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9 **Building the evidence for nursing practice: learning from a structured review of SIOP**
10 **abstracts, 2003-2012.**

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32
33 **Abstract**

34 **Background**

35 The focus of work submitted to an international conference can reflect the changing landscape
36 of a specialty and prove important for identifying trends, uncovering gaps, and providing new
37 directions for nurse-led research and clinical practice. We present an analysis of trends in

38 presentations in the nursing programme at the SIOP congress from 2003-2012 based on all
39 accepted abstracts.

40 **Procedure**

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

45 **Results**

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

53 **Conclusions**

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

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60

61 **INTRODUCTION**

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

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

83 of evaluation of care outcomes, the small percentage of studies proceeding to publication, and
84 the secondary role that research still occupies in relation to nurses' clinical duties.[6]

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

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

103 **METHODS**

104 This was a retrospective review of abstracts submitted to SIOP between 2003-2012 and
105 published in *Pediatric Blood & Cancer*. A total of 462 abstracts were analysed. A data extraction

106 form was used to ensure consistency of data retrieved (see Table I). This extraction form was
107 reviewed by all members of the team and piloted by three team members (FG, PK, CVP) who
108 analysed five abstracts in parallel to make sure it produced consistent results. The piloting of
109 the form led to simplification of the headings and the elimination of repetitive categories. The
110 final version of the form was entered into REDCap data management software [16]to allow all
111 team members to work on the form securely and simultaneously.

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

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

122 **RESULTS**

123 *Who are the presenters at SIOP?*

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

127 Since we focused on abstracts submitted to the nursing programme, we knew this would be the
128 most frequent discipline in single discipline abstracts. However, other disciplines noted

129 included paediatric oncologists, other health sciences professionals, and dieticians. In the case
130 of multidisciplinary studies, the most common combination was nursing + medicine, followed
131 by nursing + pharmacy, nursing + psychology, nursing + dentistry, and nursing + radiology.
132 Missing data do not allow more precision in terms of percentage in each combination.

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

138 Approximately 27% of the first authors in the abstracts were affiliated with a university or
139 educational institution of some sort (i.e. research centre), while 44% were affiliated with a
140 hospital. This suggests that most studies originated from practice contexts. We did not,
141 however, have enough information to determine affiliation for 25% of the abstracts; where it
142 was difficult to be precise based on the information provided, the affiliation was not recorded.
143 In the case of those affiliated to a university or educational institution, 82% of their abstracts
144 presented empirical research findings, while for those affiliated to hospitals, research was
145 presented in only 39% of the abstracts (vs. 52% which focused on clinical practice).

146 *Research and clinical practice*

147 We first divided the abstracts between those that focused on research (54%) vs. those that
148 presented some form of description of clinical practice or practice innovation (46%). When we
149 compared these two groups over the years (Figure 2), we found that in most years, there was
150 an even distribution of research and clinical practice abstracts, with the exception of 2003,
151 2007, and 2009.

152 The main areas of focus in each group also varied. The top five research areas included: family
153 needs/support, patient quality of life, symptom management, communication and delivery of
154 information, and staff working conditions and support. In the clinical practice abstracts, the top
155 five areas of focus were: education of nurses, symptom management, care protocols,
156 programme development, and the safety of medical procedures.

157 *Methodology*

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

162 Analysis of research methods by year (Figure 4), showed that survey-based studies were the
163 most common. The use of instruments was increasing, more apparent in some years such as
164 2007 and 2012, but in-depth research methods such as ethnography and the development of
165 case studies were only used in a few instances.

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

169 *Research participants*

170 We also analysed the populations under study. Among all abstracts, 31% focused on the child
171 with cancer (either on or off treatment), 27% focused on parents or family members, and 40%
172 focused on healthcare professionals (the rest focused on medical records or policies).

173 However, when we divided the abstracts into the research and clinical practice groups we
174 noticed that empirical studies focused mainly on family members (40%) while clinical practice

175 abstracts focused mainly on the experience or needs of healthcare professionals (49%). We
176 observed an increase in empirical research seeking the views of children and young people
177 direct, but overall the numbers remain disappointingly small.

178 *Publications*

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

185 **DISCUSSION**

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

194 Nurse presenters are part of multidisciplinary teams, and in most instances this collaboration
195 is with other disciplines in the broader health sciences. Collaboration with researchers in the
196 social sciences, for instance, was rare. This is surprising due to the common use of social
197 research methods in nursing and the fact that many studies aimed to carry out some form of

198 behavioural assessment or analysis of the social lives of patients (social relationships, family
199 dynamics, communication with healthcare professionals, etc.). The lack of integration of social
200 science researchers could help explain why certain research methods now used frequently in
201 health services research, such as ethnographies and case studies, were seldom found in the
202 nursing abstracts. However, it is also possible that presenters from other disciplines have a
203 preference to present at specialist conferences that concentrate on their own area of academic
204 expertise. The point to emphasise, however, is that this work is not being showcased at SIOP.

205 The comparison of multicentre and single centre studies also highlighted a trend in nurse-led
206 research. Even though there has been an increase in studies that take place in a series of sites,
207 most research is carried out in one clinical unit or hospital. There are probably many reasons
208 why this occurs, including easier access to patients in one site, delays with local ethical
209 approvals, and difficulties establishing connections with clinical teams in other sites. More
210 importantly, we suggest that funding, and the increased budget required to manage multi-site
211 research, may be a crucial factor. Our concern is that this type of single-site design limits the
212 transferability, as well as national and international application of findings.

213 Over the period of abstracts reviewed, there has been a consistent equal presence of papers
214 describing clinical practice and research, although the ratio varied, with more research
215 presented in some years. It may well be that congress location has some impact on the
216 abstracts submitted that scored as research, for example 2003 (Egypt), 2007 (Mumbai) and
217 2009 (Brazil). The proportions may be influenced by a number of factors, such as difficulties to
218 obtain travel funds for nurses in clinical practice or the converse, the availability of research
219 grant funds to support nurses to present their research; the absence of nurses from the host
220 country, where often we witness a large number of poster submissions; and the general

221 shortage of nurses, that fluctuates over the years, but may impact on the presence of clinical
222 nurses.

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

231 **LIMITATIONS**

232 This study is limited in that some of the categories in our data extraction sheet had missing
233 data. It was difficult to identify the first author’s discipline from the information provided in
234 some of the abstracts. It was also difficult to distinguish professional groups, so that on some
235 occasions we relied on the recognition of names from many years of attendance at SIOP
236 meetings by one of the authors (FG). Some abstracts were not explicit about their research
237 methods or provided inconsistent information on the theoretical frameworks used. There are
238 also limitations in our search for abstracts that resulted in publications, as we only looked at
239 peer-reviewed journals in English, and we might have been challenged where author names or
240 study titles were not be the same as those in the abstract. Also, the number of abstracts from
241 2012 that resulted in publication could be higher as there might have been articles still in the
242 process of peer review at the time of the analysis.

243 **CONCLUSIONS**

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

264 **Acknowledgment:** Thank you to Robert Arceci, Editor of Pediatric Blood & Cancer, who made
265 available the abstracts not accessible through PubMed.

266 **Conflict of interest:** We have no conflicts to declare.

267

268 **Figure Legends**

269 Figure 1. Number of abstracts per country

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

271 Figure 3. Number of abstracts by research design per year

272 Figure 4. Number of abstracts by research methods per year

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

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