

## FROM THE EDITOR - Margaret McMillan

### EMBRACING COLLABORATIVE RESEARCH

As I take up the role of Editor of the *Australian Journal of Advanced Nursing*, I would like to acknowledge the contributions of the previous Editor, Heather Dawson. Her summary of the advances made by *AJAN* over the last five years is impressive.

However, not only has *AJAN* undergone significant change, as Heather noted in the last issue, but so has the profession of nursing. I anticipate further changes as nursing professionals embrace their role as partners in more formal research, including collaborative research, with our health service colleagues. More manuscripts will result from those scholarly and practice initiatives.

There are a number of issues that are focusing the minds of nurses from a range of practice contexts in the first part of 2002.

By the middle of the year a final report on the recent review of nursing education in Australia will be delivered to the Federal Minister for Education, Science and Training. We, as a profession, need to continue our deliberations on the implications of health and education policies for the sustainable development of nursing and midwifery. We need to continue to contribute to research on issues pertaining to the cost effectiveness of the care processes with which we are involved, the appropriateness of models of care, and, our own cultural competence.

Whilst we strive to be distinctive as a discipline, we need more information on successes in achieving a greater degree of integration and comprehensiveness in our approaches to high quality care. The challenge of publishing is diminishing but we still need more evidence from rigorous research studies that will guide our deliberations on our future directions.

The global shortage of nursing personnel remains an issue. Our efforts to recruit, retain, educate and motivate larger numbers of health service personnel must be ongoing. In pursuit of this goal we need to make even greater investments in the human potential that exists within the profession.

*AJAN* is part of the effort that is required to extend the available literature and the knowledge base of nurse managers. The National Review of Nursing Education in Australia highlights the fact that the knowledge and skill requirements for nurses are varied in relation to nature and context. Students (undergraduate and graduate) need to be able to access Australian and international

literature that causes them to think about alternatives for the future education, practice and management aspects of the discipline.

Personal qualities, age, maturity, previous experiences, motivation, aspirations, and demographic factors all impact on whether a person will initially choose a nursing career, continue with informal or formal nursing education and remain with the nursing profession. Tenure in one occupation may not be a desirable or sustainable trend for the future. Traditional structures may be maintained at present for no good reason. It may be that more career avenues can and need to be made available to the nurse in lieu of the traditional and institutional arenas. To achieve and maintain a range of job options, identification and redefinition and acceptance of the work nurses' do must be considered and acknowledged.

We also need to achieve a more efficient person-job, person-education match, and therefore improve retention rates in education programs and employment. The identification and definition of the attributes of tomorrow's nurse, the methods of recruitment and factors relating to the selection of potential nurses appropriate to different contexts, need to be examined as a priority.

In some earlier work undertaken with colleagues the focus was on the transition of graduates into the workforce and on their choice of nursing as a career.

One member of the team went on to focus on the qualities required for publicity and aimed at those people thinking about entering university or the technical and further education sector to become nurses. Many authors have suggested that there may be different personal qualities that define categories of school leavers and mature age students. Besides demographic and educational factors, qualities related to motivation, coping ability, hardiness, and, the effects of life experiences warrant further investigation and subsequent publication in journals and other literature.

With the maturing of the discipline within the health and higher education sectors, many academics and educators have increased their publication effort. However, more work needs to be done to encourage output from graduates and those involved in collaborative efforts between the health and higher education sectors. *AJAN* is at the fore with its leadership role in encouraging, through publication, a better understanding of the nature and scope of contemporary nursing practice. I am looking forward to my role as editor of *AJAN*.

## GUEST EDITORIAL - Mary FitzGerald

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### REFLECTIONS ON NURSING

When I reflect on my nursing career I have vivid memories of particular events that happened over time. I can recall patients on my first ward, ward reports, cardiac arrests, the person who had a haematemesis when I was 'in charge', conversations, the laughter, frantic night duties and, of course, professional colleagues and friends.

The positive memories emanate from camaraderie (with both clients and colleagues) and a sense of achievement when challenges were met. These were the highs.

A nursing student once said to me, when enthusing about her first practical experience of nursing, that after a shift she sang all the way home on her bicycle - that simple expression of hers has always seemed to sum up the good feelings for me.

On the other hand there were the lows. The first drug error, the night sisters, working late on my 21st birthday, running out of laundry at weekends, getting 'sent to help', eating chocolates instead of meals, intolerable demands on my time and patience, feeling guilty (I did the wrong thing, I didn't do enough, I said the wrong thing, made the wrong decision, hadn't written an assignment etc), complaints and generally what is coined 'being beyond bizzie', all culminating in that rising tide of frustration that is so palpable among nurses.

There is much to learn from reflection. There are obvious similarities between the cathartic sessions where nurses gather to have a moan and outdo each other with stories of doom and gloom, drama and brave deeds. However, periods of reflection are different in both nature and purpose.

Periods of reflection afford opportunities for the development of new insights and fresh perspectives on old stories; in short, opportunities for the getting of wisdom.

Critical reflection involves such questions as: What was my contribution? Who are the other interested parties? Who stands to gain? Who might lose? How did this situation arise? What and who is maintaining it? and so on. Questions asked in order to construct a more comprehensive and fair understanding of situations and events.

Critical reflection has been subverted to the extent that it is perceived as a technique for education and learning rather than an integral part of practice. I began this commentary by illustrating an obvious balance between the positive and negative enduring impressions that I have of my experience of nursing. Balances and broader views

are a reward of critical reflection. Let me give an example. Keeping in mind the idea of balance, on reflection what emerges from my litany of memories is the distinction between those events that are nurse centred and those that are patient centred. It is the latter that seem so much more important and lead to professional satisfaction. Does an insight of this nature take us any further?

I think that it does. This is about fresh insights and new perspectives and the ability of nursing as a whole to give expression to them. The discussion document of The Review of Nursing Education (2001) highlights the frustration that nurses feel when they are unable to meet client needs. This may indicate a subsisting preference among nurses for patient centred nursing rather than nurse centred nursing and I would advocate this at every level of nursing.

It may be that the arguments put by nursing in the recruitment and retention debate should be reframed to concentrate on the development of a service that supports and promotes the best care of society rather than one that concentrates on better terms and conditions for nurses per se. The former position may, I believe, ultimately result in improved terms and conditions for nurses but for reasons that have more appeal to people outside the profession and therefore are more likely to canvass support.

I recently read an editorial from the UK (Gray 2002, p.3) about what was termed 'the no tolerance dilemma'. The health minister determined that a solution to the problem of aggression toward health professionals was to ban 'perpetrators of violence and abuse'. Apart from the other obvious shortcomings of this remedy, it is hardly client centred, and a more in-depth critique of the situation results in the editor's call for a better understanding of the causes of violence and more staff with appropriate training!

Generally I would advocate more staff, not because staff are tired, overwhelmed and underpaid (all true), but because clients are not receiving the care and treatment they need. I believe that this is a perspective that is more likely to result in nurses working in an environment that enables them to provide a first class service to clients. And by the way - to sing on the way home.

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# QUEENSLAND PUBLIC SECTOR NURSE EXECUTIVES: PROFESSIONAL DEVELOPMENT NEEDS

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**Key words: roles, responsibilities, nurse executive, professional development**

## ABSTRACT

**In a time of health care reform and rapid change, nurse executives need effective leadership skills to be able to respond to a challenging environment, provide quality cost-effective care and promote the professional development of nursing. This research aimed to provide an understanding of nursing executives' roles and professional development needs and obtain concise information for the development of strategies and professional development programs to enhance the effectiveness of the present and future roles of nursing executives.**

**A descriptive cross-sectional postal survey was sent to all public sector Level 4 and 5 nursing executives in Queensland (n=281), with a response rate of 52.3% (n=147). Financial management, human resource management and information technologies were identified as the areas where professional development was most needed. Structured educational activities such as short courses or seminars covering information technology, financial and budget management and general business management were identified as the type of activities best suited to nurse executives' needs. The most frequently reported barriers to professional development were difficulties obtaining relief staff, inadequate time, financial cost and inadequate district manager and regional support to enable access to professional development programs.**

## INTRODUCTION

The health care industry is undergoing a period of intense scrutiny and rapid change. The system is being driven by rapidly evolving technology, increasing trends towards shorter length of hospital stay and mounting pressures to minimise costs, increase efficiency and improve quality and clinical outcomes (Jobs and Steinbinder 1996). In order to meet these pressures hospitals and health services are restructuring, downsizing and streamlining the system. Nurses, clinicians, politicians and consumers are well aware that health care reform is now a national priority. To successfully function in this new century nurse executives will need to have a set of skills and leadership capabilities to be able to:

- respond to this changing and challenging environment; and,
- lead Queensland nursing to a position where it can professionally thrive whilst still delivering quality cost-effective nursing care.

Comprehensive and relevant professional development programs are essential for optimal nursing leadership effectiveness. Understanding the skills, knowledge and professional development opportunities required to become an effective nursing leader is important. This research study aimed to provide an understanding of nursing executives' roles and professional development needs and obtain concise information for the development of strategies and professional development programs to

enhance the effectiveness of the present and future roles of nursing executives. A search of the literature in CINAHL and Medline for the last 10 years revealed only limited published information on the roles and professional development needs of Australian nurse executives.

## LITERATURE REVIEW

In reviewing the literature several themes emerged concerning the competencies required of the nurse executive role. These themes may be classified into two groups: the management environment nurse executives must operate in, and the skills and knowledge required.

### Environment

The health care industry is a service industry with business needs (Buerhaus et al 1996) and health care organisations today are focusing on business performance (Sieloff 1996). The business component is intricately linked to an increasingly complex environment encompassing a focus on quality management, customer service, cost efficiency, improved outcomes and interdisciplinary role changes. Nurse executives must develop characteristics conducive to thriving in such challenging situations (Buerhaus et al 1996; Sieloff 1996). It is accepted that this new environment will mean greater spans of control and related responsibilities (Misener et al 1997), with significant expansion of the nurse executive role.

### Management and leadership skills and knowledge

Given the changing environment and role for nurse executives, it is important that nurses understand the skills and competencies necessary to perform as effective managers (Ridenour 1996). In the political environment, the competencies and knowledge required include political skills such as policy development, a global perspective, communication, organisational understanding, systems thinking and interdependency, mastering uncertainty and the creation of political strategic alliances.

In the business environment, the competencies and knowledge required are business skills including knowledge of marketing, financial and fiscal management and the use and management of information.

In the management environment, personnel management, problem solving, analytical thinking, team skills, conflict resolution and interpersonal mastery are seen as important.

For the professional environment, creativity, personal mastery, confidence, communication skills, professional knowledge, and creating professional strategic alliances were also identified as important (Misener et al 1997; Freund 1985).

There is no doubt that sophisticated communication skills are necessary for nursing executives. Critical thinking skills and an ability to articulate important organisational issues, such as cost quality linkages and effectiveness of nursing interventions in relation to organisational improvement as opposed to relying on a high level of 'intuitive' knowledge, was seen as critical by Triolo et al (1997). Personal flexibility and the capacity to negotiate and compromise are also viewed as essential skills and capabilities (Freund 1985).

Nursing leadership effectiveness has been extensively studied in the United States and a range of similar skills identified as necessary for effective nurse leadership. These include general management skills, health and nursing knowledge, human management skills, having a corporate or total organisational view, the ability to develop good medical staff relations, possessing political savvy and flexibility (Freund 1985), systems thinking and team skills (Triolo et al 1997; Sieloff 1996; Duffield et al 1995). Effective nurse leaders have an ability to assess the environment and an awareness of how it impacts on nursing (Aroian et al 1996).

An interesting factor regarding nursing leadership effectiveness is its link to the job satisfaction of subordinate nurses. Effective leadership involves using innovative strategies to increase staff retention, which is related to job satisfaction. The organisation consequently benefits from having increased staff satisfaction. Studies examining traditional leadership paradigms indicate that a nurse manager's leadership style directly impacts on the job satisfaction of staff nurses (Lucas 1991, 1989; Campbell 1986; Stamps and Piedmonte 1986).

### Professional development activities

Apart from traditional professional development activities such as workshops or formal education, mentorship was an alternative avenue of professional development identified in the literature. In one study one third of nurse executives identified having had 'mentors' who contributed significantly to their leadership abilities and success (Dunham-Taylor et al 1993). The mentors were equally divided among men and women and had often been the executive's supervisor.

There has been much debate about the appropriate education of nurse executives in order to give them the requisite skills and knowledge (Sanford 1994). However, as Sanford points out, until research determines the adequacy of different types of preparation for executives the debate may remain, in spite of a proven positive correlation between leadership effectiveness and educational levels (Adams 1990). There are obviously many contributing factors in developing effective nurse executives of which educational preparation, mentorship and certain skill sets are all important.

## OBJECTIVES

This study was part of a larger research project, of which the objectives were to:

- Identify the current profile of Directors of Nursing (Level 5s) and Assistant Directors of Nursing (Level 4s) in public sector hospitals and health services in Queensland;
- Identify their typical work pattern;
- Identify their current level of satisfaction with their current roles;
- Identify the most difficult problems they encounter; and,
- Identify the type of professional development or educational activities that would assist them to better manage these problems.

The first three of these objectives have been addressed in Courtney et al (2001). This paper will focus on the final two objectives:

- Identifying the difficult problems nurse executives encounter, and,
- Identifying the type of professional development or educational activities that would assist them to manage these problems.

## METHOD

A descriptive cross-sectional postal survey, based on Harris et al's (1998) *Health Service Managers: Roles and Careers Questionnaire* was adapted, piloted, revised and then sent to all public sector Directors of Nursing (180) and Assistant Directors of Nursing (101) in Queensland. The Queensland University of Technology Ethics Committee granted ethics approval.

The questionnaire included sections on demographic information, job description (including roles and responsibilities), career satisfaction, work patterns and professional development needs. The response rate achieved was 52.3%, with 147 completed questionnaires returned. Both the instrument and sample are described in more detail in Courtney et al (2001).

### Data analysis

Quantitative data were entered directly into SPSS for analysis. Information from qualitative items was coded before entry into SPSS. The data were analysed by level of practice, that is Levels 4 and 5. T-tests were performed to identify response differences between levels of practice.

## LIMITATIONS

A questionnaire response rate of 52.3% (n=147) was achieved. There may have been demographic or work related reasons influencing those nurse executives who did not respond. The voluntary self-report nature of this study indicates that the study results should be interpreted with some caution.

## RESULTS

### Sample profile

The majority of nursing executives had been nursing for over 20 years (73% of Level 5s, 81% of Level 4s), and employed in the Queensland Public Health Sector for longer than 10 years (76% of both Level 5s and 4s). Around three-quarters of both Level 4s and Level 5s held a Diploma or Degree. Postgraduate qualifications varied between levels, with more Level 4s holding Post-graduate Diplomas (27.6% of Level 4s; 15.7% of Level 5s) and Masters Degrees (34.5% of Level 4s; 18.0% of Level 5s).

### Roles and responsibilities

The major roles and responsibilities most frequently identified by the nurse executives were financial and resource management, human resource management, operational/executive management, clinical management, professional development of staff, quality assurance, strategic management and leadership.

### Career development activities

The nurse executives in this study were asked to identify the methods currently being used to enhance their career prospects. The majority of nurse executives reported attending skills workshops and conferences, networking and undertaking informal education activities. Approximately half reported undertaking formal education courses. A greater number of Level 5s were undertaking formal education, whereas more Level 4s had been seconded and/or applied for another position, formed partnerships and worked on a research project.

### Professional development needs

#### *Difficult problems for nurse executives*

In order to develop relevant educational and professional development programs for nurse executives, participants were asked to describe the main problems they encounter in their role.

