BODY, SELF AND IDENTITY IN ILLNESS: A STUDY IN JUVENILE DIABETES

Thesis submitted to the University of Hyderabad towards the partial fulfillment of the degree of

Doctor of Philosophy

In

Anthropology

By

UDITA RATHI

Department of Anthropology

School of Social Science

University of Hyderabad

Hyderabad - 500 046 (India)

2012

Declaration

I, **Udita Rathi**, hereby declare that the work embodied in this thesis entitled **"Body, Self and Identity in Illness: A Study in Juvenile Diabetes"**, carried out in Hyderabad, in Andhra Pradesh, by me under the supervision of Dr. B.V. Sharma has not been submitted by me for any other degree or diploma in part or in full to this or any other University.

Place: Hyderabad UDITA RATHI

Date:

Certificate

This is to certify that the thesis entitled **"Body, Self and Identity in Illness: A Study in Juvenile Diabetes"**, submitted by **Udita Rathi**, towards the partial fulfillment for the award of the degree of Doctor of Philosophy is a record of the bonafide work carried out by her under my supervision and guidance.

This thesis has not been submitted previously in part or in full to any other university or institution for the award of any degree or diploma.

Dr. B.V. Sharma
Supervisor
Department of Anthropology
University of Hyderabad.

Prof. R. Siva Prasad
Head of the Department
Department of Anthropology
University of Hyderabad

Prof.
Dean
School of Social Science
University of Hyderabad.

Acknowledgement

Praise be to God for enabling me to finish my research and giving this opportunity to thank and acknowledge all those who helped me. There is nothing that I have not received from You.

I would like to begin with thanking my Research Supervisor, Dr. B.V. Sharma for his constant support, providing various opportunities, patience, insights and very valuable comments and suggestions. Sir, it has been a wonderful experience to learn from you.

My gratitude to Prof. N. Sudhakar Rao for all his help and suggestions which have greatly benefitted my work. Thank you Sir for sparing so much time and listening to me so patiently.

I am grateful to Prof. R. Siva Prasad for all these years of encouragement and wonderful ideas. I have always come back more enthusiastic to work after talking to you. Thank you Sir.

My thanks to Prof. P. Venkata Rao and Prof. K. K. Misra for their thoughtful insights on the subject and their useful suggestions.

I am thankful also to Dr. George Tharakan, Dr. Romesh Singh and Mr. Abdul Munnaf for all their help.

I am also grateful to Dr. Purendra Prasad for all his comments and suggestions in the doctoral committee that have enhanced my research.

Once again my gratitude to all my Teachers for teaching me the value of learning...I hope one day I can make you proud.

My heart-felt appreciation to the Non-teaching staff of the Department of Anthropology for their cooperation and all their help. Thank you Mr. Shekhar, Mr. Adi Narayan, Mr. Ashok and Mr. Niranjan.

I am grateful to Dr. B. K. Sahay without whose help this research was starting to feel impossible. Thank you Sir, for allowing me to carry out my research at your clinic and giving me valuable information. I would also like to express my thanks to Dr. Sanjoy Paul for all his help and time.

I am indebted to all the respondents who allowed me a glimpse into their lives. I would like to thank all of you for sparing me your invaluable time, for your willingness to talk to me, and making this research a reality.

I would like to thank my dear friends in the department Vinay, Kusum, Kalyan Reddy, Alok, Akhono, and Mhonyani for your ever encouraging words, amazing discussions, all the help and kindness you all have shown to me.

There are friends who have helped me in the last mile of this journey...I thank Diti for the proof-reading (etc!!), Imkum Naro for discussions in philosophy, Machun, and Ankur and Shweta for opening their home to me.

Words fail me to express my thanks to all my brethren in Christ. I am grateful to Church at Cyberabad (my family in GOD) { Br. James and Lata chechi, Br. Suresh and Junaita chechi, Hemlatha aunty, Arun Uncle and Sumati aunty, Br. Jino and family, Dennis uncle and family, my dear brother Sareeth and Sajini, Gijo and Divya, George and family, Swaroop bhaiya, Thejal, Pushpa and all those who have been with me in this journey} and Church at Morena- for your prayers, teaching me incredible lessons in life, rebuke, exhortation, encouragement and love, and for always being there for me.

God has blessed my life with wonderful friend. I want to thank Khre, Lydia, Maggie, Meren, Saritha, and Sube for enriching my life. You all are my precious treasure. You are the gems that God has studded my life with. Thank you girls for being there for me, for understanding me, enduring me, loving me unconditionally and being my home away from home.

I would also like to take this opportunity to thank my new family- My parents- in-law for their support in this time and encouragement, and prayers; my brothers-in-law and sisters-in-law for their love for me as the newest member of the family, for their concern and kindness.

This acknowledgement would be incomplete without the mention of my family. Thank you Papa and Mummy for your unconditional love, support and encouragement (and especially Papa for constantly hurrying me up to finish this research). Thank you Shefali jiji for loving us all so much and taking care of us, for your ever encouraging ideas. Thank you Surabhi jiji for all the discussions and your patience in teaching me philosophy. My ideas in the research were enriched because of you. Thank you Richa (Richie) for your love, moral support and understanding me, for hearing me out when I was down, and giving me ideas how I can improve. Thank you Shubhang (my Darling brother) for helping me go on, for your endless jokes and humour that made even tough times seem fun, thank you dear for your silent understanding, care, companionship and endless laughter.

My gratitude to my spiritual parents- Joy uncle and Clarice aunty, to whom I am grateful for discipling me, and investing so much in my life. For all your love, teachings, rebuke and reproof I can never thank you enough.

My best friend, my love, my husband Kalyan who stood by me in each struggle, pursued my PhD more relentlessly than I, helped me to carry on when I almost gave up, encouraged me to do my best and reminded me, 'why?' Thank you for your friendship, your love, for being there in my life, and thank you for being who you are...

Above all the Author of all knowledge and wisdom, Lord Jesus, to whom I owe my very existence, to whom belongs all glory, honour and praise. What can I render unto You, my Lord! I shall lift up my cup of salvation and give You praise...

Udita Rathi

CONTENTS

List of Tables and Figures

CHAPTER 1
INTRODUCTION

Everyone has a body. These bodies are real and primary agents to experience. Bodies establish, to a large extent, our connection with the world empirically. Diseases also are experienced in the body and it is the body that is subject to examination and observations irrespective of the medical system. That is to say in all the medical systems like bio-medicine, Ayurveda, Homeopathy, Unani etc it is the body that is subjected to observation and examination. Even mental disorders, at least in bio-medicine, though not experienced in terms of pain in the body yet subject body to observation and examination. Bodies have been discussed, debated and analysed over various issues: Like what is the body? Does the body have boundaries which are physical or does the body go beyond those boundaries when confronted with pain, trauma, disability, illness and for that matter ecstasy and symbolism and rituals (initiation ceremonies and concept of purity /purified bodies). (Douglas, 1973; Turner, 1992; Shilling, 2004; Freund, 2005) These have been some of the relevant questions.

There is also witnessed the overlapping of the body with the self. Consequently, a second set of significant inquiries that are made are: What is the self and where is this self located? Is the self bound to the body or is 'it' beyond the paradigms of bodily experiences? Many a times self has been equated and used interchangeably with 'soul' and thus this could and does lead us in to the realms of religion, one's understanding of the cosmos and placement of self in the cosmos,. Therefore, the inquiry of self thus also becomes the inquiry of the culture of oneself and construct of cosmos.

Thirdly, is raised the connection between the two. How deeply are the body and self integrated into each other and in what manner? Is the body a part of the self or is it the self which is located in the body where the body acts as the vehicle and agent? And

very importantly are these territories negotiable and change with experiences or circumstances or may be according to the need and culturally rooted behaviour? Fourthly, how the perceptions of body and self are culturally rooted, socialized and represented. These questions have been pondered and debated over by Religion, Philosophy Psychology, and Social Science for centuries. The study touches upon the broad trends in this discussion and moves on to understanding them from a cultural perspective.

In every culture body and self have significant roles to play- the purification of body, the defiled body, the sacred body etc. Most religions prescribe symbols that are carried out in the body and reflect the status of self. There has been much discourse on body and self in the Western and especially Judeo-Christian traditions. Starting from Classical Greek to early Christian scholars to Empiricism, Rationalism, to Phenomenology, Existentialism, Epistemology to Post-Structuralist and Post-Modernism all essentially concern and deal with the issue of body and self. All of these philosophical traditions accept the duality of body and self. In the Christian theological philosophy there are three traditional views about the human constitution- trichotomy (body, soul, and spirit), dichotomy (body and soul/spirit), and monistic (holistic nature of man combining body and soul/self/spirit/psyche/mind). This trichotomy of man can be seen also as a duality where the body represents the material, and the soul and the spirit represent the immaterial thereby creating a dichotomy of body- soul/spirit. The influence of the Judeo-Christian philosophy due to the spread of Christianity and the impact of Church through the Medieval Ages and at the foundation of the Modern West is substantial even in Post-Modern philosophy (whether it upheld or critiqued). Since these philosophical traditions had immense influence on Western society, anthropologists and especially medical anthropologists, dealing with body and self related issues, trace links with them.

Amongst the Hindu philosophies too starting from *Samkhya*, (a strongly dualist theoretical exposition of mind and matter, that denies the existence of God.) to *Yoga*(a school emphasizing meditation closely based on *Samkhya*) to *Vaisheshika*(an empiricist school of atomism) to *Mimamsa* (an anti-ascetic and anti-mysticist school of orthopraxy) to *Vedanta* all centre around Body and Soul. Whereas some of these

philosophies deny the existence of God, others consider God or *Brahman* as the third in the trichotomy with soul and matter as the other two. At times the trichotomy is reduced to dichotomy when the *Paramatma* (supreme soul or reality or divinity) is considered to dwell in the *Jivatma* (each individual's soul), and *Prakriti* (matter). There is also the presence of monism in the Hindu philosophy of the *Advaita* propounded by *Adi Shankara* wherein the *jiva* exists as separate from the *Brahman* till the *jiva* realises that its true nature that it is the *Brahman*. The ignorant state of the *jiva* is the period that the *jiva* remains as the individual self. There is also much significance given to the mind and reasoning that are considered as essential for self-realisation which is the highest stage a soul can reach. Pure reasoning and knowledge are considered as crucial and over and above rituals (which are also important) for self-realisation. In *Yoga* philosophy the body, senses, and mind are controlled in order to attain perfection and realise the liberation and truth of the transcendental self. In contemporary times the *Yoga* and the *Vedantic* philosophies bear great influence in the lives of most of the practitioners of Hindu religion. (Sharma, 1987)

According to Islam the dualism between the body and soul is very clearly evident in the physical world. The body is considered as subservient and the soul is seen as in charge; however both are believed indispensable. The soul is regarded as the master while the body is the obedient servant. For the most part Muslim philosophers agreed, as did their Greek predecessors, that the soul consists of non-rational and rational parts. The non-rational part they divided into the plant and animal souls, the rational part into the practical and the theoretical intellects. All believed that the non-rational part is linked essentially to the body, but some considered the rational part as separated from the body by nature and others that all the parts of the soul are by nature material. The philosophers agreed that, while the soul is in the body, its non-rational part is to manage the body, its practical intellect is to manage worldly affairs, including those of the body, and its theoretical intellect is to know the eternal aspects of the universe. They thought that the ultimate end or happiness of the soul depends on its ability to separate itself from the demands of the body and to focus on grasping the eternal aspects of the universe. (www.missionislam.com; www.muslimphilosophy.com)

Essentially there is a body-soul dichotomy (and also trichotomy sometimes in the case of Christian and Hindu philosophy) in the three religions and the philosophy of Christianity, Hinduism[1], and Islam. Classical Greek philosophy and even Western philosophy, till the development of science and technology, considered duality between body and soul/ self which was subsequently seen as body-mind duality upholding the duality nevertheless. In the Buddhist tradition as well the separation of body and soul is recognised even though they are not considered dichotomous.

This study too proceeds from the premise of the separation and duality of body and self. This study of body and self is in relation to chronic illness. The study seeks to understand how the image of body and self may change/changes when confronted with life altering experiences that are located in the body. The impact of illness, the ideas of body and self on identity are also investigated. In this regard theories of body, self, identity, and identity in illness are evaluated.

Body

Across history we find various discourses on how Body has evolved. In the West the way the body was described and treated has changed much from 15th and 16th century to contemporary times of the post-modern era. These developments are usually seen by most scholars starting from the traditional dichotomy between the sacred and the profane especially the medieval Christianity and the Christian protestant ethic.

Both the medieval Church as well as the Reformation emphasised on the body but contrastingly. Whereas the medieval Church saw the body as profane and insisted on denial to the body it stressed upon the significance of the body and the need to control it. The protestant ideas also insisted upon the need to be in command of the body but not considering it sinister with evil passions like in the medieval Church but to exercise the virtues of diligence and thrift. (Weber, 1930/1976) By considering all work as dignified and blessed by God even body came to be seen as sacred. There was a reinterpretation of

[1] Even in the *Advaita* philosophy there is considered the separation between the *jiva* (the individual self) and the *antahkarana* (the internal organs) which are *bhautika* (composed of the five elements) in nature. (Sharma, 1987)

the body-soul[2] relationship during the period of Reformation especially in the Calvinist movement. Weber points out that the body was controlled to produce more, start enterprises, have savings and increase potential for investments that eventually led to the rise of capitalism. The capitalist ideas about body continued to be based in the Protestant ethic emphasising upon controlling the body for increased productivity. The body then subsequently underwent much change as a consequence to mass-production (a result of Industrialisation and capitalism), mass-consumption and consumerism.

Bryan Turner (1990/1996) says that if the protestant ethic was the spirit of capitalism then the Baroque[3] culture can be considered as the spirit of the post-modern body. He highlights the features of Baroque culture like sensuality, and arbitrary control which find similarity with consumerism of today. In the consumerist culture the ideas of body have changed significantly to a different paradigm wherein the terms discipline and liberty have revised meanings. The concept of 'fit' body, 'healthy' body are seen more in the relation of body representations like the athletic body or the lean, toned, docile body which also occupies a sense of virtue. Body is seen as something that is controllable and in fact that which should be disciplined or controlled in stimulation of its capabilities in order to fit into the society. (Sassatelli, 2005)

Chris Shilling too discusses the body in the realm of the modern times and the consumerist culture. She argues "…in conditions of high modernity, there is a tendency for the body to become increasingly central to the modern person's sense of self identity". (Shilling, 1993/2004:1) She discusses the surge of body image, plastic surgery and the various efforts of keeping the body young and beautiful which highlight a new kind of interest in the body. She says "…the position of the body within contemporary popular culture reflects an unprecedented *individualization* of the body. Growing

[2] Religion being the main force in the society body was seen in contrast to soul till modern philosophical tradition and Descartes "I think therefore I am" led scholars to consider mind in dichotomy to body and discard ideas of soul. Though, Descartes used the words mind and soul interchangeably.

[3] The **Baroque** is a period and the style that used exaggerated motion and clear, easily interpreted detail to produce drama, tension, exuberance, and grandeur in sculpture, painting, literature, dance, and music. The style started around 1600 in Rome, Italy and spread to most of Europe. The popularity and success of the Baroque style was encouraged by the Roman Catholic Church, which had decided at the time of the Council of Trent, in response to the Protestant Reformation, that the arts should communicate religious themes in direct and emotional involvement.

numbers of people are increasingly concerned with the health, shape and appearance of their own bodies as expressions of individual identity". (ibid: italics as in the original)

Shilling discusses the role of modernity in this exploration of body images and their redefinition and states, "With the decline of formal religious frameworks in the West which constructed and sustained existential and ontological certainties residing outside the individual, and the massive rise of the body in consumer culture as a bearer of symbolic value, there is a tendency for people in high modernity to place even more importance on the body as constitutive of the self.…Indeed, the increasingly reflexive ways in which people are relating to their bodies can be seen as one of the defining features of high modernity. Furthermore, it is the exterior territories, or surfaces, of the body that symbolize the self at a time when unprecedented value is placed on the youthful, trim and sexual body". (ibid: 2-3)

Nancy Scheper-Hughes and Margaret M. Lock in their article "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology" (1998), discuss 'three bodies'. For them the division brings out some chronological order and is more along the lines of theoretical approaches. The three bodies are: the Individual body (phenomenological approach), the Social body (structuralism and symbolism) and the Body-politic (post-structuralism).

The individual body as it suggests can be seen in terms of the phenomenological approach in the sense of the lived experience of the body-self. All people share some sense of the embodied self as existing apart from other individual bodies though the constituent parts of the body- mind, matter, psyche, soul, self- and their relationship to each other, and the ways in which the body is received and experienced in health and sickness are variable. (Hughes and Lock, 1998) With the advancement of biology and medical science body remained no more a subject of religious discourse alone but became a subject of biology and medical science wherein pain, therapy, illness and health acquired greater significance. Pain, aetiology, tolerance had been important even in the religious discourse but with the medical intervention there was witnessed an alleviation of illness and pain. Body became the subject of observation and experimentation. Body, the individual body and its phenomenological experiences have

thus acquired a new meaning and body has become very important in itself. The phenomenological discussions of body came out of medical technology and the medical technology deals primarily with the phenomenological experiences of the body. Thus, in contemporary times the discussion has shifted to negotiation between body and self from the religious discourse to locate it in the context of illness.

Freund brings up another point in the phenomenological perspective of the body. He talks about the disabled bodies and spaces and says, "From a phenomenological perspective, one can argue that disabling features of socio-material environments produce 'a vivid but unwanted' consciousness of one's impaired body (Paterson and Hughes, 1999). Anybody that cannot comfortably use and/or 'find a home' in spaces will not only feel alienated from that space, but from his or her body as well….Social material conditions thus not only influence the body itself, but how one experiences one's body-the quality of embodiment….These changes make previously 'friendly spaces and temporal rhythms 'unfriendly', potentially dangerous and uncomfortable. Hence, 'enclaves' or safe spaces may become more important, spaces in which people are not only physically safe, but exist in ways that affirm their bodily sense of self." (Freund, 2005:185) Furthermore he highlights that people being accustomed to noise and crowds do not reflect how things might be different. He says that the experience of the environment is based on the phenomenological understanding of the people, the organization of the material aspects and their sensual experience of it. Thus, the problem that the disabled face is the need to become more aware of their disability or their disabled world through the cognitive-sensual change of consciousness. (Freund, 2005)

Studying the individual body Hughes and Lock also take the Cartesian mind-body dichotomy as the starting point and then go on to discuss that mind-body dualism in western epistemology can be related to binary oppositions that social thinkers as different as Durkheim, Mauss, Marx, and Freud understood as unavoidable and often irresolvable contradictions and as natural and universal categories. Whereas Durkheim talked of 'man is double' in his "*The Elementary Forms of the Religious Life*" implying the biological man and the social man, and mechanical solidarity working towards the collective interest. Freud on the other hand talks of the individual at conflict with himself (id, ego,

and superego) due to the morals operating in the society, the Oedipus complex being disciplined by the process of socialization. Marx and others took the debate to another frontier of nature-culture opposition; external nature being transformed by human labour consequently introducing the ideas of rights over labour, and production of bodies and their regulation for economic gains. Hughes and Lock also discuss how closely related are the images of body a culture has and promotes. "Ethno-anatomical perceptions, including body image, offer a rich source of data both on the social and cultural meanings of being human and on the various threats to health, well-being, and social integration that humans are believed to experience" (Hughes and Lock, 1998: 214).

The social body refers to the representations of the body in social, symbolic and structural aspects. For instance, the Eucharist or the Holy Communion symbolizing the body and blood of Jesus Christ also at the same time integrated the universal church and the believer as one with the body of Christ (body thus, simultaneously signified the 'social body' along with the individual body. This manner of division is also made by Nancy Scheper-Hughes and Margaret Lock). Interestingly in medieval church history body or flesh came to be understood as representing the profane, sensuous, passion, separation from God. The protestant reformation changed the perspective towards the body as something to be controlled, regulated and brought under mind and reason to utilize it for production. This is highlighted in the work of Max Weber "*The Protestant Ethic and the Spirit of Capitalism*" (1930/1976). Bryan Turner too discusses the role of Christian theology in popularising Cartesian secular rationalism and the rise of ascetic capitalism. (Turner, 1996)

The ideas of anomaly and health as discussed by Durkheim in relation to society, Mary Douglas' work of seeing body as a metaphor in the rituals and around which the society is organized are works that highlight the symbolism and the location of the individual in society. Durkheim said "It is perfectly true that we are made up of two distinct parts, which are opposed to one another as the sacred to the profane…So we are really made up of two beings facing in different and almost contrary directions…" (1915/1976:262-263) This double existence of man, he states, is an extension of the double life that one leads as an individual and as a social being in the society. Because of

the dual nature of human beings there is a breakdown of moral guidance which results in rising rates of deviance, social unrest, unhappiness, and stress. The purely individual side seeks satisfaction of all wants and desires. It knows no boundaries and this leads to a condition that Durkheim labels as "anomie." The anomaly and health in the body are used as an analogy to understand the breakdown of social integration. Also there is drawn a parallel of how the changes in the society like division of labour and weakening relations between individuals and the group lead to such anomaly state in the society. The analogy, parallels drawn and the relation of individual with the society are all issues concerning the social body.

In "*Natural Symbols*" (1973) Douglas states that the social body defines the physical body and its perceptions. "There is a continual exchange of meanings between the two kinds of bodily experience so that each reinforces the categories of the other. As a result of this interaction that body itself is a highly restricted medium of expression. The forms it adopts in movement and repose express social pressures in manifold ways. The care that is given to it, in grooming, feeding and therapy, the theories about what it needs in the way of sleep and exercise, about the stages it should go through, the pains it can stand, its span of life, all the cultural categories in which it is perceived, must correlate closely with the categories in which society is seen in so far as these also draw upon the same culturally processed idea of body" (Douglas, 1973:93). She also says, "The two bodies are the self and society: sometimes they are so near as to be almost merged; sometimes they are far apart. The tension between them allows the elaboration of meanings". (Douglas, 1973:112)

In relation to health and illness recognition of symptoms, tolerance, pain, illness behaviour are perceived differently in different cultures. Mechanic (1978) discusses these at length giving examples from various societies and communities. He talks about how illness behaviour is socio-culturally constructed and gives examples of groups that are more likely to report symptoms and seek healthcare than others with the same symptoms because of their socialization and factors like finance, family relations, needs at work place etc. Socio-cultural ideas also impact the perceptions of the members of a society regarding the seriousness of symptoms, the tolerance threshold, the way

illness and sick role are seen. This also points to how even health and illness in the individual body are socially and culturally constructed.

Beside this, the way in which the body is understood and described at the time of disease or otherwise also bears the influence of the society and its historical location. In the industrial society the usage of mechanistic parallels to describe a tired body is one such example whereby the terms used are 'worn out', 'recharging' or the war analogy etc. The body politic, on the other hand, discusses the regulation and control over bodies, reproduction, sexuality, deviation and others by the society and seeks to understand how certain kinds of bodies are socially produced. Michael Foucault's works are the most prominent in this theoretical approach. His analysis of the control the society exerts over individuals through medicine, criminal justice, psychiatry by negotiating and producing new power and knowledge through discourse over the body.

Hughes and Lock (1998) state how illnesses were earlier seen to be rooted in social malady or religion, but with advances of bio-medicine and psychiatry are presently viewed as individual pathologies thereby overlooking them as social symptoms. In the societies with more "medicalization" there is overproduction of illness. Morris (2000) also supports that and states that the post-modern generation is a more sick generation. People have some or the other health problem because they have come to view health as one of the most important virtues. Because of this there is an unprecedented occupation and the need to exert control over the body, the individual body and disengaging it from the social body. This has left us in the lurch to clearly understand what bodies are and how are they to be controlled. The choices and options available to control bodies to restructure them in order to be fit for sports, or to look 'beautiful' or for genetic engineering are definitely not available to all. This along with the question 'how far should science be allowed to reconstruct our bodies?' brings us close to what Foucault talks of when he discusses bio-power and regulation of bodies.

David Morris in "*Illness and Culture in the Postmodern Age*" says "Health no longer refers, via metaphor, to the ideal social state that generates it but instead signifies the perfection of a single private self. Further, good health is not exactly the issue. What matters is that the individual body appear healthy. Image, for the body without organs is

everything...the healthy-looking body is the beautiful body; the beautiful body is the healthy-looking body; health and beauty are source of erotic pleasure. The opposite of health, beauty, and eroticism, of course, is illness." (2000:139) He further states "No one (in the postmodern times) should have to endure reversible pain or illness, but there is much to be said for learning to respect and embrace the body in all its inevitable imperfections. Meanwhile, people with infirmities ranging from combat wounds to blindness must navigate their damaged and (in some cases) irreparable bodies through a minefield culture in which the perfection of the body has become almost a national quest, a solemn duty if not a sacred rite. It is a secular religion from which the disabled and the disfigured are, of course, rigorously excluded, unless they are willing to play the ossified role assigned to them in reality-based drama as gutsy models of "personal adjustment, striving, and achievement." (2000:159) Morris also highlights that along with unprecedented preoccupation with health and a fit body there has come a heightened sense of the individual body. The healthy body being equated with beauty and health and beauty becoming the source of eroticism and pleasure there is witnessed individualisation and sexualisation of bodies in the post-modern times.

Bringing out an engaging issue of the contemporary times Shilling elaborates how transplant surgeries and virtual reality intensify uncertainty about the body and challenge the boundaries which have traditionally existed between bodies, and between technology and the body. She says, "This has very real consequences. As Turner notes, in a future society where implants and transplants are widespread and highly developed, 'the hypothetical puzzles in classical philosophy about identities and parts will be issues of major legal and political importance. Can I be held responsible for the actions of a body which is substantially not my own body?' (Turner, 1992a:37). These developments also promise to increase those dilemmas surrounding the ownership of bodies which have already been raised in relation to such issues as abortion and surrogacy (Diprose, 1994)." (Shilling, 1993/2004:4)

The three bodies that are discussed by Hughes and Lock very interestingly overlap. The individual body definitely has phenomenological experiences yet all experiences are not equally significant or at least are not considered to be so. Our

experience is normally richer in content than mere sensation. Accordingly, in the phenomenological tradition, phenomenology is given a much wider range, addressing the meaning things have in our experience, notably, the significance of objects, events, tools, the flow of time, the self, and others, as these things arise and are experienced in our "life-world". (Stanford Encyclopaedia of Philosophy- www.plato.stanford.edu) As discussed earlier Mechanic's study on illness behaviour also suggests how experiences of symptoms and pain etc. are differently perceived and reported based on the socio-cultural factors and context. The social body as seen by Douglas (1973) also brings to light that the social and cultural construct of the body defines what is relevant and important and what is not. The social body in turn is deeply influenced by the body politic which is specifically true of an age of globalization, bio-medicine and consumerist culture where these ideas impact the society and also the ideas of the society. Significantly, the ideas of body-individual, social or body politic-are not limited to the body but rather interact closely with the concept of self and identity.

Self

'Self' has been a subject of much exposition in the realms of religion, philosophy, psychology and recently of social sciences. Self over the course of history has been seen as soul, mind etc. Most philosophers used the terms soul and self interchangeably till the modern times where the idea of soul was rejected and mind came to be equated with self. Considering the purpose of study is to understand how the subjects define their self, the term is dealt with bearing that the meaning of the term may shift from social identity to a religious or a personal concept of soul to the mind.

George H. Mead has been a pioneer on the subject of self especially from a social behaviourist point of view. G. H. Mead says "The self is something which has a development; it is not initially there, at birth, but arises in the process of social experience and activity, that is, develops in the given individual as a result of his relations to that process as a whole and to the other individuals within that process." (Mead, 1974:135) He also differentiates between the body and the self saying that the body can operate independently without the self involved in the experience and that the self is

characteristic in this that it is an object to itself. The self is understood by a person not directly but once a person has understood the other. The experience of the other through communication leads to the fuller understanding and experience of self or rather it can be said the formulation of self to self. Thus, essentially Mead agrees that self is a social construction and that there are different selves that react to different social situations. Mead also points out the processes that influence the genesis of self in the society. These he delineates as: language, play and games etc. (Mead, 1974) He gives the example of children and the difference between play and organised game to explain how one comes to acquire self and self-consciousness. He suggests that when a child plays he/she usually plays a role of someone other than them but in a game there is an organised structure where one not only takes upon a role/s but these roles are organised and where his/her action is determined by his/her presupposition or presumption of others' action. He/she must then work out how others are going to act or react to a situation before acting or reacting to a situation. That is the 'other' Mead refers to and calls the social group or organised community as 'the generalized other'. This organisation of roles is essential for self-consciousness. He says, "Self-consciousness, on the other hand, is definitely organized about the social individual, and that, as we have seen, is not simply because one is in a social group and affected by others and affects them, but because his own experience as a self is one in which he takes over from his action upon others. He becomes a self in so far as he can take the attitude of another and act toward himself as others act." (Mead, 1974:171)

Further he discusses the difference between 'I' and 'Me' and states "The "I" reacts to the self which arises through the taking of the attitudes of others. Through taking those attitudes we have introduced the "me" and we react to it as "I"...The "I" is the response of the organism to the attitudes of the others; the "me" is the organized set of attitudes of others which one himself assumes. The attitudes of the others constitute the organized "me", and then one reacts towards them as an "I"." (1974:174-175) He also clarifies that the responses of "I" and "me" in any social situation also remain uncertain and is mostly known only in terms of memory (that is, the experience of "I" is in memory where "I" is located as having responded in a certain manner in the past.) and in this way one comes to experience oneself. The "I" and "me" do not appear in experiences in the

same way. The “me” being the organised set of attitudes and responses that the society or community calls for in a person thus becomes different from the “I” of the experiences in the memory. The two thus separate in the process but nevertheless remain as parts of a whole. He further stresses that in the ‘simple/primitive’ societies “me” controls the “I” because of strong socialisation and the impact of the organised attitudes and responses that are internalised in the process. Whereas, in the “civilized” societies the “I” is more prominent than the “me”. (Mead, 1974)

Mary Douglas deals with the self in more of a cultural context describing the different definitions of the self in various culture and communities. “In West Africa each person is composed of multiple souls. In India selves migrate from one body to another. Widespread in the world is the idea that a human person can be transformed into an animal and back again. There is also the separate idea that every human person has an animal shape and that everyone doubles back and forth between the two bodies, human and animal. In the West all these theories of the self are rejected. For us it is a fact that a person *inhabits* one body between birth and death; normally the *person in the body* is a rational, responsible being, deviations from the norm have legal consequences”. (Douglas, 1994: 211) (Emphasis added).

Douglas talks about the ineffable self. She discusses the way self has been seen by various scholars including Hume, Locke, Heidegger and Sartre etc. Hume and Locke denied the existence of a ‘self-substance’, and the idea of self’s identity and unity. Hume explained selves as representations brought together by similarity of experiences. Sartre said that we know self on the basis of the activities we see of knowing and there are no grounds for believing some unknowable self behind the activity. Douglas then questions this and says that we claim to know ourselves on the basis of our activities and yet we cannot validate that. (Douglas 1994) “As to persons, for public knowledge about personhood we are left without any agreed theory about when the person starts, or ends; we stand in moral dilemmas about transplant surgery, abortion, mercy killing, brain death.” (Douglas, 1994: 216)

There is also the aspect of jurisdiction that is concerned with the self. Because of the embodiment it is recognized that a person cannot claim to be at more than one

place at a time. A person with MPD cannot claim in the court that it was the other him who did the crime. Also, one cannot transfer the responsibility over to external agencies for their actions. Therefore, whereas in the Western philosophies the multiple selves are not acceptable in various other civilizations and philosophies it does not constitute any problem. (Douglas, 1994)

She also then goes on to relate the self with the culture and delineates four kinds of cultures that invoke a particular idea of world, self, good and wrong etc. They are: enterprise culture, hierarchical culture, the dissident minority enclave and one in which members are not involved in the dialogue about power. She raises three questions that test and establish how individuals as a part of a society or community come to acquire a thought style as well as an ideological bias. These questions are a) How does a person become a member of a particular society or on what basis is one exempted or expelled from that society? b) How does the higher system (of society) shape the desires of individuals in a way that is conformable to its (the system's) claims? and c) How these acceptable claims affect the theories about self? (ibid)

Hierarchical culture, she states, is not where there is an elaborate bureaucracy but where units contribute towards the maintenance of the whole. The whole is considered more important than the individual though the whole or the society never abandons its responsibility towards its members. Since priority is given to the community the claims of the individual are overridden in favour of the claims of the community. Thereby, every decision is made in order to maintain the well-being of the whole. It is a system from which it is difficult to drop anyone. Disloyalty and disobedience disqualify a person and not incompetence or infirmity. All the members are enrolled in the system and are given some place in the system. Individual claims are made through the sector they belong to. There are inequalities between sectors in the system and all the sectors are given some space to reconcile their conflicting claims. Such a system encourages its members towards conspicuous display, not so much individually as on behalf of the community. Personal desires are made subordinate to the claims of the community. Since the members cannot be dropped when they err it is usually attributed to someone or something outside them as well as outside the group. The blame does not lie with the

individual but outside of him/her. Thus, Douglas states, alongside the forensic model of self a therapeutic model of self also develops. (ibid)

Dissenting minority enclave culture on the other hand is usually sectarian and the main concern remains that none of the groups should become powerful enough to gain all the power. Because of that egalitarian organisation is encouraged. In this system, to be acceptable, the claims should be made along the lines of equality. The principles of membership and exclusion work similar to the hierarchical system with more permanent membership, where the exclusion and expulsion is on the basis of disloyalty and not infirmity or incompetence. (ibid)

In the enterprise culture the claims of the community over the individual is considerably weak. It encourages unlimited private demands for commodities and consumption. Identifying the enterprise culture with the modern industrial society Douglas states, "The culture is so organized that incompetence and weakness cannot be compensated for. Rewards go to performance and merit, there is less readiness to carry mediocrity, there is more failure, and punishment for failure is more severe. In the enterprise culture exclusion can be a silent process, almost imperceptible, by simple exit as in the market, not by complaining voice…" (Douglas, 1994: 231) Thus, it is a culture that demands complete accountability from its members. The responsibility is seen as lying with the individual and blame cannot be put upon any outsider.

The fourth culture or system explained by Douglas is one comprising of the isolates who "...are not involved in economic or political or social competition, either having been forced out, or having chosen not to be involved, also have a typical culture characterized by absence of attempt to explain or influence events, freedom from the ideological commitments which control so much of other persons' lives." (Douglas, 1994: 225)

"In conclusion, the public idea of self is part of a cultural commitment, and so is determined by a thought style which will vary according to the thought collective, …Because of the active role played by the claims of the self in the making of culture it is

difficult to put a sceptical bracket around it…Both self and community have to be examined together." (Douglas, 1994: 231-232)

Body and Self

Discussions on body and self have been either to understand how the two are separate and dichotomous or their overlap and unity. As discussed earlier most religions and philosophies see them as dichotomous or even trichotomous and rarely ever and monism. The ideas of body-self/soul/mind dualism existed even prior to rationalism but in the Western philosophy the soul or self was located somewhere in the body. The rationalism era upheld the Cartesian model of body-mind dichotomy, the separation of body from the mind or soul and equating the mind with reason and body or flesh with desire and the irrational. These ideas of body-self duality and the equating of mind with reason and supreme were not unprecedented but gained a new direction with Descartes' understanding of self/soul/mind as a non-physical entity. Descartes' "I think therefore I am" has been considered a statement that aptly defines and summarizes the viewpoint. The Cartesian dualism gave unprecedented freedom to biology and sciences for 'rationalistic' observations and experiments by separating mind from body. The famous statement of Descartes "I think therefore I am" leads to the question of who is this "I am"? When we fall hard and bruise ourselves we say "*I am* hurt". Who is this "*I am*"- the body or the mind or the thought? Also relevant here is the consideration of those that are mentally challenged or in a coma? The relationship between body and soul/self/mind has come to acquire a different meaning with the post-modern consumerist culture. As discussed earlier the body has gained unprecedented significance. Body is viewed as the site of discipline and consumption and more important in the constitution of self. (Shilling, 2004)

Daniel Dennett brings out this point remarkably in his story. The story narrates that for a mission Dennett's brain is removed and his brain and body are linked through chips and radio network. He at one instance is looking at the brain in a chamber and the thought occurs, ""Well, here I am, sitting on a folding chair, staring through a piece of plate glass at my own brain …. But wait," I said to myself, "shouldn't I have

thought, ‘Here I am, suspended in a bubbling fluid, being stared at by my own eyes’?”” (1981/1985:312). He then names the body as Hamlet, the brain as Yorick and self as Dennett which is an interesting issue considering he differentiates between the three and yet calls the self as Dennett which is his original name or social identity. Following that he seeks to understand that when the body and brain are separated what happens to the self and where is the self located at such a time. He starts out with where the body goes the self goes (“where Hamlet goes there goes Dennett” 1981/1985:313) or where the brain goes the self goes and finally arrives at the conclusion that the self is wherever he thinks he is. By the last statement he means that, “At any given time a person has a point of view and the location of the point of view (which is determined internally by the content of the point of view) is also the location of the person”. (Dennett, 1981/1985: 314)

Arthur Frank suggests, “Selves act in ways that choose their bodies, but bodies also create the selves who act. We can observe more of the first process than of the second; how bodies create selves is scarcely understood at all.” (Frank, 1995/2005: 322) Whereas, Anthony Giddens states, “body is the ‘locus’ of the active self, but the self is obviously not just an extension of the physical characteristics of the organism that is its ‘carrier’.” (Giddens, 1984: 36)

Herein it is also of interest that when Michael Foucault in his explanation of bio-power and regulating of bodies emphasizes how societies regulate the bodies and thence the selves. The control on the body in a way subdues the self as well. Thereby, in a subtle way it removes the body/self dichotomy and causes them to overlap.

What Role Do the Body and the Self Have in Illness?

The body and the self play a role in the illness. The body, primarily, because it is the seat of observation and examination, and the self in matters of control and responsibility. There are broadly two explanations of illness: Naturalistic and Personalistic. The Naturalistic explanation finds the cause of illness as impersonal and mechanistic causes in nature. The common reasons for illness are understood as:

1. Organic breakdown or deterioration (e.g., tooth decay, heart failure, senility)
2. Obstruction (e.g., kidney stones, arterial blockage due to plaque build-up)
3. Injury (e.g., broken bones, wounds etc)
4. Imbalance (e.g., too much or too little of specific hormones and salts in the blood)
5. Malnutrition (e.g., too much or too little food, not enough proteins, vitamins or minerals)
6. Parasites (e.g., bacteria, viruses, amoebas, worms)

The naturalistic causes are more to do with body in terms of both the causation as well as cure. In the Personalistic explanation illness is seen as being due to acts or wishes of other people or supernatural beings and forces. There is no room for accidents. Adherents of personalistic medical systems believe that the causes and cures of illness are not to be found only in the natural world. Curers usually must use supernatural means to understand what is wrong with their patients and to return them to health. Typical causes of illness in personalistic medical systems include:

1. Intrusion of foreign objects into the body by supernatural means
2. Spirit possession, loss, or damage
3. Bewitching

Causation and cure are thus seen essentially outside the body and placed in the supernatural world. In this the self or the soul is seen as affected and the process of healing requires addressing the soul or self and not just the body. An example of this kind of illness is found among some Hispanics in the United States and Latin America. It is called *susto*, which literally means fright or sudden fear in Spanish. The fear is of losing one's soul. *Susto* is also referred to as *perdida de la sombra* (literally, loss of the shadow). *Susto* results from incidents that have a destabilizing effect on an individual, causing the soul (*espiritu*) to leave the body. (http://anthro.palomar.edu)

Michael Winkelman in *Encyclopaedia of Medical Anthropology* discusses shamanism and soul-loss and states, "Soul loss reflects concerns with the essence of crucial aspects of the self (Ingerman, 1991), involving the loss of, or injury to, fundamental aspects of personal identity. This injury to one's essence is manifested as despair, disharmony and loss of meaning in life and feelings of belonging and connection

with others. 'Soul' constitutes a vital essence of self-emotions. Soul loss occurs from trauma that causes an aspect of one's self to dissociate. This separated aspect of the self carries with it the impact of the traumatic experiences that are unavailable to the rest of the self, arresting ego and emotional development. Reintegration of these dissociated aspects of self is central to healing. Soul recovery involves the shaman's dramatic enactment of battles with terrifying and threatening spirit images that symbolize disowned and repressed aspects of self (Walsh, 1990). Through their recovery one regains a sense of a social self alienated by trauma and feelings of disharmony and disconnectedness (Ingerman, 1990). Community participation is significant in soul retrieval, with social support vital to the healing processes and re-integration of self. Community participation facilitates social bonding and release of the body's opioids, producing a sense of well-being. The shaman's dramatic struggles with the spirit world to realize soul recovery...produce powerful experiences, transforming self and altering social relationships." (Winkelman, 2004, 148) The soul or self, in this manner, does not remain limited to the religious realm but pertains to social identity as well as becomes an important subject of the medical realm.

Not only in the cultures with personalistic explanation of illness but even in naturalistic explanations the self is important in the illness experience. Whereas in non-western societies and the personalistic explanation the self is essentially seen as soul in the naturalistic explanation the role of self is around discipline and control etc. Alan Radley's article with the same title "What Role Does the Body Have in Illness?" (1997) and Arthur Frank's "The Body's Problem with Illness" (1995/2005) are taken as the base for the study. Radley starts with raising the point that though illness has essentially to do with the body for that is where it creates disturbance and makes itself known. Yet, body is much more than machinery that goes wrong. He states, "Because of its role as a medium of communication the body is also a way of *appearing well* and *of appearing ill*. And because individuals must negotiate, with others, the movement between the states of health and illness, it is centrally involved in the communication of their personal conditions and social status. As well as this, it is the medium through which individuals live their lives, so that when ill they have to manage *with* the body that is affected by disease or injury." (Radley, 1997: 51)

The beliefs about sickness in industrialized societies are regulated by the concepts held by western medicine. In the west, Radley states, being ill cannot be comprehended as separate from having one's symptoms diagnosed, visiting the doctor, and taking a treatment and following the regime till cured or further instructions. There is a deep influence in this of how people regard their bodies and define themselves in medical terms. The body in the western medical system is highly objectified by the tests conducted and the usage of natural science vocabulary. This, Radley says, "...helps to shape the popular conceptions of body as being a 'physical thing'." (Radley, 1997: 52)

This concept of locating disease aetiology only in physico-chemical dysfunction has been challenged by psychoanalytical medicine and also social sciences. Whereas the psychologists too following the bio-medical model perceive the body as a physiological system regulated by cause and effect relationships when taken ill medical sociologists or anthropologists do not engage themselves with the diseased body but rather seek to understand the way illness is experienced by the person involved. This has recently been done by collecting the accounts of people suffering illness wherein they give a short story of their illness experience. Radley gives the example of Kleinman's work and many others. He stresses that though these studies may seem phenomenological in their approach their main aim is to get the life-world of the persons involved. The other approach that Radley highlights is of discourse wherein what is said is strategic and pre-determined.

He also underlines that with availability of medical technology the experience of illness for most in the developed world does not begin with disabling symptoms. The body is taken much for granted in the everyday life till it falls ill and needs taking care. Body's dysfunction or breaking down is seen in the context of inactivity or inability for action. Taking here two cases- of a student having a headache while working on an essay that has to be submitted the next day and of a person suffering a stomach ache while visiting a friend's parents- Radley points out the containment of the sickness is made for different reasons and stands out for affirmation to normality and display of good health. He points out that many a times the bodily eruptions which are symptoms of illness are suppressed in order to maintain social credibility. "The body's role in illness is therefore,

not a part played in a separately occurring state called 'sickness'. Rather, the 'deployment of the body' in its everyday activities involves an ongoing accommodation to the smaller or larger perturbations of physical life. It has been shown that people go to the doctor, not when symptoms are at their worst, but when this accommodation to them breaks down (Zola, 1973)." (Radley, 1997:56)

He also says that the chronically sick have the necessity laid upon them to go on with the 'normal' life, by not only doing things independently but also appearing to need no assistance. Furthermore, he discusses that the body plays many roles in the lives of the chronically ill. Since the disease or illness is located in the body and it shows impairment and thus in this respect body is seen as unwanted. On the other hand, body, continues to remain the medium through which one stays in touch with the empirical world and experiences the pleasures of the world. Attempting to rid oneself of sick status and re-entering the healthy world one makes an effort to reconstruct his/her illness and undertake activities to prove that he/she is healthy or fit. For the sick it is imperative to recover good health in order to gain the ordinary world that they have lost due to their illness; to know the world the way it was before. This is done through the mundane activities of everyday life and re-establishing the social world and regaining its membership.

Arthur Frank on the other hand deals with body's relatedness with itself, others and the issue of desire. He says that the most important change that comes in one's life due to illness is the inability to continue the normal or the pre-illness lifestyle. The ability to predict the body is lost or at least it is realized that the body is not predictable comes in with the on-set of illness. He says "…disease itself is a loss of predictability, and it causes further losses: incontinence, shortness of breath or memory, tremors and seizures, and all the other "failures" of the sick body. Some ill people adapt to these contingencies easily; others experience a crisis of control. Illness is about learning to live with lost control". (Frank, 1995/ 2005: 318) Furthermore, he states, "A body's place on the continuum of control depends not only on the physiological possibility of predictability or contingency, but also on how the person chooses to interpret this physiology. The flesh cannot be denied, but bodies are more than mere corporeality. As

body-selves, people interpret their bodies and make choices; the person can either seek perfected levels of predictability, at whatever cost, or can accept varying degrees of contingency. Most people do both, and strategies vary as to what is sought to be controlled, where, and how. How the individual responds to lost predictability is woven into dense fabric of how the other action problems of the body are managed, since the same illness provokes crises in these other dimensions as well." (Frank, 1995/2005: 319)

Arthur Frank suggests that till one is healthy one does not think of mortality consciously and thus associating the self with the body at the time of health is easy. But the recognition of mortality which comes through sickness and suffering complicates this issue. Frank also notices that while some tend to associate with their body and others tend to dissociate, nevertheless the continuum of body-relatedness is not linear but rather spiral.

According to Frank body is not limited to being self-related but expands to being related to others as well. He says, "What is my relationship, as a body, to other persons who are also bodies? How does our shared corporeality affect who we are, not only to each other, but more specifically for each other? Other relatedness as an action problem is concerned with how the shared condition of being bodies becomes a basis of emphatic relations among living beings. Albert Schweitzer expressed this concern in his phrase, the "brotherhood of those who bear the mark of pain". …Illness presents a particular opening to becoming a dyadic body, because the ill person is immersed in a suffering that is both wholly individual- my pain is mine alone- but also shared: the ill person sees others around her, before and after her, who have gone through this same illness and suffered their own wholly particular pains. She sees others who are pained by her pain." (ibid: 320). The monadic body understands the illness to be personal and considers it as existentially separate and alone. Medicine and especially the bio-medicine culture encourages the monadic body and in fact is based upon treating the monadic body. The monadic bodies are also in tune with the modernist society's emphasis on individual achievement in all spheres.

Third aspect of Frank's work is desire which he elaborates when he says, "Desire is this quality of more...", and in relationship to body and illness Frank says, "Yet

some bodies, particularly ill bodies, do cease desiring. The body's problem of desire generates a continuum between bodies that have come to lack desire and those that remain productive of desire. Illness often precipitates a condition of lacking desire". (ibid: 321). Frank then points out the cases when the chronic ill due to shock of illness cease to desire (counting it a waste considering that they are dying) and few rediscover desire as an indulgence they always wanted but could not afford due to lack of time etc. As Frank narrates, "Just as illness almost invariably plunges the body into lacking desire, illness can instigate new reflections on how to be a body producing desire. Anatole Broyard describes critical illness as "like a great permission." Part of what becomes permitted is the exploration of desires. Broyard writes that he began taking tap-dancing lessons after his diagnosis with prostate cancer. These lessons, besides probably being something he always wanted to do, were part of his self-conscious attempt "to develop style" to meet his illness: "I think that only by insisting on your style can you keep from falling out of love with yourself as the illness attempts to diminish or disfigure you"….Broyard concludes that "it may not be dying we fear so much, but the diminished self"." (ibid: 322)

Identity and Identity in Illness

The English word 'Identity' finds its roots in the French word *identité* which originated from the Latin word *identitatem* meaning *"same or* sameness, oneness". As the meaning suggests identity is usually relative in nature where there is sameness with something and distinction from others. At the primary level the identity of a person with his/her self. The difference between self and identity is usually very blurred. To another person, the self of one individual is exhibited in the conduct and discourse of that individual. Therefore, the intentions of another individual can only be inferred from something that emanates from that individual. The particular characteristics of the self determine its identity. Identity can be seen at three levels- personal, group, and social. Personal identity is the understanding one has of himself or herself and the awareness of one's identity, traits and characteristics. "Erving Goffman suggest(s) that personal identity is concerned with what makes an individual distinct from other individuals.

