

Supplementary Materials

Utilising Narrative Medicine to Identify Key Factors Affecting Quality of Life in Dry Eye Disease: An Italian Multicentre Study

Authors

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Supplement 1

List of involved expert centres in dry eye disease.

UOC Clinica Oculistica, AO Università di Padova – Padua, Italy
ISPRES Oftalmica – Genoa, Italy
Studio Oculistico Prof. Vercesi – Alessandria, Italy
Ospedale G. da Saliceto – Piacenza, Italy
Studio Oculistico Prof. Barabino – Milan, Italy
Clinica Oculistica, Ospedale San Raffaele – Milan, Italy
UO Oculistica, Spedali Civili – Brescia, Italy
Clinica Oculistica, Ospedale Molinette – Turin, Italy
Studio Oculistico Dott. Di Carlo – Turin, Italy
SCD Oculistica, Ospedale Maggiore della Carità – Novara, Italy
Clinica Oculistica AOU Integrata – Verona, Italy
Clinica Oculistica, Ospedale Maggiore – Trieste, Italy
UOC Oftalmologia, Laboratorio Analisi Superficie Oculare e Ricerca Traslazionale, IRCCS AOU Policlinico Sant’Orsola – Bologna, Italy
Ambulatorio di Oculistica, Ospedale di Ravenna – Ravenna, Italy
Oculistica, Ospedale di San Marino – Borgo Maggiore, San Marino
Ambulatorio di Oculistica, Ospedale Santa Maria della Misericordia – Perugia, Italy
Clinica Oculistica, CTO Policlinico Careggi – Florence, Italy
Policlinico Universitario Campus Bio-Medico – Rome, Italy
Clinica Oculistica, Policlinico Gemelli – Rome, Italy
Ospedale Israelitico – Rome, Italy
Policlinico Umberto I – Rome, Italy

Studio Oculistico Dott. Gualdi – Rome, Italy
Studio Oculistico Dott. Cusumano – Rome, Italy
Clinica Oculistica, Policlinico Universitario Federico II – Naples, Italy
SUN Seconda Università di Napoli – Naples, Italy
Casa di Cura Villa dei Fiori – Acerra, Italy
Clinica Oculistica Salerno, Ospedale Ruggi d’Aragona – Salerno, Italy
UOS Patologia della Superficie Oculare, Ospedale Ruggi d’Aragona – Salerno, Italy
Università degli Studi della Magna Grecia – Catanzaro, Italy
Policlinico Universitario di Bari – Bari, Italy
Studio Oculistico Convenzionato Ciraci – Bari, Italy
Ospedale dell’Alta Murgia Pirenei – Altamura, Italy
Clinica Città di Lecce – Lecce, Italy
Policlinico Universitario Paolo Giaccone – Palermo, Italy
Policlinico Universitario – Messina, Italy
Ospedale San Marco – Catania, Italy
Ospedale Civile Santo Spirito – Pescara, Italy
Clinica Oftalmologica, Ospedale Clinicizzato SS. Annunziata – Chieti, Italy
Clinica Universitaria SS. Annunziata – Sassari, Italy

Supplement 2

Narrative investigation tools: illness plots and parallel chart.

2.1 Illness plot addressed to the patient with dry eye disease

We invite you to tell your experience of living with dry eye disease. You may write instinctively and freely, regardless of the form or length of the story. Any episodes that you consider significant will be appreciated.

I, before the dry eye disease...

The first signs that something was wrong in my eyes...

I felt...

To find out what it was all about, I turned to...

When they told me it was dry eye disease...

My days were...

At home and with other people...

My activities...

Seeing was...

My face...

Treatment and healthcare professionals were...

I wanted to...

Today I feel...

Dry eye disease is...

A typical day of mine...

At home and with other people...

My activities...

Seeing is...

My face...

Treatment and healthcare professionals are...

I want...

Thinking back on my healing journey...

For tomorrow, I would like to...

2.2 Illness plot addressed to the caregiver of the patient with dry eye disease

We invite you to tell your experience of living next to a person with dry eye disease. You may write instinctively and freely, regardless of the form or length of the story. Any episodes that you consider significant will be appreciated.

I, before the dry eye disease of the person I am close to...

Her/his first signs that something was wrong...

I felt...

She/he felt...
To understand what it was all about, we turned to...
When they told us it was dry eye disease...
Her/his days were...
At home and with other people...
In her/his activities...
For her/him, seeing was...
Her/his face...
The treatment and healthcare professionals were...
I wanted to...
Today I feel...
Today she/he feels...
Dry eye disease is...
A typical day of her/his...
She/he at home and with other people...
In her/his activities...
For her/him, seeing is...
Her/his face...
Treatment and healthcare professionals are...
I want...
Thinking back on his course of treatment...
For tomorrow, I would like to...