Financial and budget management was most frequently nominated as the most difficult problem, irrespective of level of employment. Personnel problems and a lack of

human resource management skills were also frequently identified. Other problems identified by both Level 4 and 5 nursing executives included heavy workload demands, information technology, management strategies, time management skills, resistance to change and difficulty finding the appropriate staff to employ. Level 5s more frequently identified isolation in decision making than Level 4s, who more frequently identified inequity and the devaluation of nursing input into management committees. The most frequently reported problems are displayed in Table 1.

### **Professional development activities required**

As nurse executives identified specific problems in their role, they were asked to describe how to best address those problems through professional development and educational activities. There were some differences between Level 4 and Level 5 responses. Level 5s identified financial management education and networking more frequently than Level 4s, while Level 4s were more frequently interested in learning about organisational practices, management practices, executive leadership development and identified management attitudes needed to change. A range of activities identified only by Level 5s included: communication skills, acknowledgment of remote nursing and the professional development of Level 3 nurses. Activities required by both Level 4s and 5s included: educational updates, information technology training, supportive structures such as mentoring and human resource management skills. The most frequently reported activities identified are displayed in Table 2.

### **Educational activities required**

Given the many demands on nurse executives, it is imperative that relevant educational activities are developed to address their needs. Hence, participants were asked to identify the type of educational activities best suited to their needs. The nurse executives most frequently identified structured activities in management and information technology training and the opportunity for group support through meetings, networking and sharing information. Interestingly some nurse executives at both levels identified that their current academic education would address their educational needs. Level 5s also identified financial management training, time to practice these activities and the need for the education of Level 3 nurses in management and research.

### **Barriers to professional development**

To enable nurse executives to overcome the problems encountered in their role, it is important to have an awareness of and address any barriers to their professional development. Nurse executives at both levels identified similar barriers: time, the cost of professional development, distance, lack of access and support to attend professional development programs, the difficulty of finding an appropriate course, non-nursing input to senior health decision making and a lack of research funding and research skills. Level 5s identified the lack of relieving staff and workload demands most frequently, while Level 4s most frequently nominated the financial costs associated with professional development. Some nursing executives at both levels of employment (12%) reported they did not have any barriers to their professional development needs.

**Table 1: Difficult problems for nursing executives**

	Level 5 (n=61)		Level 4 (n=39)	
	n	% of cases*	n	% of cases*
<b>Financial:</b> financial and budget management, budget constraints, financial inequity, increased demands on resources	22	36.0	12	30.8
<b>Personnel:</b> industrial relations, counselling	15	24.6	9	23.1
<b>Workload:</b> demands of position, short time frames for change	13	21.3	4	10.3
<b>HRM skills:</b> conflict, behavioural, bullying, difficult staff, access to industrial awards	11	18.0	8	20.5
<b>Information technology:</b> increasing use of new technology, use of the Internet	11	18.0	4	10.3
<b>Management strategies:</b> principles, training	8	13.1	10	25.6
<b>Change:</b> resistance to, organisational, keeping abreast of	6	9.8	4	10.3
<b>Lack of time:</b> time management skills	5	8.2	6	15.4
<b>Lack of appropriate staff to employ</b>	4	6.6	2	5.1
<b>Isolation in decision making:</b> no peer support	4	6.6	1	2.6
<b>Inequity:</b> lack of acceptance, not viewed as an equal member of the executive team, discrimination	3	4.9	6	15.4
<b>Devaluation of nursing input:</b> domination of doctors and males in senior committee positions	2	3.3	5	12.8

\* Multiple answers were given to this item

Table 2: Professional development activities required

	Level 5 (n=50)		Level 4 (n=29)	
	n	% of cases*	n	% of cases*
<b>Financial management:</b> budget development, support	18	36.0	4	13.8
<b>Education updates:</b> in-service, small group updates, nursing forums	15	30.0	9	31.0
<b>Information technology training and support</b>	11	22.0	4	13.8
<b>Networking:</b> more formal opportunities, statewide networking, information networks	10	20.0	2	6.9
<b>HRM skills:</b> managing difficult people, conflict management, counselling, mediation training, industrial relations	10	20.0	5	17.2
<b>Communication skills</b>	4	8.0	0	0
<b>Acknowledgment of remote nursing</b>	4	8.0	0	0
<b>Organisational training:</b> guidance, support	3	6.0	5	17.2
<b>Supportive structures:</b> mentoring	3	6.0	2	6.9
<b>Professional development for Level 3's</b>	3	6.0	0	0
<b>Management:</b> skill development, change management, new management practices	1	2.0	4	13.8

\* Multiple answers were given to this item

## DISCUSSION

This paper has provided a profile of the professional development needs, educational requirements and barriers to professional development for public sector nursing executives in Queensland. In this climate of change, it was imperative that nurse executives' professional development needs were identified to enable programs to be developed and implemented to assist them meet changing demands on their roles.

### Roles and responsibilities

The broad range of roles and responsibilities identified by nurse executives in this study are consistent with reports in the literature of greater spans of control and expansion of the nurse executive role (Anderson 1993; Sanford 1994). The major roles and responsibilities were closely tied in with their reported professional development needs, in particular the most frequently identified functions of financial and resource management, human resource management, operational management and professional development of staff. Skills in these areas are seen as crucial for the development of competent and effective nurse leaders (Misener et al, 1997).

### Professional development needs

Financial management, human resource management, information technology and organisational and management training were the topics most frequently identified by all nursing executives as areas where they have professional development needs. These subjects are in accordance with the competencies for nursing leadership identified by Misener et al (1997): development

of strategic and business plans, using information systems for management of human and financial resources, human resource skills, conflict resolution and interdisciplinary team functioning.

Several authors have recommended the inclusion of postgraduate business/administration education in the development of effective nurse executives (Misener et al 1997; Aroian et al 1996; Buerhaus et al 1996; Sanford 1994). Within the Australian context, graduate nursing education has focused primarily on specialist clinical skills and knowledge. There has been a gap in Masters of Nursing degrees in the areas of leadership and management skills, including the topics identified in this study such as financial management, human resource management, information technology and organisational training.

All nursing executives in this study, irrespective of level, identified structured educational activities in information technology, financial and budget management and general business management as necessary for their professional development. It is therefore recommended that clinical leadership and management skills be included as core units within Master of Nursing courses in order to prepare Registered Nurses for Level 4 and Level 5 executive positions. An example of a unit of study recently introduced at Queensland University of Technology in the Master of Nursing course to address the existing gap in nurse executive educational preparation is outlined in Table 3.

Specific content of shorter courses/seminar activities could include: calculation of full-time-equivalents and costing staff establishments, Diagnostic Related Group (DRG) activity analysis, utilisation reviews using

**Table 3: Clinical Leadership and Management Unit outline**

Major topic	Content
Introduction to Leadership Management	Environment of management and leadership History of management/ dimensions of management Leadership - transactional vs transformational leadership
Planning	Planning process/strategic vs operational planning Magnet hospitals/SWOT analysis Organisational goals/goal setting
Organising	Organisational structures/culture Staffing and scheduling Financial management/Casemix and nursing
Human Resource Management	Staffing the needs of the organisation Developing human resources Performance appraisal/Legal aspects of HRM
Directing and Coordinating	Leadership/empowerment/motivation Conflict management and negotiation Communication
Quality Management	Total Quality Management Barriers to TQM Quality control
Control Measures	Evidence based practice and standards Clinical pathways Clinical audits/defining and measuring clinical outcomes

information technology, business planning and project management techniques, report writing, flexible budgeting and variance analysis, management of human resources within organisations and computing and information technology.

Level 5 nursing executives also recommended leadership and/or assertiveness training and research training for Level 3 nurses. Both Level 4s and 5s nominated the opportunity for group support, meetings, networking, and information sharing. Although some studies have identified mentorship as an important avenue for professional development (Dunham-Taylor et al 1993), only 6% of participants nominated this activity.

### Barriers

Barriers reported by all nursing executives to meeting their professional development needs were the financial costs associated with professional development and inadequate district or regional support, time, and relieving staff to enable them to attend available professional development activities. A small number of nursing executives from each group reported they had no barriers to meeting these needs and found their role exciting. Recognition by the health care industry of the importance

of the professional development of nurse executives for effective leadership is essential to overcome these barriers.

The findings of this study were confirmed in a recent report from the Queensland Government Ministerial Taskforce on Nursing Recruitment and Retention, who found there was a need for a nursing orientated business planning model covering workload, skill mix and patient dependency measures and professional development needs. At the time of writing, the 'Business Planning Framework: Nursing Resources' had been developed as an outcome of the Taskforce Recommendations. Queensland Health has also supported the development of an Executive Development Program, currently in the planning stages.

### RECOMMENDATIONS

- Identify the specific financial management needs of nursing executives through further research and develop financial management educational programs to address these needs.
- Include core units on leadership and management skills within Master of Nursing degree courses to prepare Registered Nurses for Level 4 and Level 5 executive roles.
- Promote and support nurse executives' attendance at career enhancing activities such as workshops on:
  - computing and information technology,
  - DRG activity analysis and reviews using information technology,
  - calculation of full-time-equivalents and costing staff establishments,
  - business planning and project management techniques,
  - flexible budgeting and variance analysis, and,
  - management of human resources.
- Replication of this research on a national scale.

### CONCLUSION

Financial management and budgeting, human resource management and information technologies are the areas of professional development most in need. Support and training in these areas were deemed important professional developmental activities. The most frequently reported barriers to professional development were the lack of relieving staff, inadequate time, financial cost and inadequate district manager and regional support to enable access to professional development programs. Recommendations are to: identify the specific financial management needs of nursing executives through further



research and develop financial management programs to address these needs; include core units on leadership and management skills in Masters degree programs to prepare nurses for Level 4 and Level 5 positions, promote and support nurse executives' attendance at career enhancing activities such as workshops on information technology, business planning and human resource management; and replication of this research on a national scale.

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# THE EVERYDAY REALITIES OF THE MULTI-DIMENSIONAL ROLE OF THE HIGH SCHOOL COMMUNITY NURSE

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## ABSTRACT

The traditional role of the high school based community health nurse has changed considerably over recent decades. This article describes a qualitative study, in which nine community health nurses from eight different high schools completed a diary of the interventions and events during the course of two working days in order to identify the dimensions of their role. A short demographic questionnaire was also completed by the nurses and included two open-ended questions concerning their main professional issues and concerns. The researchers sought verification of the interpretation of the data through a focus group interview with the high school nurses. Data analysis indicated that the role of the high school community health nurses (CHN) consisted of seven categories. These were provider of clinical care, counsellor/mediator, advocacy and support, liaison/referral, health promotion/education and resource agent, and professional management and research role. The findings highlight the complex and demanding aspects of the role of the high school nurse and articulate the importance of describing the contribution of such practitioners in to the promotion of health among adolescents.

## INTRODUCTION

Current adolescent health problems such as drug and alcohol abuse, injury, bullying, violence, behavioural issues, teenage pregnancy and mental health problems pose a challenge for health professionals (Hawkins and Catalano 1990). There is agreement, however, that health education and health promotion within a primary health care framework is essential to address these adolescent health needs (Hawkins and Catalano 1990; Wainwright et al 2000). High schools are an appropriate site for health service delivery to adolescents and currently high school community health nurses are ideally situated to positively influence adolescent health. As primary health care practitioners, nurses are able to provide primary and secondary prevention, offer support, guidance, counselling and health information (Pike and Forster 1995).

Over recent decades the role of the community health nurse, working in a high school context, has become more sophisticated. The expansion of the role is the result of changes in the complexity of the health problems faced by current student populations (Kozlak 2000). Although community health high school nurses work to meet the needs of students, teachers, parents and the larger community, often little recognition or understanding of the advanced practice role that they perform is acknowledged. Moreover, the different dimensions of the role are not clearly defined. Without a clear perception of the nature of the role of the high school nurse, the tendency to see the nurse as someone who is easily replaced is tempting. This is particularly so when there is a steady decline in government funding for schools (Morgan 2000) and an increasing demand from a cost-conscious health care system focussing on accountability and demonstration of effectiveness of outcomes (Denehy 2000). It is important to emphasise that we have reached a point where the

current involvement and responsibilities of community health nurses in the provision of health care for adolescents cannot be ignored as a valuable resource. Thus, the importance of gaining a clear insight into the school health nurse's role is timely considering the threats to ever decreasing services.

## BACKGROUND

A qualitative study was proposed to investigate the dimensions of the school nurse's role, and thus a preliminary review of the literature was conducted. This review suggested that the role and focus of school health nurses has become extensive in recent years and now involves such functions as primary care provider, manager and educator in addition to more typical nursing responsibilities (Proctor et al 1993). In a quantitative study that aimed to delineate the diverse roles and responsibilities of 165 school nurses in the United States, participants identified six to nine major areas of responsibility. These included direct services to students and staff, provision of health education, teacher in-service, health screening, counselling, clerical work, co-ordination and policy making (Periard et al 1999, Knecht and Birchmeier 1999). Similarly, Pavelka et al (1999) surveyed 78 practising school nurses and found that they performed a very large number of nursing interventions (114) varying from month to month. The authors concluded that school health nurses needed an extensive knowledge base for their complex and broad nursing role.

Institutional support for high school nurses needs to be considered, as an ambiguous environment is rich for potential conflict and high stress (Calkin 1988) in the enactment of the nurses' role. Economic constraints may play an important part in the performance of the role of the high school nurse. For example, when economic resources diminish, it seems feasible to replace or delete school nurses and related services because they are not perceived as being directly related to client educational outcomes (Periard et al 1999; Thurber et al 1991). The most striking example of this funding policy is the decline in public spending on schools (Morgan 2000) that is placing pressure on such services. Tension is often experienced as a result of the mobilization of resources away from the school nurse toward less costly options.

School health nurses are being challenged to closely examine their role and, consequently, legitimise their actions. It is expected that competent high school nurses should be able to measure expected outcomes. However, there is some reluctance by nurses to measure outcomes. This reluctance may be as a consequence of their poor evaluative skills, but more often than not, it is because evidence of effectiveness of interventions is not available in the short term (Denehy 2000). With primary preventative activities the outcomes may not be evident

until some years after the intervention, thus it is difficult to measure the value of their contribution to the student's health. Although these facts present a challenge to all community health nurses, they are often more difficult to overcome when the context of the nursing care involves the school population. Community health nurses who work in the high school context have competing demands from parents, teachers, health professionals and others, and face enormous pressure in their day-to-day work as they cater for the health needs of large numbers of students. However, there is little research that has described the different dimensions of the role of the community health nurse in this environment. Thus, the first step in defining the school health nurse's role is to seek a better understanding and articulation of the way in which nurses seek to contribute to the health of school children.

Consequently, this study seeks to uncover the role of the community health nurse working in a high school context. It is anticipated that this knowledge, coupled with an appreciation of the difficulties faced in this demanding context, will contribute to a better understanding of what forms the practice of the high school nurse. Furthermore, the results of this study can be used to develop, implement and evaluate educational programs specifically related to the school health nurse.

The aim of this study was to identify the dimensions of the high school nurse's role. Specifically, the study sought to provide a detailed description of the nurse's practice, activities and involvement in the school community.

## METHOD

This inquiry was an interpretative analysis of the written diaries of a group of nine community health nurse study participants. A purposive sample was utilised. The logic and power of purposive sampling lies in selecting information rich cases (Morse 1989; Patton 1990). The study was conducted between September 1998 and April 2000. The research sought to identify and describe the role of community health nurses working with high school children. The choice of the method was determined by the desire to gather descriptive data from the participants using their own words when describing their roles, activities and decision-making processes. This method gave the researchers the opportunity to gather data from the participants' every day working environment and led to an examination and description of the nurses' roles.

### Data collection

Ethics approval was obtained from the Health Service and approval to conduct the study was obtained from the co-ordinator of community health nursing of a selected health service in Perth, Western Australia. Information

concerning the study was provided to the participants by two of the research team. These researchers were well known to the community nurses in their research and staff development roles within the health service. The participants were informed at a clinical nursing meeting of the aim, purpose and benefits of the study and given information concerning the format of the study. They were informed before the commencement of the research that their participation or non-participation in the study would not affect their employment in any way. It was also communicated to the nurses that no potential risks were envisaged or anticipated and that while nursing management would receive a copy of the final research report, no individuals would be identified and confidentiality was assured. Nine community health nurses, who worked in eight different high schools in the metropolitan area, voluntarily consented to participate in the study.

