

Exploring the Role of Social Media as a Support Mechanism Among Persons with Diabetes: An Online Ethnographic Study

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ABSTRACT

Diabetes mellitus is one of the most prevalent health problem which India is facing and self management is key component in dealing with it. Self management is considered to be individual's competency in handling situations but it is perceived to be more effective if influenced by social support. This study aims to assess the use and benefits of social media among persons with type 2 diabetes in India as a well-being mechanism. The current review article reflects positive impact of usage of social media in managing type 2 diabetes, which also proves the theoretical base of social support and bio psycho-social model in managing long term illness. The results of the study adds to the current literature gap on perceived benefits of social media use in managing diabetes and it can also help health care providers to understand the role of social support which person with diabetes are considering to be important stakeholder in dealing with diabetes.

Keywords: Type 2 Diabetes, Social Media, Biopsychosocial Model, Diabetes Management

Introduction

The emergence of internet has changed the way we communicate. It has potential to move away static information to interactive, user friendly sites like social networks which gives users ample scope for both content generation and content sharing. With all other spheres of life embracing digital media especially social media, health sector is also not lagging behind. Health awareness is one of the important areas which needs to be catered to public at the right time, and for effective and efficient health communication, digital media has started playing significant role.

Communication plays integral role in delivering health care and promoting health awareness. According to Healthy People 2010 guidelines, health communication encompasses the study and use of communication strategies to inform and influence individual and community decisions that enhance health. It links the domains of

communication and health. Media is the most important platform in serving the role of being source of correct information and advocating correct health behaviour. Health sector is using different media platforms from very early days to communicate health related messages. With internet revolution, there is lot of scope for the websites and social media to give right and instant health related information on right time (U.S. Department of Health and Human Services, 2010).

With the fact that, lifestyle diseases are on rise in Urban India awareness regarding the same is essential. In the simplest term, lifestyle diseases are those which are associated with the way a person or group of people lives (IANS, 2012). It includes heart disease, stroke, obesity, type 2 diabetes etc. Drugs and lifestyle are the major reasons for causing lifestyle diseases. Adults can have lifestyle diseases from behavioural factors too like

unemployment, unsafe life, poor work culture, stress etc.

Among various lifestyle diseases, type 2 diabetes is the most common disease. Genetics and lifestyle are the main reasons for type 2 diabetes. Diabetes is a household problem in hectic urban life that causes blood sugar level to rise higher than normal. Type 2 diabetes generally happen with insulin resistance, a condition where cells fail to respond to insulin properly. Common symptoms of this disease are increased hunger, thirst and unexplained weight loss. Long term complications may increase heart disease and strokes. Onset of type 2 diabetes is prevented through proper nutrition and regular exercise. Along with diet and exercise, medications are also referred for it. To make the treatment more effective, health care professionals must strengthen the affected person by utilizing all available resources, so as to better prepare them to face diabetes (Kalra, Verma, and Balhara, 2017).

Type 2 Diabetes is a very common in India also in current situation. A trail stated that 46% person with diabetes of India are diagnosed with Type 2 diabetes under the age of 40 years. The risk factors included were high blood pressure, abnormal lipid levels and obesity (Seema, and Cornwall, 2014).

Unhealthy life styles, stress were the two main reasons for Indian type 2 person with diabetes. Increased health activity, balanced and nutritious diet, proper treatment were the remedies from this disease.

Along with conventional treatment, cyber citizens have started using social media for treatment and lifestyle management to get rid of type 2 diabetes. Along with other social networks, Facebook is considered as one of the reliable source to get information and interact with co person with diabetes. Studies show that Facebook holds a significant potential in influencing health behavior by shaping patient's perception. Facebook pages and groups has been created on diabetes management where person with diabetes have chance to interact with others, share experiences of their symptoms and simultaneously get engaged with doctors and other health professionals for receiving advices and information regarding diabetes.

With the increase in number of Facebook population, numbers have been

simultaneously increased in diabetes pages too. The pertinent question lies here is the effectiveness of Facebook in creating awareness about diabetes and whether it able to help persons with diabetes in coping with the disease.