When viewed in this way, personal identity is tied to individual autonomy and the values, qualities, attributes, and personality characteristics that make the individual unique." (McKendree, 2010: 545)

Group Identity is described by Frey and Konieczka (2010) as "Group identity exists when a relatively small number of people view themselves collectively as comprising an entity that is distinct from other entities. Whereas group identity is a group-level construct that references the extent to which members collectively view themselves as a distinct group (and are viewed as such by non-members), group identification is an individual-level construct that signifies the degree to which individual members attach significance to their association with a group (and its identity). Group identification has three components: (1) cognitive (a person categorizing himself or herself as a member of a group), (2) affective (a person's attraction to a group and its members), and (3) behavioural (a person's perception of the joint effort required among members to reach a common group goal)." (Frey and Konieczka, 2010: 316)

Social identity is also understood as collective identity and in contrast to individualistic identity. "...individuals tend to think of themselves as independent of relationships. They value autonomy and uniqueness and construe their sense of self as separate from others...Others construe their identities in terms of their relations with others. People who adopt a collective identity tend to think of themselves as interdependent with close others and define themselves by their important roles and situations. In this case, individuals place primary importance on interpersonal relationships and tend to see others as part of the self ("We"). Consequently, for people with a collective identity the definition of self includes many of the attributes of their social and familial groups." (Grant, 2010:98)

Identity negotiation is a "process of coming to know the self in relational, social, and cultural contexts...the various ways individuals come to understand themselves simultaneously as unique and as part of numerous social groups, as mainstream or dominant, marginalized or oppressed- or in fact all of these things at various moments and places....identity negotiation is ...a process through which a self

comes to represent its entity or interests in interaction with society...This process necessarily involves a boundary crossing from the internal world of thoughts and perceptions (self) to the external world of significant others. One both has an identity (avowed) and is assigned an identity by others (ascribed); one's avowed and ascribed identities often overlap, and confusion may result when an avowed identity is not mirrored in the responses of others, and vice versa." (Cooks, 2010: 365)

During illness not only the body suffers and undergoes much contemplation but also the self is brought under scrutiny. They together seek to define the identity in terms of both personal and social identity. Identity is greatly affected when a person is confronted with illness and especially a chronic illness. There is identity negotiation as the avowed and the ascribed identities come in conflict. Arthur Frank in "The Self Unmade" says "When illness happens, the disease carries a metonymic overload that compounds suffering. The disease is fully real in itself; the tip of the iceberg is still real ice. And the disease is a part standing for a larger whole, the external threat…The losses brought by the disease open up extensive fears that one's intactness has always been more imaginary than the self has wanted to believe." (Frank, 1995/2005:218)

Kelly and Millward (2004) do not see self or personal identity as having a physical location but rather a cognitive understanding expressed in language and personal thought. They highlight that the problem then around 'self' is that it has to mediate between this personal understanding and social identity. The social identity is where there is a shared meaning wherein one learns to see oneself as others may see him/her. Eventually, each person has a series of personal identities that have social meanings. Chronic illness challenges the individual's claims to these identities. They also say that identity and illness have a multiplex relationship that relates the individual to the biological world, social world etc. "In chronic illness, the self-persona, its presentation and public negotiation merge with these worlds through bodily attributions, socially structured institutions, 'doing' routines of daily interaction and through the resources of the material world. This idea captures the ways in which these worlds are saturated with identities. For 'normals', these identities often have a dormant quality. For individuals who experience chronic illness, however, their dormant status becomes volatile and their

potential to actively impact on the lives of sufferers is intensified…Illness identities are constant features of biological, social and physical modes of being. They are malleable and constant, they exist in linear time and in social experience constructed and reconstructed in language and interaction. They develop out of experience and the constituent public and private identities, identity and self, themselves interact and evolve. The experience of illness, especially chronic illness, tends to exert a force that separates self and identity empirically as well as analytically." (Kelly and Millward, 2004:15)

Kelly and Millward point out that there are various criteria that are involved in assessing oneself and others and assigning identity. It can be understood by the visible aspects of a person like skin colour, dress, accent etc. and also communal aspects of status, role, group affiliations, gender, religion, culture etc. Thus, they arrive at the conclusion that identity is of two types viz., one about others and assessing others and one regarding self and assessing self. They highlight, that there are also times that the disabled do not accept a disabled identity because impairment is not seen as an important part of their sense of self or personal identity. Thus, what is critical here is the extent to which people are able to incorporate or challenge the identities the society implies on them and the extent to which the individual as an agency can control or negotiate to refrain from negative attributes. (Kelly and Millward, 2004)

They highlight that the relationship between illness and identity is defined by the day to day social interactions and limitations invoked on the chronic illnesses by them. These limits are relative to the pre-illness self. The previous 'regular' or 'normal' roles cease to play as important a role as the illness does. There is a disruption in and disturbance to the everyday life and the roles played therein. There is a disruption in the way one defines oneself and in the time of chronic illness it becomes difficult for the idea of self to remain intact. (Kelly and Millward, 2004)

Janzen (2002), states that in many societies the common or basic platform for life-course is around the understanding of personhood and social identity. Personhood defined in social terms is clearly manifest in the way birth and death are understood and defined. This personhood through illness emerges as transformed and most of the times person returns to the prior state. But, in the case of chronic illness there is an unresolved

trauma and identity is seen to change permanently. Thus, in due course it is the illness that comes to acquire centre in defining both the personhood and the social identity. He furthermore highlights the difference in having a disease and in being the diseased.

Estroff (1993) discusses the case of the western binary notions of bounded inner and outer self. She highlights the way how suffering with illness is seen as not "being ourself". Furthermore, she suggests that though the illness is suffered in the body but is seen as a foreign object and not a part of the private personal self. She thus, points out that the quest here to derive from identity- illness statements is to understand the extent to which illness is considered a part of the self.

"Sue Estroff analyzed the ailments to which we, in American English, attribute an identity of "being", as opposed to "having". Her focus is on schizophrenia, a chronic condition that results in the sufferer "being a schizophrenic", just as we speak of being alcoholic, a hemophiliac, a diabetic, an epileptic, a manic- depressive, or being retarded, blind, deaf, paraplegic, and anorexic (1993: 258). By contrast, one "has" multiple sclerosis, osteoporosis, cystic fibrosis, arthritis, and heart disease. What is the difference? The first set is perceived in our cultural construction to be an identity-transforming affliction, whereas the latter is not so pervasive. This sharp dichotomy between the two belies the often gradual change toward more all-consuming identity change as the chronic condition progresses or becomes worse and more persistent." (Janzen, 2002: 145)

Asbring (2001) studied the impact of chronic illness in the identity-transformation among women with chronic fatigue syndrome and fibromyalgia. Asbring's study stated that the illnesses had radically disrupted the lives of the women affected and had deeply impacted their identity, particularly in relation to work and social life. The disruptions were not total but rather partial and had in turn led to identity transformation in different degrees. The identity transformation had also created new identities for women which comprised both losses and illness gains as the consequences of illness experience.

Adams et al (1997) studied the chronic illness of asthma in relation to illness and identity. They state, "Two main groups were identified: the deniers and the accepters. They differed fundamentally in their readiness to accept the identity of asthma sufferer which, in turn, was associated with very different beliefs about the nature of their problem and the meaning of the medication prescribed for it. There was also marked differences in their strategies of self-presentation and disclosure and their pattern of medication use, particularly for prophylactic medication. A third group, the pragmatists, were also identified as a possible sub-group of the accepter category who are less open within self-presentation and less consistent in their beliefs about asthma but do not reject the label entirely. Identity work, i.e. the way the respondents interpreted the social identity of asthma sufferers and managed to reconcile it with other social identities, is proposed as the most useful way of understanding the observed variation in the way people diagnosed as asthmatic conceptualise and use their medication." (Adams et al, 1997: 189)

Christiansen (1999) proposes that "...identity also provides a framework for goal-setting and motivation. It is asserted that competence in the performance of tasks and occupations contributes to identity-shaping and that the realization of an acceptable identity contributes to coherence and well-being. Within this framework, it is postulated that performance limitations and disfigurement that sometimes result from illness or injury have identity implications that should be recognized by occupational therapy practitioners." (1999:547)

HIV/AIDS and cancer have been studied from the point of view of coping with illness, stigma and negative impact on self-concept and identity by Fife and Wright (2000). They state that when stigma becomes evident to others in the society the person affected becomes an outsider and he/she internalises that as his/her identity. They clarify that the stigma associated with the two diseases is due to different reasons. Whereas HIV/AIDS are stigmatised because of deviant and immoral behaviour laying the responsibility with the individual cancer patients are stigmatised because of the fear of the illness itself. The fearfulness of cancer and the vulnerability that others feel about their suffering from cancer is avoided by avoiding the survivors themselves. Survivors

themselves do not disclose information about their illness history because of occupational and social reasons. Also though there is stigma with both the illnesses but persons with cancer still find social support more readily and are seen as survivors and as having displayed courage. They also find acceptance and support from religious groups whereas persons with HIV/AIDS feel the need to conceal about their illness in religious groups due to the nature of stigma. They propose that the type of illness did not affect the stigma and self-perception of the persons affected with the illness. The stigma being internalised impacts not only the self-image of these persons but also the way they think others view them. There is thus some self-imposed isolation in their lives and some isolation imposed by society.

Charmaz (1995) in her study pointed out that "Serious chronic illness undermines the unity between body and self and forces identity changes. To explicate how the body, identity, and self intersect in illness, one mode of living with impairment, [is] adapting... Adapting means altering life and self to accommodate to bodily losses and limits and resolving the lost unity between body and self. It means struggling with rather than against illness. The process of adapting consists of three major stages: (1) experiencing and defining impairment, (2) making bodily assessments and, subsequently, identity trade-offs, as ill people weigh their losses and gains and revise their identity goals, and (3) surrendering to the sick self by relinquishing control over illness and by flowing with the experience of it. Adapting seldom occurs only once. Rather chronically ill people are forced to adapt repeatedly as they experience new losses." (1995: 657)

Adamsen et al (2009) studied athletes who had suffered from cancer. Cancer and its treatment had adversely affected the performance of these athletes and impacted their body-image and self-image. Their physical activity had greatly come down and due to these factors these persons had acquired a negative self-identity. These athletes were much dependent upon their physical activity and bodily satisfaction and self image which they tried to regain with exercise programmes and rebuilding their former sense of positive body perception and self.

Fisher (2007) studied young adults in relation to cancer and identity. She

observed in her study that in the initial period of diagnosis the patients had a 'shattered sense of self'. There was a tendency to cling to the pre-diagnosed identity which was of a healthy person and rooted in aspects other than illness. She also studied the role that peers played in the sick identity of these patients. The presence of close friends was acknowledged in times of need but their presence also acted upon the patients as a reminder of their illness and sick identity. These women despite of their physical appearance and the full knowledge of their illness refused to accept identity around their illness. On the other hand, Whitehead (2006) suggests that self identity of patients with chronic illness does not remain static. Whitehead stresses that the "...trajectory in relation to the reconstruction of self-identity and that individual and family narratives may be different at each stage of the illness." (2006: 1030)

It is not only that illness impacts identity but also identity that bears impact on the illness. Gender (women since they are unable to assert the need for safe sex), racial (more non-white people are considered at high risk), and economic (lower income groups) identity also puts people at greater risks for contracting illnesses like HIV/AIDS. Also these identities are closely associated with diseases like HIV/AIDS and subscribe to behaviours like drug use, prostitution, and homosexuality as deviant and as the identity of the persons affected. Illness eventually brings all the attention to the diseased and disintegrating body of the person and the identity of the person therefore gets limited to the illness. (Kaitlin, 2009)

Body, Self and Identity in Illness in the Context of Non-western World

As is clear with the discussion of varied discourses on body, self and identity in illness that most work has been done in reference to the western models starting from the Judeo-Christian tradition to post-modern constructs. In this light it is essential to make note that the Asian understanding may greatly vary from western constructs and with each culture assigning distinct and specific place to body and self in such discourse it is pertinent to explore them.

Hughes and Lock also highlight the western epistemology as one among many and attempt to bring to light some non-western systems of knowledge around the concepts of body its relationship with self, culture and nature etc. They talk about the Chinese yin and yang cosmology wherein all cosmos is divided in to two- yin as masculine, light and hot etc and yang as feminine, dark and cold etc. The Islamic understanding borrows from the Judeo-Christian tradition but redefines the ideas based on Towhid -a belief of the unification through the complementarities of spirit and body, this world and the supernatural etc. Also, are discussed the Buddhist traditions of comprehending the cosmos.

Herein, they bring to notice how person, self and identity have been treated in different cultures. In the Japanese society a person finds identity in relation to others. Self too is differently conceptualized and organized in different cultures. Highlighting the socio-centric conceptions of self they state "In cultures and societies lacking a highly individualized or articulated conception of the body-self it should not be surprising that sickness is often explained or attributed to malevolent social relations or to breaking of social and moral codes, or to disharmony within family or the village community. In such societies therapy too tends to be collectivized." (Hughes and Lock, 1998: 213) In contrast are seen cultures where there are concepts of multiple selves and people are ruled by the most prominent self e.g., the Bororo and the Cuna Indians of Panama.

Nichter and Lock highlighting the case study done by Roseman among the Temiar discuss the powerful illustration of a political ecological analysis that goes far beyond a consideration of the impact of political economy on the physical environment. The change in the political set-up and impact on the physical environment also changes the concept of cosmos and sense of self deriving from their relationship to this cosmology. "Coping strategies [are] employed by the Temiar when confronted by global forces that stretch the horizons of their local cosmology. How do other groups whose sense of well-being is tied to sacred landscape cope with such challenges? How is displacement handled by these groups when they are forced to relocate? How are emergent epidemics (of infectious or chronic disease) interpreted in relation to the violation of sacred landscapes? And when such is the case, how are attempts to heal

bodies and control epidemics associated with attempts to pacify both old and new powers, purify land, reaffirm sacred trusts, and so on? We might also ask if there are parallels in the way the Temiar encompass forces of social disruption and the way we medicalize and thereby locate social disorders in our conceptual system? How do we use medicines and support groups to reorient populations to new temporal and spatial, environmental, and occupational orders?" (Nichter and Lock, 2002: 16)

This line of thought raises certain questions that are very relevant. Nevertheless, when we see the context of globalization and rise of metropolitan cities in the developing countries we notice one more kind of nexus. The attachment with land and analogy between the land and body has already been broken as far as the second or third generation city-dwellers are concerned. Life in the urban sector has another kind of analogy that is about spaces- public or private, or sanitation, or technology, etc and this needs to be explored.

The Case for Juvenile Diabetes

Diabetes (medically known as *diabetes mellitus*) is the name given to disorders in which the body has trouble regulating its blood glucose, or blood sugar, levels. There are two major types of diabetes: Type 1 diabetes and Type 2 diabetes. Type 1 diabetes, also called juvenile diabetes or insulin-dependent diabetes, is a disorder of the body's immune system -- that is, its system for protecting itself from viruses, bacteria or any "foreign" substances. A third form of diabetes, called monogenic diabetes, is sometimes mistaken for type 1 diabetes. Type 1 diabetes occurs when the body's immune system attacks and destroys certain cells in the pancreas. These cells called beta cells normally produce insulin, a hormone that helps the body move the glucose contained in food into cells throughout the body, which use it for energy. But when the beta cells are destroyed, no insulin can be produced, and the glucose stays in the blood instead, where it can cause serious damage to all the organ systems of the body. For this reason, people with Type 1 diabetes must take insulin regularly. This means undergoing multiple injections daily, or having insulin delivered through an insulin pump, and testing their blood sugar by pricking their fingers for blood six or more times a day. People with

diabetes must also carefully balance their food intake and their exercise to regulate their blood sugar levels, in an attempt to avoid hypoglycemic (low blood sugar) and hyperglycemic (high blood sugar) reactions, which can be life threatening. (http://www.jdrf.org) There is no known preventive measure against type 1 diabetes. Most affected people are otherwise healthy and of a healthy weight when onset occurs. Sensitivity and responsiveness to insulin are usually normal, especially in the early stages. Type 1 diabetes can affect children or adults but was traditionally termed "juvenile diabetes" because it represents a majority of the diabetes cases in children.

Type 2 diabetes results from insulin resistance, a condition in which cells fail to use insulin properly, sometimes combined with an absolute insulin deficiency or reduced insulin secretion. The defective responsiveness of body tissues to insulin is believed to involve the insulin receptor. However, the specific defects are not known. Type 2 diabetes is the most common type. It is formerly referred to as *non-insulin-dependent* diabetes mellitus, *NIDDM* for short, and *adult-onset* diabetes. In the early stage of type 2 diabetes, the predominant abnormality is reduced insulin sensitivity. At this stage hyperglycemia can be reversed by a variety of measures and medications that improve insulin sensitivity or reduce glucose production by the liver.

The classical symptoms of diabetes are Polyuria (frequent urination), Polydipsia (increased thirst) and Polyphagia (increased hunger). All forms of diabetes have been treatable since insulin became available in 1921, and Type 2 diabetes may be controlled with medications. Both Type 1 and 2 are chronic conditions that usually cannot be cured. Pancreas transplants have been tried with limited success in type 1 DM; gastric bypass surgery has been successful in many with morbid obesity and type 2 DM. Diabetes without proper treatments can cause many complications. Acute complications include hypoglycemia, diabetic ketoacidosis, or nonketotic hyperosmolar coma. Serious long-term complications include cardiovascular disease, chronic renal failure, and retinal damage. Adequate treatment of diabetes is thus important, as well as blood pressure control and lifestyle factors such as smoking cessation and maintaining a healthy body weight. (www.jdrf.org)

The Ayurvedic understanding of diabetes is very similar to the bio-medical explanation. The etiology, symptomatology, pathology, prognosis, and management principles of diabetes are described in detail by the physician *Charaka* in the *Charaka Samhita*. This is the earliest major medical text of Ayurveda, and it reached its present form around the first century A.D. Another term for *madhumeha* is *'dhatupaka janya vikruti*.' The first word, "*dhatupaka*," means metabolism. The entire term, roughly translated, means that derangements in body tissues take place due to discrepancies in metabolism. Description of two types of *Prameha* from management point of view is also similar to the bio-medicine. *Krisha* (Lean Diabetic) and *Sthool* (Obese Diabetic) are classified in Ayurveda on very similar grounds as Diabetics are classified in IDDM and NIDDM respectively. On the very similar pattern we find the classification as *Sahja prameh* (Congenital) and *Apathya nimitaj prameha* (Due to overeating and wrong eating habits). (www.ayurveda-foryou.com)

The underlying cause of type 1, according to Ayurvedic thought, is a *kapha* imbalance. *Kapha* is one of three *doshas*, or elements, that make up your constitution: *vata* (associated with air and coolness); *pitta* (associated with fire and heat); *kapha* (associated with earth, water, and stability). "Type 1 diabetes usually starts as a kapha imbalance during childhood, which is the kapha time of life," says Douillard. "If the diet is bad, and a child eats lots of kapha-producing foods like sugar, kapha energy can build up in the stomach, which puts a lot of stress on the pancreas. It also congests the bile duct, where the pancreas secretes insulin. When this happens, a secondary imbalance occurs in the pitta dosha." Unbalanced pitta, says Douillard, compromises the liver, puts more pressure on the kidneys, and directs kapha into the bile duct, again causing the pancreas to malfunction. All of this can go on for years and is often exacerbated by stress that starts in childhood. "In Ayurveda, stress is thought to be the cause of 80 percent of disease," says Douillard. "When under stress, the adrenal glands produce an excess of stress-fighting hormones that are toxic, acidic, and compromise lymphatic drainage. Without good drainage, kapha backs up in the stomach, small intestine, kidneys, and finally, the pancreas." The toxins are eventually stored in fat and lead to disease, such as diabetes. The key components in an Ayurvedic regimen for type 1, then, are reducing

stress and treating the dosha imbalances, with the aim of stabilizing blood sugars and minimizing complications. (www.yogajournal.com)

The essential constituents and the working principles of the body, according to Unani, can be classified into seven main groups: *arkan* or elements, comprising earth, water, air and fire as different states of matter and the building blocks of everything in the universe; *mizaj* (temperament); *akhlat* (humours); *aza* (organs); *arwah* (life, spirits or vital breaths); *quva* (energy); and *af'al* (action). Each of the four elements has its own special qualities: earth is cold and dry; water is cold and moist; fire is hot and dry; air is hot and moist. The resultant quality of the uniform body is called its *mizaj*. The temperament of a substance may be a *mizaj-e-mutadil* (balanced one) or a *mizaj-e-ghair-mutadil* (imbalanced one). Different types and shades of imbalanced temperaments are described in Unani, which believes that at birth every person is endowed with a unique and healthy humoural constitution determining the temperament of an individual. Unani also postulates that the body contains a self-preservative power, which strives to restore any disturbance within the limits prescribed by the constitution or state of the individual. The physician merely aims to help and develop rather than supersede or impede the action of this power. Says Hakim Jameel: "A Unani physician does not prescribe the strongest drug at the beginning of the treatment. He selects the drug according to the degree of variation from the normal healthy condition, and observes the effect produced by the treatment. At the same time, he instructs the patient to observe some restrictions in diet and lifestyle." He continues, "This is necessary as the therapeutic effect of these mild drugs may be counter-balanced to an extent by a faulty diet or lifestyle. Particular care has to be taken while treating a 'hot', 'cold', 'dry' or 'moist' disease with food or drug of the opposite quality." Since in Unani, health and disease depend upon the equilibrium or imbalance between the four humours, a thorough examination of the pulse is undertaken to determine which humour is dominant at the time. The examination of the urine is the next important step. Its colour, taste, viscosity, whether it has froth on its surface, if the bubbles formed are large, indicating *balgham*, or small, indicating *safra*, are scrutinised. The stool is also examined in a similar way. Some Unani physicians also examine the

blood pressure and use stethoscopes to study the breathing and heart sounds. (www.lifepositive.com)

Epidemiology of Diabetes

With an estimated 50.8 million people living with diabetes, India has the world's largest diabetes population. There are about 1 million (10 lakh) juvenile diabetics in India. Every year 27 thousand diabetic children (2 to 14 years of age) around the world die because of the disorder, 45 percent of them, more than 12,000, die in India itself. There is no count of how many die undiagnosed. India has lesser number of juvenile diabetics compared to Western Europe. Also, in Western Europe more children are marked with obesity whereas in India most Juvenile diabetic diagnosed have normal weight, or are underweight and only a few are found to be slightly overweight. More children seem to be getting Type 2 diabetes. The incidence rate or new cases of type 1 diabetes in children (less than 14 years of age) for 2010 in India was 4.2 new cases per 100,000 population per year. (International Diabetes Federation, www.idf.org) These children require two or four insulin injections per day for their survival. The cost of the insulin is estimated to be about Rs. 4000/- to Rs. 8000/- for a year along with additional medical care amounting to Rs. 2000/- to Rs. 4000/-. While that is a cause for concern, the absence of proper diagnostic facilities, especially in rural areas has caused death to many affected children, before diagnosis. Additional problems for such children are enduring the pain of daily injections and blood tests, coping up with regular onsets of low and high blood sugar, and other related complications. They also have to deal with social constraints as regards education, employment and marriage. (http://www.deccanherald.com)

Juvenile diabetes is taken as an entry point in to the subject for various reasons. Foremost, the disorder is not a visible or evident feature on the body. A person with juvenile diabetes though suffering in the body chronically does bear any such marks on the same even though the disorder completely changes the life. With the onset of the disorder the life comes to move around maintaining oneself healthy. Since diabetes is a disorder there is felt the need to take proper care of the body in order to not allow any

diseases to develop. Herein we may also find that the lay perception (of those suffering) may consider diabetes a disease and not distinguish it as a disorder. Besides this the disorder occurring among those below the age group of 20 to 25 years may give us insight as to how the illness at the important juncture of teenage years influences the ideas and concepts of body and self. The exact causes for juvenile diabetes are unknown unlike Type 2 diabetes which is mainly caused due to hereditary reasons and lifestyle disorders. Type 2 diabetes patients are also considered in order to juxtapose them with type 1 patients (This is further discussed in Chapter 2- Methodology). Whether Type 1 or Type 2, diabetes is a serious problem as each patient passes on the chances of the disorder to their progeny. The increasing number thus becomes a threat for the future generations.

Research Gaps

First and foremost, as the literature review clearly shows, all the studies of the body and self are works done by Western medical anthropologists. There has been much discourse on body and self in Western medical anthropology which is lacking in the Indian medical anthropological tradition. The major trends of medical anthropological works in India comprise ethno-medicine, ethno-medical practitioners, health seeking behaviour, reproductive and child health, and health policy. There has not been any initiative to study the constructs of body and self and their negotiation for identity in the course of sickness whether acute or chronic. In such a situation it is imperative that we look into the constructs of the body in the Indian context and the negotiations between body and self that occur during illness in such a culture. It will be useful to see herein how body and self have been understood in Indian culture bearing the influence of bio-medicine for the past few decades juxtaposed with the traditional forms of perceptions.

India is a developing country undergoing modernization and witnessing the rise of consumerism in metropolitans. The traditional understanding of body/self relationships in illness in dialogue with the modern perspective might give an insight into how the structures are in the present, how the negotiations are taking place between

body/self and how the cultural understanding of body/self influences these negotiations.[4] Some amount of research in India does deal with stigma and coping with illness, and stigma and identity but no such work has been done in the field of diabetes. The disorder was chosen specifically because of its peculiar nature that does not have much outward manifestation and yet has certain amount of prejudice or negative attitude attached to it. In diabetes also Type 1 or Juvenile diabetes was chosen because of its insulin dependency, and its occurrence at a young age influencing the formulation of ideas of body and self of the affected.

For this purpose the following objectives had been formulated:

Objective 1: To understand the constructs of Body and Self among juvenile diabetics in the metropolitan city of Hyderabad.

- Body in terms of religious construct
- Body in terms of bio-medical constructs
- Body reflected in the terminological constructs
- Body in terms of social constructs
- Self in religious constructs
- Self in philosophical constructs
- Self in social constructs
- Self in existential constructs

[4] Though the approach used is one given by Western scholars (Nancy Scheper-Hughes and Margaret Lock). The reasons for using the approach given by Hughes and Lock are -
a. It is an approach that only looks at body at different levels and deals with the different perspectives that impact the understanding and constructs of body instead of giving just one model. They deliberately use an approach that brings together the different theoretical perspectives together.
b. They also locate the body in the context of contemporary developments like science, technology, globalisation etc but do not underplay religion, culture, society etc. giving it a more wholesome approach.
c. The discourse in the Indian tradition regarding body and self remains mainly in the realm of spirituality and religion thus limiting it many ways.
d. In their article from which this research borrows the approach does not deal or locate the idea only in the Western context but rather discusses cases spread across the globe as examples of Individual Body, Social Body and Body-politic.

Objective 2: To understand the negotiations between the body and self in illness.

- The separation between body and self
- The overlap in body and self
- The illness seen in body as separate from self or in self
- When and how self is expressed in the context of illness

Objective 3: To understand how those negotiations work in formulating identity (both- self identity and social identity)

- When is body used to identify oneself- in private space; in public space; in social space etc?
- In what terms is self seen as identity?
- How narratives change from body to self as identity

Objective 4: To understand the structuring and restructuring of identity in illness.

- Analysis drawn from the above three objectives

Chapterization

The data collected and analysed for all the objectives has been organised in to six chapters. Chapter 1 is the Introduction chapter and discusses the issues related to body, self, identity in illness, and gives basic details of Type 1 and Type 2 Diabetes. The chapter also highlights research gaps and states the objectives of the study along with the check lists for each one of them.

The second chapter is of Methodology. The methodology discusses the interpretative phenomenological approach and its pertinence in the research. The chapter continues with the need of narratives as the method for this particular research work and considers theoretical discussions on narratives, the ways of collecting and analysing narratives. Beside narratives, information from social networking sites was also used and is subsequently talked about in this chapter. Study area profile, data collection and the

limitations of study are discussed followed by the socio-demographic profile of the patients.

'Constructs of body and self' is the third chapter. This chapter deals with the first objective of the study i.e. to understand the constructs of Body and Self among juvenile diabetics. The model of three bodies given by Nancy Scheper-Hughes and Margaret Lock (1998) is used for understanding these constructs of Body and Self.

Chapter four is titled 'Negotiations between Body and Self in illness and for identity'. This chapter focuses on the second and third objectives of the study- To understand the negotiations between the body and self in illness and to understand how those negotiations work in formulating identity (both- self identity and social identity). The chapter seeks to understand the separation and the overlap of body and self, their negotiation in varying issues and different spaces.

Chapter five is the last chapter and deals with the fourth objective- To understand the structuring and restructuring of identity in illness and also is the conclusion of the thesis. This chapter undertakes the analysis of the other three objectives and sees structuring and restructuring of identity in light of model *of* and model *for* "reality" discussed by Clifford Geertz (1973) followed by the last chapter- Summary and Conclusion.

CHAPTER 2
METHODOLOGY

Every research requires some philosophical assumptions underlying their research process. Methodology deals with these philosophical assumptions as well as determines the methods that must be used to collect the data required for the research. A method, on the other hand, is a specific tool or technique used to collect data following the philosophical assumptions underlying the research. In other words methodology provides the philosophical basis for the selection of different methods for data collection. This chapter deals with the methodology and the techniques of data collection used in the study, the method of narratives and various issues related to it, the use of social networking forums or internet as such for data collection, study area profile, sampling, data collection and limitations and problems faced in data collection, and the socio-demographic profile of the patients.

Methodology

The way in which research is conducted is influenced by the research philosophy subscribed to, the research strategy employed and therefore the research instruments utilised to study the research objective(s). A research philosophy is a belief about the way in which data about a phenomenon should be gathered, analysed and used. Two major research philosophies usually used are, namely positivist (sometimes called scientific) and interpretivist (also known as antipositivist).

Positivists believe that reality is stable and can be observed and described from an objective viewpoint, i.e. without interfering with the phenomena being studied. They contend that phenomena should be isolated and that observations should be repeatable. This often involves manipulation of reality with variations in only a single

independent variable so as to identify regularities in, and to form relationships between, some of the constituent elements of the social world. Predictions can be made on the basis of the previously observed and explained realities and their inter-relationships. Positivism has also had a particularly successful association with the physical and natural sciences. There has, however, been much debate on the issue of whether or not this positivist paradigm is entirely suitable for the social sciences.

On the other hand, Interpretivists contend that only through the subjective interpretation of and intervention in reality can that reality be fully understood. The study of phenomena in their natural environment is key to the interpretive philosophy, together with the acknowledgement that scientists cannot avoid affecting those phenomena they study. Interpretivism proposes that there are multiple realities, not single realities of phenomena, and that these realities can differ across time and place. They admit that there may be many interpretations of reality, but maintain that these interpretations are in themselves a part of the scientific knowledge they are pursuing.

The study about body, self and identity involves issues that are abstract and one may not be consciously aware of their own defined opinions of them. The boundaries between the body and the self are rather blurred and it is difficult to establish where one ends and the other begins. This is further complicated when one is faced with an illness and a chronic one. The study of these need analysis based on not only what is said but also how it is said (language and terminology) as well as what is not said. Gathering such information involves essentially a methodology that allows the subject to "tell their stories". The objectives of the study and the requirement of the kind of data pointed to the use of interpretive method.

Interpretative Phenomenological Approach (IPA)

The study wants to understand the experiences of Juvenile Diabetics (Type 1 Diabetics) and their ideas and perceptions about body and self, and identity in the face of a chronic illness. In order to realize these, the methodology of Interpretative Phenomenological approach has been used in the study. Interpretative phenomenological approach has been used greatly by psychologists since the last two decades. IPA, as Reid

et al (2005) put it, can "...provide meaningful and unexpected analysis of psychosocial issues." (2005: 23) In the field of psychology also IPA has been used mainly in the sub-field of health, clinical, social, cultural and cognitive psychology.

Smith and Osborn explain IPA as, "The aim of interpretative phenomenological approach (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants. The approach is phenomenological in that it involves detailed examination of the participants' life world; it attempts to explore personal experience and is concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself...Access depends on, and is complicated by, the researcher's own conceptions; indeed, these are required to make sense of that other personal world through a process of interpretative activity. Thus, a two-stage interpretation process, or a double hermeneutic, is involved. The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world. IPA is therefore intellectually connected to hermeneutics and theories of interpretation." (Smith and Osborn, 2008:53) IPA is thus a methodology that emphasises on understanding the phenomenological experiences and the meanings and the values that the subject or the participant attaches to them, and their interpretation both by the subject as well as the researcher. The researcher studies the meanings of experiences, events etc that the subject holds and interprets them as well.

The method that IPA adopts digresses from the usual quantitative and experimental methodology used in mainstream psychology but rather uses a qualitative analysis where the researcher attempts to explore the meanings the participants assigns to their experiences. The participants know their experiences the best and they are encouraged to tell their experiences or thoughts or feelings in their own words through telling their own stories. (Smith and Osborn: 2008; Reid et al: 2005)

Russell Bernard (2006) states that anthropology is positivistic as well as interpretative, in a sense that the researcher empirically observes and makes note of the

information or the data but, interpretatively analyses the data. He thus sees both the traditions used in the discipline of anthropology.

Clifford Geertz stated, "Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning." (1973: 5). Geertz, one of the most common names associated with symbolic or interpretative anthropology also imported concepts from phenomenology from Alfred Schutz. Anthropologists like Victor Turner, Edward Bruner, and Dilthey brought the interpretive anthropology and phenomenology together. They emphasised that, "Lived experience, then, as thought and desire, as word and image, is the primary reality. Experience, in our perspective, is not equivalent to the more familiar concept of behavior. The latter implies an outside observer describing someone else's actions, as if one were an audience to an event...An experience is more personal, as it refers to an active self, to a human being who not only engages in but shapes an action. We can have an experience but we cannot have a behavior; we describe the behavior of others but characterize our own experience....The distinguishing criterion is that the communication of experience is self-referential. The difficulty with experience, however, is that we can only experience our own life, what is received by our own consciousness. We can never know completely another's experiences, even though we have many clues and make inferences all the time. Others may be willing to share their experiences, but everyone censors or represses, or may not be fully aware of or able to articulate, certain aspects of what has been experienced. How, then do we overcome the limitations of individual experience? Dilthey's (1976:230) answer was that we "transcend the narrow sphere of experience by interpreting expressions." By "interpreting" Dilthey meant understanding, interpretation, and the methodology of hermeneutics; by "expressions" he meant representations, performances, objectifications and texts..." (Bruner, 1986:5) Turner pointed how 'experience' which one goes through becomes 'an experience' when it acquires a beginning and an end and has a subjectivity when transformed into an expression. (Turner, 1986)

Smith and Osborn point out how IPA has been used in research areas like, reproductive decision-making and adoption, chronic illness, spirituality and bereavement, mental health/addictions/eating disorders, sexual identity and sexual health, personal and cultural identity etc.

The methodology of IPA supports the sample of the study to be small because "...the aim of the study is to say something in detail about the perceptions and understandings of this particular group rather than prematurely make more general claims." (Smith and Osborn, 2008: 55) The participant group is usually homogeneous firstly because the participants in the group are chosen because they have experiences that the researcher is studying that is to say that the topic or issue of the study itself makes the group homogeneous. Secondly, with a small sample it is difficult to take a random or representative sample.

The methodology of IPA requires detailed accounts from the participants explaining in depth their experiences of events or states etc in their own words in the form of telling their stories. IPA research usually uses semi-structured interviews where the participant or the interviewee is given the control to narrate his/her experiences. IPA encourages interviews to be recorded and later transcripted. The central aim of IPA is to understand the meaning and the interpretation of the experiences of the participants and not just their frequency. Narratives, as a technique was found apposite for the purpose of data collection in accordance with the methodology of IPA. Thus, the technique of narratives was employed in this research. In narrative analysis we have four major traditions -socio-linguistics, hermeneutics, phenomenology, and grounded theory. In this work narratives are seen in terms of hermeneutics and phenomenology. The approach of IPA being both interpretative and phenomenological suggests that the narratives be analysed using these two traditions. Narratives were combined with data collected from social networking forums.

Narratives

Narrative is a meaning-bearing expression of an experience. That is to say, how one sees and interprets a particular experience is reflected in their narrative. Every

culture has a way of its own to organise their experiences and make them meaningful. What is significant to the culture is reinstated through their stories or the explanation they give for the way it ends. When a person tells his or her story, the very process of articulating the narrative gives wholeness to the experience. The experience becomes important and emphasised when it is put in a narrative. The experience's different meanings, implications and relevance are justified and solidified in or through the course of narration. Narrative analysis views narratives as interpretive devices through which people represent themselves and their worlds to themselves and to others.

Narratives bridge the gap between social sciences and humanities, especially linguistics, as much meaning is derived from the language, hermeneutics, and semantics of any story. A story finds deeper meaning when the terms and metaphors used, and analogies employed are also examined rather than just the plot or the content of the story. Narratives are usually characterised as accounts which contain an element of transformation (i.e., change over time) or accounts containing some kind of action and characters that are brought together in a plot line. Narratives have a temporal dimension, and characters and actions can be imaginary/fantasy. There is also the process of 'Emplotment' through which narratives are produced and digressions and sub-plots also come into the story and in completing the story. Narratives mostly have a point (a 'so what?' factor), which often take the form of a moral message. (Lawler, 2002)

There is no one particular format of narratives or stories told. That is to say that by studying stories we cannot arrive at models and then formulate a narrative structure which may be applicable to other narratives as well because then the story shall lose its difference. (Barthes, 1974:3 in Garro and Mattingly, 2000) Also, a narrative may be a written account, an oral tale or discourse, or even an enactment in a more theatrical format. The works dealing with social drama and their role in communicating culture and negotiating change could be seen as enactments of narratives.

Narratives (when used in medical anthropology) bring to light various issues like that of varying explanatory models, renegotiation of illness roles, place of individual memory in the collective memory and vice versa, arena for therapeutic negotiation and action, power struggles, enactment of narratives etc. Linda Garro and Cheryl Mattingly in

their edited book "Narrative and the cultural construction of illness and healing" emphasize "...at a pragmatic level, hearing narrative accounts is a principal means through which cultural understandings about illness -including possible causes, appropriate social responses, healing strategies, and characteristics of therapeutic alternatives -are acquired, confirmed, refined, or modified… In the Haitian village studied by Farmer (1994), stories told about known individuals with a then unfamiliar illness, AIDS, served as the medium through which broadly shared understandings gradually became established. As these examples illustrate, cultural knowledge informs stories while stories help to link personal experience and cultural meaning, mediating between particularities and generalities" (2000:26).

Garro in the same book undertakes a study of diabetes in the Anishinaabe community. Seeking to understand the perceptions of aetiology she states how life history is mixed with community history while giving an illness narrative. She gives the example of Mrs. Spence who suggests diabetes to be a "white man's sickness" as she relates the increasing number in the diabetes cases to the coming and settling of white men in the region. "Such comments clearly take a moral stand and implicitly condemn prevailing practices in contemporary society. **They can also be viewed as expressions of resistance to the tendency of bio-medically oriented practitioners to highlight individual responsibility for diabetes** through making recommendations that patient lose weight, change their diet, and get more exercise… (Thus) this collective memory has become personal knowledge, grounded in the particulars of her own life history" (2000:79) (emphasis added) Garro discusses the relevance of the framework of reference and its place in the narratives. Interactions with others, perhaps particularly those who claim knowledge of illness and its treatment, may be cited as a source of validation for one's perspective contributing to the credibility and persuasiveness of the account presented. In addition, such interactions may come to guide how an individual reconstructs the past.

At times due to illness social roles become renegotiable especially in the course of the narrative. Linda M. Hunt in her paper 'Strategic Suffering' gives example of cancer and states two cases wherein patients lost their reproductive organs due to

illness and were thus ushered in to a situation where they could reinstate their gender roles without disturbing or challenging the socially defined roles by the virtue of their illness. Hunt proposes, "They (the two cases that she has undertaken in her study) have thus found themselves in a somewhat ambiguous moment, wherein the applicability of the cultural gender norms is subject to renegotiation. In dialogue with those about them, they produce illness narratives that reconstruct their gendered social roles such that they are exempt from participation in certain prescribed behaviours which prior to their illness had proved untenable for them… Through their illness narratives they had at once found a voice for their role frustrations and created legitimated new roles for themselves, both expressing and resolving some of the difficult social issues with which they had long been grappling… This literature is concerned with the impact of these factors on individual patients' motivations to stay ill or become well, and on the tendency toward somatization. This implies that patients may consciously or unconsciously hold ulterior motives that may underlie their failure to get well." (2000: 98-99)

Reissman studying the case of infertility in India states that in India it is nearly impossible to hide illness and especially chronic illness and stigmatized ailments. She highlights that explanatory model reflects how different communities see and react to illness and discuss or share the knowledge of disability. Whereas in Europe women might consider it their right to disclose the matter of infertility to a stranger but in India it need not be the case especially where the women have a strictly defined place in the authority system headed by the in-laws and the husband. The community is closely linked and thus comes to know such matters. This is also evident with the intervention and contribution of family members and neighbours in the patient's narrative. In such situation stigma, dealing with disability/ infertility/ illness/ changed roles/ adhering to treatment need to be evaluated in new light. (2000).

Another important feature that narratives bring to forefront is the variation in (and the struggle to assert their own) explanatory models between the patient and health care provider. Laurence J. Kirmayer's study highlights the interactions of patient and clinician in the setting of psychological treatment where the patient sees her problem (symptoms of stomach pain, heartburn and chest pain) as physical problems and situated

in her body whereas the clinician is stressing the relation of symptoms to the patient's recently broken love relationship and thus locating it in the psychological realm. The author highlights how in the interaction both try to stress on their own understanding of the ailment and are trying to protect what they have at stake. That is, for the clinician his theoretical understanding training etc. and the patient the stigma of psychotherapy and "problem in her mind". (2000)

Talking of narratives Evelyn Early writes, "The therapeutic narrative employs the web of commonsense explanations which links the unique, somatic event with shared cultural knowledge about illness. These explanations serve both to valuate therapeutic activities and to make sense of experience. They situate illness within the socio-economic reality, which sets the parameters of therapeutic action….The narrative then serves as the performance arena for negotiation of right action regarding as well as interpretation of, an illness episode" (1982:1492).

Radley discusses the difference in the bio-medical construction of body to that of social constructionist perspective. "From the bio-medical perspective, the body is an entity whose pathology can be objectively studied. It is something to which psychological and social phenomena can be related, where these too, are treated as factors or variables….From the position of a social constructionist psychology, the ailing body is discursively produced. It is the subject of narratives, outside of which it cannot be properly understood. Embodiment in illness is contextual and situated. What this embodied state 'is' depends upon whose body is being considered, by whom, in what context and for what purpose." (Radley, 1997: 54)

Narratives are different from semi-structured or informal interviews and should be collected and analysed in a certain way. Narratives require the researcher to encourage the participant to tell his/her 'story' with as little interruption as possible from the researcher. Reissman states that "Not all narratives are stories in the strict (socio-linguistic) sense of the term." (Reissman, 2004 (b): 710) and goes on to talk about the narrative interviewing. Narrative interviewing is where the researcher participates (though in a limited way) with the interviewee in the conversation and together they construct a narrative. Definitely the researcher must give up some control as the

participant or the interviewee extends the narration or sub-plots or digressions find a way into the narration. She emphasises that on the other hand sometimes the experiences are hurriedly summarized and any details on them have to be probed for. Many times because of the sensitivity of the issue involved or for cultural reasons there is witnessed silence from the participants. The narrative in such situations cannot be limited to an oral or verbal 'story-telling' but must transcend to other mediums like dance, art, photography, group narrative etc.

Reissman (2004 (a)) delineates four major ways for narrative analysis. She emphasises that the four methods are not necessarily mutually exclusive rather they can be used together depending upon the research subject and objective(s). The four methods of narrative analysis are -thematic analysis, structural analysis, interactional analysis and performative analysis. Thematic analysis focuses upon what is told more than how it is told. The thematic approach is useful in studying more number of cases by taking into account common themes across the participants. Language is seen as a resource used in the communication and does not become the main objective of the study. This approach does not study the context in which the narrative is given and also by studying common and major themes overlooks the deviations or variations when reported.

Structural analysis stresses upon 'the way the story is told' (Reissman, 2004a/b: 706). Unlike in the thematic approach, language is considered important more than just referential. The researcher studies how the participant narrates his/her story making it more forceful or convincing or persuasive. The way the story is organised giving an abstract, the orientation of the story (the time, place and setting of the story), complicating action (the event, the climax or the turning point), evaluation (where the narrator pauses from the narrative to comment on the meaning or the essence of the narrative/story), resolution (the outcome of the event or the plot), and a coda (where the narrator ends the story and comes back into the present). Every story might not have all these elements and not in the same order. Due to detailed study of syntactic and prosodic analysis required this approach is not suitable for a large number. Similar to thematic approach structural approach also compromises the historical, cultural, institutional contexts and focuses more on the story and its structure.

The interactive model centres on the dialogic process between the teller and the listener. The approach does not overlook the thematic and the structural aspect of the narrative but emphasis is given to the process in which the teller and the listener co-construct the story. The story of the teller here is constructed by a question-answer process. Reissman points out the difficulty of describing gestures, facial expressions and gaze etc, which cannot be transcripted, in the interactional approach. Performative analysis on the other hand focuses upon the narration of the story as a performance, using art forms and gestures etc. There is setting, the exchange of dialogues between characters, and the response of the audience to the enactment. Performative analysis is especially useful in studies related to identity and identity construction.

For the purpose of this research thematic and interactional approaches have been used together. Common themes were noticed across the participants' narratives and these themes were issues that affected the lives of the participants and their life with a chronic illness. The focus was more on what was being told and what remained unspoken. Having used the narrative interviewing method the interactional approach came in as a consequence. This definitely brought to light the subjectivity of the researcher, the kind of questions asked and the assumptions made. The narratives as they came out in the end were always a co-construction of the teller and the listener that is, the participants and the researcher.

The issues of explanatory model, renegotiation of illness roles, place of individual memory in the collective memory and vice versa, arena for therapeutic negotiation and action, power struggles were observed also among the narratives collected. All the patients were at the time of the study taking allopathic/bio-medical treatment which suggested that they adhere to the bio-medical explanatory model. But narratives showed that was not all there was to it. Patients spoke of how they had tried everything and then settled for bio-medicine as nothing else seemed to help. Of the five aspects of explanatory model that Kleinman speaks of -aetiology, onset of symptoms, patho-physiology, course of sickness and treatment– it was seen that patients agreed most with the aspect of treatment and symptoms. And though they were adhering to/ complying with the treatment they were searching for non-allopathic treatments as well.

Many patients expressed that Ayurveda being more 'natural' might be able to give a better cure. They wanted to continue with bio-medicine till they could shift to Ayurveda. Many patients wanted a permanent cure and hoped that bio-medicine will progress enough in their life-time to provide that. Some had heard about the possibility of surgery where an insulin pump can be fitted into the patient's body which secretes insulin normally and wanted to undergo that. Most patients were dissatisfied with the treatment as it does not cure them. About aetiology though many patients did talk about pancreas not secreting insulin and that leading to diabetes yet when asked why they got diabetes many times non-medical reasons like fate, will of God and karma etc. came across through the narratives. Since the researcher could not observe the patient-provider interaction, narratives in that arena for therapeutic negotiation and action could not be examined. But patients narrating their dissatisfaction with the treatment and seeking alternative medicine speak volumes about therapeutic negotiation.

Most interviews were in English and others in Hindi (which were transcripted and translated). There was observed hardly any code switching[5] in the course of the narratives. Narratives nevertheless brought out the terms used by patients to explain their body mechanism or analogies about their body and thus gave deeper insight into how bodies are perceived and how environment and technology influence these ideas.

Narrating their illness and lifestyle changes, patients unconsciously spoke of how much their lives were affected by the disorder and influenced their identity. How patients reflected upon of the disorder and its affect on their lives either spoke of trying to prove themselves in spite of the disorder or saw the disorder as the reason for being unable to achieve what they wanted to. Through the narratives they could define their identity either away from the diseased body or rooted in the diseased body and thus redefining social roles.

The place of individual memory in the collective memory (as discussed by Garro (2000) and vice versa were not found except in one narrative where the respondent

[5] Code-switching is the concurrent use of more than one language, or language variety, in conversation. Multilinguals-people who speak more than one language-sometimes use elements of multiple languages in conversing with each other.

invokes the memories of his childhood and of good times when everyone was closer to nature and compares that to the present times. Other respondents though did not talk of individual and collective memory we find them making memories. (The respondent who had these memories is more than 50 years of age whereas most others belong to less than 30 years age group.) Their identification with other diabetics versus the society and also at times comparing India with other cultures suggested that. Narratives also used stories or anecdotes to explain the situation of the narrator. One such narrative is given below.

"Now questions over story time: I met one family last year in diabetic camp. Their daughter was having diabetes. Can u think how old she could be? She was 5 yrs old. I saw them giving her injection. I still remember her crying face. I was talking with them, when her father said "bache toh samaj jate hein hume samajne mein thodi taqlif hoti he." How such a small kid will understand? What's going on? What diabetes is? Why these people are pinching me with sharp objects? This situation is similar to my situation and my family situation when I got diabetes. I can't answer your question to that perfection but this small story I think can give you to feel what my situation and reaction would have been that time."

Power struggles with family, society all come across through the narratives. Though it was difficult to observe the family dynamics of the patients or their relationship with their peer, colleagues or society but, the narratives brought out the perspectives of the patients at least. In their narrations as they spoke of their struggles with family, peer, colleagues and issues like work, marriage the power struggles were conveyed implicitly. All these issues are further discussed under Chapter three and four.

