CONTINUITY OF CARE AND CLINICAL OUTCOMES IN THE COMMUNITY CARE OF PATIENTS WITH PSYCHOSIS

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Abstract

Continuity of care in mental health care is considered both an important objective of NHS policy and vital to clinical practice. However, it remains poorly defined and there is little research into its association with outcomes. Mental health services are unique in their ability to legally compel patients to adhere to treatment in the community and there has been no research into how this may affect continuity. My thesis aims to critically appraise the definition of continuity of care and systematically review the literature on its association with outcomes. It also measures its association with readmission by conducting a longitudinal study, and measures the association between community compulsion and continuity of care.

The literature review confirmed that continuity of care is best understood as the process of care of an individual patient over time. This is perceived by both the patient and providers of care as comprehensive, consistent, and connected. The systematic review found little evidence for an association between continuity of care and outcomes but that this may be due to persisting variation in both measures and outcomes.

Results from the longitudinal study suggested that better continuity was associated with both better and worse hospital outcomes. Community compulsion had no association with continuity of care.

My findings suggest that patient follow-up has improved considerably in the last three decades and, because of this, some traditional measures of continuity may be redundant. Measures of frequency of contact do not accurately measure the flexible, assertive practice that is a feature of current services. Continuity of care is useful as an indicator of the process of care but for it to be an effective research tool there needs to be a radical change in the way it is measured. Current mental health services are characterised by separation and specialisation into different components of care. Therefore, the most useful measures of continuity of care may be ones which successfully measure how it can be maintained between these services.

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Chapter One: Background

Introduction

The relationship between patient and doctor has existed for as long as there have been people willing to treat illness. The nature of this relationship has changed strikingly over the last 40 years. This is due to several changes including changes in health behaviours, changes from paternalistic to patient-centred medicine, and large reorganisation of national health systems (Emanuel & Emanuel, 1992; Weisz, 2006). There has been considerable concern that these changes would cause fragmentation of care and a widespread response to this fear is to improve continuity of care.

Continuity of care is a multidimensional construct which can broadly be described as the long-term delivery of care that is coordinated both within and between services and is appropriate to a patient's current needs. There is a distinct lack of consistency in defining the concept (Johnson, Prosser, & Bindman, 1997). Much of the theoretical writing has yielded definitions that are either too broad to operationalise and measure, or too narrow to fully account for all the situations in which it is applicable. Collaboration by two research groups in Canada (Reid, Haggerty, & McKendry, 2002) and the United Kingdom (Freeman et al., 2000) has identified two key features of continuity. The first is that continuity of care relates to the care of an individual rather than the structure of teams or organisations. The second key feature is that continuity of care describes care of that individual over time (Haggerty et al., 2003).

Continuity of care is particularly pertinent in mental health. Many severe mental illnesses are chronic conditions which require long term care. Patients often have wide ranging needs and high rates of comorbidity (Dixon, Postrado, Delahanty, Fischer, & Lehman, 1999), and deinstitutionalisation in the latter half of the 20th century means that they are mostly cared for in community settings (Lamb & Bachrach, 2001). The introduction of multidisciplinary outreach teams, discharge planning, and case management are examples of how mental health services have adapted to this decentralisation of care and the breadth of needs. Despite these new approaches, there is remarkably little empirical research into the effect of continuity of care on outcomes in mental health (Adair et al., 2003). Most studies focus only on a single dimension and there is little consistency of measures between studies. Furthermore, mental health is unique in medicine in that that patients are often treated against their will. No studies have investigated the effect that this compulsion has on continuity of care.

My thesis examines four aspects of the relationship between continuity of care and outcomes in mental health over five chapters. This first chapter will explore the definition of continuity of care and its application in mental health. The second chapter will systematically review the evidence for an association between continuity of care and outcomes. Chapter three will investigate associations between continuity of care and hospitalisation. Chapter four will test for an association between outpatient compulsion and continuity of care. Finally, chapter five will summarise and interpret the results from this thesis.

