

Survivorship representation at IPOS World Congress: abstract review and analysis

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Abstract

Background: Advancements in cancer treatments have enabled more people worldwide to survive cancer, but many experience lasting impacts. The International Psycho-Oncology Society (IPOS) is a global professional organization which hosts an annual World Congress. This study reviewed survivorship content from the World Congress meetings to understand areas of focus, apparent strengths and weaknesses, and global representation.

Methods: Peer-reviewed abstracts presented in 2017, 2018, 2019, and 2021 were reviewed. Abstracts were identified by searching for “survivor.” Identified abstracts were read in full to extract content of interest (population of interest, cancer type, number of participants, study design, study topic, first author/country, and international collaboration). Coding was defined a priori. Data were extracted using REDCap. Inter-rater reliability checks were performed.

Results: A total of 1813 abstracts were identified and reviewed. The proportion of survivorship-focused abstracts ranged from 13.2%–20.7% annually. Breast cancer dominated survivorship work. The most frequently addressed topics included distress/anxiety/depression (36.6%), quality of life (28.6%), and health behaviors (15.5%). Nearly three-quarters (73%) of abstracts focused on adult populations, and there was apparent international collaboration in 12%–20%. Authorships and abstracts were primarily from high-income countries (91%). Most studies were observational (44%); few were randomized controlled trials (4%).

Conclusions: This study found overrepresentation of authorship from some countries. Many topics, patient populations, and countries were not highly represented. IPOS might consider efforts to remedy this imbalance with the ultimate goal of improving psychosocial care for those affected by cancer, globally.

Keywords: survivorship, psycho-oncology, abstract synthesis, research

1. Background

The number of cancer survivors is increasing worldwide, owing to progress made in cancer diagnosis, treatment, and supportive care.^[1] People living with and beyond cancer experience significant challenges resulting from both the effects of cancer and subsequent treatments.^[2–4] Although many cancer survivors are able to return to typical functioning after treatment, others may experience significant physical, emotional, social, and financial effects^[4–8]; thus, the need for ongoing care remains high.^[7,9] Survivorship research and advocacy aim to ensure that

the needs of cancer survivors are identified and met and that their quality of life is maintained at the highest level possible.^[2,9–11] Psychosocial challenges are common among cancer survivors and include fear of recurrence, fatigue, altered sleep and cognition, and effects on sexual health, intimacy, finances, and employment.^[3,4] Addressing the psychosocial needs of this population is crucial to providing high-quality, holistic, and adequate oncologic care.^[7,12,13] Achieving this requires a coordinated effort for shared learning and collaborations to promote excellence and improve cancer care on a global scale.^[11,13]

Advances in survivorship care have lagged behind developments that have fueled improvements in cancer prevention, diagnosis, and treatment. Still, many gaps remain in foundational understanding of the comprehensive needs of these patients after a cancer diagnosis and after treatment has concluded.^[14] Although disparities in survivorship care are evident within countries, there is urgent need to share current knowledge and practice between countries and world regions. Inequities in cancer care delivery are exaggerated in low- and middle-income countries where survivorship care may be nonexistent and, when present, has much opportunity for improvement.^[15,16] Without adequate cancer survival care, the disease imparts significant morbidity leading to potential lifelong suboptimal health, function, and quality of life.^[16]

The International Psycho-Oncology Society (IPOS) was founded in 1984 with intention to promote international multidisciplinary communication and collaboration regarding the psychosocial and behavioral aspects of cancer.^[17,18] One way that IPOS works to deliver its mandate through special interest groups comprised members who share common interests or expertise in a specific area of psycho-oncology. Through these

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groups, members collaborate and exchange knowledge and resources, organize events and conferences, and develop guidelines and standards of care for their respective areas of expertise.

