Findings from the Meningitis Research Foundation 2003 member survey

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Background

Efforts have been made to catalogue characteristic and red flag symptoms and sequelae associated with meningitis and septicaemia. In 2003, when this survey was sent out, there was little information on the after-care received by those recovering from disease or on the long-term impact on quality of life. This survey aimed to gain a clearer account of members' experience as a patient and identify potential risk factors that result in poorer outcomes (e.g. impact on education/ work/ finances). An appreciation of the long-term impact of disease, would mean estimates of the costs associated could be more accurate, and investment in the NHS; specific and reflective of the needs of survivors.

Objectives

To more accurately reflect the experience of survivors by gaining information on symptoms, sequelae, after-care received and long-term impact on quality of life. To explore the links between risk factors and poorer outcomes.

Methods

Members of Meningitis Research Foundation include individuals and families affected by meningitis or septicaemia. In 2003, the Foundation surveyed active members with experience of recovery since 1988 (themselves or an immediate family member). Our analyses are based on responses from 809 subjects (a response rate of 50%). Logistic regression was used to examine risk factors for after-effects and impact on quality of life.

Findings

Sequelae

67% reported having short-term after effects

•*50% reported having long-term after effects*

•*Pneumococcal disease* was more likely to result in long, severe long-term and neurological after effects than any other disease type.

Table 1 Output from logistic regression controlling for age and disease form. Association between reporting A. long-term B. severe long-term and C. neurological after-effects and disease type.

A Covariate	N	% with long-term after effects	Odds Ratio	(95% CI)	p-value
Disease type other than pneumococcal*	716	48%	1		
Pneumococcal disease type	93	66%	2.6	(1.6 to 4.2)	<0.001

B Covariate	N	% with severe long-term after effects	Odds Ratio	(95% CI)	p-value
Disease type other than pneumococcal*	716	25%	1		
Pneumococcal disease type	93	47%	2.7	(1.6 to 4.3)	<0.001

C Covariate	N	% with neurological after effects	Odds Ratio	(95% CI)	p-value
Disease type other than pneumococcal*	716	25%	1		
Pneumococcal disease type	93	47%	2.7	(1.7 to 4.3)	<0.001

*Baseline category

After-care

For all areas of after-care there were people who had difficulty in gaining treatment soon enough, often enough or at all. The extent of recovery often depends on tests/ treatment starting soon enough, this is particularly the case for those with hearing loss. The success of cochlear implantation, to improve hearing loss, is dependent upon a hearing test being done quickly, before the overgrowth of bone prevents this from being possible. Of those with bacterial meningitis only 23% had a hearing test within the first month after being well enough to have one.

Access to physiotherapy and occupational therapy was more available than other areas of after-care; however , out of 158 people requiring physiotherapy or occupational therapy, 44% and 48% respectively had problems with access to treatment. Proportionately, those with behavioural, psychological and emotional difficulties had the least support for associated problems.

Figure 1 Hearing care pathway of those with bacterial meningitis

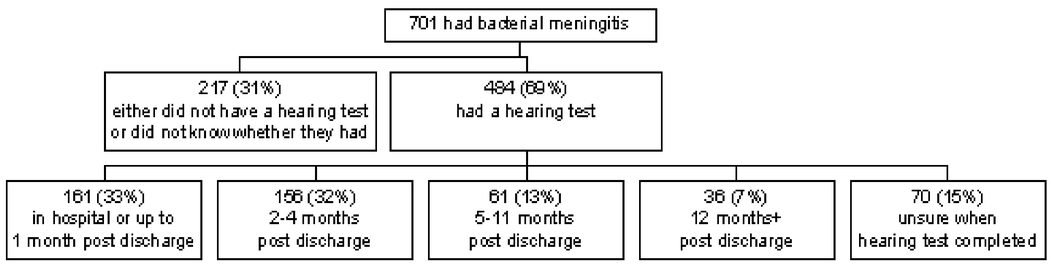
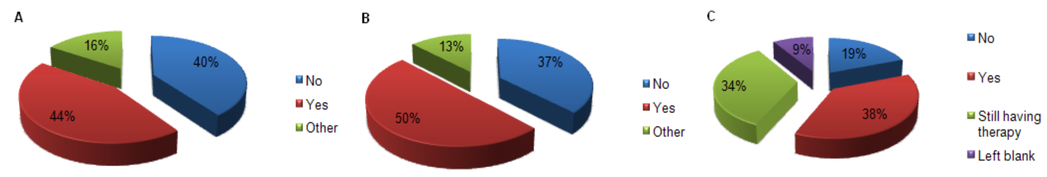


Figure 2 Percentage of those requiring speech therapy that thought it A. started soon enough B. was often enough and C. was long enough (total 88)



Of 88 people requiring speech and language therapy, 67% reported some difficulty with access (didn't start soon enough/ wasn't often enough/ difficulty obtaining).

