Original Research Article

Dental care for children with disabilities: the experience of parents-carers after the financial crisis in Greece (a quality study in Thessaloniki)

Abstract

OBJECTIVE: The purpose of the study was to explore the experiences of parents and carers of adolescents with disabilities and learning difficulties in terms of their dental problems and their access to dental care. The study focused on exploring parents daily experiences when seeking dental care. The ultimate objective of the study was to identify ways to improve the quality of dental care for adolescents with disabilities and learning difficulties.

METHOD: A qualitative study was conducted through twenty semi-structured interviews with parents of adolescents with disabilities and learning difficulties. The method of thematic analysis was employed by the researchers towards the analysis of the qualitative data collected from the interviews.

RESULTS: The following themes emerged during the thematic analysis: 1) parents' experiences from the shock of their child's first diagnosis towards the process of acceptance of their child's disability or learning difficulty. 2) Erosion of family cohesion. 3) High demands of parents' daily life. 4) Bureaucracy. 5) Financial challenges and unfulfilled health needs. 6) Organizational weaknesses. 7) Underestimation of dental care needs. 8) Search for quality therapeutic relationships. 9) Emotional distress from stigma and bulling. 10) Need for an individualized approach depending on the type and severity of the disability and learning difficulty. 11) Anxiety about the future including the need for social protection. 12) Encouragement of children's progress.

CONCLUSIONS: Many challenges have emerged during the study towards parents’ search for quality primary and secondary dental care for their children. Some of these challenges include but are not limited to the lack of provision of information, barriers inaccessibility, long waiting lists, high private expenses, etc.

. Additionally, the modernization of infrastructures in primary and secondary public dental care, as well as the development of emotional support structures for parents of adolescents with disabilities and learning difficulties is a great necessity for the Greek welfare state.There is an imperative need for greater coordinated efforts to be made in order to address this issue.

Keywords: disabled people, primary dental care ,secondary dental care ,Greece ,financial crisis

INTRODUCTION

According to the World Health Organization (WHO) disabled people, are more than 1 billion worldwide. People with mental suffer from disability(impairment) represent approximately 2% of the population and like a group, poorer health than the general population. (WHO 2021)

In the European Union 1 to 6 citizens face some sort of disability. In 2019, the 28,4% of the EU population with limited activities, are press to suffering poverty and social exclusion, comparison with the 18,4% of those who doesn’t have limitations. Furthermore the 68,0% of the population in EU with limitations of activities will have been endangered by poverty without social services(benefits), allowances or pensions, as mentioned in the EU Statistics about the income and living conditions (EU-SILC, 2021).

In Greece people with serious impairment exceed the 1 million,6 to 10 Greeks citizens with serious impairment are in the poverty line and social exclusion and 5 to 10 with mesial impairment. (ESAMEA, 2018).

In 2017, in EU and in all the member states, living in households with income below 60% of the average equivalent income has as an outcome that the children have a higher probability of unfulfilled needs for medical and dental care, with the situation worsening in single-parent families and rural areas currently results in Greece showing the highest rates of unfulfilled needs. (EU-SILC, 2021).

Purpose

The purpose of the investigation was to study the experience of parents-carers

with disabled people in their dental care problems. Our goal is to understand these obstacles directly from the population, the careers- parents. The purpose of recording their experience is to map the problems that encounters in the primary dental care, secondary dental care the information needs, access possibilities, waiting lists, private expenditure, etc. The study of surcharge, subjectively and objectively of the parents-guardians in their daily lives, looking for dental care, aims at improving the quality of dental care in the extension of the quality of life of families with disabled people.

Methodology of research

Criteria for selecting a research method

Qualitative research has been chosen because this method is an in-depth investigation of parents - guardians and can be a useful tool of understanding the circumstances they face, the individual problems that they experience, the way their attitudes are formed, the understanding and the attitudes in the research for dental care for disabled people.

