

Pilot Study on the Application of Telemedicine as a Tool for Population-Based Cancer Registry in Hlegu Township, Yangon Region, Myanmar

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A quality-cancer registry plays a unique role in planning, evaluation of cancer control program, treatment, and palliative care. To date, there is a paucity of studies in Myanmar that have focused on the implementation of a population-based cancer registry. The concept of combining telemedicine to this implementation may be beneficial to those working at the grass-roots level for the overall improvement of the processes of community reporting, effective referral for cancer care, and the establishment of cancer registries. A pilot study was therefore carried out to formulate the strategic approach for establishing a population-based cancer registry in Hlegu Township in Northern Yangon District. First, the cancer data entry software was created and installed on mobile phones as an information technology tool to initialize telemedicine. Then, 15 Health Assistants (HA) in Hlegu Township were trained for data collection to get basic information on cancer-confirmed patients using mobile phone applications followed by online-based reporting to the cancer database unit. A total of 126 patients with cancer were registered from June 2016 to May 2017. The estimated prevalence of disease is 4.6 per 10,000 people. The most common age group at cancer diagnosis was 46 to 65 years (73.58%). Among 91 registered female patients with cancer, the three most common cancers were breast (25.39%), cervix (12.69%) and uterine (11.9%). Eighty-five patients with cancer (67.46%) received their diagnosis in public hospitals. Overall, 59% of patients received combination treatment, 19% received surgery only, 16% were treated with traditional medicine, 3% were treated with radiotherapy only, and 3% were treated with chemotherapy only. This study is the first of its kind, combining the concept of telemedicine to the creation of a population-based cancer registry. A complete and true picture of the cancer burden in the studied population can be provided without using enormous resources. This strategic approach is most appropriate to collect information of every cancer case in resource limited setting like Myanmar.

Keywords: Telemedicine, Population-based cancer registry

INTRODUCTION

Cancer burden is rising and it threatens the social and economic development of low- and middle-income countries (LMIC) including the ASEAN countries.^{1,2} Good quality cancer data are essential for services such as screening, and treatment and palliative care and as a continuum, survival and quality of life of the cancer patients will improve.^{3,4} Therefore, it is critical to initiate, support, develop and expand population-based cancer registries in LMICs. According to International Agency of Research on Cancer (IARC),

the trend of cancer cases in Myanmar is estimated to be increased by 66% and death rate by 74% by 2030.⁵ In order to cope with the substantial disease burden, the development of the five-year national strategic plan for the control of cancer is underway in Myanmar. Concerted efforts are critical to move towards the establishment of the population-based cancer registry system.⁶⁻⁸ Basic health staffs (BHS) in rural areas serve as

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the first contact point in the population-based cancer registry system^{9, 10} and the situation is similar in the context of primary health care in Myanmar. Therefore, it is a necessity for incorporating the innovative approaches to establish and strengthen the existing links between the population-based cancer registries within the infrastructure of township level health system strengthening. In addition, there is a need to introduce the concept of telemedicine in terms of information technology (IT) applications as appropriate during this implementation. Telemedicine presents an opportunity to increase their accessibility to health care services and contribute to closing the gap between high- and low-resource settings.¹¹

Therefore, this study aimed to conduct the implementation study for the application of telemedicine as a tool for population-based cancer registry in Hlegu Township, Yangon Region, Myanmar, as a pilot study area and to introduce locally developed cancer register software which is compatible with international standard cancer registry software (CanReg5) into telemedicine-based cancer registry system. Such a strategic approach to establish the link between telemedicine and the population-based cancer registry in the pilot study area is beneficial to those at grass-roots for the overall improvement in the reporting process from the community, confirmation of diagnosis and effective referral for proper cancer care. Findings will also be helpful as the important inputs in evaluating and strengthening of the process of nationwide population-based cancer registries.

MATERIALS AND METHODS

This is an implementation of pilot study on application of telemedicine as a tool for population-based cancer registry, conducted in Hlegu Township in Northern Yangon District, Yangon Region. Hlegu Township was selected for this pilot study as five-year Primary Health Care System Strengthening Project in collaboration with Korea Foundation for International Health Care (KOFIH) is still ongoing in this township. The estimated population of the whole township was 270,741 in 2014: 40,078 for urban area and 230,663 for rural area.¹² There are 5 urban wards and 306 villages in Hlegu Township. Healthcare infrastructure comprises one township hospital, two station hospitals, 35 rural health centers and sub-centers.

In rural area, there are 186 voluntary health workers, 120 trained community health workers and 36 auxiliary midwives.¹³

This study was conducted in two phases. First phase intended to establish the strategic approaches to link between telemedicine and the population-based cancer registry. Mobile phones, installed with the Ondoctor software which is an android-based software application for cancer-data-record form, were given to all enlisted Health Assistants (HAs) of Hlegu Township. Then, the research team from Department of Medical Research (DMR) conducted one-day training of HAs as trainers of health workers (auxiliary midwives and community health workers) for data collection and recording the basic information of the cancer cases in their healthcare areas.

