

PARTICIPATION IN ONLINE HEALTH COMMUNITIES: DECODING THE ANTECEDENTS AND OUTCOMES

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ABSTRACT

A significant number (49 %) of Indian users tend to rely on digital media to either access health-related information or use the internet as a precursor to visit a doctor [20]. According to a report by Raheja [48], "The Internet of Things" (IoT) connection has the potential to change the malfunctioning medical system into a comprehensive, effective, and individualised system. This will allow for a more proactive approach to wellness and overall health, reducing medical expenses through these inclusive practices. Online health communities in India demonstrate significant clout to transform the healthcare industry by empowering patients. They offer a platform to all key stakeholders, that are, the healthcare professionals, patients and even the caregivers alike, to come forth, share their experiences and develop remedies for various issues faced by the healthcare industry.

This paper examines the antecedents involved in the empowerment of patients in Online Health Communities (OHCs) and the outcomes of this in the form of participant compliance. The research additionally examines the moderating impact of certain factors such as the patients' e-health literacy and health locus of control (HLOC) and the physicians' paternalism, in examining the relationship between patient empowerment and compliance.

The findings of the research propose a construct or a theoretical model for the numerous factors and moderators associated with the patient's participation in online health communities. The social support available to patients leads to more empowered patients, ultimately resulting in higher Patient compliance. Further, this patient empowerment, which comprises of sense of autonomy, competence and self-efficacy makes people more compliant. The theoretical construct between patient empowerment and patient compliance, is further moderated by the patients' e-health literacy and health locus of control (HLOC) and the physicians' paternalism.

KEYWORDS

online health communities, social support, empowerment, compliance, moderators

INTRODUCTION

When individuals are searching for the treatment of health-related issues such as acidity, indigestion, diarrhoea, aches and discomforts or even very particular problems such as shedding pounds, menstrual issues, allergic reactions, nostrils drips, hair loss etc., they tend to first and foremost hunt for any potential remedies or substitutes in their near vicinity. Further, if the medical conditions require certain sort of major or minor surgery, the susceptibility and sentimental stir in the minds of the individuals, may be even higher. This is especially so, when the attitude of the consulting doctor, is nonchalant, less supportive, less empathetic or frank in communicating the diagnosis and treatment with the patient and his family. The frustration with the doctor's ability to fulfil the patients' informative as well as emotional needs, leads to the patients' tendency to look out online and join healthcare communities and rather seek advice from the netizens available online.

The study aims to examine the variables affecting patients' empowerment in Online Health Communities (OHCs). Further, it aims to study whether the empowerment gained by joining OHCs can lead to better compliance by patients. Also, whether patients with varying health locus of control, feel more empowered by participating in online health communities. The paper further proposes that e-health literacy moderates the relationship between patient empowerment and compliance. Chin [7] observed how OHCs have modified the relationship of a doctor and a patient from paternalism to enhanced autonomy. Hence, this research study also aims to examine the moderating role of physicians' paternalism in moderating the association between patient empowerment and compliance.

SOCIAL MEDIA USAGE BY PATIENTS FOR HEALTH-RELATED ISSUES

As stated by Hughes et.al. [23], Health 2.0 can be described as the use of certain online tools (searches, websites, blogs, podcasts, wikis, etc) by various stakeholders in the healthcare system viz. doctors, patients, caregivers and even research scientists. They utilise the open-source information and content shared by users, coupled with the power of networks, and are able to not only personalize health care and also collaborate and promote health education. The "2.0" monitor in Health 2.0 refers to the drastic movement and transition from the traditional static web pages to the contemporary user-generated pages and content; which is dynamic and easy to share. Some of

these comprise blogs, video-sharing sites, social networks, Wikipedia, mashups, hosting services, and web-based software applications.