Social Networking Forums as a Source

In the studies of urban anthropology a new feature has made itself known – that of the World Wide Web. Internet has swept cities with its ability to connect, provide information and entertainment while sitting at home. Recently, social networking sites have become very popular especially in India and its impact can be seen very clearly. These networking sites enable people to establish contact with acquaintances as well as

form new friendships. Wide and uninhibited participation is seen among people in these discussion forums on social networking sites. These forums made available information which is otherwise extremely difficult to collect in urban settings. To overcome the limitations of personal interviews social networking forums were found to be a good alternative. In the early stages of research itself it was realised that many patients across the country were coming together on social networking websites and discussing their problems, concerns and to help one another. This was an avenue where patients could be observed as how they related to each other, perceived their disorder and dealt with it. Most definitely it posed the problem of defining the region or area of the study but gave insight into the globalizing world. Care was taken to consider only those discussion forums which Indians living in different metropolitans participated in. The discussion forums provided interesting information that supplemented the information gathered through narratives. Social networking sites are an important source of data collection. In an urban setting internet gives an avenue for discussions. Participants can maintain anonymity as well as participate according to their convenience. Using social networking sites as a source of information allow observing the participation, and uninhibited opinions and views of participants. The discussions were more open and frank in the forums than in most interviews. During the interviews the researcher had a structure in mind and asked some questions whereas in the social networking website the researcher had no control over the topics of discussion as well as the participation of the members. The researcher was not the stimulant, but was only an observer in the discussion. It was the platform where the voice of the participants was more prominent.

The networking site had at the time of the research 490 members. There had been as many as 48 topics initiated by the members wherein many of the topics overlapped. Not all the members would participate in all the discussions. Some discussions had as many as 70 people giving their views whereas some had been initiated by a member without any response from the others. At the time of the study the most often discussed as well as most participated in issues of discussion were dating and marriage, insulin and medicines, diet and exercises, and on-going research on Type 1 diabetes. Some of these discussions had been initiated by the members wanting to know more about a certain issue or wanting to get help.

There was a sense of the social body that reflected through the social forums. Juvenile diabetics considered themselves, by the virtue of having diabetes, one versus the others in the society. There is a sense of ease with which they discuss various issues that concern them and affect them pertaining to the ailment and otherwise. Patients were found to seek medical counsel and personal counselling on these forums. The researcher found that the issues that patients were unwilling to talk about in person, other diabetics on the forums were comfortable with in their discussions. Participants of the social forums were seen to give life advice, share their experiences, give counselling, organise awareness programmes besides giving their opinions on varied issues ranging from which insulin is better to should a diabetic marry a diabetic or a non-diabetic. It is interesting that quite frequently people also ask for urgent clarifications on these forums about bio-medical questions.

The researcher participated in the discussion forum and revealed identity as a researcher to the other participants in the forum. Excerpts from their discussions are quoted without revealing their names and thus maintaining confidentiality. Studying their discussions are extremely pertinent to the study as it gives insight into that which is not revealed in the narratives as well as also brings to light the dynamics of their social relations especially with those whom they consider equals or friends.

In urban spaces where relationships with extended family and friends is difficult to manage because of time or distance or because older forms of relationships are dwindling making “friends” on these social networking sites is not only easy but also where the individual can chose who he/she wants to communicate with. The friendships on internet are first of based on common interest and also are not demanding more than what one wants to give. One can decide when to terminate a friendship without the need for any explanation and there is barely any pressure to confirm to any group’s ideas or ideals.

The whole social networking and cyberspace representation opens up questions of identity (and also pseudo-identity) in a new way. How a person chooses to represent him/herself is completely dependent on him/her. It would be presumptuous but not without reason that on these forums one may exaggerate their stance on issues in

either extreme. In the research the discussions between the participating members of the forum brought out many times the structuring and restructuring of identity.

Study Area Profile

Diabetes is a chronic disorder and unlike infectious/communicable or epidemic diseases does not have any established data base in terms of incidence and prevalence for each state of the country. The statistics available are gross estimates for the country. The unavailability of state-wise data took away the option of carrying out the research in the state with the largest diabetes population. Therefore, a metropolitan was selected as it would provide with sufficient population base for adequate diabetes cases.

For the purpose of the study the city of Hyderabad was chosen to carry out the field work. Hyderabad is the capital of Andhra Pradesh, the fifth largest state of India. The city is located at 17.366°N latitude and 78.476°E longitude and approximately 540 meters above the sea level. It is spread over an area of 217 sq. km and has a population of more than 3.68 million with 100% urban population and 16,988 persons per km² density of population. There are about 695,906 households with the average of 6 persons per household. The male-female ratio is 933 females per 1000 males. Nearly 63% of the population lies in the age group of 15 to 59 years, and 30.9% of population under 15 years of age, leaving about 6% of population in the above 60 years category. The city has a literacy rate of 68.8%. (Census 2001 www.censusindia.gov.in)

People of three of the World's major religions- Hinduism, Islam and Christianity inhabit this city. There were 2,121,963 (55.4%) Hindus, 1,576,583 (41.1%) Muslims, and 92,915 (2.4%) Christians in Hyderabad according to the census 2001. (Census 2001 www.censusindia.gov.in) Telugu, Urdu, Hindi and English are the languages spoken.

The city has available a variety of medicine systems. According to www.hyderabad-info.greaterhyderabad.co.in there are 23 government hospitals in Hyderabad that provide bio-medical services and some of these hospitals are also speciality hospitals. There are 24 civil dispensaries according to the data given under AP

Vaidya Vidhana Parishad on www.aponline.gov.in**.** There also exist many alternate medicines facilities in the city. Some of them are:

	Colleges	Hospitals	Dispensaries	Total Facilities
Ayurveda	1	2	6	9
Unani	1	2	9	12
Homeopathy	1	2	9	12

Table1: Facilities of Alternative Medicine Available in Hyderabad in 2005.

This information was gathered from the departmental manual of AYUSH (Ayurveda, Yoga, Unani, Siddha, Homeopathy and Sowa Rigpa) 2005 and gives the data of only the government institutes and facilities available and do not include private facilities. Apart from these alternative medicine systems and their facilities there are also a few Naturopathy and Siddha medicine facilities. The city was chosen due to reasons of convenience as the researcher had a familiarity with the city and had some social network to establish links with doctors and diabetes centres to initiate the fieldwork.

Data Collection and Limitations of the Study

Following the IPA methodology and time intensive requirements of the technique of narratives the sample size was determinedly kept small. From the onset of the research the sample size was decided not to exceed 25 Type 1 or Juvenile diabetics. Having determined the size of the sample, the researcher moved on to the question of where to find the respondents? Pelto and Pelto (1996) state that in Medical Anthropology there are two basic approaches for data collection -clinical population and community based population. "A clinical population is any group of patients, clients or cases selected from the persons found at a particular health centre, hospital or individual healer's location. Clinical populations are selected for research whenever a portion of the research issues focus directly on the activities of the clinic or when it appears that a substantial

part of the "cases" of a particular illness are to be found at the clinical setting." (Pelto and Pelto, 1996: 303-304) Clinical based data collection is especially useful in studying therapeutic encounters (Finkler, 1991), patient-provider interaction and relationship (Rapp, 1988), differences in the explanatory models of the patients and the clinical staff (Cohen et al, 1994). A clinical population cannot be seen as representative of the general (community) population as a hospital or health care centre will only receive a selected non-random portion of population especially in an urban area wherein many others may go undetected or seeking alternative treatment. Clinical population also does not and cannot account for the various family and social networks that influence the perceptions of the individual regarding health, illness and decision-making etc. thereby limiting the approach's reach into the cultural set-up outside the clinical setting. (Pelto and Pelto, 1996)

Community-based approach, on the other hand, is to select community/ communities or sub-communities for the study usually because of the prevalence of a particular disease or health programme. The community-based approach is further determined by two main factors of a) the nature of the specific problem being studied, and b) the geographic characteristics of the community or communities being studied. Community-based studies have been used since the early days of anthropological research because of its holistic approach. The community-based study must nevertheless consider whether the community chosen is large enough to provide sufficient number of cases of the specific illness being studied. Community-based study can be done by having representative population from different sections or sub-groups of the society (Gittelsohn, 1989). (Pelto and Pelto, 1996)

Studies have been conducted that combine the two approaches. Finkler (1991) used the clinical approach to study the therapeutic encounters and also met the patients in their homes to get information outside the clinical setting. On the other hand, Sargent (1989) combined the community-based sample with the clinical-based sample to get a holistic perspective on childbirth and maternity in the population. (Pelto and Pelto, 1996) In this particular study the sample could have been taken from the community but the vastness of the population in the urban area, and the difficulty of where to find juvenile

diabetics posed the question of where to find the respondents and how to do sampling from the whole city or even a ward or two that would be representative of the whole population.

The number of juvenile diabetics in India according to JDRF (Juvenile Diabetes Research Forum) is currently 1 million on the total population of the country of 1.02 billion. If the distribution of the Juvenile diabetics was considered to be evenly distributed across the country the number of cases available in Hyderabad at that rate would be 3722, giving the ratio of one patient per 188 households. Thus, in order to get 25 patients the researcher would be required to at least visit 4717 households. The restraints of time and resources as well as the uncertainty of finding the patients even then highlighted the benefits of choosing clinical-based sample over community-based sample. In the case of this study this was the only possible approach taking in to consideration the specificity of the disorder. Juvenile diabetics, once diagnosed, prefer speciality clinics or centres over general physicians. Therefore, diabetes speciality clinics and centres were contacted to establish link with patients. Clinical-based samples tend to be biased as they reflect the opinions of one kind of population that is taking health care in that particular set-up (both- the choice of the medical system as well as the particular clinic). These loopholes of the approach were realised at the very beginning of the research and were later used as a controlling factor.

Many diabetes speciality clinics and centres (like Dr. Mohan's Diabetes Speciality Centre, Sir M.V. Centre for Diabetes, Dr. Sahay's clinic) were approached besides General Government Hospital and the Railway Hospital. These private or non-government clinics and centres are considered most renowned and successful in the city. The two diabetes centres, Dr. Mohan's and Sir M.V. Diabetes Centre, initially extended help by giving contact numbers of patients but later refused help. Except for Dr. Sahay's clinic, other clinics and centres were reluctant to give information and thus declined cooperation. The General Government Hospital and the Railways Hospital were approached but they could not extend help as there is no data-base of the patients and not many juvenile diabetics are taking treatment at these hospitals. Ayurcare and Ayush- two prominent Ayurvedic health care centres were also approached but they too declared that

no Type 1 or Juvenile diabetics were being treated at their centre. Juvenile diabetics do not come at a regular interval to the healthcare provider to be able to predict an encounter. Because of that as well as their limited number it was required of the researcher to visit the clinic everyday to collect narratives of at least 25 respondents. This also hindered in contacting any other clinics or centres. Therefore, the informants were those taking treatment at the one clinic (Dr. Sahay's) that consented. All the Type 1 diabetics above 15 years of age, who came to take treatment at Dr. Sahay's clinic in that period, were interviewed. The sample thus was purposive.

Narratives were collected from fifty patients (twenty-five Type 1 and twenty-five Type 2 patients) over a period of one and a half year (from August 2008 to March 2010) in Hyderabad, India. The main focus of the study was on Juvenile diabetics (Type 1 diabetes patients). Considering the time available it was recognised that it would be difficult to bring out differences among the Juvenile diabetics and it would be better to see them together in contrast to or juxtapose against Type 2 patients. Therefore, 25 Type 2 diabetics were also interviewed.

Type 2 patients are not dependent on external insulin in-take, the onset is usually later in age, and the areas of difficulty and problem are very different for the two (as discussed already in the Introduction chapter). Though the discussion in the chapters comparing or contrasting Type 1 and Type 2 diabetes is very little yet seeing Type 1 contrasted to Type 2 allowed the researcher to make generalisations regarding type 1 in spite of a small sample.

Narratives were collected from patients above the age of 15 years who came to the clinic during the period of study. Though there were many patients under the age of 15 years taking treatment at the clinic they could not be chosen for the study on the basis that they might not have clear ideas of body and self and also not be able to articulate their opinions, if any. A few of the minors (above the age of 15 years) at the clinic could not be interviewed as their parents did not consent to the interview. The patients though willing to talk were reluctant to give their phone number or allow the researcher to come to their residence for any further inquiry. Therefore, interviews could be taken only at the clinic. That meant the context of family was greatly restricted. Since some patients were

accompanied by family members only a glimpse was available of the family and social nexus.

The narratives were audio recorded and subsequently transcripted and analysed. The analysis concerned issues of language, analogies used, explanatory models and negotiations between different models, use of narratives to construct new roles and identity as have already been discussed under the section on Narratives.

Socio-demographic Profile of the Respondents

The sample for the study was purposive but was distributed in sex, age-group, religion, education level, and the onset of the disorder. There were many different social categories – sex, ethnic background, education, age, and onset of the disorder. But, two things were common between all the patients- Juvenile diabetes and the clinic. The variation in the perceptions of the respondents arising out of different clinics and different clinical encounters was controlled to quite an extent. (It is pertinent here to point out that not all respondents had only one clinical encounter. Some had taken healthcare elsewhere first and later shifted to this particular clinic and doctor because of different reasons.) Therefore, not selecting samples from different clinics was also an opportunity to standardise or control the effects of clinical encounters and the narratives of the individuals. The socio-demographic profile of the respondents is discussed under the sub-heading of sex, age-group, religion, education level, and the onset of the disorder.

Sex

	Type 1	Type 2	Total
Male	15	10	25
Female	10	15	25
Total	25	25	50

Table 2: Distribution of patients by sex in Type 1 and Type 2 Diabetes

Age group

Table 3 clearly shows the distribution of the patients in Type 1 and Type 2 diabetes by age group. More than 92% of the Type 1 diabetics fall under the age group of 45 years whereas the reverse is applicable to Type 2 diabetics, i.e. 96% of Type 2 diabetics belong to the age group of 36 years and above. The needs of the Type 1 diabetics were different not only in terms of the illness but also because of the age bracket they fell into. The things that concerned them were very different from those of Type 2 diabetics. Type 1 diabetics were more concerned about their education, career, dating, marriage, and to find a more permanent cure for their diabetic situation. On the other hand, since most of the Type 2 patients had faced the onset of the disorder after completing their education, having a stable career, and having a family life had concerns about other health problems and old age issues. These differences mark how an illness has different meanings depending upon what age-group the respondent belongs to and the age of the onset of the disorder.

Age-group	Type 1	Type 2
15-25	15(**60%**)	0
26-35	3 (**12%**)	1 (**4%**)
36-45	5 (**20%**)	2 (**8%**)
46-55	1 (**4%**)	5(**20%**)
56-65	1(**4%**)	12(**48%**)
Above 65	0	5(**20%**)
Total	25 (**100%**)	25 (**100%**)

Table 3: Distribution of Respondents by Age group (in numbers and percentage) in Type 1 and Type 2 Diabetes

Religion

Religion	Type 1	Type 2	Total
Hindu	17(**68%**)	22(**88%)**	39(**78%**)
Muslim	3(**12%**)	3(**12%**)	6(**12%**)
Christian	5(**20%**)	0	5(**10%**)
Total	25	25	50

Table 4: Distribution of Respondents by Religion in Type 1 and Type 2 Diabetes

It is interesting to note here that the number of Muslim respondents was quite less in comparison to the Muslim population inhabiting Hyderabad. It is difficult to point out the exact reason for that but some possible reasons could be:

a) The location of the clinic in the city is away from where most of the Muslims live in the city.
b) More Muslim diabetics prefer to use traditional medicine or Unani (alternative medicine) which has a differing explanatory model (from bio-medicine).
c) Coincidently during the research period there had been less Muslim patients coming to the clinic.

Education

Table 5 shows distribution of patients by their education. The table shows the distribution in terms of the highest level of education completed by the patients at the time of data collection. As the table shows, most patients, both the Type 1 and Type 2, belong to the graduate category. Amongst the Type 2 patients there is only one patient in the primary category and none in the secondary category. It is important to note that though more Type 1 patients are in the secondary category they belong to the younger age group and are still pursuing their education. Only two Type 1 patients had stopped education after senior secondary. On the other hand, most of the Type 2 patients belong to more than 45 years age group and have completed their education. Thus, it is important to study the table showing the education in correspondence to the table showing the

distribution of patients by their age group. Beside that Type 1 patients are still pursuing their education we do not find much difference between the Type 1 and Type 2 patients in terms of their education.

	Type 1	Type 2	Total
Primary	0	1 (**4%**)	1 (**2%**)
Secondary	3 (**12%**)	0	3 (**6%**)
Senior Secondary	5 (**20%**)	5 (**20%**)	10 (**20%**)
Graduate	**12 (48%)**	**15(60%)**	**27 (54%)**
Post-Graduate	4 (**16%**)	4 (**16%**)	8 (**16%**)
Above Post-Graduate	1 (**4%**)	0	1(**2%**)
Total	25	25	50

Table 5: Distribution of Respondents by Education in Type 1 and Type 2 Diabetes

Onset of the disorder

As the table 6 shows more Type 1 patients (18 patients) have had the disorder for more than 5 years than Type 2 patients (14 patients). Even among the Type 1 patients there was noticed a lot of difference in the narratives of the patients who had been diagnosed with the disorder less than a year ago from those who had been living with the disorder for more than that. There was angst, confusion, apprehensions observed in the narratives of the patients who had just been diagnosed with the disorder. One of the Type 1 patients was angry and blamed his father's sickness, that had caused him a lot of stress as the reason for his becoming diabetic. Throughout the conversation with him the researcher observed anger, resentment and denial. On the other hand, the patients with the disorder for more than one year had come to accept the reality of the disorder and were making efforts to adapt to the life with the disorder. Their lifestyles were more adjusted

to the changes required for a diabetic situation. They spoke more positively about the lifestyle changes like diet, insulin intake and exercise that were required of them. Moreover, as some of them were at the stage of deciding marriage this issue became more complex. The patients with the onset of less than a year and sometimes even less than five years had either not thought about or not yet faced the issue of marriage and thus were not perturbed about it.

	Type 1	Type 2	Total
Less than 1 year	2 (**8%**)	3 (**12%**)	5 (**10%**)
1-5 years	5 (**20%**)	8 (**32%**)	13 (**26%**)
6-10 years	8 (**32%**)	5 (**20%**)	13 (**26%**)
11-15 years	2 (**8%**)	4 (**16%**)	6 (**12%**)
16-20 years	4 (**16%**)	3 (**12%**)	7 (**14%**)
21- 25 years	2 (**8%**)	1 (**4%**)	3 (**6%**)
26-30 years	1 (**4%**)	1 (**4%**)	2 (**4%**)
31-35 years	0	0	0
More than 35 years	1 (**4%**)	0	1 (**2%**)
Total	25	25	50

Table 6: Distribution of Respondents by the Number of Years since the Onset of the Disorder for Type 1 and Type 2 Diabetes patients

The age group and the onset of the disorder table clearly show the pattern among both- the Type 1 and the Type 2 patients. More Type 1 patients are young and have had the disorder for a long time. On the other hand, most of the Type 2 patients though above 40 years of age have had the disorder for lesser number of years in

proportion to their age. The struggles of Type 1 patients is not only that they are insulin dependent but they also face issues of peer pressure as they live through teenage years with the disorder, problems at work place and struggle for marriage. But Type 2 patients get the disorder when quite old and have gotten married. There is not much peer pressure as there is an expectation of sicknesses in old age. The ideas of a healthy youthful life are affected in the case of Type 1 patients.

CHAPTER 3
CONSTRUCTS OF BODY AND SELF

Almost all cultures distinguish between the body -as the material, visible -and the immaterial, invisible and intangible which we may herein call 'self'. Body has imagery, an anatomy and physicality. Body's constitution and responses have been one of the most important aspects of its study. On the other hand, 'self' has been significantly studied concerning what it is. It has been considered as soul (in religious discourse), mind (in biological and psychological discourse) and more recently located in the social context. In this chapter an attempt is made to understand the various constructions of body and self of juvenile diabetics.

Through the experiences of life, one develops a view or understanding of the world around, how it functions, and the appropriate way for one to act in the world. One builds up a sense of his/her identity, and around that identity constructs a set of values and principles that help guide the actions of life. There is faced some difficulty with people who perceive the world differently or have a differing world view. These differences bring to question the construct one (or a culture) has about how the world should operate, and how people should act in the world. These constructs are distinctive to people and cultures. One feels most at home when one is part of a social group that shares its constructs. The perceptions and actions of those whose constructs are inconsistent with our constructs, challenge us, and can cause tension and stress. Various forces and drivers in culture, such as religious beliefs and political views, are important influences that help create an individual's construct. One's construct is also influenced by the time in which one lives. For example, in the uncertainties and insecurities of war, one develops a construct that focuses on characteristics that help ensure physical and material survival. In contrast in times of abundance one tends to focus on a different set of factors. That also suggests that our constructs are not static but change with time.

While formulating the research proposal the researcher had delineated the following as a check list for understanding the constructs of body and self. These were to drawn in order to understand how religious, bio-medical and social construct view the body and also how individuals see the body; whether any one of the constructs, a combination of them or all of them but varying on the context.

- Body in terms of religious construct
- Body in terms of bio-medical constructs
- Body reflected in the terminological (the terms and analogies used for body) constructs
- Body in terms of social constructs
- Self in religious constructs
- Self in philosophical constructs
- Self in social constructs
- Self in existential constructs

The Constructs of Body

In the course of data collection and analysis it was realised that these different drivers could be seen in the light of the model given by Hughes and Lock of "Three Bodies". This was so primarily because the framework given by Hughes and Lock sees the body at three levels and these constructs can also be seen at these three levels. The bio-medical or religious or social constructs transcend beyond one level and prevail at the level of the individual and the society and also the conflict between them. That is to say, the constructs of body influenced by bio-medicine, religion, society etc. do not only influence the individual body but also the ideas of the social body and the conflicts and power struggle involved therein. Thus, in order to understand these constructs it was determined to not see them as just religious or philosophical or bio-medical constructs but rather how these constructs are seen at the level of the individual body, the social body and the body-politic.

Nancy Scheper-Hughes and Margaret M. Lock in their article "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology", discuss "three bodies". The three bodies are: the Individual body, the Social body and the Body-politic, which according to them also suggest links with theoretical approaches like Phenomenological approach, Structuralism and Symbolism, and Post-Structuralism respectively. The three bodies are also used here to study body and self in illness. Whereas the three bodies overlap sometimes at other instances we find them addressing issues that do not necessarily/strictly come under any of them. For example, the illness experience and the anatomical discussions can both be considered under the individual body whereas the anatomical discussion comparing bio-medicine to alternative medicine may highlight issues of the body-politic. Similarly a diabetic may think of his/her individual body of religious significance and on the other hand religious construct may emphasise (for the same individual) on the social body.

Similar to Hughes and Lock's model of body even 'self' can be seen as an individual self, a social self and also a self dealing with power and hegemony. The individual self may be soul (and thus personal) or mind -the thought processes as well as the talents and capabilities of one. The social self is the social identity. The social identity may be derived from work, family, peer, marriage and even religious ideas of a social body and one's place in it. Another categorisation of 'self' would be the one that faces the challenges of hegemony, confirmation and divisions of normalcy and abnormality and faces it or resists it in different ways. This is further discussed under the constructs of self.

Individual body

Body has a way of making itself heard or known. Whenever there is a shift from the regular bodily processes body calls for attention to itself. The 'symptoms' which are different from the usual become the distinguishing markers of 'something is wrong with my body'. In case of diabetes, even when other body parts are not affected, spells of dizziness, weakness etc make one know that they are not well and that their body needs attention. Statements like, *"I think diabetes people will be knowing body mechanism*

more rather than other normal people..." and "*...**being weak and couldn't climb steps** like other normal children used to, like my classmates. I used to **feel like something is pulling me down** while climbing the steps up, like that is how I **felt something is wrong** with me..."* were numerous in the narratives. The illness episodes, descriptions of fatigue or difficulties in carrying out certain activities normal to the body essentially discuss the phenomenological experiences and descriptions of the body, bodily activities, and the disabilities experienced. These narratives also suggest as if ' the body' is trying to get attention or make its discomfort known. Such episodes over a period of time enable the person to understand how body responds in different situations and when and how it needs attention. Symptoms, pain, and illness episodes are seen in other illnesses also. In the case of diabetes insulin intake and food, weight, and exercising are additional reminders of the illness and bring to light the individual body.

There was (as noticed) a hesitation to use the word 'body' while describing either one's own body or another's. Instead of using the word 'body' most respondents employed the word 'health' to refer to their bodily condition. And not only in English but also in Hindi respondents used words like '*tabiyat*' (health) and not '*sharir*' or '*badan*' or '*deh*' which mean body. While discussing the body most often mention was made not of the body but of the organs like pancreas, kidneys, heart, retina etc. That is to say, when the 'body' was mentioned it was done in terms of specific organs and not 'body' as a whole or in totality.

This also suggested bio-medical understanding and explanation considering that the respondents used the bio-medical terms for the organs and not the alternative medicine system. The 'body' was mostly referred to when respondents spoke of how they felt weak or tired. Statements like the one referred above *"...being weak...something is pulling **me** down...felt something is wrong with **me**..."* suggest reference to the body though the word 'body' is not used.

The usage of the word 'body' was mostly when the whole body was affected or the body was threatened. Since the disorder impacts only a body part directly which is pancreas (as not being able to produce insulin) one may not be conscious of the whole body as such. Until there is pain that takes control of the whole body to make one

conscious of it one does not refer to it. The word Body is found missing in discourse but hinted upon in terms of its symptoms, pains, problems, limitations, processes etc.

Symptoms

Symptoms changed bodily processes, and all that is different from what one takes for granted as the regular processes. As such it compels one to pay attention to the body. In the case of diabetes, excessive thirst and urination, weight loss, weakness, dizziness etc. are the common symptoms. (Besides there was also pancreatic inflammation or infection that cause diabetes and also are closely related to diabetes. But this shall be dealt with subsequently.) These hindered the natural or routine life of the respondents or caused discomfort and thus invited attention. The onset of these had led most of the respondents to recognise that there was some dysfunction in their body and health which led to seeking health care. The respondents were not aware of these symptoms as of diabetes but these led them to go for a test and with diagnosis they came to know that these are symptoms of diabetes. All these symptoms given of diabetes' onset were narrated most systematically. And only these symptoms, and not others, were narrated when asked how they came to know of diabetes. These symptoms the respondents remembered well and associated closely with the disorder. The knowledge of these might have come only after the explanation given by the doctor and therefore these are closely related to the disorder and other symptoms, if there were any, are overlooked or not considered.

The symptoms themselves are about the individual body, the phenomenological experiences of a person. These symptoms speak of experiences of the body that are different from the otherwise regular experiences and show how well acquainted is one with the processes of the body to determine which processes are not a part of the regular. In case of the respondents who became diabetic at an early age when they could not recognise and differentiate the irregular from the regular it was their parents who identified the irregular occurrences. (See Na.1 to Na.7)[6]

[6] Throughout the text narratives elicited through interviews and excerpts from the social networking forum have been numbered as Na. for Narratives, SNF for Social Networking Forums, and SNFD for Social Networking Forum Discussion. SNF is used when excerpts or comments from social networking forums are quoted independently. SNFD is used where a discussion from the forum is quoted.

Na.1 *"…like, in the beginning usually I felt ah…ah…a lot of weakness and slowly started losing my appetite and then started becoming very pale and weak. Then, I used to drink a lot of water. Thirst... Thirst is the main reason or key factor to know that you have…You have, more than normal thirst and you keep drinking litres of water every day. So you know, like, that was one key point and other one…being weak and couldn't climb steps like other normal children used to, like my classmates. I used to feel like something is pulling me down while climbing the steps up, like that is how I felt something is wrong with me."*

Na. 2 *"Actually I was passing urine in my bed, so my mother recognized and took me to the clinic. In the lab it was found that I've been suffering from diabetes... weight I've lost and excess of thirst. These were the symptoms."*

Na. 3 *"Mere ko chakkar aa rahe the, doctor ke paas aaye. Gir gayi thi toh hospital mein admit kar diye. Woh admit kare baad mere ko malum nahi hua. One week…doctor ne bola, 'Weak pe hai. Dudh pila do. Doodh zyada pila dena'. Phir sugar aa gaya." (I was dizzy. We went to the doctor. I fainted so they admitted me in the hospital. After admitting also did not come to know. Doctor said, 'She is weak. Give her milk to drink.' Then sugar 'came'.)*

Na. 4 *"Excess of urine, giddiness, laziness and my legs pain when I walk. Moreover I used to feel irritated, so much annoyed. I lost weight also."*

Na. 5 *"When I was fourteen years old I was seeing some symptoms-losing weight, eating more, excess of urine, water everything. So, that time I was analysed with 'junior' diabetes. So, at that time my sugar levels are also high, some 500 with fasting only and post-length 400 like that. So, that time I am admitted in NIMS hospital. Seeing my symptoms we have a*

doctor, a family doctor. So, she told to do this test- sugar test. Then I got to know that I have…"

Na. 6 *"Mujhe chakka aa rahe the, vaise hi. Thoda dhundla-dhundla nazar aa raha tha. Gussa zyada aa raha tha. Tab college mein bhook zyada lagti thi. Us ke baad pata chala toh…ek mahine tak aise chal raha tha. Us ke baad ek dum se test karaya, mummy ke kehne pe. Nikal aaya. Bas." (I was getting dizzy, just like that. I was seeing things a little blurred. Was getting angry quickly. That time in college, I used to feel very hungry. After that came to know...for one month it went on like that. After that got the test done, just like that, on mummy's insistence. It came out. That is all.)*

Na. 7 *"Exams likhne ke time pe. Exams…exams, first mein fail ho gaya. Phir second time dene laga toh likh nahi saka. Tabiyat kharab ho gayi. Chakkar aata tha, haath-paira kanpte the. Us samay mein, haa wajan kum hua tha. Pyaas toh bahut lagti thi. Jabaan bahut sukhti thi. Main zyada pani pita tha. Phir daddy laye mere ko yahan par, Doctor sahab ko aake dikhaye. Unhe insulin dena shuru kare..."*
(At the time of writing exams...the first time I failed. Then second time when I went could not write. 'Health got spoilt'. I used to get dizzy. Hands and legs used to tremble. At that time, yes, I lost weight. I used to feel very thirsty. The tongue used to get parched. I used to drink a lot of water. Then daddy brought me here and showed me to the doctor. He started giving insulin...)

All the respondents were undergoing bio-medical treatment. The mention of pancreas, insulin, kidneys, heart, retina etc suggested bio-medical understanding of the body or at least the bodily condition. Almost all respondents while mentioning their symptoms referred to only the medical symptoms but situated these in the context of their life-history. Respondents most clearly remembered the chronology of symptoms and bodily changes that they went through, consultation with the doctor and if there were any complications. These details were marked either with dates or with other life-events.

There needs to be made a distinction between symptoms and medical symptoms. Medical symptoms are symptoms recognised by the medical practitioners as associated with diabetes and are part of their medical knowledge or education. Symptoms, on the other hand, mean the symptoms that the respondents experienced that led them to seek health care. Respondents had systematically narrated the medical symptoms. That is to say that the symptoms that were not recognised by the medical practitioners were downplayed and the symptoms retained by the respondents and narrated to the researcher are incidentally the medical symptoms.

In the cases given below (Na. 8 to Na. 11), the respondents had come to know of diabetes at the time of their pregnancy. They talk about symptoms that are not associated with diabetes but they are the ones that made them undergo examination and find out about being a diabetic and that is why they find place in the illness narrative. It is not necessary that a respondent give only those symptoms that are related to their ailment but also those that remind them of the ailment or rather all those that are associated with illness experience. Like for instance all those experiences that led them to discover their having diabetes or aggravated their diabetes or which they believe caused diabetes find a place in their narratives. The female respondents thus narrated the non-medical symptoms or the symptoms not related to diabetes. Also they sometimes do not narrate symptoms at all but the life event that marked the onset of the disorder. Their narrative signifies pregnancy and miscarriage over the medical symptoms and even other symptoms. For the other respondents the symptoms are remembered as they had created a disruption in their 'normal' life whereas for the women respondents who had suffered at the time of pregnancy and had miscarriages the disruption in pregnancy, and reproductive health became more important and closely associated with diabetes. In their memory the non-medical and pregnancy related symptoms were more prominent and closely related to the disorder. Narratives highlight what is important to the narrator. For these women respondents the more important experience, worthy to be narrated, was their pregnancy and child-birth rather than other symptoms, even the onset of a disorder like diabetes.

Na. 8 *"Actually when I was 5 months pregnant I got cold and cough and all. It was not…with any medicines it was not reducing. So, I had no*

diabetic symptom or anything. The doctor told to check up for diabetes also. At the time of examine I came to know I am diabetic."

Na. 9 *"Vomiting ka aata tha. Bahut vomitings hoti thi. Paani piye toh bhi nahi chalta. Pet mein nahi pachta tha. Delivery tak main vomiting kartich rahi." (I used to vomit. I used to vomit a lot. Even water would not stay. It would not get digested. Till delivery I kept vomiting.)*

Na. 10 *"In the last month moment delivery time…nine month mein check up ke liye aaye the hospital ko tab (in the ninth month came to hospital for check up that time) movement was not there, baby's movement and she checked once. Starting also I did sugar test that time sugar is not there. Last moment it was attacked. Baby was died in the…stomach. On that time came to know that sugar is there."*

Na. 11 *"Mere ko periods pain aata tha. Gaye…doctor ke paas gayi toh bole thoda uterus ka karvao. Check kar liye. Tab se hi diabetes ho gaya." (I used to get pain at the time of period. I went to doctor and doctor told to get uterus tested. We got it checked. Since then only diabetes 'came'.)*

The symptoms made the respondents aware about their bodies and these symptoms also act as reminders and warnings in everyday life that the body is facing difficulty. Respondents have also become adapted to the changed bodily procedures in the sense of being able to understand what a particular bodily condition demands (Na. 12, Na. 13)

Na. 12 *"Now I feel when I get low sugar, hypoglycemic attack, feel like sudden weakness. I can sense it. I can't express it in words but I can sense it. So, then I immediately return to some sweet stuff like glucose or juice and carbohydrates diet immediately. Then later when I get high sugar, in high sugar feel lot of thirst again. Then that is basically because of*

sodium-potassium imbalance. And then I start feeling weak. Then sometimes I have oedemas (?) swelling of the palms and foot. That is how I can make…And I also have some kind of taste which I get in my mouth. So I can immediately make out. And I immediately go for a blood sugar testing with my glucometer. That is how I make out whether I am hypoglycemic."

Na. 13 *"Thoda takleef hota hai. Body mein bas itna hi hai…sugar badh jaati hai toh ek dum se gussa aata hai. Woh ek hi cheeze hai. Aur bhook kabhi bhi lagti hai, kahin bhi lagti hai. Kabhi bhi bathroom aajata hai." (I used to have a little problem. In the body only that...if sugar increases immediately I get angry. Only that one thing is there. And feel hungry anytime, anywhere. Anytime I need to urinate.)*

Those who had suffered pancreatic inflammation or infection leading to diabetes discussed about the pain and the experience of being hospitalised. For them these two- the pain in lower abdomen and the diagnosis of pancreatic inflammation- are closely related to their earliest memories of being diagnosed as diabetic. For these respondents the pain was so severe that all other symptoms are not that significant (Na. 14). Other symptoms like excessive thirst, frequent urination, weight loss were only reported when probed for. For these respondents dizziness, weakness and others are mentioned referring to subsequent illness episodes. This attribution is due to the fact that they suffered intense pain and were hospitalised. Thus, pain to the body clouded other discomforts or symptoms of the disorder. It is the pain that made them more aware of their bodily state and the need to take care.

Na. 14 *"Actually when I was in VII class I got pancreas infection. That time they admitted me, severe stomach pain. They admitted me [for] one week. After one year again, in VIII class, I again got same pancreas infection. But no one told me that you will get diabetes if pancreas are not*

working. In the IX class I got to know that it was diabetes and they told that the pancreas, if get infected, then you can get diabetes."

Symptoms like dizziness, weakness that are warning signals of hyper or hypo glycaemia are well recognised by all the respondents and they remain very vigilant for any of these signs. They also notice minor injuries, cuts and even simple cold and cough taking more time to heal (Na. 15). They recognise these as manifestations of their diabetic condition. Aware of the possibility of varied complications in the future most respondents are very careful and take precautionary measures.

Na. 15 *"See in diabetes whatever the problem you get fever also that might directly impact your diabetes, your sugar level. So, some or the other way, whatever the problem be physically that also some or the other way is linked to diabetes. You put…always have in mind that there is something which is abnormal to you which is not there with others. So you need to be always extra cautious. And two three situations I had because of Hyperglycemia and because of…actually summer I used to get this rashes on my body. Because of this two times I was admitted in hospital. And my sugar levels got shoot up."*

Though the respondents do not refer to the term 'body' but the consciousness of the body in protecting it is reflected in other contexts like the pain endured and other compulsions that are followed in order to protect the body. Insulin intake is another everyday reminder for the respondents of their diabetic condition. Injecting caused pain at least initially and for some it took a long time to get used to it even to inject themselves correctly. One must also remember where they have injected themselves last, like on the thigh or arm or stomach etc., for one must not inject in the same place all the time but keep changing the point. Eventually, when one gets used to or habituated to injecting oneself twice or thrice every day, there is an acceptance of the pinching pain to the body and willingness to suffer this pain of injecting oneself everyday to protect the body from

suffering worse situations. Thus, the pain of injecting insulin becomes acceptable and a part of everyday life. (Na. 16 to Na. 18)

> ***Na. 16*** *"...Main khud hi lena shuru kiya. Ek-do baar doctor sahab bataye the phir khud liya toh takleef hota tha. Ho jaata hai kabhi-kabhi galat ho jaata hai. Kabhi-kabhi nas mein chala jata hai. Toh phir khoon nikalta hai.... Abhi generally chal raha hai. Haath mein le leta hoon, pet mein le leta hoon, thigh mein le leta hoon. Aadat ho gayi hai. Insulin…abhi aisa kuch nahi hai. Haa jab baher jaata hoon tab thodi problem aati hai." (I started by myself. Once or twice doctor sahib told then I when I took it used to hurt. It happens, sometimes it goes wrong. Sometimes it goes in veins. Then it bleeds...Right now it is going on generally. Sometimes I take it in the arm, sometimes in the stomach, sometimes in the thigh. I have become habituated. Insulin... Now nothing as such. Yes, when I go out I face a little problem.)*

> ***Na. 17*** *"Initially we went to a doctor for three months. Then that doctor told it is a life-long business so someone needs to take care of that. So, my mother learnt to give me injection. After, from my mother, I learnt. Now I am only taking."*

> ***Na. 18*** *"...actually in the initial days I don't know what that is also. During that time only I started taking insulin so, now a days….actually that has become a part of my life…Nothing special."*

Even when a child was too small to understand what was going on, what was wrong with his/her body and the implications of it, the daily injecting of insulin, spells of dizziness brought to the forefront the needs of the body. At times this very pain and suffering were also deliberately avoided or covered to assert that nothing was wrong or to not allow anything in the way of leading a 'normal' life. When pain is avoided it is linked

to the 'self'. It is like the body is under pain but "*nothing is abnormal with me*". (Na. 19, Na. 20)

> ***Na. 19*** *"I didn't take it very bad as well as far as I can remember. My father explained me well and I accepted it,* ***although the needles did hurt a lot*** *then since I was very young and the needles at that time were thick."*

> ***Na. 20*** *"Initially yes (injecting was uncomfortable) because I have to poke myself every day. But then in two months I got used to it...I just used to stab myself and then carry on..."*

Mention of the medical body finds acceptance in the social realm. That is to say, respondents talk more about their internal organs rather than the surface body while talking about their bodies (Na. 21 to Na. 24). They would only talk of pancreas, insulin, kidney, heart, eyes or pain, weakness, dizziness. Explaining body conditions or illness referring to bio-medical categories in a way depersonalises the body in the sense that one does not necessarily need to think of his/her own pancreas while describing the problem. It is an organ inside them which they have not seen and have not the need to think consciously about. Rather issues of food, lifestyle and visible symptoms become important.

> ***Na. 21*** *"When Beta cells of pancreas…when it does not function or it functions improperly or stops functioning completely then that condition is called diabetes."*

> ***Na. 22*** *"...It generally occurs after few months, after diabetic is detected, and your pancreas produce normal insulin for some time. Almost all alternative medicines I tried were of no use."*

> ***Na. 23*** *"Will be getting heart problems and kidney will be affected and more over eyes may get damaged."*

> ***Na. 24*** *"Because insulin level is low in the body that is why… Insulin helps in glucose level."*

And also the processes of the dysfunction are related to internal organs and hardly show any outward manifestation. These two -pain and processes are apparent in the case of disability and chronic diseases like cancer and HIV. Therein the body is talked of much in terms of its pain and processes (as discussed in the Introduction chapter). Wherein in the case of diabetes though the blood which flows throughout the body lacks insulin and this condition impacts the whole body one does not become conscious of the body. The effect of this on each organ is seen separately until and unless multiple organs are affected or there arises a critical health condition. For instance, if there is an eye problem the respondent thinks of his/her eye and health and not of the whole body and the processes involved. And if internal organs like kidney and heart are involved many a times the person comes to know only when they are faced with complications. It is only when the disorder leads to many diseases or affects many organs that one starts to think about the 'body' (Na. 25 to Na. 27). Viewing only individual organs as affected is because an acknowledgement of the bigger problem would affect one's idea of one's self and identity. One would then have to accept being a sick person and not just a person with some problem.

> ***Na. 25*** *"In 2007 I got admitted because of …yes my feet started swelling. I mean actually my* ***entire body*** *was bloated. So, that's when they said this could be a possible* ***kidney disorder*** *because of diabetes. So, one followed the other. The kidney problem started and then the* ***eye problem*** *started and that is when I started taking this a little seriously."*

> ***Na. 26*** *"Yeah. Yes it does. Because of the side effects that I am getting now. My eyes, my kidneys... I have internal bleeding in my eyes so I can't see sometimes so it's literally like I can see but I am blind. I can't see things clearly. If it's too bright I can't see and of course I can't come to my office regularly because of this problem I keep taking leave. Every month…even in the last 4-5 months I have had more than 20 laser treatments. So, it definitely hampers my…but it like what I said it's all my doing. I chose to ignore it and now I am paying for it."*

Na. 27 *"Nothing changed. Like I am normally only... Like diabetes means for that no problem but if some infection comes...suppose cold. It won't be easily controlled. Infection won't be controlled. It takes a lot of time. That is the main problem."*

Food

Food is a very important aspect of a diabetic life. More is a problem and less is dangerous. What to eat, how much to eat and when to eat are questions a diabetic cannot overlook and has to answer in the course of everyday life. When narrating what all has changed in their life since the onset of diabetes almost all the respondents speak about food and the change in their diet. Many also stated that it was the restrictions in food and especially prohibition to eat sweets that they missed the most of their pre-diabetic life. That is how also they differentiate between themselves and the 'normal' people saying that a 'normal' person can eat anything without having to worry or 'normal' people eat anything without being cautious of the calorie intake and how it is affecting their health otherwise. Whereas sometimes respondents feel bad that they cannot eat what they want, at other times they state as to how they have better eating habits and thus are leading healthier lives than the 'normal' people. To be able to eat anything and in any amount is what is considered 'normal' and when a person has to ration out food and exercise many restrictions it is a constant reminder of sickness (Na. 28, Na. 29). But, here we find the same argument used by the respondents to rationalise how with the restriction on food they are able to maintain a healthier lifestyle and are better than the 'normal' people. This point is given not only to the researcher but is also an assertion the respondents made to themselves which also helped them adapt themselves to the new lifestyle and follow the restrictions of the diet (Na. 30). Even at the time of other illness episodes one does differentiate between the foods that can be eaten and those prohibited. But, in a chronic ailment like diabetes there are life-long restrictions, and also very strict discipline about food. These restrictions and the discipline are what make a diabetic feel that they are not 'normal'. Food is not just about food but also smoking and consuming liquor and we also find discussions about smoking and drinking along the same lines (Na. 31).

Na. 28 *"...first I thought diabetes means something very big disease. Then I thought that my life is waste. I thought, 'What? I should not eat chocolates or anything?' But after I thought that this is very simple. For everything there is a solution na!"*

Na. 29 *"When I suffered in hospital it all came due to diabetes only. So, I used to think, 'Abba! This diabetes came that is why I am like that. If it is used to not come then I can be normal. This urine infection wouldn't come or like all go to parties and eat ice creams but I should not eat ice creams. That time I felt like that."*

Na. 30 *"I did not really find it hard in any way and as I mentioned earlier, I just took it very well. In fact it helps me live a healthier life than many others who don't refrain from eating regular unhealthy diet. I do drink but to a limit. I eat everything but only to a level my normal injected doze permits me. I don't think of myself any different to a normal healthy person unless someone purposefully points out. I accept being a diabetic in an Indian society has been tough as everyone just thinks it's a killing disease and I don't bother to correct them as it's a deficiency not a disease."*

Na. 31 *"Enjoyment will be defined different by different people. So, how you define yourself? You…if eating sweets and other things is only enjoyment then that is a disadvantage. If you feel boozing every weekend or on occasional basis – that is enjoyment or smoking that is an enjoyment then that is a disadvantage. If you see the disadvantages as the advantages, you will be happy."*

The feeling of 'missing' foods comes because of desire and that desire has come from the culture. That is to say the very culture gives significance that one should be able to eat everything to 'enjoy' life. This makes the juvenile diabetic feel bad or 'not-normal' that they are not able to enjoy life because of not being able to eat everything. Other cultures that do not give that much emphasis on food or emphasise more upon

restrained food-habits may have different response from juvenile diabetics regarding food restrictions.

The calorie and carbohydrate count of different foods and adjusting their insulin intake accordingly is something that a diabetic must do consciously every day. Respondents have become equipped to do that and also try to find out more about how to manage their diet and balance it. Discussions on related issues were also seen among the members of the social forum. The consciousness of the disorder and diet being organised around it is not just restricted to counting the calories but also the carbohydrate intake and managing sugars etc. like in the excerpt quoted from the social forum given below (SNF-1). This understanding of food in terms of nutrition, calories, carbohydrates and relating it to the amount of insulin required clearly show forth that the bio-medical understanding of food which is overtaking the socio-cultural understanding; meaning how the ideas of what is normal and healthy is changing from being able to eat anything and everything to eating balanced, nutritious, not oily and fatty foods and being conscious of the calories etc. There is a re-socialisation from the cultural understanding to the bio-medical idea. The bio-medical system has thus far been successful in instilling bio-medical values and re-socialising juvenile diabetes within bio-medical values. The ideas of self-control of the modern body is emphasised through this. Internalisation of the 'good' values and are asserted to self again and again especially at the time of feeling temptation towards prohibited foods or in the face of the popular culture of India where people still eat what they want, how much they want.

SNF-1 *"Well yes... Doc's suggestion will be the best...*
but let me help you with something...
I think your night time insulin is not enough.... as many of us have shifted to lantus + humalog and lantus splly helps in maintaing fluctuations in blood sugar you might want to ask ur doc abt it...
Now lets help you with your carb count...
you said 2 chapatis+ veggies+ dal...
carb count = 2(12)+ 20 +20=64 carbs

I've used the carb count above on a very generic amount... so it might give you an approximate number... but if you'll consult your dietician they can give u an exact amount...
there is something called carb count to insulin ratio...
In my case my carb count ratio is 10:1 that means fopr every 10 grams of carbohydrates I take 1 unit of fast acting insulin.
So If I too ate same as ur dinner of 64 carbs I would take a 6.5 units of fast acting insulin. So this will help me cover the number of carbs I ate and then I've lantus which shall not let my BG go beyond 150 in any worst case if I happened to count my carbs wrong... so at any given time my BG is never higher than 150... that is my target and thats how i manage. Even if I happen to eat an ice cream or one of my fav sweets I count the carb and adjust my insulin according to my ratio...
But again carb to insulin ratio is very crucial and you've to see that you maintain a high carb number n a low insulin number by concentrating on exercise and a stree free lifestyle..."

Many respondents mentioned that they did eat sometimes the foods prohibited to them. Some had also suffered from rising sugar levels because and subsequently from complications. Sometimes this was just because one craved for the choice of foods one could indulge in prior to the illness, but some respondents clearly mentioned defiance to the prescribed diet. (Na. 32, Na. 33)

Na. 32 *"Then, chocolates, if I eat, my mother scolds but without her knowing her also I will eat sometimes. In school time and college time I used to eat sweets and at that time my sugar levels are also high but I will be telling my mother that my sugar levels are in control, my sugar levels are in control like that. But, we should not do like that, I got to know. Again I am suffering because of the pain. If the sugar levels are high then I will feel weak and I can't do any work also....I felt so many times like that (It is my body, I will do what I want with it.) but by that what happened is that sugar levels came high and I am not able to study, hair*

loss, everything. So, then I thought I should, I need to take care of my body."

