

# How Life Would Be Without Thalassaemia: Patients' Perceptions

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## Abstract

*This article focuses on the experiences of patients with thalassaemia in Cyprus. Through a qualitative study of 10 patients and their spouses, this paper shows that thalassaemia is a restricting experience due to blood transfusions and especially iron-chelation therapy, while without such a disease, patients would be better able to fulfil their goals in life. The research participants indicated that thalassaemia impacts on patients' personal identities and the fatigue and stigma that they often experience can cause disruption to their routine, social life, and leisure activities. The study was part of a larger quantitative study of the quality of life of patients with thalassaemia and was co-funded by the Republic of Cyprus and the European Regional Development Fund (EU).*

**Keywords:** thalassaemia, chronic illness experience, Cyprus

## Introduction

Thalassaemia is derived from the Greek words *thalassa*, which means sea, and *haima*, which means blood. It refers to a kind of anaemia that presents abnormalities in  $\alpha$ - and  $\beta$ -globin synthesis (Manchin, 2014). Adult hemoglobin is 97%  $\alpha$ - and  $\beta$ -globin, and thalassaemias are autosomal conditions that consist of abnormalities in  $\alpha$ - or  $\beta$ -globin chain production. The most common forms of thalassaemia are  $\alpha$  and  $\beta$ -thalassaemia, and it is estimated that around 100 million people throughout the world are carriers of the trait (Hadjiminas, 2004). In Cyprus, the most common form of thalassaemia is  $\beta$ -thalassaemia and it is characterised by familial trait chains. Caused by defective  $\beta$ -globin genes,  $\beta$ -thalassaemia can be subdivided into the trait, intermediate and major types. Thalassaemia trait refers to a heterozygous carrier state, meaning a person has one defective and one normal gene-encoding  $\beta$ -globin (Manchin, 2014). Couples who are both carriers have a 25% possibility in every pregnancy to have a child with thalassaemia

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† Stefan Beck passed away on 26 March 2015.

(homozygous) (Hajiminas, 2004; Hatzouli, 2012).

Hajiminas, in his book *Cyprus and Thalassaemia* (2004), pointed out that thalassaemia was known in Cyprus since around the 7th century BC. This is verified by studies of bones and skulls discovered in archaeological excavations in Cyprus. Furthermore, Haldane's theory (1948, as cited in Kyrris *et al.*, 2013) supported that thalassaemia trait carriers were immune to malaria, which until the first half of the 20th century was one of the major causes of mortality on the island. This is the reason that many thalassaemia trait carriers survived and why epidemiology on the island showed large numbers of thalassaemia carriers (Kyrris *et al.*, 2013).

Cyprus was under Ottoman rule for around 400 years before it was colonised by the British towards the end of the 19th century. The British Public Health Services were determined to combat the huge problem of malaria and ultimately to identify and study thalassaemia (Hajiminas, 2004). After Cyprus became an independent state in 1960, one of the major public health problems that the public health services had to manage was that of thalassaemia. In the late 1970s a population screening programme that allowed the testing of students at school for the detection of the thalassaemia trait was planned and implemented. Thus it allowed couples who were both carriers to know in advance, through a prenatal examination, whether their child would be born with thalassaemia and to take the necessary measures. In this way, the number of children with thalassaemia dropped dramatically. In the past two decades the number of children born with thalassaemia fell to almost zero. The drop in the number of births and the low life expectancy of the people living with thalassaemia resulted also in the reduction of the number of the people who live with  $\beta$ -thalassaemia down to 650.<sup>1</sup>

This study aims at presenting the impact of  $\beta$ -thalassaemia on both persons living with this chronic disease as well as on their spouses. More specifically, it will focus on how they experience thalassaemia and how they imagine their life would be without the disease. The analysis is based on the findings from in-depth interviews conducted with five men and five women living with thalassaemia in Cyprus and 10 interviews with their spouses.

