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Competing patient and professional agendas in service development

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Competing patient and professional agendas in service development

Background

Patient involvement in the planning of health services is often promoted as a necessary adjunct to patient-centred care, but it is often assumed that patients will share the same values and agendas for service development as health care providers and commissioners, or that competing views can be subsumed within a meta-narrative of evidence based practice and cost-effectiveness, (Entwistle et al., 1998). Others have questioned this assumption, arguing that patients and professionals may want quite different things from a health care intervention, (Wagner et al., 2005). In this article we explore the differing agendas of patients and healthcare professionals in relation to the development of a community based chronic pain management service.

The prevalence of chronic pain in the UK is estimated to be 13% (Breivik et al., 2006). The cost of treatment places a burden on the National Health Service (NHS), with the care costs for back pain alone exceeding £1.6 billion per annum, (Maniadakis and Gray, 2000). The costs to sufferers, informal carers and the wider economy are also significant, creating a strong impetus towards the development of more cost effective interventions.

Government has responded by promoting 'self-management' approaches, such as the Expert Patient Program (EPP)(EPP Evaluation Team, 2005). A recent, UK-based, randomized controlled trial of EPP in 812 patients with osteoarthritis showed small improvements in anxiety and self-efficacy but no improvement in pain, physical functioning, or GP visits (Buszewicz et al., 2006; Kennedy et al., 2007; Griffiths et al., 2007). Current approaches to self-management are based in part on social cognitive theory. However, these approaches have been criticized on theoretical and methodological grounds, not least that intention to change is a poor predictor of actual behaviour change (Ogden, 2003; Marks, 2008). Cognitive Behavioural Therapy (CBT) combines insights from social cognition theory

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2
3 with ideas drawn from behaviourist psychology to generate a different approach to behaviour
4 change and the management of chronic conditions, prompting a debate about whether it is
5 cognitive change or other means of direct behaviour modification that account for the
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7 apparent success of the approach, (Dimidjian et al., 2006; Longmore and Worrell, 2007).
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10
11 Clinical psychology has developed considerably in the 20 years since the design of current
12 self-management approaches (Hayes et al., 2006), and the latest behavioural and cognitive
13 treatments do not adopt a focus on 'self-efficacy', 'positive thinking', or even the necessity of
14 pain control, but rather on changing core processes of suffering and disability, including
15 'avoidance', 'preoccupation with the past or future', 'verbally-based behavioural rigidity', and
16 'failures of values-based action'. These approaches recognize that while painful feelings,
17 discouraging thoughts, or troubling memories are ubiquitous in human life, they can often
18 have pathological effects on daily functioning (Hayes et al., 1999; Hayes et al., 2006;
19 McCracken and Eccleston, 2005). A key aspect of their amelioration is the development of
20 'psychological flexibility' or the capacity to adapt to changing circumstances by focussing on
21 long-term goals rather than short term impulses, (Kashdan and Rottenberg, 2010).
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35 These newer approaches can be referred to as Contextual CBT (CCBT) (McCracken and
36 Eccleston, 2005) and a specific example is called Acceptance and Commitment Therapy
37 (ACT). There is growing evidence of the benefits of this general approach, including six
38 randomized controlled trials (RCTs). Two small-scale RCTs of the contextual treatment
39 processes have been conducted. The first, conducted in Sweden, applied the intervention to
40 persons at risk of long-term disability due to pain, and reported substantial reductions in
41 missed workdays and health care use from four hours of treatment (Dahl et al., 2004;
42
43 Wicksell et al., 2008). In the UK the intervention has usually been delivered in specialist
44 hospital pain management units, including intensive interdisciplinary services delivered for
45 more than 90 hours. Although three large effectiveness studies of these contextual methods
46 in tertiary care have also been conducted, showing decreased disability, emotional distress,
47 and healthcare use (McCracken and Eccleston, 2005; McCracken et al., 2007; Vowles and
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3 McCracken, 2008), such care is costly and often only available to patients with very severe
4 and long-standing problems. Our hypothesis is that a much broader base of chronic pain
5 patients could benefit from CCBT if it could be provided in a cost-effective and easily
6 accessible community based pain-management programme.
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11
12 We received funding from the Research for Patient Benefit programme of the UK's National
13 Institute for Health Research [grant number PB-PG-0808-16156] to conduct a small RCT of
14 community based CCBT. Before the trial could commence we needed to re-design the
15 intervention and specify a service provision model that would be feasible in a community
16 setting and which would be acceptable to patients, primary care staff and health care
17 commissioners.
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25 The findings of the RCT are reported elsewhere (McCracken et al., 2013). Here we explore
26 the perspectives of different stakeholder groups on how to best translate and deliver a
27 feasible and acceptable community based pain management service based on CCBT, in
28 order to generate an adapted model for the proposed service, which would be evaluated in a
29 later phase of the research. It is important to note a limitation on the scope of the exercise;
30 our intention was to involve stakeholders in service design, but not in reviewing or
31 developing the basic science on which the intervention is based. This limitation raises
32 several issues that we have discussed elsewhere (Wainwright et al., 2013).
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44 **Methods**

