Towards the evaluation of integrated care: What are the questions? How do we answer them?

Kate Thomas
Medical Care Research Unit, University of Sheffield, Sheffield, UK

Thinking about how to research integrated care at this point in time is a bit like trying to hit a moving target … evaluating something that is in the process of being created. Also, the task assumes that we know what ‘integrated care’ means.

Integrated care or integrative care?
Notwithstanding these difficulties, it is possible to draw on some useful observations about the nature of integrated care as a starting point for thinking about appropriate questions and how to answer them. Various commentators have made a distinction between ‘integrated care’ and ‘integrative care’. The former is often used to mean the introduction or incorporation of non-conventional approaches to health care into mainstream care. Others do not see this as a satisfactory way of thinking about integration; insisting that ‘combination medicine is not integrated medicine’, and that it is ‘not just about adding a bit of acupuncture to the aspirin’. In contrast, the term integrative care has been used to imply the bringing together of different approaches to make a new ‘whole’ (Caspí 2001; Read and Czauderna 2001). Here, the availability of complementary therapies (CAMs) is not sufficient to create integration, instead CAMs become one vehicle for achieving the wider goal of integrative care. Integrative health care is understood as care that brings together different approaches in order to: acknowledge the ‘wholeness’ of the patient, their history and the unique context of their life; focus on health and healing rather than disease and treatment; and bring together body, mind and spirit. It implies a partnership in healing, with therapists working together with patients to maintain health and quality of life (Rees and Weil 2001). Perhaps most succinctly it has been described as ‘care aimed at producing coherence within a person or their care’ (Reilley 2001, p 120). The organisers of a recent conference on integrated cancer care (The Cavendish Centre for Cancer Care Second National Conference 2003) brought together both these approaches, defining the goal as one of ‘integrating the provision of supportive care within mainstream cancer care, using whatever interventions are judged the most appropriate to meet the expressed needs of patients’ (Cavendish Centre 2003).

System, service or patient?
Integration may take place at a system, service or individual patient level. It is tempting to think of it as something that is emerging at a service level, but it is important to remember that many patients are already striving to make it happen for themselves. This is evident in the way they seek different types of care to meet the full range of their needs; navigating what is available from the statutory, voluntary and private sectors to create personal integrated health systems through their actions. Very little research has been undertaken to investigate this way of thinking about integration, and it remains true that, to date, most attention has been paid to integration at the service delivery level. This focus has led to commentators pointing to an absence of systematic research on the delivery, organisation and financing of different integrative health care models; and on the appropriateness, quality, availability and cost of these models. Others have called for more scientific research into the effectiveness of integrative health care models (with and without an investigation of their underlying mechanisms). In an evidence-based culture, these questions are very important, but it is also worth remembering this statement from the UK House of Lords Enquiry into CAM:

It is our opinion that as long as the treatments are known to carry no, or few, adverse effects, it would be against the principal of clinical freedom to prevent patients having access to therapies which fulfil these criteria and have never been restricted. This is especially the case if the patients believe that such therapies help them and the only argument against them is that an evidence base, derived from controlled trials, does not exist. (House of Lords Report 2000, para 4.40)

This is a powerful endorsement of the patient-centred approach, and one that suggests a way forward for research that does not require questions of efficacy to be first on the agenda when integrated care has not yet had time to mature in its practice.

How is integrated cancer care perceived?
The distinction between ‘structure’, ‘process’ and ‘outcome’ offers a useful framework for identifying the different questions we may need to ask. Questions asked at the level of structure help us to understand the context of integrated care. These might include: Is there wider recognition for the need for integrated care? To what degree can
support/resistance be expected? How far can integrated care be presented as a solution to a recognised problem? Does the integrated care agenda share goals and priorities with other agendas? How widely is the transformative potential of integrated care acknowledged? Is such transformation acknowledged as positive or seen as a threat? These types of questions need to be addressed to identify the likely barriers and facilitating factors in the development of integrated care in practice (Best and Glick 2000).

**What are we doing? Could we do it even better?**
Process questions address what is being done in practice and the scope for improvement. Key amongst these will be: Can we identify the best content of ‘packages’ of integrated care? Which delivery mechanisms are most appropriate? How do we support good communication and mutual respect between practitioners? How do we ensure flexibility and continuity of care for patients? How should integrated care be funded? Is the experience integrative for patients and for practitioners? Answering these questions requires a description of what is happening, as well as assessments of how well it is being done.

**What are we aiming to achieve?**
Questions relating to outcomes are generally more evaluative. The selection of outcomes for research requires us to address the goals of integrated care to ensure that the most appropriate endpoints are measured. Outcomes are conventionally measured in terms of costs incurred and health benefits gained. Validated tools are available for a range of specific health-related endpoints (Bowling 1991), but these may not be the best measures for integrated care. The need to make outcomes relevant to patients and to the goals of care is recognised in complementary medicine research, where conventional health outcomes may not reflect the range of benefits reported by patients, such as wellbeing, hope and comfort. Measures of wellbeing are available, and some take an individualised approach that allows the patient to nominate their own concerns for which they are seeking help (Paterson and Britten 2000). Similar issues arise in integrated care. As a complex intervention, individual components of integrated care may need to be tested with suitable outcomes. But, to answer the question ‘has it achieved what it set out to do?’ we need to be very clear about what integrated care is aiming to achieve. Individualised patient outcomes can provide good descriptive data on what patients are looking for, and what aspects of care they most/least value. At this stage it is too early to say whether a new, standardised measure of ‘coherence’ or integration is needed.

**How do we begin to answer the questions?**
Randomised trials to assess the effectiveness of integrated care will be possible, even if they present real design challenges. However, they run the risk of undervaluing the benefits if the intervention is not properly understood (Fitter and Thomas 1997; Ritenbaugh et al 2003). Quasi-experimental exploratory methods are usually more appropriate as a first step. Quasi-experimental methods, such as case series and n=1 studies will be useful to assess the contribution of individual components of care (Thomas and Fitter 2002).