



**ME AND MY CARER
INTELECTUAL OUTCOMES
INTERVIEWS REPORT**

SUMMARY

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IO1 interviews report

The ECARIS project aims to improve the quality of care provided to patients with CKD or ESRD, to ease the burden on informal, family or professional caregivers and family-employed care assistants, and finally improve the QoL of both groups (caregivers and patients). Differences in how Europeans deal with caring for kidney patients could be observed, as this is strongly influenced by cultural backgrounds, family structures and availability of support services among European countries. Therefore, it is important to have a clear picture of the different country situations, in order to see how the training should be adapted to adjust to the needs of carers and different types of organizations and countries. The "ME AND MY CARER" report respond to this goal by collecting needs and experiences of families with a caring role in Greece, Spain, Denmark and Italy through consultations conducted by partners to

informal carers of kidney patients and patients themselves. The questions have explored how caring can have a different impact on carers of different countries, the types of support available, the role of education in wellbeing and coping.

1. Interviews with Informal Carers

This part presents the results of 38 interviews conducted with caregivers of kidney patients living in Greece, Spain, Denmark and Italy. To ensure geographical heterogeneity informal carers from each country have been consulted through a combination of different methods (interviews, focus group sessions, surveys) to obtain a good overview for the workshops. Due to the Covid-19 emergency, all these consultations were carried out remotely, via calls, online meetings (through Skype or Zoom) or online surveys.



The ECARIS (Educating Carers of Kidney Patients) project will focus on the needs and the problems addressed by informal carers and professionals who work with carers of patients with "End Stage Renal Disease" from Greece, Spain, Denmark and Italy.

SECTION 1: INTRODUCTORY TOPICS

Persons cared for

Analysing the interviews carried out in all the countries involved in the research (Greece, Spain, Denmark and Italy) it is possible to observe that most of the caregivers interviewed are female (65,79%, 25 out of 38 respondents). The figure they take care of is a family member, such as husbands/wives or children, and coinciding with this it was possible to observe how all the interviewees live with the kidney patient. Sometimes the caregiver has an additional burden of care, which can be a sick parent or young children: this makes the management of the disease in everyday life more complex. Many of the respondents are over the age of 65 and are therefore retired, while the younger respondents have a job; in case the patient is their child, not all caregivers are able to support a job, to care for him/her. For example in Spain, many participants to the focus groups are mothers/father of patients who have been diagnosed with kidney disease since birth. Currently, the 80% of them are working, although like other fathers or mothers they have had to interrupt their work activity on some occasions to dedicate themselves to the care and attention of their children, especially in the first years of life. Very often, however, their partner had to stop working, to dedicate him/herself to patient care, advised in some cases by a medical professional. Finally, some of them have obtained teleworking options so that they could combine personal and work life.