The survivorship special interest group was formed in 2020 to provide an international network for clinicians and researchers with interest in cancer survivorship to work together on promoting awareness of survivorship-related issues, establish a platform for dissemination of work, establish research collaborations, network with organizations that have similar goals in survivorship care, and provide guidance to the board regarding survivorship issues with the ultimate goal of promoting global excellence in psychosocial care of people after treatment has concluded.^[18]

Part of achieving this mission lies in dissemination and networking opportunities at the annual IPOS World Congress, which brings together psycho-oncology professionals from around the globe. The congress serves as a platform to advance the science and practice of psycho-oncology aimed at improving the care of people affected by cancer. The IPOS World Congress features a variety of events, including plenary sessions, keynote speeches, symposia, workshops, oral and poster presentations, and published abstracts. IPOS, being an international organization, allows for international perspectives and collaborations to enhance shared learning to improve survivorship outcomes and improve the quality of life of those directly or indirectly affected by cancer. However, to date, there has not been an in-depth assessment of the survivorship-focused research and practice models that have been shared at the IPOS World Congress, and an evaluation of the content of this work has also not been conducted. Therefore, there is a lack of rigorous understanding of the current state of international survivorship care and research trends in psycho-oncology, international collaboration, and overall direction of survivorship work. This study was undertaken to fill these gaps with the aim to identify current areas of research, understand diversity and representation in presentations, possible strengths, and identify any gaps by evaluating survivorship-related work presented at the annual IPOS World Congress over a 4-year period.

2. Methods

2.1. Reviewers

IPOS members representing the survivorship, early career, and pediatrics special interest groups used the key word ‘surviv*’ to scan each yearly World Congress program to identify abstracts of interest. On identification of abstracts, survivorship content was categorized.

2.2. Data sources

Peer-reviewed IPOS World Congress abstracts published as a supplement to Journal of Psychosocial Oncology Research and Practice inclusive of the years 2017, 2018, 2019, and 2021 (no Congress activities in 2020 due to COVID-19) were reviewed. The congress is held in various locations. In the period we were reviewing, it took place in the following countries: Berlin, Germany, in 2017; Hong Kong, China, in 2018; Banff, Canada, in 2019; and Kyoto, Japan, in 2021.^[19]

2.3. Data extraction

Identified abstracts were read in full to extract content of interest collected using REDCap. The year of publication, type of presentation (eg, oral presentation, poster presentation, published abstract), primary author’s country of origin, and

identification of international collaboration (defined as authorship from at least 2 different countries) were identified. Country affiliation was further categorized by income status (high, upper middle, lower middle, lower) using World Bank classifications.^[20] Study population of interest was identified by both participant age and cancer type (see Table 1 for definitions). Participant groups were nondiscrete and could include multiple groups (eg, children and adolescents or adolescents and young adults); for those with adult populations not defined as young adults or older adults, “adults nonspecific” was assigned. The same approach applied for cancer types, and if the abstract defined multiple cancer diagnoses (eg, leukemia and breast cancer), the abstract was assigned to both cancer types. Study design and research topic of interest were determined a priori

Table 1
Definitions of selected abstracted domains.

