# Creating a Research Culture in a Palliative Care Service Environment: a Qualitative Study of the Evolution of Staff Attitudes to Research During a Large Longitudinal Controlled Trial (ISRCTN81117481)

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**Abstract /** This study investigated the impact of a three-year randomized control trial of different models of service provision on palliative care staff associated with the hospice where the trial was being conducted. Eleven open access de-identified qualitative focus groups were held over a period of three years: three months into the trial, one year after its inception, and at the end of the trial. Four staff groups were involved: inpatient hospice nurses, palliative care outreach nurses, medical palliative specialists, and administrative staff and social workers. Initially the impact of the trial produced high levels of staff stress which largely diminished over time, to be replaced by enthusiasm for the changes achieved and sadness that post trial the perceived benefits gained would be lost. When attempting to change a clinical culture to incorporate research, and in particular where increased staff workload is involved, highly interactive levels of communication and valuing of staff input are required to minimize the stress and burden of this imposition.

**Résumé /** Cette étude cherchait à connaître l'impact d'un essai clinique sur le personnel d'un service de soins palliatifs. Il s'agissait d'un essai randomisé contrôlé d'une durée de trois ans portant sur différents modèles de soins dispensés dans ce service. On a donc au cours de cette période de 3 ans tenu onze groupes anonymes de discussions ciblées qualitatives soient: 3 mois après le début de l'essai, un an après sa mise en marche et à la toute fin de l'essai. Quatre groupes de personnes oeuvrant en soins palliatifs y ont participé: les infirmières auprès des patients hospitalisés, les infirmières en régions éloignées, les médecins spécialistes en soins palliatifs, le personnel administratif et les travailleurs sociaux. Au début cet essai a causé beaucoup de stress chez le personnel, mais cet impact négatif a grandement diminué avec le temps pour être par la suite remplacé par l'enthousiasme en constatant les résultats obtenus et, même un peu de regret, en pensant qu'après l'essai tous les bénéfices acquis seraient relégués. Lorsqu'on tente de changer la culture d'un milieu clinique afin d'y incorporer un volet recherche, et surtout qu'en ce faisant on augmente la charge de travail, il faut avoir un haut niveau de communication et d'appréciation du personnel afin de minimiser le niveau de stress et le fardeau de travail accompagnant cette nouvelle imposition auprès des employés.

## INTRODUCTION

There is a real and urgent need to conduct high-quality palliative care research in order to improve the evidence base identifying best clinical practice for people with a life-limiting illness (1,2). In the last decade, there has been a rapid increase in the volume of research conducted in palliative care (1), despite real and perceived barriers to conducting these studies (3). One of the most important challenges is overcoming the fact that research is not embedded in the culture,

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and the associated belief that research is not a necessary part of palliative care (2). Barriers to clinical staff involvement in research include: lack of training of palliative care health professionals in the collection of research data; lack of knowledge of the research being conducted; and inadequate systems and resources within palliative care programs to allow staff to collect data (4).

Historically, when palliative care programs have added research to their portfolio, the actions required to get the study done were assumed. The underlying implication was that, by introducing research into a location, somehow enthusiasm would occur naturally, paving the way to excellent research. However, palliative care clinical teams and administrative staff may not have the same expectation and experience, and indeed, may feel themselves overburdened or overstressed by the presence of research, especially if they do not feel it is relevant to their clinical practice or if they are poorly trained (1,5–7).

While there has been some work conducted looking into the synergy and disconnect between delivery of palliative care and research in palliative care, more work is needed (1,5,7). Are clinical teams burdened or threatened by the addition of research activities in their environment? If so, how is that manifested? Do they have the skills to participate? Do they receive adequate support for introducing new interventions? Do they even perceive a need for new interventions? Qualitative research provides an informative vehicle to understand the impact of newly embedding research into a clinical program. The experiences of palliative care staff as research activities are introduced into their environment can be carefully examined and documented. This information can be used to facilitate the introduction of palliative care research at new sites, iteratively improve activities, and decrease the perceived stress and burden experienced by staff as research is introduced.