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46 The study was conducted over 12 months in the south-west region of the UK. The intention
47 was to access shared beliefs, so an approach which allowed for interaction was used rather
48 than individual interviews. Focus group, brainstorming and Delphi methods were reviewed;
49 (Murphy et al., 1998), however, the Nominal Group Technique (NGT) was considered the
50 most appropriate. NGT has been used to elicit professional and patient preferences in other
51 health care contexts, including the development of a diabetes service in primary care,
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3 (Gallagher et al., 1993), and indeed, to assess the needs of people with chronic pain,
4
5 (Dewar et al., 2003). NGT entails a 10 stage process, which includes participants writing
6
7 down their key concerns prior to group discussion. All ideas are discussed by the group and
8
9 ranked and re-ranked according to their perceived importance. The rankings can be
10
11 analysed and differences between groups identified, and the discussions can be transcribed
12
13 and thematically analysed. We ran separate NGT sessions for each stakeholder group, to
14
15 enable differences between them to fully emerge. These differences were analysed,
16
17 considered and synthesised by the research team. The study was approved by the NHS
18
19 Local Research Ethics Committee (reference number, 09H010799).
20

21 22 *Sampling and Recruitment*

23
24 Recruitment was through the Primary Care Research Network (PCRN), South West.
25
26 General Practices were approached and those who expressed an interest were visited by a
27
28 member of the research team. Practices that agreed to participate were asked to recruit
29
30 General Practitioners (GPs), nurses and patients with chronic pain (using a database search
31
32 and mail out). Patients were sent an information sheet and contacted the research team if
33
34 they were willing to participate. PCRN staff also recruited commissioners from a PCT in the
35
36 south-west.
37

38 39 40 *Data Collection*

41
42 Seven NGT groups were conducted, three with practice staff, three with patients, and one
43
44 with commissioners. The commissioner group was conducted at the PCT headquarters and
45
46 the others in the premises of participating practices. The groups were facilitated by two
47
48 researchers. Digital audio recordings were made of each NGT group and transcribed
49
50 verbatim.
51

52 53 54 *Analysis*

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3 Quantitative analysis entailed comparing variations in rankings and weightings between
4 individuals, groups and sub-groups. Digital recordings of the sessions were transcribed
5 verbatim and NVivo was used to aid coding and analysis. Our analytical aims were: to
6
7 provide a rich description of the issues raised, understand the meanings ascribed to them,
8
9 and gain an insight into why particular issues were considered more important than others.
10
11 There are many approaches to coding qualitative data, (Miles and Huberman, 1994),
12
13 however given the structure of the data collection process and the nature of our analytical
14
15 aims it was felt that content analysis would be the most appropriate (Green and Thorogood,
16
17 2004). The top ten rankings were used as a master coding frame, but within this structure a
18
19 more inductive and open-ended approach was taken towards the generation of themes.
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25 **Results**

26 **NGT Group Top 10 Rankings**

27
28 Table 1 summarises the rankings from the NGT groups. The labels describing the issues
29
30 reflect the words used by the groups, but our analysis of the qualitative data suggests that
31
32 similar issues emerged in different groups even though they were sometimes labelled
33
34 differently, or grouped differently, for example, cost and effectiveness were treated as
35
36 separate issues by some groups, but linked as cost-effectiveness or cost-benefit by the
37
38 commissioners. We have attempted to resolve this by using techniques of synthesis derived
39
40 from meta-ethnography, in which the qualitative data from different groups are analysed to
41
42 assess the meanings and definitions applied to different categories and labels in order to
43
44 assess the equivalence of issues raised in different groups (Britten et al., 2002). This is
45
46 necessarily an imprecise process, but one which is consistent with the usual methods of
47
48 qualitative synthesis and we have attempted to include sufficient detail to reveal significant
49
50 nuances of meaning. The findings from this analysis were used to develop schematic
51
52 representations of the patient and professional agendas, (see figures 1 and 2 below), based
53
54 on the key themes and relationships that emerged. This necessarily entails a degree of
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3 reduction in order to meet the constraints of a concise and coherent narrative, but
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5 comparison between the schematic figures and the top ten rankings in table 1 reveals the
6
7 extent of this process.
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Table 1 Final top ten rankings for each group

RANK	Group 1 (GPs & nurses)	Group 2 (Patients)	Group 3 (GPs & nurses)	Group 4 (Patients)	Group 5 (Patients)	Group 6 (Commissioners)	Group 7 (GPs & nurses)
1 (high)	Cost	Sufferer involved in delivery	Patient selection	Understanding individual needs	Sensitive & approachable staff	Cost effectiveness & cost benefit	Efficacy
2	Location	Support between sessions	Aims and outcomes	Staff training	Quality of venue	Evidence of effectiveness	Accessibility
3	Prioritization & selection of patients	Specialist knowledge	Referral/access	Communication with patient	Physiotherapy involvement	Clinical involvement	Outcome measures
4	Tailor to local needs	Accessing service	Who delivers it?	Management of the service	Information about other services	User involvement in service design	Costs
5	Staff training	Group size	Funding	Aftercare & follow-up	Being treated like an individual	Patient acceptability	Follow-up and maintenance
6	Feedback to GP	Referral criteria	Quality assurance	Characteristics of room	Varying times	Commissioner involvement in redesign	Marketing to GPs & patients
7	Management across practices	Supportive group work	Waiting times	Education for patients	Group size/individual sessions	GP trust in service	Continuity of care
8	Timing	Duration of funding	Follow-up & on-going support	Sharing experiences	Holistic approach	Addressing inequalities	Eligibility criteria
9	Staff time commitment	Transport/parking	Management of unresolved cases	Role of GP	Accessibility	Public health input	Referral pathway
10	Patient motivation	Who provides intervention	Staff training	Opening times	Communication with patient & GP	Clinical governance	Length of treatment

