



ANÁIL QUARTERLY

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From the editor

At this time of heated public debate about the "Smoking Ban" it might be helpful to examine the facts again. In 2000 the Tobacco Free Policy Review Group issued a report on smoking in Ireland. This report recommended a change of attitude towards smoking, to support and empower smokers to quit and to protect employees exposed to smoke in work places. The Health & Safety Authority and the Office of Tobacco Control established an independent scientific working group to identify the degree of consensus among scientific authorities about the risk Environmental Tobacco Smoke (ETS) poses in the work place (HAS, 2002). This report provided overwhelming evidence about the effects which ETS has on respiratory health. As a result the Minister for Health implemented the Tobacco Smoking (Prohibition) Regulation 2003, which is to come into operation in early 2004.

While the regulations' primary intention is to protect the health of the employee, it has obvious implications for the whole of Irish society. The hospitality industry worries about business, health care professionals celebrate the regulation as a step towards genuinely promoting health and the public seem somewhat undecided.

For us as respiratory nurses these new developments will present challenges to our practice. Not only will we be faced with more referrals for smoke cessation support but we will also have to find innovative ways of how to combine an anticipated greater need for support with already stretched resources. Furthermore, we will have to question ourselves why many smok-

ing cessation interventions are not as fruitful as anticipated and why many of our respiratory patients continue to smoke.

This edition of the Anail publication has seen somewhat of a facelift. For an association that is growing and taking shape by defining itself and expanding its scope, a regular written medium is a means of communication as well as an opportunity for publication. As editor I would like to invite all members to share their expertise and opinion with the group by submitting research papers, essays, reviews and critique. Make this publication YOURS!

Bettina Korn

Clinical Research Nurse Position

The Alpha One Foundation has secured funding for a targeted detection programme for the condition known as Alpha-1 Antitrypsin Deficiency.

A Clinical Research Unit for this programme is being set up in the Clinical Research Centre in the RCSI Research and Education Building at Beaumont Hospital.

The person will have good organizational/time management and IT skills and will have an interest in research management and clinical work. An interest or experience in education will be a bonus.

The position is offered at CNM 1 rate with the usual incremental increases. However more qualified persons may be considered.

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Nursing & Chronic Illness

Geralyn Hynes, Lecturer and practitioner at the RCSI

Introduction

Chronic illness is increasingly the focus of nurse scholars in their exploration of experiences of patients and implications for nursing practice (Patterson 2001 a & b). With a strong leaning towards qualitative research and meta-analysis thereof this exploration challenges concepts that are claimed by nurses as central to the nurse patient relationship. These concepts include partnership, health promotion and education, empowerment and advocacy. In wider healthcare context medical sociologists and psychologists also highlight the difficulties faced by people with chronic illnesses in respect of loss of previously taken for granted continuity of life, adoption of coping strategies and stigma (Scambler 2002, Joachim & Acom 2000). The literature brings into sharp relief the frequent conflicts that can arise in attending to the notions of partnership in decision-making and empowerment and advocacy within the healthcare environment. This short paper will present the nature of some of these conflicts and implications for nursing practice.

Defining chronic illness

Chronic illness has been defined as that in which one '*changes from being healthy to having to live with illness in the world of health*' (Radley 1994 p 136). This definition infers a level of adaption required that goes beyond the physical in order to re-engage with the world. To draw on the writings of Sally Thorne (1999) illness might be viewed not as a clinical event but rather as lived, emotive, social and even political event. This view is all the more pronounced when it is chronic where the physical or bodily experience is illuminated in the social world (Millward & Kelly 2003). The obvious example here is the well-established link between social class and chronic illness (Blaxter 2003). It may also be argued that in a world of health illness may be judged as a deviation from the norm including cultural conventions and even an expression of failure on the part of the individual e.g. failure to contribute to the labour market, to behave in a healthy manner etc. Thus the individual's interaction with the social world, his presence and sense of self in this relationship are altered. Living with illness in

the world of health requires a re-definition of sense of self (Millward & Kelly 2003).

Nursing and chronic illness

We, as nurses, have been educated to a particular worldview of illness and its meaning and this relates to such parameters as function levels, pain and prognosis and management. On the one hand we talk of the importance of person-centred care and individualised care and on the other we adhere to theoretical concepts we have gleaned from bio psychosocial sciences, which have provided us standardised approaches, to care and with expected responses from our patients. So there are instances when we accept as normal anxiety or pain and so as experiences they become legitimate while other times these are considered inappropriate. Rather than looking to the diversity of human nature and life experiences we rely on standardised tools to define what is normal or average. These tools are juxtaposed with the standardised approaches to disease management derived from guidelines normally developed from a relatively small homogenous group of medical experts. Yet there is no shortage of evidence pointing to the uniqueness of individuals and experiences of illness events.

