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Research paper

Promoting the health of families of children with disabilities: acceptability and utility of a health-mentoring project

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ABSTRACT

Caring can have both positive and negative impacts on health, but the parental responsibility of caring for a child with a disability has the potential to result in depression, social isolation, and other physical and mental health problems. Mothers in particular bear the greatest burden associated with their child's care, which can mean that they experience a range of both psychological and physical health problems.

This research study investigated the acceptability and utility of a health-mentoring project to support mothers and families of children with disabilities, to improve their health. Action research provided the methodological framework for introduction of the health-mentoring processes, as change in family health practices was a desired outcome of the project. Purposive sampling was used to attract participants to the study. Five families, 10 final-year Bachelor of Nursing students, and two nurse academics participated in the phases of the action research cycle while they developed and implemented the health-mentoring project. Health strengths and problems were identified by the families through the mentoring process. In collaboration with students, families prioritised goals for action on health promotion, and students educated families to engage in health promotion practices. Families reported enhanced levels of wellness and coping. This project demonstrated two favourable outcomes: first, health mentoring was found to be a useful strategy for promoting the health of mothers and their families, and second, the project provided an effective method for teaching nursing students to develop the professional skills required for practice in health promotion.

Keywords: action research, carer, disability, mentoring, mother's health

Introduction

There is evidence that mothers and other family members of children with disabilities have poorer health status than families without children with disabilities (Barr, 1997; Cummins, 2001). Research investigating the health status of mothers of young children with disabilities found that mothers placed their own health issues and needs into the background of their lives, focusing instead on the health of their child with special needs (Mackey and Goddard, 2006). The health promotion project reported here was developed in response to these findings.

The project commenced in 2004 and brought together nurse academics, third-year Bachelor of Nursing (BN) students from a rural Australian university, and mothers and other family members of children with disabilities, with the aim of positively influencing the health status of the mothers and their families. The project pioneered a new approach, which involved

mentoring, to bring about change in health practices in these families. Additionally, the project aimed to enhance student learning through participation with these families and involvement in the health-mentoring process.

Caring for a child with a disability

Caring for a family member with a disability is linked to an increase in mental and physical health problems for the caregiver. Surveys of carers have revealed that '... carers experience more health problems and stress related illness than the rest of the population' (Mioche, 1995). Mothers and other family members of children with disabilities have poorer health status due to the stress associated with around-the-clock caregiving (Barr, 1997; Cummins, 2001). Barr (1997) describes chronic sorrow, depression, social isolation, and other physical and mental health problems resulting from the responsibility of caring for a child with a long-term disability. Mothers bear most of the burden associated with their child's care (Porter and McKenzie, 2000) and, as a result, they are at extreme risk of being highly stressed and clinically depressed (Cummins, 2001). In his research with 35 families of children with autism Gray (2002) found high rates of depression, anxiety and anger among mothers and fathers, with 35% requiring psychotherapy and medication. In a study by Cuskelly *et al* (1998), there were reports of physical health problems often with a stress-related component, with mothers reporting a greater level of distress associated with an inability to maintain their careers.

The degree of disability in the child has an impact on the caregiver. Hall and Hill (1996) found caring for children with high support needs had the potential to increase mothers' stress levels, reduce sleep time and quality, and create an inability to leave the child with anyone else for fear of a medical emergency. Further variables found to increase potential for health problems included the amount of assistance with, and cumulative effects of, physical care and problematic behaviour; the child's need for hands-on care over a long duration; and the number of adjustments to daily life to accommodate the needs of the child (Herman and Marcenko, 1997).

The training and education of health professionals and carers, the need for continuity of care, and access to much needed resources have been identified as necessary to support mothers with health problems associated with their roles as carer (Shu *et al*, 2002). Bomar (2004) suggests priorities when working with families in the area of health promotion, some of which include providing family-centred, community-based and culturally competent care; identifying family strengths and increasing family resilience; and promoting wellbeing of each family member.