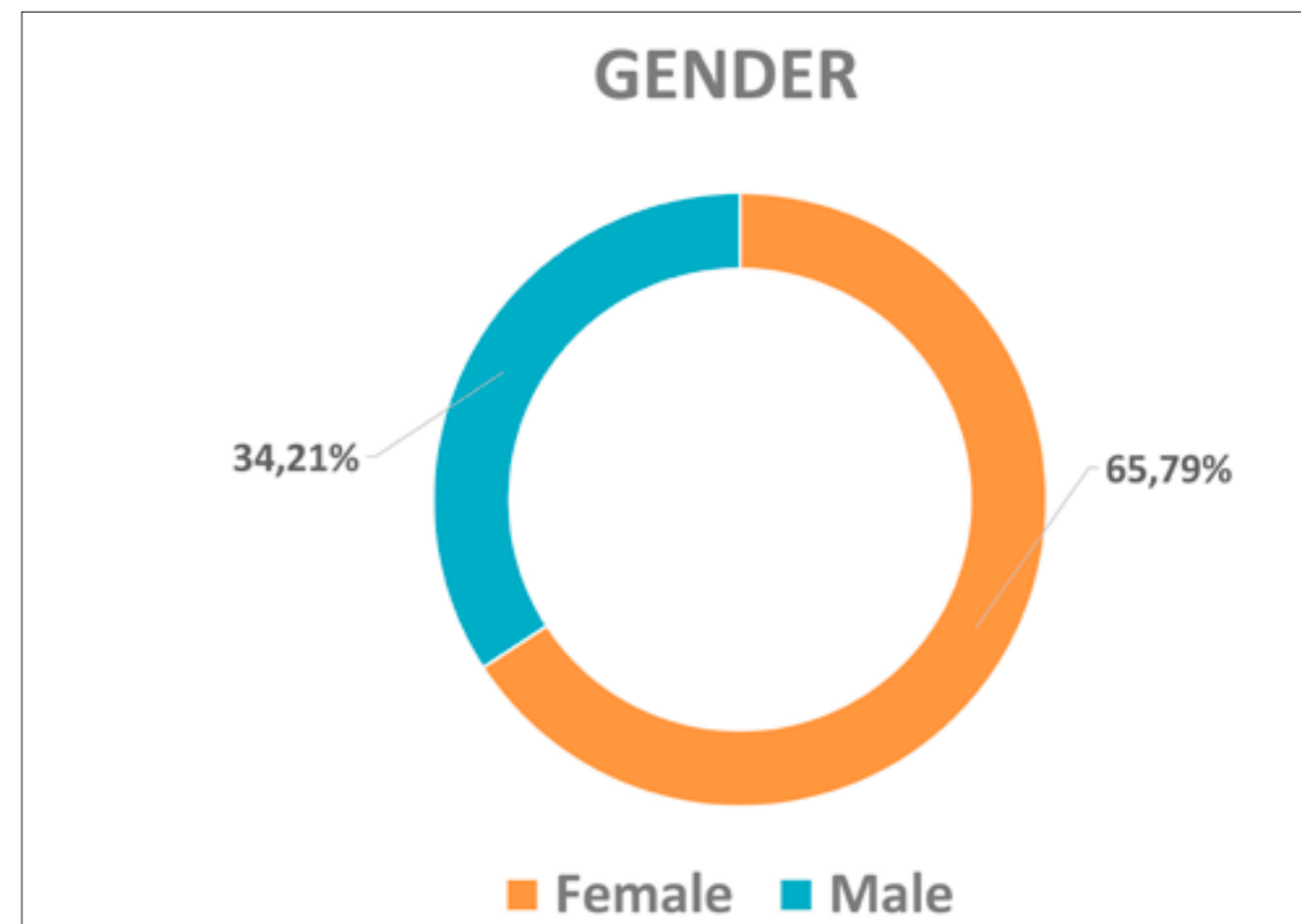


Fig 1. Gender of caregivers interviewed

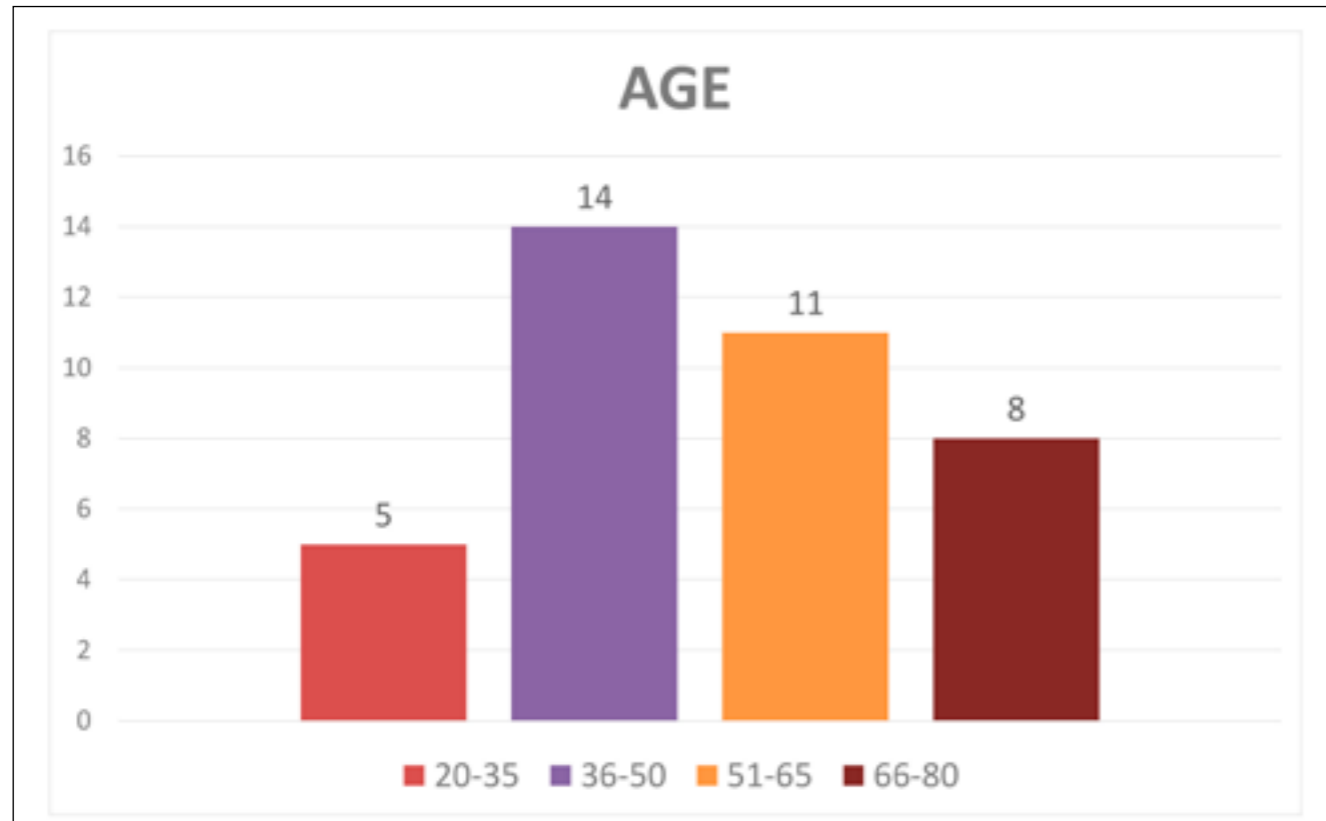


Fig 2. Age of caregivers interviewed

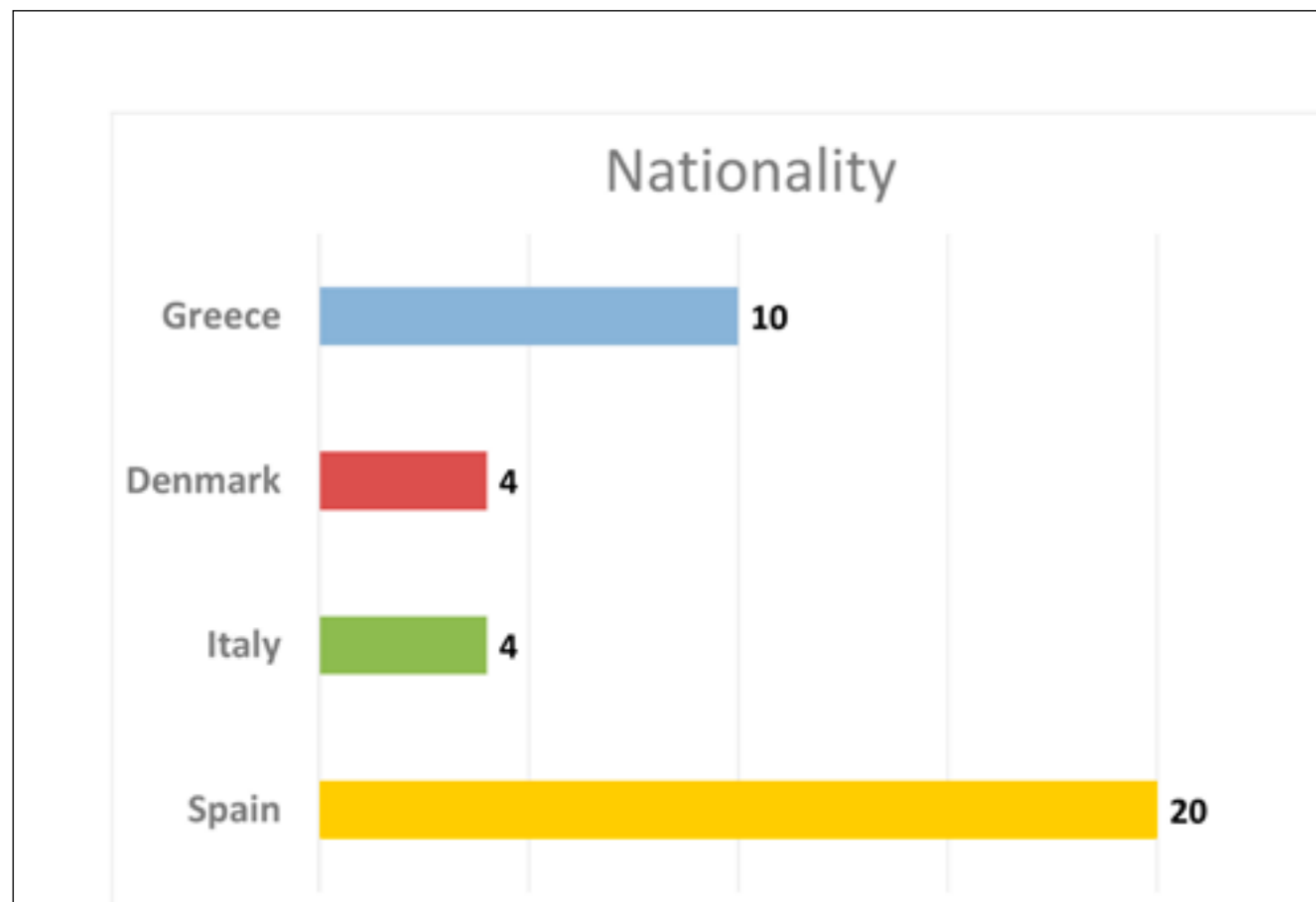


Fig 3. Nationality of caregivers interviewed

Reasons for caring

Most of the caregiver' interviews showed that the patients they care for are suffering from kidney failure, CKD, have undergone a transplant or are currently on dialysis. Thus, a diverse sample of pathological situations was observed among the interviewees, ranging from newly diagnosed patients to people who have long since undergone transplantation or are in Haemodialysis or Peritoneal dialysis. The clinical causes of the pathology are also different, ranging from alcohol, smoking or drug abuse to genetic factors and unconfirmed causes. In some cases, often the most severe, there is also comorbidity to renal pathology, such as diabetes, cardiovascular problems, liver problems and cancers. Other symptoms sometimes recorded are tremors, memory loss and detachment from reality.

Care needs

There are generally two significantly different loads for caregivers of renal patients:

1. When the patient is at an early stage of the disease, or the disease is not particularly invasive (e.g. after the patient has been transplanted), or is young in age, caregivers generally claim to provide relatively limited material support. The main activities are accompanying their loved one to the hospital, helping with household maintenance or preparing meals. In these cases, caregivers report that they do not provide for specific needs, but simply fulfil their role in living together.

In the second and more frequent case, when the pathologies are at advanced stages and the patient needs a lot of help, the burden of the cure becomes greater for the caregivers. In addition to the above-mentioned activities, there is mobility needs, finance management, medications management, enemas, operations, general health care actions and of medical tools' cleaning. In some cases, where the patient has difficulty in moving around and being autonomous, the caregiver also carries out activities such as shower his/her loved ones, dressing him/her, caring of his/her hygiene and personal cleanliness, inserting sleepers for the bed, changing the medical saks and tools and even getting him/her out of bed. So, those who have experienced home

treatment and home dialysis have become "health experts" acquiring knowledge about medical aspects and treatment techniques such as peritoneal dialysis. The most complex cases show different facets of the difficulty a caregiver can face. For example, some participants have gone through the experience of seeing their relatives go through various dialysis treatments and transplant rejections (4 or 5 occasions). In these cases, there has been a greater impact due to the continuous hospital admissions and the medical complications added to the disease and to the surgical interventions. They have spent a large part of their lives in the hospital, making it impossible for them to combine it with other tasks such as caring for the home or performing a job.

Some quotes from the caregivers interviewed:

"In the last period my father needed assistance for every action, even getting out of bed, despite being a very strong man." [IT, C1]

"The pathology was characterized by hospitalizations alternating with periods at home. In the latter, we had to organize meals specifically for the disease (i.e. low in protein, salt free), manage medications, operate enemas." [IT, C2]

"My husband has been transplanted for the second time. I don't provide any special care, just helping him remember some information because he gets forgetful because of the medication." [DE, C2]

"I remember my boyfriend to go to the hospital appointments and to order the dialysis products. I also make sure he eats the right foods." [DE, C4]

SECTION 2: SUPPORT NETWORK

Description of the support network and role of family and friends in managing the disease

Analysing the interviews carried out in all the countries involved in the research it is possible to observe that most of the caregivers involved receive a principal support from their own family. Specifically, for the Spanish and Greek participant to the research sons and daughters represent the main helpers in the care of their beloved (which often are husbands or wives). This has also emerged in Denmark, especially for caregivers over 65; meanwhile where caregivers are under 30, parents (both the caregiver's and the patient's parents, in case they are relatives) are a network to rely on. The Italian data shows strongly how the support network can often extend to friends, relatives and, in small countries, even neighbors.