This qualitative study explored the effect of a large three-year randomized controlled trial of different models of service provision on staff working at the palliative care service where the trial was being conducted. This substudy was deliberately embedded within the larger trial, and focused on four groups: administrative staff and social workers; nurses working in the inpatient hospice; palliative care outreach nurses; and medical palliative specialists. The substudy aimed to answer the following questions:

- Did palliative care staff feel burdened by the addition of the trial to their work environment?
- If so, did the sense of burden change over time, and if so, what pattern did it follow?
- Could such a qualitative study give insight into how better to conduct research studies at our organization in the future?

## METHODS

### The Larger Trial

***The Palliative Care Trial (PCT).*** The trial was a 2x2x2, factorial cluster, randomized, control trial. The 2x2x2 structure created a three-dimensional design that addressed each of the four original hypotheses of the main study, three of which were related to educational outreach visiting, and the fourth to case conferencing; all aimed to improve patient performance status and pain intensity (8). Other outcome measures included: quality of life, patient and caregiver satisfaction with care, health resource utilization, healthcare costs, and multidisciplinary input. The trial recruited 461 patients over a 26-month period; patients were followed longitudinally from referral to death or exit from the study. Full methodology for the main trial has been presented elsewhere (8).

***Trial Setting.*** Trial participants were recruited in Adelaide, South Australia, from a regional interdisciplinary specialized palliative care service that has more than 1,100 referrals per year. The model of palliative care in South Australia is consistent with the definition of palliative care articulated in the 2004 United States (US) National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (9), and with that advocated by the World Health Organisation (10). The palliative care service has more than 70 full time equivalent (FTE) staff, including community nurses, hospice nurses, nursing assistant staff, social work, bereavement, complementary care, specialist doctors, and administrative support. At the time of initiation of the PCT, this palliative care organization was relatively new to research with fewer than four industry-sponsored or investigator-initiated clinical intervention trials, and fewer than 100 patients per year in clinical trials and survey studies.

***Trial-related Responsibilities of Palliative Care Staff.*** All data items were collected by the palliative care nurses, either in the community or in the inpatient hospice. In an attempt to reduce the burden of paperwork, trial documentation was merged with clinical documentation. Measurements were taken at a patient's initial baseline assessment on admission to the service, two

weeks later, and then monthly until the patient exited the study through death, withdrawal, or at the planned study completion on November 30, 2004. Clinical assessment took approximately 30 minutes to complete. Telephone assessments, conducted at six and ten weeks, included performance status and medications, and took approximately five minutes to complete.

Nursing staff were responsible for the organization of case conferences related to the trial. Initially the intervention was to be conducted within seven days of referral; these parameters were liberalized to 28 days several months into the trial to improve feasibility. The conference involved the patient and/or caregiver; general practitioner (GP); palliative care nurse; palliative medicine specialist; and, if available, a social worker and representatives from the local community nursing service; domiciliary care; volunteers; pharmacists; or pastoral care workers, depending on the patient's needs. At the completion of the conference the nurse responsible for the conference completed the required documentation, which was circulated to all participants by trial staff. To offset the additional workload associated with the trial, two additional community nurses were employed and paid for by the trial.

### Qualitative Substudy

***Design of the Substudy.*** The researcher undertaking the substudy was an experienced qualitative researcher who worked in the palliative care field but who had not been involved in the trial and, therefore, had neither vested interests nor any particular views on this research; and who only wanted to provide an environment where people could speak freely, without fear of repercussions.

A total of 11 de-identified, exploratory, open-access focus groups (widely advertised in the setting and open to all interested parties, but for which identification was kept anonymous) using open-ended qualitative questions were held on three occasions; three months into the trial, one year after the trial had been in operation, and after the three-year trial had ended. Each of the four staff groups (administrative staff and social workers; nurses working in the inpatient hospice; palliative care outreach nurses; and medical palliative specialists) had their own focus groups. The focus groups were widely advertised throughout the palliative care service and attendance was voluntary. Because focus groups were held outside normal working hours, staff were compensated AU$50 per focus group for their time.

Analysis involved audio-recorded responses from the one to one-and-a-half hour focus groups being typologized (put into categories of emergent and repeated issues) within the question areas, and coded. Additional codes were created for new issues arising. This process was independently undertaken by another researcher who was not involved in the palliative care field. Reliability of cross-coding using Cohen's Kappa (15) was 0.801, indicating high agreement.