Joan Liaschenko (1997) develops this theme in her work on knowing the patient where she sought to examine what it means for a nurse to know a patient as a person. She describes three knowledge groups used by nurses and explores the implications of these. These knowledge types include:

Knowledge of the case: the generalised knowledge of physiology, diagnosis, treatment possibilities and statistical outcomes e.g. derived from guidelines for management of COPD (Global Initiative for Chronic Obstructive Lung Disease Scientific Committee 2001). We can learn and know this knowledge without the patient who is an entirely passive entity in this. We are concerned with our understanding of the objective path physiological and psychological data, of monitoring the functioning of this data.

Knowledge of the patient: the knowledge of an individual in context of his history, demographic data and support systems applied to case knowledge. The nurse comes to know the patient

through work routines and responses to care. However this knowledge does not extend to knowing the individual patient as someone with a unique experience and intentions and desires.

Knowing the person: the coming to know the individual as a person with a unique life story, how he/she is situated within and engages with the world.

These distinctions have clear resonance for nursing the chronically ill where we appear to place such emphasis on partnership and empowerment and advocacy. Liaschenko (1997) suggests the meaning of knowing the person includes recognising how he/she lives, engages with living, and applies meaning to living. This includes also the temporal and spatial dimensions to life where temporal refers to patterns and routines of living, engaging with the world through connections with others, work etc. Spatial dimension refers to the social and socio-political contexts that an individual occupies in sharing in the lives of others and in the social position he/she occupies and the corresponding access to resources that follow this social position. Arguably then, the *presencing of self* in the social world (Millward & Kelly 2003) occurs within these dimensions.

Illness disrupts a person's routine of lived experience – the temporal dimension. As nurses we seek to make this disruption a more manageable element integrated into the life experience of the person. Knowing a person's routine of lived experience means knowing how the order of his/her life gives meaning. Illness also impacts on a person's ability to share in the lives of others. Thorne (1999) cites the Canadian film maker, Bonnie Sherr Klein who recounted her experience following a devastating stroke where she was forced to alter her engagement with living, adapting to limited energy and to heed to her body's requirements. Her connections to others were altered in her learning to allow others to help. Knowing the person in this way takes time and demands that the nurse examines her own subjectivity, her likes and dislikes and moral ways of knowing as these will interface with her growing knowledge of the other person. In many nursing contexts knowing the person in this way is not possible e.g. acute care where the patient is discharged quickly. Importantly caring for the individual with a chronic illness necessitates

attention to the notion of *re-presencing of self*. Knowing person becomes possible and indeed desirable particularly when we talk of patients participating in decision-making or 'empowering patients'.

Patient empowerment

However while we may intuitively believe that knowing the person with a chronic illness is important to our commitment to patient care the difficulties we face must be explored if we are to pay more than lip service to the concepts of empowerment and patient participation in decision-making. Barbara Patterson (2001a) concluded from a 2-year longitudinal study of decision-making processes of 22 adults with long standing type 1 diabetes, that while empowerment might appear to offer the promise of active participation in decision-making, the reality is different. Practitioners practised in a way that actively though subtly militated against participatory decision-making or even support for experiences of their patients which differed from the textbooks. A key-factor here was the positioning of the practitioner as the expert and authority and of professional dominance.

Patterson's work highlights the conflict inherent in a policy of promoting empowerment through active participation in decision-making process in a health service environment that focuses on time management, throughout of patients and resource efficiency. Active participation in decision-making in the management of chronic illness by definition demands a longer consultation and flexibility with appointments' systems since the nature of chronicity implies complex medical, psychological and social needs that cannot be easily addressed in the time-efficient medical model of care. Conversely our seeking knowledge of an individual's life experience might be considered by some to be intrusive leaving a possible feeling of Big Brother and to cite Liaschenko (1997) potential for nurses to become instruments of surveillance. The more a nurse knows her patient, the individual with unique life experiences, the greater the potential to monitor him/her in a variety of ways.

Knowing the person significantly complicates nursing practice. This level of knowing exposes complex relationships such as that of the individual to the world of health (Scambler 2002, Koch et al 2000); of the individual to the health professional

(Patterson 2001; Radler 1994) and that of the sufferer to the past and future illness experience (Koch et al 2000 and Radler (1994). The adherence to and application of standardised guidelines become difficult against the background of an individual's life experience and values and norms. A nurse might disagree with her patient's convictions and beliefs but how can these be addressed? If I, the nurse, am to remain true to the guidelines and knowledge of best practice then I may subtly coerce the individual into doing it 'our' way. This resonates with Patterson's findings (2001a) mentioned above and conflicts with the meaning of empowerment and partnership.

