

Qualitative Research Elucidates Needs for Palliative Care

KALİTATİF ARAŞTIRMA PALYATİF BAKIM GEREKSİNİMLERİNİ BELİRTİR

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Abstract

Palliative care is a growing discipline within medicine and nursing that is beginning to be integrated into healthcare in Eastern Europe and less developed nations. Even in wealthy nations where palliative care is relatively progressive, many dying patients continue to have unmanaged pain. In the Caribbean, pain is particularly poorly managed for people dying at home. The qualitative methods used in Caribbean study are tools with which to inform public health-related policy and programs, especially those pertaining to end of life issues. When conducted with sensitivity to participant's privacy and possible distress, qualitative methods reveal unique healthcare needs, and realistic means of meeting those needs through national or community health policy and programs. Public health programs and attempts to improve health systems sometimes fail for not having recognized or responded to local conditions that bear on their sustainable success. Qualitative research is a valuable approach to consulting healthcare users and providers about their concerns and priorities regarding access to, and provision of, services. This paper argues that health policy for pain management and end of life care should be based on realistic and sensitive consultation with stakeholders, and that data derived through such consultation should guide policy and programs. The qualitative research approach used in the Caribbean is presented here as a model that may easily be used in other nations and cultures. Qualitative approaches to stakeholder consultation regarding healthcare contribute to the integration of ethical principles like respect for persons, beneficence, and justice into sustainable health programs that benefit all.

Key Words: Palliative care, health policy, qualitative methods

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Özet

Palyatif bakım, Doğu Avrupa ve daha az gelişmiş ülkelerdeki sağlık bakımına entegre olmak için başlayan, tıp ve hemşirelik içinde gelişen bir disiplindir. Palyatif bakımın rölatif olarak yaygın olduğu zengin ülkelerde bile, birçok ölmekte olan hastalar kontrol edilemeyen ağrıyı çekmeye devam ederler. Karibler'de ağrı, evdeki terminal dönem hastaları için özellikle daha az kontrol altındadır. Karib çalışmasında kullanılan kalitatif metodlar halk sağlığı ile ilgili politika ve programlar, bilhassa hayatın sonu ile ilgili konuları içerenlere ait çalışmalardır. Katılanın gizliliği ve olası sıkıntısına ait duyarlılıkla ilgili olduğunda kalitatif metodlar tek sağlık bakımı gereksinimlerini ortaya koyarlar.

Bu bildiri, ağrı idaresi ve hayatın sonu bakımına ait sağlık politikasının realistik ve duyarlı konsültasyon üzerine dayalı olması ve böyle bir konsültasyonla ortaya çıkan bilgilerin politika ve programlara önderlik etmesi gerektiğini tartışır. Kariblerde kullanılan kalitatif araştırma yaklaşımı diğer ülkelerde ve kültürlerde kolaylıkla kullanılabilen bir model olarak burada gösterilebilir.

Anahtar Kelimeler: Palyatif bakım, sağlık politikası, kalitatif metodlar

Health professionals have a duty to comfort patients who are in pain and/or dying, and to minimize their suffering.¹ Various medications and complementary approaches can be used effectively to manage pain,

dyspnea, anxiety, and other forms of discomfort. Many elderly or chronically ill patients in the US., however, endure persistent and severe pain.² The science of pain management is advancing and educational programs encourage aggressive pain management but the need for pain and symptom management remains a major concern among seriously ill patients and their families.^{3,4} The need to improve pain management also exists in Europe and release of the second edition of an extensive textbook on palliative medicine attests to the worldwide relevance of these concerns.^{5,6} Little is

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documented about pain or its' management in less developed nations, but aspects of palliative care are beginning to be integrated into Eastern Europe as well as parts of Africa and India.⁷⁻¹⁰

In Turkey there are at least two small inpatient hospices in Ankara according to Hospice Information, an information service for health professionals and the public about international palliative care.¹¹ Establishment of hospice and palliative units there is encouraging, but such efforts may be hindered by Turkey's low per capita consumption of morphine for medical use and pain relief. In 2001, Turkish consumption of morphine for medical use was 0.19 mg per capita, well below the global mean of 5.44 mg per capita.¹²