Some quotes from the caregivers interviewed:

"My oldest daughter is an intensive care nurse, and she helps sometimes" [DE, C5]
"Even though my parents were separated, I always received strong emotional support from my mother." [IT, C1]
"Living in a small town, a natural support network has been created. In addition to uniting my family, the disease has also enlarged it, creating many small 'family nuclei' ready to help us. Everyone who knew us tried to support us, we have never been left alone." [IT, C2]

Evaluation of the support received by professionals

Most caregivers of all nationalities involved are satisfied with the professional support received from different roles involved in care. Caregivers generally consider the support of doctors, nurses, psychologists and counselors as valid and useful to manage the psychological and emotional burden of the disease. Also associations and cooperatives can represent support groups with which to confront themselves, talk about their difficulties and needs. However, not all participants seem to use these services or know their presence in their territory; some of them report that they do not feel the need for any particular help (specifically the psycholo-

gical one), but rather to manage the disease on their own together with their loved ones. For example, one caregiver, of Italian nationality, recognized explicitly the need to receive professional psychological support, for herself and her husband, but she declared she didn't look for it because she was not supported by her husband. On the other side, some caregivers reported a negative experience with the professional support network. Negative experiences are due, for example, to poor communication and clarity from medical staff, sometimes generic and uninformative indications for the caregiver, and little assistance in establishing a home care plan.



Some of the interviewees reacted negatively to the discovery of the pathology, through a denial of the situation or a deep anxiety, fear and uncertainty. Here a few of the narratives we have classified within the coping strategy denial/avoidance and anxious preoccupation:

"I had trouble sleeping due to worrying. I've always written everything down during consultations so that I can ask questions and this have been very important for me to cope with the situation. I've experienced anxiety and a lot of worry." [DE, C2]
"I buried myself in housework managing getting the kids to school, making lunch for them, doing dishes etc. I felt anger, exhaustion, depression, anxiety." [DE, C5]
"My family doesn't talk about the illness. I feel that this is our coping mechanism. This also happens because my father insists that he will be the only one to speak to the doctors and because he does not want to be a burden does not like to ask for help." [GR, C1b]



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SECTION 3: IMPACTS OF THE DISEASE

Impact on practical life

For most respondents the impact in their daily lives was strong and complex to deal with. In case children are the ones with kidney disease, one of the two parents, usually the mother, needed to stop working to devote herself totally to the treatment. Sometimes, this situation was similar for some wives/husbands, who found themselves alone facing a disease in their partner. This mechanism is rarer when the caregiver is an adult children, as they tend not to be the primary caregiver and also express the need to continue their careers. The difficulties encountered are generally not financial (probably thanks to subsidies that patients receive) but are more related to the practical management of everyday life. Being in hospital frequently, interrupting their children's education due to their disease, having difficulties with their employers in keeping to schedules, the need to organize and remember the activities of their loved one are just some of the practical impacts that the disease has on caregivers. To aggravate this, any comorbidities that may have emerged due to the pathology have made management more complex for some of them (for example, blindness, amputations, diabetes, cardiac diseases and heart attacks).

