LIFESTYLE DISEASES AND WOMEN: A SOCIOLOGICAL STUDY OF JAMMU

Ph.D. THESIS

by

SWATI SHARMA

DEPARTMENT OF HUMANITIES AND SOCIAL SCIENCES
INDIAN INSTITUTE OF TECHNOLOGY ROORKEE
ROORKEE- 247667 (INDIA)
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STUDENT'S DECLARATION

I hereby certify that the work presented in the thesis entitled "**Lifestyle Diseases and Women: A Sociological Study of Jammu**" is my own work carried out during a period from March, 2015 to January, 2020 under the supervision of Dr. Anindya Jayanta Mishra, Associate Professor, Department of Humanities and Social Sciences, Indian Institute of Technology Roorkee, Roorkee.

The matter presented in this thesis has not been submitted by me for the award of any other degree of this or any other Institution.

Dated: **(Swati Sharma)**

SUPERVISOR'S DECLARATION

This is to certify that the above-mentioned work is carried out under my supervision.

Dated: **(Anindya Jayanta Mishra)**

The Ph.D. Viva-Voce Examination of **Swati Sharma**, Research Scholar, has been held on ……

Chairman, SRC **Signature of External Examiner**

This is to certify that the student has made all the corrections in the thesis.

Signature of Supervisor **Head of the Department**

Abstract

Lifestyle related diseases often referred to as Non-Communicable Diseases (NCDs) which are chronic in nature. For the purpose of this study, term 'lifestyle disease' has been selected as this study centers around the behavioural practices of the respondents who have been interviewed. Main objectives which are dealt with in the study are to analyzing the social impact of lifestyle diseases on the lives of the respondents, to study their role as a family caretaker and as a care provider of the family, role of environmental factors and health seeking behavior of the respondents. Mixed method technique has been employed, in which qualitative data, collected by interviewing female patients suffering from PCOS, T2DM (Type2 Diabetes Mellitus) and CVDs, is tabulated to gain in-depth understanding of the experiences and approach of the respondents towards these diseases. Study intends to apply theoretical framework of the sick role, social constructivism and stigma to examine these diseases.

Stigmatising nature of PCOS respondents to abstain from discussing about it openly even with their family members. It is because of not being 'female' enough that women get subjected to stigma in the society, which reaffirms their feeling of being incomplete. Knowledge construction and health seeking behaviour was also found to be taking place at familial level where onset of symptoms in one member made other member to timely opt for doctoral consultation. Conversations and exchange of knowledge by discussing personal experiences acted as main source of knowledge construction and dissemination in case of different manifestations of PCOS (oligomenorrhea, infertility etc.). However, absence of one single term to define their state was also a cause of distress which requires some special efforts to educate and disseminate biomedical information about the onset and management of PCOS. It can finally be argued that challenges posed by PCOS are more social in nature than physical.

Diabetic patients said that there was nothing much to worry about it as diabetes was all about abstaining from one's favourite food or experiencing excessive urination or parching of mouth. Sick role acquisition in the case of diabetic women was very poor, and that was mainly due to the meaning which they and their family members provided to it. Their lived experiences generated a common discourse which postulated that diabetes does not need any special care or attention. However, such meanings keep on changing with the change in the experience and future consequences of the disease. In the case of women who are the primary caretaker of the family, process of this change of meaning is even slower as they keep on prioritising need of

their family over their own health. It is due to this reason that they tend to act what Parsons (1975) called 'Hyperchondriac.' The semantics generated during the course of doctor-patient discussions had a strong impression on the knowledge production related to diabetes and its management. This shows that discourse leads to knowledge production, and provides patients and their fiduciary with the power to choose their own course of treatment. This meaning may or may not be in line with the medically approved method of diabetes care.

Study of women suffering from CVDs was analysed majorly by employing Foucauldian concept of 'Technologies of Self', in which he emphasises on the role of lifestyle factors in the management of a disease. However, before opting for these technologies, women look upon themselves as socially undesirable. It is only due to the meaning which these women have given to themselves, they follow all the instructions given by their doctor diligently so that they could make themselves socially desirable and get rid of the image of being a burden for the family. Role of *fiduciaries* was also found to be very crucial in the management of the lifestyle of a CVD patient in general and women in particular. Fiduciaries, whether they are family, friends, doctors or relatives, create an institutional pressure on the patient to acquire sick role. Many respondents in the study admitted opting for workout or to eat as per their health requirement, only after certain kind of familial pressure. This is how social institutions act as agents of social control in the field of health by recognising undesirability of an ill state and then by motivating ill persons to work towards regaining or managing their health.

In the end, it can be argued that management of lifestyle diseases is more of a social compulsion than being a physiological need for these women. Age of the onset of lifestyle diseases has a major role to play in determining social impact of the disease. If an adolescent or a young woman gets affected by any such kind of disease, it becomes a stigma for her. Another determinant of a lifestyle disease and patients' (or of their fiduciaries') approach towards it, gets reflected in the way it is being represented in everyday discourse.

Keywords: Lifestyle Diseases, Women, Disease and Illness, PCOS, Diabetes, CVDs, Social Constructivism, Sick Role, Stigma

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(Swati Sharma)

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LIST OF ABBREVIATIONS

Abbreviations	Full Name
AIIMS	All India Institute of Medical Sciences
AMI	Acute Myocardial Infraction
ASSOCHAM	Associated Chamber of Commerce and Industry
BMI	Body Mass Index
CCU	Coronary Care Unit
CVD	Cardiovascular Disease
DALY	Disability Adjusted Life Years
GMC	Government Medical College
GNM	General Nursing and Midwifery
HIC	High Income Countries
IEC	Institute Ethics Committee
IGT	Impaired Glucose Tolerance
J&K	Jammu and Kashmir
LLMIC	Low and Middle Income Countries
NCD	Non-Communicable Disease
NHP	National Health Policy
NSSO	National Sample Survey Office
OPD	Out Patient Department
PCOS	Polycystic Ovary Syndrome
SMGSH	Sri Maharaja Gulab Singh Hospital
SPSS	Statistical Package for Social Sciences
SSH	Super Specialty Hospital
T1DM	Type 1 Diabetes Mellitus

T2DM	Type 2 Diabetes Mellitus
WHO	World Health Organisation
YLD	Years Lived with Disability
YLL	Years of Life Lost

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Introduction

Lifestyle related diseases are often referred to as Non-Communicable Diseases (NCDs) which are chronic in nature. The term 'NCD' is avoided sometimes in order to escape negative connotation associated with the group of diseases. Some thinkers argue that term 'lifestyle disease' is also not a very suitable option as some infectious diseases also result due to lifestyle factors. And it also shows that people have an option to choose behaviour which can easily be altered depending upon their personal will (Ackland and Choi 2005). For the purpose of this study, term 'lifestyle disease' has been selected as it centres around the behavioural practices of the respondents who have been interviewed. At some places, terms 'chronic' and 'NCD' have also been used interchangeably, depending upon the literature available and the terminology used in those studies. However, 'lifestyle disease', 'chronic disease' and 'NCD' have the same meaning throughout this thesis.

Lifestyle diseases more commonly known as Non-Communicable Diseases (NCDs) mainly result due to three factors, namely, modifiable risk factors, non-modifiable risk factors and metabolic factors. Modifiable risk factors mainly include eating habits, consumption of tobacco, consumption of liquor and physical inactivity. Non-modifiable risk factors are factors such as age, genetic predisposition, gender and race. Metabolic risk factors are raised blood pressure, overweight/obesity, hyperglycemia and hyperlipidemia (WHO 2018d; Manning, Senekal, and Harbron 2016). Of these three factors, modifiable risk factors can be taken care of by human beings themselves and can be managed at their own will. This is why, these factors are most commonly known as 'lifestyle factors.' Modifiable risk factors are key determinants of metabolic factors and are most important in the manifestation of NCDs (Khuwaja et al. 2011; Arena et al. 2015; WHO 2019a). This is the reason that NCDs are also known as lifestyle diseases. According to WHO (2019b), onset of lifestyle diseases is not only a health issue but a developmental and socio-economic issue as well. It incurs loss of productivity, loss of income, increase in household expenditure, incessant spending on lifelong medical care, etc. These consequences add a huge burden to the national as well as household expenditure (Dans et al. 2011). The worst affected are Lower and Lower Middle Income Countries (LLMIC). Link and Phelan (1995) argued that it is necessary to understand the factors that increases their susceptibility to risk factors associated with the onset of a lifestyle disease. It, more or less, depends on the socioeconomic status and social support of

an individual.

According to World Health Organisation (WHO) NCDs are the leading cause of deaths in the world. Of all the deaths accounted during a year, around 70% people experience loss of their lives due to NCDs. Around 15 million people in the age group of 30 to 69 years die because of NCD and more than 80% of these deaths are experienced by Lower and Lower Middle-Income Countries (LLMIC) (WHO 2018a). Dalal (2015) argued that chronic diseases are those diseases which are long-lasting and often last for an entire lifetime. Some thinkers opine that there is difference between chronic illness and chronic diseases. Sociologically, illness is perceived as a subjective interpretation of the unfavourable physical state of body. So, it doesn't matter even if a person is diseased, s/he is ill only when society accepts her/him so (Fitzpatrick 1982). Casell (Dalal 2015) distinguishes between chronic disease and chronic illness. He stated that chronic disease is the disturbance of the structure and function of the body; chronic illness on the other hand is the 'disturbance in the person's extended system.' Lifestyle diseases primarily result due to environmental changes and their onset is insidious. In a developing country like India, such diseases are even more pernicious due to already existing infectious diseases, issues of maternal mortality, high morbidity rates, etc. Imitation of western lifestyle has resulted in the onset of these diseases in tropical countries and thus such diseases are also known as Western diseases. Technological advancement, change in eating habits, sedentary lifestyle, disturbance of biological clock, pollution, etc. are some of the most commonly recognised causes of the increased vulnerability towards lifestyle diseases (Sharma and Majumdar 2009). Thus, there is a dire need to bring changes in our lifestyle habits so that the threat of, now fatal, lifestyle diseases can be checked.

Another aspect of lifestyle diseases, which is studied not only by sociologists and anthropologists but by clinicians as well, is the prevalence of social inequalities which is equally responsible for the onset of lifestyle diseases. Heath (2012) analysed biological causes in the backdrop of existing social inequalities and found that 'structural violence' is highly responsible for the onset of lifestyle diseases. Structural violence justifies existing inequalities in the society and holds people responsible for their confrontation with lifestyle diseases. Hence, lifestyle diseases are not only the disease of affluent. Deprived and marginalised sections of the society are also equally susceptible to it. According to Bennett (2014), Indian share is around two-third in the total number of deaths occurring due to NCDs in the entire South-East Asian region. The contribution of top four NCDs viz. cardiovascular diseases, cancer, chronic respiratory diseases and diabetes remains 45%, 22%, 12% and 2% respectively. As per an estimation by the United Nations, these diseases are going to cost

Indian economy whopping INR 6.2 trillion during 2012-2030 (Organization and Habitat 2016). Prevalence of obesity and overweight experienced sharp increase of 22% between 2010 and 2014. Every fourth adult (18 years and above) in India now is suffering from hypertension and two-third of Indian adolescents (age between 11-17 years), as per WHO criteria, are physically inactive (Bennett 2014).

1. Review of Literature

Disease and Illness

There was a time when diseases and illnesses were viewed only within the purview of medicine. However, after World War-II importance of social factors in the onset of any disease or illness came to be recognized by the society (Hollingshead 1973). In Sociology, terms disease and illness are defined separately. According to Fitzpatrick (1982), illness is defined by society with respect to its own socially available meanings. Disease on the other hand is the state of a pathological abnormality and is explicated by means of physical symptoms. People define health as 'absence of illness' and illness is the subjective interpretation of their physical being.

Twaddle (1974) analysed health and illness from status and role point of view. He argued that sociological explanation of health entails deviance, conformity and social role. Hence, illness is labelled as a deviant behaviour and health as a confirming behaviour. However, perfect health is considered as a state which optimises one's role performance. It is therefore related to *well roles* which are labelled in the society depending upon health needs of the individuals. For example, a minor strain in the back may not affect the working of an executive whereas it will be incapacitating in the case of a person involved in the loading and unloading of a truck. Twaddle, therefore, defined health status as an interaction of the status definers with an individual.

Dingwall (1976) studied health from culture of poverty and social construction of illness approach. After going through the literature, he found that superiority of one economic group over another is displayed in terms of their access to various institutions existing in the society. For example, working class people are considered to be inferior to bourgeoisies and this is displayed in the latter's better accessibility to social institutions like health care facilities in the society. In social construction of illness approach, Dingwall mainly studied Eliot Freidson, who on the lines of Parsons, called illness a deviation. Freidson was of the view that illness is constructed socially and people rely on their cultural exposure to provide meaning and names to their physical pains and illnesses. Due to the absence of work on medical sociology by classical thinkers, Dingwall suggested that studies in this field should be done by employing

ethnomethodological approach so that researcher can easily understand how and why society govern health issues and determines health seeking behaviour of the people.

Turner (2000) provided a relativistic view of medical reality and discusses changing patterns of medicine in the Western societies. He argued that medical sociology has often embraced social constructivism to define health and illness patterns. The explanation and perception towards a particular disease is influenced by the socio-cultural patterns of a society, however its clinical descriptions remain unchanged across ages and places. He cited example of Ilza Veith who stated that description of mumps as given by Hippocrates remained same over so many years across continents whereas the way it was looked upon in the society has changed across different cultures and time period. He further explained that social constructivism in medicine does not imply that an entity is a work of fiction. In a clinical setting, how medical entities are explained is always the result of the socio-cultural exposure. Socio-cultural exposure enables medical practitioners to communicate effectively with the patients.

Armstrong (2000) stated that social theories of health and illness grew under the *shadow of bio- medicine,* and that is why first contribution of social theorising of health was to support bio- medical model of health. Identification of illness, assessment of the consequences of illness and the discovery of the causes of illness were the initial contributions of the social theorising which clearly supported bio-medical model. However, main effects of illness which are ignored by bio-medicine are the psychological threats and social labelling of the ill person. Social theory of health challenged the dominance of medical model of health for the first time in 1957 when Robert Strauss came up with the concepts of *Sociology of Medicine* and *Sociology in Medicine.* Concept of social construction of illness, as propounded by Eliott Freidson, however, added one more dimension to social experiences of illness. He argued that illnesses are basically socially constructed and hence, bio-medical explanation of every illness is an irrelevant idea.

According to Lupton (2000) social construction in the field of health is influenced by Foucauldian ideas of knowledge, power and discourse. Medicalisation of illness experiences is due to existing power structure in the field of health. Language of bio-medicine which consists of neutralising vocabulary, its pragmatic and syntax convey a meaning which reflects dominance of bio-medicine in the field of health. However, existing societal parameters also categorise human body into ‘civilised’ and ‘grotesque’ body. These parameters are reflected in terms like ‘body image’ which is dynamic and is subject to change throughout one’s life.

Charmaz (2000) emphasised on the need to study personal experiences of the patients

suffering from chronic illness in narrative style which can be useful in formulating health policy, initiating health reforms and to initiate more research and development in the field of health. She was of the view that current model of health care isolates sufferings of patients suffering from chronic illnesses and individualises their experiences. It is due to this reason these patients experience biographical disruption and stigma. These patients opt for a specific disease management regimen in which they first try to learn what their illness is; then they try to normalise that illness and finally they opt for some coping strategies to manage their disease. So, basically it is the social experience of the illness which make them an isolated being.

A. K. Dalal and Ray (2005) argued that concentrating health within the domain of biomedical model is to explain health within a very narrow domain. Hence, it is very essential to provide a holistic view on health which consists of social, economic and political life of the people. Socio-economic backwardness makes a person highly susceptible to various diseases and this is the reason that women and children are the most vulnerable groups. Environmental factors, and migration and displacement also contribute to the increase in susceptibility towards various infectious diseases. Similarly, every society always had its own health care practices which cater to the health needs of the people. By and large, these practices are studied by social scientists under sick role behaviour and social construction of illness, which shows that personal biases and cultural background also determine attitude of people towards health.

Sharma (2009) emphasised on looking at health from *People's perspectives* which should broadly be consisted of tribal perspective, women's perspective, minority perspective, alternative medicine, corporate perspective and health workers' perspective. Biomedical model looks at health only from health care planners and providers' view. Health seekers' point of view should also be taken into consideration in health studies. It is necessary to understand beliefs and practices towards health seeking behaviour of the masses. It is also essential to comprehend background of the traditional health providers.

Nagla (2018) emphasised that health is a dynamic concept which keeps on changing. Physicians compartmentalise health as a residual category of the 'absence of disease'. However, broader definition of health adds many dimensions to the bio-medical model and gradually a holistic view of studying health came up which is an integration of bio-medical, ecological and psychosocial concepts. Health is a subjective entity for which every individual, community and society has its own definition. Hence, a broader definition of health consists of physical, mental, social, intellectual, emotional, spiritual and vocational dimensions. These

dimensions are adopted by the United Nations keeping in view the prospectus of Global Health; and thus, elaborate the scope of health which is adopted by the World Health Organisation (WHO). According to WHO, health consists of physical, mental, social and spiritual dimensions. Therefore, illness is a social entity and disease is a pathological state.

Biomedical explanation of the disease does not take illness into consideration and therefore neglect the influence of social factors in the onset and management of the disease. That is why sociologists emphasise on using the lens of social constructivism to explore socio-cultural factors which are kept hidden by the biomedical model of disease. Haddad (1989) who examined the role of women as health seekers and health providers in the Middle East found that medicalization of health has made women a prime victim. This is due to the fact that women are the major health seekers and medicalization has side lined the fact that many issues can easily be taken care of just by providing basic necessities like clean drinking water, adequate food and sanitation. The biggest beneficiaries of this medicalization are pharmaceutical companies because of which women are provided with a 'gunshot' prescription full of expensive medicines, even for minor ailments. Keeping all these facts in view, theoretical approaches of sick role and social constructivism have been applied in the present study to explore impact of lifestyle diseases from a socio-cultural perspective. Application of these theories has been elaborated in the section on theoretical framework.

Lifestyle

The origin of term lifestyle is accredited to psychiatrist Alfred Adler. For Adler, lifestyle is a sum total of 'values, passions, knowledge, meaningful deeds and eccentricities' which constitute entire physical and social makeup of an individual (Hudson 2018). In sociology, it was Max Weber who introduced the concept of lifestyle with respect to the concept of rationality in the society. He talked of 'status group' in the sense that a particular type of lifestyle is followed by those belonging to a particular economic class. He used three different terms in German to elucidate the concept of lifestyle- *Lebensstil* or *Stilisierung des Lebens* meaning lifestyles; *Lebensfuhrung* meaning life conduct; and *Lebenschancen* meaning life chances. Life conduct and life chances contribute as components of lifestyle. This idea of lifestyle by Weber was employed by Cokerham to analyse health lifestyles of the people. By health lifestyle he meant various steps which people took up in order to prevent illness and other behaviours which could affect their health badly (Cokerham et al. 1993). Before discussing health lifestyle and lifestyle diseases, it is necessary to understand what lifestyle in

the context of health is.

Dever (1976) identified lifestyle factors as self-created risks which are primarily divided into: leisure activity risks; consumption patterns; and employment participation and occupational risks. These factors are more or less controlled by the individuals themselves. Horley et al. (1988) reviewed various types of lifestyles given by Adlerian and non-Adlerian thinkers and conducted two studies on urban Canadian societies by using personal projects methodology. In first study, they identified pressured, relaxed and wishful thinking lifestyles whereas in the second study they identified four types of lifestyles namely hedonistic, adventuristic, individualistic and promethean lifestyles indicating high subjective wellbeing.

According to Bliss (2007), lifestyle was a picture of the consumption set and preferences of a particular society e.g. Bohemian lifestyle which was characterised by a "happy-go-lucky" life, western lifestyle by consumerism, industrial society by strict work discipline, etc. Social change is marked by changes in lifestyle which he called 'switches of lifestyle'. These switches can be self-initiated or forceful. He called forceful switch of lifestyle as lifestyle breakdown. But no matter whether it is lifestyle breakdown or intentional switch of lifestyle, both are initiated towards betterment of society and self. So, if we analyse lifestyle in the light of Bliss' philosophy then the transformation of society is nothing but change in lifestyle. Weber's theory of *Protestant Ethics and the Spirit of Capitalism* embodies occurrence of similar change in the society which led to the rise of capitalism in West thereby setting stage for the rise of industrial revolution and bringing change in the 'consumption set' of the people there.

This idea is further supported by Bogenhold (2001) as he held the view that lifestyle research is very important for studying vertical stratification system. He provided us with an insight of the material and cultural pattern of the social stratification system. Quoting Joseph A. Schumpeter, *"...the development of capitalist lifestyles can easily and perhaps most impressively be described with the genesis of modern suits,"* Bogenhold concluded that 'levels of distribution' in the society which determine socio-economic status of an individual can be studied only under sociology of lifestyles.

Abdel-Hadi (2012) called lifestyle a way of living which is reflected in the attitudes, values and world view. It includes voluntary as well as involuntary factors that determine and shape one's lifestyle. Involuntary factors are usually determined by social environment which makes an individual to take up a particular style of living. For example, technology available makes it a compulsion for masses to update themselves with everyday introduced technical

necessities. Consumption pattern is believed to be the cornerstone of modern-day lifestyle construction. However, it may also include views on politics, religion, health or any other aspect of the society.

Since literature shows that lifestyle is the emblem of one's subjective wellbeing and consumption set, therefore, whether it's Thorstein Veblen's 'conspicuous consumption' or Pierre Bourdieu's 'class reproduction' or George Simmel's 'style of life' (Bogenhold 2001), all are the manifestations of a particular lifestyle and the change it is undergoing. The result of this change in consumption set of people and the consequential change in the living pattern has made people lethargic and habitual of ultra-comfortable and exertion free life which makes body nothing but a store house of diseases and such diseases are known as lifestyle diseases.

Women and Lifestyle Diseases

Women, the world over, enjoy better mortality rate as compared to men (Lane and Cibula 2002). This fact has a biological as well as social explanation. Biological explanation says that female sex hormones provide a protective shield against heart diseases which are the leading cause of fatality due to NCDs worldwide (Barry and Yuill 2012). Socio-cultural explanation of the difference in mortality rates is that men are over-indulged in risk taking activities like cigarette smoking, driving, adventure sports, etc. Moreover, women tend to be more expressive and defensive towards themselves and their family members, and thus visit physicians more and tend to seek consultation even for minor diseases (Barry and Yuill 2012).

Ross and Bird (1994) observed that differences in labour activities and lifestyle are the main causes behind marginalization of women in the field of health. This study was based on the observation that as women grow older, they tend to fall more ill as compared to men. Social and economic insecurity of the women and their less indulgence in the physical workout make them vulnerable to more diseases as compared to men. So even though women have longer life span but we cannot say that it is healthier as well. Oyejide et al. (1996) studied changing trends in the illness pattern of the women for ten years in a state of United Arab Emirates and finds that 83% of the deaths were due to NCDs. The study concluded that higher incident of mortality due to NCDs was attributed to the change in lifestyle and improvement in diagnostic facilities. Mozaffarian et al. (2011) in a longitudinal study in the United States found that changing lifestyle (in the form of eating habits) is directly associated with weight gain amongst females and males. It has been observed that consumption of foods rich in carbohydrates and fats was directly associated with weight gains in future whereas

consumption of low calorie food like fruit and vegetable was inversely proportional to the weight gain in future. Problem of over- weight and obesity was found to be more amongst women as compared to men.

Dhak and Mutharayappa (2009) studied mortality and morbidity patterns of Indian population and found that except for early childhood, women experience high morbidity rates throughout their lives whereas prevalence of life-threatening diseases and vulnerability to accidents was high amongst their male counterparts. According to a survey conducted by Associated Chamber of Commerce and Industry (ASSOCHAM) in 2009, more than 68 percent of working women in the age-group of 21-52 years were found to be suffering from lifestyle diseases. Most prevalent diseases were obesity, depression, chronic backache, diabetes and hypertension. It was also observed that around 75% women were suffering from anxiety and depression (IANS 2009).

Bonita and Beaglehole (2014) argued that world discourse on women's health remained limited to their reproductive health where as two in every three deaths in women result due to NCDs. Apart from exclusive focus on women's reproductive health which restricted worldview on women's health, they identified few other myths which denied special attention being paid to women regarding NCDs. First, NCDs especially cardiovascular diseases considered as the diseases of men. Secondly, NCDs amongst women were prevalent only in high income countries whereas most NCD deaths in women occurred in LLMIC. Finally, NCDs were considered as the disease of the elderly people, hence there was a tendency to pay less attention to it, considering the fact that one has to die of one or another disease in the old age. WHO has agreed to a global goal of reducing NCDs by 25% by 2025 (25 by 25). Hence, women's health need special attention since they are the potential victims of lifestyle related NCDs in near future.

According to World Development Report in 1993, except for India and China, women all over the world experienced longer life than men (World Bank 1993). However, recent World Bank data shows that now women in India also experience improved mortality rate over men (World Bank 2015; World Bank 2015b). These figures are an indicator of the improvement in health status of women in India over past few decades. However, a woman in a high-income country is still expected to survive 24 years more than a woman in a low-income country (Data 2018).

As per the categorisation of the World Bank, India falls in the category of lower-middle income country (World Bank 2018). Despite above mentioned noticeable changes in the health status of women in India, a lot more still has to be done in order to ensure a decrease in their morbidity rate which is higher than men. As a matter of fact, morbidity rate of women all over the world remains higher than men. According to NSSO data (Ghosh and Arokiasamy 2009), over all morbidity rate increased from 54 to 91 persons per 1000 of the population during the period 1995-96 to 2004; and female morbidity rate increased from 56 to 97 per thousand females whereas morbidity rate for males increased from 52 to 56 per one thousand men during above mentioned time period. For developed states of India such as Punjab, Kerala and West Bengal, morbidity rate is found to be much higher than the rates reported in the poor states of the country like Bihar and Rajasthan. Demographers argue that this variation in morbidity rates may be due to the difference in self- reporting of the disease which is an important indicator of the heath seeking behaviour of population. Factors like literacy rate and socio-economic background are determining factors in the self-reporting of the disease.

In Indian setup, variation in mortality and morbidity rate is also due to gender disparity. In many parts of the country, female child is still given ill treatment. Lack of proper diet and absence of health-related knowledge make these women vulnerable to many chronic and infectious diseases which makes it very difficult for the women to survive. Women are suffering from various lifestyle disorders like Polycystic Ovary Syndrome (PCOS), mental illness, hypertension, breast cancer, cardiovascular diseases, Diabetes, anxiety, depression, etc. During infancy and childhood, biological benefit of long life for females is overridden by socio-cultural factors which prefer males over females as children, thereby increasing vulnerability of females towards chronic diseases (AbouZahr 2014). During adolescence, lack of care and development of faulty lifestyle and eating habits make them susceptible to diseases like osteoarthritis, diabetes, etc. in young age. It has also been observed that lack of physical activity amongst girls is very high as compared to boys. Reproductive years in the life of a woman are found to be very crucial. Since men have higher mortality rate than women hence ailments of old age are found to be affecting women more than that of men. It is not only diseases but disabilities of the old age as well which affect women equally as do other illnesses (Barry and Yuill 2012).

PCOS is commonly known as disease of urban areas and is mainly found to affect those with faulty lifestyle. Eleftheriadou et al. (2012) in a study of teenage girls observed that healthy

teenagers (not suffering from PCOS) were far more indulged in physical activities as compared to those with PCOS. It was also observed that average time spent in sedentary activities like watching television, working on internet, etc. was more than required which acted as a catalyst in already existing conditions for PCOS. Pathak and Nichter (2015) observed that structural vulnerabilities in the urban Indian setup make women more prone to PCOS. These women were expected to be efficient in multi-tasking thus playing dual role of a bread earner and that of an unpaid family care taker. In addition to genetic and known lifestyle factors, exposure to personal care products (like deodorants, perfumes, hair dyes, etc.) and intake of Bisphenol A (BPA) were other major contributors to this disease. However, Bharathi et al. (2017) found in a comparative analysis of PCOS in rural and urban areas that of the total sample size, 8.34% females knew about PCOS in rural areas whereas 90.24% girls knew about PCOS in urban areas. Hence, a hypothesis can be drawn that self-reported case of PCOS is very less in rural areas due to which it is believed that that the negligible proportion of rural women is suffering from PCOS.

Nidhi et al., (2011) found in their study of adolescents suffering from PCOS, that India experiences relatively high instances of PCOS as compared to other Asian countries. This may be due to the fact that India has a very high population suffering from diabetes which is expected to increase even more in future. PCOS and diabetes share a symbiotic relation with each other, hence India represents higher instance of PCOS. Another important observation of the study was that adolescents in Asian region experience extremely high prevalence of oligo/amenorrhea than other regions. In Indian set up, embarrassment associated with the discussion of menstruation makes it even more difficult for the girls to openly discuss this disease (Zangeneh et al. 2012). Kissling (1996) talked about the euphemism which girls use to discuss about their monthly cycles, thereby giving rise to a taboo which is associated with the open discussion about menstruation. Psychological distress was another consequence of PCOS which made women develop negative self-image due to resultant physical appearance which included onset of obesity, hirsutism, male patterned hair fall, acne, etc. (Zangeneh et al. 2012). These studies led to the conclusion that there exists a negative relation between PCOS and age of finding a partner. Therefore, women tend to suffer lesser distress when age of marriage is lower.

Amongst other diseases, study by Hillier (Barry and Yuill 2012) found out that cancer of breast, cervix and uterus were the most leading causes of deaths amongst women in England. Kuper et al. (2007) tried to find out association of job strain and risk of breast cancer and found that

there was a weak association between the two. They concluded that there was no direct association between the two. However, there is possibility that stress may force women to take up such lifestyle activities that act as catalyst in the onset of breast cancer. An instance of this can be the percentage of deaths due to breast cancer in India which is very high, rising from 0.2% to 166% during the years 1990 to 2013 (Sharma 2015). Doctors at All India Institute of Medical Sciences (AIIMS), New Delhi observed that breast cancer is striking young women increasingly and has replaced cervical cancer as leading cause of deaths due to cancer amongst women. In New Delhi, rise in the number of cancer patients is mainly due to hereditary factors, tobacco consumption and faulty lifestyle. Sedentary lifestyle, unhealthy eating and bad sexual habits are the biggest contributors in the rise of cancer patients after tobacco consumption (Perappadan 2015).

Another lifestyle disease which is a huge threat and is amongst one of the four deadliest lifestyle diseases according to WHO is diabetes. According to Harikrishnan (2012), Diabetes was not a gender specific disease. However, in Indian set up it turned out to be a female specific disease. Case study of Southern Kerala showed that women seldom compromise their role of family care taker and hence give least priority to their health. It was also observed that lifestyle of women over past few decades has undergone sea change and as far as housewives were concerned, their lifestyle was even more sedentary. Thus, their vulnerability to this disease was two-fold and their role as care taker of the family further aggravates their problem. Around 60 percent of diabetic cases in India have never been diagnosed due to financial constraints. In a study conducted by Bajaj et al. (2013) on South Asian women with diabetes, various peculiar consequences have been analysed which were being faced by South Asian women only. Young women with diabetes face stigma and fail to get a suitable match for marriage. Worldwide in 2010, over 2.1 million women died of diabetes as compared to 1.8 million men. South Asian women experience relatively shorter life span than those in Western countries and this was mainly due to the fact that females in South Asian region experience social and cultural biases which result in their poor access to health care facilities. Sometimes, rural women with diabetes are subjected to family rejection and may have to experience divorce. Poverty and lack of knowledge has further implications on detection and management of disease. Ignorance resulted in delaying medical consultation, which further increases cost of disease management. Moreover, diabetic health care involves team effort of a doctor, dietitian, educator and diabetes nurse. However, lack of economic resources make it difficult to have entire team available for taking care of a diabetic patient.

Osman and Curzio (2012) argued that it was very important to understand cultural beliefs of South Asians while studying their behaviour towards diabetes as many people tend to attribute onset of diabetes to their fate. Therefore, religious leaders might be of immense help in promoting healthy lifestyles and transferring education necessary for diabetes management. In a study conducted by Ramachandran et al. (2006), it was found that progression of IGT (Impaired Glucose Tolerance) into diabetes could be checked by lifestyle interventions. In their study, they found that this progression rate was very high amongst Asian Indians as compared to Finnish, Americans and Chinese people. Though Indians were lean and had low Body Mass Index (BMI); and this lower BMI necessitated prescription of lower amounts of required drugs, yet their susceptibility towards onset of diabetes was found to be very high. In another study, Ramachandran et al. (2008) studied prevalence of diabetes in southern India and found that there was a significant increase in the prevalence of diabetes in urban and peri-urban areas. Study also concluded that urbanisation in India was expected to reach 46% by 2030, therefore rural areas were expected to make maximum contribution to the diabetic population of India. They observed a rapid conversion of IGT into diabetes, which is an indicator of sharp rise in the number of diabetic patients in India in near future.

