ORIGINAL ARTICLE

Difficulties experienced by caregivers of patients diagnosed with osteogenesisimperfecta (OI): example of a hospital

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Abstract

Objective: To identify the difficulties experienced by medical caregivers of inpatients diagnosed with osteogenesisimperfecta.

Methods: The descriptive, cross-sectional study was conducted at a university hospital in western Turkey from April to May, 2012, and comprised relatives providing care to patients who were diagnosed with osteogenesisimperfecta and were being treated in the paediatric endocrinology unit. Data was collected via face-to-face interviews with patient relatives. The 35-itemquestionnaire had 16 open-ended and 19 close-ended questions.

Results: The mean age of the 46 caregivers was 35.52±6.65 years, and 43(93.5%) of them were mothers. All of them said they felt anxious (100%), while 44(95.7%) felt sad/sorrow, 41(89.1%) puzzled, 40(87.0%) nervous, 40(87.0%) frightened, 39(84.8%) disappointed, 29(63%) shocked, and 28(60.9%) depressed when they first heard the diagnosis. Overall, 26(56.5%) experienced physical, 45(97.8%) psychological, 45(97.8%) social, and 35(76.1%) economic changes and difficulties, while 24(52.1%) had no social support. Of all the patient relatives, 38(82.6%) were unable to obtain adequate information about the disorder from the healthcare team.

Conclusion: Caregivers of patients diagnosed with osteogenesisimperfecta experienced psychological and social difficulties..

Keywords: Osteogenesisimperfecta, Caregivers, Patients. (JPMA 65: 764; 2015)

Introduction

Osteogenesisimperfecta (OI) is a genetic disorder, characterised by decreased bone mass and increased bone fragility, with an incidence rate of one in every 10,000-25,000 births.[1-4] Although 13 types of OI have been identified to date, but there are 4 clinical types according to the most common classification.[4]

OI is a disorder that affects the child and his/her caregiver not only physically, but also psychologically, socially, and spiritually.[4] The most affected family members of paediatric patients have been reported to be their parents and siblings.[5] Children and parents affected during OI diagnosis, treatment and care periods can encounter certain difficulties.[6] These difficulties can cause serious adjustment disorders and various spiritual problems in children and their family members, and lead to advanced anxiety disorders, such as posttraumatic stress disorder.[7,8] Psychosocial difficulties have been observed to elevate particularly when the support by family member caregivers is inadequate.[9] Disorders can also negatively affect the spiritual and physical well-beings of family members who provide care, as well as the patient's. It is important for families to adjust to these situations and maintain normal lifestyles both for the health and care of the children, and the health of other family members.[10]

It is necessary to communicate with not only the patient, but with the patient's family as well regarding the patient's adjustment to the disorder, rehabilitation and care. It is also essential to maintain a balance between change and consistency within the family. As a result of imbalance due to diagnosis, there may be changes in intrafamilial relationships and roles taken on by individuals.[11] While families that are able to handle these traumatic experiences can achieve new intrafamilial organisations, familial dissolution is highly likely in families that cannot. On account of all of these problems, a multidirectional approach to the treatment and care in OI is crucial. One of the main duties of healthcare professionals in dealing with OI is to evaluate and support the patients and their families as a whole while they are coping with their experiences from the disease and finding meaning in them when they do not possess sufficient power and knowledge.[12]

Literature review revealed that there were no studies on how the patients and their caregivers react from the moment they become aware of OI; what kind of biopsychosocial changes are experienced; and how they cope with these changes. As such, the present study was planned to identify the biopsychosocial difficulties experienced by caregivers of OI patients under treatment.

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Subjects and Methods

The descriptive, cross-sectional study was conducted at a university hospital in western Turkey from April to May, 2012, and comprised relatives providing care to patients who were diagnosed with osteogenesisimperfecta and were being treated in the paediatric endocrinology unit. The study site serves patients living in more than one province (in eight different cities) in the Aegean Region. Therefore an appointment for the registered patients under treatment in the hospital was scheduled beforehand.

All the caregivers were informed in detail about the purpose of the research and all of them volunteered their participation. After approval by the Ege University Ethics Committee data was collected through face-to-face interviews.

