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Adopting telehealth service for lymphedema care: Insights from a Filariasis Management Clinic, Puducherry, India

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Abstract

Lymphatic filariasis (LF) is a neglected tropical disease affecting communities in tropical and subtropical regions marked by poor socio-economic conditions. Regular hospital-based follow-up and home-based Morbidity Management and Disability Prevention (MMDP) are below par among LF patients due to reasons ranging from travelling costs to stigma. Telehealth interventions are suggested as a promising adjunct tool in such scenarios, integrating medical expertise and accessibility, but rarely used for LF. This article reflects on the insights from an LF clinic on the potential of telehealth interventions in enabling patients to access medical care and improving their home-based MMDP. Despite challenges like poor digital literacy and access to technology, the telehealth service facilitated remote consultations and dissemination of educational materials, allowing clinicians to monitor patient conditions and provide necessary medical guidance. The approach has shown substantial potential in improving lymphedema care, particularly in resource-limited settings, by offering a feasible solution to the barriers faced by traditional healthcare delivery. The pilot program underscores the importance of continued research and adaptation to optimize telehealth interventions for chronic disease management, ensuring comprehensive and accessible care for underserved populations.

Keywords

Morbidity management and disability prevention, lymphatic filariasis, telehealth, telemedicine, teleconsultation

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Introduction

Lymphatic filariasis (LF), a neglected tropical disease caused by the filarial nematodes transmitted by mosquitoes, is a debilitating condition that damages the lymphatic system and can result in abnormal swelling of body parts, inducing lymphedema and hydrocele.[1] Prevalent in areas marked by low resources and poor socio-economic conditions, LF continues to pose a significant health risk to 657 million people from 39 countries who live in endemic areas requiring preventive chemotherapy, of which 40 per cent hail from India.[2,3] The global baseline estimate indicates a high prevalence of chronic disease manifestations among the affected, including hydrocele among 25 million men and lymphedema among more than 15 million people[3]. The global response for the control and management of LF, as laid down by the World Health Organization (WHO), involves two key components, viz. mass drug administration to interrupt the transmission of infection and the morbidity management and disability prevention (MMDP) to address the morbidity induced by LF.[4–6] Once established, lymphedema is not curable and can lead to recurrent episodes of skin and soft tissue infections in the affected limbs. When unattended or under-

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attended such infections can lead to extreme disfigurement, substantially restricting the mobility of the affected, making MMDP a critical element in care.[7] Since skin infection induces acute episodes and aggravates lymphedema, home-based MMDP practices, including washing of limbs and maintaining good hygiene, are recommended to ensure continued care by the Global Programme to Eliminate Lymphatic Filariasis.[6,8]

WHO recommends MMDP services to be included in the primary health care package and promotes home-based care.[9] This dual approach ensures that the patients receive comprehensive care, minimizing the adverse impact of LF. Originally envisioned as a mutually complementing strategy, gradually home-based care and facility-based care unintentionally got compartmentalized due to reasons including poor adherence to hospital-based management regimens owing to reasons ranging from accessibility to stigma.[10,11] Some of the key reasons for poor/no adherence to clinic-based medical care cited by patients registered in the LF clinic where the authors serve included difficulties in using public transportation, accessibility issues, costs related to travel and perceived stigma in public places. Since LF is prevalent in resource-limited settings, the patients cannot frequently visit hospitals or practice MMDP. Often individuals with poor adherence to hospital-based medical care tend to have poor home-based care as well. Telehealth interventions serve as an effective adjunct strategy in such cases, but are seldom used among LF patients.[12,13] Compared to other diseases globally, the adoption of telehealth for lymphedema care is not well-developed. Telehealth has a lot to offer in improving lymphedema care, especially in the context of filariasis in resource-limited tropical and subtropical regions. Against this background, this article narrates the authors' experience regarding the practical implications, including the advantages and difficulties, of administering a telehealth programme for LF patients. The insights from this telehealth service can serve as practical lessons for extending telehealth services for underserved populations.

