Article

Patients’ experiences of receiving collaborative care for the treatment of depression in the UK: a qualitative investigation

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ABSTRACT

Objective We explored the experiences of patients who received treatment for depression during a ‘phase II’ platform trial of collaborative care in the UK.

Method Semi-structured interviews were used to obtain information from 13 patients receiving collaborative care. Patients from a range of general practitioner (GP) practices within the trial were purposively sampled. The constant comparative approach within a framework analysis was used to identify emerging concepts and key themes.

Results Three distinct themes in people’s experience of collaborative care were identified: (1) the process of collaborative care; (2) the content of collaborative care; and (3) staying well. These themes were set against a backdrop in which patients described how they had been struggling with low mood. Our central therapeutic ingredients of information giving, behavioural activation and medication management were supported by patients. Patients expressed reservations about the rigid inflexibility of telephone-based treatment.

Conclusions While most of the protocol elements were supported by patients, we have been able to amend our protocol to allow for greater delivery flexibility and more attention to the therapeutic alliance and relapse prevention. We are now testing this in a multicentre randomised controlled trial.

Keywords: collaborative care, depression in primary care, lived experience, qualitative research
Introduction

Over the last decade, research into the treatment of depression has indicated that collaborative care is a highly effective way of organising depression treatment services.1–4 Collaborative care is a complex intervention at the ‘systems level’, consisting of: (1) a multiprofessional approach to patient care; (2) a structured patient management plan; (3) scheduled patient follow-ups; and (4) enhanced interprofessional communication.2,5,6 In a recent systematic review we showed that collaborative care is effective for the majority of patients with moderate-to-severe depression, as well as for specific subgroups such as older people.7,8

While it improves outcomes over usual care,3,9–11 collaborative care has been mostly developed and evaluated in the United States (US).9 The international evidence base is much smaller and the outcome estimates far less precise. Although three studies recently showed that collaborative care can achieve similar outcomes in the UK health system,12–14 evidence of effectiveness is not sufficient for implementation. We require information on the acceptability of collaborative care for patients being treated in non-US health systems. Indeed, our recent collaborative care trial used a protocol developed in consultation with people who had had a past experience of depression (see Box 1).12,15 The trial showed that the protocol was effective and that the development input from experienced patients was critical for this success.12 However, whereas this previous work reported the views of patients prior to collaborative care, we were also interested in the experiences of patients who actually received collaborative care. This paper reports details of a parallel qualitative study of the acceptability of collaborative care from the perspective of patients who received collaborative care during our trial.

Case managers were a mix of professionals (nurse, counsellor and occupational therapist) and para-professionals (graduate primary care mental health workers), all of whom received two days of protocol-specific training in addition to their existing clinical training, and 30–45 min of supervision per week for the duration of the trial.

Aims

The aims of the study were to explore the experiences of UK patients who received collaborative care as a treatment for depression in our pilot randomised trial, and in particular their views on its acceptability. The secondary aim of this study was to compare and contrast patients’ experiences of receiving collaborative care for the treatment of depression with the views of the group of patient informants who had earlier contributed to the development of the collaborative care protocol,15 but who had not received the treatment.

Method

Sample

We purposively sampled 13 participants, ten women and three men, from a total population of 41 patients who received collaborative care in our trial (a sample size of 31% of our collaborative group). Purposive sampling involves selecting informants on the basis of a number of preconceived dissimilar characteristics,20 assuming that informants with different experiences of collaborative care may have differing views about their treatment experiences, adding to the richness of data.21 All patients had a newly identified episode of major depression, confirmed by a score of five on the depression section of the Standard Clinical Interview for DSM-IV (Diagnostic and Statistical Manual for Mental Disorders).22
Our interview sample all had moderately severe depression. We invited patients who had received collaborative care from case managers with different occupational backgrounds, working in a broad range of general practitioner (GP) practices in disparate locations, to consider participating in this study. Case managers' backgrounds included community psychiatric nurses, practice-based counsellors and graduate mental health workers.

None of our informants had any prior knowledge or experience of collaborative care, and none had contributed to the development of the treatment protocol. The collaborative care protocol involved giving information on depression, medication management and behavioural activation, a specific form of CBT designed to treat depression, delivered through an initial face-to-face appointment with a case manager followed by up to ten telephone follow-up contacts, with feedback to GPs from case managers, and supervision of case managers by mental health specialist clinicians.