In previous research investigating the health of mothers of children aged 0–5 years with disabilities (Mackey and Goddard, 2006), it was found that the mothers' health was backgrounded in time, space and the physical body, because their horizon of awareness was directed toward the needs of the child with a disability. The mothers in this study had numerous physical and mental health issues, but consistently the child's needs came before the mother's health. This prompted considerable reflection and investigation of the literature as to what could be done to encourage these women to bring their health needs into the foreground. Drawing on the ideas of Bomar (2004) and others, we decided to identify family strengths as a health promotion strategy, through empowering families caring for their children with disabilities to prioritise their own health needs alongside those of the children. An empowerment approach to family health promotion emphasises activities that build capacity, mobilise individual and family resources/strengths and enhance the development of family members.

Following appraisal of the strengths and weaknesses of a range of health promotion activities, health mentoring was chosen as a health promotion intervention for families with children with disabilities, because it promotes a partnership approach between participants, and builds on personal strengths and resources to generate change (King *et al*, 2002; Shevitz *et al*, 2003). Mentoring is a mutually beneficial relationship formed to equip, enhance and empower individuals, families and communities. It refers to a dynamic, supportive relationship between parties, in which one party shares professional and personal skills and experiences for the benefit of the other, less experienced, party (Chenoweth and Lo, 2001; Ronsten *et al*, 2005).

Study aims

The aims of the project were to develop and implement a health-mentoring programme, in a rural setting in New South Wales, Australia, that would, firstly, identify the health needs and health promotion practices among families with children with disabilities; secondly, identify their need for further support from a holistic, family-focused perspective; and thirdly, increase levels of family wellness through education and utilisation of health promotion strategies.

Method

An action research approach was utilised to develop the health-mentoring process. Action research is an approach to research that can be defined as 'inquiry

that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement ... It is a group activity with an explicit critical value basis and is founded on a partnership between action researchers and participants, all of whom are involved in the change process' (Waterman 2001, in Bellman, 2003, p. 27). The research style is participatory, with all those involved being co-researchers, sharing responsibilities and decision making (Street, 2001).

A key emphasis of this process is empowerment and hearing the voice of the participants: two key elements in the process of both mentoring and this research. Action research was selected as the appropriate method for this study because it supports the introduction and evaluation of change. This project aimed to generate changes in health and health-promoting practices in families with children with disabilities through empowerment processes of raising awareness, education and participatory decision making. The action research method is a reflexive, iterative process that involves cycles of change. These are discussed below.

Phases in facilitating the health-mentoring project

Phase 1: planning

Action research involves a cyclical process of planning action, taking action, and reflection on action. Initially, the research participants come together with an interest in common. They plan a change action, rigorously enact the change, and then reflect as a group on whether or not the action achieved the desired change. In this study, initial planning began between the nurse academics and some of the mothers who had participated in our previous research investigating the health of mothers with children with disabilities aged 0–5 years (Mackey and Goddard, 2006). The women talked about what they had gained through their participation in the research and how they had changed. They identified a raised level of awareness of health inequities experienced by their families due to the critical need in rural communities for access to health information, resources and services. The researchers considered that not only could the skills and knowledge of nursing students be channelled to meet some families' health needs, but in addition, the skills and capacity of these student nurses in the practice of health promotion could be increased.

A loose plan was devised to implement a programme for mothers and families, to increase their awareness of their health status and encourage engagement in health-promoting activities, through the actions of the nursing students. This programme involved discrete yet interrelated elements: (1) family assessments; (2) negotiated goal setting; and (3) provision of health education individually tailored to each family. The relationships between families, students and academics were considered to be critical in the development, implementation and evaluation of the programme. Once ethical approval for the project was achieved, the next phase involved forming partnerships between the families and student nurses who would work together, mentoring each other.

