Contours of coping: mapping the subject world of long-term illness

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Abstract

Medical geography has evolved from studying 'dots on maps to embodied subjects'. Involving the acknowledgement of new territories and identities, this has taken place against a backdrop of wider shifts in understanding health and illness. This paper suggests geographers are well placed to develop their existing skills of spatial exploration in order to map out these new territories. Whilst 'the map' has recently suffered from bad press, as a selective, misleading representation, this paper demonstrates it can be resurrected as a less sinister tool to aid our understanding of situated health experiences. © 2000 Elsevier Science Ltd. All rights reserved.

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1. Introduction: knowing illness

Since the early beginnings of medical science, experts have fought to get to grips with the cause of disease. As our society becomes increasingly complex, we have recognised that contracting disease often has as much to do with our social and personal environment as the absence or presence of a particular microorganism. It also seems that as a result of an ever more complex and challenging environment, we are increasingly faced with long-term debilitating conditions or 'syndromes' for which biomedicine can define no clear cause and certainly offer no cure. With such syndromes becoming a growing burden for individual sufferers and health services alike (Askwith, 1989), we need to look at ways to manage these conditions, relying more on balancing

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lifestyle and behaviour factors, than eliminating identifiable causative agents. Within this context we are also witnessing an undermining of the strict dividing lines between lay and professional modes of thought when it comes to health and illness. The growth of pluralistic care in the age of information explosion, with alternative practitioners and self help groups facilitating the exchange and development of lay knowledge, means health and illness occur in a complex social context which cannot be accessed through the discourse of 'traditional' medical practice alone (Bury, 1997).

One such debilitating, long-term condition is Myalgic Encephalomyelitis (ME) or chronic fatigue syndrome (CFS). ME often follows a 'trigger event', such as a virus, with overall tiredness with extreme muscle fatigue and pain being the predominant symptoms. A short walk, climbing on or two steps, or holding a conversation renders the patient exhausted and often bedridden for days, weeks or even months. Other symptoms include loss of memory, both short and

long-term, lack of concentration or a sensation of being continually drunk. Tinnitus, sensitivity to touch and fear of sunlight, stomach disorders, gripping chest and back pains and secondary depression, arising from a feeling of total helplessness, have all been recorded (Chaitow, 1989; Steincamp, 1989). The very nature of ME, with its broad range of symptoms and difficult diagnosis leads it to be confused with other disorders. Hence the victim may be considered to be suffering from multiple sclerosis, arthritis, chronic candidiasis or depression.

Prevalence of ME in the UK population is estimated to be anything from 0.5% to 2%, depending upon the research setting (Elliott, 1999). Despite what appears to be a growing burden of ME on sufferers and the economy, there is only a limited amount conventional medicine can do to help the patient cope. Although there are recognised centres of excellence and much biomedical research being conducted (see, for example, Fox, 1998), there are still doctors who cannot, or will not, diagnose ME (Ho-Yen and McNamara, 1991; Kilroy, 1994). There are also disputed definitions, diagnostic tests and degrees of severity, so some sufferers 'fall through the net'. Alternatives such as acupuncture or homeopathy offer an important resource for some sufferers who do not meet with success through traditional medial channels. Although not suitable for everyone, some develop support networks through self-help groups or rely heavily on lay carers and understanding from their immediate social networks (MacKian, 1995).

As a result of this, in my own research on ME I worked from the premise that since it is a sensitive issue to explore through doctors' eyes, the most fruitful line of enquiry would be to approach the illness from the perspective of the patient; in an exploratory, qualitative manner, allowing individual stories to be explored. This would enable me to develop an understanding of how individuals dealt with their illness and what resources and knowledge they had drawn on in doing so. This in many instances revealed more about the nature of ME and how it is dealt with by society and the medical profession than I gleaned from talking to doctors and researching medical references.

