

BACKGROUND

In Denmark, about 140 people are diagnosed with amyotrophic lateral sclerosis (ALS) every year. Approx. 95 percent are referred to the National Rehabilitation Centre for Neuromuscular Diseases (RCFM). The Danish Muscular Dystrophy Association (DMDA) offers peer-to-peer support groups for spouse carers of PALS. Of the 179 spouse carers of PALS referred to RCFM in 2013-14, only five participated.

OBJECTIVE

To examine why so few spouse carers of PALS participate in DMDA's peer-to-peer support groups and to develop and test a new format for peer-to-peer support for spouse carers.

METHODS

Participants were recruited among spouse carers of PALS (living or deceased) referred to RCFM in 2013-14 who did not participate in DMDA's peer-to-peer support groups for spouse carers.

An anonymous postal survey sent to participants with questions about demographics, knowledge of DMDA's peer-to-peer support groups, wishes to participate, reasons for not participating, and what would be necessary in order to participate.

Following the survey, peer-to-peer support for spouse carers was integrated and tested as part of RCFM's new experimental 6-month family support group format of monthly meetings. Spouse carers and PALS participated together three times and were then divided into two subgroups (PALS and spouse carers). Meetings were held regionally (max. 120 km). The new format was tested twice in 2016.

RESULTS

Ninety-three of the 151 (62%) spouse carers returned the survey questionnaire (55 women, 38 men, mean age 67 years). Eighty-one knew about DMDA's support groups, and 36 would have liked to participate. Fifteen lacked help to care for the PALS while away from home and/or had a bad conscience when leaving home, eight found the distance too far, and 13 reported that shorter distances and help at home would make a difference.

Sixty spouse carers were invited to participate in RCFM's new experimental family support groups. Twenty-two participated (16 together with the PALS and six alone). After six months, 16 spouse carers (14 together with the PALS and two alone) and 17 PALS decided to continue meetings within the DMDA.

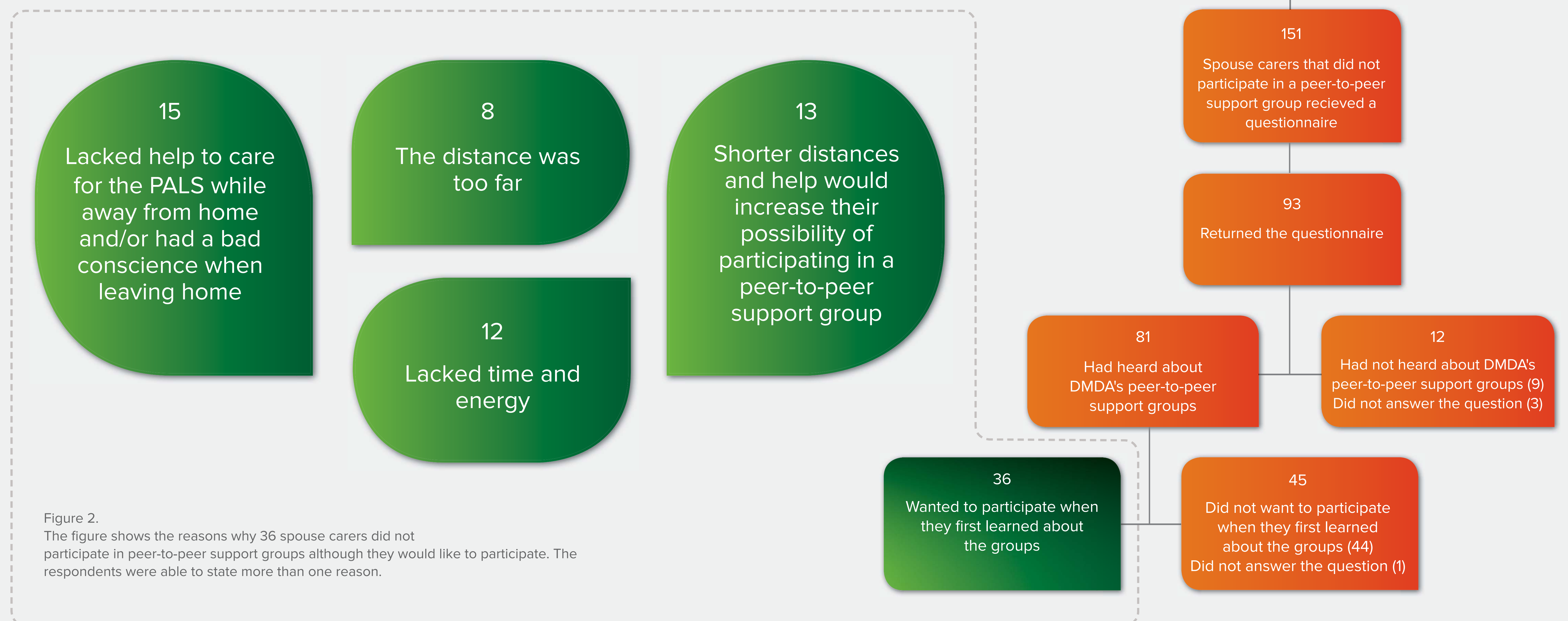


Figure 2. The figure shows the reasons why 36 spouse carers did not participate in peer-to-peer support groups although they would like to participate. The respondents were able to state more than one reason.

Figure 1. The figure shows how many spouse carers knew about DMDA's peer-to-peer support groups and whether they wanted to participate when they first heard about the groups

CONCLUSION

The survey revealed that more spouse carers wanted to join a group, but found there were too many barriers.

Integrating spouse carer groups in family support groups where PALS and spouse carers participate together and in separate subgroups provides a framework that significantly increases spouse carer participation, and gives more spouse carers the opportunity to give and receive peer support.

Acknowledgement

The Danish Muscular Dystrophy Association funded this study