in the deciduous dentition) of 2.43 primary teeth with caries experience (Ministério da Saúde, 2011). Moreover, these primary teeth with caries had the decayed component predominating and were responsible for more than 80% of the index (Ministério da Saúde, 2011). Furthermore, a nationwide study showed that approximately one-fifth of oral health teams do not perform dental care for children up to five years of age (Essvein et al., 2019), as recommended in primary Health care. At present, there are thousands of children without access to oral health care in Brazil (Essvein et al., 2019).

Children with untreated dental caries tend to have a higher prevalence of early tooth loss (Monte-Santo et al., 2018). The early loss of deciduous teeth can affect the quality of life of children and their families (Dainezi et al., 2015; Nóbrega, Barbosa & Brum, 2018; Rodd et al., 2011). This is associated with physical impacts in children, including malocclusion, delayed or accelerated eruption of permanent teeth (Bezerra & Nogueira, 2012) and phonetic and masticatory impairment (Nóbrega, Barbosa & Brum, 2018). Furthermore, psychosocial impacts result from conditions that affect aesthetics and impair social interaction (Bitencourt, Rodrigues & Toassi, 2021; Nadelman et al., 2020). It may also indirectly impact the family that cares for these children, causing the loss of working days and expenses resulting from dental consultations and treatments (Dainezi et al., 2015; Carlos & Martins, 2017). A study which analyzed data from the Family Budget Survey (2008-2009) showed that, on average, in one year, Brazilians spent R$ 42.19 on dental care and highlighted demographic and socioeconomic differences in the distribution of expenditures on oral health (Cascaes et al., 2017).

The effect of early tooth loss on children's lives is a complex phenomenon, as it is marked by changes in the 'physical body' that extend to the 'social world' in which the child lives and relates to others (Merleau-Ponty, 2002). Studying the therapeutic itinerary, identifying choices and paths taken by these children and their families to solve oral health problems based on the social context/process in which they live, has the potential to contribute to the quality of health care (Demétrio, Santana & Pereira-Santos, 2019; Gerhard, 2007).

Recent studies which aim to address the relationship between oral health and therapeutic itinerary in children and family contexts are not well explored by researchers and health managers. Therefore, this study aims to understand the therapeutic itineraries of children with the early loss of primary teeth due to caries by analyzing the access to and integrality of care.

METHODS

Study Design and Participants

We conducted a qualitative study using semi-structured interviews and qualitative thematic analysis through the lens of Merleau-Ponty. Throughout this study, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) consolidated criteria for improving the quality of qualitative research reports (Appendix 1) (Tong, Sainsbury & Craig, 2007).

The setting was the University Dental Clinic, affiliated with a Public University in Southern Brazil. Inclusion criteria consisted of being a mother, father or caregiver aged 18 years or older who accompanied the child at the dental appointment. Children were to be up to 12 years old and have early loss of primary teeth caused by caries.

Theoretical Foundations

An empirical phenomenological approach (Merleau-Ponty, 2002) was used to obtain in-depth information on the paths taken by caregivers in the search for therapeutic care. The experience of the early loss of deciduous teeth was immersed in the routines of the lifeworld by scientific knowledge. This means a body experienced by the subject as an object of scientific investigation. For this purpose, the

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understanding of lived experiences is linked to the idea of therapeutic itineraries.

The therapeutic itinerary is defined in socio-anthropological literature as the paths taken by the subjects to solve a health problem, loaded with meanings and mediated by experiences, in complex networks of social relationships (Demétrio, Santana & Pereira-Santos, 2019). The therapeutic itinerary mapping prioritized the caregivers' narratives of the children's paths and behaviours in search of extraction due to tooth decay. It identified the different points and forms in accessing the public health services before using the University's oral health service.

Data Collection

Data collection was performed in two stages and occurred concurrently with data analysis. Firstly, medical records were analyzed to identify children with the early loss of primary teeth. These teeth losses should have been due to extensive carious lesions that led to tooth extractions.