ME was selected for this research for two main reasons. Firstly, the wider framework of the research was an exploration of 'active citizenship' and a critique of contemporary models and understanding of citizenship (MacKian, 1995). I wanted to select a life experience which forced people to become 'active' in a number of ways: seeking advice from specialists, demanding rights from public services, facing challenges to economic livelihood, drawing upon formal and informal social networks in coping with adversity. These were the sorts of situations in which I saw the models of citizenship and participation being espoused

at the time were likely to prove inadequate. Within health care for example, the Patient's Charter does not offer a framework of empowerment, the voluntary sector serves only a small percentage of the population (Kearns, 1995) and not everybody lives in a supportive 'family' as understood in medical policy guidelines. The illness experience was therefore seen as a suitable avenue to explore.

The second reason determined the particular experience which would be chosen. As an undergraduate I had been diagnosed with ME following a year of debilitating illness which had me bedridden before I secured a diagnosis. I had discovered ME is an extremely disempowering experience with the potential to strip sufferers of their ability to be active and engage in a meaningful way as citizens with a variety of structures, it therefore seemed a suitable choice for my research. So, as is often the case in developing research careers, my academic interest in the burgeoning citizenship debate, combined with my own personal experiences, led me down the particular route of choosing ME to be the context for this project.

As my research with sufferers progressed and the stories unfolded it became clear that these were very situated experiences, spatially, temporally and socially; and that they were clearly structured and influenced by a series of narratives which could be read off wider social structures. This sort of situated analysis of long-term illness, drawing out the narratives embedded in the experience, has been repeated in work across many conditions which has sought to explain the way in which illness interferes with or alters the links between body, self and society (see, for example, Corbin and Strauss, 1988; Kelleher, 1988; Robinson, 1988): Hence,

> The study of chronic illness has...been an important way of examining aspects of identity, social interaction, the experience of stigma and the body in late modern society (Bury, 1997, p. 112).

This paper presents a form of 'mapping' these narratives within the context of the respondents' lived worlds as they experience them. The mapping has proved to be a useful exploratory tool when looking at the way in which individuals explain, come to terms and cope with the illness experience. Whilst the paper does not present substantive findings from the research, such as the nature of the illness or the specifics of coping strategies, it outlines one way in which we can try to understand illness management and perhaps learn wider lessons about illness in its social context and the influence of this on the individual. In particular it is a method which enables the researcher to uncover both the intensely personal nature of illness, and also its social dimension as individuals negotiate 'presentation of the self' to society (Bury, 1997).

It has been fashionable of late to criticise maps and the tools of the cartographer, for producing very selective images which, in the mind of both creator and reader, confuse reality and representation (Harley, 1992). However, Harley calls for a deconstruction of maps and an approach to them which breaks the "assumed link between reality and representation which has dominated cartographic thinking" (p. 232). If maps are to be useful exploratory and theory building tools, rather than limited descriptive tools, this more flexible approach is prerequisite. As the paper shows, this involves not only a flexible open minded reading of the map, but an equally open approach to its construction which locates body, subject and social landscapes within that person's world of experience.

2. The health of identity

Whilst biomedicine has long worked to separate the body from its physical, social and emotional setting, the new medical geography of 'embodied subjects' has sought, as have other social science disciplines, to remarry bodies with their complex surroundings. This has happened alongside a wider shift in geography as a whole, from an emphasis on material and territorial spaces, to a consideration of metaphorical and psychological places (Harvey, 1993; Keith and Pile, 1993); and hence an exploration of appropriate methodologies (Parr, 1998; Pile, 1991).

Thus central to the geographer's role in developing an understanding of the social world is constantly reconceptualising how space and place are implicated in changing formations of identity, and as medical geographers we acknowledge the centrality of space and place in the illness experience. This is complicated by an awareness of the *multiplicity* of identities each individual may have and the role of space and place in these, and an understanding that each individual has multiple ideas, frames of reference and external presentations, and hence numerous overlapping subject positions (Laclau and Mouffe, 1985). Part of this endeavour has involved an admirable ongoing attempt to 'map the subject', which has focused on the centrality of space in the constitution of the individual and recognises that the subject is both fluid and fixed (Pile and Thrift, 1995).

