Palliative Care in South Africa

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Abstract

The Hospice Palliative Care Association (HPCA) was established in 1987 by hospices in South Africa who felt the need for a national body to share best practices and to promote palliative care services in South Africa. HPCA supports member hospices in providing palliative care to people of any age with a life-limiting condition. HPCA has the further aim to ensure access to palliative care in settings other than member hospices. Many projects were launched over the years to influence policy, and to educate medical practitioners, nurses, social workers, theologians, and community caregivers; and to develop services. A key initiative was the development of a mentorship program to assist organizations to develop accredited palliative care services in South Africa. This article highlights some of the HPCA projects funded over the years by the Open Society Foundations’ International Palliative Care Initiative.

Key Words

South Africa, palliative care, mentoring, standards, funding

Background

South Africa has a population of 55 million people with a 62% urban population. It is designated an upper middle-income country by the World Bank with $12,730 GNI per capita in 2014. Life expectancy in 2014 was 57 years. In 2011, the World Bank report on human resources in health identified that there were 4.7 nurses per 1000 people and 0.8 doctors per 1000.

Mortality data from Stats SA report that in 2014, there were 453,360 deaths; 405,861 adult deaths (89.1%), 47,499 deaths of children aged 19 years and less (10.6%) of which 34,262 deaths were of children under the age of five years (7.7%). The top 10 natural causes of death for adults (using International Statistical Classification of Diseases and Related Health Problems, 10th revision [ICD-10] descriptors) were: 1) tuberculosis (8.4%); 2) cerebro-vascular diseases (5.1%); 3) diabetes (5.0%); 4) influenza and pneumonia (4.9%); 5) HIV (4.8%); 6) other forms of heart disease (4.7%); 7) hypertensive disease (3.9%); 8) intestinal infectious disease (3.2%); 9) other viral diseases (3.1%); and 10) chronic lower respiratory diseases (2.7%). Although individual cancers are not part of the top 10 causes of death in South Africa, collectively, neoplasms comprised 8.6% of all deaths.

The top 10 natural causes of death for children (aged under five years) were: 1) intestinal infectious disease (14.0%), 2) respiratory and cardiovascular disorders in neonates (10.8%), 3) influenza and pneumonia (9.0%), 4) malnutrition (4.7%), 5) other neonatal disorders (3.9%), 6) disorders related to length of gestation (3.5%), 7) infections in perinatal period (3.5%), 8) newborn affected by complications of pregnancy (2.7%), 9) other acute respiratory infections (1.8%), and 10) other bacterial diseases (1.7%).

The estimated need for palliative care using only mortality data, is that 0.52% of the population require palliative care in any year. To meet this need...
additional services within the public health sector, including community and home-based care will need to be developed. There are currently eight hospital palliative care services (two dedicated children’s palliative care services) and 150 hospices providing palliative care, about 40 of whom also provide care for children. Funding for palliative care is a limiting factor and a number of hospices closed in the period 2011–2016 because of insufficient funds.

**Home-Based Care Appropriate to South Africa**

South Africa has experienced a dramatic increase in the number of people requiring care and support because of a rise in HIV, tuberculosis, and non-communicable diseases like cancer. The South African National Department of Health (NDoH) requires the support of all government and non-government organizations (NGOs) in their vision of *a healthy life for all people of SA*.4 Although we recognize that palliative care is an approach to care that can be provided in any care setting, most palliative care in South Africa is provided by NGOs. The care provided by hospices takes place mainly within the patient’s home. Professional nurses, trained caregivers, social workers, and social auxiliary workers visit the patient and the family and provide physical, psychosocial, and spiritual care. Educating all members of the family is an important role of the visiting palliative care employee. In response to this need and in an effort to reach as many patients as possible given the insufficient numbers of nurses and doctors in South Africa, the training of community caregivers received priority attention and Hospice Palliative Care Association (HPCA) adopted the Integrated Community-Based Home Care Model,5 which was developed by the South Coast Hospice in KwaZulu-Natal (KZN). The NDoH recognized this as a best practice model and commissioned HPCA to replicate the model in urban, peri-urban, and rural communities; to determine the cost of the model and to develop a training curriculum for home-based carers. HPCA member hospices are making a significant contribution to meeting the health needs of communities where limited care is available through implementing home-based care.

