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SEAM - improving the quality of palliative care in regional Toowoomba, Australia: lessons learned

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ABSTRACT

Introduction: The proliferation of professional palliative care services in recent years has increased access for people with palliative care needs; however, gaps in services continue to exist, particularly in rural and remote areas of Australia. In order to address one gap in rural health service delivery, the Support, Education, Assessment, and Monitoring (SEAM) Service for regional and rural people in Toowoomba, Queensland, Australia, was introduced. This new model of service delivery aimed to provide palliative services to patients and their families who live in the regional city of Toowoomba and its rural catchment area. It also aimed to facilitate education, support and networking among health-care professionals, particularly general practitioners and nurses employed in general practice (practice nurses).

Method: The evaluation involved twenty face-to-face interviews with a variety of health professionals who had contact with the SEAM service from June 2003 to June 2004. Qualitative data analysis of the transcribed interviews provided the basis for the evaluation. The emergent themes regarding the SEAM service included: satisfaction and benefit of the SEAM service; knowledge of and contact with the SEAM service; the SEAM role; and expansion of the role.

Results: The data indicate that the majority of health professionals who had contact with the SEAM service were satisfied with the service and found it to be of benefit to them and their clients. Participants commented on the extensive networking and support work established by the SEAM nurse with other health service providers. Difficulties experienced with the SEAM service included poor utilisation by GPs and, therefore, clients in need of palliative support. This was predominately due to lack of knowledge of the service as well as limited understanding of the SEAM nurse role.

Conclusion: The SEAM service has resulted in increased links between health professionals providing palliative care to rural clients. The most successful strategy was the use of multidisciplinary case conferencing which not only built links among health professionals caring for individual clients, but also resulted in improved care for those clients. As a result of better integration and communication, palliative care services to rural people have been improved. However, with regard to the delivery of direct patient care, or in the support of GPs for the management of

palliative care patients, it was apparent that the service did not meet its objectives. The lack of use by GPs and patients appears to be related to a lack of awareness of the existence of the service. A positive outcome of this poor utilisation is, however, that the model has allowed the identification of factors that work as barriers to GPs and client/family utilisation of rural palliative care services.

Key words: general practitioners, networking, nursing, palliative care, service delivery.

Introduction

Palliative care has been defined as the active total care of patients whose disease is not responsive to curative treatment[1]. Australian palliative care services are available in acute care, aged care and hospice services, as well as in community based programs[2]. There are some discrepancies between rural/remote Australians and their urban counterparts. In particular, there are some indicators that rural and remote Australians receive poorer palliative care than those in urban populations[3]. Population-based admission rates to palliative care services in regional and remote locations are 30-50% lower than in capital cities, and rural patients are less likely to have access to specialist palliative care doctors and allied health professionals than metropolitan patients[3].

The need for palliative care services in the home is clearly evident, as an increasing number of people with terminal illnesses are choosing to spend their remaining time in their home[4]. The provision of care to the patient who is dying at home is the responsibility of several different sources, such as: their 'lay-carers' (family, friends and neighbours); the primary health-care team (GP and domiciliary nurses); and when applicable, the community and hospital specialists and others (eg hospice)[5]. Effective palliative care in the home can be achieved if clients receive optimal support through well-coordinated health and social services[1]. Hunt et al. found an increase in patient acceptance and support of palliative care services over recent years, although a variation in demand and need exists[6].

The city of Toowoomba, located in Queensland (Australia), has a population of approximately 90 000, with the proportion of people 65 years and over higher than the state average[7]. Anecdotal evidence has highlighted that some people in the region have not had their palliative care needs met; in other words, some of the services that were available were not being accessed by the patient and their lay-carer, through lack of knowledge and possibly lack of communication among health professionals.