Cardiovascular Diseases (CVDs) is an umbrella term for various heart related diseases and is found to be the leading cause of premature deaths worldwide by WHO. More than 80% of these casualties coming from LLMIC (WHO 2018a). Proportion of these deaths is almost equal in men and women. Absence of primary healthcare programmes meant to counter threat of CVDs and lesser access to effective and equitable healthcare services are the main reasons behind late detection of CVDs in these countries. Onset of CVDs also contribute to the onset of vicious circle of poverty in which a person spends all her/his earnings on the treatment of these ailments and these ailments further make that person unsuitable to take up any job (WHO 2017). Gupta (2013) analysed existing literature on women and CVDs in India and found that the range of hypertension awareness is 20 to 60 percent in India with rural women possessing least awareness and urban men forming highly aware population. Blood pressure control status was found to be about 10 percent in rural areas and around 20 percent in urban areas with less than 25 percent hypertensive patients being treated in rural areas and 50 percent in urban areas.

Mehta et al. (2016) in their study of the American women with CVDs found that it was not limited only up to men, and women were equally suffering from it. In fact, mortality rate of women was found to be higher than that of men from 1984 to 2000. Since 2000, mortality rate of women due to CVDs experienced a significant decline on account of the application of

evidence-based therapies and education to improve awareness level of the medical communities and masses regarding occurrence of CVDs amongst women. It has also been observed that the guidelines for the treatment of Acute Myocardial Infraction (AMI) are same for women as for men whereas bleeding risks and further complications are found to be very high for women as compared to men. Chow and Patel (2012) observed that CVDs healthcare provision for women and CVDs outcomes in India were lacking. Women were underrepresented in CVDs related researches and little available data shows that gender disparity exists in the CVDs management with worst affected females are from poor socio-economic and education background. It is more likely that women from higher socio-economic background are more vulnerable to CVDs. However, those from lower socio-cultural background are not lagging behind on this account.

Patriarchal values also play a crucial role in determining health status of women in India. Stroope (2015) analysed gendered practices in India and their impact on the rise and control of hypertension. Research revealed that women living an isolated life tend to be more hypertensive than men, may be due to social and sexual insecurities. Men, however, in such families are found to be healthy as it is believed that women in such families are submissive which help men in reinforcing their patriarchy. As far as decision making power is concerned, it was observed that women's health improve when they are given right to make their own decisions. In case of men no substantial change was observed with respect to decision making power. Therefore, it was concluded that any act of women which was a threat to the power structure of men, tend to make them hypertensive. However, social elevation of women which was not threatening to the social status of men, did not have any adverse effect on the health of men.

Impact of lifestyle diseases is manifested not only in the form of deteriorating health conditions but also in the form of social and economic burden. Engelgau et al. (2012) studied economic impact of non-communicable diseases on Indian household and found that in 2004, on an average, 40-50 percent of the per capita income was spent on seeking health care facilities. Main findings of the study emphasised on the impoverishing nature and resulting catastrophic spending due to these diseases. Thus, out of pocket expenditure was very high for lifestyle diseases thereby making it very difficult for lower income groups of our country to manage these diseases. When sufferers are most vulnerable section of the society i.e. women then management of lifestyle diseases is even more difficult.

2. Gaps in Literature

Studies are available on the factors associated with lifestyle diseases. However, research on the impact of lifestyle diseases from sociological point of view is a seldom explored area. High systolic blood pressure and high body mass index are the risk factors for disability adjusted life years (DALY) which are found to be higher in women than men in India (Dandona et al. 2017). The India State Level Disease Burden initiative study shows that in the state of Jammu and Kashmir (J&K) in 2016, CVDs remained highest contributor in the overall mortality rate in the age-group of 15 years and above. Overall disease burden of NCDs was found to be 61.3% for the same year; and DALY remained highest for NCDs (Swaminathan, Dandona, and Murray 2017). Metabolic risk factors such as BMI, hypertension, total cholesterol level, etc. which are the major contributors of lifestyle diseases, witnessed an increase in their prevalence rate. In 2016, years lived with disability (YLD) due to diabetes was found to be higher in men as compared to women whereas, years of life lost (YLL) due to diabetes was higher in women as compared to men in J&K (Swaminathan, Dandona, and Murray 2017). According to WHO (2018b), one DALY can be considered as one lost year of "healthy" life; YLL measure the incident stream of lost years of life due to deaths and YLD is the years lived by people with the health condition or its consequences.

Despite the fact that women in LLMIC have life expectancy 24 years lesser than their Western counterparts, NCDs and women is a less explored area in Indian sociology. How social constructivism paves way to the rise in number of female patients suffering from lifestyle diseases needs an attention because social nature of knowledge and the way it leads to the constitution of reality are pivotal in social constructivism in sociology, in general, and in sociology of health and illness, in particular. These social realities reproduce meanings and knowledge by means of socialisation and social interaction; and relies on shared meanings of the social events (Lupton 2000). Similarly, doctors and patients also rely on shared meanings of disease and illness; and use socially produced meanings to exchange views regarding illness. Concept of universal taxonomy does not hold good anymore and medical practitioners also rely on socially produced metaphors to interact with their patients and to explain disease management regimen to them (Turner 2000). Since, Union Territory of Jammu and Kashmir (J&K) is also reeling under the threat of harmful consequences of the lifestyle diseases and no data are available on the impact of lifestyle diseases on women there, hence, winter capital of the erstwhile J&K state, Jammu, was chosen to conduct the current study. It is expected that

by looking into socio-cultural pattern of the women in Jammu region, their lifestyle factors would be analysed which plays key role in the disease management regimen of the women.

3. Rationale of the Study

As mentioned in the literature reviewed, lifestyle diseases pose an extremely threatening situation in a middle-income country like India which is facing epidemiological transition as well. Hilly regions are often believed to have an active lifestyle and thus they are expected to experience low rate of lifestyle diseases. Jammu is in the foothill of the Himalayas and consists of hilly regions as well as plains (Jamwal 2013). Being winter capital of the erstwhile state and present union territory, flow of patients from nearby districts remains very high in Jammu. Since data were collected in 2016-17, when J&K was still a state, therefore, description of the study area is given as it existed in the erstwhile state. As per the figures of the India State- Level Disease Burden Initiative study, NCDs are on rise in J&K and situation needs an immediate check (Swaminathan, Dandona, and Murray 2017). PCOS, Type 2 Diabetes Mellitus (T2DM) and CVDs have been selected to undertake this study on lifestyle diseases, keeping in view the fact that these three diseases are associated with each-other. PCOS has a symbiotic relation with T2DM, and onset of PCOS increases susceptibility of the onset of T2DM by seven times (Wang et al. 2011). Picture of direct association of PCOS and CVDs is unclear, however onset of T2DM is directly associated with the onset of CVDs (Grundy et al. 1999). Reason of selecting T2DM and not any other type of diabetes for the study, is that T2DM primarily results due to lifestyle factors such as obesity (especially central), consumption of foods rich in saturated fatty acids, physical inactivity. etc. (Uusitupa 2002).

Form biomedical perspective, illness hampers biological functioning of an individual; and disease (pathology) is the only reason for that; whereas from a social perspective, it leads to a role conflict in the life of a patient (Wade and Halligan 2004). When patient is a female who is the ultimate care taker of the family and disease is chronic in nature, which cannot be cured but only be managed, then it necessitates an altogether different discourse which this study aims at generating. In addition to this, feeling of stigma associated with the early onset of a chronic disease, and the processes specific to female biology as in the case of PCOS, are some of the female centric consequences of lifestyle diseases which needs an exclusive research. The current study aims at analysing everyday discourse of the patients which leads to their own construction of the disease. These constructions have a long-term impact on their disease management regimen.

4. Objectives of the Study

In this study, I tried to bring out the socio-cultural characters of the lifestyle diseases by employing constructivist approach on Women in Jammu city. It aims at bringing out the sociological understanding of the lifestyle factors in the onset and management of lifestyle diseases. A thorough review of literature and identified gaps in the existing literature lead to following objectives of the study:

1. To study impact of the diseases on the lifestyle of the respondents
2. To study role of the environmental factors in the onset and management of disease
3. To study their role as family caretaker v/s patient of a chronic lifestyle disease
4. To study health seeking behaviour of the respondents

7. Theoretical Framework

Sick Role

Talcott Parsons talked of sick role in his book 'The Social System' (Parsons 1991), first published in 1951, and attempted to explain the bearing which therapeutic agencies have on deviance and social control, thereby helping in the maintenance of the social system. He called health a functional pre-requisite of the social system which makes it dysfunctional to have higher incidents of illness in the society. Illness makes an individual unsuitable for the biological and social adjustments, and medical practice is a 'mechanism' which helps these individuals to deal with illnesses. Role of a medical practitioner has patterns which include achievement values, functional specificity, affective neutrality, universality and collective orientation. This patterning shows that the person in discussion has all the required technical competence and skill to offer treatment and medication to the person in need of it. Role of the medical practitioner being a technical expert in the field of health exists with respect to the role of a person who is 'sick' and is in need of his/her medical expertise. Sick Role entails four main elements which are necessary for an individual to be worthy of acquiring sick role. These elements are the rights and duties which are bestowed upon a sick person in order to ensure his/her speedy recovery. Firstly, a sick person should be exempted from everyday 'social role responsibilities.' Secondly, sick person should be provided assistance in changing his/her state from being ill to getting back to the normal state. Thirdly, sick person should be willing to 'get well', to relinquish sick role so that s/he should be able to perform social role responsibilities. Finally, sick role can only be relinquished by seeking technical expertise in the form of a

physician, who provides biggest assistance in getting rid of the sick role behaviour. Thus, sick role is specific, particularistic and affectively neutral. However, a patient in need of medical assistance does not stop with the consultation of one physician only.

S/he may, what Parsons called 'shop around' and seek consultation from other doctors as well. Thus, doctor-patient relationship is governed around different patterns which involves the situation from the patient's point of view and physician's point of view. Patient and his/her family members face helplessness and hence, they need help. They are in need of this help because they are technically incompetent and are emotionally involved. This need for a technically competent person makes them opt for a 'physician,' as Parsons used the term for a doctor. Selection of a physician is usually on the recommendation of a family person, a friend or some relative. This brings in a situation for a physician which involves a role performance and to live up to the expectations of the patient and his/her family members.

A Physician is expected to help patient in complete recovery, in minimum possible time and in a less painful way. During this entire process, physician might have to examine the patient or might need information about the patient which involves some very personal examination or intimate information. Hence, physicians develop their own ways to handle situations which involve breaching of socially approved ways of touching or talking. Similarly, changing social structure brings in changes which are dealt with by the physician by adapting her/himself to those changes. Parsons concluded that sick role is an ideal typical situation which focuses on the doctor-patient relationship and the process by which physician render her/his technical expertise to the needy (patient).

Sick Role was criticised on various grounds and it was argued that it is unsuitable for chronic illnesses. Parsons addressed to these criticisms in a paper which he presented in 1974 at the World Congress of Sociology held in Toronto. This paper was later on published in 1975 under the title "Sick Role and the Role of Physician Reconsidered" (Parsons 1975). He began his presentation by addressing different issues which form the ground of the criticism of sick role. It was argued during the Congress by various presenters that sick role is unsuitable for chronic illnesses. The doctor-patient relationship which Parsons talked of, emphasised on the role of physician as a person of extreme importance and patient on the other hand is a passive receptor of the instructions which are provided by the physician. Parsons addressed to the issue of chronic illnesses by proposing that such patients can acquire partial sick role in the sense that chronic illnesses like diabetes are not curable but manageable. Hence, a diabetic patient can manage her/his disease by adhering to a regimen which is recommended by the physician.

Therefore, a diabetic patient can perform her/his everyday expected role performance and at the same time manages the disease. It has further been explained that illness as a deviance is defined with respect to the social control which forms an integral part of the social system. Illness as a concept, on the other hand, is associated with adaptation to the prescribed regimen (in case of chronic illnesses).

Another aspect, which is of immense importance in sick role, is of symmetry and asymmetry between patient and therapeutic agencies. Some patients tend to act 'Hyperchondriac' i.e., they refuse to accept the fact that they are suffering from some kind of illness which makes it really difficult for a doctor to control illness of the patient especially when s/he is suffering from some chronic illness. For example, in the case of a diabetic patient, if the patient refuses to accept the fact that s/he has to keep a check on her/his eating habits in order to keep blood sugar level under control, then the doctor is extremely helpless in providing such patient with best possible treatment. Hence, more responsibility lies with the patient in order to manage diabetes. Similarly, reliance is more on the medicine prescribed by the doctor in the case of an infectious disease whereas for a chronic lifestyle disease, patient has to make management of the disease as a part of her/his everyday routine. Therefore, it is very important that family members of the patient also contribute towards management of the chronic illness and share 'fiduciary responsibility' with the physician. Parsons borrowed concept of 'fiduciary responsibility' from law where a person, who is believed to be capable of and trustworthy, is provided with the assets to be taken care of. In the field of health, a doctor is a fiduciary who is considered to be responsible for restoring the health of a patient. Since, management of a lifestyle disease is more a responsibility of the patient than the doctor, hence family and friends can also 'motivate' the patient to work towards managing the disease. Doctors in an institutionalised setting perform non-therapeutic functions as well, for example they may have to perform the role of a researcher, a dean or any other administrative role which makes it impossible for them to look after patients suffering from chronic illnesses. Therefore, it is necessary that close kin of the patient take up the responsibility of assisting patient in the management of the illness.

Sick Role entails various dimensions of the doctor-patient relationship which are very important in studying social impact of lifestyle diseases. Present study attempts to incorporate these dimensions, to understand how a doctor uses socio-economic and cultural background of the patients to deal with a patient. So, whether it is state of being 'hyperchondriac' or understanding asymmetry of the doctor-patient relationship or acquisition of the fiduciary responsibility, all these dimensions are found to be a direct or indirect result of social

constructivism. The concept of social construction of illness was given by Eliot Freidson and he relied heavily on the onset of illness as a social deviance as explained by Parsons.

Social Construction of Illness

Freidson in his book "Profession of Medicine: A Study of the Sociology of Applied Knowledge" mentioned that illness is constructed socially (Freidson 1970). He begun with illness as a form of deviance which is constructed professionally by the medical practitioners and in a common sensical way by the masses. He stated that medicalisation of the illness legitimises whether a person is sick or not. Biological deviance otherwise known as disease is sanctioned through the social process of diagnosis and treatment which are peculiar to human beings only. Had it been some biological process then other living beings would also have experienced it.

Albeit sociological studies of health revolve around the medicalisation of illness yet it is not a very feasible option to do so due to various reasons. First, because medicine as a process changes from time to time and place to place. Hence, its temporal nature necessitates that concepts of health and illness should be studied in the wider perspective of the society. Second, field of medicine covers varied classes of diseases which provides heterogeneity to it and widens its scope of discussion. Third, the unique feature of sociology is to deal with social causation, instead of medical causation and consequences of the illness. This is the reason that different societies have different interpretation for the onset of diseases.

A state of illness may be acknowledged as a disease in one society and the patient may be provided with a suitable treatment to cure it. In another society, on the other hand, patient may be refused to be considered sick and hence, s/he may be labelled as a deceiver. Hence, illness entails social as well as biological deviance. However, sociologists of deviance tend not to study illness as a form of deviance and that is mainly due to the fact that medicalisation has dominated the study area of health and illness, which overshadows sociological studies. In other areas of deviance, for example, in criminology, a sociologist has the authority to label a particular human act as a deviance where as in the case of illness, complete reliance will be on medical concepts which weakens the role of sociology in biological deviance.

Another important thing which makes illness a product of social construction is the reaction of the people towards it. Illness is a secondary deviation because people are convinced that it is not the result of self-motivated actions. The person experiencing secondary deviance does not have any objectives which are meant to be fulfilled by becoming a deviant. Since, illness is a

secondary deviation, hence it is legitimate. However, this legitimacy is of three kinds, namely, conditional legitimacy, unconditional legitimacy and illegitimacy. In conditional legitimacy, patient is temporarily exempted from expected role performance and gets extra privilege with the condition that s/he would try to get rid of deviance as early as possible. In unconditional legitimacy, patient is permanently exempted from expected role performance and is provided with some extra privileges in view of her/his inability to get rid of the deviance. Illegitimacy implies that the patient would be exempted in view of the deviance which is not his/her fault and gain some privileges (if there is any), and also attains some handicapping obligations. Similarly, in case of some illnesses, patient is labelled as hypochondriac or malingering or stigmatised depending upon the time and place.

Freidson explains professional construction of illness in the light of meanings which are provided by medical practitioners in the United States. Unlike other countries, the dominant value system of the US is value of health. Just as law and religion act as a source of social control in erstwhile Soviet Union and India respectively, medicine acts as a source of social control in the US. This is why, anything and everything which is found to be disturbing social balance is defined in terms of illness. For example, problem of excessive drinking can be solved by seeking medical help; similarly, excessive sex addiction is a medical problem, agoraphobia is an illness because there is nothing to be afraid of open spaces. Thus, physician is a *moral entrepreneur* in the sense that when s/he is judging about a particular condition and symptoms which should be brought within the purview of disease and illness Physician acts as a moral entrepreneur. These moral entrepreneurs may be public spokespersons who tend to alert masses about the practices which should be undertaken and which should not be. Then, some may be the technical advisers who play a prominent role in policy making and in advising legislative bodies to form policies. Finally, a special interest group which aims at providing labels or changing labels for various illness categories. For example, to label excessive drinking a state of illness; or helping people to remove the label of stigma from epilepsy.

The main reason behind categorising any symptom as illness is to ensure that the said person is not suffering from any ailment. This is called 'decision-rule' which implies that it is better to label someone diseased and then to perform tests and treatment to ensure safety of the person; than to deny it and overlooking situations which may create trouble in near future. Thus, it is more problematic to miss a medical situation through carelessness, accident or ignorance, than to temporarily diagnose it. However, this is a medical rule, professional construction of illness may be hazardous for a patient in the society if patient is said to be suffering from a stigmatising or malingering disease. Under such situation, even though occurrence of disease is ruled out in

near future, but the label that disease carries tends to stay.

The profession of medicine tends to construct the illness and to find out a cure for it instead of constructing health and normalcy in the society. Professional construction of illness views illness as a part of the social structure i.e. how these illnesses are interpreted and dealt with in the light of existing social, political and economic institutions. Just like medical practitioners, lay people also tend to construct their illness experiences depending upon their socio-cultural backgrounds. Freidson cited number of case studies in his writing to highlight difference of illness experiences by the people belonging to different socio-cultural backgrounds. For example, in one of the case studies, Jews and Italians tended to exaggerate their experience with the pain occurring due to the onset of neurological ailments as compared to that of 'Old-Americans'. Similarly, they differed in their responses to the medical treatment. For instance, Italians were very confident of the capabilities of the doctors whereas Jews tend to be sceptic and 'Old-Americans' were anxious in the beginning but tend to be optimistic once the treatment started. Hence, people tend to come up with their own definitions of illnesses. For one particular group, illness might be the interference with daily routine activities, for others, onset of an illness might depend upon their economic background.

Layman definition of illness is necessary in the context of the use of medical services. Not all ill persons tend to seek medical consultation, and the reasons behind this attitude vary. Some societies consider black magic to be the prime reason behind the onset of illnesses, some economic classes tend to avoid seeking medical facilities due to the lack of economic resources. Others prefer to rely on traditional methods of medical care which might not be medically recommended. An ill person belonging to a particular class does not devise meaning of her/his illness by herself or himself, it is the social structure which makes this person to adopt a particular way of dealing with her/his illness. In fact, the ill person requires social sanction to acquire sick role so that s/he can seek exemption from everyday role performance. If society refuses to consider the said person as sick, then it is not possible for the ill person to seek medical and social support. The semantics conveyed during everyday communication plays a very important role in making a patient accept her/his state of illness.

Freidson (1970) talked of four referral systems existing on account of the content and structure of the system, which a patient refers to in order to check her/his illness. Under first referral system, patient tends to consult highly extended referral system which includes indigenous health services with the consultation of the members of the society. Second system is similar to the first one, except for the fact that individual acts entirely of her/his own with the

consultation of the immediate family members. In third system, person uses professional medical help with little or very less consultation. Those opting for fourth referral system belong to the cultural system which goes for professional medical services only. The types of illnesses which enter into the consultation depend upon their nature, for example mental illnesses tend to carry the label of stigma with it because of which patient tends to delay consultation or hides it from others. Hence, in the case of conditionally legitimate illnesses, people tend to seek medical consultation to a large extent; for unconditionally legitimate illnesses, lesser number of patients tends to seek medical consultation; and for illegitimate illnesses, smallest number of consultations is sought, considering the shame and secrecy associated with it. It is basically the lay referral system which makes a patient enter into the professional domain of medicine and seek consultation from an expert. This referral system is useful firstly, because it helps in assessing the utilization rate of the medical services by a particular community. Secondly, it determines the way a patient tends to decide her/his course of action after the onset of a particular disease.

It is basically the societal reaction which forces a person to seek medical consultation. However, this societal factor dilutes the moment patient enters into the door of the medical practitioner. From that moment onwards, patient becomes a client and physician, a professional, who is supposed to provide best medical services to her/his client. Freidson (1970) argues that social meanings are built up in the society by the professionals, who are supposed to be creating knowledge, formulating laws, morals and procedures. They disseminate this knowledge in the society by means of the expertise bestowed upon them for being the formulator of the knowledge. This is how social control is exercised in the society and the knowledge is imposed. The moment medicine enters into organised professional domain, it becomes medical marketplace where patient is not assumed to be free to choose services of her/his choice. However, this situation holds good for those who consider themselves to be ill and require medication, and these practices come to be known as *client-dependent practices*. These practices are undertaken when a client decides to himself/herself show up at the door of the physician. In this case, physician depends upon lay referral system where patient herself/himself explains the condition s/he is experiencing. When physician refers to this patient to an expert, it becomes *colleague dependent practice,* where a patient loses all her/his preferences which s/he is supposed to be enjoying in professional services. This is how profession of medicine takes ‘control’ which is commonly known by the euphemism ‘management’ in medical settings. This control is exercised mostly in the case of chronic illnesses. However, in case of minor ailments like common cold, cough etc., a patient

might experience brief cycles of 'sick role'.

In case of chronic illnesses, there is a necessity to maintain long term and regular interaction with the medical practitioner which makes it a compulsion for the patient to abide by the professional orders of the medical practitioner. This is how a disease tends to become 'professionally organised illness' and treatment is undertaken to 'manage' it. Treatment is communicated in different ways of interaction which Freidson termed as *'guidance-cooperation'* and *'mutual participation'*. In guidance-cooperation, patient is believed to be aware of her/his situation and accepts advice of the physician by placing physician in a position of power and authority. Thus, patient is supposed to cooperate with the physician and to follow guidelines as issued by the medical practitioner. Interaction model of 'mutual participation' is found to be functional mostly in the case of management of chronic illnesses. There is another model of interaction based on activity and passivity, which is possible only under extreme circumstances like when patient is in coma or the said patient is an infant and is completely dependent on others. These interaction patterns are necessary to differentiate between, different types of medical work; different patterns of disease management; and different characteristics of lay community which determines social approach towards an illness.

Social approach is a depiction of the social structure which exerts influence on illness. This influence is exercised by initiating a contact between the sick person and the therapist; and by organising social state of being sick. In fact, it is only when the illness is institutionalised that the patient acquires 'sick role.' This is how an ill person acts like a patient however, outside institutional settings, sick role costs a person her/his entire efforts of day and night, waking and sleeping, and expected social role performance. Hence, social meanings related to health and illness are the results of lay as well as professional people which tend to differ from each other. Whether it is symptoms of the onset, pattern of treatment and management or defining the symptoms of the illness, knowledge application of the professionals is always done in the light of existing social patterns. Social construction of illness, therefore deals with the social meaning of illness rather than a biological state.

Foucault and Social Construction of Illness

Foucault discussed construction of knowledge about human body in medical arena. Though he specifically did not work on the social construction of illness. However, his concepts of *Bio-power* and *Technologies of Self* are the disciplinary tools which have a direct relation to the process of illness construction. They are the means which makes society and a person her/himself to control the body, and to try to achieve a docile body (Barry and Yuill 2012).

Conrad and Barker (2010) say that Foucault inspired writers usually provide a detailed analysis of medical discourse by means of which they deconstruct this knowledge. They do so in order to unveil the ingrained meanings, normalising tendencies and identities embedded in the medical discourse. Discourse is a specialised way of contemplating and gestating knowledge about a particular issue. Therefore, language plays a very important role in the expression of these thoughts and generating a discourse (Barry and Yuill 2012).

Foucault talked of disciplinary forces which are being applied by the society to enable a human being to achieve and retain a 'docile body'. These disciplinary forces do not entail coercion or repression but is a voluntary confirmation towards a socially approved body (Lupton 2000). In fact, concept of power is something which holds positive connotation for Foucault as it enables masses to liberate themselves and to make their own decisions. He explained that human body is constructed in an ideal typical form by means of C*linical Gaze*. This Clinical Gaze is one sided in which patient's body is being examined and, is described as docile or not (Lupton 2000). Subjective discourses in the field of health create identities which have a bearing on the social status of the said person. Turner (1997) stated that Foucault's work enabled Medical Sociologists to formulate a new framework where medical practices take place under the influence of socio- cultural milieu. He further explained that sociology of body emerged as an important theme in the medical sociology as socially constructed nature of disease and illness revolves around it.

Concepts of *Bio-power* and *Technologies of Self* are embedded in 'Governmentality' which Murray (2007) defined as 'conduct of conduct' as it is the method of governing human behaviour by means of already defined social means for this, coercion is not used. However, attempts have been made to educate masses and to persuade them to voluntarily abide by the norms meant to fulfil social desirability. Cooter (2010) talked of bio power as an addendum to the machineries governing mentalities of the masses i.e., 'govern-mentality' through social and scientific methods, administrative measures and 'technologies of the self.' He also explained about 'biopolitical technologies of the autonomous self' which is a direct indication that bio-power and technologies of the self are ingrained in governmentality. 'Dictionary of Health and Society' (White 2006) states that technologies of the self are supported and strengthened by the ongoing discourses of the modern helping professions such as medicine, psychiatry, social work, etc. These are actually the practices by means of which individuals render themselves as subjects and evaluate themselves. This evaluation is done in terms of popular discourse about human body and constructing their own bodies in terms of those discourses, and analysing whether theirs is a docile body or not (White 2006). Lupton (1997)

mentioned that Foucault admitted in his later writings that he emphasised too much on the role of social institutions as medium of social control and domination. However, in his later writings he became more and more interested in the ways through which individuals carry on and monitor their selves in every day routine.

Bio-power is another disciplinary tool of the modern society by means of which human body is monitored and evaluated by social institutions. Foucault came up with the concept of bio-power in his early writings whereas technologies of the self-emerged at a very later stage. Foucault (Lupton 1997) stated that in seventeenth century human body was at the mercy of the sovereign, and was considered as something which is to be killed and which is not to be killed. However, with the effects of ongoing social changes, practices changed towards promoting life and health and it further aimed at promoting productivity of the human body. Bio-power is exercised through bio-politics of the population and anatomo-politics of the human body (Lupton 1997). Bio-politics is exercised when disciplinary forces are being used by social institutions to empower and bring in healthy practices amongst a particular society or community. Therefore, it is aimed at entire population whereas anatomo-politics aimed at regulating health status of an individual only.

Stigma

Stigma is one of the aspects of the social construction of illness which makes a person delay doctoral consultation and further deteriorates her/his condition. Erving Goffman's seminal work on stigma highlights this aspect of the social constructivism in illness. In his book *Stigma: Notes on the Management of spoiled Identity* he differentiates between three types of stigma namely abominations of the body, blemishes of character and tribal stigma (Goffman 1963). Abominations of the body refers to various kinds of deformities which label a person stigmatised. It is about a person whose bodily characteristics depart him/her from the socially constructed ways of physical normalcy and makes other people react negatively towards her/him. Blemishes of the character are believed to be the result of negative social behaviour such as mental disorder, drug addiction, imprisonment, homosexuality, suicidal behaviour, etc. Finally, tribal stigma is related to race, nation and religion, and is transmitted through lineages. According to Dillon (2010) Goffman worked on stigma during 1960s and since then, social structure has experienced a lot of changes due to which behaviours which were rendered stigmatised by the society have now been accepted as a part of the society. Homosexuality is one such example.

Dingwall (1976) stated that sociological studies of illnesses are done most effectively by

employing social constructivism which enables researcher to get an insight of the illness experiences of the patients as well as physicians. Therefore, three diseases which have been dealt with in the study i.e., PCOS, T2DM and CVDs, are looked at through the lenses of the sick role which people acquire in order to manage their disease; and social constructivism to get into a dialogue with others (whether it is their family or physician or any other person).

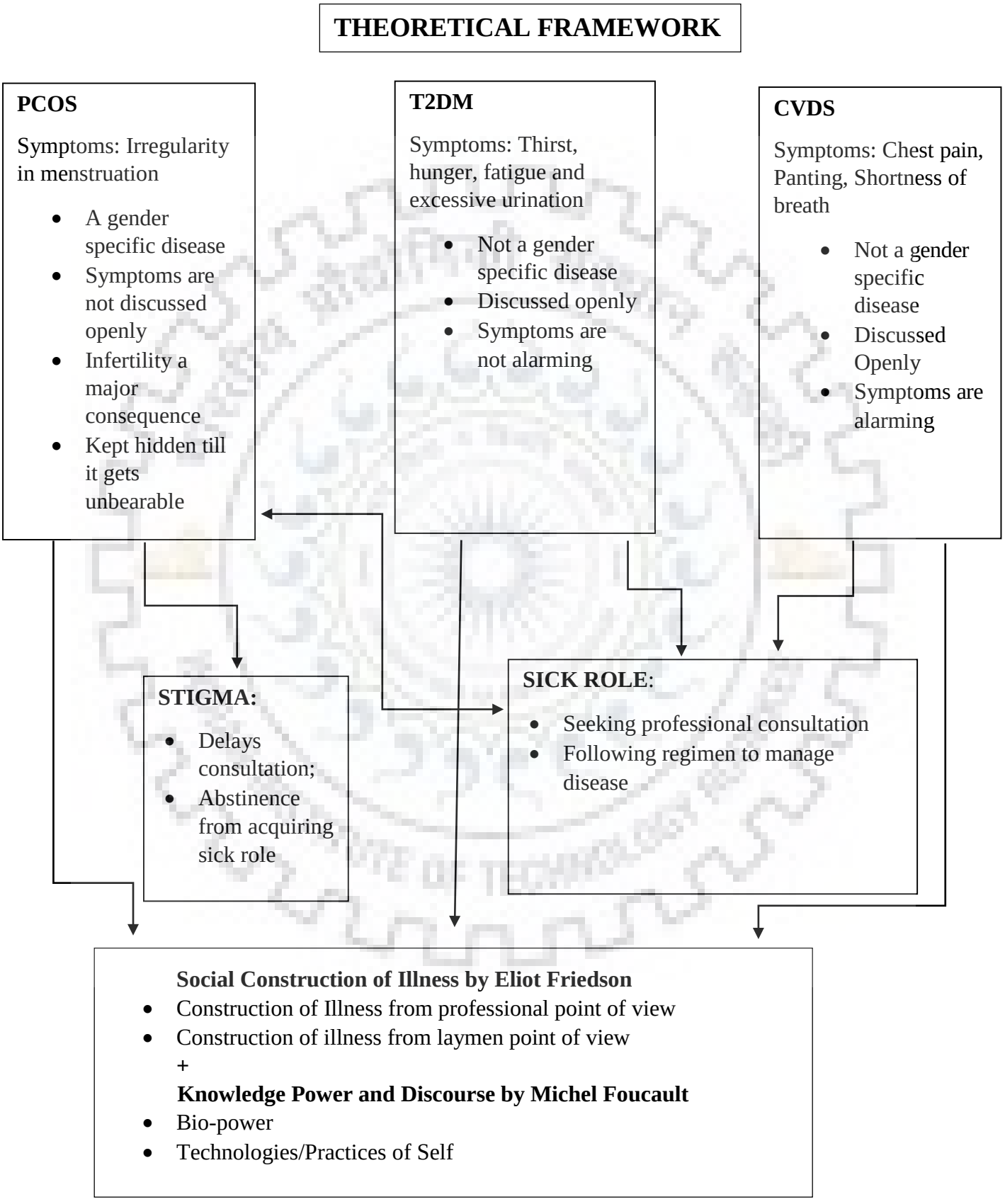
Approach of stigma is supposed to remain limited to the PCOS which is directly associated with menstrual irregularity, which is still not a very talked of subject in Indian society. Onset of menstruation is provided with various social meanings and events such as isolation of women, restriction on the entry of women in religious places, avoidance of an open discussion related to menstruation, etc. makes anything related to it a matter of social aloofness. Euphemisms such as 'periods' and 'date' are used to address to it. Since, one of the most important symptoms of PCOS is menstrual irregularity this is why it is also considered a stigmatising disease. Females fear their social labelling due to the onset of this disease and they avoid discussing it with anyone. Infertility is a major consequence of PCOS which stigmatises a woman experiencing it. Association of stigma makes adoption of 'sick role' even more difficult as they tend to delay doctoral consultation and following a management regime. This issue will be explained in the upcoming chapters.