Families were accessed through two early intervention services where information sheets about the project were circulated, and interested women invited to contact the nurse academics. Five women and their families agreed to participate in the project. The women were all aged in their 30s and married, with between one and four children, a total of 15 children, eight of whom had a range of disabilities. The children, seven males and eight females, were aged between 20 months and 13 years. In three of the five families, the child with a disability was the first born of the children. The extent of disability in the children varied. One child had mental and behavioural problems, including violent and unpredictable behaviour towards parents and others; there were two children with Down's syndrome, the oldest of whom was attending school; one young child had cerebral palsy; one child had probable autism; and another had a developmental delay.

Socio-economic status, education and occupation varied considerably among the families. Three of the women worked part-time, one engaged in voluntary work, and one did not work outside the home. All of the women were partnered and their partners were supportive of the family's involvement in the project, although initially none were interested in being actively involved in meetings with students. Four of these five men were in paid employment, while one was in receipt of a disability benefit.

A preliminary meeting was held between the women and the two academics during which their ideas for the health-mentoring project were outlined, the women got to know a little more about each other and the women's role as a group was discussed. The women determined to take a pivotal role, meeting as a group every 2–3 weeks to reflect on progress and continue planning. Already there was a palpable sense of empowerment in the group of women, simply through their beginning participation in the project.

Identification of students wanting to participate in the project

In the first week of the semester all students enrolled in a subject focused on working with people with disabilities were given information about the project and asked to consider participating. Ten students elected to be involved. They were eight females and two males, aged between 21 and 48 years, with an average age of

32.3 years. Five of the students had children of their own, another student was married with a baby on the way, and four were single with no children.

Matching of students with families

Two students were matched to each family by the nurse academics according to personality, communication styles, geographic and personal needs, and similarity of family situations. The nurse academics had worked closely with the students over the previous two years and had met with the women in one-to-one situations, and some of the women were known to the academics from previous projects and community group activities.

Reflection

At completion of the preliminary planning phase five families and 10 students were involved with the two academics in the health-mentoring project. The five mothers and two academics had formed the core project-planning group. Students were introduced to their families, and the process of developing communication and rapport between students and their families had begun. Students were engaged in planning the process of family health assessments. The objectives in carrying out these assessments were to:

- provide a focus for interaction and communication between students and family members
- identify family health strengths and problems
- identify individual and family wellness goals in consultation with the family and the nurse academics.

Phase 2: family health assessment

With guidance from a family health nurse, students selected the Calgary Family Assessment Tool (Wright and Leahey, 1994) to frame the assessment process. The Calgary Family Assessment Tool is a multicategory framework that facilitates examination of the family's structure, development and function. It has been adopted by many faculties and schools of nursing around the world, and is widely referenced in the family nursing literature (Wright and Leahey, 2005).

Students arranged to visit the families to conduct the health assessments. During these visits children were usually present, but this depended on what the families requested, and the timing of the visits. Partners were not usually present during the early visits. However, as the project progressed and the men began to see real benefits to the family from their involvement, they became more engaged and began to participate actively in the family health assessments through their presence when students visited and in offering information at interview. Later we would see some of these fathers begin to attend to their own health needs.

Students used the skills of formal and informal interview and observation to gather data about the health status of the families and individual family members. They attended up to six meetings of varying length with their families, developing a relationship with them, enhancing communication, sharing the information collected to date and validating previous data. The students were mentored in this process by the nurse academics who were present in the home for some of the meetings between students and family and who met each week with the students to reflect on process and progress, and to determine together the next action steps. Students also provided email feedback following all visits with regard to issues that arose, reflections, and arrangements for future visits. For example:

> 'C and I worked through a family assessment with N today. I think it went really well mainly thanks to N being so open with us. Rapport with N is great. She is being really considerate with us when we stumble on some of the questions.' (Student reflection)

Students learnt to reflect on the obvious and not so obvious health issues arising from their analysis of assessment data, to expand upon their knowledge of the health issues, and also to reflect on their interpersonal communication styles. This is a further component of action research which involves the collection, explication and reflection on data within each cycle, thus gaining more information (Williamson, 2000).