**Mentorship Program**

The HPCA mentorship strategy underpins the strategic goal of strengthening organizational systems and structures required for the delivery of quality palliative care at district, provincial, and national levels, by strengthening the capacity of service delivery by member hospices.

The first phase of the mentorship program initiated in 2001 was based on the Integrated Community-Based Home Care Model,6 which provided mentorship to member organizations and partnered with care providers in the community to improve patient care outcomes.

The main objectives of the mentorship program were to 1) meet the need for palliative care in SA communities, 2) make optimal use of scarce palliative care resources, 3) promote a collaborative best practice model of care, 4) facilitate the fast tracking of compliance with the palliative care standards, and 5) cascade quality care between HPCA member hospices and partner organizations. An HPCA Provincial Palliative Care Development Coordinator led a team of staff from hospices in the province, the provincial mentorship team. The initial task was to identify development needs of NGOs to meet the requirements of HPCA membership which are linked to the HPCA standards (see below). HPCA and/or hospice staff provided mentorship to the NGO staff on areas that required strengthening to meet the standards. New members were afforded one star status by HPCA. Regional mentors assisted established member hospices to progress in star rating and prepare for accreditation and mentor hospice status (five star status). The regional mentor also worked with the fully accredited hospices to maintain their accreditation to establish their credibility as centers of excellence for palliative care. The mentorship model is the foundation for a number of HPCA initiatives, some of which are described in this article.7

**Palliative Care Standards**

In 2005, the Palliative Care Standards Manual was developed in partnership with the Council for Health Services Accreditation of Southern Africa (COHSASA) to measure quality of services provided by member hospices. The standards manual has been edited twice since that time in collaboration with COHSASA and the third edition is currently in use.7

Surveyor training of HPCA and hospice staff on these standards and the training was provided by COHSASA to develop the capacity of HPCA and hospice staff to be able to conduct HPCA internal surveys. This enhanced the mentorship program that assisted hospices to progress toward accreditation.

The HPCA achievement award system, a star rating system, was then implemented for the HPCA internal process for hospices working toward full accreditation. Hospices are awarded one to four star rating after an internal survey according to their development progress. An external survey is conducted by the COHSASA and HPCA when a hospice is assessed as being compliant with the standards. Following full compliance, the hospice is awarded the COHSASA accreditation certificate and the HPCA five star achievement certificate. This accreditation process is now supported by an electronic self-assessment tool.
implemented in November 2015 and is made accessible to all hospices to conduct self-evaluations that is supported with mentorship by the regional hospice associations consisting of HPCA member hospices in the different regions. This enables the five star hospices to maintain their full accreditation status and for those working toward full accreditation to maintain their progress (Fig. 1).

An evaluation was performed on the mentorship program in 2010. The evaluation concluded that the mentorship program had evolved over the 2005–2010 period and that it had been operational in strengthening hospices to positioning them to be palliative care resources within their areas of service operation.8

The funding received from external donors contributed largely to the success of the mentor process, and it is anticipated that the HPCA mentorship program will continue to provide long-term benefits for the growth and development of individuals and organizations in South Africa.

Expanding the Mentorship Concept

Palliative Care in Correctional Services Facilities

The aim of the South African government has been to reduce disparities and inequalities in health service delivery and to increase access to improved and integrated services. These services were to be based on the Primary Health Care approach as outlined at Alma Ata 19789 and the Reconstruction and Development Programs,10 in which the government created a framework for readdressing the imbalances, and rectifying the fragmented and inequitable health services in the country. Palliative care is recognized as a human right11 and equal access to palliative care is also important. The Constitution of the Republic of South Africa,12 Chapter 2, which pays special attention to the right to access to healthcare services; hence a need for integration of palliative care in the caring of offenders in correctional service facilities. Unfortunately, over-crowding in prisons has contributed to the increase of communicable diseases with TB and HIV infections on the rise among both inmates and personnel.13

