Irritable Bowel Syndrome: The Medical Diagnosis, the Social Experience.

Main aims of the research

Irritable Bowel Syndrome (IBS) is a common bowel condition affecting 10 to 20 per cent of the UK population, in particular those around 20 and 30 years old, and those living with IBS are twice as likely to be female (National Institute for Clinical Excellence, 2015). The condition consists of symptoms such as abdominal pain with associated changes in bowel habits, such as constipation and/or diarrhoea, and bloating. IBS has been characterised as a ‘diagnosis of exclusion’, following multiple clinical investigations (Dancey and Rutter, 2005). This diagnosis raises issues of the limits of medical questioning and legitimacy of medically unexplainable conditions (Jutel, 2009: 290; Nettleton, 2006; 1170). There has been little sociological contribution to the understanding of IBS diagnosis and experience. This research will explore the following:

- to examine the medical process that individuals experience surrounding diagnosis of IBS;
- to explore how this medical labelling affects individuals with IBS and attitudes from those around them following disclosure;
- To explore the effects on individuals social identity and sense of self following their IBS diagnosis.

The research will contribute more widely to understandings of invisible and contested illnesses, in how individuals in society interpret, live and identify with the misunderstood and biological puzzles of unexplainable illnesses. Moreover, it will contribute to understanding the legitimacy of such illnesses and the importance and dominance of medical practices, testing and knowledge in wider society. Furthermore, it will continue to think critically about not only the stigma of a trivialised condition, but also one that is taboo in society due to its embarrassing symptoms. This research builds from my previous research on IBS, social relationships and everyday life and the key social interactions following an IBS diagnosis. This research fits well within the Department of Sociological Studies focus on Science and Technology Studies. My proposed supervisor, Dr Kate Reed, has substantial relevant knowledge and expertise in medical sociology to facilitate this research.

Background to the Study

Irritable Bowel Syndrome (IBS) is a common functional bowel disorder, one that is chronic, relapsing and a lifelong condition. At present, IBS has no cure, no efficient diagnostic testing and no consistently effective form of treatment (Payne, 2004). Dancey and Rutter (2005) note that whilst IBS is not considered life threatening, presumably in the biological sense, it is noted that those living with IBS have similar effects on their quality of life. Many refers to the diagnosis of IBS as a ‘diagnosis of exclusion’ or a ‘dustbin diagnosis’ (Dancey and Rutter,
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2005). Often, IBS is diagnosed when all other ‘serious’, ‘pathological’ illnesses have been tested for and eliminated. Furthermore, IBS is classified as a syndrome relating to a collectivity of symptoms, varying in severity. As such, pinpointing cause and effect is complex (Dancey and Rutter, 2005). For individuals, the labelling and acceptance is at the forefront of IBS experience. A recent report from the IBS Network states one patient’s sentiment, ‘IBS is what they tell you when they don’t know what’s wrong.’ (The IBS Network, 2015). Moreover, contested conditions like IBS are ‘illnesses you have to fight to get’ (Dumit, 2006: 578). IBS is frequently distinguished from Inflammatory Bowel Disease (IBD) which is pathologically identified and ‘serious’, despite similarity in symptoms (Defenbaugh, 2011). Previous research compared their IBS to IBD and Coeliac Disease, which they often described as ‘real things’ (White, 2015). The differences in these labels have implications for the legitimacy of experiences, and treatment from others in society. If diagnosed with IBS, then there is a high level of uncertainty in the legitimacy of the condition and the consequent experiences for those who suffer.

Much of the literature to date exploring IBS has tended to focus around a biomedical model, with a focus on the troublesome biology and thoughts of a psychosomatic influence (Payne, 2004). There is limited emphasis in the literature on the importance of sociological influences with regards to the stigma and lived everyday experience which shape the lives of those with IBS. One could also argue that there is limited literature in IBS studies due to the stigma of talking and thinking critically about bowel conditions, as Defenbaugh (2011: 45) states, ‘where is the shit in scholarship?’ Why are we not questioning it? According to Ronnevig, Vandik and Bergbom (2009) social taboos are rarely discussed with academic literature and they have the potential to restrict a person’s capacity. Sociological studies have often highlighted patterns of health seeking behaviour and patterns of responsibility in searching for a diagnosis (Annandale, 2014). Chang et al (2006) acknowledges that health and illness and conditions such as IBS, occur within a wider social context. As Williams (1984: 182) states, ‘the body is defined by its relationship to the world of social action, not in isolation from it’. This can be noted in references to IBS and its context to stigma and the spoiled or ‘(p)oiled identity’ (Goffman, 1968; Koutroulis, 2001). It is necessary and crucial to engage in a sociological viewpoint to the social experiences and processes of IBS.