Among 146 nations that reported morphine consumption data to the International Narcotics Control Board (INCB) in 2001, Turkey was in the bottom third, although it used 7.36 mg per capita of pethidine, which is well above the global mean of 3.77 mg per capita.¹³ Pethidine, however, is eight times less effective than oral morphine and has greater toxicity.¹⁴ The most recent data from the INCB shows that Turkey consumed only 0.16 mg per capita of morphine and 2.16 mg per capita of pethidine in 2003.¹⁵ The INCB plays a global role in palliative care because it administers the international system that controls the availability of opioid analgesics recommended by the World Health Organization (WHO) for cancer pain relief.¹⁶ Qualitative research would help to assess the need for pain relief and palliative or hospice care in Turkey, and might lead to new policy or programs that would increase access to aggressive pain relief.

In the Caribbean region, qualitative research methods including focus groups and interviews show that pain at the end of life is prevalent and severe, but that Caribbean people accept pain as an unavoidable part of life and death.¹⁷ This view impacts on the expectations of patients and health professionals about how their health systems should respond to pain and other symptoms associated with the end of life. Qualitative research methods can be valuable tools with which to con-

sult healthcare users and providers about concerns, needs, and priorities that bear on health services, policy, and budget. This paper argues that such efforts are necessary to national and community health policy and planning, and describes how they may be undertaken.

International and national programs designed to control public health problems or improve health systems sometimes fail for not having recognized or responded to local socioeconomic, cultural, and even geographic conditions that bear on their sustainable success. Such conditions can be highly variable even within one nation, and impact directly on access to care.¹⁸ This paper outlines the socioeconomic and cultural context in which the Caribbean end of life study was conducted, and shows how qualitative methods can be used to inform public health-related policy and programs. While doctors and nurses have a duty to relieve pain and suffering,¹⁹ policy-makers and other health professionals have a duty to consult stakeholder populations when undertaking needs assessments and long term planning.²⁰

The Socioeconomic and Cultural Context

Most Caribbean islands are independent nations with their own unique culture and socioeconomic concerns. Geographically large island nations like Jamaica, Barbados, and Trinidad have factories, universities, and daily newspapers, while small nations typically do not. Many Caribbean nations are part of the British Commonwealth and have legal, educational, and healthcare systems derived from the British. While each is unique, there are generalities among Caribbean nations and places with similar socioeconomic and/or cultural conditions.

Much of the Caribbean economy centers on tourism. Income is also generated through fishing and agriculture, small businesses, and government employment including civil service, schools, and healthcare. Computer access and use is increasing, and many Caribbean people have lifestyles and homes that are comparable to middle or upper class people in the US and Europe. The majority, however, have small and/or irregular incomes. Educa-

tion is free and literacy rates are relatively high, but the quality of education and the level of literacy vary. Many middle class families pay for private schools and/or send their children abroad to be educated.

Healthcare is free to all, but economics limit the types of care and standards of care that can be provided. Paternalism is the norm in these health systems: Patients expect their doctors to diagnose and treat them, but not to explain prognoses, treatment options, why a particular treatment is advisable, or why the patient should adhere to the treatment plan. Consequently, many patients do not take medications, even pain medications, as prescribed. Moreover, the paternalistic approach is not compatible with the informed consent process expected in much of the world today. The World Medical Association describes a globally desirable approach to the informed consent process, noting its relevance in different nations and cultures.²¹

When faced with serious illness, people from smaller Caribbean nations tend to go abroad for diagnosis and treatment if they can afford to do so. Services like dialysis and mammography are unavailable on some Caribbean nations, and there are few palliative or hospice type services. Opiates are not used aggressively for pain relief in the region. Most Caribbean governments or institutions do not have pain policies, even for cancer patients. With respect to prescribing narcotics for pain and medical use, there appears to be little adherence to the World Health Organization's (WHO) analgesic ladder.²² The WHO analgesic ladder for pain relief makes specific clinical and pharmacological recommendations for inexpensive means of managing pain; these are freely available online,²³ but many nations fail to implement them. In many nations and healthcare settings, pain assessment and management are hindered by lack of accountability for relieving pain. Health professionals, institutions, and politicians should be accountable for the services their systems provide. To systematically implement WHO's analgesic ladder requires national and/or institutional policy to do so, and training of health professionals and administrators

in advances in the science of pain management so that they are more willing to prescribe opioids aggressively when medically warranted. Doing so for patients in severe pain is beneficent, and presents no significant harm to patients.