### **Thalassaemia in Cyprus**

Until the middle of the 20th century there was no long-term cure for people living with thalassaemia. Treatment was primarily based on blood transfusions without any successful method of chelation. These caused deformities in the body and facial bones, delayed sexual and reproductive development, and triggered complications, such as

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<sup>1</sup> Latest statistics were provided by the Thalassaemia Centre, Ministry of Health. Republic of Cyprus.

cardiovascular disease, diabetes and other chronic conditions (Hajiminas, 2004). Because these serious problems were caused by old chelation therapies, life expectancy was very short and people died quite young. With modern chelation therapies, complications are prevented, life expectancy has been increased, and people with thalassaemia can survive as long as any other healthy person.

Because of the high morbidity of the thalassaemia patients and because of the high prevalence of the chromosome carriers (estimated at 12.4% of the population in the 1960s), the government decided to implement a population screening programme in schools, so as to detect thalassaemia in youths and to prevent births of thalassaemia homozygous children (Hajiminas, 2004; Kyrri *et al.*, 2013). The Church of Cyprus supported this campaign and asked couples for a certificate of thalassaemia before issuing a marriage permit, and it recommended that people who were both carriers should not get married or should not have children (Hajiminas, 2004).

### **Quality of Life and Complications**

Hours of blood transfusions, hours of chelation, body harm, social stigmatization, mainly because of deformed external features, and social exclusion are some of the factors that might cause a poor quality of life for people who have thalassaemia (Hatzouli, 2012). Studies show that bad chelation is associated with bad quality of life, mainly because of the complications, and that the modern method of chelation contributes to a better quality of life (Gollo *et al.*, 2013). Especially, long hours spent in hospitals for blood transfusions and other diagnostic tests pose a problem for people living with thalassaemia (Telfer *et al.*, 2005).

Furthermore there is a social stigma associated with thalassaemia (Hatzouli, 2012). This is associated with the general beliefs about what is considered normal and what is considered different regarding health, but it is also associated with health beliefs and the way thalassaemia is managed and treated by the individuals and their families.

Bad chelation can lead to complications due to hyperperfusion, which can cause several other conditions. Complications involve skeletal deformations of the skull, in which the person's cheek bones are more prominent whereas the bridge of the nose is depressed. Also the thorax bones can become deformed and the spleen and liver can become enlarged. Furthermore, there is skin and eye discoloration, as well as bone marrow dysplasia (Hajiminas, 2014).

It is important to be aware of the possible complications and chronic conditions encountered by patients with thalassaemia, also due to hyperperfusion. GPs can help support patients to coordinate their care between haematologists, cardiologists,

hepatologists, psychologists and genetic counselors to promote a better quality of life and improved survival (Manchin, 2013).

Because thalassaemia is a chronic condition, it is imperative here to outline some basic concepts in the sociology of chronic illness, which will be helpful for understanding our participants' accounts.

### **Chronic Disease: Some Basic Concepts**

In the past few years infectious and acute diseases have given way to chronic conditions, described as health transitions, mainly because of the great advancements of the medical science (Manderson and Smith-Morris, 2010). These changes are also attributed to the high level of industrialization and urbanization that has altered the lifestyle of people around the world. Chronic conditions account for around 60% of global mortality, and in many cases they co-occur, causing a huge burden on political and economic conditions globally.

According to Nettleton (2015) the onset of an illness means that the person's everyday life is disturbed both physically and mentally. This disturbance has an impact both on the patient as well as on the family and carers, the latter in the case the person cannot self-care. Illness reminds us that the 'normal' functioning of our minds and bodies is central to social action and interaction, especially between the body, the individual and society. At another level, the degree in which the person depends on others to be able to perform self-care and duties contrasts the well-recognized social values of independence, which is related to self-image and self-confidence. Moreover, Lazarus and Folkman (as cited in Fitzgerald Miller, 2000) recognize a series of function coping procedures which are jeopardized in the case of chronic illness. Such procedures include the maintenance of equilibrium, sound decision-making, maintenance of autonomy and freedom, meeting social demands, controlling stressful factors that can become a threat and avoiding negative self-evaluation.