The palliative care needs of offenders and detainees awaiting trial in Africa were highlighted at the 2009 International AIDS Conference in Durban. In January 2009, the HPCA met with the National Department of Correctional Services (DCS) to discuss palliative care. It was decided that a provincial partnership be piloted first, with the aim of a national rollout at a later stage. The HPCA DCS Pilot Project began in KZN. Local hospices do not have the capacity to provide palliative care services to local correctional centers, and therefore the focus of the project is to equip the health staff within the DCS to provide this care themselves. A task team with members from both organizations was formed and developed a work plan for the project, which was updated on a monthly basis. A Service Level Agreement between HPCA and KZN DCS was signed on October 2010, followed by the signing of a Memorandum of Understanding between HPCA and National DCS in 2013. This project was built on the mentorship program with highway Hospice in Durban and Msunduzi Hospice in Pietermaritzburg training health staff in the prisons to provide palliative care and training inmates as carers and providing mentorship in establishing the palliative care services within the prisons. The rollout of the project took place in seven prisons in four provinces with hospice support and mentorship. These correctional facilities have trained multidisciplinary team members (doctors, professional nurses, social workers, and chaplains) in palliative care. There are master trainers available within the DCS to sustain palliative care training for their staff. One DCS hospital has been used by other facilities for “benchmarking” purposes. Inmates were also trained in basic home-based care with a palliative care component to assist the fellow inmates who are terminally ill with the support of the professional staff from the correctional center. The training of inmates as caregivers has ensured that there is constant care provided in the facilities’ wards and also adds to the skills of discharged inmates.

HPCA and member hospices played a pivotal role during the consultative meetings in developing a national medical parole policy. Patients who are discharged on medical parole are referred to hospices for home-based care and admitted in the hospice inpatient unit (IPU) if necessary. In addition, two further policies, the Spiritual Care Policy and the Social Work Policy to include palliative care followed from this collaboration. The most recent contribution has been to the development of a palliative care strategy within the National DCS.

One of the most important highlights of the collaboration between HPCA and DCS has been the Palliative Care Guidelines for Correctional Settings,14 which were launched during the 2013 HPCA conference. It is hoped and expected that these measures

![Fig. 1. Number of hospices as per star rating, 2004-2015.](image)
Mentorship in Botswana

Scarcity of human resources in health is a challenge in South Africa, but even more so in other African countries. HPCA conducted a pilot project in London, Eastern Cape Province, to assess the effectiveness of a hospice nurse providing training, support, and supervision to community care workers employed by NGOs that did not have the resources to employ professional nurses. The success of the project was followed by a project in Gaborone, Botswana to link Pa-belelong Hospice to the Tirisanyo Home Care program. The hospice staff included four professionals, two of whom had one week of training in palliative care; four caregivers. A palliative care qualified doctor conducted weekly ward rounds at the hospice and was available for telephonic advice. Tirisanyo Home Care Program run by the diocese of Botswana included three home care groups with 15 caregivers coordinated by a social worker. There was no access to a professional nurse at the start of the project. Although caregivers in the South African setting have received training on basic home care such as bed-bathing, wound care, pressure care; this was not the case in Botswana and caregivers did not see this as part of their role. Training proceeded respecting the caregivers needs, recognizing that some of the caregivers were not literate. The input of a professional nurse had a significant impact on the home care program. If the caregivers identified a problem they contacted the professional nurse who conducted and assessment visit in the home and provided treatment or effected appropriate referral. A system of record keeping was implemented so that each patient had a file which included a care plan with records of visits and treatment. Caregivers received on-the-job practical training during supervised home visits. The assessment of caregivers’ competencies in the project evaluation phase showed significant improvement over baseline competencies. In addition to strengthening patient care, a decision was made to move the management of home care to the hospice and to enhance the palliative care training of professional staff.

Since this project was completed and with support from the African Palliative Care Association and other partners, Botswana has established a national HPCA, initiated integration of palliative care into basic nursing curricula and developed standards for health facilities that include palliative care.

Education and Training

Palliative care training and education are essential as a foundation for good palliative care service provision. HPCA provided bursaries to health care professionals to enroll in the University of Cape Town (UCT) palliative medicine diploma and degree courses. Palliative care education and training were strengthened at hospices through funding for equipment, further training of education staff and teaching palliative care to professional staff, including training in pediatric palliative care.

Post-graduate Palliative Care Training

With support from HPCA and seed funding from the Diana Princess of Wales Memorial Fund, the UCT established a world renowned palliative medicine teaching unit, which was the first postgraduate program in palliative medicine on the African continent. The Dean and Faculty of Health Sciences supported the establishment of the Palliative Medicine Unit in 2001. The Palliative Medicine Unit is placed within the School of Public Health and Family Medicine, which complements the palliative medicine initiatives through their strong clinical and health systems approaches.