T2DM and CVDs are more of socially acceptable diseases which may be due to the fact that these are not gender specific diseases. Women were found to be quite comfortable in replying to any query related to these diseases. However, lethargy in the adoption of 'sick role' was found in the case of those suffering from T2DM which was mainly due to what Parsons called "Hyperchondriac" and believed that there is nothing much to worry about T2DM. CVDs on the other hand was taken more seriously and I came across many patients in the CVDs OPD who visited to consult doctor because they experienced minor heaviness on the left side of their chest or left arm. Later on, majority of them were ruled out of having any CVDs. On the basis of personal observations, it can be said that since onset of CVDs is accompanied by symptoms which are more terrifying such as chest pain, sudden collapse and blackout, panting, shortness of breath, etc. than those of the onset of T2DM which are excessive urination, fatigue, hunger, thirst, etc. People tend to take their sick role towards CVDs more seriously as compared to T2DM.

The theoretical model used in the study is illustrated in figure 1.1

Figure 1.1

Theoretical Framework



5. Methodology of the Study

This section presents the methodology opted to execute the study. The tools for data collection, study area profile, samples and the process for the data collection are discussed in this section.

Study Area

Erstwhile state of Jammu and Kashmir (J&K) was divided into three regions namely: Jammu, Kashmir and Ladakh. These regions had been demarcated on the basis of geographical distinctions of the three main regions of J&K (2018). For administrative matters, state was divided into two administrative divisions, namely, Jammu division and Kashmir division (Directorate 2008). Jammu division consisted of ten districts viz. Doda, Jammu, Kathua, Kishtwar, Poonch, Ramban, Rajouri, Reasi, Samba and Udhampur. Jammu district, which is the main area of the study, was the winter capital of J&K state; and was also the headquarter of Jammu division (Directorate 2008; GMC 2018).

Jammu district derives its name from its headquarters. The district is divided into 4 tehsils; namely Akhnoor, Jammu, Bishnah and Ranbir Singh Pura. These tehsils have been divided into 8 Community Development Blocks, namely Khour, Akhnoor, Marh, Bhalwal, Dansal, Satwari, Ranbir Singh Pura and Bishnah. Rural Jammu consists of 852 villages which also includes 72 un-inhabited villages encompassing an area of 2190.87 Sq. km. (Census 2011). According to Census (2011), decadal population growth rate of the district is 12.74% which is much lower than the growth rate of the state which is 23.64%. Data were collected at the Government Medical College (GMC) hospital, Jammu and its associated hospitals. GMC Jammu was established in 1973 with the main aim of providing health facilities to the people of Jammu province. At present GMC Jammu caters to the health needs of, in addition to Jammu region, Kashmir region and adjoining areas of Punjab and Himachal Pradesh (GMC 2018). Tertiary health care services are provided here and this is why GMC Jammu has been chosen to conduct in-depth interviews for the present study.

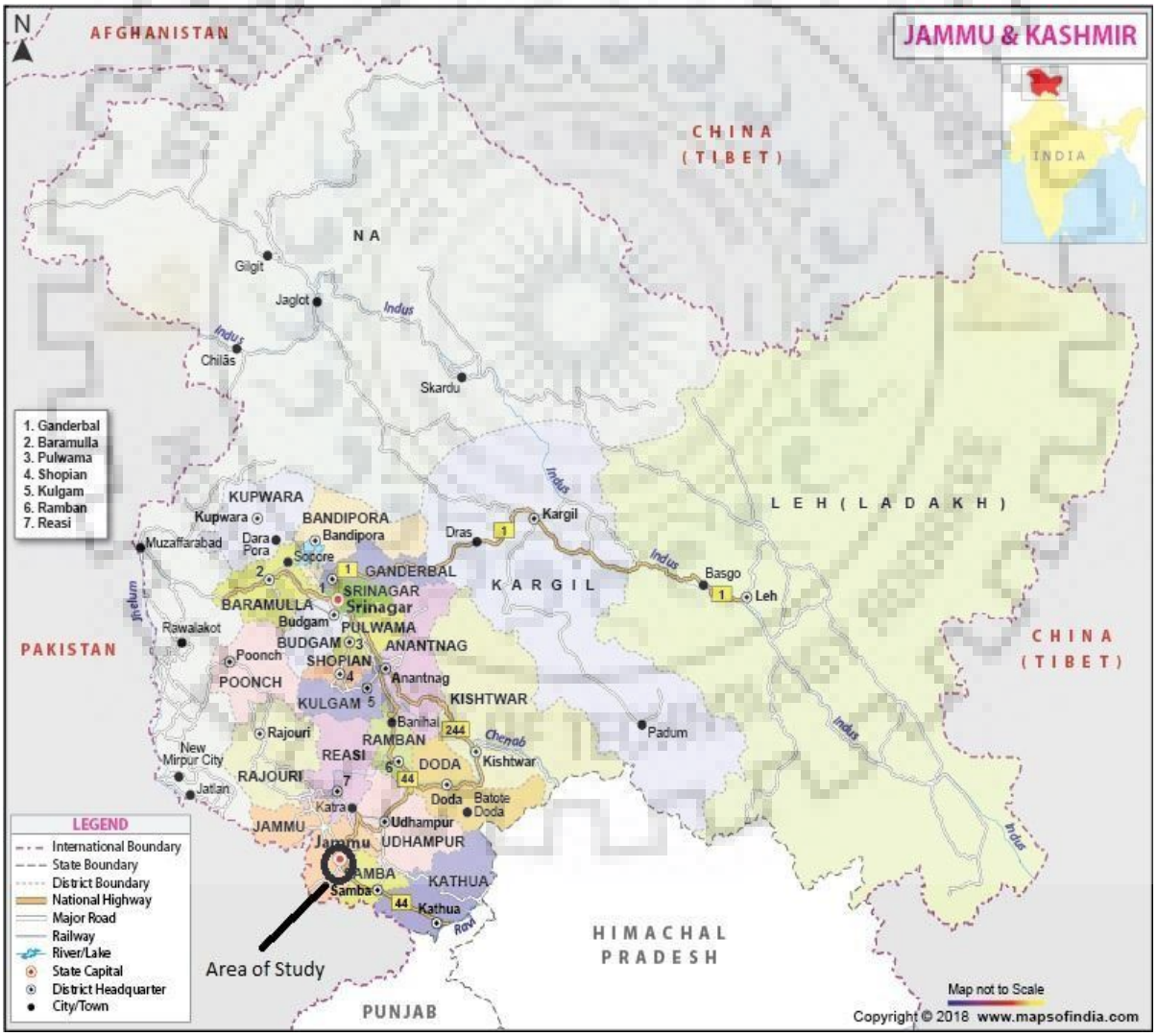
Nature of the Study

This study is based on a descriptive research design which also takes into consideration some elements of exploratory design. Qualitative methods have been employed, in which data were collected by interviewing female patients suffering from PCOS, T2DM and CVDs. However,

data are represented in tabular form as well to gain in-depth understanding of the experiences and approach of the respondents towards these diseases. The present study intends to apply theoretical framework of the sick role, social constructivism and stigma to study these diseases. The results of the study are substantiated by means of narratives generated during the course of interviews and personal observations which I gained during the course of data collection. Social impact of lifestyle diseases is studied by taking into consideration socio-economic and demographic profile of the respondents, role of environmental factors in the onset and management of lifestyle diseases, and health seeking behaviour of the respondents.

Map 1.1

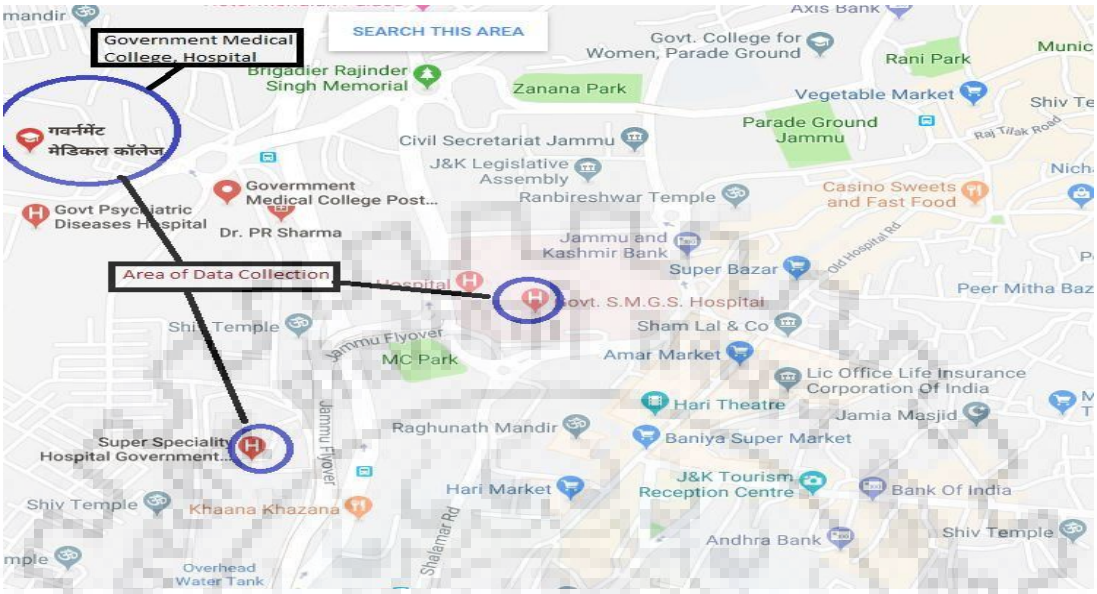
(Map of the erstwhile state of Jammu and Kashmir (J&K))



(Image Courtesy: Google Images)

Map 1.2

(Location of SMGSH, GMCH and SSH)



(Image courtesy: Google Maps)

This study also explores discourse related to the onset and management of a lifestyle disease. The discussion which people have with each other and the labels which are generated on account of these discussions have also been taken into consideration. As is seen in the case of those suffering from HIV/AIDS, they are labelled as stigmatic in the society, these labels are the results of discourses generated by what Foucault calls 'powerful people' of the society, who create knowledge (Goldstein, Pretirius, and Stuart 2003). Similarly, different lifestyle diseases attract different kinds of discourses which are explained in detail in upcoming chapters.

Selection of the Study Respondents

Respondents are the female patients suffering from PCOS, T2DM and CVDs. An interesting pattern which emerged while conducting this study was that majority of the respondents suffering from PCOS were from the age group of 18-25 years. While majority of the respondents suffering from T2DM were in the age group 30-50 years and most of the respondents suffering from CVDs belonged to the age group was 50 years and above. Therefore, these three diseases also represent three major life spans in the life of a woman viz. youth, middle age and old age.

For PCOS, data were collected at Sri Maharaja Gulab Singh (SMGS) Hospital Jammu; patients suffering from T2DM were interviewed at Government Medical College (GMC) Jammu; and data related to CVDs were collected at Super Speciality Hospital (SSH) Jammu in the departments of Gynecology, Medicine and Cardiology respectively. I conducted a pilot study outside formal setting of hospital with the view of employing snow-ball sampling technique for actual data collection. However, that turned out to be a huge failure and many times I was looked upon with suspicion. In an unpleasant incident, prospective respondent even accused me of nestling some hideous intentions behind asking questions pertaining to PCOS. She was an acquaintance of mine, who herself happened to be a researcher. Therefore, it was decided that interviewing patients outside hospital would be herculean task and finally, purposive sampling was employed for data collection; and permissions were sought to collect data in the above-mentioned hospitals.

6. Ethical Clearance and Data Collection

Permission was sought from the Principal, GMC to collect data at aforementioned hospitals. After that, ethical clearance was sought from Institute Ethics Committee (IEC) of the GMC which happens to be the parent hospital of SMGS and SSH as well and study was listed as I_{18} /C/IEC/GMCJ/16. This was followed by further consent from respective Heads of the Departments (HOD) who allowed interviewing required patients in the Out-Patient Department (OPD). For T2DM and CVDs some inpatients were also interviewed as per the recommendation of the respective HODs. T2DM inpatients were interviewed in the general ward of the Department of Medicine; and CVD inpatients were interviewed at the Coronary Care Unit (CCU) of the Department of Cardiology.

Entire Data were collected in three phases spanning over one and half year which included pilot study as well. All the interviews were conducted between August 2016 to December 2017 and more than 120 in-depth interviews were conducted. On an average, 40 to 50 interviews were conducted for each disease depending upon data saturation achieved. However, in order to ensure equal representation of all the diseases in the study, sample size was restricted to 41 for each disease which made a total sample size of 123 respondents. In addition to this, respective doctors who facilitated data collection in their OPDs were also interviewed to substantiate results. Conversation with the doctors is reproduced in the form of narratives in upcoming chapters. In addition to the fact of data saturation, various studies also suggest that

sample size of 30 to 40 is an ideal sample size for a qualitative study, especially related to health (WHO 2018b; Creswell 2007).

In addition to in-depth interviews, observation method was also employed. Instead of defining the nature of observation as participant or non-participant, a collective term of 'field research' has been used. It was used by Babbie (2004) who stated that he would prefer term field research because;

> …. field researchers need not always participate in what they are studying, though they usually will study it directly at the scene of the action (P-285)

Therefore, entire process of data collection is termed as 'field research' which includes personal interviews and observation.

Data were collected by primary as well as secondary sources:

1. **Primary Sources**: Personal interviews and observation method formed tools for the collection of primary data which was collected on account of field research.
   a) **Interview method**: For in-depth interviews, semi-structured interview schedules were framed separately for all the three diseases. It primarily consisted of questions related to their socio-economic and demographic profile, eating habits, nature of their work, family history of metabolic diseases, knowledge of the disease and their health seeking behaviour. Every single interview lasted for 30 to 40 minutes and informed consent was sought from all the respondents prior to the commencement of interviews. Contrary to the experience of pilot testing, respondents in the hospitals were very supportive and friendly. However, an interesting pattern emerged here in which those who had poor education background showed maximum interest and participation in the study; where as those who knew what research is and had good education background showed minimum interest in the participation and displayed an eagerness to end interview as early as possible. Interviews were conducted in Hindi or Dogri language and responses were transcribed on interview schedules. All the responses were later on translated into English language with the help of English language experts.
   b) **Observation Method:** In addition to in-depth interviews, researcher also got the opportunity to observe behaviour of the respondents and their family members during the course of their visit to the hospitals. It was observed that for all three diseases, the

approach of the patients and their family members was different. For PCOS, majority of the respondents were adolescent and young girls, hence they were worried about marriage and bearing children in future. In the case of T2DM, patients were found to have a very lackadaisical approach; where as in the case of CVDs, patients and their family members were found to be highly concerned and visited doctor regularly. Overdependence of patients on the doctors and inability to understand the disease management regimen were the main findings of the observation method.

2. **Secondary Source** comprises data which is not collected first-hand by the researcher, but constitutes an invaluable part of the information gathering exercise undertaken in any research (Bowling 2002). In this study, the secondary sources which were relied upon were the online data available on government websites, journal articles and books. Newspaper articles and other secondary sources, which throw light on lifestyle diseases directly and indirectly, have also been taken into consideration.

8. Data Analysis

Interview schedule consisted of open-ended as well as close-ended questions. Responses received were codified manually. For close-ended questions, there already existed definite responses whereas for open-ended questions, responses received were codified so as to make them suitable for tabular representation. Statistical Package for Social Sciences (SPSS) was used to extract frequencies, cross tables and percentages. Data analysis was done by using grounded theory approach which involved reading and re-reading of the available interview transcripts, and generating themes.

9. Experiences and Problems Faced During Field Work

This study is primarily based on field research which involved regular visits to various hospitals. However, before the commencement of actual data collection, pilot study provided me a fair idea that data collection is never going to be an easy task. Outside hospitals, patients were not willing to appear for the interview and data collection at hospital involved going through various procedures of the administrative set up.

In order to test validity and reliability of the interview schedules, a pilot study was undertaken. Pilot testing begun with the patients of PCOS which, as already explained, was a very unpleasant experience. After that I tried to contact female patients suffering from T2DM in my surroundings by asking acquaintances if they knew any woman suffering from T2DM. To this, many people asked about the benefit which diabetic patients were going to get from the study

or any financial benefits that they would be able to accrue on account of these interviews. The majority of the prospective respondents had this idea that they would get some financial benefits by appearing for the interview. And same was the case with the patients suffering from CVDs. Therefore, it was decided to collect data at hospitals. This was, again, not an easy job as one of the renowned hospitals permitted data collection in their premises with the condition that I would have to take someone from that hospital as my co-supervisor. This condition was against the existing norms of my parent institution. When I tried to explain this, I had to face humiliation at the hands of senate members of the hospital. Another reason for avoiding undertaking sociological research under the supervision of a medical practitioner was the response of the medical practitioner which she I received during my visit to All India Institute of Medical Sciences (AIIMS) New Delhi. On a library visit to AIIMS New Delhi, I happened to meet one of the high-profile medical practitioners of the Institute, regarding undertaking a sociological research in the field of lifestyle diseases amongst women. Interaction was very healthy and I received many positive inputs related to the proposed research, however, pattern of collecting data which he suggested, was out of the scope of sociology and involved the process in which I myself had to perform tests on the respondents and had to analyse their physical state. Instead of conducting in-depth interviews, a casual discussion would follow. This proposition was found to be against the very nature of a sociological research. Hence, idea of performing a sociological research under the co-supervision of a medical practitioner was rejected.

Finally, GMC Jammu allowed collection of data in their hospitals, without the appointment of a co-supervisor from their hospital. First step of seeking permission for data collection, was to send an application to the Principal GMC who granted permission for it. After that, permission letter had to be submitted to the IEC which approved the study and listed it. Finally, copies of the permission letter from the Principal and approval of the IEC had to be submitted to the Heads of the Departments which facilitated data collection. There were no administrative hiccups in the entire procedure however, it took around one month to complete all formalities. and finally, data collection process begun in December 2017. Data collection of PCOS once came to a halt due to a week-long strike observed by the doctors, due to some internal incident. Barring that interruption due to strike, data collection was without any hurdles.

Once I started interviewing patients inside hospital premises, in the presence of senior doctors, all the respondents willingly participated in the study. For illiterate respondents, it was difficult to understand my status, role and presence in the OPD. Perhaps, they considered me as one of

the junior doctors which corresponds to the study of Minocha (2002) where she mentioned that during her field visit to the hospital wards, patients mistook her as a doctor and wondered how could a doctor spare so much time while others are extremely busy and seldom spare a moment to talk to the patients.

Data collection in hospital was also helpful in the sense that I did not face problem of establishing rapport with the patients before conducting interviews. However, questions involving their socio-economic and demographic profile and family history of the disease were asked in the beginning which enabled respondents to gradually open up about their experiences and approach towards the disease. A major change in the behaviour of doctors which was observed by me was is in contrast to the experience of Minocha (2002), is that doctors positively recognised the role of sociology in Medical Sciences. None of the doctors were sceptical about the study nor did they consider these investigations to be futile, time consuming and lacking objectivity as was observed by her. On the contrary, doctor at AIIMS New Delhi and at aforementioned hospitals in Jammu were quite supportive of sociological studies as was observed during interactions with them. However, they did not have idea about what exactly is done in a sociological study. This contrast between the study of Minocha (2002) and present one may be attributed to the fact that role of sociology in Medical institutes has gained a firm ground over past few decades. She actually collected data for the study in 1960s when social set up of Medical Institutes in India was quite different than the present one.

2

What This Disease is About…I Do Not Understand: Accounts of the Women Suffering from Polycystic Ovary Syndrome (PCOS)

Polycystic ovary syndrome is one the most common endocrine disorders, affecting women during their reproductive years. Three main characteristic features to identify this situation are hyperandrogenism (excess secretion of male hormone androgen), polycystic ovaries (presence of multiple cysts in ovaries), and ovulatory dysfunction (irregularity of menstrual cycles). This syndrome can also be linked to the onset of other metabolic complications including obesity, insulin resistance, hyperinsulinemia (a condition in which excess levels of insulin circulates in the blood as compared to the level of glucose) (Barthelmess and Naz 2015). Since, women suffering from PCOS are characterised by hyperandrogenism and chronic anovulation, it is one of the leading causes of infertility throughout the world and is directly associated with the onset of other endocrine disorders like diabetes (Brady et al. 2009). Though PCOS affects women during their reproductive years, yet its consequences span over entire lifetime. Obesity, T2DM and CVDs are highest amongst postmenopausal women with PCOS as compared to those without PCOS. Onset of PCOS is directly associated with stigma and depression due to visible acne, hirsutism and obesity which are the main symptoms of the onset of PCOS (Sanchez 2014). Kitzinger and Willmott (2002) described this disease in the light of social construction of womanhood, due to which respondents in the study did not feel like 'normal women'. This was mainly due to the fact that they had to face excessive growth of facial hair, irregular menstruation or infertility. They felt 'freakish', 'different' or 'abnormal' which disqualified them from being an image of a socially constructed 'woman.' Farkas et al. (2014) emphasise that body image dissatisfaction is the biggest cause of psychological symptoms (like anxiety and depression) occurring due to PCOS which result due to infertility, eating disorders, hirsutism, acne, irregular menstruation etc.

Around 10.97% of Indian female population is suffering from PCOS as compared to 6.3% in Sri Lanka and 2.4% in China (Nidhi et al. 2011). This huge variation in the number of Indian PCOS patients as compared to other Asian Countries may be due to the fact that India is the world capital of diabetes and, PCOS and diabetes share a symbiotic relation with each other. According to a study conducted by Metropolis in India, 25.88%, 18.62%, 19.99% and 18% women are suffering from this disease in Eastern, Northern, Western and Southern parts of the country respectively. This study also concluded that such leviathan prevalence of PCOS owes

its existence to the ignorance and lack of awareness among youngsters (Metropolis 2016). In addition to genetic pre-disposition, environmental factors in the form of sedentary lifestyle, socio-psychological stress and excess consumption of fatty and junk food also contribute a lot to the onset of this disease (Pathak and Nichter 2015). So, now-a-days prevalence of this disease is mainly due to the change in lifestyle.

Table 2.1 represents Pseudonyms, age, occupation and marital status of the respondents so that their narratives can be explained clearly in upcoming sections.

Table 2.1

General Profile of the Respondents

S. no.	Pseudonym	Age	Profession	Religion	Marital Status
1	Supinder Kour	25	Housewife	Sikh	Married
2	Radhu Kumari	24	Housewife	Hindu	Married
3	Meena Devi	27	Housewife	Hindu	Married
4	Ramya	28	Student	Hindu	Unmarried
5	Afia	25	Student	Muslim	Unmarried
6	Neha Mahajan	21	Student	Hindu	Unmarried
7	Pretie	22	Private Teacher	Hindu	Unmarried
8	Tanya Ghai	17	Student	Hindu	Unmarried
9	Nikhat	18	Student	Muslim	Unmarried
10	Anita Mahajan	39	Government Employee	Hindu	Unmarried
11	Mamta	29	Housewife	Hindu	Married
12	Fariha Khan	16	Student	Muslim	Unmarried
13	Shazia	34	Housewife	Muslim	Married
14	Niti	20	Student	Hindu	Unmarried
15	Shikha Manhas	19	Student	Hindu	Unmarried
16	Deepika Choudhary	24	Student	Hindu	Unmarried
17	Geeta Kumari	20	Businesswoman	Hindu	Unmarried
18	Shameem Malik	21	Student	Muslim	Unmarried
19	Stuti	24	Housewife	Hindu	Married

20	Rohini	20	Student	Hindu	Unmarried
21	Rajni	21	Student	Hindu	Unmarried
22	Priya Kapoor	31	Housewife	Hindu	Married
23	Poonam Khatri	24	Housewife	Hindu	Married
24	Deepti Sharma	32	Housewife	Hindu	Married
25	Farida	19	Student	Muslim	Unmarried
26	Sukandya Sharma	29	Government Employee	Hindu	Married
27	Rekha Mistri	19	Student	Hindu	Unmarried
28	Rashi	19	Student	Hindu	Unmarried
29	Priya Jain	21	Student	Jain	Unmarried
30	Shilpa Sharma	14	Student	Hindu	Unmarried
31	Sumita Andotra	18	Student	Hindu	Unmarried
32	Jyoti Kalsotra	36	Government Employee	Hindu	Married
33	Vandana Khanna	16	Student	Hindu	Unmarried
34	Deepika Kumari	29	Government Employee	Hindu	Married
35	Deeksha Khanna	27	Student	Hindu	Married
36	Astha Dutta	16	Student	Hindu	Unmarried
37	Prarena Kumari	37	Student	Hindu	Widow
38	Shreshta Gupta	28	Student	Hindu	Unmarried
39	Shreya Koul	26	Student	Hindu	Unmarried
40	Tabassum Bhat	19	Student	Muslim	Unmarried
41	Gita Vaid	25	Student	Hindu	Unmarried

Results of the present study show that infertility, which is one of the major consequences of PCOS is a major cause of stigma as compared to obesity, hirsutism or acne. Females do not know what PCOS is. However, experiences of oligomenorrhea or amenorrhea (state of less than nine menstrual cycles in a year or complete absence of the cycles respectively), make them consult doctor. Results are explained in detail in the following sections.

1. Socio-Economic and Demographic Profile

Table 2.2

Socio-economic and Demographic Profile		
Education (N*=41)		
	Frequency	Valid Percent
Primary	4	9.8
Secondary	13	31.7
Higher Secondary	11	26.8
Bachelors	5	12.2
Higher Education	3	7.3
Ph. D.	5	12.2
Total	41	100.0
Religion (N*=41)		
	Frequency	Valid Percent
Hindu	32	78.0
Muslim	7	17.1
Sikh	1	2.4
Jain	1	2.4
Total	41	100.0
Occupation (N*=41)		
	Frequency	Valid Percent
Student	26	63.4
Housewife	9	22.0
Govt. Employee	4	9.8
Business Woman	1	2.4
Private Job	1	2.4
Total	41	100.0
Marital Status (N*=41)		
	Frequency	Valid Percent
Unmarried	27	65.9
Married	13	31.7
widow	1	2.4
Total	41	100.0
Family Structure (N*=41)		
	Frequency	Valid Percent
Nuclear	26	63.4
Joint	15	36.6

Total	41	100.0
Age (In Years) (N*=41)		
	Frequency	Valid Percent
10 - 14	1	2.4
15 - 19	11	26.8
20 - 24	12	29.4
25 - 29	11	26.8
30 - 34	3	7.3
35 - 39	3	7.3
Total	41	100.0
Mean Age: 23.59 years		
Monthly Income (Rupees in Thousand) (N*=41)		
	Frequency	Valid Percent
10 - 19	9	22.0
20 - 29	12	29.3
30 - 39	9	22.0
40 - 49	3	7.3
50 - 59	5	12.2
80 - 89	2	4.9
100+	1	2.4
Total	41	100.0
Mean Income: 34.02 (In Thousand)		
Number of Family Members (N*=41)		
	Frequency	Valid Percent
0 - 4	21	51.2
5 - 9	18	43.9
10 - 14	2	4.9
Total	41	100.0
Mean: 4.78 (Members per family)		

*N = Total Number of the Respondents

According to Merkin et al. (2011) low childhood socioeconomic status is directly associated with the increased risk of PCOS. Since, their area of study is the U.S., therefore, it cannot be claimed that whether same holds good for Indian population as well. Stringhini and Bovet (2017) argue that for lower and lower middle-income countries (LLMIC), social patterning of NCDs vary as local factors have a dominant influence on the onset of NCDs which cannot be generalised. In addition to other risk factors, geographical conditions and sex also play a prominent role in determining socioeconomic factors responsible for the onset of a NCD in LLMIC.

Table 2.2 shows socio-economic and demographic profile of the respondents suffering from PCOS in the present study. Education profile of the respondents in the present study shows that four (9.8%) respondents went to school only up to primary level; 13 (31.7%) respondents studied up to secondary level; and 11 (26.8%) respondents up to Higher secondary. There were five (12.2%) respondents who had Bachelor's degree; 3 respondents had Master's degree or more than that; and remaining five (12.2%) were doing Ph.D. Out of total 41 respondents, 78% (32) respondents belonged to Hindu religion; seven (17.1%) respondents were Muslims; one respondent was Sikh; and remaining one was Jain. As far as profession of the respondents is concerned, 26 (63.4%) of them were students; nine (22%) were housewives; four (9.8%) respondents were working in government sector; one was a business woman; and another one was working as an accountant in a private company. For marital status, 27 (65.9%) respondents were unmarried whereas 13 (31.7%) were married; there was only one respondent who was a widow. There were 26 (63.4%) respondents who belonged to nuclear families and remaining 36.6% (15) belonged to joint families.

Age category of the respondents show that more than 50% of the respondents were either in their late teens or early adulthood, as 11 (26.8%) respondents belonged to the age group of 15 to 19 years; 12 (29.4%) respondents belonged to the age group of 20 to 24 years; only one respondent belonged to the age group of 10 to 14 years. Out of the total respondents, 26.8% (11) respondents were in the age group of 25 to 29 years; 7.3 % (three) respondents belonged to the age group of 30 to 34 years and another 7.3% (three) respondents belonged to the age group of 35 to 39 years. Income is another important factor which helps in assessing socioeconomic background of the respondents. As per data collected, it was found that nine (22%) respondents belonged to the family income group of 10 to 19 thousand Rupees per month; for 12 (29.3%) respondents, monthly family income was between 20 to 29 thousand; another nine (22%) had 30 to 39 thousand Rupees per month family income. There were three (7.3%) respondents who belonged to the income group of 40 to 49 thousand; 12.2% (five) respondents had monthly family income between 50 to 59 thousand; 4.9% (two) respondents had income between Rupees 80 to 89 thousand per month; whereas remaining one respondent belonged to the income group of more than one lakh rupees per month. As far as number of family members of the respondents is concerned, majority i.e. 21 (51.2%) respondents had not more than four members in their families. However, 18 (43.9%) respondents had five to nine members in their families and remaining two (4.9%) respondents belonged to the families which had 10 to 14 members.

Socio-economic factors also determine awareness level and health seeking behaviour of the patients as it was found in the present study that two respondents who were studying General Nursing and Midwifery (GNM) course were aware of the symptoms of PCOS and its aftereffects. They self-reported about PCOS and were seeking treatment in order to avoid long term complications of the disease.

Neha Mahajan, aged 21, was a GNM student who stated:

> *I am a GNM student, therefore I knew about the symptoms of PCOS. I am getting married next year and do not want to face infertility issues; and my growing weight also made me to consult doctor regarding PCOS.*

Radhika, aged 21, was also a GNM student and in order to avoid future complications of infertility, she decided to consult a gynecologist on noticing symptoms which were an indicator of the onset of PCOS. She mentioned:

> *I am getting married next month. Being a GNM student, I already knew that irregularity of monthly periods and sudden increase in body weight are the major indicators of PCOS which also leads to infertility. Therefore, I consulted doctor, and it was established after ultrasonography that I was suffering from PCOS.*

However, not all the respondents, who can be termed as literate (qualification bachelors and above), knew about PCOS as it is going to be explained in the next section.