In 2003, the Toowoomba Division of General Practice (GP Connections), in partnership with the Toowoomba Hospice (Queensland, Australia), received funding for the Support, Education, Assessment and Monitoring (SEAM) project under the Australian Government's Caring Communities Program. The aim of this national program was to improve the quality of palliative care in the community by assisting families, lay-carers and health service providers to give better support to people who are dying[8]. The primary aim of the SEAM project was to develop, implement and evaluate an integrated service model of palliative care that would focus on improving rural people's access to services, and would be sustainable by the end of the second year of the project.
The SEAM service was a model of rural palliative care service delivery that aimed to:

- increase the palliative care support available to clients and their families
- provide palliative care education for patients and their families and health professionals
- assess the palliative care needs of clients and their families
- increase networks among care providers to overcome communication barriers and decrease duplication of palliative care services
- provide a care coordination model of service delivery for palliative care
- increase the role of GP and practice nurses in the care coordination of people requiring palliative care.

At the same time the SEAM service was funded, the Toowoomba Hospice opened. The Hospice is a community-owned facility for clients with palliative care needs. To maximise the effectiveness of the SEAM service, the SEAM nurse was located at the Toowoomba Hospice, rather than operating from GP Connections as was originally proposed.

Method

This project utilised an action research methodology in which continuous monitoring is essential in the ongoing development of the project. Participatory action research (PAR), which is the primary methodology chosen for the project, is founded in critical perspective that is grounded in social change. PAR was critical for this project because it is concerned with 'identifying the barriers and facilitators of human agency and participation toward the goals of action and social change' [9].

Participants and data collection

The Centre for Rural and Remote Area Health (CRRAH) at the University of Southern Queensland (Toowoomba, Australia) was contracted by GP Connections to undertake an independent evaluation of the SEAM Project. The evaluation was primarily qualitative in nature, and used a semi-structured interview tool to collect data from 20 participants. Participants included the SEAM nurse, four GPs, one pharmacist, three health service managers and 11 registered nurses from various health-care settings (hospital, community nursing providers). All the participants were employed in Toowoomba or surrounding rural areas.

Because the objectives were focussed on clients and their families it was important to include this group of participants. However, due to clients being too sick or having died, and their lay-carers experiencing grief, it was the decision of the researchers, in collaboration with GP Connections and the SEAM nurse, that these people would not be included in the sample. The objectives that were associated with clients and their families were to be measured indirectly through the various health professionals interviewed.

Interviews

Interviews are a valuable means to collect qualitative data as a greater depth of information is gleaned from individuals[10]. The semi-structured interview was used for this project to gain consistency in the data collection process. It also allowed for participants to convey information outside the question framework. The schedule developed for this study included a set of prompts to ensure that study objectives were met. The prompts were designed to gain information about the participants' knowledge and utilisation of, perceived benefits from and issues with the SEAM service. Different interview schedules (and therefore different prompts) were developed for GPs, nurses, allied health-care professionals and palliative care referral services.

Ethics

The study was approved by the Human Research and Ethics Committee of the University of Southern Queensland. Prior to the interview, participants were given a plain language statement which outlined the evaluation's aims and procedures. After allowing for the opportunity to ask questions and clarify issues they might have had about the study, participants were asked to sign a consent form. Participants were advised that they could withdraw from the study at any time. They were also given details of how confidentiality of their data would be maintained.

Data analysis

According to Fossey et al.[11], an analytical procedure associated with qualitative analysis typically involves three levels of analysis: (i) review, identification and coding of recurrent themes within the data for each participant; (ii) identification of common themes and areas of divergence across participants; and (iii) bringing identified themes back together into meaningful relation with each other. The qualitative data obtained from the interviews were transcribed verbatim. Each transcript was checked by the project officer against the tape to ensure accuracy of the transcription. To increase the reliability of the emergent themes utilising the above analytical procedure, two research staff conducted separate data analyses, using Fossey et al.'s guidelines and compared the findings. The two research staff came to a consensus as to the emergent themes.

Results

The main themes which arose from these interviews were: satisfaction and benefit of the SEAM service; knowledge of and contact with the SEAM Service; the SEAM role; and expansion of the role.