Na. 33 *"It was for me at that point of time what I got I ate, irrespective whether I could or could not. I was aware that yes, probably it is prohibited for me. I am not supposed to eat it but I still went ahead and ate it. Like I said, I was very negligent."*

Weight and Looks

The discussion on the constructs of body especially the individual body cannot be complete without talking about the concepts of beauty and looks. The issue of looks brings the health and popular ideas of trim, slim and muscled bodies together. As Shilling has said, "Indeed, the increasingly reflexive ways in which people are relating to their bodies can be seen as one of the defining features of high modernity. Furthermore, it is the exterior territories, or surfaces, of the body that symbolize the self at a time when unprecedented value is placed on the youthful, trim and sexual body". (Shilling, 1993/2004:2-3) Popular ideas of health have come to be associated with exercising the body, maintaining fitness which is reflected in weight watch and control, muscled body and no excess fat. There is a lot of focus on the fitness and beautifulness of the body. For the diseased health is more important than beauty and takes more effort. Especially for the juvenile diabetics the ideas of beauty do not confirm with the popular social ways. Whereas the society is inclined towards weight loss and 'size zero' for juvenile diabetics being slim is not synonymous with being either healthy or beautiful especially since most of them lost a lot of weight and think that they are too thin. Also the weight loss is a symptom that is closely related to the onset of the disorder and a reminder of their diabetic condition. For most of them losing weight is not a problem rather gaining is and many of them want to put on weight. And the body maintenance, calorie count or intake are mainly to maintain health and not due to beauty. Many lost a lot of weight with the onset of the disorder and complain of very lean/slim/thin bodies. Those who recovered some weight also remember clearly how at the onset of the disorder they had lost a lot of weight and they looked sick and '*had lost (my) beauty*'. Interestingly more male

respondents were concerned about weight gain and good physique (Na. 34, Na. 35). Though the female respondents did report weight loss but they do not want to lose weight or become thin or slim either. Also the bigger issues for the female respondents are marriage and childbearing and thus they are more concerned about these than their looks. Many stated that they wanted to gain weight in spite of contrary medical advice given.

> ***Na. 34*** *"...Weight loss hua tha, Paanch-cheh kgs kea as-paas kariban kuch hua tha.... Mujhe bole ki weight mera badhna chahiye nahi kum hona chahiye. Doctor ke kehne ke anusaar. Main andar se chahta hoon ki badhna chahiye..." (I had lost weight. Approximately 5-6 kgs. I was told that I should not gain weight. According to the doctor, I should not gain weight. I want that the weight should increase.)*

> ***Na. 35*** *"..for example, if I was a normal person this would be very strong (pointing to the forearm). But here it is a little kind of elastic. It is not that elastic but it is a little loose. So I don't have that very physically fit, strong body"*

For the respondents being healthy is equated with being beautiful, and some of them talk of 'the inner beauty'. It needs to be noted that they are all thin and thereby according to the popular constructs they are slim and compared to the overweight have a good body. But, the respondents knowing their health condition consider themselves weak or too thin. And do not subscribe to the popular ideas of beauty but rather emphasise upon good health as a sign of beauty. That is to say, in spite of being thin and according to the popular notions having a good body they consider beauty to be not in thin or slim bodies but in good health which they realise they lack (SNF-2). Even for those who reported having gained weight were upset because it was affecting their health and not because they were unable to meet the popular image of what is considered beautiful or good-looking. (Na. 36 and SNF-3 to SNF- 5)

> ***SNF-2*** *"But why sometimes I think that - there is something where I am lacking, whenever sugar level is normal everything goes on fine ,in fact there is a kind of glow and cheer in my face, it feels to be in high spirits.*

But on the other hand when the sugar level goes high, all charm lustre goes out, and again a dull face appears, whenever I look at the mirror and all the confidence then goes down."

Na. 36 *"...Like I go to the gym. I work out. Because if I don't go, like last year I didn't go to the gym and I used to eat all sort of oily stuff and so my cholesterol levels were shooting high. It is like 'HPLF' which is good cholesterol was going down and 'LDL' was going high. So that is a risk factor for heart attack. So, like, I had to go to the gym and made a proper work out and brought it under the normal level. So, that is how I managed this and recent reports have shown that all the diagnostic tests are normal. So, I have no worries with that. Actually, I find that other guys who go to the gym and they work out they have very strong body like muscles because in diabetes ah...ah your muscles don't tend to build up fast because of either [they] lack or access of sugar in your body. So, it is like when you work out there is not a proper, proper stretching of the fibre, muscle fibres. So, it is like, your body, for example, if I was a normal person this would be very strong (pointing to forearm). But here it is a little kind of elastic. It is not that elastic but it is a little loose. So I don't have that very physically fit, strong body.*

SNF-3 *"...The problem here is some people like me do not have a good appeal and women will not even think about loving us. What shall we do?"* (A Juvenile diabetic on the social networking website while discussing dating)

SNF-4 *"I was concerned about as it made me look very thin. Very thin means very thin. When I saw my face, body really I felt very sorry about it. Moreover others made much comments about it. That made me much worst."*

SNF-5 *"People are much worried when they were overweight or over loss. No one try to reduce their weight if they are in proper weight with their relation to height. In my case I was over weight-loss. Actually with respect to my height my weight must be 78 kg. But during that time my weight was 62, so almost my weight was 16 kg behind. Moreover it affects my health also I felt much tired I was not able to do my regular work due to my weight loss."*

The following is a dialogue between the juvenile diabetics on the social networking website (SNFD-1). This particular discussion was termed 'Weight watch'. There is sought advice on how to gain weight from other forum members. There is an unconscious attempt to construct the idea of a healthy and good looking body and understand the ways to achieve it.

SNFD-1 a) *"Hey people how do I put on some weight?"*

b) *"Man don put on weight. thin is better than fat anyday. Once u get fat, it'll b real hard. anwz u'll put on weight as u get older, so don hurry"*

c) *"hi everybody ...im a Type 1 diabetic...dignosed 6mnths ago...ive put on about 10 kilos..i need to get it off sumhuw...cud sumone help me??plzz i reli wnt to do dis."*

d) *"dear, u seem to b very desp to lose weight. Please don resort to takin tablets, crash dietin, etc. bein a type-1 only way u can do is by doin lotsa cardio exercises(walkin, runnin, aerobics, swimmin, yoga etc) n have an active lifestyle. and eat only what is required (maintain the min calories tht ur doc has told u)."*

e) *"I m stunned to see that u ppl are putting on weight. I donno how?*
I m a diabetic for last 10 years and at that time my weight was just 48 kilos and now it is hardly 60 kgs. i.e. underweight by near 10 kgs."

f) *"Will anyone tell me how to gain weight as i m having a keen interest in*

having a good physique."

g) *"Even after doing a regular workout, i gained only a little bit of muscles, but i need some bulk too."*

h) *"I am suffering from juvenile diabetes since I was 8-9 and now I am 18, and my body is very slim. Is it 'coz of diabetes or can be sumthing else ?? if ur body is also mine type then plz tel me so i should stop worrying about it. i am even trying to gain weight but m unable to do so...."*

Similar to the justification of healthy food given by the juvenile diabetics healthy body finds much significance and justification. Regarding the looks also there are changed values among the respondents. There is an internalised idea to look good from the popular culture. The pressures of the social body do act upon them as they work on others regarding the ideas and perceptions of beauty, and good looks etc. The changed values are in terms of giving more significance to health and healthy body over beauty or looks. Also the healthy body for the juvenile diabetics is not in how it looks but the healthy functioning of their body. Also the weight-loss and thinness that the respondents had experienced was involuntary and uncontrolled. This thinning down or weight loss is distinguished from the 'managed' thin bodies of those who have voluntarily and in a controlled manner lost weight.

The idea of a trim, toned body is also a modern idea and this idea has gained considerable significance in the popular culture today. The need to confirm to the popular culture regarding looks and beauty are very much present among the juvenile diabetics. This is also reflected when being thin they want to gain weight to look good or match the idea the society has about good-looks. The male respondents being thin reported their desire to gain weight and more so muscles which they were unable to because of the disorder. For the women respondents, being slim is enough. But for the male respondents the popular perception of trim, toned body of the popular culture cannot be achieved because of the disorder. There is thus an incongruity in popular perceptions of men's body and the body of the juvenile diabetic men. For women there is no such incongruity

and thus there is no issue of resolving the situation. But women face another incongruity for childbearing and that issue becomes more important. For both -male and female respondents the issue of health became more important than good-looks. Health is a basic necessity for them whereas looking good is a luxury, which they cannot afford right now. Unlike food the popular culture is not overruled or discarded in the realm of weight and looks but the new values are prioritised. Health occupies their mind. This is also reflected in exercising.

Exercising and working out at the gym are done for good health, to control cholesterol and bring sugar under control. Yet, it does stop there. The respondent also wants to be strong and have muscles. He equates strong muscles with being physically fit and having a strong body. Exercise is another important aspect for a diabetic. Though exercising is encouraged vigorous work-out is usually not supported. Participation in sports and other vigorous activities were avoided by most but a few respondents continued to play sports or even go to the gym. For some it was because of health reasons and others due to the pressure of studies or work. Some respondents reported that they had been discouraged to play sports by family or school because of their diabetic condition even though at that point of time they were in no way facing any health problems (Na. 37). Some respondents reported that they were continuing to take up other such activities like dancing and were in no way having trouble managing their diabetes.

> ***Na. 37*** *"I remember being a good runner and I think I would have been a sporty person but at school it was not promoted as a good idea again thinking something might happen so I had to back out of competitions."*

Some respondents had to give up sports due to their sugar levels dropping constantly. Exercising was encouraged for the diabetics but not exhaustive sports. Walks and yoga were most advised and followed. It is noted that bio-medical practitioners themselves recommended yoga and some home remedies to the diabetics. We find that many respondents were either doing yoga or at least at one point had practiced yoga.

Explanatory Model

Arthur Kleinman developed the idea of explanatory models. Explanatory model is defined as the "notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman, 1980) –including the physician. The doctors acquire knowledge of health and illness, mainly through professional training in which the bio-medical model dominates. On the other hand, the respondents' notions are influenced by various sources which do not necessarily conform to the bio-medical model. The doctor-patient interaction may result in remodelling of the patients notions. Kleinman also states that EMs are different from the general beliefs about sickness and healthcare. He says "...general beliefs belong to the health ideology of the different health care sectors and exist independent of and prior to given episodes of sickness. EMs, even though they draw upon these belief systems, are marshalled in response to particular illness episodes. They are formed and employed to cope with a specific health problem, and consequently they need to be analysed in that concrete setting." (Kleinman, 1980; 106) We find something very similar here. The EMs held by the respondents are not general or pertaining to general ideas of health and sickness but are in response to the specific problem of Juvenile or Type 1 diabetes. They have come about with the onset of the disorder.

There are five elements of the explanatory model as discussed by Kleinman. They are aetiology, onset of symptoms, pathophysiology, course of sickness, and treatment. The onset of symptoms as discussed earlier, were located in the bio-medical explanation. They were combined with life history events and other symptoms were also narrated that were linked with the onset of the disorder. Pathophysiology deals with the understanding and perceptions about the processes of the body and the processes of the physiology in sickness, that is to say, physiology means the processes of the body and pathophysiology takes into account the physiology and the changes in it during an illness. For example, according to the bio-medical explanatory model the secretion of insulin in the body is normal physiology and the stopping of secretion is the patho-physiological condition in diabetes. Many respondents had talked about the stop in secretion of insulin when explaining how diabetes happens and what happens in diabetes. It was interesting

to note that not many respondents referred to other organs or any other details like blood sugar etc about the pathophysiology related to the disorder. (Na. 38, Na. 39)

> ***Na. 38*** *"...Disorder means it is science only no. That beta cells is getting damaged, and it is not able to produce insulin. It is only the disorder. So, if you are just giving early that insulin that disorder will be ordered. That's all."*

> ***Na. 39*** *"...when…if you don't keep your sugar levels normal, it will do utmost harm to you. So always keep in your mind that keep your sugar levels somewhat normal. If it fluctuates ok but constantly it should not be high."*

Course of sickness includes the degree of sickness -acute, chronic and impaired, and sick role. Type 1 Diabetes is a chronic disorder at least in the bio-medical understanding. Most respondents accepted the chronic nature of the disorder. Respondents exhibited hope in the ongoing research about the disorder to find a cure or some means that will not require a daily injecting of insulin. Most of the respondents did not take up a chronic sick-role. They insisted that they were normal only or that they were leading normal lives doing regular chores. The few who took upon the sick-role were either those who were suffering from some complications that arise out of diabetes or those who had discontinued education, and did not pursue a career or were facing problems at their career and social front. Some respondents had made statements like, *"My life got spoilt"* suggesting the severity of the disorder and its impact on their lives.

Regarding treatment respondents had tried alternative medicines with the hope that it could be cured. But when none of them helped they have pinned all their hopes on new developments in bio-medicine and are waiting for some possibility of a cure. This was stated in the interviews and also was being discussed in the forums on the social networking website. Some respondents were disappointed that bio-medicine has not yet developed a cure for the disorder. One respondent (Na. 40) stated that there was available a pump which can be placed inside the body and would secrete insulin into blood. Her

statement, "...***we will not even know that we have diabetics"*** suggests that she sees this as the closest cure for the disorder. The disorder would remain but she would not need to be consciously aware of its presence.

> ***Na. 40*** *"That some insulin pump came it seems. Have you heard about it? That in America some doctors, they gave. Doctor told... We are thinking to get that pump next month. It will take directly to the body. It is placed inside the body and if we keep it will automatically take insulin and* ***we will not even know that we have diabetics****...It is a very nice thing. It is better. It will automatically inject foods and sweets also it will digest..."*

Respondents spoke of the lack of insulin and incapability of body to produce insulin as the cause of diabetes. Only few mentioned the malfunction or dysfunction of pancreas. Only one respondent differentiated between what happens in diabetes and why it happens (pancreas vs. genes, obesity etc) Respondents nevertheless did talk about heart, kidneys, eyes etc getting affected because of diabetes. They said that the doctor had explained to them the reason for their medical condition but most of them could not remember it. Some of the narratives are given below (Na. 41 to Na. 47).

> ***Na. 41*** *"Haa. Batayaa tha. Actually aisa batayaa nahi kyun hota hai. Pancreatic cells kaam nahi karne ki wajah se hota hai bataya." (Yes. [He] told. Actually he did not tell why it happens. He told that it happens because of pancreatic cells not working.)*

> ***Na. 42*** *"Mujhe diabetes kyun hua? Can't say. I think ki mummy ko tha isliye mujhe hua. Main sochta hoon. Baki main shuru se exercise vaghaira karta tha. At that time main school mein sixth yaa seventh class se, jabse hi main exercise vaghaira karta tha... Fit tha ek dum."(Why did diabetes happen to me? Can't say. I think because mummy had it that is why it happened to me. That is what I think. Otherwise earlier I used to exercise etc. At that time, when I was in sixth or seventh class in the school from then I used to exercise.... I was absolutely fit.)*

> ***Na. 43*** *"I used to scold God also that you gave me this disease."*

Na. 44 *"I don't know. Maybe I have eaten a lot of oily foods outside studying. Because, if we eat lot of oily stuff while studying we will be getting diabetes. I ate a lot of outside food. Yes, in the beginning I got (angry with God), but it is my fate I think.... But my mother believes. She says, she has done some sins that is why it has come to her daughter. And that is the cause my daughter has to suffer.... Whatever sins I have committed this is the going punishment. Next life will be good."*

Na. 45 *"Kuch mistake nahi kiye the. Main tho socha tha magar kuch nahi hai." (I had not made any mistakes. I thought but, there is nothing.)*

Na. 46 *"That actually hereditary na. Hereditary…So it is my what…my father's elder brother is having. So might be that is one of the reasons. Otherwise maybe I am some what…To me…to me it was destined so I got…so…May be God gave me an opportunity to prove with this disorder also you can prove, you can lead a good life, you can achieve so many things."*

Na. 47 *"Actually as per Bible and all this disease is coming due to the problem of devil only. Devil only is creating this sin…disease. And once disease comes means it will become where it will turn one to God. So, in my knowledge it is in the plan of God. This disease came for me. To me and to my family…Maybe the disease will be, not will be, might be a divine plan. I am thinking like that."*

The bio-medical aetiology or cause is not known by most of the respondents. The cause is not known because both the doctor as well as the patients feel it is not significant to know the cause (Na. 48). The doctor had explained to the diabetics how it happens as well as what happens in diabetes but not why. This is perhaps because bio-medicine is still researching the exact reasons behind type 1 diabetes, and moreover, the ideas of bio-medical knowledge remain esoteric in nature. Though the cause of diabetes is not explained but the consequences are considered as very important by both -the

patient as well as the provider. Thus, the consequences are very clearly explained by the doctor to the patients in order to ensure adherence.

> ***Na. 48*** *"During some situations it will come na. "Why, why it has come to me?" "Why all this…" "Ok. I am not ok," all this will come. But it is a childish thing. In some particular moments in our life it will come. It used to come to me also. But now I …it…now I am adjusted to it…to that condition. I am a diabetic. "Why it has come?" means it is a meaningless question. It already happened. If I am asking also it will be no use. Now I am not at all worried. But earlier, during that earlier stage it used to come. That's all. Earlier…now it is not. The query is meaningless."*

The bio-medical cause is not known but there seems to be many times a combination of factors leading to the disorder in the understanding of the respondents (as the narratives Na. 41 to Na. 47 discussed earlier show). They see the causes as hereditary or eating oily foods or too much sugar and these are combined with religious reasons of fate, destiny, karma, punishment from God or the work of devil. These explanations co-exist without any conflict especially with the consequences, and the treatment. Probably, this is due to the world view where one believes that there are two worlds one physical and the other spiritual. The spiritual affects the physical and thereby they locate the causes in both physical and spiritual or religious realms. And, whatever may be the cause- even supernatural- what one can do is only take care of the body and work towards a cure and if that is not possible to keep the body as healthy as possible. Sometimes when the respondents said that they do not know why they got this disorder they are searching for a reason that is non-medical. It seems that if they can somehow locate that reason then they can also take control of the cure. The supernatural explanation also suggests "*I am not responsible for my sickness*" in the sense of any immoral or irresponsible behaviour that may have led to the disorder. Taking such responsibility is to deny moral and social support from the society. Not being responsible for the disorder and seeing the reason or cause lie elsewhere one can expect moral and social support and at least sympathy from the people. Therefore, since they cannot take responsibility the supernatural causes are appropriated.

The disorder is also seen as having psychological effects that is the disorder also affects the mind. Most respondents said that good health is in the body and also in the mind (Na. 49, Na. 50). For some it extends also to the soul (Na. 51). One reason is that because of stress when sugar levels go high these respondents suffer or have suffered. They thus recognise a connection between the two. This also suggests the impact of the growing significance of psychiatry in the medical understanding of the respondents, and also influence of the models suggested by alternative medicine. The explanatory Model of the respondents is thus influenced by more factors than one and is usually a combination of different explanations. If not, then at least there is an acceptance of the other medicine systems being able to help and are not seen in contradiction with bio-medicine (Na. 52). These medicine systems are seen as scientific and yet natural, and not doing any harm to the body. If they are not adhered to it is because the respondents realise their dependence on taking insulin which these other medicine systems do not offer.

> ***Na. 49*** *"Long term diabetes affects both body and mind. You can get nerve damages, organ failures and many numerous diseases. And all this will create distraction."*

> ***Na. 50*** *"Health definitely affects mind and body. If you take good care of your diet, do a bit of exercise, sleep well, your mind really responds well. Unhealthy body makes your mind dull and also effects how positive you are about life."*

> ***Na. 51*** *"Healthy body according to me is the complete state of an individual being physically and mentally and emotionally stable... As I have already mentioned health is a combination of mind, body and soul. Yes, it certainly reflects my mind along with body since it is a combination factor. It is after all the normal human nature of suffering. I told it is a combination of the 3 factors which is essential for an individual to feel in a state of well being it is a concept based on/derived from holistic*

medicine. There is no health in soul but always there is soul involved in a person's health."(A Medicine student)

Na. 52 *"...Ok. Yes, if, I don't think that if people are going there (referring to alternative medicine) again and again with recommendations to other people.... It must have worked for them. It could be anything why it worked. But it worked for them. It has to have some logic why it's worked and the only thing I would relate to is science in its own way. Its different angles probably but nothing to do with religion I believe. No spiritual stuff. I have read articles and I've seen the way Ayurveda works. Probably in the end everything burns down to we are working on the same mechanism but probably looking at things from a different angle. If you, say use turmeric for so and so thing. It is an antiseptic you are using and probably you are using it in a different angle also. So, that's the way I look at it."*

All the respondents were taking bio-medical/allopathic treatment but some of them had tried alternative medicines as well. Whereas some reported that they had tried only ayurveda or homeopathy there were a few who had tried naturopathy, unani, and even *rudrakash* (magic beads) treatment. All these had been of no avail. Respondents reported how these medical systems do not do any harm as they are 'natural' but they are ineffective for juvenile diabetes which requires regular, monitored intake of insulin. They spoke of their body giving a reference of bio-medical anatomy and interestingly almost all the respondents knew about the precautions and the requirements of the treatment and were complying with it. Of the five issues of explanatory model discussed by Kleinman of aetiology, onset of symptoms, patho-physiology, course of sickness, and treatment, we find adherence to all (with the bio-medical explanation) except an understanding of aetiology. This suggests that though the respondents may not understand the aetiology but they follow the treatment as it benefits them. Suggesting that there is focus on cure and not causation. It is pertinent here to note two important points. One, it is not that the respondents have a clear understanding of and firm belief in any one medical system but

the bio-medical system seems to be the prime one. This could be since they are all taking bio-medical treatment and also bio-medicine has become the leading medical system. Secondly, though they do not understand the allopathic explanation of their disorder completely yet they are complying with the treatment as this alone has been able to help their health condition. It could be because understanding causation or diagnosing a disease, especially in bio-medicine' is a highly specialised discipline and it is considered to be the job of specialists. Hence, the respondents focus more on cure as they feel in control or that it (the cure and their body) is in their hands. This could also be affirmed as the respondents had tried alternative medicine while continuing to intake insulin. This pointed out how for them relief and cure are the ultimate aim and they are willing to try any and/or all possibilities for gaining that.

As stated earlier most respondents referred to the bio-medical EM while explaining why the disorder occurs. But detailed understanding was limited to those either medicine students or those pursuing higher education like research even though in non-medical subjects. Whereas the other respondents talked of the bio-medical anatomy, the respondents who are medical students or pursuing research (in other subjects like chemistry) talked in terms of genes, mutation, beta cells etc. For the medicine students it is more so since they are studying bio-medicine. The explanation and the use of technical terms also convey their specialised knowledge. The narratives of the respondents with high education also reflected more detailed knowledge of and belief in the bio-medical explanations of the disorder. (Na. 53 to Na. 55)

> ***Na. 53*** *"Well there is absolutely no history of diabetes in my family tree though I have an aunt and uncle and now even my mom recently diagnosed with diabetes which I think is highly negligible to say that it is an* ***acquired hereditary disorder****. As far as* ***genetics*** *is considered it basically because of the* ***mutated gene in the islet cells of pancreas*** *that caused a permanent damage inhibiting the normal production and* ***synthesis of beta cells*** *that produce insulin...."*

Na. 54 *"NO, it is for sure not advisable for diabetic men to marry diabetic women the main reason being if we make a* ***genetic mapping of the gene expression*** *it will show that 3 out of 4 children will suffer from diabetes which is genetically inherited. But, if the male is diabetic and woman is non-diabetic it will show that there is no risk of diabetes in any children except that the female child is* ***carrier of the disorder****. So, the disorder is not expressed rather it is suppressed because it is carried as a part of* ***autosomal recessive gene****."*

Na. 55 *"Basically DM (Diabetes Mellitus) is caused due to* ***impaired metabolic processes*** *that could be caused by a number of factors the most common among them being life style changes, hereditary, concerns like pancreatic stones etc. But my case can be probably categorized under my life style that triggered my whole life the reason why I personally feel that I got diabetes is because of 3 cups of coffee with excess sugar that caused complete destruction and wash out of my beta cells that produce insulin. What I feel is that when excess sugars taken with caffeine can cause extreme fluctuations in the blood glucose level causing a change in the* ***DNA sequence of the beta cells*** *that has lead to* ***mutation of the cell growth****. So, my sincere advice to all young guys and gals would be to stop being a coffee freak with excess sugars."*

Future Complications and Body

Diabetes is a disorder which can lead to many complications and diseases. The possibility of future complications also makes one conscious of the individual body. Uncontrolled diabetes can adversely affect the eyes, heart, kidneys, legs etc. leading to loss of vision, increased risks for heart and kidney failure, and gangrene and amputation. All the respondents were aware of these complications. Some of them were already suffering some complications of eyes and kidneys which had made them more conscious towards their body and careful towards other complications. In general the respondents reported that they were careful about their health so that they do not suffer from any of

these consequences of uncontrolled sugar. They avoided the proscribed foods because they knew that if they indulge now they will have to suffer the consequences later. It is not just a fear of pain or inconvenience but the fear about the health of the body in totality, and of the body getting damaged. Fear of problems in the future had made the respondents take care of their body. But, the type of care and approach towards life varies depending on whether the respondent has type 1 or type 2 diabetes. Differences between type 1 and type 2 diabetics viewing their individual body, health, complications and death are clear. More type 2 diabetics on their own talked of death and their 'time being near' or even talked of having lived a very fulfilling life. On the other hand among the type 1 diabetics some did confess having fear of amputation and death but most of them stated that they were young and in control and had no reason to fear these (Na. 56 to Na. 59). Interestingly it is their being young and having diabetes which is the reason for most difficulties in their lives and has upset their social standing as 'normal'. So, may be to some extent they have control over their lives though not being 'normal' whereas for type 2 diabetics the sickness is normal and has only one conclusion varying only in degree and time. Thus, control of the body in the present is very important to prevent future complications.

> ***Na. 56*** *"Yes I have feared amputations and that is the reason I really try to keep my levels under control."*

> ***Na. 57*** *"Scares me…as of now as I am young so there is no problem for me, like you will find me physically fit and active. But I don't know about the future. Future complications like for me it is ok. I am studying medicine so I am aware of it. I can also manage myself. Keep my sugar levels within the normal range. But for the others I feel like, even including myself if I don't take care, I feel I can cause further complications like failure of organs, leg amputations as I have already told, and things like that. And it can cause major problems like diabetic retinopathy, nephropathy. Sugar levels have to be always maintained within the normal range."*

Na. 58 *"...Yes. I do. If I am not, consequences will be severe. That makes me constantly conscious about diabetic because of fear and future loss, much more about my family welfare I need to be conscious about it."*

Na. 59 *"I am not unhealthy nor very* ***old*** *so never felt and hopefully will never."*

For the female respondents the issues of reproduction, sexuality and pregnancy are some additional issues that create anxiety. Though even male respondents faced rejection at the time of marriage proposals more female respondents expressed worries about difficulties in conceiving and child-bearing. The male diabetics are possibly rejected because they are perceived to be inept providers for their family which is expected role for a man. For the women one of the expectations of their gender role is bearing children. Motherhood is considered essential to prove womanhood and thus it becomes their greatest concern when that is threatened (SNFD-2). For the male respondents they struggle with the ideas of strong, fit, healthy providers that society prescribes for men (Na. 60).

SNFD-2 a) *"...what about diabetic girls...do they also have healthy offspring...healthy in the sense not diabetic or non diabetic...healthy in general...being pregnant ,controlling sugar levels and then healing after delivery...sounds scary."*

b) *"Yes, sometimes I think it is different that I could marry and if I marry how my child will be born. Like that I used to think."*

c) *"What kind of precautions the woman of type-I diabetes, should take to give birth to healthy child????How much effect will occur on the child if the sugar of woman is fluctuating frequently during pregnancy?"*

d) *"...Whether the diabetic woman can give birth normally or she undergoes strictly through Operation????? Due to lots of blood comes out of body during delivery, in what way it will affect to me???"*

Na. 60 *"My idea is that…there is a notion that diabetes people are not that much healthy. It is true. It is right somewhat. And it true also because they are prone to all disease. Maybe if ... one cut is coming it will take more time and if correct time medicine is not there they will be weak. If correct time food is not there they will be. All heart attack it can come early. This eye disease, kidney disease all these things can come. And in later stage any cuts and wounds are coming then it means we may have to remove one leg or hand like that. Who will give…who will consider all these things and get or give their daughter for marriage. "What is the need of taking a risk?" They will think, like that. In this universe, in this world lot of healthy people are there, good people will be there. What is the need of taking risk. They will think like that. It is right. So, from their experience they might think diabetes people are somewhat weak. They are not that much strong. They will not be able to lead a that much powerful, healthy family life. He, a person with diabetes will not be able to lead his family as the head of the family. He will not be a complete success. There is a…Anyway it is not…If diabetes or any disease…any other disease. If he is having asthma, if he is having any other disease, is a person with a disease, any disease. Diabetes or anything. That is the same."*

Social Body

Individual bodies live in a society and the society makes the individual body comprehensible. Especially the ideas of health, illness, healthy bodies, good looks or physique are socially constructed, communicated and upheld. "Illnesses have both bio-medical and experiential dimensions. Although often unnoticed or taken for granted, certain illnesses have particular social or cultural meanings attributed to them. These

meanings adhere to the illness and may have independent consequences on patients and health care. Cultural analysts point out that illnesses also may have metaphorical connotations. Susan Sontag (1978), for example, argued that negative metaphorical meanings of cancer, as evil or repressive, are common in our society and significantly impact those afflicted with the disease. Similarly, Barry et al. (2009) examined how obesity metaphors, such as "obesity as sinful" (gluttony), affect individuals' support for different public policies aimed at reducing obesity....all illnesses are not the same. For instance, some illnesses are stigmatized, and others are not; some are contested, and others are not; and some are considered disabilities, while others are not. What is important about these distinctions is that they exist for social rather than purely biological reasons." (Conrad and Barker, 2010:S69)

Though it is not easy to see the constructions of illness influenced by the Social Body but the relationship can be seen in the individual's perception of illness and individual construction of illness. Hughes and Lock (1998) under the social body also discuss the issues of symbolic representations and parallels drawn between body and society and technological developments, embodiment of the world, body's relation with social relations etc. (discussed also in Chapter 1) that show forth the social constructions of body, health, illness, beauty etc.

Hughes and Lock (1998) alleged that in non-western societies there is a tendency to understand body in terms of the natural world around them and to understand the natural world in terms of the body. They say "We could multiply by the dozens ethnographic illustrations of the symbolic uses of the human body in classifying and "humanizing" natural phenomena, human artifacts, animals, and topography...In such essentially monistic and humanistic cosmologies as these, principles of separation and fusion, imminence and transcendence influence interpretations of illness and the practice of healing" (Hughes and Lock, 1998: 216). This particular research does not witness any embodiment of the natural world. It is possibly because the respondents all live in urban areas and do not draw parallels between the natural world and their bodies. There is not much closeness between the lives of the respondents and nature leading to any 'humanizing' or embodiment of nature. In that case it was interesting to inquire whether

there was any embodiment of the urban world, like embodiment of the city space. We do not see an embodiment of the city space (like roads or traffic or sanitary system or electricity or the way a city is organised and functions etc) either but there is seen in many narratives parallels drawn between body and health with machinery, war, destruction, and genetic make-up. Terms become prominent due to cultural or historical situations and these terms get absorbed into a vocabulary. These terms thence get used in different situations and contexts and thus acquire popularity as well as are used in contexts different from what they are introduced in. For example usages like anti-bodies **fight** antigens; germs **attack** the body; anti-bodies **protect** the body; infectious **agent** etc use terms that are essentially war terminologies. Similarly, the usage of the term 'labour' and 'deliver' with regard to giving birth entered the vocabulary of the people with the ideas of production and Marxism upholding child-bearing as productive and important for society. These terms are adopted at times as they are considered to appropriately describe the phenomena. Some of the narratives (Na. 61, Na. 62) highlighting the usage of different terms are given below.

> ***Na. 61*** *"To achieve my final dream I need to* ***fight*** *this. Because if I can keep the balance between my professional and my this health then only I can…That is what actually is the disorder. That is actually I can say I have something deficiency or whatever you may call it. Other people need to* ***fight*** *only professional or whatever but I* ***fight*** *my own health care and this also. I need to balance…keep the balance then only I can…****hit the target****...*

> ***Na. 62*** *"...So, whatever the problem or whatever you are having how…how do you* ***fight*** *with that and how you adjust to that, that is more important....I will tell you the final thing. I am* ***fighting*** *a lost* ***battle****. Ok? But…I will* ***fight*** *until I* ***lose*** *the* ***battle****, na? Till the date I am there I will* ***fight****, like that. I know some or the other day…I might be someday…Until then I will hold on. I will…I am thinking that way....Means, I know my problem. After knowing my body is having a disease some or the other day*

*all these problems might **attack** at a time or one after the other. So, some or the other day everyone will **lose** their **battle** here. At least until then I would like…Before that I need to…I need not **lose**."*

The usage of certain terms indicates something specific that the individual is stating about his/her situation. Like the ideas of fighting, fighting a battle, hit the target, and about losing and winning suggest the struggle the respondent feels he is undergoing. At one level he wants to 'hit the target' and overcome the struggle that he is facing in his life and on the other hand he acknowledges death as invincible and that he cannot win this but will fight till he loses.

The following narrative (Na. 63) highlights the educational and professional orientation of the respondent, trained as an engineer, brought forth by his usage of terms like engine, fuel etc. and the explanation of the disorder and body-mechanism along those lines.

Na. 63 *"In our mechanical line, suppose there is **engine** and **fuel supply**. **Fuel** is there **engine** is on. **Fuel** is not there **engine** will definitely stop. Suppose if we mix water in the **fuel**, even then it works. It works. But you don't know when it will stop. So in this suppose if real **fuel** is over and only water is left even though it is water the **engine** will go on. Then it will stop. So, here what happened…One more example, in engineering terms it is a **system failure**. Diabetes is nothing but **system failure**. God has given us a **system** we have **broken** that **system. System failure** in the sense there is a **system** in our body for distribution of blood, sugar level, for **energy**, **system** for pancreas. They were putting daily **load** directly on that. What will happen? **Completely break**."*

The following three narratives (Na. 64 to Na. 66) came forth from individuals trained in chemistry and bio-medicine. Similar to the narrative quoted above these reflect the impact of their education on the usage of terms used to explain bodily conditions and the disorder. The third narrative especially clarifies the difference the respondent makes

between diabetes as genetic problem and other infectious diseases and uses terms that highlight his medical training.

> ***Na. 64*** *"...entire system of our body, they remove all* ***toxins*** *from the body and all the joints are given proper protein and for heart, kidneys also and urinary tract..."*

> ***Na. 65*** *"I got diabetes is because of 3 cups of coffee with excess sugar that caused* ***complete destruction and wash out*** *of my beta cells that produce insulin. What I feel is that when excess sugars taken with caffeine can cause extreme fluctuations in the blood glucose level causing a change in the DNA sequence of the beta cells that has lead to* ***mutation*** *of the cell growth."*

> ***Na. 66*** *"Diabetes is just a prior warning to a multiple number of diseases alerting to be conscious and manage the life style so that the risk factors are taken care off. Disease primarily means a state of* ***pathologic*** *condition that tends to adversely affect the health by* ***impairing the body's normal physiologic function.*** *Disease is always associated with an* ***infectious agent*** *unlike diabetes which is not a result of an* ***infectious agent or a vector****. Diabetes basically is a result of an* ***alteration in the genetic make-up*** *of an individual that is* ***a disorder triggered by abnormal impairing of the gene that causes a permanent change and destruction of the pancreatic cells.*** *"*

People have different concepts of health, illness, and beauty. What marks good health varies from culture to culture. The bio-medical definition by WHO of holistic health upholds the idea of physical, mental and emotional well being whereas in some cultures the markers of good health are ability to work, to eat anything and everything. On the other hand, illness is seen as the inability to work, requiring more than regular amounts of rest, inability to eat what is desired, either because the body is not

cooperating for its absorption or the consumption of certain foods can lead to furtherance or advancement of the illness. Self imposed restriction(s) made in order for recovery from an illness or for preventing further deterioration suggested by some competent health practitioner is also taken as the basis of defining a healthy state of body from an unhealthy state. These ideas, as stated earlier, vary from culture to culture because these ideas are socio-culturally constructed. As discussed in the Individual Body respondents though had tried alternative medicine and believed its general effectiveness yet they used bio-medical descriptions regarding medical symptoms, patho-physiology, and adhered to bio-medical treatment. This clearly conveys that the ideas of the respondents regarding the conceptualisation of their individual body, and health and illness, at least in the context of the disorder, were primarily influenced by the bio-medical perspective.

There were other issues also that were seen to bear influence upon the perceptions of health and illness of the respondents. These ideas of health, illness were found to be located in the religious realm or the idea that health is required to serve the society. The ideas as upheld by a Christian medical student (Na. 67), a businessman (Na. 68), a Christian student (Na. 69) and a retired government official (Na. 70) respectively are given below. Each one here states not only what is health or good health but also how or why health is important and to what purpose. Their ideas are based on what is relevant and significant to them.

> ***Na. 67*** *"Healthy body according to me is the complete state of an individual being physically and mentally and emotionally stable.... As I have already mentioned health is a combination of mind, body and soul. Yes, it certainly reflects my mind along with body since it is a combination factor. It is after all the normal human nature of suffering....I told it is a combination of the 3 factors which is essential for an individual to feel in a state of well being it is a concept based on/derived from holistic medicine. There is no health in soul but always there is soul involved in a person's health."*(Christian Medicine Student)

Na. 68 *"Main chahta hoon ki dus saal baad mera business toh successful hoga mujhe bharosa hai apne aap pe. But the thing is as well as meri health. Meri health mere saath ho. Actually 20-30 yrs aur kaam kar saku. Health na ho toh aap achche kaam nahi kar sakte. Thodi der ke badd aisa lagta hai I can't do, bharosa nahi hai. Kabhi aise takleef aagayi. Toh bharosa nahi hai ki main kar paonga. Kahin aa-jaa sakonga...Main chahta hoon dus saal mein aisa lage…aisa na ho. Meri health achchi rahe....Achchi health hone ke liye kya matlab hai, matlab, you know fit you can say. Har tareh se jaise aankhein kamzoor na hoon, body achchi hoye....."(I want that after ten years my business shouls be successful and it will be that much confidence I have in myself. But the thing is as well as my health should support me. Actually [I] should be able to work for 20-30 years more. If health is not there we cannot do good work. After some time I feel I can't do, do not have that trust. If some time a problem came. Then do not have the confidence that I will be able to do. If I will be able to go anywhere...I want that in ten years [I] should feel...this should not happen. My health should remain good...good health meaning you know fit you can say. In every way like, eyes should not become weak, body should be good.)* (Young Businessman)

Na. 69 *"Life is…God has given the life. For every person death is there. So I have to live a good life. Pure life beside my God and I have to go on. After my life I have to go. That's all. Health and illness, I told you, it will be there for each and everybody. So if it is coming we just have to accept. You have to admit it and adjust regarding that. No need of running away. You have to admit it totally. You have to accept…we have to make our life under that conditions. We are…we cannot run away from our circumstances. Our life, what all God [has] given, we should pray for that. If are getting better also praise and we have to admit whatever our circumstances. No need of running…if you are running away from circumstances it is not good at all. By faith with courage we can face it*

…with the help of God, I think. My hope is I can complete my life and after life death will come and I will go to my God. That's all." (Christian)

Na. 70 *"Healthy body…you have to be in a position to maintain yourself, achieve your goals and along with that you have to support others also. Help also, sacrifice also. That much health is essential. In a sense, I am one body, if I maintain five more persons' health along with me. See how much care I have taken, then definitely I can help 4-5 persons. Even my family if my wife is not with me. Health…is not only dependent on the food we are taking. It is not merely what food we are taking..."* (Retired Government official)

One of the ideas of health is also seen as harmony, integration when talking of individual body and good health. One of the respondents while talking about diabetes asserted the disorder in the society, problems with the system and lack of knowledge and information being the reason for diabetes. He saw the lack of order in body and in the society as the reason for diabetes and other health problems as well like heart problem, hypertension etc.

Similarly the perceptions of beauty and beautiful body were also seen as deeply influenced by the ideas of health. Respondents saw beauty as secondary to health (as discussed also in the Individual Body) and also perceived it as more than skin-deep. The equation of healthy body with beautiful body and healthy mind, and beauty with a healthy mind (or thinking) as seen in the narrative given below suggests a different perception of beauty from the popular ideas in terms of trim, toned, sexual body and rather upholds health and the social values of 'inward' beauty as more important or as the real beauty. (Na. 71)

Na. 71 *"...Healthy body will be only beautiful body. Healthy body means healthy body in sense of healthy by mind, and physically everybody will not be healthy. And healthy by mind means it will be beautiful. And if it is not healthy also what is actually beautiful. Physical beauty is different and*

inward beauty is different. So, we cannot tell like that. Hai na? [Isn't it?] One girl is having diabetes and she is very beautiful. Physically she is very beautiful and her mind we cannot correlate with the disease. If she is very good by her mind then what is the problem. If she is having a loving heart what is the problem."

Respondents also narrated (Na. 72 to Na. 74) how diabetes is a disorder and not a disease their understanding bearing the influence of bio-medical definitions of disease and disorder. Also the information about the disorder had influenced their ideas of health and illness in general. They perceived health and illness in terms of diet and exercise which were reinforced by the diabetic regime that they were following. Viewing the disorder as a deficiency, and an inability to manage or balance professional life and health suggests that the respondent did not view the disorder only as a medical issue but as the disorder that had affected his life and the disorder that diabetes had created in his life. The third narrative given below reflects the respondent's knowledge of the bio-medical distinction between disease and disorder, and his selective usage of it only in the presence of diabetics. His suggesting that other than the terminological difference diabetes is a disease only points out the general perception in the society which first of all does not make bio-medical distinctions, and secondly, stresses that even if there is a difference he is 'a diabetic'.

Na. 72 *"Diabetes itself is not a disease. Diabetes is a disorder. You just order the things, it will be normal. That's what I have read....Disorder means it is science only no. That beta cells is getting damaged, and it is not able to produce insulin. It is only the disorder. So, if you are just giving early that insulin that disorder will be ordered. That's all."*

Na. 73 *"As I told you, diabetes is just a disorder. Disorder in the body which can lead to problems, which can lead to problems....So, if you are conscious about your disease and you should read your disease and if read yourself properly you can have a happy life. Otherwise the harm*

that…that diabetes is going to do that cannot be done by your enemies also. Because that will show impact directly on your nervous system. It will show impact on your heart. Everything…everything organ in the body that will directly shows impact. So, it is having its own disadvantages also. So, it's part of life....Because if I can keep the balance between my professional and my this health then only I can…That is what actually is the disorder. That is actually I can say I have something deficiency or whatever you may call it. Other people need to fight only professional or whatever but I fight my own health care and this also. I need to balance…keep the balance then only I can…hit the target....What is good health? Hmmm. I think I am not the right person to answer that… (laughs)...Habit…food habits and…now a days this food and exercise, body exercise. These are very important to any person. Because now a days not only diabetic people…if you see 100 people more than 70 people, they will be having some or the other disorder. I might be diabetic. Some other person might be having high BP. No person…no one in this universe is 100% healthy... So, whatever the problem or whatever you are having how…how do you fight with that and how you adjust to that, that is more important. Problems with the disease…I don't feel something as good health. Because now a days even very small children ahhh…from their birth some or the other disorder."

Na. 74 *"If I was talking with some diabetic then would have said disorder otherwise really it is a disease only. And doesn't matter whatever it is, I am diabetic."*

Religious Construct

Beside the medical construct of the body every society also has a construct of the body in the context of its religion. Body in terms of religious construct has two aspects. One, the way a religion divides the body as natural from the supernatural or their relationship, the relationship between the individual bodies with the deity of that

particular religion etc. The other aspect is where the religious ideas influence the understanding of the structure and the processes of the body, the possible reasons of sickness and the measures of relief. These ideas are upheld individually but are communicated and enforced socially. Religion is not just about an individual's beliefs but also social interpretations and adherence of that particular religion. The community following the particular religion popularises and adds sanctions to certain ideas and proscribes certain others. Religion also relates the individual to the society he/she lives in and is a part of. Most religious ideas and regulations act upon the individual but are regulated by the society and in order to maintain social well-being and harmony. Therefore, the religious constructs of body are analysed in the realm of the Social Body.

Three religions -Christianity, Hinduism, and Islam were dealt with in the study because the respondents belonged to one of these three religions only (as has been discussed in Methodology, Chapter 2). All three religions Hinduism, Islam and Christianity place importance on the body. Christianity says that body is the temple of God and one has to keep it pure in terms of morality in issues like sexuality, dissipation etc. Hinduism also believes in keeping the body pure in terms of purity and pollution regarding dietary rules, rituals, and customary observances. In Islam one is required to do good deeds as one shall be judged by and rewarded for them in the end. All the three religions thus emphasise on the purity of the body. Nevertheless, the ideas of purity and pollution differ.

There is a belief in all the three religions of having a body even after death. There is a concept of heaven in Islam and Christianity and of having real bodies in which one will reside in heaven. On the other hand, Hinduism, like other Eastern religions, believes in reincarnation- the belief that the soul of a dead person returns to earth in another body. Even in '*Moksha'* or salvation the body as a shroud or cloth will be left behind and only the spirit shall be united with the Godhead. However, the beliefs about re-birth and resurrection in Hinduism, and Christianity and Islam respectively provides different outlook towards dealing with body and illness.

According to the '*Karma'* understanding of Hinduism, body is a site of punishment for sins of previous births or life. Thus, a person accepts the disease,

attributing it to reasons beyond his control. He tries to do his best within given limitations and aspires for a better next life. Islam believes in resurrection but not in a physical body but rather a 'spiritual' body, a body made of the good or the bad deeds done in the body while alive. Though there are both physical and spiritual pleasures that can be enjoyed in heaven. In Christianity body is seen as important as the soul; the body will decay and one will be given a resurrected or new or glorious body which can never fall sick or decay eventually and shall live eternally in the spiritual realms to enjoy spiritual joys. This enables one to accept and endure pain and the sufferings.

Among the respondents interviewed it was seen that most Hindus and all the Christians spoke about God or religion in their narratives. The Hindu respondents spoke of fate, destiny, being angry with God for giving them this ailment and praying to God to take away the disorder. Christians spoke of the will of God, the work of devil and the power of God to heal them and prayer. They found explanations that are outside their body and in fact outside the realm of the natural/physical world and rather rest in the realms of the supernatural or divine world. The Muslim respondents did not make any reference to God or their religion in their narratives. One of the possible reasons for that could be that the body is not that significant in Islam in the context of afterlife, unlike Christianity where there is much discourse on risen glorious bodies, and Hinduism wherein a major precept is re-incarnation or multiple births for a soul. Therefore, the Muslim respondents do not necessarily see the two -body and religion in any relationship.

Some of the narratives quoted under explanatory models in Individual body clearly reflect the respondents' ideas about their body which are rooted in religion. The way they understand their body and illness is based somewhere in their religious understanding. Though their understanding of their body's anatomy is very much influenced by bio-medicine and they are adhering to bio-medical treatment nevertheless they find cause in religion. As stated earlier this suggests the belief that there are two worlds- one physical and the other spiritual. The spiritual affects the physical and thereby they locate the causes in both physical and spiritual or religious realms. The spiritual reasons must be addressed in the spiritual realm of either doing good karma or accepting it as the will of God or praying sincerely. And the physical problem must be addressed

with the best physical measures. The best possibility they find is in bio-medicine. Cure or care of the sickness is something that they have to take care of in spite of whatever may be the reason for the disorder. The influence of bio-medical could be because of the education system that teaches biology and gives some basic understanding of the anatomy of the body, and also since the respondents were seeking healthcare from a bio-medical practitioner. The coexistence of the explanation of the disorder in religion with bio-medical treatment (and belief in the efficacy of it) also suggests that the two do not have to exist mutually exclusively.

Shilling states, "With the decline of formal religious frameworks in the West which constructed and sustained existential and ontological certainties residing outside the individual, and the massive rise of the body in consumer culture as a bearer of symbolic value, there is a tendency for people in high modernity to place even more importance on the body as constitutive of the self…." (1993/2004: 2-3) Shilling thus suggests that with the decline of religious frameworks in the West that had supported the reasons and explanations of existence as supernatural and existing outside the individual and the rise of consumerism in modern times has led to individuals laying responsibility for health and illness in themselves. That is to say, in the modern West people no more seek the causation of their illness in religious factors but rather take upon themselves the responsibility for maintaining health and evading illness. The question that rises here is if this is true of the West then what about India where religion remains central in most lives? And would that mean that people in India still see existential and ontological reasons or explanations outside their body? And is that why many could not explain, in bio-medical terms, why they got diabetes but rather saw supernatural or religious reasons as having led to their being diabetic? These are some pertinent questions that need to be further inquired into.

Social Relations

Society communicates to individuals through family, relations, friends, colleagues. The way a diabetic relates with one of them also influences his/her relations with the others. The social relations one shares with family and other members of their

society has a two-fold effect. One, the impact the social relations bear on the individual's constructions of their illness etc, and two, the social consequences of the individual's illness.