With easy access to digital technology, patients are able to share health-related information promptly and are in fact way ahead of healthcare professionals. Social media tools, owing to its participative and collaborative nature, are proficient at creating and retrieving information and further sharing it with patients or other health care consumers. Kaplan and Haenlein [24] categorise social media into various kinds viz. blogs, microblogs, multimedia groups, websites for socialising, collaborative projects and simulated universes. Hernandez-Tejada et.al [16] conducted research on the usage of social media in healthcare and observed the following key insights:

- Around 42% consumers use social media to check for patient reviews of doctors, clinics, hospitals and lines of treatment
- The 18-24 age group of consumers, use social media to share health-related information and almost 40% of them claim that this information sharing significantly impacts their health-related decisions.

RESEARCH QUESTIONS

The present paper involves a comprehensive study to explore the relationship between perceived social support in OHCs and patient empowerment. It further checks if higher patient empowerment leads to increased compliance in the form of medication adherence. The paper also proposes the moderating impact of the patients' e-health literacy and HLOC and the physicians' paternalism, in explaining the relationship between patient empowerment and the patients' compliance.

RQ1: Is there a relationship between perceived social support in OHCs and patient empowerment?

RQ2: Does an increase in patient empowerment leads to increased compliance in the form of medication adherence?

RQ3: Do factors such as the patient's e-health literacy, impact the above relationship?

OBJECTIVES OF THE STUDY

1. To look at the aspects that contribute to patient empowerment in OHCs.
2. To examine the connection between patient empowerment in OHCs and patient compliance

3. To investigate the moderating effects of patients' e-health literacy and HLOC, as well as physicians' paternalism, in understanding the link between patient empowerment in OHCs and patient compliance.

METHODOLOGY

A critical and comprehensive analysis was conducted on the expansive literature available on online health communities. A narrative literature review (NLR) was used to achieve this broad objective. The propositions were formed based on an analysis of the body of literature and secondary sources. The following requirements had to be met by the studies in order for them to be considered for the overview:

INCLUSION AND EXCLUSION CRITERIA

Publications that were selected were: Peer-reviewed articles, English-language publications, studies with an interpretive or exploratory design, studies addressing the relationship between social support and empowerment, consideration of empowerment as an independent variable and evaluation of patient compliance as an outcome variable. The search period for this study was for publication between 1/10/2021 and 1/3/2022.

Publications that were excluded were the ones not available in English or the ones mostly about over-the-counter medicines.

SEARCH STRATEGY

An exhaustive list of keywords was identified based on preceding searches and the relevant academic terminologies used. As a result, we first looked into various databases for review articles relating to patient compliance and/or empowerment. Key terms linked to patient compliance or empowerment and related constructs, were combined with one another in the main search. Social support, empowerment, compliance, Online Health Communities - are few of the search terms used. The following Boolean operators were used to connect the keywords: "Social support" AND "Empowerment", "Empowerment" AND "Compliance".

The vetted research outcomes were characterized by the objectives and scope of the research. The empirical findings of all the research papers were categorized by looking at the data and making preliminary notes inductively. After analysing the articles, we framed the

propositions that are being discussed in the following section.

FINDINGS AND DISCUSSION

Wiley, PubMed, Scopus, Springer, Taylor & Francis were the main academic databases used for this research. In Wiley, we found 140 journal articles in English, 150 in PubMed, 110 in Taylor & Francis, 100 in Springer, 100 in Scopus. Papers that were found relevant to the topic, were selected by using a predefined inclusion and exclusion criteria. This was followed by an additional round of screening in which 450 studies were rejected and removed from the combined pool of 600 research studies. In the next step of screening, the titles and abstracts of the examined papers were assessed by both the authors with appropriate knowledge of the conceptual boundaries.