Basic information (name, age, gender, national identity {not for analysis but as one of the steps to prevent duplication}, education, occupation, place of diagnosis, mean of diagnosis, site of primary cancer, site of secondary, treatment taken) of confirmed cancer cases in their healthcare area, whether the patient is alive or expired, were collected into the installed mobile software and ensuring them for regular monthly reporting through mobile phones to cancer database unit at DMR.

They were also trained to report for any problems among the registered cancer cases and to seek an advice to be provided by skilled persons at DMR and oncologists through mobile phones. Auxiliary midwives and community health workers collected the data of confirmed cancer cases in cancer-data-record forms and sent the forms to HAs. HAs recorded the collected data in the installed mobile software and regularly reported through the mobile devices to database unit at DMR, Yangon. Qualitative interviews with implementing BHS were conducted to identify the challenges encountered in population-based cancer registry system and their suggested practical solutions.

Based on the strength and weakness learned from Phase 1, Phase 2 of the study followed after 1 year. Data from cancer-data-record of Phase 1 were recorded again in Phase 2 by using locally developed cancer registry software which is compatible with international standard cancer registry software, CanReg5. In-depth interview to each BHS was done at the end of Phase 2 and

the challenges and technical difficulties they faced during data collection and data recording processes were evaluated. Data from cancer registry application were cleaned and descriptive analysis of variables of interest was conducted with the aid of SPSS version 22.0. Thematic analysis of the qualitative data was carried out using ATLAS-Ti version 6.

Ethical consideration

This study was approved by the Ethics Review Committee of Department of Medical Research (ERC No. 003216).

RESULTS

From June 2016 to May 2017, a total of 128 cancer cases were collected by HAs and 112 midwives during their routine field survey and the collected data were reported during their regular monthly report. Among them, 126 histologically-confirmed cancer cases were studied, 2 patients were excluded because although the patients reported their diagnosis as blood cancer, hospital records revealed their diagnosis as thalassemia. Mean age of the patient was 50.52 ± 16.27 , youngest was 2 years and oldest was 86.

Female preponderance with male and female ratio was 1:3. Majority of the patients in this study were Bamar (120, 95.24%), Buddhist (122, 96.83%), attained primary school as highest education (46, 36.5%), married (93, 73.8%) and employed (65, 51.58%). More than 67% of the patients got their diagnosis at public hospitals and 80.95% of the patients got confirmed diagnosis by histological investigation. Commonest cancer among participants was breast cancer (32, 25.39%), followed by cervical cancer (16, 12.69%) and endometrial cancer (15, 11.9%). Common metastatic sites were liver (7, 5.55%), lung (6, 4.76%), brain (6, 4.76%) and bone (4, 3.17%), however, half of the patients (66, 52.38%) were free from secondary metastases. Almost 60% of the patients had undergone surgery (75, 59.53%), half of the patients were on chemotherapy (63, 50%) and 15% of the patients took radiotherapy. Socio-demographic and clinical characteristics of the patients are listed in Table 1.

During in-dept interview, BHS reported that the key challenge they encountered was difficulty in obtaining complete and good quality data. Data incompleteness was seen mainly in the topology,

staging and cancer treatment information. Some cases could not be registered when the documents such as biopsy records, clinical notes were not present.

Table 1. Socio-demographic and clinical characteristics of cancer patients, Hlegu Township (N=126)

	No	%
<i>Age (Mean±SD)</i>	50.52±16.27	
<i>Gender</i>		
Male	35	27.78
Female	91	72.22
<i>Race</i>		
Bamar	120	95.24
Kayin	4	3.17
Shan	1	0.79
Rakhaing	1	0.79
<i>Religion</i>		
Buddhist	122	96.83
Christen	2	1.59
Hindi	0	0
Islam	2	1.59
<i>Education</i>		
Primary school	46	36.50
Middle school	22	17.46
High school	17	13.49
University student	2	1.582
Graduate	12	9.52
Monastery education	11	8.73
Illiterate	2	3.16
Not answer	12	9.52
<i>Occupation</i>		
Employed	61	48.41
Unemployed	65	51.58
<i>Marital status</i>		
Married	93	73.8
Divorced	2	1.59
Widow/Widower	6	4.76
Unmarried	23	18.25
Not answer	2	1.59
<i>Diagnostic center</i>		
Specialty hospital	11	8.73
Public hospital	85	67.46
Private hospital	16	12.70
Specialist clinic	13	0.31
Others	5	3.97
<i>Diagnostic investigation</i>		
Clinical examination	43	34.13
Imaging	59	46.83
Biopsy	102	80.95
<i>Commonest malignancies</i>		
Breast	32	25.39
Cervix	16	12.69
Uterus	15	11.90
Colon	14	11.11
Head and neck	10	7.93
<i>Metastasis</i>		
No secondary	66	52.38
Not know	31	24.60
Liver	7	5.55
Brain	6	4.76
Lung	6	4.76
Bone	4	3.17
Others	5	3.70
<i>Treatment taken</i>		
Surgery	75	59.53
Radiotherapy	19	15.08
Chemotherapy	63	50
Traditional medicine	12	9.52
No treatment	9	7.14
Other (western oral drug)	1	0.79

