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Abstract

Background

The focus of work submitted to an international conference can reflect the changing landscape of a specialty and prove important for identifying trends, uncovering gaps, and providing new directions for nurse-led research and clinical practice. We present an analysis of trends in
presentations in the nursing programme at the SIOP congress from 2003-2012 based on all accepted abstracts.

Procedure

A total of 462 abstracts were analysed. A data extraction form was used to ensure consistency of data retrieved. Paired researchers were assigned two years of abstracts for assessment: approximately 80 to 100 abstracts each. Data were entered into REDCap data management software.

Results

Most abstracts came from presenters affiliated with institutions in Europe and North America with a noticeably significant under-representation from developing countries. There was an equal representation of papers focused on empirical research with family members and clinical practice focused on the professional role, although this varied in some years. Analysis of research methodology revealed a predominance of surveys, with a recent increase in qualitative and mixed method studies. Out of all abstracts only 18% were subsequently published.

Conclusions

Gaps have been identified, such as the limited involvement of nurses in developing countries, and lack of studies self-reporting from children. Much needs to be done to promote a greater diversity of research frameworks and more dynamic research designs. The small percentage of abstracts from nurses that are eventually published may hinder translation of the findings into clinical practice.
INTRODUCTION

Nurses have been regular participants at the International Society of Paediatric Oncology (SIOP) congress since the meeting in 1987. Over the years the nursing programme has become more established, increasing in number of days as the quality and number of abstracts have increased. There has been a consistent submission of abstracts reporting clinical practice, with an increase in research-focused presentations since 1994, which together have contributed to the evidence-base for clinical practice in childhood cancer where both are valued to inform care,[1 ]however more research is needed to foster evidence-based practice. The characteristics and focus of these presentations can offer a reflection on the changing landscape on our specialty and prove important for identifying trends, uncovering gaps, and providing new directions for nurse-led research and clinical practice. We present an analysis of the trends in presentations in the nursing programme at the SIOP congress from 2003-2012 based on abstracts accepted for poster and oral presentation.

Common patterns in research undertaken by nurses have already been reported in the literature in relation to the development of research questions, methodology, study purposes, and the selection of the populations under study. From an international perspective, there has been an increase in the development of research to inform clinical practice.[2 ]Research designs have changed from being primarily quantitative, to a more even distribution of qualitative and quantitative studies and even mixed methods.[3,4,5] Research approaches have also become more holistic and integrative, often including multiple groups (patients, healthcare professionals, and family members) and different aspects of care (clinical, psychological, social, etc.).[6] Limitations or research gaps have been identified such as the lack
of evaluation of care outcomes, the small percentage of studies proceeding to publication, and the secondary role that research still occupies in relation to nurses’ clinical duties.[6]

There is international variation in this research, as nurses tend to focus on the issues that are most relevant to their geographical, economic, and political context.[2] However, there have been attempts to establish international nursing research priorities with the purpose of promoting and guiding future research. In 1997, the World Health Organization (WHO) published a list of priorities for nursing research which included cultural aspects of care, home care, workforce and working conditions, ethics, health in vulnerable populations, and the effects of health system reforms. Since then, several nursing publications have put forward their own lists of priorities for specific subfields of the discipline,[7,8] or particular regions of the world.[9,10,11] In the case of children’s cancer nursing, studies have found that the highest research priorities centre on symptom management, quality of life, communication in relation to care provision, home care, and late effects.[12,13]

The Children’s Oncology Group (COG) has highlighted the increase in nurse-led research and evidence-based practice in its recent Blueprint for Research.[14] According to the COG, updated knowledge of the available evidence can “promote excellence in protocol-related nursing practice by standardizing care, reducing undesirable protocol-related nursing practice variation, and promoting best nursing practice based on scientific evidence whenever possible”.[14] COG nursing leadership has in fact purposively focused on research undertaken by nurses since the group’s formation in 2000.[15]

METHODS

This was a retrospective review of abstracts submitted to SIOP between 2003-2012 and published in Pediatric Blood & Cancer. A total of 462 abstracts were analysed. A data extraction
form was used to ensure consistency of data retrieved (see Table I). This extraction form was reviewed by all members of the team and piloted by three team members (FG, PK, CVP) who analysed five abstracts in parallel to make sure it produced consistent results. The piloting of the form led to simplification of the headings and the elimination of repetitive categories. The final version of the form was entered into REDCap data management software [16] to allow all team members to work on the form securely and simultaneously.

Once the format of the form was finalised, paired researchers were assigned two years of abstracts for assessment (approximately 80 to 100 abstracts per person), requiring approximately seven months for all abstract data to be entered and cleaned.