***Ethical Approval and Registration.*** The main trial was approved by 12 independent Australian human research ethics committees and US institutional review boards, including the Australian Department of Veterans Affairs, and Australian Health Insurance Commission, Canberra, Australia, and registered, ISRCTN81117481 (http://www.controlled-trials.com/isrctn/trial/81117481/0/81117481.html). This qualitative substudy was approved by the research ethics committee at Repatriation General Hospital in Daw Park, South Australia.

## RESULTS

### Focus Groups: Round 1

Five focus groups were held in August 2002, three months into the trial, with administrative staff and social workers (n=10), hospice nurses (n=10), outreach nurses (n=10), and specialist medical staff (n=3; the total number employed at the time), for a total of 33 participants.

Four major question areas were investigated in an open-ended qualitative manner to allow for the emergence and exploration of related issues most relevant to the participants:

1. General views of research in the setting.
2. The impact of the trial on current duties.
3. The effect of the trial on staff stress levels.
4. The impact of the trial on patients and patient care.

Although these four issues were used to guide the groups, the data gathered from questions 2, 3, and 4 tended to overlap, so the results are presented under two headings.

***1. Views of Research in General.*** There was overall agreement that research was valuable and exciting to be part of, however, considerable concern was expressed by all groups:

- that the immediate (or even long term) benefits of much of the current research being undertaken were unclear;
- that the palliative care service was perceived as being in danger of prioritizing research

rather than becoming a facility which produced outstanding care first and excellent research second; and,
- that clinical staff were at risk of becoming "data collectors" first, and caregivers and patient advocates second, and therefore patient care was at risk.

2. *The Impact of the Trial Specifically.*

> It does feel like it [the trial] is sucking on the program to a degree. It feels like there's this great big thing growing there that's taking on huge importance and we [the rest of the service] are getting in the shadow of it....There's a feeling of being a bit neglected....To use a family analogy, it's not like there's just been a new baby, but there's been quadruplets.

Every staff sector interviewed said that, at this point in the trial, they had experienced an increase in workload relating directly to the trial. In the case of some clinical staff, this excess workload was seen as creating considerable stress.

Administrative staff and social workers indicated extra hours had been spent in organizing case notes, files, and meetings; hiring research staff; setting up databases; and assisting with finance and surveys. Social workers said they were providing extra support for trial staff making initial approaches to distressed patients. None of this group indicated that their stress levels had risen because of this extra work.

Hospice nurses were undertaking extra work filling in pain scale forms for the participants within the hospice and, although this was seen as involving minimal time, there appeared to be significant confusion about the purpose of the trial and what was required with regard to the forms. Although information sessions had been held some time earlier, nurses had forgotten, "not understood the language used", or had been unclear as to what their role would be. In addition, there had been considerable staff turnover, with people leaving, and new part-time and agency nurses coming in who said they "hadn't got a clue" as to the finer details of what they were supposed to be doing. Other concerns related to their discretionary power to postpone or stop collecting pain information if they judged it to be too intrusive for a patient (who was too ill/dying). Overall, there appeared to be few nurses who were fully informed and none had any idea where they should go for clarification of any concerns.

Medical specialists said that the trial was "putting another layer of tasks over an already stretched workload". Overall, workload had increased in a situation where there was understaffing. The working day had elongated, with extra paperwork being done late in the evening or not at all. They said their visits to nontrial patients were fewer because of the extra workload. Other extra tasks involved:

- assessing trial patients, attending case conferences, and completing the work of overworked community nurse colleagues;
- conducting early case conferences, which were seen as being badly timed with "three people sitting round staring at each other and wondering what the hell its all about"; and
- doing liaison work the nurse no longer had time to do "in order to get it done", because of the extra loads carried by outreach nurses.

Screening patients for research whom the specialists felt should not be in the trial in order to meet triage criteria or "numbers" was a concern. Screening often led to the first contact with the service being with a researcher rather than a member of the clinical team. This was viewed as completely inappropriate, as patients had just been told they were being referred to palliative care, and were distressed, often confused, and vulnerable.