Despite the complexity of the subject, it is possible to identify a degree of commonality within or across social groupings, in the form of widely accepted inter-subjective rules which cut across individual experiences and identities; what Jordan et al. (1994) refer to as the 'shared culture'. This shared culture provides a set of common resources in terms of social rules, institutional codes and associated repertoires. Thus in the example of long-term illness, although each individual will develop their own unique history, patients will also refer to many of the same themes, concepts or places which are implicated in the experience; support groups, doctors or biomedical language. However, these common resources are not used by everyone and are frequently exclusionary and experienced negatively. Hence in the case of ME, the language and practice of biomedicine often serve to marginalize the patient who does not fit the mould.

This research was designed to explore the ways in which people weave together such common resources to cope with their own interpretation of the world, whilst remaining sensitive to the complexity of individualised identities which arise. One individual's world will differ from another's, and over time it will shift and change. It is these discrepancies, these apparently contradictory experiences which enlighten us as to why an individual reacts to their long-term illness in a certain way, and can help us better understand how to treat and engage with that illness.

One aim in my analysis was to map the way in which people draw on shared resources at a specific time and place, and weave them into unique, yet sometimes similar patterns. Inevitably this endeavour is still open to the criticism that the very act of mapping breaks the time of constant subject experience, as with more traditional forms of mapping. However as there is so little understanding of the whole trajectory of coping with ME (Elliott, 1999), whilst simultaneously a huge interest in the *meaning* of long-term illness in society, it seems acceptable as a starting point to take a 'snapshot' of one section or moment of that trajectory and (re)present it in the form of a map of the subject's total context; the total context including human, non-human, the 'real' and 'imagined'.

2.1. Theorising space

Pile (1993) uses psychoanalysis as a tool for developing a new model of the lived world. In drawing upon the work of Lacan he identifies three kinds of space, Real, Imaginary and Symbolic, which can be used to articulate the multi-layered, ambiguous world we live in. However Pile shows no promise of how this may be articulated outside the mind and related to the world by geographers practically. Together, Keith and Pile (1993) move beyond this by conceptualizing the relationship between the three spaces using the notion of *spatiality*. Spatialities draw upon the links between the three spaces and inform our interaction in the world. By implication it does not really matter *where* the three worlds originate only our understanding of them and interaction with them.

Werlen also explores the idea of representing exist-

ence in three distinct worlds so this is a theme which is repeated in the work of several authors (Bowie, 1991; Keith and Pile, 1993; Pile, 1993; Werlen, 1993). The first world, the *subjective* world, consisting of the subjective consciousness of the agent in the form of 'stock knowledge' acquired over time in relation to interaction with others. The *physical* world as the 'paramount reality', containing those physical things which the subject is aware of; and the *social* world consisting of other agents and their actions.

This triadic split appeared to be reflected in the experience of long-term illness and became an emerging theme in my analysis. The individual 'lives in' these three worlds during which he or she undergoes a constant and continuous stream of experience. Werlen argues that as a result of this constant process of experience, there is only ever a 'now'; however the 'now' will be differentiated and can be present, past or future orientated. It is this 'now', and its orientation, which I wanted to capture and reveal through mapping.

However, he states that the physical world is constituted via a body centred system of spatial co-ordinates and the conscious self's experience of its own body in movement. For me this appears to be a simplification of the physical world, since not all *awareness* or *appreciation* of the physical world need come about through bodily movement within it. The physical world, although being something which is out there and we 'go to' it, also exists 'out there' in our own interpretations of that world and we will react to it and interact with it according to our own stock of knowledge and experiences, as well as in relation to its concrete rootedness in 'space'.

Although I suggest we should not reduce space and place to Euclidean concepts, it is important to stress that this is not prioritizing the individuals' ability to create or define their world at will. In fact by acknowledging the complex interplay between the individual's interpretation of their world and wider structural and social determinants, this method addresses the embeddedness of experience and is sympathetic with Giddens' structuration moulding human experience (Giddens, 1984).