Talcot Parsons (1951, as cited in Nettleton, 2015) analysed what he described as the 'sick role', making a distinction between the biological and the social basis of illness. On the social level he describes illness as a form of deviance from what is considered normal. However, the sick person is allowed certain rights and privileges, but also obligations. Privileges include the right of the sick person not to fulfill everyday normal social obligations. The person is not held responsible for his/her illness. However, the person has the obligation to want to get well and must seek medical help in order to treat the condition of sickness. Furthermore, as Friedson argues (1970, as cited in Nettleton, 2015), the sick role is related to a wider social context and therefore it is also associated with the changing identity of the person because of this very experience of

illness. Friedson also distinguishes three types of legitimacy of the sick role. The first type refers to when the sick person's condition is temporary and curable, and therefore his access to the sick role is temporarily legitimate. The second refers to when the patient suffers from a lethal disease and cannot take action to overcome illness, in which case the patient's access to the sick role is legitimate. The third case refers to when the illness is stigmatising (e.g. AIDS) and societies do not encourage the person to have access to the sick role and to seek help in order to become well. (Constantinou, 2014).

According to Bury (1997), chronic illness can cause biographical disruption in two ways. First, patients may experience disruption of routine. Such disruption may cause feelings of uncertainty because lack of routine is linked with lack of sense of safety and predictability. Second, patients may experience disruption of their biography in the sense that the person's identity is lost or changed. This is associated with the fact that the person is adopting a new self, based on the new adopted role that is inevitably acquired with chronic conditions or disabilities.

## Methodology

This qualitative sociological study was part of a bigger survey that explored the psychological and social needs of people living with  $\beta$ -thalassaemia in Cyprus, which is the most common form of thalassaemia found on the island. The qualitative part is based on in-depth interviews with 10 people with thalassaemia and their spouses which were conducted between 2013 and 2014. The sample was randomly selected from the list of members of the Cyprus Thalassaemia Association and it included persons living in urban and rural settings in the area controlled by the Republic of Cyprus. The in-depth interviews were based on a semi-constructed questionnaire that contained basic questions that were used for comparison purposes. Furthermore, there was a free discussion between the researcher and the interviewee that allowed the interview to take the form of a narrative.

The questions were based on the impact of thalassaemia on everyday life of both the person as well as his/her family. In particular the interviewees were asked about the burden caused by the need for frequent blood transfusions and the chelation methods, the anxiety or stress that the interviewees perceived they suffer from because of the treatment methods, but also from the possibility of suffering future complications that is quite often the case for people living with this condition, the impact that thalassaemia has on planning for the future, and the social stigmatisation that they may have encountered over the years. The interviews were recorded and transcribed and they were then coded and analysed using the Atlas-Ti software. The study was conducted after being evaluated and approved by a national bioethics committee. All interviewees signed an informed

consent, but all information was treated anonymously, for purposes of personal data protection.

The sample consisted of five men and five women who have thalassaemia and are between 31 and 58 years old, and their spouses. All of the persons with thalassaemia perform blood transfusions and chelation. The older persons with thalassaemia present the characteristic external physical features that are the result of bad chelation methods of the past. The younger people do not have these features because modern chelation methods (usually oral) do not cause deformities of any kind.

This paper focused primarily on the question posed both to the person living with thalassaemia, as well as his/her spouse, asking how they would imagine life without thalassaemia.

## **Findings**

All the persons living with thalassaemia who participated in the study are treated with blood transfusions and chelation. There were three different chelation methods used by the group. The majority performs chelation with a pump; two of them use a pump in combination with oral chelation, and two of them use only oral chelation.

Blood transfusion is commonly performed once a week or twice a month depending on the needs of each patient. The patient has to visit the specialist thalassaemia centre where the transfusion is done, and it can take up to four hours. The length of time required to complete a blood transfusion places a huge burden both on the person as well as the family, as admitted by both the person as well as the spouse.

