Supporting Cancer Patients in Jamaica – A Needs Assessment Survey

D Spence[1], R Crath[2], A Hibbert[1], K Phillips-Jackson[1], A Barillas[2], T Castagnier[2], H Ghul[2], M Lambda[2], K Stemeroff[2], N Webley[3]

ABSTRACT

Objective: *Global cancer incidence is rising rapidly, particularly in the developing world where a majority of people present with advanced disease. In the English-speaking Caribbean, there is very little published data on the needs of cancer patients, their caregivers or those of allied health professionals. The research team sought to redress this balance by undertaking a needs assessment survey in the South Eastern Health Region of Jamaica to identify unmet needs and to make recommendations for improved service delivery.*

Methods: *A mixed methods, cross-sectional study design was used involving formal and semi-formal interviews and focus group discussions.*

Results: *The study results indicated that there were significant barriers to accessing healthcare. These included prohibitive costs of diagnosis and treatment, a mistrust of, and poor communication with doctors, compounded by people's fears, belief in folk wisdom and lack of knowledge about cancer. Recommendations offered by the study participants focussed on a community-based model of support to address the multiple needs of people facing life-limiting illness and their caregivers. Healthcare practitioners recommended the development of specific policies, targeting, in particular, improved drug availability and palliative care education in order to guide development of appropriate services for the large numbers of cancer patients in need.*

Conclusion: *A multiplicity of unmet needs was identified by cancer patients, their caregivers and allied health professionals. Recommendations by study participants and the authors echoed the guidelines as set out by the World Health Organization (WHO) in its 1990 Public Health Model for the integration of palliative care into existing healthcare systems.*

Keywords: Cancer, community health, palliative care

Apoyo a los Pacientes de Cáncer en Jamaica – una Encuesta para la Evaluación de las Necesidades

D Spence[1], R Crath[2], A Hibbert[1], K Phillips-Jackson[1], A Barillas[2], T Castagnier[2], H Ghul[2], M Lambda[2], K Stemeroff[2], N Webley[3]

RESUMEN

Objetivo: *La incidencia de cáncer global está aumentado rápidamente, particularmente en el mundo en vías de desarrollo, dónde un gran número de personas se presentan con la enfermedad en estado avanzado. En el Caribe angloparlante, se ha publicado muy poca información sobre las necesidades de los pacientes de cáncer, sus cuidadores o los profesionales de salud asociados. El equipo de investigación buscó restablecer el equilibrio emprendiendo un estudio de evaluación de las necesidades en la Región de Salud Suroriental de Jamaica, para identificar las necesidades no satisfechas y hacer recomendaciones encaminadas a mejorar la prestación de servicios.*

Métodos: *Se empleo un diseño de estudio transversal con métodos mixtos, contentivo de entrevistas formales y semi-formales así como discusiones de grupos focales.*

Resultados: *Los resultados del estudio indicaron que había barreras considerables para el acceso a la atención a la salud. Estas comprendían costos prohibitivos para el diagnóstico y el tratamiento,*

From: [1]The Hope Institute Hospital, Kingston, Jamaica, West Indies, [2]Departments of Social Service Work, Seneca College, Toronto, Canada, and [3]Department of Social Work, The University of the West Indies, Kingston 7, Jamaica, West Indies.

Correspondence: Dr D Spence, The Hope Institute Hospital, PO Box 100, Kingston 7, Jamaica, West Indies. Fax: (876) 702 2485, e-mail: dinglespence@ gmail.com

West Indian Med J 2010; 59 (1): 59

desconfianza y pobre comunicación con los doctores, agravada por los miedos de la gente, la creencia en la sabiduría popular, y la falta de conocimientos sobre el cáncer. Las recomendaciones ofrecidas por los participantes en el estudio se centran en un modelo basado en la comunidad. Este modelo permite abordar las múltiples necesidades de las personas que enfrentan enfermedades limitantes de la vida, así como las necesidades de sus cuidadores. Los practicantes de cuidados de la salud recomendaron el desarrollo de políticas específicas, encaminadas especialmente a mejorar la disponibilidad de medicamentos y educación de cuidados paliativos para guiar el desarrollo de servicios apropiados para el gran número de pacientes necesitados, enfermos de cáncer.

