LIVING WITH UNDIAGNOSED ILLNESS: AN EXPLORATORY STUDY
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Executive Summary

1. INTRODUCTION

This exploratory study set out to examine the experiences of people who live with illnesses which are undiagnosed. Practitioners working within all medical specialities see patients with undiagnosed symptoms, but neurology tends to see more than most. The proportion of patients who present with medically unexplained symptoms (MUS) in neurology clinics has been estimated to be between 20 and 40 per cent. The symptoms are often intensely painful and can be associated with varying degrees of impairment, which may be endured for years, even decades. Although there are medical and ‘health service research’ literatures on this topic, it has not been matched by sociological research. In particular there has been very little exploration into the views, lives and experiences of people who live with undiagnosed illnesses.

2. AIMS AND OBJECTIVES

The aim of the study was to examine the narrative accounts of patients living with undiagnosed illnesses. The objectives were to:

- examine the medical literature on MUS;
- carry out circa 20 interviews with neurology outpatients with MUS who varied in terms of their age, gender and the severity and duration of their illness;
- undertake a narrative analysis of the interview data; and to
- identify issues for further research

3. FINDINGS

3.1 The literature review

The review of the medical and related literatures revealed that the term ‘medically unexplained symptoms’ is a relatively recent label which is used to classify those patients who have symptoms which are not associated with a pathological abnormality. It is considered to be more ‘acceptable’ than terms such as: ‘functional illness’; ‘non-organic illness’; ‘somatisation’; ‘abnormal illness behaviour’; ‘factitious’; ‘hysterical hypochondria’; and ‘psychosomatic’, although these terms are still used today. Such patients represent a ‘problem’ for biomedicine. Because they have no identifiable ‘disease’ which can be treated and ‘managed’ medical practitioners may feel impotent and patients may feel marginalised. To use the phrase of one author – they in effect – become ‘medical orphans’. ‘Explanations’ of their health status oscillate between the biophysical, the psychological and the social. The anomalous status of these ‘patients’, and the
partial nature of available explanations on which both patients and their doctors are able to draw upon, were issues that were also evident in the qualitative interview data.

3.2 Qualitative Interviews

In depth, qualitative interviews were carried out with 5 men and 13 women, all of whom were white British, with ages ranging from 28 to 67, and whose symptoms varied in terms of their nature, severity and duration. Symptoms included: blurred vision; spasms; ‘fitting’; paralysis; ‘black outs’; collapsing; extreme fatigue; shaking; restricted mobility; and intense pain. The interviews were carried out in the participants own homes. The data were analysed in two ways; both thematically and via narrative analyses.

3.2.1 Thematic analysis

Thematic analysis identified 7 issues. These were:

- **Uncertainty**: Participants no idea how their symptoms might progress, whether they would be temporary or permanent, or how they should be managed. Planning from day-to-day was virtually impossible, so too was planning for future especially for housing, employment and financial issues;

- **Lack of information and social support**: Participants were unable to access information, leaflets, support groups, and treatments. Many felt isolated, and in some instances desperate, that they had nowhere to turn to for help;

- **Social and family relationships**: Whilst some participants have supportive relatives, asking for help becomes especially difficult for those who already felt that they were placing a burden on others;

- **Relationships with doctors**: Having symptoms acknowledged as genuine was the main reasons for participants assessing doctors as ‘good’ or ‘bad’. Participants recognised that medicine is not clear cut, and so were more anxious to secure ongoing support rather than a disease label;

- **Lack of credibility and legitimacy**: The lack of medical confirmation of their illness meant that they are no clear route into the ‘sick role’ with all its attendant rights and privileges;

- **Self and social identity**: Words such as ‘fraud’, ‘time waster’, ‘hysteric’, ‘fake’ and ‘hypochondriac’ were replete throughout the interviews. Participants found that they asked themselves: ‘Am I imagining it?’ ‘Am I just being lazy?’ and,

- **Searching for explanations**: Participants drew upon a various theories and ideas to try to make sense of their illnesses. The explanations were
invariably rooted in their biographies, but also drew upon psychological, social and biomedical explanations.

3.2.2 Narrative analysis
The narrative analysis provided insights into the cultural and social factors that shaped the participants' experiences. The narrator invariably draws upon the language, beliefs, ideologies, metaphors and representations that are available to them. The discourses used by the study participants resonated with those found in the medical literatures, and in particular the tension associated with trying to reconcile psychological and biophysical explanations.

The analysis of the structure of the accounts built upon Frank’s (1995) work on ‘illness narratives’. Frank identified three types of narrative. First, the restitution narrative, wherein a person gets ill, finds out what is wrong, seeks help, and treats the condition. Second the quest narrative, wherein a person gains something from his or her experience, such as self awareness. Third the chaos narrative where in a person is unable to identify a clear beginning, middle or end for their story. Consequently his or her narrative lacks structure; there is no clear ‘plot’. This is also the most embodied form of story; and it reminds the listener of her own vulnerability.

The narratives told by the study participants had many of the features of chaos narratives. There was uncertainty surrounding the initial onset of symptoms; the narrators had seen so many practitioners, had so many tests, examinations, results, and hospital visits that they could barely recall the details. Participants welcomed the opportunity to talk about their experiences, because very often others did not want to ‘hear’. Some participants told how other people simply failed to acknowledge the existence of their illness, or alternatively, offered them ‘well meaning’ suggestions. The narrative force of ‘restitution’ is such that friends and relatives seemed to feel compelled to offer them a way forward; with special diets, exercise, rest, alternative therapists and, worse of all, bring them copies ‘success stories’ from magazines and newspapers.

4. CONCLUSION

Patient with MUS are in an anomalous position and to some extent become ‘medical orphans’. Conventional biomedicine has little to offer; there are no answers, no drugs, and no technological interventions. What is striking is the absence of information, advice and support. Diagnoses can enable people to access leaflets, support groups, the internet, books and other people living with the illness. A more holistic person centred medicine might however provide support and advice about symptom management and work with the uncertainty. This is important because an overwhelming finding of this study was just how isolated this group of patients feel. Patients who have illness which cannot be explained in organic terms hover precariously on the boundaries of the pathological and the psychological, and as a result have no clear route for advice, treatment and support.