

Exploring barriers to the provision of palliative care in Australia

Kieran G Allen

Third Year Medicine (Undergraduate)
Monash University

Kieran is a joint recipient of the 2009 Monash University Chris Silagy Award for his exceptional project in the Community Based Placement Program. Kieran is currently placed at Eastern Health. He hopes to further his interests in palliative care and its implementation into the health profession training programs.

Sadid F Khan

Fourth Year Medicine (Undergraduate)
Monash University

Sadid also received the 2009 Chris Silagy Award with partner Kieran Allen for their project into palliative care as part of their Monash University Community Based Placement Program. He has numerous interests in medicine and surgery, as well as in medical education.

Palliative care provides assistance for people living with a terminal medical condition, for which the primary goal of treatment is improving quality of life. There are numerous barriers to the provision of palliative care. There is little research into barriers to the provision of palliative care and little with an Australian context. This research explores barriers to palliative care in Australia through questionnaires and interviews with stakeholders. One hundred and one questionnaires were given to South East Palliative Care (SEPC) community nursing and allied health staff, general practitioners and aged care facility staff. Five interviews were conducted with representatives from SEPC, Palliative Care Australia and two aged care facilities. Most agreed that palliative care was essential in the community, hospital and aged care setting. Four major themes were identified from interviews: 1.) Education & stigma barriers; 2.) Communication barriers; 3.) Aged care barriers; and 4.) General practice barriers. Inadequate prescriptions of pain medication were a significant issue. These themes were supported by questionnaire data, with 25.6% identifying education and 28.2% identifying resources as major barriers. Knowledge of palliative care was poor in both aged care staff and GPs, only 8.3% and 38.5% respectively answering all palliative care questions correctly, compared to 64.2% amongst SEPC staff. The study addresses a deficit in previous research, identifying barriers to palliation in aged care. The data collected has potential for further research or interventional approaches to improve the provision of palliative care for Australians.



have been found to be inexperienced in the management of pain in palliative care. [9,11] Consequently, many patients experience severe pain in the final stages of their lives. [9,12] This failure of adequate pain management may be attributable to the fears of doctors in prescribing palliative doses of analgesia, often due to anxiety surrounding physical or psychological addictions to opiates or the stigma associated with analgesia-related deaths. [9,11]

This study seeks to further investigate the barriers to the provision of palliative care in an Australian context, through cross-sectional qualitative and quantitative data collection. It aims to explore barriers relevant to the provision of community palliative care, as well as grossly assessing knowledge of palliative care in healthcare professionals and determining potential suggestions to address any identified barriers.

Introduction

The World Health Organisation (WHO) defines palliative care as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of suffering... and treatment of pain and other problems – physical, psychological and spiritual.’ [1]

Much of the current research into barriers to the provision of palliative care relate to psychological and spiritual issues. Research into barriers to palliative care is scarce in an Australian context. Additionally, there are deficiencies in the literature relating to the provision of palliative care in aged care facilities; a setting where many palliative patients reside. [2-5]

The provision of palliative care is impeded by barriers of varying nature. Often these barriers involve interactions between healthcare professionals, particularly General Practitioners (GPs). [2-6,10] Improvement is required in both the frequency of referrals and communication with palliative care facilities. Additionally, there is a need for increased communication and interactions between aged care facilities and palliative care providers. [2,9]

Inadequate teaching and experience of palliation in the medical profession has been seen to be a major issue, repeatedly being identified by doctors as a major contributor to an apparent lack of understanding. [3-6,10] A large proportion of doctors (72-76%)

Methodology

The methodology aims to elicit the best understanding of the barriers to the provision of palliative care through the involvement of the following stakeholders:

- Community palliative care nursing and allied health staff from South East Palliative Care (SEPC)
- Aged care facility (ACF) carers & nursing staff
- Palliative Care Australia - the peak body for palliative care policy advocacy and implementation in Australia
- GPs.

The results were gathered using a combination of questionnaires and semi-structured interviews. The questionnaire was distributed to SEPC, aged care staff and GPs. Consent for participation was implied upon completion and return of the questionnaire. The questionnaire contained three collection methods. The first required respondents to indicate the degree to which they agreed with a given statement, using a Likert scale (strongly disagree=1, disagree=2, neutral=3, agree=4, strongly agree=5). Secondly, questions were posed to ascertain the respondent's level of knowledge surrounding palliative care. Open ended questions enabled the collection of qualitative responses, allowing respondents to elaborate on their beliefs surrounding barriers to palliative care.

Questionnaires were distributed to 30 SEPC staff, 30 aged care staff

and 41 GPs. The GPs and the aged care staff were randomly selected from an online database of Melbourne based units/practices. A computerised random number generator was used for this purpose.