Conclusión: *Se identificaron una multiplicidad de necesidades no satisfechas, por parte de los pacientes de cáncer, sus cuidadores y profesionales de salud asociados. Las recomendaciones hechas por los participantes en el estudio y los autores, siguieron al pie de la letra los lineamientos trazados por la Organización Mundial de la Salud (OMS) en su Modelo de Salud Pública de 1990 para la integración del cuidado paliativo en los sistemas de cuidado de salud existentes.*

Palabras claves: Cáncer, salud de la comunidad, cuidado paliativo

West Indian Med J 2010; 59 (1): 60

INTRODUCTION

Global cancer incidence is rising rapidly. The World Health Organization (WHO) predicts that by 2020, 15 million new cases will be diagnosed annually and that 70% of these cases will be in the developing world (1). Patients, in many of these countries, often present with far advanced malignant disease, and as many as 70% will be incurable at diagnosis as education, prevention and early detection initiatives have yet to make an impact (2, 3). Given these pressing realities, the WHO has argued that palliative and supportive care and pain relief, although neglected policy areas, remain the most relevant healthcare approach for the large numbers affected (3). Palliative care has been defined by the WHO as “the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families” (WHO Technical Report Series No. 804).

Fundamental to devising strategies for addressing issues of late presentation, suffering and pain, is the need for published material on quality of care for, and levels of suffering of, people with malignant disease (4). In 1999, a WHO sponsored, five-country study in Sub-saharan Africa highlighting the needs of people with HIV and cancer, subsequently informed the creation of palliative care policy in some of these countries (5). In the English-speaking Caribbean the needs of those with advanced disease appear to be similar to those in East Africa (6), although there is a dearth of published information in this area.

This project set out to provide an essential, first-step corrective to this paucity of information by addressing the following two research questions: What are the needs of cancer patients, their caregivers and allied health professionals within a Jamaican context and what modifications to delivery of current formal and informal services at governmental, institutional and community levels would effectively address these unmet needs. The intention is to use the results from this investigative research to inform a pilot community-based palliative care project in the greater Kingston, Jamaica, area. The needs assessment survey was thus concerned less with the preliminary assessment of curative treatments offered than with the types of support available from a palliative care perspective.

STUDY DESIGN AND METHODS

The study, conducted in the South East Regional Health Authority (SERHA) between March and May 2007, employed a cross-sectional, mixed methods design. Cancer patients (n = 56) in all stages of the illness presenting at, or admitted to, eight rural and urban-based health facilities were sampled by convenience and interviewed through a structured questionnaire. Twenty-five additional patient questionnaires were administered at three different community settings (total patient interviews n = 81). Caregivers (n = 51) accompanying patients to these facilities were interviewed with a separate, structured survey. In addition, a semi-structured questionnaire was administered to healthcare professionals at each Health Facility. Those interviewed included ten registered nurses, four physicians, three social workers, two healthcare assistants and a public health nurse. Semi-structured interviews were also held with seven key informants within four local communities. They included a priest, two pastors, a naturopath, a patient who had experienced healing from a ‘madda’ (female revivalist healer), a vice-chairperson of a cancer support group and a community health nurse volunteering in a church-run community health clinic. In addition to the interviews, focus groups were held in four different community settings. Focus groups were held in the following locations: Spanish Town YMCA (A Reach to Recovery group for Breast Cancer Survivors), Open Bible Congregation, inner-city Kingston, Morant Bay Seventh Day-Adventist Congregation, St Thomas and

Church of Christ, August Town. Each focus group consisted of 8–12 participants who had been invited by a community leader previously identified by the research team.

All survey questionnaires and interview guidelines were adapted from a WHO palliative care project in Africa (7) and modified to fit the Jamaican situation. Ethics approval was obtained from the Ministry of Health, from South East Region Health Authority (SERHA) and from the University of the West Indies Ethics Review Board. Informed consent was sought from all participants in the study. Descriptive statistics derived from the structured interviews with caregivers and patients were assessed using SPSS Version 15. Content analysis was performed on the qualitative data (transcripts from focus group discussion, interviews with health practitioners and community healers) and relevant themes extracted. Generalizability of all data cannot be presumed given the research methods employed.