Satisfaction and benefits of the SEAM service

The majority of health-care professionals taking part in the evaluation had positive experiences with the SEAM service. Comments included:

> *I've had a lot to do* with [the SEAM nurse], *and if I ever had a problem I certainly wouldn't hesitate and ask her for advice, or for her assistance.*

Some participants noted that the SEAM service was a resource to tap into, providing palliative care information that was timely, relevant and accurate. Others, as indicated in the following comment, found that the SEAM service provided helpful and practical advice to health care professionals:

> *I find it beneficial in that I can make enquiries and get a reasonable response and assistance, and everyone is ready to help, they're all there ready to help whenever you need anything….*

Utilisation of the SEAM service also assisted health-care professionals to provide a smoother transition of clients from the community into the hospital or the Toowoomba Hospice. The SEAM nurse was a prime initiator of the weekly case conferences conducted at the Hospice for residential clients. The case conferences involved a number of health-care professionals from various disciplines and were perceived by the participants as very beneficial to clients and the health professionals involved in the care of the clients. One respondent explained:

> *I've been along to a couple of the case conferences. … I think, just the ability to sit down and talk with the other people that are involved in the person's care, is highly valuable. It means that we're all working towards the same goal. It means the information that I have about the patient and the background and history is able to be shared with the other people involved in their care, which I think brings them up to speed a lot quicker.*

Knowledge/awareness of and contact with the SEAM service

Knowledge of the SEAM service was expressed by participants at varying levels, ranging from not being very aware of the service at all, to being able to fully explain the role. One respondent explained:

> *I've read about it in the GP Connections newsletter, and yes, when I'm at the hospice, because I attend the hospice meetings once a month, I've even picked up a couple of brochures.*

Good knowledge of and contact with the SEAM service often coincided with those services where good networks had been established, particularly other palliative care service providers. Poorer understanding was found in services that only had very limited contact or where the SEAM service was seen not to be of great benefit. For example, some practice nurses and palliative care nurses had a limited understanding of the role, minimal contact, and could not see how the SEAM service fitted into the current models of palliative care service delivery. One respondent indicated the lack of contact with the SEAM nurse:

> *I know that* [SEAM nurse] *is very knowledgeable and I know that she does visits in the community, but … she certainly doesn't come and visit our clients, she only hears about them in the case conference, and sort of offers her input there, but there's been no direct benefit, that I've experienced, anyway.*

The majority of health professionals who knew about the SEAM service sourced this information through GP Connections or contact with the Toowoomba Hospice. Other sources included direct contact with the SEAM nurse or through pamphlets, newsletters or posters. Patient referral to the SEAM service occurred primarily through general practice or referral services such as the community liaison nurses from the hospitals. One respondent commented on her experience of referring a patient to the SEAM nurse:

> *I have always asked the patient of course for their consent to contact* [SEAM nurse], *and then she has followed them up promptly, which is always helpful, and provided me with feedback, and that's helpful in my role…*

According to one health professional, there appeared to be a relatively limited awareness of the service among the general community. A lack of marketing of the service other than to health professionals appears to have been a contributing factor. One participant explained:

> *I'm not sure if there's very much public awareness. I certainly mention it to my families about the service, and about* [the SEAM nurse's] *coordinating role and things, but I'm not sure whether the general public, there's so many families that have loved ones with cancer, I don't know if a lot of them know that this service is available and how it reaches out in the community as well as in the hospitals, so I guess I'm not sure how many people know about it, other than the GPs.*

The SEAM role

The SEAM service provided a small number of patients and lay carers with support, education and assessment. The central activities undertaken by the SEAM nurse have been in the areas of: (i) networking with health professionals; (ii) capacity building between palliative care service providers; (iii) support for these providers; (iv) liaising with and advising health-care providers about patient care; and (v) resource provision to GPs, practice nurses, and some clients. Networking, support and capacity building were mentioned by the following respondents: 'So, that involves basically the support education and assessment and monitoring.'