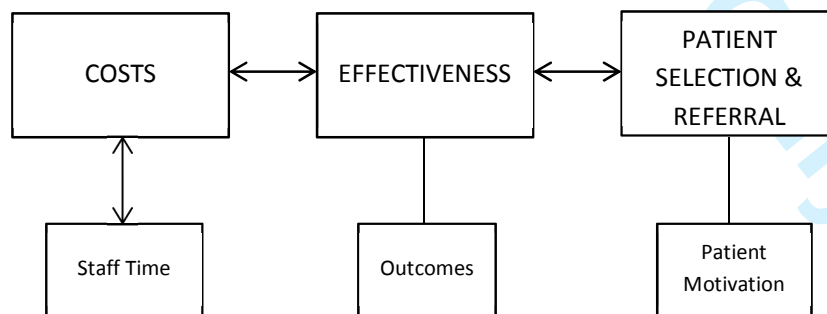
Although each of the groups had a unique top 10 and some themes were discussed by patients as well as by GPs/Nurses or commissioners, it was possible to draw a rough distinction between a patient agenda and a professional agenda, (arguably the commissioners had a slightly different agenda to the GPs/nurses, but we felt that they overlapped sufficiently to be treated as one).

The Professional Agenda

We have listed issues that were of primary importance to the professionals under the heading of the professional agenda, and those that were more important to patients under the patient agenda, but have included insights from patients on issues that fall under the professional agenda and vice versa.

Three key themes emerged: cost, effectiveness/outcomes and patient selection/referral, (see fig. 1).

Fig. 1. The Professional Agenda, (GPs, Nurses and Commissioners)



Costs

Costs or funding were prioritised by all of the GP/nurse groups, as were effectiveness, efficacy and outcomes. Only the commissioner group formally linked them in the category of cost-effectiveness, but the sense of a trade-off between costs and efficacy was also discussed by the GP/Nurse groups. Categories such as efficacy, effectiveness and

1
2
3 outcomes have specific meanings in academic discourse and are far from synonymous;
4
5 however, they were used more loosely by the groups. We have retained the terminology
6
7 used by the participants, clarifying meaning where appropriate.
8

9
10 Costs were a concern for all of the professional groups, but the GPs and nurses were
11
12 particularly exercised by the possibility that additional costs would accrue to the practice:
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14
15 “...we’re a little bit jaded because there’s a steady trickle of services that were
16
17 previously provided in secondary care which it’s [now] expected that primary care will
18
19 do, but no additional funding follows. And there just isn’t any slack in the system. So I
20
21 think it cannot be perceived by the PCT as a way of saving secondary care funding
22
23 by just transferring it into primary care without additional funding for it.” (Group 3:
24
25 GPs/Nurses).
26

27
28 Underpinning this concern was the belief that practice staff might be expected to provide the
29
30 intervention and that their time might be more effectively used in other ways:
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32
33 “We’ve already taken some of our secretaries and trained them up as healthcare
34
35 assistants, to become phlebotomists, and we’ve got healthcare assistants who are
36
37 doing the anti-smoking clinic. And all the chronic disease management is done by
38
39 nurses. There’s no slack and I don’t see any GP taking it on.” (Group 3:
40
41 GPs/Nurses).
42

43
44 However, there was also recognition that the new intervention might generate savings, both
45
46 for the practice and the broader health economy, by reducing the number of GP
47
48 consultations, prescribing, and costly referrals:
49

50
51 “If it saved us a number of consultations per year, could be number of prescriptions,
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53 number of referrals to secondary care because we’re getting penalised for referring
54
55 to secondary care.” (Group 7: GPs/Nurses).
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3 Not all participants in the GP/Nurse groups were concerned about costs or savings to their
4 practice, but there was recognition that there were wider costs and savings which might be
5 important to other stakeholders, not least the Primary Care Trust which (at the time of data
6 collection) held responsibility for commissioning:
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11
12 “I’ve put costs to the patient, cost to the doctor, cost to the health service and tax
13 payer.” (Group 7: GPs/Nurses).
14
15

16
17 The commissioners appeared to have few doubts about the primacy of containment and the
18 need for new interventions to generate net savings:
19

20
21 “Honestly right now in the current climate it’s how much money is it going to save?
22 That’s what we’re judging it on, because we have this massive income challenge.”
23
24 (Group 6: Commissioners).
25
26
27

28
29 The commissioners claimed that in the current climate of austerity any new service would
30 need to yield a 160% return on investment in order to be commissioned, that is, all the costs
31 of providing the intervention, plus a further 60%, would need to be recouped from savings
32 generated elsewhere. If this claim is valid, it marks a substantial tightening of cost-
33 containment, beyond prevailing definitions of cost-effectiveness. The National Institute for
34 Health and Clinical Excellence (NICE) judges interventions to be cost-effective if they cost
35 less than £20000 to £30000 per Quality Adjusted Life Year (National Institute for Health and
36 Clinical Excellence, 2010). While all of the professional groups had an awareness of the
37 cost-containment agenda, the patient groups barely mentioned the issue, making this a
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Effectiveness

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63 Closely allied to the question of costs was the theme of effectiveness, most directly as the
64 justification for the costs. The following quotation from the commissioners’ group
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3 emphasises the importance of evidence of effectiveness in persuading stakeholders in the
4
5 commissioning process that the intervention is worth commissioning:
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8
9 “What is the evidence behind it? And making sure that your local public health team
10
11 and consultants understand what you’re doing and are brought into that... so it’s
12
13 about stakeholder management really.” (Group 6: Commissioners)
14
15

16
17 The link between costs and effectiveness was also important to primary care staff, although
18
19 this was often expressed in terms of saving time and resources for the practice rather than
20
21 as an element of the commissioning process:
22
23

24 “It comes down to efficacy. If you can prove to me that this really works and my work
25
26 load is going to reduce as a result of this and my referral pattern is going to reduce
27
28 then that would be quite tempting.” (Group 7: GPs/Nurses)
29
30