### ***Time Scheduling***

The hours spent on blood transfusion seem to cause a problem regarding the fact that scheduled days need to be very well programmed. One man described the time lost as being booked for the whole day:

‘It is not so much the suffering; it is that I have to go every week and I need about 2 hours to transfuse one bottle of blood. You somehow get out of your general schedule, because you need to have one whole day blocked specially for this purpose.’

Another woman stressed:

‘You do miss a day from your life. It is not just the two or the three hours you will lose, but you need to also schedule the children not to have any classes, because who will give them a lift? I need to finish early if nobody else can pick them from classes.’

Time schedules seem to also have a certain impact on the work life of some people, especially since the work hours often coincide with the transfusion hours. One

participant pointed out that it was necessary to make special arrangements with his bosses at work so that he can leave earlier:

‘The transfusions are usually in the afternoon. I need at least three to four hours each time. Now I have a problem at work as the civil service has changed the work schedule and I get off work at 15.30 the earliest. The thalassaemia clinic closes at 19.00. You understand that I cannot get there at 16.00 and have two bottles transfused. I would have to make it very quickly and this might have an impact on my health condition. I am still negotiating with my superiors on how to arrange this matter. They tell me not to worry, but when you have to leave earlier all the time, you can understand that it is an issue.’

This is also combined with the fact that sometimes there is no blood available on the day scheduled for transfusion, which is something that also poses a problem at work. Some people get off work later, especially in the private sector where work hours are different than the civil service, and they need to take time off for the transfusion. This means that they need to alter days off, something that causes additional problems with work schedules.

### *Fatigue*

Fatigue seems to be an important factor, which could potentially have a negative impact on patients’ daily life and integrity. One lady described the level of the fatigue she feels:

‘You won’t know what fatigue means. I feel that I am tired, especially when it is due time for a transfusion. I feel weak, I feel tired, I feel that I cannot cope with everyday chores. In the old days, when I was alone, I could maintain my haemoglobin at the same level, but I would come back home (from transfusion), sit and rest. Now I have the children, I have to help them with homework, to take them to afternoon classes, to do this, to do that...to... There are so many things to do and you get even more tired. And when night comes, the only thing you want to do is sleep early, by 10 p.m. the maximum.’

On the other hand, transfusions do not seem to bother the spouses, but they point out that they empathise with their spouse for having to go through this whole procedure:

‘It does not bother me personally, because it concerns him as an individual. It bothers me to see him come back at 7.30 in the afternoon tired from the transfusion, after a whole day’s work; it does bother me at the psychological level that what he is doing is so tiring and difficult, however he never complains. But to be bothered personally otherwise, no, it doesn’t. It is just the sentimental thing .... It is only that I know that he suffers.’

Another problem that arises due to blood transfusions is travelling abroad, as people need to schedule their travelling around their blood transfusions. This means that it is difficult to be away for more than a week, because as time passes, the body has a greater

need for transfusion, and the more fatigued the person tends to get. Also it is not easy to have blood transfusions in another country, as there is a lot of bureaucracy involved. The problem with travelling abroad was mentioned by the persons with thalassaemia themselves as well as by their spouses.

Fatigue is not only caused by blood transfusions, but it is also associated with the chelation methods that were used in the past, although chelation methods have been modernised since then. Pump chelation, according to the participants, means that on a daily basis a pump is inserted with a special needle into the body and has to remain there until the long process is completed. One woman, who was the oldest of the participants, focused on the fatigue that was caused mainly by the discomfort of having to pierce the body every day to use the pump:

‘Look, I have been using the pump since the age of 10. For the past years, a period of 30 years, I used the pump. Eh, I reached a point that my body could not take it any longer. I mean that I could not endure it any longer psychologically. I was disturbed mainly by the piercing and the swelling of my feet, because it is administered subcutaneously and it makes your feet swell and everything.’

Another woman, who is a teacher, said she prefers to use the chelation pump only in the summer, because the pump is visible under the clothes and she does not want the students to ask questions about it:

‘It is a 24-hour thing. When I go to school, because life at school is very active, I sweat a lot and the pump causes extra perspiration. It also causes me itching as it is administered under the skin. So I prefer to do it in the summer when I am at home, although the doctor insists that I do it year-round. I only do it in the summer and in the winter I prefer to take the tablets, which, of course, is not sufficient. However this safeguards that the pump, which is covered in plastic, will not slip away from perspiration, running the risk of the children noticing it. It might fall out of my pocket, or the wire might hang out.’