Data collection

We collected data using face-to-face semi-structured interviews. Interviewing followed a predetermined topic guide to explore patients' views of all elements of the collaborative care intervention. Patients' views on barriers to the successful implementation of the treatment protocol were also explored. Interviews lasted approximately 45 minutes and took place in patients' own homes.

Data analysis

We analysed data using a framework analysis. All interviews were recorded and transcribed verbatim. One author (AS) initially acquainted herself with the data by reading and rereading interview transcripts. The preliminary reading of transcripts enabled an overall impression of the narratives and contexts to be formed, and a thematic framework was then developed to identify key concepts and themes. Transcripts were analysed thematically in the context of each interview as well as across each interview, using the constant comparative method. This method involves analysing each transcript and labelling each statement, which is then compared with all others allowing similarities or differences to be identified, and enabling subthemes and key themes to emerge from data. Original transcripts were frequently revisited to clarify contextual meaning(s). Data were then interpreted and re-analysed by a second author (SH), within the thematic framework to ensure the credibility and interpretation of key emerging themes. The whole process was designed to ensure that emerging themes represented coherent grouped areas of data. Interviews continued until researchers achieved data saturation. Data saturation is a hypothetical point at which no new material emerged that might significantly add to the theoretical framework. Given that the study reported here used a pragmatic topic guide to explore the main characteristics present within the collaborative care treatment intervention, data saturation was achieved relatively quickly after nine interviews. However, data collection continued up to 13 interviews to ensure that this was indeed the case.

Results

Three main themes emerged from the thematic analysis: (1) the process of collaborative care; (2) the content of collaborative care; and (3) staying well. These themes emerged against a backdrop in which patients commonly described how they had been struggling to cope with low mood. This common context will now be explained, after which each of the three themes relating to the provision of collaborative care will be presented in more detail.

Ethics

The UK Southwest Multisite Research Ethics Committee approved the study. Although we excluded from the study patients reporting active suicidal plans, depressed patients remain a vulnerable group. We were careful to safeguard participants' anonymity and to ensure their responses were not attributed to them, to health professionals involved in their care, or in any reports. We gave verbal and written information on participants' right to withdraw from the interview at any time, without explanation and without compromising their routine treatment with their GP. However, all patients interviewed spoke openly about their experiences of receiving collaborative care and none exercised their right to withdraw from interview.

The context in which patients sought assistance for low mood

For all patients, access to treatment was through a GP consultation. While some patients were aware at the initial consultation that they were becoming stressed or depressed, others described being uncertain...
about what exactly was wrong. Some patients reported that they had initially thought the symptoms of depression (especially tiredness) indicated that they were becoming physically unwell, and there was a sense of surprise as well as concern when the doctor explained the diagnosis as depression.

'I thought I was really, really ill as though there was something really wrong with me, tired all of the time, I just couldn’t figure it out.' (patient 1)

'I didn’t even realise that I was depressed because I said to the doctor “I’m just tired”, and he said “it’s depression actually”.' (patient 2)

Taking the initial step of attending a consultation with a GP was very significant for patients. They described struggling to perform the routines of everyday life and how hard it was to keep going. Patients acknowledged the difficulty of admitting to having a problem. This difficulty was compounded by uncertainty regarding the nature of the ‘problem’ and being unsure how best to explain the experience to the GP.

'It’s a lot to admit that you have got a problem isn’t it?' (patient 3)

'You just can’t help it or explain it, it’s very difficult to explain to someone else when you don’t 100% understand it yourself.' (patient 4)

Patients also reported a sense of stigma surrounding being depressed that contributed to them trying to simply ‘keep going’ with the routines of daily life rather than to seek professional help.

'I think there is a stigma to it isn’t there? You know people think oh you’re just shirking work or there is nothing wrong with you, just get on with it, that’s life.' (patient 5)

In summary, therefore, the common context in which patients sought help from their GP involved patients struggling to understand their symptoms, their difficulty accepting they had a problem with low mood, and the stigma associated with help seeking.

**Theme 1: The process of collaborative care**

Following diagnosis by a GP, patients were referred into the trial and, if randomised to the active treatment arm of the trial, met with a case manager and commenced collaborative care.