The study design included the participants completing a detailed diary of interactions and events that occurred during the course of two working days. A focus group was organised to verify the data and participants were also asked to complete a very short questionnaire outlining demographic characteristics and two open-ended questions concerning their main professional issues and concerns. The nurses were allocated the specific days they were to record their nursing practice and daily activities in the school. This direction ensured that nurses did not bias the recording by choosing either their quiet or busy days. Diaries were hand written by the participants then transcribed and checked by the researchers. The data obtained from some diaries were relatively rich but others were brief and contained superficial information.

The focus group was held following the initial interpretation of the data and included seven of the nine participants. The interview was facilitated at the local community health centre by two of the research team to give participants an opportunity to review the researchers interpretation of the data. They were asked to comment on the accuracy of the information presented to them. The participants were also afforded the opportunity to comment further on the complexity of their role in high schools and discuss their main activities within the school.

To ensure adherence to ethical research principles, the diaries, typed transcripts and questionnaires of each of the participants were placed in a locked filing cabinet when not being analysed. Each participant was assigned a code number, as was each diary. All of the diaries, transcripts, information about the participants and codes were kept separately in a locked draw to ensure confidentiality of data.

The participants ranged in age from 42 to 55 years. Furthermore, their educational level ranged from hospital certificate to bachelors degree in nursing. All participants had completed various professional educational short

courses related to their area of expertise and, at the time of the study, two were enrolled in professional education courses. The remainder had no immediate desire to return to study.

The nurses' experience in working with high school children ranged from two years to 16 years and all were involved in high schools with student numbers ranging from 800 to 1390. Two nurses were employed in the same school, whereas the rest indicated that they were the only registered nurse working in the school.

## Data analysis

Transcripts of the nine diaries and the focus group were the sources of data analysed by the researchers. Data analysis based on the diaries was supplemented and validated by the information gained during the focus group. These data were analysed following the standards of qualitative data analysis procedure, that is: coding, finding categories and clustering (Streubert and Carpenter 1999). Diaries were read line-by-line and significant words and phrases were identified. Following this procedure the major thrust or intent of the diaries was conceptualised (Field and Morse 1990). The next step was clustering these concepts and comparing them again with each other to ensure that they were mutually exclusive. Finally, a list of categories was created.

Following this interpretive analysis, the written interpretation of the data was sent to the participants to enable them to read and consider the findings prior to the get-together. The focus group consisted of the researchers and seven of the nine participants of the study. This interview was one way in which the researchers and participants could share information and verify data.

During the focus group, the researchers shared the preliminary research findings with the group and sought verification of the interpretation. As a result of this discussion a few issues were clarified and the findings refined. Participants suggested changes in wording to more accurately reflect their roles. The discussion included open-ended questions being asked of the participants, promoting an environment that was conducive to the sharing of experiences.

All of the participants were acquainted with each other prior to the study thereby creating a relaxed atmosphere. Field notes were taken during this session. Furthermore, following feedback from this group, the seven major categories were revisited and reordered.

## Trustworthiness

Trustworthiness of the data was ensured by member checks. Data were presented to the participants for information and verification. An audit trail was maintained to document all aspects of the study, data analysis and description of the findings. In addition, journaling was

used throughout the analysis, that is, the researchers kept diaries of their thoughts and ideas related to the study. This assisted in the analysis and ensured a thorough and trustworthy approach to the research.

## FINDINGS

Analysis of the data indicated that the role of the high school community health nurse consisted of seven categories. These were provider of clinical care, counsellor/mediator, advocacy and support, liaison/referral, health promotion/education and resource agent, and management and research. Although these categories appeared as separate and individual items, it is important to emphasise that each component of the high school nurses' role was enmeshed with other components. For example, the category of 'provider of clinical care' involved the nurse not only delivering 'hands on' treatment but also included counselling, referral, liaison, health education and the management and research role. Furthermore, the findings themselves are organised in such a way as to allow the data to speak for itself.

### Provider of clinical care

Analysis of the data revealed that although the provision of care focused on the student population, frequent references to other school personnel were found. For example, when the client was a member of staff a participant wrote:

*Part of [the] school nurse role is to support staff members as well as students...*

Both student and staff clients that the nurses encountered presented with a variety of problems including such complaints as headaches, nausea and vomiting, hay fever, tiredness, dysmenorrhoea, asthma and respiratory symptoms, obesity, hypertension, abdominal pain, lacerations, sports injuries, occupational health and safety, and health education issues. Students also presented to discuss mental health issues such as stress, bullying, trauma, drug and alcohol problems, family conflicts, pregnancy concerns, depression, sexual abuse or for attention deficit disorder medication. This list is not exhaustive but represents the varied array of student and staff health problems for which the high school nurses provided care. An example of the reasons clients presented to the nurses is reflected in the following extract:

*Mr A presented with abdominal pain and vomiting and requesting something for it. Mr A is a regular in the health centre - was previously a heroin addict. He is 15 years old and ceased using [heroin] two-three months ago.*

Participants demonstrated in various ways that providing care was central to their role. Nurses provided the initial assessment and care, making a referral, when

necessary, to a doctor or the most appropriate professional required for the situation. For example:

*Trauma assessment of a 15-year-old girl who has been hit in the mouth by a cricket ball. Initial assessment; girl shocked - reassured, frightened - facial damage - reassured and told extent of injury to her face. Given first aid. Parents advised to arrange dental appointment today as teeth have been pushed out of alignment.*

Nursing assessment encompassed the collection of both objective and subjective data and provided the basis for the provision of care. The high school nurses' ability to assess their client group and to observe individual situations, was essential to enable them to fulfil their role. Furthermore, the data also revealed that as part of the nurses' decision-making process all nursing assessments and interventions were carefully evaluated. An example of the assessment process is as follows:

*Sensible year 10 [student]. [He has] been to [the] health centre twice in three years. Looked unwell. Pulse and temperature satisfactory. Nil neck stiffness. Nil blows to head. No improvement after rest. Couldn't tolerate fluids...*

Another participant noted:

*14-year-old girl escorted to the health centre by concerned friends after she had fallen down and hit head against a metal pole. Neuro assessment done [basic only] as girl observed on presentation, walking, smiling, no LOC [loss of consciousness], no skin breaks, bruise but feeling giddy and with headache. Observed while resting 1/24. Presented as vague, uncertain, wanting to rest, pale: questioned by me for her present state and girl observed that she had previous falls recently and usually didn't realise she was falling - Blood pressure checked and normal. Also stated she has been having lots of tests at doctors. Vague about why. Back to class after sleep, food and reassessment.*

On completion of the initial assessment the high school community health nurses implemented many and varied nursing interventions such as the administration of over the counter (OTC) medications after discussion with parents. As mentioned earlier, the provision of care involved health education and health promotion activities that were conducted with all members of the school community. The following participant wrote:

*I presented him with a range of common triggers for a headache [low blood sugar level, dehydration, injury, fever] and explained that by identifying the possible trigger[s] and dealing with them was the best way to lose the pain. I explained that paracetamol does not generally do anything to stop the cause of the pain but is designed to try to break the pain message...*

Significantly, injuries were a usual complaint. For instance, data revealed that participants were frequently

taking care of students with hand or knee injuries due to falling and sport activities. The delivery of first aid, therefore, was an aspect of the nurse's role but reflected only a small component of their work. Data revealed that first aid was conducted following an individualised nursing assessment, with the nurse's description of their decision-making revealing the use of advanced nursing skills in the delivery of care. The following excerpt demonstrated the delivery of first aid:

*...presented with pain and swelling over lateral side of left ankle - an old injury aggravated by stair climbing... Ice pack applied for 20 minutes. Ankle strapped. Advised to return to physiotherapist...*

Although students presented to the centre with different complaints, such as the ones previously mentioned, headaches were a frequent concern. A simple headache alerted the nurse to the necessity to observe the student further. The students often used a headache as a reason to attend the health centre. Participants also reported that students often attended the health centre when they wanted to be reassured, to ask questions or just simply to chat. Participants indicated that they used this opportunity to assess, treat and advise students regarding their complaint. One participant reported:

*The student did not appear too distressed by his headache. It was appropriate to spend time discussing headaches, their causes and management and the appropriate use of analgesics.*

As a provider of care the high school nurse was required to have advanced skills in assessment, intervention and evaluation of nursing care with regard to a variety of health issues. It is also evident that the concerns of the school population were varied and across both the physical and psychosocial domains.

### **Counsellor/mediator**

One of the major components of the nurse's role involved counselling. Many clients attended the high school nurse with problems and concerns related to their well-being. The participants showed interest and concern and listened to the problems of their clients and offered support and understanding. For example, one participant wrote:

*Mary [pseudonym] and I have a good rapport with each other. I have known her since primary school, which is probably why she came to the health centre. She is quite able to identify her feelings and associate them with anxiety rather than physical illness.*

Another participant indicated that he had a 'general discussion [with a] year 12 student and [his] mother regarding a [chronic] condition'. He also indicated that this was an ongoing support counselling process where the discussion focussed on 'hospitalisation over holidays,

ongoing management and future conditions'. Moreover, the data revealed that the nurses were dealing with time consuming and complex situations. The following account illustrates this point:

*Because I have built up a rapport with Mr A over the past two months, I knew there was more to it. Having then established what the cause of the problem was, it was then necessary to take steps to try and avoid it happening again. Mr A does not want to use heroin again but because he was an addict, drug taking had become a lifestyle for him and it is necessary to try and work through with him to enable him to forge a new lifestyle. As part of this lifestyle change, this camp is a big part. It was necessary to still encourage him in this case. He got 'cold feet' and decided not to go.*

Another participant wrote:

*Miss C came to see me a few weeks ago with depression ++ and some suicide ideation. I had managed to see her today to see how the strategies we had put in place were working.*

The counselling skills, of the high school community health nurses, were not only available to the student population but also to the teaching staff. The nurses' clients came from all levels of the school population. Often members of the teaching staff approached the nurse to discuss personal issues. One participant wrote:

*Administrator requested consultation with me regarding a staff member experiencing stress attending to family duties of looking after elderly sick relative and her job responsibilities. My ongoing counselling of [the] staff and her inability to change [was] stated ...I ascertained that the administrator also was aware of her current problem and advised that [the] staff [member] required professional counselling.*

Other concerns expressed by the participants were counselling issues related to bullying, conflict with parents, family dynamics, drug abuse, and depression. Participants expressed their dismay at insufficient resources available for services involving psychosocial issues. For instance, one participant stated that the psychologist accepted only appointments and relied on the nurse to fill the gap. The nurse was required to have an open clinic together with a heavy clinical workload. This was aggravated by the constant interruptions during counselling sessions.

### **Advocate and support**

The role of advocate involved support and assistance of the students in varied circumstances including coping with classroom situations and supporting current health promotion initiatives such as an immunisation program. Data revealed that this component of the high school nurse's role was intertwined with all other aspects. For

example, a major part of the role of liaison was that of advocate. Although nurses reported to the teacher about students' physical health often they acted as an advocate of students. The advocacy role involved talking to others on behalf of a student, explaining difficult situations and 'being there' for a student. As one participant stated:

*Whilst working closely with the members of the school administration, year coordinators and class teachers as a school nurse I am aware that my main role is an advocate for the student. Although it is necessary to share information I practice 'need to know' sharing.*

The supportive aspect of the role referred to having time to listen to students or making themselves available. One participant wrote:

*Inflamed swelling. Have only seen it when opened by student. I dress it but he takes it off and comes back to the health centre, sometimes three times a day, always on class time. Student has a history of faecal incontinence, transferred out from last school because of bullying related to same. Gossip has carried his history to this school. Recently another student has started telling him he stinks. The student comes to me to have confirmation that he does not smell. It gives him confidence to ignore or resist as he sees appropriate...I remain available...*

Furthermore, one participant indicated that the major concern for her work was getting the teachers to understand youth issues and gaining their support. Another indicated that the need to keep parents and guardians well informed caused difficulties because of time constraints.

### **Liaison/referral**

A liaison/referral aspect of the high school nurses' role was grounded in a broad and specialised knowledge base and was directed at all members of the school community including students, parents, and staff members. The role of liaison focussed on the provision of specialised knowledge to help in the care of the school population. Intrinsic to this role was the necessity for the nurses to contact and liaise with a variety of agencies and health care and community professionals inside and outside the school. This included general practitioners, independent counsellors, adolescent health services, mental health services, family planning, Cancer Foundation, Asthma Foundation and the Communicable Disease Control Branch of the Health Department. For example one participant reported:

*Phone call to Communicable Disease Control Branch to discuss problems with collecting immunisation history from our overseas students.*

Another participant stated:

*Phone conversation with [the] Cancer Foundation re: speaker for a parent's morning tea.*

The high school community health nurses worked closely with family members, medical practitioners, health services, the school's chaplain, counsellors and teaching staff, as well as other community support groups. For example, one of the participants of this study indicated:

*[I had a] phone call from a parent concerned about the local drug group meeting held yesterday.*

The same participant added:

*[Had another] phone call from [a] health education teacher wanting some information on drugs.*

Another example of liaison function within the role:

*...I discussed this with Dr Smith [pseudonym], head of adolescent ward and I suggested [that] a staff member ... could do this...*

The diary of another participant indicated the following:

*[I had a] phone call from the year 12 coordinator to set up an appointment for a year 12 girl who is having problems with stress.*

School nurses often spent time reporting situations derived from their job to the principal or deputy principal. Several notes revealed that participants discussed students' situations with the teachers and the school administrator. For instance one participant stated:

*I am on a student services committee. One of the roles of this committee is to follow up with the students who are at academic risk usually due to non-attendance. An example of one of these is one student who has missed a lot of class, so I interviewed her and found out that she had previously been diagnosed with depression. Had been on medications but had ceased that herself and now refused to see any counsellor. With this in mind, we worked out a plan where she would come and see me at regular interviews to work out on strategies to help her attend school and deal with her depression as well. The depression was largely relational and there was polydrug use involved as well as some bulimia. It is an ongoing situation with unfolding dramas almost weekly. However, for the most part, she is attending school.*

Some examples of the specialised problems the high school community health nurses encountered were family conflict, drug use and sexual abuse. Other areas involved were the assessment and management of students who were suicidal and making nursing diagnoses of students who were suffering states of depression and panic attacks. As mentioned earlier, the nurses were always willing to refer clients to a more appropriate resource if they deemed their client's problems were outside their scope of practice. This person could be a general practitioner, psychologist, another staff member or the principal. One participant explained this:

*I wanted to learn more about her view of the world whether she is already linked to a counselling service. I identified parent-child conflict, problems with peers at present as well as the additional stress of changing schools mid-term. I clarified what counselling services she has or is using ... I will notify her year coordinator and our school psychologist of her difficulties so we can monitor progress.*

This liaison role required the nurses to conduct follow-up interviews with the students, their families and professional bodies outside the school. In some cases, the high school nurses had to organise home visits in order to liaise with parents, to assess the home environment and to provide support to the student. Other activities were related to making appointments and discussing areas of concern, such as student problems and occupational health and safety issues, with teaching staff. As mentioned previously, liaison with outside sources such as general practitioners, psychologists and community resources was an important component of participants' work.

The following example illustrates this point. A participant cited a recent case of child abuse and suicide ideation. Her immediate role was to assess the child and ensure his safety. Then the necessary arrangements had to be made to discuss the situation with the parents. Furthermore, she contacted the social worker from the adolescent psychiatric services. The situation was reported and discussed with the school principal. The same participant added that she had to discuss the student's situation with the psychologist. Following this, she organised a family meeting to discuss the admission of the student to the hospital.