RESULTS

Table 1 illustrates the characteristics of patients and caregivers interviewed by formal survey. The results suggest that many of the patients who responded to the interviews were from lower socio-economic groups (based on occupational status), 61.7% were male and 96.3% were over 35 years of age. Most patients lived in relative proximity to a road, and to a health-care facility, 52% had only a primary school education and 62% were currently unemployed or not working due to their illness. The majority of caregivers had secondary education (51%), were employed in a variety of sectors (a number did suggest that they were being paid for their caregiving services) and 78% were family members of the patients for whom they were caring. Most focus group participants also came from low to lower middle socio-economic groups, although two groups also consisted of participants with some level of post-secondary education and higher income levels.

Table 1: Characteristics of study participants interviewed by structured survey

Characteristics		Caregiver (n = 51)		Patient (n = 81)	
		Frequency		Percentage	
Gender of patient	Male			50	61.7
	Female			31	38.3
Age of patient	18–35			3	3.7
	36–55			38	46.9
	> 56			40	49.4
Proximity of household road	Across the road			15	19
	< 1 km			55	68
	– 5 km			10	12
	> 5 km			1	1
Proximity of household to health facility	Across the road			2	3
	< 1 km			27	33
	1 – 5 km			33	41
	> 5 km			19	24
Status on land	Lease			14	17
	Owner with title			44	54
	Other			23	28
Material of house	Permanent (concrete)			71	88
	Semi-permanent			10	12
Household water source	Pipe			70	86
	Stand pipe			3	4
	River			2	3
	Other			6	6
Average household size				4	
current occupation	Labourer (or Farmer)	5	10	17	21
	Hospitality/Service	4	8	4	5
	Professional	9	18	10	12
	Self-employed	5	10	2	3
	Currently unemployed	13	26	50	62
	Paid Caregiver	8	1 6		
Education level	None-Primary	13	26	42	52
	Secondary	26	51	27	33
	Tertiary	12	24	12	15
Marital status	Single	21	41	32	40
	Married	21	41	31	38
	Widowed	7	14	13	16
	Divorced	2	4	5	6
Caregivers relationship to patient	Family member	40	78.4		
	Friend	8	15.6		
	Other	3	5.9		

Barriers to seeking treatment

* Consultation experiences with Health Professionals

Themes of mistrust and poor communication with healthcare practitioners were uncovered, principally during focus group discussions and interviews with key informants. Thirty per cent (30%) of caregivers interviewed together with participants in all focus groups and several of the key informants felt that the attitudes of doctors, and the way in which patients were treated by them, were significant barriers to seeking medical treatment. Participants felt that people often "do not trust doctors to tell the truth". It was believed that doctors fear that the patient might not be able to cope with the diagnosis or that patients would not be able to pay for treatment options, and so telling the truth became pointless. The groups identified the inability of healthcare practitioners, particularly doctors, to deliver information in a language that is accessible to them as being another significant barrier to accessing healthcare. The groups felt that inaccessible language, combined with the low literacy level of many patients, and compounded by minimal consultation times, often resulted in a patient's lack of understanding of their diagnosis and treatment options. This contributed to feelings of being patronized or discriminated against. The word "disrespected" was used frequently in this context. Finally, "horrendous and debilitating" waiting times were also recognized as a factor in discouraging people from seeking medical attention.

These themes of mistrust and disrespect helped explain why some people seek treatment from bush doctors and spiritual healers. Participants from the August Town Group and Open Bible congregation, together with the three religious leaders of inner city communities argued that their community members often want instant, reliable information that doctors may often be unwilling to provide. Bush doctors and spiritual healers in contrast, are seen as offering an immediate diagnosis of the problem along with a clear formula for treatment. Moreover, it was felt that spiritual healers take the time to build a rapport and a personal relationship with the person, using language that is accessible and dignifying. What is important to note is that these community leaders felt that many of their community members do choose medical treatment as their first option, but, because of their experience of feeling disrespected, their mistrust of doctors, and the expense of treatment options, will often choose spiritual or bush treatments as a more accessible solution**.**

