



# Information and support needs of carers: Do specialist cancer services for adolescents and young adults add value?

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## Introduction and aim

Carers are profoundly affected by their caregiving role yet little attention has been given to identifying and meeting their needs. In particular, the experiences of carers of young people with cancer are not described. We aimed to identify carers' unmet information and support needs of young people participating in BRIGHTLIGHT. Further, we sought to examine any differences associated with the extent of exposure to specialist teenage and young adult cancer care.

## Methods

BRIGHTLIGHT participants nominated their main carer to complete a Carer Questionnaire addressing information needs, healthcare service experience, emotional and psychological wellbeing and support needed/received. Questionnaires were completed six months after diagnosis. Comparisons were made according to where young people's care was delivered: *all* in a Principal Treatment Centre (PTC), *some* in a PTC, or *no* care in a PTC.

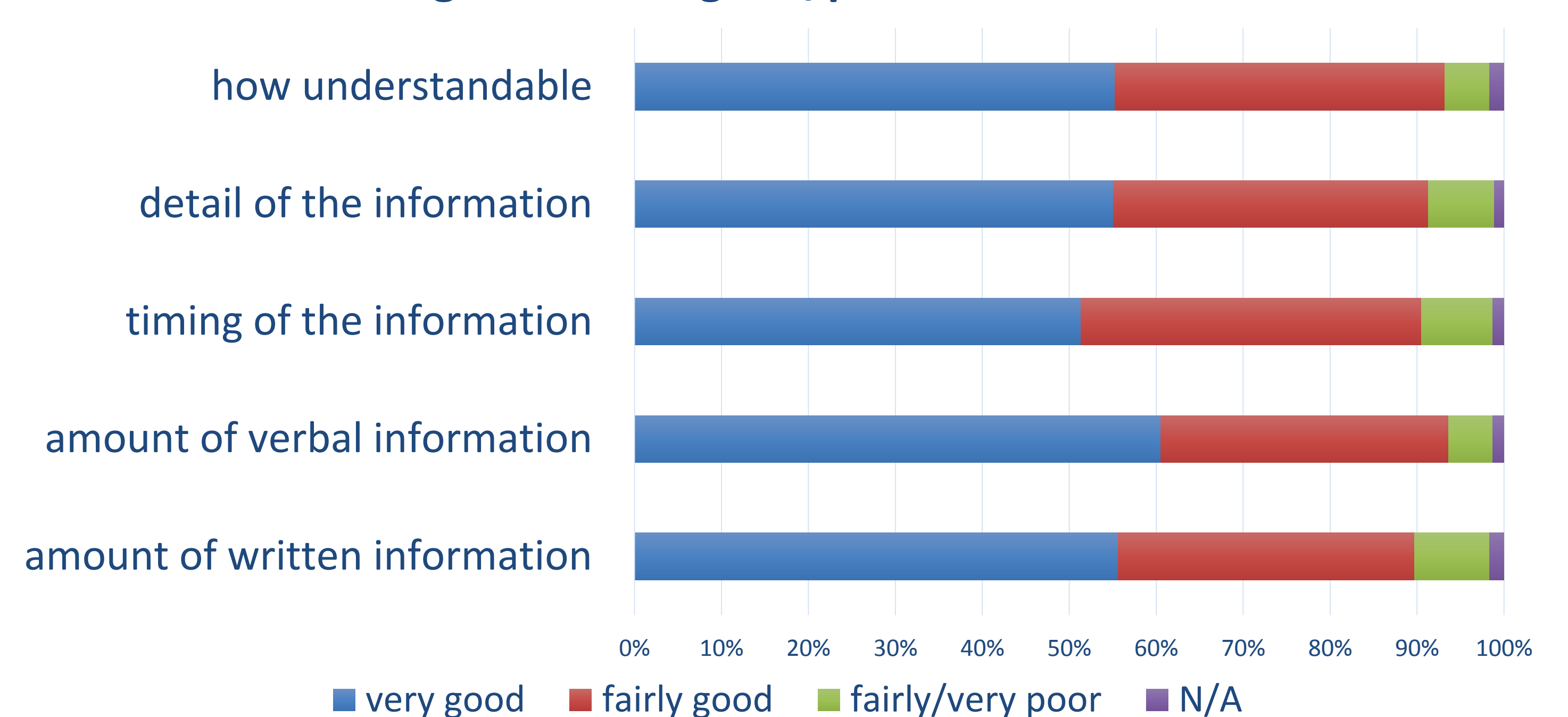
## Results

Four hundred and seventy-six questionnaires were returned (57% response rate). Mean age was 45.9 (+/-10.5) years, 381 (80%) were female and 401 (85%) were parents.