A 35-item questionnaire, consisting of 16 open-ended and 19 close-ended questions, was developed for the interviews. The questionnaire included questions aimed to identify the patients' contact information, sociodemographic characteristics, information on the patients that they were providing care for regarding diagnostic and treatment processes, their level of knowledge, and perceptions regarding OI, and their feelings regarding OI and its effects, coping status, and level of psychosocial support that they received.

Data was analysed using descriptive statistics and the relation between variables was evaluated with Ki-Kare analysis.

Results

Of the 46 parents providing care, the mothers had a mean age of 35.52±6.65 years and fathers had a mean age of 40.26±6.88 years. There were 24(52.2%) mothers and 23(50%) fathers who were literate or elementary school graduates, while there were 6(13%) mothers and 1(2.2%) father who were illiterate. Besides, 44(95.6%) mothers were housewives and 29(63%) fathers had a paying job. Among the caregivers providing basic care, 43(93.5%) were mothers; 17(37%) had consanguineous marriage; and 37(80.4%) had more than one child. In 33(71.8%) cases, children diagnosed with OI were seven years of age or older; 12(26.1%) had been under treatment for one year or less; 14(30.4%) two to five years; and 20(43.5%) six years or more.

Overall, 44(95.7%) caregivers described OI as "a disease that requires attention; fragile bones"; 20(43.5%) "very bad; a curse; indescribable"; 18(39.1%) as "a difficult and permanent disease that requires sacrifices"; and 12(26.1%) as "a tragic disease that causes nervousness and despair".

Besides, 45(97.8%)reported that they had not participated in any educational and/or psycho-educational programme on OI before, 38(82.6%) reported that they were unable to obtain

Table-1: Subjects regarding osteogenesisimperfecta on which caregivers wanted information.

Causes of the disease n=22 (47.8%)	**Treatment of the disease n=45(97.8%)**
◆ What are the genetic triggers?	◆ Does the disease affect mental development?
◆ How will the children of ill individuals be?	◆ What lies ahead?
◆ What are the information on the genetics aspect of the disease?	◆ How will his/her life be like in the future?
◆ What are the causes of the disease?	◆ Can other problems arise?
	◆ What are the effects of this disease on other systems?
Non-governmental organizations and legal regulations n=20(43.5%)	◆ Is this disease permanent or temporary?
	◆ Will he/she be able to get better?
◆ Are there any organizations that provide information and support?	◆ Will he/she be able to walk?
◆ Are there any associations on the disease?	◆ How will the course of treatment be?
◆ What will the mandatory military service of male children be like?	◆ What are the effects of treatment with medicine?
	◆ Does the medicine have any side effects?
	◆ How is the response to treatment?
	◆ How long will the treatment last?
	◆ Are there any developments regarding the treatment?
	◆ Are there any other treatment methods?
Care during the course of the disease n-25(54.3%)	**Educational opportunities n=29(%63)**
◆ How should nutrition be?	◆ Are the healthcare personnel trained on this disease?
◆ How to take good care?	◆ Is any information about this disease provided to the society?
◆ How to prevent traumas?	◆ Are there any regular education programmes for the patients and their families?
◆ What are the responsibilities of the family?	◆ Where can patient families receive training on physical therapy?
◆ How should personal care be?	
◆ What is the importance of physical therapy?	

sufficient information from the healthcare team regarding the disease, and 42(91.3%)reported to have inadequate knowledge, while all 46(100%) reported that resources in Turkish regarding the disease were insufficient. In addition, 22(47.8%) caregivers stated that they would like to obtain information on the aetiology of the disease, 25(54.3%) care, 45(97.8%) treatment, 29(63%) individual and common educational opportunities, and 20(43.5%) non-governmental organisations and legal regulations (Table-1).

Table-2: Distribution of caregivers according to the psychological, social, economic, physical and occupational and/or work-related changes.