The information generated was discussed among the seven women at their regular meetings, with due consideration for confidentiality. The women also talked about the students' visits and their influence on family life and health practices at these meetings, which were held every two or three weeks over a six-month period. The meetings were fairly informal, friendly gatherings in which the seven women shared information about progress in the family health assessment process, shared a meal, and continued to develop their identity and strengths as a group. Although informal, these were important meetings, as the outcomes, determined by the women as a group, influenced each stage of the health-mentoring project implementation.

Reflection

In conducting the family health assessments the students developed skills in communication, utilising assessment tools and doing health assessments. The families learnt more about their health through their participation. The mothers' role as mentors to student learning empowered them to reflect on their involvement in the health assessment processes and to provide feedback to students. For instance, the women

agreed that the early data generated from the health assessments lacked insight into specific health issues, and they suggested students might get more information at interview by taping the interviews rather than taking notes, and by visiting individually rather than in pairs.

The academics responded to this feedback and encouraged students to utilise the health assessment tool more closely, and to seek more constant clarification of data with the families. Students identified increased skills and competence levels as a result of this process, especially time management, communication, building relationships with clients and health assessment.

Relationships between all participants developed consistently, and everyone's knowledge was enhanced through the process of conducting the health assessments. The ongoing nature of this process allowed trust to develop over time. This facilitated a deeper level of communication between students and the mothers in particular, which was reflected in their feedback. For example:

> 'I was concerned in the beginning that the students wouldn't be comfortable with us and us with them. I also had reservations about confidentiality. Both these concerns weren't an issue. The students were very understanding of our privacy and fitted in well with the family.' (Mother's reflection)

Phase 3: identification of health goals

Mentoring sessions between the academics and students now involved further guided analysis of the data, identification of health issues and strengths, and determination of individual and family goals aimed at increasing levels of wellness, social interaction and positive coping strategies.

The Functional Health Patterns Framework (Gordon, 1987) was used to organise the data collected during family health assessments for analysis and identification of the families' health strengths and actual and potential problems. The women all considered themselves and their families to be in good health and, indeed, the assessments determined this to be the case. This positive self-assessment of health status was a strength for all the women, and is significant for the health of the family, as mothers are recognised as being central to the health and health promotion of the family (Bomar, 2004). Each family was functioning as a unit, reflected by their commitment to each other despite their difficulties and the amount of time they spent together as a family (Bomar, 2004).

The analysis revealed a number of health issues in each family (see Appendix). All five mothers had one or two significant health issues around both physical and mental health. Additionally, lack of sleep and the need for respite were significant health issues for four families. Three issues related to men's health including concern for their partner's health and anger regarding their child's disability, three more to weight or nutrition. There was an issue in one family concerning self-esteem in mother and daughter, and a number of families felt that problems in interacting with health professionals were impacting on their health. Some of the health issues were clearly interrelated, such as lack of sleep, stress and depression and the need for respite. These issues had largely been ignored by the families, backgrounded in awareness, prior to their participation in the project.

Based on the data analysis, students identified what they considered to be possible health goals for each individual family. Goals for family health promotion included strengthening the family unity through the facilitation of respite and improved sleep patterns. Additionally, goals were proposed to enhance communication within the families and their capacity to manage stress.

Many of the students wanted to 'fix' the health problems they had identified, before collaboration with the families or the nurse academics. For instance, one student arranged with a therapist friend to see 'his' family about their back pain. This demonstrated their novice understanding of the health promotion process (Benner, 1984). Students were refocused to the identification of goals, with the need to seek out the family's views on their own goals and priorities. Health promotion cannot be introduced into a family without the parents taking an active role, for they are the 'ultimate decision makers in identifying goals and determining intervention strategies' (Whitman *et al*, 2002).