Family as the social body deeply influences how one perceives their individual body. As the researcher could not meet the family members or friends or colleagues this assessment is made on the basis of what respondents spoke in their narratives. They affected the ideas of the course of sickness, the ideas of its severity and sick role, for the diabetic. Respondents who had always lived with their families and had few friends showed trends of more dependency on the family and were stopped by the family from moving away either for education or work. Is it that the respondents who are not able to work and stay at home most times develop closer relations with their family or is it that they are closer to the family as they prefer to stay at home most of the time? The respondents who were mostly at home and did not have friends mostly saw their lives more around their ailment compared to others who considered the disorder only a part of their lives. (Na. 75 to Na. 77)

> ***Na. 75*** *"...Actually they went to Bangalore trip. I was very eager to go because with friends we will be very happy to enjoy but I can't go. That time I felt a little bit bad. Because there the food will be changed and insulin I won't be...Everything will be changed and here means Mom will be here. She will take care of me. Everything. Time to time food...everything will be there. I felt a little bit bad for that. I can't go anywhere. If I have to go in Hyderabad only... just here...if I go in the morning I should be back in evening. I can't stay in night in friends' house like that.* ***That is why I spend more time with my family members only****."*

> ***Na. 76*** *"...Hmm educational life means in some way it was affected because that my parents also did not allow me to go out of Hyderabad. Because of that whatever the course that are available with that only I have adjusted my…I completed my education. Now I fought with them and finally I went out and proved myself that ok if I stay alone also I can live my life."*

Na. 77 *"…when I come to my home... Just I will sit and chit-chat with my brother and my mom, that's all. When I am in my office I will be… I will get up in morning around 6:30-7:00, cook my lunch and take my lunch and 9 to 5 office and then come back and sleep."*

Those who had friends and colleagues, who knew about their disorder and felt comfortable discussing about it, had their friends and colleagues as their social body too. At times friends and colleagues helped the respondent take care of their body and empathised in times of need (Na. 78). At times the family, in their absence, entrusted the care to friends.

Na. 78 *"I am lucky enough to have manager who understand my problem. So, they give me various options. I can work from home, or I can delegate my work to somebody. So, it's just that they want me to ensure that the work is being done irrespective of how. And that's what I do. I've just come back. I had taken 3 weeks of leave and it's unheard of in this work that I am getting 3 weeks of sick leave. So, that way I am very lucky, I am very fortunate."*

More often than not family remained the only social body for the diabetics and friends and colleagues were completely left out. When that happened it was either a deliberate attempt by the respondent to avoid disclosing the ailment or the family was so close (or protective) that it did not allow the development of other relationships. For those who had deliberately kept this information from their friends and colleagues spoke of fear of rejection, of losing jobs, of becoming uncomfortable with friends and colleagues, of receiving unwanted sympathy or pity (Na. 79 to Na. 81). Some of these fears are based on previous experiences and some are self-imposed.

Na. 79 *"I don't want sympathy from anybody. That sympatheticness. Some people will…some sympathy is good but that is not true sympathy- some*

people. Some people want to hurt that is why they will act like sympathetic. And they will ask questions like that. And they will say to each and everybody. I don't want to be like that. I don't want to get sympathy that's why. I don't want to disclose. I feel to very few people only I have disclosed. To very honest people only I have disclosed."

Na. 80 *"I never felt that way. In front of me nobody can do that on my face. I don't have habit of asking help and rarely go to somebody for favour. But these things of making you feel otherwise or abnormal comes when I meet with my relatives. They will say something or do something and most of time is hard to reply them as in Indian societies you can't say anything to elders. And because of that I always avoided going to family functions and gatherings."*

Na. 81 *"No my colleagues do not know about… Because I fear I may lose that job also…When in the previous job they came to know suddenly I have got a memo."*

One also sees his/her body as part of the social body. The responsibility of family makes one view his/her body and health differently. Like in the following narratives (Na. 82, Na. 83) which suggest that the roles asserted by the social body while imposing some obligations actually contribute to the wellness or at least the desire and the need for wellness of the individual body.

Na. 82 *"...till probably my first son was born I never realized the seriousness of this. So, I am talking good 10-12 years. So, I never took care of my diabetes...I have a wife and two small sons. I have a lot of responsibilities. So, I need to take care... Sometimes I think because I have responsibilities I have 2 kids and my wife to take care. And then I don't know. That is the way I have always been living, I don't have future plans. I think that is one more thing that changed now I have started thinking. If I have to do, I have to do it. So, now I think that I should ensure that if anything happens then at least my kids and my wife are safe."*

Na. 83 *"I know the damage is already done but I am trying to see what best I can do...I have a wife and two small sons. I have a lot of responsibilities. So, I need to take care..."*

The expectations of the society from a man to be able to care and provide for his family comes in to question when he is faced by a chronic disorder gone beyond control and paving way for many critical complications. The social body then comes in to the picture because the disorder and thereby the disease have ruptured not only the smooth living of the individual but also the family and thereby (his immediate) the society.

The social body (family and society) are also blamed for the sickness as stated by some respondents. (Na. 84, Na. 85)

Na. 84 *"Hamare daddy ka bhi kidney ka theek nahi tha. Do saal ho ke guzar gaye woh bhi. Kidneys kharab hua toh dialysis kara leke gaye. Unke peeche phir-phir ke hum bhi aisa ho gaye. Unko ek dus saal se dialysis karate the. Phir dono kidneyon kharab ho gaye."* (My daddy also had kidney problem. It is two years since he passed away. Kidneys were not working so we got him on dialysis. Running after him I also became like this. He was on dialysis for ten years. And then both the kidneys failed.)

Na. 85 *"...That is the problem in India.* ***My mother*** *never changed her food habits, never had any special preparation for her children.* ***My wife*** *is also doing the same thing. And this I argued with so many of my colleagues and friends. What happens is in India if you want to change something change it from the* ***ladies****. In the kitchen. They are having some particular habits that they are not willing to change. You know why I got?* ***I blame my wife. She is to be blamed not I myself****. She needs to take care. She has to...Even when I go to office, I eat. Who has stopped her from preparing the food in time? And when I am taking food like this, she should have anticipated something and taken me to the doctor. They are not doing anything. That is really a minus point in India. They are going to get diabetes problem more than 80% within 10 yrs. I am damn sure.*

The culture in north and the culture in south that also is different if we see in India. In north, diabetic attack is very slow and in south it is very high. Why so? Same thing. Ladies there in north are so liberal about so many business activities and also in mingling in so many business activities. They are well-informed and they don't follow the things developing in the market. Even after knowing that I've got diabetes, she has not changed. After seeing the report she will prepare roti that day. That's all. What about the next day? What about at the time of giving tablet? She can't give me tablets. She loves me like anything. We are good and everything. But, regarding this thing, she is zero. I am fighting like anything for improvement in things like this in India and even in my own house she is not cooperating. She is very much against all these things. I told her I am getting very good results. Not happy. Why? This is…"

The respondent holds his wife and his mother responsible for his diabetic conditions. He says because of bad food habits at home he got diabetes. There are contradictions observed in his narratives. At times he contrasts his growing up years and good diet with the present day pollution and unavailability of good food which is leading to more cases of diabetes in the present times. He nevertheless holds his mother and her cooking habits responsible for his health. On the one hand, he says because of the work he used to do and even now comes back for lunch or eats lunch around 3 pm. Yet, he blames his wife that she does not serve food in time. In the narrative quoted above the respondent's remark on women in general makes it clear that he holds women and their habits regarding cooking and kitchen as responsible for most health problems. His arguments seem based on his expectations of gender roles and his perceived deviation from them. It also seems he wants the reason for his ailment to lie outside his individual body and thus he holds others, including his family, as responsible for his diabetes. Thus, aetiology finds place in the social body. The social body, in this case the family, is suppose to share responsibility for the ailment, its causation as well as the process of treatment.

Wherein the earlier people found causation in fate, destiny, spirits and God for crises in life now they locate it even with the social body. When people wish to be more scientific, modern or rational this explanation suits them as these explanations seem more empirical and reasonable than blaming mystical things. May be these explanations also help the respondents to deal with their ailment better. The narrative given earlier and also the following narrative highlight this where the higher level of education and 'scientific', 'rational', 'modern' thinking of the respondents makes them locate the cause of their illness outside the realm of the mystique, and with the social body. The narrative (Na. 86) given below holds the general or the society at large responsible for the increasing health problems.

> ***Na. 86*** *"...these days people discuss about tension. What is tension? Pay attention then no tension. Simple if you pay attention. But people become panic on the roads and how they fear. You pay attention that's all. There are hundreds of accidents happening everyday because no one is paying attention. That's why I am telling. Am I correct? So, these things should be eradicated. Like "bakras"(goats) our humans stand. And they see bus is coming. There is a 150m road widened recently. People stand where? In the middle of the road. Driver is driving with people standing in the middle of the road. So one day what will happen is that the driver will become diabetic and BP patient and so, we are making others in tension."*

Besides family, friends or peer group and colleagues operate as the social body. Many a respondent had not disclosed their disorder to their friends. Among those who had shared with their friends and colleagues they preferred not to talk about it. Respondents not disclosing their disorder itself is a sign that they do not consider themselves as normal. They do acknowledge the support of the social body or at least the need of their support yet do not disclose due to the fear of rejection. Though there are pressures from the social body yet by choosing not to disclose the ailment one emphasises ultimately upon the individual choice. It is like 'my body, my wish'. Social body can be reminder of the restrictions but cannot restrain one from indulging in that which is proscribed or to divulge information about oneself. This places body primarily

under the individual realm. Fearing rejection pressurises the individual. Respondents recognise that divulging of information can put them in a weak position and that is why they hold back the information about their illness. The withholding of information from the social body is also done for the sake of the individual (both body and self).

In the narratives (Na. 87 to Na. 90) given below one can see how the respondents saw the social body of friends as opposed to the individual body. Sometimes they perceived them as a threat to the health of his individual body and the association with new found friends, either other diabetics on the social networking website or otherwise, were seen as more suitable for the individual health.

> ***Na. 87*** *"Yes you are right now we have friends who want us as we are and not tempt us with parties and merriment all the time. We are also more tuned to our bodies and the best thing is we never hurt anyone because we know the pain it causes."*

> ***Na. 88*** *"I was never comfortable talking this matter to my friends but still few were still concerned about me but I almost never gave them a chance to talk on this...The same also applies to my relatives. All they could tell me is to take care of myself and pray to God.... All of my friends know that I'm diabetic but I never wanted them to talk on this reason being I was just not comfortable when they keep asking me a 100 questions which I had to keep explaining to them."*

> ***Na. 89*** *"No. I did not say (*tell my friends*)... They will be feeling bad regarding that. If I tell it will be helpful I know somewhat. That I have sugar they will be helping, I know. They will understand what is my problem..."*

> ***Na. 90*** *"...probably that age was such that we never knew that this could, you know, in future be so serious. Yes, for them*(Friends) *they know that I have a problem and my mom would update them that I shouldn't be doing*

this but even when they see me they tell me once that you are not supposed to do that and I would say 'that's ok' so then even they would say ok. So, that age is such that probably we never gave so much of heed to the advices.....From the time I realized the seriousness of this. At least I know that if I start mingling with my friends, I start going to parties where I used to I cannot refrain myself I will definitely go and jump the gun and get back to the old ways of life. I can't do that because I know that if I do that anymore then it will be a point of no return. So, I don't want to do that. It is my own choice that I want to ignore that part of me. Yes, I do meet my friends but I don't meet them at parties. So I don't go to parties. I just meet them outside probably at my house or over the weekend."

The fact of being diabetic not disclosed or deliberately hidden so as to get married suggests clearly about social perceptions, non-acceptance and the social identity one receives from the society. In the issue of marriage there is a conflict between the individual and the society, the family and the society, and also between the individual and the family. The individual because of being a diabetic usually faces rejection from the society. This was stated by most of the respondents as they had faced rejection in marriage proposals because of their being diabetic. The conflict thus raises the question to the individual as whether to disclose the disorder or not. The society does not look favourably upon the diseased especially with regard to marriage and insists on revelation of such information (Na. 91, Na. 92). The family also faces similar conflicts with the society and faces the same dilemma of whether to disclose information about the disorder or not. This leads to the conflict between the individual and the family where the individual may want to reveal about his/her illness but the pressures from the family might work against that decision. This conflict is represented in the figure given below followed by the narratives of the respondents as well as the discussions on the social networking forum.

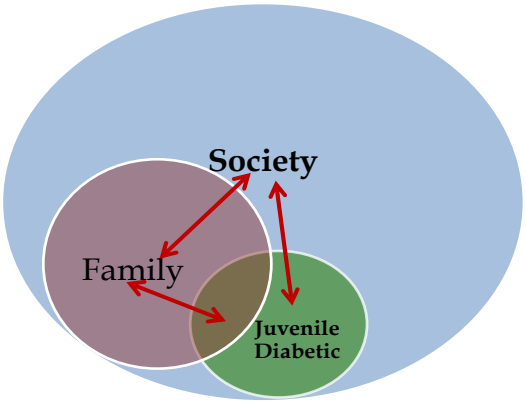

Figure 1 Representing the conflict between the Juvenile Diabetic, Family and the Society

Na. 91 *"...if anyone knows [that I am a diabetic] then how can I get to marry. If anyone knows...they will mention that I am diabetics then they will stop me...they will not get married."*

Na. 92 *"...Yes I am facing difficulty getting married because of diabetes. Every now and then someone will meet my parents with a marriage proposal. And when they get to know that I am diabetic will either walk away directly or make some ugly face or will say something really bad. My parents have lost hope that I am going to get married and they have stopped trying as well."*

SNFD- 3 a) *"I have a serious problem .....please guys help me out with this .....i am diabetic from long time more than 7 to 9 years .....the thing is my parents want me to get marry and they are looking matches for me the problem is they are not telling my problem to the opposite person*

family and i'm forcing my parents to tell everything abt me but they are not listening .....plz guys tell me wat u want me to do now .....so that in future no one should get hurt with any thing"

In the last narrative (SNFD-3a) the respondent is seen recognising the responsibility of an individual to the social body that one should not cause hurt to others and yet the forces of another social body, of the family, are not easy to resist. The respondent here expresses helplessness while dealing with these two forces and interestingly seeks help from a third group, which is the virtual social body. In response to that post in the forum on the social network website is seen support revealing the information, not hurting another person by hiding the information about the disorder, and sympathy with predicament of the participant, and his desire to reveal his condition in spite of the family pressures. He also finds fault with the social body for not respecting the individual, seeing the individual only as a diseased person and preventing marriage of those who are diseased and thus hindering the realisation of one's aspirations to lead a normal life. He expresses the desire to be accepted as he is, that is, to be accepted despite his having diabetes. The response on the forum supports and empathises with him, and encourages him to disclose his diabetic situation to the prospective spouse and family. One of the responses from the forum in this discussion is given below (SNFD-3b).

SNFD-3 b) *"Dear Brother ur parents r doing totally wrong. Tell every thing in beginning so that tum baad main koi problem face na karo. I had bad experience n then i knew that society has not changed. i got a proposal, they know my family n know that i am MBA n doing job but don't know that i m diabetic. When they came 4 marriage proposal my father told that he is Diabetic, it depends on u now.....response..... They never came back. what the experience..... what they think.... what society think... they think that we can't do anything.... we r dependable..... they don't know that anything can happen in life. a girl or boy can be a diabetic even after the next day of marriage..... Main to chahta hu ki main jasia hu log mujhe waisa he accept kare. N tum bhi jhoot mat bolna*

kyuki aaj kal divorce hone main bhi time nahi lagta..... i m sorry mujhe ye sab kahna pad raha hai par kya kare yahi reality hai. Try karte raho tumhe koi na koi good girl jaroor milegi....."

Another narrative (Na. 93) given below highlights the same conflict again, underlining the pressures one feels in the conflict between himself, family and society.

Na. 93 *"Nahi, 2-3 months baad hai abhi... actually nahi pata hai... Kya kare?... mujhe kharab lagta hai. Dil mein takleef hoti hai. Soch raha hoon bata du. Aisa I need time. Thoda aur time soch raha hoon bata du toh achcha rahega. Woh hi doctor sahab se puchna tha. (No (I am not Married) It is after 2-3 months. Actually (they) do not know. What to do? I feel bad. It hurts me. I am thinking that I should tell. I need time. A little more time I think I should tell then it will be good. That only I wanted to ask the Doctor."*

In all the cases there is a conflict. They want to disclose their real situation and identity as a juvenile diabetic but are restrained because of the family and societal pressure, and fear of the proposal not working out eventually because of this information. There are many who reported rejection in marriage proposals because the information was revealed to the other party. The last narrative suggests how the respondent wants to disclose and feels bad that he has not been able to. He wants the counsel of his doctor on the matter. He trusts his doctor and is seeking his opinion, on such a personal matter, beside that of his family. This suggests like the first case stated above that one looks to social body (friends, virtual social body, ideals of a social life etc) to resolve the issues of conflict with the social body (of family and society in general).

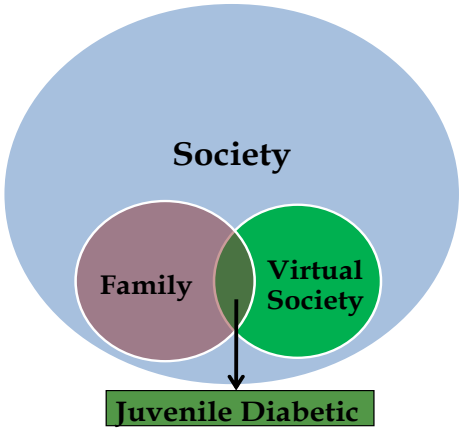

Figure 2 Representing the relationship between the Juvenile diabetic, Family, the Virtual Society, and the Society

There is an identification of the Juvenile Diabetics with other diseased people and other diabetics, and "normal" persons are seen as the other (Na. 94, Na. 95). There is an extension of the social body from family, friends, and colleagues to the other diabetics. We see the whole idea of creating a 'society' on a social networking forum as a reflection of that where diabetics relate to the other diabetics as their social body and the others or the 'normal' people as the outsiders. (SNFD-4)

> ***Na. 94*** *"...But, **we** have disease that means **we** will have to take care that much..."*
>
> ***Na. 95*** *"...I think **we** are better because **we** take more care to our health but normal people, they do not..."*
>
> ***SNFD-4 a)*** *"...Us Diabetics are normal people, we can live a normal life..."*

b) *"I think diabetes people will know body mechanism more than other normal people. Somebody not having any disease they will not care that much. But,* ***we*** *have disease that means* ***we*** *will have to take care that much."*

c) *"I only hope that everyone out here get the feeling of NOT BEING WANTED because of DIABETES out of their heads... I really feel if any non diabetic refuses to accept a diabetic it would not be because of he/she being a diabetic but rather because of their insufferable nature towards their own self...!"*

d) *"We diabetics are not some "NON TOUCHABLES" We all have developed a condition... not a disease... so here the conditions are to eat good, take insulin on time, exercise regularly and not take much stress!!!And then trust me my dear friend.... we would be the healthiest humans on this earth!!!! and ofcourse sweetest too!!!"*

This goes beyond than just identification; consultation about medicine, advice about life-style and important matters are also sought from this social body which a virtual family. People give their comments and suggestions as well as the unspoken rules that govern any society or culture are also found here where one ought to respect other's opinions and be empathetic. People sought consultation on technical issues like what insulin to take, how much, how to inject insulin, what foods to eat, how to measure calories and other nutritional values in food etc. This forum also provided virtual space to seek counsel, give encouragement and discussing issues of common concern and welfare to juvenile diabetics which probably they are hesitant to discuss with their non-diabetic friends and even family. Even desiring to date and marry a diabetic is suggestive of how society has influenced them to see themselves and what kind of social relations they are aspiring for. Some of the discussions (SNFD-5 and SNFD-6) are given below.

SNFD-5 a) *"Giv me the right method of take an insulin shot ?"*

b) *"Insulin must be injected in the layer of subcutaneous fat. Therefore, injecting it at skin or muscle level is not required- infact, it reduces efficiency. The correct way to do it-*
1) Pinch up your skin between forefinger and thumb.
2) Inject at 90 degrees, holding the syringe like a pen. Push plunger/button.
3) Slowly release fingers.
4) Pull out the syringe.
You may disinfect the area with denatured spirit before injecting yourself or wash with soap and warm water. FYI- You can also inject yourself through a layer of clothing, though it's not the most advisable thing!"

c) *"can i use surgical spirit to take insulin?"*

d) *"yes u can use surgical denatured spirit to clean the injection site.....take care that once u have cleaned the site let it dry else it will hurt a bit when u inject the needle"*

e) *"Hey... you can always take ur shots on ur arms, abdomen, thighs and butt.You need to make sure you have enough fat.Also remember to keep rotating your insulin shot site!Never take it twice at the same site... it might form lumps.The best way is suggested up... 90* straight in! Good luck!"*

f) *"hey I thought syringe must be held at 60 degree during injecting..."*

g) *"No dear, 90 degree is the right way to take insulin."*

SNFD-6 a) *"check my sugar before walk ie when i woke up is 75 and 30 mins after finishing my walk and without any food intake it touches 200. i m a type-1 diabetic"*

b) *"75 on glucometer is nearly hypo for type I like us. it is good but tell me do u take anything before a walk ie a cup of tea or snacks or anything.*

otherwise it seems to be a condition called rebound meaning when body is depleted of sugar a hormone kicks into action and draws sugar from fat cells in the body to replinish for low sugar. but this mechenism is one way and it does not know when to stop so chances are sugars shoot up if hypos are not treated promptly. fasting 75 wil drop further when u walk for 30 mins. just check out your sugars without having a walk in the morning for a few days maybe a week. that should help in adjustment of your workout routine. also please get in touch with your doctor and dieticien for the same. do they know about this ? you are always welcome for any querries."

c) *"hey,i just wanted to knw dat shud i prefer a gym of just jogging in the morning..im confused between it..i dont knw wich wud work better...to keep mah sugar in control!!!"*

d) *"... check sugar before and after jogging. if after jogging it drops below 80 and before jogging if it is normal then take half or 3/4 cup of skimmed milk without sugar and then go for jogging else everything will be fine"*

e) *"First of all, pls say no 2 sacharin as it is a petroleum by-product (i really mean it) now come's aspartame and other sweeteners vich r also very bad 4 health. I CAN PROVE THIS POINT - u can clearly c d release of 'SUGARFREE NATURA' vich says it does not contain any saccharin or aspartame, but again dont use it 2 much as it also contains Sucralose which is never advised good 4 health. RAther u may occansionli take Steviocal(a swtner frm a herb called Stevia, prbobly from sum african country) ANYWAYS THE BEST natural sweeteners are nature's fast foods (i.e. FRUITS).SO try to eat those fruits vich r allowed to diabetics instead of artificial swtners PLS."*

Upset with diabetes, sometimes even after 15 years, people find the changes, the ailment difficult to deal with and remember that they are not normal. They want to be

normal. At such times also they were seen to seek help from other diabetics on the forum (SNFD-7).

SNFD-7 a) *"Hi!! I know I may sound very pessimistic but did u ever get sick of being a diabetic?? I am normally take it very casually that I am a diabetic..I mean ofcourse I take care of my self and all..but I assume that now its a part of me n i have to live with it..right?? But since few days its just been pretty rough for me..I just hate the fact that I am a Diabeticu know..it feels as if y the hell is it me? I just wanna be free of it..I know that I can overcome it but its just it feels like a burden...I am diabetic since past 15 years..n till now it was fine..but now things are getting tougher.I have to face a lot of complications...and since One is gettin older tensions increase and due to that my levels go ballistic!!.....I am doing MBA and I am in my last semester...Till now I had the full support of my family and now time has come when I have to move on my own path...and it just scares me..will my health issues cause any kind of trouble for me..cutting long story short..I do not want to be a diabetic anymore....."*

b) *"this is a phase that almost everyone goes through.... i've just got out of my mental sick phase actually.. dont worry..... its v v normal... u'll get over it soon."*

c) *"....bt hw did u manage in that time? I mean wat did u do? its just gettin tougher day by day.."*

d) *"change something... start thinking fresh... i always do that..."*

e) *" we all are aware of the fact that stress affects our sugar level.*
1. physical stress
2. mental stress.
right now, your mental stress is too much as ur thinking abt ur health and

maybe other circumstances in ur life. this has filled u with tension,depression n irritation etc.
solution :1. take out time from ur routine and watch good movies, go shopping
2. listen to songs, sing (i.e if u like to sing :))
3. join a hobby class (dance, painting, cooking, personality grooming workshop, photography... anything that you like)
4. if ur a student, then set a deadline to study a certain subject, and challenge urself to achieve it. if ur working, then do likewise for ur work. if u arent studying or working, then start thinking abt a career.
(write these 4 points in ur diary/mobile and read them every morning as u get up)
these will really help u get over the mental stress. and with that, half the battle is already won :) . at this stage ur filled with confidence and the next thing to achieve is physical fitness. with ur mind set and clear, you can achieve tht too...
all this is from personal experience..."

Even though there are claims of normalcy and striving towards it by the juvenile diabetics on social networking website strive towards it (to accept selves as normal and make a place in the society.) they do not want to remain diabetic. It is not an identity they are glad or proud of. All possible researches and findings that can cure their situation are discussed with great interest as well as hope of complete healing/recovery. There is a desire for 'normalcy' and to get rid of diabetes. To the general social body the respondents make the constant assertion of being 'normal' and fight the 'not normal' status. But, the individual body is diseased and all the respondents do acknowledge that. Therefore, stories of better management of diabetes, of healing, on-going research are carefully followed and hope for complete recovery is always maintained. How so ever much the respondents say that they have accepted diabetes as a part of their life they nevertheless want to change that situation and desire complete healing. They want to be 'normal' and that itself suggests that they are not 'normal' even in their own perception.

The family works as a primary social body for most respondents providing them with physical support in everyday life. The virtual society also as a part of the larger social body gives moral support to the individual. There is another sub-group that supports the individual -the health sub-system. The health sub-system gives legitimacy to the claims of the juvenile diabetic. The health practitioners though on the one hand help the diabetics understand their body-mechanism and the disorder, and deal with thus identifying them with the disorder. On the other hand, they encourage the diabetics to think of themselves as normal and pursue life goals like any 'normal' person in the society. The individual thus uses the health sub-system to legitimise both sick role as well as the 'normal' identity. These claims of legitimacy given by the health sub-system were also appropriated by the family and the virtual society.

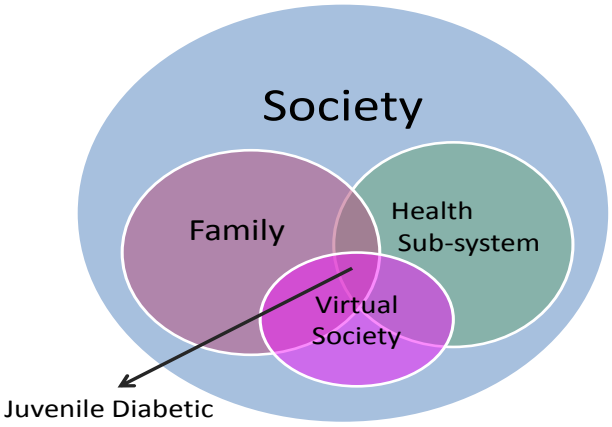

Figure 3 Representing the Family, Health sub-system, and Virtual Society as the support systems for a Juvenile Diabetic

There is definitely a clear understanding that they have received from the social body about the ideas of health, disease and how the diseased are to be treated.

These ideas are internalised and influence their perception of themselves. They talk of Indian society while expressing these perceptions of the society about the diseased. The following narratives (Na. 96 to Na. 98) highlight the respondents' problem with the Indian society and the society's views and understanding and ways of dealing with diabetes.

> ***Na. 96*** *"Abnormality… see because of the conditions that are there in* ***India*** *and the conditions that are there outside are totally different. See if you…I went to* ***US****, I went to* ***Singapore****. There sugar means it is just a disorder. Ok? In* ***India*** *sugar means it is a very big problem. The [way] people look at you will be different. The problem will be same throughout the world but the people views in different ways."*

> ***Na. 97*** *"That was…my childhood days people used to feel diabetes is a big problem. So, people were very cautious to me. When I…when I…they used to give me…or while sending their children to play with me also if I fell down or anything happened they will be in big problem. So, how can…now also I can tell that the awareness levels are still very low till date. Whatever I saw in 1980's, 87 still I am seeing the same awareness level. Which I feel is a very big problem."*

> ***Na. 98*** *"But I feel now that I have some severe problem and something lacking then most other guys. When you have to get married and have disease like this, you start feel really limited. Now I have to handle typical reasoning and thinking of* ***Indian society****... I never felt that way in front of me nobody can do that on my face. I don't have habit of asking help and rarely go to somebody for favour. But these things of making you feel otherwise or abnormal comes when I meet with my relatives. They will say something or do something and most of time is hard to reply them as in* ***Indian societies*** *you can't say anything to elders. And because of that I always avoided going to family functions and gatherings. In* ***Indian***

> ***Society*** *most of people doesn't have any knowledge of what Type 1 diabetes is? And they don't want to know as well. And most, they have done is to pull diabetics leg, or criticize them, or make them inferior....Yes many people think that as I am diabetic I am somewhat retarded not only mentally but physically as well. And in* ***India*** *if boys are more health consciousness then people think he is somewhat gay or psycho."*

These respondents say that the society has not changed, it (the society) does not know sufficiently about type 1 diabetes and also does not want to know. There is dissatisfaction with this attitude of the society along with the discrimination faced from them. Yet the need for the social body remains. This need is addressed in the virtual society. In the virtual society, on the social network websites, one can choose which group to be a part of and thus avoid that section of the society that 'has not changed' or has a pejorative attitude towards the sick. The virtual society offers the option to express one's opinion while remaining anonymous and the freedom to participate or withdraw without any obligations to the 'society'. The virtual society in many instances does act as the real society giving advice, help, counsel, encouragement etc. and offers friendship as between equals.

Whose body is it? / Body-politic

Individual bodies are not always owned by individuals exclusively. Family, society, religion or religious groups lay claim on them. An initiation ceremony is as much about the individual body as much as it is about the social body. The individual body becomes the site of a social ritual and manifests the claims that the Social body has over the Individual body. The Individual body in such times comes to acquire symbolic meanings that can only be deciphered socially. Circumcision, tattooing, body art, fasting etc. are all examples of such assertions of society, culture and especially religion that lay a claim upon the Individual body.

The rights to the individual body that religion and society lay claim upon, the demands that they make upon it, the meanings they attribute to it, and the determination of what kind of bodies can be accepted or not raises the question 'whose body is it?' Health, illness, beauty, looks are not only about the individual body but also the social body as these ideas are socially constructed, communicated and upheld. The interaction between the individual body and the social body with relation to ideas like health, sick role, image and representation goes beyond these issues. The relationship between the individual and the social body also deals with power, control, and the struggle for it. Hughes and Lock (1998) borrowing from Douglas (1966) discuss how with a threat from outside or another group the social body levies control over the individual body in terms of purity and pollution, regulations and surveillance. They state, "The three bodies- individual, social, and body politic -may be closed off, protected by a nervous vigilance about exits and entrances....In each of these instances the body politic is likened to the human body in which what is "inside" is good and all that is "outside" is evil. The body politic under threat of attack is cast as vulnerable, leading to purges of traitors and social deviants, while individual hygiene may focus on the maintenance of ritual purity or on fears of losing blood, semen, tears, or milk" (Hughes and Lock, 1998: 217). They also discuss the ways in which societies control bodies in general, when there is no crisis, by proclaiming certain features as better than the others, and socialising these ideas about what is a good body and elaborate on it with the example of the contemporary healthy, trim, toned, and sexual bodies as the 'ideal' in the modern society. They further examine the role of bio-medicine and the problem of 'medicalization', and the state sanctioned power and control that medicine and medicalization hold upon the individual and the regulation of their bodies. Similar themes are discussed in this research also.

Decision-making

Alderson (2007) discusses the controversies about children's consent to healthcare and research. He explores the competence of minors to take decisions, and their abilities to calculate risk. He further points out the risks of either completely excluding the children from decision-making in order to protect them or exploitation of their involvement because of limited competence and inability to calculate risks. In this research as well it was observed that many minors were not allowed to be interviewed by

their parents about their illness. In fact many were not even allowed to be contacted by the researcher and had to be approached through the parents. Some parents considered their thirteen years old children as too young to be interviewed without even taking their opinion. This may as well as be the first step of denying personhood to a juvenile and not giving credit to their ability to understand their own body and self, leave aside defining it. This may also indicate that body and identity are considered adult issues and teenagers are thought incompetent to handle them as also suggested by Alderson (2007). Some parents were willing but on the condition of confidentiality. At times even 20 years old diabetics had to take the permission or agreement of their parents to talk to the researcher. The intervention of family was also seen in decision making about which doctor to go to, what treatment to take. At the level of decision making, in the process of not giving consent to interviews, the owner of the diseased body itself is denied to tell his/her story because of the presumption that the body is not "grown up enough" to have authority over 'self' or may be the 'self' is not grown up enough to explain about and have authority over the 'body'. This is also where the family, relatives act as the social body and influence the decision-making process.(Na. 99, Na. 100)

> ***Na. 99*** *"Because my aunt was working at NIMS, as she is a nurse there, she suggested/told to go to the endocrinologist there. So, I went there and I was under his treatment."*

> ***Na. 100*** *"The doctor gave me (after the diagnosis) to take insulin. He told to take 10mg. Only one day I had taken. The next day my parents felt very bad. We are only two children. Sister got diabetes and 'he'* (referring to himself) *also got diabetes, it means it is a very pathetic situation for my parents, because, they are not having any diabetes. Why it has come to their children? They told we will try from an Ayurvedic treatment. We went to an Ayurvedic doctor. And he told to stop insulin and I had taken only one day. So we went to the Ayurvedic medicine. Some oil, some powder to drink, to mix with water and drink. While I stopped insulin for almost six months I continued that Ayurvedic medicine. In between I will*

be checking, the sugar level will be around 250. Sometimes it will come down to 200 or 150 like that but not maintaining. I am becoming very weak... For six months I have not taken insulin, till June 1999. After that what I have done is I have discussed with my sister, whether it is good for my health to continue my Ayurvedic medicines. And June onwards I have started insulin continuously. Then it has come to somewhat normal."

Even though, in the above case, the respondent witnessed the sugar levels not stabilising and going very high, he did not raise objections to his parents' choice of medical care option or insist upon changing the medical care he was adhering to for a long time. In fact, the change from bio-medicine to Ayurveda as a decision was taken not by the respondent but by the parents and also the shift back was after a consultation with a close family member who too suffers from the same ailment. This raised the questions - whose body is it? And who exercises control over whose body? For example the following narrative (Na. 101, Na. 102) shows even though the respondent reported ill-health his parents did not take an action till much later. They had their own explanations like *"Because you are not eating your breakfast", and "They are traditional kind of people who used to say that "keep praying and everything will be fine".*

Na. 101 *"I used to feel like something is pulling me down while climbing the steps up, like that is how I felt something is wrong with me. So I told my mom. She told, "Because you are not eating your breakfast." I never used to eat my breakfast, for 2 years during my intermediate course. So…she used to tell me, "You eat your breakfast everyday and go, and the thing was she started giving me for breakfast milk with sugar and I did not know that I had diabetes so the sugar levels were highly shooting up. Then someday I told my mom, like I cannot bear it anymore so please take me to the doctor. They are traditional kind of people who used to say that "keep praying and everything will be fine". I told her "No take me to the doctor. Something is wrong with me." Then finally one day we made it to the doctor and he examined as I told you already...."*

Na. 102 *"My reaction to that was, initially, I did it. When they told me I did it. I had to do it because I was a kid at that time. I did not know anything about it. Later I told, like my condition was going down, so I told them, "No. it is not ok for me to like keep praying or…yes prayer is a part of life, it is required. But we need also do something from our side. It is that we are completely dependent on God for every good and every bad. So, you need to work out from your side. It is told in the Bible 50% you do and 50% I give you. So, it is not like you keep praying sitting down there and saying, "Jesus, please help and you come down here." You know it is not like that. I told my mom that she has to go to the doctor because I feel something odd about myself and later on they like, seeing my condition they took me to the hospital. And that is how I was diagnosed with diabetes."*

Once again these narratives bring to our attention that though 'body' is primarily in the individual realm one cannot reject the social body or that the social body cannot be ignored in decision making or laying its claims to the individual body. The religious constructs (as already discussed earlier) also re-define the body and what should be done with it in times of crisis.

Tradition and Modernity

The influence and the hegemony of bio-medicine have gradually come and got established in the Indian set-up. The education system of the country and the government policies upholding and popularising bio-medicine are factors that have persuaded the shift from traditional and alternative medical practices to bio-medicine. In the politics between bio-medicine and alternative medicine bio-medicine had come to assert its power successfully where people too accepted the power and authority of bio-medicine, at least in the case of Juvenile diabetes. The influence of bio-medicine on the respondents was seen in their explanatory models.

Explanatory models are important for first and foremost they establish how a diabetic perceives his/her body. We can assume that since most of the respondents were seeking only bio-medical treatment they do not have an alternate explanation of the body.

Many respondents did not know how or why diabetes is caused in bio-medical terms either. Most respondents when asked "why or how diabetes is caused?" gave symptoms of diabetes and few could explain the patho-physiological changes that take place for a person to become diabetic. The bio-medical symptoms are recognised, the treatment is followed but aetiology is neither known nor inquired in to. Respondents understand the implications of the disorder on their life, the complications that can arise due to neglect or lack of appropriate care and the lifestyle adjustments that need to be made, to which they are adhering or making an effort to adhere to following the bio-medical system without making reference to their bodies in detailed bio-medical terms. Bio-medicine has nevertheless greatly penetrated into the understanding of the respondents. As discussed in the Individual Body, the ideas of calories, carbohydrates, diet and nutrition, and weight, have greatly impacted the ideas of health for the respondents. Respondents used bio-medical terms of explanation rather than terms of reference given by alternative medicines. Their usage of these terms expresses how they see their bodies and the prominent explanatory model in their understanding of diabetes. (SNFD-8)

> ***SNFD-8 a)*** *"When you take alcohol,* ***your body*** *treats it like poison. So, your* ***kidney*** *tries to drain them out of your body as early as possible. So, if it was doing some other job, it keeps them on hold and gets rid of alcohol first. If you drink too much, kidney becomes too occupied in draining them and ultimately* ***the glucose level of your body*** *comes down- sometimes too dangerously!!! But this is only the* ***metabolism*** *part of it. On the other hand, if you are a regular drinker and drink too much at a time,* ***the calorie intake (a peg of alcohol has about 120 calories-absolute unutilized)*** *makes an adverse impact on your* ***blood sugar and sugar level*** *keeps on going up."*
>
> ***b)*** *"So, if you are an occasional drinker, go for it. But not more than 2 pegs at a time with sufficient* ***healthy carbs*** *in snacks like pulses (Chhole, Chana, Green Salad, Green Peas, Peanuts) and not nasty ones."*

c) *"As far as smoking is concerned, it is like* ***sodium*** *intake for diabetics. Just like sodium, which may not directly increase your blood sugar but will have other adverse effects on a diabetic(all doctors tell diabetics not to eat Papad- whose actual* ***glycaemic index*** *is only 36!!!!), smoking also might not immediately shoot your blood sugar over the roof, but gradually enhances your* ***neurological and cardiovascular*** *conditions go worse."*

Terms like healthy carbs, calorie in-take, neurological and cardiovascular, glycaemic index etc all refer to the bio-medical explanations. On the other hand, we do not see any reference made to Ayurvedic or unani or any other alternative medicine in the explanations or narratives of the respondents though most of them have tried these alternative medicines too. One of the respondents (Na. 103), a retired engineer, explained about Ayurveda as...

Na. 103 *"Definitely Ayurveda. It is very old in India and abroad also. It is natural because it is made of panch-dhaath (5 elements). You know paanch-dhaath? The secret is in that. But paanch-dhaath is not there in any other thing. Like allopathy, homeopathy. It can treat the disease. You can treat the disease in whatever manner you like but try to live with the natural way. You are facing problem. Ok. You have got four departments- Allopathy, Ayurveda, Homeopathy and Siddha. But try to live the natural way. Natural way is the correct formula for good health. In that Ayurveda comes. It is directly made from plants. And application is very difficult that is why in our modern life it is avoided."*

Beside that he also sees Ayurveda being combined with nano-technology (which suits his reasonable, rational, engineering mindset). He being educated and belonging to field of science and technology cannot simply accept Ayurveda. Yet, the roots of religion, explanatory model of 'natural' and traditional is also visible in his explanation and understanding of body. Thus, the combination of the two alone is seen as

profitable. He wants to highlight the science in Ayurveda and the closeness of nature in nano-technology. (Na. 104)

> ***Na. 104*** *"...In Ayurveda, nanotechnology. Any combination is there? Nothing is there. But see. There is nanotechnology in Ayurveda."*

Ayurveda is understood as 'natural' and even though it does not help the juvenile diabetic situation it is seen as harmless. Some respondents had tried Ayurveda alongside allopathic treatment. Their faith or belief in Ayurveda has not diminished even though it cannot help with juvenile diabetes. And there might be other ailments for which they take Ayurvedic medicines. Respondents did say that Ayurveda is good for treating Type 2 diabetes but not Type 1 thereby emphasising that Ayurveda is effective and it is just in the case of Type 1 diabetes that it cannot help. (Na. 105, Na. 106)

> ***Na. 105*** *"Yeah, I mean at least because it (allopathic medicines) gives me instant relief. I am not saying that Ayurvedic does not work or its ineffective because of late I got to know a distant relative of mine, he is 47 years old and he has a kidney problem and his "cretan" loss was close to 0.7. I mean it was close to death only. Doctors gave up hope and they said there is no chance of recovery. He started, he told me, this water therapy. I got to know of it very recently and he was on Ayurvedic medicines and now his "cretan" loss has dropped down to 6 which is close to normal. I mean not close to normal but comparatively the stage he was in. It's amazing. And this has been over the period of what nine months or over a year. He is actually coming down to take me to that person. Now I am ready to believe in it, I've learnt that it works. Because one- I am not moving away from allopathy while I am taking that treatment. So, I am focused on it. So the things are under control. But two- it might help me because my cretan loss is just 2.8 compared to his 47. So, definitely let me see, if it can help."*

Na. 106 *"It depends on…I've tried yoga actually. But then it resulted into back pain for me. Probably I was not doing it right or my instructor was not up to the mark. It could be anything. It could be that my body is not willing to accept it or the moment I got the pain I gave it up. It could be anything. But then it does not work for me so I don't have faith in it. I've…they started giving me some Ayurvedic treatment; it was a rudraksh (magic beads) treatment. I was made to drink rudraksh water day in and day out. My entire room was full of rudraksh; I was sleeping on rudraksh. I don't know. It was crazy and it didn't work for me. So, I don't believe in it. The only thing that worked or gave me relief was allopathy and I struck by it."*

The traditional medical systems have not been completely rejected and the modern and the traditional have found place with each other. Most definitely the bio-medical system has replaced the traditional terminology and understanding. Nevertheless the traditional systems seen as part of the native culture in contrast to the foreign Western bio-medicine retain their significance. There is seen also a negotiation between the traditional and the modern when Ayurveda and Nano-technology are seen together and as complimentary.

Beside medicine systems Yoga was another important feature regarding the traditional practices in the narratives of the respondents. Interestingly even though respondents are not seeking treatment from any alternate medical systems some of them do yoga and find it beneficial. They also saw yoga as not only benefitting their body but also helping with their mind to be relaxed. (Na. 107)

Na. 107 *"I do yoga every day morning for an hour. Evening I used to go for walking. It has helped a lot. It helped me to relax a lot and my mind to be free. And I am taking insulin so it enters better and it works a lot."*

It was seen that Hindus and Christians had tried Ayurveda and yoga or were still doing it but none of the Muslim respondents had either tried Ayurveda or yoga. The Christians saw Ayurveda as a just another medicine system and yoga as an alternative form of exercise. Even though it may not find a place in their religious understanding they also do not find it offensive to their basic faith. But none of the Muslim respondents having tried Ayurveda or yoga suggests reasons related to religion for making such a choice. Also in that sense Allopathy or bio-medicine can be seen as a neutral medicine system one which does not have any religious attachments and therefore becomes approachable to people crossing over such boundaries.

Doctors usually suggest some form of exercise like brisk walk to diabetics. Yoga was also suggested to the diabetics by the doctor as an alternative form of exercise and seen as complimentary to bio-medicine. Definitely allopathy doctors do not uphold the idea that Ayurveda can help in Type 1 diabetes but they too find common ground with it in respect to prescribed and proscribed foods. Therefore, yoga finds a place in the bio-medical system and there is some negotiation or concession made with Ayurveda also.

We find here the amalgamation or coming together of the traditional with the modern. The two are used, both by doctors and patients, in differing proportion but nevertheless they find a place in the explanatory model of both. When they are combined by the patients the efficacy of each is emphasised. And when the traditional is denied, the explanation always upholds its general effectiveness, goodness, and benefits and clarifies its limitedness in the particular case of Type 1 diabetes thereby never rejecting it as a whole. On the other hand, there has not been exclusive compliance to bio-medicine by any of the respondents highlighting their hope in the traditional systems as well as reservations regarding the new and modern, the foreign, and the ‘outside’.

Competent Bodies and the Society

The narratives about marriage and social relations with friends and colleagues, job point at how the ideas of healthy, competent body are ideal and aspired for. The diseased body is looked down upon. The changing economy, globalization and a fast

moving market have no place for bodies that hinder growth or delay progress. Unlike societies where those moving fast, seeking individual gain/profit were considered greedy and looked down upon we find here a very different scenario. To be physically fit, be able to work, and compete is a pre-requisite for today's society. Not giving work is one factor which emphasises that one needs to have a competitive body. On the other hand, denying marriage proposals because of the sick status of a person makes a statement of another kind. It suggests the desire to stop progenies from carrying the disorder besides avoiding the complications of the disorder in the life of the spouse. Time and again the respondents in their interview and also in the discussions on the social networking website stated how they see the India society as oppressive and opposed to the diseased individual. They talk about the mentality of the Indian society which has discriminated against them either in the form of friends or colleagues, relatives, job, and most significantly at the time of marriage.

On the forums of the social networking website the angst was shared and discussed very openly. The usage of "Us diabetics", "We are better", "We do not need..." highlight that the participants on the website see themselves as one group or a social body versus the larger social body. Statements of how they are better than the 'normal' people and how they should start ventures that will only employ and cater only to the diabetics press the point of the virtual social body fighting against the society's outlook about the diabetics. A discussion on the forum (SNFD-9) is given herewith. Herein was witnessed the remonstration of the sub-group and even of the individual through the sub-group. The individual member of the forum found ways to express him/herself against the social body through the sub-group where other members were in agreement with him/her. The avenue of the social networking site and the discussion forum provided the individual with the platform from which to communicate his/her woes with the social body. This is represented also in the figure given below followed by excerpts from the discussion forum.

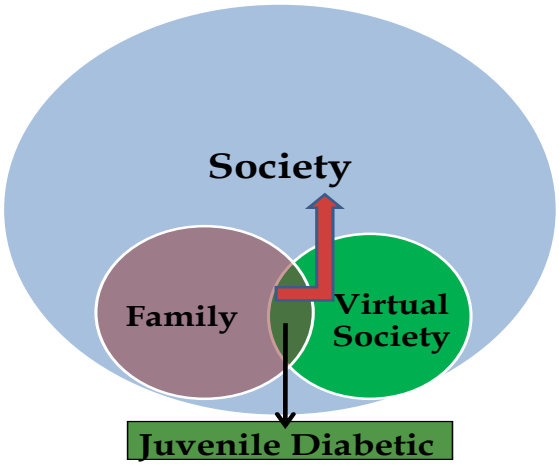

Figure 4 Representing the virtual society as a means for individual Juvenile Diabetic's communication with the larger social body

SNFD-9 a) *"Hmmmm... I know... and at this point I can only say that Iam aiming very high... I am aiming to form an organisation which can adopt kids from poor families who abandon their children because they have diabetes... several kids die without knowing wat went wrong... I'll adopt them... educate them and make them capable enough to earn their living... this is just a part of my big dream... I'm working on it... it will take quite sometime to achieve what I desire but I'll achieve it one day! This is gonna be pure diabetes related thing... I wanna have a company which will hire only diabetics...! Just imagine.... I mean no more companies will reject young professionals just cox they have diabetes!!!!... We'll achieve all this... I'm just waiting for the right time to start on this project head on... WHO is certainly very supportive of my plans!!! It'll work out and we'll have a cure too... not just medically but socially as well!!!"*

b) *"wonderful dream and i will try to help as much as you can in realising the dream.....adopting poor or orphons or neglected diabetic kids and making their life is an excellent idea we have an organisation juvenile diabetes foundation (jdf) to educate jd's and parents and provide insulin at subsidised rates to all and free to jd's who cannot afford.....we find donors to adopt the kids as far as insulin and glucometer/strips costing is concerned.....we also have a team of doctors, psychiatrist, dietiens and diabetic educators for the cause"*

c) *"thts v nice.... n i have a wish too.... im a typical teenager who loves to hang out with frnds n v r regular customers of coffee shops... n all u get there is tempting sweet coffees, cakes, brownies, ice creams stuff..... i do get tempted n have them too..... but then my guilt doesnt let me sleep....my wish is to start my own happening food joint which will have tasty but healthy food n stuff..... which anyone can have without thinking twice... n this will be especially for diabetics or just any other person too.... i dunno when will i be able to do this... but it will happen someday.. i've dreamt big too..."*

d) *"what you've seen as a dream for yourself and that in turn will do so much for diabetics... I'm basically thinking this way... when we adopt kids or teenagers and train them and teach them english only then they can be employed... and then when you plan to open your healthy joint food chain... you'll hire only diabetics... I mean see it for yourself... you are producing job opportunities for ppl just like us...! If everyone of us plan for something like this... to start off even in a small way..it will help..I want this place to generate its own revenue... Initially we'll need great financial support from people as well as organisations but once its established it can generate its own revenue...*
I mean we can have a big company which can be into anything from

interior decoration, fashion designing, engineering, software, hospitality.... etc etc etc... you name it and we can do it! This is what I see as a DREAM!"

e) *"But I do believe I can be "DIA-BUDDY" that is the name i give my diabetes buddies...!!! Yeah I plan on making a whole new world of diabetes!!! I live for it... literally!!!!"*

Respondents talking about creating a 'world' that caters to the needs of their like, of making opportunities that the society at large has denied them brings the diabetics together as a group that is united by the common thread of not caste, race, religion or gender but of their diseased status versus the society of the 'normal'.