	Count	%
Changes in life		100
Yes	46	
Physical changes		
Yes	26	56.5
No	20	43.5
Physical changes *		
Having a chronic disease	10	38.5
Headache	6	23.1
Back-neck-arm pain	5	19.2
Fatigue	22	84.6
Psychological changes		
Yes	45	97.8
No	1	2.2
Psychological changes *		
Anger	22	48.9
Sorrow	42	93.3
Anxiety/depression	35	77.8
Stress	35	77.8
Discouraged/exhausted	24	53.3
Psychological adjustment	2	4.4
Social changes		
Yes	45	97.8
No	1	2.2
Social changes *		
Pulling away/isolation	26	57.7
Limited social life/restriction	41	91.1
Being protective to reduce the risks	43	95.6
Social labeling	18	40
Reorganization at home	20	44.4
Occupational/job-related changes		
Yes	5	10.9
No	41	89.1
Occupational/job-related changes		
Quitting the job	5	100
Economic changes		
Yes	35	76.1
No	11	23.9
Economic changes		
Social security and referral system, treatment and transportation costs	35	100
TOTAL	46	100

*N=46 Each participant provided multiple responses. Line percentage was calculated.

Table-3: The statements of caregivers relating to the changes in their lives.

Physical Changes

Having a chronic disease: I have been diagnosed with diabetes, cancer or high blood pressure.

Headache: Having a headache.

Waist, neck and arm pain: My waist, neck and arm hurt a lot.

Fatigue:I'm nearly dead with fatigue.. All my body hurts.

Psychological Changes

Anger: I have become a frustrated, nervous person.

Sorrow: I have diabetes and cancer because of sorrow. We are always in grief..I always feel myself sad and nervous.

Anxiety-depression: I'm very anxious for my child. I'm crying all the time and couldn't accept that I'm psychologically ill. I have isolated myself from outside world.

Stress: I'm now a distressed person..

Crestfallenness / Fatigue: I'm sick of everything.

Psychological adaption: At first, I was very sad but then I have learned to live with that. Now I see the life more positively.

Social Changes

Withdrawal / Isolation: We don't go to crowded places. We don't meet with our friends or relations. We are usually at home. We feel isolated from other people, so I have ended my social life. I don't want to see other people.

Limitations/Restrictions in social life: We now don't go to weddings or join social activities. Our social life is very restricted.

Being protective to reduce risks: I'm being very protective for my child. I don't allow others to love him. I don't meet others in order not to leave him alone. We take him to the school.

Social tagging: Everybody now see us different. No one loves or touches my child. His teacher is scared. Others don't behave tactfully.

Arrangements at home:I have re-designed the entire house just for him.

Occupational Changes

Quitting the job: I have to quit my job. I don't work now.

Economical Changes

Social security and referral system: We had to pay in cash when we couldn't be referred. We had to come to private hospitals until we got the Green Card and thus we sold all we had.

Treatment and road spending: We were in trouble economically. We changed several hospitals until the diagnosis and that was an economic burden for us. We are still in trouble economically. The medicines we use for growth retardation aren't paid by government and they are a burden for us. I couldn't look after my child and had to give him to the nursery.

The caregivers who obtained information from physicians were 38((83.3%). When the caregivers were asked about how they felt when they were first told about the diagnosis, all 46(100%) felt anxious, 44(95.7%) felt sad/sorrow, 41(89.1%) puzzled, 40(87.0%) nervous, 40(87.0%) frightened, 39(84.8%) disappointed, 29(63%) shocked, and 28(60.9%) depressed. Caregivers reported that they tried to cope with the situation by trying to obtain information about their children in 31(67.4%) cases, receiving social support from close acquaintances 30(65.2%), through religious faith 25(54.3%), by following the physician's advice and receiving support from healthcare personnel 21(45.7%, while 20(43.5%) said they tried coping with the situation by pulling away from people. Overall, 26(56.5%) caregivers experienced physical,

Table-4: Distribution of caregivers according to the difficulties they experienced while providing treatment and care.

Difficulties experienced	Count	%
Obtaining information from the physicians	40	87
Personal care and treatment at home	35	76.1
Financial	32	69.6
Transportation to the treatment center	28	60.9
Prolonged hospitalization	9	19.6
Frequent change of physicians	7	15.2

45(97.8%) psychological, 45(97.8%) social, and 35(76.1%) economic, and 5(11%) occupational and/or job-related changes and difficulties (Tables-2 and 3).