The filariasis management clinic and the telehealth service

The institute that the authors are affiliated with runs a dedicated Filariasis Management Clinic, which caters to nearly a thousand patients affected with lymphedema in and around Puducherry, India. The majority of the patients that the clinic serve hail from poor socio-economic conditions and are above 45 years of age. A significant number of them come from distant places and remote villages to avail some of the specialized care services that the clinic offers which are not available in primary health settings. However, despite the efforts of the clinic to extend comprehensive care to the patients, many are unable to attend the clinic for follow-ups regularly due to reasons like accessibility, difficulties related to transportation, costs involved in transportation etc. A considerable portion of the patients also fail to practice home-based care effectively, adversely affecting their health. Multiple factors, including the disability itself, comorbid conditions, poverty, lack of caregivers and neglect by the family were contributing to this non-adherence to home-based MMDP. To provide the patients with expert care and improve their home-based MMDP, a telehealth package was developed and piloted in August 2023.

Telehealth is a broad concept that involves the exchange of medical information through Information and Communication Technology (ICT) to improve patients' health which can include clinical services as well as non-clinical services like training, education and communication.[14] Telemedicine is a concept falling within the spectrum of telehealth which involves 'the use of electronic communications and information technologies to provide clinical services when participants are at different locations'.[15] Considering the unique nature of the setting and need for comprehensive care for lymphedema, a broader telehealth approach was opted. The telehealth multi-disciplinary team was constituted of clinicians, registered nurses, ICT technicians and other support staff who were trained in telehealth service delivery. The telehealth programme had four major components, discussed in the following section.

Demonstration and training for patients and caregivers

Two of the key challenges in implementing telehealth services are digital literacy and access to digital technologies, with education and age being key determinants.[16,17] Most patients registered with the facility were older adults with poor socio-economic backgrounds and mostly having only primary-level education. The patients, based on their digital literacy and access, fell under three major categories, viz. the digitally literate, those with no access and those with access but not digitally literate. The latter two, viz., those with no access and those with poor digital skills, fall in the first and second levels of the digital divide, respectively, and are often deprived of the benefits of digital health interventions.[18] In order to ensure that the patients falling in these categories could effectively benefit from the telehealth programme, comprehensive demonstration and training programmes were provided at the onset.

Lymphedema patients from distant places and those with travel-related difficulties were given priority and were encouraged to register. Since August 2023, the facility has had 40 registered users. A case-by-case demonstration and training for each registered patient and their caregiver was provided in the facility. Three different scenarios were present in this context. Those patients who were

digitally literate were assisted by the personnel in installing a video calling application, such as *Zoom*, on their smartphones, and a demonstration of the teleconsultation was provided. Those patients who were not digitally literate were assisted by the personnel in the installation of the video calling application, and training and demonstration were provided to the patient and a caregiver who would later assist the patient in availing the teleconsultations. Those patients who did not own or had no access to a smartphone were provided support through their neighbours. The email addresses and cellphone numbers of the patient, the caregiver and the neighbour, as applicable, were gathered, and the invitation links to attend the teleconsultation were delivered prior to the day of the consultation.

Medical care through telemedicine

Telemedicine for patients residing in remote areas has become prevalent as a result of advancements in telecommunications infrastructure brought about by the proliferation of smartphones and ICT.[19] Telemedicine optimizes patient outcomes by improving follow-up probability and reducing missing appointments.[20] The telehealth programme of the LF clinic involved a telemedicine component through *Zoom* meeting based teleconsultation where the physician interacted with the patients and asked them about their problems. The caregiver presents the limb to the physician for examination, and the clinician assesses and gathers data on the beneficiary's health condition. Whenever required, medications are prescribed via email. If any patients required advanced medical attention, they were advised to report to the clinic at the earliest. A devoted helpline line was also in place during the working hours of the clinic to facilitate the patients and caregivers in case of emergencies and for scheduling online or in-person appointments. However, it was made sure that telemedicine was used as a complementary strategy rather than replacing in-person delivery of health services, as mandated by the WHO recommendations.[21] The aim was to improve healthcare access and increase the follow-up of patients from remote locations or those facing mobility-related problems.