Children with the early loss of primary teeth were considered to have had a record with the absence of one or more primary dental elements in the clinical examination of the dental history. The period considered was at least one year before the eruption of the permanent successor (Araújo, 2002). In cases where a radiographic examination was present in the medical record, the evaluation of the early primary loss was complemented by analyzing the eruption stage of the permanent successor tooth. This is because the early loss happens before the complete coronary formation and when the root formation has already begun (Nolla Stage up to 7) (Moyers, 1991). Medical records with inconsistent information that were difficult to understand and those in which the dental clinical examination was not complete were excluded from the study.

In addition, individual interviews were conducted with the caregiver by a single researcher (FVB), who the senior researcher trained in qualitative methods (RFCT). To minimize possible biases and maintain methodological rigidity, one researcher transcribed every five interviews conducted, and each interview was randomly selected to be simultaneously heard and read by the researchers. All interviews were performed in a private room to avoid any embarrassment and unnecessary exposure of the study participants. A scripted semi-structured interview was used for data collection, which facilitated the introduction of questions to deepen the level of information given by caregivers. Forty-four caregivers were invited to participate in this study during the child's dental appointment at the University Dental Clinic. At this stage, the objective, format of the interview and data confidentiality were explained. No participants refused to participate or were excluded from the analysis. Each interview lasted around 40 minutes.

The interviews were recorded by a tape, fully transcribed, and then reconstructed in a narrative form. The same researcher transcribed the audio recordings verbatim within seven days of the interviews and reviewed by a senior researcher (RFCT) for accuracy. The interviews, original transcriptions, and data analysis were in Portuguese. The interviews were translated into English and then backtranslated by a professional experienced in the field to ensure meanings were retained.

The sample size was defined by the principle of saturation criterion (Fontanella, Ricas & Turato, 2008). The data collection ended when the researchers observed that responses were being replicated in the interviews, and the last interview brought no new insight or information. We obtained saturation on the sources with forty-four participants.

Data Analysis

The qualitative analysis comprehended the transcriptions of the interviews, in-depth material reading, the mapping of findings, the writing of a narrative summary and categories, and finally, the therapeutic itinerary elaboration to provide an understanding in a temporal perspective of the path taken by children with teeth loss.

The textual material produced by the interviews was imported into the software ATLAS.ti (Visual Qualitative Data Analysis) and interpreted through the analysis of thematic content proposed by Bardin (2011) (Table 1). The analysis followed the stages of pre-analysis, exploration of the material, treatment of

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the results obtained and interpretation. Pre-analysis included free-floating reading and exhaustive contact with the collected data. During the exploration stage, the raw data material was coded to reach the text's core understanding. In the stages of pre-analysis and the exploration of the material, information was sought that described the paths/services/spaces travelled by these children and their families in the search for oral health care until they arrived at the University Dental Clinic. This step highlighted feelings, barriers, and facilitators of these experiences. In the treatment of the results obtained, the researchers performed inferences and interpretations according to the theoretical framework and the proposed objectives (Bardin, 2011).

Confidentiality was assured by using numbers instead of names (e.g., interview 1, interview 2) and removing identifying information from the transcripts.

Ethical Consideration

The study was approved by the Ethics Committee of the Federal University of Rio Grande do Sul (#1.652.310), following the Helsinki Declaration of 1975 on experiments involving human subjects. The study objectives and voluntary nature of the study were explained to participants, and oral informed consent was obtained from all participants before each interview. All audio recordings and transcripts were saved on a password-protected document and device.

RESULTS

Forty-four caregivers of children with early tooth loss due to caries and whose children were undergoing dental treatment participated in the study. Of the interviewees, 28 were mothers, 10 were fathers, 4 were grandmothers, and 2 were aunts with an age range between 20 and 59 years.

Table 2 represents the therapeutic itinerary taken by the families for the oral health of the child until they accessed the University Dental Clinic.

From the analysis of the narratives produced by the caregivers, three main categories emerged. These categories expressed the ways and meanings that these families attribute to the health-disease-care process of their children.

Therapeutic Itinerary: Choices and Paths

The caregivers' reports showed that different health care settings - public and private - were used by families for the oral health care of their children until they arrived at the University Dental Clinic.