SOCIAL SUPPORT

Albrecht and Adelman [2] define *social support* as "verbal and non-verbal communication between recipients and providers that reduces the uncertainty about the situation, the self, the other, or the relationship, and functions to enhance the perception of personal control in one's experience". Patients that take an interest in their healthcare and are health-conscious frequently employ social media channels to learn from and educate one another about different therapies and ailments. OHCs are a platform where users with common interests, make new friends, upload photos and remain in contact with old pals. Boyd and Ellison [6]. OHCs are going to play an important part as pandemic has impacted the physical and mental well-being of people from all walks of life, be it academia, Kumar et al. [28], healthcare workers Pujari & Kumar [46].

The amount of time people spend in online groups is closely related to their social network usage and improved contentment with the online assistance they receive, delivering more advantages to those with poor self-esteem, life satisfaction, and the number of Facebook friends. Wright [63]. Cohen and Hoberman [8] while researching peer support in healthcare communication have shown a beneficial connection between social support and medical results. Past research [Ellison et al. [10,11]; Valenzuela et al., [57] emphasised that utilising Facebook greatly promotes social capital and individual psychological wellness, and thus has an advantageous connection with perceived support from others and creating less anxiety and elevated fulfilment in life,

particularly in excessively anxious categories. Nabi et al. [37].

Numerous definitions of social support identify three major forms of social support: societal integration, perceived support from others, and performed social assistance. Vangelisti [58]. The perspective on *social embeddedness* focuses on "an individual's connections to others or the available social ties in their social environments". Stokes [55] *Perceived social support* is pertinent to mental or intellectual assessments of positive interactions and can be described as "the social support that people believe is available to them" Procidano & Heller [45]. The third component implemented social help, is defined as the activities that people take while assisting others. Barrera [4]. Shafi et al. [52] indicate that supportive resources have four dimensions viz. sentimental (e.g., nurturance), instructive (e.g., guidance) or relationship (e.g., a feeling of belongingness); observable (e.g., financial assistance) or invisible (e.g., unique guidance).

Emotional social support is a form of interaction that addresses an individual's psychological or affective needs. *Esteem support* is communication that boosts a person's self-confidence or belief in their capacity to solve a problem or complete a goal. Network support refers to the communication and support that confirms people's network membership. Informational social influence is described as one's behaviour of monitoring another person's experience in their social network prior to carrying out a planned action, for instance purchasing an object. Kim & Srivastava [25]; Lee et al. [36].

Shavazi et al. [53] researched few virtual peer support groups for individuals with multiple sclerosis (MS) and discovered that informative social support comprises guidance, recommendations, scenario evaluation, lessons, and expressing intimate knowledge. Compliments, validation, and blame release are examples of esteem social support, whereas network support includes access, presence, companionship, and so on. Finances, straight assignments, secondary duties, readiness to help, and active involvement are examples of material support, whereas emotional support comprises words of encouragement, interactions, compassionate empathy, meditations, confidentially, virtual affection, discussing surviving doctrines and spiritual support.

One of the primary benefits of participating in OHC was identified as psychological support. Kim et al. [26], Rodgers

& Chen [50]. Psychological assistance assists patients in dealing with the burden of living with and combating illnesses. Qiu et al. [47] In comparison to educational support, emotional support encourages patients to stay longer at OHC. Yi-Chia et al. [60]. Companionship, according to Wang et al. [59], is a strong forecaster of users' sustained engagement, although informational assistance is the most commonly requested social support in OHCs.

PATIENT EMPOWERMENT

OHCs such as PatientsLikeMe, WebMD, MedHelp and many others, help patients to share their experiences related to health, extend support to others and engage in meaningful discussion with the experts i.e., the doctors. They also play a crucial role in transforming the age-old relationship of the doctor and the patient from the traditional patient-centred relationship to a contemporary patient-empowered or patient-centred relationship; this phenomenon is known as PERP (*Patient empowerment in the relationship with the Physician*). Patient Empowerment, as defined by the WHO, is "a process through which people gain greater control over decisions and actions affecting their health".

Patient empowerment can be classified into two varieties: the first empowerment emphasizes on the transformation of an individual patient while the second emphasizes on the relationship between doctor and the patient Petric et al. [42].

