A PHENOMENOLOGICAL ACCOUNT OF USERS’ EXPERIENCES OF ASSERTIVE COMMUNITY TREATMENT

JAY WATTS AND STEFAN PRIEBE

ABSTRACT

Assertive community treatment (ACT) is a widely propagated team approach to community mental health care that ‘assertively’ engages a subgroup of individuals with severe mental illness who continuously disengage from mental health services. It involves a number of interested parties – including clients, carers, clinicians and managers. Each operates according to perceived ethical principles related to their values, mores and principles. ACT condenses a dilemma that is common in psychiatry. ACT proffers social control whilst simultaneously holding therapeutic aspiration. The clients’ perspective of this dilemma was studied in interviews with 12 clients using the ‘grounded theory’ approach. Results suggest that clients’ disengagement is as much a historical and cultural phenomenon as a result of lack of insight. Many clients had experienced rejection of early help-seeking behaviour and all had been subject to coercive interventions. These coercive interventions were experienced as an attack on identity. All felt that their voice had not been listened to in previous interactions with psychiatric services. Consequentially the clients had an increased level of arousal around issues of power, which needs to be incorporated when examining the ethics of community psychiatry. Traditional notions of the difference between persuasion and coercion – for example – may need to be adapted for this client group. Results are compared with the provider perspective. We conclude that the perspectives differ on two key dimensions. Such an empirical approach to examining psychiatric ethics may ensure that we incorporate the subjectivities of various interested parties in the clinical decision-making process.

Community psychiatry – as evolved since the advent of deinstitutionalisation – involves dramatic alterations to psychiatric
practice. These include changes to the locus of care, as well as treatment approaches and funding resources. It aims to provide the range of services once provided within the asylum in the community. These include accommodation, social support, treatment monitoring and vocational support. However ethical changes in community psychiatry have been generally ignored.¹

ASSERTIVE COMMUNITY TREATMENT (ACT)

De-institutionalisation has occurred simultaneously with a movement towards consumerism and empowerment in psychiatry. The empowerment movement focuses on increasing the autonomy of clients. One key change has been the theoretical change from paternalistic models of the therapeutic relationship (‘Doctor knows best’) to a more collaborative relationship where clients are accepted as experts about their own illness process.² Concurrently, recent policy developments have suggested an increase in the use of coercive powers within the community – for example community treatment orders where clients are forced to comply with medication in the community. In the UK, many such policy developments have emerged from rare but much reported cases of homicide involving psychiatric clients. These lead to pronouncements that ‘care in the community has failed’.³ Such cases produce a climate of blame for clinicians where the locus of risk moves from the client to the clinician, thus producing false positive assessments of risk. A false positive assessment is when risk is overestimated so that clients are restricted unnecessarily. For example between 1989 and 1993 the number of compulsory admissions increased by 27% in the UK.⁴ As Harrison notes, ‘large numbers may be drawn into supervision programs having a custodial and coercive therapeutic focus. . . . There is a significant risk that mental health professionals will resort to inpatient care, or over-restrictive styles of therapeutic care, because of risks not to their clients but to themselves should something go wrong.’⁵ The ‘case management’ approach has been adopted to ensure

³ Frank Dobson (Health Secretary). House of Commons, UK, 1999.
⁴ Szmulzer, op. cit. note 1.
continuity of care and co-ordinate service provision. Various models of ‘case management’ have been proposed to manage individuals within the community. Key functions include: assessment, development of a care plan, monitoring, and evaluating progress and follow-up. ‘Standard’ care management is not very effective, leading to the development of several intensive case management approaches.

ACT was developed in the early 1970s in Madison, Wisconsin, to treat difficult-to-engage clients who have a history of a so-called ‘revolving door’ cycle of admission-disengagement-readmission. Recently ACT has been adopted as a treatment model across the industrialised world, and replication studies are bountiful. ACT has been described as the most examined non-pharmacological intervention for clients with schizophrenia. It may be seen as a panacea for governments worried about the safety of ‘care in the community’. ACT aims to provide a complete care package. This includes treatment within the community (rather than statutory offices), a high level of staff support, a high staff to client ratio, an emphasis on practical activities of daily living, and a team approach to case management so that clients have access to a number of staff. ACT is reported to reduce the number of days in hospital for clients, though the effect on other outcomes is less clear. ACT may be applied either as a component of generic community mental health teams or in specific teams focusing solely on administering ACT for a small group of clients with severe mental illness. Assertive Outreach Teams are an example of the latter.