**Initial face-to-face interview**

Patients reported that it had been important to meet with the case manager prior to subsequent telephone consultations. This confirmed the appropriateness of initial face-to-face consultations, a feature of the collaborative care protocol that had been included following interviews with professionals and patients in our protocol development stage.15

'It’s nice to see who you are going to speak to on the phone, so that you can put a face to them.' (patient 6)

'It was nice being able to put a face to the voice, I felt comfortable knowing I’d met her.' (patient 3)

Case managers were able to demystify depression, offer information on treatment and promote a sense of hope that depression could be treated effectively. They helped patients to overcome the sense of stigma.

'I came away from my first session feeling eased, like a weight off my shoulders.' (patient 7)

'He [case manager] made me believe that I would get over this ... kind of boosted my confidence and made me believe that I will get over this.' (patient 8)

'I suddenly realised that I was depressed and that it was nothing to be ashamed of.' (patient 9)

The initial face-to-face consultation was, therefore, helpful in developing rapport and trust, forming the basis for a helping relationship that could be developed during subsequent contacts.

**Interpersonal skills**

Case managers were regarded as being easy to talk to, informative and friendly, with a high level of expertise/knowledge around the topic of depression.

'He [case manager] felt like a friend ... If I had any questions about it [depression] he could answer them and I was really impressed by that.' (patient 2)

'She [case manager] had the kind of voice that was kind of calming and pleasant and she sounded like she genuinely cared.' (patient 7)

However, some patients expressed concern that the intervention ended too soon.

'I think it needed to go on for a little bit longer. I wasn’t ready to finish.' (patient 2)

**Telephone work**

Most patients regarded the use of the telephone positively. Some patients overcame initial scepticism and it was clearly possible for case managers
to develop and maintain a therapeutic alliance with patients over the telephone. This was true even where patients suggested they would have preferred increased face-to-face contact with the case manager.

‘At first I was a bit sceptical about it because I was so down and I thought that I possibly would need contact, you know, face-to-face contact. But as it turned out I looked forward to that phone call every single week and it was nice because I didn’t have to put on a front to anybody.’ (patient 5)

‘I actually don’t like telephones very much normally, but I thought that it was very useful on both sides and it seemed to be quite convenient.’ (patient 9)

‘She came across as a really caring person. You know she really cared about me.’ (patient 5)

‘I would have liked to have talked to her face-to-face more. But I was happy with the telephone conversations that we had.’ (patient 3)

Patients thought it was actually easier to discuss things with the case manager over the phone. This was a function of the interpersonal ease of telephone contact, and convenience. Patients commented that they felt better able to be open and honest about feelings when the case manager was not sitting in front of them but rather was on the phone. For patients who were in work or returning to work, talking on the telephone was often much more convenient than attending a face-to-face appointment; indeed in some it cases it was the critical determining factor between being able to accept the treatment or not.

‘Probably it was easier that I was speaking over the phone because I was busy at work and it was convenient.’ (patient 10)

‘I think in some ways, some people might find it better on the phone because when they are with someone they might find it difficult more to talk.’ (patient 2)

‘This has suited me just fine, because it just fits in, just counselling on the phone, no appointments or anything.’ (patient 6)

‘If I’d have taken time off work I would have felt pressured.’ (patient 11)

‘Because I work full time it would have been very difficult, I wouldn’t want to take the time off ... I didn’t mind which way it was done, and I didn’t have a problem with it over the phone. Some people might have but I didn’t.’ (patient 12)

There were, however, some negative comments about the telephone. Some patients desired face-to-face appointments to facilitate more in-depth conversation about their problem histories. These patients expressed a desire for more ‘counselling’-type interventions, not provided for by case managers in the collaborative care protocol being implemented. These views indicate a need for case managers to better manage patient expectations about the nature of the intervention, and for case managers to pay more attention to developing and maintaining the therapeutic alliance during telephone calls.

‘I sometimes felt that rather than speaking on the phone I would rather have met face to face ... although the phone conversations did help, sometimes I felt that where I could see somebody, I would have spoken more about it.’ (patient 8)

‘If the therapy had been delivered face to face ... it would feel personal, I wouldn’t have felt like a number. I would have felt like a person. I did feel like the person [case manager] cared but only for about half and hour ... when the phone goes down that’s it, it’s somebody else’s turn.’ (patient 7)

Patients also raised concerns about privacy when taking telephone calls at home. They stated that it wasn’t always easy to ensure privacy at home.

