

WINIFRED RAPHAEL MEMORIAL LECTURE - 2005

PATIENTS' PERSPECTIVE & RESEARCH DILEMMAS

Introduction

Pleased to be invited because of long time association with the RCN, which has had a significant influence on my whole career.

When I was invited to give this lecture I was asked to speak about consumer/user involvement issues in nursing, in relation to nursing research. I chose the title Pts' Persp. & Research Dilemmas because it married two career long interests. (I use the term 'Patients' because neither my mates nor I like being a user or a consumer.)

When I accepted, I remembered the difficulties I had met in the past, in measuring patient satisfaction and standards of care and I thought it would be interesting to find out how these dilemmas have been tackled over the years. It has been a very interesting exercise which I am looking forward to sharing with you this evening.

Reminiscence

However, from the greyness of my hair, the falseness of my teeth and the creaking of my back you can tell I am in my anecdotage so
..... I am going to start with some reminiscing.

I started nursing over 50 yrs ago – NHS 3 yrs old. Brave new world for nursing, which at that time was considered to be the best in the world.
Othopaedics and general training.
1957 Staff nurse in psychiatric unit at St Thomas's and eventually did psychiatric training.
Joined the RCN on qualifying as SRN – for insurance

Just after qualifying in 1957 I offered to speak at 1st R.C.N. staff nurses conference in the Cowdray Hall.

Met two influential people ~ one encouraged me to attend RCN branch meetings - which I did thereafter.

The other was the main speaker who talked about her research about qualified nurses- Gertie Ramsden – who I continued to meet at the RCN branch meetings through the years.

Much later, when being a general nurse tutor & doing ward teaching, I met the difficult patient problem and wanted to explore it so I sought advice from Gertie Ramsden, and.....

.... she took me along to meet her research minded friends - who were Winifred Raphael and some early nurse researchers and these gatherings at Winifred's house eventually evolved into the RCN Research Discussion Group, & then Society.

Winifred Raphael was a sociologist and very interested in nursing & research and was having difficulty with a 'patient satisfaction survey'. Because we are here as result of WR's life-long interest I thought you would like to hear a little of those early days

The reason for setting up W R's Patient satisfaction survey was as **a response to hospital administrators' need** to compare standards in wards across different hospitals

Designing the study & questionnaire posed many problems that I won't go into but mainly about getting patients to fill them in and return them. Eventually resulted in an attractive and useful tool.

The results showed nurses' approach & interaction being the most important factor for patient satisfaction - as have most other published studies.

Continued my career, and some years later....

.....Working as psychiatric tutor at Tooting Bec ~ still attending RCN meetings and was the Branch Representative for several years but had stopped going to the research group
Had arrogant wish to reform mental nurse training
Saw advert: for Research Assistants for the 'Study of Nursing Care Project' and saw this as a tool to further this wish.

Project set up by the Ministry of Health for the Prices and Incomes Board to provide a technique for measuring 'quality of nursing care' – to enable monitoring of effects of changing the composition of nursing teams.

Quality of nursing care in the NHS was accepted as OK

Original aim was not possible to achieve but....

.....Gave some insights but didn't produce measures [show books]
(The Proper Study of the Nurse – Jean McFarlane.)
(Towards a Theory of Nursing Care – Ursula Inman)

I was very fortunate to be one of the six people to be appointed to the first team.....

..... with the result that two years later the study that I undertook was published as *The Unpopular Patient*..... and I became the most unpopular nurse.

Towards the end of doing the study I married and by the time it was published, I had two daughters and moved to Lancashire, and returned to tutoring at the local psychiatric hospital.

Some years later my husband died and I retired to a very interesting and varied and sociable life, and then seven years ago...

..... I met Derek

He was a 50 yr old acquaintance who had Crohn's disease, and needed major surgery.

He asked me to be his advocate while in hospital and I became his constant visitor and shared with him and observed many lacks in his nursing care, until he died eleven months later, with infection from three different strains of MRSA present.

He was looked after in seven different wards, with the care similarly poor in all of them.

I observed nurses who appeared overworked, under-skilled, under resourced and not well organised.

Not just a local problem. It is a national issue.

Over the year – and it still happens – I received many similar examples of poor care experienced or observed by family and friends from all over the country + lots of media reports.

I spent a lot of time and effort trying to understand why nursing had changed & identified many factors ~ but not relevant to this talk.

After Derek died – I decided to share my observations with:-

Director of Nursing Services at the hospital.

Someone with authority at the University [Martin Johnson} – and discovered both had used *The Unpop Pt* in their PhD's.