There are questions left unanswered by Werlen's thesis, not least of all 'what do these worlds *look* like?' However he also suggests that understanding should first be grounded in the agent's perspective, this will then allow us to locate the agent and the worlds by means of 'adequate spatial concepts'. It is these adequate spatial concepts which I have endeavoured to

uncover in the experiences of my respondents, and the ideas presented by Werlen, the questions he left unanswered and my own early formulations of the three spaces, prompted me to rethink traditional approaches to text analysis in qualitative research, and explore how spatial analysis could deepen our understanding of illness coping strategies. I therefore set about determining how we may take these ideas further through empirical work.

2.2. Analysing spaces

People experience their everyday life *as a whole* and this is presented to us in the research encounter. People seldom break down the social, physical and subjective components, since they do not consciously move between the three worlds, even though as researchers we see them emerging as we theorise their worlds. This 'everyday world' therefore becomes broken down into its component parts once interrogated through analysis. But how are we to identify and place them in this analysis process? I am a visual person and wanted to 'see' the worlds of my respondents therefore, as a geographer, it seemed perfectly natural and logical for me to map them.

In qualitative analysis, it is usual to begin with identification of recurrent themes in an interview transcript, and patterns of repetition within the text. As the text stands these themes remain sequentially ordered in terms of the interview process, but are not yet related to the whole lived experience of the subject. Since it is this lived experience and not the structure of the interview we are aiming to elucidate and understand it is vital to interpret the significance of these constructs. We must determine whether or not a recurrent or dominant theme is integral to that lived experience or indicative of another process or relationship not revealed to us through the text alone. Themes at this stage are little more than points on a number line. The interview text in itself reveals little more than the respondent's ability to use the spoken word to convey messages and the interviewer's ability to grasp the meaning of these words and from them pose further questions and facilitate the art of conversation. Hence we are illuminating certain commonplace intersubjective actions or experiences and not yet touching upon the subjective world of the respondent. As researchers we are clearly aiming for more than proof that we are good conversationalists; so we begin to rework the text to discover the buried meaning. It is necessary to try and fathom out how the blocks of texts, the identified 'constructs' or 'themes', are ordered in the world of the respondent, and how this ordering informs that person's relationship and engagement with the world[1].

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[1] I refrain from using the term 'action' since this implies a physical 'getting out there and doing something', whereas my use of 'engagement' can be a purely passive, subjective 'link'; this is particularly important in physically restricting illness.

2.3. Mapping spaces

One of my developing areas of interest was the extent to which an individual feels engaged or disengaged, included or excluded, as a result of long-term illness. This engagement and disengagement can be conveyed metaphorically by the notion of distance. Hence a now distant sphere features further away from the centre of the respondent's world. In this way a lived world can be constructed visually; the interview text can be 'mapped'. We all 'distance' ourselves from things occasionally as we make sense of our lives; and we make comparisons or group things and ideas that seem logical in relation to our experience of the world. It is this process which is depicted in the map.

The cartographic rules for constructing these maps are not conventional, but are shaped to fit the world of the respondent. This may appear a very idiosyncratic approach, but it should be seen as presenting a tool box of ideas for each researcher to use as they wish. For example, an axis (if there is one) can run in any direction, and time may or may not be a tool to construct the map depending upon how central time is to a person's story and how mobile they are through it. The only guiding rule for constructing the map is to assume some orientation to start drawing. In light of the fact that my first question in this research was always 'how did you first realise something was wrong?' the answer invariably began with some form of locating this experience within a wider context; either temporal

> I'd been back and forth to the doctors all term. Polly

Or a more social context

> My friend who does aromatherapy told me about ME and I wondered whether that could be it. Kate

The initial coping pattern of many people faced with debilitating long-term illness is to cut contacts with some of the usual arenas they engage with, for example

work or busy social circles. Later on in the illness sufferers may start to look for new avenues of support or help, thereby extending both their physical and social spatialities by engaging in new arenas. So for example, in some cases the orientation may take the form of a time axis which orders this process, drawn running west–east in the initial stages of the interview (a readily accepted written construct in the West), as the respondent retells a period of months or years leading up to the diagnosis. This axis can then be broken, reversed or altered as the map construction progresses, dependent on how important that time dimension continues to be. Others may have no such movement, as some people live more 'stagnant' lives. The shape of the map is therefore governed by the approach of the individual to their experience and contextual circumstances, and hence the 'lived' world begins to unfold[2].