The role of liaison meant that the school nurse had to respond to requests for help and advice. Furthermore, the nurses' needed to discuss issues with teaching staff, organise appointments for the students, conduct home visits or interview students. Frequently these participants had to refer these cases to other professionals.

### **Health promotion/education and resource agent**

The high school community health nurses acted as a resource agent for the school community. The participants mentioned utilising resources such as the QUIT program with clients and demonstrating how they could be used. One participant stated:

*Sixteen-year-old girl requested support and help to quit smoking... discussed her motives to give up. Went through QUIT package with her. Confirmed who her QUIT buddy will be.*

Another aspect of the health promotion role involved the organisation of health promotion activities within the school to maximise health department campaigns. The high school nurses were also a resource agent at the school administrative level where they attended student services

meetings. Most of those meetings involved the planning of the utilisation of health resources to enable students to reach both their educational and personal potential. Participants discussed this in the following ways:

*Present at health committee meeting as chairperson. Discussion took place [nine present] ... 2. Invitation of guest speaker for staff on skin cancer. 3. Asthma promotion...*

and:

*Case conference with parents of year 9 girl, psychologist, deputy, year coordinator and myself [nurse] and district social worker...*

Health education involved the nurse in preparing teaching sessions for high school students about topics relevant to their health. Participants gave examples of the topics discussed with the students. These included areas such as smoking, eating disorders, grieving, use of contraceptives and drugs. This aspect of the role also involved sharing health information with teachers, students and parents. Moreover, health education meant keeping up with new information and preparing relevant educational material. Often health education activities were incorporated on a one to one basis with the provision of care. However, it was also reported that some teachers had difficulties with the role of the nurse in a high school. For instance, one participant wrote:

*Teachers have difficulty seeing nurses do more than first aid. In particular, I spoke [at the teachers' meeting] on the role of the nurse in a high school and what we can help with.*

A few participants mentioned their concern regarding the level of motivation of health promotion activities among students. One participant identified the overloaded students to be most at risk. For some, it was a challenge to find ways of motivating students to take care of their health.

### **Management and research**

These aspects of the role included several activities that were an intrinsic part of the role of the high school community health nurse. It refers to the components of professional accountability and responsibility. The management and policy role covered aspects of administration such as documentation, time management, conflict resolution, policy development and implementation. In addition, attending staff meetings as well as participating and contributing to those meetings was also an important element. The data indicated that the school nurses were expected to participate and contribute in their position as a member of the school student services meetings and were actively involved in the development of school policies. One participant stated:



*School does not have a drug policy. I have negotiated with [the] principal a team to write one. We are at the end of a four-month writing process. Our draft has been circulated to teachers for comment. This meeting is to review the feedback and adopt it if appropriate...*

Furthermore, it is noteworthy to indicate that some participants, as part of their role, were involved in research activities. The purposes of these activities were to find information about relevant topics affecting the school population. Such topics included minor sports injuries, back care and community needs assessment. For example one participant recorded the following:

*I am part of an inter-agency group, which conducted a survey of residents...last year. [The] key findings were that there is precious little for the youth to do in this area outside school...I see community development as part of my role as health educator...*

## DISCUSSION

There is little doubt that the high school community health nurse has a complex and comprehensive role to fulfil. As described by Pavelka et al (1999) school nurses in this study care for clients with a wide range of health related needs. Thus, to work in this specialty area requires an extensive knowledge base and advanced nursing skills to enable the provision of a complex array of nursing interventions.

Traditionally, the role of the school nurse involved the control of communicable diseases, keeping records and providing first aid (Kozlak 1992). However, although this is still a function of school health, the results of this study demonstrate that these nurse participants perform many and varied additional activities while fulfilling their role.

The current study, in demonstrating the seven categories of nursing practice; provider of clinical care, counsellor/mediator, advocacy and support, liaison/referral, health educator/health promoter and resource agent and management and research role, supports Proctor et al's (1993) summary of the extensive role of the school health nurse.

Similarly, the role of the high school nurse reported by Periard et al (1999) is also supported. Indeed today, the high school nurses' role incorporates service provision for both students and staff, health education, teacher in-service, health screening, counselling, clerical work and a valuable contribution to school decision-making and policy making.

The results of the study confirm previous research that described school nurse's activities according to five major categories. The survey found activities were related to physical care, facilitation, instruction, administration and clerical work (White 1985). Replication of this study by

Thurber et al (1991) supported the initial findings. However, the authors argued that the inability of school health nurses to clearly document and articulate their role to others, resulted in misinformation about their valuable contribution. This current research shows that the role of the high school nurse is multifaceted and the researchers consider that it is essential that the complexity of the role be understood, so that diminished economic resources in schools does not lead to the misguided belief that others can fulfil the nurses' role.

The central role of all nurses is as a provider of clinical care, therefore, it is not surprising to find that this aspect of the role emerged as a strong category. In providing care nurses essentially assess the client, provide care, evaluate their care and make referrals.

The findings of this research study emphasises the need for school nurses to be well educated in order to possess a broad knowledge base and a high skill level. This knowledge base and skill level includes training and education in counselling, high level communication skills both written and verbal and advanced assessment skills. This finding is consistent with earlier studies that confirm that school nurses must be current in their diagnostic and technical skills concerning an array of issues, because students come to school with complex and varied health problems (Kozlak 2000). Furthermore, the finding is also supported by a study conducted by Calabrese et al (1999).

The researchers found that school nurses spent a considerable amount of time caring for and educating children, their families and staff. Given the findings of the current study it is time school nurses were acknowledged for their expertise, skill level and advanced practice role within nursing.

Another significant finding of the current study is the role that high school community health nurses play in counselling students and members of the staff. On some occasions the students and staff faced dramatic life situations involving the well being of a range of people. The nurses spent some time listening to the clients and offering support and understanding. This finding is supported by the work of Nelson (1997) who claims that among the challenges confronted by school nurses is the need to listen to adolescents who are often searching for adults whom they consider to have special knowledge.

Earlier studies also support the concerns reported by school nurses regarding issues affecting high school children. Shelton (2000) cites the work of Bryant et al who found that neglect, abuse, poor parenting skills, family dysfunction and substance abuse predispose children to poor life outcomes. These are all situations frequently encountered by the nurse.

The findings of the current study parallel those of Bradley (1997), who claimed that school nurses make a positive impact on patterns of health behaviour. However,

she states that although nurses provide health education to clients, the role of school nurses in health education is less well defined. Bradley continues, saying that health education is part of a comprehensive school health program and that health promotion is a responsibility shared with other school staff to ensure that the school environment is safe. The participants of this current study emphatically claim that their role was in health promotion and not only in health education.

Bradley also proposes a specific advocacy role. She claims that the school nurse has an advocacy role in health education that can be achieved by participating in committees and sharing data related to health behaviours and needs of students. This role can be extended to the community at large and in particular being involved in activities at the community, local, state and federal level. This proposition is supported by an earlier study that claimed that advocacy in nursing is political (Orb 1993). In this current study, the role of advocacy is contained within the boundaries of the school and the relationship of the high school nurse with their clients, parents, staff and other health professionals.

Furthermore, although the various roles of the school nurse emerged from the data as individual categories these roles were usually interrelated and multifaceted. For example, several nurses reported that when they were providing clinical care, they were at the same time involved in health education or making referrals to other health care professionals.

Moreover, in the focus group session, participants spoke at length of their involvement in conflict resolution and mediation. Often this mediator role overlapped with their counselling role. For example, many participants talked of their experiences in helping students, trying to mediate and counsel them at the same time. In some of the cases, the enactment of this role occurred with junior high school students, making the task very difficult because of their immaturity.

The findings of this current study indicate that various high school nurses reveal extensive experience with students who had a high suicide risk. These findings are of particular importance when Leane and Shute's study (cited in King et al 1999) found that Australian high school teachers had a low knowledge of how to recognise students at risk of suicide. With these findings in mind, the school nurse has a significant role in the development of educational programs for teachers.

### Limitations of the study

Although this study was limited to a small group of community health nurses, it does indicate the value of the participants' contribution to the care of high school

students. The findings of this study cannot be generalised. The researchers recognise that this study represents a snapshot of one group of high school community health nurses in the Perth metropolitan area.

## CONCLUSION

The main goal of the present study was to examine the various aspects of the role of the high school community health nurse and describe the activities derived from their practice. The findings indicate that high school nurses have several components to their role which they perform everyday in their work. Often these roles overlap and are difficult to identify as one dimension. Nurses play a key role in interacting with students, teachers, parents and other bodies outside the school. They participate in health promotion and education activities as well as in the provision of care. Moreover, they tend to fill the gap when resources are not allocated for other health care professionals. The large number of the student population in the every day reality of the job results in a heavy workload.

This study also highlights the complexity and demanding aspect of the role of the high school nurse and articulates the importance of such practitioners in the promotion of health among school children. It indicates that community health nurses are practising in an area that requires the application of advanced knowledge and skills. It is hoped that this study provides insight into the demanding role of these nurses and demonstrates that high school community health nurses deal with health issues that are complex in nature. The current role of the high school nurse does not only focus on the students but also on their families and teachers. The descriptions of the role provided in this study substantiate the contribution of the high school nurse to health care and legitimises the importance of the role. This study demonstrates that the role of the high school nurse should no longer be undervalued, as nurses make a substantial contribution to the health of the community. Therefore, attention should move from an emphasis on cost-savings, and focus towards the effectiveness and high quality of care provided by community health nurses in high schools. Although this study serves only as an introduction to the role of the high school community health nurse, it does highlight the different dimensions of the role and its significance in contributing positively to educational outcomes by maintaining and promoting student health. It is important to claim that the roles carried out by high school nurses are consistent with the demands of the student population and the social context of the schools.

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# LIVING WITH LOSS: DEMENTIA AND THE FAMILY CAREGIVER

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## ABSTRACT

Two focus group interviews with 15 relatives, investigated family caregivers' perceptions of having a relative in a dementia care unit. Data analysis revealed the significant theme of living with loss. The results demonstrate that the burden of care giving creates growing stress and tension that continues even when the family member is placed into a residential care setting. The findings suggest that health professionals must be prepared to assist family members with the anticipatory grieving of losses that accrue with the changing relationship with the relative and health care staff. Furthermore, there is a need to look for a means of helping and supporting family caregivers so that they can develop a sense of satisfaction and accomplishment in their care giving role.

## INTRODUCTION

Loss is often a very real issue as people age. Friends, family members or a spouse may die; there may be a loss of bodily functions to face, a fear of loss of functioning, or a loss of autonomy as one's health declines as a result of a disease process. It is not difficult to comprehend loss and the grief experienced as a result of the death of a loved one. However, it is not only death or a loss of one's own body function that may result in a feeling of loss and grief. There is also evidence that the family caregivers of persons with Alzheimer's disease also experience stress and 'predeath grief' as a reaction to the 'nondeath' losses which arise from the deterioration of the person as a result of the dementing syndrome (Lindgren et al 1999; Hooker et al 1998; Collins et al 1993; Theut et al 1991). Family members have described their predeath grief as 'raw, overwhelming, and wrenching', and related to the loss of the person as they were once known (Collins et al 1993). Furthermore, the stress and burden of caring for a family member with dementia may result in caregivers feeling helpless and hopeless about their current life and about the future (Acton and Wright 2000).

### Dementia

There are approximately 135,000 Australian people over 60 years of age who have moderate to severe dementia (Woods 1997). These numbers are expected to increase because of the ageing of the Australian population, with the prevalence rates for dementia expected to rise by 65% by the year 2016 (Cummings 1995). Many of these people will be cared for in the home setting by family caregivers, at least in the early stages of the disease process.

As the disease progresses a number will be placed in an institution often unwillingly by family members who have been unable to cope with the crippling demands of the

disease progress. Family caregivers have reported that the decision to place a relative with dementia in a nursing home is one of the most difficult and painful decisions that they will ever make (Fink and Picot 1995).

While many caregivers face the decision of whether to place a loved one in a nursing home the insidious progression of the disease generally means that most caregivers must face not whether to place the person in a nursing home but when is the best time for this to occur.

However, there have been a number of changes and challenges created for family caregivers as western society has moved rapidly towards de-institutionalisation of people with disorders such as dementia, resulting in family members being pressured into taking on informal care giving in the community (McMurray 1995). Such changes have resulted in an increase in caregivers' research over the last decade as a means of facilitating community care giving that is sensitive to the needs of the caregiver and to the individual with dementia. Such research (eg Almberg et al 1997; Buck et al 1997; Noonan and Tennstedt 1997; Naleppa 1996; Ponder and Pomeroy 1996; Adams 1994; Gilhooly et al 1994) has emphasised the rational and functional aspects of care giving at home for relatives with dementia. This research has demonstrated the loss and grief experienced by spouses and families in caring for family members with dementia, and the significant burden that can lead to a breakdown of family care arrangements if not managed appropriately. Furthermore, a key variable in preventing institutionalisation appears to revolve around the family member's willingness to assume and continue the caregiver role (Robinson 1990).

The majority of this research has investigated care giving while the dementia sufferer is in the family home. There is a paucity of research, which explores the family care giving experience once the family member is placed in an institution. The research available indicates that even though placement relieves caregivers day-to-day care of relatives, it engenders sources of stress associated with the institutional setting (Aneshensel et al 1995; Zarit and Whitlatch 1992; King et al 1991; Townsend 1990). It is important that such research is carried out in the Australian setting and that health care providers understand this experience so that they may provide appropriate support for family caregivers of people who have been institutionalised.

The impetus for research into having a relative with dementia living in an institution, came not only from the paucity of research but also from a group of family caregivers whose relatives resided in a long-term dementia care unit in Brisbane, Australia. During information sessions explaining research being undertaken of nurses' experiences of caring for people with dementia (Clinton et al 1995) the relatives asked if they could 'tell their story'. They believed their contribution would strengthen the

researchers' exploration of care in dementia units. With this in mind and at a later date, the researchers set out to investigate family caregivers' perceptions of having a relative with dementia living in an institution.

## METHOD

### Study design

A qualitative exploratory framework was adopted for the conduct of this research. This design was chosen to enable exploration of an area that had not previously had extensive exploration. Focus groups were chosen as the data collection method to enable a reasonable size number of participants to be interviewed and to also provide the opportunity for discussion and collaborative information sharing within the group.

### Participants

Following ethics approval from the Queensland University of Technology's Human Research Ethics Committee and the Institution's Bio-Ethics Committee a mailed open invitation to attend a focus group interview was extended to individuals identified on resident care plans as next of kin of residents in the long-term dementia unit. Information and consent forms were included with the invitation to allow potential participants the opportunity to read the aim of the research and to be assured that their participation was voluntary and that participation or non-participation would not change the care given to their relative. Furthermore, the information sheet also included what was required of their participation in the research and cited contact people if they wanted to discuss the research further. Potential participants were also informed data would be collected through focus groups which were described as 'a semi-structured group setting, with the purpose of collecting information on a designated topic' (Carey 1994, p.226).

### Focus group format

Two focus group sessions were arranged during the unit's scheduled 'relative meeting times' to ensure interview times were convenient for relatives. Interviews were held in a comfortable room away from the dementia unit and presence of nursing staff to provide participants with the opportunity to express their experience without fear of reprisal. Nine wives and two daughters attended one focus group, and three daughters and one son-in-law attended the other. Although 15 is a small number of relatives when compared to the number of residents in the unit (n=36), this participation figure was not surprising given that many of the residents in the unit did not receive visitors or any indication of people expressing an interest in them. In contrast all of the research participants were

found to visit their relatives on a regular basis and expressed to staff a desire to be involved in the care provided.

In a group situation the relatives were asked to respond to the following open-ended question: *'Can you tell us what it is like to have a relative here?'*

Probing questions were kept to a minimum to give participants every opportunity to comment as fully as possible on the issues raised. The participants freely discussed a variety of issues related to having a relative in a dementia care unit. Although the interviewers came with a list of possible questions with which to explore the topic, it was found that participants quickly covered the areas once they found that they were being given the opportunity to tell their story.