Abstract category	Category choices	Description
Population of interest	Children	Infancy through age 19 years
	Adolescents	Ages 13–19
	Young adults	Ages 20–40
	Adults	Nonspecific aged 18+
	Older adults/geriatric	Ages 60+
Study design	Not specified	No ages of participants disclosed
	Randomized controlled trial	Two groups with random assignment
	One group intervention	One group with pretest/post-test design
	Quasiexperimental	Nonrandom assignment
	Observational	Prospective, retrospective, and cross-sectional
	Qualitative	Only used qualitative methodology
	Mixed methods	Mixture of quantitative and qualitative methods
	Pilot	Initial clinical study/pilot study
	Measurement	Creation or validation of measurement tool
	Review	Summary, systematic, or integrative reviews
Study topic	Commentary	Opinion pieces, guidelines, or nonresearch
	Quality of life	Addresses holistic health, daily life, and impacts of therapy
	Health behaviors	Encompasses behaviors to maintain health after treatment
	Sleep	Includes sleep quality, sleep disorders, and sleep management
	Fatigue	Symptoms of fatigue distinct from sleep
	Pain	Includes all pain (acute and chronic) after treatment
	Stress, anxiety, depression	Stress, distress, anxiety, PTSD, depression, and chronic sadness
	Fear	Includes fear of cancer recurrence or disease progression
	Fertility and sexuality	Sexual functioning and fertility impacts of treatment
	School/cognitive	Academic functioning, neurocognitive impacts, and brain fog
	Work/employment	Impacts of cancer on regular employment and maintaining a job
	Caregivers	Research focused on caregivers of cancer survivors
	Psychosocial	Social function, mental health support, and psychological function
	Financial	Financial impacts, costs, and debts related to cancer treatment
	Survivorship care	Structures, programs, and delivery of survivorship care
Others	Not specific to any above category	

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through consensus from the reviewer group to reflect aims of the project. Similar to the above, the topic was nondiscrete, and each abstract could address multiple domains of interest. Definitions of selected abstract domains are presented in Table 1.

2.4. Data analysis

To evaluate consistency of data extraction for each abstract, 20 abstracts (6% of total) were selected at random to undergo inter-rater reliability evaluation. Two authors individually re-extracted data from the 20 abstracts and compared results to original outcomes. For discrete domains (presentation type, country of origin, international collaboration), the proportion of full agreement was determined. For nondiscrete domains (population of interest, study design, and study topic), the proportion of mismatched selections was calculated from total possible options to allow for the highest level of specificity. Descriptive analysis was conducted on the variables of interest. Percentages and proportions have been reported.

3. Results

3.1. Inter-rater reliability of data abstraction

There was unanimous (100%) agreement on all discrete fields (presentation type, country of origin, internal collaboration). For population of interest, there were 2 discrepancies out of a possible 120 options (6 items x 20 abstracts reviewed = 120), leading to a 1.67% discordance rate. For study design, of the 180 total options (9 items x 20 abstracts reviewed = 180), there were 2 discrepancies or a 1.1% discordance rate. There was a 3% discordance rate for study topic from 9 discrepancies out of a possible 300 total options.

3.2. Abstract origin, collaborations, and country income status

Across the four years, a total of 1813 abstracts were reviewed. The proportion of survivorship-focused abstracts ranged from 13.2-20.7% annually (20.7%, n = 77 in 2017; 19.2%, n = 84 in 2018; 13.2%, n = 65 in 2019; and 19.6%, n = 100 in 2021). Similarly, survivorship-focused abstracts with international collaborations ranged from 12%–20% (12% in 2017, 13% in 2018, 20% in 2019, and 19% in 2021).

The first author country income status for survivorship abstracts for the four years analyzed includes 91% high income, 8% upper middle income, and 1% lower middle income. There were no abstracts with primary authorship from low-income countries. Notably, nearly half (48%) of survivorship-focused work had first authors from one of just four countries: Australia, Canada, the United Kingdom, and the United States, all of which are high-income countries.

Figure 1 presents IPOS membership, membership of the survivorship SIG, and abstract representation by income status of countries.

3.3. Study designs

Study designs of the survivorship abstracts per year are presented in Figure 2. Over the four years, the design of studies was observational (44%), followed by qualitative (14%) and pilot studies (13%). Few abstracts reported on randomized controlled (4%), quasiexperimental two group nonrandomized (6%), and one group intervention pretest/post-test (4%) trials. Half of all studies had <100 participants, 36% had 100-499 participants, and 14% had >500 participants.

3.4. Cancer diagnoses, study topic, and population of interest

The most frequent diagnosis of interest over the 4-year period was a mix of cancer types (33%). The most frequent disease-specific diagnosis was breast cancer (32%). No abstracts reported on survivorship issues specific to patients with liver malignancy or sarcoma. Childhood cancer diagnoses represented 5% of survivorship abstracts. These included studies focusing on cancers in infancy through age 19 years. Figure 3 presents the proportion of abstracts for specific diagnoses and mixed diagnosis studies for the four years.