To date, the Palliative Medicine Unit has enrolled 384 post-graduate (PG) students from SA and other African countries of whom 350 have successfully completed their studies and have graduated with a Diploma or MPhil in Palliative Medicine, and 17 are continuing their studies. During the first two years, participants came from South Africa. The postgraduate palliative medicine training at UCT since 2004 and has consistently provided bursaries to enable health care professionals to enroll in this advanced palliative care training. To date, there have been 80 international students (outside South Africa) enrolled in the program since 2003. Countries represented include Namibia, Botswana, Zimbabwe, Malawi, Zambia, Kenya, Rwanda, Uganda, Tanzania, Nigeria, Ethiopia, United Arab Emirates, Swaziland, Lesotho, Ghana, Singapore, U.S., DRC.

The Postgraduate Diploma in Palliative Medicine is a one-year distance learning program with three contact sessions to equip health care professionals with the knowledge and skills to provide palliative care in
their work setting. The Masters in Philosophy degree is a research degree with teaching in advanced palliative care and in research methods which includes a research study to develop the evidence-base for palliative care in Africa.

Research Training
From the medical field, we have trained hospice doctors, general practitioners, oncologists, pediatricians, a pediatric surgeon, and internal medicine physicians. The UCT, Faculty of Health Sciences has recognized the importance of training all members of the interdisciplinary team in palliative care; and in 2009, the Faculty of Health Sciences and UCT Education Department agreed that the course could be open to disciplines other than medicine and the course has been restructured to allow for core modules and elective modules that will meet the needs of different disciplines. Post-graduate students have enrolled from other clinical disciplines including nursing, social work, dietetics, physiotherapy, occupational therapy, and aromatherapy. The degree is awarded as Palliative Medicine. This is an innovative approach within the Faculty of Health Sciences and is designed to meet the needs of palliative care staff and their patients within Africa emphasizing the interdisciplinary nature of care.

Since the start of the program, grants for scholarships have been received from the HPCA, Diana Princess of Wales Memorial Fund, Medical Education for South African Blacks, and Hospice U.K. through funding from the Wolfson Foundation. The availability of funds for bursaries is essential for the continuation of this training to equip health care professionals to provide palliative care in their communities.

UCT palliative medicine alumni are employed in each of South Africa’s medical schools and have integrated palliative care training at undergraduate level in these medical schools in their areas. Alumni in other African countries have provided leadership in the development of palliative care in their own countries. Postgraduate training in palliative medicine is integrated into the specialist training of family physicians and the palliative medicine staff at UCT are assisting in integrating palliative medicine into the curricula for pediatricians, internal medicine physicians, and oncologists in South Africa.

Building Partnerships Between Palliative Care and Traditional Health Practitioners in South Africa
The HPCA and hospice project to partner hospices and traditional health practitioners (THPs) was to train traditional healers in palliative care. Traditional medicine is the sum total of knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures that are used to maintain health, as well as to prevent, diagnose, improve, or treat physical and mental illnesses.

In an effort to increase access to care for patients with end-stage HIV, work is being performed to build partnerships between Palliative Care and THPs to up-skill both sectors. Within South Africa, KZN province has the highest rate of HIV infection—more than half (54%) of the adult people living with HIV live in KZN. The estimated number of people living with HIV in the province is 15.8% of the total population.16

HPCA initiated formal meetings between THP leaders and palliative care practitioners, where current clinical challenges, approaches to end-stage illness, priorities, and possible solutions were discussed. It was decided that knowledge-sharing and up-skilling in a bi-directional manner would benefit both sectors and their patients. A task team consisting of representatives of both sectors was formed to develop the curricula. Phase 1 of the project focused on developing the THPs training manual on Western approaches to HIV, TB, and other life-threatening illnesses. The curriculum included universal precautions, prevention, treatment, and referral options. Phase 2 focused on palliative care practitioners training and understanding of THPs’ approach to life-threatening illness, end-stage illness and death.