Access to Primary Health Care services has been highlighted in the experiences of these families as the reference service for their children's dental care. The search for care in Primary Health Care was motivated by situations of dental pain/emergency and fractured teeth associated with caries disease that led to extractions and the early loss of primary teeth. Families reported situations where they could not access dental treatment due to the absence of the oral health team in the Primary Health Care, leading them to seek other health services.

When families accessed the oral health service through the Primary Health Care of the National Health System, the families reported that the care provided was not resolutive, considering the children's needs for specialized treatments (root canal treatment due to pulpitis) or intraoral radiographic exams. These experiences contributed to the families having to seek another service for the continuity of the treatment. In these situations, involving a lack of a resolution to complex oral health problems, a loss of working days for caregivers and loss of classes for children, families have resorted to private dental services to continue treatment before gaining access to the University Dental Clinic.

As a first choice, other families have opted for dental care directly in the private service. Repeatedly there were reports of a lack of resoluteness to the children's oral health issues in these services. In the perception of the families, the high costs generated by the payment of treatments brought financial impacts, leading to the search for a new health facility for the dental treatment of their children. In different reports, referrals to the dental clinics of the University

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were provided by the dentist themselves, who were performing the children's treatment in other services.

Resilience and Challenges: Access and Continuity of Care

Despite the difficulties related to the continuity of dental treatment, the families showed an ability to adapt, overcoming the challenges experienced and constantly seeking solutions to care for their children's oral health.

There was a sense of responsibility and guilt among the caregivers for the illness and suffering of their children, associated with problems involving the `mouth-tooth-body´ connection.

In this context, the possibility of continuing the treatment until its conclusion brought the family the perception of "not failing the child", rescuing their role as being responsible for the care and a resolution of their children's health problems.

Expressions of Experiences

At the end of the treatment, the families expressed the impact of the experience of resolutive care in the lives of their children, who were happy, without caries, pain, and reports of discrimination due to their oral health condition, enabling them to return to their daily activities.

The caregivers perceived the mode of treatment as a "different experience from the one they had with dentists" when they needed dental treatment, leading to the perception of the creation of bonds with these professionals. They mention the "attention, calm, and patience" in the professional-patient relationship as characteristics that differentiate professionals in the University Dental Clinic.

DISCUSSION

Our study uniquely captured a deeper understanding of therapeutic itineraries among children with the early loss of primary teeth due to caries by analyzing access to comprehensive care. By conceptualizing caregivers as the expert on their child's life experiences, we identified the impact of dental caries and the search for resolutive treatments. The analysis concerned the dynamics of family organization and making decisions related to the health of their children, who were not yet fully able to verbalize their emotions and anguish.

While prior research has explored tooth loss experience and its biological impact (Spodzieja & Olczak-Kowalczyk, 2022), our findings underscore how these caregivers access the health service to resolve the early loss of primary teeth due to dental caries in the different levels of care. We consider this research unprecedented in that it expresses the experiences of a body with its human interactions, not separating it from the world in which these experiences are lived (Merleau-Ponty, 2002). In addition, our findings can support actions for care reorganization and provide opportunities for future research and insights on the subject.

The prevalence of caries in Brazilian children, at the age of five years old, is approximately 53.4%. Dental care is a vital strategy for evaluating oral conditions. Comassetto et al. (2019) revealed that 68.2% of children up to 5 years old have never been to the dentist. Their main reason for not having had a dental appointment was due to a lack of access to a health centre, with the most searched locations being private dental offices (43.9%) and public health centres (39.5%).

The present study highlights the early loss of primary teeth, for which caries are the main reason. Despite the advances, the Brazilian epidemiological situation related to caries and tooth loss in children from low-income populations is a cause for concern. Allied to that remains a limited number of offers and procedures performed by specialized services in Pediatric Dentistry. Paim (2018) demonstrated that throughout the 30 years of SUS, even though Brazil has expanded the offer and access to health services and actions, there is an insufficiency of public infrastructure and a lack of ascendant planning. Moreover, there are difficulties with the regionalization of networks and impasses for change in the models of attention and health practices compromise the universal and equal access to health actions and services. Regarding children, specifically among the factors that hinder access, there is a delay in care due to a lack of professional availability and a

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lack of time for the child's guardian (Damasceno et al., 2021).

