

**Review Article**

**STIGMA IN THE LIVES OF ASTHMA PATIENTS: A REVIEW FROM THE LITERATURE**

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**ABSTRACT**

The main purpose of this review article is to synthesize the empirical literature on stigma and how stigma affects the lives of asthma patients. Limited search and strong evidence from the asthma management guidelines and news coverage conveying stigmatizing or destigmatizing messages are the provoking factors to write this review. The stigma associated with asthma is one of the important contributing factors for frequent patient anxieties, delayed diagnosis, denial and limited disclosure of being asthmatic, limited physical activity and avoidance of inhaler use in public.

Pubmed (Medline), PsycInfo, Science Direct, Sage Pub and Wiley databases were used to review the work done to date on measuring stigma related to asthma by using the key terms of stigma and asthma combined with stigmatization/stigmatisation, questionnaire and scale. In addition, Google search engine was used to search the national and international guidelines, newspapers and related work done on stigma of asthma that was beyond the scope of publication by research databases. No time limit was used for the year of publication to address the issue of stigma thoroughly and deeply.

In total 452 research articles were identified that addressed different dynamics of stigma by using the combination of a forementioned search keywords. Out of these 39 studies were included in this review addressing specifically the asthma related stigma. From these, four studies aimed to develop the questionnaire for the direct assessment of stigma in asthma patients. These instruments required rigorous validation and reliability assessment in the different population. The stigma of asthma has adverse consequences in the lives of asthma patients. Therefore, a vigorously validated and good reliable instrument is required to understand the dynamics and underlined causes of stigma of asthma in a comprehensive way. The instrument that can reflect and capture the phenomenon of stigma in asthma patients more accurately, may be served for more effective stigma reduction interventions and comparing stigma intensity in diverse populations and communities. Following the review, suggestions were made for future workplace anti-stigma interventions and evaluation for such intervention programs. Furthermore, stigma in the lives of asthma patients is the area for future research and actions for health care professionals and clinical researchers for better asthma management programs.

**Keywords:** Asthma patients, Anxieties, Stigma intensity.

**INTRODUCTION**

Stigma is considered as one of the major obstacles to public health and a barrier to the provision of healthcare services. Health-related stigma affects the life chances of individuals by increasing their vulnerability to risks and limiting access to protective factors that lead to increase in the burden of disease. Measurement levels of stigma are very imperative for guiding policies, designing and evaluating interventions, advocacy works and further implementation of disease management programs [1]. The phenomenon of stigma has been associated with different chronic health conditions that included mental illness, HIV/AIDS, leprosy, epilepsy, tuberculosis, obesity and physical disability [2]. The indescribable sufferings were observed because of stigma and its psychosocial consequences in stigmatized patients [3]. The dynamic phenomenon of stigma in chronic illnesses can be categorized into two categories; one from the perspective of the non-affected person (perceived and enacted stigma) and other from the perspective of the affected person into internalized, perceived, and experienced stigma [4]. The main purpose of this review was to synthesize the empirical literature on stigma experienced by the asthma patients. This review aimed to carefully review and summarize existing knowledge and identify key characteristics of research, which will guide future directions and efforts for better asthma management and control.

Anciently, Greeks first used the word stigma to identify unusual or deprecating signs of one's moral status. They referred stigma as a mark often cut or burned into the flesh of slaves, traitors or criminals for devalued social identity and shameful differences. In 1963, Goffman glossed the term stigma as "a situation of an individual who is disqualified from the full social acceptance" [5]. According to Weiss, Ramakrishna and Somma (2006), the term

stigma also has the religious background. Similarly, the word stigmata was used for the marks that resulted from crucifixion of Jesus Christ and were found very easily on the bodies of saintly persons as a kind of supernatural empathic connection with Christ as a symbol of their devotion. The people with such belief system consider stigmata as a focus of admiration and awe. Medical literature about a century ago described this in terms of pathological markings like petechia or lesions as a sign of particular disease. The zoologist and botanist referred stigma to particular markings on the wings of insects and part of pistil of flowering plant impregnated by pollen [6].