The telemedicine component also involved an assessment of the home-based MMDP by the patients. The examination of limbs by the clinician was followed by instructions for the patients on home-based care, including hygiene, skin and wound care, elevation, exercises, and wearing compression bandages and suitable footwear.[12] During the follow-up sessions, the patients were encouraged to narrate how they had practised home-based care since the last consultation. This ensured that the patients were motivated to practice MMDP and the clinician had a record of the MMDP practice of the patient, successfully integrating medical care and home-based MMDP into a single package.

Dissemination of e-health tools

Guided self-help is one of the key components of telehealth interventions, which involves disseminating self-help information through web platforms like a website or through a smartphone.[21] In the context of LF, guided self-help could be achieved through e-health tools. The e-health tool dissemination involved two stages. First, a dedicated YouTube channel of the LF clinic was created and videos pertaining to hygiene, skin and wound care, exercise and other MMDP components were uploaded to the channel.[22] The limb care manual was also digitized and uploaded to the channel. Demonstration videos were prepared in English as well as the local language, Tamil. The language used was basic to make it easy for the patients and caregivers to follow effectively. All the MMDP practice steps were demonstrated with a volunteer patient, in simple steps understandable to the patients. The patients and caregivers were encouraged to watch the videos and learn various aspects of MMDP on their own so as to practice them effectively. They were also advised to call the helpline to clarify their doubts pertaining to the demonstrated practices. In addition, the feedback was taken from the patients and/or caregivers during the 'facility-initiated follow-ups'—described in the next subsection—to understand if the video tutorials were actionable. Any challenges faced by patients were addressed through clarifications by the personnel at the LF clinic, reinforcing the effectiveness of the video-based guidance in helping patients practice home-based care. However, it is to be noted that the patients and/or their caretakers were provided with a comprehensive in-person demonstration of MMDP during their first visit to the LF clinic. The videos are designed to supplement the home-based self-care of the patients by serving as a resource for helping them recall the steps involved in MMDP practices, which they learned from the LF clinic. The video tutorials thus served as a complementary component in tandem with expert advice, helping the patients practice home-based MMDP more effectively.

Sustainability through facility-initiated follow-ups

One of the key challenges in lymphedema management is poor adherence to home-based care and poor follow-up for medical care. As discussed earlier, these factors are intertwined with each other and facilitated by multiple factors ranging from LF-induced physical disability to socio-economic factors. To address this problem, the telehealth package included a facility-initiated follow-up component. The date of follow-up consultation is decided during the current consultation of the patient and the online invitation for the follow-up consultation is sent a day or two prior to the scheduled date to ensure the participation of the patient. In case of inconvenience, an alternate slot is provided to the patient and ensured that the patient

Table 1. Patient profile and telehealth statistics[a].

Number of patients enrolled for telemedicine	40
Patient profile	**Frequency and percentage**
Age	
Below 40 years	09 (22.50%)
40–50 years	06 (15%)
50–60	18 (45%)
60 years and above	07 (17.50%)
Gender	
Male	21 (52.50%)
Female	19 (47.50%)
Grade of lymphedema	
Gr II	12 (30%)
Gr III	12 (30%)
Gr IV	16(40%)
Distance of the residence of patients from the clinic	
Less than 20 km	02 (05%)
20–50 km	17 (42.50%)
50–100 km	08 (20%)
100–200 km	09 (22.5%)
More than 200km	04 (10%)
Educational qualification	
No formal education	02 (5%)
Primary school	09 (22.50%)
Middle school	08 (20%)
High school	12 (30%)
Intermediate or Diploma	04 (10%)
Graduates and above	05 (12.50%)
Telehealth statistics	
Status of online consultations	
Total number of appointments given	97
Number of online consultations attended	68(70.10%)
Number of online consultations missed	29(29.89%)
Ability to avail telemedicine consultation	
Availing of telemedicine on their own	15(36.84%)
Availing with assistance from a family member	20 (50%)
Availing of assistance from neighbours/friends	05 (37.50%)