Qualitative Research Methods Can Elicit and Expose Hidden Perceptions

In the Caribbean study, participants included the families and caregivers of those seeking healthcare at the end of life, and the doctors and nurses providing that care. Each of these groups can be defined as stakeholders in their national healthcare system. Stakeholder groups might also be broadened further to include patients themselves, policy makers, and others. The Caribbean study offered no incentives to participate, but succeeded in stimulating dialog in a cross cultural setting where local people are typically reluctant to share their thoughts with foreigners. The information obtained illustrates that socioeconomic and cultural influences are not always readily apparent, but that these bear on local perceptions, needs, and priorities.²⁴ When conducted with sensitivity and respect for participants or stakeholders, qualitative methods reveal the unique needs and priorities of a given population, and elucidate conditions and circumstances that will impact upon the utilization and success of healthcare programs.

The Caribbean data was obtained through focus groups, interviews, and personal narrative, and was analyzed by the content analysis method wherein data is conceptualized and organized into themes derived from the data itself.²⁵ The use of pre-existing groups (a group of teachers who regularly ate lunch together, for example) and several open ended themes for discussion (instead of a series of questions) were particularly valuable to the Caribbean study. Themes to initiate discussion included relationship of caregiver to the deceased, place and perceived cause of death, pain experienced by the deceased, and the role of spirituality at the end of life. Like other qualitative approaches, this open ended approach elicits descriptions of things as they naturally occur, and

reflect participant's experiences and perspectives, rather than the views of researchers or others.^{26,27} While the methods used were published elsewhere,²⁸ they are discussed in greater detail here to substantiate the argument that such consultation contributes meaningfully to national and community health policy and planning, and to assist those who seek to use this approach in their own settings.

The value of qualitative methods became clear as the Caribbean data began to substantiate previously heard anecdotes of severe pain. Significantly, it elucidated cultural and language-related nuances that might otherwise have led to misinterpretation of the data. Most participants whose loved ones died at home initially described their dying loved ones as "comfortable", but they subsequently revealed that these same loved ones were also in severe pain. Further discussions within groups clarified that what participants meant by "comfortable" was that the loved ones were taken care of (given food they liked, bathed regularly, had clean clothes and bedding, and had remained at home with easy access to family and friends in a familiar setting). There was a sense among participants that they bore the responsibility for keeping their loved ones comfortable, and that they could and were obligated to do so even if the patient was in severe pain.

It did not occur to patients or caregivers in the study to request medication or treatment for patient's pain, dyspnea, anxiety, or other symptoms. Such symptoms were perceived as facts of life that medicine could not treat. These were unpleasant for patients and caregivers. But comfort was perceived as something the family and caregivers could contribute, even in the face of ongoing and/or severe pain. Without sensitive open ended discussions, this insight (that people can sometimes be described as comfortable even when they are in pain) would likely have remained hidden. Sensitive discussions were necessary to show that pain was common among those dying at home. Without such discussions, the data would have stopped with the view initially expressed by participants, that their loved ones were comfortable when

they died. Qualitative approaches to research and consultation can, therefore, highlight sociocultural and other nuances that bear on healthcare needs, access to care, and deficiencies in the system.

The Caribbean participants were recruited by word mouth, and through personal referrals from local colleagues. Such referrals were vital to establishing potential participants' trust, and hence, their willingness to speak openly. Caribbean culture, like some others, does not encourage sharing information about oneself with foreigners. In one instance, a local religious leader was asked to suggest possible participants. He encouraged an interview with one of his elderly parishioners; she subsequently recruited her prayer group for a focus group. When focus groups were comprised of people who already knew each other (like teachers or community group members) participants were more willing to participate, and quicker to share their views and discuss their personal experiences.