> *I think the networking between different professional groups is one of the big strengths, bringing together you know like* [hospital] *community liaison and* [name of service], *and also the hospice, and the hospital if there are issues between the different services, then they can be discussed and hopefully addressed, … and I think it also helps continuity of care for patients if all the services are working in the same direction and saying the same things.*

A majority of participants who contacted the SEAM service found that the ongoing networking enabled closer links with the various health-care services and providers, particularly those in palliative care. Palliative care education sessions conducted by the SEAM nurse in collaboration with other health-care professionals, such as the 'Doctors Bag for the Dying for Nurses', were very well received as the following comment indicated:

> [SEAM nurse] *and* [doctor] *and have done 'the doctors bag for palliative care' and have got the RNs from the nursing homes to come in and they had a session here at the hospice and it was just fantastic. They had so many people here and had to turn so many more away, and they're doing other sessions throughout. And I see that as really important too, because that's really improving people's confidence in regard to palliative care, giving them good information.*

The following respondent commented on the SEAM nurse's role as a liaison position:

> *I think she fulfils a very important liaison position, because it would seem to me that she not only attends our case conferences, but it seems as though she might also attend palliative care meetings at the base hospital …*

Weekly case conferencing through the enhanced primary care (EPC) Medicare items was identified by some GPs as being of benefit to them and their clients. One GP pointed out:

> *Basically, I had two, three, three occasions when I had the patient who had cancer in the hospice. We had a Thursday afternoon meeting, and, which was a case conference, and basically the* [SEAM nurse] *wrote up the case … conference for me and sent a copy to me, so I have that copy here in the notes, …*

There was some confusion about the role of the SEAM nurse, particularly among health professionals. Participants believed that many GPs would not use the SEAM service due to lack of knowledge of the service, relative low numbers of palliative care clients attending their clinics and contentment with the existing

palliative services they have accessed in the past. One participant explained:

> *Well I don't think most GPs are aware of the services. … a lot of the times … I've been fairly happy catching up through the nurses in the palliative care service from the* [public hospital or community service], *that come in, because … they're seeing cancer patients sort of all the time, whereas what happens generally with the GPs, or with myself anyway, is that … I might have one or two, and then none for a while, and then another one, and then none for a while, and then another one.*

Some participants expressed the view that the SEAM service could cause confusion for some clients at a time when they may not want to deal with more than one service provider. Linked to this issue was the concern that the SEAM service was duplicating education and training sessions to health professionals, and that this duplication was a poor use of already limited resources. The following comment identifies the respondent's concern with having multiple people involved in the care of a client:

> *Many people are involved when someone is at a palliative stage of their life, that quite often they get quite confused about who's who, and it's also a part of their life where they can get quite introspective and so they don't really want any more strange people intruding on their life, whereas if it's someone who they already have a rapport with, like the practice nurse, then hopefully if they can get in early and build a rapport with the domiciliary nursing service and through to the hospital, those sort of people. That rapport's built up and then it's not just this extra person, sort of intruding.*

Expansion of the role

Participants identified that the SEAM service could be expanded into other areas to fill gaps in service delivery in Toowoomba and region. These included expanding the role into Indigenous palliative care, working more as a bereavement service, or changing the focus to mental health, aged care or family care. The following participant highlighted two of the potential areas that the SEAM role could expand into:

> *I do think it is something that would work really well in, like aged care and perhaps mental health as well, because I know mental health is another area, there's a big lack in case management.*

Discussion

The primary aim of developing, implementing and evaluating an integrated service model of palliative care that provided services to rural people was only partially achieved. The project was not as successful as intended primarily because of a significant change in the SEAM nurse role. More emphasis was placed on the networking, support and education to health professionals. There were many strengths and limitations associated with the changes throughout the project. These will be discussed under the following headings: strengths and successes of the SEAM service, and limitations of the SEAM model.

Strengths and successes of the SEAM service

The SEAM model of palliative care service delivery was successful in many aspects from the positive experiences of contact with the SEAM nurse, to the increased networking/capacity building function of the service and the increased education of rural nurses.

Positive contact with SEAM service: There were many positive experiences of contact with the SEAM service. These included the SEAM service's provision of: (i) a palliative care resource which could be tapped into by health professionals; (ii) timely, relevant and accurate palliative care information; (iii) helpful and practical advice not only to health-care professionals; and (iv) a smoother transition of clients from the community into the hospital or the Toowoomba Hospice through weekly case conferences. This has been achieved mainly through the professional conduct of the SEAM nurse, including her excellent communication skills, good rapport with GPs and visionary thinking.