After all data were entered into REDCap, one member checked the consistency of recording, and resolved discrepancies and cases of missing information (CVP). The data were analysed according to the following research questions: Who are the nurse presenters at SIOP? How have the numbers of abstracts presenting research and clinical practice changed over time? What are the main topics of presentation? What are most common types of research design and methods used? Who are the research participants? How many presentations have led to published articles and how has this changed over time?

**RESULTS**

**Who are the presenters at SIOP?**

Our initial analysis of the abstracts focused on identifying a series of variables that could define the presenters such as: combinations of disciplines in multidisciplinary research, country of affiliation of the first author, and if the authors were based at a university.

Since we focused on abstracts submitted to the nursing programme, we knew this would be the most frequent discipline in single discipline abstracts. However, other disciplines noted
included paediatric oncologists, other health sciences professionals, and dieticians. In the case of multidisciplinary studies, the most common combination was nursing + medicine, followed by nursing + pharmacy, nursing + psychology, nursing + dentistry, and nursing + radiology. Missing data do not allow more precision in terms of percentage in each combination.

We organized the number of abstracts per country on the map in Figure 1. Most abstracts came from presenters affiliated with institutions in Europe and North America. There were also many presenters from Australia. There is still a significant number from unrepresented countries, particularly those found in the PODC (Paediatric Oncology in Developing Countries) SIOP category.

Approximately 27% of the first authors in the abstracts were affiliated with a university or educational institution of some sort (i.e. research centre), while 44% were affiliated with a hospital. This suggests that most studies originated from practice contexts. We did not, however, have enough information to determine affiliation for 25% of the abstracts; where it was difficult to be precise based on the information provided, the affiliation was not recorded.

In the case of those affiliated to a university or educational institution, 82% of their abstracts presented empirical research findings, while for those affiliated to hospitals, research was presented in only 39% of the abstracts (vs. 52% which focused on clinical practice).

Research and clinical practice

We first divided the abstracts between those that focused on research (54%) vs. those that presented some form of description of clinical practice or practice innovation (46%). When we compared these two groups over the years (Figure 2), we found that in most years, there was an even distribution of research and clinical practice abstracts, with the exception of 2003, 2007, and 2009.
The main areas of focus in each group also varied. The top five research areas included: family needs/support, patient quality of life, symptom management, communication and delivery of information, and staff working conditions and support. In the clinical practice abstracts, the top five areas of focus were: education of nurses, symptom management, care protocols, programme development, and the safety of medical procedures.

**Methodology**

The comparison of research designs across all years (Figure 3) indicated that designs have varied, with some years such as 2003 exhibiting a clear qualitative preference and the opposite trend in 2007 and 2011. There are an increasing, but small number, of mixed-methods studies represented across all years.

Analysis of research methods by year (Figure 4), showed that survey-based studies were the most common. The use of instruments was increasing, more apparent in some years such as 2007 and 2012, but in-depth research methods such as ethnography and the development of case studies were only used in a few instances.

Comparison of studies that took place in single centres vs. multi-centred studies across all years (Figure 5) showed that single-site research was higher in all years and the number of studies taking place in multiple centres remained low.

**Research participants**

We also analysed the populations under study. Among all abstracts, 31% focused on the child with cancer (either on or off treatment), 27% focused on parents or family members, and 40% focused on healthcare professionals (the rest focused on medical records or policies). However, when we divided the abstracts into the research and clinical practice groups we noticed that empirical studies focused mainly on family members (40%) while clinical practice
abstracts focused mainly on the experience or needs of healthcare professionals (49%). We observed an increase in empirical research seeking the views of children and young people direct, but overall the numbers remain disappointingly small.

**Publications**

We were interested in determining the percentage of abstracts that were then developed into articles and published in peer-reviewed journals. Out of all abstracts (research and clinical practice), only 18% were subsequently published. When looking solely at the research abstracts, this percentage increased to 34%. The main journals selected for publication were (by order of frequency): *Journal of Pediatric Oncology Nursing, European Journal of Oncology Nursing, European Journal of Cancer Care, Cancer Nursing,* and *Paediatric Nursing.*

**DISCUSSION**

We were able to identify trends in the abstracts presented at SIOP from 2003 to 2012. It is clear that most presentations continue to be from developed countries and specifically those from the Global North. It is alarming, but perhaps unsurprising, to see that countries continue to be unrepresented at the conference, particularly those from the developing world. This is an issue that deserves attention, as it means that the realities of nurses, children, and family members in a significant part of the world are not being represented, even though 80% of childhood cancer cases are in the developing world, with survival averaging 20 percent, and only 20 percent of cases are in the developed world, where more than 80 percent survive.[17]

