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Research and Theory

The myth of patient centrality in integrated care: the case of back pain services

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Abstract

Purpose: The purpose of this paper is to critically examine the extent of patient centrality within integrated chronic back pain management services and compare policy rhetoric with practice reality.

Context: Integrated chronic back pain management services.

Data sources: We have drawn on theories of integration and context specific journals related to integration and pain management between 1966 and 2006 to identify evidence of patient centrality within integrated chronic pain management services.

Discussions: Despite policy rhetoric and guidelines which promote ‘patient centrality’ within multidisciplinary services, we argue that evaluations of these services are scant. Many papers have focussed on the assessment of pain in multidisciplinary services as opposed to the patients’ experience of these services.

Conclusions: A latent measure of the reality of its magnitude needs to be captured through analysis of the patient’s perspectives. Capturing patients’ thoughts about integrated services will promote patient centrality and support the reality rather than endorse the rhetoric.

Keywords

integrated care, back pain, patient centrality

Introduction

Pain frequently demands holistic care management approaches which embrace diversity and combine aspects of health and social care theory. As such, the management of chronic pain needs to be multifactoral and engage a variety of interventions and therapies. The Royal College of Anaesthetists [1] contends that effective pain management should energetically promote multidisciplinary working. In addition, good multidisciplinary working is advocated as a central stratagem to ensure the individualised management of pain. This is especially pertinent when considering the complex needs of patients who suffer from chronic back pain. Such complexities suggest that the patient should ideally sit at the heart of multidisciplinary care decision making in multidisciplinary services. This notion of ‘patient centrality’ within service provision, however, has received little attention. Pain

management in any context has the potential to provide cross boundary working between professionals in primary and secondary services and ensure that patients play a central role in their care.

Whilst creators of multidisciplinary services strive to develop structures to support ‘seamless’ services, few have evaluated the extent of this integration within pain management services. Alarming, and given the impetus to secure the patient perspective in contemporary health care, even fewer evaluations are based on the service users’ perspective. This problem is further compounded by the academic quagmire of definitions and concept analyses surrounding the notion of integration. This theory paper draws on concepts of integration and pain management and suggests that evidence of patient centrality from the service user perspective has not been satisfactorily explored.

The international context of back pain

Back pain is becoming a major global problem. Recent surveys by the United Kingdom (UK) Health and Safety Executive reveal that 437,000 people suffered from a muscular-skeletal disorder affecting their back and subsequent work [2]. Globally, the incidence and prevalence of back pain are comparable [3]; throughout Europe, for example, it is estimated that 42.1% of the population of Greece have been affected by back pain and will suffer from a low back related problem, and in Finland over 39.6% have had their health affected by back pain [4]. In the United States (US), it is suggested that low back pain is one of the most common symptoms which cause adults to seek health care [5]. The devastating effects of chronic back pain, and its subsequent treatment, equates to the health impact of an acute chronic illness.

Back policy in the UK NHS

Driven by targets and key population needs, the public health policy of the UK National Health Service (NHS) has focussed on preventative measures such as the promotion of safe moving and handling. Despite these efforts the number of back pain sufferers continues to rise [2] and this pattern is not confined to the UK; it is estimated that back pain costs billions per year in the United States, and Europe [6–8].

Given this economic and social burden, it is not surprising that an escalating pressure to provide effective treatments and rehabilitation has been supported by government and local policy. Increasingly, the complex and subjective nature of pain necessitates involvement of a range of professionals to ensure the successful management of patients with pain. As a result, it could be argued that *any* type of chronic pain *should* be treated using multidisciplinary methods.

The effectiveness of multidisciplinary team involvement in general care is not disputed. In particular, it is suggested that the multidisciplinary approach is most suited to chronic back pain sufferers. This is particularly resonant within current professional policy and guidance [9, 10] and a range of strategies and documents have ensued which promote quality multidisciplinary chronic pain management services. These include recommendations derived from an extensive review of pain services in the UK by the Clinical Standards Advisory Group [10]. The guidelines are similar to those produced by equivalent American organisations and advocate a shift of back pain care provision from the acute to the community setting. Both guidelines recommend a multidisciplinary approach to therapy and treatment, in addition the

Clinical Standards Advisory Group guidance also recommends that local chronic pain teams should be led by a named individual (whose role is clearly defined), have adequate administration and support staff, ensure a recognised role in relation to preventative and management aspects of chronic pain, devise and discuss all care plans with patients and ensure their availability to other members of the team and ensure that the service is audited.