The semi-structured interview was conducted with members of SEPC and aged care facilities in person and a Palliative Care Australia representative by phone. The interview aimed to explore the stakeholder's ideas surrounding barriers to palliative care, as well as their opinions on ways to reduce these barriers. Individuals who were interviewed were not given a questionnaire to fill out to avoid replication of results. The interview was conducted by two students. Questions were asked by the same student through all interviews and transcribed directly.

Questionnaires were anonymous and were numbered and filed based on response group. The results were to be compiled according to frequencies of responses, and short response questions and the semi-structured interview results were analysed for common themes using the meaning condensation method [13] for qualitative data, and compared with the literature.

Ethics approval was granted for this project by the Monash University Standing Committee on Ethics in Research involving Humans (SCERH).

Results

Interview Results

Four prominent themes regarding barriers to palliative care were elicited: 1.) Education and stigma; 2.) Communication; 3.) Barriers in aged care; and 4.) Barriers in general practice. These themes highlight more specific barriers (Table 1).

Table 1. Major barriers to the provision of palliative care highlighted in interviews.

Education and stigma
<ul style="list-style-type: none"> Poor awareness of palliative care services Inadequate direct education in palliative care in the medical profession Negative connotations associated with palliative care in the community Fear surrounding death and dying
Communication
<ul style="list-style-type: none"> Poor communication between healthcare providers, especially between GPs, aged care facilities and palliative care referral services Poor understanding of patients' cultural, language and spiritual issues surrounding death
Barriers in aged care
<ul style="list-style-type: none"> Under-training of aged care facility staff, particularly carers Lack of advanced care planning, despite regulations requiring it to be discussed Inadequate access to appropriate pain medication
Barriers in general practice
<ul style="list-style-type: none"> Inexperience in palliative medication prescription Legal issues and confusion differentiating palliative interventions from euthanasia Lack of exposure to palliative patients in general practice

Questionnaire Results

The questionnaire was distributed to 101 individuals. The questionnaire response rates are summarised below:

- Fourteen South East Palliative Care community nursing and allied health staff replied (46.6%)
- Thirteen general practitioners replied (31.7%)
- Twelve aged care facility carers replied (40%)
- Total response rate = 39 out of 101 (38.6%).

Table 2. Questionnaire responses regarding attitudes to palliative care.

"I feel comfortable discussing death and dying with people"
<ul style="list-style-type: none"> Respondents generally agreed with this statement (mean = 4.2). Three (25%) aged care respondents answered 'neutral.' A further two (16.7%) did not respond to this question.
"I felt/would feel comfortable referring someone to a palliative care service"
<ul style="list-style-type: none"> Respondents strongly agreed with this statement (mean = 4.6). Four (33.3%) Aged Care staff answered "neutral."
"Referrals to palliative care services are common in my organisation/practice"
<ul style="list-style-type: none"> Respondents typically strongly agreed with this statement (mean = 4.4). Seven respondents (18%) answered "neutral."
"I believe a palliative assessment is necessary on admission to an aged care facility"
<ul style="list-style-type: none"> Large variance in responses. Many respondents agreed with this statement (mean = 4.0). Aged care respondents agreed more strongly than the other respondent groups.
"Palliative care is "giving up" on regular treatment"
<ul style="list-style-type: none"> Respondents strongly disagreed with this statement (mean = 1.6). Four (25%) aged care respondents answered "neutral." A further two (16.7%) did not respond.
"Language and cultural differences are likely to result in poorer outcomes for palliative patients"
<ul style="list-style-type: none"> Large variance in responses. Most respondents agreed (mean = 3.6). Nine (23.1%) respondents answered "neutral."

"To my knowledge, palliative care is usually provided ..."
<ul style="list-style-type: none"> The correct response was "from diagnosis of a terminal illness." This question was generally well answered: <ul style="list-style-type: none"> 26 respondents (66.7%) correctly answered this question. Aged care staff answered this question best (91.7% correct). Seven (53.9%) GPs answered this question correctly. Eight (57.1%) SEPC staff members answered this question correctly. One (7.1%) SEPC staff member and one (7.7%) GP did not answer this question.
"Palliative care ceases to exist for a patient and their family in the following time-frame..."
<ul style="list-style-type: none"> The correct response according to current Victorian practice is "twelve months after death." Eleven (78.6%) South East Palliative Care respondents identified the correct response. No GPs or Aged Care staff answered this question correctly.
"Palliative care may involve..."
<ul style="list-style-type: none"> One (8.3%) Aged Care staff member could identify the various aspects of palliative care. Five (38.5%) GPs could identify the various aspects of palliative care. Only nine (64.2%) SEPC staff members accurately identified all aspects of palliative care. Two (15.4%) GPs and two aged care staff (16.7%) believed euthanasia forms apart of palliative care.

Table 3. Questionnaire responses regarding knowledge of palliative care.

