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How Palliative Care Social Workers across the Globe Overcame Practical Challenges to Engaging in Research

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Abstract

With the unique set of values underpinning the social work profession, evidence-based practice must be informed by practitioners well versed in the impact of cultural, political, geographical, economic and general social factors on clinical work. Within the speciality of Palliative Care Social Work (PCSW), these factors influence the level of integration and upskilling of Palliative Care Social Workers (PCSWs). This article describes the collaborative methods used by Palliative Care Social Work (PCSW) practitioners and research-active academics to conduct a global survey of PCSWs about their professional experiences during the Coronavirus COVID-19 pandemic, with a view to better understand their respective roles and identities across regions. The authors of this study suggest that collaboration is key to drawing upon a diverse number of clinical, pedagogic and academic networks to optimise the survey response rate and raise the profile of PCSWs. The authors describe and reflect on the practical and cultural challenges encountered in conducting the survey.

Keywords: collaboration, innovation, palliative care, pandemic, social work

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Introduction

According to the academic literature, social work practitioners are generally interested in engaging in research, yet face several obstacles when utilising, designing and implementing research (Pope *et al.*, 2011). In a recent cross-sectional survey of social workers from a large National Health Service (NHS) Trust, researchers found that whilst the majority (73 per cent) of those surveyed highly valued research and evidence-based practice (EBP), a minority (10 per cent) engaged in conducting research (Wakefield *et al.*, 2022). Participants identified barriers, which included a lack of knowledge related to initiating research activity, the lack of evidence that research activity improves practice and the challenges of allocating time and resources to conducting research. In the UK, as well as internationally, there is growing recognition of the need to invest in supporting and training social work practitioners, to increase research activity and overall confidence in conducting research (Shaw *et al.*, 2014; Drisko and Grady, 2019).

For several decades, there has been an increased focus and commitment to EBP (Fineout-Overholt *et al.*, 2005; Mullen *et al.*, 2008; Pope *et al.*, 2011). Despite the International Federation of Social Workers (IFSW) incorporating the need for social workers to employ methods that are based on sound evidence regarding the effectiveness of interventions into their Global Standards for Social Work Education and Training (IFSW, 2020), only a small percentage of social work practitioners engage in research activity that improve clinical outcomes associated with the implementation of EBP (Wakefield *et al.*, 2022).

The following paper examines common barriers to social work practitioners engaging in research and presents how collaboration with social work academics helped to overcome some methodological and practical barriers. One of the key principles to research collaboration is to promote wider involvement in designing and conducting research, as this can confirm that the project best addresses the needs of individuals and communities, and can ensure that different forms of knowledge, experience and expertise are valued and used throughout the research process from the earliest stages (United Kingdom Research and Innovation (UKRI, 2022). Altilio (2022, p. 107) highlighted the importance of the 'care partners crosswalk' where specialities, such as academic partners, collaborate with practitioners to reciprocally enhance practice education or placements, and through conducting and disseminating research.

Aims and objectives

The aim of this article is to reflect on the collaborative approach used to conduct an international research survey of PCSWs, across twenty-one

different countries, which captured their experiences of delivering PCSW services during the COVID-19 pandemic (Roulston *et al.*, 2023). The objectives of this article include identifying the methodological and practical steps required, the benefits of practitioners partnering with academics and the challenges of collaborative working.

The authors present the challenges and benefits of collaboration between front line Palliative Care Social Workers (PCSWs) and research-active academics, who draw upon existing international networks to conduct an online survey of PCSWs. Ultimately, such international scholarly collaboration endeavours to illustrate the role and value of PCSWs, which is still evolving in many regions (The Economist Intelligence Unit, 2015).

According to Head and Middleton (2022), although social workers have been an essential component of palliative and hospice care since the beginning, the profession ‘struggled to clarify, describe, and justify their role on the interdisciplinary team’ (p. 877). An ‘Advisory Committee’ conducted a job analysis prior to agreeing the following practitioner definition: A hospice and palliative social worker provides psychosocial assessment and services to the patient, family and caregivers, facilitates patient-centred goal setting and a plan of care and seeks to improve the quality of life through education, addressing needs and onward referral to appropriate resources (Head *et al.*, 2019 cited in Head and Middleton, 2022).