This nevertheless does not stop here. One of the respondents compares his state of sickness, the attitude of the society (which is Indian!) with the foreign representation of the Indian society (Na. 108). He is equating himself with the Indian nation and how outsiders always see or portray India in bad light which is very discouraging. This scenario he compares with his own situation wherein he is looked down upon and discriminated by the society (Indian) and is discouraged by such a treatment. He states how India is seen as only a poor and illiterate country and society by the foreign nations. Similarly, he perceives that even the Indian society sees only his diseased status and all the effort and hard work that he has put in to achieve something are being discredited by the society. And he does not want to be a part of that 'failure story' where only the grim is highlighted.

Na. 108 *"Your questions are really discouraging. I am really living on ray of hope, hoping to see better future and don't (want to) see any light in present. I know what life is, I have seen that very closely, not only because of diabetes but due to other reasons as well. Most of guys who have diabetes or cancer or TB they remain alive just because of hope.*
If you have seen any foreign movie or documentary on/about India you will see only poverty, poor life, illiteracy. You will never see good about

India. Check latest 'Slumdog Millionaire' for example. Your report seems to be that only with very bad conclusion...
I don't want to be part of a failure story."

The Interaction of Individual, Social and Body-Politic

The individual body, social body, and body-politic influence and impact each other. We see that there are issues where they overlap. For instance, the individual body deals with its pains and processes, looks and others. What pains and processes are accepted and what looks are usually socially approved and communicated. It thus remains not an issue of individual body but also social body. The weakness of the individual body finds rejection in the social body. The weak cannot compete. To carry them together might mean slackening the pace for others and thus they are rejected or treated as abnormal. This brings the three- individual body, social body, and the body-politic together.

Food and diet are about the individual body but the ideas upheld by the social body, that a healthy person can eat all that they want, reminds the respondents of their diseased state especially since food or diet are very important in the diabetic regime. When the respondents faced situations wherein they were forced to take foods that 'normal' people can consume but are proscribed for diabetics they either took some or avoided them giving some other explanation rather than disclosing their disorder. The respondents tried hard to keep the diseased status of the individual body concealed from the social body. The 'normal' identity is sought by either hiding that they cannot eat everything or by explaining how low sugar, low fat, low carbohydrate foods are healthier and better. There is an effort to meet the social ideas with new constructs of what is healthy and what is not.

In terms of looks, thinness (as much as obesity or even being fat) is a symptom of ill-health which the respondents want to avoid so that no one asks them or suspects their health. Being muscled is masculine and is a social image deeply incorporated by the individuals and they aspire to attain that. Yet all these images are

either justified or rejected in the light of what is 'healthy' or beautiful. 'Healthy' not only in terms of how society perceives it but bearing in mind the medical implications of the same.

The individual body is also hidden while interacting with the social body on the issues of work and marriage. The power of society impacting individuals regarding marriage and work is significant and thus the need to not disclose the diseased body also becomes very important to the individual. Social body exerts pressure on the individual body. At times the individual body complies and competes by rules of the social body, like by trying to be competitive in studies, work, and achieving what is considered important by the society. At other times the individual body rebels or opposes these pressures. Denying the 'sick role' or asserting to be 'normal', disregarding the social ideas of ideal, healthy body, and choosing to disclose or hide the diseased body (the fact of it) may be counted as some. The virtual society or social body is another form where a sub-group is formed to deal with the pressures of the social body. Therefore, at times it is the individual body that rebels and at other times it is the sub-group that is the face of the protest.

The idea that alternative medicine is natural and all good as opposed to bio-medicine is passed on through the social body. It is also in a way rejecting or at least questioning the power and validity of bio-medicine by alternative medicine which is traditional, ancient knowledge as opposed to the modern medicine. We see here that the ancient or the traditional is not completely rejected in spite of it not being able to help the situation. On the other hand the modern is accepted as 'not-so-natural' because of instant relief and the only available option. What is traditional and old is treasured and what is new does not replace the old but finds space because of its efficacy.

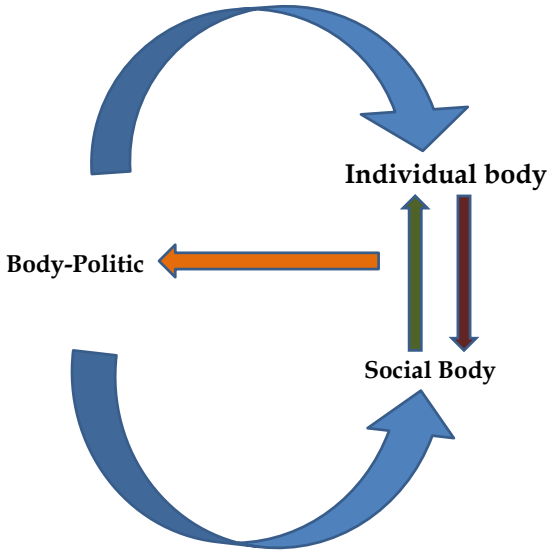

Figure 5 Representing the interaction between the three bodies- Individual, Social, and Body-politic

The Constructs of Self

Similar to body we can view self also along the lines of the model given by Hughes and Lock i.e. individual self, a social self and also a self facing control and subjugation. The individual self may be soul or mind (the thought processes as well as the talents and capabilities of one). That is to say, that the 'Soul' and 'Mind' are different and the individual self may be perceived as 'Soul' sometimes and sometimes as 'Mind'. The social self is the social identity. The social identity may be derived from work, family, peer group, marriage and even religious ideas of a social body and one's place in it. And the third self- Self-politic is to be located in the context where one faces the challenges of hegemony, confirmation and divisions of normalcy and abnormality and confronts it or resists it in different ways. The diabetics' perception of 'Whose problem is it?' 'Who is

to be blamed and held responsible- the individual or the society?' are the ideas that the self-politic deals with. These ideas of self also are constructed and exist in a social context and influence the way a person sees his/her individual self, the social identity and questions hegemony. These constructs of self- Individual Self, Social Self and Self-politic are discussed below with reference to the narratives elicited.

Individual Self

Grace Harris' study (1989) discussed and distinguishes between individual, self, and person. According to Harris "A concept of the individual is one focusing on a human being considered as a single member of the human kind." (Harris, 1989: 600) Cultures differ in their conceptualisation and boundaries of the individual as discussed also by Douglas (mentioned in the Introduction-Chapter 1). Every individual does not acquire the position of person. Person, as Harris states, is an agent in the society. "Dealing with a concept of persons entails conceptualizing the human or other being as an agent, the author of action purposively directed toward a goal. By "Human person" I mean a human being publicly considered an agent. In this sense, to be a person means to have a certain standing (not "status") in a social order as agent-in-society" (Harris, 1989: 603). Person can be a non-living human, a deity or even a disease. Many societies perceive their world which its members share with persons that are non-human like deities, spirits and others. Cultures vary on their concept of 'person' but these ideas of non-human entities or persons are somewhere or somehow influenced by the ideas of the living human person.

Self is different from individual and person. Self is not just an individual or a single unit. Self is also not person in the sense that all selves are not agents in the society or when persons are located in the context of non-living or non-human entities. The concept of self situates the human-being as the locus of experience, even the experiencing of the self. Self is an object and a subject at the same time. That is, as an object it can be observed and as a subject self observes self in a way no other can. As a subject the self knows that self is oneself and different from others. As an object the self continuously studies and examines itself as an 'object' that can be observed and brought within its own

purview. For self to exist it has to be a living human being (according to Harris it can be animals too) and be self-aware[7].

In the study it was observed reference to the self (just like in the case of body) was not made directly but was implied. One referred to oneself but not to one's self. In other words respondents talked of 'myself', 'I', and 'me' but did not discuss their 'self' as an object. That is to say when one said "*I will be suffering*" or "*I have to take care of my health*" one referred to oneself but did not speak about one's self consciously as soul or mind. Also, one is self and the self may change or shift (from soul to mind to identity) but rarely does one refer to the self as 'the self'. People talk of oneself but not one's self not just in the context of illness but in general also wherein attitudes, likes and dislikes, nature, feelings, experiences, frustrations are narrated when speaking of oneself to express oneself and identify oneself juxtaposed to others.

Though one rarely consciously makes reference to his or her 'self' as such but this does not mean that one is not self-aware. The references to self were in suggestions of soul or mind or social identity though sometimes these specific terms were used and sometimes not. Therefore the data analysis also takes in to consideration the absence of these terms or rather their representation by other words as significant.

Sometimes 'I' representing 'self' also referred to 'the body'. Statements like, *"I must take care or I will be suffering",* sees the body as the self. The 'I' that will be suffering talks of the suffering that body will have to endure because of the sickness. The respondents who were suffering in the body (complications) or were facing discrimination from the society associated their self more closely with the body and that too as the diseased body. Turner (2001) discusses the embodiment of self and states, "Who I am cannot be separated from how I am embodied, and thus any traumatic disruption of my body through accident or disease brings about disruption to the self (Turner, 2001: 254)". And the statements like, *"I am diabetic"* led to an important

[7] "In Western psychological terms, the critical related faculty is the second-order monitoring that we label "self-awareness" (Harré, 1979: 282)." (Harris, 1989: 600) The subject of self-awareness then subsequently raises the question of whether people with mental disorders especially schizophrenia have a sense of self or remain self-aware. In the case of multiple-personality disorder or in cultures where the ideas of multiple selves is common the issue of self-awareness becomes intriguing.

question of whether these statements speak of the body or the self or sees the diseased body as the self? For such respondents their social identity was steeped in their sickness and the stigma attached with it. And eventually they saw themselves also as diseased. The narrative quoted below (Na. 109) also suggests how a respondent did not see diabetes as a disorder but as a disease whereas many other respondents took consolation or comfort in their sickness status by saying that diabetes is a disorder and not a disease and suggesting his viewing of his self as a diseased person.

> ***Na. 109*** *"If I was talking with some diabetic then would have said disorder otherwise really it is a disease only. And doesn't matter whatever it is, I am diabetic."*

Respondents did talk about mind or thoughts but that was rare. The disorder in the body was seen affecting the mind by the respondents. They stated that health is in the body and in the mind. Disease in the body adversely affects the mind by causing stress and tension. Health in the mind or the state of mind also affects the body. Respondents stated that when they were under work pressure or stress their sugar levels went high affecting their body adversely. Mind was thus spoken of clearly as dichotomous to body. Yet, this did not imply that they saw mind as 'the self'. The mind is here seen as separate from the body because the body is identified as having the sickness and not the mind. On the other hand, the mind alerts one- 'the self'- about the ailment thereby suggesting that the 'mind' is also separate from the 'self'. The separation of mind and body, and mind and self is reflected in the following narrative (Na. 110) where the mind is also owned by 'me' and the mind is not 'me', which exercises the control and takes decisions.

> ***Na. 110*** *"Yes,* ***my mind*** *always keeps* ***me*** *alerting that* ***I'm*** *diabetic and that helps* ***me*** *stick on to* ***my*** *limitations."*

In this study religious construct of self as soul was also observed. The term soul was used rarely and but was implied through other terms and explanations. Only Christian respondents used the term soul whereas the Hindu and Muslim respondents did

not. As discussed earlier, the Muslim respondents hardly made any mention of religion or God in their illness narratives. The Hindu respondents spoke of fate, destiny, and karma thus implying the role of their soul in their illness but did not use the word soul per se. The Christians made a direct reference to soul, the Hindus made an indirect reference to soul and the Muslims made no reference to soul at all. The world view of these religions impacted greatly the ideas of self and self as soul for the respondents. For the Hindu respondents the religious construct of cycle of life, death and rebirth and so forth persuaded them to believe in karma and destiny and these are the explanations that were used to understand the cause of their illness. These ideas were predominant to them. On the other hand, for the Christian respondents who believe in one life and after that judgement, the immortality of the soul and the resurrection of the body, body and soul were the terms interwoven with their faith and world view and these very terms were used to explain the self.

The religious paradigm thus was seen to play an important role in the conceptualisation and explanations of the individual self. That is to say, the respondents see their self as soul because of the religious constructs that influence them. And because of this the terms that are manifestly used in the religious discourse also become a part of other discourses like sickness and health. (Na. 111 to Na. 113)

> ***Na. 111*** *"My…Actually it is a concept actually. One is having body, soul and spirit…Body is having one desire and soul and spirit will also be having own desires. So, if we are…if our body…body will be having its own desires, worldly desires it is having. Our soul is divine only. If soul is…is just converting from divine to devil. It will…our soul will lead our body to do wrong things. Then it will get united. And it will do wrong things and if soul and spirit are totally controlled by God. Our body also will be totally united with it. And these three things will be a unit. So, as far as my concern sometimes…almost all the times I will be controlled by God only. So, my body is in [under] control of my spirit…control inside my…my inside this thing. If sometimes very…I am going outside my God's control means my body desires do wrong things due to my body pleasures.*

Then it will go out. Then again if you are coming back it will-it will be rectified. My concentration is I should be totally in control of God. God…means my soul should be in the hands of God. My soul and spirit is in the hands of God means my body also will be. God is guiding our souls and spirit and body will be united with the soul and spirit. We cannot differentiate with that. Totally united." (Christian)

Na. 112 *"I told it is a combination of the 3 factors which is essential for an individual to feel in a state of well being it is a concept based on/derived from holistic medicine. There is no health in soul but always there is soul involved in a person's health... you have to keep praying so that, that can build up your inner soul. I mean it can make you grow in a right way. So, I believe that ah ah praying is like the key thing to keep yourself in track so that you don't go off the track. And that is very much required to feel positive about yourself."(Christian)*

Na.113 *"In the beginning I got (angry), but it is my fate I think. But my mother believes... She says, she has done some sins that is why it has come to her daughter. And that is the cause my daughter has to suffer... Whatever sins I have committed this is the going punishment. Next life will be good." (Hindu)*

The individual self is the one that exercises control and exerts the need to know all that pertaining to oneself. Even in the embodied self, the need to know 'what is going on with my body?' was taken very seriously by the respondents. There is definitely the recognition of the health-care practitioner holding specialised knowledge yet, there was also felt the need, which was vocalised, to be well-acquainted with the self, to know what self wants. The charting of calorie and carbohydrate intake, the adjustment of insulin according to diet, consumption of alcohol, amount of exercising and so on all clearly show the individual self taking control of the embodied self.

Self in Existential Construct

Self is also an existential issue. The existence and prolonging of that existence were issues of prime concern to the respondents. Even while considering the body and its health the protection or security of the self became the main factor (Na. 114). That is to say, when body is protected and effort is made to keep it healthy it is towards extending the existence of the self. The 'self' became quite prominent in the discourse regarding the existential constructs of self and dealt primarily with the individual self. It hints also at the social self as the existence becomes meaningful in relation to others.

> ***Na. 114*** *"After knowing my body is having a disease some or the other day all these problems might attack at a time or one after the other. So, some or the other day everyone will lose their battle here. At least until then I would like…Before that I need to…I need not lose."*

What the respondent (Na. 114) is trying to say here is that everyone is going to die one day and he because of this disorder is more at risk. But, he does not want to 'go' or 'lose the battle' before he absolutely must. He wants to preserve his health and his self as much and as far as possible. The ideas of existential concerns of the individuals become more apparent in the negotiation between individual body and individual self. This is further discussed in the negotiation between body and self in chapter four.

Social Self

There are two approaches held by psychologists and sociologists respectively about 'self' and the study of 'self'. The approaches are -the self to the individual or himself, and the self in relation to the society. That is to say, how an individual, being self-aware sees himself/herself in a certain way and has certain ideas of self. And beside that he/she also tries to locate self in relation to the society and try to ascertain their place in the society. Social identity is not only how one sees himself in relation to the society but also what society gives him/her by the way of socially upheld notions of normal/abnormal, acceptable/unacceptable and the treatment met out. The notions and treatment of society in turn impact and influence the way one sees oneself. Thus, in that sense it is very difficult to actually separate the individual self from the social self.

As Douglas suggests that self knows itself and only self knows itself in the sense that no other can know it. And self seeks to understand itself in terms of its predictability of response. This predictability or self awareness comes when juxtaposed to the other. (Mead, 1974; Douglas, 1973; Harris, 1989) That is to say, one becomes aware of oneself when one contrasts oneself with others and sees self versus the other. On the other hand Harris (1989) suggests that any social discourse or interaction is impossible if there is not a mutually understood idea of personhood, selves and identity and thus meaning that selves, identity and ideas of personhood find basis in social context and discourse.

Anna Wierzbicker (1989) states in paper how 'mind' is essentially an English word and is a folk concept reflected in the English language. The body-mind dichotomy, which is believed to have arisen out of the Cartesian model (based in turn in traditional, western, Christian philosophy) is also not body-mind but body-soul duality. It is understood that the works of Descartes and Freud suffered due to translation wherein the word 'mind' was substituted for 'âme' (French) and 'seele' (German) that are closer in their meaning to soul. Today, with the progress of physical and biological sciences (psychology included), this dichotomy of body-mind finds base in the works of these scholars even if that is not how/what they meant. 'Mind' in the English language has come to mean that which is not material and thereby different from body. But it has restricted the way in which the non-English folk concepts view it and express it. She states that body-mind dichotomy is not as much a Western idea but an Anglo-Saxon concept and gives the example of the Russian culture wherein 'Telo' (body) is not conceptually opposed to 'duša' (which when translated in English could mean soul/mind/heart depending on the context).

Most respondents talked of the self in reference to their social identity, even though implicitly. The way the society sees them has deeply influenced their social identity. That is the reason why most respondents have not disclosed about their ailment to their friends or colleagues. Some have kept this also from their relatives. Understanding their self in relation to the others they saw their 'self' in contrast to the 'normal' people. They saw their self as somehow impaired and impacted by the disorder

and thus, not 'normal'. It is because of that they hide the information about the disorder from others and also want to prove 'themselves' in spite of the disorder. Work, workplace, and the need to prove oneself at that avenue also signify the same. (Na. 115, Na. 116)

> ***Na. 115*** *"Once I started growing up and everyone started going out and doing this. But I never had any dreams. Whatever everyone started doing this- that I thought I might not go, ok. So, then during that I thought, "Ok! This is the time I need to prove myself. I was having this thing also. Then only I can become role model or I can tell something to the people. In spite of having this disorder in me also I can…I proved something in life. From that day onwards I started. I think…I think…in the middle. That's why my sugar levels are shooting also. To achieve my final dream I need to fight this. Because if I can keep the balance between my professional and my this health then only I can…That is what actually is the disorder. That is actually I can say I have something deficiency or whatever you may call it. Other people need to fight only professional or whatever but I fight my own health care and this also. I need to balance…keep the balance then only I can…hit the target."*

> ***Na. 116*** *"...now a days I am struggling profession…professionally and seeing the pressure. From last 3-4 times, from almost six months my sugar levels are constantly high because of the pressure that I am taking. As I am growing professionally my pressure is also getting increased. So that the pressure that I am handling there that I am not able to cope up with my full exercise and my professional level. So, still there is some gap in me that I used to resolve myself..."*

The respondent in the above narrative (Na. 116) is struggling to maintain balance between professional life and his sugar levels. Body and health are important to survive and on the other hand one pursues the struggle so as to prove himself or his 'self'. Accomplishments or achievements recognised by society are important to assert self and establish one as a normal member of the group or the social body.

Na. 117 *"I never felt any such thing before. I did well in my career worked for one multinational company where I was among most trusted employees. I have worked for whole month, more than 16 hrs a day including Saturdays and Sundays for my previous project, that landed me into hospital. This year also I was awarded with best employee of the year... where I was working as part time employee. But I feel now that I have some severe problem and something lacking then most other guys. When you have to get married and have disease like this, you start feel really limited. Now I have to handle typical reasoning and thinking of Indian society."*

Besides work, marriage is another aspect where one's 'self' is questioned. Marriage is not only about the individual self but also extends to the social self. Marriage does not pertain only to gratification of individual needs; it is also an issue of social identity. In the Indian society marriage elevates the status of a person in the society and gives that person the recognition of being adult and responsible. Not getting married after reaching a certain age is looked down upon. And the reasons or problems that prevent a person getting married have serious implications on their social identity on the whole affecting every aspect of life. Thus, the denial of marriage to a diabetic also affects their social self and social identity. Both, the male and female diabetics, face difficulty in getting married. The male diabetics are rejected because they are thought to be weak and at a high risk of health complications thus, making them poor prospects for marriage. The idea of men as providers and protectors of the family, the stigma associated with widowhood prevent arrangements of marriage between a diabetic male and a 'normal' female. (Na. 130)

Female diabetics stated that it is more difficult for a diabetic girl to get married than a diabetic boy and even a male diabetic would not like to marry a diabetic female. One reason for that is the inferior status of women in the society. Secondly, women diabetics are bio-medically considered to have a higher chance of genetically passing-on the disorder to their offspring. In social identity women respondents found themselves in another matrix related to reproduction that impacts their identity as women

in the Indian society. The disorder has impacted their bodies in one more aspect than it would of a male's. It is common knowledge that there are high chances for a diabetic woman to suffer miscarriage, have complications in pregnancy and delivery and even risk the life of both-mother and child. Their reduced reproductive abilities also reduce their social standing. Among those who are married some of them have already had multiple miscarriages and many others fear that. The narratives of these women respondents are interspersed with the grief of losing their children. For one of the women respondents who had experienced multiple miscarriages and finally could not have any children the whole narrative (Na.134) was around this point. Even on the social discussion forum this issue found space (SNFD-2, SNFD-10, and SNFD-11e).

For the diabetic males the sexual potency was an issue of anxiety though only implicitly expressed. Male respondents did not refer to this directly but the narratives hinted at them when they stated how they were worried about their 'married/ family life' and had talked to the doctor at length regarding that or when they had expressed the desire for more children and their reduced sperm count. (Na. 130 to Na. 133)

> ***SNFD-10 a)*** *"...what kind of precautions the woman of type-I diabetes, should take to give birth to healthy child???? how much effect will occur on the child if the sugar of woman is fluctuating frequently during pregnancy?"*
>
> ***b)*** *"I had gestational diabetes during last 3 months of pregnancy which now has turned to T2. I used to take 4 shots during pregnancy.*
> *I'm now planning for second baby and have done a lot of research- The first 3 months (1st trimester) is very critical since the baby's organs develop during this time. So need to be extra cautious about your sugar levels to avoid any complications to the baby. So the doctor advised me to have tight control before planning since by the time you realize your pregnant its already a month."*

c) *"the effects of lantus on devoloping fetus have not been studied..(you may know that there are drugs that cause dangerous damage to fetus)"*

d) *"Thanks for this info to all of my SWEET frnds.*
I want to know tht
1.whether the diabetic woman can gv birth normally or she undergoes strictly through Operation?????
2.Due to lots of blood comes out of body during delivery ,in what way it 'll affect to me???"

Self-Politic

The self-politic is to be located or seen in the context of who- the individual self or the social self power over the other. The society would like to exert some power or right over the individual self; the right to know who is 'normal' and who is not. This right is exercised in certain contexts. It is in these contexts the self-politic emerges. The social self exerts some pressure on the individual self by labelling[8] them and pressurising them

[8] *Social Pathology* (1951) outlines Edwin Lemert's approach to what many consider the original version of labeling theory. Lemert, unhappy with theories that take the concept of deviance for granted, focuses on the social construction of deviance (Lemert 1951). Lemert (1951) describes deviance as the product of society's reaction to an act and the affixing of a deviant label on the actor. *Social Pathology* details the concepts of primary and secondary deviance. According to Lemert (1951), primary deviance is the initial incidence of an act causing an authority figure to label the actor deviant. This initial labeling of a deviant act will remain primary as long as the actor can rationalize or deal with the process as a function of a socially acceptable role (Lemert 1951). If the labeled deviant reacts to this process by accepting the deviant label, and further entrenches his/herself in deviant behavior, this is referred to as secondary deviance (Lemert 1951). Lemert considers the causes of primary deviance as fluid, and only important to researchers concerned with specific social problems at a certain time. In the years following *Social Pathology*, Lemert argues for the decriminalization of victimless crimes, advocates pre-trial diversion programs, and has backed away labeling determinism (Wright 1984).
Howard Becker's approach to the labeling of deviance, as described in *Outsiders: Studies in the Sociology of Deviance* (1963), views deviance as the creation of social groups and not the quality of some act or behavior. Becker (1963) criticizes other theories of deviance for accepting the existence of deviance and by doing so, accept the values of the majority within the social group. According to Becker (1963), studying the act of the individual is unimportant because deviance is simply rule breaking behavior that is labeled deviant by persons in positions of power. The rule breaking behavior is constant, the labeling of the behavior varies (Becker 1963). Becker (1963) describes rules as the reflection of certain social norms held by the majority of a society, whether formal or informal. Enforced rules, the focus of Becker's (1963) approach, are applied differentially and usually facilitate certain favorable consequences for those who apply the label. In short, members of the rule-making society may label rule breaking behavior deviant depending on the degree of reaction over time (Becker 1963). https://www.criminology.fsu.edu

to reveal information about themselves. There is the right to information that the society holds over the individual and the divisions of 'normal' and 'abnormal' made by the society that coerce the individual self. Reissman (2000) discusses the case of infertility in South-India and points out how others in the family as well as the society exercised the right to know and speak about the woman in question (discussed in Chapter 2). The individual self when does not want to accept this pressure counters it with certain attitudes. They know the way society will treat the knowledge of their illness status and thus to prevent that they deny this information to the society and thus exercise a control over their self and identity. This suggested an attitude of 'my body, my wish'. The individual self thus denied the pressures of the social self to reveal information which will impact their social identity negatively. The individual self thereby resists the society when one tries to hide the diseased body. Not revealing information about the disorder is a way that the respondents denied the society power over themselves.

Similarly, when the society knew of their bodily condition and did not accept them as 'normal' the self rejected that both individually as well as together in group. They asserted their normalcy many times in the interview and also in the discussions on the social forum. They (the respondents) have tried to achieve the standards prescribed for the 'normal' people by having a good health, proving themselves at studies and work place. Thus they have tried to prove themselves by the parameters their social self recognises and has set for their individual self. The place where the defiance becomes the strongest is where the denial is maximum- at the juncture of marriage. This is where we find the maximum amount of conflict between the respondents and the society. Asserting that they are normal are the diabetics who are rebelling. They are rebelling against the socially established ideas of health and what is normal and what is not. These two sections of resisting and rebelling (Fig. 6) are probably due to the influence of the family, friends and their own experience with discrimination.(Some narratives like Na. 78,79, 87,88,90, and SNFD-4 a,c,d discussed under the three bodies reflect these two attitudes of resistance and rebellion.) The individual self denies the right to know. Even if, the right to know is given the individual still does not give the society the right to discriminate. When these two cannot be achieved the individual self submits to the social self.

Figure 6 Representing the pressure of Social self on Individual self and the two attitudes and responses of the Individual self.

The Interaction of the Three Selves

Philosophy has always studied the dichotomy wherein body constitutes one and the other has been contested to be soul or mind or self. Scholars have disagreed or rather refuted soul and mind as constituting the other, the unseen and the non-material in the dichotomy. Recent philosophical works assert self as the other part of the dichotomy. Social behaviourists and anthropologists like G.H Mead (1974) and Mary Douglas (1973, 1994) highlight how this self exists in relation to the others and in a social context. Herein it becomes interesting as it suggests that a person in a religious society sees his self essentially as a soul and in relationship to other souls. The social context and relation to others influences the way the person comes to acquire that idea or the concept of self. Similarly, when in a rationalistic society one sees one's self as essentially mind it has its social context.

Bio-medicine has upheld the Cartesian model of body-mind duality and in order to deal with that it has branched out into two divisions of physiology and

psychology. To view the self as mind is in itself abiding by that model and overlooking self seen as soul or social identity. In Indian society we find a different picture. It is the social identity that is primary to an understanding of self. Soul is a very personal matter and the term as such hardly came up in discussions except with Christian respondents. (May be their world view is all around the concept and also located in the religious social body.) Nevertheless, the religious construct of self remained prominent in the construct of self for most all respondents. On the other hand most respondents showed how important the social identity was even if they were in rebellion to the society's view of them as not 'normal'.

Based on the understanding that only self knows itself and yet not completely we can make three assumptions. One, self grows in its knowledge of itself. Two, self grows in this knowledge in relation to others by juxtaposing itself to others (Mead) and therefore the third, self-realisation has been considered an important activity if not the highest state of self by most religions (where God may be thought of as the highest point to be reached) or realising the maximum potential of one's mind. For instance, for a Hindu for a soul to reach the highest spiritual stage is to accomplish self-realisation; for a Muslim to do good deeds; for a Christian to become like Christ.

The objective of the study is not to prove which of the three -soul, mind or social identity- is the real self. The debate for that has been going on for centuries and remains unresolved. Further, the idea of self may vary from person to person and also society to society. Rather it reinforces that whether it is the soul or the mind or the social identity the idea of self develops in the social context. Also, the way one may see their self will be closely associated to the way their society sees self. For example, if one sees 'self' as a soul it is mainly because the individual is located in a religious paradigm and the individual acquires and asserts this idea being rooted in that network. Even in case of mind the concept gained acceptance and popularity in some societies and due to the developments in biological and psychological sciences. Mind does not construct self. Self is constructed in the social context. An important example could be how different societies define and view mental diseases and disorders wherein 'mind' is seen differently and mental disorder is spoken of as 'not being like oneself'.

Issues of transplantation, plastic surgery, surrogate motherhood, sex-change surgeries, and virtual reality in the modern times have raised important questions regarding the constructs of self that were traditionally understood ideas and boundaries of body and self (Shilling 1993/2004; Turner, 1992). On the other hand, are the traditional perceptions held in certain cultures about multiple selves, souls travelling between bodies and residing in two or more bodies etc. (Douglas, 1994) add a completely different perspective to the constructs of self. These constructs of self were not found in the constructs of self of the diabetics as these situations of transplantation, plastic surgeries etc were not relevant to them. The constructs of self and especially the embodied self, in the case of diabetes, are of a different nature than these issues. They (the respondents) did not have any ideas of multiple souls but there were multiple 'selves' in their perception where one self subdued the other (Na. 121). The idea of multiple selves then also goes on to the level of negotiation between these multiple selves. This is discussed further in Chapter 4.

CHAPTER 4

NEGOTIATIONS BETWEEN BODY AND SELF IN ILLNESS FOR IDENTITY

Having explained the constructs and interaction of the body and the self in the last chapter, in this chapter it is attempted to present the interaction and negotiation between body and self. In different aspects of health and illness like, ideas of health and illness, regulations, prescriptions and proscriptions body and self come to the forefront in different ways. The three bodies- individual, social, and body-politic and the three selves- individual, social, and self-politic negotiate among themselves to assert themselves. This varies from situation to situation. These different situations, spheres and arenas are appropriated by the individuals depending upon what they may perceive shall be most acceptable and beneficial to them. It is interesting to identify how the three bodies interdependently act or act and react and see how contradictions, paradoxes, or conflicts are seen amongst them and how they respond to each other. It is pertinent here also to note that the body-politic and the self-politic usually capture the negotiations between the individual body and social body, and individual self and social self respectively. Yet they also enter the negotiations at certain places and also play a part in the negotiations.

There is separation of body and self and also overlap. The two at times struggle for identity and at other times merge for the same. In the case of juvenile diabetes (and even a type 2 diabetic to a certain extent) the issues of food, insulin, work, marriage and reproductive abilities are of much significance. These were taken as avenues to study and understand how body and self negotiate, in which aspects the struggle and conflict are more pronounced, and how each asserts itself over the other.

Furthermore, these arenas of assertion, conflict, and negotiation are seen in the context of private sphere, public sphere, and social sphere.

A schematic representation of the negotiations between the three bodies and the three selves is given below in figure no. 7. This figure demonstrates how the three bodies and the three selves interact with each other and negotiate. It is also important to note here that at times with negotiations one (of the three bodies or three selves) is able to assert itself so much that the others surrender to that for identity. Sometimes the others adjust or are accepted in a complimentary way. Yet, sometimes the conflict between the three bodies and the three selves remains unresolved. In such times there is witnessed an ongoing, perpetual conflict leading to a confused identity.

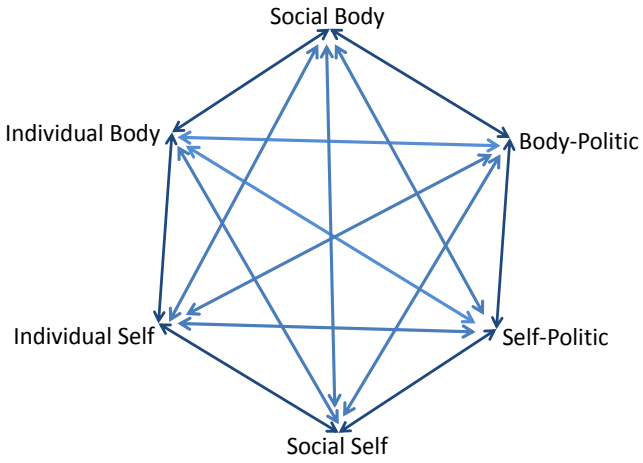

Figure 7 Representing the interaction and negotiation between the three bodies and the three selves

The Separation and Overlap Between Body and Self

There are issues where body and self separate, making their distinction very clear, and in many other issues they come together blurring their difference. Even in different realms where one identifies with either the body or with self one separates them. For instance, when a patient says he/she is normal and denies the diseased body he/she seeks to separate between the body and self and is in fact suggesting that the 'self' is normal because obviously the body is not. They seek their identity not in the body or at times subjugate their bodily identity to the self. Whereas when patients try to achieve something and prove themselves 'in spite of being diabetic' the two- body and self- come together in formulating the identity.

Because there is a separation between the body and the self, there is conflict and negotiation too between them for space. The distinction between the body and the self is made clear when patients used words like 'my body'. The 'Body' belongs to or is owned by 'me'. The usage of 'My body' sees a separation of body from 'me' or 'my'. Suggesting that the 'my' is other than the 'body' and 'body' is owned by 'my' or 'me'. The 'I' knows the 'body' and its functioning. The 'I' has the body and the related mechanisms under control like in Na. 118 and Na. 119.

> ***Na. 118*** *"Every day* ***I*** *think that* ***my body*** *is better.* ***I*** *should take care of* ***my body*** *and… **I** think we are better because we take more care to our health but normal people, they do not."*

> ***Na. 119*** *"**I** am telling from my ten years experience... **I** can understand more about **my body** mechanism. If **it** is growing weak, very weak we can understand..."*

At times the 'I' was clearly the mind or the social self. As in the following narrative (Na. 120) respondent talks of two or more 'I'. There is made a differentiation between the individual and the social body as well as the individual self and the social self. Sometimes the individual body, the social body, individual self and social self- all can be seen together. The following excerpts show the differentiation and negotiation between these. The negotiation highlights the priority given to the individual body over

the social body as well as the social self. And the individual self comes together or overlaps with the individual body in order to preserve the body (also shown in figure 8).

> ***Na. 120*** *"...Yes, I sort of felt that it is all in here (pointing to his head). That's what my theory was, my philosophy was. It is all in the mind. The moment you keep thinking that you are a diabetic – you shouldn't do this, you shouldn't do that, actually kills you off already. You just keep worrying 'can I do this', 'can I do that' or probably 'should I do this or should I do that'. So, yes, like I was able to and I did segregate it. The* ***diabetic part of me*** *was always taking back seat and the* ***non-diabetic part of me*** *would still just carry on. It is all in the mind."*

The respondent in the above narrative separated the individual body, which has a disorder, and the individual self which was normal or in his words *'the non-diabetic part of me'.* The respondent also stated how he would suppress the diabetic part of him, meaning his body, and allowed the individual self, the non-diabetic part of him to take over or exercise control. In the narrative (Na. 121), given below, one witnesses negotiation between the individual self and the social self. The individual self, realising the critical condition of the individual body, asserts itself against the social body and the social self. The respondent makes a deliberate choice to 'ignore' his social self.

> **Na. 121** "*...From the time I realized the seriousness of this. At least I know that if I start mingling with my friends, I start going to parties where I used to I cannot refrain myself I will definitely go and jump the gun and get back to the old ways of life. I can't do that because I know that if I do that anymore then it will be a point of no return. So, I don't want to do that.* ***It is my own choice that I want to ignore that part of me.*** *Yes, I do meet my friends but I don't meet them at parties. So I don't go to parties. I just meet them outside probably at my house or over the weekend."*

As in this narrative (Na. 121) and in many others obtained, a health crisis brings the two - body and self on one front. It becomes difficult to differentiate between them. Like in this excerpt we find the individual body and individual self versus the

social body and social self. The respondent talks about his realisation of the seriousness of his condition (individual body), pressure of friends, parties and his social obligations (social body), and his own choice (individual self) to ignore that part of him which would still like to party with friends (social self). Herein the individual body and the individual self come together and negotiate with the social body and the social self. Thus, the negotiation here is not between the body and the self but rather between the individual (body and self), and the social (body and self).

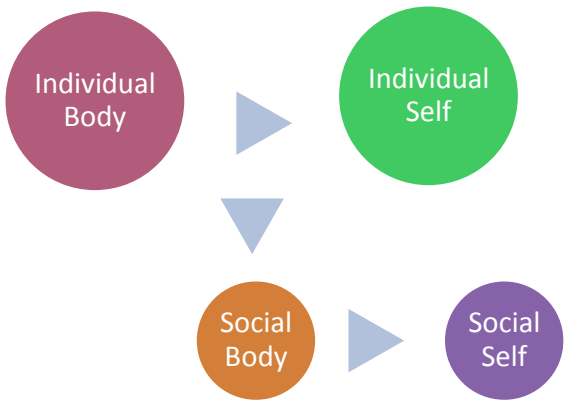

Figure 8. Showing the influence of Individual Body on Individual Self and their assertion upon Social Body and Social Self

As stated earlier the avenues of food, marriage, exercise, work were chosen to study the negotiations between the three bodies and the three selves. Diet, exercise, insulin intake had gained much significance in the lives of the respondents with the onset of the disorder. Diet and exercise had come to acquire a new meaning and understanding because of the respondents' diabetic condition. Their outlook toward these (diet and exercise) had changed and these issues held much importance in their everyday lives. On

the other hand the issues of marriage, sexuality, reproductive abilities, work etc were already important in the lives of the respondents but the disorder had impacted these aspects in a major way. The disorder had altered the position of the respondents vis-a-vis the society regarding these aspects of their lives. The respondents felt at a different and at times at a disadvantageous position in the society regarding issues of marriage, work in comparison with the other 'healthy/ normal' members of the society. These are thus the issues where one faces conflict and negotiation. The negotiations between the three bodies and the three selves with regard to these issues are further discussed below.

Food

Food makes all the difference to a diabetic's life. The right amount at the right time is essential to maintain the required sugar level. Foods with high sugar content are to be avoided. And the prescribed diet is to be adhered to. There were usually two ways in which the issue of food was dealt with -avoidance of the prohibited food, and indulgence in the prohibited foods. The avoidance of the prohibited foods prioritised the diseased body over the self. The diseased body was chosen over the wishes of the individual as well as the social self. Respondents had internalised the 'good values' of a balanced diet and the individual self would assert that to itself at the times of temptations or even when denying oneself the foods one desired. This internalised value was also asserted to the researcher where the self justified the denying of prohibited foods as something good and healthier than what the society is currently practicing. They had also stated how they would say no to their friends and relatives when offered foods that are prohibited for them. Thereby, saying no to the social body. All this is done for 'self'- preservation. On the other hand, indulgence in the proscribed is done to assert self over the body and paradoxically the body is used to subdue the body. That is to say that when one asserts oneself over the body and indulges in the foods harmful for the body one uses the body only to consume those foods.

The self is seen as asserting dominance over the body. Even in times when a particular habit or practice can be dangerous for the body, patients go ahead with it to assert that "they" are in control. Only when the body faces an extreme crises or experiences pain or difficulties or comes to the level of fatal risk does "the self" realise its

incapability to control matters and the body is given its due significance. Body, which is the vehicle of the self or its agent of expression, is acknowledged only when the self finds itself confronted with the question of life and death. In fact, even at the time of asserting the self to disregard the precautions to be taken, it is the body that is used. This was what a juvenile diabetic wrote in a social forum (SNF-6). The statement reflects the subtle distinction the patient makes between 'body' and 'self'.

> ***SNF-6*** *"Does anybody binge on sugary stuff to make blood sugar levels reach peak to destroy you up like having litre of ice cream, packs of cookies and stuff? I do...It is because I hate this diabetic condition and now that I have it I love to make it worse..."*

Similarly the following excerpts (Na. 122- Na.125) emphasize this.

> ***Na. 122*** *"Probably I did not know the seriousness of it at that point of time...The only thing that changed in my life was I used to carry a glucose packet...It was for me at that point of time what I got I ate irrespective of whether I could or could not. I was aware that yes, probably it is prohibited for me. I am not supposed to eat it but still I went ahead and ate it. Like I said, I was very negligent...My whole body was bloated it was kidney disorder...and that is when I started taking things a little seriously. I know the damage is already done but I am trying to see what best I can do...I have a wife and two small sons. I have a lot of responsibilities. So, I need to take care..."*

> ***Na. 123*** *"The age was such that we never thought that it could get so serious. They (friends) knew that I have a problem and my mother had told them that I shouldn't be doing this but then even when they saw me they would say once that, 'You are not suppose to do that', and I would say, 'That's ok'. And they would say, 'Ok that is your call.' Actually that age is such that we never gave heed to such advices... I never gave a serious thought to it."*

Na. 124 *"...Believe me I ate ice-creams daily for a year and did not miss even a day, because I hated my diabetes but after a year it only worsened my conditions nothing else. And now I try to keep myself as healthy as I can."*

Na. 125 *"Yes, I miss eating sweets. But, I have to. I have to or otherwise I will be suffering."*

Definitely this 'I' in the *"...I will be suffering..."* is not away from the body but rather refers to it and the pain and suffering experienced by it. And this 'I' of the body is also not distinct from the 'I' of the self because the existence of the self and its expression is dependent on 'I' the body. So, even when the self works to preserve the body, the self is actually working to preserve itself. This is about the individual body.

Exercise

Similar to food is also the case of exercise. Exercise is taken as a discipline. It is also the factor which many reported differentiated between 'normal' people and diabetics. Diabetics reported how they had to wake up and exercise or go for walks while their other family members slept. Also how the 'normal' people did not need to exercise but for a diabetic it was essential. At times reference was made to it highlighting its various benefits and suggesting how a diabetic thus takes care of his/her health more than a 'normal' person. At other times diabetics complained that they had to exercise whereas 'normal' people did not need to. This marked the difference between a diabetic and a 'normal/ healthy' person to them. This mandatory aspect of regular exercise emphasized, for the respondents, their diseased body. The discipline brought the self and the body together whether it was self asserting itself over the body to discipline it or self was prioritising the needs of the diseased body. In either situation both the body and the self were being regulated and disciplined. Regarding food and exercise when the body is denied prohibited foods and is disciplined to exercise, the individual body is brought under subjugation so as to ensure the preservation of the 'self'-the individual self. (Na. 126, Na. 127)

Na. 126 *"... I think* ***we*** *are better because* ***we*** *take more care to our health but normal people, they do not. Actually, I go everyday for walk. It is compulsory to do exercise but for normal people it is not so necessary...."*

Na. 127 *"...Like, I go to the gym. I work out. Because if I don't go, like last year I didn't go to the gym and I used to eat all sort of oily stuff and so my cholesterol levels were shooting high. It is like "HPLF" which is good cholesterol was going down and 'LDL' was going high. So that is a risk factor for heart attack. So, like, I had to go the gym and made a proper work out and brought it under the normal level...Actually, I find that other guys who go to the gym and they work out they have very strong body like muscles because in diabetes ah...ah your muscles don't tend to build up fast because of either lack or access of sugar in your body. So, it is like when you work out there is not a proper, proper stretching of the fibre, muscle fibres. So, it is like, your body, for example, if I was a normal person this would be very strong (pointing to forearm). But here it is a little kind of elastic. It is not that elastic but it is a little loose. So I don't have that very physically fit, strong body."*

Where the exercises were neglected, explanations of lack of time, overload of work (causing fatigue and weakness) and much physical activity in everyday life were mentioned. The needs of the body were relegated at times in terms of exercise. Thus, it is seen how the individual body is disciplined for the sake of good health but it is done by the individual self or at times by the social body also wherein the social body reminds the individual body of its needs. Sometimes both the individual body and the individual self relax on this discipline. If it is because of the weakness in the body or some ailment the self lightens up the discipline. And, if it is because the self does not want to submit to the regime of exercise the needs of the individual body are overlooked and only considered when they reach a crisis situation.

Education and Work

In the sphere of education and work also there are seen two kinds of outlook. The respondents either talked about trying to prove themselves in spite of their diabetic

condition or they held diabetes responsible for not being able to work or study. To prove 'self' in spite of the diseased body is to aspire for 'normal' identity and the diseased body is denied or overlooked to affirm the 'normal' self. In the process, the diseased body is tempered, disciplined and at times overworked to assert the 'normal' self. The need to prove 'self' is also the individual body and individual self trying to assert themselves in the context of the social body and the social self. Herein the self also tries to prove the body, that is, the diseased the body can be managed and compete with the healthy ones. The self seeks to prove itself and the self also tries to prove the capabilities and strengths of the body. (Na. 128, Na. 129)

> ***Na. 128*** *"I am struggling profession…professionally and seeing the pressure. From last 3-4 times, from almost six months my sugar levels are constantly high because of the pressure that I am taking. As I am growing professionally my pressure is also getting increased. So that the pressure that I am handling there that I am not able to cope up with my full exercise and my professional level. So, still there is some gap in me that I used to resolve myself. At least some exercise I need to include."*

> ***Na. 129*** *"My boss will be scolding 'Why you are always in the office?' I need to prove myself. Professionally I need to prove myself means I need to work hard. Then only I can prove that I am different from others."*

He is struggling to maintain a balance between professional life and his sugar levels. Body and health are important to survive and on the other hand one pursues the struggle so as to prove himself- "self". Accomplishments/ achievements recognized by society are important to assert self and establish one as a normal member of the group/social body. On the other hand, are narratives like the one that follows (Na.130). The respondent here blames his sickness as having 'spoilt his life entirely'. He holds the disorder responsible for the situation of his present job and the removal from the earlier employment.

> ***Na. 130*** *"It affects intelligence also; the intelligence level ...My life got entirely spoilt because of this diabetes only. Everything now days depend*

upon strength and all, stamina...Basically, strength is not there. Regular jobs I am not able to do. Present job, somehow I am managing…When in the previous job they came to know suddenly I have got a memo."

When weakness or inability are expressed by the respondents as limiting them from achieving what they want or what others are able to it, the diseased body takes a foreground. The individual body and the individual self come together as one, take up the diseased identity and stand up against the social body and social self desiring sympathy, help, benefit, and exemption from work- the secondary gains of the sick role as discussed by Parsons (1951).

The 'sick-role[9]', and the secondary gains of sick role as explained by Talcott Parsons have been questioned for a chronic illness like diabetes. "Kassebaum and Bauman (1965)...attempted to investigate the dimensions of this role model [of sick role] as it applies to chronically ill patients. Their findings indicate that sick role expectations vary among patients with different types of illness. Indeed, the chronically ill patient differed from the "ideal type model" (based on acutely ill patient) in a number of important respects. For example, Kassebaum and Bauman point out that chronic illness by definition is not temporary. Consequently, the role expectations that one should try to get well, overcome the condition and resume functioning in a "normal pre-illness"

[9] "Parsons defined four aspects of the institutionalized expectation system relative to the sick-role: (1) the sick person is exempt from normal role responsibilities, relative to the nature and severity of the illness. (2) The sick person cannot be expected to get well purely by an act of will. His illness is not his fault. (3) The state of being ill is in itself undesirable and carries an obligation to get well. (4) There is the further obligation to seek technically competent help, usually a physician, and to cooperate in the process of trying to get well (Ablon, 1981: 6)." The Parsonian model of sick role has been contested to be fit for temporary and acute illnesses and unsuitable in the case of mental disorders and chronic illnesses (like diabetes) (Kassebaum and Bauman, 1965; Friedson 1979; Segall, 1976; Ablon, 1981). To this critique Parsons responded, "There are many conditions which are, in any given state of the art medicine, incurable. For them the goal of complete recovery becomes impractical. However, recovery is the obverse of the process of deterioration of health, that is, a level of capacities, and in many of these chronic situations tendencies to such deterioration can be held in check by the proper medically prescribed measures based on sound diagnostic knowledge. An outstanding example is diabetes, where diabetics, by such measures as a modest regulation of diet, and stimulation in the milder cases by oral medication, in the more severe ones by the use of insulin, can maintain a relatively normal pattern of physiological functioning and the many activities of life which depend on normal physiological functioning…The cost consists, above all, on the diabetics part, of adhering to a proper regimen and of deferring to a competent professional authority in defining what it should be. The fact then, that diabetes is not, in the sense of pneumonia, "curable", does not put it in totally different category from that of acute illness (Parsons, 1975:259)."

capacity are inappropriate. In the case of chronic illness, the individual is faced with the necessity of adjusting to a permanent condition, rather than striving to overcome a temporary one. Furthermore, since many chronic patients (e.g. diabetics) are ambulatory, exemption from performing usual social roles is more often partial than total (Segall, 1976: 164)."