Thus the objective of the paper is to analyze the effectiveness of social media especially Facebook in getting information about diabetes and helping persons with diabetes to cope with the disease.

Literature Review

With regard to usage of traditional media in terms of health communication, literatures are many. The practice of social media in terms of health communication is an emerging area of research, thus it lacks availability of literatures. Despite of the fact, literature shows that social media is a very feasible option that is easy to adopt for health communication.

According to a study, modern science has improved sanitation, vaccination, antibiotics and medical attention. All these have helped us fight against most infectious diseases. This indicates that, death from lifestyle diseases are now on rise (Khanna, Kaushik, & Kaur, 2012). Too many people are dying relatively young from various forms of lifestyle diseases. Lifestyle diseases appear more dominantly in industrialized nations. While defining lifestyle diseases it is said, that it includes atherosclerosis, stroke, obesity, heart diseases and type 2 diabetes (Daniel, 2014).

According to a newspaper report ,lifestyle ailments such as diabetes, cardiac problems and cancer are expected to cost India income losses of about \$236 billion by 2015 (Thacker, 2008). The Times of India, report indicates that India ranks next to China in the highest number of person with diabetes in the world, as per the estimate by International Diabetics Federation and World Health Organization (WHO) (Mascarnhas, 2016). It is also mentioned that modern lifestyle changes are the cause in more than 50% cases. Polycystic Ovarian Syndrome (PCOS), a largely lifestyle related disease in women of reproductive age is on rise in India, especially among young girl. Several studies have been conducted by different organizations to identify the magnitude of lifestyle diseases in India (Jomon, 2017).

According to the survey conducted by the Associated Chamber of Commerce and Industry of India (ASSOCHAM), 68% of working women in the age between 21-52 years were found to be afflicted with lifestyle disorders such as obesity, depression, chronic backache, diabetes and hypertension ("Assocham",n.d.). It is essential for health care professionals to incorporate education, counselling and support system in their routine practice along with medication (Kalra, Verma, and Balhara,2017)

In an article authors mentioned that the development of interactive social networks has enabled people with diabetes to create supportive online communities and share experiences of living with diabetes (Cooper, & Kar,2014). They have harped to the point also that both healthcare professionals and person with diabetes should be aware of online resources available to them in terms of diabetes management. In another research done "Online Social Networking by Person with diabetes: A Qualitative Evaluation of Communication with Facebook" authors harped on the fact that several disease specific information exchanges on Facebook and other sites which help people to be more aware about diseases ("Facebook", n.d). In a report by American Diabetes Association titled *Diabetes Care* authors have emphasized on the fact that Facebook improve glucose control in person with diabetes. Researchers had conducted a one-year study on two types of persons with diabetes. One using social media and another group using traditional media for diabetes control. They found that social media use allows persons with diabetes to gain knowledge about diabetes and interact in their daily insulin adjustments (Diabetes Care, 2017).

To understand how diabetes community works, a research which compared 15 popular social network diabetes forums and found that each of them vary in authenticity of content, the way people use etc. (Shrank, et.al., 2011). Another research reviewed 233 wall posts and comments and 457 discussion topic comments from ten groups on Facebook (Greene, et.al.,2011). They found that persons with diabetes with diabetes, their family members, and their friends were actively using these groups to request information (13.3 % of the messages), provide information (65.7 %), and provide various support (28.8 %). With

medications, a sense of companionship is also required for a patient, which social media is able to give. Social network, social support and social influence leads to change in one's thought and disease management behaviour.

Methodology

This study primarily draws from the online ethnography of four online communities online,which are formed with the interest to support and inform the individuals living with Diabetes. The online communities used for this study include a Facebook group titled 'Diabetes support', a global online community with 27 K members, 'Diabetes contact group - A diabetic support group', a closed group with nearly 7000 members',and another group titled 'LCHF (low calorie, high fat diet) which discusses aforementioned diet as a solution to Diabetes and the other life style diseases. This article doesn't mention the name of the another online community, which is controlled by a private organization, given its dubious nature. However, the same is used to show how and what ways even the dubious ideas on medicine do make reach and takers online.The methods used in this study involve participant observation of the activities of the online community and content analysis of the activity in the group. This study is also supplemented by online interviews with eight participants who are actively taking part in the online communities on Diabetes.