An example – the case of Mr. B, whose case is typical of the participants interviewed – may help illustrate the ethical implications of ACT:

Mr. B is a 31-year old gentleman of African-Caribbean origin with a diagnosis of paranoid schizophrenia and a history of minor forensic offences. He has had around 20 admissions to

8 Ibid.
11 M. Marshall, et. al., op. cit. note 7.
hospital all under various statutory sections of the Mental Health Act, and does not attend outpatient appointments. Generally, he has been managed through depot medication, which he defaults on shortly after leaving hospital. Mr. B identifies one of his key problems as gambling and has many debts. The ACT team manages his money so that Mr. B gets regular income each week. Mr. B is satisfied with this arrangement but does not want to have any more interventions from ACT. He describes a time – several years ago – when he tried to engage with psychiatric services through his GP and the Accident and Emergency Department of the local General Hospital. Mr. B states that professionals told him there was nothing wrong with him. After several years, he became acutely ill and was sectioned and restrained by the police. Mr. B talks of finding psychiatry coercive, and talks with nostalgia of being a popular and charismatic leader at school.

The ACT model condenses a paradox faced in community psychiatry. The model has the therapeutic aspiration of increasing personal autonomy, yet the program aims to engage people whose actions exemplify that they do not want to be involved with psychiatric services. This paradox is present throughout community psychiatry, but is far more acute in ACT where the clients are by definition difficult-to-engage. This raises a number of ethical questions. For example, if clients are not a danger to themselves or others – the criterion for compulsory detention in the UK – do we have the right to force a ‘therapeutic’ interaction? Are the restrictions of the asylum being transported to the community without the statutory controls? ACT clinicians do not generally consider their work to be ethically challenging, and few articles have been written about the ethical implications of the approach. Tellingly, users’ perspectives on ACT have rarely been studied, and it is unclear how they experience ACT.

Though there is no univocal concept of coercion, the concept refers to a range of pressures used – implicitly or explicitly – to gain a patient’s compliance with treatment. The therapeutic relationship between clinician and patient tends to be more intense in ACT given the clinician is responsible for a variety of generic needs – for example social skills rehabilitation in

addition to medication. Persuasion is an appeal to reason. However the intense relationship may afford opportunities for other exertions of power. Leverage is a type of interpersonal pressure, which can be exerted because of the intensity of a relationship – there may be an emotional bond that produces an internal pressure to comply. Wertheimer has argued lucidly that the difference between threats and offers can be defined in the following manner: a coercive proposal is one where refusal would leave the client worse off than at a ‘moral baseline’. If an offer is not accepted, the client will be no worse off compared to this baseline. Though this is a useful heuristic, clients with paranoid schizophrenia tend to have a low threshold for experiencing both anxiety and paranoia. This may stem from aspects of the illness process, from historical experiences within psychiatric services, or from cultural experiences – for example the historical experience of association between psychiatry and the criminal justice system for British African-Caribbean individuals. Thus we may benefit by examining their intrapsychic experience of pressure phenomenologically.

**EMPIRICAL RESEARCH**

Can medical ethics help us address such questions? To counter the claim that medical ethics are characterised by inevitable generality, an anthropological approach may be used to address various subjectivities in the debate about the ethics of community psychiatry. Such empirical work can be used to examine ethics from the nature of all interested parties in community psychiatry – these include clinicians, managers, the client, the general public, and families. Such an approach allows levels of moral explanation so that neither provider nor client is favoured. Further, the approach corresponds with the nascent emergence of the post-modern perspective within psychiatry – such a perspective argues that there are no universal

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truths of health and illness, or capacity to be acultural or impersonal.\textsuperscript{17}

Central to scientific research are the core philosophies that guide researchers’ choice of methodology. Qualitative research recognises the social world is constructed from multiple dynamic realities.

\textit{Method}

Participants were recruited through care co-ordinators of an Assertive Outreach Team in an impoverished inner-city area of London. The sample consisted of eight men and four women with an average age of 38. Nine of the participants were British African-Caribbean, one was British Asian, and two were white British. The majority of participants lived alone (n = 9), and were single (n = 9). All the participants had been compulsorily detained in hospital within the last year, and all had a primary ICD-10 diagnosis of schizophrenia.\textsuperscript{18} The mean number of psychiatric admissions was seven.