Medical specialisation and the changing clinical relationship between patients, doctors, and the health system

The doctor-patient relationship

The doctor-patient relationship is formed when a doctor takes responsibility for the medical treatment of a patient (Wilson & Cunningham, 2012). It incorporates all the interactions between doctor and patient and the different ways in which they relate to one another. Interactions between doctor and patient which are seen as high quality, such as joint participation in history taking and the physicians ability to convey accurate information to the patient, have been associated with better outcomes in emotional health, symptom resolution, functioning, physiological measures (e.g. blood sugar and blood pressure), and pain control (Stewart, 1995).

Yet the nature of the doctor-patient relationship has changed over time. For the majority of medical history, most patients were treated by the same doctor throughout their lives and for most of their ailments (Wilson & Cunningham, 2012). Doctors lived within the same rural settlements as their patients, or in bigger cities doctors were personal physicians for the social elite who could afford them (Weisz, 2006).

This relationship between a single doctor and their patient over a patient's lifetime would change drastically in the 19th century with the advent of specialisation and in the 20th century with the introduction of public health services. It was also transformed in the late 20th century by an ageing population and the movement towards *patient-centred medicine*.

The stratification of care through technological, organisational, health, and social change

Specialisation is the dividing of medicine in to distinct branches which are classified by technique (surgery or medicine), organ (e.g. obstetrics, cardiology, psychiatry), or age (e.g. paediatrics, geriatrics). Specialisation in Western medicine emerged in the 19th century due to the rapid expansion of medical knowledge, population growth, and the centralisation of health care (Weisz, 2006). Specialisation was originally a framework for research and medical education in universities rather than a clinical divide. By the beginning of the 20th century specialisation had moved from a local to a national phenomenon alongside the state's need to provide care for an increasing number of people due to industrialisation and also the movement of people into cities. Health systems needed to divide medical populations into smaller, more manageable categories.

Increased life expectancy and the need to treat chronic illness and comorbidity in an aging population have also influenced care practices (DuGoff, Canudas-Romo, Buttorff, Leff, & Anderson, 2014; Lozano et al., 2012). Health services are organised by specialty which means that patients with chronic illness and comorbidity need to access multiple services. These services are then required to interact with each other more frequently in order to manage a patient's many illnesses simultaneously over time (Wagner, Austin, & Von Korff, 1996).

A further influence has been the academic, social, and political movements towards patient involvement in healthcare, or *patient-centred medicine*. Critiques of the paternalism of doctor-patient relationship by academics such Szasz and Hollander (Szasz & Hollender, 1956), the human rights movement, and criticism of the biomedical model (McWhinney, 1984) have all changed the doctor-patient relationship and increased patient choice in healthcare. Policies such as the Patient's Charter (Department of Health, 1991), and the 1997 White Paper "The New NHS: modern, dependable" (NHS, 1997) are a modern political reflection of this change in public health. Alongside the move toward patient-centred medicine came a change to the structure of medical teams known as multidisciplinary working. The roles and skills of other healthcare providers became more prominent during the management of patient illness. For example, in mental health care, the traditional role of care coordination moved from the sole responsibility of the psychiatrist to one that is shared between the psychiatrist and a designated care coordinator.

The result of this stratification of care through technological, organisational, health, and social change is that patients now see a multitude of different professionals across periods of illness and through their lifetime. For example, a 70-year old patient with diabetes might need to see her general practitioner for check-ups, an ophthalmologist for eye complications related to her diabetes, a nephrologist for renal failure, a podiatrist for foot care, and a cardiologist if they had diabetic cardiomyopathy.

This need for input from multiple health services raises a number of important questions. How can the doctor-patient relationship be maintained? How can medical professionals treating a patient be sure they have a full and accurate medical history? How can a patient's medical journey be coordinated between professionals in order to sustain high quality medical care? The answers to these questions all concern continuity of care.

The Development of the Definition of Continuity of Care

The definition and conceptualisation of continuity of care has evolved along with changes in care practices. Attempts to clarify and establish a consensus of what it should encompass have been hampered by the rate of change in healthcare provision. Terms such as continuity of care, coordination of care, integrated care, and quality of care are often used interchangeably. This led Reid and colleagues to state that continuity of care's meaning is "more often presumed than defined" (Reid et al., 2002, p. ii). This part of the introduction will describe the development of the concept of continuity of care, outline the current understanding of the term and in doing so, distinguish it from other related terms.

Early understanding of continuity of care.

