

Longitudinal trial of smart-phone based social media applications for remote monitoring of cancer patients in the context of a LMIC: compliance, satisfaction, and cost-benefit analysis

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Abstract

The cancer burden is expected to reach 20 million new cases annually in low and middle-income countries (LMICs) by 2025. Few estimates suggest that thyroid cancer could become the third most common cancer diagnosed in women by 2019. Health care services need to gear up to provide close clinical follow-up care for patients especially in LMICs where there is already a shortage of healthcare personnel. We conducted this study to assess the effect of remote monitoring using tele-follow up on compliance, satisfaction and economic benefit. Participants were recruited to traditional hospital follow-up (consultation, clinical examination, and investigations as per hospital policy) or tele-follow up based on social media. Outcomes included information needs, participants' compliance, and satisfaction, post-op complications, clinical investigations ordered. A total of 64 patients with thyroid cancer were recruited- 24 in hospital follow up group and 40 in the remote monitoring group. There were no significant differences between groups regarding satisfaction with information received. Responses were significantly more positive in the social media group, with a higher percentage reporting "very satisfied". Wound evaluation through tele-follow up was on par with OPD follow up. If all of these 40 patients would have come to our OPD follow-up, they would have travelled on an average of 930 kms per patient. This study shows that social media is a practical tool in follow-up of cancer patients in LMICs where traditional telemedicine tools are restricted and conventional follow-up is economically challenging to patients. It also ensures compliance which is a major issue with conventional follow-up due to poor infrastructure.

Keywords: supportive care, surveillance, disease management, telemedicine, remote consultation, cancer care

Introduction

Currently, the world population is growing by 1.18 per cent per year or approximately an additional 83 million people annually. The world population is projected to increase by more than one billion people within the

next 15 years, reaching 8.5 billion in 2030, and to increase further to 9.7 billion in 2050 and 11.2 billion by 2100 [1]. During 2015-2050, half of the world's population growth is expected to be concentrated in nine countries: India, Nigeria, Pakistan, Democratic Republic of the Congo, Ethiopia, United Republic of Tanzania,

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United States of America (USA), Indonesia and Uganda, listed according to the size of their contribution to the total growth [1]. All of them are LMICs (Low and middle-income countries) except the USA. According to the World Health Organization (WHO), cancer has become the leading killer surpassing deaths by all coronary heart diseases or stroke [2]. Over the next decades, the cancer burden is expected to reach 20 million new cases annually in LMICs by 2025. The rate of incidence of thyroid cancer has increased more than any other cancer worldwide [3,4]. The United States has seen >300% increase in the prevalence of thyroid cancer within the past 30 years [4] and few estimates suggest that thyroid cancer could become the third most common cancer to be diagnosed in women by 2019 [5]. This global epidemic will lead to a substantial challenge for health-care providers especially in low-resource settings, regions of the world which are already facing the heat of shortage of health care services. The greater challenge lies in postoperative long-term follow-up required for these malignancies, as evidenced by the low rates of follow-up in many low-income and middle-income countries. Given the excellent prognosis of patients with a diagnosis of differentiated thyroid cancer and long survival, long-term follow-up is of paramount importance as nearly one-fifth of patients with thyroid cancer will experience a recurrence of their disease [6,7]. Apart from occasional remedial treatment for recurrent disease and adjuvant radioactive iodine therapy, adjustments to thyroid hormone supplementation is routinely required. Hence, all such patients are kept on lifelong surveillance. Medullary thyroid cancers, another type of thyroid cancer, are associated with multiple endocrine neoplasias in up to 30 percent of cases involving adrenal and parathyroid glands. These patients are kept on lifelong screening for the detection of the development of these endocrinopathies (pheochromocytomas and primary hyperparathyroidism) [8]. With prolonged survivorship, the cost of follow-up is becoming more relevant as well as physical and psychological challenges faced by these patients during follow-up. Hospital-based telemedicine system has been proved to be effective in carrying out the continuity of care after primary treatment is over and are being used in both developed and developing regions of the world

[9-13]. Although, cost-effective in comparison to hospital-based follow-up, this system requires infrastructure and prior appointment. Many cancer survivors have unmet practical, physical and psychological needs [14] as well as economic challenges. Alternative models of follow-up have been developed and in some places implemented to address these needs, providing promising results due to the increasing familiarity of the current cancer patients with technology and their increasing utilization of digital healthcare information [15-18]. Various studies have now established that telephone-based follow-up is effective in cancer patients as well [19-21]. The evidence is growing on remote consultations by social media such as Skype, mostly from the developed countries [22-24]. Few studies on patient satisfaction or acceptability of remote monitoring have also been published [25-27]; however literature is silent on use of this media for healthcare delivery in developing world.

We conducted this study to assess the effect of remote monitoring using social media on compliance, satisfaction and economic benefit in a LMIC.

Materials and methods

In this longitudinal trial we examined whether, despite foregoing face-to-face OPC (Out Patient Clinic) consultations and clinical examinations, patients in the telefollow up arm using social media (ORC; online remote consultation), of the study had compliance, satisfaction, disease detection rate that were no different from those of patients in the hospital arm.