At each of the focus group interviews one of the researchers facilitated the discussion while another observed and participated in the process to ensure that all participants were given the opportunity to be involved in the discussion. The focus interviews were approximately one and a half-hours in length and were audio taped to facilitate analysis. The interviews were transcribed verbatim and the transcripts were content analysed to identify common emergent themes and category codes. Content analysis identified the major theme of 'Living with loss' and within this theme the following six sub-themes:

1. Relief versus burden of loss.
2. Loss from observation of the cognitive decline.
3. Loss of companionship.
4. Loss creating fears and frustration.
5. Loss of personhood.
6. Losses - the anticipation of death.

These sub-themes are discussed below.

## FINDINGS

### 1. Relief versus burden of loss

The participants recalled positive aspects of placing their relative in the dementia unit. They suggested the placement *'relieved their stress'*, had *'made a difference to their family life'* and *'that it was good to see their relatives in a safe, secure and loving environment'*. They commented that they had found caring for their relative at home had become more difficult and stressful as the disease progressed and that this had been the impetus for finding placement.

These findings are supported by research suggesting that the caregivers' relationship with the dementing

relative may deteriorate because of psychological, physical, social and financial stress (Almberg et al 1997; Brodaty and Hadzi-Pavlovic 1990; George and Gwyther 1986).

Furthermore, poor mental health has also been identified in carers who live with the dementia sufferer (Brodaty and Hadzi-Pavlovic 1990; Fitting et al 1986). Burden amongst caregivers has been shown to be related to variables such as age (Fitting et al 1986); for example, looking after an elderly person when the caregiver is also elderly is burdensome, and gender (Almberg et al 1997; Gilleard et al 1984) where women are frequently the ones left to manage their male spouse or father. Further stresses have been identified as a result of such things as the caregivers' reluctance to go out of the house for fear of the sufferer's dysfunctional behaviour, incontinence or immobility, as well as the dependency of the dementia sufferer on the carers ability to socialise (Brodaty and Hadzi-Pavlovic 1990). Thus, it is not surprising that when the family caregiver is relieved of such constant stress that they would feel less burdened.

However, despite the caregivers' initial positive thoughts and contrary to popular belief, the placement of a dementing relative into a residential care setting did not result in an absolute relief of the family caregiver's burden or stress. This move created the reality of further loss as a result of being away from the family member and raised other concerns that were not evident while the relative was at home. The placement of the relative resulted in the beginning of another potentially difficult and stressful situation. This type of situation was far removed from the relative's thoughts when they had admitted the family member.

Having a relative in the unit caused the participant's great anguish. The wives showed the most visible distress and expressed concern in relation to their coping with a new situation where they were no longer the caregiver the relative relied on for constant support. All of the participants described difficulty with knowing how to redefine their new role from one of being a constant caregiver to one of being *'a family caregiver at home'*, or in other words a caregiver from afar who was no longer totally responsible for the care situation. They had imagined that their new role would be easier once the family member was institutionalised, but they found their new situation was just as difficult, if not more difficult than when they were with their loved one at home. Townsend (1990) supported the participants' concerns as she also found that institutionalisation created new family tensions such as conflict over family members' obligations and unclear expectations about the caregivers' involvement in the residents' care.

## 2. Loss from observation of the cognitive decline

Participants noted that the relative's cognitive limitations continued to be of concern whether the individual was institutionalised or was in-home care. Participants described their situation as *'devastating', 'difficult to watch the decline', 'depressing to remember them as they were', 'it tore you apart', 'you reminisce and are desperate for them to be normal and to do normal things'*. Reflection on the past was a constant reminder of not only the changes to the family member but also changes to the caregivers' role. Without the distraction of providing care for the relative, family caregivers found that they concentrated on and wanted to recall *'their previous life'*, a life without the complications of dementia; whereas previously they had been too busy to give this more than a passing thought. The anguish of watching their loved one deteriorate may help to account for some of the reason why some relatives stop visiting once the family member is institutionalised.

In particular, caregivers expressed their anguish and guilt in relation to making the decision to admit the relative as well as remembering how the family member once was. Their reflection on past life experiences with the family member was far from stress relieving but rather captured the enormity of the situation, which was now seen as a different stage in their life, and one that they had never thought would eventuate. They now felt they had no control over the situation which they believed they had been managing well while the individual was at home.

The caregivers craved support as well as distraction for their guilt and anguish. Although one would imagine that health professionals would be there to help family caregivers work through their concerns participants did not recall health professionals helping them to overcome their grief. It appeared that nursing staff in particular catered for the sufferer's needs but did not extend their practice to include relatives. The family caregivers felt lost and alone as they tried to adjust to their new role where they felt they were no longer the essential person in the family member's life. Concern also arose with how to manage their relationships with staff and with the family member. They felt the need to avoid conflict with staff so that staff would approve of their relative and provide them with the best possible care.

Thus, it appears that family caregivers have to cope not only with their relative's deterioration but also with an adjustment in their relationship with the relative, as well as the establishment of a new relationship with staff members. Conflicts with staff members are common in such situations where time is not given to discussion of the issues (Rosenthal et al 1992; Townsend 1990).

## 3. The loss of companionship

The family caregiver deliberated between their perceived loss of companionship with their loved one and lost opportunity. They thought they were no longer able to demonstrate to the sufferer the extent of their love via their care giving. In spite of the stress of providing on going care at home, relinquishing this role was difficult for the caregiver to suddenly give up. The family caregiver had initially believed that once the relative was institutionalised that they would have more time to concentrate on other things in their life. However, the time taken up with care giving was now filled with other burdens concerning the family member. Family caregivers became constantly concerned with practical issues such as when to visit, difficulties with travelling to and from the institution, financial and legal issues, and dealing with household maintenance, particularly when this had previously been the role of the dementia sufferer.

Whereas communication and care for the dementia sufferer had been difficult for sometime, the family caregiver had felt comfortable doing what they believed was best for their loved one in the confines of their home. They now felt that their lives were always on display and no longer their own as their relationship had been intruded upon by another stranger - nursing staff who were always around to watch and observe their performance. This is supported in previous research where Townsend (1990) reports on caregiver difficulty with having enough time and energy for visiting and Hertzberg and Ekman (1996) report on relatives' concerns about what to do or talk about during visits with the family member.

## 4. Loss creating fears and frustration

Participants pondered between knowledge that on the one hand the care provided in the residential care setting was considered as *'good'* and on the other, their concerns with the care. They acknowledged that *'staff were flexible with residents'*, staff were perceived to *'have the knowledge and techniques on how to handle the residents and their behaviours'*, and *'residents were taken on outings and activities were organised for them'*.

On the other hand participants raised their concerns and frustration with the care provided. They often thought that they wanted to inform nursing staff that they knew better ways to provide care, but they felt that this would create unwanted conflict. They voiced fears about making demands on staff by stating that *'relatives don't like to complain'*, but they *'want[ed] residents to do more and more normal things'*.

They could not accept that relatives were left in chairs or beds, rather than participating in activities they used to enjoy such as gardening, shopping, cooking or walking. They wanted *'staff to talk with them more'* and for them to be offered the opportunity *'to be involved in decisions made*

- especially when the relative was first placed as [they viewed that] carers [are] reluctant to give over the care'.

The family caregiver compensated for the loss of their loved one by shifting the blame for their relative's condition onto the staff and facility. Underneath their apparent contentment they were seething with anger at their lack of control of the situation. The researchers contend that staff need to encourage relatives' involvement in resident's care as this may assist family caregivers to adjust to their new role and provide a means of retaining their value in the care giving of their family member.

## 5. Loss of personhood

Participants expressed their need to retain control of the situation and to keep their relative as they remembered them. These concerns may help us to understand the most frustrating issue voiced by participants. All participants raised concern with the clothes their relatives wore as they said they were not dressed in clothes of their own, or in clothes brought in by the family. The clothes which they had purchased with great care and attention were worn by other residents or simply seemed to disappear from their relative's wardrobes. The clothes given to relatives to wear were commonly either too big or too small, or not the type of clothing they knew their loved one would like to wear. The participants stated they believed that '*clothes are a way of keeping your loved one as much as possible as they were*'. Furthermore, they stated that '*buying their clothes was often the only thing that relatives can do*' and that '*clothing gives people dignity*'.

When consulted about this issue the nurses had not considered that this might be of concern to relatives. They attempted to place individuals' clothes in wardrobes but were frustrated that sometimes clothes brought in by relatives were not considered suitable for an incontinent resident, or they were either too big or too small.

There was also the problem of clothes being removed by residents and placed in someone else's wardrobe. Nurses stated they found it easier to dress residents in tracksuits that could be pulled down or removed quickly for toileting or changing. They found dresses or tailored trousers that needed belts were difficult to get residents in and out of and they believed that some materials would not tolerate the frequency of washing required. They had forgotten that many of these residents might never have worn a tracksuit, loose clothing, or have gone out of their house without make-up on or their hair done. Thus, rather than considering residents as individuals with individual needs they had objectified residents, treating their condition from the nurses' perspective of 'saving time' rather than from an individual need and one that required that they knew something about the person's past life.

While clothing was obviously important to these family caregivers Gilhooly et al (1994) on the other hand found

when examining the predictors of breakdown of family care of the dementing elderly that physical appearance of family members was considered by the caregivers to be of reduced importance. The fact that Gilhooly et al investigated family homecare may help to explain this difference. Whereas, at home the family caregiver had many things to be concerned about, when the family member was placed in an institution concerns appear to change to activities that the family caregiver no longer has direct control over. This area is certainly worthy of further investigation.

## 6. Losses - The anticipation of death

In spite of the perception that the family member was already in a sense dead, because they no longer resembled the person they once were, the anticipation of planning for the event of death was summed up as '*planning for the worst*'. The anticipated death of the loved one was longed for, considered as a blessing and as a means of relieving the stress of living with loss. But, the anticipation of death was also perceived to be another fear that the participants had to fight to stay on top of.

The anticipatory grief experienced by participants is supported by research (Laitinen 1993) that suggests the belief that residential care settings are '*houses of death*' and encourages the view that the move into a residential care setting is one step closer to losing this person altogether. Furthermore, when nursing staff objectify care to the disease process rather than a holistic approach to practice, the worthlessness of the individual further encourages this concern.

### Living with loss

The losses incurred by participants continued despite the relative being placed into a residential care setting. The family caregivers described their reactions and thoughts towards the situation as stages similar to a grieving process (Kubler-Ross 1986). These are outlined in Table 1.

**Table 1: Stages of loss and grief experienced by the family caregivers**

Stage 1	Grief and guilt
Stage 2	Anger and hurt at loss of control
Stage 3	Having to adjust to situation
Stage 4	Resignation of decline and their inability to provide the type of care needed
Stage 5	Acceptance - ' <i>cannot go on grieving forever</i> '

They described the initial phase of institutionalisation as '*devastation*', and '*grief and guilt about having to place their loved one [in an institution]*' and one of concern at '*watching the decline in their relative's abilities*'. This was followed by feelings of anger and hurt with the situation as



they felt that they were often not in control of (eg, the clothing issue). The third stage was described as having to adjust - '*some things you learn are important and [others] unnecessary*'.

Some of the things they described as having to learn to adjust to were relatives wearing what they sensed were inappropriate clothing and their not wearing dentures or glasses. Thus, the family member no longer seemed to be the person they once knew. The fourth stage was described as resigning themselves to the ongoing decline as they recognised they could no longer provide the type of care they recognised their relative needed. The final stage described was acceptance of the situation, as they came to realise that they could not go on grieving forever, and they recognised that the relationship with the family member was no longer what it was previously. Thus, they come to the decision that they would have to continue on with their life, a life that did not include their loved one.

### **Coping with the situation**

The participants coped with the situation by seeking support from staff, family and other relatives who visited the units. Relatives spent time helping each other as they stated that this was important to them as '*we know what they're going through*'. As part of their adjustment they also started to reduce the number of times they visited and the time they took their relative out. Thus, they were preparing themselves for the final conclusion in their life - that of life without the family member.

The emptiness experienced by family caregivers did not appear to abate when the family member was institutionalised. The burden of caring for the family member at home had taken so much of their energy that they felt physically and emotionally drained when their loved one was admitted. Unfortunately, this energy had not been recouped once the family member was institutionalised. Instead the sapping of energy continued with the burden that endured.

### **The need for change**

The research findings highlight the need for family caregivers to continue to have community support even when their relative is institutionalised. Family caregivers with institutionalised relatives need support in helping them to adjust to their new role and assistance in planning for their future, without the true presence of the loved family member. Community organisations or even institutions could help with this task by facilitating family caregivers to get together to discuss their situation and to provide support to one another.

Support offered by such groups may help the caregiver to become empowered and to regain a sense of mastery and satisfaction. Such groups will also help both in-home caregivers and relatives of institutionalised individuals to

confront and cope with their difficult care giving situation (Spall and Smith 1996). Group members may be encouraged to reminisce about the good times they had together as a way of coming to terms with the tragedy. Education on the disease process may also unleash some of the guilt felt by family caregivers as they come to realise that there is nothing that they can do to stop the disease process.

Nursing staff, who form a therapeutic alliance with relatives, will encourage relatives' trust and respect. Thus, relatives' fears and frustration can be discussed and opportunities provided for relatives to be more involved in the care of their loved one. Nursing encourages a holistic perspective to practice. Yet, relatives in this situation have described stories in which they have not been involved with the care of the family member, and their needs and concerns have not been respected. To encourage a therapeutic situation nurses must involve not only the client but also relatives in order for mutual trust and respect to take place.

Grief therapy may also help the caregiver reframe the challenge of care giving as an opportunity for growth (Langner 1993). As many family carers are elderly and have few family support services they can call upon a variety of support services are required to provide both tangible and emotional support to the caregiver.

Furthermore, helping family caregivers to chose clothing for relatives that can be washed and removed easily and which still provides the wearer with a semblance of their previous clothing colour and style may help to prevent such concerns as raised by these participants. Moreover, nursing staff could assist further by ensuring the relative is dressed in a favourite piece of clothing for family visits.

## **CONCLUSION**

Ageing of the Australian population creates a challenge for society, as the number of people with dementia is likely to continue to rise. Care giving for family members with dementia has been found to be burdensome but it is frequently considered to be a family responsibility and one which may be done out of love or obligation.

The care giving role may result in poor physical and emotional health of the caregiver as providing care for a family member with dementia may set in motion a cycle of isolation, frustration and sadness as the family member's condition deteriorates.

Contrary to popular belief, placing of a relative into a care setting does not result in a lifting of the burden, but often results in the beginning of another potentially difficult and stressful situation. This area of research is

most important as the number of family caregivers with institutionalised family members is anticipated to grow.

It is essential that health professionals assess the family care giving situation so that appropriate support can be offered not only to the family caring for the member in the community but also to the family with an institutionalised member. Health professionals must also be prepared to assist family members with anticipatory grieving of losses that accrue with the changing relationship from a loving and close relationship to a difficult filial care giving relationship.

Finally, there is a need to respond to the caregiver research and to look for a means of helping and supporting caregivers of people with dementia so that the caregiver can develop a sense of satisfaction and accomplishment in their role, whether it be direct community caring or institutionalised care. This has the potential to improve upon not only the sufferer's but also the caregiver's quality of life. Finally, the authors consider that further research is needed that investigates caregivers' health status following the death of their family member.