‘You sometimes have other people around you at home and you can’t really talk.’ (patient 8)

 Severely depressed patients were sometimes unable to cope with the pressure of receiving telephone calls, and reported not taking telephone calls during times of ‘dark depression’. These patients chose to re-engage with case managers’ calls as their depression improved and became less severe.

‘When I had a really dark depression I felt a lot of pressure. The phone call was getting to me ... I just pulled the phone out ... but when I was coming out of it I found the helpfulness and usefulness were very good.’ (patient 4)

In summary, therefore, an initial face-to-face appointment followed by telephone contacts was supported by patients. There is a need to pay more attention to maintaining the therapeutic alliance during subsequent telephone calls, and case managers should inquire about the continuing suitability of the use of telephone interventions for patients who are not responding well or are having difficulty settling to telephone contact. Interspersing some additional face-to-face appointments could be
considered in these cases, and there needs to be a degree of flexibility around the duration of the intervention, with further work required around ending the relationship.

**Theme 2: The content of collaborative care**

*Providing information*

Patients were given written information about depression, including sections explaining depression, antidepressant medication, behavioural activation and examples of patient recovery stories. Although the volume of information given to patients was large, patients were generally unperturbed by the amount of information and stated that the written material acted as a useful source of information and support in between sessions with the case manager.

 ‘They worded it better than I imagined they would. Not lots of long ridiculous medical terms. It was good information ... It was well written. It wasn’t like reading a text book.’ (patient 7)

 ‘[Reading] people’s personal experiences and how they had felt ... I could like look at it and think ‘yes that’s how I feel’, so that made me feel better knowing that other people out there .... it didn’t make me feel so isolated.’ (patient 8)

 ‘I read them and used them. They are still upstairs; I have kept them in a folder, so if I need them at any time I can refer back to them.’ (patient 2)

Patients also commented that they were able to share the information materials with members of their family/supporters in order to develop other people’s understanding of depression.

 ‘I put them down for my husband to read and he read through them and I think even my sons [read the material] when they came ... they were good.’ (patient 12)

 There were suggestions that the presentation of the information needed to be improved and organised into a clip file or booklet. Patients commented that it was sometimes difficult fumbling with sheets of paper while on the telephone to the case manager. Further, it was suggested that it might be beneficial to give the information in audiotape format, as it was difficult to concentrate on reading early in the intervention period.

 ‘... they were good but they were just stapled together, I think they would have been better in a ring binder ... so you could just turn them over instead of fiddling with paper while you were on the phone.’ (patient 4)

 ‘I suppose one way of doing it might be to put [the information] on tape ... it’s easier to sit and listen to something than it is to read and take it all in.’ (patient 4)

*Behavioural activation*

This psychological intervention is designed to amend the balance of reinforcement for depressed people by reducing avoidance behaviours and increasing positive activities. This involves (re)introducing routine, pleasurable and necessary activities and monitoring this using a diary. Encouraged by case managers, patients thought this was an appropriate and acceptable approach.

 ‘She encouraged me to get off my backside and go out and try and make myself more involved in things rather than sitting at home thinking about everything.’ (patient 9)

 ‘He [case manager] encouraged me to find something that I enjoyed doing and to put that into my day. He also encouraged me to do things that had to be done but I kept putting on the back burner.’ (patient 6)

 ‘I normally just used to sit there and let them [the children] play their games, I never got involved. So I brought some games that I could get involved with and it was nice, it was rewarding and I never thought it would be but it was.’ (patient 3)

 ‘I was sort of fighting doing the things that I enjoyed doing. I was fighting them for some reason and I don’t know why.’ (patient 13)

 ‘Well he [the case manager] would say things like “have another go at another time, don’t give up ... have a go when you feel you are ready to do it”’. (patient 1)

 Opinions on using a diary were equivocal. Some found it helpful, others reported that they were unable to maintain a written diary but still used behavioural activation. However, there was agreement that structuring the day and changing daily routines did help to alleviate depressive symptoms.