In 2003 the Royal College of Anaesthetists and the British Pain Society [1] introduced joint guidance on the management of chronic pain. The guidance specified the need for multidisciplinary cooperation and the ability to refer to other specialist consultant services. Similar to other policies, these guidelines also stipulated the need for audit and evaluation of services and that there should be sufficient numbers of staff who are adequately prepared to meet the needs of the patient. A later publication by the British Pain Association also provided a practical guide to the provision of chronic pain services specifically for adults [9]. Although particular to the primary care context, objectives contained within the guidance are comparable to other recommendations. For example, the need for clear, shared objectives between the team are emphasised along with a shared understanding of chronic pain, good liaison and communication with other services and a sustained commitment to audit and evaluation.

Over the past 10 years, however, the extent of pain management programmes has grown. Recognising the changes in the evidence base and salient problems inherent within service delivery, the British Pain Society has revisited and modernised their original 1997 guidance—*Desirable Criteria for Pain Management Programmes* [11]. Following this, the Association of Anaesthetists of Great Britain and Ireland and the Pain Society working party developed proposals for the future development of pain management services [12] (see Box 1). The impetus to revise the guidance was based on the premise that service delivery has not kept pace with the change in the evidence base, public demand and awareness. Pain management programmes are now advocated as key strategies to rehabilitate patients using psychological principles and long-term self-management strategies, with application of cognitive and behavioural principles through multidisciplinary approaches.

The multidisciplinary team: is it the best way forward?

There is an abundance of guidance from professional bodies and good evidence about the nature and

Box 1. Pain management service development

Service Proposals 1997	Service Provision 2003
<p>The provision of services is shared.....but with varying degrees of responsibility [12]. Recommendations included</p> <ul style="list-style-type: none"> • Appropriate fixed resource sessions for medical personnel • Specialist nurses • A greater role for psychologists and occupational therapists • "Inter-departmental relationships should be encouraged" [12, p. 6] 	<p>The provision of individual, inter-disciplinary approach for each patient [1] co-operation exists between</p> <ul style="list-style-type: none"> • Specialist pain medicine doctors • Primary care physicians • Specialist nurses • Clinical psychologists • Physiotherapists • Occupational therapists • Pharmacists

purpose of multidisciplinary therapies. Of these, the majority recommend that any approach should concentrate on improving function and quality of life rather than seek curative ideals. To attain this, the multidisciplinary team is undoubtedly seen as key in supporting the rehabilitation of patients with chronic back pain. Uncovering the potential efficacy of multidisciplinary teams in chronic pain management has resulted in a number of systematic reviews. Such reviews are considered to be of value to the NHS as they facilitate the appraisal of vast amounts of evidence, the cumulative findings of which provide useful foundations for practice. For example, Flor et al. [13] and Guzman et al. [14] conducted independent systematic reviews of the efficacy of multidisciplinary pain management services. Each identified strong evidence to uphold the use of intensive multidisciplinary programmes and supported the notion that these treatments were superior to single treatments. It should be noted, however, that there are methodological problems inherent in some systematic reviews due to ambiguous operational definitions used. In relation to pain management, problems may occur as a result of the different ways in which chronic pain management services have been defined and delivered [15]. This problem is not unique to the field of pain management and it must be acknowledged that systematic reviews remain a valuable resource when exploring the evidence base for efficacy of treatments and therapies.

Other recent research has promoted the continued presence of the multidisciplinary team within chronic pain management services [16, 17]. Cumulative research findings also indicate that ineffective multidisciplinary working can lead to unnecessary suffering, increased waiting and lengthy pain duration. Integration is, therefore, posited as a crucial characteristic needed to ensure the success of such services, yet it may not necessarily provide an accurate reflection of the reality incurred. It *assumes* that the involvement of the multidisciplinary team means that effective integration occurs within *all* services. However, it is also acknowledged that the process of integration, its occurrence, extent and interpretation varies between

organisations. To date, the 'seamless service' strived for by so many, has eluded description and assessment. This could be due to the conceptual ambiguity associated with ill-defined constructs of integration. Conceptual clarification may, therefore, support the development of future services and enhance the quality of patient care.