The lack of an identified liaison person, accessible to all staff, was noted as adding to the fairly considerable stress being experienced.

Outreach nurses appeared to be experiencing excess workload and resultant stress in triaging patients, collecting baseline data (1–2 hours), and undertaking regular follow-up reviews. In addition to confirming issues raised by the medical specialists (above), they were concerned that:

- The role of nurse as caregiver (and empathetic listener and problem solver) was being overtaken by the role of data collector; most nurses found difficulty in reconciling the two.
- Considerable extension of workload was occurring. The extra meetings required in order to gather data from trial patients were already affecting the time available for visiting nontrial patients, whose contact was being reduced to phone calls, usually initiated by the patients. The employment of two extra positions by the trial was not mitigating "unmanageable" workloads, and shifting workloads around had led to a lack of continuity with clients.
- Patients had commented on an excessive focus on paperwork. Although some appeared delighted to be contributing to knowledge

by being in the trial, others seemed very confused, or indicated they wanted to leave the trial because of the stress caused by the intrusion of multiple staff "visiting" them, particularly in the home setting, when they were trying to get used to a new diagnosis and get their lives in order.

### Focus Groups: Round 2

Four focus groups were held one year into the trial: hospice nurses (n=7); outreach nurses (n=9); administrative staff and social workers (n=3); and specialist medical staff (n=2), for a total of 21 participants. The same people who were interviewed in Round 1 chose to participate in Round 2. Informal feedback indicated that the lower numbers were a result of staff turnover and the belief that some of the initial problems had been addressed. One broad question area was investigated: What has the effect of the trial been on your current duties, personal stress levels, on patients, and on patient care?

Overall, the general attitude toward research appeared more enthusiastic than in the earlier round (Table 1), with outreach nurses and consultants exhibiting considerable enthusiasm toward both the trial and the possibility of future research. Stress levels seemed to be much reduced.

*Continuing Concerns.* The administrative staff and social workers had been minimally affected in the first set of focus groups, and this pattern persisted. Concerns expressed were with patient and caregiver knowledge; considerable confusion had been exhibited in phone calls as to which staff were from which area and whether coming off the trial meant patients no longer had contact with the service.

Hospice nurses still had a very poor level of understanding of what the trial was about, what the data they were collecting were being used for, and how this was of benefit to the patients. A known liaison person was still lacking

**Table 1 / TYPICAL RESPONSES OF THE 4 GROUPS OF PARTICIPANTS OF THE LONGITUDINAL FOCUS GROUPS SHOWING CHANGES OVER TIME**

| | Focus Group 1 | Focus Group 2 | Focus Group 3 |
|---|---|---|---|
| Nurses: Hospice | It feels like there's this great big thing growing out there and its taking on huge importance and we (the rest of the service) are getting in the shadow of it.<br><br>I haven't got a clue as to the finer details of what I am supposed to be doing or why it is important. | You know if I can't see the relevance to the client you are working with...why should I add it to my workload?<br><br>We need to understand it. If the data we have provided is relevant then we need to take some ownership, have some control over it. We really need to be part of the trial; we are just sitting out here on a limb. | Well it's been great to be involved in it and see the possibility of improved service. I'm just worried that it is now all going back to the way we were and the whole thing will just have been a waste of effort. |
| Nurses: Outreach | Our roles as nurses have been overtaken by our roles as data collectors, with an overfocus on paperwork with those patients on the trial are getting much more attention than those who are not. | We're not just data collectors any more, we've certainly had input into the formulation and revision of documentation. | We've really enjoyed being involved and feel the research team has respected our input. But post trial, the loss of extra staff and the movement back to line managers is not good either for us or for the patients. |
| Administrative staff and Social Workers | We have had to put in extra time organizing case notes and files, meetings, hiring staff, and setting up databases, but these tasks have not impacted too heavily on our workloads. | Our workloads are not a problem, but we are concerned that patients and carers coming into the hospice are not well informed about what their participation in the trial means for them. | None attended |
| Medical Palliative Care Specialists | It's just another layer of tasks to be done over an already stretched workload. | I really do think people can see the benefits both in terms of clinical practice and are also reassured that this research is actually going to go somewhere. | The outcome for patients has been great in terms of better care coordination and care continuity, but the loss of case conferencing and the reversion to more patients dying (post trial) in hospital rather than at home is sad to see. |

and, although shiftwork made communication difficult, they were not impressed by the trial's attempts to date to help them understand the trial or to value their contribution.

