

# Measuring caregiver Quality of Life; which aspects really matter?

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## Background & Objectives

Previous studies have measured caregiver Quality of Life (QoL) based on standardised QoL measures. These have identified anxiety, depression and pain as the main drivers of poor QoL outcomes among informal caregivers [1,2].

❖ We aimed to identify whether there are other health domains which impact greatly on informal caregivers' wellbeing, but which might not necessarily be captured by a generic QoL measure such as the EQ-5D.

## Methods

- A web-survey (Qualtrics ®) of individuals providing non-contracted care for chronically ill patients
- 320 international and EU patient associations were invited to cascade the survey to their network of patients and their informal caregivers.
- Collected data on caregivers'; i) Demographics, ii) Productivity losses, iii) QoL (EuroQoL 5-domain; EQ-5D-5L) and EQ-5D-5L VAS, iv) Other, non EQ-5D domains which impacted greatly on their wellbeing and v) Emotional burden (Zarit Burden Interview)
- Microsoft® Excel 2010 was used to generate descriptive statistics

## Results

- 77 responses across 17 patient diagnoses\* and 18 countries\*\*
- Caregivers had 15% ( $\pm 23\%$ ) utility loss compared to the general population (Table 1).
- 6.3 hours were devoted daily on caregiving tasks, resulting in productivity losses for 50% (n=39) of the employed (44%, n=34) sample (Table 1).
- Poor EQ-5D outcomes were attributed to problems with anxiety/depression (77%), pain/discomfort (55%) and performance of usual activities (53%) (Figure 1).
- 40% (n=31) of respondents identified other important QoL domains missing from the EQ-5D, such as; "Neglecting personal needs" (21.5%), "Time limitation" (16.7%) and "Sleep deprivation" (9.5%) (Table 2).

\*Mainly Myelodysplastic syndrome (14%), Blood (9%), Kidney (8%), and Breast (6%) cancers, Ehlers Danlos Syndrome (4%), Rheumatoid Arthritis (3%), Asthma (3%).

\*\*Mainly UK (51%), Denmark (8%), Australia (6.4%), Croatia (5%), Greece (4%), Germany (4%), South Africa (4%).

Figure 1. Decomposition of EQ-5D-5L scores.