31 However, the focus on effectiveness was not purely driven by economic rationality; staff
32
33 were also concerned with the benefit to patients:
34
35

36 “... you’re not going to get GPs to refer to a service that there’s no firm evidence
37
38 base. You’re not going to get patients to commit to something that they don’t think is
39
40 going to help them either so I think you need to be clear about how efficacious it is
41
42 and what benefits are likely to be gained from it.” (Group 7: GPs/Nurses)
43
44

45 This raises the question of what constitute successful outcomes. Reports comprised a
46
47 mixture of: resource savings, benefits for patients, and also savings/benefits for the wider
48
49 society:
50

51 “I think there should be a high rate of return to work, reduction in analgesic use [...]
52
53 you still probably would do the investigations and referrals because we want to make
54
55 sure there isn’t anything underlying it. But as I say if they’re waiting for referrals and
56
57 they got better on the therapy, you’d say that was a success.” (Group 3: GPs/Nurses)
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3 Staff were also concerned about the possibility of adverse outcomes, particularly for patients
4 whose symptoms were not ameliorated by the intervention. The question of who would
5 benefit from the intervention leads into the next theme in the professional perspective.
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7
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9 10 *Patient Selection and Referral*

11
12 A key concern for professionals was how to select patients who would benefit from the
13 intervention and what the referral process should comprise. The aetiology of chronic pain
14 includes physiological, psychological, and social factors with many cases remaining
15 medically unexplained or non-specific. In addition, the planned intervention aimed to change
16 behaviour patterns and improve functioning rather than being curative in intent. This raised
17 questions about who should be referred and when. Some professionals preferred patient
18 self-referral, not least because it was easy for the GP, but most expressed the need for GPs
19 to prioritise patients or ration the service:
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29
30 “I think we’ve got to be much more up front about rationing [...] this is a service that
31 inevitably isn’t going to meet absolutely everyone’s needs. It’s got to be rationed and
32 therefore you’ve got to ration it to the people who you feel will get most from it and
33 that requires triage.” (Group 3: GPs/Nurses)
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38
39 The type of chronic pain condition, its duration and the extent to which other interventions
40 had been tried, were suggested as triage criteria, but overwhelmingly participants felt that
41 psychological factors and particularly the patient’s motivation were the key criteria for
42 referral:
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44
45
46

47
48 “...I’m not sure that you can necessarily alter the level that patients’ motivation is at,
49 to change the situation they’re in, but what you can do is make sure that whoever’s
50 referring is given clear guidelines or is able to select those patients who would
51 appear to be motivated rather than kind of ‘oh my God, what am I gonna do with this
52 patient, let’s just send them on that to get them out of the room’.” (Group 1:
53
54
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57
58 GPs/Nurses)
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60

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3 Many professionals used the term “heart-sink” to describe long-term chronic pain patients
4 who had received several interventions without amelioration of symptoms and who
5 continued to consult their GP. It was suggested that such patients often lacked the
6 motivation to overcome their difficulties:
7
8
9

10
11 “[There are] those that really want a fix [and] will be motivated, and there’s a group
12 that actually likes the label.” (Group1: GPs/Nurses)
13
14
15

16
17 Given that the aim of the intervention is to change the patient’s responses to their illness, it is
18 ironic that responses entailing “negative attitudes” should be seen as a reason not to refer.
19

20 However, this view was also found among the patients themselves:
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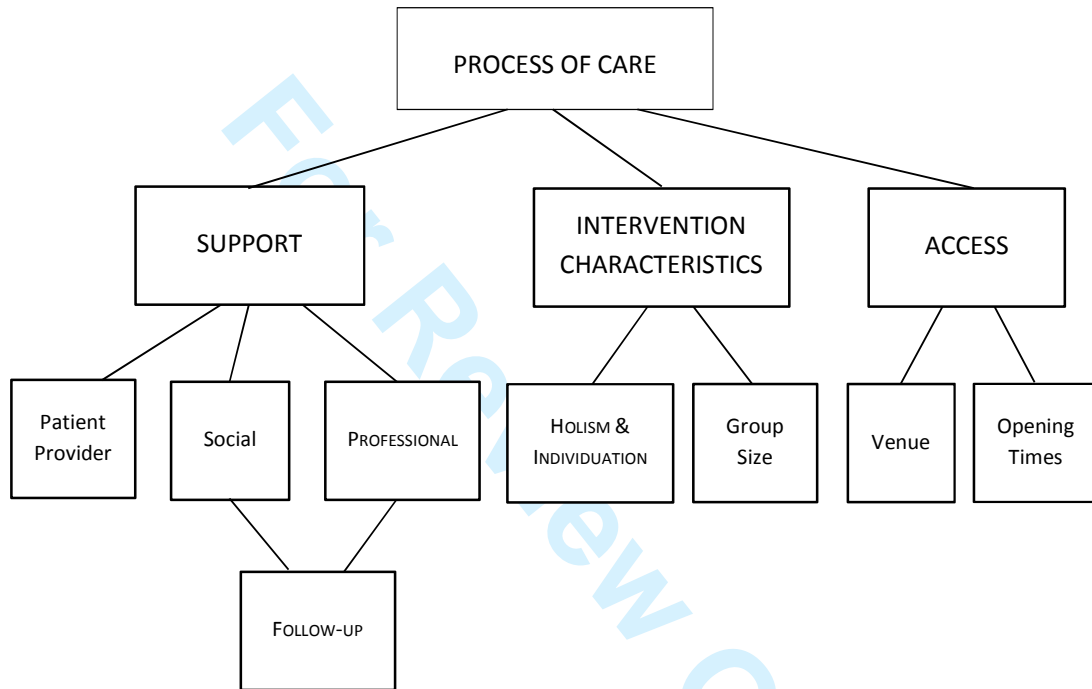
22
23 “One of the issues I think is suitability of the patient and the GP’s assessment of that
24 patient as to whether they’ve got a negative approach to it or a positive approach to
25 it. I think if you have a very negative mind-set you’re going to go into this and you’re
26 going to waste NHS funding because you’ve got to the bitter stage and you don’t
27 want help.” (Group 2: Patients)
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34
35 The dilemma of deciding which patients to refer links with the earlier theme of cost-
36 effectiveness. The intervention was initially developed to enable patients with seemingly
37 intractable chronic pain to improve their functioning by enhancing ‘psychological flexibility’.
38 However, from the narrow perspective of cost-effectiveness it might be considered more
39 efficient to prioritise patients with less entrenched difficulties who may be more likely to
40 respond positively to the intervention.
41
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47 **The Patient Agenda**