The broad aims of the study were explained to all the participants and written informed consent for participation was obtained including permission to publish and to quote. Ethical approval was obtained from the local research ethics committee. Participants were assured of the anonymity and confidentiality of information they provided.

\textit{Procedure}

A qualitative ‘grounded theory’ approach was used meaning that theory is grounded in themes emergent from participants’ spontaneous conversations rather than a priori assumptions.\textsuperscript{19} This method uses the ‘constant comparison’ technique so that themes which emerge from initial open-ended interviews are compared to later interviews to allow the development of a model based solely on data from participants.\textsuperscript{20} During the initial


interviews, participants were simply asked: ‘could you tell me about your experiences with mental health services’ with non-value laden probes used to continue the conversation. Interviews took place until ‘saturation’ was achieved i.e. further interviews did not yield or challenge any categories. All interviews were audio taped. Coding and the identification of categories took place manually throughout data collection to ensure constant comparison and theoretical sampling. The research group examined the transcripts to assess inter-rater reliability of categories.

Results

The results were contrasted with ethical issues discussed in the psychiatric ethics literature, and arising from the authors’ ethnographic experiences in ACT teams across London.

To present the interview results, it may be useful to provide a participant’s view of the psychotic state. Psychosis can be characterised by a basic disturbance of the ‘transcendental trust … the constant presumption that experience will continue to unfold according to some constitutive style’. The personal impact of these psychotic states was evident from the interviews. One participant recalled: ‘I had my benefit book, which was due, and I didn’t know. … I was looking at it the wrong way, I was walking around broke, and my book became battered and torn, and I lost quite a bit of money then … and I thought it was another month.’ Anxieties pertaining to this fundamental experience frame both participants’ and providers’ perceptions of the ethics of interventions. As the concerns are direct and indirect respectively, so both parties have different phenomenological experiences of what is acceptable.

Early help-seeking behaviour

Many of the participants interviewed had lost significant others, including family members, partners and key clinicians early in their psychiatric career. For example: ‘I started hearing voices, I started talking to myself, she couldn’t take it anymore, the relationship broke up … and I ended up on my own’. Many initial attempts at obtaining help for the psychological distress

were met with rejection: ‘It took two years before anyone listened to me and admitted me. So two years I was trying to be admitted but nobody would have me because they kept telling me I was fine, but two years without no treatment, no medication, nothing, and I pretty well flipped . . . after two years I was so far gone that they had to admit me. It didn’t have to come this far’. The literature on chronic illnesses, such as cancer and arthritis, show that the overwhelming implications of illness on identity is mitigated by affirmation from significant others.22 By the time services intervened, the client had often ‘given up’ on help, necessitating a crisis intervention. For example, Mr. B felt anger that he was subject to police restraint as a result of having his request for help for his psychotic symptoms ignored years earlier. Mr. B is thus prone to experience services as aggressive, coercive and paternalistic and has ambivalence towards engagement despite benefiting from social help. Most of the participants expressed relief at being given the opportunity to discuss their previous experiences of coercion and the images were very vivid: ‘When you are on the ward, you get staff that think it’s a prison or something. And that you’ve done something and they try and boss you around. Control you, control you.’ It has been suggested that the experience of being sectioned may in itself produce Post Traumatic Stress Disorder.23 This would obviously increase the baseline for anxiety around issues of power making the line between persuasion and coercion even more sensitive for this client group. Possibly such anxiety may be experienced more acutely by clients from specific cultural groups for example British African Caribbean men due to historical disparities of power.

Identity

Most of the participants described the psychiatric system and the labelling of diagnosis as an attack on their identity. For example: ‘I get sick, I get cracked up, and this is my life. I can’t keep fighting against it and trying to be someone else. As a young boy, growing up at school, a lot of people used to come for protection


to me. I had people that could depend on me. I liked independence, I liked to do my own thing, you know: To lead, and I am not in a position to lead no more.’

Identity dilemmas are common in many chronic illnesses and may produce non-compliance with medications. Rates of non-compliance are equivalent in the general medical and psychiatric populations. This suggests the processes of adaptation to an illness are not necessarily dissimilar to that of other populations, for example men with cancer.

