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Title: Family care in advanced COPD: Perceived difficulties and expectations of support from services

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Body: Chronic Obstructive Pulmonary Disease (COPD) is an incapacitating, highly prevalent disease which often requires intensive support from patient's family members. However, knowledge about the difficulties experienced by family members in their caregiving role remains scarce. This study aimed to explore the difficulties experienced by family carers, and their expectations towards social and health support services. A qualitative, cross-sectional study was conducted with 21 family carers of COPD outpatients at advanced grades (GOLD 3 and 4). Semi-structured interviews were performed to collect data. Participants were mostly female (n=20), with a mean age of 60.90±12.35 years old, spouses (n=12) and caring for more than 4 years (n=18). All interviews were audiorecorded, transcribed and submitted to content analysis by 2 independent judges. The major difficulties reported are related to: i) provide support in basic [washing (n=6), dressing (n=2)], and in instrumental activities of daily living [preparing meals (n=4)]; ii) communication with patient (n=2); and iii) restrictions in social activities (n=2); Six carers did not identify any difficulty. Most of participants (n=12) could not identify how formal support services could help them. Only 3 participants reported the need of help to provide support in activities of daily living. Carers reported several difficulties in their caregiving role. However, they were unable to identify how social and health services could support them. The lack of information about community resources might explain these results. Strategies towards effective flow of information must be addressed in order to prevent caregivers' burden.