Researchers have used quantitative methods to identify and assess factors associated with access to oral health services among children (Azanedo et al., 2017). However, the research does not provide in-depth information to support the facets between the life trajectories of children and experiences of tooth loss in health services from a phenomenological perspective. Therefore, in this study, the therapeutic itineraries mapping prioritized the caregivers' narratives of the children's itineraries and behaviour in demand for extraction due to tooth decay. The categories emerging from the analysis on the mapping of therapeutic itineraries should be viewed through two key concepts of 'body' (i.e., the 'physical body' and the 'social body'). While the physical body represents the body of lived experiences, the social body symbolizes the culture and the individual's personality.

Given the need for a qualitative analysis to better understand the behaviour and beliefs of children and their families, this study provides the different paths to access public health services before using the University Dental Clinic. In this research, the results showed children affected by caries disease with complex oral health care needs had to go through different services to solve their health problems. For the families that accessed the public service, the advanced clinical condition of their children's dental problems (which were already indicated for endodontic treatment not solved in Primary Health Care), led to a rupture in the guarantee of the constitutional principle of the integrality of care in the SUS. With this fragility in the flow of care in the oral health care network, families tend to seek private health services, which impacts the budget of Brazilian families (Moraes et al., 2022). In many situations, this makes the continuity of dental treatment and comprehensive care unfeasible.

Comprehensive care is an essential attribute in assessing the quality of care and health services, which must respond to the needs of people, families, and communities at different levels of care to function as a network (Conill, 2004; Fontoura, 2006). Our findings are supported by a qualitative study which used focus groups with families of children and adolescents with chronic diseases (Nóbrega et al., 2015). In the research, the itinerary of families in the health services was characterized by gaps such as the long waiting time for health care and fragilities in long-term care. These gaps leave children with chronic diseases (i.e., caries) and increased vulnerability due to a lack of follow-up and adequate management of the disease in health services. Understanding each person´s state of health can be challenging. The health-disease-care process refers to all the variables that involve health and disease, considering that both are interconnected and are the consequence of the same factors (i.e., biological, social, cultural, and economic) (Santos et al., 2014). Thus, addressing the meaning that each person attributes to this process can help us understand their choices of therapeutic itinerary in search of preventive measures and adherence to treatment, and the integrality of care.

Upon arrival at the University Dental Clinic, caregivers showed satisfaction with the care received. This feeling, which was previously one of "guilt/blame" for their children's condition of disease and suffering, was transformed into satisfaction for "not failing." This was expressed both by the possibility of performing all the necessary oral health procedures, solving their children's oral health problems and by the bonding relationship established with the professionals. This finding corroborates what has been found in the literature, showing that care is only possible where there is a professional-patient relationship and that the care provided has effects not only on the person with the disease but also on the way of life of each caregiver and the family (Corrêa et al., 2011).

Another issue to highlight is the analysis of the therapeutic itinerary from the perception of families, who are concrete human beings living in a specific time and place (Merleau-Ponty, 2002), and are responsible for making decisions related to the life of their children. This approach allowed a more profound understanding of how much the oral health condition of children has the potential to affect the dynamics of the family organization (Matza et al., 2004; Talenkar et al., 2005). Our theoretical reasoning allowed us to analyze and explore how families experience health disparities and overcome these disparities by providing culturally specific sources of

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resilience and strength. The results showed that families were affected financially and emotionally by the oral health condition of their children, leading caregivers to miss days of work and their children's schooling and blame themselves for the children's pain and caries disease. Health policymakers should not neglect such findings, and the findings should be part of the care strategies. Our results reinforced the previous evidence that health problems can produce impacts that tend to increase family stress (Hattangadi et al., 2020).