The sample of the research were the parents of the disabled people who they are students in the special schools of the secondary educational system of Thessaloniki, the sample was with the criterion that in their age there is a record of their experienced in the dental problems and a certain picture of the dental health of disabled people. Furthermore, in the town of Thessaloniki there are some of available units of Primary and Secondary care.

Data collection

20 interviews were received

The interviews of the parents - carers of disabled people were not carried out within school premises and daring school hours without the presence of their mentors. No bioethics committee was required. The participants were adults, healthy volunteers, parents - careers of disabled people attending special schools.

Method of analysis of data

- Transcript of the interviews.
- Thematic analysis of the content of the interviews.
- Gathering and processing of results.

Results

The Thematic analysis of the interviews highlighted the following themes

1. **The treatment and acceptance of the relationship between the parent and his/her disabled child and their needs was raised as a primary theme in the analysis of interviews.**

The first diagnosis is a biological milestone, a turning point in the life of the parent and his relationship with the disabled child. The treatment of this relationship and the level of acceptance are decisive for the daily behavior, dedication, and care of the disabled child. The total number of parents has mentioned emotional charge in the procedure of first diagnosis at the early childhood of his child, when they are two or three years old. They referred to long-term procedures in which they were leaded without education and guidance.

Mother: Because we were going from bad to worse and when you are struggling and you want to learn what is wrong, or if you are wrong, if you can fix something and if they are making fun of you, because you don't know anything, and afterwards, we because your child is above all. We have been through a lot of situations after we went to the pediatric department but with a big delay. They didn't guide us. I was looking to find a solution…
Mother: and like parents, let's say and everyone shifted the responsibility, we went through a lot to compromise with situation, until we understand what was happening, we had a lot of issues. You finally realize to understand what is wrong.

The torturing route from the anguish and guilt in infidelity and acceptance. This is a course of emancipation and personal development, when the parent must breakthrough from the weights of social reconstructions that keep him in denial and the guilt that he's a body of evil uterus and elevates himself to a new framework for the defense of his child.

2. **A significant influence on the disabled person is also the interactions of family members and the potential erosion of family cohesion.**

The presence of a child with disabilities, and with mental retardation, is disturbing the family relationships and creates new balances. The quality of interaction between family members also affects the disabled child, through all the range of his/hers. Most of the fearlessness interviews, as one-parent families, with the mother bearing the burden of raising the child. The marital relations that they have endured, they have high level of cooperation, and only one family gave birth to another child after the diagnosis of their first child.

Mother: So, I will not... say that there was the support we would like, in the sense that there were relatives who learned which was the problem and they were terrorized and walked away... had some cousins in the same age that could help the child in socializing, and all of them stepped aside for some reason that we don't understand why. Because of fear, ignorance? This is how some people think. I understand. ... the other little brother, until he realizes, to understand what's going on with the Panagiotis, and there were a lot of things, why Panagiotis is like that? Why doesn't he behave like a normal brother? Why do I have such a brother? There are signs of indignation coming out on this subject...

Father: The grandmothers, all right. You realize it's very difficult for them to admit certain things. They understand it through time, it took some time.

Mother: Look at the parents, his father doesn't care. Will the state care? Well, yeah, that's why the ex-husband left us. He can't stand, he said, and he's gone. And 80 - 90% of men with such children, boys or girls. Generally divorced mothers for the same situation.

Social links and the supportive environment are particularly important for each person. Disability, and in particular mental demonization, is faking and this leads to erosion of social relations. Ignorance, neglect, flaring and fear make social factors in leading disabled people to isolation and exclusion.

3. **Dental care is added to the already high requirements of daily routine and studied the parent's responsiveness, especially when combined with high rates of single-parent families**.

Mother: We concluded in attending AHEPA hospital, Hippocratic Hospital and the Pediatric Hospital, where the little boy has been doing speech therapy and occupational therapy.

Father: The child was hospitalized in the ICU for 27 days... He considered it as a kindergarten in the pediatric department. He was used to the white lab coat, he's not afraid of them.

