McDonnell S, Lynch SA:

Who supports the support workers? Cross-sectional survey of support workers' experience and views.

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Supporting the Support Worker

Support groups provide information and emotional support to families of disabled children or adults. McDonnell and Lynch present a research-based picture of the structure and working patterns of support groups in the UK. Support groups may be the only link that families under stressful conditions will use. To ensure that support workers give appropriate advice under difficult circumstances, support to these workers is essential. Although in the UK practical advice and training courses are provided by the 'Contact a family' organization, the authors state that there are no formal structures in place that provide support for the support worker.

In this study, 112 support groups were selected that encompassed all common chromosomal, genetic and sporadic conditions. To identify the structure of these groups, their training needs and support given to the workers, a cross-sectional survey was performed using an anonymous questionnaire existing of 24 fixed-choice and open-ended questions. The outcome measures included amongst others: the structure of the organization; the method used to give information; training needs; coping mechanisms, and support available for staff if problems arise in their work.

The completed questionnaires that were received from 50 of the 112 support groups showed that the majority of the workers are females (85%) who work on a voluntary basis (90%), and are either affected themselves (30%) or have an affected relative (65%). More than two thirds of the workers (71%) had no formal training and although 35% would welcome this, the majority (43%) did not want training. In addition, no group employed an independent clinical supervisor. These results contrast with the fact that two thirds of the

respondents admitted times when they struggled to cope in their work and 41% admitted concern over the care given by a client to an affected relative. Another important dilemma that the authors describe is the fact that a lot of support workers risk losing their privacy because they find it their job to 'always be there for their clients'. The results indicate that to deal with those problems, there is a need amongst support workers (78%) for a structured support network rather than training.

Comments

The article describes support workers as being a group that is highly committed to their role. Previous studies have focused on the patient benefits of belonging to a support group and no one has canvassed the opinions of support group workers to establish the level of commitment involved or the problems that might occur. This study gives a welcome insight into the views, problems and needs of these workers. It is obvious that they experience difficulties and need advice when dealing with difficult cases, for example when child abuse is suspected. Despite the experienced difficulties, the majority of the support workers felt that training was not necessary as illustrated by the remark of one respondent: 'I am a parent of an affected child which means I am probably more qualified than medical professionals'.

The contrast between the problems experienced and the negative attitude towards training courses needs further attention. The authors suggest to take care of formal arrangements with experienced professionals to allow support workers to discuss difficult issues. However, this study does not give a definite answer on what the difficult issues are and how they should be dealt with within those arrangements. Future research should focus on the needs that support workers have, their views on training and the kind of advice that is both wanted by support workers and improves their support given to patients according to the standards of Health-Care Professionals (HCPs).

From this article it seems clear that the question of how the relation between HCPs and support workers can be optimized needs further attention. Support workers are an important link between the HCPs and families of disabled children/adults.

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