The outcome

I discovered I was famous and not infamous.

I didn't tell either of them anything they didn't know.

IMPORTANT TO SAY.....

- 1. The hospital and university concerned figure high in the league tables***
- 2. In both places there are able and dedicated staff striving and managing to do a good job in really difficult circumstances.***

3. Since then things are improving but a long way to go.

At last that leads me to what I am here to talk about.....

I HAVE TO IMPRESS UPON YOU THAT...

This is NOT a researched lecture ~ It is all about impressions.

When I state anything as fact you are at liberty to take it or leave it.

So..what is the patients perspective?

Becoming of increasing interest to me and my friends as we age.

- What do patients want?
- What do patients need?

Being admitted to hospital – major life event –always remembered because of.....

.....High anxiety levels –Ill –cut off from support – a stranger in an established group – not in control of own destiny.

Main want - to feel physically and emotionally safe ~

Pts will put up with a lot if they FEEL in safe hands

small +ve inputs have big calming effect

but small –ve inputs have big anxiety effect

Adrenalin, and other stressor hormones, racing round the system interfere with healing processes.

Reassurance that has to be **given** is not reassuring

What do patients need from nurses?

- Lots of attempts to define nursing all around the world
- Study of Nursing Care Project couldn't do it.

Not the place to go into definitions

As RCN members you will know the recent RCN definition.

As registered nurses you will be familiar with the NMC Code of Conduct and you are all the paragons of nursing virtue they expect you to be.

My definition = “the task of nursing is to ensure the physical and emotional safety and the physical and emotional well-being of patients, in support of the treatment from the medical team – 24/7”

Easy to say but difficult to do.

Nurses need sound knowledge, well honed skills and good organisation to carry that out.

My personal belief is that they should not take on extended and extraneous roles until there are enough nurses doing that well, throughout the service

What do patients not need?

To be problem solved . To be care planned
To be risk assessed. Case assigned
Clinical governanced Benchmarked etc.

They need safety, comfort and dignity and don't care how it is delivered.

As an aside – not nursing – they don't want choice ~ **they want where they are at, to be good enough.**

Don't want information if it smacks of people shifting responsibility

Don't want the burden of decision making for the same reason.

Don't want list of horrifying side effects pre-op

So where does research fit in?

In late '60's when we were visiting lots of hospitals for the study, it was accepted that nursing was in 'good shape' ~ some less than good practice observed, but at worst the patients were safe and adequately cared for.

In late '90's nursing care on many criteria was less good.

Many factors that contributed to difficulties in the wards but..... it did appear that the nurses seemed under-skilled – was there evidence of this?

Was there research activity that addressed improving conditions and standards?

?answers

In trying to answer these questions for this talk I have had the most interesting time.

I started by asking people to point me to any landmark research studies that provided measures of patient satisfaction or measures of standards of nursing care ~ and answers came there none.

So I set myself the task of exploring what research findings were available, and what had been added to the body of knowledge in this area since The Study of Nursing Care Project.

I started with the shelves of books on nursing research in the library.... Then the dozens of papers in innumerable volumes of the many journals devoted to nursing research.... And then I mastered the Reference Manager software to refine my searching and found

‘masses of published research’

An early internet search turned up 8,403 results for quality of nursing care and 47,557 for patient satisfaction.

I gave up trying to count the number of journals that regularly publish nursing research papers ~ endless issues and volumes full of them.

And then there are the unpublished MA and PhD dissertations that must be around in their thousands

What does all the research add up to?

There was lots of jargon and statistics and it reminded me of the definition of psychology “putting what everyone knows into language that no-one understands” – and often the only recommendations were that further work needed to be done

WHAT HAPPENS TO THE FINDINGS??

Do they get translated into better care or better conditions, and if so, how?

I asked lots of people who might know – could they give me any instance of where research findings had translated into improved care & they replied:-

we’ve got ‘clinical governance’

we’re using ‘benchmarks’

there’s ‘evidence based care’

and ‘NICE directives’

.... And to inform myself about these things I went to the internet ~ and needed to get myself hitched up to Broadband!!