The present study emphasizes the need for integrated and continued care for children in Primary Health Care, concerning services that address the most complex oral health problems, such as dental caries and its sequelae. Both are still prevalent in modern life and are the most frequent cause of early tooth loss in the deciduous dentition of Brazilian children (Bezerra; Nogueira, 2012; Brandenburg; Casanova, 2018). A qualitative study conducted in Primary Care Units in Brazil using a hermeneutic methodological framework proposed approaches to the integrality of children's care through two dimensions. The first dimension is attitudinal and involves the health team and the family, where there is a focus on humanized care, with qualified attention to health problems. Secondly, an organizational dimension exists to establish adequate health system flow (Finkler et al., 2014). Actions focusing on health promotion beyond the treatment of oral diseases should be valued in Primary Health Care and integrated into the health care network in the country. These actions might include the family context in the care process from the child's first years of life (Comassetto et al., 2019; Pereira, 2020).

This study has the limitation of having been conducted with a sample of children with complex oral health needs, seen in a University Dental Clinic, whose access is limited to a restricted number of patients covered. Multicenter qualitative studies involving services of the National Health System care network are recommended to analyze the reality of access to health care and the integrality of Brazilian children in the right to receive health care.

IMPLICATIONS

The qualitative analysis of the therapeutic itinerary of children was enhanced by the inclusion of the caregivers' perceptions, as this made it possible to understand the complexity of knowledge, practices, and health needs. The findings contribute to the greater dialogue necessary between the clinic and the biography of children and their families.

CONCLUSIONS

The results of this research, in a specific and restricted service of oral health care linked to a Public University in Southern Brazil, show a plurality of paths taken by the children and their families. The findings suggest there are weaknesses in ensuring the completeness of care for children in the SUS network. When families could not follow the therapeutic path established for the treatment of their children, care was interrupted, and a new and more complex health demand was generated. This caused short- and long-term consequences that expressed themselves in pictures of pain, discomfort, and prolonged and costly treatments, which can lead to early dental loss, affecting children and families.

It is necessary to expand the spaces for discussion and improve the permanent education on specialized services in odontopediatrics for more complex cases. Future research related to the oral health of children should include their families to understand better the strengths and challenges present in the network of care in the SUS.

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Table 1. Synthesis of the meanings that emerged from the interviews

Meaning Unit	Condensed Meaning Unit	Theme
"She [child] had treatment at the health centre. In the end we lost work, we lost classes, we lost ... and it wasn't being solved. Then I paid privately. And now we are doing it here".	Report of the different health care spaces sought in search of effective treatment	Oral health care: choices and paths travelled
"He's super happy that he's getting his teeth fixed and going to school, doing all his activities normally. Something that was bad and decayed has come out and something new will come"	Resolutivity care perceived by the family	Resolutivity care and its consequences
"What it takes up is time because time is lost to come here, to spend time waiting. Although I am not complaining, I am exposing what this causes. It is necessary to change the routine, I have had to change shifts, so I don't miss out because I think the work of the University Dental Clinic is very important"	Changes experienced by families and their children in the search for a resolutive health service	Resilience facing the challenges of resolutive care

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Table 2. Characteristics of participants according to therapeutic itineraries, sex and degree of caregiver's kinship and their children

Therapeutic itineraries	Caregiver's sex	Degree of caregiver's kinship and their children	Total
Primary Health Care, University Dental Clinic	8 women 2 men	8 mothers 1 father 1 aunt	10
Primary Health Care, Private service, University Dental Clinic	4 women	3 mothers 1 grandmother	4
Private service, Primary Health Care, University Dental Clinic	4 women 1 man	4 mothers 1 father	5
Private services, Primary Health Care, University Dental Clinic	2 women	2 mothers	2
Private service, Primary Health Care, Public hospital, University Dental Clinic	1 woman	1 grandmother	1
Private service, University Dental Clinic	7 women 4 men	6 mothers 4 fathers 1 grandmother	11
University Dental Clinic, Private service, University Dental Clinic	1 woman	1 mother	1
University Dental Clinic	6 women 4 men	4 mothers 4 fathers 2 aunts	10

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