Diagnosis is not only important for medical legitimacy, but also to have recognition from those around us (Arroll and Dancey, 2014, Nettleton, 2005: 1167). Seeking help due to the stigma of bowel issues is problematic, further complicated by the fact that there are no tests which can positively identify IBS. This uncertainty may affect the doctor-patient relationship, with some professionals seeing it as trivial and time wasting, a psychosomatic condition, or ‘all in their head’ (Leston and Dancey, 1996; Lee, 2011: 1). Living with a chronic condition such as IBS also makes life questionable (Williams, 1984). The sociology of diagnosis is a relatively new area of inquiry (Jutel, 2009; Jutel and Nettleton, 2011). As Jutel and Nettleton note, ‘diagnosis now represents much more than a patient consulting a practitioner with illness symptoms and coming away with confirmation of disease, if indeed it ever did’ (2011, 793). The Parsonian sick role perspective does not fit with the blurred boundaries of
identifying IBS and the lack of successful treatment. Annandale (2014) documents how access to the sick role has been regarded as more complex, with illnesses such as IBS subjected to opinions on its seriousness and its legitimacy. A sociological insight can allow us to examine how the IBS diagnosis is constructed, and socially and medically treated (Brown, 1995). As a result, the management of IBS in everyday social life is problematic, and responsibility, understanding and care go to the individual patient.

**Methodology**

This proposed research will use a qualitative methods approach which is suited to a reflexive study design aimed to produce rich understanding of the processes involved in IBS diagnosis and the complexity of the lived experiences (Mason, 2008). The study will use semi-structured interviews and the creation of timelines to explore how individuals feel about their IBS diagnosis, and how this affects their illness identity and understanding. It will also explore the patient perspective when negotiating their IBS identity with others. Furthermore, interviews will seek to explore the understandings around diagnosis of digestive illness and how this has further implications for IBS sufferers’ social life and meaning. I plan to interview approximately twenty five to thirty participants who identify themselves, whether self-diagnosed or medically, with IBS. Participants will be recruited from The IBS Network, the National Charity for IBS, whom have supported my previous IBS research. I aim to sustain these relationships, both with the charity, and the research participants and ethical considerations will be reproached following this. Interviews will be audio recorded with field notes being taken following interactions to capture the context of interviews and activities within. Following data collection, there will be a narrative analysis, which aims to capture the meanings and stories of the individual's experience of coming to their IBS diagnosis, and what this means for their sense of self and place in everyday social life (Reissman, 2008).

**Ethical Considerations**

Investigating health and illness, particularly ones that are taboo and often ‘embarrassing’ for individuals, such as bowel habits, medical procedures and experiences, ethical considerations are paramount in the research process. The project will seek ethical approval through the University of Sheffield’s ethical committee and adhere to such guidelines. The research will aim to obtain written informed consent from the individuals who participate. Due to the sensitive nature of IBS, diagnosis and its symptoms, the research will be conducted delicately according to its subject matter and the participant’s rights, ensuring that they are comfortable and confident in participating throughout the research process. All participants will remain anonymous and all data will be kept strictly confidential and stored securely. All participants will be kept fully informed and up to date with the research, ensuring that they are happy with the research outcomes. The research will remain closely to the National Charity for IBS, who will be on hand to provide support, advice and guidance for any participants should they require it.

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Through conducting this research, I hope to develop understandings to the complexities of IBS diagnosis from a sociological point of view, and consider the implications of this for those suffering in society. Moreover, the research will contribute more broadly to understanding diagnosis, the experiences of diagnosis and the connotations, and the impacts and dominance of medical knowledge and labelling.

**Timetable:**

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<tr>
<th>Year One – Literature Review and Theoretical Development</th>
<th>Months 1-6</th>
<th>Develop understandings of qualitative research methods suitable to research. Dedicate time to explore existing literature surrounding IBS and medical diagnosis.</th>
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<td>Months 6-12</td>
<td>Explore theoretical approaches surrounding the sociology of diagnosis, understanding IBS and methodological challenges. Refine Research Questions.</td>
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<tr>
<td>Year Two - Fieldwork</td>
<td>Months 12-18</td>
<td>Begin recruiting participants. Maintain and/or re-establish links with past participants and the National Charity for IBS, The IBS Network, to facilitate and promote this research.</td>
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<td>Months 18-24</td>
<td>Critically engage in existing literature and re-examine according to progression of research.</td>
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<td>Year Three – Writing up Research</td>
<td>Months 24-30</td>
<td>Analyse and write up findings and build links from existing research and theoretical perspectives.</td>
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<td>Months 30-36</td>
<td>Finalise theoretical approaches. Reflect on research practice, challenges within method and create suggestions for further research. Complete thesis.</td>
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**Bibliography**


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