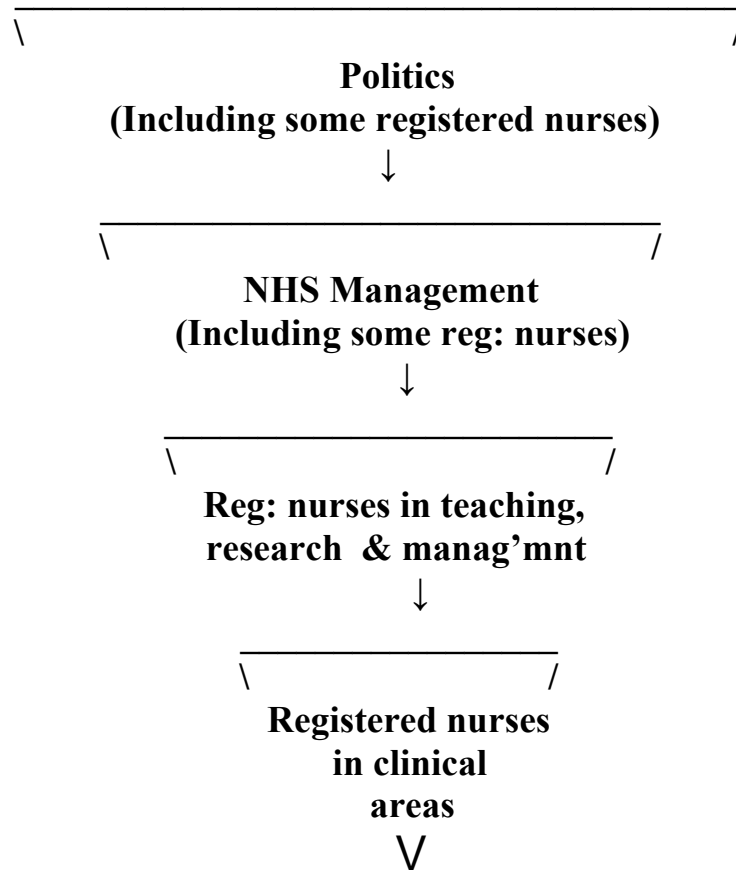
Masses of information about theseand many other

- initiatives
- strategies
- frameworks
- developments
- indicators etc etc.

- [For each of these there were reams of information ~ 66 pages on the first site on Clinical governance and it got worse.]

As I tried to find something concrete amidst all the verbiage my poor brain became bogged down and I lost track in looking for relevant research recommendations, because an image in my mind took over. The image is an upturned pyramid

THE UPTURNED PYRAMID



At the tip ~ registered nurses working in practical nursing situations in the NHS, not always adequately prepared and not nearly enough, but supplemented by foreign nurses and care assistants.

At the next level ~ ‘bearing down’ on the practising nurses ~ Registered nurse managers and registered nurse teachers/researchers. (Numbers have increased over the years, esp. with Project 2000)

Above that are the Hospital Managers and financial pressures and planning ~ 'bearing down' on the levels below. ~ There will be some registered nurses at this level.

The uppermost layer of the pyramid consists of all the people devising & implementing the social and political pressures, including star ratings and targets etc. There will be registered nurses at the Dept of Health & NMC

The pyramids effects

All these pressures bear down on nurses at the coal-face, making the daily tasks more onerous (more people to communicate with; more form filling, more demands, etc), & any ward-based research being carried out, piloted or implemented can be a pressure too much [Not made easier with students who have to be taught supervised and assessed, while patients are more ill and turnover speeded up.]

Also these upper layers of the pyramid are likely to be drawing on 'the brightest and best' of the nurses to join their ranks, after minimal time at the work face.

[I have no idea how far up the pyramid John Reid goes to collect his nursing number statistics!]

This image gave me lots of food for thought...

Thoughts

- Nursing is the cornerstone of the NHS
- Thousands & thousands beavering away yet standards of care still give cause for concern.
- The nursing profession seems to have got itself into a mess.
- How did that happen?

Going back to the study of nursing care project –

It got funding to provide a tool for management and whatever else it achieved, it didn't manage to achieve this.

However beyond that task there was a hidden agenda ~

A band of senior nurses frustrated by nursing becoming marginalised in the increasingly complex NHS, wanted change and they desperately wanted a legitimate professional status for nursing and with it more power and influence.

[1968 the Salmon Committee was set up to generate a senior career structure – but Lord Salmon disparaged nursing and prescribed the Nursing Officer roles to be divorced from any clinical engagement.

Got some higher pay scales

Did nothing to enhance the professions standing or influence **BUT** had the effect of diminishing the value of working in the clinical situation, within the profession.]

Thoughts cont.

In the past the ward sisters had been regarded as the props and the stars of the profession

At the RCN discussions about the Salmon proposals, many nurses had wanted a medical style career structure with continuing clinical input, but they lost out and so, turned instead to seeking academic professionalisation.

The study of nursing care project was a small beginning towards making the nursing profession ‘research literate’ and knowledge based.