* Folk wisdom/myths/lack of understanding

Focus group participants together with alternative healers identified that peoples' fears, lack of knowledge and belief in folk wisdom can play a significant role in either late presentation, or reluctance to access healthcare facilities for suspected cancer-related illness. A diagnosis of cancer is often understood as an instant "death sentence", and peoples' lack of information about the trajectory of different cancers, about treatment options, and about the benefits of early detection, exacerbate these fears. Currently held beliefs include "only evil people get cancer", that cancer is a form of "God's punishment" or that cancer is a curse. These beliefs can lead to the social ostracization of a person with cancer. Thus, because a cancer diagnosis is thought to have deep spiritual roots, it is often felt that 'madda' and 'obeah' are better equipped than medical doctors to diagnose and treat what is properly a spiritual rather than a medical disorder. In Jamaica, the term "obeah" is used to refer to witchcraft, evil magic or sorcery by which supernatural power is invoked to achieve personal protection or the destruction of enemies. "Obeah" has also been used somewhat loosely to describe any non-Christian beliefs, practices and rituals.

Participants of all four groups were markedly vocal about the stigmas and misconceptions attached to gender specific cancers. For numerous men, they argued, prostate cancer – from diagnosis to treatment – represents a serious threat to their masculinity and sexuality, and fears of impotence loomed large. For many women, loss of a breast or breasts also represents an affront to their sense of sexuality and gender. There is a perception by some that a mastectomy might result in rejection by a sexual partner or stigmatization. One breast cancer survivor stated that "some women would rather die with two breasts and an active sex drive than deal with breast cancer". Cervical cancer is often linked to sexual promiscuity, and many younger women avoid early detection screening, or if diagnosed, veil their diagnosis in secrecy.

* Financial Barriers

Costs associated with diagnosis and treatments were mentioned as being prohibitive for many people. Indeed, lack of financial resources was identified as the most significant barrier to accessing healthcare. Approximately, 70% of patients questioned identified financial barriers as the single most important factor for non-compliance with treatment regimens or follow-up care. (Since the completion of this study, payment of user fees in the public healthcare system has been abolished).

Needs of Patients and Caregivers

The most pressing needs of cancer patients, as identified from the patient and caregiver questionnaires, key informant and health practitioner interviews and focus group participants can be outlined as follows:-

* Need for financial support

The need for financial support was a recurring theme. Sixty-nine per cent of patients interviewed stated that they had problems paying for cancer treatments and 67% reported the inability at times to afford medications. Only a small percentage (4%) of patients identified transportation costs associated with visits to healthcare facilities on a regular basis as being prohibitive although this might have reflected the demographic realities of people sampled as opposed to those living in more rural parts of the country. Focus group participants together with inner city religious leaders argued that maintaining household financial stability is difficult if the illness affects the ability of the patient or caregivers to work. Patients are often concerned about the long term financial security of their family, which may mean they are reluctant to put all their resources towards their own healthcare. Finally, the inability to access affordable and nutritious foods together with hygiene products were also identified by several participants in August Town and in Morant Bay as being barriers to the patient's ability to heal or enjoy a decent quality of life.

* Need for access to pain medication and other medicines

The need for pain medication and improved access to pain medication was identified as being a key area of concern. Fifty-six per cent (56%) of the patients interviewed admitted to having experienced pain during their illness to date, and a further 20% to some form of physical discomfort. However, 42% of those experiencing pain or discomforts were not currently taking any form of prescription medicine, and 67% said they had problems affording medication. Seventy-five per cent (75%) of caregivers identified pain management as the most pressing need of the person for whom they were caring.