The 'map' will include the main points of the interview but translate them into the lived world of the individual. It is not simply a summary of the text, it is a visual metaphor for the everyday world of the respondent as represented in the interview, and is a valuable heuristic tool. Although as with any type of analysis the researcher inevitably affects the end product, this does allow us to visualise more clearly the relationships between the experiences and influences in the respondent's life. Thus it is in essence one way of transposing the interview into a representation of the lived experience and a 'map' of the engagement, disengagement and movement through time and space portrayed in that interview.

The map includes aspects of the physical and social world, it has links with institutions, structures and other collectives, and it has purely subjective elements. This is not really revealing anything more than is hidden in the text of the transcript. But the text is merely the story *as the respondent remembers to tell it to us*. Repositioning the elements in this way reveals them in a way which is sympathetic to the lived world of that respondent. This seems particularly pertinent in the study of ME where long-term fatigue, mental exhaustion and frustration can leave the memory jumbled and erratic at times, rendering the interview process inherently unreliable.

Thus the visual transformation of the raw text, although a construct of the researcher and therefore somewhat subjective, serves a useful purpose in that it allows us to create a meaningful interactive 'whole' out of a less 'lived' line of text. The maps may not add significantly to understanding of the *content* of the experience. Their strong point is that they reveal the *structure* of that experience and the relative positions and importance of the elements contained within that experience. Therefore it offers

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[2] It is important to note that this 'map' of the interview is neither a map pertaining to any of our familiar notions of spatial relations or a 'cognitive map' in the usual sense of the word. Although spatial metaphor is drawn upon in positioning certain constructs, that spatiality is not fixed or absolute, but fluid and relational. It is also not a subjective representation of physical reality, which a traditional 'mental' or 'cognitive' map is. Neither is it 'mapping the subject' (Pile and Thrift, 1995), but rather mapping the terrain through which the subject, body, object and others move.
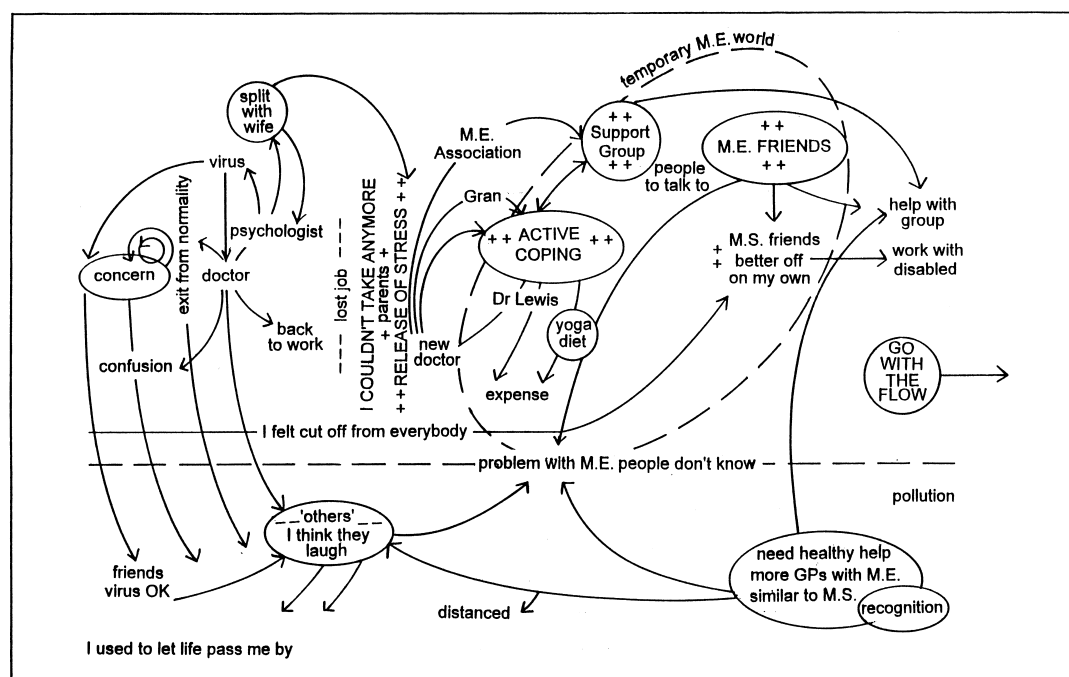
Fig. 1. Mark's map.