Mother: we couldn’t make it because I had to bring the child by myself and it was hard, we had to cooperate with his father, sometimes he could sometimes he couldn’t, and then spring came, with the good weather we left it behind, after covid-19 came.

Medical problems, morbidity often occurring, require a large amount of daily energy by parents. The situation is aggravated by the high rates of single-parent families.

4. **The treatment of bureaucratic procedures resulting in the search for public health care had a crucial role in taking care the child. Parents describe it as an odyssey for every medical practice**.

Father: To get my ticket to take it to my fund, from my security service and from there... facing a third-world situation resulting filing the numerous hospitalization and discharges.

Mother: We found ourselves trapped into spider’s web, filing papers. It was a hell of a time-consuming process. We paid from our own pocket up to a point, because the NHS system is a nightmare. You stand in line, and this never ends**.**

The procedures are so time-consuming and psychologically affects parents, who prefer to personally bear the cost of treatment processes privately .in order to avoid the suffering that is repeated every month.

5. **The financial obstacles faced by the family and the inscrutable and impertinent health needs, that arise determine the child’s the oral health.**

Mother: The children are being watched by young people at the University of Dentistry in Thessaloniki... I searched on my own and went over there. We were doing a lot of work over there, we paid less, so let's...My older son wanted braces, but prices are high, and I was unemployed at the moment. This year I was struggling. Some days we went to dental school. The money they wanted, though, was too much for me. They wanted 1800 euros. That’s a lot of money right now. ... I can only tell you that we nearly lost our home from giving money here and there. It's been a month since we couldn't pay the bank because we were giving money to very serious gentlemen for a diagnosis.

Father: Everything had to be done by the NHS. Don't you dare go out...

Father: Dental work, it had to be performed in clinics where a lot of money had to be given.

Mother: And of course, if something happens, yes, having surgery in a public hospital must wait six months. 6-7 months minimum. And if it's something that's urgent, I'll go to Agios Loukas and give 4,000 euros to make a filling. That's it. And it's true this is the amount that you have to pay, it’s true. Come on, there's a scaling at the same time, cause there's going to be total sedation, that. If it's something that's urgent and the child hurts, shouldn't it be done immediately? So, it's going to happen, yeah, I mean, the dental thing is one of the only things that scares me so much. I mean, I look the mouth every night to see if he's got anything, no black... Honestly, I wander what I should do.

Dental needs are often left unsatisfied because of the financial cost. Although PTY as well as Secondary care is the Hospital takes care of disabled people, it does not cover orthodontic treatments that are common and necessary. Also, the inability to co-operate children with mental retardation implies treatment under general anesthesia and the offer is minimal and the waiting lists are large.

6. **The most important is the access to services, adequate updating and minimizing lists, where a parent seeks public dental care for the child.**

Mother: So, when I talk to people I know that I do most of the research through people I know, internet research and TV shows. I would like for him/her the best treatment bey specialists and from people who didn’t try to take advantage of me. I have experienced this behavior numerous times. There must be structures protecting us from such mistreatments.

Father: What a parent does in Greece... what he does, he only does it only from experience. It doesn’t exist nowhere. I mean, show me a website right now, even private, saying five things... there are no facilities to be consulted, give a line to the parent. Do it, take care of it…

It is of key importance for parents as carers of the dental health of their children to have both information and education in the care. The implementation of prevention plans by the PMS and the availability of secondary care in a hospital environment show that they are a necessity.

7. **If the caretaker is unable to read a single problem, it is led to an understatement of the needs of dental care.**

Mother: Uh, a couple of times he was afraid at some point, I don't know, he's got two teeth sharp in the front region, and I don't know if they should be there, or if they should be taken out, I don't know.

Father: The abscess was something more serious, because it was then the age, combined with the fact that we had a little neglect it in that period of time, was the age that he did not complain us about any problem, that is, the type of pain, but even now it never tell us about any pain, he never complain to us.

