

1800 121 2096 Diabeteshelp – A toll free helpline for people with diabetes

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People with diabetes mellitus require long-term care that is timely, patient-centered, community-based and sustainable. Any deficiency in care increases the risk of developing complications like Diabetic Retinopathy. Patients or their carers also have numerous questions and doubts during this long-period of care. This increases the pressure on health systems that are struggling with a lack of skilled human resources. One option is to provide counseling support using a dedicated helpline. Over the last five years a major initiative to tackle visual impairment due to diabetes was rolled out in India by the Public Health Foundation of India supported by the Queen Elizabeth Diamond Jubilee Trust, UK. One component of the initiative was establishing a toll-free helpline (1800 121 2096) to address the lack of awareness and to empower people with diabetes in Telangana and Andhra Pradesh states in India. Over a 1-year period, the helpline received 4406 calls, making a case for a national service for people with diabetes.

Key words: Awareness, complications, counselling, diabetes, diabetic retinopathy, helpline

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The number of people with diabetes in India increased from 26 million in 1990 to 65 million in 2016,^[1] and 50% remain undetected, resulting in complications.^[2] People with diabetes require long-term timely, patient-centered, community-based sustainable care. Health helplines are integral to contemporary health care as they offer an opportunity for an affordable intervention with unrestricted access to information.^[3] Telephonic helplines have been used to support self-management of cancers, alcohol addiction, smoking,^[4,5] and recently, diabetes.^[6] Stigma is common among people with diabetes who report substantial feelings of guilt, shame, and disgust,^[7] making a case for an anonymous source of accurate information. While most telephonic helplines are based in high-income countries, these have been recently assessed in low- and middle-income countries.^[8] The present study reports a similar initiative in India. The helpline was set up to serve three purposes: (1) to empower people with knowledge about diabetes and provide essential information, such as the location of facilities for treatment; (2) to provide emotional and psychological support to people with diabetes and to help improve their quality of life; and (3) to educate people about the complications of diabetes, including diabetic retinopathy (DR) and make them active partners in the prevention of diabetes and lifestyle management to improve

their control of diabetes and risk factors for complications. This included the need for an annual retinal examination.

Methods

We launched the toll-free helpline (1800 121 2096) to address awareness and to empower people with diabetes in the states of Telangana and Andhra Pradesh in May 2018. The diabetes helpline addresses questions related to diabetes or complications due to diabetes. Trained counsellors also give psychological support to callers who may have concerns about their diabetes or are caregivers of someone with diabetes.

We conceptualized the helpline in three phases. In the first phase (June 2015–2016), we established the scope of questions that the counsellors could answer on the helpline. We considered several conflicting issues involving both the counsellors and people with diabetes: (1) medical advice versus psychological support by the counsellors; and (2) knowledge of availability of routine care versus care in public health facilities. As medical advice is best given by physicians, we concentrated on providing psycho-social support by the counsellors. The team drew up a list of Frequently Asked Questions (FAQs) with responses which were reviewed by a group of experienced endocrinologists and ophthalmologists. The project team then

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populated a customized software developed for the helpline with these FAQs [Table 1].

In the second phase (June 2016–17) the team worked with a software company to develop the helpline software and hired counsellors. The helpline software is an interactive web-based application with four sections:

1. A bank of FAQs that the counsellors could update,
2. A list of hospitals in the public sector that provide services for people with diabetes,
3. Information about callers that they are willing to share, and
4. Emergency numbers that counsellors could provide to callers during an emergency.

Counsellors updated the questions each time a caller asked a new question. Responses to these questions were again drafted and sent to experts for review. The database was updated with the caller details if they were willing to share their name,

demographic details and associated health issues. This helped save time because repeat callers need not repeat their health history. The helpline software recorded all calls, with the permission of callers, to help track the quality of responses given by the counsellors and to list the question trends. The project recruited persons with diabetes with experience in diabetes management and trained them in psychological counselling. Their training included diabetes care and management, social and communications skills, listening and empathy skills.

The helpline was operationalized in the third phase (June 2017–18). This phase involved rigorous training sessions for the counsellors, followed by mock calls to test their abilities. Acquiring the toll-free number “1800 121 2096” was also done in this phase. The famous Indian cricketer, Mr. VVS Laxman, launched the diabetes helpline in Hyderabad on 12 June 2018.