They also noticed that the patients' families usually stopped seeking for correct diagnosis or proper care once cancer is highly suspected or diagnosed and most of them turned to traditional/ alternative/religious healers. Some family members were reluctant to discuss about the diagnosis or to provide details about the disease. Moreover, cost for cancer healthcare is also crucial factor that families consider to continue cancer treatment. For those who expired, family members rarely keep the documents of the patients after his/her death or did not bring the records when the patient died at the hospital. Technical difficulties such as getting familiar with installed software, saving the collected cases in their phones were also reported. Another challenge during case collection was the expectation of patient/care giver for the financial or other type of support when they are registered.

Frequently asked questions were mainly concerning symptom management such as pain, nausea, dyspnoea, Dos and Don'ts during cancer treatment etc. Oncologist and skilled person from DMR provided prompt responses through mobile device. When the patients or relatives requested to pass their final days at U Hla Tun Hospice (Charity Hospital), PI contacted to responsible person and assisted the proper referral. One advanced breast cancer patient and one cervical cancer patient were referred to the Hospice during study period.

DISCUSSION

Cancer registry has been shown to be critical in many countries worldwide as a good solution for determination of cancer burden. It is essential not only for collecting accurate and complete information on cancer incidence and prevalence but also for monitoring the trend over time, planning treatment, operating cancer prevention and control measures and preparing for follow-up.^{3, 4, 14}

Success of a population-based cancer system depends on the proper guideline, adequate resources and well-connected cancer network, collaboration of clinicians in supportive leadership, and accurate translation of evidences into policy and action.⁵ In Myanmar, healthcare sector is struggling with lack of adequate healthcare providers, weak infrastructure to operate population-based cancer registry. One of the most practical ways to establish nationwide

cancer registry programme is to link telemedicine with cancer registry that was done in one pilot township to achieve population-based cancer registry through expansion to every township nationwide in future. This is the very first study under the guideline of national health strategic plan for cancer control, implementation of population-based cancer registry, using telemedicine as a tool. This study attempted to introduce internationally compatible cancer registry software by using mobile application and introduced an innovative approach to establish and strengthen the cancer registries within the infrastructure of township level in resource-constrained setting like Myanmar.

Result from this study could support and add value to ongoing Health Promotion Programme. Commonest cancers prevailing in Hlegu Township were not compatible with those of Yangon General Hospital, which is the largest public hospital with tertiary cancer centre in the country. Female preponderance in this study led to higher prevalence of female cancers such as breast, cervix and endometrial cancers. Study result showed that more than half of the patients (67%) received diagnosis and treatment at the public hospitals. As cancer patients often face unpredictable or unmanageable costs and public hospitals could provide a proportion of treatment free-of-charge, many patients relied on public hospitals¹⁵ and study result showed that more than half of the patients (67%) received diagnosis and treatment at the public hospitals.

Study findings also highlighted that accuracy, completeness and timeliness of data records are essential for reliable population-based cancer registry. It is important to convince Myanmar patients and their family to willingly take part in cancer case record programme. Common cultural practice to avoid the term 'cancer' usually limits cancer care.⁵ Continuous involvement of all stakeholders, the collaboration of clinicians, pathologists, and administrative staff in ensuring access to their data should also be assured.⁵

In addition to recording and reporting the confirmed cancer cases using mobile application, any problem of the registered cancer cases were reported throughout the project period and necessary advice were provided by the oncologists and skilled persons at DMR through mobile devices. These kinds of experience symbolize the important first step for the establishment of telemedicine in oncology care.

During FGD, BHS reported cultural and financial barriers exist in seeking proper cancer care and this condition posed as a challenge for BHS. To assess community's perception towards cancer is not included in the aim of the study. However, while approaching the patients and families to collect required information, BHS also noticed that people in the studied community were reluctant to talk about the cancer, to let the patients know about their diagnosis and prefer to go to traditional healers once cancer was diagnosed. This is most probably due to the lack of knowledge on cancer, reliance on traditional healers and partly due to financial burden of proper cancer treatment. The only possible limitation in this study was that the practice of collecting cancer registry in community by BHS might deviate from the concept of population-based cancer registry. However, the attempt in this study could record every cancer case in a defined pilot township because BHS are the very first contact point in community.

Conclusion

This study is the first of its kind in applying the concept of telemedicine to the creation of a population-based cancer registry. Cancer registry mobile application based on locally adapted CanReg5 software is introduced as an important step in the establishment of population-based cancer registry in Myanmar. More concerted efforts are needed to sustain or extend cancer registry programme in other resource-limited areas across the country. The availability of electronically stored cancer cases will lead to more quantitative statistical analysis which can be used for further cancer control measures and other public health program planning.

Competing interests

The authors declare that they have no competing interests.

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