Seven (15.2%) caregivers reported that their children accepted the disease and demonstrated adjustment, 21(45.7%) children accepted the disease but were occasionally rebellious, 13(28.3%) children were unaware of their condition due to their young ages, and 5(10.9%) children never accepted the situation.

Caregivers were asked about the effects of their children being diagnosed with OI on their spouses and other children, to which 17(37%))replied as having increased support between them and their spouses, while 27(58.7%)argued with their spouses frequently, 26(57.8%) had relationship with their spouses deteriorating, 21(45.7%)felt angry towards their spouses, 23(50%) got angry at their spouses and other children, and 22(47.8%) experienced a decrease in attention towards their other children. Besides, 13(28.3%) caregivers received social support from close acquaintances, 9(19.6%) from social organisations and/or associations, while 24(52.1%) received no social support from anyone in any way.

Further, 40(87%)caregivers reported to have experienced difficulties in obtaining information from their physicians regarding treatment and care, 35(76.1%) in obtaining information regarding personal treatment and care at home, 32(69.9%) financial difficulties, and 28(60.9%) in getting to hospita). Also, 9(20%) said it was difficult to have long hospitalisation periods, and 7(15.2%) frequently changing physicians (Table-4). Moreover, 45(97.8%) caregivers also stated that the uncertainty of the prognosis made them

Table-5: The relation of psyhological changes with other changes that the caregivers experienced.

		Anger	Stress	Sadness	Anxiety-Depression	Exhaustion
Family Relations	The deterioration of relations with spouse	X^2= 6.002 P= 0.019*				
	Making spat with spouse	X^2= 5.576 P= 0.038*	X^2= 6.226 P= 0.024*	X^2= 6.226 P= 0.024*		
	Responsibility sharing between spouses	X^2= 6.379 P= 0.016*				
Related to Treatment	Anxiety of the external appearance	X^2= 6.109 P= 0.020*				
	Being afraid of the treatment process	X^2= 4.506 P= 0.042*			X^2= 4.779 P= 0.043*	
	Anxiety of lack of information		X^2= 4.779 P= 0.043*			
Social Change	Social withdrawal		X^2= 8.648 P= 0.005**	X^2= 5.695 P= 0.030*	X^2= 0.004 P= 0.005**	X^2=19.596 P= 0.000**
	Limitations and restrictions in the social life		X^2=9.699 P= 0.009**	X^2=18.598 P= 0.003**	X^2=9.699 P= 0.009**	X^2=6.120 P= 0.019*
	Protective act		X^2=10.211 P= 0.011*	X^2=13.584 P= 0.017*	X^2=10.211 P= 0.011*	*
	Social tagging	X^2= 7.053 P= 0.015*	X^2= 5.477 P= 0.032*			X^2= 11.506 P= 0.001**
	Editing the home environment					X^2=10.980 P= 0.001**
Physical Changes	Exhaustion	X^2= 7.002 P= 0.017*	X^2= 5.091 P= 0.038*		X^2= 5.091 P= 0.038*	X^2= 10.645 P= 0.001**
	The presence of social support				X^2= 4.927 P= 0.036*	

*Chi-square analysis according to between variables were statistically $p < 0.05$ düzey has a significant relationship.

**Chi-square analysis according to between variables were statistically $p < 0.01$ düzey has a significant relationship.

anxious, 36(78.3%) being unable to obtain sufficient information, 26(56.5%) being frightened, 8(17.4%) due to aesthetic appearance, and 6(13%) because of the possibility of an incomplete treatment got anxious.

The disease had negatively affected 43(93.5) families, and 1(2.2%) reported a positive effect. The families affected negatively stated that "the disease caused a collapse in the family; caused much sorrow and anxiety; put them in a difficult situation; dismayed, wrecked, and destroyed them; torn them to pieces; worn them out; negatively affected them in every way; caused a great struggle; changed the order of life as they knew it; and encumbered them with great responsibilities." Further, the caregivers reported that they were worried about their ill children's conditions and futures, and whether the other children in the families would have the same disease or not. The majority 43(93.5%) of the caregivers believed that families/caregivers should be more extensively informed in order to more effectively cope with the disease, 28(60.9%) believed that families should receive biopsychosocial support, and 21(45.7%) believed that there should be organisations and/or associations for guidance.