Attaining conceptual clarification of integration is it a utopian dream?

Integrated care has become an international health care buzzword; yet conceptual clarification has proved problematic. The concept of integration and its meanings have resulted in methodological chaos with some advocating that integrated care is context specific and therefore eludes adequate definition. Indeed, Schneider [18] poses the question of whether functional integration is an attainable vision or simply a utopian dream. He suggests that, despite the limited clinical resources, functional integration is indeed attainable, yet some authors are dissatisfied with this stance and argue that a major difficulty in actually understanding (and therefore utilising) integrated care is its lack of a sound analytic paradigm [19]. This apparent lack of a meaningful paradigm led Kodner [19] to search for solutions which could help develop a framework to analyse new and existing programmes of integration within an elderly care context. His study identified crucial factors indicative of successful fully integrated care. These included (amongst others) intensive multidisciplinary team care coupled with a 'geriatric philosophy', which suggests that the patient context and patient centrality is a determining success factor. Later work by Kodner and Spreeuwenberg [20] in this journal, suggests that the notion of integration, certainly within the UK, is most frequently equated with shared care [20] and like integrated care may only be understood by examining both context and logic.

To address this, attempts have been made to explore the concept of integration; indeed Kodner and

Spreeuwenberg's [20] analysis of the meaning, logistics and application of integration helped develop a patient-oriented definition of integration. They proposed that integration is "*a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors*" [20, p. 3]. The goal of these methods and models is to "*enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long-term problems cutting across multiple services, providers and settings*" [20, p. 4]. The concepts outlined in Kodner and Spreeuwenberg's paper [20] illustrate the generic phenomena of chronic pain management.

Whilst not specific to chronic pain or back pain conditions, the paper by Von Koff et al. [21] considers the 'generic' nature of chronic illness management and suggests that the attributes to successful management are potentially transferable to other sample groups. Von Koff and colleagues write that collaborative management should support self-care in chronic illness and ensure effective maintenance systems are in place. Thus the need to ensure that those systems include a range of professionals and services can be viewed as paramount to supporting patients. Like other authors, Von Koff et al. [21] question whether the rhetoric of collaborative management reflects the reality. Although experimental studies highlight a gap between health service provision and the care that patients actually receive, Von Koff et al. [21] argue that this disparity illustrates the need for reassessment of current service provision.

Findings from Von Koff [21] and Kodner [20] emphasise the importance of the patient's centrality within care management decision making and suggest that self-care and medical care are enhanced by effective collaboration between the patient, their family and health care providers. As such, it could be argued that in any collaborative management process, the patient should be an equal partner and central in the relationship. The potential of patient centrality to empower the patient within their own care could be considered a key attribute in the management of any chronic illness which further exacerbates the need for patient centrality within integration to support working across professional groups. In addition, patient centrality has the potential to promote tailored programmes of care which can be agreed by all involved.

Contact with health care providers through this process is also seen as crucial to the success of collaborative management [21]. Whilst it is argued that no grand strategy exists to support the reorganisation of systems to improve integration [21], Von Koff proposes

that traits such as increased integrated community involvement and active cooperation between community based and health care systems can help increase patients' participation in self-care which further engenders and supports chronic illness management [21]. However, others, for example Suprina [22], explored the efficacy of a biopsychosocial model by single practitioners (accustomed to the biomedical model) as opposed to the integration of the services *per se*. Using a case study of young women with chronic low back pain Suprina [22] presents a convincing argument for the use of a biopsychosocial within chronic back pain management arguing that both the mental and physical origins of pain need to be considered, one cannot be distinct from the other. In support, Wright's *Passions of the Mind* [22] theory is used which suggests that the power of the mind to affect the body should not be underestimated. In addition, patient characteristics such as gender, age and some would argue more ephemeral attributes such as attractiveness, are linked to the judgement of pain by the clinician and the patient. Effective treatment for chronic pain, therefore, should take into account the "*multi-layered subjective nature of the patients pain experience beyond either physical, mental or social contributors and include all three*" [22, p. 185]. However, Suprina's discourse becomes contentious when he argues that single practitioners could provide an 'integrated' approach—equal to that of the multidisciplinary team. Suprina [22] appears to exclude patient centrality when he advocates the uni-professional as the sole provider of integration. Given the strength of the multidisciplinary approach, Suprina's integrated theory could be seen to contradict current multidisciplinary chronic pain management theories.