Students prepared an information folder for parents and children, which presented the individual family's health strengths and problem areas for improvement, and suggested individual and family wellness goals. In preparation for the meeting with the families to present and discuss the information folder and to finalise the content, students were encouraged to reflect on their style of communication. The need for tact and diplomacy in reporting findings from health assessment was discussed. Students were also encouraged to work together to develop a plan for drawing their involvement with their particular family to an end. This process of completion is considered by Wright and Leahey (2004) to be an important component of nurses' professional interaction with families.

Reflection

A strength that was not identified by the students in the initial analysis of family assessment data was the influence of participation in the health-mentoring project on the health of the families. However, when

students returned to the assessment data they discovered that a number of health issues that had been identified early in the assessment process by the families had been, or were starting to be, addressed simply through the family's involvement with the project. For instance, one of the fathers had finally sought treatment for a long-standing cardiac condition, while one of the mothers had established a regular exercise programme.

The women's group did, however, recognise the influence of participation in the project on the women individually and as a group. In working with the students on the health assessments the mothers gained acknowledgement of their extensive knowledge of their family's health and the skills they utilised to maintain their health. Being involved in the processes of mentoring and action research facilitated realisation of their own strengths, as seen in this comment from one mother:

> 'I now recognise that I do have valuable input and with my skills will be an asset for voluntary groups, etc.'

The mothers were also less bothered by their 'failings', exemplified in the statement:

> 'I don't feel guilty if I haven't worked at my child's OT [occupational therapy] or speech therapy.' (Feedback from mother)

This highlights the capacity to enhance their own health that lies untapped in families and also the effectiveness of mentoring in creating space for families to bring their health into the foreground of awareness.

Phase 4: health promotion intervention

The collated information about family health, priority health goals and suggested health promotion strategies was presented to the individual families and discussed in meetings with students, families and the academics. Once goals were determined and strategies to achieve them were agreed upon, students prepared a health education package for each family. This included health education information and health promotion guidelines to empower the family to address health problems and enhance strengths.

Health issues addressed included physical problems, such as exhaustion, lack of restful sleep, smoking, back care, and psychosocial problems, including low self-esteem and feelings around grief and depression. The content of the information folders was extensive but individualised to the particular family. However, some information was generic. For example, all families requested health education information about back care. The information provided in the folder included a vignette or data illustrating the issues around back care for the family; some information about causes of back pain and general prevention strategies; suggested management strategies, such as physiotherapy, massage, exercise, home and functional assessment; contact details for relevant health professionals and agencies; a list of websites; information sheets; and a list of useful readings.

Reflection

While benefits to the family in terms of health accrued throughout the project, the health education package was intended to actively encourage family awareness and utilisation of health promotion practices, and to enhance coping strategies. Early evaluation indicates that this aim was achieved, as suggested by the following comments from parents.

> 'We now have some strategies in place to assist with the issues that were identified during the project. We were provided with great information regarding some of our health issues and also given contacts for other support we may need.'

> 'I don't know whether it was a coincidence or it was from this project but ... we are learning how to concentrate more on our health ... now we don't have cordial in the house, we just have bottled water and our water intake is much higher.'

Feedback from students about what they gained from this stage of the project included:

> '[It has] built upon my communication skills, knowledge base and nursing skills and I have learned to find appropriate resources, to be assertive with agencies without being aggressive.'

Importantly, students gained an understanding that while families who have a child with a disability face a range of physical and mental challenges, these families also have resources or strengths that help to maintain the health of the family and upon which family health promotion can be built.

Evaluation of the project

The project was evaluated on an ongoing basis through the reflection processes of action research, as detailed herein. Regular feedback was also provided by participants – verbally, in written form, individually and in groups. On completion of the project, all participants were asked to complete an evaluative questionnaire, students provided written feedback about their overall involvement in the project and some of the women participated in in-depth interviews.