From a global perspective, there are varying rates of integration of Palliative Care (The Economist Intelligence Unit, 2015) and the role remains quite diverse. For example, in some settings, the PCSW is an integral part of the interdisciplinary team and highly trained, whilst in other regions, psychosocial palliative care is under-recognised or provided by par-professionals (Oltmann and Gerson, 2022). It can be argued that collaborative research between practitioners and academics, and promoting EBP will be instrumental in upskilling PCSWs and may bridge the gap between the desire of social workers to engage in research and the reality of actively participating in research. Existing regional, national and international networks may help forge links between front line, clinical PCSWs and academic researchers, thereby expanding access to important resources such as training and knowledge, research participants and databases.

Regional and international networks

The European Association of Palliative Care (EAPC) Social Work Task Force, established in 2009, is the main networking agent in PCSW across Europe. It developed core competencies for PCSW in Europe (Hughes *et al.*, 2014, 2015) and it captured tasks and roles that PCSWs perform in different European countries (Bitschnau *et al.*, 2020). It consists of thirteen PCSW practitioners, academics and researchers, who represent their

respective country and have a commitment to disseminate information across their regional networks.

The EAPC SW Task Force aims to offer leadership to PCSWs across Europe, to upskill PCSWs as leaders, practitioners, educators and researchers, and to meet the identified need for PCSW education at undergraduate and postgraduate level across Europe. Experiences shared by front line PCSW practitioners at bi-monthly EAPC meetings, highlighted the challenges they faced during COVID-19, due to the implementation of government restrictions, high levels of staff absence through sickness or redeployment, working from home or remotely and the suspension of some core services. Therefore, the rationale for the project was proposed by EAPC Task Force members who worked as front line PCSWs throughout the pandemic across the UK and Europe, and the project was supported by EAPC members who were in academic or research roles and recognised that PCSWs, alongside many other key workers, were struggling with the impact of COVID-19 on their practice, emotional well-being and service delivery.

Collaboration on the design of the survey

Academic members of the EAPC Task Force, who are research active and have dedicated research time within their substantive posts, agreed to work in collaboration with PCSW practitioners to identify the key research questions and to co-design the project. The primary aim was to provide PCSWs with the opportunity to indicate how COVID-19 impacted them, using an online survey, which contained both quantitative and qualitative questions. The survey captured participants' demographic data (i.e. age, gender, highest level of education, country) and work-related information (i.e. employment status, work setting, years in PCSW). Questions covered services provided pre-COVID, (i.e. population, place and description), and how COVID-19 affected the number of referrals received, the workforce and service provision by PCSWs. Questions were proposed and agreed at bi-monthly meetings with all members of the EAPC Social Work Task Force, which ensured international collaboration across practitioners, academics and researchers from the outset.

International co-production to translate the online survey

Given the geographical location of EAPC Task Force members and their respective regional networks (i.e. Austria, Czech Republic, Germany, Holland, Ireland, Italy, Romania, Portugal, Slovakia, Spain, Sweden and the UK), it was agreed that the survey would need to be translated into different languages, to widen access and to encourage participation. Relevant EAPC members, who were fluent in English, agreed to

translate the questionnaire into Italian, Slovak, Czech, German, Portuguese and Spanish. To avoid members, who were either academics or front line practitioners, feeling under pressure, a realistic timeline was agreed for translation. One challenge the research team overcame during the translation process was how to translate the nuanced differences between specific settings, based on resources available within each country (i.e. community palliative care, outpatient services or day hospice). The team agreed additional explanations, to reduce the risk of confusion, given the questionnaire would be completed online.

Translated drafts of the survey were informally piloted by members of the Task Force, and each member shared it with one social work colleague. The aims were to check how easy the survey was to complete, how long it took to complete, if the questions made sense and if there were any perceived gaps. Consequently, revisions were made as some questions had too many options (work setting) or were too repetitive (population and place where services were provided pre-COVID). Making the agreed revisions shortened the time required to complete the survey, which was regarded as a benefit, amidst the increasing work pressures associated with the pandemic. The final versions were used by a Research Fellow to generate online surveys in different languages using Qualtrics software. Each link was tested prior to circulation.

Ethical approval across regions

Initially, formal ethical approval was obtained by the Principal Investigator from the School of Social Sciences, Education and Social Work Research Ethics Committee in The School of Social Sciences, Education and Social Work at Queen's University Belfast (Ref. 107_2021). Some Task Force members obtained an ethical approval within their respective countries or jurisdictions, which caused minor delays. However, this ensured that the study applied ethical principles including informed consent procedures, voluntary participation, secure storage of data and anonymised data in reports, publications or presentations.