2.3 Parallel chart addressed to the treating ophthalmologist

We invite you to tell your experience of caring for a person with dry eye disease. You may write instinctively and freely, regardless of the form or length of the story. Any episodes that you consider significant will be appreciated.

The first time I saw this person, I thought...
The patient and her/his family told me...
From the accounts of the symptoms, this person could/could not ...
Her/his life had changed...
I felt...
I said...
And I did...
When I told her/him the diagnosis...
Today this person...
At home this person...
In its activities...
The people next to her/him...
To treat her/him, I...

My goal for this patient is...

The treatment of dry eye is...

With her/him I feel...

For tomorrow, I would like to...

Supplement 3

Narrative samples.

3.1 Narrative of a patient with dry eye disease

Before the dry eye disease, I was a normal person, I had expectations from life, I led the same life as my friends, I went out at night, went to the gym, cared about my physical appearance, travelled, had a social life, could go to the beach, was not afraid of the sun. The first signs that something was wrong with my eyes: I was at the gym, suddenly a stinging pain in my eyes that never went away. A month earlier a kind of occasional conjunctivitis that lasted a week, but then the abyss. I felt that something was happening to me that I did not understand, I was in a total panic, I could no longer sit with the others, I had to leave. To find out what it was, I went to dozens of ophthalmologists, I wandered for over two years on a pilgrimage from one to another, and unfortunately, they were all worse than each other. All diagnosed with allergic conjunctivitis, but the treatments didn't work, and I kept changing ophthalmologists, after the 20th one told me it was dry eye. When I was told it was dry eye disease, I didn't understand what it was, yet another ophthalmologist told me it was not due to Sjögren's because according to him I didn't look like someone who had Sjögren's. Absurd, to say the least. He pumped me full of eye drops that made it worse, I went back a second time, just like the first time. It was time for a change of air for the thirtieth time, meanwhile three years had passed since the first symptom. I decided to go to Milan to the famous centre for dry eye, and there too they gave me a treatment that the ophthalmologist said would solve the problem, the dry eye was due to my work at the computer, a small improvement for a month, and then it was the same again... After three years I found my current ophthalmologist who realised that an autoimmune disease was behind it and referred me to a rheumatologist.

At home and with others I avoided all social contact, only my elderly mother, who now understands little, paid no attention. I worked from home at the PC, with many breaks because it made things worse for me, I went out in the evenings when there was no light, it is still like that. Seeing was painful, just turning my gaze, opening my eyes in the morning, I often had to open them a drama in addition to the pain. I had and still have deepening black circles under my eyes, a sad expression, now my life is destroyed, I live a faded copy of what a life is, I consider myself an invalid, I will soon be applying for disability. I do not understand how one cannot understand when this disease destroys one's life. The treatment and caregivers were inadequate in every respect, lots of tests, diagnostics, but no way to solve the problem of burning and inflammation. I wanted to get it over with, of course.

Today I feel sick all the time, every now and then I change my Sjögren's medication and hope that something will work, but the tiredness is very strong. The dry eye disease is crippling. A typical day for me: when I wake up I have to wait at least half an hour before I open my eyes, I have to clean them with blepharitis foam, put eye drops in, after breakfast I start to work, I take breaks, put eye drops in, work with little light, have lunch, often in the afternoon I go out for analyses, diagnostics or for visits to doctors' offices or the hospital. If I don't have examinations, I prefer to go out in the late afternoon for shopping. With extreme tiredness and photophobia, I can go for short walks, I must stop, pause, and start again. Ideally, I should always be at home in the dark, but sometimes I

go out anyway, and often I come home with a headache, as well as the usual corneal neuralgia and therefore burning eyes. At home I live with my mother who, due to her advanced age, understands little of what happens to me and just goes along with it. My friends know that I am ill, they don't ask much because they don't want to know about my illness, and I don't want to bore anyone with the details of my misfortune. They talk about themselves, sometimes I envy their enthusiasm for things in life, I listen to them even if it's nonsense, it helps distract me from the tragedy that has befallen me. My sporting activities are nil, if a day happens that is less bad than the others, I try to do the exercise bike and the stepper I have at home. I miss being able to travel, I also have the famous brain fog, I get distressed by these holes in my memory that I suddenly have. Seeing is an effort, I always must check. My face is sad, I try to be ironic, but it is difficult in this condition. The treatments are insubstantial, I have spent a lot of money and never had any benefit. Sometimes scleral lenses help, but not always and it is difficult to wear them. Doctors have no understanding for the drama I experience, not even ophthalmologists understand it and that is the worst thing, because it is they more than others who should understand the state of physical and psychic destruction this disease causes. One of the last ones advised me to do sport, of course with a new body without Sjogren's and bionic eyes it would be possible. As if I were lazy and would be happy not to do sport anymore. I want to solve it one way or another, I don't know how long I can go on like this.