### Information needs

- The majority of carers rated the information received as very good (Figure. 1)
- However, one in three stated not receiving information about:
  - the young person's emotional needs
  - how to care for the young person on a practical level
  - local health services

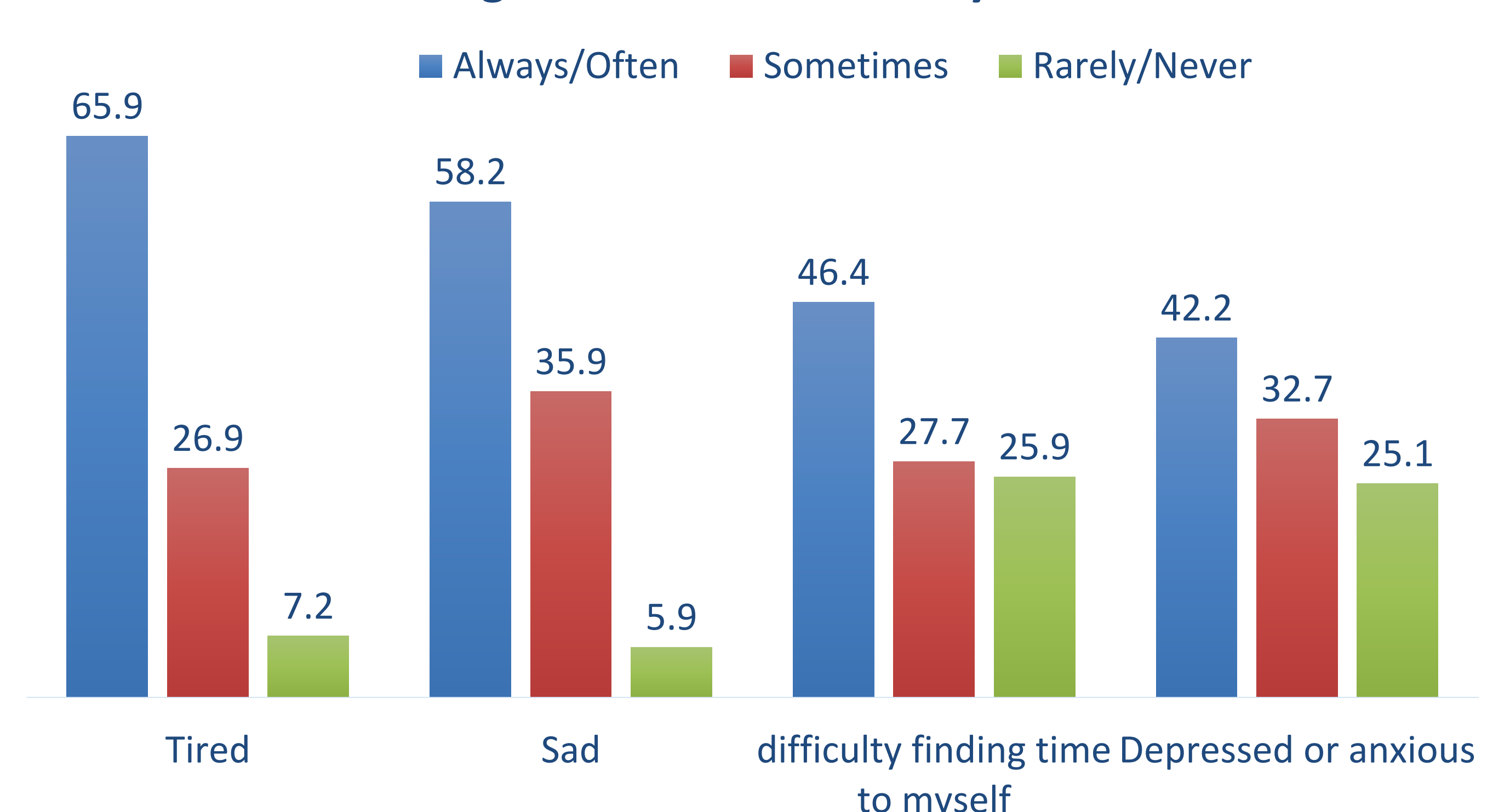
Figure 1. How good/poor was the information %