The neglection of parents of disabled children for the rehabilitation of the child's dental treatment of dental diseases occurs because of their ignorance of the effects of dental diseases on the stomatognathic system and general health. It is of particular importance to provide information and training the parents - carers of specialized

.

8. It was investigated if the parent seeks for a qualitative therapeutic relationship for his child and how he specifies it.

Parents are looking for healers who will be able to be supportive to their children, specialized in coping with their disability, and expressing themselves in relationships and attitudes without stereotypes.

Father: When my child was in the 1st or 2nd grade... we went to a dentist who practically refused us to do a filling, it was a primary tooth…. And after she refused, she referred us for total sedation in the hospital. After the shock, we suffered. we went to a dentist who respected both his profession and his patients and first befriended the patient and then treated him.

Father: He got to the point of having an abscess on his tooth. We made an appointment... there's a Dental Unit, the staff, in the Hippocratic Hospital, who examined him and set us a surgical appointment after a while, we got lucky because another appointment was cancelled within a 7-month period., when that happened because it was completely borderline. Well, then it became a rough sedation. Afterwards, he suffers from nausea and vomiting.

Treatment under general anesthesia is recorded as traumatic experience by the parents of children with mental retardation and as a last resort in their deadlock. It is common ground, moreover, that where prevention is absent, the resulting treatments are more painful and costly at times.

9. A mental burden on stigma and intimidation

Mother: These kids don't have insurance. And even, let's say, we walk down the street, make fun of us, do us, not even the education exist in Greece. There's nothing wrong with the kids to teach them in schools some manners, to protect them. I didn't read such a thing in any of their books. Ignorance, superstition and fear lead to isolation and social exclusion of disabled people and their families and constitute a major obstacle to their progress. Social marginalization reduces opportunities for a disabled person for integration, building trust relationships and cooperation, elements necessary for the acceptance of dental care**.**

10. The need for an individual approach according to the type and severity of disability by qualified staff has been demonstrated.

Failure to cooperate with the dentist, the lack of training of dentists, difficulties in access and financial costs may give parents serious reservations about dental treatment. They're asking for something more.

Father:... there must be a cover for these children, at least, I think there should be some dentists, one, two in Thessaloniki, who only deal with such children.... with people with special needs, not just with children. That's where I'd feel very comfortable. In a state structure. At the very least, be in the center of the city, to serve all Thessaloniki, people with disabilities, wheelchairs, etc., etc.

Mother:... in every specialty and for dentists too, there are specific care for children with special issues, and in everything, so it's a matter of the state, clearly, to get people to help this situations. At all levels, whether it's dental, or it's psychological, manifest, whatever support they need, even the whole family. The states believes that these are trivial issues and their change of behavior is wishful thinking

The absence of a dental integrated care service for people with disabilities at the state level is evident.

11. Parents expectations and anxiety about the future were detected.

Parents feel that as long as they live, they will be able to protect their children. There is no social protection net for the future.

Mother: Things should be done as abroad. These children have no future in Greece. They do not have the treatment they deserve What will the future be for these children. The lack of permanent support structures for people with permanent and heavy disabilities as well as their families make the burden of the future unbearable. Mental empowerment and practical support through social benefits and structures are a political task.

12. The factors that encourage them were also identified.

The families of children with mental retardation live in isolation. Social support networks are weak or completely absent. Social ties are weakening.

Communication between them is primarily for information and management reasons.

Courage draws on the progress of their children in the conquest of autonomous functions.

Mother: when my Panagiotis was a child and put everything in his mouth and he didn't chew anything...after a while he got to eat his own cheeks, etc. chewing them well, no longer holding them in his mouth without swallowing them, well, that gave me a lot of joy.

Mother: Yes, it encouraged me and I see, that these maybe baby steps but not going backwards going forward. I don't mind. Let it be a step forward at a time and not taking any backwards. That’s what I see, and I am glad, and I will keep on trying...