Patient Empowerment can be defined as the patient's communicative behaviour in connection to his or her physician Zimmerman [66]. Self-efficacy, sense of control, and competency are three characteristics of Patient Empowerment. Self-efficacy refers to a patient's conviction in his or her capacity to achieve goals during a doctor's appointment, as well as awareness of the results desired. In a relationship with a physician, the patient's sense of control denotes the willingness and eagerness and capacity to involve in decision-making and individualised therapies. Finally, competencies refer to the abilities and talents required to have a productive conversation with a medical professional. As a result, PERP is a kind of communicative orientation and behaviour that has the potential to influence the physician-patient relationship. It can lead to a lack of trust between the patient and the physician, the patient being viewed as difficult, the patient turning overly confident, or the patient inciting and acting aggressively toward the healthcare provider.

PERP could have functional or dysfunctional consequences depending upon orientation towards the doctor which could be communicative or strategic. In a strategic orientation, patient is more on the receiving end and is more concerned about his/her benefits and thus aims at fulfilling his/her goals. S/he might not recognize the doctor's interests which further leads to a misleading, insincere and disrespectful relationship with the doctor.

On the contrary, the power originating from open interaction is aimed at realising a settlement. Thus, in a functional PERP scenario, patients exercise self-efficacy, better control and proficiencies while having a conversation with the doctor.

According to Barak et al. [6], OHCs provide informational, emotional and relational supports which further help the patients to have better control over themselves, higher confidence, and personal autonomy and acquaint them with sociable skills to manage their own problems and well-being. Arnold [3] conducted a study on pregnant women and observed that these OHCs help them to exchange knowledge and build empathetic relationships, leading to higher empowerment.

Several other studies have found that OHC users' diverse actions result in Patient Empowerment, which manifests itself in a variety of good outcomes for OHC users: increased self-esteem, self-efficacy, and control and management of one's health problems; improved social well-being and quality of life; more confidence in interactions with doctors; more competent use of health services; and even improved social well-being and quality of life. According to Oh and Lee [40], online community involvement has a good impact on computer-mediated social support, which allows patients to take control of their self-care. The relationship between computer-mediated social support (CMSS) and the intention to actively engage with the doctor was shown to be mediated by the patient's sense of empowerment. User CMSS, according to Pontevia and Menvielle [44], has a good impact on user empowerment and engagement during consultations, which affects user commitment to the physician's relationship.

The social interaction of people can be explained by two main theories: the social exchange theory (SET) and the economic exchange theory (EET). SET places more emphasis on the social-emotional parts of participant relationships, whereas EET places more emphasis on the

material, more monetary aspects of the exchange connection Shore et al. [54]. Individuals must believe their contribution is valuable enough to share with others in order to provide new value. They also anticipate taking advantage of some of that value Pontevia et al. [43].

Hornig [17] investigated those personal variables (viz. satisfaction, generosity, pleasure, confidence, credibility, reward); structural capital (interaction); cognitive capital (tenure); relational capital (reciprocity, identification) are the factors which affect the intention to participate in a virtual community. As a result, it is claimed that-

Proposition 1: Consumers' perceived social support in an online health community (OHC) will be positively associated with their empowerment.

Proposition 2: People seeking emotional and psychological support engage in OHC for a long time as compared to people with informational and esteem support.

PATIENT COMPLIANCE

Compliance by patients refers to the extent patients are following the medication referred by the doctor. Laugesen et al. [29]. It includes adherence to medicines as well as adopting healthy lifestyles Lu et al. [31]. Additionally, patient compliance helps to build a healthy relationship between a doctor and a patient; especially in the case of chronic diseases, where patients' regaining depends on self-administration and self-tracking Horwitz & Horwitz [18]. Tustin [57] has emphasized that compliance by patients can have better effectiveness in their treatment; especially when the diagnosis and treatment prescribed is good. Horwitz & Horwitz [18] further added that patients with high compliance are healthier than those with low levels of compliance. OHCs increase patient empowerment with more information now by their side Petric et al. [42]. Lu and Zhang [33] have also observed that conversations that take place between the doctor and the patient help in better patient compliance.