2. Impact of PCOS on the Lifestyle of the Respondents

Table 2.3

Impact of PCOS on the Lifestyle of the Respondents		
Knowledge of PCOS before its onset (N*=41)		
	Frequency	Percent
Never heard of it	33	80.5
family history of diabetes	3	7.3
Work place information	3	7.3
Sister/cousin has same symptoms yet does not anything	2	4.9
Total	41	100.0
Any other disease respondent is suffering from (N*=41)		
	Frequency	Percent
None	32	78.0
Hypothyroidism	7	17.1

Hypothyroidism and Hypertension	2	4.9
Total	41	100.0
Age of the Respondent at the time of Menarche (N*=41)		
	Frequency	Percent
10 - 12	9	22.0
13 - 15	28	68.3
16 - 18	4	9.8
Total	41	100.0
Mean Age: 13.63 years		
Age of the Respondent at the time of the onset of Disease(N*=41)		
	Frequency	Percent
11 - 13	1	2.4
14 - 16	12	29.3
17 - 19	8	19.5
20 - 22	7	17.1
23 - 25	6	14.6
26 - 28	1	2.4
29 - 31	2	4.9
32+	4	9.8
Total	41	100.0
Mean Age: 20.63 years		
Time Duration between two Menstruation Cycles (N*=41)		
	Frequency	Percent
After 45 days	30	73.2
35-45 days	5	12.2
25-35 days	4	9.8
Within 15 days	2	4.9
Total	41	100.0
Whom does the Respondent discuss Menstrual problems with (N*=41)		
	Frequency	Percent
Mother	9	22.0
Mother and Father	4	9.8
Mother and sister	4	9.8
Mother and known females of the family	22	53.7
Mother, husband and known females	1	2.4
Known females	1	2.4
Total	41	100.0

Discussion of Menstrual Problems with Male members of the family (N*=41)		
	Frequency	Percent
Never	38	92.7
Yes	1	2.4
Not Directly	2	4.9
Total	41	100.0
Do You Feel Incomplete as a Women for not being able to conceive		
	Frequency	Percent
Yes	11	26.8
Not Applicable	26	63.4
Have Children	4	9.8
Total	41	100.0

*N = Total Number of the Respondents

In order to assess impact of PCOS on the lifestyle of the respondents, firstly, they were asked about the prior knowledge of the syndrome which they had before its onset, and it was found (as shown in table 2.3) that 80.5% (33) respondents did not even hear of it. There were three (7.3%) respondents who admitted that they had family history of PCOS, and that is how they knew about it; and another three (7.3%) respondents knew about PCOS because of their profession. Of the three respondents who had workplace information about the syndrome, two were studying GNM course and remaining one was working as a contractual superintendent in the gynecology department of the hospital. A peculiar scenario which was observed during the study was that patients did not know that they were suffering from PCOS. For those respondents who did not know that they were suffering from PCOS, entire course of discussion took place in terms of the symptoms of the disease. I could not interfere in the working of OPD by guiding patients and making them understand about the presence of multiple cysts in the ovaries which results in oligomenorrhea, hirsutism and acne. Therefore, interviews were conducted in terms of the symptoms of the disease which mainly involved ovulatory dysfunction (irregular menstrual cycles). Rashi, aged 19, narrated her experience thus:

> *I consulted a dermatologist for acne treatment and he referred me to a gynecologist. Since then I am seeking treatment of the gynecologist and she told me to reduce my weight instead of prescribing any ointment. I do not know what this disease is.*

Radhu Kumari (24), who got married recently, stated:

> *I had irregular periods ever since I remember. However, I found it to be a blessing which spared me from going through the ordeal of bleeding every*

month. After my marriage, my mother-in-law noticed that I was not having regular menstrual cycles and she also observed that I was not conceiving either, so she took me to the gynecologist who told me that irregularity of menstrual cycles is stopping me from having a baby.

When asked about the disease she was suffering from, Sumita (18) who was in her third year Bachelors degree, stated:

My monthly cycles are not regular for quite some time and I am worried about it. Doctors say that I need to cut down the consumption of junk food and have to reduce weight. How this all is related to my irregular periods, I do not know.

In total there were 31 respondents, who did not even know the name of the disease they were suffering from. These patients were interviewed by asking questions in the context of the persisting symptoms of the disease. When the respondents were asked if they were suffering from any other disease apart from PCOS, 32 (78%) respondents mentioned that they were not suffering from any other disease; however, seven (17.1%) respondents stated that they had hypothyroidism (when not enough thyroid hormones are produced by thyroid glands); and remaining two respondents had hypothyroidism and hypertension (High blood pressure).

Oligomenorrhea is one of the main symptoms of the onset of PCOS. Direct association of PCOS with menstruation process is one of the main reasons that it is considered a stigmatising disease by the respondents in the present study. This observation adds another dimension to the existing literature which says that PCOS is stigmatising disease because of the lack of confidence and body disfigurement (in the form of acne, hirsutism and obesity) resulting due to the onset of PCOS (Kitzinger and Willmott 2002; Brady, Mousa, and Mousa 2009; Farkas, Rigo, and Demetrovics 2014). The respondents in the present study preferred not to discuss about PCOS mainly because of its direct association with menstruation. Montgomery (1974) analysed biological, psychological and sociological theories referring to the origin of menstrual taboos. Biological explanation says that production of menstrual toxins is related to the spoilage of eatables and therefore, women were restricted from participating in the day today activities; from psychological point of view, mere idea of a menstruating vagina was thought to be the reason enough for detesting menstruating women; and sociological theories state that in order to relax women from the burden of household chores during menstrual cycles, taboos were associated with it, and this is the reason that relationship of menstrual taboos is inversely proportional to the nuclear households and monogamous marriages. Johnston-Robledo and C.

Chrisler (2013) say that Menstruation is an illustration of all the three types of stigma which were explained by Erving Goffman. Women represent less powerful section of the society and more powerful members (men) associate a feeling of disgust and loathe with it because of which females tend not to discuss it with anyone except immediate female members of their family. Kissling (1996) analysed social process associated with menstruation process and the way it is dealt with in the society. She observed that adolescent girls tend not to discuss it openly with anyone and use various euphemisms while talking to each other about menstruation.

It is mainly due to this fear of being labelled that patients in the present study and their family members tend to remain tight lipped about this disease and preferred not to discuss it with anyone. In fact, majority did not discuss it with any of the male members. Therefore, respondents were asked about the person with whom they talk about their disease. To this question, more than half i.e. 22 (53.7%) respondents replied that they preferred to discuss it with their mothers or known female members of their families; nine (22.0%) discussed it with their mothers only; four (9.8%) discussed it with their mother and father; another four (9.8%) respondents discussed it with their mother and sister only. There was only one respondent who discussed it with her mother, husband and other known females of the family; and remaining one discussed it with known females only as her mother expired. Regarding question of the discussion of their menstrual problems with male members of the family, 37 (90.4%) respondents never discussed it with the male members; whereas two discussed it directly with the male members of their families; and remaining two started discussing it indirectly with their fathers after the onset of the disease.

Shreshta (28), mentioned that onset of menarche in her case was quite early which became a matter of concern for the whole family.

> *I was just nine when I had my first periods. That time I was the only child of my parents and it became a matter of grave concern for them. I was taken to the doctor who told them that I would never be having normal periods. Since then, menstruation became an open topic in our family. And now I do not hesitate to talk to my father about my condition. However, I avoid talking about it with less familiar people especially males. Because there are chances that they might not be able to understand my situation and try to mock at me.*

Infertility was another major issue which made married childless women to consult gynecologist for the treatment. There were two unmarried girls as well, who were getting married in a span of few months, were seeking treatment so that they could not face infertility in near future. Femininity and child bearing is closely related to womanhood which many women think completes them (Kitzinger and Willmott 2002). Therefore, married women in the study, often felt incomplete due to their inability to bear children. They were asked about their experiences on account of not being able to bear a child. All the married women except for those who already had children felt incomplete due to their inability to experience motherhood. Though this question was not applicable to unmarried girls yet, the women who were going to get married soon, mentioned it clearly that they did not want to face infertility in near future and that was why they were seeking treatment for PCOS. Therefore, 11 (26.8%) respondents stated that they felt or would feel incomplete for not having a baby; for 26 (63.4%) respondents, this question was not applicable as they were unmarried and also did not know about PCOS and its future consequences; and remaining four (9.8%) already had children so they never got to experience anything related to infertility.

It is argued that age and weight of the women at the time of menarche has a strong bearing on the onset of PCOS (Carroll, Saxena, and Welt 2012). Therefore, respondents were asked about their age of experience of the first menstrual cycle (menarche) to which, nine (22%) respondents mentioned that they experienced it between the age of 10 and 12; 28 (68.3%) respondents had their menarche between the age of 13 and 15; however, remaining four (9.8%) respondents experienced it between the age of 16 and 18. As far as age of the onset of PCOS is concerned, a huge variation was found. However, in majority of the cases, outset was during their teenage, as 21 respondents encountered it between the age of 11 and 19. For one respondent, inception of PCOS was between the age of 11 and 13 years; 12 (29.3%) respondents were found to be suffering from PCOS between the age of 14 and 16; eight (19.5%) respondents experienced it for the first time between the age of 17 to 19 years; and age of onset was between 20 to 22 years for seven (17.1%) respondents. There were six (14.6%) respondents who started experiencing symptoms between the age of 23 to 25 years; for one respondent, age was between 26 to 28 years; two respondents experienced it between the age of 29 to 31 years; and for remaining four (9.8%), age group was above 32 and above when they experienced onset of PCOS for the first time. Therefore, in the present study, age of menarche was not found to be an important indicator of the onset of PCOS.

Time period between two menstrual cycles is the indicator of polymenorrhea (occurrence of menstrual cycle in less than 21 days), oligomenorrhea or amenorrhea. About the question of time duration between two menstrual cycles, 30 (73.2%) respondents stated that it was after 45 days which was the main indicator of oligomenorrhea; for five (12.2%) respondents, it was between 35 to 45 days; for four (9.8%) respondents, this duration was between 25 to 35 days; and for remaining two respondents, it was less than 15 days. Therefore, almost all the respondents were suffering from irregularity of menstrual cycles.

Immediate and long-term complications of PCOS have a grave social impact on the life of women. As already mentioned, it is associated with body self-image and infertility. Pathak and Nichter (2015) studied urban middle-class women in Mumbai, and argued that 'structural vulnerabilities' upset lifestyle of the adolescents and working women. They have to perform dual role of a family caretaker and that of a bread earner, which makes them overburdened and leads to hyperandrogenism. Structural vulnerabilities of a person exist with respect to her/his position in the hierarchical order and are the product of structural violence. Structural violence results when a person gets subjected to social inequalities and gets exposed to violence by means of not being able to fulfil minimum basic needs. This kind of violence results due to existing social set up (Quesada, Hart, and Bourgois 2011; Rhodes et al. 2012). However, women in present study did not have a lifestyle typical of an urban middle-class Indian yet they were experiencing onset of PCOS, which was an intriguing case and when it was discussed with the gynecologist, he replied:

> *Present lifestyle of rural areas is not physical anymore. And pot bellies of rural women are clearly visible, however unlike western societies these women are not concerned about their body disfigurement in the form of obesity. They eat high carbs diet and perform household chores which do not require much of physical labour. And considering their socioeconomic background, it is not possible for us to make them understand the importance of various nutrients (like vitamins and minerals) in food and physical workout. They are highly vulnerable towards lifestyle diseases and this is why women in rural and peri urban areas are also highly susceptible to the diseases like diabetes and PCOS.*

Bharathi et al. (2017) in their study of South India observed that PCOS in urban areas is much higher than it is in rural areas and is inversely proportional to the level of awareness of PCOS amongst respondents. The results of their study show that 20% of the rural population was symptomatic and had not visited a physician yet. Of this entire rural sample, 69.5% had

oligomenorrhea which was not reported to any doctor. Those who had symptoms of acne and hirsutism were least bothered about it. This resonates with the results of the present study where respondents opted for mechanisms like bleach and face waxing and therefore, it was not much of a concern for them.

Ramya visited gynecologist because she put on weight and was suffering from obesity. She talked about her facial hair:

> *I use bleach to hide my facial hair, though they are not much of a concern. I am worried only about my increasing weight. If I keep putting on weight, then no one will marry me.*

Geeta Kumari assists her father in his business. She was also not concerned about the hair growth on her face, about which she mentioned:

> *I use thread to remove my facial hair. Growing weight is my only major concern. I am of marriageable age and because of my excess weight it might get difficult to find a suitable boy of my choice.*

Meena Devi, aged 27, who was married for five years, was also obese. Yet she was neither concerned about her facial hair nor about obesity, her only concern was to have a child. She articulated her experience:

> *Growth of facial hair and obesity are not problematic for me. I get my face waxed every month. All I am worried about is that I do not have a baby even after five years of marriage. Now even my mother-in-law taunts me for not giving them any grandchild for so long.*

Similarly, infertility was the main motivation for majority of married women to consult gynecologist. Motherhood marks the onset of an important phase in the life of a woman which is mainly characterised by 'self-loss' as women tend to redefine themselves during the entire course of looking after their child (Laney et al. 2015). Oberman and Josselson (1996) argue that motherhood makes a woman to lose herself in order to evolve and enter into adulthood, which is very significant in the life course development of a woman. Even feminist literature also epitomises motherhood as a defining moment of the completeness of a woman (Kitzinger and Willmott 2002). Psychosocial factors tend to construct motherhood as the most important event in the life of a woman without which, all her purpose of being a woman gets lost.

Purpose of consulting doctor for married women in the present study was to conceive and to have a baby so that they should not become a subject of social mockery. Sweety Ahuja, aged

33, stopped being a part of social gatherings as she missed being a mother so badly that having a glimpse of the children of her friends and relatives reminded her of her own incompleteness.

> *I do not go to parties and functions, especially birthday parties and Mundans (ceremony of the first balding). Such parties remind me of my own incompleteness. I have been seeking infertility treatment for quite some time and if required, I might consult doctors of repute in other states as well. I feel so inferior and incomplete.*

Many young women who were married for few months or years also became a subject of atrocities at the hands of their in-laws due to their inability to give birth. Poonam Khatri (24) was married for two years was being treated as a domestic help by her mother-in-law for not being able to produce an heir for the family. She stated:

> *My mother-in-law says that I am of no use as I could not give them a grandchild. Therefore, she treats me like a maid servant and says that I am good for nothing but to work as a domestic maid.*

Supinder Kour (25) was suffering from oligomenorrhea and was seeking medical treatment before her marriage as well. She mentioned:

> *I did not tell my mother-in-law that I was suffering from irregularity of periods even before marriage, and was consulting doctor for that. She would insult me and call me a 'defective thing' which was imposed on her son.*

Therefore, negative self-image does concern respondents in this study and it is mostly in the form of irregular menstrual cycles and infertility. Reported cases of hirsutism and acne becoming a cause of body disfigurement were very less. Unmarried women were worried about excessive weight because they were worried about their marriage, and fear of future infertility and irregular periods made them feel incomplete and less feminine. Almost all the respondents with even minor problem of hirsutism had one or another mechanism to manage it. PCOS was more of a social situation than a medical situation for the respondents.

Only Farida (19) found it difficult to cope up with the problem of hirsutism and she avoided going out. She said:

> *I do not like to go out with my friends. My facial hair is the most disturbing thing I am facing right now. I consulted dermatologist as well which was of no use*

and he referred me to the gynecologist. I do not know of how much help is this treatment going to be.

Shikha Manhas (19) thought of herself to be less of a woman due to irregular periods:

I feel myself to be incomplete and unhealthy because my periods are not normal. When I look at my friends, this feeling gets strengthened that I lack femininity and I am diseased.

Similarly, Afia (25) also felt distressed due to irregularity of periods and even consulted a godman as well. She believed that this was due to the impact of some kind of black magic.

Therefore, social impact of PCOS on the life of these women had varying dimensions, however its onset could not bring much of change their lifestyles. As it will be shown in table 2.4, their eating habits and workout regimen did not change much though they felt disfigured, incomplete and abstained from discussing it openly and discussion with male members was also a matter of embarrassment for them.

3. Environmental Factors

Table 2.4

Environmental Factors		
Eating Habits of the Respondents before onset of disease (N*=41)		
	Frequency	Percent
Consumption of oily and fatty food	18	43.9
consumption of rice, oily food and potatoes	8	19.5
Normal food habits	5	12.19
Rice, junk and oily food	6	14.65
Oily and Non-vegetarian food	4	9.76
Total	41	100.0
Change in Eating Habits after the onset of PCOS (N*=41)		
	Frequency	Percent
No Change	34	82.9
Reduced consumption of fried food	3	7.3
Reduced consumption of junk food	3	7.3

Reduced consumption of rice	1	2.4
Total	41	100.0
Workout Before the onset of PCOS (N*=41)		
	Frequency	Percent
No	36	87.8
Yes	3	7.3
Irregular	2	4.9
Total	41	100.0
Workout After the onset of PCOS (N*=41)		
	Frequency	Percent
No	29	70.7
Yes	6	14.6
Irregular	6	14.6
Total	41	100.0
BMI (N*=41)		
	Frequency	Percent
Overweight	23	56.12
Normal	14	34.13
Obese	4	9.75
Total	41	100.0
Transportation (N*=41)		
	Frequency	Percent
Public Transport	19	46.3
Owns a car	19	46.3
Prefers to walk	3	7.3
Total	41	100.0
Psychosocial Stressors (N*=41)		
	Frequency	Percent
To bear a child	5	12.2
Work Pressure	13	31.7
To bear a child and professional pressure	5	12.2
To bear a child and household chores	1	2.4
Irregularity of periods	1	2.4
Overweight	1	2.4

No Response	15	36.6
Total	41	100.0

N*= Total number of Respondents

The term 'environment' in the case of living beings is not limited to the physical environment. It consists of all the external factors which affects a human being (Nagla 2018). So, whether the factors are social or economic, they are equally a part of the environment which increases susceptibility of the people towards lifestyle diseases (Thamilarasam 2016). Main environmental factors which boost the onset of PCOS are obesity, insulin resistance, eating pattern, stress, geography and socio-economic status (Merkin et al. 2016). PCOS is a genetic disease, however its onset is not entirely due to genetic factors. Environmental factors provide a huge impetus to its manifestation.

Eating habits and workout regimen of the women are the most crucial environmental factors for the onset and management of PCOS. Doctors say that incorporation of healthy eating habits and weight loss are suggested as first line of treatment for PCOS patients. As a matter of fact, PCOS women with excess body weight are found to be suffering from more PCOS related complications as compared to those with controlled body weight (Pasquali and Gambineri 2004; Douglas et al. 2006; Sedighi et al. 2015). Since, overweight PCOS females develop more clinical complications than lean ones, risk of oligomenorrhea, hirsutism and fertility complications prevail more in them. Basically, dietary intake and physical inactivity are the two main factors which determine the extent of increase in weight and its impact on the development of PCOS (Hivert and Baillargeon 2007).

Stajcic (2013) stated that food is a part of the culture which shapes personalities, helps in communication and constructs identities. Therefore, food which is consumed and the resultant taste is a part of socialisation process which is being taught, and does not come genetically. This is why, food is one of the main cultural factors which plays a crucial role in the onset and management of a lifestyle disease in general, and PCOS in particular. As shown in table 2.4, respondents mentioned their eating pattern before the onset of the symptoms. There were 18 (43.9%) respondents who preferred oily and fatty food (in the form of *Parathas* (fired Indian bread) and *Pakoras* (fritters)); eight (19.5%) respondents claimed that in addition to oily and fatty food they preferred to eat rice and potatoes as well. There were 12.19% (five) respondents who preferred not to eat oily and fatty food (as they preferred to consume pulses and vegetables instead of fatty and starched food). And six (14.65%) respondents preferred oily and junk food

(like burger, *momos* (a type of dumplings) and noodles); remaining four (9.76%) preferred to eat red meat or chicken cooked in good amount of oil or clarified butter. After the onset of the symptoms and even at the recommendation of the doctor, very few respondents changed their eating habits as 34 (82.9%) respondents reported to adopt no change in their eating habits. However, three (7.3%) respondents mentioned that they reduced the consumption of fried food; another three (7.3%) respondents reduced the consumption of junk food and remaining one reduced the consumption of rice.

Regarding frequency of workout before onset of PCOS, 36 (87.8%) respondents stated that they never opted for workout before the onset of PCOS; for three (7.3%) respondents, their workout was always regular before the onset of the disease; and remaining two (4.9%) opted for irregular workout. And this frequency did not change much even after the onset of PCOS as 29 (70.7%) respondents reported that they still did not opt for any kind of workout; whereas six (14.6%) respondents made one or another kind of workout as their regular habit; and remaining six (14.6%) respondents were irregular with their workout routine.

Since, PCOS is directly associated with weight gain, therefore it was necessary to assess BMI of the respondents which was measured by measuring their weight and height, and then by dividing their weight by the square of their height in meters (Thamilarasam 2016). It was found that 23 (56.12%) respondents were overweight; 14 (34.13%) had normal BMI; and four (9.75%) were obese. Increasing weight also creates self-image issues as Geeta Kumari, one of the respondents, consulted doctor to deal with it. However, she denied taking any steps for managing it. When asked about going for walk, she explicitly mentioned that she was not involved in any kind of workout. She said:

> *I assist my father and brother to look after family business. And I also have to perform house hold chores. Since, I am the only female in the family, cooking and cleaning job lies with me only. And whenever I have to go out, I take a ride on my two-wheeler. I remain busy throughout the day and therefore, cannot afford time to go out for walk or for any kind of workout. However, I am thinking of joining a gym very soon.*

Most interesting reason behind consulting a doctor was that she wanted to reduce weight so that she could get a match of her own choice. However, she was not interested in bringing any kind of change in her eating habits.

Jyoti Kalsotra (36) had her son hospitalised in the department of pediatrics. She had been experiencing oligomenorrhea for quite some time and since, gynecology department happened to be the adjoining department of the pediatrics, she decided to visit the OPD in order to consult doctor. When she was asked whether she went out for walk, she replied:

> *In the morning, I encounter a lot of street dogs outside my house, and inside it is not possible to manage walk. In the evening, I remain busy with kitchen chores. Therefore, I cannot afford a daily walk.*

Walking contributes to a major source of workout and few respondents preferred to walk instead of opting for a vehicle to commute from one place to another. Regarding preferred mode of commutation, 19 (46.3%) respondents preferred public transport; whereas another 19 (46.3%) respondents had a vehicle at their places which enabled them to avoid walking in order to reach their desired destination. Only three (7.3%) respondents preferred to walk instead of opting for any kind of vehicle to commute.

Concept of 'docile body' changes with respect to society and culture. Docile body is the one which is in lines with socially defined ideal body (Barry and Yuill 2012). And this definition varies with respect to sex and gender as well. In the present study, docile body of a woman is something which is not experiencing any medical deformity. Therefore, there should not be any menstrual disturbance and no problem in the acquisition of motherhood. However, being ignorant of the role of excess weight in the onset and management of PCOS, these women seldom try to make an effort to control and manage their weight. They hardly strive to opt for healthy eating habits and physical workout. Mass scale unawareness is the main reason that disciplinary forces of the society in the form of 'anatomo-politics' remain unable to compel these women to regulate their lifestyle behaviours. This is a big hinderance in the 'sick role' acquisition for the women suffering from PCOS. Therefore, lack of awareness takes a huge toll in the management of PCOS.

Stress is another environmental factor which plays a prominent role in the onset of PCOS and social factors themselves become a cause of psychological stress in the life of those suffering from PCOS. When respondents were enquired about any psychosocial factor which is acting as a cause of tension for them, five (12.2%) respondents replied that the only strain which bothered them was to have a child; another five (12.2%) respondents mentioned that in addition to the burden of giving birth to a child, they also had work place pressure which acted as a source of mental stress for them. There were 13 (31.7%) respondents who were teenage

students, claimed that they had to work veryhard in order to perform well in their studies; one respondent was burdened because of the pressure to bear a child and of household chores; another respondent mentioned that she was stressed only because of irregularity of her periods; and one respondent was in distress because of her increasing weight. This is how 'structural vulnerabilities' also act as environmental factor in determining the course of PCOS. Remaining 15 (36.6%) respondents said that they were not worried about anything at all.

Tanya Ghai was going to appear for her higher secondary exams in sixth months. This made her remained pinned to her chair in order to study. However, this was taking a toll on her health as she was stressed because of studies, and longer sitting hours made her life sedentary which was increasing her weight. She narrated her problem as:

> *I have to perform well in board exams. This is why, I stopped playing with my friends. My mother says that it is a matter of few months, then I will be free to play and hang out. However, suddenly my periods got irregular. Earlier, I used to get periods within 30-40 days where as now it has been two months since I had my periods. Doctor says that I should reduce my weight, and that needs time. I attend coaching classes after the school and after that I need time for self-study as well. I do not have even fifteen minutes to go for walk.*

These structural vulnerabilities are the main factors which is leading to the rise of PCOS in urban middle-class Indians (Pathak and Nichter 2015). However, as mentioned earlier, respondents in the present study belonged to different socio-cultural and regional backgrounds varying from urban, semi-urban to rural. Therefore, structural vulnerabilities are not area specific, and exist with respect to social and economic status of a person.

4. Health Seeking Behaviour

Table 2.5

Health Seeking Behaviour		
Present Knowledge of PCOS (N*=41)		
	Frequency	Percent
Nothing	31	75.6
Leads to lifestyle diseases like diabetes	5	12.2
leads to infertility	1	2.4
Presence of multiple cysts in ovaries	3	7.3

leads to irregularity of periods	1	2.4
Total	41	100.0
Source of Present Knowledge About PCOS (N*=41)		
	Frequency	Percent
Discussion with friends and doctors; internet	4	9.8
Discussion with friends	1	2.4
Discussion with Doctor	1	2.4
Discussion with sister	1	2.4
Internet	3	7.3
No Response	31	75.6
Total	41	100.0
Type of Treatment Opted (N*=41)		
	Frequency	Percent
Allopathic	25	61.0
Allopathic and Ayurvedic	4	9.8
Allopathic and Godman	4	9.8
Not seeking any treatment	1	2.4
Allopathic and home remedies	7	17.1
Total	41	100.0
Any Difficulty in the Management of PCOS (N*=41)		
	Frequency	Percent
Household chores and workplace pressure	3	7.3
None	23	56.1
Work place pressure	7	17.1
Household chores	4	9.8
Lazyness	4	9.8
Total	41	100.0
Who Provides finance for the treatment (N*=41)		
	Frequency	Percent
Father	20	48.8
Father and Mother	1	2.4
Self	5	12.2
Husband	11	26.8
Mother	4	9.8
Total	41	100.0

N*= Total Number of Respondents

Health seeking behaviour refers to the process of disease management which is being sought by the patient. And it mainly depends upon the knowledge level of the disease. More than physical distress, PCOS has psychosocial distress in the life of women suffering from it. As it has been mentioned in the earlier sections that women face stigma, lack of self-esteem and incompleteness. Therefore, these women try to manage it in best possible manner. The factors which play a crucial role in the disease management are henceforth discussed in detail.

Indian women suffer from lack of awareness about PCOS, literature shows that majority of females in the country do not know about the harmful effects of increased weight and physical inactivity. Impact of PCOS changes during different stages of life as during adolescence patients suffer from hirsutism and it gets aggravated when it results in infertility during adulthood. However, irregularity of menstruation always remains an important manifestation of PCOS (Rajkumari et al. 2016; Pitchai, Sreeraj, and Anil 2016). Awareness level of the patients about PCOS was found to be very poor. As shown in table 2.5, respondents described present knowledge of the PCOS, which they gathered on account of the onset of PCOS. They were asked to explain about the disease they were suffering from and 31 (75.65%) respondents still knew nothing which they could explain about the disease; however, for five (12.2%) respondents PCOS leads to the onset of other lifestyle diseases like diabetes and can also lead to infertility; for one respondent, PCOS leads to infertility; three (7.3%) respondents said that it occurs due to the presence of multiple cysts in ovaries; and remaining one respondent stated that it leads to irregularity of periods. Since, 10 respondents knew something or other about the disease following its onset, therefore, they were further asked about the source from where they could gather this information. There were four (9.8%) respondents who discussed it with the doctor and their own friends, and also surfed internet to gather information about it; one of the respondents discussed it with her friends and came to know about PCOS; for another respondent, her gynecologist explained her about PCOS; another respondent discussed it with her sister who was working in hospital and came to know that the disease she was suffering from was PCOS; and remaining three (7.3%) respondents explored only internet to gather information about PCOS.

In this context, Rohini stated:

> *I know I am suffering from PCOS but this is all I know. I tried to read literature on it and to understand this disease. However, I couldn't understand anything, so now I do not even try to understand it.*

Mamta, who was married for 6 years, came to know about PCOS from her sister. She expressed her situation:

> *My sister works in a hospital and she discussed my condition with a gynecologist there. Doctor suspected that I was suffering from PCOS; and without the information of my in-laws, I visited doctor and performed tests which were recommended. Reports confirmed that I had PCOS and it was the main reason I was not being able to conceive. Long back I told my in-laws that I should consult a doctor to seek fertility measures. However, they said that due to the impact of some black magic, all their daughters-in-law could not conceive in time, so it will also take me few years to experience motherhood. Now I am consulting a gynae without the information of my in-laws.*

Not only Mamta's in-laws believed in black magic but few other respondents as well; and also believed in consulting a godman as an alternative source of medicine. Friedson (1970) stated that layman construction of an illness is driven by many forces as result of which not everyone tries to seek medical consultation for curing it. It is not necessary that by believing oneself to be ill, one opts only for bio-medical services. Social sanctions and cultural exposure lead them towards a socially more desirable way of treatment. And this course of treatment can be and cannot be bio-medical (Friedson 1970). Therefore, respondents were asked about the type of treatment they opted for in order to keep PCOS under check, and 25 (61%) respondents replied that they were opting for allopathic treatment only. There were four (9.8%) respondents who opted for Allopathic as well as Ayurvedic medication in order to either regularise their periods or to help them in improving their fertility; another four (9.8%) respondents admitted that in addition to allopathic treatment, they were consulting a godman as well. One of the respondents stated that she was not seeking any kind of treatment as she had two children and did not feel the need to regularise her periods. Remaining seven (17.1%) respondents opted for home remedies as well as allopathic medicines.

Shameem wore a *Taveez* (amulet) to protect herself against the evil eye and to regularise her periods. She believed that *buri nazar* (evil eye) was the main reason that disturbed the functioning of her body. However, she had a rich history of metabolic diseases in her family and her mother was also suffering from PCOS.

Similarly, Nikhat also consulted a godman. In her words:

> *I do not know why I encountered irregularity of periods. It is absolutely disturbing and I thought peersaab (godman) could be of great help. So, my*

mother took me to him. Medication and seeking blessings of the almighty are two different things however, I just want to regularise my periods by any means.

While seeking treatment, patients come across different kinds of suggestions from friends and relatives. When respondents were asked about the suggestions which they received to manage their disease, they replied that they never discussed it with anyone. However, married childless women did receive suggestions pertaining to fertility, and were advised to go to a particular godman or suggested to eat one or another thing which could help them to conceive. Respondents said that such suggestions were extremely annoying and they did not like them at all. About the matter of not discussing PCOS openly just like other diseases. One of the respondents, Neha Mahajan stated:

Menstruation is not an openly discussed entity in our society, therefore people really have an extremely weird approach towards it. If I happen to explain it to anyone, then there are chances that the person might not be knowing it; and even if I make her/him understand what this disease is, I am sure that their reaction would be awkward and might make me uncomfortable.

Fearing such awkward reactions, Deepti avoids discussing infertility with anyone but her doctor and husband.

I can hide that I experience irregular periods but how can I hide that I have not given birth even after eight years of marriage. This attracts many unwelcoming suggestions which irritate me a lot.

Such incidents lead to the labelling of an illness and the person suffering from it in the society. This labelling has a negative impact on the health seeking behaviour of the patients as they fear that open consultation might further strengthen negative connotation associated with the disease. This negative labelling is the stigma which gets associated with the patient. This stigma in turn disturbs normal routine of the patient and leaves her/him ashamed, and distressed (Friedson 1970).

Respondents were also asked about the problem(s) which they encounter while following the regimen meant for disease management. To this question, 23 (56.1%) respondents replied that they do not have to face any kind of problem; however, for three (7.3%) respondents, it was the burden of household chores and workplace pressure which did not allow them to go for walk. There were seven (17.1%) respondents who claimed that their studies or jobs (workplace pressure) does not leave them with time to follow instructions of the doctor regarding workout

and eating; four (9.8%) respondents had the burden of household chores as an obstacle. Remaining four (9.8%) respondents felt too lazy to go out for walk and to reduce their weight.

Most important factor which determines health seeking behaviour of any person or community is the expenditure incurred on the management of the disease. Indian women are mostly dependent on their male counterparts for their financial matters, therefore, respondents were asked about the source of money which they receive for the treatment. To this, 20 (48.8%) respondents replied that their fathers paid for the treatment; for one respondent, both the father and mother paid for the treatment; five (12.2%) respondents self-financed their treatment; 11 (26.8%) respondents relied on their husbands for the financial support; and for remaining four (9.8%) respondents, their mothers paid for their treatment.

Health seeking behaviour is also determined by familial experiences which act as a source of knowledge production and dissemination. It was observed in the case of Stuti and Rohini who were real sisters. Stuti was married for eight months however, she was not able to conceive even after many attempts. So, her own mother took her to the doctor where it was discovered that the irregularity of her periods, which she was facing for many years, was the actual cause of the trouble. After witnessing Stuti's case, her mother decided to bring unmarried Rohini to the doctor as well because Rohini was also suffering from oligomenorrhea. Onset of fertility complications in the life of Stuti made her mother to be concerned about the future of Rohini as well.