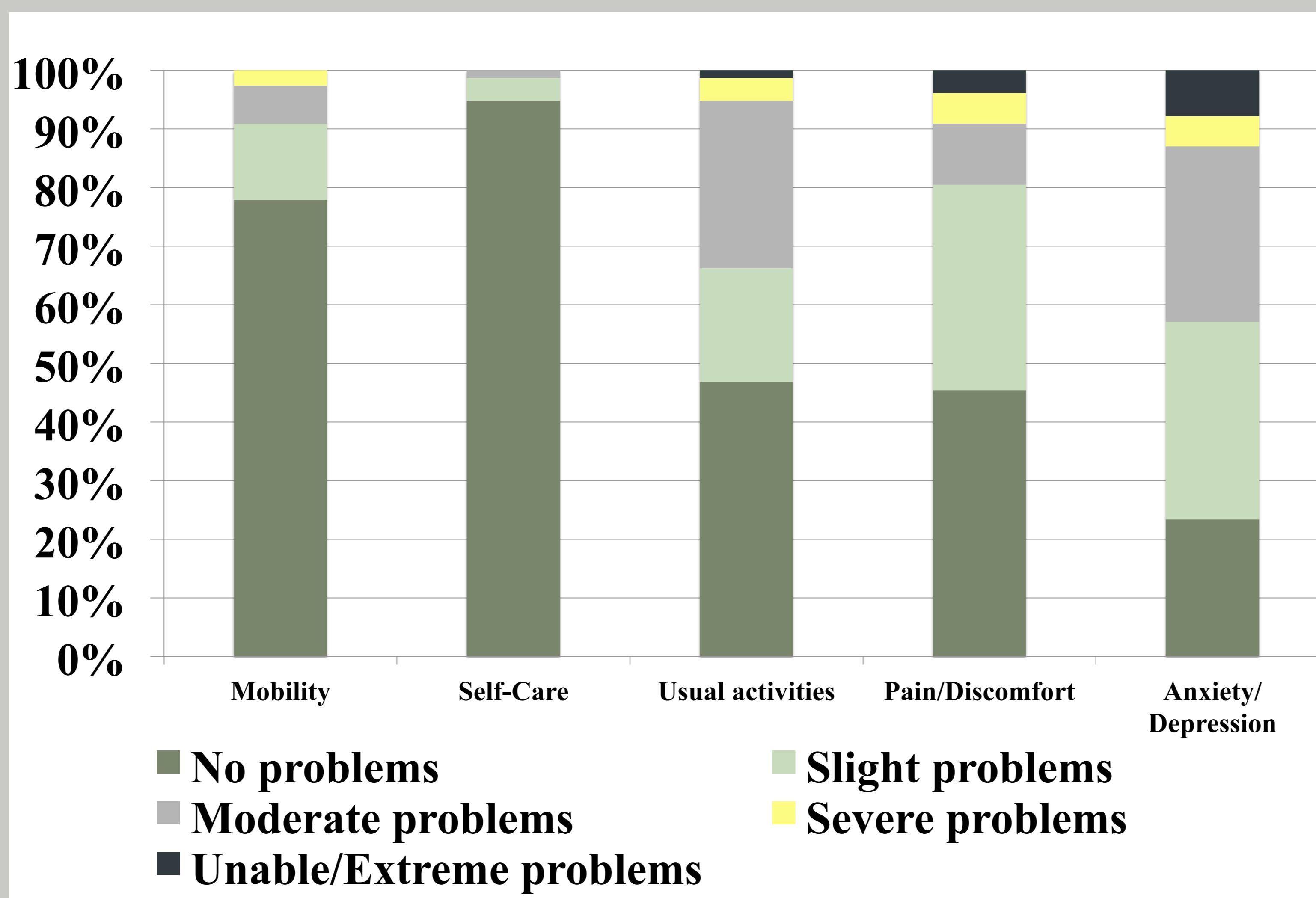


Table 1. Caregiver demographics and QoL; Mean (SD) or n (%).

Age	54 (11.8)
Gender: Female	61 (79%)
Employed	34 (44%)
Retired	26 (34%)
Housewife/husband	9 (12%)
Work limitation (last 12 months) - If employed (n=34)	17 (50%)
Early retirement - If retired (n=26)	5 (6.5%)
EQ-5D-5L Utility	0.72 (0.23)
Utility loss	0.15 (0.23)
EQ-5D-5L VAS	69 (20.7)
Zarit burden score	35 (9.4)

Table 2. QoL aspects which according to the respondents were not captured by the EQ-5D but impacted greatly on their wellbeing.

Aspects not captured by EQ-5D	n(%)	Sample response
Neglecting personal needs	21.5%	"Neglecting true care for my own chronic autoimmune disease", "I can plan nothing and sometimes have to abort shopping trips etc. so I have become very isolated and don't look after my own health"
Time limitation	16.7%	"The amount of care required increases and this impacts time left for other family members, spontaneity and leisure time"
Anxiety/Depression	14.3%	"Feeling depressed about the future", "I have become very stressed (NOT depressed) since looking after my husband".
Issues with health care services	10.5%	"Much of the stress created for me is around poor and lack of communication with the services who are supposed to be assisting my mother: ie hospital, community physiotherapy, GP, nursing home services"
Sleep deprivation	9.5%	"Sleep, time for yourself", "Broken sleep if husband has a bad night"
Financial burden	7%	"I'm having financial issues", "Financial burden"
Fatigue	7%	"Tired", "I am often tired and feel the mental strain more as time goes on. This sometimes affects me physically"

## Conclusions & Future directions

We demonstrated a clear worsening of caregivers' QoL compared to the general population and that EQ-5D-5L does not capture all the health aspects which are important for shaping the wellbeing of these individuals.

❖ Based on our research, using EQ-5D-5L as the sole measure of caregivers' QoL will fail to capture key aspects of their wellbeing. Further investigations are required to strengthen our understanding on caregivers' experiences and QoL preferences.

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