The idea of appearing strong and in control is evident in the overrepresentation of men in ACT. Men’s identity dilemmas tend to evolve around certain binary oppositions, such as: risking activity vs. forced passivity; remaining independent vs. becoming dependent; maintaining dominance vs. becoming subordinate. The importance of these oppositions is culture-specific with risking activity a feature for men in cultures of African Caribbean origin: ‘When you’re coming from as a psychiatric patient is a big difference. It doesn’t seem like a lot, but its the whole of your morality and freedom that goes when you have to, a life where you’re full of energy and zest and doing your own thing all of the time to try to come to terms with being a um, find (. ) yourself in the sickness.’

Does non-compliance correspond with the construct of insight? Many participants used biomedical language or concepts to describe specific situations. Participants accepted aspects of psychosis, such as hearing voices, and would use the term ‘schizophrenic’ of himself or herself – ‘I diagnosed myself as schizophrenic’ – but would not accept being treated as a patient. Is this resistance related to a lack of insight associated with psychosis? Whilst 40% of outpatients with schizophrenia are non compliant, so are about 50% of all participants in general medicine. Thus compliance may not be confounded with insight. It appears intuitively probable that there may be a low threshold for anxiety and paranoia even when a client has recovered from psychosis through medication. This may cause a client to experience intense internal pressure from leverage

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tactics based on the clinician-client relationship. However the aetiology of this may be as much a result of the historical experiences of psychiatric services and social exclusion from the community as a consequence of the illness process. Such diachronic arguments must be considered when we evaluate the ethics of community psychiatry.

The reaction to an intervention directly corresponded to the locus of the intervention in relation to the body. Certain interventions were experienced as more threatening to the identity. This was especially true for depot – injectable – medication which was generally described by strong visual images of side effects: ‘I prefer it (oral medication) to the depot, ’cos when they used to give me the depot they used to inject me and I couldn’t walk properly. My legs were buckling, my hips were . . . then they took me off of the injection. I stopped hearing voices but the side effects were so bad I’d prefer to hear the voices’. Newer ‘atypical’ anti-psychotics – such as olanzapine and risperidone – produce significantly fewer side effects than older ‘typical’ anti-psychotics. However these medications can only be taken orally. When providers are concerned about compliance, they often prescribe depot – injectable – medication. This facilitates monitoring of compliance.

In contrast, interventions focusing on more distal interventions for participants, such as housing and benefits, are described as satisfactory: ‘(a social worker) was the best one because he used to really plough through my problems. Housing benefits and everything. He’d come by, sort it out, work out the ratio, and put it forward to me.’ Participants seemed to appreciate the rationale of such interventions when stable – even when they described having felt under pressure to comply.

The therapeutic relationship

Many of those descriptions arise from distrust in therapeutic relationships based on previous experiences. In previous relationships, the approach focused on medication. Relationships were seen as impersonal and paternalistic because of short appointment times and frequent turnover of staff who did not have much time to see the client: ‘I had that with my social worker named Lucy. She was . . . something else. That time I was very, very sick and I was trying to tell her my situation and she said I look very confident, ’you should be able to cope with this’, you know what I mean? I was thinking ‘what’s wrong with this lady. Can’t she understand I need help?’ The additional resources in ACT allow
an opportunity to remodel the relationship between provider and client.

Visits to participants may continue even when a client explicitly asks for them to be stopped. Often the more a client tries to disengage, the more a team will attempt contact. This notion of beneficial coercion often conflicts with the principle of personal autonomy: ‘Just trying to work out how I can stop them seeing me now. I don’t have a choice, they just come. They don’t listen sometimes. They’ll change some appointments but they won’t change them all …’. Though the service cannot be described as voluntary, the aspects of coercion are not legally decreed, and therefore participants do not hold legal rights to appeal.

In ACT, the team approach means participants are keyworked by many members of the team collectively. All workers have a generic role in addition to their specialist role, so a psychologist or social worker has multiple roles such as counsellor, advocate and medication manager. This role diffusion may lead to boundary diffusion especially given clinicians meet participants within their own environments.