Recruitment and procedure

Participants were drawn internationally from the PCSW workforce via members of the EAPC Social Work Task Force. Following an initial phase of recruitment, EAPC members, who were also members of the World Hospice Palliative Care Social Work (WHPCSW) network, agreed it would be important to widen dissemination given the global impact of the COVID-19 pandemic and different experiences of PCSWs.

Founded in September 2020, the WHPCSW network consists of over sixty PCSW members from across the globe. With representation from twenty-two countries, the network aims to bring together a diverse group of social workers dedicated to amplifying the voice of palliative social work and psychosocial palliative care. Through collaborative research, presentations, sharing of resources and scholarly publications, members of WHPCSW partner across clinical, academic and research settings to promote the role of the PCSW.

Inclusion criteria for participants included working as a PCSW in one of the approved countries and being over eighteen years of age. Nominated members of the EAPC Social Work Task Force and the WHPCSW network contacted eligible participants through existing email lists to inform them about the survey and to distribute the dedicated Qualtrics web link. Participants who accessed the Qualtrics link obtained access to the participant information sheet, consent form and the survey questions. Recruitment was conducted between 6 October and 12 November 2021.

Based on the collaborative approach, the survey received a total of 362 responses from across twenty-one countries. The mean age of respondents was 44.57 years, and the majority were female ($n=309$; 85.36 per cent). The majority had a Master's degree ($n=190$; 52.49 per cent), 105 had a Bachelor's degree, 19 had a PhD, 38 had another qualification and 10 'preferred not to say'. The majority were employed full time ($n=226$; 62.43 per cent), and respondents have been working in palliative care from less than one year to thirty-nine years. The demographic data on participants illustrate the high levels of formal qualifications, with most qualified to Master's degree level and an average of 9.52 years of experience. The high standard of professional training of PCSW practitioners, academics and researchers across cultural contexts has been internationally recognised (Berkman and Stein, 2018; Bitschnau *et al.*, 2020).

The sample was predominantly female and work full-time, which reflects the SW workforce in terms of direct care and academia (Boniol *et al.*, 2019). During COVID-19, professional women dominated employment and played a central role in front line care, providing physical, emotional and economic responses to those in need (Organisation for Economic Co-operation and Development, 2020).

As illustrated in Table 1, most responses came from Italy ($n=77$), followed by the USA ($n=71$), Germany ($n=33$), Czech Republic ($n=29$) and Austria ($n=27$). See Table 1 for a full breakdown of responses by country. The 'Other' category includes countries with fewer than three responses (i.e. Wales, Hungary, Poland, Singapore, Hong Kong, Zimbabwe and Portugal).

Repeated invitations to participate were emailed during the recruitment period, members disseminated information about the survey at

their regional and national meetings and conferences, and updates on recruitment were reported at bi-monthly EAPC Task Force meetings, which highlighted levels of recruitment.

International reflections on recruitment and response rates

As illustrated in [Table 1](#), a very high response was obtained from Italy, which was achieved by The National Network for Palliative Care Social Workers, Italian Society of Palliative Care and Palliative Care Federation promoting the study, publishing the survey on their websites and sending the announcement to the mailing list of the social work members. Furthermore, the high level of participation by Italian social workers could be attributed to an interest in tracking the impact of the COVID-19 pandemic on Italian PCSW, with the potential to compare findings with other participating countries and the need to raise the profile of PCSW by creating supranational connections with the awareness of the benefit of working from a network perspective.

In Northern Ireland and the Republic of Ireland, response rates were approximately 80 per cent of their respective PCSW workforces. When invited to reflect on how high response rates had been achieved, the Task Force members representing these countries associated the outcomes with their respective leadership roles within long-standing PCSW networks (i.e. The Northern Ireland Association of Palliative Care Social Workers and the Irish Association of Hospice and Palliative Care Social Workers). In person or online meetings provided natural opportunities to share the rationale for the online survey, to provide regular reminders and to update members on recruitment across participating countries.