Of the 39 surveyed, 35 indicated that they had referred someone to a palliative care service. For example, in the case of SEPC, this referral often occurred as an escalation of care to an inpatient specialty unit. Table 2 summarises the responses to questions regarding attitudes to palliative care. A Likert scale (strongly disagree=1, disagree=2, neutral=3, agree=4, strongly agree=5) was used to grade responses to these questions.

Table 3 summarises the levels of knowledge surrounding palliative care in the various cohorts. Questions presented several options to the respondent, requiring them to select the correct option(s).

Figure 1 shows a visual comparison of knowledge of palliative care across the different respondent groups. Notably, the number of ACF staff and GPs that were fully aware of palliative care principles highlighted a deficit in their knowledge base.

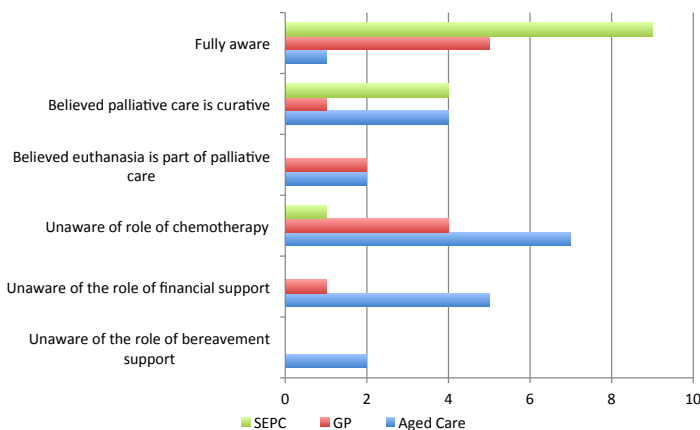


Figure 1. Comparison of knowledge of palliative care between various respondent groups.

Level of palliative care knowledge was directly related to frequency of specialist palliative care referrals:

- SEPC staff referred most frequently (usually weekly).
- GPs generally referred once every few months.
- Eight (66.7%) aged care staff had no experience of palliative care referrals.
 - The major reason given for not referring was that it was not the respondent's responsibility.

Summarised below are the main responses given to extended response questions (Table 4). Respondents were encouraged to describe their personal opinions on the barriers to palliative care.

Table 4. Responses to Extended Response Questions.

"What are some of the barriers to the provision of palliative care?"
Responses by frequency:
<ul style="list-style-type: none"> • Lack of resources/funding (28.2%). • Poor knowledge of services by healthcare professionals (25.6%). • Poor knowledge of services by the community (20.5%). • Fear of death and "palliative" label (20.5%). • Language and cultural barriers (15.4%). • Curative focus of medicine (12.8%).
"How could these barriers be addressed?"
Responses by frequency:
<ul style="list-style-type: none"> • Community advertising/education (30.8%). • Education and training of healthcare professionals (25.6%). • Increased palliative resources (15.4%).

Discussion

Results of both data collection methods highlight key barriers to the provision of palliative care. Both reflected the barriers previously identified within the literature. In particular, barriers relating to education, communication and GPs were consistent with previous findings. [2-4,6-10,14] The results support the evidence indicating inadequate prescribing practices in relation to pain medications. [9,11] The interview results highlighted issues surrounding aged care facilities, despite significant interventions to improve palliative care provision in the aged care sector.

Interviewees reached a consensus that palliative care is important in any healthcare setting. This information was reflected in the questionnaire results, where respondents strongly agreed that "a palliative level of care is an important part of the management of a terminally ill patient." This highlights the relevance of the topic in a healthcare context as well as the need for the barriers to palliative care to be addressed.

Most respondents felt comfortable discussing death and dying with patients. However, several respondents from the aged care cohort answered "neutral" or did not answer this question. This may highlight that the aged care respondents feel uncomfortable or may not have come into contact with this situation before.

Respondents strongly agreed that they would feel comfortable referring patients to a palliative service and did not believe that palliative care was akin to "giving up" on treatment. These results indicate that personal prejudices in the healthcare professions are unlikely to be contributing as a barrier to palliative care. Interviewees felt that these sentiments were not reflected in the wider community, which may associate palliative care with negative connotations.

Respondents strongly agreed that palliative care assessments should be an important part of the intake process of aged care facilities. Aged care staff were, understandably, most likely to agree. This question did not address whether this process is currently conducted at aged care facilities, presenting a weakness in this question. However, interviews with aged care staff highlighted that although procedures did exist for palliative assessments, these were often not implemented appropriately. Reasons suggested for this were mostly due to the family or patient's refusal, often due to unwillingness to discuss issues pertaining to their death.

Interviewees felt the main barriers to the provision of appropriate palliative care relate to a lack of awareness and education. Results from the questionnaires supported this, with many respondents believing knowledge of palliative services was poor amongst the healthcare professions, as well as the general population. This suggests a deficit in education of palliative care in healthcare training as well as the wider community. Improvements in community education programs and direct palliative education for training healthcare professionals were suggested from qualitative data collection to help to address this deficit.

