

# Research within the Field of Blood and Marrow Transplantation Nursing: How Can It Contribute to Higher Quality of Care?

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## **Abstract**

Nursing Science and research within BMT started in the early 80s and has been shown to be a useful contribution to obtain and maintain high standards of care. Trial and error are no longer accepted. The first studies were conducted together with the clinical developments and focused specifically on symptom control and management of the treatment. The term “evidence-based nursing” (EBN) is nowadays often used to describe the influence of research on practice. And yet we find that in general, care given by nurses is not yet based according to the guidelines established by research. There are several reasons why care is not (yet) based on results from research, like language barrier, diversity in health care and nursing educational systems, financial restraints and different roles and perceptions of nurses around the globe. Many nursing or multidisciplinary research studies have been conducted worldwide on areas such as the prevention or care for patients with mucositis, fatigue or pain, care for the central venous access devices, outpatient management of care, care for the donor and aspects of quality of life. Results have implications on practice and start to show their impact on quality of care. Many questions remain unanswered. Results from basic science (e.g. the discussion around fetal liver and embryonic derived stemcells and their use in treatment other than hematologic malignancies) and developments in medical treatments (e.g. introduction of tyrosin-kinase inhibitor, biotherapy and genetherapy) have an impact on nursing and should therefore be investigated closely to develop clinical pathways. It is obvious that much more time, finances, collaboration and support is needed to conduct powerful studies that can influence care for the BMT patient. This presentation will focus on developments through nursing research within the field of BMT and discuss gaps that will need to be filled in the near future.

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## **1. Introduction**

### *1.1. Historical Overview*

Nursing Science and research within Blood and Marrow Transplantation (BMT) has a long tradition it has been a useful contribution to obtain and maintain high standards of care. The first studies evolved in the early 1980's (Haberman, 1995; Haberman, 1997). Trial and error are no longer accepted. The first studies were conducted together with the clinical developments and

focused specifically on symptom control and management of the treatment (Larson et al, 1993; McGuire et al, 1993). Quality of life was also often the center of nurse researchers (Ferrell et al, 1992a; Ferrell et al, 1992b; Haberman, Bush, Young, & Sullivan, 1993) as well as care for the central venous catheter (Keller, 1994; Shivnan, et al, 1991; Ulz et al, 1990). Most of the studies in the beginning were empirical papers, nowadays more and more randomized clinical trials are performed.

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often used to describe the influence of research on practice.

## 2. Advances in Clinical Care through Research

Many nursing or multidisciplinary research studies have been conducted worldwide on areas like the prevention or care for patients with mucositis, fatigue or pain, care for the central venous catheter, outpatient management of care, care for the donor and quality of life.

To get an overview on what is known and what is not known, we can categorize it into a model. By this we can break down how much we know and start to focus on the most fundamental or critical areas within the field of interest.

Examples are:

- Mucositis
- Fatigue
- Care for the central venous access device
- Outpatient management
- Quality of life

Within all of these topics there is quite much knowledge generated already, but questions still remain and new clinical developments have asked again for more knowledge. An example is how non-myeloablative therapies influence oral care or outpatient developments in the future. Results will have implications on practice and start to show their impact on quality of care.

## 3. Barriers and Accelerators of Nursing Research

### 3.1. Discrepancy between Theory and Practice

It is obvious that there is a need for better integration of research and practice (Tierney, 1999). To answer the questions why clinicians don't find research relevant to their work it is too simple to say that "...clinical nurses do not perceive research findings as relevant to their practice because frequently they are NOT relevant..." (Greenwood, 1984).

There are several reasons why care within hematology is not (yet) based on results from research.

The language barrier plays a major role, because most research publications are in English but not all nurses read and understand enough English to really judge the meaning and significance of the findings. It is often difficult to understand a second or even third language.

We also have to deal with the lack of common professional language (Glaus, 2001). Research needs to be disseminated and communicated to potential users of the findings. That has to be in terms which clinical bedside nurses understand and can transform into practice. It is clear that there are enough journals and other recourses available for researchers to publish their work. But accessibility of journals and other publications via the Internet must be guaranteed to open the option of using it in practice.