a conceptualisation of the whole which is difficult to obtain using selected quotes from a transcript.

At the risk of providing too explicit a statement of procedure, I tentatively offer an illustration of the proposed interpretation in real terms from my analysis of one of the interviews.

3. An example: interview with Mark

Mark is a loyal member of a voluntary ME support group and has been ill for 2 years. He is 27 and shows steady but slow improvement. Before his illness Mark was married, a construction worker, owned his own house and socialised regularly with friends. His emphasis in life was work, in order to earn money for his home and wife. He said he used to let life pass him by and never took much notice of it.

Mark's marriage broke down, he feels as a result of his illness, and he is now living with his parents. His values have altered radically and he puts his illness partly down to the old way he led his life, involving high stress, continual striving for pecuniary advance-

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³ Although I also conducted detailed analysis of the text it is the map as a tool which is of interest here so details are not included.

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ment and never appreciating life. Once he let go of all the stress (work, wife, mortgage) he began to concentrate on getting himself better and appreciating life more³.

Mark began by telling the story of how he was constantly retracing his steps, going back to his GP and failing to get any kind of diagnosis. Hence we begin with circular backtracking on the map, until he reaches a break off point where he could take no more (Fig. 1). He then entered an area of taking control and coming to terms with his illness, forming his own strategy of active management. In this area key 'anchors' appear which are repeatedly referred to or linked with that space — e.g. his 'ME friends', his yoga and acupuncture. In this section of the map Mark begins to draw parallels in order to explain the situation he finds himself in. He begins to rationalise the attitude of 'others' (old friends, family) to his illness. He shows an awareness of a split within the world of ME itself, with some sufferers unable or unwilling to handle the illness positively.

At this stage these other people become integral to the map and the experience. Mark continually refers to what other individuals or groups are feeling and his reaction to this. He separates distinct areas for his ME friends, his old friends who don't understand, 'others with ME' and 'others who do understand'. Those who

do not understand become more distant and are in fact placed beyond his dominant spaces of engagement. Beyond this 'border' is a space of subjective explanations in which he places and orders the attitudes of others, together with his own explanations of both his immediate experience and the wider experience of ME. This space progresses linearly with time parallel to the normal social world. It is another world of engagement he does not physically engage with because it is not helpful to his chosen route to recovery, but it is an important part of the way in which he constructs his own subjective understanding of his experiences. Thus although as he lived the experience he was unaware of his parallel world, as he retells it 'now' it begins to unfold quite clearly.

The end of the mapped experience rejoins the time path and projects into the future. This becomes a more directed and thus narrow part of the map — the space he occupies now being the more active and busy area. The future is seen positively and hence the map projects forwards and not backwards (another generally accepted Western metaphor for positive forward thinking). None of this implies a causality. Mark cannot singlehandedly alter social meanings of illness for example. However he does position these elements in relation to each other as he makes sense of them.