Study design

All participants had been treated for thyroid cancer at a specialist endocrine surgery unit in a tertiary care centre in northern India. Inclusion criteria included patients diagnosed with thyroid cancer and undergoing surgery and further follow up with access to a smart telephone with internet access and consenting to use social media for data transmission and consultation.

We identified consecutive eligible patients in the hospital, discussed the study after appointments, and subsequently contacted individuals for verbal and written consent. Patients who consented were kept under ORC group and once a year hospital follow-up if needed and those who did not give consent were kept under OPC follow up.

Investigations and consultations

Participants in the OPC group continued with outpatient clinic follow-up as per departmental policy. After surgery, patients are reviewed every week with reports of serum calcium for adjustment of calcium supplementation and at six weeks, with serum thyroid stimulating hormone (TSH) report for levothyroxine dose adjustment. Then patients are kept on yearly follow up with serum thyroglobulin (Tg)/ antithyroglobulin (ATg), high-resolution ultrasonography of neck and TSH. Patients of MEN 2 are similarly followed up with yearly serum calcitonin, serum parathormone (PTH) and 24-hour urinary metanephrine and nor-metanephrines. MEN 2 patients who are diagnosed as pheochromocytoma and started on alfa blockade therapy two weeks prior to surgery are required to daily or alternate day OPC follow up with blood pressure (BP) values for prazosin dose adjustments. After surgery for pheochromocytoma and discharge, they are required to be in constant touch with OPC with blood pressure charts for the requirement of anti-hypertensives or dose adjustments and then after two weeks for wound evaluation. Preliminary work for the study had indicated that OPC consultations primarily consisted of a clinical examination, a check on whether hormone treatment was being taken as prescribed and ordering investigations as appropriate. OPC consultations could be conducted by health professionals including consultant surgeons or senior residents.

Participants consenting to ORC were asked to mail their discharge summary using various social media tools at intervals consistent with hospital follow-up policy. They were asked to send the medical reports on one of the senior residents' smartphone and follow his advice. This system was on the go and no prior appointment was

required. But the senior resident used to reply usually in the evening unless there was an emergency. If the patient had specific complaints or did not feel reassured, an additional appointment was made for patients to consult the hospital.

General data protection regulation (GDPR) is a regulation that requires businesses to protect the personal data and privacy of EU citizens for transactions that occur within EU member states. As this study was conducted in India, GDPR compliance was not required. But we have devised the following steps to ensure compliance. We communicated to patients about the processing of data, retention periods, the right to withdraw when unhappy with our implementation and that their data can be subjected to analysis and presentation at scientific forums. WhatsApp was used after they started end-to-end encryption, which ensures only doctor and the person he is communicating with can read what's sent, and no one else in between, not even WhatsApp. Furthermore, only a single smartphone with this application was used which was accessible with only one physician's fingerprint. No one else could open or read the messages. All the images received were transferred to a secure hard drive regularly and data from smartphone was deleted permanently. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Outcome measures

Outcomes included information needs, participants' compliance and satisfaction, post-op complications needing hospital consultation, clinical investigations ordered, and change in treatment strategy. Data were collected by the researcher when patients returned to the hospital for their follow up or via questionnaire mailed to the participants. Patient satisfaction with remote monitoring care was measured by a numeric scale ranging from 1 to 5 (a low score of 1 to a high score of 5).

Statistical analysis

SPSS17.0 was used for data entry and analyses. Descriptive statistics were used to analyze the demographic and disease characteristics of the patient. Frequencies and percentages were used to calculate patients' response to specific questions. The mean scores for satisfaction scale between the groups were compared by t-test. A value of $P < 0.05$ was considered statistically significant.

Results

Sample characteristics

A total of 64 patients participated in the trial. The clinical characteristics at baseline were similar between groups; the patient demographic and disease characteristics are presented in Table 1.

Information needs

Participants clearly indicated their specific information needs (Table 2). The highest need was related to the information about the blood investigation report evaluation, the lowest for information on medical fitness certificate. There was little difference between the groups in information needs.

Table 1. Socio-demographic and clinical characteristics of patients with thyroid cancer.

Characteristics	OPC Group (%)	ORC Group (%)
Age in years (Mean \pm SD)	44.23 \pm 7.83	43.13 \pm 9.53
Gender		
Male	14 (58.3)	18 (45.0)
Female	10 (41.6)	22 (55.0)
Level of Education		
Low	06 (25.0)	14 (35.0)
Middle	12 (50.0)	16 (40.0)
High	06 (25.0)	10 (25.0)
Distance from OPD in Kms (median value with range)	600 (3-1200)	930 (10-1500)
Diagnosis		
DTC	20 (83.3)	34 (85.0)
LADTC	04 (16.7)	02 (05.0)
MTC without MEN 2 A	00 (0.0)	02 (05.0)
MTC with MEN 2A	00 (0.0)	02 (05.0)

OPC - Out patient clinic, ORC - Online remote counselling, DTC - Differentiated thyroid carcinoma, LADTC - Locally advanced differentiated thyroid carcinoma, MTC - Medullary thyroid carcinoma, MEN 2A - Multiple endocrine neoplasia type 2A.

