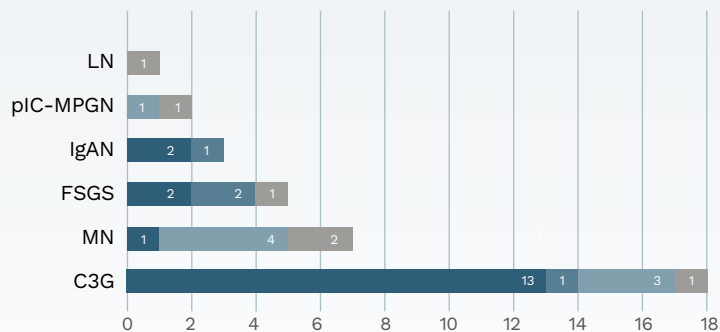


## Demographics

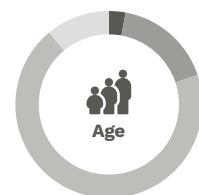
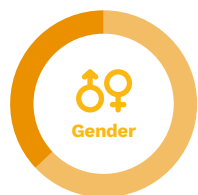
### Caregivers' distribution by country and disease of their care recipients



Number of caregivers who reported caring for a patient diagnosed with the prioritized rare glomerular diseases. Three respondents reported they care for someone with more than one condition

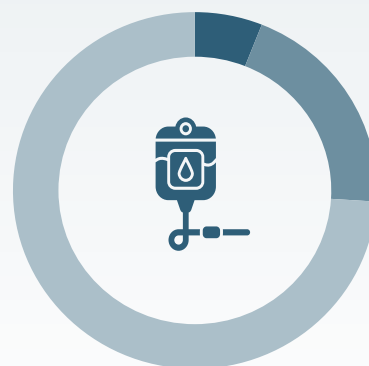
### Caregivers' distribution by gender, age, and country (n=35)

Most caregivers surveyed are women, most are of working age and a majority provide care for their children, whether they are adults or minors.



## Impact on work and school

1 in every 4 caregivers cares for a patient currently on dialysis or who has received a transplant in the past



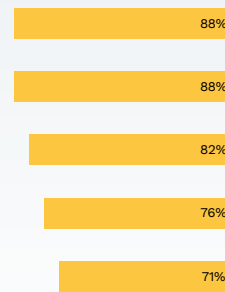
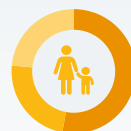
Current treatment of patients cared for by surveyed caregivers (n=35; patients on dialysis = 2; transplanted patients = 7; patients not on kidney replacement therapies = 26)

**For almost all caregivers who responded, the home is the main setting for care.**

## Socioeconomic burden

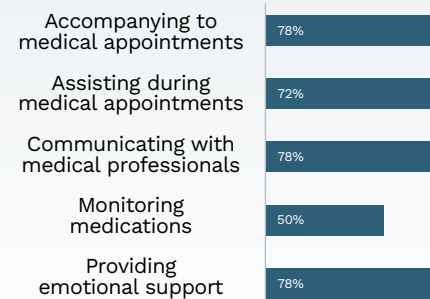
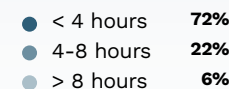
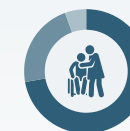
1 in 4 caregivers of children spend >8h per day in caregiving, compared to 1 in 18 caregivers of adults. Patients and caregivers need consistent, psychosocial, financial and workplace support to mitigate the impact of rare kidney diseases.

### Carers of children



### Carers of adults

### Carers of adults



Time spent per day on caregiving duties and types of day-to-day support provided by caregivers to their care recipients (n=35; caregivers of children = 17; caregivers of adults = 18).

**Abbreviations:** AAV: Anti-neutrophil cytoplasmic autoantibody (ANCA) - associated vasculitis; Anti-GBM: anti-glomerular basement membrane disease/ Goodpasture syndrome; C3G: C3 glomerulopathy (including Dense Deposit Disease); FSGS: Focal segmental glomerulosclerosis or steroid-resistant nephrotic syndrome; IgAN: Immunoglobulin A nephropathy (Berger's disease); LN: Lupus nephritis; MN: Membranous nephropathy; pIC-MPGN: Immune complex-mediated membranoproliferative Glomerulonephritis

# Key Data from the Rare Kidney Diseases Barometer Survey

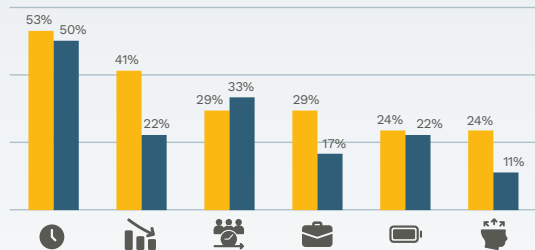
● Carers of children  
● Carers of adults  
 LEGEND FOR ALL CHARTS



## Socioeconomic burden

### IMPACT ON CAREGIVERS' DAILY LIFE

#### Caregiving affects all areas of life

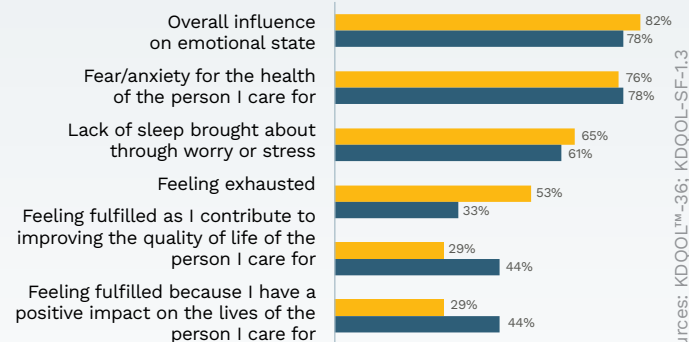


- Impact on daily activities
- Accomplished less than I would like
- Cut down the amount of time spent on social activities
- Cut down the amount of time spent on working/studying
- Had difficulty performing social/ other activities (e.g., it took extra effort)
- Haven't been able to concentrate when being social or taking part in other activities