In the research study it was observed that the diabetics did adhere to sick role on all the four points. Depending upon the seriousness of the disorder or their health condition the respondents did claim exemption from their normal social roles and responsibilities. They sometime even quit education and jobs (as discussed later). The second point that the illness is not the individual's fault and he/she cannot be expected to get well by an act of his will was very obvious in the case of diabetes. The chronic nature of the disorder strengthened this point that one could not get well purely by an act of his/her will. The members of the discussion forum and many of the respondents talked about the ongoing research and their desire to get well. They spoke of the options available in the medical realm that will help them to forget about their diabetic condition. This suggests that the state of illness is undesirable to them and they felt an obligation to get well. They were all seeking technically competent health care and were trying to follow the prescriptions and thereby cooperate with the physician in order to keep the disorder in check or control. The secondary gains of the sick role were most definitely being appropriated by the diabetics to seek exemption from certain social roles and responsibilities.

In times where the secondary benefits or gains of sick role became more important than the 'normal' identity the individual body became more important than all the others -social body, individual self, and social self. The body-politic and the self-politic also in such times favoured the individual body and utilised the health sub-system's explanation of the disorder to justify the same.

Marriage and Reproduction

The issue of marriage brings body and self together. The diseased individual body and individual self cannot be separated when seeking a spouse. That is possibly also the reason that juvenile diabetic patients face their biggest struggle with the society in this

sphere. One is the stigma[10] from the society and secondly, their own anxiety whether a non-diabetic would be able to understand and empathise with them in the way a diabetic would. The need to be accepted and understood by their married partner was expressed by all the respondents and even those on the social networking website. The society had associated the stigma of being diabetic which had disabled many from being able to marry successfully.

Hopper (1981) in her study refers to Goffman and states that "...diabetics fall in the category of "discreditable" rather than "discredited" precisely because of the hidden nature of the disorder... However, as Goffman uses the concept of stigma, it most dramatically applies in impersonal interaction where stereotyping is strong. While this is often the case for diabetics, they can also be strongly stigmatized in familial and intimate relationships for it is here that issues such as special diet, physical symptoms and nervousness, impotence, and limited energy and mobility become most apparent....Another important change which may stigmatize a diabetic is the potential for disabling symptoms and premature death....Diabetics are stigmatized for this potential in various ways, within their work situations and family and social relations, as well. Increased knowledge by others of the likelihood of disability, contributes to increased stigmatization. In addition, younger diabetics, facing dating, marriage, and career planning encounter different forms of stigmatization (Hopper, 1981: 12)." She also discusses how diabetes runs in the family and is carried forward like any other genetically transmitted disease. Beside that the increased risk of health complications, low life expectancy etc thus make diabetics "poor marriage risks" (ibid: 14).

In this study also many respondents stated as having been rejected by the family of a prospective spouse at the knowledge of their diabetic condition. This stigma

[10] Illness has been seen as a deviant state especially when there are moral judgments associated with them. The legitimacy or the illegitimacy of illness depends much upon the society's perception and social taxonomy and certain states become stigmatized. Stigma permanently changes and spoils the normal identity of the person. Goffman quoted in Ablon describes stigma as, "…While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind- in the extreme, a person whi is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap (Ablon, 1981: 5)"

was also reinforced by the families of the diabetics whence they deliberately hid the information from others. Women respondents also expressed their fears and anxiety about getting married because of their diabetic condition which makes them poor partners. The high chances of diabetic women having miscarriages, stillbirths, congenital malformation and neonatal morbidity and mortality added to the genetic nature of the disorder places them in a more difficult situation than the male diabetics. The issue of marriage brought the social body in conflict with the individual body and individual and social self. There is social distancing done by the society with the stigmatized (Albrecht et al, 1982). The individual body and self are subordinated to the social body and the social self is greatly altered because of that. The protection and the preservation of the social body become more important than the needs and aspirations of the individual body and the individual self. Also the non-diabetic, 'normal' individuals (individual body and individual self) gain an upper hand in making the decisions regarding marriage. There is thus also the body-politic involved in the negotiations here between the diabetics and the 'normal' others. Some of the diabetics in such conflict and struggle choosing to marry other diabetics thence retaliate against the society in the power struggle of the body-politic and negotiate with the social body and their individual and social self. Below are given some excerpts first from an interview (Na. 131) and then from a social forum discussion (SNFD-11) regarding the issue of marriage.

> ***Na. 131****"Yes I am facing difficulty getting married because of diabetes. Every now and then someone will meet my parents with a marriage proposal. And when they get to know that I am diabetic will either walk away directly or make some ugly face or will say something really bad. My parents have lost hope that I am going to get married and they have stopped trying as well."*

> ***SNFD-11 a)*** *"Actually I'm 19 yr. old diabetic boy looking for a diabetic girl for a relationship.... so if any girl thinks the same then please contact me and I'm not joking I want a serious relationship"*

b)*"Yeah !!!!!!!!!!!! You've written what the others r too thinking about..... and I think this kind of relationship will have oodles of happiness in it 'coz both can be 100 empathetic..... in sharing their feelings....."*

c) *"Right Going Brother. I appreciate your idea. We need the partner we can understand each other very well."*

d)*"I do have the same opinion that non-diabetic don't accept diabetic whole heartedly. They always have a doubt."*

e)*"Hi.....actually I'm older to you....:-) by the way.....I want to say that.....for a diabetic boy.....I think it is easy to find a partner but for a diabetic girl...it is difficult...and I think even a diabetic man will never want a diabetic partner.....but I'm surprised as you are an exception....so my friend it is my experience that I have been rejected many times as a diabetic to be a partner.....it is my story but not fit for all.....So buddy.....all the best!"*

f)*"Guys in nutshell, there could be a problem to find a right partner if we are looking for arranged marriage coz then all the pros and cons are considered no matter if you are a male or female diabetic..."*

g)*"I accept that a true lover will understand my feelings. The problem here is some people like me do not have a good appeal* (meaning appearance) *and women will not even think about loving us. What shall we do?"*

Related to marriage are also issues of sexuality and reproduction which came to a head in different contexts. The following narratives (Na. 132- Na. 135) highlight that not only female respondents but even the male respondents were concerned about their

fertility, strength and subscribed to the ideas advocated by the society regarding healthy bodies, marriage and family life. There was the worry whether they will be able to have a 'normal' and successful family life or not. These fears were sometimes because of their sickness and at other times were based in the way the society or the social body sees and treats the diseased individual body. The individual body and self come together here trying to understand their role and expectations and assessing their abilities in accordance with the standards set up by the social body. For the female patients their safety in pregnancy and delivery become questions of great significance. The social expectation of the 'complete woman' associated with motherhood takes a toll when these female diabetics are unable to bear children. The attitude rendered to the infertile or barren women gets extended to the women with miscarriages as they too in the end do not have any children. (Na. 136)

> ***Na. 132*** *"...there is a notion that diabetes people are not that much healthy. It is true. It is right somewhat. And it true also because they are prone to all disease. Maybe if some... one cut is coming it will take more time and if correct time medicine is not there they will be weak. If correct time food is not there they will be. All... heart attack it can come early. This eye disease, kidney disease all these things can come. And in later stage any cuts and wounds are coming then it means we may have to remove one leg or hand like that. Who will give…who will consider all these things and get or give their daughter for marriage. "What is the need of taking a risk?" They will think, like that. In this universe, in this world lot of healthy people are there, good people will be there. What is the need of taking risk? They will think like that. It is right. So, from their experience they might think diabetes people are somewhat weak. They are not that much strong. They will not be able to lead... that much powerful, healthy family life. He, a person with diabetes will not be able to lead his family as the head of the family. He will not be a complete success. There is a…Anyway it is not…If diabetes or any disease…any other disease. If*

he is having asthma, if he is having any other disease, is a person with a disease, any disease. Diabetes or anything. That is the same."

Na. 133 *"I was interested in discussing something but due to their time lagging I never used to discuss. I…tried to discuss regarding diet, regarding my future, any problem will occur, my family life, like that any problem will be there doing marriage like that I wanted to ask during that time but I didn't ask....after…then I got matured and I just inquired if in marriage any problem will occur. I asked to Dr. And Dr. told, "You are a normal person. There is no obstruction like that. Now diabetic not a big problem. Peaceful family life."....Haa (yes). Major, major my doubt was that. Important doubt. One person's important thing is family life only. I am believing like that. Not career or profession. Profession is important but family is important. If we are not able to lead a family life then what is the need of a life. So it was…it used carve me inside. "Arey, what is happening? Any health problem?" Like that. So,…I asked them. So, they have clarified saying "No problem."*

Na. 134 *"It affects the power of fertility. That makes me feel worst... because I want more children but because of this diabetic last 1 and half year we are trying to have our next child but we cannot. I think my sperm count also may be reduced. Now I am taking treatment for that also."*

Na. 135 *"...later in life I had problems in my relationship as it wasn't accepted by the girl's family (that's happened twice actually). So I do realise that it poses certain limitations and barriers.... Relationships usually are fine till the family involves. It is hard for the Indian parents to accept a diabetic spouse for their child. Even though I know I am much healthier than most normal people but to family, it is a bad disease with only complications - in a lay mans term, I wouldn't survive long and healthy to run a family."*

Na. 136 *"Actually when I was 5 months pregnant... I had no diabetic symptom or anything. The doctor told to check up for diabetes also. At the time of examine I came to know I am diabetic. So, since beginning doctor said you should take insulin otherwise the child will be affected. So, I started insulin...*

Since I came to know I am diabetic, so many people told 'You will be having much trouble with child.' All Diabetics children will be…I mean something like crippled…I was just going on thinking. If the child is like that it will be difficult na. Anyway in some months…miscarriage, so, afterwards I was not pregnant at all…This was first that and now I don't have any children....

I was…I mean…very much upset but I had almost 3-4 abortions and one time, they kept me in hospital for complete 9 months. They said it will be under the…doctor's this thing…so you be in hospital for complete nine months. So, I was there. But when it was born it was a still born child....

At the time of fourth pregnancy, when the child was still born in the hospital then I told my husband 'What is the use of my taking so much precaution. I have taken full care. Still this has happened.' So, at that time it was a little bit of…moment for me. That's all...

I was…I never used to speak to anybody in my home. I was reminded of the same thing. Then other people… What to say? (Tears rolling out). I am unable to say. Doctor, she was the only lady who told me, "Asha, don't think of your thing…which…What is gone is gone. Now if you think of it also, there is no…if you think of it also."

I had seven…six abortions, one stillborn, and one seven month baby was born…survived for 46 hours. And at that time I was thinking that this child will survive. But even that did not."

There is the constant conflict between the social body on one side and the individual body and individual self on the other. The social body sees the individual body as diseased and unsuitable for marriage and family life. The individual self contests that

and states that one is 'normal' and ought to be treated normally by the society giving them also a chance at marriage and family life. The individual self does take into consideration the illness in the individual body, either by managing the disorder and thereby maintaining the health of the body or by highlighting the 'not-diseased' self claims 'normalcy' in the society. The individual self thus also strives for a 'normal' status for the social self. Many respondents said that they considered themselves normal and desired a 'normal' person as a spouse rather than a diabetic. Some stated that the chance of offspring having diabetes increases when both the parents are diabetic and that is why they do not want to marry a diabetic person. The respondents thus themselves reflected the ideas the social body has about 'normal' and 'not normal'. They express the desire to be treated as 'normal' but do not want to treat other diabetics as 'normal'. Thus, inadvertently they become the medium of their own stigma.

The Social Body and Negotiation for Identity

The sub-groups of family, health sub-system, and virtual society play a significant role in the negotiations between the three bodies and the three selves. In this section the role of family, health sub-system, and virtual society as the immediate social body or the sub-groups of the social body is considered while understanding the negotiations between the three bodies and the three selves. The sub-groups mentioned are interesting and significant to these negotiations as they sometimes merge and become one with the individual (especially the virtual society) and at other times are the representatives of the larger society in conflict with the individual.

The social body of family sometimes upholds the individual body and self's claims of 'normalcy' and at other times reinforce the ideas of the larger social body regarding health and illness. The struggle an individual faces to get a normal identity is sometimes prevented by their family. As discussed in chapter three, some respondents had reported their closeness and dependence upon their families to the point of exclusion of all others. Families discouraging the individual to reveal their diabetic situation, not allowing the individual to live away from the family etc (as mentioned in Chapter Three) not only highlight the family acting as a support system for the individual but also a force

in reinforcing the sick-role (in terms of not only seeking competent healthcare practitioner but also relegate their responsibilities) to the individual. Families also in some cases supported the individual's decision to quit education or a job. Thus, families supported and strengthened the diseased identity of the individuals. The individual self also at times prescribed to this idea when they wanted to seek the diseased identity and found sanction in the family (discussed earlier with regard to sick role and secondary gains).

The health sub-system as stated in Chapter Three provided legitimacy to the diabetics in terms of both normalcy, and the sick role. Though the health sub-system encouraged the diabetics to pursue their life goals and stressed on 'normal' identity and did not support the availing of secondary gains of sick role. The health sub-system only supported the seeking of a competent health care aspect of the sick role and rarely advised the diabetics to refrain from work or other responsibilities. Yet, the very involvement of the health professionals (as discussed by Parsons, 1975) in the managing of their chronic illness reminded the diabetics about their diseased identity and this identity and the sick-role associated with it was employed by them when they (the diabetics) wanted to avail the secondary gains associated with sick-role. The health sub-system on the one hand recognised the disorder of the diabetics, their chronic illness, and their dependence on medication life-long. On the other hand, they counselled the diabetics that they were 'normal'. The health sub-system supported the claims of the diabetics of 'normalcy' which was in contradiction to the society's or the larger social body's perception of them. The health sub-system thus also came in conflict with the social body. Respondents appropriated the health sub-system to resolve their conflict with the larger society or at least to strengthen their opposition to the society's labelling of them as diseased. Stating diabetes as 'a disorder and not a disease' was a reflection of this appropriation by the respondents of the health sub-system and its explanatory model against the perspective of the society regarding diabetes. Taking the bio-medical perception, respondents make a distinction between disease and disorder.[11] The disorder

[11] There has been made a distinction between disease and illness in the Medical Anthropology (Fox, Fabrega, Casell, Eisenberg, Kleinman etc). Yet, now with bio-medical classification between disease and disorder such differentiation also becomes relevant to anthropological study as to the meanings attributed to them and their significance in explanatory models of the people concerned.

is also ‘dis-ease’ but there is consolation derived out of the bio-medical explanation that one is suffering from a ‘disorder’ and that they are not ‘diseased’. The negotiation that they are normal is located in the bio-medical explanatory model. The bio-medicine helps their identity. They seek bio-medicine not only because the bio-medical treatment helps with their illness but also the bio-medical explanation helps their identity. Bio-medicine is good for their body and the bio-medical explanation is good for their self.

The role of virtual society or the virtual social body has already been discussed in detail in Chapter Three. The individual body and individual self greatly identified with the virtual social body and became one with it opposed to the larger social body. In fact when in the discussion on the forum members made statements like *‘**we** are better than the normal people’* it suggested the virtual social body was seen as one with the individual and as a social body. They made statements how ‘they are normal’ and it is the problem of the society that the society which is not willing to accept them and instead discriminates against them. The conflict here was between two social bodies- the virtual social body and the larger social body where the individual was a part of both but related more with the first and opposed to the latter. The virtual social body also derived its validity and the strength of argument from the health sub-system which was frequently quoted in the discussions.

Society also faces an inherent conflict with the individual as well as the society itself. On the one hand, the diseased are seen as deviants and encumbering the society and on the other there is the need in the society to make place for the diseased. The society cannot overlook the diseased as a part of itself and thus is required to make place for them in order to maintain the harmony of the society. The conflict also arises while answering the question- where to place the diseased. Also the distinction between disease and disorder is made by bio-medicine and the diabetics but not the society and that is why society associates stigma with diabetes.

The Illness in Body as Separate from Self

Statements like, “I am normal only”, “I am leading a normal life” taken from the bio-medical perspective or any other medical system also do not stand true for the

body because the body is not functioning properly or is not in harmony or is in imbalance. But there is made the assertion of being normal or 'like normal' by the respondents. This suggests that the illness is seen in the body and as separate from self - both individual and the social. Then whether the individual self is soul or mind or social identity, it is 'normal'. Though the self may get affected because of the illness but it remains 'normal'. For instance, respondents said that any sickness obviously affects the mind also. Stress plays a role in sugar levels fluctuating. But, they nevertheless insisted that nothing is wrong with their mind or rather the disorder is in the body and not in the mind. (Na. 137)

> ***Na. 137****"Long term diabetes affects both body and mind. You can get nerve damages, organ failures and many numerous diseases. And all this will create distraction."*

The 'Why me?' question that respondents asked themselves when diagnosed with diabetes is also not about the body or else the answer to that question would be sought respectively. Also then the question would be what is wrong with the body? The why me, is more to do with the self and life and is usually located in the religious realm. This is where the religious aspect of self comes into the picture. The question is asked comparing oneself to others around- why me when there are so many others who are 'normal'. The reason of karma, fate, God's will clearly state not only the equating of self with soul but also the self (as soul) having a role to play in the context of illness. The self thus does have a part in illness.

The individual self is encouraged by the social body of other patients to accept the identity of the individual body and its state of illness. This virtual social body encourages the individual self to assert normalcy in spite of the illness in the body (SNFD-12). This also suggests that the social body itself differentiates between the body and the self for identity. This is also where the virtual social body is seen to question the ideas of self constructed by the larger social body whereby the sickness in the body has led to denial of many benefits in the society.

> ***SNFD-12 a)*** *"Friendship does not have any conditions. Two people can be best of friends today irrespective of their differences...but if I am*

meeting a person for the first time (for arranged marriage), then I won't be surprised/shocked if he does not accept me with my diabetes. I will not get affected by his decision as he is unknown to me."

b)*"Man.....u ppl r scaring me... is it the end of my love life before it starts"*

c)*"No it is not the end of your love life before u start.....but before u start be open about your diabetes and if you are accepted then it will be bliss for the whole life this is my own experience so believe me."*

Changing Narratives from Body to Self as Identity

The narratives of the respondents shifted between body and self for identity. It was not like the respondent consistently thought of his/her identity in the body or in the self. Especially with the illness one was reminded of the body time and again. One was reminded also of the social body and the placing of the individual body and self in that social body. The following narratives capture some of these shifts (Na. 138- Na. 140). In the first narrative (Na. 138) the respondent at times asserts that he is normal and at other times his illness takes the forefront. He is aware of his sick status and because of it he has been suffering different hardships but on the other hand he wants to emphasize to himself, the researcher and the society that he deserves to be treated like any normal person. He has tried hard to prove himself at the front of education and career and yet feels discriminated by the society and sees himself as a failure by the standards of the society. He sees the researcher also as a representative of the society that he perceives as having been unfair and unsympathetic towards him (Na. 108 quoted in Chapter Three). In his narratives is witnessed a shift between the body and the self for identity. He faces a constant conflict between body and self as his identity.

Na. 138 *"I never felt any such thing before. I did well in my career worked for one multinational company where I was among most trusted employees. I have worked for whole month, more than 16 hrs a day*

including Saturdays and Sundays for my previous project, that landed me into hospital. This year also I was awarded with best employee of the year for Brunel University where I was working as part time employee. But I feel now that I have some severe problem and something lacking then most other guys. When you have to get married and have disease like this, you start feel really limited. Now I have to handle typical reasoning and thinking of Indian society...I never felt that way (stigma) in front of me nobody can do that on my face. I don't have habit of asking help and rarely go to somebody for favour. But these things of making you feel otherwise or abnormal comes when I meet with my relatives. They will say something or do something and most of time is hard to reply them as in Indian societies you can't say anything to elders. And because of that I always avoided going to family functions and gatherings....I feel a diabetic should marry a diabetic as its will be hard to understand a diabetic by a non-diabetic. There are lot of problems and issues with diabetes and don't know how a non-diabetic person will understand all these things....never gave a true effort to overcome (my leanness) that, but it was always in the back of my mind. Before it was due to lack of knowledge and now it is due to lack of support and time. Yes I am facing difficulty getting married because of diabetes. Every now and then someone will meet my parents with a marriage proposal. And when they get to know that I am diabetic will either walk away directly or make some ugly face or will say something really bad. My parents have lost hope that I am going to get married and they have stopped trying as well... If I was talking with some diabetic then would have said disorder otherwise really it is a disease only. And doesn't matter whatever it is, I am diabetic.... Long term diabetes affects both body and mind. You can get nerve damages, organ failures and many numerous diseases. And all this will create distraction....Yes many people think that as I am diabetic I am somewhat retarded not only mentally but physically as well. And in India if boys are more health consciousness then people think he is somewhat gay or

psycho....Yes I know I am not completely healthy as my BMI is low, underweight and also I am diabetic."

The following narrative (Na. 139) changes back and forth between body and self. Whether it is work, friends or family life all aspects bear the influence of the respondent's diseased body and formulate his identity based on the same. The respondent talks of his family life then his deteriorating health condition and various complications, talks then about weakness, inability to work, lack of friends and social life because of diabetes, failed marriage because of the disease, again inability to work, entire life getting spoilt because of the disease and his constant lack of strength and stamina. The narrative moves from body to social body and social self and back. The diseased body is so prominent that everything else is seen as affected by it. Yet, the narrative moves from one to the other (body and self) bringing the two together and highlighting the respondent's need for negotiating with the role defined for him by himself and according to his perception by the social body.

Na. 139 *"I was shocked. I was in a dilemma stage....No family life... parents are there. They were also shocked. Two years ago I married but she left.... It was an arranged marriage. She left without informing anybody...because of disease only. She knew from before. We told her. At that time she agreed but afterwards what happened I don't know... I never used to go with friends and all because of this problem. I never used to enjoy with my friends....Friends basically, they were also shocked. But I don't have many friends. Why? I don't mix-up well. Social life is not there...because of diabetes only.... Now I've developed this kidney complication also.... neuro (neurological) complication is also there and then this also developed. I am not able to do any work. Weakness is there. Continuous weak. Sugar level if it comes down then trembling and hunger. Everything now a-days depend upon strength and all, stamina. I am working as a librarian and that is also not going very well. I am not able*

to work and concentrate on the work and job now. I am going on just like that.... My life got entirely spoilt because of this diabetes only."

The shift from body to self in this narrative (Na. 140) is used by the respondent to state that the body is weak and diseased and the self 'struggled' to achieve its dreams.

Na. 140 *"I was diagnosed to have positive Ketone bodies at that time before I was put to insulin therapy but ever since I had no complications and I'm perfectly fit physically and mentally. I'm comfortable other than some hypoglycemic attacks that occur once a while. Well so, I consider it as my best friend always being there for me throughout my life that's the only way I had to accept it part of my daily routine life. Hopefully soon there is some cure for diabetes researchers are still working on it and it is said that diabetes is a step short of a miracle. I'm myself interested in this field and keen to work on stem cell research which could at least bring a hope for diabetics around the world.*

I'm studying medicine right now in the Philippines. As a child my dream was to become a doctor and practice medicine as my profession but I had to face up a lot of problems to achieve what I have turned out to be today. When I was diagnosed to be a diabetic initially the major problem I faced a setback in my academics which let down my dream of being a future doctor. I had to discontinue my studies for about a year following my illness and I almost gave up my hopes of being a doctor because initially I wasn't able to cope up with my studies and stressed out college life. That was the time ***I had to really do something to help myself achieve my dreams, treat myself, be a physician to myself and set my targets and goals by having a positive approach****. I was almost out of my basics which couldn't help me fetch a seat in an Indian medical college but I managed to review my basics in biology which helped me come back to my basics that I had missed out and bring back my hopes to achieve what I dreamed*

of. So that way today I'm here in the Philippines doing my Doctor of Medicine."

Wysoki (2002) in his paper asked the question to juvenile diabetics he interviewed of 'how would they know if they had succeeded in managing diabetes when they are an adult?' He suggested that if the answer pertained only to managing diabetes the identity of the individual was limited and regulated around the disorder. The individual was thus "living to control diabetes". On the other hand, if the individual defined success in terms of achieving important life goals which included maintaining diabetes but went beyond that then they were "controlling diabetes to live". In this way they do not grow in a way that they define their identities primarily in terms of diabetes. That is to say when the future was seen by the respondents in terms of managing illness then identity remained mainly rooted in the illness and when other aspects became more important than illness then the identity though considered the illness but was more around other aspects and other life goals. Some narratives (Na. 141, Na. 142) are quoted here reflecting the attitude of 'controlling diabetes to live'.

Na. 141 *"I want to do C.A. and I don't want to take diabetes as a reason not to do."*

Na. 142 *"Waise main chahta hoon mera business, achcha hi hai, yeh is June mein mera 3 years complete ho raha hai is field mein. Main chahta hoon ki dus saal baad mera business toh successful hoga mujhe bharosa hai apne aap pe. But the thing is as well as meri health. Mein health mere saath ho. Actually 20-30 yrs aur kaam kar saku. Health na ho toh aap achche kaam nahi kar sakte. Thodi der ke badd aisa lagta hai I can't do, bharosa nahi hai. Kabhi aise takleef aagayi. Toh bharosa nahi hai ki main kar paonga. Kahin aa-jaa sakonga, you know, two-wheeler pe phirta hoon. Dhul-matti…sardi-khauri ho jaati hai. Main chahta hoon dus saal mein aisa lage…aisa na ho. Meri health achchi rahe."*

Between the three bodies and the three selves negotiation are made easily and the resolution of conflicts is easy in some aspects. And in some issues there is a perpetual conflict. The conflict or negotiation between individual body, social body, individual self, and social self is easily resolved in favour of individual body and individual self in the aspects of food, insulin intake, exercise. Individual self in order to protect the individual body and thereby to preserve itself asserts itself and subdues not only the social body and the social self but also the individual body.

On the other hand, sometimes the conflict between individual body and individual self becomes important when individual self either denies the needs of the individual body (when deliberately indulging in prohibited foods and other activities) or when the individual body becomes very important (due to critical health conditions) that individual self is relegated to a secondary position. Nevertheless, the negotiation between the two is usually not prolonged and is resolved for self-preservation.

The conflict and the negotiation between individual body, social body, individual self, social self through the body-politic and self-politic remains unresolved in terms of issues like marriage and work. Individual self to gain a favourable social self subdues and disciplines the individual body. But the social body through the body-politic and self-politic rejects the claims of 'normalcy' of the individual body and the individual self. The conflict continues and impacts the identity of the concerned person. There is a conflict between the identity he/she claims and the identity that others assign to him/her.

Similar to these issues around which the negotiations take place, are resolved or remain in conflict between the three bodies and the three selves the resolution of conflicts is also sometimes easy like in between individual body and individual self (for self-preservation) whereas between individual body and individual self and social body the negotiations are more pronounced and difficult. The individual body and self merge easily but remain in conflict perpetually with the social body and social self. The conflict or struggle between the individual body and self with social body and self usually remains unresolved. The negotiation between body and self is not generic but rather it was seen that body and self negotiate differently in different context. The negotiation is analysed in three spaces –Private space, Public space, and Social space:

Private Space

Private space is taken to signify where one deals only with oneself. Definitely this dealing is also located in a social context yet this is the space where one deals with and forms ideas about his/her body and self. In this space one witnesses how one sees his/her body and self personally and how the two- the body and the self- negotiate in the personal or private realm. In this specific context of juvenile diabetics it was seen that in private space one's realisation of his/her illness is prominent and insulin intake, diet, episodes of illness mark it. Here is much reference to body whether in terms of bio-medical explanations or illness episode narrations. It is in the private realm that illness is most talked about and quite comfortably. The illness episodes, diet, insulin intake, exercising brought it to the forefront and discussions on these also reflected how the body and the self negotiate in the personal realm, which of the two gain prominence in this realm. This is where one negotiates between body and self as it affects his/her personal choices. The body might desire certain indulgences which the self may deny to maintain a healthy body and thus preservation of the self (Na. 143). Certain aspirations of self may be avoided as the body cannot endure it. The negotiation occurs only in relation to the person himself.

> ***Na. 143*** *"No I never worried about diabetes getting in the way of achieving anything but yes I was too young to realise some things then which I gradually did for example I was keen on flying and joining the air force or something but couldn't because of this.... I would really like to camp in the wild sometime in the nature but that is something I can't because insulin needs to be stored under certain favourable conditions or it won't retain its functional properties. So travelling in hot climate conditions can be a bit of issue at times."*

At times the self is seen as asserting dominance over the body even when a particular habit or practice can be dangerous for the body. Patients go ahead with it to assert that

"they" are in control, thereby risking the body and thus also the self as has already been discussed earlier.

Both body and self remain significant in this space and also overlap much. The preservation of body, taking care of it in spite of chronic illness is important and required to preserve the self. Thus, most times the body and the self are seen coming together in this realm. The conflict and negotiation in this realm is more subdued. Respondents mentioned putting bodily desires in terms of wanting to eat more or exercise second to self and the self also let go of aims or goals that were not compatible with the body.

Public Space

Public space denotes the close social circle that one deals with on an everyday basis. The people in this group are those who represent the society to the patients or are the face of society that a person interacts with and through whom understands the perspectives and stands of the larger society.

Most Juvenile diabetics avoided disclosure of their illness and thereby diseased identity, at least in their public space. Important information about the individual body was withheld from friends and colleagues. In family, the body remains significant as it needs help and cooperation from other members about diet, rest, exercise etc. But not disclosing or rather deliberately keeping this information from friends and colleagues imply fear of rejection, discrimination and stigma from the society. Many respondents thus had only family in their public space. Relations with relatives, friends, and colleagues were very distant. In fact many stated that they did not have any close friends and their parents or siblings were their friends. Here the body was subjugated and 'normal' self was projected and identity was sought in the self where body found only nominal space in the context of friends, colleagues etc.

Identity is seen in self when one tries to assert one's normalcy. To overcome the diseased body identity one uses the self to identify oneself. Whereas the body is used for identity when the diseased body is to be highlighted and there are social roles adjusted

to accommodate the diseased body. Self is also used for identity when seeking career and marriage. Even in the aspect of friendship and love one prefers the self for identity and not the diseased body. All these aspects are about the individual and social self. It is about the social identity of the person. The information about the diseased body is held back from the social body in order to protect the social self or the social identity even if withholding the information can sometimes bring the body to great risk. And thus it can be witnessed that in the public sphere of life one identifies with the self over the body for identity.

Social Space

Social space is where the individual deals with the larger, unseen society that one is a part of, what is also known as the collective self. In the social space, especially for marriage, career and social roles, body comes in to the picture, sometimes involuntarily and sometimes otherwise. For example in marriage the body and self cannot be separated. Similarly at the workplace one tempers the body and seeks its cooperation in order to attain the set goals. Most times it was the society in general, 'the Indian mind-set' that was blamed/accused of discriminating against diabetics. Patients, especially on the social networking website, time and again stated how they are normal and it is the problem of the society that they are not willing to accept them and showing them discrimination.

In the social space we also see that by coming together as a group, even though virtual, juvenile diabetics are speaking volumes about their diseased identity and them versus the society. Just like the society in general is anonymous to a large extent so is the virtual group. Patients are a part of both- the society and the social networking group. (Anonymity for the larger society is due to its number and for the virtual world because it is again people without faces. People interact while maintaining anonymity.) At times they subscribe to the standards of the society and other times question them through the sub-group. In the forum discussions clearly marked the difference and presented the society as the other. The ideas of the society towards diabetics were discussed and argued against in the discussions. Even in the narratives patients stressed

on being ‘normal’. If disease is seen by the society as a limitation, something to look down upon, competent and healthy bodies are to be aspired for and that image is passed on to the individual. Thus, it was witnessed that many of them spoke of struggling to make a mark in studies or career in spite of having diabetes. To be normal and compete in the society or to be even considered competent one ought to be healthy and that is what juvenile diabetics are trying to prove. Either the diseased individual body was controlled by the social body through marriage and work or the virtual social body arose against the larger social body. The individual body and self found space to assert a normal social self through this virtual social body to the larger social body. This is where the hegemony of the social body was questioned; sometimes the questioning was also through compliance to ideas of the social body of competency and then asserting the ‘normalcy’ of the body and self.

Towards the end of an interview the respondent (Na. 108) was upset enough to say, *“...I am not going to answer anything anymore. I know your thesis must be important to you, but can't help you anymore....If you have seen any foreign movie or documentary on/about India you will see only poverty, poor life, illiteracy. You will never see (anything) good about India. Check latest 'Slumdog Millionaire' for example. Your report seems to be that only with very bad conclusion....I don’t want to be part of a failure story.”* What is this ‘failure’ and what is the link between India’s poverty and juvenile diabetes?

CHAPTER 5
STRUCTURING AND RE-STRUCTURING OF IDENTITY IN ILLNESS

There is a definite duality in terms of body and self or else there would not be any conflict. Body may be the agent or vehicle through which the self asserts 'itself'. The self may choose to take care of the body or not and the body working on its own mechanisms responds accordingly. Yet, the ideas of body and self become more interesting in terms of how each culture understands them and defines them especially when confronted with that which threatens the body and thereby also the self.

Body and self may be threatened by various issues or causes. In the situation of threat to the body the degree of threat also varies and matters; the extent to which the threat is perceived to hurt the body or self. For instance where the threat is very high the focus shifts to the protection of the body because the self needs a body to assert itself (as mentioned earlier). The sources of threat to the body and the self are different and that which threatens one affects the other. As body is important for self to exist, the self when threatened also affects the body. Body asserts its needs to the self so that the self would take certain decisions to protect the body because without the self taking pro-body decisions the body cannot continue. Also, when people do not like their self their body also suffers. It is at such times when one does not want their self to continue that there is thought of termination of self, which comes out in the terms of termination or ceasing of the body to exist.

It is interesting to find out the negotiations between body and self in the setting of juvenile diabetes where a chronic disorder can lead to life threatening diseases. Disease is a threat to the body but not merely confined to the body. In case of a mild

illness that lasts for just a few days with no longstanding consequences life is not threatened. However, in case of a chronic illness the whole life is altered. The disease or the disorder, as in this case, though in the body does not remain limited to the pathological or physiological level. It also brings to question one's self and identity in the society. Thus, the negotiations between the body and the self become prominent for identity especially in the context of illness.

Society does recognise that there will be some who are not in the ideal state that is, some ill people are always assumed to be present at any point of time. However, from the society's perspective it is at an impersonal and collective level. But the sick person finds it difficult because the whole process of coping up is at the personal and individual level. There is also particularly the struggle faced by the individual in the form of meeting the expectations of social responsibility. This also brings in the significant others-parents, relatives, spouse, children. They are subject to worry not only because of the close ties shared. Also where the young are expected to grow up, progress and take care of the parents in old age or of the younger siblings, there is an added pressure of being 'normal' and fulfilling these expectations. In this situation if a young person realises that he/she cannot perform as his/her peers it can affect their identity in a significant manner. Marriage is another example of how this identity struggle is manifested. The social factor looms large with regard to marriage and especially for women in childbearing because the two and particularly childbearing are not a physiological matter alone in the Indian society but is seen as a matter of social status and significance.

These issues in turn influence their identity. Identity can be seen on three levels- personal, group, and social (discussed earlier in Chapter 1). Personal identity is the understanding one has of himself or herself and the awareness of one's identity, traits and characteristics. "Erving Goffman suggest(s) that personal identity is concerned with what makes an individual distinct from other individuals. When viewed in this way, personal identity is tied to individual autonomy and the values, qualities, attributes, and personality characteristics that make the individual unique." (McKendree, 2010: 545)

A juvenile diabetic is seen to assert the personal identity and character traits at most places of interaction and attempts to acquire a normal identity. This identity is supported by others depending on the context and approval of their (diabetics') proven abilities (at education, work) and when there is an unawareness of the disorder. Their personal identity is rejected or overlooked against the diseased identity in certain aspects like marriage. In fact on the social networking website patients discussing dating and marriage counselled that 'if a person proves himself/herself to be healthy and capable then it should not be a problem to get married.' Personal characteristics were upheld against diseased identity by these individuals and the group.

Group Identity is described by Frey and Konieczka (2010) as "Group identity exists when a relatively small number of people view themselves collectively as comprising an entity that is distinct from other entities. Whereas group identity is a group-level construct that references the extent to which members collectively view themselves as a distinct group (and are viewed as such by non-members), group identification is an individual-level construct that signifies the degree to which individual members attach significance to their association with a group (and its identity). Group identification has three components: (1) cognitive (a person categorizing himself or herself as a member of a group), (2) affective (a person's attraction to a group and its members), and (3) behavioural (a person's perception of the joint effort required among members to reach a common group goal)." (Frey and Konieczka, 2010: 316)

Group identity as a diabetic and not regional, gender or professional identity takes precedence when interacting within the group. Patients did not talk of this group identity during the personal interview. They did not deny the group identity but also did not subscribe to it. It is possibly due to the lack of a visible and immediate group. The group identity was stressed upon when in the group, that is, during discussions in the social networking discussion forum. References were made such as '**We** are better', '**We** are competent' '**We** are normal' so on and so forth. But these references were limited to discussions on the social forum and were missing in the personal interviews. In the personal interviews respondents sought to undo the group identity as diabetics and

wanted rather to be seen as normal and belonging to other groups based on criteria other than the sickness/ disorder.

Social identity is also understood as collective identity and in contrast to individualistic identity. "...individuals tend to think of themselves as independent of relationships. They value autonomy and uniqueness and construe their sense of self as separate from others...Others construe their identities in terms of their relations with others. People who adopt a collective identity tend to think of themselves as interdependent with close others and define themselves by their important roles and situations. In this case, individuals place primary importance on interpersonal relationships and tend to see others as part of the self ("We"). Consequently, for people with a collective identity the definition of self includes many of the attributes of their social and familial groups." (Grant, 2010:98)

Social identity acts at two levels. One is the larger society, the ethnic group, regional, national or even pan-world religious identity. On the other hand, the society or the social group which is immediate to a given person; the social nexus in which they live in and interact with. For a Juvenile diabetic both play a role. The immediate society impacts the everyday decisions and the larger society, though anonymously, influences important aspects of their lives by treating them as diseased and formulating basic idea of where the diseased are to be located. Thereby pressing them to either adopt the personal identity highlighting positive characteristics and traits or take up a group identity that does not deny the diseased body but supports by claiming that as 'normal'. That is why whereas group identity can be based upon other aspects like profession, education, gender, caste and others which the diabetics also have and assert in different realms, they choose to leave that 'normal' identity and subscribe to the group identity of diabetics. There is thus a negotiation between the group identity and the social identity of these persons and the group identity takes precedence. Through the group identity the diabetics react to and reject the social identity ascribed to them. Their personal identity also thence finds a medium in the group identity to resist their social identity as diseased persons.

There is a constant struggle between the individual body and self and social body and self for identity. The negotiation between these for identity varies in private,

public and social sphere as discussed already in Chapter 4. This chapter now moves on to explore how identity is structured and restructured. The model *for* and model *of* given by Geertz (1973) is used to understand the structuring and restructuring of the constructs of body, self, and also identity.

Model *for* and Model *of*

Geertz in 'The Interpretation of Cultures' discusses 'models' and points out how there are two ways of understanding models. He distinguishes between model *of* and model *for* "reality". He says, "In the first, what is stressed is the manipulation of symbol structures so as to bring them, more or less closely, into parallel with the pre-established non-symbolic system, as when we grasp how dams work by developing a theory of hydraulics or constructing a flow chart. The theory or chart models physical relationships in such a way- that is, by expressing their structure in synoptic form- as to render them apprehensible; it is a model *of* "reality". In the second, what is stressed is the manipulation of the non-symbolic systems in terms of the relationships expressed in the symbolic, as when we construct a dam according to the specifications implied in an hydraulic theory or the conclusions drawn from a flow chart. Here the theory is the model *for* under whose guidance physical relationships are organized: it is a model for "reality"."(Geertz, 1973: 93)

In other words, model *of* reality is a representation that makes the reality apprehensible or understandable. It is like giving a parallel or an example or a simulation of reality. The model *of* "reality" expresses a structure in an alternative medium. On the other hand, model *for* "reality" is when the model is followed or imitated to guide the reality that is, when a theory or set of directions are followed to do something in the physical realm. The model or the theory guides the reality and the theory becomes the model under whose guidance physical relationships are organized. And these two influence and shape each other. The model *for* is usually located in the ideas a society holds and passes on to its members about what is the ideal and should be the guiding principle.

Model *of* and model *for* come together if there is any relation between the representation given *for* the "reality" and the guiding principle *of* the "reality" or the physical realm. That is to say, that which is used for explaining the structure is also being used to guide the structure. When there is a difference between the model *for* and model *of* usually the model *of* (like through the narratives) is used to either challenge the model *for*, or negotiate with it by replacing the old model *for* and creating a new model *for*. In that sense it can be said that the model *for* influences the structuring of the identity and the model *of* is the process of restructuring of identity. The constructs of body and self derive from the model *for* and model *of*. The model *for* formulates the structure first. There is an ideal for body, self and identity. The model *of* -the representation or the flow chart is used to explain the lived reality and does the restructuring of body, self and identity.

The structuring is conveyed through the narratives and the restructuring is done through the narratives, that is to say, through the narrative one conveys consciously or sub-consciously the model or the theory (model *for*) that guides their "reality". Also through the narrative one may narrate the model *of* or a representation of the reality and there by negotiate with the model *for* and restructure identity. The narration is the medium through which the patients restructure their identity and therefore model *of* is very important to observe. Thus, it can be said that the model *for* and model *of* negotiate through narratives to construct the ideas of body, self and identity and thus structure and restructure identity.

Sometimes the model *for* and the model *of* go hand in hand. Sometimes there is difference between them and there is negotiation between them for identity. At times through the narratives the model *for* is changed to suit the model *of*. For instance in the case of dietary regulations to be followed by the diabetics the respondents complained that not being allowed to eat all they wanted, as much they wanted was the most difficult part of diabetic life. This is what they missed the most. They differentiated between themselves and 'normal' people with this factor. This part of narrative brought to light their (respondents') model *for* 'normal' or healthy and the model *for* food. The narrative later moved on to how the respondents had become more careful with their eating habits

and ate healthy food, and in regulation. And they were practicing a healthier life than what the 'normal' people were doing. The good values of the new diet were compared to the old. The model *for* good health which was seen in eating all one likes in any quantity was questioned and replaced by the model *of* the good, balanced, nutritious, low-fat, low carbs, low- sugar diet.

Similarly, the model *for* good looks, as upheld by popular culture, was subtly passed upon by emphasising upon the model *of* good health. As discussed in chapter three the respondents did not discard the popular ideas of good looks or trim, toned bodies but rather prioritised health and the healthy body over it. Therefore, here too one witnessed difference between the model *for* and model *of* reality for the respondents. The two models negotiate and there is restructuring of identity along the lines of the model *of* reality.

There is structuring of identity in work and achievement. The narratives very clearly pointed out that the model *for* acceptance in the society and a successful living is to have good education and career. This model *for* provided by the society was internalised even by the respondents. This model *for* was not discarded but rather negotiated at two levels. Where the respondent was unable to fit the model *for* he or she stated that the illness had reduced their intelligence level, and strength and stamina required to work. The illness was seen as the reason for reduced efficiency and thus the respondent was unable to meet the standards of the society regarding work and achievements. The model *of* recalled the space for the diseased in the society and the leverages allowed to them because of their illness towards the requirements of the society regarding work.

The respondents also negotiated the model *of* with model *for* in another way. When the respondent said that he had not disclosed about his illness to his colleagues he reasoned it saying that in his previous job he had suddenly received a memo without a reason because the employers had come to know of his diabetic situation. He does not question and does not allow the listener to question his ability at work but rather holds the employers responsible and above all the disease responsible for the discrimination as well as sacking.

Similarly, when marriage or friendship breaks down the reason given is the illness. The narrative is used to state that the respondent did all he/she could and even declaring about the diseased state and yet failed to maintain the relationship. The responsibility lies either with the 'other' person or the illness but not the individual. The ideals of having a good social and family life, and social identity with a successful career are not discarded but are restructured through the narrative highlighting the illness which the respondents believe must be taken into consideration in the structuring of their identity. Thus/thereby they restructure their identity through the narrative.

On the other hand, when respondents talked of how they worked hard to prove themselves in spite of the illness there is another kind of negotiation at work. Their trying to maintain good health like or better than others around them of the same age, working hard at education and career, getting married without any problems in spite of the illness is an effort to restructure their identity as someone fighting a double battle and thus deserving greater appreciation from society and not rejection. The narrative or the model *of* here is used to portray the respondent as the 'hero' in the situation unlike the way the society would like to relegate to them with a diseased identity.

Chapter 4 discussed how most of the respondents stated that they wanted to marry a non-diabetic or a 'normal' person. They had insisted upon their being 'normal' and thus wanting to marry a 'normal' person only. By this they first of all suggested their model *for* marriage (which was based in the ideas the social body holds) that one should marry a 'normal' person. Through the narratives they constructed the model *of* stressing upon their being 'normal' but also upholding the diseased identity of other diabetics. Thereby, inadvertently they reaffirmed the ideas of the social body that perceives them as diseased. The model *of* was unknowingly used to strengthen the model *for* in subscribing them the diseased identity.

One clear instance where the model *of* upholds the model *for* is the case of women who do not have children. The reasons may be the miscarriages which are quite common among the diabetics or any other reason for remaining childless. This overlapping of model *of* and model *for* can be elicited through the narratives of women who had multiple miscarriages. They feel that because they are childless their lives

remain incomplete which is also the model *for* that the society holds for women and womanhood; where being a complete woman is to become a mother.

Likewise, the very ideas of youth as active, healthy in contrast to the health problems and suffering of the old age is a model *for* health in the society and these juvenile diabetics vary from that reality. The society also relates depletion, disease, death and decay with old age which may be based on religion. It is accepted and many a times expected that old people will face them. But to have children suffer especially with disorders of chronic nature and which are associated with the old raises anxiety and worries about their future. There is an expectation for children and youth to be healthy. Youth symbolises health and vigour and when the young face sickness and chronic illness it becomes perplexing/baffling.

The struggle to restructure the identity is common among the younger respondents as seen above. In case of the Type 2 diabetics, there is less or no such intensity to restructure identities. On the other hand, the Type 2 diabetics find it easier to accept their diseased identity as an expected situation in their lives at that juncture of age according to the popular model *for* health by the society. Their model *of* also reflects that when they say that they are old and in old age different health problems will come anyway. It is because of the belief that after a certain age, the body has to undergo a change and disease is a common issue in old age. By saying so they become passive and refrain from carrying on the struggle or are driven by the notions like the world is for the young people to enjoy though they may work towards prolonging their life by being cautious and realising their limitations.

Related to the ideas discussed above is the negotiation between the model *for* and model *of* health as held by biomedicine and religion. In the following narrative (Na. 144) the model *for* healthy body is given including mental and emotional health. The respondent, a medicine student shows the model *for* held by biomedicine. The respondent in the narrative speaks of soul, bringing religion also into the model and thus reflects his model *of* healthy body.

Na. 144 *"Healthy body according to me is the complete state of an individual being physically and mentally and emotionally stable...As I have already mentioned health is a combination of mind, body and soul. Yes, it certainly reflects my mind along with body since it is a combination factor. It is after all the normal human nature of suffering...Yes, my mind always keeps me alerting that I'm diabetic and that helps me stick on to my limitations...I told it is a combination of the 3 factors which is essential for an individual to feel in a state of well being it is a concept based on/derived from holistic medicine. There is no health in soul but always there is soul involved in a person's health."*

The respondents were constantly evoking the body or the self to claim normal identity. There is a certain model *for* upheld by the society about what is normal and healthy and the respondents seem to be evoking the normal self as their identity where the model *for* by the society actually talks of the body. Thus, the restructuring is done through the narratives by stating "I am normal only." and highlighting the normal self. The model *of* is created discarding the model *for* created by the society.

Viewing the sickness only in the body and seeing the self as 'normal' by the respondents (Na. 145, Na. 146) suggests the structuring of their diseased identity around the body and the restructuring of identity around the 'normal' self claiming the benefits meant for the 'normal' in society. That is to say the diseased body is acknowledged but the identity is seen in the 'normal' self. Therefore, the model *for* 'normal' by society that includes healthy body and mind are negotiated through the narratives by stressing upon the 'normal' self and creating a model *of* where the diseased body is subdued to the 'normal' self.

Na. 145 *"I should…I should be. Otherwise I have to suffer. That should be na. Otherwise silently heart attack will come. One day. So, we should be conscious. I am trying to be conscious, that's all. Someday, somewhat…I …don't think all people are that much conscious.* ***Somewhere we will also***

become normal people. If our life is going somewhat normal we will also somewhat become normal people *and we will continue like this."*

Na. 146 *"I think diabetes people will know body mechanism more than other normal people. Somebody not having any disease they will not care that much. But, we have disease that means we will have to take care that much. So, sometimes if I am feeling weak or dizzy I will come to know that I have to take care. And time by time I should eat like that the conscious will tell otherwise I will be in trouble. So, I think I am more conscious than a non-diabetic."*

There is also a structuring and restructuring of identity as diseased versus 'normal'. The respondents and the members of discussion forums on the social networking website were negotiating with the model *for* and creating a new model *for* by their model *of* reality. Their saying that they are normal or should be accepted as normal is to deny the model *for* identity given to them of being diseased. The respondents believe that they are normal and have to be recognised as such. Their insistence is actually a denial of the model *for* identity attributed or ascribed by others. Even when the diseased body is acknowledged the terms in which one then talks about oneself or even in the discussion forums the way the participants talk about diabetics as a group is to be confident and proud of oneself. The members of the group were encouraged to prove themselves in spite of the disorder. This reflects that the respondents with their narratives assert to themselves, each other and even to the listener a different identity than the one given to them by the society—of being diseased and thus incapable.