Maybe as a result of the early loss of caregivers, many participants expressed difficulties with the boundaries between client and clinicians. Several participants mentioned that there was little point in forming a relationship with clinicians as they would always leave, or have too little time, as if it was favourable to keep some psychological distance rather than risk another rejection: ‘the clients don’t know that boundary well enough, they don’t know how to handle that distance properly. They start thinking ‘oh he and she is always talking to me, and they’re very nice to me’, so they keep pushing and pushing and pushing. And ultimately, you know, what you are facing is rejection. They will have to reject you’. The ACT team approach can therefore be an advantage: ‘it’s a good thing because they’ve got to leave anyway, they only stay for about two or three years so, you don’t get attached to them’. One client succinctly explained: ‘it’s all about dependency, isn’t it? It’s a fine line’. Participants may be aware that information they transmit to one member is shared amongst the whole team, and indeed the wider service.

Participants described critical ingredients in becoming engaged with ACT as revolving around social interventions. The positive therapeutic relationships reported were characterised by an emphasis on reducing anxiety through coordinating the wider social environment, for example through help with housing or benefits or providing social contact: ‘There are lots of outings to the cinema. That stops the isolation …

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keeps up communication’. Further participants responded positively to acceptance, or at least acknowledgement, of their own worldview: ‘With the help of people like X, you do have assistance, and they do care. You haven’t got to hide nothing. That’s what I like. I tell them my background and about my marijuana and . . . I feel comfortable with them. Once my interest is at heart . . . I am with them.’ These factors influencing perception of a positive therapeutic relationship agree with those found in other clinical populations such as psychiatric outpatients.

Provider perspectives

If participants regain trust in the therapeutic relationship, they ‘graduate’ to services that, through resource deficits, focus on the proximal interventions that made them disengage, repeating the problems and paternalism. The only solutions to this revolve around seeing engagement as a goal within itself, rather than focusing on compliance. From the provider perspective, ACT programmes have an underlying monitoring remit so that participants who refuse treatment tend to be visited more often, whilst participants who engage with treatment are likely to ‘graduate’ from ACT to standard care. Given the resources and political impetus associated with ACT, graduation will generally mean the client is re-referred to a community mental health team from which he has already disengaged and a return to time-limited interventions which focus on medication. This produces positive reinforcement to disengage from services again.

Beneficent coercion necessarily exists in a discipline with a statutory duty to look after the individual and others. But with it comes a responsibility to know what ‘mental health’ looks like especially given the amount of people we restrict for the prevention of a few incidents.

Discussion

The paradox of ACT is the disparity between outcomes aspired to by a number of interested parties namely participants, carers, clinicians and the community. For Mr. B, his desired outcome was to be free from psychiatric services with a job and social network unrelated to mental health. For the clinicians, the emphasis was on reducing admissions and keeping Mr. B on atypical, as opposed to typical, anti-psychotics. Alternatively, Mr. B’s community might seek more ‘normal’ social behaviour such
as not responding to auditory hallucinations in the street. It is not obvious who has moral status within philosophical approaches to bioethics, and whether the participants’ or the clinicians’ view carry equal weight. How can we describe the differences between the providers’ and patients’ perspectives?

Diachronic versus synchronic assessment

Participants and providers can be seen as communicating in two different types of reasoning. Synchronic reasoning is concerned with events existing in a limited time period, and ignores historical antecedents. By contrast, diachronic reasoning relates to phenomena (such as language or culture) as they occur or change over a period of time. These concepts may be used to explain the differing focus of the clients and providers.

The interviews suggest that the reasons for disengagement arise – at least partly – from clients’ previous experiences of mental health services and rejection in their private lives. This history must be acknowledged when deciding what we can categorise as beneficent coercion. For example, Mr. B has a history of being forcibly admitted to hospital and does not accept a pattern of events necessarily leading up to these admissions. Mr. B states he is happy that the ACT team manages his money, but feels he is forced to take depot medication to continue this relationship. Mr. B says he respects the ACT team, and that they are an improvement compared to previous teams, but would prefer to be left alone to ‘continue with his life’. Mr. B recognises he experiences psychosis, but would prefer to live with the voices given the consequences of taking medication on his social and sexual life. Given Mr. B’s previous forensic history, the providers are most concerned with medication whilst Mr. B would like more help with his social circumstances. We believe that the evidence suggests disengagement is not simply a consequence of a lack of insight. Yes, a client may have heightened levels of anxiety as a result of paranoid schizophrenia. However this appears to be coupled with historical antecedents in the life and experiences of the individual. Disengagement may thus be seen as a rational choice. The only solution to avoid an impasse – and one afforded by the ACT model – is to model a more collaborative therapeutic relationship. There is pressure to keep

individuals out of hospital because of the resource drainage. It may be tempting to use coercive strategies to keep people on medication and in the community. However in the long run it may be more cost effective to risk this possibility and give clients the right to say ‘no’ whilst increasing their social welfare.