Unlike Suprina [22], Collett et al. [23] supported Kodner's [19] notion of connectivity, and suggested that the strength of the multidisciplinary team is emphasised by the equal involvement of the patient and family. A study by Collett et al. [23] was based on women with chronic pelvic pain and the requirement for the multidisciplinary team to ensure clearly defined aims and joint assessment of the patients' needs. Unfortunately the extent of multidisciplinary team function or its modes of practice are not disclosed. Analogous to Collett [23] and Von Koff [21], Keel [24] also advocates multimodal pain treatments for patients with Fibromyalgia who typically present with complex and disparate pain problems. As with Von Koff et al. [21], Keel [24] sees the patient as a central component in the delivery of integrated treatment programmes. A diverse range of strategies are used in multimodal programmes. However, Keel emphasises the need for therapists to share a clear and common goal and unite in the same therapeutic regimens.

Is there evidence of patient centrality for integrated back pain care?

If Von Koff's [21] notion of patient centrality is considered, what does the evidence base disclose about the nature and extent of integrated services from the patients perspective? The current evidence base indicates a distinct lack of research which has specifically explored the extent of patient centrality within integrated services. In particular, the patient's experience and understanding of multidisciplinary working has not been reported. Despite a range of evidence supporting the use of multidisciplinary approaches to pain management, there are few which have devoted their evaluations of such services on the *patient's experience*. It appears that the patient experience of multidisciplinary working is absent in any citations in recognised professional websites and aggregators. This dearth is surprising given the importance of patient centrality to the multidisciplinary treatment in global health care systems. This suggests that little has been done to evaluate the patient's perspective of multidisciplinary working to help develop integrated services. To redress the imbalance of the current research evidence base, researchers should be encouraged to use more qualitative approaches to explore and understand multidisciplinary working from a patient's perspective. Without this insight, patient centrality is at risk of becoming tokenistic, merely presenting an ensemble of policy rhetoric and diffused from the reality of pain management.

This polarised perspective is also evident in a study exploring the management of acute pain in Australia [25]. Despite key recommendations which advocate patient centred services, the survey highlighted deficits of actual patient input into the provision of pain services. In addition, the authors state that "*patients' views of appropriate outcomes do not appear to have been sought*" [25, p. 4]. Seeking patient views are now a priority for the NHS and the UK Government now promote patient centrality by attempting to ensure that patients are involved in every aspect of their care [26]. The resultant policy [26] was designed to shape a patient-led service whereby patients are "*respected for their knowledge and understanding of their own experience*" [26, p. 8] and where it is recognised that the "*best judge of their experience is the individual*" [26, p. 8]. Key to the development of NHS planning, the Wanless Report [27] also advocated that patients should be fully engaged in their healthcare, fuelling the notion of a patient-led service.

Listening, understanding and responding to the patient's views provides valuable information which

can be transferred into organisational delivery to better shape services that meet the individual needs of the patients. It is evident, therefore, from a policy perspective that the pre-requisite for patient centrality should sit at the heart of any service. Policy rhetoric has gained support through advocating integration as a key determinant of successful health and social care delivery. Sceptics such as Hudson [28], whose initial contentious observations dispute the reality of integration, contend that early ministerial rhetoric to pull down the 'Berlin Wall' between health and social care and promote integration has actually failed. It is unclear whether this polarised view is evident between health care professionals and patients; however, the assumptions made about the effects of multidisciplinary treatments on chronic back pain management have not taken into consideration the impact of such care based on the *patient's perspective*.