Nurse presenters are part of multidisciplinary teams, and in most instances this collaboration is with other disciplines in the broader health sciences. Collaboration with researchers in the social sciences, for instance, was rare. This is surprising due to the common use of social research methods in nursing and the fact that many studies aimed to carry out some form of
behavioural assessment or analysis of the social lives of patients (social relationships, family
dynamics, communication with healthcare professionals, etc.). The lack of integration of social
science researchers could help explain why certain research methods now used frequently in
health services research, such as ethnographies and case studies, were seldom found in the
nursing abstracts. However, it is also possible that presenters from other disciplines have a
preference to present at specialist conferences that concentrate on their own area of academic
expertise. The point to emphasise, however, is that this work is not being showcased at SIOP.
The comparison of multicentre and single centre studies also highlighted a trend in nurse-led
research. Even though there has been an increase in studies that take place in a series of sites,
most research is carried out in one clinical unit or hospital. There are probably many reasons
why this occurs, including easier access to patients in one site, delays with local ethical
approvals, and difficulties establishing connections with clinical teams in other sites. More
importantly, we suggest that funding, and the increased budget required to manage multi-site
research, may be a crucial factor. Our concern is that this type of single-site design limits the
transferability, as well as national and international application of findings.
Over the period of abstracts reviewed, there has been a consistent equal presence of papers
describing clinical practice and research, although the ratio varied, with more research
presented in some years. It may well be that congress location has some impact on the
abstracts submitted that scored as research, for example 2003 (Egypt), 2007 (Mumbai) and
2009 (Brazil). The proportions may be influenced by a number of factors, such as difficulties to
obtain travel funds for nurses in clinical practice or the converse, the availability of research
grant funds to support nurses to present their research; the absence of nurses from the host
country, where often we witness a large number of poster submissions; and the general
shortage of nurses, that fluctuates over the years, but may impact on the presence of clinical nurses.

The small percentage of abstracts that resulted in publications also caught our attention, as the wider community of researchers, health practitioners and policy makers cannot use unpublished research findings to design future studies, inform changes in practice or develop new policies and subsequent interventions. This is particularly important with the increasing emphasis on evidence-based practice because the “evidence” is not reaching publication. Thus, in spite of greater numbers of research presentations, we are missing an important translational link between research and clinical care through a lack of dissemination in relevant journals that might reach the international community of nurses in our field.

LIMITATIONS

This study is limited in that some of the categories in our data extraction sheet had missing data. It was difficult to identify the first author’s discipline from the information provided in some of the abstracts. It was also difficult to distinguish professional groups, so that on some occasions we relied on the recognition of names from many years of attendance at SIOP meetings by one of the authors (FG). Some abstracts were not explicit about their research methods or provided inconsistent information on the theoretical frameworks used. There are also limitations in our search for abstracts that resulted in publications, as we only looked at peer-reviewed journals in English, and we might have been challenged where author names or study titles were not the same as those in the abstract. Also, the number of abstracts from 2012 that resulted in publication could be higher as there might have been articles still in the process of peer review at the time of the analysis.

CONCLUSIONS
This study represents outputs from a newly formed group under the discipline of nursing within SIOP: a virtual international faculty (formed in 2012), with a current membership of all authors of this paper, a number we hope will increase at each congress. The review of SIOP abstracts allowed us to identify common trends in nursing presentations, research designs, and research outputs. This brief glimpse proved beneficial in helping us identify gaps such as the limited involvement of nurses in developing countries and presenters from outside of the medical sciences. Furthermore, we were able to see that much work needs to be done to promote a greater diversity of research frameworks and more dynamic research designs (e.g. mixed-methods, multicentre research). There is also a need to encourage other academic disciplines to share their work at meetings such as SIOP. The lack of translational link enabled through publication was apparent, although there may be a higher rate of publication than revealed here. In an attempt to expand the findings of this study, we are currently planning a second review based on the abstracts that were developed into academic publications. We will explore how the research was reported, the strategies used to disseminate findings, and where we can comment on the impact of the research on practice. The publication of the findings of nurse-led research and assessments of clinical practice needs to become a mandatory feature of the work of nurses undertaking research, as this is the only way our discipline can move forward. We advocate for increased national and international nurse partnerships, built through SIOP and other key collaborations, to accelerate the advance of research and policy development.

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Conflict of interest: We have no conflicts to declare.
Figure Legends

Figure 1. Number of abstracts per country

Figure 2. Number of research and clinical practice abstracts by year

Figure 3. Number of abstracts by research design per year

Figure 4. Number of abstracts by research methods per year

Figure 5. Number of single-centre and multi-centred abstracts per year
REFERENCES