Discussion

Many challenges have emerged during the study towards parents’ search for quality primary and secondary dental care for their children. Some of these challenges include but are not limited to the lack of provision of information, barriers inaccessibility, long waiting lists, high private expenses, etc.

Parents affected by this issue often experience abandonment and injustice in their effort to access primary and secondary dental care for their children. This is also exacerbated by their financial situation, bureaucracy and other obstacles related to challenges in accessing quality dental care services.

Disabled children face high dental care needs with predominant ulcers and periodontitis, exacerbated by orthodontic problems and the occlusion problems. In a vicious circle, unsatisfied dental needs have a negative impact on the general health of those who are vulnerable. Despite the increased need for prevention and recovery, disabled people have poorer oral care than the rest of the population, resulting in one in three disabled persons never having visited a dentist. (Rojas Fernadez et al., 2011).

From all the health requirements of disabled people dental care is the most neglected and unsatisfied medical need (EOO,2005).

Disabled people have great peculiarities and increased needs for dental care, which are required to be provided in a hospital environment, particularly in cases of mental disability that the patient is unable to cooperate in a private dental office. The difficulties in access, long waiting lists, problem-lists, and the communication problem with the carers leads a high proportion of disabled people not to satisfy their dental needs and in several surveys of the oral health of disabled people fall short of those who are healthy (Lewis Ch. et al., 2005; Desai M. et al., 2001; Al Agili D.E. et al., 2004; Ad De Jongh et al., 2008; Mitsea A. et al., 2001).

Barriers to the treatment of disabled people experience shortages in the state programs to treat those people in primary and secondary care. (Zervou -Valvi F et al., 2008).

At the time of the economic crisis, Greece was found without organized Primary Dental Care and without the design and support of Secondary dental Care, the so-called Hospital dentistry. (Zervou - Valvi. et al.2008; Esamea 2009).

It is mandatory not only the carers of disabled children who undertake their daily care is crucial to have the adequate information and education from specialist staff and but also the dental team that is going to treat them must have a special training for the management of disabled people, because problems may occur in their collaboration does to the disability as well as comorbidities which sometimes require specialized treatment or general anesthesia as a treatment plan. (Gizeni S., 2011, Benaveli A. et al 2016; Dimitriadis D.et al 2008,Giannopoulou A et al. 2015).

In order to overcome the access problems that disabled people are facing in the quality of the dental care, oral care and dental care must be integrated in the national fulfilled and coordinated health services to the citizens, so that poverty does not function as a factor of the extension of disability. (Scambler G., 2011).

Conclusions and Proposals

Individuals suffering from physical, emotional, mental, emotional, or social disabilities need support in their mammary health, both in children and in their adult lives. If they end up in painful situations, with partial or total sluggishness, it is often a result of the knowledge and choices of their supportive environment.

Information and prevention for disabled persons, specialized staff, modern infrastructure at the level of the secondary and primary health care system as well as the mental support and support structures of the parents and careers of disabled people, is a major necessity for the social Greek State.

Primary health care should be strengthened with infrastructure and staff to be the main driver for the care and care of disabled people and **Secondary health care** to supplement the treatment when requiring emergency-care with anesthesia or repression.

The nature and scope of undergraduate dentistry training could create the ability to manage people with disabilities at the level of routine dental care, while postgraduate specialization would provide access to more complex care needs.

The state should recognize the **increased costs** of dental care in disabled people due to the multiple time that these patients require as well as the importance of early intervention that should not lead to costly treatments in hospital bypass with general anesthesia.

Perhaps the creation of special dental care sections for people in need should be a constructive suggestion. Is it also proposed **the home-based treatment or in institutions with mobile dental care units** for people who can hardly be moved from a primary health care center to a Secondary health care center .

Greater coordinated efforts should be made for **a large-scale epidemiological survey, followed by the application and merciless of a single-transverse dental health care program for children and adolescents with disabilities**.

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