Nursing degrees were introduced and nursing research came on stream..... but too slow.

The Apprenticeship method of ‘training’ was seen as the big handicap, so moves were set in motion to dismantle it.

That eventually resulted in the setting up of a university based education – Project 2000

What are the effects of Project 2000?

- Not for me to ask here whether it has gained status & influence for nursing
- Or to ask how effective it is in preparing students for nursing practice.
- But to question whether academic research, which is an essential part of it, is help – or hindrance – from the patients’ perspective.

Referring back to my experience alongside Derek.....

.... when patients see work left undone/mistakes made or they feel neglected, they well may ask of nurses and nursing.....

Do they not know how to do it?

Do they not want to do it?

Are they too busy to do it?
Are they 'too posh to wash'?

And there is a feeling abroad that university nurses aren't as good as the old sort.

What are the dilemmas of nursing research?

Why isn't the huge amount of research activity overcoming the many difficulties facing nursing and getting translated into improved standards of care and increased patient satisfaction?

From my observer stance I would say there are some intrinsic difficulties in translating findings from academic research into improved conditions and standards of care, but I think there are some dilemmas beyond that.

There are difficulties of actually doing and testing research in the clinical areas – nurses too busy, move too often
patients too ill, and stays too short.
agency and bank nurses
needs of students conflicting.

Moving research findings onwards to the clinical guidance and NICE etc. endeavours doesn't help to implement useful change at the workplace for the same reasons, plus there are extra burdens when attemptedtoo much form filling.

I was forced to the conclusion that academic research of itself generates a real dilemma from the patients viewpoint. Because it seems to take more out of the clinical situation than it puts in!!!

Several months into preparing this talk I felt total GLOOM

- With the pyramid image in my mind I was horrified by the implications
 - Decided to go back to expounding on intrinsic dilemmas of research – of deciding what to measure and designing appropriate tools to do the measuring, when
- a knight in shining armour came to my rescue via my computer.

Len Bowers who is Professor of Psych Nursing at City University, posted on the Psych Nursing emailing forum, the web address of the write up of a study his team had carried out, on patients absconding from acute psych wards. As I read the account of the project on the internet I saw that :-

- It was carried out in the clinical situation
- It involved the patients and their relatives and all other personnel that are relevant to the problem throughout the project
- Researchers were based in the ward.
- The solution emerged. The findings were readily accessible
- A workbook had been made available plus other bonuses [show booklet.

Action Research

I recognised this study as being something I called action research, which had been around in industry since the 1940's but had never been seen as legitimate research in academia, and I had long thought was a possible technique for solving problems in nursing.

In talking to Len about his teams research, two things came across:-

1. That type of research method was not properly Action Research – but to my mind, whatever it was called it served the same purposes
2. That there were other teams around who were using similar techniques, and he referred me to the RCN Practice Development Unit ~ and I have had encouraging phone conversations with them about what they are doing. And then by chance I discovered that UCLan also has a Practice Related Research Unit...

.....and where there are a few there are probably lots of others.

Recommendations

So from my explorings and musings I guess I am saying that the huge amount of research generated so far has failed to make a significant difference for nurses and patients at the work-face.

And being cheeky enough to make recommendations I suggest:-

The nursing Profession has to take the bull by the horns and declare **Unilateral Independence**

.....and first of all restore what Salmon denied and gets senior nurses into the wards - with an increase & role extension of nurse consultants and introduce another role of high status 'resource' nurses to cover all the clinical areas, who could teach & assess students and have a practice type research commitment, in liaison with the university.

The universities would need to become experts in Practice Related Research, in its various forms, which is carried out at the work face, and prove it can have academic legitimacy, with the same academic discipline and value for awards as traditional research....

Nursing faculties are very important to universities – for their contribution to funding. – and they contribute high status when they score high assessment points – so they should be in a strong position to negotiate change.

Comments

Implementing a senior clinical nursing career structure that has close integration with the university and research would put the care of patients back at the center of the nursing profession's ethos
It could provide a 'nursing' career in addition to those in management, teaching and research 'supervision'.

Having senior nurses actively engaged in nursing would restore the status of bedside care within the profession, which is now seems to be somewhat lacking.

Having skilled nurses linking theory to practice and monitoring the students' placement experiences, would maintain and improve standards of care.

Placing more research focus on the doing of nursing has the potential to improve practice, offer more individual job satisfaction and enhance the status of the profession.

So, with great generosity I offer you an exciting challenge, which of course you may take or leave

.....but either way I shall scuttle back to the pleasant pastures of retirement.