Online Communities on Diabetes- Nature and Style of Operation

It can be observed that the online communities on Diabetes are created and managed by people with variety of motivations. There are two broad categories of online communities on Diabetics can be seen. The first category is a coming together of person with diabetes or family of the persons with Diabetes who share information and knowledge on ways to overcome the disease and improve their condition. These communities, as said to the researchers in the interview, are managed by persons with diabetes or their relatives. One such community in its description says 'this group is meant for people to come together to share tips, inspiration and discuss the journey involved with managing Diabetes'. This community also suggests its members not to provide any advise in this public forum which construes a "medical advice" as medical advice can only be provided by a medical Practitioner

licensed by the Medical Council. It furthers that members are free to share their experiences and provide information on healthy foods and alternatives but no medical advice as this may affect someone's health. This includes a member cannot prescribe people to stop or start a medication but can advise them to talk to their doctor to prescribe such medication.

The second category of the online communities on Diabetes are created by either individuals or organizations who claimed to have developed medicines or techniques to heal diabetes, like a particular diet plan or healing methods like Reiki. They use attractive and precise titles such as *"heal diabetes without medicine, diet plan to deal with Diabetes etc"* to name their communities. The nature of social media platforms like Facebook, which provides multiple ways to get visibility ranging from being visible on the search options, being shared by the already existing members and facility to reach target audience through paid or sponsored options etc make many such online communities popular, without much questions asked about their authority. As a representative example, one online community started by two people to discuss about the "simple diet plan to deal with the diabetes" got 72,000 members in a short span of one year. However, it is evident that such individual or organization based online communities are more interested to spread their ideas and practices rather than engaging in a critical debate with the members of the group. It is clear from the introduction of an online community which discusses about Keto diet plan, a high-fat, adequate-protein, low-carbohydrate diet, as it says *"This group is exclusively to discuss about Low Carb High Fat Diet. Questions and doubts regarding LCHF can be placed here. Those who disagree with this concept need not join here. No debates. Agreed?"*.

Online Platforms as a Coping Mechanism for Individuals Living with Diabetes

Many individuals living with Diabetes find online platforms as a great source of emotional support and confidence building in their fight against Diabetes. As said by many participants, they find great amount of relief in the process of engaging with the strangers online who suffer from the same condition. This is mostly expressed in the form of sharing pictures of Glucometer which shows their

normal sugar level. Such pictures are often received with appreciations and encouragements from the other online community members. During the interview, many participants said that the progress of other persons with Diabetes fills them with confidence and help them to come out of the despair and frustration. However, all community members are not necessarily sharing positive messages. Many do share their anxiety and fear regarding their high levels of sugar. Such posts receive responses in the form of better diet plans to fight the disease, personal accounts of overcoming Diabetics and comments which give emotional support.

The following Facebook post in the online community of person with diabetes where a participant posted her progress is an example of how the community members boost the confidence of each other and gain support in the process. The post says "I have worked really hard since diagnosis in November to change everything in my life and I was very pleased to learn today my a1c went from 11.7 to 5.4. This groups support and ideas are great." This post got encouraging comments such as "Wow", "Fantastic", "That's great", "Amazing progress", "Truly fantastic". The aforementioned comments clearly show that members of the community take genuine efforts to appreciate the hard work of the other participants. The encouragement and support play significant role in the case of a life style disease like Diabetics in which behavioral change is key as a Diabetic patient needs to take lot of efforts to come out of their condition.

As a representative example, someone posted as follows.

"My sugar was 203 after 2 cups of coffee and a small bowl of sugar free icecream. Dran water went down to 142. Now can't stop shaking and dizzy and light headed should i go to doctor?"

This post got lot of emotional support through statements with human touch such as "I hope you are doing ok", "are you feeling any better now etc". It shows how virtual provides new form of emotional support to the persons with diabetes.