 ‘I could see from just doing the diary how I needed to change myself. And I knew how I needed to change ... over the telephone we went through things like what I had got in my diary. What I had been doing and what I had prioritised as a necessity or vital to do now, you know, to things that weren’t vital or a necessity.’ (patient 8)

 ‘To me it was like going to see a counsellor without having to step out of the door. She got me going out of the house, which I wasn’t doing. And I never actually set eyes on the lady or anything and she was giving me all of these goals and I just used...” (patient 9)
to feel so proud of myself when I had done them.’ (patient 5)

‘It’s all right putting it down on paper, but it means nothing if you don’t carry it through. But through myself wanting to do it and through the fact that she [the case manager] made me feel that it would help ... I went and did it and it did help.’ (patient 10)

‘I think the diary has helped me greatly because I have seen probably why I was depressed.’ (patient 8)

‘I don’t think it [diary writing] was necessary. I really didn’t. I knew that I was trying to help myself and I didn’t think I needed it, other people might but I was busy going to work.’ (patient 12)

‘He [the case manager] did say that I did it [diary writing] I was supposed to be doing it but for some reason I couldn’t put pen to paper.’ (patient 7)

**Medication management**

Patients were often uninformed and ambivalent about taking the antidepressant medication prescribed by their GP. They were concerned about addiction and side-effects and doubted the ability of antidepressants to help in situations where there were social issues underlying their depression. Case managers were able to give detailed information to patients regarding medication and advice on how they should be taken, which was seen by patients as helpful to resolve misconceptions about the drugs and allay their fears.

‘I had heard that you get addicted to them and they didn’t really help and I have always thought that I didn’t really need them because at the end of the day they don’t take away the problem that’s causing the depression in the first place.’ (patient 4)

‘The tablets I was taking at the time were making me feel sick and dizzy. I have actually changed them now but I did actually feel quite a lot worse at the start than I did before I started to take them.’ (patient 8)

‘I did talk it through with her [the case manager]; we went through what the antidepressants were, she reassured me really.’ (patient 9)

‘I had a bad reaction to the first tablets that I tried. It was bad and it put me off. They both encouraged me [GP and case manager] to try another one and that had no side-effects at all … without the encouragement of them both I don’t know if I would have dared risking another one.’ (patient 6)

‘[the case manager explained] the reason why it needed to get into your system over a long period of time and once you start feeling better why it’s important to keep taking it, so it has resolved a lot of doubts.’ (patient 4)

**Monitoring progress with the PHQ-9**

Patients’ progress was monitored using the Patient Health Questionnaire (PHQ-9) at the beginning of each contact with a case manager.25 Patients found this acceptable and a useful way of evaluating progress, feeling encouraged when their scores improved and recognising the need to take more action if not.

‘It was easy to understand, not too technical.’ (patient 4)

‘For quite a long time they [the scores] stayed the same and then they started dropping slowly and that was a big boost.’ (patient 2)

‘He [the case manager] would go through the questions. And I knew that I was getting better, just through the answers I was giving.’ (patient 12)

‘It made you realise if you were having a good week or a bad week. What you had managed to do or how I was actually feeling.’ (patient 3)

‘I seemed to improve every time we filled that in, so that was encouraging as well.’ (patient 9)

‘It was like a goal to try to bring it down.’ (patient 1)

In summary, patients found all the content aspects of the protocol acceptable and helpful. Information giving, behavioural activation and medication management received approval, as did the use of the PHQ-9 to help monitor symptoms, particularly when scores were fed back regularly to patients.

**Theme 3: Staying well**

**Keeping well**

As a consequence of their increased understanding of depression, patients were confident they would be able to recognise future symptom presentation. Patients who had successfully implemented behavioural activation thought that they would use these techniques again should their symptoms return.

‘I mean I still worry about going back into depression, but at the same time I feel a lot more secure now that I have little techniques to sort myself out, rather than having to run to the GP and say “oh I’m feeling down again”.’ (patient 13)

‘... probably [if depression were to reoccur] I would sit down again and look at what I am doing and probably do my own diary and just see if I had gone back into my old ways.’ (patient 8)

‘[If depression were to re-occur] I would probably re-start my diary again.’ (patient 1)

‘I am able to spot the trigger signs and start doing things that I enjoy doing.’ (patient 13)
'There were some things that were suggested to me to do that I am still doing. I might not feel down but I am still doing them just because I don’t want to go back into that situation.' (patient 13)

'You can deal with it [depression], it’s like anything isn’t it, you can deal with it when you know what it is.' (patient 12)

Patients stated that this increased understanding meant they would go to see their GP sooner should their symptoms reoccur, rather than struggling alone.