Table 2. Information needs in two groups.

Information Needs	OPC (%)	ORC (%)
HPE report evaluation	24 (100.0)	38 (95.0)
Blood investigation report evaluation	24 (100.0)	40 (100.0)
Drug dose adjustment	24 (100.0)	36 (90.0)
Physical fitness	24 (100.0)	40 (100.0)
Wound evaluation	24 (100.0)	26 (65.0)
Family concerns	14 (58.3)	38 (95.0)
Genetic evaluation	4 (16.7)	07 (17.5)
Medical certificate	12(50.00)	02 (5.0)

HPE - Histopathological examination

Table 3. Satisfaction with information received by groups.

Level of Satisfaction	OPC (%)	ORC (%)	P value
Very satisfied	04 (16.7)	30 (75.0)	<0.05
Satisfied	20 (83.3)	08 (20.0)	-
Not Satisfied	-	-	-
Very unsatisfied	-	-	-
Did not receive information	-	02 (5.0)	-

OPC - Outpatient clinic, ORC - Online remote counselling.

Clinical investigations ordered

There were no differences between groups in whether clinical investigations were ordered for participants as a result of appointments (hospital 100% vs telephone 100%, $\chi^2=1.10$, $df=1$, $p=>0.05$). In most cases, investigations comprised serum calcium, serum TSH, serum Tg/ATg, serum PTH and HRUSG neck. Other investigations mentioned by both groups at all stages of the study included nine chest x-ray investigations, six fine needle aspirations/biopsies, and two PET scans.

Compliance and satisfaction

There were no significant differences between groups regarding satisfaction with information received (Table 3). There was no difference between groups but at the end of the trial, responses were significantly more positive in the telephone group, with a higher percentage reporting “very satisfied”.

Economic outcome

If all of these 40 patients would have come to our OPD for follow-up, they would have travelled 930 Kms per patient on an average, and in addition to this would have lost work hours as well. Formal estimation of loss of work hours was not made in this study, but just looking at the cost of travelling suggests that a significant amount of money was saved. Indian railways round trip fare for second class travel for this distance is INR 484.00 (USD 7.5) per person. [28]

Discussion

To the best of the author’s knowledge, this study is unique in addressing the role of social media in resource-limited countries like India in remote monitoring of cancer patients. It was encouraging that nearly 62% agreed to participate, given that patients find hospital visits reassuring. Those in the ORC group reported greater satisfaction with the information received and reported appointments as most helpful in meeting their needs. All participants required information on specific needs at a point other than their scheduled ORC, many patients retained a need for information long after discharge and in-between scheduled ORC. There were no differences in terms of investigations ordered between groups. A lack of visual cues did not result in more tests being ordered. Data on patient satisfaction or acceptability was comparable to other trials on remote monitoring [25-27]. Beaver et al. reported that most women with breast cancer had equivalent satisfaction with tele-follow up as compared to hospital-based follow up [25]. Kimman et al. found that nurse-led telephone follow-up had high satisfaction scores [21,26].

Our data show that remote monitoring based on social media is more cost-effective than telephone-based follow up for both health services as well as patients. Beaver et al. concluded that telephone follow-up was more costly for health services as patients on telephone follow up had approximately 20% more consultations and longer consultations; however telephone follow-up was less costly than hospital-based follow-up for patients [27].

The ORC intervention has several advantages- patients find repetitive information reassuring, information at leisure and without an appointment. Patients might also feel more comfortable in their own homes, where they do not have to wait in hospital clinics.

Remote monitoring, using tools based on social media, maybe a partial solution for the many challenges faced in our setting. Due to the limited availability of tertiary care centers in our country, patients travel long distances for treatment followed by recommended follow-up. The second issue is related to limited public transport infrastructure and patients have to travel on trains or buses which are almost always packed. When patients reach the hospital, then taking an appointment, waiting for a consultation, and getting all the ordered investigations takes at least a few days. This whole process is extremely unfriendly to the patients and their attendants. Smartphone-based applications can be a way forward because rapid economic growth has led to the expansion of internet services even in the remotest part of the country. By 2022, there will be 829 million smartphone users in India, accounting for 60% of the population, according to Cisco's 13th annual Visual Networking Index (VNI). But there are few data in the peer-reviewed literature evaluating its application in health care especially in the context of LMICs.

Conclusions

Follow up of cancer patients in developed countries is not a problem- better communication system, transport system, and educated patients. Low and middle-income countries need an eHealth revolution using cost-

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effective and easily available technology like social media to achieve the goal of health for all as availability of health care facilities is a problem in such geographical locations in addition to lack of human resources as compared to patients needing healthcare.

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Conflict of interest

Authors declare no conflict of interest

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Informed consent

Informed written consent was obtained from the patient.

Author contributions

Sanjay Kumar Yadav, Saroj Kanta Mishra, - literature search, figures, study design, data collection, data analysis, data interpretation, writing. Chandan Kumar Jha, Raoef Ahmed Bichoo, Abhishek Krishna, Prathima Gopinath - Revision and editing of manuscript

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