The persons with Diabetes use online communities as a space where their queries

are answered, in the process of fight against the disease and live with the challenges of the disease. The queries seen in an online community like “what brand of sugar can be used by Diabetes” and “can someone recommend an app to track just blood sugar” are an example. Even queries like this, which are more of like seeking information, are responded with words filled with emotional support such as “May God give you relief” etc.

In the case of certain members of this online community, they wish to extend the support available online into offline as well. The following conversation, where the participant wishes to start a local face to face support group of person with diabetes is an example to this.

“Does anyone who is a caretaker or family member, especially us newcomers, feel like they wish there was a local support group for those of us need to learn and vent a little. What a weird and difficult disease this is!”

Reply 1 : “I agree...I would prefer Face-to-face group... that's why I am starting one soon in my area”

Sharing of Personal Experience or Medical Advice - Concerns around Online Communities on Diabetes

One of the major concern around discourse in the online communities on Diabetes is one can't draw a proper distinction between sharing personal experience and medical advice. Often the personal account intermingles with medical advice as the line of the difference between both is thin and can't be drawn easily. Unlike giving a personal account coupled with medical advice in an offline context, giving the same online has lot of differences. Firstly, a personal account online gets larger reach and appreciation in the form of likes and shares if it is well written. Here, the linguistic skills of a person becomes the parameter than his or her authority as a medical practitioner. Secondly, the online discussions are often unmindful to the fact that the body type of a person is key in deciding upon the medicines and diet. However, it is a positive signal that some participants often remind other members of the community about how medicines vary depending upon the body type. However, it is surprising to note that there is little or no presence of medical professionals in the discussions which are taking place online on

medical issues in general and Diabetics in particular.

The following discussion in an online community throws light into how experience sharing online turns out into medical advice.

The one who posted asks “what should one eat during hypo glycemic condition. many times I wake up at 2am -3am with BS level of around 60 . I eat some chapati (Indian roti) bread +peanut butter, or dates etc, but this results in high sugar level of 200-250, when I wake up at 6am.”

Reply 1 “15 grams of carbohydrate in simple sugar form. Glucose tablets work well. For me if I am 60 ish I have a piece of fruit”

Reply 2 “I have tried one or two sugar cubes when that happens to me. Is that okay?”

Reply 3 “Read your package label yes to simple sugar but 15 carbs and wait for your sugar to get above 80, then have a light snack of protein and a little starch and fat to hold it up.”

Reply 4 “For a quick “fix” try 1/4 cup juice that has at least 15 grams sugar. You can also try a carb/protein combo snack before bed.”

Reply 5 “My doctor told me that peanut butter is one of the best things it brings your sugar up and it levels it out try that before you go to bed.”

Reply 6 “consult your Diabetic Doctor, who is the best person to advice you. As you say Roti is made of wheat. Some people do have dates but does no harm, But for some it does not work. Try Jowar roti, which mostly Indians Who have sugar problem eat.

If some food Does not go with your system please Keep it away.That's my doctor's advice to me.We all have different Body system!

Conversation -2

The one who posted asks “can anyone recommend a multivitamin good for Diabetic.”

Reply 1 “Multivitamins are actually not good to people with any health issues. They are low basis use for average people health in need of boost. Multivitamins are made up of vitamins

and minerals which interact between each other.”

Reply 2 “Always best to let the Dr and your blood work guide it”

Reply 3 “That is when you have a doctor open to hear you. How many would be in a "support" group if our doctor were the best only option? After all, if they were as great at doing their job, how is it so many of us end up diabetic?.”

Reply 4 “Disagree. A multi-vitamin with the natural forms of vitamins has done wonders for me. I use Thorne research. Not only did my regular doctor agree but so did a functional medicine doc. I drink tons of water to make sure it all absorbs.

Reply 5 “Don’t play doctor, if you’re not one.”

In an online community to discuss about “diet that would help overcome Diabetes and other life style diseases” people make queries such as “feeling back pain after following this diet/ gained back same few months after had stopped the diet, I am having diarrhea after following this diet”. It is quite clear that any answer to the above questions would constitute as medical advice. However, such questions are answered by the other members of the group who are not medical practitioners just based on their personal experience.