Table 1. Survey responses by country

Country	<i>n</i> (%)
Australia	13 (3.59)
Austria	27 (7.46)
Canada	3 (0.83)
Czech Republic	29 (8.01)
England	15 (4.14)
Germany	33 (9.12)
Italy	77 (21.27)
Netherlands	5 (1.38)
Northern Ireland	14 (3.87)
Republic of Ireland	18 (4.97)
Slovakia	23 (6.35)
Spain	6 (1.66)
Sweden	19 (5.25)
USA	71 (19.61)
Other	9 (2.49)

In contrast, the number of respondents from some countries, such as the USA, Australia, Canada and Great Britain was regarded as disappointing, given the number of PCSWs known to be in employment. The survey researchers attribute the lower response rate to several factors, including time constraints secondary to increased clinical activity during the pandemic, high email volume within the professional Listservs through which the survey was disseminated and many of the networks surveyed primarily comprising clinicians. Having nominated ambassadors from each country, with clear lines of accountability and responsibility for dissemination and recruitment (UKRI, 2022), and natural opportunities to discuss the study in person, answer any questions, and provide regular updates on recruitment, may have enhanced participation.

Discussion

PCSW remains an evolving social work speciality with varying rates of integration around the world (Gerson and Firth, 2022). Key to highlighting and amplifying the role of PCSWs is systematic research to evidence the value of psychosocial palliative interventions. The original research survey enabled PCSW practitioners, researchers and academics from around the world to collaborate on a project exploring the impact of the COVID-19 pandemic on PCSWs and the services they delivered, which is reported elsewhere (Roulston *et al.*, 2023). The findings illustrate how PCSWs adapted during the COVID-19 pandemic and raise the profile of PCSWs across the globe, which is an important role of many networks (i.e. European Association of Palliative Care, IAHPSCW, etc.).

Whereas this article demonstrates how researchers and practitioners collaborated on the design, development, translation and distribution of the online survey. Doing so ensured the survey captured the experiences of PCSW practitioners in a meaningful way, maximised accessibility using available resources and demonstrated the potential for future research collaboration and ways to promote EBP, which is in keeping with the IFSW (2022) and professional social work standards (Institute for the Advancement of Social Work Research, 2007; NISCC, 2019). The approach adopted mirrors the Honour Society of Nursing Guidelines in conducting international nurse research, which consisted of collaboratively defining the goals, aims and outcomes of the project, identifying resources required to complete the project, determining country-specific issues for conducting international research and defining the roles of the collaborators, prior to project implementation (Montegrigo *et al.*, 2023).

According to Bagshaw *et al.* (2007), collaborative international research requires teamwork that values diversity, allows time to build trust and a shared research idea or question. Although the research team consisted of international members from the EAPC social work task force,

some had only recently joined the group, and it took time to establish leadership roles and trust. Furthermore, valuable lessons were learned regarding international collaboration and optimising survey responses. For example, from a methodological perspective, time delays were experienced when working collaboratively to identify aims of the research, the nature and format of survey questions, to translate and pilot the survey instrument, to sensitively address different interpretations of terminology and nuances within the survey and to ensure that ethical standards were maintained and relevant approvals were obtained prior to dissemination. However, recognising the importance of accessibility, diversity and reciprocity are key principles of research collaboration ([Social Care Institute for Excellence, 2022](#)).

Distributing the range of survey links through invested stakeholders and networks, dedicated to amplifying the PCSW role, and using existing leadership roles to promote the project, ensured a higher response rate from some countries. This highlights the importance of having nominated ambassadors, who have regular meetings with PCSWs in front line clinical practice, education or research settings and can clarify the rationale of projects and encourage participation, as appropriate. A similar approach has been adopted with the appointment of 'Patient Research Ambassadors', who are enthusiastic about health research, can provide patient and public involvement from the inception of research ideas, to avoid tokenistic gestures and can encourage people to participate ([Skilton *et al.*, 2016](#)).

In summary, this article demonstrates the benefits of PCSWs collaborating with research-active academics to co-design the study, co-produce the survey instrument and co-author an article for dissemination. Furthermore, this work reflects the collaborative, multidisciplinary manner by which the social work profession builds knowledge to effect change ([IFSW, 2014](#)).

Conclusion

In conclusion, an expansive collaborative approach not only optimises the research process, but it is also rooted in the basic tenets of social work, particularly the incorporation of innovative approaches, collective responsibility to serve those in need and attentiveness to cultural, political, geographical and socio-economic diversity in the global setting. Given the highest level of academic qualifications held by participants and members of the relevant networks, it is hoped that the collaborative working relationships established will underpin future PCSW research projects, policy developments and innovative practice.

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