Figure 3 Percentage of those requiring physiotherapy that thought it A. started soon enough B. was frequent enough and C. was long enough (total 151)

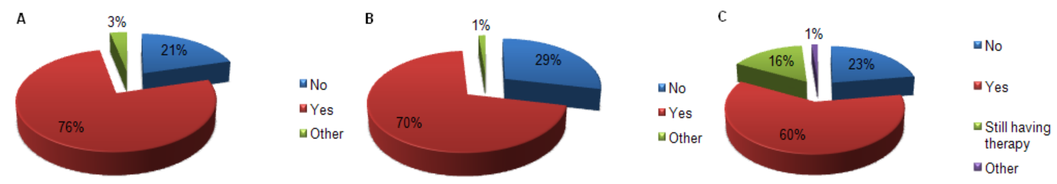


Figure 4 Percentage of those requiring occupational therapy that thought it A. started soon enough B. was frequent enough and C. was long enough (total 60)

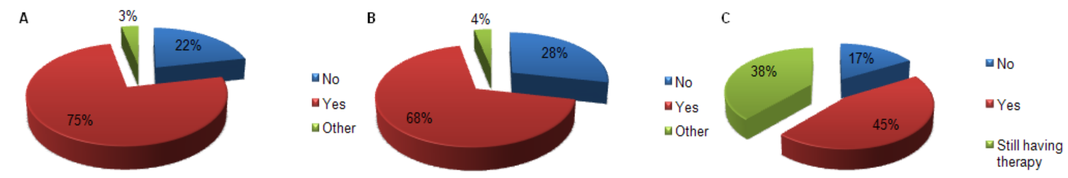
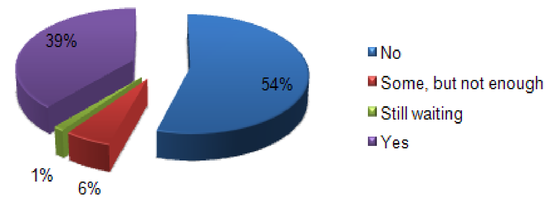
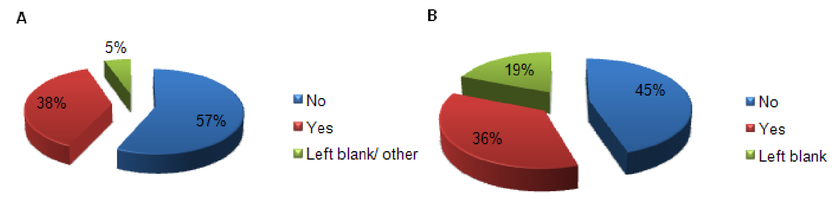


Figure 5 Percentage of those with behavioural, psychological or emotional problems that received support for those problems (total 301)



Impact on work and education

Figure 6 Percentage of those reporting an impact on A. education and B. work if in education at the time or after illness (total 455) or in employment (total 184) respectively



•7% of those in education at the time or after illness were given a special educational needs statement

Table 2 Output from logistic regression controlling for age, disease type and disease form. Association between reporting an impact on work and reporting long-term after effects

Covariate	N	% with long-term after effects	Odds Ratio	(95% CI)	p-value
No impact on job*	743	46%	1		
Impact on job	66	92%	8.2	(3.1 to 22.0)	<0.001

* Baseline category

Conclusions

•Short-term after effects are common and reported for all pathogens.

•Long-term and neurological after effects are more common in those reporting pneumococcal infection.

•After-care required was wide-ranging and access to care varied. Members' experience suggests that improvement is needed in access to, and provision of, care for those affected after they have been discharged from hospital.

•Long-term sequelae are likely to have a negative impact on education and employment.

•In order to gain a full appreciation of the cost of meningitis and septicaemia it is necessary to incorporate information on long-term impact of disease . This includes the consequences for the NHS, for peoples' work, education and quality of life in general.

Acknowledgements

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