The relation of the psyhological changes with other changes that the caregivers had experienced after diagnosis of illness were also noted (Table-5).

Discussion

The results of the study revealed that 97.8% mothers were in reproductive age (15-49 years) and considerable part of them (37%) were in a consanguineous marriages. OI is a genetic disorder[2-4] and it is believed that the families have a high probability of having children, again, and that they need genetic counseling.

It was determined that families of 78.3% patients were living in small settlements outside the city centre and children of 26.1% of them were under treatment for less than one year. In other words, they were diagnosed recently. Because children who have OI, but not yet diagnosed, were only treated symptomatically (e.g., orthopaedic treatment for broken bones) at regional hospitals, instead of comprehensive hospitals where specific treatment and care for the disease could be provided and most of the children were diagnosed with sensitivity of physicians about this subject by chance. Families also reported that they experienced difficulties in the process of diagnosis of their children.

A high ratio of the caregivers (95.7%) emphasised the fragility aspect of the disease when describing it. In other descriptions regarding the disease, the caregivers were focused on emotional labels, such as desperation and weakness that the disease had caused, and no other symptoms of the disease (e.g., teeth, blue sclera, dyspnoea, developmental retardation, middle-ear deafness, excessive sweating) other than bone fragility were mentioned.[4,13-16] This was an indicator of how the caregivers were not aware of all aspects of the disease. In fact, quite a high ratio of caregivers (91.3%) stated that they had insufficient knowledge regarding the disease. Although at a low ratio, the caregivers who indicated that they had adequate knowledge about the disease were actually observed in the interviews to have inadequate knowledge regarding the accompanying symptoms, genetic aspects, and prognosis of the disease. In fact, besides "maintaining care and treatment at home" and "financial difficulties", they indicated that they also have difficulty in "obtaining information about the disease". They stated that they essentially wanted information on the "causes of the disease, treatment and care for it, and educational opportunities".

While all the caregivers stated that they experienced many adjustment problems following the diagnosis, the levels of acceptance and adjustment in their children were higher. During the treatment period of chronic diseases, well-organised social support systems are highly important for families when coping with the disease.[17] However, it was determined in the present study that patient relatives did not receive adequate support in this sense. The absence of a non-governmental or official organisation that provides support to OI patients and their caregivers contributed to this outcome in Turkey.

All of the caregivers indicated that they experienced anxiety following the diagnosis. They reported that they were frightened, worried and anxious about certain matters, such as early termination of treatment due to financial problems, uncertainties regarding the course of the disease, and recurring surgeries. The causes of anxiety in the mothers, identified in a study that was conducted with mothers of children with a chronic disease, were similar to the findings of the present study.[11] It was believed that the root cause of this anxiety arose from insufficient knowledge about the disease. Thus, 93.5% of the caregivers emphasised the necessity of providing extensive information to the families and/or caregivers in order for them to effectively cope with the disease. Having insufficient knowledge about the future can cause loss of control and uncertainty, and, in turn, anxiety.[18] Informing caregivers about OI would help them develop appropriate coping strategies by helping them understand the course of the disease.[12] In a study, it was determined that providing information on the disease and cognitive strategies to the parents and teachers of the patients had positive effects on the understanding or emphasising approach of the teachers towards the children, and in guiding their behaviour.[19] These positive effects increase psychosocial adjustment to disease by alleviating the caregiver's anxiety. However, resources allocated to rehabilitation programmes for caregivers were scarce in Turkey.[12]

Caregivers who provide care to patients with chronic diseases change their lifestyles and interpersonal relationships.[11] A study showed that caregivers experienced physical, spiritual and social problems during the care giving period, and that these problems affected them intensely.[20] Similarly, in the present study, all the caregivers indicated that they experienced biopsychosocial and economic changes following the OI diagnosis. Those who reported to have a physical chronic disease indicated that it originated from sorrow, and that they psychologically experienced shock, depression, dismay and nervousness. It was determined that the physical symptoms experienced by the caregivers were of psychological origin, and that these complaints indicated psychosomatic symptoms. As reported in literature, these are reactions that any parent can experience when they find that their child is ill. Families may need professional help during the periods in which they experience these reactions.[18] These findings indicate the necessity of developing biopsychosocial support for families.