What kind of life is this, without anyone understanding, living in pain every day, every night, how many more years can I go on? There is a lot of indifference. When I think back on my course of treatment, it was a failure in every respect, even the painkillers didn't help much. For tomorrow I would like to return to a normal life or end this agony.

3.2 Narrative of a caregiver of a patient with dry eye disease

Before my mother's dry eye disease, I felt more complicit with her because we did more things together. My mother used to complain of eye pain. It was many years ago, I don't remember how I felt. My mother always felt her eyes were tired. To find out what it was, we went to an ophthalmology professor who we later changed. Dry eye was diagnosed after a few years, but it was downplayed. Artificial tears were prescribed. My mother's days were affected by eye pain, the environment, the weather, many factors.

At home it was disturbing to see her wearing dark glasses. The others mocked her and did not understand the appearance of dark glasses all the time. I was very worried and felt helpless. She had to be helped in her activities, or she had eliminated them. For her seeing had become painful and tiring. Her face had changed, her gaze closed, contracted. Treatments were disposable artificial tears due to an allergy to preservatives and constant changing of professionals in search of hope. I wanted the best, to cure her.

Today I feel sad when I think of what she has lived through. She feels tired from what she has lived through, but above all from the misunderstanding she has suffered and from always having to be organised for visits, tests, travelling to other cities to be cured. The dry eye disease is disabling, not recognised, known, and understood in depth.

I work as a clerk and then look after my mother as best I can, I am 100/100 disabled and I am in a wheelchair. I follow her mainly for medical examinations, I organise everything and discuss with the

doctors to follow her as best I can. She is a strong woman who has learnt to live with the physical pain, and with others she plays down because she knows they wouldn't understand.

My mother has no activities in particular because she is conditioned by the situation, but when her eyes allow it she cooks delicacies or tries to do gardening and other things. She does not help me in my day because she is exhausted by so many things. It is tiring for my mother to see. Her face, now that she has therapy, is more relaxed.

The treatment is the therapy, but it is often the hospital in P., the curative doctor is the ophthalmologist at the cornea centre in our provincial town. I want there to be less complicated treatment and, in our city, to avoid stress.

Thinking back on our course of treatment, for my mother and her suffering, I still feel the helplessness and little empathy: 'There is no cure, resign yourself and protect yourself as best you can...'. In the meantime, the pain and dry conjunctivitis put her to the test.

For tomorrow, I wish that all this pilgrimage and pain for the sick, including being left alone, would never happen again for anyone! That research would be funded, that there would be reference centres in every city, and above all that more information would be conveyed in the most appropriate way for everyone.

3.3 Narrative of a treating ophthalmologist

The first time I saw this person I thought it was a very serious case of dry eye, the likes of which I had never seen. In fact, I had recently specialised and in the clinic, I had attended there was no outpatient clinic dedicated to dry eye disease.

The patient told me that she had been diagnosed with Sjögren's syndrome and was being followed in rheumatology, but the burning in her eyes was getting worse by the day despite frequent treatment with artificial tears and the use of topical corticosteroids. She was almost unable to carry out normal daily activities such as watching television, going for a walk outside, reading a newspaper... The burning and pain in her eyes were continuous and she found it difficult even to rest at night.

I felt unprepared to handle such a case. However, I told the lady to take it easy, because there were other therapies that could be done to get better. In the meantime, I prescribed eye drops serum and a check-up shortly afterwards. Within a few days, however, the lady suffered a corneal perforation. When I informed her of the need for surgery, despite her concern, she was always confident that she would get better. Unfortunately, after the first tectonic keratoplasty, a second corneal perforation occurred. Only after starting appropriate systemic therapy for Sjögren's syndrome with immunosuppressants did the situation start to improve.

This person has now been stable for years with the use of systemic immunosuppressants, topical cyclosporine and artificial tears. Unfortunately, in the meantime, an Alzheimer's disease had also set in, which got progressively worse. By now, the lady has almost completely lost her autonomy. Fortunately, she is being looked after with great care by her daughters who continue to administer the therapy on a regular basis.

Over the past year, she has been unable to visit the outpatient clinic for routine check-ups, but her daughter reports that her eyes have not worsened.

This case taught me how important it is in following up patients with dry eye to collaborate well with the other specialists treating them, in this case the rheumatologist.

Dry eye is a condition that should not be underestimated, which in some cases has an extremely rapid evolution. The treatment of dry eye is always a challenge, it must be adapted to each individual patient and suitably modified over time.

Regarding this lady, I feel that I could have intervened earlier and perhaps avoided the complications that have left her with low visus.

For tomorrow, I would like to be more experienced in treating dry eye disease and I would like to be able to give real relief to patients by improving their quality of life.