Evaluating the psychological impact of newly implemented infection control measures for the nontuberculous mycobacterium Mycobacterium abscessus

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Objectives: The nontuberculous mycobacterium (NTM) Mycobacterium abscessus (MABSC) is now thought to be frequently transmitted between individuals with CF despite conventional cross-infection measures [1]. New national NTM guidelines have been developed to enhance infection control although their psychological impact on patients is unknown. Since other infection control measures may result in feelings of stigmatisation, isolation, and loss [2–4], we wanted to explore patient experience at one centre following implementation of NTM guidelines to inform ongoing service development and strategies to minimise psychological distress.

Method: Adult CF patients attending Papworth Hospital with positive cultures for MABSC were asked to complete a questionnaire about their experiences of changes to their care, with a subgroup interviewed to obtain in-depth qualitative information.

Results: Results to date indicate that patients value information provision and the opportunity to discuss concerns with members of the multi-disciplinary team. Several reported psychological distress and have suggested ways to make the changes more acceptable. These include enhancing clarity surrounding the changes, achieving greater equality of services, and improving communication and information provision.

Conclusions: We anticipate that the results will allow us to minimise potential psychological distress when implementing new infection control measures. We hope that this exploratory study will inform further research about supporting this group of patients.

Reference(s)

Cystic fibrosis patients acting as carers for their older relatives – the ‘cared for’ becoming the carer

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Objectives: As survival of people with 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. However there is currently no evidence as to the prevalence of this situation and the implications. We therefore conducted a prospective pilot study aiming to assess the impact that caring for an older family member has on CF patients’ mental and physical health.

Methods: We approached patients that we had already identified as carers and asked them to complete a questionnaire. The survey asked their age and gender; which family member they had cared for and why; whether their own health had suffered as a consequence; how acting as a carer had made them feel (scored on VAS, 1=mild to 10=severe) and whether they felt they needed more support.

Results: We have currently recruited 5 patients (1 male, median age 48 yrs), who had acted as carer for 9 older relatives (7 parents, 1 mother-in-law, 1 grand-parent). Patients had acted as carer for (median) 17yrs, 15.5 hrs/wk. 4/5 felt that this had adversely impacted on their own health. Carers had resulted in the following emotions: stress (median severity 10/10), anxiety (8/10), isolated (6/10), depressed (7/10), resentful (8/10) and angry (7/10). 3/5 felt that they needed more support at home.

Conclusion: People with CF find that caring for their older relatives is physically and emotionally challenging and that this adversely impacts on their own health. These patients are likely to need additional support and this should be considered as part of holistic CF care.