The survivorship study topics per year are shown in Figure 4. Over the four-year period, the most frequent topics represented in survivorship abstracts were depression/anxiety/stress (24%), followed by quality of life issues (19%). The least frequently covered survivorship topics in the four years included pain (2%) and financial aspects of care (1%).

4. Discussion

This study examined survivorship-focused abstracts submitted to the IPOS World Congress over a 4-year period. We found that



Figure 1. Membership and abstract representation by income status.

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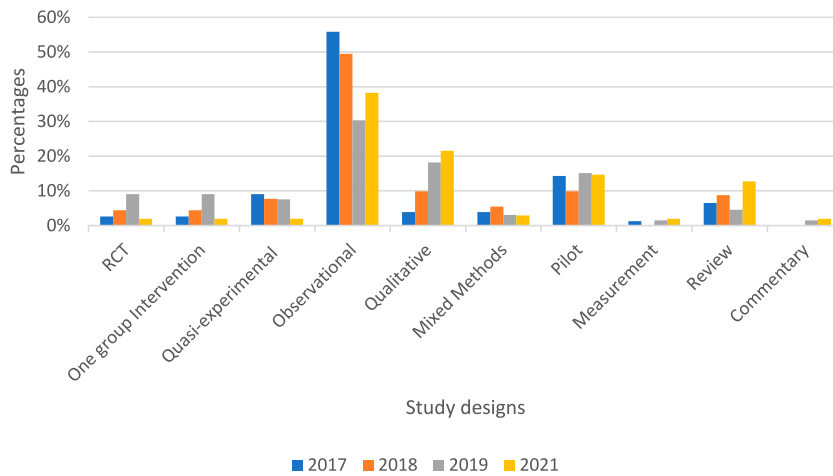


Figure 2. Study designs per year.

although there are areas that have received “significant focus,” there are other areas that seem to be less represented. In addition, findings show limited geographic representation and few international collaborations. Moreover, there is minimal diversity of study topics, diagnoses, populations, and study methodologies.

Most survivorship-focused presentations were from authors based in high-income, western culture/predominantly English-speaking countries, with overrepresentation from the United States, the United Kingdom, Canada, and Australia with limited contributions from upper middle-income, lower middle-income, and low-income countries and minimal international collaborations. At the time of this analysis (July 2022), the 705 current IPOS members represented 91 countries, 63% from high-income countries, 20% upper-middle income, 15% lower middle income, and 2% from low-income countries. The survivorship interest group included 55 members from 23 countries: 73% high-income, 14% upper middle-income, 13% lower middle-income, 0% low-income. Although overall IPOS membership has representation from all country income levels, it is expectedly skewed toward high-income countries. Abstract representation, however, is further exaggerated along the same pattern with an

overwhelming disproportion of presentations coming from high-income countries and a complete lack of low-income country representation and more closely matches the distribution of survivorship Special Interest Group membership. These results are consistent with a recent publication audit from the Journal of Cancer Survivorship that found that most articles published since the journal’s inception came from the United States, Australia, and the United Kingdom.^[21] Although this may represent the higher volume of post-treatment survivorship research in high-income countries, it may also be a reflection of current IPOS membership, thus the need to attract membership from underrepresented countries. In addition, it may be a reflection of research priorities in low- and middle-income countries which tend to focus on prevention, screening, detection, and treatment systems.^[22,23] However, owing to the recent data suggesting an overall rise in the number of cancer survivors worldwide,^[1] it is imperative for IPOS to leverage its global membership to encourage and support post-treatment survivorship research in underrepresented low- and middle-income countries. This could include targeted outreach and collaborations with researchers and organizations in these countries to increase their representation and involvement in survivorship care research. Through