Number of caregivers who feel specific daily activities were impacted by their caregiving duties over the last 6 months (n=35; carers of children = 17; carers of adults = 18)

### PSYCHOLOGICAL IMPACT

#### The majority of caregivers indicate a significant effect on their mental well-being.



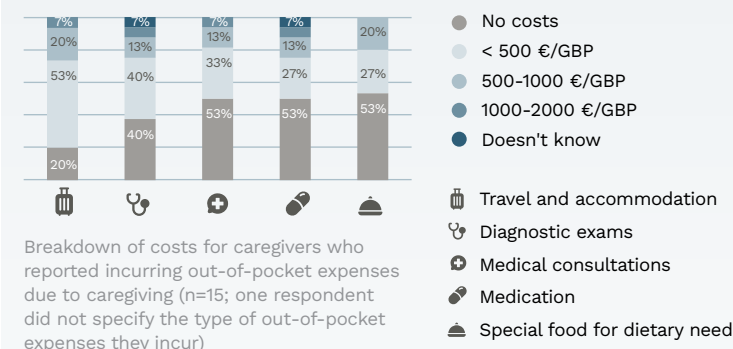
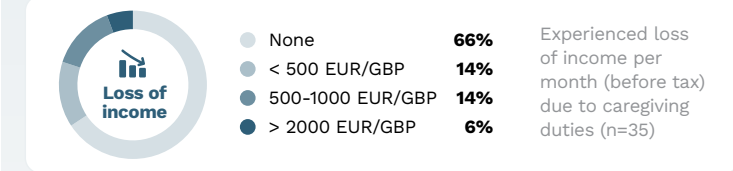
Sources: KDQOL™-36; KDQOL-SF-13

On average, **80%** of caregivers feel their caregiving duties negatively influenced their emotional state. **40%** already sought professional psychological support.

Emotional impact of caregiving (n=35; carers of children = 17; carers of adults = 18)

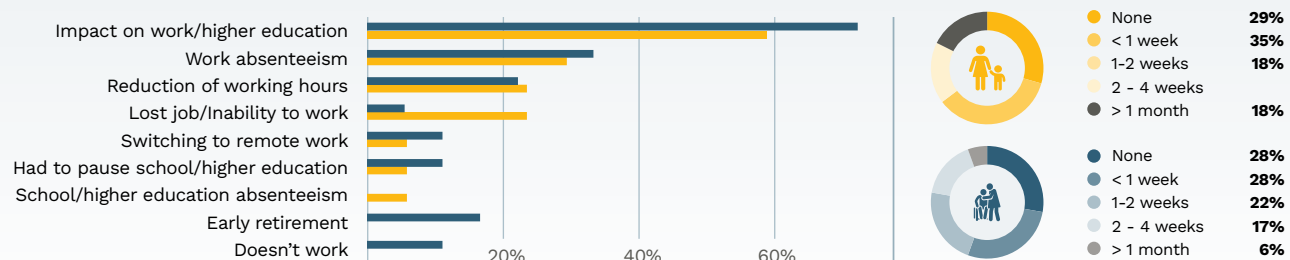
### FINANCIAL IMPACT

#### One in three caregivers experience loss of income, and 42% of caregivers incur out-of-pocket costs



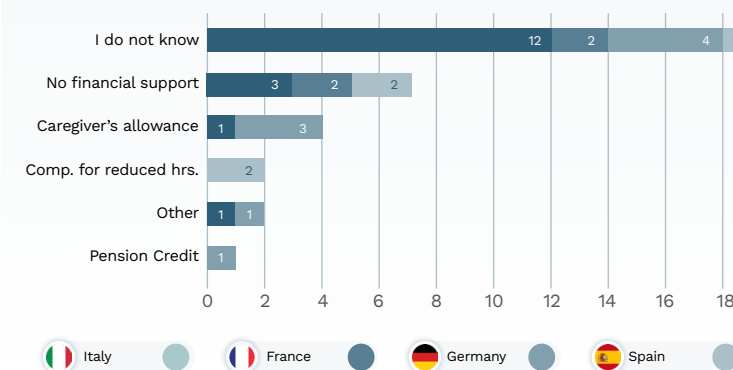
### IMPACT ON WORK AND SCHOOL

#### The majority of caregivers indicate that their work or academic performance is adversely affected, often experiencing higher rates of absenteeism and a decrease in their working hours due to their caregiving duties.



How caregiving affected work or school performance and time missed from work or school due to caregiving responsibilities over the previous 6 months (n=35; carers of children = 17; carers of adults = 18)

#### A considerable portion of caregivers do not receive financial assistance from the government, either because such support is unavailable or due to a lack of awareness about it.



**Abbreviations:** AAV: Anti-neutrophil cytoplasmic autoantibody (ANCA) - associated vasculitis; Anti-GBM: anti-glomerular basement membrane disease/ Goodpasture syndrome; C3G: C3 glomerulopathy (including Dense Deposit Disease); FSGS: Focal segmental glomerulosclerosis or steroid-resistant nephrotic syndrome; IgAN: Immunoglobulin A nephropathy (Berger's disease); LN: Lupus nephritis; MN: Membranous nephropathy; pC-MPGN: Immune complex-mediated membranoproliferative Glomerulonephritis