It was revealed that following extensive and adequate information about the disease, a supporting network, religious beliefs, advice from the physicians, and support from the healthcare personnel are crucial for caregivers to be able to cope with the feelings they experience at initial diagnosis. In line with literature, it was observed that caregivers take refuge in religion with positive interpretations of the situation, and that they try to get support from close acquaintances and healthcare personnel in order to be hopeful about the future.[11,21,22] In addition, with a protective instinct, nearly half of the patient relatives tried to cope with these feelings by choosing to pull away from people in order to create a safer social environment for their children. In line with these findings, psychosocial services involving an extensive and adequate education, creating a supportive and safe environment, and a multidisciplinary team approach could be effective for caregivers of OI patients to cope with these difficult situations.

Besides the caregivers who reported that the disease negatively affected their families, a number of caregivers indicated that their families bonded stronger and became more emotional after the diagnosis. Similarly, a study conducted with the families of patients with chronic diseases reported that collaboration, sensitivity, compassion, empathy, respect, personal maturity, and family unity were increased alongside negativity in interpersonal relationships and duties.[23]

Caregivers emphasise that it is necessary for the society, healthcare professionals, patients and themselves to be extensively informed about the disease in order to be able to effectively cope with it. A study determined that parents who indicated to have chronically ill children at home and little information and practical advice on how to adjust to the situation experienced five times the insecurity and desperation that parents who indicated to have received adequate information did.[24] Another study with 29 mothers of children with chronic diseases determined that developing an interaction based on mutual respect and good relations contributed to good adjustment and sufficiency.[25] It was also emphasised that it is necessary to have societal organisations to facilitate sharing of common information and socialisation, and that public institutions should work towards solving these issues. One study[26] emphasised that it is a complex process for parents with chronically ill children to adjust to the disease, and indicated that during this period, social support (e.g., obtaining information about the disease, seeing other ill children, and talking to other parents), parents feeling good in general, their behaviour towards their children, and children's adjustment to the disease are crucially correlated.[26] In the light of these findings, it is believed that providing an extensive, informative programme to caregivers about OI, difficulties experienced, and ways to cope with these effectively would increase their adjustment to the disease.

In a study,[27] with the families of the patients with OI, the diagnosis of the illness in the children of the families in the test group was found not to have affected their physcial life qualities, psychological conditions of social relations considerably. In contrast, the psychological changes of caregivers can be seen to affect their feelings for the treatment, relations between family and the social and physical changes they have experienced. The feelings of anger of caregivers can be seen to be in a relation with two variables (the treatment process and relations between family) basically. The difficulties in the treatment of the children, the restrictions in the social life and the feelings related to unexpected financial sacrifices result in anger. And therefore this causes family dynamics to change by affecting the family's relations in a negative way.[28]

According to the family functioning model, the stress factor causes distress for the parents and consequently this brings forth disputes between couples and difficulties in their relationships.[29] The reaction to the stress can cause the interaction between the child and his/her parents to detoriarite and the care of the child to worsen in the short term. In this study, feelings of stress, sadness, anxiety-depression and exhaustion were determined to affect especially the social lives of the caregivers negatively. This finding is notable for the importance of the phychological support along with the physical treatment services for resolving of problems; in other words, for re-providing their social adaptations, such as restriction in the social life, withdrawal or stigmatisation that occurs as result of the difficulties the caregivers have experienced.

Conclusion

The caregivers experienced certain psychological changes which affected their relation between family and social lives negatively. The negative changes resulted from the difficulties experienced basically in three fields: "information about the illness", "the maintenance of home care and treatment" and "financial".

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