**Theoretical and philosophical background of stigma**

Erving Goffman, a pioneer social science researcher, defined the term stigma as "an attribute that is deeply discrediting" and reducing the bearer "from a whole and usual person to a tainted, discounted one". In his point of view stigma means "a special kind of relationship between an attribute and a stereotype" and the discrepancy between "virtual social identity" (how the society characterizes the person) and "actual social identity" (the attributes really possessed by a person). Likewise, Sontag described stigma as a transition of an individual from the "kingdom of the well" to the "kingdom of the sick" [7]. Jones and coworkers recommended the term "Mark" to describe the deviant condition that might consider the individual as flawed or spoiled in the society [8]. Link and Phelan redefined stigma as a social condition that originates when the elements of labelling, stereotyping, status loss and discrimination exist in a powerful situation that activates them [9]. In the same context, Weiss and Ramakrishna viewed health related stigma as a social process or related personal experiences manifested by exclusion, rejection blame or devaluation as a result of experience or significant anticipation of an adverse social judgment about an

individual or a group of individuals. So health related stigma refers to a 'social disqualification of individuals and populations who are identified with particular health problems' [10]. According to Brakel and colleagues, stigma refers to the feeling of discrimination experienced by the patient that leads to limited social participation [2].

Erving Goffman (1963) had laid down the foundation of contemporary perspectives of stigma. In his classical book titled as "Stigma: Notes on the Management of a Spoiled Identity", a person is said to be stigmatized when his/her single characteristic is used to represent the whole person (stereotyping), and that specific characteristic is devalued by the society or subculture [11]. These stereotypes and evaluations are generally widely shared and well recognized among members of a community, consequently, they become a basis for excluding or avoiding members of the stereotyped category. The groups of individuals are categorized as systemically stigmatized when they share such devalued characteristic e. g. people with dark skin, people having linguistic problems as foreigner in other communities and people with certain religious beliefs as in the case of Arabs during attacks of World Trade Centre September, 2001. There are some attributes that draw a line of separation between normal and stigmatized individuals, in short they are considered as poor partner for social exchange (e. g. a convict), carrier of parasitic infection (e. g. a physical deformity) or as a member of an out-group that can be exploited for in-group gain [12].

Stigma is not only confined to interpersonal process but it is influenced by broader cultural perspective of stereotypes, social values, ideologies and meanings interpreted by that particular characteristic. Stigma is generated and propagated in a series of steps. First of all such individuals are identified and differentiated. Secondly, labelled persons are associated with undesirable characteristics in terms of stereotyping. Thirdly, a distinction line is drawn and grouped into "them" and "us" from the labelling group, followed by, the experience of discrimination and loss of status for those in the labelled group as a fourth step. Finally, there is an exercise of power by the labelling group that leads to stigmatization as the consequence of the whole process [13]. Inequalities between stigmatized and non-stigmatized groups are by no means inevitable and the power differentials inherent in stigma, create substantial obstacles that make the reduction of health disparities especially challenging [14]. The process of stigmatization is pervasive because it serves multiple purposes. People may stigmatize others for certain reasons e. g. to reduce the complexities of understanding them as multifaceted individuals, to feel superior about themselves, to feel better about their groups, to justify their preferential social status, to validate important world views, or to defend the exclusion of people who are seen as a threat to the functioning of a social group [15].

Stigma constructed in literatures mostly identify following main types of stigma: enacted stigma, perceived stigma and internalized stigma. Enacted stigma, also referred as 'experienced stigma' and 'perceived discrimination', is actual discriminatory behaviours (labelling, stereotyping, and discrimination) by other people toward the stigmatized patients [16]. The perceived stigma represents the subjective awareness about stigma. It is an emotional response to the enacted stigma and may result into feelings of solitude and exclusion of the individual from the society [17]. Internalized stigma reflects the degree of agreement of individual with existing social stigma and stereotypes regarding health related condition. It is directly linked to deleterious consequences of low self esteem, reduced self efficacy and loss of motivation for achieving life goals and/or compulsory treatment [18]. Internalized stigma endorsed cultural stereotypes in relation to the particular group of individuals. Furthermore, courtesy stigma is another type of stigma that affects those persons who are in close circle like family members, friends and even the professionals that are closely associated with stigmatized individual [19]. Additionally, a phenomenon of stigma layering originated when patient had two or more stigmatized illnesses at the same time, for instance, People living with HIV and HCV co infection experience multiple layers of stigmatization from both infectious diseases [16].