The chelation device also causes problems for people who want to participate in outdoor activities during the summer, especially swimming: ‘I refused the device because it is quite thick and you cannot conceal it if you wish to. And of course I cannot deprive my child from going to the sea in the summer to swim, because of the device.’

The spouses also seemed to realize that chelation processes are an additional source of inconvenience for their husband or wife, but they thought that the person is accustomed to it, although, in combination with transfusion, it seems to have a physical and psychological impact mainly on the persons themselves:

‘Yes, ok. Definitely it is something that affects her (his wife), because surely she would feel differently if she did not have this additional burden; the visits to the doctors, the

chelation, the transfusion. All of these are definitely negative, but she accepts them. They are incorporated in her life.'

### ***Further Treatment***

Medication and tests are another factor that is part of the life of a person living with thalassaemia. They need to be constantly alert for both medication as well as further testing:

'... You take a lot of pills. Every 15 days you need to go to the hospital to have blood tests in order to be able to determine further treatment, when you have to do your transfusion, how much blood you need to transfuse. You understand that this is a constant friction, from the moment you discover that you have the anaemia, until your time comes to leave this earth.'

In addition to blood transfusions and chelation, people living with thalassaemia have tests to do, which are related to transfusions (for example as stated above, they need to check their blood before the next transfusion), as well as to complications of thalassaemia (Hajiminas, 2014). Such complications can be cardiovascular, diabetes mellitus, and osteoporosis. Persons living with thalassaemia have to go through regular testing, either in order to prevent such complications, or in order to treat them if they are already present. This means that our participants have to spend additional time in hospitals for the testing or to get further treatment: 'Diagnostic tests have to be done with other specialists, for example with a cardiologist. I have to have MRIs, thorax X-rays, abdomen ultrasounds, etc. You can realize that these are morning appointments; I have to leave from work again.'

### ***Childhood Experience of People Living with Thalassaemia***

Most participants admitted that they had a difficult childhood due to the need for blood transfusions and the bad chelation methods. When they were children, they were different from their peers because they frequently suffered from fatigue and they were considered very frail, due to their weakened immune system. Some of them admitted that they often had infections. For these reasons they were frequently marginalized and bullied. Also, they were stigmatized, mainly due to the fact that people with thalassaemia often died young from complications caused by poor chelation methods. This negative situation was also reinforced by the general public's lack of awareness on what thalassaemia really is and how it is treated.

A man, who is now in his 40s, described his life when he was a child:

'In my school life there were many things that my classmates could do and I could not .... For example gymnastics, sports, going out in the evenings. I was young and I felt confined. I did not go out 3-4 times a week like my friends did, or go around every day.'

I knew that I had to study, go out and play a bit, come back and take my bath and install my pump, so that I would finish my chelation early enough to be able to go to school the following day. I couldn't for example go to the amusement park.'

One woman said that she had wanted to take ballet lessons when she was a girl, and another man said that he had wanted to follow a football career, but both of these were unthinkable, especially for their parents who always felt they had to protect them.

The general public's lack of awareness about thalassaemia was also an issue, since quite often people were bullied and mocked. A woman described the conditions she had to live through during her school years:

'I was mocked at school. There was this girl that kept chanting at me that I am anaemic and that I will pass it on to her (she thought it was contagious). I told my mother and she said I should not listen to what they say....but I was extremely frustrated and so I beat her and pulled her hair out. I was deeply offended, but after that nobody dared say anything to me.'