48
49
50 The patient agenda comprised three main themes: patient support; intervention
51 characteristics; and access, (see fig. 2).
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Fig.2. Patient Agenda



The patient agenda could also be characterised as sub-categories of an over-arching theme called 'the process of care', by which we mean the non-technical aspects of service provision and organisation, which include: the location and timing of delivery, attitudes of staff especially regarding courtesy, respect and compassion towards patients, and other non-clinical factors that influence the patient experience.

Support

We have used this broad theme to cover several related topics: empathy and emotional support from service providers, knowledge and advice (beyond the intervention itself), and

1
2
3 follow-up. This theme was of central importance to the patient groups, with 'access' and
4
5 'intervention characteristics' secondary to it.
6

7
8 The first sub-theme, 'patient provider' focuses on the extent to which patients or fellow-
9
10 sufferers should be involved in the delivery of the service. A key motive was the desire to
11
12 evoke deep empathy from the providers of the intervention:
13

14
15 "I don't think it really matters per se who would run the session. I rather think that
16
17 somebody that's actually suffered from chronic pain and has had training to stand up
18
19 there with your GP or your nurse or whoever and has actually experienced what
20
21 you're going through to one degree or another... but I think that it's very important
22
23 because you can be spoken to and you think 'you haven't got a clue, you don't know
24
25 what it's like'. That would be my main issue." (Group 2: Patients).
26

27
28 Such a person would be able to inform professional providers of what was achievable and
29
30 appropriate and make patients more receptive to the intervention:
31

32
33 "It would probably make you more receptive to what you're being told, because
34
35 you're not sitting there thinking 'you haven't got a clue' [...] you can talk at me all you
36
37 like but if you've experienced it I'm going to listen and I'm going to take it on board."
38
39 (Group 2: Patients).
40

41
42 It was suggested that patient service providers might also bring tacit knowledge, gained
43
44 through their lived experience of the illness, that might not be available to a professional, but
45
46 the problem with knowledge gained from personal experience of illness is that it can be
47
48 idiosyncratic:
49

50
51 "...the only problem with that [patient provider] is then you tend to personalise it as a
52
53 patient and talk about your erm... You need to be more open to everybody's point of
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55 view rather than...that's where the needs of others come in. If you're doing the
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3 tutoring then basically you need to be open to other people's needs rather than throw
4
5 over your own." (Group 4: Patients).
6

7
8 It was also felt that involving patients as providers might not be necessary if professional
9
10 providers established effective communication with patients:
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12
13 "But you can have patient involvement through the session anyway; if the people
14
15 taking the sessions make sure that everybody understands that it's open, that any
16
17 time if you need to ask questions or you want to say something you are quite
18
19 welcome to do so and then that way you get patient input as well as get over what
20
21 you want to say." (Group 4: Patients).
22

23
24 This notion of informal input from patients leads into the next sub-theme, social support.
25
26 Empathy is an important aspect, but social support extends to other psychological benefits
27
28 arising from contact with people experiencing similar symptoms and problems. Exchanging
29
30 practical tips for coping and sharing lay expertise was mentioned in some groups, but more
31
32 often participants spoke of the loneliness of enduring chronic pain and the support and
33
34 comfort they gained from talking to fellow sufferers:
35

36
37 "...it's more about emotional support than technical support. [...] I just feel the group
38
39 sessions can be more effective sometimes, talking to other people, you do feel very
40
41 alone and just understanding there are other people that have this" (Group 2:
42
43 Patients).
44

45
46 Most of the discussion of social support was positive, but some negative views also
47
48 emerged, for instance the claim that extensive discussion of each other's problems might be
49
50 'depressing' or a distraction from the actual intervention:
51