Qualitative research has provided us with a means to explore meanings and experiences of illness thus assisting us examine these issues. However this approach is not without its difficulties e.g. limited in generalizability and vulnerability to the deep-seated norms and values of the researchers as identified in a meta-analysis of qualitative studies on chronic illness (Patterson 2001b, Thorne 1999). In her work exploring the meaning of chronic illness, Thorne (1999) raises important questions concerning nurses' participation in the social and health worlds of their patients – the spatial dimension. As nurses we must examine our role in and contribution to the often hostile socio-political healthcare environment and contribution to our patients' experiences therein. Such an approach offers us scope to become advocates at local and national level. To quote Liaschenko (1997):

'Acting on knowledge of what it means for a person to have a life may require that nurses take a stand against received wisdom, be it religious, legal or medical. Yet to do so is no small matter' (p 36)

Health and illness

Returning again to the individual and his concept of health, it might be useful to explore it in the context of his illness. Elizabeth Lindsey (1996), in her work on health within illness, draws on the work of Nietzsche, the philosopher, and Tillich, the theologian, to make the point that health and illness are not separate entities. Rather health and illness are each part of our existence, our organic whole, which appear to us in varying degrees at different times in our lives. The point here is that by focusing on the illness experience, we fail to see the

whole picture because we omit the health experience. Lindsey illustrates this in her reference to large studies undertaken in Canada that found between 60% & 70% of people living with chronic conditions considered their health to be good or excellent. Interestingly findings from the Central Statistics Office Quarterly National Household Survey Third Quarter 2001 indicated that people in Ireland tend towards positive perceptions of their own health compared with our European neighbours (Department of Health & Children 2003a). Such findings indicate a need to reconceptualise health within chronic illness and draw on the life experiences of the individual – knowing the person rather than knowing the patient. Barbara Patterson (2001b) presents us with a means of addressing such a need in her proposed *Shifting Perspectives Model of Chronic Illness*. This offers nurses scope to move from a linear approach to care in which a plan of care is developed at start and seeks to inform care based on exacerbations and remission thereafter towards an approach that recognizes the experience of chronic illness as being dynamic and contextual.

This leaves some interesting questions for nurses working in Ireland amidst the current debates and proposals for the Irish Health Care System. Recent documents (Department of Health & Children 2001 a & b, 2003b) perhaps illustrate the invisibility of people with chronic respiratory illnesses. In the consultation forum (Department of Health & Children 2001b, that was part of the development of the health strategy (Department of Health & Children 2001a) there is remarkably little reference to respiratory illnesses and none to chronic obstructive pulmonary disease. Given the fact that chronic obstructive pulmonary disease is primarily smoking related and therefore leaving a sense of being 'self-induced' by both the sufferer and health professional the possibility of reticence as a result of stigma and guilt cannot be ignored. The proposed restructuring of the health care system (Department of Health & Children 2003b) is radical but leaves questions as to how the Primary, community and continuing care pillar will interface with the Acute pillar within the Health Services Executive. In human terms how will it be possible for nurses to advance an approach to care that recognizes the experience of people with chronic respiratory illnesses that require a two-way flexible and on-

going communication at the primary/secondary interface? Perhaps more fundamentally how can nurses working within healthcare teams advance a truly critical perspective of individualized care?

Conclusion

Chronic illness impacts on the individual's interaction with social world (Thorne 1999, Millward & Kelly 2003) in a profound way that necessitates a reappraisal of identity in adapting to living with illness in the world of health (Radley 1994). Thus the process of adaptation is integral to coping and managing chronic illness. In the current climate of health care delivery where chronic disease management places emphasis on self care, patient empowerment and advocacy nurses are in a position to engage with patients in the process of adaptation (Liaschenko 1997). However such engagement brings into relief the tensions that exist between individualized patient care and implementation of standardised guidelines resulting in disempowerment and alienation for the individual. As nurses increasingly assert their presence in exploring these tensions there is significant scope to influence a reappraisal of approaches to care. Paradoxically the potential power of nursing in bringing about a shift in approaches to care lies not in claiming an *expert* label. Rather the power lies in the nurse becoming a participant in the individual's process of adaptation.

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Mark your calendar!