A part of the respondents say they have not seen a strong impact in their lives. This is especially caregivers caring for patients between the ages of 20 and 35 but it is mentioned by respondents of any age. For some of them it has changed slightly because of the autonomy of their care recipient. Only a little part of the sample claims to be the only source of income, the rest of the participants declare their partner works despite the disease

Some quotes from the caregivers interviewed:

"It was difficult to reconcile the cure to my life because I did not want to give my employers the idea of being frail, therefore I sustained very hard rhythms. I worked every day and then went to hospital every night with my father during hospitalizations. Often I did not sleep, except when my brothers took turns. But I always wanted to keep working, it was important for me to keep doing it." [IT, C2]

"Yes, it has impacted in my daily life. My husband was diagnosed with CKD in 2019, we've gone to the hospital when we were on vacation and a few months later they had to amputate his leg due to vascular problems. Everything has changed a lot." [SP, C4]

"When my son was 5 years old, he had a heart attack, and he lost his speech and many cognitive abilities; he was secondly diagnosed with CKD at 16 years old. The care he required was not compatible with stable contract jobs, so I only worked temporarily, the economic income was that of his father and some financial help from our relatives." [SP, C5]

"I had a good employer, that have respected that I needed to go to follow and be a part of my husbands' illness. My coworkers were very understanding." [DE, C2]

"The illness has low impact on my life, we have continued our lives as before the diagnosis. We eat the same foods and do the same things." [DE, C3]

"We adapted our family plan, with the help of my wife, to the needs of my cousin's treatments and daily care. It would be a lie to say that the whole situation did not affect us as a family, especially in the first trimester when the patient had to follow a specific diet and pay attention to fluid intake." [GR, C3]

"My husband doesn't face any particular problems in his daily activity. Thankfully, we both are working and he's under a flexible work schedule, due to his dialysis schedule." [GR, C4]

Impact on emotional life

The disease has had a strong emotional impact on both patients and their families. The experience appears to be characterized by similar emotions for all respondents, of any nationality: they say they felt fear, disorientation, sense of helplessness and weakness, sadness at the time of the diagnosis and when medical problems arise (such as peritonitis, problems with vascular access, transplant rejection, blood tests). Some of them have also suffered from generalized anxiety and sense of panic with regard to the situation, but rarely claim to have resorted to psychological help. After an initial period, however, almost all caregivers claim to have learned to manage their emotions and to feel more ready to cope with the various occurrences due to the disease. Some patients declared that the step from dialysis to transplantation represented an important change, improving the patient's quality of life and therefore of the caregiver too. They express liberation in certain tasks but also indicate that other responsibilities come, such as adherence to pharmacological treatment and control of laboratory tests. All of them know that in managing a chronic disease any new day could be a challenge, so they try not to think much about what will happen and live in the moment. The strong emotions felt have generally strengthened the relationship with the patient and within the family, willing to be close to him/her in this path and support him/her.

Some quotes from the caregivers interviewed:

"At first I used to cry in secret so he wouldn't suffer, and sometimes I do it even now. But I feel strong about this problem. I want to fight with him. Nothing has changed between us, our relationship has remained the same." [IT, C3]

"The psychological impact of my husband's illness was very strong, but I never asked for help to anyone. My husband is always nervous and let out his frustration on me.

In particular when the possibility of transplanting was proposed to him, he was very afraid. He refused twice before deciding to do it. When he had stopped fighting, I supported and convinced him to face the difficulties." [IT, C4]

"When contracting the disease with almost 85 years, the physical limitations are many as well as the emotional load for the care of the relative. I cannot help with the mobilizations since I suffers from osteoarthritis and osteoporosis and when he needs to go to the bathroom, all I can do is put on a diaper." [SP, C4]

"I got a shock when my husband was diagnosed, followed by worries and thoughts about how to handle the disease. In the beginning you worry about how to handle your daily life. I've been extremely distressed, but I have learned to handle the illness by learning by doing." [DE, C2]

"I had a strong feeling of uncertainty for a long time, because I could not control anything with the illness. For a long time, I was anxious and worried about what could happen. I'm very angry on the illness on my boyfriend's behalf because I ask myself: why can't he just not be like every other young person? Nobody deserves being sick, but I feel that it is unfair because he is so young." [DE, C4]

"In the beginning my wife was hospitalized in a section where almost half of the patients died. This cau-

Impact on practical life

Similarly, to other aspects of impact, also in this case the extent of impact of the pathology on the family and social life of the caregiver and the patient depends on the stage and severity of the patient's pathology and its consequent autonomy. On the one hand, some caregivers narrate that they have had to limit their social life, their closeness to friends, because of their care commitment. They affirm that only the closest and most sincere friends have remained in their lives, sharing with them daily concerns and needs, supporting and helping them whenever needed, also in some cases offering to donate their organs. Those who didn't know how to deal with the situation, gradually left. They also expose that there is very little information in this regard and some services entities and association have helped them to obtain information on not-sanitary aspects, as psychological care and couples therapy, cooking workshops, meeting of kidney people, international trips, employment, social benefits. Furthermore, knowing other people who live the same condition alleviated the burden and made it more natural.

On the other hand, if the patient has remained independent, caregivers generally narrate that their social and family life has not undergone major changes. The relationships have remained the same and they lead their social life in a similar way as before, only with a few more precautions regarding the sick person. Caregivers affirm that overprotection over time it's not successful, since it makes patients become more dependent; they advised some strategies for patients to take responsibility for their disease.

What does not seem to change from these two different experiences of care is the strengthening of family relationships. Whether the disease has manifested itself in a particularly severe way, with a strong impact on the life of the patient and the family, or whether the disease is more easily manageable, the relationships within families generally appear reinforced, more cohesive in facing problems together (except some individual cases).

Some quotes from the caregivers interviewed:

"From 17 to 24 I assisted my father, so I probably missed some experiences that my peers had. I realized that my life could not take place beyond a radius of a few kilometres from home, so obviously there was an impact." [IT, C1]

"This experience has strengthened many relationships for me. The only radical change was that I broke with the boyfriend I had for a long time, but in retrospect I rate it as a positive event because he couldn't measure up with that situation. On the other hand, the relationship with a person, who is now my partner, has strengthened." [IT, C2]

"Neither of my two kids have been on dialysis treatment, so we've had no limitations regarding outings or vacations. The older had a circle of friends which are aware of the situation and no problem has ever been raised, the CKD is taken into account only when planning the diet." [SP, C2]

"My husband's medical situation has brought us closer together. The same happened with our friends: the group has existed since childhood and this reality has brought us closer together." [SP, C3]

"It's hard to imagine how it would be if my wife wasn't sick. It has become a different life, but it has been my own choice. I enjoy being home, which is a positive thing, because now we have the time and possibility to do so." [DE, C5]

"We are very active people, intensely socialized, with several close friends. From the first moment of my wife's illness, our friends were aware of the disease's progression and actively contributed to our psychological support. In fact, 3 of them have become organ donors." [GR, C1]