Idea of motherhood has been given extreme importance in all societies and is directly associated with the completeness of a married woman. Even, doctors pay more attention to this aspect of the disease. As Niti mentioned:

> *I was sixteen years old when I heard that I had POCS. I knew nothing about it, it was just a situation of irregular periods for me. When gynecologist talked to my mother, she said that I would not be able to conceive in near future, if this condition persists. I was so scared at the mention of pregnancy at such a tender age that I started crying.*

Similarly, Fariha visited doctor because her own mother was also suffering from PCOS and was very well aware of the main symptoms of it. Therefore, personal experiences also work as sources of knowledge production for the patients which determine their health seeking behaviour.

5. Discussion

Knowledge construction in the field of health takes place at the level of physician and at the level of patient (Friedson 1970). Here, I would like to argue that knowledge production and its dissemination at the level of patient, in case of PCOS, further takes place at two levels viz. at the level of deciphering PCOS and at the level of health seeking behaviour. Studies on PCOS from social angle till now focused on the Western perspective of the disease (Lynn Ellerman 2012; Kitzinger and Willmott 2002). However, study by Pathak and Nichter (2015) focused on Indian women yet it was limited to the middle-class women who were residing in a metropolitan city, also known as India's economic capital, Mumbai. Therefore, women from rural and semi urban areas cannot connect themselves to PCOS but to a labyrinth of peculiar symptoms. These symptoms sometimes increase their weight, may also lead to hirsutism, sometimes leads to oligomenorrhea or causes infertility. Results of these symptoms is the loss of their self-confidence, questioning of their own identity, avoiding social interaction. Sometimes, these symptoms do not create any social or personal disturbance at all, as women do not feel their femininity being challenged on account these symptoms. Parsons (1991) when talked about sick role, argued that it is important for the person to be acknowledged by the society to be deviated (secondarily) which qualifies him/her for the sick role. Therefore, patients tend to construct themselves to be incomplete, disfigured and lacking femininity which is further approved by their family members, and qualifies them to acquire sick role.

It is because of not being 'female' enough that women get subjected to stigma in the society, which reaffirms their feeling of being incomplete. As it was observed in the case of Anita and Jyoti, they were both above thirty-five and had children which spared them from being subjected to stigma and therefore from the acquisition of the sick role. Mere visit to the doctor and asking for medicine, does not qualify them to be a performer of the sick role. There was no personal or familial concern associated with their visit to the doctor. Jyoti visited doctor because her own son was hospitalised in the adjoining department; and Anita, being an employee in the same hospital thought of paying a visit to the doctor and to discuss her symptoms with the doctor. School going teenagers and young adults visited doctor to get rid of the symptoms which were challenging their self-confidence and making them vulnerable to future threats which respondents felt might get them socially ostracised.

Since patients did not know that the disease they were suffering from was PCOS therefore, they tended to restrict the discussion up to irregularity of periods and infertility (in majority of the cases). This had a bearing on their health seeking behaviour as seeking consultation from a godman was believed to be a source of restoring femininity. Such alternative sources of medication provide a glimmer of hope to these patients. Similarly, exchange of disease knowledge with friends provide them with a scope of better management of the disease.

When human body is constructed on account of the impact of a disease, it is constructed as civilised or grotesque (Lupton 2000). Women in the present study tend to suffer from a grotesque body. And it is not because of its appearance but because of its inability to suffice the definition of a socially constructed woman. Only those women were found to be distressed who found themselves unable to experience 'normal' womanhood. Prevalence of oligomenorrhea, resulting infertility, appearance of men like hair were the symbols which challenged their femininity (Kitzinger and Willmott 2002). Susan Sontag (Lupton 2000) mentioned that '*Nothing is more punitive than to give a disease a meaning- that meaning being invariably moralistic one.'* However, such meanings are always being contested by means of incessant attempts being made by the patients to transform their bodies from grotesque to civilized. And this process leads to different set of knowledge construction about PCOS from patient's point of view.

Knowledge construction and health seeking behaviour was also found to be taking place at familial level where onset of symptoms in one member made other member to timely opt for doctoral consultation. Conversations and exchange of knowledge by discussing personal experiences acted as a main source of knowledge construction and dissemination in the case of different manifestations of PCOS (oligomenorrhea, infertility etc.). However, absence of one single term to define their state was also a cause of grief which requires some special efforts to educate and disseminate biomedical information about the onset and management of PCOS. This is how *anatomo-politics* has a bearing on the disease management routine of the patients. Societal pressure to acquire a docile body is an indirect disciplinary act of the society to make these patients opt for *technologies of the self* and strive to attain a PCOS free health condition.

Therefore, this section was full of intriguing results which directly resulted due to social construction of PCOS and made it a stigmatising disease because of its direct association with menstruation, onset of infertility and psychological distress. Since, doctors also rely on their own cultural exposure to construct ways of dealing with the patients. Therefore, it was due to

their sociocultural experiences that doctors treated PCOS patients by communicating with them in terms of the symptoms and not in terms of PCOS. However, gynecologist did not explain the reason of not detailing about this disease to the patients. It can be assumed that just like diabetes, PCOS also needs a whole team of experts which deal with the different aspects of PCOS. It can finally be argued that challenges posed by PCOS are more social in nature than physical because of which studies dealing with the impact of PCOS never miss out on psychosocial impact of PCOS (Lynn Ellerman 2012; Brady, Mousa, and Mousa 2009; Farkas, Rigo, and Demetrovics 2014; Kitzinger and Willmott 2002; Pathak and Nichter 2015).

3

This Disease Is Not A Big Deal; It Can Easily Be Taken Care Of: Narratives of The Diabetic Women

Around 500 million people are suffering from diabetes worldwide; and of this half billion population, nearly 80% reside in low and middle-income countries (Aldworth et al. 2017). The total number of deaths due to diabetes in India in 2015 were nearly 5 million which was more than combined number of lives lost due to infectious diseases like HIV, cholera, Tuberculosis and malaria (Tripathy et al. 2017). India houses 69.1 million diabetic patients of the world and is next only to China, as per figures of the year 2015 (Aldworth et al. 2017).

Indians are found to be centrally obese due to which their BMI remains higher than other races (Joshi 2015). They are highly susceptible to central adiposity which is strongly associated with impaired functioning of glucose (Ramachandran et al. 2001). India is expected to house 134.3 million diabetic patients by 2045 and will take over China as the country with highest diabetic population in the world. Right now, she stands second in the world on the number on deaths due to Diabetes, next only to China (Aldworth et al. 2017). Despite of having a huge chunk of population suffering from diabetes, more than 50% diabetic population in India remains undiagnosed (Joshi et al. 2008). Body size of Indians is very small whereas their adipose tissue accumulation is very high. It is due to this reason, Indians are *thin-fat.* And in spite of having Body Mass Index (BMI) under 25 kg/m^2, susceptibility of Indians remains very high for diabetes and other metabolic diseases (Yajnik 2004). It is important to note here that the type of diabetes which results mainly due to socio-cultural and economic factors is T2DM. Type1 Diabetes Mellitus (T1DM) on the other hand, is considered to be an auto-immune disease which results mainly due to hereditary factors. T2DM on the other hand is an adult onset disease and lifestyle factors play a prominent role in the onset of this diabetes (Ferzacca 2012).

In 2012, diabetes was found to be the fifth leading cause of death amongst women. Moreover, amongst WHO nations, women are found to be less physically active than men; with 27% women and 20% men found to be physically not active as per requirement. This percentage is even worse for adolescents as 84% girls and 78% boys were classified as not meeting minimum criteria of physical activity. Therefore, women are more obese or overweight than men. WHO recognises women as one of the poorest groups of the society who can seldom afford time to indulge in physical activities meant to control their BMI (WHO 2016b). Therefore, women

throughout world are facing challenge of increase in body weight. If specifically, Indian women are to be mentioned, in addition to rising percentage of obesity, they also face challenge of social and cultural disparity and lack of health care facilities which makes it necessary to go through these factors using sociological lens to explore the impact of rising menace of diabetes amongst women.

Table 3.1 represents Pseudonyms, age, occupation and marital status of the respondents so that their narratives can be explained clearly in upcoming sections.

Table 3.1

General Profile of the Respondents

S. No.	Pseudonym	Age	Profession	Religion	Marital Status
1	Anita	49	Housewife	Hindu	Widow
2	Bharti Kundal	42	Accountant	Hindu	Married
3	Phoolan Wakhloo	54	Housewife	Hindu	Married
4	Manisha	44	Govt. Teacher	Hindu	Married
5	Pushplata	61	Rtd. Accountant	Hindu	Widow
6	Priya Kohli	54	Assistant Accounts Officer	Hindu	Married
7	Surinder Kour	72	Housewife	Sikh	Married
8	Snehlata	62	Rtd. Peon	Hindu	Married
9	Sunita	38	Housewife	Hindu	Married
10	Yogmaya	64	Rtd. Chief Accounts Officer	Hindu	Married
11	Harbans Kour	48	Housewife	Sikh	Married
12	Tripta	52	Housewife	Hindu	Widow
13	Raj Kumari	45	Domestic Help	Hindu	Married
14	Hamida Begum	48	Housewife	Muslim	Married
15	Kailasho Devi	40	Housewife	Hindu	Widow
16	Dev Kanya	69	Housewife	Hindu	Married
17	Rajni	35	Housewife	Hindu	Widow
18	Prakasho Devi	61	Housewife	Hindu	Married
19	Sushma	65	Rtd. Govt. Teacher	Hindu	Married

20	Ratna	34	Housewife	Hindu	Married
21	Lajwanti	69	Housewife	Hindu	Widow
22	Kusum	54	Housewife	Hindu	Married
23	Dhanwanti	58	Housewife	Hindu	Married
24	Bimla	56	Housewife	Hindu	Married
25	Banita	54	Housewife	Hindu	Widow
26	Rajkishori	53	Housewife	Hindu	Widow
27	Lajjiya	50	Housewife	Hindu	Married
28	Kanta	56	Housewife	Hindu	Widow
29	Sulakshna	70	Housewife	Hindu	Widow
30	Poonam	50	Housewife	Hindu	Widow
31	Sonia	54	Govt. Teacher	Christian	Widow
32	Sulekha	46	Govt. Teacher	Hindu	Widow
33	Toshi	51	Housewife	Hindu	Married
34	Prabhjot Kour	48	Housewife	Sikh	Widow
35	Lata Kumari	52	Housewife	Hindu	Married
36	Geeta Devi	51	Housewife	Hindu	Widow
37	Kamla	52	Housewife	Hindu	Widow
38	Kulwant Kour	38	Factory Worker	Sikh	Married
39	Premlata	62	Housewife	Hindu	Married
40	Pushpa	44	Housewife	Hindu	Married
41	Neena	61	Housewife	Hindu	Married

1. Socio-economic and Demographic Profile

Table 3.2

Socio-economic and Demographic Profile of the Respondents		
Age (N*=41)		
Age Group	Frequency	Valid Percent
30 - 39	4	9.8
40– 49	10	24.4
50– 59	16	39.0
60 – 69	9	22.0
70 - 79	2	4.9
Total	41	100.0

Mean Age: 53.29		
Religion (N*=41)		
Religion	Frequency	Percent
Hindu	35	85.4
Sikh	4	9.8
Muslim	1	2.4
Christian	1	2.4
Total	41	100.0
Occupation (N*=41)		
Occupation	Frequency	Percent
House wife	30	73.2
Government Job	5	12.2
Retired from Government Job	4	9.8
Daily wage earner	2	4.9
Total	41	100.0
Monthly Income of the Family (Rupees in Thousand) (N*=41)		
Income Group	Frequency	Percent
< 10	1	2.4
10 - 19	5	12.2
20 - 29	14	34.1
30 - 39	5	12.2
40 - 49	3	7.3
50 - 59	6	14.6
70 - 79	5	12.2
100 >	2	5
Total	41	100.0
Mean Income (In Thousand): 37.19		
Family Structure (N*=41)		
Family Structure	Frequency	Percent
Nuclear	20	48.8
Joint	21	51.2
Total	41	100.0
Number of Family Members (N*=41)		
Family Members	Frequency	Percent
2 - 3	8	19.5
4 - 5	23	56.1
6 - 7	9	22.0
8 - 9	1	2.4
Total	41	100.0
Mean score: 4.60		

*N= Total number of respondents

According to WHO, socio-economic and demographic factors are the major determinants of the health status of a population. With a decline in fertility, income increases; increase in income leads to urbanisation and availability of better medical facilities which ultimately shifts disease burden from infectious diseases to NCDs or lifestyle diseases. Increase in the level of education, especially amongst women, has a great impact on their health status (WHO 2009). Marmot et. al. (1987) say that social class is not a variable in health studies but an important source of analysing relation of social structure and determinants of health.

According to Data collected for the study, as shown in table 3.2, majority of the respondents i.e., 16 belonged to the age group of 50-59 years forming 39% of the total population; 24.4% (10) respondents belonged to the age group of 40-49 years; age group of 60-69 years was the third most suffering group due to diabetes with 9 (22%) respondents falling into it; 9.8% i.e., four respondents were from the age-group of 30-39 years whereas only two respondents belonged to the age-group of 70-79 years. Age distribution of diabetes among women in Southeast Asia shows that most vulnerable age-group for females is 60-69 years; age-group of 50-59 years is the second most vulnerable age group of women; for women of 70-79 years, they are placed on the third spot regarding their susceptibility towards diabetes; and 40-49 years old women are the fourth most suffering group because of diabetes (International Diabetes Federation 2017). Both the data sets lead to the conclusion that women in their post-menopausal period experience highest susceptibility towards diabetes in the entire Southeast Asian region.

Religious composition of the respondents shows that majority of the respondents (35) were Hindus forming 85.4% of the total respondents whereas four (9.8%) respondents belonged to Sikh religion. There was only one Muslim and one Christian respondent. Religious beliefs have a bearing on the health seeking behaviour of the patients, and hence it is important to document it. Hamida Begum (48) was the only Muslim respondent of the study, stated:

> *In our religion, it is believed that women, who go out of house for walk or running are morally corrupt and not fit for taking care of the family. Therefore, I abstain from going out.*

Amongst other factors determining socio-economic and demographic profile of the respondents, majority of the respondents were housewives and were directly dependent on male members of their family for economic support. In total, 30 respondents (73.2%) were housewives and five (12.2%) respondents had a government job. There were four (9.8%)

respondents who were retired from government job and two respondents were working as daily wage earner. One of them was working as a domestic help and another one was a class IV employee. As far as income group of the respondents is concerned, majority of the respondents (34.1%) had family monthly income between 20,000-29,000 and six (14.6%) respondents belonged to the income group of 50,000-59,000. There were five (12.2%) respondents who had monthly family income between 10,000-19,000; another five respondents (12.2%) had monthly income between 30,000-39,000; and another group of five respondents belonged to the income group of 70,000-79,000. In total three (7.3%) respondents had monthly family income between 40,000-49,000; two respondents belonged to the income group of more than Rs.1,00,000 per month and remaining one respondent had monthly family income less than Rs.10,000. Out of total 41respondents, 20 respondents (48.8%) were from nuclear families whereas majority i.e., 21(51.2%) belonged to joint family structure. As far number of their family members is concerned, more than half of the respondents, i.e., 56.1% (23) respondents had 4-5 members in their families; there were 6-7 members in the families of 22% (nine) respondents; 19.5% (eight) respondents had 2-3 members in their families; and remaining one respondent had 8-9 members in her family.

2. Impact of Diabetes on the Lifestyle of the Respondents

Table 3.3

Impact of Diabetes on the Lifestyle of the Respondents		
BMI (N*=41)		
	Frequency	Percent
Overweight	21	51.2
Normal	12	29.3
Obese	3	7.3
Lean	5	12.2
Total	41	100.0
Year of Onset of disease (N*=41)		
	Frequency	Percent
< 2000	1	2.4
2000 - 2004	4	9.8
2005 - 2009	10	24.4
2010 - 2014	20	48.8
2015 <	6	14.6
Total	41	100.0
Perceived Cause for the onset of Diabetes (N*=41)		
	Frequency	Percent
No Idea	20	48.8

Stress	11	26.8
Lifestyle	3	7.3
Excess consumption of table sugars	5	12.2
drug Induced	2	4.9
Total	41	100.0
Family Members with Diabetes (N*=41)		
	Frequency	Percent
Father	5	12.2
Father and Brother	2	4.9
Brother and Son	1	2.4
Father and Mother	1	2.4
Father, Mother, Brother and Sister	4	9.8
Mother	5	12.2
Brother and Sister	6	14.6
No Idea	12	29.3
No response	5	12.2
Total	41	100.0
Eating Habits of the Respondents before the onset of Diabetes (N*=41)		
	Frequency	Percent
Excess consumption of rice, oily and fatty food	14	34.1
Excess consumption of Non-vegetarian, oily and fatty food	8	19.5
Excess consumption of oily and fatty food	8	19.5
Excess consumption of starched rice	5	12.2
Normal eating habits	6	14.6
Total	41	100.0
Change in eating habits after the onset of Diabetes (N*=41)		
	Frequency	Percent
Yes	33	80.5
No	8	19.5
Total	41	100.0
Role of Table Sugar in the onset of Diabetes (N*=41)		
	Frequency	Percent
Yes	17	41.5
No	8	19.5
No Idea	16	39.0

Total	41	100.0
Role of Mental Stress in the onset of Diabetes (N*=41)		
	Frequency	Percent
Yes	27	65.9
No	5	12.2
No Idea	9	22.0
Total	41	100.0

* N= Total Number of Respondents

There is no uniformity in diabetes prevalence in India as socio-cultural, regional and economic differences make different causes responsible for the onset of diabetes amongst people belonging to different categories (Mohan et al. 2008). Data suggests that the rate of diabetes prevalence is lower in rural areas. However, nearly 70% of Indian population still lives in rural areas which implies that more vulnerability towards diabetes lies there (PTI 2013; Viswanathan 2017).

BMI is one of the major determining factors for the onset of diabetes. BMI is particularly helpful in assessing adiposity and its association with lifestyle diseases like T2DM, cardiovascular diseases, osteoarthritis, sleep apnea etc. (Thamilarasam 2016). Metabolic and cardiovascular risk factors among South Asians are very high as compared to Caucasians. So, for Indians, BMI limits have been revised keeping in view the rising menace of lifestyle diseases. Revised BMI limits to categorise an Indian as normal should be 18.5-22.9kg/m^2. Person with BMI <18.5 is an underweight whereas any one with BMI 23.0-24.9kg/m^2 is overweight and individuals with BMI ≥25 are obese (Aziz et. al. 2014). Obesity is further categorised as class I obesity, class II obesity and class III obesity, depending upon increase in body weight. Relative risk of developing diabetes due to over weight is 1.5; for class I obesity it is 2.5; for class II, relative risk is 3.6; and for class III it is 5.1 (Ganz et al. 2014). Results of the present study show that respondents developed irregular eating habits before onset of diabetes and faced high BMI levels. As shown in table 3.3, more than 50% (21) respondents were overweight and 29.3% (12) respondents had normal BMI. There were five (12.2%) respondents who were lean whereas three (7.3%) respondents were obese. Interaction with these patients revealed that they had even higher weight ratio before detection of the disease, it was due to the impact of diabetes that they lost their weight.

As far as year of onset of the disease is concerned, as shown in table 3.3, more than 50% respondents developed diabetes during last 13 years. There were 20 (48.8%) respondents who

were detected diabetic between 2010 A.D.-2014 A.D.; and onset of diabetes was detected in 10 (24.4%) respondents between 2005 A.D.-2009 A.D. For remaining 11 respondents, 6 (14.6%) respondents were found to be suffering from diabetes after 2015 A.D.; 4 respondents developed diabetes between 2000 A.D.-2004 A.D.; there was only one respondent who experienced onset of diabetes before 2000 A.D. Age of the onset of a disease has a great impact on the social stigma related to it. South Asian females and their family members tend to hide their disease from the prospective grooms and their family members because chronic illness in general, and diabetes in particular are seen as potential barrier in getting a suitable prospective groom. It is also said that many times bridal side ends up paying huge amount of dowry to get their girl married, if she is suffering from diabetes (Goenka et al. 2004; Singh, Cinnirella, and Bradley 2012).

There always exists a biological explanation of the disease. However social explanation of the disease is something which dominates the course of action which is being followed by the patients. Friedson (1970) explained that identification of illness and acts of diagnosis and treatment are social activities which are exclusive to human beings. Therefore, sociologists select/identify questions which aim at studying social situations of a 'medically diagnosed illness.' Therefore, it was observed that patients perceive one or another factor responsible for the onset of an illness. These perceived factors may or may not be in tune with the medical explanation of the illness. Therefore, it is necessary to understand the factors which people think, made them diabetic. During the course of present study, it was found that majority (20) of the respondents (48.8%) had no idea as why they got afflicted with diabetes. There were 26.8% (11) respondents who attributed mental stress to be the cause of onset of diabetes; 12.2% (five) respondents attributed excess consumption of table sugar to be the reason for the onset of diabetes; for 7.3% (three) respondents, their lifestyle was the main reason which made them diabetic; and two respondents claimed that their diabetes was drug induced.

Respondents constructed their encounter with diabetes which was found to be in tune with the Foucauldian ideas of knowledge, power and discourse where common discourse and exposure to other sources of information enable an individual to formulate her/his own perception about a disease (Turner 2000). Speaking on the lines of Foucault, Chris Shilling (Lupton 1997) talked about lived experiences of the body which are always surrounded by discourse which affects as well as gets affected by knowledge and society. It is important to mention here that unlike Marxist and Weberian thinking, knowledge for Foucault is a source of power generation, a micro entity, which is embedded in a day activities (Turner 1997).

Of 11 people who attributed stress to be the main reason behind onset of their diabetes, none of them were told by medical practitioners about it. However, exposure to the sources of mass media and interaction with other diabetic people made them conclude so.

Priya Kohli, a 54 years old working woman in government sector, narrated:

> *My husband died of coronary artery disease, father died of Myocardial Infraction and my brother is also suffering from diabetes. So, I did have genetic predisposition and my lifestyle is still sedentary. However, onset of diabetes in my case is due to mental stress.*

During the course of interview, she also mentioned that long back she developed backache and doctor told her to do exercise to reduce her weight. She added:

> *How was it possible for me to do exercise when I was already suffering from backache! What if exercises would have worsened my condition. Medicines were of no help so, now I have opted for physiotherapy.*

She opted for physiotherapy on the recommendation of a friend of hers. This is one of the cases in which respondent herself constructed ideas governing the course of her treatment. It does not mean that her approach was fabricated or a work of fantasy, it was a medically acceptable approach. However, it was not what she was suggested by the doctor to do. This is how social construction of illness from patients' point of determine their course of disease management.

In addition to lifestyle factors, genetic susceptibility also increases vulnerability towards T2DM many times. All the respondents of the study had one or another member in their family suffering from diabetes. Results show that 12 (29.3%) respondents did not know whether they have any person suffering from diabetes in their family or not; and six (14.6%) respondents had their brother and sister suffering from diabetes in their family. There were 12.2% (five) respondents who had their father suffering from diabetes; another 12.2% (five) respondents had their mother suffering from diabetes; and one more group of 12.2% (five) respondents came up with no response to the question. For four (9.8%) respondents, their father, mother, sister and brother were suffering from diabetes; for one of the respondents, her father and mother were suffering from diabetes; another respondent had her brother and son were suffering from diabetes; and remaining two respondents said that they had their father and brother suffering from diabetes.

According to Turner (2000), social constructivism in medical sociology entails three important dimensions. First is the meaning of social reality which is a product of social exchange and hence, keeps on changing. Secondly, these meanings are always contested hence, they can never be taken for granted. Thirdly, human beings keep discussing and striving for changing these meanings. In this context, it has been observed that people provide a meaning to the food which they eat and this meaning is contested by the doctor. Patients again strive to provide a new meaning to it as their attachment with food is not only biological but social and emotional as well. In a study of the impact of Nepalese food habits on the Nepalese diabetic patients residing in Nepal and Australia, Sapkota et al. (2017) found that people have a social and emotional attachment with their food and food habits which poses a barrier to the diabetes self-care management. Preparation of carbohydrates rich food is a way of expressing hospitality during parties and dinners. It is considered very impolite to refuse these dishes; hence, patients face a very tough task in managing their diabetes. This corresponds to the pattern which was observed in the present study as it has been found that people are not ready to compromise their eating habits. India and Nepal share cultural affinity and their culinary traditions also form a part of it (Ghosh 2015). Thus, food has sentimental and cultural value with which people cannot compromise so easily. So, to satisfy their taste buds is more important for the patients, than managing their disease. As far as eating habits are concerned, excess consumption of oily and fatty food was a common phenomenon for majority of respondents before onset of diabetes. There were 14 respondents who (34.1%) consumed rice, oily and fatty food in excess before the onset of diabetes; for eight (19.5%) respondents, it was excess the consumption of red meat, oily and fatty food which acted as a factor for the onset of diabetes; and another eight respondents (19.5%) said that they ate oily and fatty food in excess before the onset of diabetes. There were 12.2% (five) respondents who used to consume excess of starched rice before onset of diabetes; and remaining six (14.6%) respondents had normal eating habits earlier. However, after the onset of diabetes more than 80% (33) respondents changed their eating habits and tried to follow the diet which was suggested by their diabetologist.

During the course of interviews, a small group of diabetic patients happened to get together and approached doctor and requested him to allow them to eat rice. At this the doctor rebuked and said:

Isn't it much better that by restricting yourself from one food item, you can spare yourself from an extra tablet. I left rice long ago and haven't died yet, and so will you. Rest is up to you, if you still want to eat rice, then go ahead because I cannot use physical force to stop you from eating rice. But being your medico, it is my duty to educate you about the harmful effects of rice on your health.

As depicted in the eating habits section of the table 3.3, before the onset, major diet of the respondents consisted of carbohydrates and fats. Excess consumption of carbohydrates is one of the main reasons behind increase in BMI. Asian people gorge on high carbohydrate foods which poses a major challenge in diabetes management. Countries with the highest intake of carbohydrates are either developing or underdeveloped in nature; and malnutrition amongst children in these countries is explained by high carbohydrates intake and low protein consumption (Hu 2011; Joshi 2015). Therefore, food which is being consumed is a major determining factor for diabetes onset and its management.

Sulekha (46) changed her endocrinologist because she did not like the behaviour of her pervious doctor. Her brother-in-law recommended this doctor to her because his medication is very effective and costs very less. So, she basically did not consult any doctor for a year and stayed without medication despite of knowing the fact that she was diabetic. She explained her liking to the food as:

We cannot eat Chapatti (Indian Bread) without ghee (clarified butter) or butter as it sticks in the throat. However, I take good care of myself and try to keep a check on my blood sugar.

This statement of hers was interrupted by her daughter who accompanied her to the

OPD. She said:

She (Sulekha) never tries to control her taste buds and eats whatever she likes. Fruit curd consisting of banana and pomegranate with added sugars is an everyday delicacy in our meals. As far as walk is concerned, it is impossible to send her for walk. She gives us very hard time.

Excess consumption of table sugar and mental stress emerged as two main causes which were perceived to be the biggest contributors in the onset of diabetes, therefore, respondents were asked about their perception of table sugar and mental stress as main contributors for the onset of diabetes in general. To this, 17 (41.5%) respondents believed that table sugar was a potential

contributor in the onset of diabetes; whereas 8 (19.5%) respondents said that they had no idea about it. However, 16 (39.0%) respondents were affirmed that consumption of table sugar does not lead to the onset of diabetes. With respect to mental stress, 65.9 % (27) respondents said that mental stress is a potential factor for the onset of diabetes; and 22% (nine) respondents had no idea about it. However, 12.2% (five) respondents negated the role of mental stress as a contributor in the onset of diabetes.

3. Role of Environmental Factors

Table 3.4

Role of Environmental Factors		
Nature of everyday Work (N*=41)		
	Frequency	Percent
Sedentary	39	95.1
Physical	2	4.9
Total	41	100.0
Workout regimen of the respondents before the onset of Diabetes (N*=41)		
	Frequency	Percent
Yes	8	19.5
No	33	80.5
Total	41	100.0
Workout regimen of the respondents after the onset of Diabetes (N*=41)		
	Frequency	Percent
Yes	19	46.3
No	18	43.9
Occasionally	4	9.8
Total	41	100.0
Awareness about long-term complications of Diabetes (N*=41)		
	Frequency	Percent
Yes	16	39.0
No	25	61.0
Total	41	100.0
If respondents ever got their eyes and kidneys checked (N*=41)		
	Frequency	Percent
Yes	23	56.1
No	18	43.9
Total	41	100.0
If respondents ever got their feet checked (N*=41)		
	Frequency	Percent
Yes	11	26.8

No	30	73.2
Total	41	100.0
If respondents keep their health in mind while cooking (N*=41)		
	Frequency	Percent
Yes	22	53.7
No	16	39.0
Sort of	3	7.3
Total	41	100.0

*N= Total Number of Respondents

Term 'environment' in the case of living beings is not limited to the physical environment. All the outer factors which exist outside human body contribute to the environment of an individual (Nagla 2018). So, whether the factors are social or economic, they are equally a part of the environmental factors, and the diabetes arising on account of these factors is T2DM (Thamilarasam 2016). Environmental factors which are consequential in triggering diabetes is an interaction of biological and behavioural risk factors. Western lifestyles, dietary supplements, obesity and glycemic control are some of the non-genetic environmental factors. These factors produce obesogenic environment thereby acting as a breeding ground for the onset of diabetes (Mariana et. al. 2012).

Nature of everyday work is a major determining factor of the workout routine of the respondents. As shown in table 3.4, out of total 41 respondents 39 (95.1%) had a sedentary nature of everyday work; and remaining two (4.9%) were documented to have physical lifestyle because they occasionally assisted their husbands in their farming work. Their husbands were small scale farmers. Even though more than 90% respondents had a sedentary lifestyle yet many of them did not even try to indulge in workout and when enquired about workout regimen of the respondents before the onset of diabetes, 33 (80.5%) respondents said that they were not involved in any kind of workout before the onset of diabetes. Only eight (19.5%) respondents used to go for regular walk even before the onset of the disease. However, an improvement was witnessed after the onset of diabetes as 46.3% (19) respondents started going for regular walk. There were 43.9% (18) respondents who still not opted for any kind of workout and two of them were those who earlier used to go for regular walk. When enquired about the reason of leaving workout after the onset of disease, they replied that due to physical weakness, they felt unable to go for walk. There were four (9.8%) respondents who started going for occasional walks after the onset of diabetes. Parsons (1975) emphasised that for chronic illnesses 'management' of the disease should be opted for, and great importance should be given to

doctoral advice. However, it is also necessary that patients tend not to act 'hyperchondriac' and follow the management routine diligently (Parsons 1975).

It was observed that patients tend to rely more on their own perception of disease management than the one which is medically recommended. Zelber-Sagi et al. (2017) stated that illness perception has a big role to play in the self-efficacy of a patient in his/her lifestyle modification. This statement is testified by other studies as well which say that individual perception about the disease has maximum bearing on the disease management regimen (Katavić, Tanacković, and Badurina 2016; Van de Velde et al. 2019). The knowledge of the disease which these patients had was not deep enough to make them acquire their sick role seriously and to indulge in necessary disease management regimens. It was also observed that women with married sons had even more sedentary lifestyle. They claimed that body weakness caused due to diabetes made it extremely difficult for them to do household chores, therefore their daughters-in-law look after all the domestic chores.

Kailasho Devi, a 40 years old housewife said:

> *I get tired very quickly and performance of household chores became a challenging task for me. I found it very difficult to cook food and to serve it to my family. So, I got my elder son married at the age of 21. Now, his wife takes care of all the domestic work, and life has become quite easy for me.*

49 years old Anita, who had three unmarried daughters, was dependent on them for household chores. She was obese and said:

> *I do not have to do household chores; my daughters take care of everything. I just sit around and take rest.*

Ratna was 34 years old and was the wife of a small-scale peasant, said that she was suffering from thyroid and hypertension as well; and yet she consumed foods rich in sugars and carbohydrates. Even after this she denied opting for any kind of workout. However, still she claimed that she took proper care of herself and managed her disease efficiently.

44 years old Pushpa, who helped her husband in his business said:

> *I need to keep moving around to help my husband in his business. So, this is how I keep walking and manage my disease.*

Sonia was a 54 years old widow who, recently lost her brother to diabetes, said:

> *Earlier I used to go for regular walks and used to regularly check my blood sugar level. However, ever since my bother expired, I lost all the faith in life and stopped going for walks. Today, doctor threatened to put me on insulin if I would not resume my walking routine.*

Lajjiya was 50 years old house wife. Her husband worked as a small-scale farmer; she described her state as:

> *I have been suffering from diabetes for last ten years and follow all the instructions of the doctor diligently. However, I cannot eat chapatti (flat Indian Bread) without ghee (clarified butter). My husband is not keeping well for quite some time so I am going to fields in place of his.*

Though she claimed that she took care of her disease, she never went for walk or indulged herself in any kind of workout.