The crude knowledge assessment of palliative care reflected this lack of education in the healthcare setting. Respondents from all survey groups (GPs, SEPC community nurses and aged care facility carers) indicated deficiencies in various aspects of holistic care. Whilst most respondents were able to correctly identify that palliative care is provided from the time of diagnosis of a terminal illness, only those respondents from SEPC could accurately identify that holistic palliative care may extend for twelve months after death. This deficiency is most prominently expressed in the GP and aged care staff cohorts.

A minority of the aged care and GP cohorts believed that euthanasia may form part of palliative care, which is illegal under current legislation in all jurisdictions of Australia. This could represent either a lack of knowledge about palliative care or of the definition and legal status of euthanasia. Regardless, it is imperative that healthcare professionals understand the distinct difference between palliative

care and euthanasia. As suggested previously, [9,11] it is possible that these respondents may believe that the progressive increase of pain medications, which may ultimately result in death, is a form of euthanasia. Current guidelines note that the intention of the intervention is most important. Hence, as the intention of palliative pain management is to alleviate pain and suffering, rather than death, it is not considered euthanasia.

Communication barriers highlighted an inadequacy of appropriate communication between various professional groups. Difficulties here were felt to lead to inadequate or inappropriate referrals between organisations, ultimately resulting in squandered resources and poorer patient care. Communication breakdowns between GPs and aged care staff were thought to result in inadequate access to pain medication. This suggests that these problems are due to issues surrounding poor education of aged care staff and the communication of drug orders. Improvements need to be made to ensure the GP maintains an effective role in the provision of palliative care in aged care facilities through education and improved communication and liaison.

Due to the nature of the semi-structured interview, certain limitations and a degree of bias exist in the questioning and recording of responses. In order to maintain consistency in the interviewing technique, the same interviewer was used for interviews. The recorder transcribed onto a laptop as the interview took place. This method of recording does not account for error in the documenting of discussion points by the recorder. That is, there is a potential for error as the recorder interprets the meaning of the discussion points and documents them. This was minimised due to consistency in the recorder throughout all of the interviews. The recorder's capacity was limited by their typing speed whilst maintaining intelligible notes. Whilst this may be a source of error, this was not a major issue as the recorder was able to keep pace throughout the majority of the interview. Some questions overlapped in the interviews and were covered in different areas. This could suggest that the questions could have been more generalised, or grouped better to allow for better compilation of data and minimise the time required to sort through and categorise data. Additionally, stakeholders were selected from a variety of roles in palliative care, but had a more clinical presence than bureaucratic. This may create a bias towards identifying more clinically related barriers and suppressing bureaucratic barriers through the analysis method used in this study.

It is important to note that results from both the interviews and questionnaires are only from a select few individuals. Although interview candidates were selected due to their key positions and would have a good knowledge of barriers in palliative care, it is by no means a comprehensive analysis and is from a select demographic of authoritative figures. This could potentially result in a bias towards the identification of administrative barriers rather than barriers related to

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actual field work. Questionnaire respondents filled this demographic and assists to eliminate some of the bias in this case. The questionnaire results, however, may not offer a proportionate representation due to the poor response rates on the questionnaire. This was further compounded by the frequency of "neutral" responses to some questions, particularly in the aged care cohort. This may indicate a lack of understanding or poor clarity of the questions. Further research should be conducted on a wider scale to ascertain a greater level of accuracy in the results.

This research would serve as a good groundwork for future research in either barriers to palliative care or more interventional approaches in order to address these barriers and improve the provision of palliative care. Specifically, suggested interventions into staff education, especially in aged care facilities, and community awareness programs were identified in the study as potential avenues for future implementation. Examples of this could be information brochures about palliative care being made available to staff and patients within the aged care facilities, integrating palliative care in training of palliative care assistants or running education seminars for aged care facility staff. Further education is vital to ensure that training healthcare professionals, particularly in the medical profession, are aware of the crucial role that palliative medicine plays.

Conclusion

Palliative care plays a critical role in the Australian healthcare system. There are many barriers which limit the effective provision of palliative care to those in need. This research investigated these barriers and identified the major issues through questionnaire and interview results from key stakeholders. Four salient themes were identified overall: communication between organisations and professionals; inadequate education of health care professionals; lack of knowledge surrounding palliative care; and insufficient pain management. Significant knowledge deficits were highlighted amongst GPs and aged care facility carers regarding palliative care. Future health promotion projects could focus on education within aged care facilities and general practice. Addressing these barriers is an integral step in furthering the effective provision of palliative care in Australia.

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Conflict of interest

None declared.

Correspondence

K G Allen: kgall1@student.monash.edu

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