"The gradual decline in the function of my wife's kidneys, as well as the underlying diseases, have long since transformed me from a husband to a nurse / psychotherapist. However, I accept it without hesitation and I'm glad to do that. The only thing I complain about is that we have significantly reduced our social contacts with friends and relatives." [GR, C2]

"My relationship with my father is deteriorating." [GR, C2b]



SECTION 4: COPING STRATEGIES

To observe, analyse and recognize the different coping strategies adopted by caregivers to cope with the pathological event, we have referred to the classification made by Watson et al. (1988), which had identified, in relation to cancer patients, 5 different styles of coping towards neoplasia. Coping mechanisms are the strategies people often use in the face of stress and/or trauma to help manage painful or difficult emotions;

they can help people adjust to stressful events while maintaining their emotional well-being. The classification of the possible coping strategies (e.g. reactions, behaviours, attitudes) is composed by:

hopelessness / helplessness, characterized by high levels of anxiety and depression, by the absence of cognitive strategies, to manage and deal the situation.

fighting spirit, characterized by moderate levels of anxiety and depression and by full acceptance of the diagnosis, an optimistic attitude, determination to combat the disease a desire to participate in treatment decision (the patient tries to reduce minimizing the diagnostic impact).

denial / avoidance characterized by the absence of anxiety-suppressing manifestations and the absence of cognitive strategies. Characterized by rejecting or minimizing the seriousness of the cancer diagnosis as well as avoidance of thinking about or discussing their disease.

stoic acceptance (or fatalism), characterized by low levels of anxiety and depression and acceptance of the diagnosis but adoption of a resigned, fatalistic stance toward the disease.

anxious preoccupation, characterized by constant rumination about disease, fears that physical aches or pains signal disease spread or recurrence, and a continual need for reassurance.

1. *Styles of coping with cancer: the Italian version of the Mini-Mental Adjustment to Cancer (Mini-MAC) scale.* Grassi L, Buda P, Cavana L, Annunziata MA, Torta R, Varetto A *Psychooncology*. 2005 Feb; 14(2):115-24.

Caregivers generally responded strongly to their loved one's pathology, overcoming a first moment of despair and fear to fight the disease together with the patient. Here a few of the narratives we have classified within the coping fighting spirit strategy:

"Initially, the first few days we all felt terrible, but after a while he started to react strongly, telling his experience. He doesn't want to be victimised at all. He's fighting the disease. Sometimes it reassured me too. I feel strong about this problem. I want to fight with him." [IT, C3]

"I have always reacted and I have faced new challenges day by day" [IT, C4]

"The hospital provided us with all the help we needed, they have informed us of aid and benefits, and of the services of the ALCER Association, through which my son has obtained a job, which makes him happy because he is going to provide economic independence and social integration. We have been able to adapt." [SP, C5]

"I reminded myself of the benefits of caregiving and focused on the positive aspects of caregiving to feel less stressed. Developing positive aspects of my role as a caregiver provokes an improvement in relations among the family and helped us to reframe and address a difficult situation." [GR, C3]

"I try to obtain new information and new skills so to help decreasing stress. I believe that knowledge itself can help me better managing my stressful situation. Learning about ESRD and dialysis treatment's details and different aspects of caregiving can offer me understanding and feeling more confident about my father's situation." [GR, C5]



SECTION 5: EDUCATIONAL NEEDS

The last question asked to caregivers investigated the training needs related to the pathology. This question was asked in order to collect opinions, necessities and useful suggestions to design educational activity programmes to improve the wellbeing of carers and the care relationship between them and patients living with renal failure. The main indications of educational/informational content raised by them are:

- Information on the pathology, its course and possible outcomes (e.g. the possibility of organ rejection after transplantation, treatment and therapies, conferences on medical advances or research projects);
- Practical information on how to manage the disease at home (e.g. how to make an enema, how to give injections, how to replace medical sacs, how to apply sleepers);
- Psychological and professional support for the primary caregiver and the patient, which experience the greatest emotional load (e.g. courses about mental health of caregivers, space for sharing experience with other caregivers, how to manage stress, burden of care, fear);

d. Information about the integration of social and work life (e.g. illness and incapacity for work, workforce legislation, the rights for early retirement of disabled persons, service guides, social resources and information for safe places for dialysis and holidays in Europe);

e. Detailed, non-generic, instructions on the nutrition to be followed (e.g. weekly menu, foods that the patient should not eat, recipes and food preparation);

f. Network between caregivers and between caregiver-health care professionals (e.g. communication of personal experience of patients and families, more emphatic professional communication, group therapy, family and patient meeting).

The psychological and professional support for the primary caregiver and the patient, which experience the greatest emotional load, it's a one of the key needs.

SECTION 1: INTRODUCTORY TOPICS

The patient and the persons who takes care of him/her

As observed in the caregivers' interviews, the patients involved in the research reported that the main informal support is given by a family member. Many of the patients, aged over 65, are retired, while the younger ones often had to retire early due to pathology. Some of the interviewees are still independent and manage the disease independently, but this number is lower than the previous ones.