## Consequences of stigma

Multiple psychological and behavioural processes are strongly disrupted by stigma [14]. Stigmatized individuals are permanently avoided by the other members of the community in which they live and consequently their personal and social well beings are badly affected. Such negative experiences in turn leads to inequalities not only in health care settings but also in educational career and employment opportunities [20]. Stigma, associated with various diseased conditions including HIV, mental illness and sexual preference, is not only disadvantageous to the stigmatized individual but major source of stress in their lives also [21]. Impact of stigma on the lives of people living with chronic illnesses is even more than their physical health itself [22]. Stigma affects the people living with chronic illnesses in variety of social contexts and acts as a barrier for regular health care access that can be critical factor to control symptoms of chronic illness. The chronically ill patients report feeling of shame with guilt, low self esteem, illness related embarrassment and compromised quality of life as an output of being stigmatized [23]. Besides this, stigma also influenced the patients living with chronic diseases in terms of social rejection, loss of employment and poor health care. In addition to this, stigma can be transmitted from the stigmatized individuals to the other members of the family and contaminate them equally. Sometime stigma is considered as a crisis for both; at intra personal and interpersonal level, at an organizational/institutional and at a community/governmental level, or at multiple levels simultaneously [24]. Stigma remained associated with poor mental health, physical disability, reduced an academic accomplishment, infant mortality, low social status, poverty, and limited access to housing, education, and employment [12]. Fears of rejection, negative evaluation and fear of others discovering the stigmatized status, are major obstacles that lead individuals to avoid entering close relationships, this results into social stress and isolation [14].

## Search strategy

As a first step reviewers developed a set of key areas to guide the review. These were grouped according to concept of stigma, its dynamics and main features of health related stigma. The second key component of the review was the degree of stigmatization in asthma patients, its adverse consequences and underlined reasons of stigma origination in asthma patients, development and validation of instruments used to determine the stigma in asthma patients. For sake of research strategy, Pubmed (Medline), PsycInfo, ScienceDirect, SagePub and Wiley databases were used to review the work done to date on measuring stigma related to asthma. The search strategy was divided into two steps according to the aforementioned scope of this review. In first step search was conducted by using the search terms of stigma, health related stigma and stigma in chronic illnesses. In second step titles and abstracts were thoroughly explored for search terms of stigma, asthma, stigmatization/stigmatisation, questionnaire and scale. The Internet was searched for additional data for instance the international reports and publications that were not formally published in scientific journals. Manuscripts published in English language, were selected only. No time limit was used for the year of publication to address the issue thoroughly and deeply. The research articles that used the questionnaire were explored for the psychometric properties also. The complete information of the scale was described as reported in the article or asked by the corresponding authors after contacting by email. In addition to this potentially relevant citations were identified from retrieved articles.

Abstracts were reviewed independently by two researchers (SA and NE). The conclusive decision to include or exclude the abstract was then compared. In case of disagreements, rationale and evidence for the papers were addressed through discussion. In accordance with scoping review principles, and in order to facilitate subsequent identification of yet unknown key issues and arguments within the literature, selection criteria were purposefully broadened. The research articles whose central focus was not asthma were excluded i.e. non empirical papers (e. g. Commentaries, editorials, and discussion pieces). In total 452 research articles were identified that addressed different dynamics of stigma by using the combination of a fore mentioned search keywords. Thirty nine research articles

were identified as relevant to stigma in the lives of asthma patients, full papers were obtained. The review articles identified by these searches allowed us to map the broad issues around which the remainder of this paper is structured. We then used the reviews, alongside key papers cited within them (which we obtained) in order to explore the degree of stigmatization and its bases deeply and thoroughly.

