

## BACKGROUND

Approximately 140 people in Denmark are diagnosed with amyotrophic lateral sclerosis (ALS) each year. The National Rehabilitation Centre for Neuromuscular Diseases (RCFM) are sole providers of patient education courses for PALS. About 80% of PALS who are offered this type of course do not participate.

## OBJECTIVE

To examine why PALS choose not to participate in patient education courses in order to develop a program format that increases participation.

## METHODS

Participants were recruited among patients referred to RCFM in 2013-2014. Nineteen participants (43-78 years old, 11 men, eight women) referred to RCFM 2-23 months prior to time of interview were selected using purposeful sampling. All 19 had declined one or two invitations to a patient education course. Eleven were married and eight single. Semi-structured in-depth interviews were conducted in the participants' own homes (n=18) and in a hospital (n=1). Duration 1-2 hours. The interviews were audiotaped, fully transcribed, coded in NVivo 9, and analyzed.

## RESULTS

Four self-perceived barriers to participation were identified:

Practical obstacles, e.g. transportation, finances, and fatigue.

*"I can't use public transportation anymore and it's getting increasingly difficult to get into a car"*

*(Man, 60 years old, single)*

Participation in patient education courses challenges one's preferred way of living with ALS.

*"I think it is better to take one day at a time and get the most out of the day"*

*(Woman, 67 years old, married)*

Practical obstacles

Identity

Meeting others

Timing

The timing was not right at the current disease stage because the topics were related to future challenges.

*"It's good there are courses but it's too early for me. We do not want to seek out knowledge before it's necessary. The topics are relevant later but not now"*

*(Man, 55 years old, married)*

Meeting others with ALS gives a glimpse into one's own future and can result in increased worries about the future.

*"I know what is coming and I accept it but I don't want to be confronted with it"*

*(Man, 66 years old, married)*

## CONCLUSION

In order to increase participation in ALS related courses it is important to prevent practical obstacles, to ensure topics are relevant for the participants at the given time, and to avoid that individual coping mechanisms are compromised by premature participation.

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