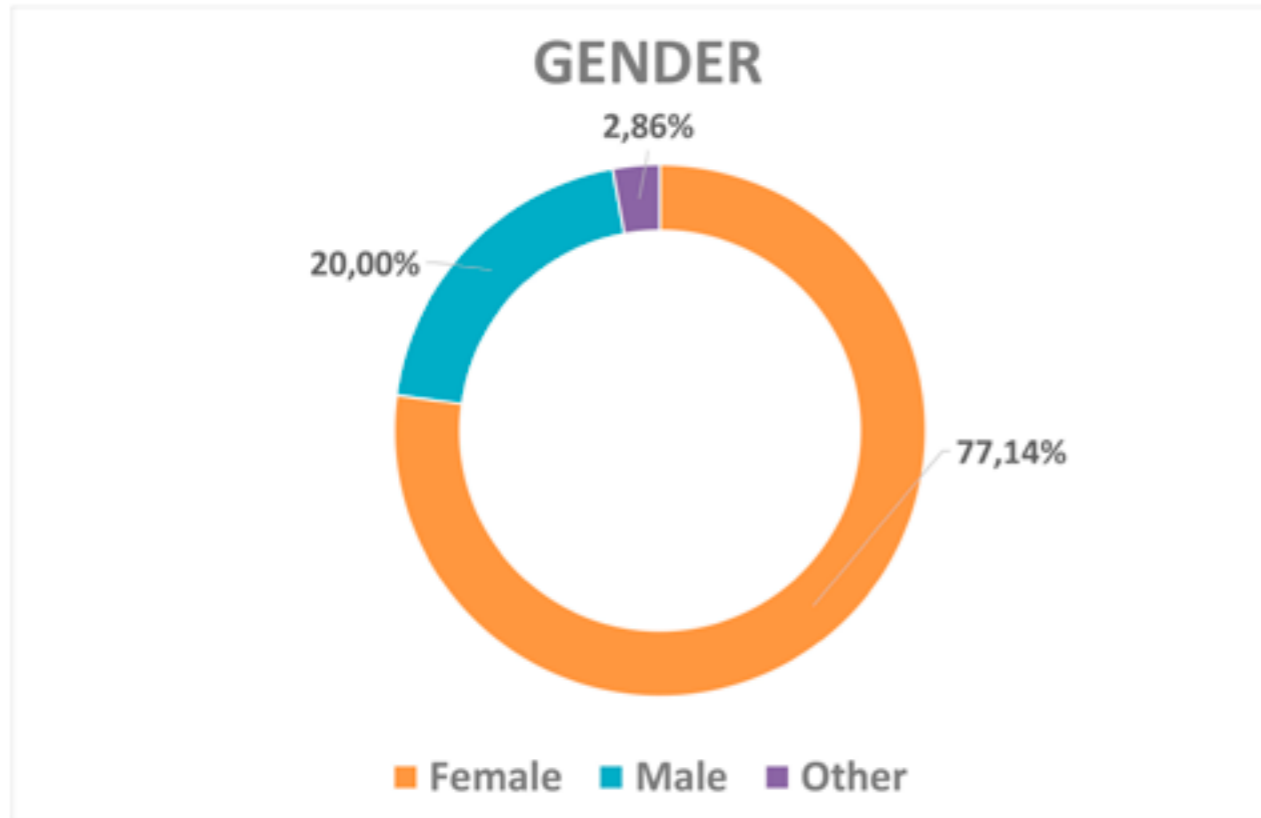


Fig 1. Gender of patients interviewed

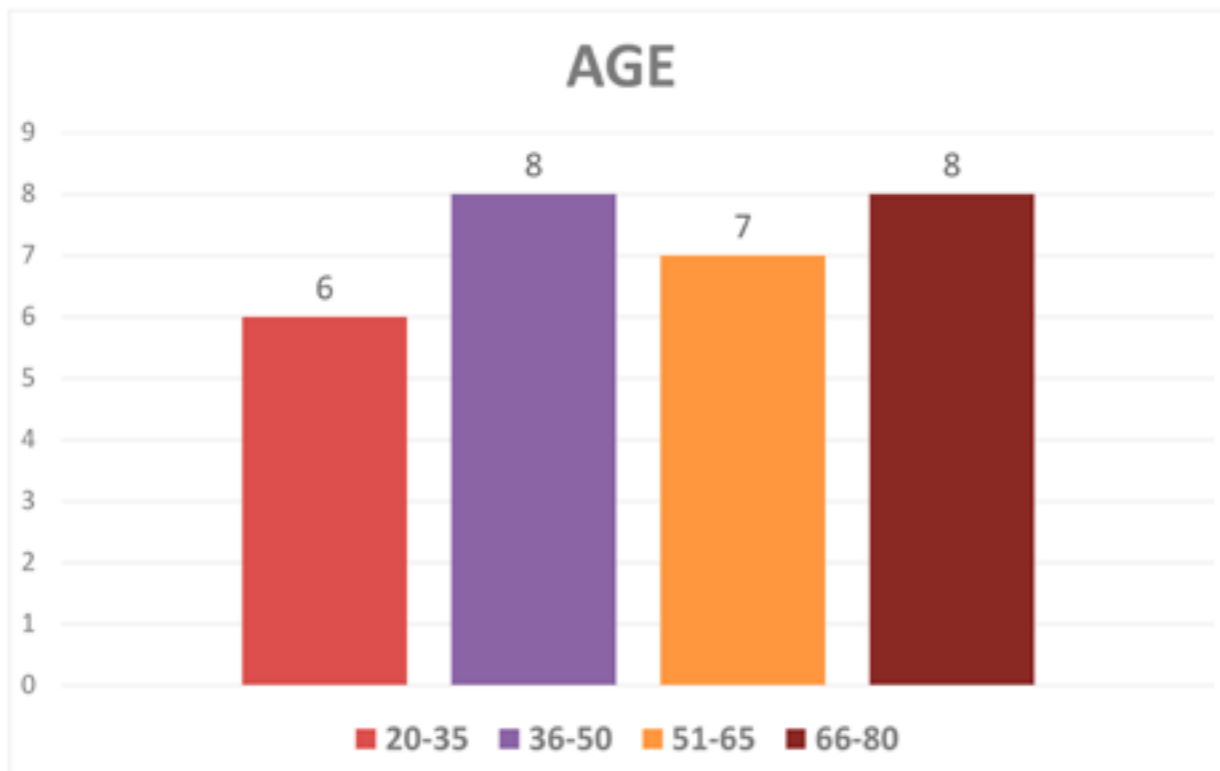


Fig 2. Age of patients interviewed ²

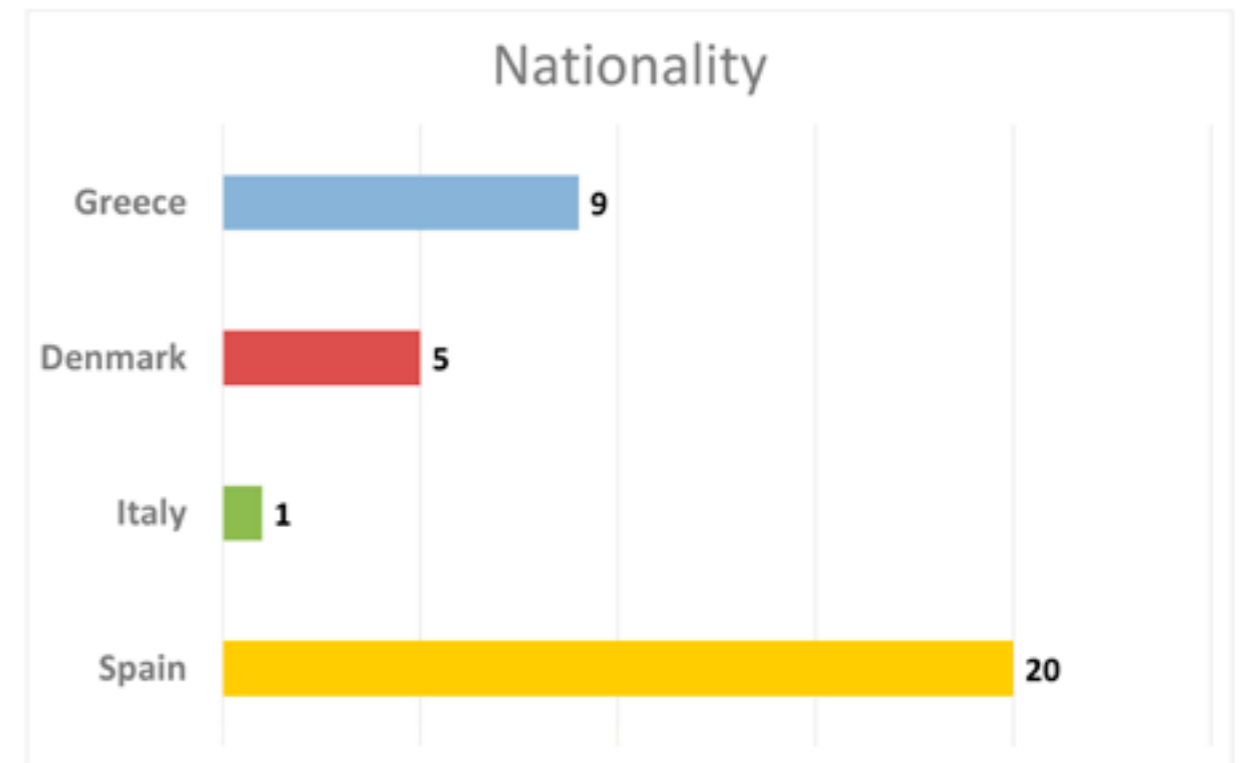


Fig 3. Nationality of patients interviewed

Pathology and comorbidities

Patients have reported different types of kidney disease, at different stages of severity, as well as numerous comorbidities. Most respondents have had at least one organ transplant or are waiting for the operation. Below, a short list of the main diseases collected:

² Some respondents preferred not to answer that question.

Type of Kidney Disease	Renal Therapy	Comorbidity
Chronic kidney disease Glomerulonephritis Kidney cysts Alports syndrome Lack of drainage to the kidney	Peritoneal Dialysis Hospital Haemodialysis Transplant	Diabetes mellitus Hepatitis C Cardiovascular disease Low blood pressure Hypertension Heart attack Visual deficit Limb Limitation (also due to leg amputation) Renal osteodystrophy Partial hearing loss (due to antibiotics and therapies) Spinal stenosis

Care needs

As recorded when interviewing caregivers, patients generally declare themselves autonomous in the management of the pathology where they have already undergone a transplant and/or their kidney disease is under control, at first stages.

The necessities become greater and the need for help from a caregiver increases when the stage of the disease is advanced. Generally, the main needs are:

- Daily life activity (bathing, dressing)
- Home maintenance (household chores)
- Meal preparation and planning (cooking and following simultaneously nutrition restrictions)
- Mobility management (transportation to dialysis unit)
- Health care (medicine management, remembering to order dialysis products)
- Finance management
- Cleaning of utensils and surroundings
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SECTION 2: SUPPORT NETWORK

Description of the support network and role of family and friends in managing the disease



Analysing the interviews carried out in all the countries involved in the research it is possible to observe that most of the patients receive a prior support from their own family. Specifically, they are primarily husbands or wives, where the patient is married, and also eventually adult children. When the patient is under 30 and single, parents and/or siblings are generally the main support network. Friends also play an important role, especially if they share a pathological situation with the patient. In fact, patients of all ages value acceptance and support from friends as fundamental, as it allows them to “normalize” their situation and live it with greater serenity. All patients who have managed to maintain a friendly network declare that they don't want to be treated as “special” and that they don't want their pathology to be the focus of conversation. In some cases, the patient doesn't want their friends to have knowledge of their disease, since it is not visible, to prevent others from asking them or showing grief pity for their situation. However, what has emerged is that it's necessary to be able to rely on at least one figure (a parent, a partner, a friend) in order to better manage one's pathology.

However, what has emerged is that it's necessary to be able to rely on at least one figure (a parent, a partner, a friend) in order to better manage one's pathology.

Evaluation of the support received by professionals

Patients from all countries involved in research generally rate the medical and psychological help they receive as positive and satisfying. In details, those who benefit from psychological service state that they would not know how to manage the burden of the disease without that help; other patients that tend to be more closed only benefit from the help of family members for the emotional burden.

Among the respondents, few patients are not satisfied with the professional help received, describing it mostly as insufficient in terms of time spent and given. In this case they refer mainly to home care service operated by nurses, social workers and health care assistants.

Some quotes from the patients interviewed:

“I'm very satisfied with the help that the municipality provides, I do not have a long waiting time.” [DE, P2]

“I need help for everything except eating. The home help service provided by the City Council of 2 hours for 2 days a week is not enough to cover those needs.” [SP, P5]