### **Stigma in the lives of asthma patients**

The issue of diversity and perspectives of stigma has been addressed in various chronic illnesses including asthma. It is evident from the literature that stigma is a major concern for individuals living with asthma [25]. The stigma in asthma has caused considerable negative repercussions on social support, patients' daily functioning and quality of life of asthma patients.

Three types of research methods showed the attachment of stigma in asthma patients. These methods included questionnaires (both open and close ended questions), qualitative methods by interviewing the key informants, focus group discussions, participant observations and quantitative instruments that were intended to give a numerical results in terms of severity or extent of the stigmatization degree of asthma. The stigma in asthma patients may affect negatively with the quality of life of countless individuals and effectiveness of many public health programs. Asthma patients never feel comfortable to use asthma medications especially inhaler in public because by this act they feel stigmatized [26].

Asthma is considered as a stigma in the society because of lack of awareness in the community. The social stigma of the asthma is one of the contributing factors to the patient anxieties. The likelihood of being depressed was twice in asthma patients as that of normal individuals. In addition to this, the greater chances of medication non adherence are reported in literature [27]. The parents of asthmatic patients use to deny the status of asthma as disease because of its negative consequences. For instance, they used to deny asthma in their adolescent girls so that they can receive good marriage proposals for their daughters [28]. The community education is the key area to work on. The lack of consistency in the findings on asthma, its prevalence in South Asians and other ethnic communities could be better explained by the greater degree of stigma in group of people with lower literacy level. The underlined barriers related to these facts included the wrong beliefs; for instance, asthma medicines may be more harmful than beneficial and improvement in asthma is more subject to faith and chance than to treatment effectiveness [29].

Asthma awareness in the community is not satisfactory. Lower self-esteem is observed in children living with asthma. The awareness ridden campaigns are required to address this issue of stigma in asthma patients. The stigma is communicable from children to their family members and it can put significant social and psychological strain on the nerves of the growing child. Majority of carers don't want to mention the need of proper technique of inhaler use only because of social stigma attached with inhalers [30]. The higher degree of stigma in asthma patients and lack of confidence in their self management was found to be the triggering factors to use bronchodilator inhalers early in an acute attack. Similarly, John and colleagues observed that the greater extent of panicky and fearful attitude was linked with the excessive use of bronchodilator. The reduction in stigmatization degree may reduce the inhaler use but sometime the prompt use of bronchodilator becomes the desired therapeutic intervention, for instance in acute attacks. This makes the likely benefits questionable. Furthermore, the weak impact of behavior and attitude of asthma patients on self-care, suggested that some other factors also contributing in self-management behavior [31].

### **Stigma and asthma diagnosis**

The diagnosis of asthma is always pivotal for the proper management of asthma from patients' and health care professionals' perspectives. The proper diagnosis of asthma in clinical settings, is always helpful to avoid undue use of potential asthma medications and prevention of unwarranted social stigma of asthma [32]. In

asthma patients, the denial and hiding the diagnosis is very common. The patients' parents also follow the same approach for their children's diagnosed with asthma. In a study conducted by Grover and coworkers, almost half of the parents enrolled in their study reported they preferred to hide the asthma diagnosis of their children from extended family members, friends or the child's teachers due to the stigma of asthma [33]. According to Ungar and his colleagues, the diagnosis of asthma is often denied both by children and their parents so there is a need to anticipate the expectations in these families due to stigmatization [34].

In addition, this denial and hiding of diagnosis follow the same trend in both genders. Women tried to hide their diagnosis of asthma by pretending themselves as being normal and flexible with responsibilities or hiding their condition because of stigma. According to Scherman and co-researchers, both men and women interpreted their asthma symptoms as normal by themselves and pretending themselves as healthy as people without asthma [35]. Velsor-Friedrich and coworkers observed that boys as well as girls recognized the hidden risk of potential stigma and labeling in disclosing their diagnosis to others [36]. The stigma associated with the diagnosis of asthma affected badly the employment and socio-economic standing of the patient. The perception of stigmatization may lead to inappropriate symptom control of asthma especially in public gathering and work place as a result making asthma difficult to manage by health professionals [37]. For instance, in the Asia-Pacific region there are significant cultural challenges following a diagnosis of 'asthma' in children of any age that included community ridden stigma associated with asthma diagnosis that leads to poor understanding of the condition and its management [38].

