378 The use of internet technology by adults with CF to overcome perceived barriers to socialization resulting from the CF Foundation's Infection Control Guidelines

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Background: The Cystic Fibrosis Foundation's Infection Control Guidelines acknowledge the paucity of studies on the guidelines' impact on socialization among patients with cystic fibrosis. Isolation of CF patients from each other has led Internet-savvy individuals to use new media as social forums to create social networks while avoiding the risk of person-to-person transmission. Whereas online networking among non-CF individuals is commonplace, CF-specific Web-based opportunities remain scarce, although some CF-specific websites permit interaction between individuals; i.e. the CFF has an active Facebook page.
Experience at our center: A unique friendship developed between two adults at our program as a result of a caregiver's recognition of a common interest. These patients never met in person; their entire relationship was documented in e-mails. Recently the patients posted their e-mails as a blog [1], with the aim of inspiring young adults who feel they are struggling with illness alone. All are invited to post comments, which are screened by the authors. Topics that have emerged include "Living with CF", "Death and Dying", and "Religion".
Conclusions: Online social networking provides an outlet for CF patients to communicate about intensely personal topics and to give and receive valuable peer support. CF caregivers should recognize the power of these tools and endeavor to make more connections among patients. We plan to implement a series of program-specific Web sessions, facilitated by a CF patient and a team member, structured by topic. Web-based profiles created by individuals will be included so that individuals can follow up on their own.

Reference(s)

[1] www.brianandbobbyspeak.com.

379 Parents' perceptions of infant vulnerability in the context of newborn screening

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Objective: Identify factors predicting parental perceptions of child vulnerability following a range of newborn screen (NBS) results.
Methods: 257 parents of 135 infants classified by NBS and diagnostic results: healthy with normal results (n = 37), heterozygote cystic fibrosis carrier (n = 40), congenital hypothyroidism (n = 35), and cystic fibrosis (n = 23) completed assessments of parenting stress, infant temperament, and perceptions of child vulnerability when infants were 12 months old. Frequency of infant illness was documented by a review of medical records.
Results: Mixed logit structural equation modeling showed that mothers were more likely than fathers to perceive their infants as vulnerable. Variables influencing maternal perceptions of child vulnerability included CF diagnosis, high illness frequency, and high parenting stress. Parents who perceived their infants to have difficult temperaments reported high levels of parenting stress which mediated maternal, but not paternal, perceptions of infants as vulnerable. Infants with CF and infants who were CF carriers had more documented illnesses than infants with normal NBS results. The congenital hypothyroidism group was not significantly different from the group with normal NBS results on any variables and had no paths to perceptions of infant vulnerability.
Conclusions: Factors contributing to parental perceptions of child vulnerability include parent gender, parenting stress, infant diagnosis, illness frequency, and infant temperament. The significantly higher frequency of documented illnesses among infants identified as heterozygote CF carriers as compared with the comparison group warrants further investigation.

380* Health-related quality of life measurement in cystic fibrosis: examining questionnaires at an item level

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Background: Several generic, respiratory and CF-specific health-related quality of life (HRQoL) questionnaires have been evaluated for use in CF. Different HRQoL instruments ask different questions and therefore provide different information. The same domain names (e.g. emotional functioning) occur in different questionnaires but they may measure different constructs. Conversely, questionnaires may contain domains that have different domain names but may measure similar constructs. This work examined the instruments at an item level to (a) unravel the constructs that are being measured and (b) to compare and contrast these constructs across the HRQoL scales.
Methods: HRQoL instruments that have undergone psychometric evaluation for a CF population were identified from the literature. All domains and items from these questionnaires were tabulated for comparison.
Results: Most questionnaires have domains with conceptually similar names. Examination of the items revealed that often conceptually similar names are used for different constructs. For example, 'emotional functioning' on the CFQ asks patients if they feel worried, useless, sad, lonely or have difficulty making plans, whereas the CFQoL asks if they feel resentful, angry, embarrassed, irritable, fed up, anxious or frustrated. Also, different domains measure similar constructs. For example, the SF36, CRDQ and CFQ have an 'energy' domain, but 'energy' is part of the 'physical functioning' domain of the CFQoL.
Conclusion: These findings highlight that it is very difficult to interpret HRQoL outcomes without detailed examination of the items on the questionnaire. It is not sufficient to rely on the names of the domains.

381* Quality of life (HRQoL) in cystic fibrosis: the parents' perception and the comparison with children's QoL

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Objectives: In the last two decades the survival of patients with CF has dramatically improved, whereas treatments became more demanding. Growing interest has been therefore devoted towards the investigation of patients' Health Related Quality of Life (HRQoL). Our main objective has been to assess the CF-specific HRQoL in Italian children (7–13 years-old), comparing patients' and parent's perception.
Methods: The inclusion criteria were: being regularly followed up, ⩾7 years of age, ability to read Italian and absence of mental illness. The age-specific versions of the Cystic Fibrosis Questionnaire (CFQ; Henry et al, 1996) was used with permission. They were translated into Italian, and back-translated into the original language (French) to check for semantic equivalence. Higher scores indicate better quality of life.
Conclusions: The lowest scores among 48 patients were observed for the domain of Treatment Constraints. There were no overall significant difference between parents and patients except for the domain of Energy, which was perceived more compromised by parents than by patients (mean score 67.9 versus 77.0). Significant correlations were found between parents and children on HRQoL domains of Physical functioning, Body Image and Eating Disturbances. HRQoL is perceived differently by each single parent in comparison with her/his CF affected child.