Another important disease managing factor which is crucial for the diabetes management regimen of the respondents was their level of awareness about diabetes. Literature says that South Asians throughout the world have highest susceptibility and minimum awareness of diabetes. Women tend to possess minimum awareness about the risk factors and management of diabetes (Gujral et al. 2013; Deepa et al. 2014). These patients were asked about the long-term complications of diabetes. It was found that only 16 (39.0%) respondents were aware of the long-term complications of diabetes; whereas 25 (61%) respondents admitted that they did not know anything about long-term complications of diabetes. This awareness was in terms of the effect of diabetes on eyes and kidneys. When respondents were enquired about whether their kidneys and eyes have been examined by the doctor, 56.1% (23) respondents replied in a 'yes' and 43.9% (18) respondents replied in a 'no'. In the case of feet examination, situation was even worst, and when patients were asked about it, 73.2 % (30) respondents said that their feet have never been examined; only 26.8% (11) respondents underwent feet examination. When doctor was asked about the reason of not examining eyes, kidneys and feet regularly, he replied:

> *Diabetes management is team work which involves a dietitian, a diabetic nurse and doctors. Here ratio of availability of doctor to the number of patients to be examined is so high that many times we need to sit hours beyond official hours of the OPD to examine all of them. In such a scenario, it is not possible for a doctor*

to educate patients about diabetes, motivate them to take medicine regularly and to do other examinations as well.

This resonates with what Bajaj et al. (2013) found in their study and concluded that diabetes management is a team work which includes dieticians, educators, diabetes nurse and the doctor. However, entire team is not always available in all hospitals; and doctors compromise their time which is to be utilised for patient examination in order to accommodate maximum number of patients.

Diabetic foot ulcers are one of the most common long-term complications of diabetes and need regular feet examination. It is estimated that approximately 45000 legs are amputated every year in India and of these amputations, 75% result directly or indirectly due to diabetes (Pendsey 2010). It has been observed that socio-cultural factors such as walking bare feet in the house or places of worship, wearing wrong shoes and to not to consult a physician till foot infection becomes incurable are some of the main characteristics of diabetic foot in India. In case of married women, metallic toe rings which they wear also acts as a catalyst in the aggravation of diabetic foot (Pendsey 2010). As shown in data, many respondents in the study were not aware of diabetic foot ulcers. Or even if they were aware of it, they were not much bothered. Only 52 years old Kamla happened to be aware of what diabetic foot ulcers can lead to. She said:

My husband died of diabetes. He was very care-less about the disease management due to which he lost his feet. Then he developed diabetic nephropathy and retinopathy. In the end, he died a very slow and painful death which I do not want to experience. Therefore, I follow every single instruction of the doctor very carefully. I also take care of what to eat and what not to eat.

So, Kamla used to cook food keeping in mind her health needs. However, same was not true for every respondent of the study. As shown in table 3.4, when respondents were asked, whether they keep their health in mind while cooking food, 16 (39.0%) said that they did not, whereas 53.7% (22) respondents replied that they did. Remaining three (7.3%) respondents 'sort of' keep their health in mind' while cooking. However, to cook food exactly as per their health needs was not possible as taste of the entire family was a major concern for them.

Kulwant Kour who worked in a factory was the only earning member of a family of three. she said:

I cannot cut down consumption of potatoes as it is the major food requirement of the entire family. It looks really odd to cook something separately for my own needs.

This was a typical case of sick role compromise for the sake of family. However, not all the women had to face same situation. Premlata was the wife of a retired physician. Still she never bothered about being obese and seldom tried to keep a check on her eating habits. At the time of interview, she was insulin dependent and used to get injected twice a day. However, her attitude was still very carefree and she enjoyed eating foods of her choice. This is how technologies of the self are being governed by environmental factors. These technologies are very much influenced by the knowledge level of the patients which is a result of the personal exposure to the after effects of diabetes. This exposure can be in the form of economic adversity, some personal loss or no effect at all. Exposure to the effects of diabetes has a bearing on the knowledge construction of the patients and influences their awareness pattern, which ultimately has a pertinence to the health seeking behaviour of the diabetic patients.

4. Health Seeking Behaviour

Table 3.5

Health Seeking Behaviour		
Information about diabetes before its onset (N*=41)		
	Frequency	Percent
Just heard of it	18	43.9
Never heard of it	19	46.3
Family history and affects lifestyle diseases	4	9.8
Total	41	100.0
Information about diabetes after its onset (N*=41)		
	Frequency	Percent
Nothing	22	53.7
Affects eyes and kidneys; control of lifestyle factors	6	14.6
control of lifestyle factors	7	17.1
Caused due to mental stress	2	4.9
Excessive hunger and urination	1	2.4
Silent Killer	2	4.9
Almost everyone is suffering from this disease	1	2.4
Total	41	100.0
Type of Diabetes, respondent is suffering from (N*=41)		
	Frequency	Percent
No Idea	38	92.7

Type II	3	7.3
Total	41	100.0
Medication opted by the Respondents (N*=41)		
	Frequency	Percentage
Allopathic	17	41.50
Allopathic and Ayurvedic	7	17.10
Allopathic and Home remedies	11	26.80
Allopathic, Ayurvedic and Home Remedies	4	9.80
Allopathic and Godman	2	4.80
Total	41	100
Seeking Doctoral Consultation (In months) (N*=41)		
	Frequency	Percent
1 - 2	19	46.3
3 - 4	7	17.1
5 - 6	5	12.2
7 - 8	3	7.3
11 - 12	4	9.8
>12	3	7.3
Total	41	100.0
Mean: 4.29 Months		
Does patient receive any unwanted suggestion or guidance from relatives and friends (N*=41)		
	Frequency	Percent
Yes	25	61.0
No	16	39.0
Total	41	100.0
How does respondents feel about these advices (N*=41)		
	Frequency	Percent
Does not like unnecessary advices	9	22.0
Tend to ignore what they advise	9	22.0
Shows people's concern	2	4.9
People are not Doctors	2	4.9
Advise to go to godman	1	2.4
We all advise each other in every matter	1	2.4
No Response	17	41.5
Total	41	100.0

Who takes important decisions about health matters of the respondent (N*=41)		
	Frequency	Percent
Husband	17	41.5
Self (financed by husband)	5	12.2
Self (financed by son)	1	2.4
Self	12	29.3
Husband and Son	4	9.8
Son	2	4.9
Total	41	100.0
Do your Family members tell you to go for walk or to abstain from eating restricted food items (N*=41)		
	Frequency	Percent
Yes	30	73.18
No	11	26.82
Total	41	100

N*= Total number of the Respondents

Health seeking behaviour is defined as the care sought by a person who is suffering from an ailment. It is always preceded by decision making process which governs the kind of treatment opted by the patient depending upon the social, cultural, economic and household factors (Oberoi et al. 2016). Therefore, there is a huge variation in the health seeking behaviour of the patients. MacKian (2018) talks about two approaches to health seeking behaviours. First one is *utilisation of the system*, which is defined as series of actions taken to improve ill health of the masses. Second approach is the *process of illness response*, which refers to health choices being made by people. These choices may be related to their style of living or making use of medical facilities. She also analysed case of T1DM and found that doctor-patient relationship here plays a key role in helping patients to make healthy choices and to improve their health seeking behaviour (MacKian 2018). However, in Indian context, reliance of patients on their doctors is far more than it is required in the case of lifestyle diseases. Aneeta Minocha (Bhardwaj 2014) talked of the peculiar behaviour of Indian patients because of which they entrust their full faith in the treatment recommended by the doctor in terms of medicine. Patients and their family members seldom try to get into the technical detailing of the medication offered by the doctors.

As shown in table 3.5, majority of the respondents did not know anything about diabetes before its onset, as 46.3% (19) said that they never heard of it before its onset, whereas 43.9% (18) respondents just heard of it and nothing else. There were four (9.8%) respondents who had family history of diabetes and were therefore sufficiently aware of the disease. While replying

to the question of what they know about diabetes after themselves experiencing it, 22 (55.7%) respondents responded that they still could not say anything about it. However, 13 respondents said that one needs to control one's lifestyle in order to manage it. Of these 13 respondents, six (14.6% of the total) felt that in addition to lifestyle factors, it affects functioning of eyes and kidneys as well. There were two respondents who believed that it is caused by mental stress and another set of two respondents said that it is a silent killer. Only one respondent felt that it leads to excessive hunger and urination, and remaining one respondent replied that almost everyone is suffering from diabetes these days. It has been observed that the description of diabetes, made by the respondents, was the result of their personal experiences with the disease. The problems which they faced and the examinations which they underwent had a strong bearing on the way they described diabetes. This is why their description had traces of personal beliefs and majority of the respondents were ignorant about the long-term consequences of diabetes. Personal experiences are the major source of knowledge construction in general, and in the field of health and illness in particular (Charmaz 2000). Perhaps this is the reason that they did not know that there existed any type of diabetes. When asked, 92.7% (38) respondents said that they had no idea about the type of diabetes they were suffering from; in fact, many of them were surprised at the question and were wondering if there existed a type of diabetes. Only three (7.3%) respondents in the study knew that they were suffering from T2DM.

Since data were collected in a government hospital therefore, it was obvious that all the patients would be opting for allopathic form of medication and treatment. Therefore, it was a common form of medication opted for managing diabetes. However, majority of the respondents were relying on other forms of treatment as well. There were 17 (41.50%) respondents who were relying only on allopathic medicine whereas 11 (26.80%) respondents were using home remedies as well; 17.10% (seven) respondents said that they used allopathic as well as ayurvedic medicine and four (9.80%) respondents were using allopathic, ayurvedic and home remedies to treat diabetes. There were two respondents who were consulting godmen as well as relying on allopathic medication. Foucault (1988) stated that 'Technologies of the self' enable masses to acquire means which enable them to attain perfection, purity, wisdom etc. In his later writings, he insisted that one should keep oneself above others and, even if scriptures say that *"our morality, a morality of asceticism…….is that which one can reject"*, knowledge of the self is a fundamental principle of modern society. However, it was found in the present study that these technologies of self are influenced by the social construction of illness on the part of the patients. Personal experiences of the respondents were very much a determining factor of their health seeking behaviour and the way they describe their illness and its course

of management. This also had a bearing on their follow up with the doctor. Regarding frequency of their visit to the doctor, 46.3% (19) respondents said that they visited their doctor every 1-2 months; for seven (17.1%) respondents, frequency of their visit was 3-4 months; and 12.2% (five) respondents visited their doctor every 5-6 months. three (7.3%) respondents used to visit doctor within 7-8 months and frequency of four (9.8%) respondents to consult doctor for follow up was 11-12 months. There were only three (7.3%) respondents who visited doctor after 12 months. There were two respondents of these three respondents who actually stopped consulting doctor, and at the time of interview, their diabetic complications were so severe that they had to return for doctoral consultation after years. The third respondent in this category had the habit of changing her doctor every now and then so it was not possible to determine actual frequency of her visit to the doctor.

Doctor-patient relationship in this study emerged as a very intriguing entity which needs detailed discussion. There were some respondents who believed that they could manage diabetes of their own and did not need any doctoral interference; there were some who believed that only doctor could cure them and they did not know that diabetes is a manageable disease. Very few respondents were aware of the fact that diabetes management seeks doctor-patient cooperation. Few observations made in the cardiology department of SSH (while collecting data for CVDs) and department of medicine (where data for diabetes were collected) strengthened this argument.

A woman visited doctor to seek consultation for diabetes. When she met with the doctor, she had a booklet in her hand. Doctor asked for the prescription which would be issued to her during her previous visits to the hospital. To this, she replied that around a year ago she was hospitalised in the emergency section on account of some diabetic complications and that time she was issued this booklet regarding her treatment in the emergency ward; so, she had only that booklet with her and nothing else. Doctor then told her that she should go back and get all the tests done, which he scribbled on a piece of paper, and told her to come back for his consultation in his next OPD. However, that woman did not come back for the consultation. In fact, during the entire span of data collection in medicine department, I did not see that woman again. When doctor was enquired about their method of dealing with such patients, he replied:

Such patients belong to socio-economically poor background and it gets really difficult to make them understand that their own effort is more helpful in the

management of their disease than the medicine prescribed by us. However, they still expect that we should check their pulse and prescribe them with some medicine which would cure them of diabetes.

This behaviour exists irrespective of gender. A male diabetic patient visited doctor in the cardiology department and explained his condition to the cardiologist as:

I got my blood sugar tested two years ago at my own and found that I was diabetic. However, I never consulted any doctor and manage it at my own by going for walk every day. For last few days, I have been experiencing pain in my left arm, so I thought that I should consult a cardiologist.

It has been observed that the approach of this patient was entirely different for diabetes and CVDs. For diabetes, he decided to manage at his own, whereas a small doubt of pain made him so concerned about his heart health that he decided to consult a cardiologist.

All these observations are made in the light of Parsonian asymmetric doctor-patient relationship, which states that depending upon the nature of disease, responsibility of curing/managing disease shifts between doctor and patient (Parsons 1975). However, results of the present study reveal a peculiar pattern of doctor-patient relationship here, where either complete responsibility lies with the doctor or there is no responsibility at all.

A respondent of the CVDs study was hospitalised in Coronary Care Unit of the Cardiology Department. She developed cardiac complication because of diabetes mismanagement. She narrated her story as:

I live in a very remote area. Long back when wounds started developing in my feet, I consulted a local quack. However, that was of no help and one day I was rushed to district hospital where my family members were suggested to shift me to GMC. At GMC, doctors discovered that I was diabetic and immediately amputated my feet to stop further deterioration.

When endocrinologist was asked about the provision of counselling the patients regarding diabetic foot ulcers, he said:

We can only diagnose an ailment and provide medication for that. Doctors have to perform multiple roles which makes it impossible for them to counsel patients about various ailments which arise on account of diabetes.

This corresponds with Parsons' argument where he explained that a doctor has to devote significant

amount of time to non-therapeutic activities, hence fiduciary responsibility should be shared by the patient and his/her family members as well (Parsons 1975). Difference of approach regarding health seeking behaviour of diabetic patients is quite common in this part of the country which was revealed by observation during data collection and informal interview with the doctors. Factors determining social construction of treatment play a very crucial role in determining their health seeking behaviour. One such example is the *suggestions* which patients received from relatives and friends regrading doctoral consultation and management of the disease. When patients were asked about it, 61.0% (25) respondents replied that they do receive such kind of suggestions. However, 16 (39%) respondents stated that they seldom or never received such kind of suggestions. Next question asked to the respondent was about their reaction to such suggestions; or if they happened to receive such suggestions. There were 17 (41.5%) respondents came up with 'no response' to the question. However, nine (22%) respondents expressed that they did not like unnecessary advices and other nine (22%) preferred to ignore such suggestions. Only two respondents felt that it shows the concern of the person we are in talk with, whereas another two respondents stated that people are not doctors so they should not come up with unnecessary advices. There was only one respondent who said that she was advised to go to a godman and remaining one felt that all human beings tend to advise each other on every matter, therefore, it is a normal phenomenon. These suggestions are also influential in making people adopt alternative sources of medication as one of the respondents received suggestion to go to a godman.

Similarly, 38 years old, Sunita stated:

> *My father is also suffering from diabetes and recently he ordered a medicine which was advertised on television. If he gets benefitted, then I would also try it out in future.*

Most important factor which determines health seeking behaviour of diabetic women is who takes all the important decisions related to their health matters. So, when specifically asked about the person who takes social and economic decisions related to their health matters, most of them (17 respondents) replied that their husbands took decision about their health matters. For five (12.2%) respondents, they themselves made decisions related to their health matters. However, they were financed by their husbands. There were 12 (29.3%) respondents who themselves bore all their health-related expenses and were themselves responsible for other decisions as well. For four (9.8%) respondents, money was provided by son. However,

respondents themselves took all other decisions related to their health. There were four more respondents who were dependent on their husband and son for the entire course of treatment; and for remaining two respondents, sons made all the decisions on behalf of their mothers. It is important to note here that of 12 respondents who were themselves responsible for taking all their health-related decisions, five were widowed and were receiving pensions on behalf of their late husbands. Therefore, money is a matter of great concern for the patients as lifestyle diseases demand life-long management. Yesudian et al. (2014) analysed existing literature on economic burden of diabetes in India and concluded that economic burden falls heavily on the patients and their families, leading to high out of packet expenditure to manage diabetes. In addition to this, poor accessibility of medicines may be the reason that available data shows lower need of diabetic medicines in rural India. Resonating the same argument, Henk Bekedam, WHO representative to India, stated that families with poor income bear the highest brunt of diabetes. Drug costs represent costliest affair in the management of diabetes, there by contributing more than 50% of the diabetes expenses (WHO 2016a).

During the course of interviews, many patients explained that diabetes management demands money which made it difficult for them to afford it in the midst of household expenses.
48 years old Sumitra, a housewife, belonged to a joint family. She narrated her family condition:

> *Our economic condition is very bad. I spent a lot of our family savings on the education of my son, yet he could not find any job and is still unemployed. My brother-in-law is also undergoing treatment. He underwent surgery, few months ago and hospital authorities demanded 40,000 rupees from us. We paid 20,000 in advance and promised to pay remaining 20,000 once he gets fully recovered. However, he could not recover and all our money went away. Now, he also has to be taken care of and whenever he feels fine, he sets up his fruit stall to earn money. However, that is not regular and therefore, our sources of earning are very limited whereas expenditure on illnesses is an additional burden.*

Economic burden of diabetes for a lower income household makes them cut off their other necessities. As Rajkishori, a widow who was getting pension on behalf of her husband told her story:

> *My sons have to get their children admitted to good schools where tuition fees are very high. They are delaying their admissions because economic burden of my*

disease is too much. So, I told them that they should get their children admitted to those schools, I will bear the cost of treatment form the money I receive from their father's pension.

Kanta was a 56 years old widow, she narrated her condition:

My son is unemployed and my expired husband's pension is the only source of income for our family. Every month I come from a town which is 200 kms away from Jammu. This all requires a lot of money which we do not have.

Similarly, other patients also explained economic burden of diabetes

Kulwant Kour told her story as:

I am the sole bread winner of my family and our resources are very limited. We can hardly manage potatoes and rice. Non-vegetarian food is a delicacy which we can seldom afford. In such a deplorable condition, this disease is an additional economic burden.

Some other patients also explained economic burden of diabetes

Phoolan Wakhloo who was a Kashmiri Migrant (54 years) expressed her situation:

Government pension is our only source of income and both of us (husband and wife) are suffering from multiple diseases. We are managing our disease with great difficulty in such a meagre amount of money.

*I get Rs1000 as pension from government and another one thousand is given to her by her son. Taking care of medical expenses in such a small amount of money is very difficult. (*Lajwanti, 69)

52 years old Harbans Kour, who lived with her diabetic daughter stated:

Our only source of income is the pension which I receive on behalf of my late husband. He was a drunkard and his drinking habit was a source of mental stress for me. Now, though he is no more but we do not have sufficient income to look after ourselves (mother and daughter); and this disease needs a lot of money to be taken care of.

In the end, attempt was made to assess concern of the family members of the respondents, about their disease and it was found that majority 30 (73.18%) respondents were told by their family

members to indulge in regular workout and to refrain from eating restricted food items. However, 11 (26.82%) never experienced that.

Sulakshna shared her experience as:

> *I cannot eat food of my choice as my sons keep a strict vigil on my eating habits. But whenever I go to weddings or parties, I eat foods of my choice as none of my sons can watch me.*

> *My son has prepared my diet chart and he keeps a strict vigil on my eating habits. In addition to this, he keeps motivating me to go for regular walk. Actually, my entire family keeps an eye on my diabetes management regimen.* (Babita, a housewife)

These family members keep monitoring walking regimen and food habits of the patients. This is usually done keeping in mind *Parhej* (abstinence from high glycemic and carbohydrates rich food) which is recommended by the doctor.

5. Discussion

Self-care management of diabetes is the most essential way of living with it. Shrivastava et. al. (2013) identified seven essential factors of diabetes management namely healthy eating, being physically active, monitoring of blood sugar, compliant with medications, good problem-solving skills, healthy coping skills and risk-reduction behaviours. This implies that looking after one's lifestyle is instrumental in diabetes management and also to ensure a healthy and long life. However, results represent a different picture and it can be argued that respondents in the present study lack resources and awareness which is a must for diabetes management. They tend to compromise their sick role due to social and economic factors; and also rely on socially constructed popular ideas of disease management.

Women being primary caretaker of the family, prioritise their role of a family care taker; many housewives of young age tend not to go for walk as they have to make their family members ready for their roles in their respective work places. Some respondents believed that they were too weak to go outside for morning or evening walk. Few of them had their daughters-in-law or other members in their families who could look after household chores for them. Certain housewives could not spare time for workout due to the pressure of household chores. Therefore, personal factors and notions about the disease made them opt for a particular way of managing it. In a study of diabetic housewives in Saudi Arabia, Bakhotmah (2013) found that housewives tend to be more obese than men as being unemployed, they are largely inactive

and tend to put on a lot of weight. This may be due to their personal belief that the body movement for carrying out household chores is equivalent to the physical workout meant for diabetes management. Foucault's technologies of self was also influenced by Plato's *Alcibiades* (Foucault 1988). While explaining his own version, he substituted Plato's pedagogical model with a medical model. He came up with the theory that medical care is permanent in the care of the self, and this should be sought after in order to prepare a person for the entire life. Therefore, some practices should be cultivated to look after oneself (Foucault 1988). This can be interpreted that Foucault was concerned with the lifestyle practices which should be incorporated by the masses in order to promote their own well-being. Awareness has a crucial role to play in promoting these lifestyle practices. However, notion of self-care of the respondents was found to be clouded by their own perception which made them believe that their bodies needed rest to cure diabetes, or their role of family caretaker is more important than their sick role, or they do not have resources to take care of their diseases. Cases were different whereas their experiences and social exposure to the disease was the determining factor of their management regimen.

Cases of the women who relied on the belief that their bodies needed rest, corresponds to what Charmaz (2000) identified as major problems being faced by patients of chronic illnesses namely: making sense of bewildering symptoms; reconstructing order; and maintaining control over life. These women make sense of the symptoms as body weakness which requires rest, and this is how they reconstruct order; finally, they control their life activities by transferring them to other family members so that role conflict (of a family caretaker and of a patient of chronic illness) should not disturb existing order of the family. This is one of the examples of fiduciary role which is being played by the family members of the patients. Monitoring food habits and to motivate patients to go for walk also form a part of this fiduciary responsibility.

As far as doctor-patient relationship is concerned, it was more of symmetric in nature in which patients were either completely dependent on the doctors or completely on themselves. This symmetric doctor-patient relationship was also due to popular discourses which were carried out by respondents or their kin during their discussion with other diabetic patients or the kin of these patients. Such discussions, allow patients to choose one doctor over another. During these discourses, patients and their kin tend to analyse shared experiences and they formulate their own perception. These discourses involve effect of medication which is prescribed by the physician, things which can be eaten in order to keep blood sugar under control (these things

form a part of self-medication), generalisation of socially constructed methods of diabetes self-care management (even if these methods are not medicinally validated) etc. These discussions help them to opt best available treatment which also suits their pockets. Selection of one diabetologist over another by the respondents or their family members, results mainly due to the recommendation of a friend, relative or neighbour who himself/herself happened to consult that doctor earlier. Such experiences are usually expressed as, "neighbour of mine consulted him and he said he is a very good doctor" or "uncle of mine consulted him and said he is a very good doctor". So, the semantics conveyed during the discourse helps them in constructing their preference for one doctor over another. And thus, they also take into consideration that cure lies in medicine only and not in workout; or may be vice versa. The 'relatives and kin' of these patients, who have been discussed here are mostly male members of the families who decide the course of their treatment. Since, out of pocket expenditure in diabetes is extremely high, therefore they opt for cost effective treatment which is suitable for their pockets.

Another interesting pattern which emerged during the study was that diabetic patients tend to act what Parsons (1975) called 'hyperchondriac', in the sense that they believe there is no need of doctoral intervention to manage their disease. Not consulting doctor or believing that one can manage diabetes by going for walk are some of the instances which show that patients, especially suffering from diabetes refuse to accept the fact of biographical disruption arising on account of diabetes. Even if they do, they try not to be considered as invalid adults, by acting partially hyperchondriac and manage their disease of their own (Charmaz 2002).

Therefore, it can be concluded that since, diabetic women in this part of the country are mostly married and belong to middle age group, the most women centric aspect of this disease is their economic and social dependence on their male counterparts and their role of a family care taker. Apart from these two aspects they face challenges of diabetes which are more or less same as faced by men. Had these women being younger in age, then there is high probability that they would have faced stigma as well, of being diabetic at an early age; and may had very less chances of getting a suitable match for marriage (Bajaj et al. 2013).

4

I am an Additional Burden for My Family: Description of Women Suffering from Cardiovascular Diseases (CVDs)

According to American Heart Association (AHA) Cardiovascular diseases (CVDs) refer to number of conditions which involve various diseases directly or indirectly related to heart such as heart attack, stroke, heart failure, arrhythmia, heart valve problems, etc. (ASA 2019). Therefore, CVDs is an umbrella term used to refer to any kind of disease which is related to human heart. According to the global burden of the disease study, age standardised death rate attributable to CVDs in India is much higher than global average, i.e., 272 per 100000 as compared to global average of 235 per 100000 population (Prabhakaran 2016). Percentage of population suffering from CVDs in India increased more than twice in sixteen years ranging from 27.5 million in 1990 to 54.5 million in 2016 (Prabhakaran, Jeemon, et al. 2018). CVDs are also responsible for high out of pocket expenditure which initiates a vicious circle of poverty in which a poor person spends all her/his earnings in the management of the disease. Caucasians enjoy genetic edge over South Asians as far as onset of CVDs is concerned as, short height and increased abdominal adiposity increases susceptibility of South Asian people over others in the onset of CVDs (Prabhakaran, Singh, et al. 2018). In addition to this, dietary intake of fruit and vegetables is also very low in Indians especially amongst socio-economically weaker sections owing to the high cost of these eatables. Also, vegetables which are consumed by an average Indian household are generally overcooked. Not just food intake, level of physical activity amongst Indians is also far below satisfactory with every one out of two Indians is considered to be physically inactive. Another major factor which affects CVD detection and prevention in India is the under reporting and underdiagnosis of CVDs (Prabhakaran 2016). In addition to eating habits and workout regimen, diabetes and high blood pressure (Hypertension) are also recognised as potential risk factors for the onset of CVDs.

In her message on the occasion of World Heart Disease day in 2015, Regional Director, WHO South-East Asian Region, Poonam Khetrapal Singh said that majority of premature deaths due to CVDs can be avoided simply by opting for regular workout, by avoiding tobacco and alcohol, by consuming healthy diet and by managing stress. She also added that risk factors of CVDs in women are somewhat identical to that of men which includes lifestyle factors such as lack of healthy diet and absence of workout in everyday routine of women, and also emphasised on recognising and addressing potential gendered factors which are responsible for increase in

the number of women suffering from CVDs in South Asian region (WHO 2015). Therefore, four main lifestyle factors which play key role in the onset of CVDs are consumption of alcohol, consumption of tobacco, consumption of unhealthy food and physical inactivity. However, percentage of women with overdependence on the consumption of alcohol and tobacco is very less in India, therefore eating habits and physical inactivity contribute as major lifestyle factors in the onset and management of CVDs amongst women in India (WHO 2014; Prabhakaran 2016; WHO 2015).

Table 4.1 represents Pseudonyms, age, occupation and marital status of the respondents so that their narratives can be explained clearly in upcoming sections.

Table 4.1

General Profile of the Respondents

S.No.	Pseudonym	Age	Profession	Religion	Marital Status
1.	Pushpa Devi	50	Domestic Help	Hindu	Married
2.	Neeta Devi	45	Housewife	Hindu	Married
3.	Rajjo Kumari	72	Housewife	Hindu	Widow
4.	Pushplata	65	Housewife	Hindu	Widow
5.	Kiranpreet Kour	50	Housewife	Sikh	Married
6.	Sulakshna Devi	60	Housewife	Hindu	Married
7.	Soma Kumari	55	Housewife	Hindu	Widow
8.	Supinder Kour	32	Private Job	Sikh	Widow
9.	Kamla	42	Housewife	Hindu	Married
10.	Garima Devi	45	Housewife	Hindu	Married
11.	Daya Kumari	37	Housewife	Hindu	Married
12.	Satnam Kour	70	Housewife	Sikh	Widow
13.	Tripta Devi	56	Housewife	Hindu	Widow
14.	Kaushalya Devi	40	Housewife	Hindu	Married
15.	Sharmishta Devi	60	Housewife	Hindu	Widow
16.	Reema Koul	54	Housewife	Hindu	Married
17.	Seeta Sharma	55	Housewife	Hindu	Married
18.	Karandeep Kour	55	Housewife	Sikh	Married
19.	Maya Mehra	55	Housewife	Hindu	Widow

20.	Neerja Kumari	39	Housewife	Hindu	Widow
21.	Gayatri Sharma	50	Housewife	Hindu	Married
22.	Gomti Devi	45	Housewife	Hindu	Married
23.	Purshottama Devi	50	Housewife	Hindu	Married
24.	Lata Badyal	76	Housewife	Hindu	Widow
25.	Prema Goswami	64	Retired School Teacher	Hindu	Widow
26.	Kanta Mahajan	51	Housewife	Hindu	Married
27.	Asha Rani	40	Housewife	Hindu	Married
28.	Neena Khjuria	55	Housewife	Hindu	Married
29.	Rashmi Bala	50	Domestic Help	Hindu	Married
30.	Kanak Lata	42	Nurse	Hindu	Married
31.	Saroj Devi	53	Housewife	Hindu	Married
32.	Devpriya Gupta	58	Housewife	Hindu	Married
33.	Lajjya Angural	44	Tailor	Hindu	Married
34.	Vaishno Digra	56	Housewife	Hindu	Married
35.	Nasima Begum	81	Housewife	Muslim	Widow
36.	Kusum Vaid	44	Domestic Help	Hindu	Married
37.	Rajinder Kour	54	Housewife	Sikh	Married
38.	Shehnaz Bashir	72	Housewife	Muslim	Married
39.	Taro Sambyal	61	Housewife	Hindu	Married
40.	Ravipreet Kour	71	Housewife	Sikh	Married
41.	Asifa Bano	41	Housewife	Muslim	Married

1. Socio-economic and Demographic Profile

Table 4.2

Socio-economic and Demographic Profile of the Respondents		
Education (N*=41)		
	Frequency	Percent
Illiterate	15	36.6
Primary	14	34.1
Secondary	8	19.5
Bachelor	3	7.3

Higher studies	1	2.4
Total	41	100.0
Religion (N*=41)		
	Frequency	Percent
Hindu	32	78.0
Sikh	6	14.6
Muslim	3	7.3
Total	41	100.0
Occupation (N*=41)		
	Frequency	Percent
Housewife	35	85.4
Domestic Help	3	7.3
Retired Government Teacher	1	2.4
Tailor	1	2.4
Nurse	1	2.4
Total	41	100.0
Marital Status (N*=41)		
	Frequency	Percent
Married	29	70.7
Widow	12	29.3
Total	41	100.0
Family Structure (N*=41)		
	Frequency	Percent
Joint	22	53.7
Nuclear	19	46.3
Total	41	100.0
Age (N*=41)		
	Frequency	Percent
25 - 34	1	2.4
35 - 44	9	22.0
45 - 54	11	26.8
55 - 64	13	31.7
65 - 74	5	12.2
75 - 84	2	4.9
Total	41	100.0
Mean Score: 53.9		
Number of Family Members (N*=41)		
	Frequency	Percent
1 - 4	15	36.6
5 - 8	21	51.2

9 - 12	3	7.3
13+	2	4.9
Total	41	100.0
Mean Score: 5.70		
Monthly Income of the Family (Rupees in Thousand) (N*=41)		
	Frequency	Percent
1 – 10	3	7.3
11 - 20	12	29.3
21 - 30	14	34.1
31 - 40	7	17.1
41 - 50	3	7.3
51 - 60	2	4.9
Total	41	100.0
Mean Score: 25.70		

*N= Total number of Respondents

Association of health status of an individual and socio-economic status dates back to the dawn of industrial revolution when life expectancy of an industrial worker was expected to remain only half of the wealthier citizens of the same city (Clark et al. 2009). Although life expectancy has increased many folds in the post-industrial times still individuals belonging to socio-economically weaker sections face discrimination in their overall health status which also holds good as far as onset of CVDs is concerned. LMIC are now replicating the process of High Income Countries (HIC) where socio-economic status is a major determining factor for the onset of CVDs; and economically weaker sections are now found to be more susceptible to the onset of CVDs as compared to economically well off people (Clark et al. 2009; Yu et al. 2000; Glymour, Clark, and Patton 2014). According to Glymour, Clark, and Patton (2014), socio-economic factors predict the susceptibility of a particular social group towards CVDs and also help in reducing this vulnerability by bridging up social inequalities. Socio-economic disadvantages accrue over entire life time of an individual, thereby increasing susceptibility towards later part of the life course of a human being.