### **Global perspectives of stigma of asthma**

The international reports on stigma of asthma and frequent reporting from the literature highlighted its worldwide prevalence. In Lebanon and other Middle East countries, to avoid the social stigma of asthma, the terms of chest allergy or recurrent dyspnoea are preferred to mask the chronic nature and functional impairment of the illness [39]. According to one UK based study, Williams and co-researchers (2008) demonstrated about 80% of secondary school students identified that the major limitation of asthma was the inability to participate in sports and as a result of this potent stigma leads to the spoilt identity. It is the risk of significant stigma and labelling because of which both boys and girls never want to be identified as asthmatic [40]. Furthermore, Asian Asthma Patient Coalition (2007) reported and explored the stigma attached with asthma and reluctance in asthma patients to admit that they have asthma (panting). This Coalition included patient group representatives, asthma patients, nurses, social workers and caregivers from Australia, Bangladesh, Hong Kong, Malaysia, Korea, Singapore, Sri Lanka, Taiwan, Thailand and Vietnam. In addition to this there is high degree of denial to asthma and they remained house bound because of stigma of asthma [41]. In 2001, the first Respiratory 'Master-class' meetings for developing countries (DCs) were organized in Malaysia and Kenya. The sessions, run by the GlaxoSmithKline (GSK) Respiratory Centre of Excellence in conjunction with local respiratory societies, brought from each together experts region to share their knowledge and experience in the treatment of asthma. A total of 24 delegates from Bangladesh, Cambodia and Myanmar gathered in Kuala Lumpur for the first Master-class. It was reported that high levels of under treatment and/or under diagnosis in asthma were caused principally by stigma, lack of training and knowledge among healthcare providers compounded by affordability and access issues of health care settings [42]. People with low literacy level feel the greater degree of stigma attached with asthma. Therefore, the findings on prevalence of stigma were inconsistent between South Asia and other ethnic communities [29].

### **Asthma stigma in different age groups**

Stigma of asthma caused hazardous outcomes originated and observed interactively within a cultural and dynamic social circles worldwide [43, 5]. The feelings of stigma varied from age group of the asthma patients. Stigma of asthma is being influenced by social context. Asthmatic children are not aware of the social context of

stigma; hence, their stance on stigma is neither fixed nor summative. The dynamic nuances of people's social interaction on film should be pro-social and responsible [44].

In personal and social lives of the young adults, asthma had some serious implications. A qualitative study conducted by Cole and his colleagues, reported highly prevalent stigma; respondents shared their feelings on being 'excluded from team activities, football and things like that', and 'just wanting to be like the rest and not to have to stop and put this thing in my mouth'. Some patients considered being asthmatic as embarrassing experience and regarded inhalers as something 'to hide in a bag'. Furthermore, the daily life restrictions faced by young adults included difficulties in dancing, embarrassment on using a bronchodilator during sexual intercourse, inability to stay over at friends if they forgot to take their bronchodilator with them and avoidance of wearing tight, fashionable clothes that could restrict the breathing [45]. Kolbe and his colleagues observed that stigmatization may lead to inappropriate symptom control especially at the workplace and in public. Kolbe remained indecisive on underlying asthma severity or influence of stigmatization as more subtle [37]. The social stigma of being "sickly" or "weak," negatively affected the asthma patients either directly i.e. avoiding asthma medication in public, or subtly i.e. perpetuating an attitude of despair and cynicism [46].