The pilot training took place at UMgungundlovu District in KZN at Msunduzi Hospice. Palliative care training was conducted for 18 THPs in 2012. It is a five day course and is divided into three days with a month’s break for practical implementation of the learning, then two days to conclude the training. Twenty three more traditional THPs were trained in 2014.

In keeping with the vision of HPCA, which is “Palliative Care for All,” the development of the THPs training manual was in English and isiZulu (Zulu) and has also been translated into seven languages including Sesotho, Tshivenda, isipedi, Siswati, Setswana, isiNdebele, and isiXhosa for the further roll out of training for THPs. This means that the training is available in seven of the nine official South African languages, a major achievement supported by the Department of African Languages from University of South Africa.

A “Train the trainer” course was conducted for six professional nurses to facilitate the training for the THPs course to be rolled out in other provinces. Subsequently, training was also conducted in Limpopo, Gauteng, Mpumalanga, and the Eastern Cape.

In 2013, a short message system (sms) was developed by Owen Herterich and Claudia Bernett from the Parsons School of Design in New York under a partnership with the OSF’s Public Health Program’s Health Media Project. The THPs were then trained on the system with the aim of providing THPs with
information and advice on palliative care; the THPs were enthusiastic about using the new system. Messages were also sent out monthly giving the THPs information about various aspects of care. To make the sms system more cost effective, a local service provider was sourced to provide a similar system and this has been recognized by the THPs as most helpful.

The system allows for ongoing monitoring of usage as depicted in Figure 2.

Visits to several THPs consulting rooms showed that the training certificate and learner manuals were displayed prominently showing pride in the learning that they have received. They acknowledge that the learning has brought a change to their practice and value the respect that has been shown to them through this project.

Advocacy Initiatives

A key advocacy group is the Alliance for Access to Palliative Care, which draws together people from HPCA and hospices, government health facilities and the NDoH, academic institutions, and other palliative care champions. An early external evaluation of the Alliance for Access to Palliative Care reflected that the “greatest overall achievements of the Alliance thus far were identified in the following areas:

- Drafting contributions to policy and planning;
- Enhancing government involvement in and awareness of palliative care.”

The strength of the Alliance comes from the committed network it has created of multiple stakeholders who represent diverse aspects of palliative care and who can take the message of palliative care to their own constituents. This collective expertise enriches the policy contributions that emerge from the Alliance, and enhances its sphere of influence through the diverse networks represented in the group.

This influence bore fruit in the support the South African government provided as a member of the World Health Organisation Executive Committee in co-sponsoring the World Health Assembly Resolution 67.19 “Strengthening of palliative care as a component of comprehensive care throughout the life course.” The South African commitment to implementing this resolution has led to the appointment of a National Steering Committee for Palliative Care and a draft Policy Framework and Strategy for Palliative Care in South Africa. The Alliance continues to advise the Steering Committee on the response to the WHA resolution.

Working With the Media

Palliative care is still widely misunderstood by many people and working with the media is essential to address this problem. Working with the media can also help dispel myths by sharing facts with patients, family members, friends, and other health professionals. Traditional and modern media play a strategic role in sensitizing people, for example, community leaders, politicians, and decision-makers on issues relating to palliative care. These may include palliative care champions, palliative care success stories, issues such as access to medicine, or issues of palliative care education. To draw the interest of government and to sensitize the community on the role of palliative care it is important to work with the media.

In 2008, HPCA received technical assistance on working with the media from OSF’s Health Media Program Director, Brett Davidson. Brett conducted a two-day workshop in Durban, which was attended by HPCA advocacy team members including hospice representatives.

This workshop equipped HPCA staff with the necessary skills to work with traditional news media and has assisted HPCA and hospices in using the media effectively, especially around the annual hospice week and World Hospice Palliative Care Day.

Legal Aspects of Palliative Care

Hospice patients face legal and human rights issues, and it appears these problems increase emotional
stress in patients and families, impacting the way they cope with illness. It was proposed that legal information could help social workers become more aware of legal issues, and capacitate them to assist patients with legal problems.

HPCA invited law students, and legal non-profits to run information sessions at hospice, and then developed its own training for social workers and orientation for lawyers. Lawyers and palliative care writers also took legal problems raised by hospice staff, and paired up to co-write chapters in a book, with each chapter addressing a problem from both sides: palliative care and law. The book titled *Legal Aspects of Palliative Care* has 13 chapters with contributions by 21 co-writers and co-editors (the book was reviewed in 2012) and is used as a training manual for hospice staff and legal practitioners. In the foreword, South African Constitutional Court Judge Justice Edwin Cameron writes it was “a practical reference guide for use in palliative care services and legal practice.”