The map is initially drawn as a two dimensional surface, as in Fig. 1. However the maps can be simplified to represent coherent spaces of engagement which take on different forms and symbolise the type of behaviour. Some areas of engagement appear to be flat 'planes' a respondent is exploring, others are 'balls' of intense activity. There are 'barriers' to action and significant elements which 'anchor' the experience or 'balloons' which literally 'keep the person afloat'. The world becomes three dimensional as these spaces of engagement take shape as a result of the story being told through the text.

In Mark's summary map, he is moving positively through a difficult time, physically engaged in active management which is moving him forwards (Fig. 2). This is cushioned by a social world which he sees as normality and a subjective world where he orders his explanations to help him rationalise and deal with his illness. Thus deconstructing the written text and reinterpreting it in the form of the map allows us to develop a visual terrain which can clarify the complexity of experience and identity.
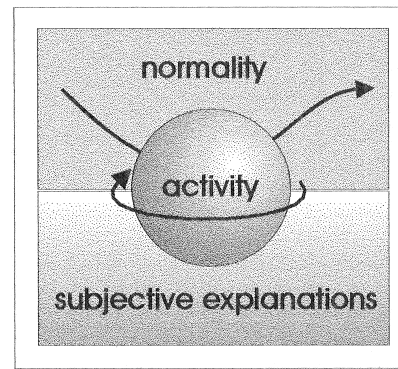
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[4] Meaning for example that 'the family' may be important physically for one person as a resource they rely on for mobility, and yet subjectively important to another in their less tangible support through the illness.

Fig. 2. Mark's simplified map.

4. Beyond the particular...

Thus the initial complex map helps to visually inform our understanding of how an individual's world is structured and how they respond. The simplified maps then effectively portray the interaction of distinct social, subjective and physical spaces within that structure and what rules or shared culture are drawn on in which space for a particular individual. Thus in the initial map the social, physical and subjective world interrelate, just as in the everyday lived world of the subject. By summarising the maps, the way in which the respondent behaves in these complex spaces can be seen and the dynamics of the experience come to life. The dynamics of the map, or the individual's use of the three worlds[4] can subsequently be used to identify a particular 'type' of experience, grouping respondents together if so desired; for example drawing upon ideas of movement or engagement. For the purpose of this paper I have chosen to explore briefly three types of 'spaces', shown in Figs. 2, 3 and 4, which emerged out of this analysis.
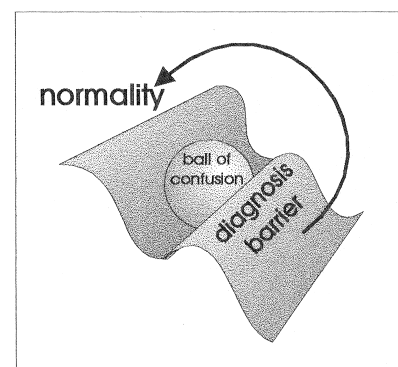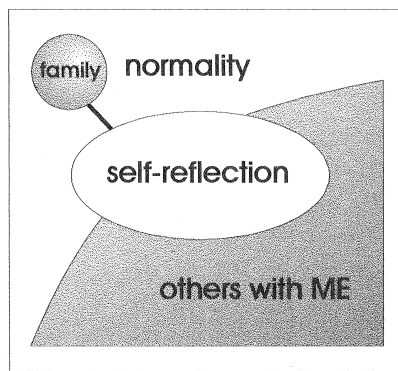

Fig. 3. Polly's simplified map.

Fig. 4. Kate's simplified map.

4.1. Spheres of activity (Figs. 2 and 3)

The maps can reveal distinct areas of activity or engagement. We saw how Mark was actively managing his illness and that most of his physical engagement was concentrated in this area. Polly also has most engagement concentrated in one distinct area. In her case a 'ball of confusion' she is temporarily locked into is preventing her from moving forwards. This is an intersubjective space where she is dealing with a lack of understanding from work colleagues and friends, and a delay in receiving a second medical opinion.

4.2. Temporal dynamics (Figs. 2, 3 and 4)

The maps serve to open up the dynamics of the world of the respondent. For some there is little movement, for example both Kate and Polly are temporarily 'stuck'. However Kate is moving slowly around a plane of self reflection and is not prevented from moving forwards as Polly is but is instead taking time to reflect and gather her resources. For Mark the map clearly reveals a movement through time.