aCompiled by the authors from the data till 31-08-2024

does not miss out on the consultation. These follow-ups also ensured that patients remained motivated to practice home-based care through support from the healthcare personnel. The benefit of the facility-initiated follow-up over the patient-initiated follow-up is better adherence and availability of an alternate consultation schedule in case of missing out on a previously decided date. This ensured the long-term sustainability of medical care and home-based care.

Patient profile and telehealth statistics

The details of patients enrolled in the telehealth programme and the relevant statistics pertaining to the telehealth programme are discussed in Table 1. The adherence to online consultation was found to be slightly above 70 per cent, indicating a good level of participation.

Benefits, challenges and future directions

The telehealth package was rolled out with the aim of bridging medical care and home-based care into a comprehensive care package for patients with accessibility-related challenges. The implementation of this package provided insights that can help advance telehealth approaches for LF patients. Telehealth, especially telemedicine through video consultations, offered several benefits to the participants. One of the major advantages was the ability to receive specialized medical treatment at the convenience of the individual's residence. Patients suffering from

lymphedema and significant disability would like to avoid the inconvenience of travel, often leading to poor facility-based follow-up. Another significant advantage of telemedicine was reduced costs for the participants. LF is prevalent among economically disadvantaged communities, often hailing from remote rural locations who can't often bear travel costs for follow-ups. Teleconsultation positions as a cost-effective communication solution, significantly alleviating the challenges of travelling long distances with a physical disability while also reducing the financial strain and time commitment.[23] Additionally, it saves time and prevents loss of income for the caregiver. Another important benefit of online consultation is its usefulness in managing adenolymphangitis (ADL) attacks. Travelling and seeking in-person service during ADL attacks is challenging for people, especially for those from remote locations. This difficulty can be effectively managed by telemedicine. A preliminary evaluation can be made over teleconsultation, and depending on the severity, the clinician can decide whether the patient needs to take an in-person consultation in the clinic or medication can be prescribed online. In both situations, telemedicine presents an effective alternative to in-person follow-up visits for ADL attacks. Patients can be scheduled for an online appointment after 2 days of prescribing the antibiotics, and their status can be assessed and travel inconvenience can be avoided in several instances.

One of the critical challenges, which also presents an opportunity, is the limited digital literacy of the participants. Training the patients in ICT for health services can also benefit in addressing the broader digital divide. Patients with lymphedema may benefit from remote learning and self-empowerment through the use of eHealth technologies. By utilizing video technology and online tools, patients are better able to understand and participate in complex lymphoedema topics, such as the lymphatic system's operation and exercise routines.[13]