Socio-economic and demographic profile of the respondents is shown in table 4.2. Results show that more than half of the respondents had very low literacy level with 15 (36.6%) respondents admitted to never attending a school in their lifetime whereas 14 (34.1%) respondents studied only up to primary level; eight (19.5%) respondents received education up to secondary level; three (7.3%) respondents had bachelors' degree; while remaining one respondent received a Masters' degree in History. As far as religion of the respondents is

concerned, 32 respondents (78%) were Hindus; six (14.6%) were Sikhs; and remaining three (7.3%) respondents were Muslims. Occupational profile shows that 35 (85.4%) respondents were housewives; and three (7.3%) respondents were working as domestic help. Of remaining three respondents, one was working as a teacher in a private school; another one was a tailor; and remaining one was a nurse in a government hospital. Out of total 41 respondents, 29 (70.7%) were married and remaining 12 (29.3%) were widows. More than fifty percent of them were living in joint families as 22 (53.7%) respondents reported belonging to joint family structure whereas 19 (46.3%) were living in nuclear families.

Age is another major factor for determining impact of socio-cultural factors on the onset of CVDs and during present study, it was found that respondents belonged to varied age groups as one of the respondents was 32 years old; nine (22%) respondents belonged to the age group of 35 years to 44 years; 11 (26.80%) respondents were from the age group of 45 years to 54 years and remaining 20 respondents were 55 years old and above. Of these 20 respondents, 13 (31.7%) belonged to the age group of 55 years to 64 years; five (12.2%) respondents belonged to the age group of 65 years to 74 years and remaining two were between the age group of 75 years and 84 years. As far as number of family members in the families of the respondents is concerned, 15 (36.6%) respondents had one to four family members in their families; 21 (51.2%) respondents had five to eight members in their families; there were 9 to 12 members in the families of three respondents; and remaining two respondents had more than 13 members in their families. Income profile shows that three respondents had monthly family income between rupees one thousand and ten thousand; 12 (29.3%) respondents belonged to the income group of 11,000 per month to 20,000 per month; for 14 (34.1%) respondents, family income group was between 21,000 per month to 30,000 per month. There were seven (17.1%) respondents who belonged to the income group of 31,000 to 40,000 per month; three respondents had a monthly family income between 41,000 to 50,000; and remaining two belonged to the income group of 51,000 to 60,000 rupees per month.

Socio-economic factors have a strong bearing on the onset and management of CVDs as many respondents were found to be additionally burdened due to the onset of CVDs. One of the respondents, Pushpa aged 50, had to borrow huge sum of money to undergo stenting. She said:

> *I became debt ridden due to this disease. Now I do not understand how all this money will be paid off.*

Neeta Devi who was also suffering from diabetes narrated her story as:

> *My blood sugar level rose up to 700 and I had to be hospitalised. My entire stay in the hospital cost my family whopping rupees 30,000. Now I have to undergo stenting which requires 40,000 rupees and I do not understand how to arrange this large sum of money.*

Not only financial burden of the disease poses a challenge to its management but role of women as family care taker and habitual factors also pose a hurdle in the management of CVDs in case of women as explained in following sections.

2. Impact of CVDs on the Lifestyle of the Respondents

Table 4.3

Impact of CVDs on the Lifestyle of the Respondents		
Body Mass Index (N*=41)		
	Frequency	Percent
Normal	14	34.1
Overweight	20	48.8
Obese	7	17.1
Total	41	100.0
Any Other Disease Respondent is Suffering From (N*=41)		
	Frequency	Percent
Diabetes	10	24.4
Hypothyroidism	9	22.0
Diabetes and Hypothyroidism	4	9.8
NA	18	43.9
Total	41	100.0
Eating Habits of the Respondents Before onset of CVD (N*=41)		
	Frequency	Percent
Excess consumption of oily and fatty food	15	36.6
Excess consumption of oily, fatty food and red meat	9	22.0
Normal eating habits due to already existing diabetes	17	41.5
Total	41	100.0

Perceived Cause for the Onset of Disease (N*=41)		
	Frequency	Percent
No Idea	29	70.7
Stress	6	14.6
Excess Consumption of Oily and Fatty Food	2	4.9
Due to Diabetes	2	4.9
Old age	1	2.4
Genetic Predisposition	1	2.4
Total	41	100.0
Change in lifestyle after onset of CVD (N*=41)		
	Frequency	Percent
Yes	37	90.2
No	4	9.8
Total	41	100.0
Changes Brought in Lifestyle (N*=41)		
	Frequency	Percent
Reduced consumption of Oily and fatty food	14	34.1
Avoiding oil and salt	2	4.9
Reduced Consumption of oily, fatty and junk food	18	43.9
Make workout a part of daily regimen	1	2.4
No Reply	6	14.6
Total	41	100.0
Role of Mental Stress in the Onset of CVD (N*=41)		
	Frequency	Percent
Yes	15	36.6
No	4	9.8
No Idea	22	53.7
Total	41	100.0

*N= Total Number of Respondents

Women are most likely to perform the role of a family caregiver which expose them to care giving stressors (Chiou, Chen, and Wang 2005; Sharma, Chakrabarti, and Grover 2016). This was found to be the most profound impact of CVDs on the respondents in the present study. However, lifestyle related changes which were the indicators of disease burden were assessed in the form of their BMIs, eating habits before and after the onset of disease, perceived causes for the onset of disease, etc.

Table 4.3 shows factors depicting the impact of CVDs on the lifestyle of the respondents. It was found that 14 (34.1%) respondents had normal BMI whereas 20 (48.8%) respondents were overweight and remaining seven were obese. About the question related to any other disease respondent was suffering from, it was found that they were either suffering from hypothyroidism (when not enough thyroid hormone is produced by thyroid glands) or diabetes or both. Hypothyroidism and diabetes are endocrine disorders which are directly responsible for the onset of CVD and are considered as major risk factors for CVDs (Udovcic et al. 2017; Dokken 2008). Existence of these diseases reflects increased susceptibility of the patient towards CVDs. Data collected shows that 10 (24.4%) respondents were suffering from diabetes; nine (22%) were suffering from hypothyroidism; four (9.8%) had both the diseases; and remaining 18 (43.9%) said that they were not suffering from any disease other than CVD.

Eating habit is one of the most significant modifiable risk factors which is crucial in the manifestation of CVDs. Winham (2009) stated that food habits, determined by culture, plays a very important role in determining eating related lifestyle habits of the masses. He studied different immigrant communities of the USA and observed that with the passage of time, eating habit of the people change and they get more dependent on carbohydrates and starch rich foods. These habits are the main triggering factors for the onset of CVDs amongst them. As shown in table 4.3, 15 (36.6%) respondents admitted consuming excess of oily and fatty food (in the form of *Parathe, Pakode, samosa* etc.) before the onset of CVD; nine (22%) respondents mentioned that in addition to excess consumption of oily and fatty food, they also ate large amount of red meat; and remaining 17 (41.5%) said that they did not eat anything which was harmful to their bodies even before the onset of disease. However, 14 of these 17 respondents were already suffering from diabetes, therefore they already stopped eating foods rich in carbohydrates, fat and cholesterol. Respondents were also enquired about the lifestyle changes which they brought about in their everyday routine. There were 37 (90.2%) respondents who did bring some changes in their lifestyle in order to manage CVDs. However, four (9.8%) respondents did not bother to change anything in their daily routine. In total 14 (34.1%) respondents said that they reduced consumption of oily and fatty food after the onset of CVD; two respondents mentioned that they reduced the consumption of oil and salt in their meals; 18 (43.9%) respondents, in addition to the reduced consumption of oily and fatty food, also reduced the consumption of junk food; one respondent made every day workout an integral part of her everyday routine following the onset of CVD; and remaining six (14.6%) did not reply to this question as four of them were those who did not bring any change in their lifestyles.

Perception of an individual towards onset of a disease is a key indicator of her health seeking behaviour. Keeping this in mind, respondents were asked about the perceived cause for the onset of CVD to which 29 (70.7%) respondents said that they did not have any idea; six (14.6%) respondents attributed it to psychosocial stressors; for two respondents, their encounter with heart disease was due to excess consumption of oily and fatty food; two more respondents attributed onset of CVD to already existing diabetes; one respondent attributed it to the old age; and remaining one felt that it was due to her genetic predisposition towards heart diseases. Respondents were also asked about the role of mental stress in the onset of CVDs, to this 15 (36.6%) respondents replied that mental stress plays a key role; whereas four (9.8%) respondents were against this idea; and remaining 22 (53.7%) had no idea about the role of mental stress in the onset of CVD.

One of the respondents named Rajjo aged 72, believed that excessive medication made her a heart patient. she said:

> *I used to consume a lot of medicines for body aches. I had to take bulk of anti-biotics as well. This excessive consumption of medicine made me a heart patient. and slowly all my body parts started getting involved.*

Many respondents attributed their life shattering experiences as the reasons responsible for the onset of CVDs. For Pushplata, aged 65, loss of her husband was too much to bear and this resulted in her heart problem. Similarly, Kiranpreet Kour, aged 50, narrated her story as:

> *My son met with a serious accident and lost his voice. I was extremely stressed with the fact that my only son would never be able to speak. This stress took a huge toll on my health and I developed heart problem.*

Sulakshana Devi, aged 60, was an ardent follower of religious sect "Radha Swami Satsang, Beas" and visited Beas every month, despite her poor health conditions. She was suffering from diabetes as well. She said:

> *None of my four children stays with me. They left our house long ago and I terribly miss them. Had any of them been living with us (she and her husband), I would never have developed this disease. My children do not understand my situation.*

Soma Kumari, aged 55, lost her husband long back when her three children were in their early adolescence. She was still mourning her died husband:

God alone is responsible for my deplorable condition. I was so young and there was no financial independence. Overnight I was homeless with three young children to look after. Only I know how terrible all those years were. For so long I did not consult any doctor as I could not afford any treatment. I am still under that shock. However, now my son has a job and he can afford my treatment. So, I told him to take me to the doctor.

According to Friedson (1970), most elementary way to express discomfort arising on account of an illness is 'pain', and ways of expressing this pain are most likely to be driven by social exposure. This is why, different patients react in a different way towards same kind of pain. Concept of pain is actually associated with the discomfort (impact), with the deviation from normal or something which is desirable (Friedson 1970). According to Charmaz (2000) chronic illness experiences lead to the usage of metaphors, providing meanings to physical symptoms, moral judgements, ethical dilemmas, reconstruction of the self-identity etc. Foucault described illness experiences in the context of human body which gets disfigured and is a deviation from 'docile body.' However, in his later writings he emphasised on 'technologies of self' which were different from what he earlier proposed as 'body' or 'subject' (Lupton 1997; Fox 1997). In the words of Nick J. Fox:

> 'Practices of the self' mark the engagement between discourses of the social and the individual, such that power is integral to the autonomous ordering of individual's own lives… Personal identities thus emerge not as prior and privileged ontologically, but 'in a battlefield', in which difference and opposition are the means by which identity and the boundaries of others become discernible. (Fox 1997: 42)

Therefore, Foucault was also convinced that self-experiences or 'technologies or practices of the self', as he called, are paramount in the manifestation of the impact of an illness. Impact of a disease in the form a particular identity formation for the self or in the form of role-conflict is inevitable which has a bearing on the disease management approach of the patients. Identity formation was found to be the major consequence of CVDs in the life of Supinder Kour who said:

I lost my husband at a tender age of 22 and since then I am living with my parents. I am raising my son as a single mother which was already too much for me and now additional burden of this disease. Collectively these factors do not make me feel good about myself. Although financial burden of the disease is taken care of by

the company, I am working with yet emotional burden of this disease and my personal life is something which is too much to bear.

Unlike Supinder Kour, family of 48 years old, Kamla was bearing additional cost of her disease, and she herself was trying to be a perfect homemaker amidst the deplorable situation of unstable angina (a situation which can lead to heart attack):

This disease is an additional financial burden which is worrisome……I cannot spare time for walk or any other kind of workout as my husband and children have to leave for their respective workplaces in the morning and it is absolutely my responsibility to prepare meal for them. What my family needs is most important for me and therefore I cook food depending upon the taste of entire family and not specifically on the basis of what I require to eat.

Garima Devi, aged 45, was struggling with negative identity formation because of her inability to perform house hold chores. She was also worried about the increase in financial burden of the family:

I had already been suffering from diabetes and now onset of heart problem makes me feel like a huge burden on the family. These diseases are physically exhausting, and I feel terrible when I fail as a mother and as a wife. In addition to this, monthly expenditure has also increased because of my health.

Therefore, 'pain' inflicted on account of illness need not always be physical but can also be due to 'social effects of being sick'. Another way of defining 'health' or absence of illness is the ability to carry out tasks which a person in good health can do (Friedson 1970). Respondents in present study, largely being unable to carry out those tasks formulated an identity for themselves which inflicted more pain on them than the physical discomfort of the disease. Daya aged 37, was another such patient who was struggling with her role as homemaker and was, therefore, compromising her 'sick role'. She was suffering from diabetes as well. In her words:

I cannot spare time for workout due to household chores. And this is why, I also avoid cooking separately for myself. Family requirements come before my personal requirements.

An intriguing case was of 70 years old Satnam Kour who refused to comply with the instructions given by doctors. She believed that she had already lived her life to the fullest and it was unnecessary to practice abstinence from the things (food) of her choice, in order to

manage her disease. This resonates with the study of Bonita and Beaglehole (2014) who observed that one of the main reasons that NCDs are not taken care of, by women is because they consider it to be the disease of the elderly and believe that anyways one has to die of one or another cause in the old age.

Therefore, negative self-image and role conflict emerged as major social impact of CVDs amongst women in the present study. However, inability to be with the loved ones was a commonly perceived reason which had a psychosocial impact on these women and also made them feel poor about themselves in terms of their incompleteness, solitude or being a deviant in the socially defined family structure.

3. Role of Environmental Factors

Table 4.4

Role of Environmental Factors in the Onset and Management of CVDs		
Nature of Work		
	Frequency	Percent
Sedentary	37	90.2
Physical	4	9.8
Total	41	100.0
Mode of Commutation		
	Frequency	Percent
Prefers to walk	18	43.9
Public Transport	10	24.4
Owns a Vehicle	13	31.7
Total	41	100.0
Workout Before Onset		
	Frequency	Percent
Yes	11	26.8
No	25	61.0
Yes (Started due to Diabetes)	5	12.2
Total	41	100.0
Workout After Onset		
	Frequency	Percent
Walk	13	31.7
Irregular Walk	8	19.5
No	20	48.8
Total	41	100.0

Whether Respondent keeps her Personal health in mind while Cooking Food		
	Frequency	Percent
Yes	23	56.1
No	14	34.1
3	4	9.8
Total	41	100.0

*N = Total Number of the Respondents

Environmental factors play a crucial role in the manifestation of CVDs. Of all the environmental factors which are responsible for the onset of CVDs, built environment is considered to be paramount in creating atmosphere conducive for the rise of CVDs (Bhatnagar 2017; Chow et al. 2009). This is the built environment which determines eating habits of the patients, their exposure to physical activities and rise in the levels of obesity (Chow et al. 2009). In addition to this, smoking also plays an important role as an environmental factor in the onset of CVDs, however, in Indian scenario smoking is not found to be an important determinant of CVDs amongst women (Bhatnagar 2017; Rani et al. 2003).

Lifestyle factors of physical activity and heating eating habits constitute major contributing factors for the onset and management of CVDs (Buttar, Li, and Ravi 2005; Ignarro, Balestrieri, and Napoli 2007). As shown in table 4.4, 37 (90.2%) respondents were involved in everyday activities which were sedentary in nature, and only four (9.8%) respondents' nature of everyday work was physical. About the question related to most common means of transport used in everyday life, 18 (43.9%) respondents said that they preferred to walk whereas 10 (24.4%) respondents replied that they commute in public transport, remaining 13 (31.7%) had a vehicle of their own therefore, they do not have to walk much. Workout is a major determining factor for keeping a check on the obesogenic environment which results in the onset of various lifestyle diseases. Therefore, when respondents were asked about their workout routine before the onset of CVDs, only 11 (26.8%) respondents said that they were involved in one or another kind of workout; majority of the respondents i.e., 25 (61%) did not do any kind of workout before the onset of the disease. Remaining five (12.2%) respondents were involved in workout (mostly in the form of walk) because they were already suffering from diabetes. This scenario did not change much even after the onset of CVDs as only 13 (31.7%) respondents opted for regular walk where as eight (19.5%) respondents used to go for irregular walk. Even after the onset of CVDs, 20 (48.8%) respondents did not opt for any kind of workout. Many of them could not go for walk as they were told not to do so by the doctors however, still majority of

the respondents did not opt for it due to personal reasons such as body weakness, inability to spare time for walk, unwillingness etc.

One of the respondents, Tripta Devi, aged 56, said that she always keeps boiled *Daal* (lentils) aside for herself so that she should not eat foods which are bad for health and claimed that she took good care of herself. This statement of hers was interrupted by her son who accompanied her to the hospital. He mentioned:

> *She never opted for workout and started eating boiled Daal only few months back, when doctor told her that her health was deteriorating. Ever since I have got married, she has altogether stopped working and now she just sits throughout the day.*

Similarly, Kaushalya Devi also stopped doing household chores after her son got married. She admitted that performance of household chores was her only physical activity which she used to do and at the time of interview, she was relieved of that as well.

Final question which was asked to determine role of environmental factors in the onset and management of CVDs was related to the methods of cooking. Respondents were asked whether they kept their personal health in mind while cooking food, and to this 23 (56.1%) respondents said that they do eat food keeping their health in mind whereas 14 (34.1%) respondents replied that they never keep their health in mind and cook food according to the needs and taste of the entire family. There were four (9.8%) respondents who 'sort of' kept their health in mind while cooking food, which implies that they try to use less amount of oil and salt in the food so that they can protect their families as well from the future onset of these diseases. Cooking of food is still primarily a woman's job and this is an expression of love and care which is related to their femininity (Furst 1997). This might be the reason that these women care more about the need of their family members than their own health as it happened in the case of Daya. Some respondents also avoided cooking separately in order to save money. Sharmishta Devi, aged 60, lost her husband when her children were very young. She said:

> *When my husband expired, there was a lot of financial burden on me as I had to get my four daughters married. This may have led to the onset of heart problem….We always cooked food in Dalda ghee (Hydrogenated vegetable oil) and I could never make separate food for myself as this would have cost us more money.*

Sociomedical categories are broadly categorised into two views. The first one emphasises on the objective classification of the human health category and therefore, stresses upon looking at the human health activities falling outside of what is defined as normal health activities. Second view holds that health behaviours are culturally defined as healthy or unhealthy and are, therefore, socially constructed. Latter view helps health experts in understanding the difficulties which are being faced by people (Rubinstein, Scrimshaw, and Morrissey 2000). Foucault (Gastaldo 1997) argues that from eighteenth century onwards, human body is looked at from economic and political point of view, and looking through the lens of social constructivism, this was a major change in the approach which centered around killing an individual before eighteenth century. This life promotion was expressed by Foucault in terms of 'bio-power' which may be defined as mechanisms to increase productivity and health status of a human body. Bio-power is usually operated by means of 'bio-politics' and 'anatomo-politics.' Anatomo-politics perspective looks at human body as a machine which is best utilised by means of disciplinary actions taken by institutions like family, schools, hospitals etc. Therefore, individuality construction, in therapeutic arena, is focused around disease, symptoms, lifestyles etc. and, defining and managing of these processes by the medical core. This makes 'clinical gaze' a paramount instrument which is being used by the doctors in examining and defining healthy lifestyles (Gastaldo 1997). These are the main difficulties faced by masses in health sector and by means of social constructivism health experts try to explain and help people manage their disease. This is why environmental factors are critical in determining lifestyle of the masses.

Respondents who were already suffering from diabetes were found to have a very laid-back attitude towards diabetes which might have resulted into the onset of CVDs later. In total, 14 respondents (table 4.3) experienced onset of diabetes before the onset of CVDs and most of them admitted not to control their eating habits or not opting for workout even after the onset of diabetes.

Reema Koul was one of the respondents who used to go for walk before the onset of diabetes and also used to do *Yoga* on irregular basis, however she stopped doing that after the onset of diabetes due to body weakness. Seeta Kumari, who was hospitalised in the Coronary Care Unit (CCU), lost both her feet following the onset of diabetes due to which she could not go for walk or opt for any other kind of workout.

Another respondent, Karandeep Kour, aged 55, was suffering from diabetes for 10 years however, she never bothered to take this disease seriously. She said:

> *I am suffering from diabetes for last 10 years however, I never found it to be a matter of concern. And as far as going out for walk is concerned, I do not feel like going for it. To be honest, I am too lazy to do it…. our food has always been cooked in Dalda Ghee because it tastes so good and I never cooked, or told the person who so ever is cooking, to prepare a separate diet for me. I never thought it to be necessary to have separate diet for myself.*

It has often been observed that patients with diabetes do not consider diabetes to be a matter of grave concern and therefore seldom bother to opt for doctoral intervention. Many times, even when they consult a doctor, they never consider it to be a matter too serious to follow all the instructions given by the doctor which eventually results in CVDs (Leon and Maddox 2015; Wang and Reusch 2012; Zgibor and Songer 2001; Dalewitz, Khan, and Hershey 2000). Therefore, role of women as family caretaker, lack of workout (due to family chores, unwillingness or being a matriarch), inability to consume food which is required to maintain good health, and not to consider diabetes a potential risk factor are the main factors identified to be responsible for creating a conducive environment for the onset of CVDs. This is how individual bodies are examined as social bodies to formulate a defined set of knowledge which is used to exercise disciplinary powers in order to get healthy lifestyles (Gastaldo 1997).

4. Health Seeking Behaviour

Table 4.5

Health Seeking Behaviour		
Information about CVD before its onset		
	Frequency	Percent
Nothing	27	65.9
Just Heard of It	12	29.3
Results due to genetic causes	1	2.4
Causes Breathless	1	2.4
Total	41	100.0
Frequency of Visit to the Doctor		
	Frequency	Percent
As prescribed	32	78.0

Every month	2	4.9
As Per own wish	7	17.1
Total	41	100.0
Information about Disease after Onset		
	Frequency	Percent
Nothing	39	95.1
Heartache, Faster heartbeat and Panting	2	4.9
Total	41	100.0
Type of Treatment opted for		
	Frequency	Percent
Allopathic	31	75.61
Home Remedies for diabetes and allopathic for CVDs	2	24.39
Total	41	100.0
Any Social Strain due to Disease		
	Frequency	Percent
No Stress	17	41.5
Excessive breathlessness and eating restrictions	6	14.6
Stopped going to social gatherings	7	17.1
Body Weakness	10	24.4
Due to Diabetic foot amputation	1	2.4
Total	41	100.0
Family Restrictions on Eating Habits		
	Frequency	Percent
Yes	27	65.9
No	13	31.7
No Reply	1	2.4
Total	41	100.0
Kinds of Restrictions posed by Family		
	Frequency	Percent
Avoid eating oily and fatty food	8	19.5
Eating Restrictions and keep a vigil on medicine intake	5	12.2
Monitor her diet	13	31.7
No	2	4.9

No Reply	13	31.7
Total	41	100.0
Decision Maker in the Family		
	Frequency	Percent
Husband	17	41.5
Self (financed by husband)	6	14.6
Son(s)	11	26.8
Husband and Wife	1	2.4
Nephew	2	4.9
Self	4	9.8
Total	41	100.0

*N = Total Number of the Respondents

Health seeking behaviour is recognised as a gendered phenomenon worldwide where less attention is paid to women's health in under developed and developing countries. Many times, women themselves postpone their health requirement and prioritize health necessities of male members of their families. This is mainly due to the fact that their indirect contribution in family earnings go unnoticed (Saikia, Moradhvaj, and Bora 2016). Health seeking or care seeking behaviour in case of women is more of a cultural necessity than being a biological one (Das et al. 2018). It is due to this fact, female CVD patients have to face various barriers to their health seeking behaviour. In addition to financial burden of the disease, another major barrier which is identified by doctors, pertaining to Indian context, is mismanagement of diabetes mellitus. Knowledge distortion and non-compliance to doctoral instructions are the main reasons that patients reach cardiologists by the time their heart conditions have already deteriorated (George et al. 2016; Pratte 2016). However, onset of CVDs makes these patients more concerned about their condition and making efforts to comply with doctoral instructions despite of increased out of pocket expenditure (Wang and Reusch 2012; Leon and Maddox 2015).

Health seeking behaviour of women suffering from CVDs was assessed by asking questions pertaining to their knowledge level about CVDs, frequency of their visit to the doctor, type of treatment they have opted for, role of their family members in the management of their disease etc. As shown in table 4.5, when respondents were asked about any information they had about CVD before its onset, 27 (65.9%) respondents replied that they had no knowledge about any kind of heart disease before getting the disease; however, 12 (29.3%) respondents mentioned that they just heard of it; one of the respondents said that it results due to genetic factors; and

remaining one said that it is caused due to breathlessness. This knowledge, regarding their own disease, did not change much even after the onset of CVD as 39 (95.1%) respondents still could not explain what their disease was, except for the fact that it was related to their heart; for remaining two respondents the heart problem leads to heartache, faster heartbeat, panting etc. About the question related to their frequency of visit to the doctor, majority i.e., 32 (78%) respondents replied that they visited doctor as per doctor's recommendation; there were two respondents who visited doctor every month; and remaining seven (17.1%) respondents visited doctor as per their own wish. All these seven respondents belonged to peripheral regions which needed extra time and money to pay a regular visit to the doctor.

One of the respondents, named Maya Mehra aged 55, was staying with her only son in Doda district (200 kms away from Jammu district). Her only source of income was her late husband's pension as her son was unemployed. She said:

> *It is not possible for me to visit doctor every month. It requires many things. Firstly, I need to stay in Jammu overnight which means that I will have to put up at some relatives' place. Then it requires various expenses like travel fare, cost of eating outside etc. Hence, I visit OPD at my ease, when I think that I can spare some extra time and money for it.*

It was interesting to note that none of the 41 respondents opted for any kind to alternative treatment other than allopathy for managing CVDs. However, out of 14 respondents who were suffering from diabetes as well, 10 respondents opted for alternative medication in the form of Ayurveda or home remedies to cure diabetes only. This approach of the patients poses a challenge to the cardiologists as diabetes is a major risk factor for the onset of CVDs. Management of CVDs becomes many times more challenging for the doctors when patient is already suffering from diabetes (George et al. 2016). One of the respondents, Kanta Devi said:

> *Diabetes can be taken care of at home as it is nothing but all about body weakness and excessive urination. Heart disease, on the other hand, is extremely alarming as one gets immediately unconscious and, god forbid, many people lose their lives as well. Diabetes does not pose any such terrifying threats.*

Regarding problem of facing any kind of social stress due to CVD, 17 (41.5%) respondents replied that they do not have to face any kind of social stress due to their disease. There were six (14.6%) respondents who mentioned that breathlessness and restrictions on their eating habits were troublesome for them; seven (17.1%) respondents stopped going to social gather-

ings such as marriage parties because of their disease; 10 (24.4%) respondents complained about body weakness; and remaining one was unable to even move around as she had to undergo foot amputation due to diabetes.

Role of a fiduciary is of immense importance in determining health seeking behaviour of any patient. Therefore, respondents were asked about the restrictions imposed on them by their family members in order to manage their disease. It was found that 27 (65.9%) respondents had one or another restriction imposed on them by their family members. Remaining 13 (31.7%) respondents said that their family members never interfered in their disease managing regimen. Disease management was usually in the form of eating restrictions or encouraging respondents to go for walk or to keep a vigil on the medicine intake of the patients. There were 8 (19.5%) respondents who were told by their family members to avoid eating oily and fatty food; five (12.2%) respondents said that their family members keep a strict vigil on their food habits and medicine intake. For 13 (31.7%) respondents, their family members regularly monitored their diet and remaining two respondents could not explain about the kind of restrictions imposed on them by their family members.

One of the respondents named Asha Rani, aged 40, shared her experience in this regard:

> *I always fail to spare time for walk due to household chores but my husband keeps a strict vigil on my entire routine. It is only because of him that I seldom skip my walking routine. Due to his profession, he cannot always monitor my diet, however we usually eat dinner together and he does not let me eat left behind food. I think that it is not good to waste food therefore, I should eat it instead of throwing it away. He, on the other hand, says no matter how much food is to be thrown away but I should not eat anything which is not good for my health.*

Another respondent, Neerja Devi, said that her sons keep a strict vigil on her diet. She further added:

> *Wherever I go, my children never let me eat anything harmful for my health. I keep getting instructions about what to eat and what not to eat.*

Similarly, Tripta Devi, was also told by her son to go for walk. Gayatri Sharma, aged 50, was hospitalised in CCU at the time of interview. She was also suffering from diabetes, she narrated:

My daughter never lets me eat anything consisting of artificial sweeteners. She is very particular about my walk and makes sure that I go for walk, if not every day, then definitely every alternate day.

Another significant factor in determining health seeking behaviour of women in general, and those suffering from CVDs in particular, is the main decision maker in the family. Being predominantly patriarchal in nature, cultural factors in Indian society make women completely dependent on their male counterparts for all the important decisions of their lives, particularly their health (Sen 2012). Therefore, majority of the respondents were dependent on the male members of their families regarding health expenditure and choice of treatment. Majority of the respondents i.e., 17 (41.5%) said that they were dependent on their husbands for all the medical expenses and choice of treatment; six (14.6%) respondents themselves made choice of their course of treatment however, their expenses were borne by their husbands. There were 11 (26.8%) respondents who were dependent on their sons; and four (9.8%) respondents were themselves responsible for all the decision making. It is important to note here that all these four respondents were widows and were surviving on the pension of their late husbands. There were two respondents who were dependent on their nephews for decision making and in the case of remaining one respondent, husband and wife jointly made all the decisions related to her health.

Overall, it was observed that economic burden of the disease and role of women as family caretaker were the biggest determinants of the health seeking behaviour of the respondents. It has already been mentioned that many respondents did not bother to look after their diet or to go for walk either due to the burden of house hold chores, or due to financial incapacity or due to the taste preferences of the entire family.

Similarly, many other respondents had to compromise with their health seeking behaviour due to financial constraints. Gomti Devi, aged 45, was also suffering from diabetes and had four more diabetic patients in her family. She said:

We are in total five members in the family who are suffering from diabetes. Now, I have been detected with heart problem as well. Our financial position is not sound, therefore, we consume medicine in shifts. Sometimes, I do not take medicine so that it can be given to my mother-in-law. Other times, some other member skips medicine so that it can become available to some other patient in the family. Doctor

was telling my husband that a pacemaker has to be inserted in my heart which costs a lot of money. I think this disease will make us debt ridden.

Purshottama Devi, (Padma Devi) aged 50 was another respondent who underwent stenting recently. She also had to borrow money for the entire procedure. In her words:

My family will have to repay this money in 24 instalments spanning over two years. We were already living in hand to mouth condition and now this borrowed money is a cause of additional stress for entire family.

Lata Devi, aged 76, was completely dependent on her nephew for the treatment:

My sons are still students, they cannot bear their own expenses how can they pay for my treatment. My nephew looks after my health expenses. But he also has a family of his own and young children to feed.

Prema Devi, was a retired school teacher. She explained her situation:

My son is married with two children. However, he is still unemployed and his entire family of four members is dependent on my pension and my late husband's pension. I get money from these two pensions to look after myself, my disease and my entire family expenses.

Therefore, technologies of the self, as Foucault talked of, can be mastered in order to produce a new human being. These are the power regimens exercised by individuals themselves to create a different power or knowledge structure necessary to manage their lifestyles (Schneirov and Geczik 1998). These technologies of the self are constructed in the light of various external factors which in the case of present study are financial background of the respondents, their role as family caretaker and their cultural construct which makes their health more of a cultural necessity than being a biological necessity. Role of fiduciary is another important factor in the effective disease management, however, being primary caretaker of the family, women often themselves act as fiduciary to the entire family.