52
53 "... all patients obviously need to get their point across and need to be able to ask
54
55 questions but I also believe that in a lot of meetings that I've been to the people that
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57 are giving the session also have a structure to get through and I sometimes wonder
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3 whether it can actually go off track when you all discuss... because I mean we're all
4 so passionate and frustrated about our own conditions that we could probably sit
5 here for hours all of us talking about it to each other." (Group 4: Patients).
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10 Turning to the next sub-theme, professional support; chronic pain patients often feel
11 delegitimized by the suggestion that their condition might have a psychological element
12 rather than being exclusively bio-mechanical, (Wainwright et al., 2006), and prior to data
13 collection we thought that this might make patients reluctant to participate in an intervention
14 delivered by a psychologist. However, this was not the case. Patients were not concerned
15 about the provider's profession, so long as they were well-trained in the intervention and
16 able to build an empathic relationship with the patient, thus continuity of care was considered
17 important:
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27 "And that we can build a relationship with them you know through the group
28 sessions. I think it's important so you don't have to start all over again with somebody
29 else." (Group 2: Patients).
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34 Again, this focus on the quality of the relationship between patient and provider was driven
35 by the desire to generate deep empathy on the part of the provider, not as a desirable add
36 on with little therapeutic benefit, but as a fundamental determinant of the intervention's
37 effectiveness:
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43 "If the people that are dealing with you don't understand what it's like for a person in
44 chronic pain then they've got no right to be...really because there are so many
45 emotions you go through when you're in chronic pain you get angry, you get
46 annoyed, you get frustrated and those can be another symptom on top of your
47 chronic pain. So you need somebody in that position that is going to understand why
48 you feel like this." (Group 4: Patients).
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3 Empathy and understanding were highly salient and often reported as essential
4 requirements, but one patient group raised the point that this should not preclude
5 challenging the patient's perceptions:
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10 "You do need people who are sensitive but sometimes you do need the challenge so
11 it's all about having people with common sense and skills and taking a balanced
12 approach. Being able to weigh up the person they're speaking to I guess is a part of
13 it." (Group 5: Patients).
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19 This point was not widely made, but it does raise an important question about an intervention
20 that is designed to challenge chronic pain patients' perceptions about the limitations and
21 constraints of their illness, but which also relies (in the opinion of many patients) on deep
22 empathy. This tension, between the need to support and comfort vulnerable people and the
23 desire to see them achieve autonomy and optimise their full potential, emerges in many
24 health and welfare contexts. It also emerged in the final sub-theme which concerns 'follow-
25 up'.
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34 The intervention was designed to have a fixed number of treatment sessions without follow-
35 up. Patients questioned this design, first because of their desire to receive on-going
36 emotional and social support:
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40 "Regular contact really, because sometimes you can feel you're alone [...] if you ring
41 [the] pain management [service] a lot of the time it's an answer machine or
42 somebody takes a message for one of them to ring you but that can take several
43 days so just someone at the end of a telephone some days when you are particularly
44 bad." (Group 2: Patients).
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52 Secondly, it was suggested that the effects of the intervention might wear off over time, or
53 that symptoms might return and require further attention:
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3 "...it would be nice if it is was, 'okay you've done what you can and we think you've
4 reached a plateau now but you can drop back into the service 6 months down the
5 line if you have a relapse...when you hit a low', it would be nice to duck back into the
6 service, ring them up and say 'look, you know, it's flared up again, can I come back
7 in?'"
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14 Patients suggested that chronic pain tends to recur and that the curative orientation was
15 therefore less appropriate than on-going support. Up to a point this perspective was shared
16 by some of the professionals:
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21 "...most of these patients have a chronic condition and I suspect that behavioural
22 techniques are a great way of trying to deal with that, but I suspect they need
23 boosting from time to time in this personality group. I would have thought that there's
24 a good response in the first six months following behavioural therapy and then all
25 those techniques begin to, you get a bit lazy about them and doubt them and there is
26 a fall-off and so I wonder whether with this group if you had an annual refresher
27 course..." (Group 3: GPs/Nurses).
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36 The professional perspective on the need for follow-up may be close to that of the patient,
37 but there are also differences. Professionals tended to see the recurrence not just as a
38 failure of the body, but also in terms of the personality of the patient and the behavioural
39 orientation of the intervention, that is, they recognised the intervention as an on-going project
40 of behaviour change akin to smoking cessation or weight loss programmes:
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47 "Well they've found with dieters and weight watchers and smoking cessation and all
48 sorts of things, that if you have a patient helpline the rates of people [...] reaching
49 target is much, much higher than just being left alone in isolation and that's just the
50 holding hand bit which is a therapy in its own right." (Group 3: GPs/Nurses).
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56 A more significant difference was the tendency for professionals to recognise that follow-up
57 sessions would add significantly to the costs and possibly extend waiting times:
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3 “... the cost would rocket if you’re adding another group that’s a follow up...how
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5 much would that add to the cost?” (Group 3: GPs/Nurses).
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8 Again, this concern was linked to what is almost a moral judgement about the chronic pain
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10 patient:

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12 “ But then again if you’ve got a massive number of patients you’re going to have to
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14 say how many treatments you’re going to allow them otherwise it’ll just get out of
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16 hand won’t it? [...] That’s when the chronic people would like it to last forever.”
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18 (Group7: GPs/Nurses).
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21 While both patients and professionals recognised the desirability of follow-up, only the latter
22
23 began to make the trade-off with cost-effectiveness.
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25 26 *Intervention Characteristics* 27