Table 1: Sample FAQ's

Question	Answer
Why is that only I got diabetes?	Diabetes is a common disease. You are not alone. Many lifestyle factors will cause diabetes. If you can control them, we can lead an almost normal life.
I have nobody in my whole family with Diabetes, how did I get it then?	Family history certainly is an important factor; at the same time being Indian, we all have high-risk tendency for Diabetes. Remember it is not your fault that you have Diabetes. You just happened to be the person who got it.
Does diabetes cause any other complications?	If blood sugar levels are not controlled properly, people with diabetes can develop heart damage, kidney failure, eye damage, stroke, nerve damage and delay in wound healing leading to removal of limb.
Do eating bitter things help to control sugar?	No. Proper diet, exercise and medicines help in controlling Diabetes.
Are there any diabetic friendly biscuits?	No
Will diet and exercise help to lower my sugar?	Yes
Will my organs be affected due to diabetes?	If Diabetes is not managed properly it can affect the Brain, Heart, Kidneys, Eyes and Nerves
I have heard about some non-allopathic medicines. Can I try them?	It is better to avoid such medicines as their efficiency and side-effects are unknown.
When is the best time to do exercise?	Morning or in the evening.
Do I need to check my eyes?	Yes. As Diabetes can affect eyes, retina needs to be examined.
Will checking sugar everyday reduce the quantity of blood from my body?	No.

Table 2: Distribution of calls received by the helpline in a one-year period

Period	Calls received	Calls missed (could not be answered)	Total calls	(% missed of total calls)	Average duration of calls (minutes)
June-August 2018	1551	1138	2689	42.3	7.9
September-November 2018	161	41	202	20.3	6.6
December 2018-February 2019	153	81	234	34.6	5.8
March 2019-July 2019	898	383	1281	29.9	4.7
Total	2763	1643	4406	37.3	6.2

Table 3: Common reasons for calling the helpline

Reasons	Number	%
Diet	970	35.1
Diabetes and control measures	746	27.0
Diabetes complications	689	24.9
Medication	358	13.0
Total	2763	100

Results

The helpline counsellors handled 4406 calls between June 2018 and July 2019 [Table 2]. We received a large number of calls in the first quarter after the launch, which declined thereafter. To address this, a range of strategies were adopted to increase the call-flow to the helpline. These included displaying posters in health centers and other public places, discussing DR and the helpline on popular radio talk-shows, radio advertising, news-scrolls on health channels and a dedicated website for the helpline. These efforts led to an increase in the number of calls received, and a decrease in missed/unanswered calls in the last quarter of the reporting period.

Table 3 lists the most commonly asked questions and answered ($n = 2763$) on the helpline during this period. Most questions were related to diet, and a little more than 10% of the questions were on medication.

Discussion

A toll-free helpline could supplement over-stretched health systems. The helpline's two key successes were sustained promotional efforts using a variety of media, and recruitment and retention of counsellors. One of the key selection criteria for the counsellors we hired was that they had to be living with diabetes or caring for someone with diabetes, as they would have experience grappling with diabetes on a daily basis. The counsellors also received extensive training to give psychological support to callers who may have concerns about their diabetes or are caregivers of someone with diabetes.

The number of callers in the initial period was very high as it was a novelty and many people who did not have diabetes also availed the service. This initially resulted in many missed/unanswered calls—the two counsellors were overwhelmed by the call volume. Soon, however, the call volume began to decline. The numbers plateaued out from the 2nd quarter as only genuine callers used the service. Initially we ran the helpline round the clock. However, we noted a paucity of calls between ten pm and six am. So, the helpline now functions from six am to ten pm only. We also observed that there was a need for continuous social advertising. The helpline was able to bridge the gap between the need for information and the

available sources for providing scientifically valid information to people with diabetes particularly from rural areas.

Conclusion

Health helplines are integral to contemporary healthcare, offering fast, low-cost, and geographically unrestricted access to health information and advice.^[3] They can bring basic health information and care even to people in low-income areas where there are few healthcare facilities and doctors. Telephonic helplines have been used to support self-management of cancers, alcohol addiction, smoking,^[4,5] and recently, diabetes. 1800 Diabetes Helpline does precisely that, providing psychological counselling services, free-of-cost to people with diabetes.

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Conflicts of interest

There are no conflicts of interest.

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