Nevertheless, there are certain constraints as well. Online consultations cannot serve as a substitute for an in-person consultation, as direct human interaction is absent. It can only be administered as a complementary strategy in conjunction with in-person delivery of healthcare services.[21] Also, the examination of the patient virtually has limitations. Sometimes network issues may interrupt the procedure. Videos may not be clear when the network connectivity is poor, which is often the case in many remote rural settings and we faced this difficulty on several occasions. Another major obstacle arises when patients or caretakers are either devoid of the necessary gadgets or lack the proficiency to use the gadget. Despite enormous progress in digitalization efforts in the last few decades, only 25 per cent of the rural households in India are digitally literate.[24] Hence a twofold problem of the digital divide i.e. lack of access and lack of digital literacy, exists in many settings.[25] Among the digitally illiterate, some individuals are not capable of being trained.[23] This could be overcome by training patients whenever possible and seeking help from caregivers, neighbours and community health workers like Accredited Social Health Activists (ASHA), as the situation demands. Another practical constraint associated with telemedicine consultation observed in our setting is the difficulty in disbursing medications and materials like crepe bandages. When the patients attend the clinic in person, apart from medical consultation, they can collect the medications from the pharmacy, which is not possible during teleconsultation. Purchasing medications from private pharmacies can be expensive and unaffordable for some patients. Yet another major concern in implementing telemedicine facilities is ensuring data privacy and data security.[13] This posits a significant concern from the provider and beneficiary perspectives, as ethical practices concerning data privacy and data security need to be ensured while dealing with patient data. At our LF clinic, we addressed these concerns by adopting a few practical steps that are feasible in other resource-limited settings as well. The measures included manual scheduling of appointments rather than relying on automated tools, which require a transfer of patient information, storage of patient data in a local storage device rather than cloud-based storage, access to patient information strictly limited only to key programme officers and finally a strict policy of no recording of teleconsultations. However, despite certain limitations, the overall benefits of the telehealth programme outweigh the limitations.

The insights from this pilot telehealth service initiative have proven to be immensely beneficial for LF patients. However, evaluating the efficacy of eHealth technology in lymphoedema care requires a thorough investigation. When designing eHealth resources, it is important to assess how these resources can impact the patients' lives, how practical they are, how accurate they will be, and how difficult they will be in terms of usability.[26] From the learnings gained from this pilot programme, we believe that telemedicine consultations, when conducted periodically alongside in-person consultations, can significantly improve the health prospects of LF patients.

Conclusion

Based on the experience from this pilot venture, we recommend telehealth interventions as an adjunct mechanism in combination with in-person consultations for the supportive care of LF patients. We advocate for the wider adoption of telemedicine and various e-health tools in the care of filarial lymphedema-affected individuals who hail from remote locations with limited financial resources and mobility-constraining disabilities. Telemedicine can increase the follow-up frequency and improve the home-based MMDP of such patients. Telemedicine offers a comprehensive package for LF patients integrating 'ease' and 'expertise',

levelling down the inequities in healthcare delivery. Also, ICT training associated with the telehealth programme can serve as a starting point for closing down the digital divide for disadvantaged sections like the LF patients from remote rural settings, who can build upon the learnings to master ICT effectively. The efforts to advance telehealth interventions for LF patients can effectively be integrated into the healthcare system by establishing teleconsultation facilities at the Community Health Centres (CHC) or Primary Health Centers (PHC) and connecting to remote sub-centres where ASHA workers or ANM can help the patients at the sub-centres in connecting to the CHC or PHC online. Systematically expanding telehealth networks for remote locations through public health systems can address the problem of accessibility for remote communities, not just for LF patients, implying its potential utility in addressing health disparities. Guided by the positive insights from this pilot programme, we advocate for the wider adoption of telehealth strategies for LF patients in need of continuous care.

Limitations

There are a few limitations originating from the service-based nature of the programme reported here. Firstly, since the program was a routine healthcare initiative rather than a structured research project, individual-level measures of patient improvement are not presented. Secondly, there are no comparative statistical analyses in this manuscript. Only improvement in follow-up rates is reported which should be interpreted as preliminary observations.

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Ethical considerations: The telemedicine programme reported in this manuscript is a newly initiated patient service at the LF clinic, where the authors are affiliated, not a research project. Hence, only clinic-level descriptive data has been reported, and no ethical clearance is associated with the manuscript. However, participation was ensured to be voluntary. The service was offered to selected patients and was extended only to those patients who showed interest and orally consented to be part of the telemedicine programme. The service was designed to improve accessibility to healthcare for LF patients without compromising their standard of care. Regular consultations with trained healthcare professionals continued, and patients had the choice to opt out of telemedicine services at any stage without affecting their ongoing medical care.

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