Sometime placing individuals into "them" categories is responsible for beginning of stereotypes or simplification of the group. For instance, the use of word "them" for "asthmatic children" might increase the degree of stigmatization to higher level. That in turn may lead to further embracement and more chances to lose control on management of the illness [47]. Another commonly used term that is responsible for the stigma origination is "afflicted children" such terms are usually linked with certain marks. These marks are recognizable cues used to identify and affected individual from the group. For example, a "constant mucous flow" is used as a mark to identify asthma patients, found to be the responsible factor that increases the feelings of discrimination. In addition to this some attributions of asthma that included perceptions about individuals that they chose themselves to be a part of the stigmatized group, hence it is their problem to solve by themselves. On larger scale this might lead to group labeling that promotes separation phenomenon between "us" and "them", between "we" and "they", causing greater social distances between the stigmatized group and remaining population [47].

### Impact of stigma on asthma patients

According to Global Asthma Report (2014), symptoms of asthma especially breathlessness is responsible for fear, emotional and psychological suffering of the patients living with asthma. The stigma attached with asthma is one of the major barriers as it can delay health seeking and case detection, decrease the adherence to long-term asthma management. The stigma associated with asthma usually accompanied by certain thought processes. These processes in turn hinder everyday social life. In some cases people reported reluctance to marry a person with asthma to avoid passing the disease on to future offspring. Some asthma patients always try to avoid to use inhaler in public gatherings also [48].

The stigmatization degree of asthma has different harmful impacts self-management of asthma as it directly affects self-efficacy, and the barriers it places on patients' access to health care and social relationships. The unfortunate implications of stigma, are increased morbidity and a reduced quality of life. People were living with asthma experience poorer quality of life, more psychological problems and worse social functioning than those without asthma [49].

Asthma had disrupted and restricted patients' lives and aspirations in terms of moving to specific schools, altering the employment opportunities and even sometimes the formidable chosen carrier [45]. Study conducted by Gupta and his colleagues (2011) observed that the majority of patients (especially illiterate people, females and rural subjects) avoid to use an inhaler in the public places and preferred to use small sized inhalers and in the single dose. Besides this, they possessed the feeling that inhalers are to be used in serious illnesses and for the rest of life [50]. Hazir and his coworkers

reported that stigma of asthma being communicable may put a considerable amount of social and psychological strain on the growing child, who may develop a low self-esteem resulting in his inability to play his full role in the community as an adult [30].

Asthma control and self-management of asthma are badly influenced by degree of stigmatization [25]. The stigmatization of asthma affects negatively on employment and socio-economic standing of the patient. Furthermore, high stigmatization degree may lead to inappropriate symptom control of asthma especially in the public gathering and work place [37].

Stigma was considered as one of the major obstacle for good health and poses a great risk to the asthma sufferers. The experience of being stigmatized could cause refusal to seek treatment, medication noncompliance, unemployment and social rejection [51]. Low self-esteem feelings of guilt or ashamed, work area discrimination and social isolation may be the consequence of internalized stigma of the illness [52]. The fear of asthma attach in turn increased patients' anxieties that included, worry over performance at the workplace or school environment, social stigma attached with asthma and fear related to medication usage. The depression was prevalent by two folds in asthma patients than the normal population. In addition, the chances of being non-adherent were three times more in depressed patients [27]. Asthma sufferers often face detrimental effects of stigma in terms non-adherence to the treatment [53]. The young adults take a dangerous approach to manage their asthma because of the high cost of medication, stigmatization and poor acceptance of their condition [54]. The underlined reason for this approach may be the social stigma of being "sickly" or "weak," negatively affected the asthma patients either directly i.e. avoiding asthma medication in public, or subtly i.e. perpetuating an attitude of despair and cynicism [46]. In one news report of Jennifer, stigma and shame attached to the asthma patients especially in their young people. While interviewing, a young patient reported that because of stigma patients feel embarrassed when they are not being able to participate, being left behind and being different than the rest of healthy society. The Stigma attached with asthma had some similarities to the stigma attached to depression [55].

