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ME AND MY CARER: A REPORT TO COLLECT NEEDS AND EXPERIENCES OF INFORMAL CARERS OF KIDNEY PATIENTS AND PATIENTS THEMSELVES

The majority of patients with Chronic Kidney Disease (CKD) and patients with kidneys insufficiency are supported by their family members in daily activities and medical care. Studies report that a good family support could have a positive effect for a successful patients' adaptation to dialysis treatment and compliance with a dietary regimen. However, sometimes patients do not follow the therapy Because they feel they're becoming a burden on family.

However, caregiving is regarded as a chronic stressor factor due to the demanding activities and the emotional involvement.

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

The "ME AND MY CARER" report responds to the 1st project aim, collecting needs and experiences of families with a caring role in Greece, Spain, Denmark and Italy through a study conducted with patients affected by Kidney Diseases, living in Greece, Spain, Denmark and Italy.

The questions have explored how caring can have a different impact on carers from different countries, the types of support available, the role of education in wellbeing, impact on practical, emotional, social and family life and coping strategies.

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.



Analysing the interviews carried out in all the countries involved in the research, it is possible to observe that most of the interviewed caregivers are female (65,79%, 25 out of 38 respondents).

Many of the respondents are over 65 and are therefore retired, while the younger respondents have a job; in cases when the patient is a daughter or a son, not all caregivers are able to keep the work-life balance and reconcile work, private life and duties linked to their role.

Generally, carers of renal patients face two significantly different loads:

1. When the patient is at an early stage of the disease, 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 assistance for specific needs, but simply fulfil their role as member of a family.

2. In the second and more frequent case, in addition to the above-mentioned activities, there are mobility needs, finance management, medications management, enemas, operations, general health care actions and of medical tools' cleaning.

Most caregivers of all nationalities involved are satisfied with the professional support received from different roles involved in care.

The project has its own dedicated website <https://ecaris.eu/> and the full report in each partner's languages will be available here <https://ecaris.eu/outputs/>

NOTES TO EDITORS

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