

I'm the one who has the cancer

will someone please listen to me?

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What have nurses learnt from cancer patients over the last few decades?

Critical and comprehensive analysis over the last 40 years indicates that cancer nursing research will continue to provide an important integrative role in helping the whole therapeutic community [ie doctors, nurses, social workers, psychologists etc] understand how it must be for a person to have cancer, and how this disease impacts on the family of that person. It is only through this kind of research that we can hope to better understand the impact this disease and its treatment has.

There is one overriding, yet very simple maxim:

In order to ensure that our care is truly person centred, cancer nursing researchers need to work alongside patients and their families as true partners.

It is vital that the theory developed from cancer nursing research continues to be translated into practical, multi-disciplinary education - ensuring that we thus further refine the service and care we offer for the future

Problems in gathering the data for nursing research

Cancer impacts patients' lives and families like nothing else does and nursing research is often at the sharp end of patient treatment and care – a place where the gathering of uniform quantitative data is, by definition, difficult [although not impossible, as we shall see].

Typically, therefore, the methods used by nurse researchers are frequently derived from older research traditions such as anthropology, social science and psychology. Thus, qualitative methods, such as in-depth interviewing or participant observation are frequently used when gathering nursing research data.

However, despite the fact that cancer, because of its ever changing face and impact on patients' lives is often not amenable to being routinely herded into convenient and quantitative research boxes, nursing research nevertheless still manages to make frequent use of quantitative methods.



Thus, the use of detailed questionnaire surveys is now widespread - with patients and families being invited to reflect on their experience of care environments, therapies, transitions between care environments, and on how these experiences subsequently impact their lives. Indeed, for many clinical nurse researchers this type of research becomes automatically embedded into their clinical work as a cancer nurse, and it therefore reflects the exact reality of nursing care as seen on a day-to-day basis in the cancer unit, ward, outpatient department, or within the community.

Working alongside patients, cancer nurses have therefore over the past few decades become pivotal in ensuring that patients receive the best and most appropriate symptom control. Thus, much work over the last 25 years has demonstrated that where patients have more control over their environment and their symptom management they feel more satisfied with care. Current cancer nursing research therefore also constantly seeks to find newer and better ways of empowering patients in the management of their day-to-day lives.

Modern cancer nursing research therefore concentrates on the 'lived experience' - the 'what it's like to have cancer and be affected by it' experiences of patients and relatives. It then uses these findings to develop interventional nursing strategies to improve the care and quality of life of patients who are undergoing cancer therapy

Some examples of current interventional nursing research projects at the Royal Marsden are listed below.

Research projects in progress

Do members of minority ethnic groups experience equity of access to cancer services in the South West London Cancer Network? *E Anionwu, P Ellison, S Dolan*

Evaluation of a new wound assessment chart and a new self-assessment chart to assess symptoms and psychosocial problems related to chronic wounds. *W Naylor, S Dolan*

The experience of patients undergoing manual lymphatic drainage for lymphoedema. *M Woods, S Dolan*

The 'lived' experience of patients undergoing a stem cell transplant. *M Stephens, S Dolan*

A study to explore trained cancer nurses' perception of their role in telephone assessment and management of chemotherapy induced toxicities in patients with gastrointestinal cancers. *R Siamvaram, S Dolan*

The critically ill patient - the need for nursing research in this area

The Royal Marsden has the only Critical Care Unit (CCU) devoted to cancer patients in the UK. Patients with cancer who become critically ill either as a result of their surgery or other therapies often face more treatments following their recovery. Patients undergoing major surgery may well face repeated major surgery in a few years. It is essential, for example, in these types of acute areas of care that we listen to the experience of our patients, and then set about shaping practical nursing responses accordingly.

Currently, we have two research projects addressing the issue of critical care:



Shelley Dolan and Rachel Townsend with a patient in Wilson Ward

1. *The experience of ward nurses receiving patients from Critical Care: a study to improve ward nurses' satisfaction, transfer from Critical Care to the ward and subsequent patient outcomes (Natalie Pattison and Shelley Dolan)*

The background to this project is that as the demand for CCU beds in the UK grows, so there is ever increasing pressure to discharge patients as quickly as possible from the CCU and into a general ward. Accordingly, a previous national survey of clinicians in 325 UK and Ireland CCUs, identified discharge from Critical Care as being one of the key research questions for the future. Thus, what is the impact for patients [and also the perspective from their family's point

of view] to being moved from a unit where they have, until then, had one-to-one nursing, and the secure knowledge that they were in an environment where they were being monitored closely at all times by both clinicians and nurses. We know from our own experience, as well as from data from other research, that patients often find this time very frightening; frequently feeling at their most vulnerable.