Some participants were recruited without prior referral. Some of them were concerned enough about the research topic and/or trusted the researcher/recruiter enough that they subsequently recruited others to the study. Being recruited by someone participants knew personally also helped gain their trust and willingness to talk openly. Additionally, affiliation with a local institution or group helped instill trust, and thus engage stakeholders in dialog, even with researchers from other cultures and nations. This multifaceted approach avoids the potential bias of recruiting or consulting the researcher's friends and/or peers, and ensures broader generalizability of the information obtained. The therapeutic opportunity of talking about ones' loss probably also contributed to the decision of some to participate. This opportunity is a potential benefit to participants, but when researching end of life issues, it is vital to be sensitive to the physical and emotional distress and privacy of patients and their loved ones. Research designed with this in mind can enhance our understanding of healthcare needs at the end of life and how to meet them. Moreover, it benefits participants by offering a safe outlet in which

they can express and share their difficult experiences, and giving attention to them and their concerns.

The Caribbean study did not control for socioeconomic or educational status, however it became apparent early on that participants represented both low and middle income levels. When data from these participants was saturated such that no new concepts or themes arose, additional contextual data was sought through a focus group of physicians, and through interviews with hospital nurses. These methods were the most convenient means of gaining the participation of the two respective groups. Like the other participants, physicians and nurses were recruited by word of mouth through local colleagues. Their socioeconomic status was seemingly higher than that of other participants, but their views substantiated the data obtained by the others, thereby enhancing the reliability and generalizability of the data. Reliability was also verified by participants' interactions during focus groups. For example, body language like nodding their heads often indicated acceptance of and/or lack of surprise at experiences described to the group.

Conclusions

Qualitative data reflects participants' experiences and perceptions. It can provide realistic contextual information about a given setting, and it is more generalizable than a single clinical case study. Its value is that it identifies stakeholder realities and opinions, instead of accepting assumptions made by experts from other locations and contexts. Thus focus groups and interviews arranged by local referral are a useful means of consulting stakeholders about health and healthcare. Anecdotally, community gatherings and one to one approaches in market areas are also effective at recruiting broad participation. In any case, having a local affiliation and/or support from local community members helps to win participants trust, and thereby gain realistic information relevant to the local setting. This approach is also likely to promote better compliance with public

health prevention or control programs because as a result of participating in the consultation process, stakeholders know more about the issues and have more invested in resultant programs.

Pain generates anxiety, depression, a feeling of losing control, and reduces ability to enjoy sex or affection.²⁹ Pain relief is invaluable to recovery and/or to ensuring a peaceful death. Qualitative research to explore relevant aspects of healthcare and health systems should be used to consult stakeholders about their priorities and needs for pain relief and end of life care, and national and community health policy should respond to those needs once they are identified. Stakeholders in pain management include patients, potential patient populations (which include all of us, and particularly the elderly), families, caregivers, doctors, nurses, and other health professionals including administrators and policy makers. Data generated can contribute significantly to documentation of needs within a specific community or culture, and to finding realistic and sustainable approaches to managing pain in a given setting. Such consultations should be used to inform and evaluate effectiveness of new or existing health programs and policies.

Much pain and suffering could be alleviated by generating deeper understanding among clinicians, administrators, and policy makers about the different types of pain and suffering that patients and caregivers endure. Such understanding may help them to implement more effective pain and symptom management strategies involving medication, social services, voluntary organizations. To do so systematically requires national and/or institutional policy. The use of qualitative methods like those described herein would contribute significantly to such understanding.

The goals of medicine and nursing are to heal both trauma and illness, but also to comfort and alleviate suffering. At the community level, these goals will be more easily met if qualitative research is conducted to involve stakeholders at the individual, community, and national level. This

involves generating awareness of developments in the science of pain management, and endorsing and implementing WHO's analgesic ladder and guidelines for managing pain. It requires communicating more effectively with patients to offer sympathy and comfort, and trying to improve the healthcare system.

The ethical principles of respect for persons, beneficence, and justice are important considerations in any health program. Justice is particularly important in encouraging equal access to aggressive pain relief when medically warranted, as for advanced stage cancer patients. Beneficence refers to acting in the patients' best interest, which means making all reasonable attempts to alleviate pain and suffering when possible. Respect for persons requires that health professionals, institutions, and policy makers facilitate the dignity and peacefulness of people near the end of their lives. Thus each of these principles promotes effective management of acute or chronic pain. Such management is possible through prescription of opioid medications that are scientifically and medically sound and encouraged by the WHO. Qualitative approaches to consulting stakeholders in end of life care and other areas of public health research can contribute to the integration of these principles into sustainable health programs that benefit all.

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