### *Stigma*

Many of the above experiences are associated with social stigmatization. As Alonzo and Reynolds (1995) define it, stigma refers to a category of people who are devalued by the broader society and whose life chances are lessened, with an ultimate consequence on their social intercourse (Green, 2009). Literally, stigma is 'a mark branded on the skin', and in another dimension it is a 'distinguishing mark of social disgrace'. According to Irving Goffman (1963), stigma is a social product generated by social interactions involving usually two individuals in separate roles, one of the normal and one of the stigmatized (Nettleton, 2015).

In the case of thalassaemia, the person's deformed external features, as well as being more susceptible to catching infections, and having to curtail various activities, play a crucial role in the social stigmatization of the individual. Moreover, as mentioned above, for many years thalassaemia was associated with a short life expectancy. The other significant thing is that for those who are trait carriers, others refer to them as 'having the stigma', meaning they have the particular chromosome, in layman's language. The whole stigmatization process has been reinforced by the population screening programme, which, according to some interviewees, it has contributed to the definition of thalassaemia as something evil, a disease that we should get rid of, so as to avoid people dying young. Hatzouli (2012) describes social stigmatisation of people who are heterozygotes as 'having the stigma', as the beginning of social stigmatisation for those living with thalassaemia.

One woman described the severity of the impact that social stigmatization had on the family:

‘Parents need to be supported, so that they will be able to help their child to hold on, to adhere to the treatment without feeling embarrassed. Too many thalassaemics, just because they lacked support and they did not have the right treatment, their parents were too embarrassed for this thing; the children grew up in a closed home. They even closed the windows and stayed indoors in order to get their treatment and they came out the following day and neighbours and relatives never knew.’ The same person faced discrimination and bullying from her boss, who felt obliged to employ her, although she never wanted to.

Especially regarding employment, some of the interviewees stressed the fact that it was difficult to get a job in the first place because of their external appearance. In their opinion, because of the small-sized communities in Cyprus, people are more prone to social stigmatization. The following statement by a man who was often bullied by peers is very characteristic:

‘As it happens in most peer groups of youngsters, there are some people who want to present themselves as “chiefs”, who are more crazy, who like to mock other people... Even if your ear is a bit small or big, they would mock you for it. Just think of me having this huge problem with my health, being bullied that I have this problem with my health. They mocked me that I was the “bloody guy” (because he had to have the blood transfusions). This is still in my mind very vividly after so many years. Many years might pass, but this will always be in my mind, because when they did this I was deeply disturbed.’

### **Imagine Life without Thalassaemia**

Participants were asked to try to imagine what their life would be like if they did not have thalassaemia. The first thing that would make a huge difference is that they would not have to have the blood transfusions, the chelation and the medication that cause inconvenience in their life:

‘I would not have to take so many tablets early in the morning. I would not have to get stressed about whether I have to take the tablets for thalassaemia, because if I do not, I will have problems with my iron levels and possible complications from there onwards. I would not have to spend my time in hospitals, to do my treatment, the blood transfusions, the blood tests, the MRIs, the CT scans, the osteoporosis tests, etc.’

Possible complications of course play their role, since they are a source of stress and anxiety, as described by one man:

‘Ok, the only thing that is sure, no matter what you might think, I would not have all these worries: doctors, hospitals, transfusions. I would have more time and less worry that I have to do all this in order to stay well. And of course, because of thalassaemia

there were other complications, like osteoporosis, like the one that old people have. And for this I have to take medications and have tests all the time.’

Time seems to play a crucial role, as many of respondents stated that they would not need to spend so much time in hospitals for blood transfusions, tests and treatments and they could be spending all this time doing other things. The matter of fatigue was also emphasised, as it also causes difficulties with coping with all family obligations and their everyday duties and housework. However, there were some positive things said that mainly had to do with thalassaemia being an important contributing factor in their upbringing and in the way their character was formed. One person feels that his character would not be so good without thalassaemia:

‘...For me thalassaemia has been a form of blessing; I feel it has protected me, it has made me a bit wiser and sensible, a bit more humble. I think if I did not have thalassaemia I might have followed other routes, more wild. I think it has helped me become a better person than if I didn’t have it. I am saying this in the sense that it has made me think more of others. My lifestyle might have been a bit more...if I did not live with thalassaemia, I would have a more lewd life. My passions would be more intense, like gambling for example. This means that thalassaemia has kept me away from all this. I became a better person.’