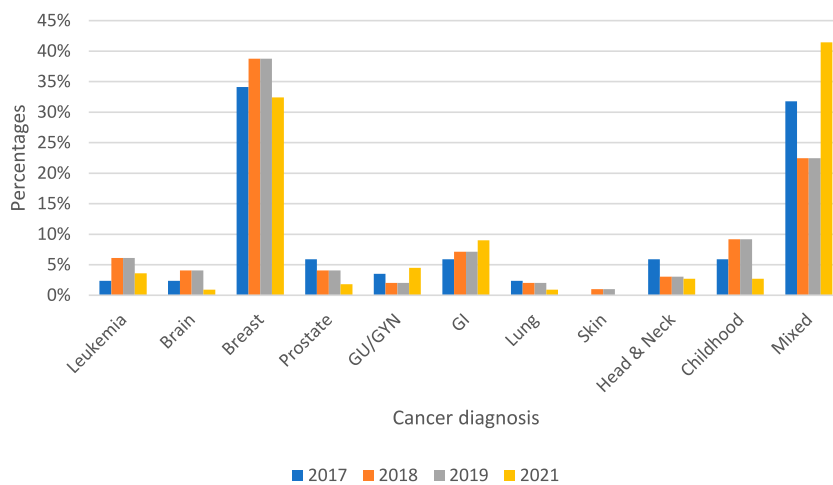


Figure 3. Cancer diagnosis of interest per year.

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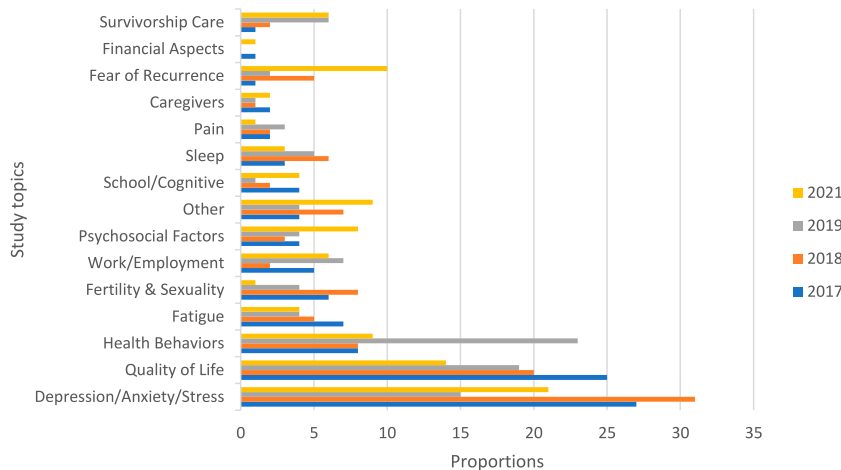


Figure 4. Survivorship abstract topics per year.

collaborative efforts, best practices can be shared and potentially adapted to suit these countries’ needs and contexts.

The study designs and methods varied greatly with observational studies being the most common and few interventional designs, such as randomized controlled trials. Although observational study designs could be less expensive to conduct, relatively faster, and effective in examining associations between variables, they cannot determine cause and effect or explore prediction.^[24] In addition, although the choice of study design depends on the specific research questions and logistics including costs, IPOS World Congress scientific committee should consider encouraging submissions of studies using rigorous causality-determining or experimental methodologies in the future. Related audits have also highlighted this research gap.^[14,21,25,26] Overall, more interventional studies to address known survivorship issues, such as fear of recurrence, fatigue, cognitive issues, and financial toxicities, are needed. Consequently, this would enable the development and delivery of comprehensive and evidence-based quality survivorship care. It is possible that these studies are presented at other meetings; however, this study was not able to ascertain whether this is the case. In addition, although the location of the congress could potentially influence the geographic diversity, we did not determine such an influence in the current review.