“Professional support is very important in my life. My wife is his psychologist and emotionally it is essential. I doubt if there would be other people who could attend to me like her, I refuse other aid.” [SP, P4]

SECTION 3: IMPACTS OF THE DISEASE

Impact on practical life

The lives of patients who participated in the research have generally been modified by the disease. Most of respondents had to stop working due to the pathology, especially when the diagnosis occurs suddenly and unexpectedly, resulting sometimes in financial problems due to limited state pensions. Some Spanish patients affirm that have been unemployed for years without income and support themselves with the financial help of relatives with whom they live. The disability acquired by many of them has led to a radical change in everyday life, changing habits and having to adapt to what the disease allows. They don't consider themselves capable of carrying out any activity due to the physical difficulties they have and the mental exhaustion of the disease. Among the therapies,

dialysis appears to be the most invasive and time-consuming treatment. Patients say they need a lot of help from their loved ones, where someone can offer it.

Only a part of them have managed to maintain their habits and their work or study paths, handling to reconcile them (both practically and emotionally) with the therapies. The patients to whom the disease was detected earlier, although they felt fear, have not had a great impact on their lives, since they have been able to adapt more progressively. Specifically, the ones who have obtained a disability certificate found it easier to find a job compatible with their treatment and state of health, or to participate in a family business. The latter tell how often it has been a challenge to face daily life after the diagnosis, but how this has made them happy with their autonomy.



Some quotes from the patients interviewed:

"My treatment's schedule (day after day) was a serious obstacle at my workplace, so that I decided to receive an early retirement. Now, although I've been transplanted, I'm not thinking of working again." [GR, P1]

"My illness has a major economic impact as I receive a disability pension which is quite low. I had to give up my job as a nursery teacher because I kept getting viruses and infections. Also, I did not start a family as a conscious decision after I had the heart transplant." [GR, P1b]

"I was a carpenter but I could not continue my career due to KD. I started taken single lectures (HF-enkel-fag) but could not finish either because of the time I had to spend in dialysis. [...] I used to be active before KD, owned a motorcycle and an ATW (four-wheeler)." [DE, P1]

"We left Greenland, where me and my wife had lived most for 37 years with our business due to my disease. I was the first in Greenland to get a at home dialysis machine. But as my health has gotten worse, we moved back to Denmark. I retired early due to my illnesses." [DE, P3]

"In studies I had problems with curricular adaptation due to my visual limitations, even so, I was able to finish them, although late in the school year. The CKD has not had much impact on the training aspect, but it did have a role in finding a job, since it affected me as a person with a disability, where labor integration is more complicated and requires specialized employment services." [SP, P1]

"I was diagnosed with the disease at 34 years old. I worked as a teacher in an institute and then went to university and I was able to combine working with my first peritoneal dialysis treatment: in the morning I went to my workplace and dialyzed at night. I was able to travel and enjoy vacations." [SP, P4]

**Impact on family and social life**

As reported by the caregiver's interviews, the situation has also strengthened the closest family and friendship relationships for most patients. On the other hand, however, some friendships, especially the younger and less mature ones, have been lost due to the complications that the disease situation entails. This has led to suffering and a sense of frustration for many patients. Moreover, a part of the participants confesses they had problems of misunderstanding due to their health situation in the couple relationships that led to divorce or separation.