Travelling seems to be an important factor for people living with thalassaemia. One man described what it means to be able to travel for someone who lives with thalassaemia and how different travelling would be without it:

‘Only one thing would be different, that I am sure of and this is the capability to travel. Thalassaemia deprives you of the possibility to go on a long journey...this is because you need blood. If I decide to go to another country and stay a month, I cannot really do that, because I need the blood transfusion. If you wish to go to study abroad, as I did, you need to talk to doctors in that country, locate hospitals and everything else. Apart from that, there is nothing else I would wish for.’

Studying abroad is something another man emphasised, who decided not to go abroad to study because of his thalassaemia:

‘Ok, you can make some thoughts for example. I might have gone to another country to live if I did not have thalassaemia. I might have studied further abroad, if I could continue my studies. Now just with the thought of going abroad, you would need to think of your circumstances: blood transfusion elsewhere, chelations elsewhere, new things, and more difficult. Your whole life would be more difficult. Ok. I am now working in our family business and I am doing well.’

Some of the respondents reported that taking part in sports activities would also be different. There are two factors that contributed to them not getting involved in sports

activities – one being the requirement to provide a health certificate to sports officials to be allowed to join a group:

‘I would certainly engage in sports. I did engage in sports up to the age of 18....It was impossible to continue, as a health certificate was required. Otherwise your team cannot cover for you. For example what will happen if you collapse on the sports ground? You do understand that these people would be in a lot of trouble, won’t they?’

The other reason for not getting involved in sports is that the persons themselves were persuaded that they could not do it. One woman described her own experience:

‘I continuously felt that I could not be involved in anything. For example I became 30 years old and I still wished that I could climb a tree, because I could not climb when I was a child. This is actually what stigmatised me: that I was 30 and I still wanted to climb a tree because I never did it when I was little. I went to the sea and did water ski, after my thirties. I went twice. I went to do things that I could not imagine before.’

Spouses also gave their own opinions of how life would be without thalassaemia. One of the things that seem to be important is the freedom of movement, as now they feel that this is limited, mainly due to the treatment schedules:

‘Freedom of movement is the most important thing. We are limited because when we go abroad we need to hurry back because of the blood transfusion in 15 days. Then theoretically it is ok, but as the day of the transfusion approaches, she cannot get up easily, she has pain in her bones, she is nagging, she complains. I know it is her own matter, but I am also disturbed as a human being. I cannot tell her that I want to go out today, if I see that she cannot do it, neither could I leave her alone at home. Of course you get accustomed to some things over time....When you decide to get into this relationship; you know all of this from the beginning. You compromise. I knew that and I still chose to proceed.’

One spouse was concerned about her husband because he had developed diabetes as a complication, since he frequently suffers from hypoglycemia. Living without thalassaemia would also spare the person from such worries.

Time planning was a factor that respondents said would be different if there was no thalassaemia:

‘It plays an important role in the sense that if there was no thalassaemia we would probably not have to do so much planning in our family life. This is because when he knows that on the scheduled day he will have to have the blood transfusion, we know in advance that we can schedule nothing else for that day. This strict need for planning

does of course affect the whole family. We all need to follow a certain schedule. Other than that thalassaemia has not really deprived us of anything.'

## Discussion

Thalassaemia is a chronic illness that needs special treatment throughout the individual's life. Unlike other chronic diseases that might appear later during one's lifetime, the onset of  $\beta$ -thalassaemia appears soon after a person is born. It can even be detected during pregnancy. Therefore it is not easy to assume that, as a chronic illness,  $\beta$ -thalassaemia is expected to disrupt the person's biography, as described by Bury (Nettleton, 2015; Constantinou, 2014, 2012). Beta-thalassaemia is incorporated into the person's life from their childhood and their life course is planned and scheduled depending on the treatment and the course of therapy, and on their competence in the management of their condition. As for spouses, as soon as they entered into a permanent relationship with the person living with thalassaemia, they become aware of all the consequences and complications that thalassaemia carries with it and they have willingly and consciously taken on the 'burden' of living with a person with thalassaemia.