World COPD Day 2004:
November 17

World COPD Day 2005:
November 16

Respiratory Information Day

Lindsay Brown, Respiratory Clinical Nurse Specialist

St. Vincents University Hospital provided the venue for the annual Respiratory Information Day. This was held in the Education and Resource Centre on Saturday 13th of September. Forty delegates attended from both hospital and community settings.

The content of the day was designed to give a multidisciplinary perspective on the management of respiratory patients per se. Further we hoped to generate an impetus for nurses to aspire to undertake research contributing to evidence based practice. Similarly the idea of pursuing the role of Advanced Nurse Practitioner was explored.

On balance the day was weighted theoretically with many challenges to nurses to look critically at their practice and appraise honestly their ability to provide "holistic care" in its purest sense.

The day was opened by *Professor Walter McNicholas*; Director of the Respiratory Education Centre.

A synopsis of the attending speakers follows:

Paula McBrearty; ANP in the emergency department at Mater Misericordiae. Paula offered us a comprehensive pathway towards developing the role of the ANP; highlighting the prerequisites demanded by The National Council for Nursing and Midwifery in order for the post to be accredited. She made reference to the legal implications of assuming an autonomous role whilst working within the protocols laid down in the emergency department. She was particularly encouraged at the continuity of patient care and follow up that has emerged since the ANP became prominent.

Paula indicated the rigorous academic path that the ANP must follow; namely achieving a Masters degree and completing the ANP course at St. James Hospital, whilst continuing to work full time. Further the ANP is expected to be at the forefront of nursing research.

Geralyn Hynes; lecturer and practitioner within the RCSI introduced us to the concepts of health capital, holism, consequences and significance. She provided innumerable definitions of chronic illness and its implications for our practice as nurses and our understanding of the individual patients experience of illness.

Geralyn challenged us to look at our role as nurses advocating for our patients, managing our patients holistically. She asked us to consider how we as nurses influence the socio-political environment within which our individual patients live. Can we say we do this? If not do we truly treat them holistically? Again Geralyn asked us to consider the notion of our patients as well people living with a chronic illness, and how this would impact on our approach to nursing care. Overall this talk was stimulating, thought provoking and progressive.

Valerie Swan; Sleep Nurse Specialist at St Vincents University Hospital offered a practical approach to the management of patients requiring Bipap/Cpap. She indicated the patient selection process, contraindications and that the importance of patient preparation prior to initiating the suggested therapy was paramount. Feedback from the audience indicated that nurses want to hear more about NIV and desire practical hands on experience. Perhaps a one-day workshop run quarterly would satisfy this demand.

Halog Mellett; Senior Dietician in Cardiothoracic Surgery and the Lung/Heart transplant unit at Mater Misericordiae spoke eloquently re optimising the nutritional status of patients with chronic respiratory disease to maximise their respiratory muscle strength, mass and function to enhance patients overall status and prognosis. Halog adopted a scientific approach to this subject, which was refreshing and incredibly informative. The key issue of note was that 20-35% of COPD patients have fat free mass depletion directly associated with deconditioning, prolonged use of corticosteroids which increase

proteolysis and gluconeogenesis, recurrent infections and poor oral intakes. Halog intimated that chronic respiratory patients' need upwards of 3000 calories simply to maintain their current weight. She advocated nutritional support to maintain ideal body weight, which has been shown to improve pulmonary function, improve peripheral muscle strength reduce occurrence of respiratory infections and extend longevity.

Katherine McKeown; Counselling Psychologist at St Vincents University Hospital working more so with the Cystic fibrosis patient cohort introduced us to the complexities of man's psyche. Katherine discussed the loss of sound self that accompanies respiratory disease progression. The individual having to learn to live with a less efficient and less dependable body, adjust to a restricted lifestyle with fewer choices and the repercussions of how this impacts on family and friends.

Katherine explored how we can support the individual in maintaining a sense of normality.

Dr Anne Marie McLaughlin; Specialist Respiratory Registrar currently researching genetic polymorphisms in Cystic Fibrosis at UCD presented an extremely useful talk on how to utilise on line databases to access evidence based information. She spoke about the relative merits of certain sites, and especially those ones she has found of greatest value personally. Feedback suggests that

nurses' needed this talk a long time ago and more assistance re getting started in research would be beneficial.

Claire Keane; Senior Pharmacist at SVUH based on the respiratory wards offered a comprehensive overview of respiratory medicines inclusive of their role, duration of action, dose, frequency of use, adverse reactions and device availability. Further Claire made reference to the BTS guidelines for Asthma management encouraging nurses to read this document from cover to cover. She also spoke of the BTS guidelines on COPD and emphasised the unfavourable risk benefit profile of using long-term oral corticosteroids in this patient group.