Liaison/networking/capacity building: Another area the SEAM service has been successful in is in the building of networks within the oncology/palliative care services in Toowoomba. The SEAM service has established valuable links across the private and public health sectors and disciplines. The establishment of regular case conferences involving a variety of health professionals has

contributed to this success. Also instrumental in this success was the willingness of the SEAM nurse to actively pursue good partnerships and work collaboratively on training programs and the development of resource materials. A systematic review conducted by Mitchell[1] identified that clients receiving palliative care by their GPs are best served if their GPs work as part of a palliative care team. This team approach enhances mutual learning and consolidation of skills and ensures that GPs are providing sound palliative care. Further to this, Street and Blackford[2] found that the most effective networks between GPs and palliative services were established when a palliative care nurse consultant was involved in the liaison and coordination activities. Continued effort by the SEAM nurse to maintain and expand networks, particularly with local GPs, will further enhance this valuable outcome and ensure that palliative care services in this region work more closely together.

Nurse education on palliative care: There was evidence of palliative care education for nurses, which had a positive and successful impact. For example, nurses located in Toowoomba who dealt with palliative care clients in various settings (such as, general practice or aged care facilities) attended several in-service programs provided by the SEAM service. The excellent response by nurses to the education sessions indicated that the SEAM service was meeting a need among these health professionals for further education and training. Studies on access to education and training for rural nurses[12] and practice nurses[13] suggest that little targeted education and training is currently available to rural nurses. As the SEAM education sessions were free-of-charge, the results also suggest that the affordability of these sessions also made them more accessible for these rural nurses[14].

Limitations of the SEAM Model

Despite the strengths and successes of the model, there were a number of unforeseen circumstances that resulted in an evolving model different to that first envisaged. The limited provision of support and the potential duplication of services for clients and their families created barriers to overcome during the project. Other limitations included a lack of knowledge of the service among target groups, the lack of accessibility to clients, the lack of utilisation by GPs, and finally the lack of sustainability.

Provision of support for clients and their families: Despite the original intentions of the SEAM role, according to the SEAM nurse, the service provided few clients or their families with support. This part of the role was evident in the first few months of the SEAM service, but over time it diminished, with the SEAM service concentrating on providing a resource base for health professionals. It is possible that the changes in the focus of the SEAM service were influenced by the development of the Toowoomba Hospice and expansion of palliative care services within Toowoomba.

Duplication of services: Early in the implementation of the SEAM service, other health professionals voiced their concerns about duplication of already existing palliative care services in the region. These concerns directed resulted in the almost entire exclusion of a hands-on patient care role. This created a further barrier to the sustainability of the project because direct access to clients was required in order to access the EPC items for income generation.

Lack of knowledge of the service: The data suggested that clients and their families (according to the service providers) as well as some health professionals had little knowledge of the availability of the SEAM service. This lack of knowledge of the service was identified as one factor contributing to low utilisation rates of the SEAM service. Ahmed et al[15] found a general lack of knowledge and education about palliative care and services among health and social care professionals, as well as clients and their families. They suggested placement of educational material in health care and public places, such as supermarkets and libraries, in order to improve public knowledge on issues of death and dying.

Lack of utilisation by GPs: The data suggested that the GPs did not utilise the SEAM to its full potential. Cairns and Yates[16] argue that due to current workforce shortages, 'even enthusiastic GPs who see only two to four palliative care clients per year may have difficulty maintaining their practical skills'. It was envisaged that the SEAM service could assist rural GPs in the provision of the most updated information of resources in palliative care. While this aim was not achieved, there may be a number of reasons why GPs did not fully utilise the SEAM service. For example, Shipman et al.[17] identified that GPs use palliative care services primarily as a

resource. This use is closely linked to a number of complex circumstances, such as the needs and preferences of the client; the ability of the client/GP to access services; and poor clarification of GP's roles and responsibilities within the entire palliative care team dealing with the client.

Additionally, the lack of knowledge and poor utilisation of the SEAM service by these rural GPs may explain the poor utilisation of the service by clients with palliative care needs and their families, because GPs were to be the referring body to the SEAM service. According to a study by Greiner et al.[18], many health professionals desire more information and education on palliative care, as well as access to palliative care experts, thus indicating that continued promotion and publicity of the SEAM service (which did not occur) to rural health professionals may be one way to improve full utilisation of the service.