Both the attitude of the individual who lives with thalassaemia as well as that of the spouse seem to contribute to a smooth coexistence, acceptance and successful management of the situation. This is probably due to the fact that they might be sharing common beliefs and values about health and illness that have helped them to face hardships and cope with the condition. Årestedt, Benzein and Persson (2015), in a qualitative study on family beliefs on health and illness, show that 'when illness was viewed as a natural part of life, being aware of and prepared for new situations caused by illness was included' (p. 223). The results of their study also showed that families have beliefs that illness is a family affair, and therefore it was a matter of course to be there for each other within the family. It can also be the case that the couples that participated in the study share family beliefs that do contribute towards a positive attitude of the management of thalassaemia. These attitudes and beliefs also seem to contribute to the willingness of the spouses to take on additional responsibilities in order to secure the smooth function of their family and household.

The theme under question, which was how people with thalassaemia and their spouses imagine their life would be without thalassaemia, revealed that one of the most important barriers that thalassaemia poses is the number of the hours needed for the treatment and management of thalassaemia. Blood transfusions and chelation treatments take many hours, which means time away from work and from family life. In a study by Telfer *et al.* (2005), which examined the quality of life of 119 people living with thalassaemia in Cyprus and in the UK, nearly 40% in both surveys were

missing a great deal of time from work or school because of their transfusions or other thalassaemia treatments. In that study, patients suggested that arranging for transfusions during the evening, overnight, and on weekends would reduce absence from work or school and would enhance social integration.

Although many patients in our sample, as well as some of the spouses stated that life would be the same without thalassaemia, there are still some parameters that might be different and that would contribute to a better quality of life for the persons living with thalassaemia and their families. Such features were not mentioned before in other studies and it is the first study that explores the attitudes of both the patient and the spouse on this matter. In this sense, freedom of movement seems to be valued, meaning that thalassaemia would not be a barrier to travelling and to being involved in sports and physical activities. Another patient also mentioned that if she did not have thalassaemia, she would not be stigmatized, as she has been since her childhood.

It is also understood, and this agrees with other findings (Hatzouli, 2012; Telfer *et al.*, 2005;), that chelation methods in the past posed a hardship to patients, resulting in complications and deformities of their physical appearance, whereas new chelation methods prevent these complications. Thus, younger patients do not face the same problems as the older ones, and life without thalassaemia for them would not be that different.

### **Limitations of the Research**

This survey has studied people living with thalassaemia and their spouses. It is apparent that over the years these people have developed a positive attitude towards their condition and that it has not had a negative effect on their self-esteem. This is probably the reason that they have proceeded with their life and enjoy good working and family lives. It would be interesting if an additional investigation could look at the lives of people living with thalassaemia who did not get married or did not progress with their lives in the way expected by Cypriot society. The sample that we studied had no problem in revealing the condition of their thalassaemia and the various parameters that give their lives a different dimension. However the participants themselves stressed that many patients with thalassaemia, with the cooperation of their families, conceal their condition, feel stigmatized and are ashamed about their situation, thus resulting in low self-esteem and no self-confidence in planning and living a meaningful and productive life, including getting married and having a family. It is the suggestion of the researchers that these people should also be studied, and it is a limitation that such cases were not included in the sample in the first place.

## Conclusion

People living with  $\beta$ -thalassaemia undergo the same experiences as in any chronic illness. In the course of their lives the need to treat thalassaemia prevails, meaning that they must spend a great deal of precious time in hospitals and having treatments, which are often painful for the subjects. Time lost in treatments means time deprived from family, work and social encounters. However a positive attitude seems to play an important role in combating all negative situations that may arise from their conditions. This is possible also with the support and understanding on behalf of the spouses.

Life without thalassaemia then would not be that different except for where the various treatment requirements and their restrictions pose obstacles to a person's freedom of movement and ability to engage in activities.

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