### Interventions to reduce stigma of asthma

The role of media in the provision of education to the public is always pivotal to reduce the stigma of asthma in asthma patients. Without proper education of the public, asthma can be a scary and stigmatized illness to asthmatics. Hence, an accurate portrayal and framing of asthma in the media is very important to deal with the stigma, fear, challenge, and management concerning asthma care [47].

For health professionals, to understand the feelings of patients stigmatization especially in the children always found helpful to understand, educate and provide better care to them. Children have their own views about the disease etiology, treatment compliance, and strategies for coping with their condition that is totally different as that of adult asthma patients [56]. In adulthood, the feelings of stigma of asthma and subsequently normalizing strategies usually perpetuate indicating the need for change in public awareness, asthma familiarity for better asthma control and management [57]. The harmful effects of stigma can be buffered by the support of people from patient's close circle i.e. Friends and family members, especially when they consider asthma ordinarily and help to patients as normal as possible [44]. Stigma is among the six famous themes in the work of Cole and his colleagues. The five remaining themes were comprised of an impact of asthma, coping, explanatory models, rationalization of inhaler use and costs [45].

The stigma of asthma can be reduced by anticipating the expectations of patients and their families. Asthma related stigma produced fears of using sprays, long term treatment, disabilities and drug dependence. Stigma is also responsible for the under diagnosis of asthma, hence launching effective educational programs and campaigns are compulsory to address this issue particularly [58]. In order to avoid the undue use of toxic asthma medications and prevent the social stigmatization among asthmatics, proper diagnosis of asthma in clinical practice is very necessary [32]. Group

education showed better results in terms of offering support and reducing feelings of solitude and stigmatization than that of individual education, is a well established fact through comprehensive studies conducted in USA, Germany and Australia [59]. According to Sawyer and Aroni (2003), "The Adolescent Asthma Action (Triple A) Project" decreased the feelings of stigma by improving asthma knowledge and attitude of the young students by the involvement of peer educators from the school community. This concept encouraged the asthmatic students to take better steps to improve asthma management and as a result of this, student leaves due to asthma were decreased significantly [60].

The language that can originate stigmatization degree has been divided into few stigma cues. A high proportion i.e. 28% of total asthma articles used at least one asthma cue. The most common among these was "them" language, such as "The problem for asthmatics." [61]. Such cues of asthma stigma caused the isolation of asthmatics from the general population and a source of discouragement [62].

Chadwick and his colleagues conducted a UK based study and found that about 80% of enrolled secondary school pupils reported that the inability to participate in sport was the worst thing about having asthma and regarded this as a highly potent source of stigmatization that may lead to the spoilt identity [63].

#### **Instruments used for stigma of asthma**

Four potential studies were identified from the searched data in which attempts were made to either report or develop the questionnaire to determine the degree of stigmatization in asthma patients. Beginning with the early writings, Snadden and Brown (1991) established that asthma has psychological components and among these components stigma and self-confidence are significantly correlated with asthma morbidity. Snadden identified issues such as non disclosure, self-blame, and embarrassment over medication use in public [64].

First attempt was made by Sibbald and coworkers and Snadden and Belle Brown. They examined the experience of stigma in asthma patients. For today, their work had two major limitations for today that included; their work was quite outdated i.e. Conducted two decades ago and secondly, they considered stigma as a part of belief of the patients rather than a single comprehensive phenomenon. But they identified some particular issues such as non disclosure, self-blame, and embarrassment over medication use in public among asthma patients. Recently, according to findings from one European study, 22.5% (230 of 1022) of participants expressed feelings of stigma experienced while taking asthma medication in public giving a clue that little has changed on this aspect of asthma-related stigma.