The diversity in health care and nursing educational systems plays a role, because results can not always be transferred into a system where healthcare is organized

differently. The level of the basic training of nurses differs not only between countries, but even within countries. Some emphasize on hands-on-care, others highlight more the need of a broad theoretical and analytic background. Access to university systems, where research is often performed or supported, is a major contributor to the integration of research into practice, but it is not always accessed easily. Some universities still seem "unreachable" for bedside nurses and are viewed as an ivory tower.

Research costs money and it is often underestimated how much research costs. Financial restraints and difficulties in receiving research grants or support from other sources are presently hindering the conduct on clinically meaningful research studies. Finances for research will need to be generated. Within BMT we must considerate that the population is usually rather small so multi-center studies are mandatory to get enough power for a study since results from an underpowered study can not necessarily be generalized.

The roles and perceptions of nurses differ tremendously around the globe. Nurses in one country are perceived as equal to the medical profession and have their own lobby within the government, in other countries they still fight for their position and authority in questions regarding the care of the patient.

Also there are practical problem of small patient populations, which means that often single center studies have only a pilot study character or are underpowered. Therefore multicenter studies must be conducted. Networks must be established to have access to data within a region, country or even broader. Within Europe there are collaborations evolving through the EBMT-NG (European Blood and Marrow Transplantation Nurses Group) or the EONS (European Oncology Nursing Society). These collaboration must be financially and mentally supported. We can learn from the medical profession where this collaboration has a long tradition. One problem in psychosocial research then could be cultural differences but that needs to be investigated in the near future.

## 4. Future of BMT Nursing in the Light of a Triangular Perspective

### 4.1. Research

A research agenda within hemato-oncology will need to be developed. Research questions will need to be generated by practitioners and discussed within a multidisciplinary team. The research agenda could be developed for a single unit, a region, a country or between several countries like within Europe. This means that the participating countries will collaborate on different topics and each will contribute to the body of knowledge.

Research should not only be undertaken for primarily course work to achieve a Masters or PhD degree. It is not a substitute for larger scale research that can be generalized. Knowledge from research needs to cumulate

to research lines.

Results from basic science (e.g. the discussion around fetal liver and embryonic derived stem cells and their use in treatment other than hematologic malignancies) and developments in medical treatment (e.g. Glivec and other new medical treatment modalities) have an impact on nursing and should therefore be investigated closely to develop e.g. clinical pathways.

#### 4.2. Implementation into Practice

To be able to introduce research into practice, the environment must be open for changes. Time and money will support the introduction of research into practice, but more important is that nurses are aware of quality changes and have the chance to implement state-of-the-art nursing practice based on results of research. Research must address relevant topics for practice and should not focus on something that is irrelevant at that particular moment. Only then results will be used by bedside nurses. The updated Stetler-Marram (Stetler, 2001) Research Utilization Model could support the process. It focuses on an integrative review methodology, targeted evidence concepts and the continuing experience through using this model. Important is to judge the appropriateness, desirability, feasibility and way of using results from research into practice.

#### 4.3. Management Issues

There must be a shift from individual endeavor to collective (organizational) effort and responsibility to an organizational climate and system which is open for changes it needs not only an individual commitment but more important is the organizational structure in which research is welcome or even supported by time, money and other facilities.

Multidisciplinary collaboration and partnership

To conduct effective research and make it an important part of your practice, the role of an advanced nurse practitioner or clinical nurse specialist could be a solution. Hamric (Hamric, 1989) describes four important roles to be performed: act as an expert in the clinical field, offer consulting role, take an active part in education and teaching, and interpret and perform actively nursing research. The role of an innovator should be added as the ANP plays an important role in changes and introduce results of research into practice.

### 5. Conclusions

Many questions are answered, topics have been addressed by researchers. Still, many questions remain unanswered. It is obvious that much more time, finances, collaboration and support is needed to conduct powerful

studies that can influence care for the BMT patient.

This presentation will focus on developments through nursing research within the field of BMT and gaps that need to be filled in the near future.

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