Outreach nurses thought routine screening of patients for the trial still needed better management. They also felt their considerable input into the research design and data collection required formal recognition "so we'd accept to have all our names first!" (on documentation emerging from the study).

Medical specialists were much more supportive than previously. Research screening was still causing concern and did not appear to be being done immediately when referrals came in. It was suggested that referrals go through a qualified health professional rather than administrative staff, thus preventing the current gap between referral and first contact, and allowing a more informed process of triage. Continuity of clinical personnel was also cited as a problem—it was deemed preferable for the same consultant to see a patient for the duration. Early case conferencing was now seen as useful for long-term planning and involving the GP, but resources could be saved if some were conducted in the hospice as outpatient visits rather than in the GP's surgery or patient's home.

**Focus Groups: Round 3**

Two focus groups were held after the trial had finished: a mixed nurse group (n=4) and medical specialists (n=2), for a total of six participants. Again, the same people from previous rounds participated, with the reduced numbers reflecting staff changes and lessening concerns. One broad question was again explored and all issues subsequently raised by participants were pursued: In retrospect, what were staff experiences of the trial and the transitional changes from trial to post trial?

Looking back, most felt that the trial had had a huge impact in a number of areas. There was a change in how they viewed their clinical practice, how they now appreciated the trial's effect on their work environment, and how they had moved beyond being just data collectors to becoming involved in research in an active participatory manner.

Nurses expressed concern about the loss of useful changes put in place during the trial:

- Loss of the research screening process meant loss of a triage system which had allowed initial contact to be made during the first 24–72 hours.
- Without the trial, there was a loss of continuity of care. Patients in the trial were seen regularly over the three-year trial period, and both patients and nurses became very attached, particularly those patients who had been seen by outreach nurses every few weeks for 12 to 18 months. Cutting back this contact was difficult for all, particularly as the end stage approached. This form of contact could not be maintained once the two staff employed by the trial left and higher caseloads were in place;
- Loss of structured patient evaluations. The trial forms had introduced new question areas (e.g. sexuality, feelings, and quality of life assessment) that allowed the patient to clarify aspects nurses might previously have judged without asking. Unfortunately, these questions were lost from the clinical service documentation with the ending of the trial.
- Loss of the empowerment and autonomy gained when suggestions made to the research team had resulted in tangible changes. Nurses felt that the trial provided an alternative model of work and a sense of stability. With the change back to a traditional line manager model and a work situation where they were simply "told what to do", nurses grieved for the loss of the work environment created by the research trial.

One area of enduring concern from the nurses was that, because of medical dominance, the names of medical staff who were felt to have been largely invisible and uninvolved, would feature on the project documents and publications, while the nurses who collected so much of the data, and without whom the trial would not have happened, would only be recognized in small type at the bottom of a page.

Medical specialists saw advantages in case conferences with their opportunity to talk to the GP, to educate, to raise questions, and to allow reflection on practice. The opportunity to talk things through with patient, caregiver, and family (in particular, the issues of pain, finances, and family issues) had also been good. The patients had benefited from knowing that the GP and the palliative care clinicians were on the same wavelength and communicating. The disadvantage was the time needed to organize these (half an hour to one hour of nursing time), and to travel to and run these often took a half day. When these were organized in clinic time, the appointment stretched from 20 to 40 minutes, putting the overall clinic time behind and way behind if there was more than one case conference.

## DISCUSSION

This qualitative study of the impact of large clinical trial on a relatively research-naïve palliative care service clearly showed that the introduction of the trial produced great staff stress and perceived burden, but that the initial concerns diminished over time. In fact, by the end of the three-year trial period, staff's greatest concerns related to loss of perceived benefits from the trial such as systematic patient evaluations, documentation, and continuity of care.