Feedback showed that the families gained awareness of a wide range of health issues that affected them and

had on hand a resource file that offered a range of health promotion strategies to address these issues and enhance their health and wellness. The women had a greatly increased understanding of their role in the health promotion of their families and the capacities they could bring to that process:

> 'I am a lot more comfortable discussing my child's special needs and the effect it has had on the family. Overall I think I have become a better communicator as a result of this project.' (Feedback from mother)

The fathers benefited from focusing more on their health and having the opportunity to talk about their feelings around having a child with a disability:

> '[I learned that] I'm not odd, everything I've been thinking is quite normal.' (Feedback from father)

The students gained enhanced skills and competencies in working with families, particularly in the areas of time management, communication and health assessment:

> 'I have increased confidence in communicating with a family, team members and lecturers.' (Student feedback)

Lastly, the nurse academics gained experience in the application of mentoring to health promotion for families who have a child with a disability, while developing their skills and knowledge in the facilitation of student learning in the area of disability.

Study limitations and future directions

The purposive sampling and single location used in this study limits the extrapolation of the findings to other settings. Only a small sample of families participated in the study, which also constrains the application of the study findings. However, this was a study in which a new approach to family health promotion was being trialled, and it is not unusual for pilot studies to utilise small sample size. The mentoring process developed in this study will be implemented with more families in a variety of settings and contexts in order to further refine the process and perhaps to develop a workable model for integrating undergraduate student practice in the area of disabilities with family health promotion. Additionally, this research does not reveal whether the families maintained the changes to health practices triggered by their participation – whether long-term health benefits were achieved for the families. Ongoing evaluation will be carried out to determine the longer term outcomes for the families' health and health promotion practices.

Conclusion

Project evaluation indicates that the health-mentoring process, developed and introduced through an empowering action research approach, was effective in positively influencing the health status of the participating mothers and families, through their adoption of health promotion strategies and attention to existing health issues that had been pushed into the background of awareness. This approach to health promotion shows promise in improving the health status of the families with children who have disabilities, and in other settings. Additionally, this study has introduced a novel approach in the clinical education of nursing students which enhanced students' skills in working within a team, negotiating and prioritising, and developed their skills required for building social capital and community capacity, which are so vital in achieving a health-promoting approach to nursing practice.

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CONFLICTS OF INTEREST

None.

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Appendix: family health issues

Family 1

- *Mother*: flu over 10 months, run down, exhausted, disrupted sleep, asthma, no time alone, back pain
- *Father*: depression, flu, work stress, long hours, back pain
- *Child 1*: nil health issues
- *Child 2*: overweight, eczema
- *Child3*: history of pneumonia, hypothyroidism, ventricular septal defect, delayed development and speech

Family 2

- *Mother*: back injury, colitis, grieving, respite, needs information from health professionals
- *Father*: health condition, pericarditis, grieving, back pain and respite
- *Child 1*: frequent seizures

Family 3

- *Mother*: overactive thyroid (medication), pernicious anaemia (vitamin K supplements), tiredness, guilt, low self-esteem, need for respite
- *Father*: tiredness
- *Child 1*: no identified health issues
- *Child 2*: no identified health issues
- *Child 3*: developmental delay
- *Child 4*: no identified health issues

Family 4

- *Mother*: lack of sleep, depression, past and present addictive behaviours, low self-esteem, sexual health: pap smears and breast checks, early menopause, sexuality issues, attention deficit hyperactivity disorder (ADHD) in self and children, allergies
- *Father*: pain management not appropriate, aggressive behaviours, depression
- *Children* (4): diet/nutritional issues, sensory issues, sleeping patterns, nightmares, continence (youngest two)

Family 5

- *Mother*: depression, women's health, sleep problems, self-esteem, time out, smoking, exercise, prioritising, and budgeting skills
- *Father*: phobia, sleep problems, respite to increase communication with partner
- *Child 1*: waking in the night, food allergies
- *Child 2*: self-esteem issues
- *Child 3*: nil health issues