* Need for home care support

Thirty-one per cent of patients interviewed indicated a preference for home care, 46% for in-hospital care and 21% expressed no preference. Of those who cited a preference for hospital care, the majority identified better care in hospital and inadequate home care provisioning as reasons for their preference. In contrast, 71% of caregivers stated a preference for their relative to be cared for at home. The reasons given were that they felt that it was more convenient (30%) and that the patient would receive better treatment (58%) in the home setting. Only 16% of caregiver respondents reported receiving some form of training in delivering home-based care. The respondents were clear about a need for instruction in the following areas:- general care basics, knowledge about cancer and nutritional needs of the patient. These educational needs were reinforced by a number of healthcare practitioners who argued that although patients' preference is often to be treated at home, there was concern about the ability of caregivers to provide adequate support for the physical, nutritional and medical needs of people in their care. Even when training is offered (only one health facility provides such education), there are currently no resources available to offer ongoing support to patients and caregivers once patients are discharged from hospital.

* Need for emotional support counselling and education

Several participants from the focus groups, together with key informants and alternative health practitioners spoke at length about the need to offer ongoing emotional, spiritual, and social support for both patients and their caregivers. "Reaching out and providing love" was identified as being essential to combating depression, fear of death and isolation. As a corollary to this need for support, numerous stories emerged about people in various stages of their illness experiencing stigma, rejection, abuse and neglect by family and community members. Focus group participants argued that sharing a diagnosis of cancer may result in rejection, discrimination or ridicule by both neighbours and family members. As one participant said "people cope through secrecy". This discussion stands in contrast to the experiences of the majority of respondents (79%) sampled through formal survey, who, when asked about their experiences of support did feel supported by family and the community. However, 20% of respondents did not feel supported and 13% faced some form of discrimination. Finally, focus group participants and key informants spoke about the need for accessible education focussing on the following issues:- dispelling myths and misconceptions about cancer (*eg* cancer as a result of promiscuity or sin), understanding the mechanics and trajectory of the illness, comprehending different treatment options and nutrition counselling.

* Needs of healthcare practitioners

Healthcare practitioners were questioned on the capacity of their respective health facilities to provide both palliative care and home care support for patients who are terminally ill. The majority of respondents felt that the capacity to deliver effective care to the terminally ill was curtailed by gaps in government support at both regional and national levels. They felt that there were no strategies, protocols or policies in place for palliative or home based care in the region, and that there is a lack of appropriate training in this important area of healthcare. Many practitioners questioned were poorly informed as to what palliative care actually is, or what it could offer. Several practitioners noted that restrictive government policies over access to certain analgesics presented challenges to delivering effective pain management.

DISCUSSION

The present findings suggest the presence of numerous structural, cultural and informal barriers that inhibit the ability of cancer patients to access adequate and sustained healthcare services and treatment over the trajectory of their illness. These barriers can be thought of as part of an intricate and dynamic system that manifests itself across multiple lines of address, from the family, to the community, to health service provision, and also to policy-making levels (8). Fig. 1 illustrates this complex network that, in effect,

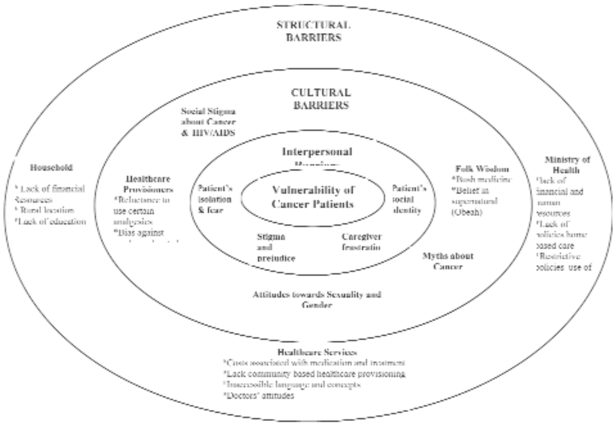

Fig. 1: Barriers to accessing and receiving effective cancer care and support

Fig. 1: Barriers to accessing and receiving effective cancer care and support.

situates the cancer patient and their caregivers in a position of vulnerability.

At a structural level, the lack of policies to support palliative or home-based care means that there is no formal system of care provision for cancer patients at a community level where it is often most needed. Restrictive policies with regard to accessing strong analgesics, along with lack of availability of these medicines results in many patients experiencing undue suffering at the end of life. The perceived attitude of doctors, together with prohibitive costs associated with medication and treatment, results in some patients seeking alternative forms of treatment or seeking medical treatment too late in the progression of their disease. Finally, the level of household financial resources, educational levels of household members and proximity to healthcare facilities all play a role in exacerbating a patient's experience of vulnerability.