Claire Reilly; Senior Cystic Fibrosis Physiotherapist at SVUH provided us with a powerful and insightful talk into the role of physiotherapy in optimising lung volume via patient positioning, mobilisation and breathing exercises. Further she referred to retained secretions and the techniques employed by the physio to assist mucociliary clearance. She highlighted means of reducing the work of breathing. Finally Claire advocated pulmonary rehabilitation as a valuable strategy in returning patients to their highest functional capacity. She felt strongly that this should not be a last ditch management strategy.

Non-invasive ventilation course at Letterkenny Hospital

A non-invasive ventilation course recently commenced at Letterkenny Hospital. This course runs over a six month period with two contact study days in November 2003 and two further days in March 2004. Completion of the course will give participants 30 CATS points towards a diploma and will be category registered with An Bord Altranais. The course has previously been held over 16 weeks for NWHB staff with encouraging response. Ms. Patricia McLaughlin, Respiratory Nurse Specialist at Letterkenny General Hospital is the course facilitator and organises it in conjunction with the Respiratory Education and Training Centres (ETC), Liverpool, UK.

Contact: Ms. Patricia McLaughlin at Patricia.McLaughlin@nwbb.ie or ETC by phone at 0044 151 529 2598

The spring edition of the ANAIL Quarterly will follow the development of the course and report on the experiences of both the facilitator and the course participants.

European Respiratory Society Annual Congress 2003

Maria Lawlor, Respiratory Clinical Nurse Specialist

The 13th Annual European Respiratory Society Congress took place in Vienna, Austria from September 27th to October 1st 2003. The Austria Centre (conference centre) was a superb location and adequately catered for the 14,000 delegates from around the world.

There was an abundance of symposia, postgraduate courses, and oral and poster presentations to attend. I attended the Allied Respiratory Professionals two-day package, which comprised of two postgraduate courses from 9am to 5.30pm on the first day and symposia on evidence based practice, critical appraisal and COPD on the second day. The registration cost for this package was Euro 170. There was a choice of postgraduate courses, which were pre booked when registering for the conference. A word of caution from my colleague who also attended – read the content of the courses carefully before booking because they range from basic to advanced levels. The second day was tailored made for nurses, physiotherapists and respiratory technicians.

Although a predominantly medical and scientific meeting, at all times the allied health professionals were remembered and encouraged to participate. The ERS is aware of the different needs of the many different professionals working in respiratory care.

The registration fee included admission to the opening ceremony, where the welcoming address and award ceremony was interlaced with a repertoire of classical and modern Viennese music and photographic scenes from around Austria. A cocktail reception for the allied respiratory professionals was held on the second evening where one could mingle and get to know fellow allied respiratory professionals.

On a less positive note this two-day package was intense and offered little time to browse the poster presentations and exhibition stands, or to sight see in the beautiful city I had heard so much about. Next year I would hope to have a longer stay at the conference

because there was an endless choice of topics that interested me over the five-day conference and which I could not attend.

I would highly recommend respiratory clinical nurse specialists from Ireland to attend next year's conference in Glasgow. Start booking early because I have heard that hotels are already booked up! If going to the conference isn't a possibility, respiratory clinical nurse specialists can also avail of the affiliated ERS membership for Euro 45, which entitles the member to on line access of ERS journals, e-learning resources and membership of various groups and the ERS newsletter.

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Presentation of Higher Diplomas in Respiratory Nursing Care at the RCSI

A conferring ceremony took place at the RCSI in late November, where nine graduates received a Higher Diploma in Respiratory Nursing Care. This is the first group of students being accredited a HDip for their studies in this speciality by the National University of Ireland (NUI).

The course is being facilitated by Ms Geralyn Hynes, lecturer at the RCSI and was steered in conjunction with experienced respiratory nurse specialists from Dublin based hospitals St. James Hospital, St. Vincent's Hospital Elm Park, James Connolly Memorial Hospital in Blanchardstown, AMNCH in Tallagh, Peamount Hospital and the Mater Hospital.

On behalf of the graduates the editor would like to acknowledge the invaluable contribution these nurses have made towards the success of this course. Their input, thought and enthusiasm for the speciality created a learning experience that allowed each student to rise above the rim of their own area of work, broadening the horizon and producing a strong sense of connective strength within this speciality of nursing.

Another group of students is currently studying in its second and final year.

For information on the course programme please refer to the article by Ms. Geralyn Hynes in issue 5 of the ANAIL Newsletter (p.4).