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29 It was explained to participants that the content of the intervention could not be modified, but
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31 the way in which it was delivered could be. Even so, participants challenged the assumption
32
33 that the service should comprise a single intervention (CCBT) and suggested a range of
34
35 other interventions that should be bundled with it, including physiotherapy, massage,
36
37 hydrotherapy. Often the rationale for this pluralistic approach was expressed in terms of the
38
39 need for holism and individualisation, that is the belief that the management of pain requires
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41 an approach that focuses on the whole person, and that therefore a constellation of
42
43 interventions tailored to the needs of the individual is required:
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46 “Yeah it is being treated like an individual but it’s also looking at the patient as a
47
48 whole. [...] rather than, ‘well you fit into that box so you’re going to have all that
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50 treatment that goes with that condition’. [...] physiotherapy, massage, helps your
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52 body cope and your mind then copes better.” (Group 5: Patients).
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56 It was suggested that health care professionals are not always in agreement with this
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58 approach:
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3 “It’s the whole, it’s the whole thing but also if you are receiving other...I mean I’ve
4 seen a kinesiologist recently and I’ve been seeing an osteopath for some time and
5 when I spoke to the person that was treating me at the [hospital] she was really
6 dismissive of those treatments and I felt well actually do you know, what you were
7 doing for me wasn’t sufficient, it wasn’t helping me to get to the point that I’m
8 currently at but she was like I say just completely dismissive of these other things
9 that have helped me.” (Group 5: Patients).
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18 The professional groups often discussed the multi-factorial nature of chronic pain, but did not
19 express this in terms of holism or individualisation.
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23 A second characteristic of the intervention discussed by the patient groups was the size and
24 composition of the intervention groups. Preferences for group size varied from 8 to 12, but
25 some participants felt that more than 10 would be intimidating for some members and limit
26 their contribution. There was also discussion about whether carers should be able to attend
27 to provide support for patients, but again there were concerns that this might lead to an
28 intimidatingly large group size:
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36 “... 8 to 10 patients or 8 to 10 patients and partners? Because if you start adding the
37 partners all of a sudden the groups become very big and unmanageable.” (Group 2:
38 Patients).
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43 There was no clear conclusion to this dilemma, although it was suggested that carer
44 involvement might be allowed under particular circumstances, but not be routinely offered. It
45 was also suggested that the intervention might be offered on an individual basis to patients
46 who were too vulnerable to join a group. However, there was also recognition that the
47 smaller the group size the longer patients might have to wait to access the intervention:
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54 “If you keep it too small, like the [hospital based pain management service], you’re
55 waiting up to 18 months to get on a coping skills [course]. If it’s [a group size of] 4 or
56 whatever it’s going to take forever isn’t it?”
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3 This was the only area in which the patient groups raised the trade-off between service
4 quality and resource constraints, although it is expressed in terms of waiting times rather
5 than costs.
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9 10 Access

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12 We have already noted concerns about waiting times, but this theme relates more to
13 physical access, including the geographical location of the service, transport to and from it,
14 'opening times' and the extent to which the venue was adapted to meet the needs of
15 patients with chronic pain. The aim of the study was to evaluate the transfer of the pain
16 management intervention from the tertiary care setting, into local communities, thereby
17 improving geographical accessibility. There was broad support for this objective, but
18 considerable discussion about 'how local' the service should be.
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28 "If you choose a GP surgery you've got to stay local to you so if it's held at a GP
29 surgery you're 99.9% sure you can get there. [...] But if it's in Oxford you're not going
30 to bother. [...] It's going to take so much longer out of your day. It might take you an
31 hour to get there and an hour to get home..." (Group 2: Patients).
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37 Some of the groups tried to quantify the distance that patients might be prepared to travel, 5
38 miles was proposed as a maximum, but others felt that distance was less important than
39 good transport links and parking.
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44 "... it's not how far, it's 'can I drive? Can I park close? How much pain inducing
45 movement have I got to go through?'" (Group 2: Patients).
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49 These concerns were shared by the professional groups, who drew on experiences of
50 similar referrals where geographical distance had diminished uptake:
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54 "We send patients off for pulmonary rehab and all sorts of other bits and pieces and
55 sometimes the uptake isn't good [...] purely because either they can't drive or they
56 can't get there and they want something on their doorstep." (Group7: GPs/Nurses).
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3 A further sub-theme was the suitability of the venue for patients with chronic pain many of
4 whom have limited mobility and often find remaining seated for lengthy periods very
5 uncomfortable; several practical requirements were identified: that the service be located at
6 ground level to avoid stairs; a range of different types of furniture because what is
7 comfortable for one patient might not be for another; sufficient space for patients to get up
8 and walk around; provision of somewhere to make drinks during breaks; easy push doors
9 and disabled parking.
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12 Finally, the scheduling of the sessions was highly salient for the patient groups, but no
13 consensus emerged due to the varying needs and preferences of participants:
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23 “Unfortunately some people are better in a morning, some people like myself are
24 better in an afternoon. If you’re working how on earth are you going to do a 6 week
25 course if it’s mornings or afternoons. You’d have to have a very understanding
26 employer who’d let you go for 6 weeks.” (Group 5: Patients).
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32 It was suggested that the intervention should be made available at a range of different times,
33 including out-of-hours, and that patients should be able to choose an iteration that was
34 suitable for them.
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37 38 **Discussion**