5. Discussion

Female patients suffering from CVDs face various challenges in effective management which is mainly in the form of role conflict, negative self-image formation and unwillingness to comply with the routine meant to manage diabetes. All these factors are directly or indirectly associated with financial constraints and self-beliefs which are instrumental in the management

of any lifestyle disease. From the results mentioned above it can be argued that women form a deprived section in seeking care for CVDs. Technologies of the self in the case of health management are nothing but change in lifestyle which can ensure effective acquisition of the sick role by these patients. Unlike in the case of diabetes women suffering from CVDs had more faith and reliance on the expertise of a doctor with zero dependence on alternative sources of medication. However, despite being a CVD patient, these respondents still had faith on alternative sources of medication for diabetes management.

Friedson (1970) explained that social construction of illness takes place at the level of patient based on her/his own experiences. The meaning which is being given to diabetes and CVDs by these patients is based on their own experiences. Since, they have not encountered any event (can be their own or others) which could transform their perception of the disease, their approach towards diabetes and CVDs management would be the same. This is the present scenario of these diseases which can be changed in the future depending upon the course of events that can take place on account of aggravation or recovery of these diseases. Therefore, meanings are provided to the disease depending upon immediate experiences. These meanings are always contested by changing the course of social interactions and experiences. Reflexive actions of human beings to these interactions and experiences keep bringing changes in these meanings (Turner 2000). Technologies of the self are governed by these changing meanings which acts as stimulus for the individuals to work towards improving their bodies and working for self- mastery (Schneirov and Geczik 1998).

Disease management is more of a cultural necessity than a physiological one for these women because onset of CVDs lead to role conflict and resultant negative self-image formation. Das et. al. (2018) studied health seeking behaviour of women in Kolkata and found that women opt for traditional sources of medication because they feel it to be culturally secure, pocket friendly and easy to access. However, in the present study women sought doctoral consultation in order to be able to perform their role of a family caretaker effectively. It had other implications as well, as women prioritized their family requirements over their health requirements and were not effective with their sick role performance. This role conflict was also manifested in the form of negative identity formation or 'pain' where these respondents were found to be suffering from social impact of the CVDs. This pain was inflicted when respondents could not perform their role of a home maker or when they found that they were too young to experience outset of a CVD or when they make an addition to the pre-existing heavy household expenditures.

It is mainly due to this pain that the role of fiduciaries becomes a key role in the disease management of women. Many respondents were reluctant to look after their health, however, constant instance by family members was a strong motivation for them to opt appropriate disease management routine. Therefore, it will not be wrong to argue that fiduciary responsibility is a type of anatomo-politics in which patient gets constantly motivated by her family members to ensure appropriate disease management as it has been argued throughout the study that women tend to compromise their sick role while performing their role as family care taker. Therefore, it is necessary that they should be constantly propelled to.

Ohashi et. al. (2014), in their study of Egyptian women found that those who get support of their family in general and of their husbands in particular are more particular towards effective management of their disease. This is how fiduciaries act as, what Parsons (1975) called, agents of social control. They aim at realising sick person that 'health is a good thing and illness by and large a bad thing' and patients should strive towards bringing balance in the society by working towards gaining health.

Therefore, role of women as primary care taker of the family is the biggest challenge in the management of CVDs. Friedson (1970) suggested a pattern of 'mutual cooperation' amongst all the stakeholders of an illness to ensure efficient social organisation of an illness. He further adds that initiation of a 'therapeutic interaction' is very important in order to keep a check, especially, on chronic illnesses by means of mutual cooperation. Therefore, it is necessary that doctors, patients and their family members, all work towards effective management of CVDs. However, role of state in the formulation of an effective health policy would be a key to control unchecked menace of CVDs.

5
Conclusion

In this study, I tried to delineate the role of socio-cultural factors in the onset and management of lifestyle diseases in the lives of women from Jammu region. This study can be helpful in generalising the nature of lifestyle disease onset in India. Three lifestyle diseases have been selected to examine how women deal with these diseases. Entire study is based on the fact that, in present times, lifestyle factors have maximum role to play in the manifestation and management of lifestyle diseases. These lifestyle factors emerge from the socioeconomic and cultural set up of the society.

The first chapter broadly deals with the existing literature, research gap, objectives, methodology, area of study and challenges faced during the study. Three diseases which have been examined in the study are PCOS, Diabetes and CVDs. The first chapter aims at providing an understanding of the social context in the research of lifestyle diseases. These three diseases have been chosen by keeping in mind the fact that CVDs contribute to the maximum number of deaths occurring due to lifestyle diseases, diabetes is a major risk factor for CVDs. Diabetes also has a symbiotic relationship with PCOS which is a female specific disease. Therefore, these three diseases are directly related to each other, and physiologically onset of one has a bearing on the onset of another. By means of review of literature, I tried to put forward the challenges which are being faced by women while dealing with lifestyle diseases. Existing gap in the literature shows that despite being an important cause and consequence of multiple sociocultural factors, lifestyle diseases are seldom looked at from sociological point of view in Indian context. By using social constructivism, I tried to analyse how knowledge and discourse are related to these diseases. I also attempted to explain how social construction of illness from layman perspective has a strong impact on the entire course of the disease in the life of a patient. This chapter provides an idea of the objectives which are being dealt with in the study.

Second chapter is based on the socio-cultural aspects of PCOS. Main concern with respect to the disease was the stigma associated with its open conversation. The respondents were worried about their body disfigurement, marriage options and post married life. The results show that these women had to face problem of stigma due to irregularity of periods, infertility, hirsutism and increased body weight. The situation which was peculiar to PCOS was that patients did not know that they were suffering from PCOS. Their communication with the doctor was taking place in terms of the symptoms and discomfort arising because of PCOS. Absence of physical

workout and consumption of foods rich in carbohydrates acted as a base for obesogenic environment which is the breeding ground for all prominent lifestyle diseases. In addition to this, structural vulnerabilities contributed to a stressful atmosphere which further made it difficult for the respondents to manage their disease. Some visible vulnerabilities were the pressure to perform and score well in the examinations for the students; for married women, it was the compulsion to have a child in order to extend their families; married working women had to manage their household chores, their role at their work place and then stress of producing a child. Therefore, sedentary lifestyle, inappropriate eating habits and structural vulnerabilities acted as crucial factors in the onset and management of PCOS.

Third chapter deals with the onset and management of diabetes. Patients suffering from diabetes also had their own way of knowledge production related to the disease and it had a bearing on their methods of diabetes management. Major impact of diabetes on the lives of the respondents was witnessed in the form of compromise which they had to make in terms of their food. Many respondents were upset with the fact that they could not eat rice and sweets following the outset of this disease. It was also observed that they built a discourse about the factors responsible for the development of diabetes in their lives. Sedentary lifestyle of the respondents also acted as a major environmental factor leading to the manifestation of diabetes amongst participants in the study. In fact, there were a few respondents who left workout following the onset of diabetes. The respondents were found to be concerned less about diabetes management as compared to other lifestyle diseases, which they think can have deadliest impact on their lives. This result is particularly important in suggesting the fact that personal experience has a strong influence on providing a certain meaning to a particular disease. Since, the meaning which these patients provided to diabetes did not make them worry much about it, therefore they were quite irregular with their visit to the doctor as well. However, there were certain respondents who had complete faith on the competency of their physician and did not believe that their diet or physical exercise can play any role in their disease management regimen.

Fourth chapter is about the female patients suffering from CVDs. Lifestyle factors of patients suffering from diabetes and CVDs bear a strong resemblance. However, disease management techniques of patients bear a strong dissimilarity. Similar to the case of diabetes, women suffering from CVDs also faced trouble due to their role as a family caretaker. Therefore, major impact of CVDs was witnessed in the form of role conflict which these women had to face. Majority of the patients developed negative self-image due to their inability to perform household chores and at the same time for being an additional financial responsibility for the

family. Some respondents were distressed due to early onset of the disease for which they thought themselves to be 'too young to acquire a heart disease', others considered themselves not 'a good wife' or 'mother' because they were failing in these role performances. Therefore, negative self-image formation was the biggest impact of CVDs. However, scenario was different in the case of women in their old age. Their main perception was that one has to die of one or another disease in one's old age so be it a heart or any other disease.

1. Main Issues

This study of lifestyle diseases has led to the emergence of various issues which are quintessential in understanding the pattern of emergence and consequences of lifestyles diseases in the life of women. These issues have been put into following headings:

Making Females not so feminine: PCOS

The process of knowledge construction and method of dealing with 'pain', in case of PCOS, determines the 'sick role' for these patients. Their immediate experiences restrict pain related to PCOS to infertility, irregularity of periods, body disfigurement, and resulting negative self-image. For unmarried women, it is the feeling of being less feminine which brings them to the gynecologist and is associated with their pain; for married women, this pain is inflicted in the form of being 'infertile'; for others, it is in the form of not being able to have a desired body or due to the onset of acne and hirsutism. It is really intriguing to know that immediate social experiences determine impact and future course of action for PCOS by these women. Although this disease has many more long-term complications which can adversely impact their own physiological composition and of their offspring, yet these women are not concerned about that part of the PCOS.

In addition to pain, knowledge construction related to PCOS also has a bearing on the approach of these patients towards the disease. It can be argued here that women in rural and peri-urban areas cannot connect themselves to this disease. Women in urban areas are aware of the term PCOS and the symptoms which it entails. However, those from rural and peri-urban areas fail to understand the process and management regimen of PCOS. Their feeling of lack of femininity arises on account of their failure to suffice socially defined image of a woman. This failure acts as a motivational force for them to consult a doctor and to regain their femininity. Additionally, alternative sources of medicine which now-a-days are considered to be unconventional methods of medication like drinking a potion, wearing an amulet or a regular

visit to a godman also aim at seeking relief from the 'pain', restoring femininity, and adds another dimension to the knowledge construction related to PCOS.

Disease which is Not so Deadly: Diabetes

Sick role acquisition in the case of diabetic women is very poor, and that is mainly due to the meaning which they and their family members provide to it. Diabetic patients rely on the common perception of diabetes management which emphasises that it is not a very harmful disease. Their experiences postulate that diabetes does not need any special care or attention. However, such meanings keep on changing with the change in the experience and future consequences of the disease. In the case of women who are the primary caretaker of the family, process of this change of meaning is even slower as they keep on prioritising need of their family over their own health. It is due to this reason that they tend to act what Parsons (1975) called 'Hyperchondriac.' Another major aspect of the study of diabetes is the asymmetry of doctor-patient relationship where patients are either completely dependent on doctors or completely dependent on their personal management techniques. A balance reflecting reliance on both is a very rare phenomenon. The discourse generated on account of their discussion with their relatives and friends usually determines their disease management regimen. The semantics conveyed during the course of these discussions have a strong impression on the knowledge production related to diabetes and its management. This shows that discourse leads to knowledge production, and provides patients and their fiduciary with the power to choose their own course of treatment. This meaning may or may not be in line with the medically approved method of diabetes care.

Role Conflict and Increase in financial burden: CVDs

Female patients suffering from CVDs face challenges of role conflict, negative self-image formation and unwillingness to comply with the routine meant to manage diabetes. These act as potential barriers in their CVDs management routine. All these factors are directly or indirectly associated with financial constraints and self-beliefs which are instrumental in the management of any lifestyle disease. Female CVD patients tend to consider themselves undesirable due to their ill health. This makes them to opt for 'technologies' to manage their disease so that they could make themselves desirable again and perform their everyday expected role efficiently. The meanings which these patients provide to themselves are subject to constant transformation due to the impact of ongoing change in their experiences with the

disease. The resulting reflexive actions to these transformations bring changes in these meanings and their approach towards disease management.

Role of fiduciaries is also a very crucial factor in the management of the lifestyle of a CVD patient in general and women in particular. Fiduciaries, whether they are family, friends, doctors or relatives, create an institutional pressure on the patient to acquire sick role. Many respondents in the study admitted opting for workout or to eat as per their health requirement, only after certain kind of familial pressure. This is how social institutions act as agents of social control in the field of health by recognising undesirability of an ill state and then by motivating ill persons to work towards regaining or managing their health.

Social Compulsion in Lifestyle Disease Management

In the end, it can be argued that management of lifestyle diseases is more of a social compulsion than being a physiological need for these women. Age of the onset of lifestyle diseases has a major role to play in determining social impact of the disease. If an adolescent or a young woman gets affected by any such kind of disease, it leads to her labelling in the society. This has a direct impact on her future marital prospectus as well. In a study by Bajaj et al. (2013), it was observed that young women with diabetes have to face stigma while searching for a groom. Bride and her family always gets concerned about her sexual and reproductive life, and they also have doubts about revealing this fact to the groom and his family. Nag and Ghosh (2013) found out that young women with CVD tend to ignore the disease due to high cost of treatment and stigma associated with the early onset of CVDs. In case of PCOS patients in the present study, respondents associated it with stigma, due to the possible difficulty arising on account of finding a suitable groom and fear of not being able to give birth to a child.

Another determinant of a lifestyle disease and patients' (or of their fiduciaries') approach towards it, gets reflected in the way it is being represented in everyday discourse. Respondents used euphemism *Sugar* to define diabetes and *Heart Problem* to define CVDs whereas they had no single term or an elaborate way to explain their encounter with PCOS. Every respondent had her own way of explaining symptoms which had varied dimensions. Some were suffering from oligomenorrhea, others from infertility, a few had problem of obesity, some girls felt challenged because of hirsutism and some were quite fine with the existing symptoms as it was not creating any kind of social or physical hurdle for them. These varied symptoms with no single term to explain the disease was quite disturbing for them. The absence of any common term in colloquial language made it almost impossible for the respondents to create any kind

of general discourse by means of which they could provide a popular meaning to PCOS. At individual level, however, there were varied narratives. But at common level there was none. For diabetes, common narrative made respondents to believe that diabetes can be taken care of quiet easily; in the case of CVDs, this discourse made them to be very diligent about their medicine and doctoral consultation. However, in the case of PCOS, there was no single approach which could emerge as a characteristic feature of the population suffering from PCOS. It was due to this fact that there was lack of communication, interaction and knowledge production amongst respondents which could be contested and can lead to a change in the existing meaning of the disease. Therefore, it can be argued that different kinds of lifestyle diseases have different meanings, depending upon the experience of common masses with it. These diseases can be called by using an umbrella term 'lifestyle diseases' but their social impact is exclusive as well as inclusive in nature.

2. Suggestions and Recommendations

Negative self-image formation, role conflict of a family caretaker versus sick role and fear of stigma are some of the social consequences of lifestyle diseases which act as major factors determining health seeking behaviour of these women. In addition to this, financial dependency and their role of a matriarch are also found to be prominent barriers in their health seeking behaviour. Social impact of these diseases is usually of socio-economic and cultural in nature. Therefore, study of lifestyle diseases needs a gendered perspective, not only in social sciences but in medical sciences as well.

Women usually perform the role of primary care giver and men are primary care seeker. This factor is a key determinant of the health seeking behaviour of women. National Health Policy (NHP) 2017 (Welfare 2017) of India emphasises on reducing pre-mature mortality due to top four NCDs by 25% by 2025, which is similar to NCD prevention provision adopted by the WHO. In addition to this, it also aims at establishing National Institute of Chronic Diseases for monitoring these diseases. However, no special provision has been incorporated for females except for breast cancer monitoring. Here I would like to suggest that provisions of NHP 2017 cannot be achieved without opting a gender specific approach in which factors determining onset and management of lifestyle diseases amongst men and women should be monitored separately.

3. Limitations of the Study

The present study is limited to a selected group of women which is not a representative of the entire Indian population. Though Jammu city was selected for data collection yet respondents from various peri urban and rural areas also participated in the study.

Due to the paucity of time and other resources, sample size was limited to 123 respondents. A larger sample size helps in strengthening the generalisations drawn from the study. Another major limitation of the study is that it focuses on the sociocultural aspect of lifestyle diseases from patients' point of view. Physicians'/ Doctors' point of view could have been valuable in widening the scope of the study. That involves a different bureaucratic approach to seek permission for data collection and different literature to design the study. Therefore, it could not be included in the present study.

This study has also not focused on the policy and provisions which are there for the wellbeing of masses in general and women in particular suffering from lifestyle diseases. Sociological exploration of these policies and provisions needs an altogether different theoretical approach which was not convenient to be undertaken in this study.

4. Future Course of Research

Examination of socio-cultural factors in the onset and management of lifestyle diseases from physician's point of view is a very important dimension of the study of lifestyle diseases. It would not only be an extension but an altogether different approach for the study, and important factor in the policy formulation meant for lifestyle disease management. A large-scale study of the same nature with bigger sample size and covering different geographical locations would be more helpful in delineating socio-cultural factors associated with these diseases.

Similarly, studies based on varying socio-economic groups would be another important course to the future research of lifestyle diseases. Inclusion of diverse socio-economic groups in the study of lifestyle diseases will provide useful insight into disease management and will help in policy formulation in health sector.

Since, lifestyle diseases need lifelong management, therefore, it is necessary to keep in mind the challenges that women face while doing so. It is not uncommon to find women acquiring the role of a fiduciary when they need to acquire sick role. This has an additional bearing on the physiological composition of women which is already facing genetic inferiority over Caucasians, being of South Asian origin. Lifestyle diseases are not gendered however, its

management is a gendered phenomenon which needs further exploration and being a problem, it needs redressal as well. Therefore, another sociological study of lifestyle diseases focusing on males' style of living and the problems being faced by them can also be undertaken to widen the scope of this research.

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Appendices

Appendix 1

INDIAN INSTITUTE OF TECHNOLOGY

ROORKEE UTTARAKHAND-247667

INTERVIEW SCHEDULE-I

Strictly Confidential
(For Research Purpose only)

Social Impact of Lifestyle Diseases on Women: A Sociological Study of Jammu District

Date of Interview.....

Place of Interview.....

Time (beginning)..... Ending.....

Name of Interviewer.....

Number of Schedule.....

Dear Friends

We are conducting this personal interview to seek your valuable views on the above-mentioned topic. We would very much appreciate your participation in the survey. Information provided by you will be used for academic purpose only and to formulate strategies for future action on the above said topic. This survey will not take more than 30 minutes and the information provided will be kept strictly confidential.

Participation in this survey is voluntary and if you think that information related to any particular question is too personal to be revealed then you can skip that question. However, we hope that you will offer your support to this survey. In case you need more information about the survey you may contact in the given e-mail id: abhigayanam@gmail.com or call at 07830669717.

(I) Socio-economic Profile of the Respondents

1) Age
2) Educational profile
3) Religion (Caste)
4) Occupation
5) Marital Status
6) Monthly Income of the family
7) Type of Ration Card holder
8) Family Structure: joint/Nuclear/Extended
9) Number of family members
10) Family Background:

S.no.	Relation with the Respondent	Age	Sex	Education	Occupation	Marital Status

I) Impact of disease on the Lifestyle of the respondents

1) Height and Weight of the Respondent:

1.1) Did you hear of PCOS before the onset of this disease?

a) Yes
b) No
c) Never heard of this disease
d) Don't know what PCOS is
e) I have family history of PCOS

1.2) (In case, reply is (e)) Who else is suffering from PCOS in your family?.....

2) Any other disease you are suffering from apart from PCOS.....

2.1) History of any other metabolic disease in the family (Diabetes, Hypertension or any other disease) .....

3) What do you consider yourself?

a) Bulky
b) Lean
c) Obese
d) Normal

4) Age of the respondent at the time of menarche.....

5) Age of the respondent at the time of onset of the disease.....

6) What is the normal duration of your monthly periods?

a) Less than 3days
b) 3-5days
c) 5-7days
d) More than 7 days

7) After how many days you do get your cycles

a) After 15 days
b) Within 25-35days
c) Within 35-45 days
d) After 45 days

8) Any physical activity which was a part of the daily routine of the respondents before onset of the disease.....

9) Any physical activity which is now a part of the lifestyle of the respondent in order to keep PCOS under check.....

10) Any major changes brought about by the disease in the daily routine of the respondent (eating/ workout/ways of applying makeup etc.) .....

11) One-word experience of the disease

a) Irritation
b) Frustration
c) Freakish
d) Normal
e) Any other (specify)

12) How do you feel about it?

(a) Hirsutism
(b) Obesity

(c) Infertility

13) Do you discuss menstruation related issues with:

A) Mother

B) Father

C) Brother

D) Husband

E) Any other member

13.1) Do you discuss menstruation related abnormality with your family members? Yes/No

13.2) If 'No', then is it due to internalised taboo that you do not discuss it with the male members of the family except with your husband?.....

14) Do you feel stigmatised due to infertility?.....

14.1) Due you feel incomplete as a woman that you cannot conceive?.....

II) Environmental factors contributing to the onset of PCOS

1) Nature of Work:

a) Physical

b) Sedentary

2) General eating habits of the respondents at the time of onset of the disease

a) Excess consumption of rice

b) Reliance on Junk food

c) Excess consumption of oily and fatty food

d) Excess consumption of Non vegetarian food/meat

e) Other food habits (specify)

2.1) Any changes in eating habits brought about by the respondent after the onset of disease.

.....

3) Sleeping routine and average time duration of the sleep before the onset of disease

.....

4) What are the socio-psychological stressors of everyday life experienced by you?.....

6) How do you commute from one place to another?.....

III) Health Seeking Behaviour of the Respondents

1) How much do you know about PCOS?.....

1.1) Source of knowledge (books, internet, Television, newspaper etc.) .....

2) Kind of treatment, respondent has opted for:

a) Allopathic

b) Homeopathic

c) Ayurvedic

d) Home-made remedies

2.1) If reply is (d) then the homemade remedies which respondent uses very often.....

4) General suggestions respondent receives regarding management of the disease from friends and relatives.....

5) Is there any peer pressure on you to attend late night parties or to eat junk food?.....

6) Do you face any difficulty in order to improve lifestyle:

a. Burden of household chores
b. Pressure to perform in work sector
c. Both the factors
d. Any other problem
e. No Difficulty at all

7) Who pays for the treatment?.....

8) How do house hold responsibilities of the women create a problem in the management of the disease.....

Appendix 2

INDIAN INSTITUTE OF TECHNOLOGY

ROORKEE UTTARAKHAND-247667

INTERVIEW SCHEDULE-II

Strictly Confidential

(For Research Purpose only)

Social Impact of Lifestyle Diseases on Women: A Sociological Study of Jammu District

Date of Interview.....

Place of Interview.....

Time (beginning)..... Ending.....

Name of Interviewer.....

Number of Schedule.....

Dear Friends

We are conducting this personal interview to seek your valuable views on the above mentioned topic. We would very much appreciate your participation in the survey. Information provided by you will be used for academic purpose only and to formulate strategies for future action on the above said topic. This survey will not take more than 30 minutes and the information provided will be kept strictly confidential.

Participation in this survey is voluntary and if you think that information related to any particular question is too personal to be revealed then you can skip that question. However, we hope that you will offer your support to this survey. In case you need more information about the survey you may contact in the given e-mail id: abhigayanam@gmail.com or call at 07830669717.

(I) Socio-economic Profile of the respondents

11) Age

12) Educational profile

13) Religion (Caste)

14) Occupation

15) Marital Status

16) Monthly Income of the family

17) Type of Ration Card holder

18) Family Structure: joint/Nuclear/Extended

19) Number of family members

20) Family Background:

S.no.	Relation with the Respondent	Age	Sex	Education	Occupation	Marital Status

(II) Impact of Diabetes on the Lifestyle of the respondents

1) Height of the Respondent:

1.1) Weight of the Respondent:

2) When was diabetes detected?.....

3) Any other disease you are suffering from?.....

4) You think you developed diabetes due to:

(a) Your genetic predisposition

(b) Lifestyle

(c) Stress

(d) Excess consumption of table sugar

(e) No idea

(f) Any other (specify)

5) Who else in your family is suffering from Diabetes?.....

6) General eating habits of the respondents at the time of onset of the disease

f) Excess consumption of rice

g) Reliance on Junk food

h) Excess consumption of oily and fatty food

i) Excess consumption of Non vegetarian food/meat

j) Drug Induced

k) Other reasons (specify)

7) Did you change your eating habits after the onset of disease? Yes/No

7.1) If 'YES' then, what major changes did you bring in your eating habits after the onset of disease?

a) Reduced consumption of rice

b) Reduced consumption of junk food

c) Less consumption of oily and fatty food

d) Less consumption of non-vegetarian food/ meat

e) Workout (specify) is now an integral part of the lifestyle

f) Other changes

7.2) Did doctor advice you to observe some changes in your dietary habits? Yes/No

7.3) If 'Yes' then what are the changes?.....

8) According to you, how does consumption of table sugar contribute to the onset of diabetes?.....

9) According to you, how does mental stress contribute to the onset of diabetes?.....

.....

III) Environmental factors contributing to the onset of Diabetes

1) Nature of Work:

a) Physical

b) Sedentary

2) How do you commute from one place to another?.....

3) Did you workout before the onset of disease? Yes/No

4) If reply is 'YES' then, what kind of workout you were involved in:

a) Walking
b) Running
c) Yoga
d) Exercise
e) Any other (specify)

5) Do you workout now? Yes/No

5.1) If reply is 'YES' then what kind of workout your are involved in:

a) Walking
b) Running
c) Yoga
d) Exercise
e) Any other (specify)

6) Did you ever get your eyes or kidneys checked after the onset of diabetes? Yes/No

7) Did you ever get your feet checked by the doctor after the onset of disease? Yes/No

8) Do you keep your personal health in mind while cooking food?.....

IV) Health Seeking Behaviour of the Respondents

1) What prior information did you have about diabetes at the time of its detection?.....

2) What information now you have regarding this disease?.....

2.1) Source of information (Books, Internet, Television, Newspaper etc.)

3) Which type of diabetes are you suffering from:

a) Type I
b) Type II
c) Gestational
d) No Idea

4) What type of treatment have you opted for:

a) Allopathic
b) Ayurvedic
c) Homeopathic

d) Home-Remedies

e) Any other (please specify)

5) How often do you visit doctor?.....

6) Do you find any social restrain because of this disease while meeting your friends and relatives?.....

7) Does your family observe any restriction on your food? Yes/No

7.1) If 'YES' then please elaborate.....

7.2) How do you feel about these restrictions?.....

8) How do your family members, friends or relatives try to guide you with regard to the disease?.....

8.1) Does this guidance bother you sometimes? Yes/No

8.2) Why?.....

9) Do you take all the important decisions related to your disease or someone else (finances and deciding the course of treatment)?.....

10) Do you find this disease a hindrance while performing house hols chores?.....

Appendix 3

INDIAN INSTITUTE OF TECHNOLOGY

ROORKEE UTTARAKHAND-247667

INTERVIEW SCHEDULE –III

(Strictly Confidential)

(For Research Purpose only)

Social Impact of Lifestyle Diseases on Women: A Sociological Study of Jammu District

Date of Interview.....

Place of Interview.....

Time (beginning)..... Ending.....

Name of Interviewer.....

Number of Schedule.....

Dear Friends

We are conducting this personal interview to seek your valuable views on the above mentioned topic. We would very much appreciate your participation in the survey. Information provided by you will be used for academic purpose only and to formulate strategies for future action on the above said topic. This survey will not take more than 30 minutes and the information provided will be kept strictly confidential.

Participation in this survey is voluntary and if you think that information related to any particular question is too personal to be revealed then you can skip that question. However, we hope that you will offer your support to this survey. In case you need more information about the survey you may contact in the given e-mail id: abhigayanam@gmail.com or call at 07830669717.

(I) Socio-economic Profile of the respondents

21) Age

22) Educational profile

23) Religion (Caste)

24) Occupation

25) Marital Status

26) Monthly Income of the family

27) Do you hold any Ration card: Yes/No

7.1) If 'Yes' then is it BPL or APL

28) Family Structure: joint/Nuclear

29) Number of family members

30) Family Background:

S.no.	Relation With the Respondent	Age	Sex	Education	Occupation	Marital Status

(II) Impact of Cardiovascular Diseases (CVD) on the Lifestyle of the respondents

1) Height and weight of the Respondent:

2) When was CVD detected?.....

3) Any other disease you are suffering from?.....

4) You think you developed CVD due to:

   a) Your genetic predisposition

   b) Lifestyle

   c) Stress

   d) Excess consumption of oily/fatty food

e) No idea

f) Any other (specify)

5) Who else in your family is suffering from CVD?.....

6) General eating habits of the respondents at the time of onset of the disease

a) Reliance on Junk food

b) Excess consumption of oily and fatty food

c) Excess consumption of Non vegetarian food/meat

d) Other reasons (specify)

7) Did you change your eating habits after the onset of disease? Yes/No

7.1) If 'YES' then, what major changes did you bring in your eating habits after the onset of disease?

a) Reduced consumption of junk food

b) Less consumption of oily and fatty food

c) Less consumption of non-vegetarian food/ meat

d) Workout (specify) is now an integral part of the lifestyle

e) Other changes

7.2) Did doctor advise you to observe some changes in your dietary habits? Yes/No

7.3) If 'Yes' then what are the changes?.....

8) According to you, how does mental stress contribute to the onset of CVD?.....

.....

III) Environmental factors contributing to the onset of CVD

1) Nature of Work:

a) Physical

b) Sedentary

2) How do you usually commute from one place to another?.....

3) Did you work out before the onset of disease? Yes/No

4) If reply is 'YES' then, what kind of workout you were involved in:

a) Walking

b) Running

c) Yoga
d) Exercise
e) Any other (specify)

5) Do you workout now? Yes/No

5.1) If reply is 'YES' then what kind of workout your are involved in:

f) Walking
g) Running
h) Yoga
i) Exercise
j) Any other (specify)

6) Are you aware of long term complications of the CVD? Yes/No

6.1) If 'YES" then what information do you have?.....

7) Do you keep your personal health in mind while cooking food?.....

IV) Health Seeking Behaviour of the Respondents

1)What prior information did you have about CVD at the time of its detection?.....

2) What information now you have regarding this disease?.....

2.1) Source of information (Books, Internet, Television, Newspaper etc.)

3) What type of treatment have you opted for:

a. Allopathic
b. Ayurvedic
c. Homeopathic
d. Home-Remedies
e. Any other (please specify)

4) How often do you visit doctor?.....

5) Does your family observe any restriction on your food? Yes/No

6) How do your family members, friends or relatives try to guide you with regard to the disease?.....

7.1) If 'YES' then please elaborate.....

7.2) How do you feel about these restrictions?.....

8) How do your family members, friends or relatives try to guide you with regard to the disease?

8.1) Does this guidance bother you sometimes? Yes/No

8.2) Why?.....

9) Do you take all the important decisions related to your disease or someone else (finances and deciding the course of treatment)?.....

10) Do you find this disease a hindrance while performing house hold chores?.....

Appendix 4

Socio-economic and Demographic Profile of the Respondents

Education (N*=123)		
	Frequency	**Valid Percent**
Illiterate	25	20.30
Primary	23	18.70
Secondary	25	20.30
Higher Secondary	23	18.70
Bachelors	11	8.95
Higher Education	11	8.95
Ph.D.	5	4.10
Total	123	100
Religion (N*=123)		
Hindu	99	80.48
Muslim	11	8.95
Sikh	11	8.95
Jain	1	0.81
Christian	1	0.81
Total	123	100
Occupation (N*=123)		
Student	26	21.13
Housewife	74	60.16
Government Employee	10	8.14
Retired Government Employee	5	4.06
Business Woman	1	0.81
Private Job	7	5.70
Total	123	100
Marital Status (N*=123)		
Unmarried	27	21.95
Married	67	54.48
Widow	29	23.57
Total	123	100
Family Structure (N*=123)		
Nuclear	65	52.84
Joint	58	47.16
Total	123	100
Age (In Years) (N*=123)		
01-20	15	12.20
21-40	40	32.52
41-60	50	40.65
61-80	16	13.01
80<	2	1.62
Total	123	100
Mean Age (In Years) = 42.36		
Monthly Income (Rupees in Thousand) (N*=123)		
>10	4	3.25
10-19	26	21.13
20-29	40	32.52

30-39	21	17.08
40-49	9	7.31
50-59	13	10.56
60-69	5	4.10
70-79	2	1.62
80<	3	2.43
Total	123	100
Mean Income (Rupees in Thousand) = 31.97		
Number of Family Members (N*=123)		
0-4	44	35.77
5-9	72	58.53
10-14	7	5.70
Total	123	100
Mean: 5.49		

*N= Total Number of the Respondents

List of Publications

- Sharma, Swati and Anindya J. Mishra (2019). "Diabetes Self-care Management: Experiences of the Socio-economically Backward Sections of Jammu" *Diabetes & Metabolic Syndrome: Clinical Research & Reviews* 13(2): 1281-1286 https://doi.org/10.1016/j.dsx.2019.01.025 (Elsevier)

- Sharma, Swati and Anindya J. Mishra (2018). "Tabooed Disease in Alienated Bodies: A Study of women suffering from Polycystic Ovary Syndrome (PCOS)" *Clinical Epidemiology and Global Health* 6(3):130-136 https://doi.org/10.1016/j.cegh.2017.09. (Elsevier)