4.3. Hidden battles (Fig. 2)

The mapped representations are an effective means of visualising and clarifying personal battles or coping strategies alongside the more tangible worlds of engagement which appear in the subtext of interview transcripts. Mark, is an example of this, with the clear space of explanations which runs throughout his illness path.

These three types of spaces or engagement illustrate some basic elements of the mapped representations which were repeated across respondents. These can subsequently be analysed by returning to the words used in the text, analysing the content of social, subjective and physical worlds and assessing how the lived world of experience affects behaviour. As shown, the 'simplified maps' which portray dominant areas of activity, engagement, disengagement and dynamics of the respondents' worlds, also allow comparisons to be drawn between individuals.

5. Conclusion

This paper set out by outlining very briefly one area of concern in contemporary health studies, and the idea that professional approaches to dealing with ill health need to adapt to cope with changing circumstances. After the detour 'into the field' of empirical research, I now wish to return, equally briefly, to my original starting point.

Society is facing complex syndromes which biomedicine and medical professionals are presently ill-equipped to deal with. However, by marrying wider theoretical debates within the social sciences with our approach to understanding health and illness, it has been seen on many occasions that it is possible to make a significant and real contribution (Bradshaw, 1994; Dyck and Kearns, 1995; Sevenhuijsen, 1998). Two forces in particular demonstrate how timely it is for us to develop a greater understanding of the strategies developed by individuals in response to their own illness experiences and wider circumstances. Firstly the growing acceptance that 'lay' individuals have a wealth of relevant knowledge which affects their illness behaviour and can therefore influence the health outcome (Bury, 1997). Secondly, recent policy initiatives leaning towards the service user taking a pro-active role in their treatment (see, for example, Our Healthier Nation, DOH, 1998).

Having returned to a number of my respondents with the mapped analysis, they responded very positively, and were amazed at how much 'sense' the maps made in relation to their own experiences. The maps therefore not only serve as an interesting visual device to uncover the complex worlds of individuals, but can also be shown to have a clear validity in the eyes of those individuals. In one instance the respondent laughed out loud at herself and said "*now* I understand why I was never dealing with it back then!" Social settings can put up powerful blocks restricting behaviour. This was particularly apparent in the case of this respondent. However, she had not 'told me' in so many words, or even understood herself how forces were shaping her behaviour until she saw the map.

Spatial metaphors and references are found throughout our everyday lives as we make sense of our experiences. It would also seem that developing such spatial

metaphors allows a clearer understanding of why people behave as they do. Engagement, disengagement, withdrawal and involvement all have spatial connotations, and as my sufferers demonstrated we can quickly understand our own world and the way in which we engage with it in this way. So the maps aided me as the researcher in understanding why individuals had approached their illness in a particular way, but could also act as a useful self-analysis tool for the respondents. Although some caution should be exercised here, as a social scientist I do not want to play at amateur psychoanalyst (Parr, 1998; Burgess et al., 1988).

In this paper I have attempted to offer one solution to exploring and representing the complex experience of long-term debilitating illness. I do not claim my method is revolutionary or faultless, but it does take a significant step by providing the analyst with a means of visualising the constructs and relationships which are woven through the text. Hence it provides not only a sensitive understanding of identity(ies), but also a useful insight into the blocks and enablers which exist in an individual's coping strategy. The mapped representations of interview transcripts were developed through a concern with the robustness of methods of qualitative analysis. It was an attempt to reveal the reality of a particular experience within a contextual world but the 'tool' is transferable to a wide range of research questions grappling with the complexity of identity beyond the health research agenda. Many interesting questions presented themselves through the process and I am excited by the possibilities offered by this small step to turning those 'dots on maps' into 'embodied subjects' (Dyck and Kearns, 1995); whilst not losing what is so dear to me as a geographer — the maps!

Acknowledgements

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