### Thoughts and feelings

- 66% of carers reported often/always feeling tired and 58% feeling often/always sad (Figure. 2)
- 20% never received support when they felt depressed or anxious or never received support to find time to themselves
- 66% worried about cancer returning and about young people's emotional/psychological wellbeing

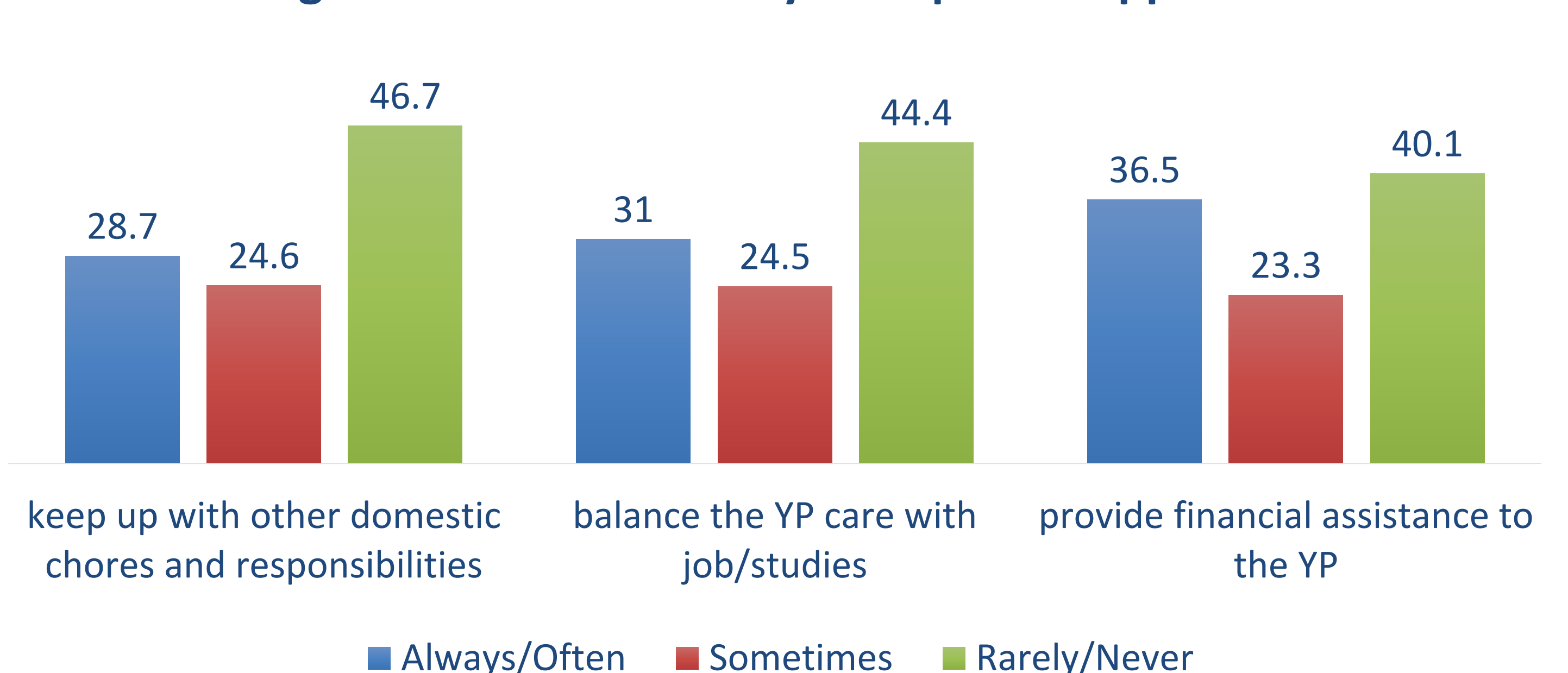
Figure 2. How often did you feel... %



### Support

- 47% of carers could manage balancing their job/domestic responsibilities with caring for the young person (Figure. 3)
- 25% received no support to facilitate this
- 40% of carers could manage providing financial assistance to the young person (Figure. 3)
- 26% received no support to facilitate this

Figure 3. How often did you required support... %



Carers who had *no* exposure to PTC care were:

- less likely to receive information about financial support/benefits
- less support to manage social consequences of cancer
- less contact with other carers
- less access to healthcare professionals

## Discussion and Conclusions

We have identified unmet support needs of carers of young people with cancer. This includes lack of support for tiredness, sadness, depression and anxiety. Carers with no access to PTC care had more unmet needs. These data support the value of specialist services for young people with cancer.

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