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# PREGNANT WOMEN'S EXPERIENCES OF MODELS OF CARE IN SOME HOSPITALS IN VICTORIA

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## ABSTRACT

During the data analysis of a much larger study on 13 women's experiences of their first pregnancy, their interactions with the health system emerged as significant. Two grounded theory procedures, the *making of comparisons* and the *asking of questions* were used to analyse their experiences. Elements of three models of care were identified, medical/technocratic model, midwifery model, and a feminist perspective model. In some instances, there was blurring and overlapping of models. Tape-recorded, individual interviews were held with 13 pregnant women (aged 34-42 years) in their homes at the end of each trimester and with 10 women again 10-14 days post birth. (Three women were unavailable.) All the women delivered their babies in hospital. Eleven women had an epidural anaesthetic and 11 women had an episiotomy. Information received at antenatal education classes had a marked effect on the women's expectations and the reality of their experiences. The future of implementing midwifery models of care into the hospital system will depend on effective change management and an acknowledgment of consumer needs by administrators.

## INTRODUCTION

In the analysis of a grounded theory study of 13 women's experiences of their first pregnancy, their interactions with the health system emerged as relevant and important for health professionals. The women's interactions with the health system included antenatal visits, antenatal education classes, and hospitalisation. This paper explores which models of care the women experienced and also how useful the women found the information disseminated at antenatal education classes. Direct quotations from the women are included.

The frame of reference for the present discussion depicts pregnancy as a social phenomenon. The social nature of pregnancy is obvious: human beings are part of a family, community, and society. Pregnancy is constructed through human beings' actions, that is, the cultural creation of mores and conventions. These actions take place through social interactions in social institutions (Davis-Floyd 1992). Pregnancy and birth have cultural and biological definitions. Herein lies the paradox. The medical model of care espouses, indeed prescribes, behaviours for interacting with the health care system, and there is much evidence that hospital midwives perpetuate the prescriptions while often encouraging the women in antenatal classes to question these same prescriptions (Callaghan 1993).

Feminists and some midwives champion a humanistic, woman-centred, holistic approach to pregnancy and childbirth within a *wellness* and natural framework with increased choice and control and without unnecessary intervention (Crouch and Manderson 1993; Gregg 1995; Lazarus 1994). They also ask for equality of women and men (whoever and wherever they are), and a ritual reintegration of the new mother into society. In addition, midwives advocate continuity of care and a 'partner' relationship between the women and themselves (ACMI 1999; Barclay and Jones 1996).

Both midwives and feminist groups encourage women to ask questions, ask for information, and insist on participation in making decisions about their care. A labouring woman entering the hospital cannot but be in conflict. The messages received during her antenatal visits and education program have engendered a list of behaviours, often conflicting; the community, and often her own preference, are urging her to behave otherwise. The phenomenon of pregnancy is thus prescribed, but the meanings attached to a particular pregnancy at a particular time are individual, specific, and unique.

### Recruitment of participants

A convenience sample was obtained through placing flyers, with the researcher's name and contact number, advertising the study in the Health Clinic at La Trobe University, and the Royal Melbourne Institute of Technology (RMIT) both in Melbourne, Australia. Permission to attend a maternity hospital's antenatal clinic was granted. During the initial phone call, the requirements and voluntary nature of the study, and issues of privacy and confidentiality, were explained in a way that enabled the women to give their consent from a position of knowledge and understanding of the purpose of the research. An appointment was then made for the first interview.

In depth interviews, lasting about one hour were conducted with 13 women (aged 34-42 years) in their homes at the end of each trimester. Only 10 women participated in the post birth interview. Three women were unable to keep their appointments. Multiple interviews were chosen because many women experience marked differences between the three trimesters of pregnancy. The interviews were taped and transcribed *verbatim*. Hard copy was posted to each woman giving her the opportunity to read her transcript and make modifications if appropriate.

## METHOD

Two qualitative research approaches are incorporated in this study, namely, grounded theory, and a feminist, phenomenological interviewing technique, sometimes called '*phenomenological interviewing*'. This method refers to 'an interviewee-guided investigation of a lived experience that asks almost no prepared questions' (Reinharz 1992, p.21). Data were coded and categorised using the grounded theory method (Strauss and Corbin 1990). The categories created became the concepts that were then examined theoretically. Subcategories that related to the key questions facilitated the grouping of the concepts. Concurrent with the process of identifying concepts were theoretical sensitivity and memoing (Strauss and Corbin 1990). A colleague knowledgeable in

the grounded theory method was invited to read an unmarked first trimester transcript. There was agreement on the numerous concepts and categories identified. This process was followed by axial coding, that is, integrating categories according to their relationship, and selective coding, that is, selecting the core category (Strauss and Corbin 1990). The core category was initially named *adaptation to pregnancy*. Using the *constant comparative method* of data analysis, the aim was to establish the extent of the congruency between what each woman was experiencing and the technical literature in the area. All the data were analysed manually.

To facilitate reading, where models of care are identified, they are compared with the literature from which they are derived, followed by a discussion on antenatal education classes.

## RESULTS

### Models of care

The women did not experience only one particular model of care, rather aspects of the three models on different occasions during their antenatal visits and hospitalisation. Some women appeared to experience clear instances of one or another model, but generally, they experienced only the medical model. For example, the rigid medical model they encountered during their hospitalisation was occasionally tempered by a particular midwife's philosophy and care either at the bedside or in antenatal education classes. Some childbirth-parenthood educators spoke about the philosophy underlying midwifery and feminist models in their classes, and encouraged the women to behave accordingly, that is, to ask questions, question procedures, and be aware of their choices and options.

During the first interview at the end of the 1st trimester, the women had visited the clinic only once or twice and appeared to be trying to cope with the physical symptoms of fatigue and nausea. They all expressed concern about their inability to control the symptoms. Instances of the pervading medical model during their visits were apparent in their responses.

*The person who did the ultrasound didn't give me a chance to look at the baby - he was moving the probe around so quickly. I asked him to slow down - he was just so business-like.*

*When I told the doctor that I had some spotting he said I should come back next week because 'you could miscarry or anything. Come back and we'll see if you're still pregnant'. I was very upset.*

*I felt I couldn't ask the doctor any questions - he was very quiet and very busy.*

Initially, and during early labour, some women were assertive in their requests to be included in the consultation process. However, by virtue of the fact that all the women considered having an epidural anaesthetic, they were aware that they would be placed in a 'patient' role. Earlier protestations and plans to make their own decisions were no longer relevant. Eleven women had an epidural anaesthetic and 11 women had an episiotomy. Thus, conflict was experienced during hospitalisation when it became clear to them that the environment was not always conducive to permitting alternative choices. However, the women accepted the status quo without question and were very satisfied with their experience. They rationalised that hospitals require rules, regulations, and protocols to function effectively.

### The medical/technocratic model

A clear and unequivocal philosophy underpins the medical/technocratic model; the nature and progress of pregnancy are viewed in relationship to an obstetrician, midwife and hospital (Duden 1993; Tavris 1992). The doctor is in charge, the midwife subordinate to her/him, and the woman subordinate to the midwife (Barclay and Jones 1996). The medical model that views birth as potential pathology where anything can go wrong at any time, is the dominant model (Lazarus 1994) that permeates hospital birth and is focused on standards and outcomes (Brodie 1999). Duden (1993, p.75) suggests that the ultrasound plays a 'symbolically predominant role' in antenatal care because of the financial advantages to the doctor and the manufacturers, and 'it promises information, certainty, and control'. Moreover, with the increased use of technology a pregnant woman begins to believe that others are better informed about her condition (Bluff and Holloway 1994). Indeed, even before she embarks on motherhood, 'she is habituated to the idea that others know better and she is dependent on being told' (Duden 1993, p.29). There is evidence to suggest that all health professionals working in the medical model are perceived as experts, and this perception places them in a position of authority, permits them to make decisions for the labouring woman, and thus, tacitly assume control. As a result, the medical model of care has fostered dependency (Ernst 1994).

In western society, it is acknowledged that pregnancy and birth are under the control of the medical profession (Reinharz 1992). One aim of this position is to optimise the safety of mother and foetus/baby during pregnancy and labour (O'Meara 1993). With the increase in sophisticated technology and medical intervention during this period, one adverse effect is that women no longer feel in control of what had always been considered a natural process (Willis 1989). In other words, the greater the sophistication of the technology used, the less control a woman has. Another important aspect of hi-tech childbirth

is that the woman, who would like to know that the technology is available should it be needed, must perforce deliver her baby in a hospital.

Since pregnancy is socially constructed, it is assumed that the women's views reflect, more or less, the views of the health professionals, family, and friends, and those in the literature. However, adding to the confusion is the absence of concord among health professionals on such basic tenets as: whether pregnancy is a natural event or a medical condition; whether birth is as safe for low risk pregnant women inside a hospital as it is at home; the safety of medical intervention (ie, epidural anaesthetic and analgesics during labour); whether women should be encouraged to hand over their care to health professionals at some stage, if at all; the extent to which pregnant women should not only participate in decision making about their care, but also be permitted to make decisions (eg, refuse an episiotomy), and finally, the notion of rights and choices. Some comments about control illustrate that some women, early in their pregnancy, did not feel ambivalent about handing their care over to the health professionals:

*I suppose that while I say I like to be in control, I still have enough confidence in health professionals that ... at certain times I understand that I'm going to have to put myself in their hands and accept what's going to happen to me.*

*I'm not making decisions about what's going to happen any more. I've rationalised that what will happen will happen and I'll just take it as it comes.*

*I want to be in a position to make decisions, but of course the doctor knows better than I do and will make the ultimate decision.*

### Midwifery models of care

Midwives have responded to the criticisms of the medical model and the erosion of their role by restating their claim to 'being with the woman' throughout pregnancy and the postpartum period. According to a discussion paper (ACMI 1999, pp.v-vi), women have indicated:

*...a growing preference for midwives to be their primary carers, are wanting improved continuity of care and caregiver, increased choices about their birth place, avoidance of unnecessary intervention, and humanistic rather than technical care.*

Midwifery models attempt to address women's demands for a midwife primary carer (Goer 1995; Johnston 1998), and increased choice and control over their pregnancies (Campbell and MacFarlane 1994; Davies and Evans 1991; NHMRC 1996; Rowley 1995).

Midwives espouse a woman-centred model of care within a natural framework (ACMI 1999); midwife as primary carer throughout the pregnancy to postpartum period, continuity of care, humanistic rather than technical care, increased choice and control, and avoidance of unnecessary intervention (ACMI 1999). This philosophy is congruent with their *wellness* framework.

In terms of the childbirth process (care, information, family involvement, technology, and outcome), another midwifery model of care (Barclay and Jones 1996) provides continuity of care, an holistic, positive outlook, shared information, the presence of family members, and the woman's active participation in decision making. The desired outcome is a healthy mother and infant. The women's interactions with midwives during the antenatal period were positive and appreciated.

*I'm having shared care. When I saw the doctor my visit was always hurried, but the midwives were patient and friendly and answered all my questions.*

*I really didn't have much opportunity to ask the doctor any questions. If I had questions, I asked the midwife at the classes.*

*I'm having shared care and I've been lucky to have nice doctors and midwives.*

### **A feminist perspective of pregnancy and childbirth**

The feminist perspective demands that women should be free to choose from a variety of options of procreative technologies; individual rights and choices are emphasised as is the need to contextualise a pregnancy (Gregg 1995). The 'right to choose is an essential value and key organising theme for feminist health activists and the women's health movement' (Gregg 1995, p.11). The message from consumers and feminist movements is that pregnant women must control their lives, accept responsibility for their health, become assertive, and make choices in treatment options (Lazarus 1994).

But prior to this directive, a much older edict from the health professionals, especially the doctors, had been inculcated into the community. The warning was that pregnancy can be hazardous and frequent monitoring is necessary. It would be simplistic to leave the matter there. The situation is compounded by a dual dilemma: from a woman's perspective something can go awry with her pregnancy and birth, and she feels safer in the hospital environment. From the doctor's perspective, s/he must maintain a close watch on the progress of the woman's pregnancy not only in the interests of good antenatal care, but also because of the prospect of litigation. Decisions that were once controlled by the doctor are now controlled by insurance companies (Lazarus 1994).

The feminist critique of the medical model of birth is that the interventionist procedures are not always in the

interests of the woman, and that the model is not conducive to providing the woman with a 'natural' childbirth experience (Crouch and Manderson 1993).

Another problem feminists have with the medical model is that it assumes control of the reproductive process, and, therefore, the woman and her unborn child. Also, the medical model portrays pregnancy as pathology: it is an illness model. Feminists want a woman-centred model. Although feminist perspectives on procreation differ in some respects, collectively they want a model that encourages freedom of choice, with emphasis on rights and choices based on a woman's understanding of her own best interest, the equality of women and men (whoever they may be), and that she should be involved in developing, using, evaluating and disseminating information about the available technologies (Gregg 1995).

There is a view that feminist theories have acted to emancipate nurses and women from medical ideologies (Fleming 1992), but it appears that nurses have been slow to accept feminism as a strategy for liberating themselves (Speedy 1987). Speedy argues that from a feminist perspective nurses are an oppressed group because they do not have autonomy, a criterion of a profession. Nurses exhibit characteristics of oppressed groups (eg, dislike of other nurses, lack of interest in participating in professional organisations, a desire to avoid others in a similar situation, and low self-esteem) (Speedy 1987). And lastly, nurses may have been unwilling to embrace feminism 'due partly to the confusion of what is meant by the concept' (Speedy 1987, p.25).

### **Antenatal education classes**

The importance of antenatal education cannot be overemphasised or overvalued. Antenatal education programs are probably the single greatest source of information for pregnant couples. A central aim of the program is purportedly to provide women with the knowledge to prepare themselves emotionally, physically, and intellectually for their pregnancy, delivery, and subsequent care of themselves and the infant. The information and guidance provided in these programs have the potential to facilitate active participation in decision-making.

To participate in this process, both client and practitioner enter into a dialogue in which the client explicates her needs and expectations. This is clearly a reciprocal process. Dialogue with the client regarding her participation in decision making is often neglected by health professionals who are accustomed to assuming responsibility for the client and making decisions for her (Bluff and Holloway 1994). There is little evidence that any informal discussions are initiated by professionals about choice of place of birth and models of care (Simic et al 1995).

Childbirth/parenthood preparation, or fundamental education, has avowedly two principal components (Birrer 1977, p.276); the first is to prepare couples for the reactions each may feel during the pregnancy, that is, promoting pregnancy adaptation, and the second is to prepare the mother 'for the optimal patterning of the transition period, that is, promoting maternal adaptation'. Collectively, these aims are designed to assist pregnant women and their partners to develop realistic expectations of pregnancy, labour, birth, and early parenting. This view is supported by Nolan (1997) who believes that the pregnant woman and her experiences should be the focus of the educational program.

According to the Ministerial Review of Birthing Services (HDV 1990, p.61), the objectives of childbirth education classes in Victoria are 'typically quite ill-defined' and no apparent systematic evaluation of the classes exist. Also, in respect of qualifications, Brown (1999) found that of the 14 childbirth/parenting educators she interviewed, only one had undertaken a short eight hour course.

Regarding antenatal education programs, the women in the present study made positive comments about the information they received, the friendliness of the childbirth/parenting educator, and the social benefits of being part of a group. They found sharing experiences useful, and felt comfortable and supported by being with other pregnant couples. They all felt that the classes were their major source of information.

*The classes are OK, but I think they could have been more realistic. They could have spoken about an induction and this is why we do it. But the explanation about the birth process was good.*

*I thought the classes were good. I don't think any of us in the group wanted to have a natural birth - I mean without drugs. I think everyone was really keen to find out the pros and cons of pain relief. The midwife brought in a lot of her medical books and we had good discussions.*

At the post delivery interview, the women were asked to reflect on the information they had received in the classes and to comment on the extent to which they felt that the classes had prepared them for the onset of labour, delivery, breastfeeding, infant care, and the early days at home. Their comments indicate that, in retrospect, they believe that nothing could have prepared them for these events, especially the intense emotional and physical experience of labour and delivery. They appeared unanimous in the view that too much time was spent on talking about labour (about 10 hours were spent on labour and pain relief, and one half to two hours were spent on breastfeeding, infant care, and going home). They thought that more time should be spent on informing them about breastfeeding (and bottle feeding), looking after oneself following delivery (eg, episiotomy care, pain on passing

urine and having a bowel action, tiredness), infant care and behaviour (eg, how to soothe a crying baby, colic, appropriate responses to infant behaviour, the baby's bowel actions, cord care) and going home. In general, the classes were conducted in six two-hour sessions.

