406 Sleep problems in patients of an Adult Cystic Fibrosis Centre

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Introduction: Individuals with Cystic Fibrosis have been shown to experience sleep problems and it has been suggested that addressing these should form part of routine CF care. An evaluation was undertaken to address the hypothesis that there was unmet need in this area at MACFC.
Method: 66 consecutive adult outpatients with CF (21% of MACFC clinical population) completed a structured self-report sleep questionnaire specifically designed for the evaluation.
Results: Many respondents experienced sleep problems – 33% most/a lot of the time, and 44% occasionally.
41% of respondents were taking medications considered to affect sleep.
Perceived types, causes, and impacts of sleep problems were wide and varied.
73% of respondents stated they had not been asked about sleep problems at MACFC.
Only 16% of those experiencing problems reported being offered help with these at MACFC.
25% of participants reported already using strategies (psychological, medical & alternative) to aid sleep.
59% of those reporting sleep problems stated they would like interventions for them to be available at the MACFC e.g. relaxation techniques, good sleep strategies, stress management.
92% of all respondents thought sleep problems were an area that the MACFC should consider in the care they deliver.
Conclusion: Sleep problems appear to be significant in this CF population; however there appears to be a lack of opportunity for routine enquiry, follow-up and intervention in this area.
Patients view sleep problems as important area of concern in their routine CF care. The majority of causes and impacts of sleep problems identified have psychological aspects and point to psychological intervention, suggesting a central role for psychological services.

407 Introducing a programme of education for health care professionals working with adolescents

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Introduction: Increasing numbers of adolescents with cystic fibrosis (CF) are moving through the transition process. To offer appropriate care to this group of young adults health professionals require education specific to this area.
Aim: To improve knowledge and awareness of adolescent issues enabling healthcare professionals to be more effective in their provision of the best possible care.
Methods: Six sessions (adolescent development, adolescence in the hospital setting, communication, boundaries, adherence and mental health issues) were provided. Sessions were open to all healthcare professionals. Thirty-six online evaluations were sent to participants and lecturers, with 18 replies.
Results: Two thirds of participants (67%) strongly agreed that the content was relevant, the majority (80%) of participants and lecturers reported that the programme was satisfactory, all (100%) found it relevant to their needs and 100% reported the teaching methods as appropriate. All (100%) of lecturers enjoyed preparing and delivering the lectures. Half (50%) of participants and 80% of lecturers reported that they would like to participate in future programmes as lecturers. Half (50%) of the participants reported that patients' experience and care was the most important outcome. Other comments included the importance of learning as a team, sharing a common expertise and that the programme contributed to their knowledge.
Conclusions: Providing care for adolescents with CF can be a demanding and often challenging experience for the CF Team. CF teams work closely together and offering a specific education programme based on a joint learning approach, available to all members of the multidisciplinary team appears to be well received. This programme will be run at regular intervals with contributions from team members.

408 Cystic fibrosis: what do teenagers really know?

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Education regarding cystic fibrosis (CF) in a clinic where children are predominantly detected on a newborn screening programme is directed towards the caregivers. Education for individual teenagers specific to their own needs as they take on increasing self-responsibility can be overlooked despite some general educational tools.
Aim: To prospectively evaluate teenagers with CF aged 13–15 years on their knowledge of the disease and appropriate self-management, and to re-assess following educational sessions on "What is CF?" Respiratory Management and Nutrition. Physiotherapy techniques were also critiqued.
Method: An education package involving 3 individual sessions were developed by the Respiratory and Liaison Psychiatry teams at Starship Children's Hospital, Auckland, New Zealand based on the North American CF Family Education Programme. Teenagers attending the CF clinic for all care were invited to be part of the study. Questionnaire assessment of their CF knowledge was undertaken prior to, and after, these sessions. Prospective ethics approval and informed consent from participants and their families were obtained.
Results: 14 teenagers were approached – 1 declined, 1 dropped out after 1 session and 12 completed the study (median age 13.8 years, 8 boys). The mean knowledge score for all questions improved from 67.3% (range 51–95%) to 88% (range 70–97.5%), an increase of 19.62% ($p < 0.0001$). The respiratory section of the questionnaire showed the greatest improvement in knowledge. In addition, participants relished the opportunity to discuss at length their own concerns and fears away from the traditional clinic setting.
Discussion: Knowledge of CF can be improved with an individualized education programme. We hope this translates into increased adherence to self-management.

409 Patient held drug information cards

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Patients with Cystic Fibrosis (CF) often have very complex drug regimes. We were aware that many of our patients when questionned appeared to have a limited understanding of their medication. This included lack of knowledge about the action of their drugs and also any interactions or side effects.
In order to address this and ultimately improve patient compliance with treatment, we developed a series of small 9×5 cm sized cards which included simple, relevant information about each drug. Patients were then given cards pertaining to their treatment regime. Presently we have cards for 11 commonly used drugs. Initial patient feedback has been extremely favourable.