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41 Our analytical conceit is that a patient agenda can be differentiated from that of health care
42 professionals. Before discussing these agendas, it is important to state some caveats. First,
43 the agendas are not mutually exclusive; professionals expressed some of the concerns of
44 the patients and vice versa, albeit often with different nuances of meaning and differing
45 degrees of salience and priority. Nor is it the case that the two groups unequivocally
46 subscribed to the agendas we have attributed to them – as with any group, there were
47 individual differences of opinion and emphasis. We have attempted to illustrate the overlaps
48 and internal disagreements in our presentation of the results. What remains are two broadly
49 distinguishable standpoints.
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3 Our analysis suggests that the primary concern on the professional agenda is cost-
4 effectiveness, while the primary concern on the patient agenda is the process of care.
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6 Among the professionals the commissioners were particularly exercised by the necessity of
7 new interventions generating absolute savings. The generation of savings was raised by
8 other professionals, but more often in terms of cost-containment, particularly for the
9 practices to which they were attached. All of the professional groups were concerned that
10 the intervention should be based on sound evidence of effectiveness and achieve optimum
11 health gain for the resources invested.
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20 It is striking that cost-effectiveness was far less salient to the patients. Some were
21 concerned that small treatment groups or extensive follow-up might increase waiting times,
22 but this was rarely articulated in terms of financial costs. In the UK most health care is
23 funded through general taxation and largely free at the point of delivery, which may explain
24 why costs were not salient to the patients. When the NHS was established health care
25 professionals were also putatively sheltered from consideration of the costs of their practice;
26 our findings support the claim that the marketization of the health care economy has
27 heightened their awareness of costs (Frith, 2013). Since April 2013 Clinical Commissioning
28 Groups have been established with the aim of involving GPs and other health care workers
29 more directly in budgetary management. This initiative has not yet been fully evaluated, but
30 evidence from the GP fundholding initiative of the early 1990s suggests that involvement in
31 budget holding can increase awareness of costs at least for some GPs, (Wainwright and
32 Calnan, 2011).
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47 The professionals' concern with effectiveness is also explicable by reference to the
48 commissioning process (which GPs are increasingly involved in) and the broader rise of
49 Evidence Based Practice within professional discourse (Broom and Adams, 2011). But why
50 were the patients apparently unconcerned by the effectiveness of the intervention? There
51 are several plausible reasons. We briefed participants that there was an established
52 evidence base relating to the effectiveness of the intervention in the tertiary care setting and
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3 patients may have assumed that this could be generalised to the primary care setting, or that
4 the NHS simply would not provide an ineffective treatment. More contentiously, many
5 chronic pain patients have a long history of on-going symptoms, multiple referrals and
6 uptake of interventions that have had limited effectiveness in ameliorating their symptoms;
7 might it be that many of them no longer prioritise the pursuit of an effective 'cure', and are
8 more concerned with obtaining deep-empathy and emotional support from service
9 providers?
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18 We use the 'process of care' category to span a range of factors relating to the lived
19 experience of receiving an intervention. Some were practical, for instance, opening times,
20 and the comfort and location of the venue. But the process of care factors about which the
21 patients felt most strongly were affective rather than practical, for example, the desire to
22 evoke deep-empathy from service providers, the emphasis on emotional/social support and
23 on-going follow-up. These factors were not reported as desirable additions to the therapeutic
24 content of the intervention, but as essential pre-requisites or even intrinsic elements of the
25 intervention. Many of the patients did not appear to be seeking a 'cure' for their symptoms,
26 but rather a degree of understanding, sympathy and support that would strengthen their
27 capacity to endure their suffering. These findings are consistent with the literature on 'peer
28 support' which Dennis has reviewed, offering the following definition:
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40 "peer support, within the health care context, is the provision of emotional, appraisal, and
41 informational assistance by a created social network member who possesses experiential
42 knowledge of a specific behaviour or stressor and similar characteristics as the target
43 population, to address a health-related issue of a potentially or actually stressed focal
44 person." (Dennis, 2003: 329).
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52 The professionals were often aware of this orientation towards on-going support rather than
53 curative medicine among chronic pain patients but tended to construct it negatively, for
54 example, through references to 'heart-sink' patients, who 'like the label', and the need to
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3 refer patients who were motivated to recover, rather than wanting the intervention 'to last
4 forever'. This negative construction may stem from the desire to avoid the 'emotional labour'
5 that on-going support for patients with chronic problems entails (Larson and Yao, 2005). It
6 may also stem from the curative orientation of the bio-medical model and the moral
7 imperative for patients to relinquish the 'sick role' at the earliest opportunity (Parsons, 1951).
8 These expectations do not always fit well with chronic illnesses where the best achievable
9 outcome is often satisfactory adaptation or coping (Parsons, 1975).
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19 There is a tension between the professional agenda driven primarily by cost-effectiveness
20 and the patient agenda that prioritises the process of care, but can this tension be resolved?
21 Theoretically, the two are not incompatible. If process of care factors can be costed and their
22 contribution to the achievement of outcomes such as independent functioning and wellbeing
23 can be measured, then they can be evaluated and compared with any other health care
24 intervention. However, in practice even if the process of care can be shown to improve
25 outcomes, it is perhaps unlikely that an intervention with open-ended follow-up and labour
26 intensive social/emotional support would fare well in a commissioning process driven by the
27 desire to maximise health gain within scarce resources, when compared with short-duration
28 lean interventions that offer more 'bang per buck'. Indeed, the rapid increase in the
29 availability of CBT interventions is substantially due to the claim that they can achieve
30 positive outcomes quickly and cost-effectively. The *Improving Access to Psychological*
31 *Therapies* initiative which has substantially increased the provision of CBT in primary care,
32 came about largely because of Richard Layard's successful attempt to persuade the
33 previous Labour government that every £1000 spent on CBT would generate £3000 savings
34 for the treasury, (Layard, 2005). Extending the duration of CBT or addressing other process
35 of care factors might erode that favourable ratio.
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56 Process of care issues top the patient agenda, but for them to be adequately addressed in
57 the design and provision of interventions, evidence of their cost-effectiveness is required. In
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3 the absence of such evidence, service planners will need to make trade-offs between cost-
4 containment and patient satisfaction. Our methodology did not allow for such trade-offs to be
5 put to participants in a structured form. However, such techniques are available, for
6
7 example, Conjoint Analysis (Ryan and Farrar, 2000) which forces participants to make trade-
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9 offs between, say waiting time and the distance travelled to access a service. There may
10
11 also be value in bringing together patients and professionals in joint focus groups, and other
12
13 deliberative processes, such as citizen's juries, deliberative polls and consensus
14
15 conferences, to see if the gap between their different agendas can be bridged through the
16
17 critical exchange of information and discussion, (Culyer and Lomas, 2006). However, these
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19 techniques should be used with caution, lest they become a means for manipulating patients
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21 into contributing to a discourse of consumer preference that does not reflect their actual
22
23 beliefs and may not be in their interests, (Wainwright, 2003).
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