Lack of sustainability: Poor utilisation of the SEAM service by GPs, clients and their families has led to the lack of sustainability of the service once project funding ends. The ending of the SEAM service would mean that the successful networking and support for health professionals would cease and revert to the original model where this lack of communication had lead to clients' palliative care needs not being met. In the original proposal, it was envisaged that health assessment of palliative care clients, and case conferencing would be major part of the SEAM nurse's work and the income generated from the use of these EPC items would cover the costs of the service. EPC items were not utilized. The major cause of this lack of utilisation was the low client numbers referred. Additionally, to access the EPC item 'health assessment', the client must be over 75 years of age. During the time the SEAM service was operational, the majority of palliative care clients referred through the Toowoomba Hospice and, therefore, to the SEAM service, were under 75 years of age. During the interviews, several participants suggested that the SEAM service could target the aged-care sector, thus overcoming the age limitation, as well as increasing the scope of the current service. It is well recognised that residents of aged-care facilities are found to receive the least coverage of palliative care services[6], predominately because of limited staff training and lack of staffing resources. However, it was not clear how the extension to the service would be funded once Australian Government project funding ceased.

Conclusions

Lessons Learned

Despite the many successful outcomes of the SEAM model of service delivery, there are a number of lessons that were learned through the duration and at the completion of the project.

Importance of efficient promotion: One limitation of the SEAM model was the lack of knowledge and education about the service. The data suggested that the placement of educational material in health care and public places should improve public awareness of palliative care issues, and that these types of promotional activities needed to be taken to promote the SEAM service more widely. Additionally, the SEAM service could have utilized the assistance of Toowoomba oncologists, chemotherapy units or the Queensland Cancer Fund to promote the existence of the service. Further, a focused media campaign in the local newspaper or on the regional ABC (Australian Broadcasting Commission) radio station may have reached people who could benefit from the SEAM service, particularly those in outlying rural areas

Maintenance of clinical role: Sustainability of the SEAM service required primarily a clinical role in which the SEAM nurse would provide health assessments of palliative care clients and participate in case conferencing. These duties would enable the generation of sufficient income to cover the costs of the service. The evolution of the service toward a networking/capacity building role impacted upon the nurse's ability to perform a clinical role. Focus on and maintenance of a hands-on patient care approach would have increased the service's ability to be sustainable at the completion of the project.

Clarity of charter and role clarity: The initial aim of the service was to fill one gap in palliative care service delivery. In the early stages of the project, it was perceived by other health professionals that the service would duplicate already available and accessible palliative care services in the community. This misconception led to the SEAM nurse altering the primary duties required of the role. This suggests that there was a lack of clarity in

how the service was promoted to other health-care professionals. The variation in the duties also suggests that the role of the SEAM nurse was not entirely clear. Promotion in clarity of charter would have assisted to avoid the perception that the SEAM service was a duplication of the current palliative care services in Toowoomba. Also, further education and promotion of the role clarity of the SEAM service would have assisted to increased uptake of all aspects of the service.

Nature of GP access: Only a small number of GPs in the Toowoomba area utilised the services of the SEAM project. This lack of access possibly resulted in low numbers of clients accessing the service, thus limiting the service's ability to be sustainable over the longer term. As indicated earlier, the reasons for lack of utilisation are linked to client needs and preferences, accessibility of palliative care services, and lack of GP role clarity. Further investigation is required to clearly identify which, if any, of specific aspects are impacting on low referrals from GPs to existing palliative care services in Toowoomba.

The establishment of the SEAM service in Toowoomba, Queensland, has made significant inroads in the area of networking and building of partnerships with existing rural palliative care services. Aspects of the SEAM service have positively impacted on those health professionals involved in the delivery of palliative care services, and has been one outstanding feature of the service. The many lessons that have been learned from this project will assist in the development and implementation of future health service delivery models. Future research could incorporate a study of the reasons for the low referral rates among the various palliative care health providers. It is envisaged that Street and Blackford's work[2] on communication issues for the interdisciplinary community palliative care team will help to inform the research.

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