'It’s a nice relief to know what depression actually is and how you can control it ... I feel as if I can ask for help now and not be ashamed of it.' (patient 3)

In summary, patients felt empowered in both help seeking and self-management of their depressive symptoms, expressing greater confidence about managing relapse.

**Discussion**

In this study we have demonstrated that patients receiving collaborative care regard the clinical aspects of the UK protocol as helpful to their recovery, and that the manner of its delivery was broadly acceptable to them. In particular, information giving by case managers about depression, and their support for both activity and medication were empowering, to the extent that patients felt better prepared for any potential relapse or recurrence of symptoms. Although patients considered the telephone to be convenient, and in some cases preferable to face-to-face appointments, it was also regarded as rather rigid. Despite the initial face-to-face appointment, which was thought to be essential, some patients would have liked greater flexibility and at least the possibility of further face-to-face contacts. The interpersonal skill of case managers in establishing therapeutic alliances was highly valued by patients, although occasionally deficient in the later stages of the intervention.

Two of these themes reflect those in our earlier study: the balance of face-to-face and telephone contacts and case manager’s use of ‘common factors’ in developing a therapeutic alliance.15,26,27

One implication of this study for the further development of our clinical protocol is that case managers should be free to offer some additional face-to-face appointments following the first one. Although the intervention was initially designed to be a telephone-delivery-based treatment, some patients expressed the clear view that they would value increased face-to-face time with case managers. Secondly, case managers need to pay more attention to the development and maintenance of the therapeutic alliance, as well as to its initial establishment. This may be through attention to potential ‘ruptures’ in the alliance and application of responsive strategies for ‘rupture repair’.26 Previous research suggests that patients attribute a large part of their recovery to support from mental health workers rather than the application of specific techniques,26 hence the importance of this aspect of the protocol. Attention to common factors in supervision should be a requirement of a revised protocol.

Finally, our protocol should be amended to include more specific preparation for the ending of contact with patients. Patients regard new skills as potentially insulating them against relapse, and so more could be made of this aspect of the intervention, specifically preparing patients for the end of treatment with the development of a relapse-prevention plan.

**Strengths and limitations of this study**

Although we attempted to recruit a varied, purposive sample of informants, the sample was small, so there may be limited generalisability of the findings presented here. However, we were also reassured that we captured differing views by the variety of opinions presented in areas of contention identified in our previous study;15 for example the use of the telephone for the delivery of the intervention, and in the diverse views elicited on behavioural activation diary keeping.

Our framework analysis was purposefully structured and may have inhibited the emergence of information which was not aligned to our topic guide.23 While this inhibited the phenomenological elements of our study, it was not our purpose to conduct an open and detailed identification of qualitative themes. We were interested in patients’ views on specific aspects of our protocol in order to investigate its specific acceptability, and so we felt justified in constraining our analysis.

Our study reports the views of patients receiving one specific model of collaborative care. Many of the component parts of collaborative care could be delivered by a GP or other primary care worker, although resources are currently extremely limited for this kind of intensive care approach in UK primary care. It may be that our results in part reflect the extra care and attention case managers were able to give to patients and that they may not be entirely specific to the collaborative care protocol we were testing.
Patients’ experiences of Collaborative Care

Conclusions

We have now developed and tested a collaborative care protocol in the UK. It is based on a careful phased development which has included consumer input, and has now been shown to be acceptable as well as potentially effective. This most recent study has confirmed that the essential elements of our protocol are valued by patients and has enabled us to refine it to include greater flexibility around delivery. We have also been reminded of the importance of common factor skills which will now be built into case manager supervision. As a consequence of these investigations, we are conducting a large-scale, fully powered multicentre phase III trial, to determine the definitive effect of collaborative care in the UK.

ACKNOWLEDGEMENTS

We would like to thank the patient participants for their willingness to share their views with us.

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**FUNDING**

This work was funded by the UK MRC Grant Number ISRCTN63222059.

**CONFLICTS OF INTEREST**

None.

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Received 2 June 2008
Accepted 3 July 2008