*When the contractions started I remember thinking of all the things they taught us about being active, and walking around and using different positions - but I just couldn't do anything.*

*There was too much information on labour. No one can explain the pain to you. I don't think it's true that we don't want information about baby care and going home.*

*The classes were OK. We have different labour and different pain thresholds, so you can't tell people what to expect, and so you can't be prepared in one sense, and there's nothing you could learn that would have made any difference.*

*The classes didn't prepare me for the reality of labour at all but I don't think they could. It didn't happen at all like they said. The best part of the classes was the social aspect.*

In particular, most women found the onset of labour distressing because it did not correspond with what they had been told - a unanimous complaint was that '*it didn't happen at all like they said*'. The conflicting information about breastfeeding made some women feel anxious particularly for those women who had difficulty getting the baby to latch on, and if breastfeeding was not established prior to discharge. With the exception of one woman who managed to breastfeed without assistance from a midwife, all the women felt that they were not given sufficient advice and support during feeding times.

## DISCUSSION

The women all gave birth in a hospital. Twelve women asked for an epidural anaesthetic, but only 11 women had one. One woman was refused an epidural because of her advanced stage of labour. The medical model was clearly identified but only elements of the midwifery and feminist models became apparent and these mainly through discussions in antenatal education classes. However, the context for each model was different. All the women appeared to be assertive. They had declared during our interviews that they would ask questions, question their treatment, and make decisions about their care. However, most of the women did not engage in any discussions with health professionals regarding their care. Only one woman firmly told the doctor that she did not want an episiotomy. The doctor complied with her request and her perineum did not tear. The other women, having chosen an epidural anaesthetic, were perforce restricted to bed, and assumed a 'patient' role. They had their partners with them, were satisfied with the care they received, and were happy to let

the doctor, midwife, or even their partner, make decisions for them. In fact, two women had instructed their partners to tell the doctor that s/he was not to perform an episiotomy. Since they had asked for an epidural anaesthetic, their instruction was irrelevant. They felt that the health professionals knew best, notwithstanding that the women had previously said that they wanted to be included, and even consulted, in the management of their care.

There is abundant evidence (Brown and Lumley 1994; HDV 1990; McKay and Yager-Smith 1993) that women are not always given the opportunity to assume responsibility for their health and their bodies. Decision-making is crucially bound up with what information is available, what significant others do with any information they have, and how others communicate their own prejudices.

The quality of the information available in turn depends upon how well informed the health professionals are. Simic et al (1995) found that there was little evidence that any informed decisions were initiated by health professionals regarding place of birth or models of care. The women in their study made few demands on the professionals for information: they remained passive. It has been suggested that both health care professionals and consumers become passive in their interaction within an 'established system' (Simic et al 1995, p.40).

## CONCLUSION

Trying to determine the particular model of care the women in this study experienced was not difficult. In fact, there were no instances during their hospitalisation that the women experienced anything but the medical model. In defence of this model, having an epidural anaesthetic of necessity results in a woman being restricted to a bed and reliance on health professionals to assist her with the birth. There were glimpses of aspects of midwifery models in some antenatal education lecturers' philosophy. The feminist model was apparent in one instance only: one woman wanted to give birth in a birth centre but was prevented from doing so because of her baby's breech presentation.

If health professionals are serious about getting the community to accept responsibility for their self-care, and the demands on the decreasing health dollar indeed make this imperative, then they must be equally serious about educating their clients so that they are equipped to accept this responsibility.

Messages from the health professionals conducting antenatal education classes are less clear. In many instances, midwives were encouraging the women to be assertive and make their choices known. However, there were occasions when the midwives told the women that the information and procedures discussed in class may

differ from hospital to hospital, and that what was said in the classes was not necessarily the same in the hospitals.

This kind of information and advice may be confusing for some women who want to participate in decisions about their care, particularly in the absence of continuity of care, when the midwife is not present to support them.

The impasse arising from issues surrounding antenatal education classes needs to be addressed as a matter of urgency. Pregnant couples are now asked to pay a fee for the classes and the educators should perforce be made accountable for the information they are disseminating. Hospital administrators should employ suitably educated, qualified, and accredited personnel for this important task. Teachers should articulate an understanding of educational philosophy to direct program content, and have a sound knowledge of teaching and learning strategies. An educational conceptual framework should be used for program development, implementation, and evaluation.

It seems that the future of implementing midwifery models of care into the hospital system will depend to a large extent on effective change management and a very real desire on the part of hospital administrators to acknowledge consumer needs, and make the necessary changes to improve the delivery of services.

## IMPLICATIONS FOR HEALTH CARE

If health professionals agree that women do have options and the right to make choices, the hospital environment should be examined for the feasibility of introducing midwifery/feminist models of care. The question of continuity of care needs to be addressed by hospital administrators in the interests of providing the best service: this means continuity of care from the first antenatal visit to the home visit post birth. Together with this activity, an investigation should be conducted into what choices and options are realistically available to pregnant women, and the criteria the women use when making choices.

In order to alleviate some of the anxiety and feelings of loss of control experienced during the 1st trimester, health professionals could focus on preparing the women at their initial and early subsequent visits for the physical and emotional symptoms and thus circumvent the distress they experience at this time. Introducing midwifery models of care into the system will *ipso facto* ensure continuity of care.

Antenatal education classes are a very important source of information and almost all pregnant couples enjoy the social aspect, receiving information and having the opportunity to discuss their concerns. In light of the women's experiences and comments, it is timely for a review and evaluation of the classes and their content. Directives about the course of a pregnancy, labour and



birth are inappropriate: these processes are seldom predictive. Health professionals conducting antenatal education classes should have current knowledge, an understanding of teaching and learning principles, and good teaching skills. Finally, consideration should be given to producing *broad national guidelines and standards* for the classes.

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# THE EXPERIENCE OF SEEKING HELP FOR POSTNATAL DEPRESSION

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**Key words:** postnatal depression, support, phenomenology, understanding

## ABSTRACT

This qualitative study sought to explore women's experiences of support and treatment for postnatal depression. In-depth interviews from seven women were analysed using the phenomenological method described by Creswell (1998). Findings indicate that partners provided women the most support. The women did not know where to seek professional help, often being identified and helped by the maternal health nurse who monitors and guides the progress of their babies' development. Hospital programs were criticised for not informing and involving family. The women were dissatisfied with hospital doctors and their GPs claiming they had limited time for counselling, preferring to prescribe medication that alleviated symptoms but reinforced feelings of inadequacy. Recommendations are made to involve families and to use the unique position of the maternal health nurse in assessing new mothers.

## INTRODUCTION

Postnatal depression (PND) is a commonly occurring clinical depression that usually begins within weeks following birth (Spinelli 1997) and is considered a serious problem in terms of the consequences for a mother and her family. PND has been associated with marital, familial and relational conflict, child maltreatment, an increase risk of accidental injury to the child, neglect and at the extreme end, maternal suicide and infanticide (Spinelli 1997). Cooper et al (1996) postulate that PND can have a harmful impact on the mother-infant relationship, and this in turn, may endanger the subsequent cognitive and emotional development of the infant.

The incidence of PND ranges from 10-40% worldwide (Barnett 1991), but because of the complexity involved in identifying women with PND, it is thought to be frequently undetected and untreated (McIntosh 1993). Compounding this situation is the anger or shame women feel at having to consult a doctor or psychologist and the fear of being stigmatised as having a 'mental illness' (McIntosh 1993). Furthermore, women are often unaware of what they are suffering from and consequently fail to consult a professional (Sweet 1996). In support of this last point, Whitton et al (1996) found that while 90% of women recognized that something was wrong, only 30% believed they suffered from PND and 80% had not reported symptoms to health professionals.

PND has been associated with a lack of social support (Bebbington 1998). The risk of PND has been found to increase when the level of social support is low or absent (Morse et al 2000; Pederson 1999). This fact is not surprising when considering that parenting consumes enormous quantities of time, energy and effort on a daily basis (Morse et al 2000). The substantial work entailed in being a new parent comprises 4-10 feeds every 24 hours, with each feed lasting 5-90 minutes, and a total of 4000-5000 nappy changes across the period of infancy (Barry 1997). Social support not only provides practical help but can aid the mother emotionally by hindering the common experience of rumination (Beck 1992) as partners, friends and family can engage the mother's attention and allow her little time for rumination.

While husbands or partners may also be experiencing postnatal adjustment difficulties, Morse et al (2000) found they still provided the greatest emotional and instrumental support to new mothers. Partners can be indirectly supportive as they have also been found to influence the mother's coping responses (Barry 1997). After partners, Morse et al (2000) rated family and then friends as providing frequent and satisfying support of an instrumental and emotional nature. Terry et al (1996) suggest families are in the best position to offer non-threatening assistance and support, especially for the mother with a temperamentally difficult infant.

Outside the mother's immediate network of family and friends, sources of support are generally in the form of treatment by service providers such as doctors, psychiatrists and hospitals. The health care setting is an ideal venue for the intervention and treatment of PND (Sheppard 1997; Taylor 1997; Balcomb 1996) as the health centre nurse is usually the first port of call for new mothers to obtain advice and counsel (Whitton et al 1996).

Qualitative research on PND is scarce. Cheryl Beck (1992) completed the first phenomenological study to explore women's experience of PND. Beck (1992) focused on identifying the theme clusters that comprise the structure of PND and did not address the experience of seeking help. However, in a study by McIntosh (1993), the absence of help and support was found to be fundamental to women's experiences of PND. Although desperately wanting help, only 26% of women with PND actively sought it, preferring to remain silent. They dared not approach even family or friends for help, fearing shame and embarrassment at what they felt represented personal inadequacy and failure. The ten mothers who sought professional help saw this as a last resort, having reached a stage where they could not function properly. Nine of the mothers that sought professional assistance were not satisfied with the advice or help they received. They rejected the advice, especially the prescription of drugs, feeling this was an inappropriate solution to their problems (McIntosh 1993).

Consistent with this finding, Wood and Meigan (1997) found women with PND did not perceive health professionals to be beneficial as they failed to meet their need for understanding, and often did not take them seriously. The women reported being given antidepressants without alternative treatments being discussed. Furthermore, the possibility of their infant ingesting drugs via breast feeding, were not considered or discussed. Although ambivalent regarding drugs, the women felt their views were considered unimportant. One mother reported being prescribed medication over the telephone without a consultation or assessment, and another severely depressed mother had to wait six months to see a psychologist.

These findings are similar to the results of two qualitative studies that focused on the experiences of women undergoing treatment for depression (Hood et al 1999; Steen 1996). Although the clinical signs and symptoms of depression are not identical to those of PND, they are comparative (Terry et al 1996). As there are no studies that explore the avenues women with PND have sought for support, these studies help to highlight the experiences of women accessing and receiving treatment and support from service providers for a condition similar to PND. The studies above found that GPs had limited time and counselling expertise, rarely referred women on to specialist mental health services, and generally provided medication as treatment without adequate assessment. While the women felt medication was useful for managing symptoms, they perceived its use as a personal weakness in not being able to cope without it. Counselling was found useful when the women believed that the counsellor understood them and met their perceptions of what they needed. This finding supports Burns and Nolen-Hoeksema (1992) who found therapeutic empathy to be positively associated with clinical improvement in patients with depression, and highlights the importance of the therapeutic relationship as documented by Gelso and Fretz (1992).

To date, Beck (1992) is the only phenomenological study that explores the lived experiences of women with PND. However, she does not explore women's experience of seeking help and support. Thus, the aim of this research was to investigate (i) what avenues of support and treatment women with PND access and (ii) how the women experienced these avenues (that is, were they helpful or not). The phenomenological method is useful in producing rich descriptive data that can be used to enhance treatment and intervention for women with PND by nursing, medical and other health care professionals.

## DESIGN AND METHODOLOGY

This study employed phenomenology where the purpose of research is to capture the essence and meaning of a phenomenon through descriptions of lived experience (Creswell 1998). The 'hermeneutic or interpretive method' was taken where presuppositions are not bracketed but are used to frame the search for meaning (Creswell 1998). Using the psychological approach as proposed by Creswell, the meaning of individual experiences rather than group experiences, were central. Being sensitive to the women's feelings, the interviewer established a confidential atmosphere in which the women felt safe enough to talk freely about their feelings and experiences (Kvale 1996). The women were interviewed individually in their own homes and asked a range of questions about their experiences with postnatal depression. The interviews were audiotaped and averaged 90 minutes in length.

Seven women participated. Mary, Emma, Karen, Mandy and Stacy (pseudonyms), were referred through a postnatal support group in a community health service, while Jill and Lee were referred through a specialist sexual assault centre. Both places are located within a suburb of a major Australian city. While Stacy was in a defacto relationship, the other women were married. However, Stacy and Mandy separated from their partners within months of delivery. The women had an average of 1.7 children each and were aged between 24 and 43. Eligibility in the study required the women to be currently suffering from or have a recent history of PND. The study was approved by the Victoria University Ethics Committee, and according to the ethical guidelines, the women signed consent forms before participation.

## DATA ANALYSIS

The phenomenological method involved a number of steps in analysis as described by Creswell (1998, p.55). The entire interview transcripts were read to gain a sense of the whole experience, and then divided into statements. These units were transformed into ‘clusters of meanings’ or themes and then linked to make a general description of what was experienced and how it was experienced. These steps provided an ‘essential, invariant structure (or essence)’ of the perceived experiences of seeking help for PND.

To help ensure credibility of the data, a member check (Guba and Lincoln 1985) was done by five of the seven mothers who reviewed the description of the findings to validate that it captured their experiences.

## FINDINGS

Four theme clusters were identified by the women’s experiences as they sought support for PND (see Figure 1). Figure 1 indicates these theme clusters of support networks are: interpersonal support; maternal health nurse; medical professionals such as general practitioners (GPs) and psychologists; and postnatal support groups.

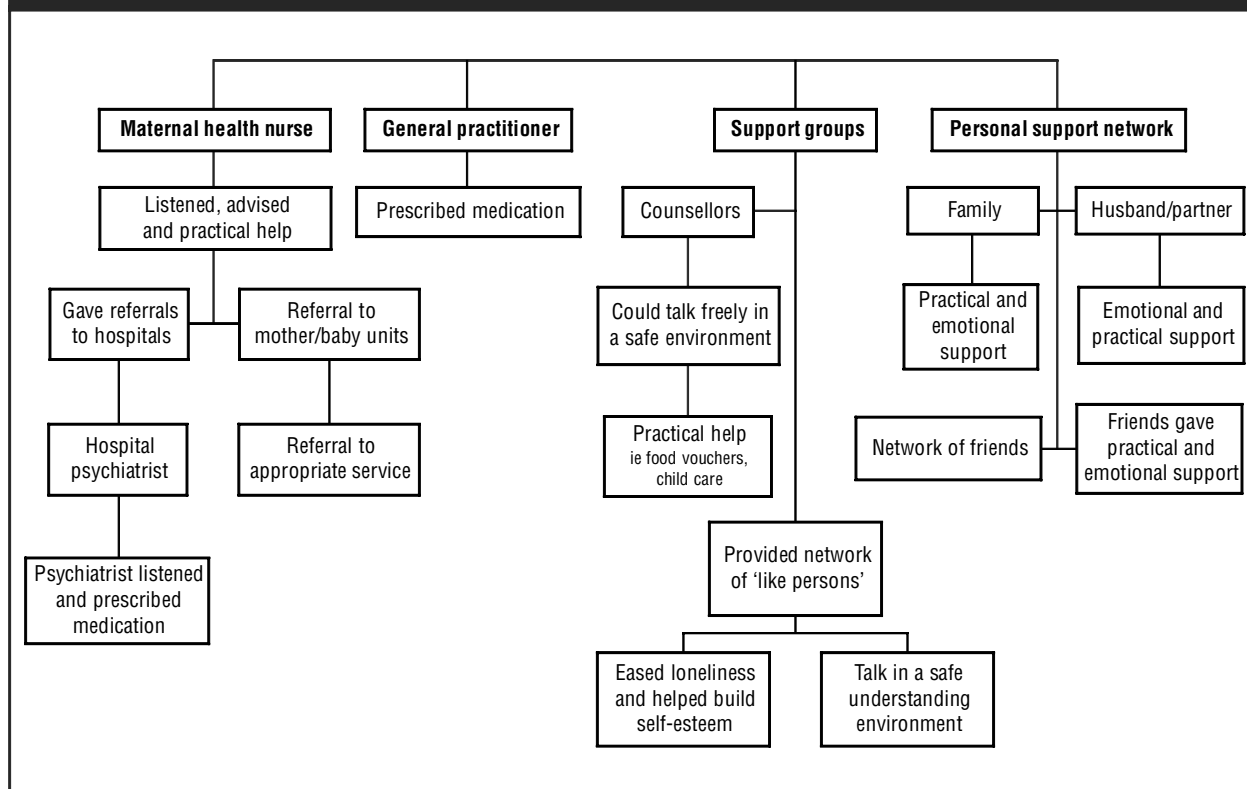
Referrals were made by these sources to hospitals, psychiatrists and mother-baby units. The women’s perception of these four support networks is the focus of the findings.