Empowered patients, bring in better health outcomes Lorig et al. [30], effective use of health services, improved health status Bergsma & Carney [5] and medication adherence Hernandez et al. [16].

Pontevia et al. [43] also investigated the relationship between patient empowerment acquired by means of collaborative online health communities and patient compliance and found that patient empowerment raises

patient compliance with physician-proposed treatment. As a result, it is suggested that-

Proposition 3: High patient empowerment leads to increased patient compliance in the form of increased medication adherence.

The patient's participation on the online platform and use of social media continues to provide several obstacles. The most significant of them is privacy, as some people are unwilling to discuss their health difficulties amenably. Wensing [62]. Other obstacles or zones of worry for patients and physicians while utilising social media include: a lack of refuge for personal information, identity management, inaccurate information, and a large number of people's incapacity to utilise a computer and the internet properly. Househ et al. [19]. However, it may be claimed that these issues will alter for patients with differing levels of e-health literacy, medical paternalism, and health locus of control.

E-HEALTH LITERACY

Norman and Skinner [39] define electronic health or e-health literacy as "the ability to seek, locate, interpret, and utilise health information using electronic resources and use this knowledge to solve health-related problems". It attempts to assist people in making educated healthcare decisions by utilising e-health resources. Norman and Skinner [39] and is seen as a critical tool for enhancing wellness and eliminating fitness disparities Wu et al. [64].

OHC which is a particular sort of digital society makes it possible for "social networking, participation, apo mediation, collaboration, and openness within and between different health-related stakeholders" Eysenbach [13]; Hara & Hew [21]. Healthcare consumers and patients can exchange health knowledge and social support Huang et al. [22] and make online appointments with health professionals Guo et al. [15]. Empowerment was found to have a substantial relationship with improved health among medically literate people. Nafradi et al. [38]. Petric et al. [42] also found that people who find meaning in OHCs and had high e-health literacy were less likely to develop dysfunctional competences and control. High level of patient autonomy should be accompanied by equally high level of health literacy for adherence/compliance to occur Schulz & Nakamoto [51] According to Freeman et al. [14], e-health literacy is crucial in the daily lives of teenagers and can encourage healthy behaviours such as vigorous physical activity and a balanced diet. Lu and Zhang [32] also verified that patients' e-health literacy in OHCs can assist increase their

adherence by directing their communication behaviour with physicians, generating a health information seeking behaviour, and enhancing their assessment of the quality of information in OHCs. As a result, it is claimed that

Proposition 4: People with high e-health literacy will feel more empowered after participating in OHC and will comply more as compared to people with low e-health literacy.

PHYSICIAN'S PATERNALISM

Paternalism is "a pattern of behaviours, by a person or organization, which limits liberty or autonomy of an individual for that person's or group's own good, regardless of the will of the individual". Paternalism i.e. "the medical expertise a doctor has about a disease" and Autonomy i.e. "the personal expertise that a patient has about their own body" are the two ends of a continuum.

The patient loses all autonomy when a doctor practises full paternalism. Patients believe they are unable to make educated judgements about themselves, and as a result, they abdicate all responsibility for their health situation.

The "paternalistic" concept of the physician-patient interaction promotes the "sick role" of patients, especially when individuals and physicians have dramatically different degrees of expertise, experience, and authority in health-related concerns. Emanuel and Emanuel, [12]. Patients who are in a dangerous or unknown medical scenario rely on a trustworthy physician and his/her specialised expertise to guide them care.