At a cultural level, numerous barriers exist that inhibit the freedom of people with cancer to seek the support and treatment they need. Preliminary evidence suggests that prevailing attitudes towards sexuality and gender are reinforced by myths that circulate about the origins of cancer. The resulting stigmatization, discrimination and misconceptions further shape the experience of, not only what it means to disclose a cancer diagnosis, but the experience of seeking treatment or of seeking a diagnosis in the first place. Moreover, the desire to turn towards folk remedies including spiritual consultation with 'obeah' and 'madau', either because of deeply held convictions or because of household financial restraints, can result in an illness going untreated or late presentation in the trajectory of the illness. Finally, the use of exclusive and often inaccessible language, together with perceived, disrespectful attitudes on behalf of certain health practitioners, suggests an inadvertent bias against uneducated patients and patients from lower socio-economic groups (inner city; rural areas). This can deter those patients from seeking ongoing treatment.

Also operating at a cultural level, in both medical and nursing communities, is the overall prevailing attitude towards the prescription of certain analgesics for pain. Strong analgesics such as morphine are perceived as being dangerous and addictive and are simply not prescribed or appropriately administered in both inpatient and out-patient settings. Lack of familiarity with the policy of the Ministry of Health regarding narcotic prescription compounds this issue.

Patients' vulnerability is also expressed at an interpersonal level. A diagnosis of cancer is often difficult to embrace by the patient because of its perceived negative consequences on social relationships with loved ones and community members. Moreover, inadequate financial, medical and educational support to the household can result in caregiver frustration which may have an impact on the emotional and physical health of the patient.

CONCLUSION AND RECOMMENDATIONS

These preliminary research findings suggest that an integrated tri-level system based on government policy, edu-

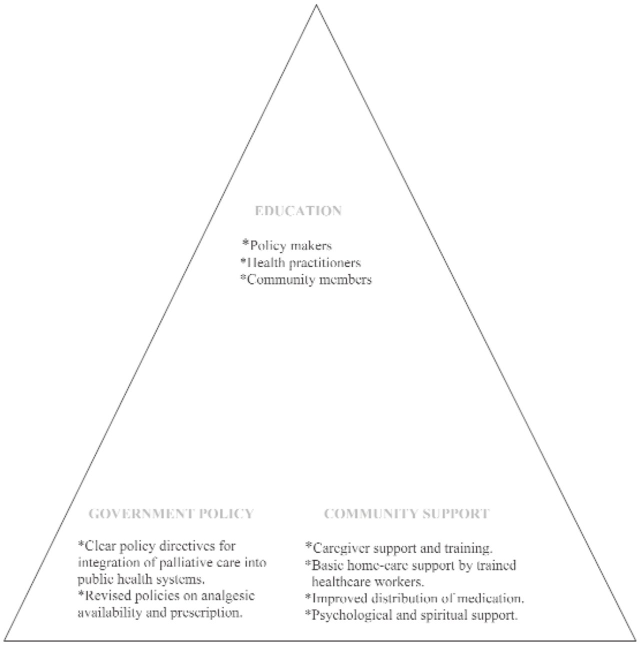

Fig. 2: Creating a tri-level system approach to supporting cancer patients and their caregivers.

cation and community-based care (Fig. 2) would best address the medical, emotional, spiritual and financial needs of cancer patients and their caregivers. This challenge was reiterated by many research participants. Anti-discrimination and de-mythologizing education that employs popular cultural idioms, everyday language and even biblical scripture could be released through the mass media, and taken up by local community groups, including churches. Indeed, participants noted the powerful role that church communities could play in combating discrimination, prejudice and ignorance about cancer at a local level. In addition, in order to challenge prejudicial practices and use of inaccessible language by healthcare practitioners in general, and doctors in particular, the development and implementation of communication skills training and sensitization to the multiple barriers that exist for cancer patients is crucial. These measures would go a long way towards improving doctor/patient relationships and to developing a mutual understanding between the two groups.