Rarely social life is therefore the same as before, but while in some cases patients claim to have managed to maintain or even improve some relationships, in others they have lost their network, thus perceiving themselves as lonelier.

Participation in events, parties, trips is also more complicated and has often imposed restrictions on respondents; also those sports activities such as soccer, rugby, basketball, races, which involve great physical efforts have had to be abandoned. Only a few patients, the younger ones who still have physical autonomy, claim not to have experienced any particular impact in their social life.

Some quotes from the patients interviewed:

"I established friendships without problems and at a family level we are very close. I participate to events with my friends, although I don't like my illness to be the main topic discussed among us. I don't want to be considered special." [SP, P2]

"We no longer go on trips, but we are still seeing our friends, also if it takes extra organization because of the dialysis." [DE, P4]

"I cannot attend events. We go out and eat, but I never go to the buffet. I have family parties where there is a buffet table. There is a lack of acceptance from my surroundings. They don't understand it, they say you can just get a new kidney. Just not everyone gets better. They forget to tell you that you will not always get well. I get 56 pills a day. And it's not vitamin pills, after all" [DE, P5]

"My friends are distant. They are unable to understand the situation I'm obliged to address. Because of that I often feel frustrated, sad and lonely. My family is the shelter where I appeal for moral and practical support." [GR, P2]

"I've lived no great negative impact on my family relations and social life as the illness has brought us all closer. Of course, I don't have a lot of spare time to spend with my friends, as the dialysis takes a lot of time and I've to go to bed early at night. So, I cannot socialize in the evening." [GR, P1b]

Participation in events, parties, trips is also more complicated and has often imposed restrictions on respondents

SECTION 4: COPING STRATEGIES

Analysing the interviews carried out on patients, through the classification of Watson et al. (1988), it was possible to observe different coping strategies to face the pathology.

The majority of patients interviewed responded strongly to their pathology, overcoming a first moment of despair and fear to fight the disease. Here a few of quotes we have classified within the coping fighting spirit strategy:

"I always believed, even before CKD diagnosis, that positive emotion could be helpful problem-focused coping. Undoubtedly, being diagnosed with kidney disease or kidney failure can be a stressful experience involving with a lot of emotion condition's changes. Therefore, I think we must learn to live with their disease by developing various coping strategies as never give up and seeing dialysis as a lifesaver." [GR, P4]

"I felt anger at first, but as I always knew that I would need dialysis, I rapidly accept my condition." [DE, P4]

"I try to maintain a responsible attitude, knowing the disease, the symptoms, the limitations or restrictions; that helps me to plan and organize everything without problems. I've been in contact with the Association [ALCER partner] since I was very young and I've participated in many meetings of relatives and patients. I highly value the information provided in each of them, since they gave me tools and resources to develop my autonomy and manage stress." [SP, P2]

Other patients however showed less functional ways of dealing with the situation:

"I believe that with the increase of the age, several factors as progression of the disease and comorbidity, complications related to physical and psychological aspects might play an important role in developing disruptive feelings of uncertainty, dread and fearfulness." [GR, P3] - Classified as stoic acceptance

"After 12 years on dialysis I still feel unable to comply with the treatment's dimensions such as nutrition rules, limit my fluid and medication intake. I find myself very often feeling sadness, anorexia, and depression." [GR, P5] - Classified as hopelessness/ helplessness

"I accuse myself of negligence, because I was aware, 10 years ago, of my kidney insufficiency, but I avoided the scheduled visits and I did not follow the recommended diet. I often wish to approach the end of my life as soon as possible, to stop being a burden to my family." [GR, P7] - Classified as hopelessness/ helplessness



SECTION 5: EDUCATIONAL NEEDS

The last question asked to patients investigated the training needs related to the pathology. This question was asked in order to collect opinions, necessities and useful suggestions to design educational activity programmes to improve the wellbeing of carers and patients and the care relationship between them. The requests made overlap with those previously recorded in interviews with caregivers, specifically:

a. Information on the pathology and about the help services available;

b. Information on the diet and on physical exercise, in order to develop autonomy and be able to discharge the main caregiver (e.g. light exercise program for transplanted patients, nutrition advices and diet restrictions);

c. Networking. Being able to communicate with other people who suffer from the same disease, to have emotional and social support. (e.g. associative support network: patient groups to be created where subjects expose different points of view, open lines of communication and learn about what is being done at the level of CKD in other countries; sharing how they cope with the disease, how they manage the fluid restrictions and what they do to support their caregivers).

d. Psychological and professional support (e.g. courses about mental health, how to manage stress, burden of care, fear; professional and specific guidance for knowing how to be protect from COVID-19 or other infective disease);

e. Information about the integration of social and work life (e.g. illness and incapacity for work, legal advice, work disability, social and economic resources for patients and families, suggestions for travel destinations that are safe for dialysis and transplanted patients).

3. Summary

From what has just been described it appears that the needs of caregivers and patients are similar, and concern both the **concrete-physical and psychological impact** that the pathology has on the life not only of the patient but also of the caregiver. Generally, **kidney disease has brought** about a major change in the lives of those affected and their families, leading to a **limitation of social life, daily activities and autonomy**. Emotionally, it seems complex to deal with this diagnosis, which sometimes cannot even be anticipated by a particular lifestyle, as it involves a radical change in habits. Specifically, dialysis therapy is extremely tiring, both physically and in terms of time, for both groups of participants under investigation. What is positive is that **this difficult situation has often led to the strengthening of family relationships and stable friendships**, thus giving both the patient and the caregiver the strength to face the disease. Focal is therefore the theme of **interaction and communication, networking**. Precisely with regard to training needs both groups express how to get in touch with other people in the same condition is necessary, to share experiences and concerns, to draw strength and determination from others. This is also linked to the implicit **need for emotional support**, even from professionals. A psychological support in fact could lighten the burden of care for both parties, allowing a further exchange of opinions and strategies to manage the situation. Another aspect that has emerged is the **need for concrete and practical information**, more than notions, on the pathology. What could be the implications of the disease, how to prevent them, how to follow a healthy lifestyle through diet and exercise, which services to turn to when travelling or how to apply for early retirement, are just some of the elements mentioned by the interviewed groups. In conclusion, the ECARIS project should generate from these suggestions a training that can address the shortcomings reported so far.



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