Recently, Andrew and her coworkers adopted the questionnaire on self-stigma that was used in Mental Illness. After making slight adjustments and establishing reliability and validity, found that the majority from the respondents i.e. n= 33(51 %) encountered low stigma because of asthma. 9 (14%) respondents reported feeling no stigma. Only Moderate degree of stigma was reported by 14 respondents (21%). High degree of stigma was found in 9 (14%) patients. The questionnaire totally consisted of 19 questions that were sub categorized into three scales of disclosure, discrimination and positive aspects

Similarly, an instrument was developed, underwent psychometric evaluation and linguistic validation by Sohail and co-researchers in Malaysia. They vigorously tested the instrument for its reliability and validity by modern test theory using Rasch Model (Bond and Fox®) and one month test-retest reliability. In addition instrument was validated for content, face and construct validity. The questionnaire was adopted and adapted from King *et al.* work but few adjustments was made by keeping in mind the cultural contexts of Malaysia. The questionnaire assessed the degree of stigma in asthmatic adults by using 22 items of the Stigma Scale for Mental Health (originally 28 items: 5 items were omitted due to the specific relevance to mental health and 1 item was omitted as that was perceived to be repetitious) adapted [65]. There are 3 subscales (factors) to address the complexity of stigma, namely: (a) disclosure

by the patient about asthma (total = 8 items; item number 3, 8, 10, 11, 12, 19, 20, 22); (b) discrimination felt by the patient due to asthma (total = 10 items; item number 1, 5, 7, 9, 13, 14, 15, 16, 17, 21); and (c) perceived positive aspects of being asthmatic (total = 4 items; item number 2, 4, 6, 18). 152 patients were recruited in this study. The unique additional characteristics of this study were that the correlations, associations and relationships of stigma with patients' knowledge, self-esteem and socio-demographic data vigorously explored in their study [25].

#### **CONCLUSION**

The dynamics and underlined causes of stigma of asthma in a comprehensive way can be understood by the development of a vigorously validated and good reliable instrument. The development of the instrument is the assurance of more accurately reflected and captured the phenomenon of stigma in asthma patients. This in turn may be served for more effective stigma reduction interventions and comparing stigma intensity in diverse populations and communities. Additionally, it would help to make adjustments in the health care settings and society for a better control of asthma and stigma as a whole.

Stigma reduction initiatives should be introduced to target individuals living with asthma in the health care system as well as in the society. This will in turn lead to improve social support, course of illness, and quality of life. The literature from many countries over several decades shows a clear pattern of stigma association with asthma and its negative impact on management of asthma across different populations. The reduction in stigma of asthma holds great hope as a means of improving asthma control, social report and management of asthma. Hence, it is strongly suggested in the light of this review of stigma in asthma to develop effective, multidimensional stigma reduction initiatives from health care system as well as society point of view. In these initiatives, the experiences and impacts of stigmatization degree of asthma should be taken into consideration while taking initiatives to improve patients' stigma and provide concrete productive solutions for asthma patients, their families, general public and healthcare system.

#### **Directions for future research**

Both health care professionals and researchers observed the stigma in adult asthma patients either patients felt internally or encountered actually. The exact underlined mechanism of emergence of stigma in asthma patients is still not known. Given the literature provided, stigma may be considered as a process moving from the public to the individual levels of self and family [66, 9]. Thus, it is important to develop scales to measure each of these types of stigma. This will allow researchers to examine the associations between different types of stigma and learn about the impact of stigma on individuals and families, something that the available scales permit only partially and incompletely. The findings of this review suggested the need of additional qualitative as well as quantitative research in a group of asthma patients and also preferable to incorporate one scale for their family members also. Previously the literature grouped stigma as a part of patients' attitude, beliefs or behaviours but now these concepts are outdated and no longer relevant in the present day. In addition to this the recently developed questionnaire suggests the emerging interest in this area but further validation procedures need to be applied i.e. face validation, content validation, construct validation and reliability assessments. Hence, to start with, at first stage a proper instrument that can measure the degree of asthma patients should be constructed in order to identify stereotypes specific to asthma patients. As a result, these stereotypes can be helpful to identify the stages of proposed self stigma model because of asthma [67]. Furthermore, more emphasis should be put actual experiences of stigma of asthma for patients as well as their families, perceived public stigma and self-endorsement of (self-stigma about) oneself or one's family member. These aforementioned suggestions will allow researchers to parse out the relationship between these factors to establish and measure different aspects in the broader picture of stigma in asthma patients.

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**CONFLICT OF INTERESTS**

Declared None

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