The key point here is people are giving suggestion to the issues of the others based on their personal experience. In the process, the difference in the body type of individuals is ignored which needs to be clearly checked by a medical practitioner. In other words, the mere personal experience of a stranger in the virtual world becomes a substitute to the years of training and knowledge by expert medical practitioner. When personal experience substitute expertise, it puts serious challenges to the public health in general.

Pseudo-science and alternative medicine online

Some online communities on Diabetes show an unprofessional trend of knowledge related to health and medicinal practices, either scientific or not, are shared by lay people with a potential to reach a large audience. Along the lines, the alternative medicines, without

any check on their ability to prove their claims, could be able to reach many takers thanks to the nature of the digital platforms where the circulation of the information is not subjected to scrutiny. The following claim on a social media community is a representative example to this. The claim goes as given below.

“A natural remote healing (patient lived in Dubai) and we were healing patient from India. We may need 6 to 7 months to reduce patient’s excess 20 KGs weight. This patient also now showed significant improvement in her glucose level after losing 3 KGs of weight. We have also to successfully healed obesity (excess fat) and diabetes, cholesterol, Blood pressure, irregular period, etc. using our remote/distant healing methods. If we achieve in this greater milestone, all the people across the world can get a major relief of saying goodbye to visiting hospitals.”

In yet another Facebook post, this group also bring together pseudo- medicine and herbal medicine together in their attempts to reach more takers. Their claims go as given below.

“If you are a person with Diabetes, you can either come out of it using herbal remedies or through our natural energy healing techniques (Reiki, Mexican, Crystal or Melchizedek Healing). If you are a border case of an individual living with Diabetes, then my advice for all of you is to go for herbal remedies. If you have uncontrollable glucose levels despite of taking strong doses of allopathic medicines, herbal remedies may not work. You definitely need to go for energy healing (Reiki or Mexican Healing with this we can energize Pancreas and cleanse your liver and metabolic systems). This is for Type1, Type 3 or Type 2 Insulin dependent patients.”

While this healing technique lack any scientific proof or standard testing method to validate its claims, those who run this community use the testimonials given by the persons with diabetes as a proof to establish the authority of it. The testimonials given by the persons with diabetes are not a universally accepted mechanism to validate a healing method as manipulation can be possible in the same. Whereas, testimonials, either in the visual or text form, have long history as a marketing and promotion tool given its great emotional appeal. However, amidst all these concerns, it is quite shocking to note that there are long list

of people who take appointment with the concerned person of the aforementioned platform. The significant portion of their comments are on the cost of the treatment and process to take appointments. During the interview, a participant said the testimonials given by many other persons with diabetes as a factor which boosted his confidence. The discourse in the above online community shows the large trend of how the discourses online pauses new challenges to the public health in general.

Results of the study

This study finds to many, the online communities on Diabetes provide a great source of emotional support and confidence building in their fight against Diabetes. The online communities on Diabetics provide better diet plans to fight the disease, personal accounts of overcoming Diabetics and comments which give emotional support. It was evident from the responses of many members of the online communities on Diabetes that the encouragement and support play significant role in the case of a life style disease like Diabetics in which behavioral change is key as individuals living with Diabetes needs to take lot of efforts to come out of their condition.

This study also finds two trends coming from online communities on Diabetes which pause challenges to the public health in general. Firstly, in the online communities, one can't draw a proper distinction between sharing personal experience and medical advice. Often the personal account intermingles with medical advice as the line of the difference between both is thin and can't be drawn easily. It is also observed that the online discussions are often unmindful to the fact that the body type of a person is key in deciding upon the medicines and diet. This appears as a first serious challenge to the public health in general paused by online communities on Diabetes.

Secondly, some online communities on Diabetes show an unprecedented trend of knowledge related to health and medicinal practices, either scientific or not, are shared by lay people with a potential to reach a large audience. Along the lines, the alternative medicines, without any check on their ability to prove their claims, could able to reach many takers thanking to the nature of the digital

platforms where the circulation of the information is not subjected to scrutiny. This appears as a second challenge to the public health coming from online communities on Diabetes.

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