In addition, and not surprisingly, for nurses working on the general wards, this transfer period also represents a challenging time, as they seek to establish an appropriate level of 'step

down care'- whilst at the same time attempting to ensure a calm and efficient transition for the CCU patient into the new environment of a general ward.

We have started to look at this 'transfer period' from a nurse's perspective. Our research approach has been to gather both quantitative and qualitative data, using a semi-structured questionnaire sent to 200 nurses working on general wards. Key themes that underpinned the questions asked were centred around 'information giving,' both in preparation and communication, and we also asked for suggested recommendations for future improvements. In addition, nurses were asked to describe an example of a 'transfer' that they felt had gone well and also one that they felt had been problematic.

The quantitative data that result from the study will be analysed for any statistical correlations. The qualitative data will be examined for emerging themes and concepts informed by a grounded theory approach. The overall findings from this project will be presented to nurses both on general wards and within the CCU, and a collaborative action plan will be subsequently developed. From this action plan, an optimal standard for transferring patients will be written, in order to ensure improved communication between relevant hospital areas. This should have the overall effect of improving patient outcome. This 'transfer standard' will then be regularly audited in practice.

2. A study to investigate the provision of 'follow up' care for patients who have received critical care following major surgery (Shelley Dolan and Rachel Townsend)

There is a growing body of evidence that patients who have been cared for in a critical care environment suffer psychological and physiological problems for some time after they leave that environment. Existing Critical Care follow-up clinics have also provided evidence of patient inability to move forward with their lives until some of the critical care issues have been resolved. Typical examples of unresolved psychological issues are 'flashbacks', auditory hallucinations, nightmares and fear of sudden death. Examples of unresolved physical issues include poor or delayed healing of tracheostomy stomas, operative sites and sites of previous central venous catheters, muscle weakness and profound fatigue.

In the UK, there are currently less than 10 centres offering formal follow-up from CCU. The Royal Marsden is the first centre to offer this service to patients in the form of a prospective research study

Thirty patients who have undergone complex major surgery for cancer and have been cared for on the CCU for greater than 72 hours have been invited to join the study. During this descriptive exploratory qualitative study these patients will receive the following nursing interventions:

A visit from an expert critical care nurse on the first and fifth day after transfer from the Critical Care Unit. During these visits, the patient and nurse together explore the experience of the critical illness and any relevant anxieties or fears. Some patients are taken back to the CCU in order to be able to place noises or the environment in a less frightening perspective.



Shelley Dolan with a patient in the Critical Care Unit

Patients are then seen in the outpatient setting twice, at 3 and 6 months post-CCU, and on the same days they see their surgical teams.

Finally, at 12 months after their critical care experience, patients are invited to complete a questionnaire to voice their impressions of the follow-up service, and to make their recommendations for any changes to the service.

In a further attempt to ensure this study was properly designed and that it would meet the needs of future patients, ten people with cancer who had been patients in the CCU over the last 12 months were invited to become a patient advisory group for the study. The study design was formulated and sent to them to critique, with particular emphasis on their comments regarding the questionnaire. These ten patients, who did not receive any formal follow-up, were also asked to reflect on the need for such a service and for any recommendations they would also like to make. The information gained both from the patient advisory group and the study group will be used to shape the follow-up service for future CCU patients at the Royal Marsden.

Collaboration is key to ensuring quality - Workflow Information Systems for European Nursing Care (WISECARE)

As cancer nursing research grows, so we need to recognise the value of multicentre collaboration and research. The WISECARE study, the first phase of which was sponsored by the European Commission, has enabled clinical nurse researchers across Europe to collaborate on an exciting interventional study.

The study utilised web-based IT technology to allow both nurses and patients to reflect on major symptoms during chemotherapy treatment. Patients use an internet tool to map their pain, fatigue, nausea and vomiting and oral health during cycles of chemotherapy.

Notably, during the first phase of this project, patients reported feeling encouraged on seeing their symptomatology graphically represented. They also felt they could then use these data when consulting with their nurses and oncology physicians.

The second exciting phase of this project, sponsored by The Royal Marsden Hospital Charity, has just commenced and now encompasses patients in their primary care setting. Patients across Europe, with lymphoma, leukaemia, sarcoma, lung, breast and colorectal cancer, will be invited to play a major role in the management of their symptoms, not only whilst they are in hospital but also while in their own home. Cancer nursing interventions will be mapped against the disease, chemotherapy regimen, and the degree of symptom relief or management as expressed by the patient.

This study has many advantages: primarily it seeks to ensure that the person with cancer is empowered in their own management of symptoms; it also aims to assess the efficacy of nursing interventions.

The WISECARE study allows nurses across Europe to collaborate in clinical nursing research, through the use of IT