The patient's story

The reasons why the patient's experience is promoted as a favourable method to evaluate pain management has been explored in some depth. However, this is manifest in evaluations of patient *satisfaction* rather than *exploration* and *expectation*. Comparable studies which explore the relationship between expectation and reality are few. In addition, studies which have used patients with chronic pain such as back pain are even scarcer. One exception, however, is McCarthy et al. [29] whose recent study explored the expectations and satisfaction of patients with low back pain attending a multidisciplinary clinic. This research was driven by the limited existence of any meaningful research on low back pain within a multidisciplinary setting. McCarthy et al. [29] examined the strength of association between patient satisfaction and expectations of the service. They clearly state that their paper was the first to explore such events and actively promote continuing research into this neglected field of pain management. In the main, the benign paternalistic nature of health care professionals was evident within a succession of health care settings. This has negatively impacted on patient centrality and created an unhealthy dependency [30]. Involving patients in partnerships and decision making can reduce anxiety; improve satisfaction and biomedical outcomes [31], yet it remains that accounts of the patient centrality are limited, especially within integrated service provision.

Most notable, however, is accounts of the patient's experience in the field of pain assessment and management *per se*, as opposed to the extent of integration to support the management of pain services. The principal philosophy of integration, seamless service

and whole systems approaches which involves the service user and which are promoted by best practice guidelines have only received partial attention. The application of research which has explored pain assessment to the concept of integrated care provision seems to have been ignored.

The reliance on pain measurement and assessment has taken precedence in the evidence base resulting in sparse data about the nature and extent of integrated services from the patients' perspective. However, knowledge about the fundamental need for patient centrality has existed for many years. As early as 1981, authors such as Bond [32] noted that regardless of the diverse range of pain-relieving methods, doctors' methods of treating pain continued to rely on 'time hallowed' rituals as opposed to care, consideration and analysis of the patients needs. Moreover, Bond [32] argues that pain is innate and the subjective nature of pain invariably signifies that it is best judged by the sufferer and clinical observer. Bond's convincing argument illustrates the need for healthcare professionals to accept the intrinsic link between pain physiology, personality and the psychological and social consequences of pain.

Contemporary literature has exaggerated this stance through research which has explored, experimented and described the pain phenomenon from the patient's unique emic perspective. Of these, research projects which involve using patients to describe or quantify their experience of pain management services are most prevalent. This frequently places the patient at the centre of the research, thus propagating the notion of patient centrality. This impression is readily visualised in Bibby's paper [33] which used patient's experiences of the management of chronic neck pain to develop a guide for best practice. The study is a lucid example of how semi-structured interviews were used to elicit the evidence pertaining to the patient's journey prior to attending the pain management service. The journey undertaken by the patient provided the research team with rich data which was then used to reorganise service provision. The relationship between pain and service utilisation was also explored by Holzemer, Henry and Reilly [34]. Exploring AIDS patients' pain experiences helped Holzemer et al. [34] to determine the effectiveness of nursing pain management strategies. Although this particular study

focussed on measuring the patient's pain, the findings verified the need to ensure that patients' are central to any decision making and that their unique accounts are crucial in the successful management of pain. In Carson and Mitchell's [35] eloquent summary "*pain is managed as a problem instead of attending to the person who is living the experience as the leader and teacher of how to live with pain when it is a persistent presence*" [35, p. 1243], yet the experience of living with chronic pain appears to be a concept largely ignored in the literature.

Summary

The dearth of evidence which uses the patient's perspective to evaluate multidisciplinary chronic back pain services has resulted in ambiguity about the effect and impact of integration within such services. The successful management of pain is obviously the ultimate goal for any pain management service, yet, without patient centrality, this may indeed be a utopian dream. Frameworks to support best integrated practice such as those recommended by the Clinical Advisory Standards Group [10], conjure up visions of partnership and reciprocity. Whilst admirable, the extent to which integrated care flourishes within pain management services is unclear. Certainly, a latent measure of the reality of its magnitude may be captured through analysis of the patient's perspectives. Without this emic view, the phenomenon that *is* chronic pain management may yet be elusive to researchers. Evaluation which takes account of the patients' thoughts about such services could potentially support the development of services which support the reality rather than endorse the rhetoric.

Reviewers

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