This substudy provided dramatic insight into the needs of staff as research was introduced. Indeed, the qualitative substudy describing the needs of clinical staff became an intervention in its own right. First, it gave trial investigators insight into how to conduct the current trial better. For example, the initial focus groups demonstrated that the administrative complexity of organizing a case conference made conducting the case conferences within a week of referral to the palliative care service nearly impossible. In response, the timeframe for organizing the conference was liberalized to 28 days from referral to palliative care, after appropriate consultation with all study investigators and protocol amendments were approved by the ethics committee. Iterative changes such as these were possible provided they did not substantially change the intervention nor impair ability to test pre-stated hypotheses. Weekly "research coffee meetings" were established after the first round of focus groups to facilitate communication and monitor needed changes. Community nurses and medical specialists readily attended. Second, this substudy gave insight into how to introduce new research activities after the current trial was finished. A durable example is that new investigator-initiated studies conducted within the palliative care organization have nurses involved in the research design. Third, the last round of focus groups demonstrated that an organization supporting research is an important way to support best practice and enable best practice to be incorporated into the service. The weekly "research coffee meetings" endure and provide an important forum for new ideas, ways to sustain transfer of recent evidence into practice, and a sense of ownership within the research process.

The focus groups facilitated change in organizational culture. After each round, copies of the focus group reports were distributed, as well as investigator responses and plans for action. The focus group transcripts showed that tangible responses to concerns engendered support for the trial and that initial adversaries among staff could become advocates. For example, initially the nurses did not want to have anything to do with research or the trial, however, by the second and third focus groups, they wanted their names associated with the trial and even suggested authorship.

Nonetheless, trial investigators could not attend to all the concerns identified. First, complaints that specifically reflected the internal activities of the clinical or governing health care organization were outside the purview of the trial. For example, staff concerns about patient reassignments were more reflective of changing philosophy within the palliative care organization than of a trial requirement. Second, some requests were inconsistent with the original specific aims of the trial and could not be carried out. For example, requests from nurses and medical specialists to delete a case conference for convenience reasons, even though the patient was allocated to a case conferencing trial arm. Third, nurses requested a role in publication and dissemination of trial results. There was a disconnect between the academic expectations of authorship reflecting intellectual input versus the nurses' argument that true "horsepower", in terms of data collection and conduct of the study, should result in authorship. Other authors report similar challenges (11). In order to deal with this, all nurses were explicitly acknowledged in the published trial methodology manuscript (8) and on an enduring trial Web site. Individual names were listed in the slide set during every trial-related presentation. All palliative care staff were offered the opportunity to nominate questions of interest and write research reports, with support from trial investigators and staff (e.g., data analysis, writing assistance). This offer was taken up by some of the medical staff, especially senior registrars, who were involved in the trial.

The addition of an independent qualitative researcher to the trial environment was beneficial. Initially, that researcher was completely independent but, as she conducted the substudy, her observations became more informative to the day-to-day activities of the trial. Over time, she became an objective but integrated voice within the trial. Nonetheless, each of the recommendations from the qualitative researcher needed to be reviewed carefully in the context of all pros and cons. Some recommendations, such as improved communication, were em-

braced and carried out with enthusiasm. The weekly coffee hours, trial bulletins, and staff presentations were a direct result of feedback from the focus groups and qualitative researcher. Other advice, such as changing categorical values recorded on data forms into open-ended text items, were not possible to execute while maintaining fidelity to the specific trial aims. If changes in the trial were not possible, this was reflected back to clinicians so that they recognized they had been heard.

### Recommendations Arising From Focus Groups

Several durable research recommendations were collated from all groups, including:

1. Improved communication. Clinical, administrative, and research staff need regular updates on the project. Regular presentations, open days, and email newsletters resulted.
2. Ethical concerns. The research and ethics committee or institutional review board of the hospital should always consider the potential impact on staff of any project. Indeed, this qualitative study was the trial investigators' attempt to address this issue carefully. Subsequently, a research review board for the palliative care service was instituted that had "review of studies for impact on staff" as a core objective. The institutional research and ethics committee would not approve any new studies unless they had been through this review.
3. Transparency. Staff involvement should be transparent and properly negotiated before permission to proceed is given. The research review board helped ensure this. Medical, community nursing, hospice nursing, and administrative staff representatives are on the board and required for quorum.
4. Input in research design and study procedures. Staff should have input in research design and especially in the development of study procedures that affect them or the patients for whom they provide care. Examples include input into timing and volume of data collection, inclusion of certain patients, and timing of interventions. It is imperative to balance staff input with the requirements of the proper research designs and procedures necessary for unbiased ethical research to provided clean and meaningful data. For example, staff requests for greater flexibility of timing of data collection and more observational (rather than tick box) comments were not carried out because they would have led to results that could not have been fully interpreted. On the other hand, nurses had direct input into triage and screening algorithms for the trial, design of data forms, and scripts used by trial staff during participant recruitment. This led to clearly meaningful improvements in trial procedures.
5. Workloads. Workloads of palliative care staff needed continuous review, especially community nurses and medical specialists. Some elements of this are clearly a palliative care organizational issue (i.e., the organization is responsible for appropriate staffing to meet patient volumes), but it was directly affected by the new research brought to the organization. The research trial added two nursing full time equivalents to the community nursing team in order to meet case conferencing and data collection requirements, but also required reorganization of nursing activities in order to accommodate the structured screening process. Iterative objective review allowed documentation of workload and more equitable redistribution of work; the focus groups facilitated this. As reflected in nursing reports between focus groups 1 and 3, the redistribution was important for relieving burden. Ultimately, at the conclusion of the trial, nurses worried about the loss of staff and patient continuity. At the end of the trial the requirements for staff dropped considerably, and iterative documentation and redistribution of workload was again required.

### Limitations

Two types of limitations in this study have been identified: limitations due to the qualitative substudy design and limitations in trial investigator's ability to respond to concerns identified in focus groups.

Given the vehemence and urgency of concerns identified in the first round of focus groups, the facilitator was unable to remain completely objective and distanced from the process. Reports generated were followed up on to ensure the facilitator delivered on the requests of focus group participants.

There was attrition in the number of focus group participants over time—the third round had just six participants. This may have reflected staff turnover and a lack of concern/interest by new staff, a loss of interest, or a sense that there would be no relationship between participation in focus groups and meaningful

change. Alternatively, it may be indicative that the two-way communication strategies put in place early in the trial had served to provide a platform where negotiation could occur and, therefore, most concerns had been met over the period of the trial. According to participants in the third round groups, the changes put in place by the trial, which had been so determinedly resisted in the first round, were now seen as considerable improvements to practice when compared with the earlier modes of care practice which had been reverted to.

Use of quantitative surveys of staff satisfaction and burnout would have provided useful correlates to transcript narratives. Researchers in Western Australia included such measures as a part of a palliative care demonstration project, documenting decreased staff satisfaction and increased burnout as the research project progressed (12). Grounded theory analysis using structured codebooks would have strengthened the results (13,14).

The most prominent example of the trial investigator's ability to respond to concerns identified in focus groups was seen in the repeated and unchanging concerns voiced by hospice nurses over time. Hospice nurses said they were confused about trial objectives and procedures. They repeatedly identified the need for a trial liaison and improved communication. Attempts by trial staff to provide informational sessions (including after hours sessions), posters, and other communication pieces were seen as insufficient. Staff turnover and agency nurses complicated the picture. Disagreements between hospice staff and senior administrators frequently played out in focus group discussions and were often difficult to dissect from concerns related to research. Unfortunately, the "weekly coffee hours" were not accessible for hospice nurses, and were really a forum focused on the community nursing team and medical specialists. New research within this palliative care organization which interfaces with the hospice nursing team should include a regular, focused forum for this group that accommodates shiftworkers.

## CONCLUSION

The cultural change required to add new research to an established palliative care program inherently resulted in staff stress and increased burden. When changing a clinical culture to incorporate a research orientation, considerable negotiation and communication, in which staff can speak without fear of repercussions, is very important; the qualitative focus groups used in this substudy facilitated the process. The readiness of clinical and administrative staff to share concerns needs to be matched by a research team prepared to be flexible, meet concerns, and recognize the input of staff. These findings are applicable to palliative care research in general, not just the kind of trial studied in this instance, and are also applicable beyond the research setting to any time new initiatives will require shifts in organizational culture in order to be accommodated.

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