Though there is a need for risk assessment within community care, the current climate of blame may bias false positive assessments. For example, a clinician may not risk changing a client from injectable medication to oral medication – such as in the case of Mr. B – because it is more difficult to monitor compliance in this case. There may be a systemic overemphasis of the chances of a client defaulting on medication, and further of the consequences of such an occurrence.

Further training emphasises identifying and treating pathologies rather than recognising and developing mental ‘health’. Experiments have demonstrated that if people are in an environment where they are expected to be schizophrenic, pathology will be found even in ‘normal’ people.28 Clients such as Mr. B, who have a forensic history, will always come out as a high risk on objective risk assessment measures. Given mental health professionals are not trained to recognise mental ‘health’, this negates Mr. B’s chance of leading an independent life – unless he disengages from services. In the national health care system of the UK, the blame culture is particularly prevalent since the government is ultimately responsible for the quality of the system. Thus, any failure and untoward incident in health care can become a political issue, which other political parties and the media are likely to exploit. This creates a climate for accountability, which may lead to scapegoating and blame.

Proximal versus distal interventions

The locus of intervention – from those directly affecting the body to those focusing on the wider social environment – appears to be critical in differentiating which interventions are experienced as coercive. This can be conceptually defined as follows. Proximal interventions – such as medication – directly interfere with the body. Distal interventions – such as housing and benefits – are situated away from the point of origin, especially of the body. In standard care clients complying with proximal interventions are described as engaged with services and may then be offered more distal interventions focusing on the social context such as aid

with benefits and housing. However, the clients interviewed described a pattern where non-compliance with proximal interventions was confounded by clinicians with non-compliance with distal interventions provoking non-engagement. The participants interviewed described feeling more coerced when interventions were proximal—for example being restrained, medicated, or compulsorily detained. When interventions were more distal, pressure or leverage was recognised but the participants could recognise the value of these interventions.

The advantage of ACT is that the additional resources in the model—for example the increased staff:client ratio—can afford the opportunity to focus on distal interventions as a leverage to engagement. These may be used to monitor clients with statutory—rather than implicit—coercion needed if the risks dictate this. However to allow this, services need to recognise engagement as a goal within itself. Further, our research reveals a systematic flaw namely the assumption by other services that non-compliance with proximal interventions means non-engagement with services per se. This appears to reflect an imposition of a positivist view of what is ‘good treatment’ for individuals with psychosis.

CONCLUSION

The ‘lived experiences’ of participants embed ethics within a past and a future. Clients’ narratives provoke questions about the ethics of the therapeutic relationship, the locus of coercive interventions, and the potentiality for recovery within community psychiatry. Although the participants’ accounts of the diachronic implications of beneficent coercion differ from the providers’ more synchronic approach, common themes are apparent. In our opinion, an act of coercion will be experienced—and should be examined differently—for an individual without a history of psychiatric services who is subject to ‘early intervention’ treatment, and a client who has been shown to disengage continuously.

Phenomenological analysis examines ‘the grounded experiences of sick persons, families, and healers in local contexts’. 29 We hope to have shown that such approaches are necessary to examine different perspectives in the ethics of community psychiatry by recognising that there may be levels of moral explanation. 30 The complexity of community psychiatry necessitates attempts at the dialectical integration of diachronic

29 Hoffmaster, op. cit. note 14.
30 Yesley, Gracia, op. cit. note 16.
consumer empowerment principles, and synchronic social control principles.

Jay Watts and Stefan Priebe
Unit for Social and Community Psychiatry
Bart’s and the London School of Medicine
Queen Mary, University of London
East Ham Memorial Hospital
Shrewsbury Road
London E7 8QR
UK
j.m.a.watts@qmul.ac.uk
s.priebe@qmw.ac.uk