The discussion on the social networking forum on creating a 'new world for the diabetics', 'creating jobs only for the diabetics', 'starting food joints for diabetics' shows how the model *of* was used to state problems with the model *for* and to create a new model *for* their own world by creating their own world.

Hiding the information about the diseased body was done to keep the self from facing the prejudices from the social body and to maintain the social self. For the

purpose individual self was seen asserting control over the individual body. The social self felt the burden and the guilt for not revealing this information to the social body. The burden to reveal was also added by the group, the discussion forum. The group encouraged the individual self to take pride in revealing the information about the diseased body because to hide such information would be to deceive the social body and thus incorrect. This was also supported by reasoning that the individual self would feel happier when he/she is accepted as they are i.e. along with their diabetic situation. The virtual social body thus emphasise upon the value given to the social body and the rules of the social body. But the power to the social body is denied by taking pride and encouraging taking pride in the diseased identity. The model *of* doing the right thing by revealing the diseased status was supported by the model *for* being accepted as one is. The model *of* nevertheless also continued to contest the social body, in this case the family members who were stopping the member from revealing about his diabetes to the family of the prospective family. Respondents also resisted the diseased identity that was imposed upon them by the society and reinforced through the family by stating that being diabetic is not something to be ashamed of.

The structuring and the model *for*, as stated earlier, are usually located in the established ideas a society holds and find their legitimacy also in the same. The restructuring or the model *of* also needs competent and authentic basis to question, resist, reject or even accept the model *for*. In this study it was seen that at most junctures where the model *of* either changed the model *for* or negotiated with it based itself on the bio-medical explanations of that particular issue. The bio-medical explanatory model has been internalised by the diabetics and this explanation legitimises their restructuring through the model *of*. In this manner their (diabetics') very model *for* had been changed from the socially established ideas through the restructuring and model *of* finding base and authenticity elsewhere thereby changing the very framework along the lines of which the process of structuring and restructuring of identity take place.

SUMMARY AND CONCLUSION

This thesis commenced with an assumption of dichotomy between body and self. The Separation of body and self and the duality between them is apparent from the discussions in the preceding chapters. This duality is sometimes very pronounced and stark, and at other times it is difficult to distinguish between the two- body and self.

Body and self and their negotiations have been analysed in different contexts like religion, philosophy, and psychology. But, an attempt has been made here to locate the two– body and self in the context of health and illness. In the context of health and illness also body and self have been examined in relation with other diseases and ailments like cancer, HIV/AIDS, leprosy etc. Diabetes is a peculiar disorder that poses questions different from other diseases and disorders. The nature of this chronic disorder is markedly different from cancer, HIV/AIDS and others. Diabetes, in bio-medical terms, is not a disease but a disorder that can lead to diseases related to heart, kidneys, eyes etc. Diabetes also does not bear any visible marks on the body of the affected nevertheless altering the course of life. The ideas of body, self, and identity get established firmly through the adolescent years and the presence of an illness at such a point in life would have a bearing of the conceptualisation of these. Thus, Type 1 or juvenile diabetes was narrowed down upon to locate the impact of a chronic disorder upon the ideas about body and self of the affected.

The constructs of body and self were explained following the approach given by Hughes and Lock (1998) of the Individual body, Social body and Body-politic. However, unlike the framework of Hughes and Lock, body and self were not combined but were studied at different levels. This research segregated them and saw their

constructs at these three levels separately. That is to say just like the three bodies discussed by Hughes and Lock, this study also tried to understand the constructs of the three selves- Individual self, Social self, and Self-politic.

The constructs of the Individual body were seen along the lines of symptoms, diet and insulin intake, weight and looks, explanatory models, and threats to the individual body. The initial experience of symptoms of diabetes and the explanation given by the health care provider has led the respondents to associate these symptoms closely with diabetes. Even though they were unaware of these symptoms' relation with diabetes at the onset of the disorder, they remembered them clearly and stated them systematically. For the women respondents who had been diagnosed with the disorder at the time of their pregnancy or had suffered miscarriages narrated those episodes and related symptoms instead of the other symptoms associated with diabetes. This suggests a differentiation between medical and non-medical symptoms wherein the former means symptoms recognised and categorised by medical practitioners as specific signs of a certain ailment, and the latter are symptoms that are not related to the illness that a person is suffering from but lead that person to seek health care. Recounting of symptoms also reflected on how the phenomenological experiences of the body of everyday life are taken for granted but the changes in them that cause discomfort are quickly noticed and help is sought to bring the bodily process back in order.

Diet and insulin are extremely important in the life of a diabetic and they need to maintain the delicate balance between them. The study observed that the changed diet of the respondents affected them the most. Prohibition on foods of their liking reminded them constantly of their diseased body. The distinction made with the 'normal' people was also on the basis of being able to eat anything and in any quantity or not. Food has acquired different meaning in the lives of the diabetics; it is measured in calories and counted in terms of carbohydrates, proteins, sugars and so on. The cultural ideas of health associated with ability to eat anything and in any quantity is being replaced with the bio-medical idea of healthy, balanced, low-fat, and low-carb diet. These explanations not only help the diabetics maintain their sugar levels but also equip them to adapt to the

changed diet. The values of the modern body as fit, healthy, exercising discipline and self-control are conveyed through bio-medicine and thus internalised by the diabetics.

Body has a surface and 'surface value'. Beauty, looks, weight have become more relevant in today's time of consumerist culture. Interestingly, though these were important to the respondents health remained more valuable. Beauty and looks took a backseat and weight was important in order to maintain good health. With the onset of diabetes most of the respondents had lost a significant amount of weight and were thin. There thinness is no way in opposition to the ideas of beauty held by the society but their thin bodies are a reminder of their illness and lack of health. For them being healthy is beautiful. Male respondents expressed a desire to gain weight and muscle which is again in accordance with the socially upheld ideas of masculinity whereas female respondents being thin were more concerned about getting married and bearing children.

In the course of the disorder and its treatment diabetics had acquired an understanding of their individual body with reference to the disorder. Their explanatory model was highly influenced by bio-medicine because they were all taking bio-medical treatment. Most of them had tried alternative medicines at some point of time or the other for diabetes though without much help. Nevertheless, respondents did uphold alternative medicines as 'good', 'natural', and effective for other ailments just not for type1 diabetes. Respondents shared four out of five issues of explanatory model with bio-medicine explanation. Respondents had reported symptoms, patho-physiology, and course of sickness as upheld by bio-medicine. They were also complying with the treatment prescribed by their bio-medical practitioner. It is aetiology that they either did not understand or held varying ideas from bio-medicine. The research also pointed out that in spite of not sharing the explanation of aetiology with bio-medicine the respondents were nevertheless adhering to the treatment given by bio-medicine. They held different explanations regarding their disorder yet the medical system that was able to help them deal with the disorder is complied with irrespective of whether they have a complete understanding of it or believe in the medical system completely.

Future threats or fear of complications also made the respondents conscious of their individual body. Respondents were aware of the disorder's impact on other organs.

Some feared these complications whereas others stated that they were young and in control of their body and health. This was also an issue where the type 1 diabetics differed from the type 2 diabetics. For the type 2 diabetics sickness, complications related with the disorder were an expected event. They were dealing not only with diabetics but other ailments too. On the other hand, type 1 diabetics being young and diseased had put them at a disadvantageous position in the society and made them more cautious towards their health and controlling future complications.

The social body dealt with the terms used to identify body with nature or other analogies drawn to explicate the body, religious constructs, social relations, and the virtual social body. Identification with nature or even urban space was not there but analogies of war, engineering and even bio-medical and genetic explanations were observed in some of the narratives. The socially held ideas of health, illness, normal, and beauty deeply influenced the respondents' perspective. The impact of bio-medicine was immense and evident. Another factor influencing the ideas of health and illness was religion. Religion was seen to bring the natural world and supernatural world together. The reasons for the illness which was experienced in the natural world are to be sought in the supernatural realm. And, though the illness is believed to be due to supernatural reasons yet, cure and healing have to be pursued in the natural world.

Social relations also constitute the social body. Family, relations, peer, and colleagues are mediums through which the society communicates with the individual. Respondents sometimes held their family responsible for their illness and at other times felt a greater need to keep a control over their diabetic situation because of their responsibility towards their family. Respondents who had close relationships with their family and depended on the family for dealing with the disorder usually withdrew themselves from friends. They withheld information about their diabetic situation from their friends and colleagues. This was due to either their fear of rejection from the society or the close relationship with the family did not allow them to develop any other close bonds or relationships. On the other hand, respondents who had disclosed this information found their friends and colleagues helping them in the managing of the disorder.

The fear of rejection or receiving unwanted sympathy were two major reasons because of which the respondents had not disclosed their diabetic condition. This also reflects the social perception of the diseased that the diabetics felt towards themselves. The social body had discriminated against them in the sphere of job and marriage. The ideas of health, illness, and 'normal' were also conveyed through the process of selecting 'healthy' life-partners and rejecting diabetics.

Another aspect of the social body was manifested through the virtual body. There are social networking websites where diabetics had forums and had online discussions about various issues that concern them. Facing rejection from the society diabetics have formed their own sub-group wherein they encourage and counsel each other. The social roles that friends and colleagues are to play are being played by those on the social networking website. This virtual social body also has become the face or the front of the individual diabetics while dealing with the larger social body and the stigma of being diseased.

Body-politic dealt with the power struggle between the individual body and the social body regarding decision-making, the utilisation of the virtual social body as a sub-group of the social body by the individual body in the power struggle against the larger social body, the conflict between the traditional and the modern in terms of medicine, the ideas of competent bodies in the society. There is observed the power struggle over the individual body. The individual lays claims on it through the decision-making about care, restrictions, and even about revealing information about the body. The social body contests it through the same. Family, relations all try to influence, if not dictate, the health care to be taken, decisions about doctor and medical system, and even demand the right to know all information about the individual body. Minors are denied a selfhood on the basis of their age and decisions regarding revealing information are held by the parents. This was observed not only with minors but even with respondents even in the category of majors. The individual body thus does not remain in the realm of individual control but sees the involvement of the social body.

Body-politic also dealt with the negotiation between the traditional and modern medicine. The 'modern' medicine or bio-medicine has found a place in the

explanations of the respondents but has not completely replaced the traditional medicine systems. Alternative medicines are still considered as efficacious, better and 'natural' by the respondents. They are believed to have no side-effects and thus harmless. Their effectiveness is limited only in the case of type 1 diabetes which does not completely render them futile. The modern is embraced reluctantly and without letting go of the traditional.

The research also brought to forefront the ideas of competent bodies and the desire for healthy and fit bodies that the social body imposes upon the individuals. The diseased, incompetent and unfit are denied the same status as the 'normals'. The social body works its pressures through denying marriage and jobs to diseased individuals counting them as unfit. On the other hand, the virtual social body resisted this labelling through emphasising other factors that stressed upon the 'normalcy' of the diabetics, their being competitive enough and having attributes that makes them equivalent if not better than the 'normals' of the society.

The constructs of the Individual self highlighted the embodied self, the existential aspect of the self, mind, and soul. The diseased body had made the respondents conscious of the embodied self. Their standing with the society had been disrupted because of the disorder in their body and the self had to consider its embodied nature. Respondents did sometimes speak about themselves in religious contexts suggesting soul as self. Few did talk of mind where mind was dichotomous with body but not equated with self. That is to say, mind was talked of in dichotomy with the body but it was not seen as synonymous with self. In fact, respondents in their narratives stated mind alerting 'the self' about the conditions of the body. The existence of the individual self is extremely important and the body is disciplined and regulated towards that end. The health of the body ensuring its existence is required for the existence of the self. The embodied nature of self thus becomes all the more important because one cannot exist without the other.

The Social self primarily was around the social identity the respondents had, and this aspect came to the forefront in relation to work, marriage, gender and so on. In the social self one locates him/herself in relation to others, and also sees him/herself

depending upon the socially upheld ideas regarding gender, 'normal' etc. Due to the perception of society that looks down upon diabetics most respondents had not revealed information about their diabetic condition to others. They had come to see themselves the way the society sees them. They viewed themselves as somehow impaired and constantly made efforts to prove themselves, in spite of the disorder, on the parameters of success set by the society. These parameters were usually education, excellence at jobs, maintaining good health. One aspect where they invariably discarded to 'prove themselves' was at the altar of marriage. Marriage is not only about the physical and emotional needs of a person but also ascribes a certain status upon a married person. Marriage thus contributes to the social identity of a person and thus their social self. When marriage is denied it impacts the social self of a person immensely. This impacts men and women differently. For the men it raises questions on their masculinity as providers in the family, strong and dependable, and even their ability to procreate. For the women the ideas of reproduction and child-bearing are more important and are reinforced through the ideals of womanhood and motherhood held by society.

The self-politic tried to capture the conflict between the Individual self and the Social self in terms of right to information, the conflict between the two regarding ideas of 'normalcy' and stigma, and the pressure upon the Individual self to ascribe to and abide by the ideas of Social self. The individual self dealt with pressures of the society by either resisting and thereby withholding information from the society, exhibiting the attitude of 'my body, my wish' or rebelling against the society and rejecting their labelling by society as diseased. The rejection of the labelling done by the society was attempted both individually as well as through the virtual social body as a sub-group of the larger society. The study also agreed that self varies between body, soul, mind, personal identity, and social identity. And the self chooses, based on the context, which of these- embodied self, soul, mind, personal or social identity to use to represent itself.

The three bodies and the three selves interact with each other and negotiate for identity. The negotiations between these were prominent in the issues of food, exercise, work, marriage. The three bodies and the three selves negotiate among themselves to

assert themselves. There are spheres and arenas that are appropriated by the individuals depending upon what they perceive shall be most acceptable and beneficial to them. For instance, food, insulin intake, exercise, and fear of future complications bring to forefront the individual body. In the ideas of health, illness, looks, social body takes the prominent place because the individual body needs to be protected and this the individual could do without getting into a conflict with the society or the social body. These are issues where the social body passes the commonly held ideas regarding them to the individual and the individual tries to adhere to the same. Even if the adherence was difficult the negotiation was subtle. And where there is conflict, where the individual body struggles with the social body, body-politic becomes pertinent. The individual self comes to the front to take control over the body for its self-preservation and at times to assert its primacy in definition of identity and define who one is. Similarly, the need to prove self, locating the self in relation to the society the social self asserts itself. And when the self rises against the socially imposed ideas like normalcy, the self-politic predominates.

The constructs of individual body, individual self, and social self that a diabetic has are seen to come in conflict with the social body. Whereas the individual would like to limit his/her disorder to the body and see the self as 'normal' the social body restricts that by associating diseased identity to the person, creating social distance, and attaching negative attitudes regarding dating, marriage, job with them. Individual finds it difficult to reconcile his/her ideas to the ideas of the social body. This leads to negotiation between individual body, individual self, social body, and social self for identity. Social body and social self greatly influence one's perception of their individual body and individual self. Also, the individual self's perception of the individual body and the social self are because of the social body.

Identity is fluidic and assumes a different shape using the three bodies and the three selves depending upon the situation. The private sphere, public sphere, and social sphere witness the dynamics of the relationship of the three bodies and the three selves and their negotiations. There is constant identity negotiation as well in these spheres. Identity negotiation is "...a process through which a self comes to represent its entity or interests in interaction with society...This process necessarily involves a boundary

crossing (although certainly not one way) from the internal world of thoughts and perceptions (self) to the external world of significant others (including mediated others). One has an identity (avowed) and is assigned an identity by others (ascribed); one's avowed and ascribed identities often overlap, and confusion may result when an avowed identity is not mirrored in the responses of others, and vice versa." (Cooks, 2010: 365) The identity that the social body ascribes to the diabetics is in conflict with the identity the diabetics ascribe to themselves. This conflict is not one that necessarily leads to exclusive assertion of one over the other. Rather the conflict invokes a negotiation because the social self or self exist in an environment of mutual influence. Thus, there is identity negotiation. As has been discussed in Chapter four the respondents' perception of themselves are different from the way they think the society perceives them. They consider themselves as leading a 'healthier' life than many others and count themselves as any 'normal' person. But, at the same time, they also believe that the society views them as diseased which they are not, at least in their own perception. The identity negotiation in their case tilts to their avowed identity.

The three bodies and the three selves are constructed through the model *for* and model *of* these. The model *for* or the ideal and the model *of*, the analogy of the lived reality, together construct the ideas of body and self. The negotiation between the bodies and the selves also takes place through an interaction between the model *for* and the model *of*. There is negotiation between the structure given by the society in the model *for* which is restructured by the individual or group through the model *of*. Through this process there is structuring and restructuring of identity.

Structuring is done by the narratives and restructuring through the narratives. That is to say, the narratives speak of the structures present and through the narratives these are agreed upon, questioned, resisted, modified, and even rejected. Sometimes the model *for* and model *of* support each other and thence reinstate one another. At times the model *of* accepts the model *for* but negotiates with and restructures identity and in other instances rejects and replaces the model *for*. The model *for* is usually the established ideas of the society and find basis in that. Model *of* as well in order to contest and question the model *for* derives its authenticity from some accepted and authoritative base.

The research inferred that the bio-medical explanation of diabetics as a disorder and not a disease had changed the very framework of negotiation and led to the creation of a new model *for* health, diet, exercise and others generating new structures.

Throughout the research it was observed that people talked more about body than self whether it was about their own body, the society or the social body or the conflict with the society and thus the body-politic. The disorder has made them aware of their own individual body, highlighted the role of the social body, and increased conflicts and negotiations in the realm of the body-politic. And that is what becomes prominent in and through the narratives. The narratives implied that the disorder in the body has made the respondents more conscious of body. There is also involved in the process of narrating one's story the politics of who is telling his/her story to whom in what context. And since the researcher initiated the discussion with the respondents in the context of their disorder the narratives also revolved more around the site of this disorder– the body.

The research carried out concurs with Morris (2000) the study observed the impatience with the diseased body and their deliberate exclusion of the diabetics from the mainstream society in the post-modern times. The ideal body is associated with the healthy and beautiful body and the diseased and disabled body is viewed as the opposite of that ideal. Morris highlighted how in the post-modern times health and beauty, pleasure, eroticism and consumerism are closely associated and held as secular virtues, illness, disability and unfit bodies are themselves negative identity. In the body-politic and the self-politic this is the struggle that is most evident between the individual and the society. The social body attempts to exclude them by denying marriage with the 'normal' or denying jobs at the work place. The respondents of the study narrated as having met this attitude from their peer and colleagues. In some cases this denial or exclusion is asserted through the family which is a primary support system but on the other was the one to strengthen these ideas of stigma and rejection for the diseased in the minds of the diabetics. The views regarding the ideal, healthy, beautiful body that are held by the Social body were also visible in the perception of the diabetic respondents. The respondents had either internalised those values or had come up with alternative values to

deal with the Social body. When neither of them was possible they rejected the model of health and 'normalcy' held by the Social body.

Morris (2000), Shilling (1997, 2004), Turner (1992, 1997, 2001) all highlight the increased individualisation of post-modern bodies and the emphasis of post-modern society on individual rather than community. They stated the unprecedented importance given to the individual body in the contemporary times. Not overlooking that, the research also confirmed the strategic position society or community still holds in the constructs of individual body, individual self, and social self, and even the way the individual self sees the individual body. The very idea of having a social body, in terms of having the various social relations, placing oneself in the nexus of those relationships, and the social body in the religious constructs, goes beyond the individual and the individualisation of the body. Definitely the individualisation of the body also draws from the social body and its changing constructs of the individual body. But, the social body in contemporary times (as the research shows) not only influences the individualisation of the body but also the forces of the social body have remained pervasive that the individual body and the individual self retain their 'socialness'; they remain essentially a part of the social body.

The study also confirms with Mead (1974), Douglas (1973, 1994) and others that the ideas or the constructs of self are pre-dominantly influenced by the social context of the individual. When self is perceived as soul or mind or social identity by the individual it is because of what the society upholds or gives prominence to. In a religious society the perception of self is closely associated with the idea of soul and the members of such a society locate themselves in the realm of religion and view themselves as souls. On the other hand, in a society which discredits religion and upholds science and technology, mind is equated with self. Whereas, the societies that are organised around strong social relations and locates everyone in relation to others in the society, self is seen as the social identity. The society that upholds the religious perspective viewing the self as soul is usually in contradiction with the society that views the self as mind. But, the same cannot be said of a religious society and a society with strong social relations where self is seen as social identity. In fact many times these two seem to co-exist and overlap

each other. This is observed in societies where society is strongly knit together and finds its base in religion. At times it is the religious doctrines of a particular society that insists upon a close-knit, interdependent society wherein one derives one's identity in relation to others. This research observed something similar. The self was located in the religious realm or in the social identity of the respondents pointing to the nature of the social context in which the ideas of self had developed for the respondents.

There is an unprecedented individualisation of the body and yet the body has retained its 'socialness' whereby the social body maintains its hold on the body. Douglas' (1994) enterprise culture and hierarchical culture (discussed in Chapter One) in relation to self and culture were witnessed in the study. Enterprise culture is identified with the modern industrial society where the claims of the community over the individual are weak or limited. The culture promotes unlimited private demand for commodities and consumption. Also, enterprise culture demands competence and incompetence cannot be accommodated. The culture requires complete accountability from its members. Individuals have to bear responsibility for their actions and cannot blame outsiders for any kind of laxity in performance. The hierarchical culture on the other hand prioritises the community over the individual wherein the society remains responsible for its members. Instead of incompetency disloyalty and disobedience disqualify a person in such a culture. All the members are given a place in such a culture. Conflicts between groups are resolved in the favour of maintaining the whole. Since no member can be dropped out of such a culture responsibility and blame usually lie outside the individual and at times even the society.

The society is seeing a transition from hierarchical to enterprise culture whereby on the one hand the individuals subordinate themselves to the community and they cannot be dropped (hierarchical culture). But, weakness and incompetence cannot be tolerated (enterprise culture). The exclusion of the weak is done silently. In this mix the blame sometimes lies outside the individual whereby it is not the individual's fault that he has diabetes. But, the responsibility lies with the individual in terms of not letting it get worse as well as denying opportunities to work and get married to someone 'normal'.

The responsibility lies with them in the sense that now they have the disorder they must not complaint but silently bow out.

Juvenile diabetes was chosen because of its peculiar nature of being a disorder and not a disease and its chronic nature that changes the life of the affected forever. It is also relevant to see it in contrast with other chronic ailments like HIV/AIDS and cancer. There is difference in the nature of the diseases like HIV/AIDS and cancer, and diabetes. The way these illnesses affect the person, their aetiology, and the treatment required influence the way they are responded to by the person affected, his/her social circle, and the larger society. The impact of HIV/AIDS and cancer is more critical and is unlike diabetes which is somewhat controllable. The visibility of the illnesses is also more in cancer and HIV where either due to treatment, hospitalisation or because of the illness itself there are bodily manifestations of the diseased body. This is not the case with diabetes. The disorder if maintained does not hinder everyday life. There are not any outward manifestations of the disorder making it obvious to others.

As discussed by Fife and Wright (2000) that HIV is stigmatised because of the immoral behaviour associated with its causation and cancer is stigmatised because of the fear of the disease. Diabetes falls somewhat in the category of cancer. The responsibility does not lie with the affected person, especially if one became diabetic in their childhood or in infancy. Yet, the social support given to cancer patients due to the critical nature of their illness, which views them as survivors and heroes, is missing in the case of diabetics. Though they (the diabetics) do see themselves in that light as ‘survivors’ and ‘heroes’ who are trying to prove themselves in spite of their impeding disorder. Probably the lack of support is due to the fact that the danger of death is not proximate in diabetes as in cancer. Also in case where death or mutilation is impending in diabetes it is attributed to the lack of restraint by the patient unlike in cancer where situation is beyond ones control.

The way body and self are perceived and the way they negotiate also varies depending upon the illness. Due to the critical nature of the illness the body becomes dominant in the identity of cancer and HIV patients whereas for diabetics the negotiations

are more subtle and layered. A further detailed study comparing the constructs of body and self and their negotiation of these illnesses would be very relevant.

When addressing the issue of discipline, control and power over the body in various ways it is significant to point out how the reasons for exerting control and power vary and impact the body and the self. That is to say just like the prisoners, the bodies of soldiers are also disciplined and regulated and regimented. They are also denied freedom in certain realms. But that which makes the difference are: i) it is a voluntary decision of a person to submit to the rigours of such life in contrast to the society's punishment to one, and ii) the social self gains a favourable outlook in the former situation a sense of prestige attached to valour and a negative outlook in the latter situation because of the stigma attached to the deviants. Thus, the discipline though pertains to the body it is also about the individual and social self. On the other hand when a diseased person subjects him/herself to the 'disciplines' prescribed by the medical system it is considered mandatory for the recovery and compliance is expected. Sympathy varies from disease to disease and what is the believed reason for it. If the reasons for the disease are considered deviant according to the religious (wrath of God, fate) or medical (smokers with lung cancer) or moral (immoral behaviour e.g. HIV and sexual immorality) norms of the society the responsibility is believed to lie with the individual and there is stigma instead of sympathy associated with the diseased in spite of their difficult situation. This of course has a bearing on their individual and social self. What happens to the body affects the self; the body also becomes the carrier of the self, the site of punishment, discipline and reward. And when the body is disciplined, or punished or rewarded it is the self that is being disciplined, punished or rewarded through that. Similarly, when exercise or any kind of disciplining of the body is done the self tries to exert control over the body in order to bring about a change that will enhance the image of the self.

The bio-medical model has changed the way body and self are seen. A diseased person constructs his/her body and self influenced by the bio-medical explanations. Also the process of structuring and restructuring of identity has changed. There has been a paradigm shift or change in the very framework of structuring and restructuring of identity. Earlier if the structuring was done along the lines of religion or

social norms the restructuring was done by adjusting around them or questioning them or rejecting them raising alternative religious or social values. With the coming-in of bio-medicine there has been either a shift of the framework of structuring and restructuring along the lines of bio-medicine or now the questioning and rejection of the structure or model *for* which might be religious or social in nature is done through adopting the model *of* provided by bio-medicine. This model *of* eventually has changed the model *for*. That is, through the restructuring the structure has been changed and become the new model *for* or the ideal.

Bio-medicine has been discussed in relation to power and the politics of bio-medicine. This research also brought out another aspect of bio-medicine's relation with people. Bio-medical explanations and its power are also appropriated by people, in this case diabetics, for negotiating their perception of self and their identity. The power and authenticity associated with bio-medicine strengthens the assertion of the diabetics that they are normal; that they 'have a disorder' and that they are not 'diseased'. The authority that bio-medicine has acquired provides the base on which the diabetics build their arguments of 'normalcy' and rebel against the society's labelling of them as diseased.

The research pointed out how the respondents time and again faced conflicts, resolved them, and negotiated for their identity. Some of them asserted themselves as 'normal' or were able to resolve conflicts and negotiate successfully but some others were not. It thus needs to be ascertained why some were able to negotiate and others surrendered to the ascribed identity giving-in to the pressure of the social body. Further research is required in order to identify who are the people that are able to negotiate in times of conflict, those unable to, and those who face perpetual conflict, and why?

Respondents' reaction and negotiations need to be located in the context of their relations with their family, peers and colleagues. This research was clinic-based and could not contact the family and peers of the respondents and thus, was limited in its understanding. It is important to find out the perspective of family, friends and colleagues of the respondents in order to get a better understanding of the subject. Also, getting the perspective of the significant others like family, peers on the subject will help comprehend if there are differences in the constructs of body and self in the perception of

the non-diabetics when juxtaposed with the diabetics. The narratives collected have pointed to the stigma that diabetics feel they face from the society. It is pertinent to acquire the society's outlook on the subject as well to have a clearer picture of the situation. These are some of the issues that the study identified and that require further exploration to advance the study.

Understanding the duality and the intermeshing of body, self, and identity is an unending pursuit. Comprehending body, self, and identity have always been important to man because they are the very essence of our being. They are so intricately enmeshed and interwoven that it has been difficult to clearly separate them. The complexity of this issue is evident from the quest from times immemorial which still continues to evade a final understanding or consensus. The presence of illness/disease/disorder adds another facet to it. This research pointed out the dilemmas and conflicts faced by the respondents in trying to assert themselves and their identity facing a chronic illness. It is but natural that all could not succeed in such endeavours because the negotiation for identity is a complex process. In a body that is free of disease identity is dependent on other factors. However, when a chronic illness like diabetes is carried in the body the dynamics of body and its role in the identity changes radically and constantly. This ensues in the negotiations for a 'normal' identity with the presence of a 'not-normal' body. For some this negotiation may be painful and disturbing whereas some struggle and succeed. There are respondents who have done the same with ease. To that extent being successful in the negotiation for identity involves sustained efforts by the diabetic both to validate his/her claims about fitness or normalcy and counter the pressure exerted by the social body. The success or the perpetual struggle is not only dependent on the individual traits/inclinations but also influenced by the host of environmental conditions for instance the family, peer group and others. Whereas, the successful negotiations refresh us through the indomitable spirit displayed the conflicts remind us of the perpetual struggle between the individual and the society wherein, the definitions of 'normal' are constantly being redefined or re-affirmed. The research reinforced the fact that identity is not defined by the body or self alone but by intricate and fascinating negotiations that persist incessantly.

BIBLIOGRAPHY

Books

1. Bernard, H. Russell (2006), *Research Methods in Anthropology: Qualitative and Quantitative Approaches* (4th ed.), Thousand Oaks, CA: Sage Publications.

2. Bernard, H. Russell and Gery W. Ryan (eds.) (2010), *Analyzing Qualitative Data Systematic Approaches*, USA: Sage Publications Ltd.

3. Blacking, John (ed.) (1977), *The Anthropology of the Body*, London: Academic Press Inc. Ltd.

4. Bourdieu, Pierre (1988), *Outline of a theory of practice*, Great Britain: Cambridge University Press.

5. Brown, Catrina and Tod Augusta-Scott (2007), *Narrative Therapy: Making Meaning, Making Lives*, USA: Sage Publications Ltd.

6. Brown, Peter J. (ed.) (1998), *Understanding and Applying Medical Anthropology*, USA: Mayfield Publishing Company.

7. Csordas, Thomas J. (ed.) (1994), *Embodiment and Experience. The Existential Ground of Culture and Self*, Cambridge: Cambridge University Press.

8. Dennett, Daniel (1981/1985), *Brainstorms- Philosophical Essays on Mind and Psychology*, USA: MIT Press.

9. Douglas, Mary (1973), *Natural Symbols*, England: Penguins Books ltd.

10. Douglas, Mary (1994), *Risk and Blame: Essays in Cultural Theory*, London: Routledge.

11. Durkheim Emile, (1915/1976), *The Elementary Forms of the Religious Life*, (translated by Joseph Ward Swain), Great Britain: George Allen and Unwin.

12. Foucault, Michael (1979), *Discipline and Punish*, USA: Vintage Books Edition.

13. Freund, Peter E.S. and Meredith B. McGuire (2003), *Health, Illness, and the Social Body*, New Jersey: Prentice Hall.

14. Geertz, Clifford (1973), *The Interpretation of Cultures*, New York: Basic Books.

15. Good, Byron J. (1994), *Medicine, Rationality and Experience*, Great Britain: Cambridge University Press.

16. Hahn Robert A. (1995), *Sickness and Healing: An Anthropological Perspective*, New Haven and London: Yale University Press.

17. Janzen, John M. (2002), *The Social Fabric of Health: An Introduction to Medical Anthropology*, New York: Mc Graw-Hill.

18. Kleinman, Arthur (1980), *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry*, Berkeley: University of California Press.

19. Leary, Mark R. and June Price Tangney (eds.) (2003), *Handbook of Self and Identity*, USA: The Guilford press.

20. Lock, Margaret, Alan Young, and Alberto Cambrosio (2000), Living and working with the New Medical Technologies, Great Britain: Cambridge University Press.

21. Lupton, Deborah (2003), *Medicine as Culture*, Great Britain: Sage publications ltd.

22. Mattingly, Cheryl and Linda Garro (eds.) (2000), *Narratives and the Cultural Construction of Illness and Healing*, California: University of California Press.

23. Mead, G.H. (1974), *Mind, Self, and Society: From the Standpoint of A Social Behaviorist*, Chicago: The University of Chicago Press.

24. Mechanic, David (1978), *Medical Sociology*, New York: The Free Press.

25. Mellor, Philip A. and Chris Shilling (eds.) (1997), *Reforming the Body: Religion, Community and Modernity*, Great Britain: Sage publications ltd.

26. Morris, David B. (2000), *Illness and Culture in the Post-Modern Age*, London: University of California Press.

27. Parsons, Talcott (1951/1975), *The Social System*, London: Routledge.

28. Raghuramaraju, A. (2006), *Debates in Indian Philosophy Classical, Colonial and Contemporary*, New Delhi: Oxford University Press.

29. Sharma, Chandradhar (1987), *A Critical Survey of Indian Philosophy*, Delhi: Motilal Banarsidass Publishers.

30. Shilling, Chris (2004), *The Body and Social Theory*, Great Britain: Sage publications ltd.

31. Shweder, Richard A. and Robert A. LeVine (eds.) (1984), *Culture Theory: Essays on Mind, Self and Emotion*, Cambridge: Cambridge University Press.

32. Stone, George C., Frances Cohen and Richard Lazarus (eds.) (1979), *Health Psychology- A Handbook: Theories, Applications, and Challenges of A Psychological Approach to the Health Care System*, San Francisco: Jossey -Bass publishers.

33. Taylor, Ross J. et al, (2003), *Health and Illness in the Community*, New York: Oxford University Press.

34. Turner, Bryan S. (1992a), *Regulating Bodies: Essays in Medical Sociology*, London: Routledge.

35. Turner, Bryan S. (1996), *The Body and Society*, London: Sage publications ltd.

36. Turner, Victor and Edward M. Bruner (eds.) (1986), *The Anthropology of Experience*, USA: University of Illinois Press.

37. Williams, Simon J. (2003), *Medicine and the Body*, London: Sage publications ltd.

38. Weitz, Rose (2001), *The Sociology of Health, Illness and Health Care*, USA: Wadsworth.

39. Weber, Max (1930/1976), *Protestant Ethic and the Spirit of Capitalism*, Great Britain: George Allen and Unwin.

Articles

40. Ablon, John (1981), 'Stigmatized Health Conditions', *Social Science and Medicine*, Vol. 15b, pp.5-9.

41. Adams, Stephanie and Roisin Pill and Alan Jones (1997), 'Medication, Chronic illness, and Identity: The Perspective of People with Asthma', *Social Science & Medicine,* Vol. 45, Issue 2, Pp- 189-201.

42. Adamsen, L. et al, **(**2008), 'Struggling with Cancer and Treatment: Young Athletes Recapture Body Control and Identity Through Exercise: Qualitative Findings from a Supervised Group Exercise Program in Cancer Patients of Mixed Gender Undergoing Chemotherapy', *Scandinavian Journal of Medical and Science in Sports*, 2009 Feb; 19(1):55-66. (Epub 2008 Feb 4).

43. Albrecht, Gary L., Vivian G. Walker and Judith Levy (1982), 'Social Distance from the Stigmatized', *Social Science and Medicine*, Vol. 16, Pp- 1319-1327.

44. Alderson, Priscilla (2007), 'Competent Children? Minors' Consent to Health Care Treatment and Research', *Social Science and Medicine,* Volume: 65, Issue: 11, pp- 2272-2283

45. Asbring, P. (2001), 'Chronic Illness – A Disruption in Life: Identity-transformation Among Women with Chronic Fatigue Syndrome and Fibromyalgia', *Journal of Advanced Nursing*, Volume 34, Issue 3, pp- 312–319.

46. Becker, Gaylene (1998), 'Coping with Stigma: Lifelong Adaptation of Deaf People', In Peter J. Brown (ed.) *Understanding and Applying Medical Anthropology*, USA: Mayfield Publishing Company, pp- 311- 315.

47. Bourdieu, Pierre (2005), 'Belief and the Body', In Mariam Fraser and Monico Greco (eds.), *The Body: A Reader*, New York: Routledge, pp- 87- 91.

48. Blaxter, Mildred (2004), 'Life Narratives, Health and Identity', In David Kelleher and Gerard Leavey (eds.) *Identity and Health*, London: Routledge, pp- 170-199.

49. Charmaz, Kathy (1995), 'The Body, Identity, and Self: Adapting to Impairment', *The Sociological Quarterly* Volume 36, Issue 4 (Sep. 1995), pp 657–680.

50. Chattoo, Sangeeta and Waqar Ahmad (2004), 'The Meaning of Cancer: Illness, Biography and Social Identity', In David Kelleher and Gerard Leavey (eds.) *Identity and Health*, London: Routledge, pp- 19- 35.

51. Christiansen, C.H. (1999), 'Defining Lives: Occupation as Identity: An Essay on Competence, Coherence, and the Creation of Meaning', *American Journal of Occupational Therapy*, Nov-Dec; 53(6), pp-547-58.

52. Conrad, Peter and Kristin K Barker (2010), 'The Social Construction of Illness: Key Insights and Policy Implications', *Journal of Health and Social Behavior*, Vol. 51, No. 1 (Suppl.), pp- S67-S79.

53. Cooks, Leda M. (2010), 'Identity Negotiation' In Ronald L. Jackson II and Michael A. Hogg (eds.), *Encyclopedia of Identity*, Vol. I, Mexico: Sage, Pp- 365-367.

54. Dein, Simon (2007), 'Explanatory Models and Oversystematization in Medical Anthropology', In Roland Littlewood (ed.) On Knowing and Not Knowing in the Anthropology of Medicine, California, Left Coast Press Ltd, pp- 39-53.

55. Estroff, Sue E. (1993), 'Identity, Disability and Schizophrenia: The Problem of Chronicity', In Shirley Lindenbaum and Margaret Lock (eds.), *Knowledge, Power and Practice: the Anthropology of Medicine and Everyday Life*, California: University of California Press.

56. Fife, Betsy L. and Eric R. Wright (2000), 'The Dimensionality of Stigma: A Comparison of Its Impact on the Self of Persons with HIV/AIDS and Cancer', *Journal of Health and Social Behavior*, Vol. 41, No. 1, Pp-50-67.

57. Fisher, C.M. (2007), 'A foot in two worlds: Young women and identity construction in the context of cancer', *The Australian Sociological Association*, Tasmania, Australia, pp. 1-9.

58. Frank, Arthur (2005a), 'The Self Unmade: Embodied Paranoia', In Mariam Fraser and Monico Greco (eds.), *The Body: A Reader*, New York: Routledge, pp- 216- 218.

59. Frank, Arthur (2005b), 'The Body's Problems with Illness', In Mariam Fraser and Monico Greco (eds.), *The Body: A Reader*, New York: Routledge, pp- 318-323.

60. Freund, Peter (2005), 'Bodies, Disability and Spaces: The Social Model and Disabling Spatial Organisations', In Mariam Fraser and Monico Greco (eds.), *The Body: A Reader*, New York: Routledge, pp- 182- 186.

61. Frey, Lawrence R. and Stephen P. Konieczka (2010), 'Group Identity', In Ronald L. Jackson II and Michael A. Hogg (eds.), *Encyclopedia of Identity* Vol. I, Mexico: Sage, Pp- 316-319.

62. Friis, Robert and G. Nanjundappa (1986), 'Diabetes, Depression and Employment Status', *Social Science and Medicine*, Vol. 23, No.5, Pp- 471-475.

63. Grant, Fiona (2010), 'Collective/ Social Identity', In Ronald L. Jackson II and Michael A. Hogg (eds.), *Encyclopedia of Identity* Vol. I, Mexico: Sage, Pp- 98- 100.

64. Harris, Grace (1989), 'Concepts of Individual, Self, and Person in Description and Analysis', *American Anthropologist*, New Series, Vol. 91, No. 3 (Sep. 1989) pp- 599-612.

65. Hopper, Susan (1981), 'Diabetes as a Stigmatized Condition: The Case of Low-Income Clinic Patients in the United States', *Social Science and Medicine*, Vol. 15b, pp. 11-19.

66. Jonathan A. Smith, Paul Flowers and Mike Osborn (1997), 'Interpretative Phenomenological Analysis and the Psychology of Health and Illness', In Lucy Yardley (ed.) *Material Discourses of Health and Illness*, London: Routledge, pp- 68- 91.

67. Jonathan A. Smith and Mike Osborn (2008), 'Interpretative Phenomenological Analysis', In J.A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods,* London: Sage Publications Ltd, pp- 53-80.

68. Kelly, Michael P. and Louise M. Millward (2004), 'Identity and Illness', In David Kelleher and Gerard Leavey (eds.) *Identity and Health,* London: Routledge, pp-1-18.

69. Kleinman, Arthur (2005), 'Hypochondriasis: The Ironic Disease' In Mariam Fraser and Monico Greco (eds.), *The Body: A Reader,* New York: Routledge, pp- 219- 229.

70. Lawler, Steph (2002), 'Narrative in Social Research' In Tim May (ed.), *Qualitative Research in Action,* London: Sage, pp- 242-258.

71. Logan, Sadye L. M. (2010), 'Identity Diffusion', In Ronald L. Jackson II and Michael A. Hogg (eds.), *Encyclopedia of Identity* Vol. I, Mexico: Sage, Pp- 362-365.

72. McKendree, Amanda G. (2010), 'Personal Identity versus Self-identity', In Ronald L. Jackson II and Michael A. Hogg (eds.), *Encyclopedia of Identity* Vol. II, Mexico: Sage, Pp- 545- 548.

73. Munir F, S. Leka and A. Griffiths, (2005), 'Dealing with Self-Management of Chronic Illness at Work: Predictors for Self-Disclosure', *Social Science & Medicine,* Vol. 60, Issue 6, March 2005, Pp-1397-1407.

74. Murphy, Robert F. (1998), 'The Damaged Self', In Peter J. Brown (ed.) *Understanding and Applying Medical Anthropology,* USA: Mayfield Publishing Company, pp- 322- 333.

75. Naus, Mary J. et al (2009), 'Cancer Survivor Adaptation Model: Conceptualizing Cancer as a Chronic Illness', *Journal of Clinical Psychology*, Vol. 65(12), pp- 1350-1359.

76. Pelto and Pelto (1996), 'Research Designs in Medical Anthropology', In Carolyn F. Sargent and Thomas M. Johnson (eds.), *Medical Anthropology Contemporary Theory and Method* (Revised Edition), USA: Praeger Publishers, pp- 293-324.

77. Radley, Alan (1997), 'What Role Does the Body have in Illness?', In Lucy Yardley (ed.), *Material Discourses of Health and Illness*, New York: Routledge, pp-50-67.

78. Reid, Katie, Paul Flowers and Michael Larkin (2005), 'Exploring Lived Experience', *The Psychologist*, Vol. 18, No. 1 (Jan. 2005), pp-20-23.

79. Reissman, Catherine (2002), 'Analysis of Personal Narratives' In J. F. Gubrium and J.A. Holstein (eds.), *Handbook of Interview Research*, Thousand Oaks: Sage Publications Inc, pp-695-710.

80. Reissman, Catherine (2004a), 'Narrative Analysis', In Michael S. Lewis-Beck, Alan Bryman and Tim Futing Liao (eds.), *The Sage Encyclopedia of Social Science Research Methods*, Vol. 2, USA: Sage Publications, pp-705-709.

81. Reissman, Catherine (2004b), 'Narrative Interviewing' In Michael S. Lewis-Beck, Alan Bryman and Tim Futing Liao (eds.) *The Sage Encyclopedia of Social Science Research Methods*, Vol. 2, USA: Sage Publications, pp-709-710.

82. Rivera, Jason E. and Zachary P. Hohman (2010), 'Psychology of Self and Identity', In Ronald L. Jackson II and Michael A. Hogg (eds.), *Encyclopedia of Identity* Vol. II, Mexico: Sage, Pp- 601-608.

83. Rosaldo, Michelle Z. (1984), 'Toward an Anthropology of Self and Feeling', In R. A. Shweder and R. A. LeVine, (eds.), *Culture Theory: Essays on Mind, Self, and Emotion,* Cambridge: Cambridge University Press, pp. 137–157.

84. Sassatelli, Roberta (2005), 'The Commercialization of Discipline: Keep Fit Culture and its Values', In Mariam Fraser and Monico Greco (eds.), *The Body: A Reader*, New York: Routledge, pp-283- 287.

85. Scambler, Graham, Steffan Ohlsson and Konstadina Griva (2004), 'Sport, Health and Identity: Social and Cultural Change in Disorganised Capitalism', In David Kelleher and Gerard Leavey (eds.) *Identity and Health*, London: Routledge, pp- 99- 122.

86. Schechtman, Marya (2005), 'Experience, Agency, and Personal Identity', In Ellen Frankel Paul, Fred D. Miller Jr., and Jeffery Paul (eds.), *Personal Identity*, USA: Cambridge University Press, pp- 1-24.

87. Scheper- Hughes, Nancy and Margaret M. Lock (1998), 'The Mindful body: A Prolegomenon to Future Work in Medical Anthropology' In Peter J. Brown (ed.) *Understanding and Applying Medical Anthropology*, USA: Mayfield Publishing Company, pp- 208-224.

88. Segall, Alexander (1976), 'The Sick role Concept: Understanding Illness Behavior', *Journal of Health and Social Behavior*, Vol. 17, No. 2, (June 1976), Pp- 162-169.

89. Sen, Satadru (2004), 'Schools, Athletes and Confrontations: The Student body in Colonial India', In James H. Mills and Satadru Sen (eds.), *Confronting the body: The Politics of Physicality in Colonial and Post-colonial India*, London: Anthem Press.

90. Siegel, Karolynn and Helen-Maria Lekas (2002), 'AIDS as a Chronic Illness: Psychosocial Implications', *AIDS*, 16 (Suppl. 4), pp- S69-76.

91. Smith-Morris, Carolyn M. (2005), 'Diagnostic Controversy: Gestational Diabetes and the Meaning of Risk for Pima Indian Women', *Medical Anthropology*, 24, pp-145-177.

92. Stelter, Reinhard (1998), 'Body Experience, Self and Identity: The Formation of Personal and Social Constructions of the Self through Sport and Movement', *The European Yearbook of Sport Psychology*, Vol.2, pp-1-32.

93. Steedly, Mary Margaret (1988), 'Severing the Bonds of Love: A Case Study in Soul Loss', *Social Science and Medicine*, Vol. 27, No. 8, pp- 841-856.

94. Turner, Bryan S. (2001), 'Disability and the Sociology of the Body', In Gary L. Albrecht, Katherine D. Seelman and Michael Bury, *Handbook of Disability Studies*, USA: Sage Publications, pp- 252- 266.

95. Turner, Bryan S. (2009), 'The Sociology of the Body', In Bryan S. Turner (ed.), *The New Blackwell Companion to Social Theory*, Singapore: Wiley- Blackwell.

96. Weinberger, Morris, Stuart J. Cohen and Steven A. Mazzuca (1984), 'The Role of Physicians' Knowledge and Attitude in Effective Diabetes Management', *Social Science and Medicine*, Vol. 19, No. 9, Pp- 965- 969.

97. Whitehead, L. (2006). 'Toward a Trajectory of Identity Reconstruction in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Longitudinal Qualitative Study'. *International Journal of Nursing Studies*, 43, Pp-1023-1031.

98. Wierzbicka, Anna (1989), 'Soul and Mind: Linguistic Evidence for Ethnopsychology and Cultural History', *American Anthropologist*, Vol.91, No.1, pp- 41-58.

99. Winkelman, Michael (2004), 'Shamanism' In Ember and Ember (eds.), *Encyclopedia of Medical Anthropology*, pp- 145-154 (published by ????)

100. Wysocki, Tim (2002), 'Parents, Teens and Diabetes', *Diabetes Spectrum*- Vol. 1, No. 3, (April-June 2002), by American Diabetes Association (ADA) USA, pp- 105-107.

Magazine Article

101. Miller, Lisa (2010), 'Body and Soul: Far from Heaven', adapted from the book *Heaven: Our Enduring Fascination with the Afterlife*, In *Newsweek.com*, April 12, 2010, pp-44-45.

Thesis

102. Bindhulakshmi P., 2006, Women and Mental Illness: An Ethnographic Study in Kerala, Ph. D. Thesis, Department of Humanities and Social Sciences, Indian Institute of Technology, Bombay, India

103. Kaitlin Jessica Schwan, 2009, HIV/AIDS and Identity Recovery: Stitching the self back together, M.A. thesis, Department of Art, Queen's university, Kingston, Ontario, Canada

Websites

- **www.anthro.palomar.edu**
- **www.aponline.gov.in**
- **www.ayurveda-foryou.com**
- **www.censusindia.gov.in**

- **www.cnn.com**
- **www.criminology.fsu.edu**
- **www.deccanherald.com**
- **www.hyderabad-info.greaterhyderabad.co.in**
- **www.idf.org**
- **www.indianmedicine.nic.in**
- **www.jdrf.org**
- **www.lifepositive.com**
- **www.missionislam.com**
- **www.muslimphilosophy.com**
- **www.plato.stanford.edu**
- **www.yogajournal.com**