

Cystic fibrosis patients acting as carers for their older relatives

– the ‘cared for’ becoming the carer

EF Nash, S Cammidge, Z Dallow, R Rashid, J Whitehouse, A Regan

West Midlands Adult CF Centre, Heart of England NHS Foundation Trust, Birmingham, B9 5SS,
UK



BACKGROUND

- As survival of people with cystic fibrosis (CF) continues to improve, they are increasingly likely to be placed in the position of having to act as carer for their parents and other older relatives.
- This could potentially impact on their own physical and mental health and result in adverse outcomes.
- However there is currently no evidence as to the prevalence of this situation and the health implications.
- We therefore conducted a prospective study aiming to assess the impact that caring for an older family member has had on CF patients' mental and physical health.

METHODS AND MATERIALS

- We approached patients that we had already identified as carers and asked them to complete a questionnaire when attending CF outpatients.
- The questionnaire asked:
 - patient's age and gender
 - which family member they had cared for and why how long they had acted as carer
 - how many hours per week on average they provided care
 - whether they get any welfare benefits to help provide care
 - whether providing care impacted on their ability to look after their own health and if so how
 - whether they felt that their own health had suffered as a consequence
 - whether acting as a carer had made them feel stressed, anxious, isolated, depressed, resentful, angry, low in confidence, sleep deprived (scored on VAS, 1=mild to 10=severe)
 - whether they found caring for their family member rewarding or fulfilling (scored as VAS from 1-10)
 - whether they felt they needed more support
 - whether they felt more research needs to be done into the effects on CF patients of caring for their family member and if so would they be interested in taking part.

RESULTS

- We recruited 5 patients (1 male, median age 48 yrs, range 32-54 yrs), who had acted as carer for 9 older relatives (7 parents, 1 mother-in-law, 1 grand-parent).
- The reason for providing care given were: “learning difficulties”, “blindness”, “multiple sclerosis”, “diabetes/fibromyalgia”, “mobility”, “memory issues”, “vascular dementia”, “health problems”.
- Patients had acted as carer for (median) 17 yrs, 15.5 hrs/wk.
- None of the patients received any welfare benefits for providing care.
- 4/5 felt that providing care had adversely impacted on their own health.
- Reasons for this adverse impact given were: “more tired/less energy”, “tiredness/irritability/forgetfulness”, “very draining”, “tired/huge effort to carry out treatments”.
- Caring had resulted in patients feeling the following emotions: stress (median 10/10), anxiety (8/10), isolation (6/10), depressed (7/10), resentful (8/10) and angry (7/10), low in confidence (4/10), sleep deprived (6/10).
- Caring was reported to be: rewarding (5/10) and fulfilling (5/10).
- 3/5 felt that they needed more support at home
- 4/5 felt that more research was needed in this area and would be interested in taking part.
- One participant wrote the following: “Guilt is a huge emotion because you are aware your parent gave up huge amounts of time to care for you. Overnight I went from being ‘cared for’ to caring for my mom as her only available relative. There was little or no support available to help me deal with this huge change.”

CONCLUSIONS

- People with CF find that caring for older relatives is physically and emotionally challenging and report that this adversely impacts on their own health.
- This scenario is likely to become more common as prognosis improves.
- These patients are likely to need additional support and this should be considered as part of holistic CF care.
- Patients feel that this should be a future research priority.

ACKNOWLEDGMENTS

- We would like to thank the patients that took the time to take part in this study.