The research findings also suggest that most healthcare provision for people with life threatening illnesses, especially in the palliative stage could best be served at a community level where there are already rich systems of support in place. Research participants argued strongly for the presence of mobile healthcare units that would offer nursing, medical and social support. This would include management of pain and distribution of pain medication, the training of caregivers and local community groups in the provision of basic medical care and nutritional counselling and help for patients in complying with treatment regimens. The community based care units would also act as a liaison between hospital or hospice and the patient and their family. Participants also pointed to the exciting role that church and other community groups could play in providing informal psychosocial and spiritual counselling, bereavement support and fundraising initiatives, by partnering with local businesses and charities to help households in need of support.

Models already exist for the provision of this type of community-based palliative care (9). In 1990, the WHO outlined a public health strategy to integrate palliative care services into existing healthcare systems (10). This included advice and guidelines for governments on how to implement national palliative care programmes into existing healthcare services. In order to achieve effective integration, the four components of the model need to be addressed. There must be 1) appropriate policies, 2) adequate drug availability, 3) education of healthcare workers and the public and 4) implementation of palliative care at all levels throughout the society. This process needs to be addressed within the context of the culture, disease demographics, socio-economics and the healthcare system of the country (11).

We strongly recommend that, in order to provide effective institutionally and community based palliative and supportive care services for people with cancer, there needs to be a clear set of directives from the Ministry of Health with regard to policy guidelines, education and training, and greater access to appropriate analgesic medication as outlined by the WHO above.

Limitations

Several limitations of this study should be noted. First, the study design was cross-sectional which disallowed for an examination of people's needs over the trajectory of their illness. Moreover, this study was carried out in the Kingston region where access to some form of medical care is readily at hand. However, over fifty per cent of Jamaica's population lives in rural areas, and further studies will be needed to thoroughly elucidate their particular situation. Thirdly, the external validity of the sample was compromised in several ways: all of the patients and caregivers were sampled by convenience and interviewed at healthcare facilities, thus limiting the representativeness of those interviewed to people who we were able to access or who felt comfortable accessing a medical facility. Further study is required to examine attitudes and behaviours of those who do not access allopathic treatments. Moreover, the surveys were completed by a disproportionate number of male patients, and by patients with relatively low levels of education and who occupied low paying occupations, thus skewing the representativeness of the data to lower socio-economic groups. Finally, the survey instrument itself proved to be somewhat limited in its ability to address, with precision, the following: key concerns that were raised by key informants and by focus group participants: patient's experiences of pain and their methods of coping experiences of home care and experiences while receiving treatment from healthcare professionals.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the generous financial support of the CHASE Fund, and Seneca College, Toronto, Canada, and also to the SERHA for human resource contributions to the research.

REFERENCES

1. Sikora, K (ed). Developing a Global Strategy for Cancer. World Health Organization Program on Cancer Control; 1998.
2. Spence D, Merriman A, Binagwaho A. Palliative Care in Africa and the Caribbean. PLOS Medicine 2004 **1:** 1–10.
3. Cancer pain relief and palliative care: report of a WHO Expert Committee. Geneva, World Health Organization, 1990 (WHO Technical Report Series, No. 804).
4. Singer P. Quality Care at the End of Life. BMJ 2003; **327:** 1292.
5. Kikule E. A Study to Assess the Palliative Care Needs of Terminally Ill Persons and their Caregivers in Kampala District, Uganda, May 2001.
6. Kreitzschitz S, Cox Macpherson S. End of Life Care: Perspectives from Families and Caregivers'. West Indian Med J 2003; **52:** 311.
7. World Health Publication "A Community Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa", 2004.
8. Mullaly B. Challenging Oppression: a Critical Social Work Approach, Toronto, Oxford University Press, 2002.
9. Jagwe JGM. The introduction of palliative care in Uganda. J Palliat Med 2002; **5:** 160–3.
10. World Health Organization. National cancer control programs: Policies and Managerial guidelines. Geneva: World Health Organization CAN/92.1, 1993 and 1995.
11. Stjernsward J, Kathleen M, Foley, FD Ferris. The Public Health Strategy for Palliative Care. J Pain Symptom Manag 2007. **5:** 486–93.