Setting up a male support group to meet the needs of men who are informal carers

Exploring the process and challenges of setting up a support group to help men who provide informal care, and practical roles that nurses can play

INTRODUCTION
An informal carer is someone who cares for another person – a family member, friend or both – ‘without pay and largely without training or formal recognition’ (The Princess Royal Trust for Carers, 2009a; Carers Association Southern Staffordshire, 2009). This is in contrast to formal carers such as nurses, social workers and doctors who are trained, paid and regulated to care.

As a Birmingham–based nurse and male informal carer, I was well aware of several support groups for carers in the city. I had used and been involved in many over the years. I noticed patterns in both service provision to carers and take-up of services. For example, regardless of the type of support group, many tended to be helped and even run by care professionals, the timing of meetings tended to be during office hours and most of those attending were women. Consequently, many of the activities organised by and for these groups tended to be those that would appeal and be relevant to women.

As a result, many men acting as informal carers could feel even more isolated, as their needs were not being met by existing support mechanisms.

In some support groups and forums run by care professionals, there was also the possibility and risk of two agendas emerging – one from carers and one from care professionals (Mitchell, 1996). Although there would be overlap, there is a risk that the agenda of the care professional would dominate.

It was in this context that I decided to set up a support group for men who were informal carers in Birmingham in June 2007.

THE PROCESS
The following journey that led to forming the men’s carers’ support group, Carersjoin, took place from late May to early July 2007.

I realised that men’s needs were often not being met by existing support groups, forums and networks. When I discussed the possible need for a separate, male-oriented support group with a staff member at the Birmingham Carers Centre, they pointed out that many existing support groups were open to both men and women and that a support group specifically for men could be segregationist and counterproductive.

I carried out a literature search for support groups for male informal carers using BNI, OVID and Social Care Online, using ‘male carers’, ‘carers support groups’ and ‘male carers support groups’ as search terms. This unearthed very little relevant research.

I also carried out an internet search on Google using the same terms. This uncovered a small number of websites connected to male carer support groups, with the group organisers’ contact details. I contacted these organisers and the conversations convinced me to challenge the initial advice.

I discussed the idea with the Birmingham Carers Centre again and we agreed that it would provide the meeting space, refreshments and administrative support. A simple poster advertising the group was designed and displayed in the centre, and a short advert was put in its newsletter.

The poster and newsletter led to a small number of people calling me and we agreed to meet at the carers centre during a weekday lunchtime in early July. We decided to meet once every two weeks at the centre with the option of using a local cafe and/or pub for meetings if members chose, as these provide a relaxed environment.

I made it clear to members that, although I was a registered nurse and therefore a care professional, I was also an informal carer and it was in this context that I had set up the group.

We discussed the group’s name, as members felt the ‘men’s group’ or the ‘men’s carer support group’ were rather lame. We decided that ‘Carersjoin’ was a much better name and we adopted this, along with a group logo.

We established basic ground rules around confidentiality, respect and dignity during the first few meetings. I circulated short notes to members after each meeting to keep both those who had attended and those who could not up to date with events.

Carersjoin was continuously advertised through posters in the carers centre and adverts in the centre newsletter, which helped to attract new members. By the end of August 2007, group membership peaked at around nine men who were informal carers.
EVALUATION

The Birmingham Carers Centre staff were extremely helpful in providing the meeting space, refreshments and basic administrative support, all at no cost to the group or its members.

Once group members became familiar and comfortable with each other, differing needs and personalities emerged. All members wanted information and advice on carer, financial and welfare issues and services.

One member said he hoped that Carersjoin would take on a campaigning role not only for informal carers in general but also informal male ones in particular. Some members wanted social activities such as go-karting and orienteering, while others just wanted somewhere they could stop being carers for a while.

All views were equally valid and necessary to ensure a lively and vibrant group. The problem was that some members came across as over-dominant, an issue that led to power conflict in the group, which, in turn, prompted the resignation of one of the founder members.

In retrospect, the potential for unhealthy conflict should have been anticipated and dealt with before it became a problem. Clearly set out and agreed terms of reference and activity programmes to meet the hopes and expectations of all participants might have gone some way to prevent the power conflict and resulting resignation.

IMPLICATIONS FOR NURSES

The involvement of community nurses in what should be a user-led initiative is arguably a double-edged sword for several reasons.

In my experience, many vocal and militant carer support groups often do not need outside help in either establishing or running themselves. Nurse or any other professional intervention may not be welcomed and may even be rejected.

Where nurse involvement is requested and is appropriate, nurses’ first role is to be aware of carer issues and how these affect male carers. This could be achieved by reading carer-related articles, books and consultation papers. Nurses could also read legislation such as: Carers (Equal Opportunities) Act 2004 (Office of Public Sector Information, 2004); Carers and Disabled Children Act 2000 (OPSI, 2000); and Carers (Recognition and Services) Act 1995 (OPSI, 1995). For useful websites, see Box 1.

While this may seem demanding and time-consuming, the resulting awareness helps to place local male carer needs in a national context. This national context can then be applied at a local level by asking male carers what they would need or like to help them cope with the demands and stresses of being not only an informal carer but also a man who is an informal carer.

This could be achieved through: informal one-to-one conversations; individual interviews; focus groups and group discussions/interviews; clinics; or by questionnaires or surveys given to men who are identified as or may be carers.

On a practical level, nurses’ role is likely to involve providing information in appropriate formats and guidance to male carers who would like to start or join support groups, and helping groups by providing ideas and resources (Rose, 1999). Indeed, all six original members of Carersjoin wanted information and advice on healthcare issues affecting men, financial and welfare matters and caring.

Nurses will almost certainly have a role in health promotion as many men, including those who are carers, often find it difficult to access health services for themselves (O’Dowd, 2007). Finally, it could be argued that the nurses’ role is to help any male carer support group to evaluate itself, make plans and pursue independence from professional involvement.

CONCLUSION

Carersjoin was set up because of a perceived need for a support group for men who are informal carers. It appeared that this need was not being met elsewhere.

Throughout 2007 and 2008, some men left the group while others joined. Meetings continued to be held every two weeks at either the Birmingham Carers Centre or a local cafe.

February 2008 saw a formal launch event which attracted local newspaper coverage. However, as a result of falling attendance, meetings were abandoned from May 2008. I decided to restart the group as a virtual community and internet-based support network in early 2009 (see web link in Box 1), with the possibility of forming a national network of male carer support groups.

Mitchell (1996) found that the carers benefited from attendance and participation in support groups. In line with Mitchell (1996), I would argue there is a need for support groups for men who are informal carers and these could be run in different areas of the UK.

REFERENCES

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