OHCs for health issues and health, online communication, health and medical content on the internet, patient portals from providers and employers, data capturing and personal health record systems all give an alternative to the physician-directed paternalistic approach. OHCs empower patients through informed decision-making with varied levels of psychological engagement, in order to present facts (informative), exchange perspectives (deliberative), and extract their opinions (interpretive). Petri and Petrovcic [41] discovered that the physician's perceived paternalism had a moderating effect on the functional components of empowerment while having a considerable influence on the dysfunctional components and control.

Lu and Zhang [33] investigated the impact of physician-patient communication on patient compliance by

mediating perceived quality of online health information, decision-making preference, and physician-patient concordance. They observed that physician-patient conversation in OHCs improves patient compliance. Patient compliance can be enhanced by directing physician-patient contact in OHCs. Physician-patient conversation, according to Roberts et al. [49], can result in patient compliance. Online health information, according to Laugesen et al. [29], can improve physician-patient communication and, as a result, patient compliance. On the basis of the above debate, it is consequently argued that-

Proposition 5: More paternalistic physicians lead to lesser Patient empowerment in OHCs and lesser Patient compliance despite the social support that the patient gets.

HEALTH LOCUS OF CONTROL (HLOC):

HLOC is a concept that internal and external variables impact an individual's health. Devin et al. [9]. When a person believes in external control, he believes that external forces or the power of others dictate life events, but when he believes in internal control, he believes that life events are under his control and that he is accountable for them. Macsinga & Nemeti [34].

Internal locus of control (ILOC) and external locus of control (ELOC) are two types of multidimensional health locus of control (MHLOC). ELOC can further be subdivided into sub-dimensions such as Powerful Others, Doctor, Chance, and God HLOC Wallston et al. [61].

Wulandhari et al. [65] discovered that chance HLOC and adherence have a negative relationship. Ahmedani et al. [1] discovered a link between God's HLOC and medication adherence. The HLOC and adherence to powerful others

were found to have a negative association. People having a high doctor HLOC, according to Theofilou [56], are more likely to stick to their prescribed medical regimen.

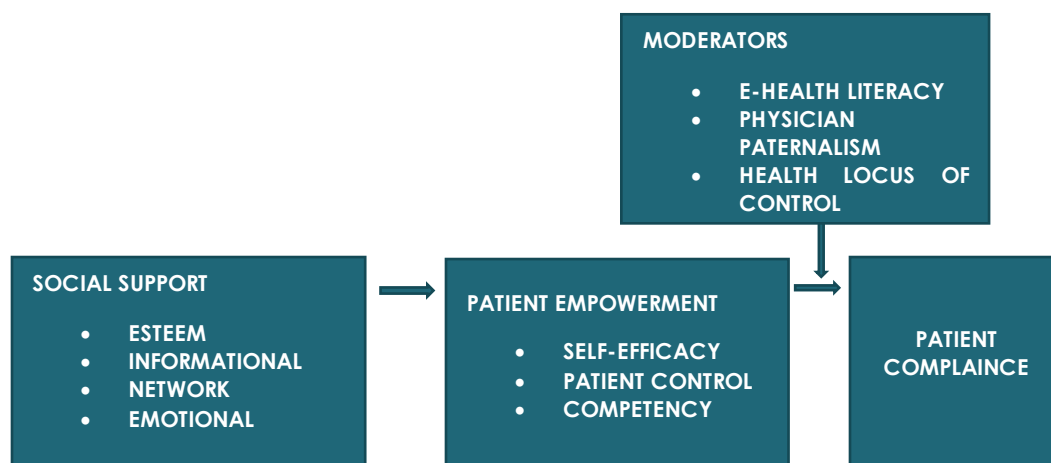
Individuals who think they have extraordinary control over their health (internal control) benefit psychologically and behaviourally. Individual loneliness and impotence, as well as an undesirable struggle against illnesses, would come from disbelief in this issue (external control). The term "internal locus of control" refers to personality traits and characteristics that can assist people in gaining more control over their life. Individuals with an external locus of control have more mental issues than those with an internal locus of control.