Regarding cancer types and populations, the analysis revealed that mixed cancer types received the highest research attention overall. In relation to specific cancer types, breast cancer was the most frequently studied. Although breast cancer research has been prevalent in the field of survivorship,^[21,27,28] it is important to also prioritize research on other types of cancer that may have a significant impact on the quality of life of survivors. Other highly prevalent survivor groups are those with a personal history of prostate cancer, colorectal cancer, melanoma, and lymphoma. Some of these cancers may contribute to even greater impairments in quality of life and therefore require increased attention in survivorship research.^[29] For instance, our audit found that there were no abstracts that specifically addressed survivorship issues in people with rare cancers, such as liver malignancy or sarcoma. Although this highlights a gap in survivorship research for underrepresented cancers,^[29,30] it may also be a reflection of existing infrastructure priorities and funding patterns.^[28,31] Overall, the finding that most studies included mixed cancer

types is encouraging considering that in many cases, cancer type is not always the primary determinant of how and whether survivors experience social and psychological issues, and interventions can be effective for a broad range of cancers. This potentially increases applicability and reduces the need for repeated studies across different cancer types.

Notably, only 5% of the congress abstracts were about childhood cancer, encompassing the age range from infancy to 19 years, which is a small proportion compared with the amount of research generated in the childhood cancer domain and the known potential severe and long-term consequences of treatments.^[32-34] IPOS may consider calling for more presentations relating to childhood cancer. In addition, survivorship research activities focused on underrepresented populations, who might have additional needs, should be encouraged.^[35] These include sexual minority groups and survivors living with disability.^[36,37]

Presentations related to depression, anxiety, and stress were the most common, followed by quality of life. Topics, such as pain, financial toxicity, fear of cancer recurrence, and return to work, were represented in only 1% of abstracts. To ensure that survivorship care is comprehensive, there is a need to diversify research activity to include other topics of interest to survivors. Financial toxicity, for example, is a significant burden for many survivors, affecting their ability to afford necessary care, pay for daily expenses, and maintain their quality of life.^[38] Conversely, considering that IPOS has done substantial work in topics, such as fear of recurrence,^[18] our current search might have missed some relevant work on these topics.

4.1. Strengths and limitations

The strengths of this study include the 4-year time frame, which helps limit bias by possible year-to-year variations. The process of coding with inter-rater reliability checks and group consensus on coding domains ensures that our findings are reliable across coders and reflect domains of importance to the survivorship community. A limitation of our study includes possible missed abstracts that had survivorship information but did not include the word “survivor,” or permutations, in the text. In addition, publication of abstracts is optional, and some authors of survivorship abstracts may have declined publication and thus were not included. The COVID-19 pandemic could have been a

deterrent for many submitting abstracts, particularly for 2021. Finally, all abstracts are required in English language and this may limit the geographic and income diversity of our findings.

5. Conclusions and next steps

This study highlights and increases the awareness of survivorship content at IPOS World Congress meetings and will allow the organization to consider underrepresented areas. For example, the lack of income and geographic diversity identified has led the survivorship specialty interest group to reach out to the low- and middle-income interest group to discuss increased opportunities for partnership. Although we acknowledge that these findings might not be entirely reflective of the entire global survivorship research portfolio, the findings suggest several gaps that should inform priorities for future work. Furthermore, our findings may be used to inform recruitment of underrepresented research areas that are of interest to the survivorship specialty interest group and IPOS as a whole.

An ethical statement is not required for this article.

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Conflicts of interest

Authors have no conflict of interests to declare.

Author contributions

All authors contributed to this research and article:

Conceptualization: K.R. and M.J., Data Extraction and analysis: K.R., C.P.T., F.S., Y.L. and I.G., Writing original Draft: I.G. and K.R., Review and editing: C.P.T., F.S., M.J., Y.L. and K.R.

Data availability

The data that support the findings of this study are available on request from the corresponding author.

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