### Interpersonal support

A support network of significant others included partner, family and friends. Consistent with Morse et al (2000), partners were a great support for four women who reported caring, loving husbands. Karen stated:

*He’s (husband) always been very, very open and very supportive. I’m lucky, he’s a gentle, gentle man. But we’ve always been able to talk about anything.*

Figure1: The avenues of support and treatment reported by women experiencing postnatal depression.



However, Mary, Mandy and Stacy complained about the lack of emotional and instrumental support once they went home from hospital. Mandy reflected on this lack of physical support in the home:

*And then I went from the hospital home and the minute I walked in the door, I started doing washing ... I started cleaning!*

Mary perceived her husband as unsupportive because of cultural practices:

*He was of that era and thought these were women's problems. I never really talked to him.*

In these non-supportive relationships, marital conflict was evident, directly giving weight to Brown's (1996) view that conflict is a factor in PND. Indeed, two relationships with 'unsupporting partners' ended within weeks or months of the baby's birth. However, it remains unclear if the lack of support from partners contributed to or maintained the depression, or if marital conflict was ongoing as a complication of depression.

With family (excluding husbands), the findings indicate mixed support. While Stacy, Mary, Jill and Lee reported having supportive families, Mandy, Emma and Karen's families were unaware of their PND until they were either hospitalised or broke down. These families were unable to be supportive until crisis hit. Consistent with Barnett (1991), the women feared the revelation of their PND would cause them shame and embarrassment at having a mental illness.

Lee and Jill's families were unsupportive as an artifact of sexual abuse. Jill talks about her mother:

*She gave me no help like you think a mother would do for a daughter ... we had a big fight as she just wants me to forget about it [sexual abuse by father] completely.*

### Maternal health nurses

The women reported not knowing where to go for help as Mary explains:

*I don't think I sought outside help because I didn't know what help to get.*

The help they got was incidental as having a baby placed the women in touch with their maternal health nurse who checked the mother and baby's health regularly. The maternal health nurse usually identified that the women either had or were at risk of PND and were in need of support, and would make appropriate referrals. However, Stella's experience was not perceived as supportive. It undermined her self worth by adding to a sense of guilt for being unable to cope with the role of motherhood. Stella explained:

*The health sister nurse was a bitch. I went there one day and she kept saying that 'she's like this because of you. She's picking up on how you're feeling, it's all your fault*

*basically!' I left there howling because it's all my fault, you know.*

More generally and consistent with the findings of Whitton et al (1996), the maternal health nurse was considered helpful as she listened and gave advice. Often she had children so mothers felt she understood their experiences. She made referrals to hospitals, mother-baby units or PND support groups that could offer appropriate help. Mandy declared:

*My maternal health nurse was the only person that was really really helpful ... she knew what was going on in my marriage and put me into Queen Elizabeth [hospital].*

Some referrals led to hospitals and mother/baby units where mothers had helpful and unhelpful experiences. Experiences were perceived as unhelpful when family were uninformed or ostracised from the hospital setting. Emma stated:

*They [family] had been excluded before, it was like this patient confidentiality thing, we're not going to tell you anything, it's up to Emma what you know. And basically, they just didn't know anything and I wasn't capable of telling them.*

Karen reported a positive experience in a hospital:

*The nursing staff there were just great. They were really good to me.*

### Medical professionals

Consistent with Rout and Rout (1996), all of the women received treatment by general practitioners (GPs). As found by Hood et al (1999), GPs did not make referrals to counsellors or psychiatrists. The bulk of referrals came from the maternal health nurse, hospital or community groups. Ultimately, the women were seeking support and understanding from medical professionals as stated by Mary:

*You are looking for the human understanding, not the man or woman behind the seat that tells you what you have to do to feel better. And 'if you don't do it the way you should do it, well what are you coming here for.*

Instead of understanding, the women reported occasional patronising attitudes from doctors towards their symptoms that exacerbated feelings of low self-worth and guilt at being unable to cope. These experiences are supported by Steen (1996) who found that women felt GPs and psychiatrists were often disinterested, and even GPs considered sympathetic were thought to be too busy to have the time to really listen. Jill stated:

*(The Dr) was very concerned and understanding, but unfortunately, I know that GPs have 10 people waiting and they've only got their 10 minutes.*

It remains unclear if the women were sensitive as a result of their depressed state, angry and shameful for

having to consult a practitioner as suggested by Barnett (1991) or if some practitioners fail to appreciate PND as a real illness. Mary stated:

*I kept going to this doctor and he used to give me a pep talk and send me home. I am with three children and a walking distress ... because I had no car ... those years were horrible because virtually he said to me ... that I would just have to put up with it and shut up!*

Furthermore, women complained that without private health cover, they had to wait lengthy periods to see a psychiatrist during which time they became vulnerable to self-medication. Stacy tells:

*And then I had to wait two months to get into a psychiatrist, so I nuked [sic] on those Valium when I needed them.*

Overall, as also noted by Hood et al (1999), the women found GPs and psychiatrists helpful because they prescribed medication that helped alleviate their symptoms. The women reached a time when they could not function and medication became a common way of coping. Supporting Steen's (1996) findings, the women felt medication helped them regain some level of control so they could work out how to deal with what was going on in their lives. Emma explained:

*Once the medication started to kick in I started to get some functioning back and some level of control back.*

Nonetheless, medication was a 'no-win situation' as the women felt shame at not being able to cope alone and stigmatised for taking medication. The use of medication reinforced their feelings of personal weakness in being unable to cope alone, a finding consistent with that of Hood et al (1999). Karen tells:

*Faced with living on medication is very scary. It's just the stigma most of us have. We don't like being supported, we don't like to think we can't cope on our own.*

Without medication, the women feared they might go insane, harm themselves or their baby, and were generally anxious about how they would survive. Jill explained:

*I can't cope with day to day life. Without them, I yell and I scream at the kids ... I cry, I have panic attacks ... I think bad things all the time and then I have got to the stage where I have thought about suicide.*

Furthermore, GPs and psychiatrists did not provide women with enough information to make their own informed choices about medication and treatment. Consistent with Steen (1996), lack of information often led to anger, frustration and fear of the unknown, feelings that served to exacerbate the women's fragile emotional states. The women did not understand how hospitals could help or what was expected from medication. Consequently, they became anxious and often desperate when medication caused side effects like weight gain or

the perception of 'living in a cloud'. Many women had to endure a process of trial and error to find the right medication and dosage compatible with their body chemistry. Lee stated:

*I put on 20-something kilos. . . it was one of the side effects I wasn't told about.*

## Support groups

Support groups were predominately seen in a positive light. As proposed by Steen (1996), the women felt support groups provided them with a network of 'like women' and a safe environment to express whatever they wished without fear of condemnation. The friendships that developed helped to ease loneliness and provide understanding and acceptance as explained by Karen:

*Finding people who were going through the same thing, having that support ... I knew someone was there.*

Furthermore, Jill stated:

*I never talked about anything, so just talking about it helped me to feel better after.*

Mandy reported that while initially benefiting from the postnatal support group, she became overloaded with her own life and was unable to take anyone else's problems on board:

*I'm just sick of hearing about it. I'm sick of going there and everyone just sitting around saying the same thing. I'm fed up with it ... I just feel like my head's ready to explode most of the time anyway.*

These cases suggest that support groups are useful when women feel they meet their identified needs, but may not offer the total solution.

Jill and Lee identified a need to be part of a group focusing on the issue of sexual abuse rather than PND for while the birth of the baby was a trigger, sexual abuse was fundamental to their own experience of PND. While the support group provided the essential elements of listening and understanding, Lee wanted more than understanding, feeling she needed to play an active role in helping herself:

*I needed feedback ... I needed something to work with, like practical method thing, I wanted to work in it, not just talk about how I feel today or how things are going.*

## CONCLUSION

An important issue that emerged from the data is that most women did not know how or where to seek support outside of their home. Consistent with Whitton et al's (1996) findings, all the women recognised something was wrong, but as most of them were first time mothers, they did not actively seek help for PND as they were unaware they were experiencing it. The help they received was

mostly incidental, being identified by the maternal health nurse when she checked the baby's health. This finding confirms the crucial role the maternal health nurse can play in identifying those mothers at risk and providing them with help and support. The maternal health nurse was generally perceived as being most helpful and supportive, providing information, practical help, referrals to other health professionals, empathy and understanding. Her close contact with new mothers places her in a strategic and responsible position that should be promoted to the advantage of women with PND.

Commonly, the women sought support from their GP. The therapeutic relationship with GPs was hindered by limited time and understanding as found in previous research. By increasing the time spent with patients, GPs could address the need to be understood by developing therapeutic empathy via discussion of women's concerns, treatment options and possible side effects of medication.

The issue of medication is important as the women were ambivalent about its use, for although they needed it to function, its use reinforced personal beliefs of being weak and unable to manage on their own. This stigma needs to be addressed by health professionals as it forced women to remain silent about their PND, cutting them off from their own families until their ordeal became unbearable. Ultimately, the help they desperately wanted was to simply be understood. Understanding was achieved when someone took the time to listen. Unfortunately, for many GPs, Medicare issues may limit time, and if so, this is a situation that needs to be addressed.

Partners were supportive in all respects, unless marital conflict was evident. Families were also supportive but were often unaware of the mother's condition. As the mother was frequently incapable of telling them, recommendations are made that health professionals consult and seek the mother's permission to inform her family. Families can then be included in the recovery process, providing appropriate support to the mother.

It is suggested that further study be undertaken describing women's perceptions of the efficacy of psychosocial interventions such as counselling, and medication in the management of the physiological and psychological symptoms of PND.

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## RESEARCH ROUNDUP A summary of research reports from nursing and medical journals

### FEWER ICU NURSES MEAN MORE COMPLICATIONS

Patients undergoing high-risk surgeries are more likely to have postoperative complications, including difficulty breathing, if their hospital's intensive care unit (ICU) isn't sufficiently staffed by nurses, according to a recent US study. Results of the study, in *Effective Clinical Practice*, indicate that while the optimal nurse-to-patient ratio remains to be determined, intensive care units having ratios of one nurse for every three or four patients, rather than one or two, have significantly higher rates of post-surgical complications. Overall, 47% of patients treated in hospitals with fewer ICU nurses had at least one complication compared to 34% treated in hospitals with more ICU nurses. Patients treated in hospitals with fewer ICU nurses were more likely to have medical complications (43% vs 28%) or respiratory failure (21% vs 13%), or need a breathing tube re-inserted (21% vs 13%). Nurse staffing did not affect the risk for surgical complications. For the study, researchers analysed hospital discharge data for 2,606 abdominal aortic aneurysm patients who were treated at 38 hospitals in Maryland between 1994 and 1996. The authors also surveyed 39 local ICU medical directors and nursing directors about their ICU staffing, including the nurse-to-patient ratio during the day and evening. Seven hospitals with a total 478 patients had fewer ICU nurses, compared with 31 hospitals with a total 2,128 patients that had more.

#### Reference

Pronovost, P.J., Dang, D., Dorman, T., Lipsett, P.A., Garrett, E., Jenckes, M. and Bass, E.B. 2001. Intensive care unit nurse staffing and the risk for complications after abdominal aortic surgery. *Effective Clinical Practice*. 4:199-206.

### RADIATION RISK TO NURSES LEADS TO NEW GUIDELINES

Researchers at a British hospital have calculated that on just the second day of looking after a patient undergoing iodine-131 treatment for thyroid cancer or an overactive thyroid, a nurse will have received a radiation dose of up to 1.3 millisieverts. British safety guidelines state that members of the public should not receive more than one millisievert a year. This led the researchers to draw up guidelines to ensure nurses receive less than 0.5 millisieverts. They include limiting shifts to six hours in the two days after the patient is given iodine-131, and each nurse doing one shift only. When the guidelines were put into practice, dose meters worn by nurses showed a reading of no more than 0.25 millisieverts.

#### Reference

Greaves, C.D. and Tindale, W.B. 2001. Radioiodine therapy: care of the helpless patient and handling of the radioactive corpse. *Journal of Radiological Protection*. 21:381-392.

### FIZZY DRINKS AND BONE LOSS IN WOMEN

Women who drink caffeinated fizzy soft drinks excrete high levels of calcium, an American study has shown. The study, in the *American Journal of Clinical Nutrition*, analysed the effects of four drinks, two caffeinated and two non-caffeinated on 30 women who regularly drank between two and seven 330ml cans of carbonated drinks daily. Researchers found small but significant increases in urinary calcium excretion in women consuming the two caffeinated drinks. No effect was seen among women consuming non-caffeinated beverages. The researchers also confirmed earlier studies that showed that caffeine also led to a compensatory drop in calcium excretion during the following 24 hours. The authors suggest that although caffeinated carbonated drinks increased urinary calcium loss this was partly offset by the subsequent lowering of calcium excretion. According to the researchers, the main effect of drinking caffeinated fizzy soft drinks is when they replace milk in an individual's diet.

#### Reference

Heaney, R.P. and Rafferty, K. 2001. Carbonated beverages and urinary calcium excretion. *American Journal of Clinical Nutrition*. 74:343-347.

### SCREENING FOR MALNUTRITION MAY IMPROVE OUTCOMES

Routine screening of patients for malnutrition before their admission to hospital would improve outcomes and reduce hospital stays according to recent research in the *Internal Medicine Journal*. The study which looked at 820 admissions to Sydney's St Vincent's and St George hospitals found that 36% of patients being admitted to hospital were suffering from malnutrition. The malnutrition was associated with increased mortality and longer hospital stays. The malnourished patients, who were predominantly elderly, had a significantly higher annual mortality rate of 30% compared with 10% of well-nourished patients. However, patients previously identified as malnourished and who'd then had appropriate interventions did not have increased mortality rates. Malnourished patients had an average hospital stay of 17 days compared with well nourished patients' 11 days. 'Despite the well-known negative outcomes [of malnutrition], nutrition remains a low priority in hospitalised patients with multiple medical problems, and few strategies are routinely implemented to address the issue of identification of malnourished patients in Australian hospitals,' the study's authors note.

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Middleton, M.H., Nazarenko, G., Nivison-Smith, I. and Smerdley, P. 2001. Prevalence of malnutrition and 12-month incidence of mortality in two Sydney teaching hospitals. *Internal Medicine Journal*. November 2001. 31(8):455-461.