Empowerment is an energising aspect that encourages individuals to take control of their health habits and disease treatment is one of the patient-related aspects. Empowerment may be interpreted as an individual choice, referring to the patient's authority and power in the medical setting, or as a relational concept, underlining the existing equality in the physician-patient relationship. Nafradi et al. [38] observed that patients' perceptions of their capacity to control their own health, i.e., ILOC- a component of patient empowerment- were connected to higher drug adherence. As a result, it is argued that-

Proposition 6: People with internal HLOC feel more empowered and comply more as compared to people with external HLOC.

In conclusion, we propose a model for Patient Empowerment and Patient Compliance (Figure 1) for the several variables and facilitators related to the engagement of individuals in online health communities.

FIGURE 1: MODEL OF PATIENT EMPOWERMENT AND PATIENT COMPLIANCE



MANAGERIAL IMPLICATIONS

The outcomes of the present study will benefit medical professionals to develop strategies for providing more emotional and psychological support as compared to informational and esteem support so as to increase participation in OHCs. Medical professionals should incorporate strategies to increase patient e-health literacy as it tantamount to patients feeling more empowered after participating in OHCs.

SOCIAL IMPLICATIONS

The present paper will benefit medical practitioners as medication adherence can be increased when patients feel empowered i.e., they feel that they have the autonomy and competence to improve their well-being. Efforts should be done to improve patients' health as well as digital literacy so that patients can co-create value for themselves too. Online health communities serve as a powerful tool to change patients' HLOC from external to internal.

Health professionals should also strive to reduce their paternalism in OHCs and make efforts to make people realize that their health is an outcome of their internal locus of control.

THEORETICAL IMPLICATIONS AND DIRECTIONS FOR FUTURE RESEARCH

According to the present studies, social support encompasses all types of verbal and nonverbal communication that minimises confusion about the situation. The psychological or cognitive supports, which are available to patients from their social environments, instils confidence and skills in them needed to have a meaningful discussion with physicians, thus, enabling empowered patients. Patient empowerment which comprises of sense of autonomy, competence and self-efficacy make people believe in following compliance i.e. medication adherence which is also in line with the results of Nafradi et al. [38].

Patient e-health literacy relates to a patient's ability to communicate with the outside world and mitigate the harmful impacts of environmental influences. Because proper e-health literacy increases patients' capacity to self-manage their health and interact with clinicians, e-health

literate patients have a stronger sense of autonomy, competence, and self-efficacy. In accordance with the outcomes of Nafradi et al. [39], the present paper also supports that ILOC is positively associated with medication adherence i.e., patient compliance. Patients who feel greater sense of autonomy and competence also believe themselves in control of their own health and thus portray higher medication adherence. Paternalistic attitude of physicians seems to lower patients' self-competence and autonomy, thus lowering patient empowerment and thus leading to a breach of trust in the relationship of physician and patient and hence reduced patient compliance.

This paper has only studied the impact of social support on patient participation and engagement. Future research can study which type of social support viz. informational, network, emotional or esteem, is more important for patients' continued participation in OHCs. The paper has explored the case of OHCs alone. Future studies can investigate the proposed hypotheses in case of mobile health technologies i.e., mobile health apps as well. While the present paper proposes internal and external HLOC, the components of external HLOC have not been discussed in detail. Future research can analyse the moderating impact of external HLOC components (such as chance HLOC, God HLOC, powerful others HLOC and doctor HLOC), in explaining the relation between patient empowerment and patient compliance. Patient's self-esteem also impacts life satisfaction when they join health communities. Kong and You [27]. It would be interesting to see how self-esteem mediates the relationship between social support from online health communities and patient empowerment, in future.

The opposite of participation in OHCs is the trust and privacy factor while sharing personal information in social healthcare communities. Madaan et al. [35] also concluded that participation in IoT devices gets severely impacted due to data breach concerns. Future studies can explore how to tackle data privacy concerns of participants/members of online communities.

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