Legal information provided valuable information to volunteer home-based-carers, making them more aware of their worker rights, processes to access pension benefits, and aware of the duty of pension fund administrators to investigate surviving beneficiaries before awarding pay-outs to family members. HPCA’s partnership with OSF’s Law and Health Program provided additional legal expertise.

The hospice law training for social workers/orientation for attorneys has been recognized by the College of Justice (which trains officers of the court), and a Memorandum of Understanding has been signed between HPCA and Legal Aid South Africa. Legal Aid SA has 64 branches and 64 satellite offices nationally. A next step would be to negotiate with the South African Council for Social Service Professions.

Post-training assessment revealed the many benefits of this training including 1) increased knowledge in the laws relating to children in South Africa, 2) understanding the difference between intestate/testate (dying with or without a will) and confidence to draft a simple will, 3) change in attitudes in that participants recognized a link between patient pain, stress, and legal problems, and 4) increased understanding of the legal problems that patients may experience.

**Palliative Care Costing Tool**

HPCA developed a costing tool for the NGO sector that will enable the costs of home-based palliative care and in-patient palliative care to be accurately determined. Costing of palliative care services can be combined with measurement of patient-reported outcomes to document cost-effectiveness and this will give service providers the evidence needed to access greater financing and justify budgets for palliative care services.

The Romanian Model of costing palliative care developed by Hospice Casa Sperantei was used with permission as a starting point in the development of the Unit Costing Model. The model was modified and adapted to suit South African conditions. Unit costing was assessed for hospice home-based care services and for IPU costs. The information used included staff salaries, number of patients, number of beds in IPU, support costs such as administrative and transport costs, and costs of patient supplies. A number of hospices were assessed, and through an iterative process, the Unit Costing Model was developed to its current form.

The actual figures from the initial roll-out to 50 hospices in 2012 showed a wide spread in the costs of services provided, from just under $20 a month to $207 per month for home-based care. The average cost was $96 a month. Costs per bed per day in IPUs ranged from $35 to $206 per day. The average cost was $91 per day.

The costing model can accurately determine the costs of palliative care both in home-based care and in IPUs in South Africa. Initial results have shown that there is a very wide variation in the cost of this palliative care. There are many factors that appear to affect the costing and these include the size of the hospice and geographical location. This information will be useful in not only assessing the effectiveness of individual hospices, but also in advocating with the Department of Health, medical insurance groups, and donors.

**Conclusions**

Philanthropy has made much of HPCA’s work possible and sustainable and has assisted HPCA in its mission to support member hospices in the provision of quality palliative care. HPCA is also committed to supporting the National and Provincial Departments of Health in implementing key strategies to improve health care in South Africa through training, policy development, and the implementation of palliative care standards. Through philanthropic funding, HPCA has been able to reach groups previously ignored such as THPs and DCS. The implementation of legal aspects of palliative care was a special milestone, adding another dimension to the holistic care provided through palliative care in South Africa.

Palliative care is receiving attention from the South African Minister of Health who states that as a co-sponsor of the World Health Assembly resolution, South Africa has a responsibility to implement the resolution. The minister has appointed a national Steering Committee for Palliative Care, and a policy framework budgeted strategic plan is being developed.
to present to the minister in February 2017. The World Health Organisation includes palliative care as part of universal health coverage and South Africa has embarked on an ambitious plan to realize universal health coverage through a proposed National Health Insurance. The National Health Insurance white paper includes palliative care as an essential service. This should translate into palliative care being included in all health facilities and funding being available for hospice palliative care. In addition, there is attention on training of health care practitioners with on-line learning being offered to health care professionals from all disciplines. The learning includes face-to-face learning for communication skills and pain management. HPCA has secured the 16th of April each year on the National health calendar as healthcare planning day to publicize opportunities for people to consider their preferences for care in the event of serious illness. The challenges to palliative care remain funding and peoples’ perceptions of palliative care. It will be important to frame palliative care awareness messages as improving quality of life and helping people to live as actively as possible with chronic illness.

References