Concern about continuity of care, or lack thereof, first appears in general medical literature in the 1940s. A reference to continuity in a nursing journal was used to emphasise the need to care for patients beyond admission and discharge from hospital (Carn & Mole, 1949). An article in the 1950s on caring for children with learning disabilities refers to continuity of care as the continued contribution of a physician's care throughout a child's life (Deisher, 1957). Fears of fragmented care in the 1960s, the rise of the human rights movement, and rapid advances in medicine drove the need to re-organise patient care in both general medicine (AMA, 1966; NCCHS, 1967) and psychiatry (Saultz, 2003). Continuity of care was identified as a necessary feature of this organisation. Even though continuity of care was an established term in these early accounts, it was referred to as something intuitively understood rather than clearly defined.

The first attempts to define continuity of care emerged in the 1970s. Bass and Windle (Bass & Windle, 1972) addressed both the definition of continuity of care and its measurement. They defined continuity of care as "the relatedness between past and present care in conformity with the therapeutic needs of the client" (pg. 197) and outlined four *continuity dimensions*: Transitions between services; stability of the doctor-patient relationship; communication between staff; and efforts to stop disengagement from treatment.

Hennen (Hennen, 1975) defined five dimensions of continuity for general practitioners. *Chronological*, which is care over time, *geographic*, which is providing care by the same person in the same location, *interdisciplinary*, which is being competent in treating different medical conditions, *interpersonal*, a good doctor-patient relationship and a sense of continued responsibility for a patient, and *informational*, providing a consistent record (whether written or by the providers knowledge) of a patient's illness.

Both accounts highlight two important features of continuity of care. First, continuity of care takes place over time. Bass and Windle, writing about psychiatry, emphasise its longitudinal dimension as the care over time for a distinct period of illness whilst Hennen, a general practitioner, places longitudinality as long-term care both during and between illnesses. Second, both indicate that there is a continuous relationship between patient and doctor. Following these two early accounts, definitions of continuity of care broadly followed two approaches, conceptual definitions and operational definitions.

Conceptual Definitions

Conceptual definitions attempt to understand the underlying phenomena of continuity of care. Descriptions of the phenomena include "the extent to which medical care services are received as a coordinated and uninterrupted succession of events, consistent with the medical care needs of the patient" (Shortell, 1976, pg. 378), and "a process involving the orderly, uninterrupted movement of patients among the diverse elements of the delivery system" (Bachrach, 1981, pg. 1449). These quotes simply describe the process of care, but conceptual definitions of continuity of care go further by attempting to divide it up into constituent dimensions to account for the different ways in which care can be provided. Table 1.1 describes and lists the dimensions of highly cited conceptual definitions between 1970 and the present.

Definitions vary in complexity from two to seven dimensions. Bacharach's (Bachrach, 1981) widely cited comprehensive seven-dimension definition has so far proved too abstract to operationalise. Its strength was in strongly emphasising that continuity of care is a multidimensional concept and that all dimensions need to be realised to achieve good continuity of care in a service. As a result of these early conceptually complex definitions, multidimensional approaches are now routine in continuity of care research (Haggerty et al., 2003).

Despite differences in early definitions of continuity of care there were underlying common features. Toward the end of the 1990s Freeman and Hjortdahl (Freeman & Hjortdahl, 1997) identified two types of continuity common to most of the definitions and added a third which amalgamated a number of dimensions from previous studies. These three dimensions are precursors to current conceptualisations of continuity of care. Their three dimensions were:

- *Longitudinality* (care over time beyond individual bouts of illness).
- *Continuity* (the movement of information between contacts).
- *Personal continuity* (the ongoing quality of relationship between patient and doctor).

Table 1.1. List of definition of continuity of care by author and date[1].

Author & Year	Description & Dimensions
Bass & Windle (1972)	The relatedness between past and present care in conformity with the therapeutic needs of the client. Consisting of: • Transitions between services • Stability of the doctor-patient relationship • Communication between staff • Efforts to stop disengagement from treatment
Hennen (1975)	• Chronological, which is care over time • Geographic, which is providing care by the same person in the same location • Interdisciplinary, which is being competent in treating different medical conditions • Interpersonal, a good doctor-patient relationship and a sense of continued responsibility for a patient • Informational, providing a consistent record (whether written or by the providers knowledge) of a patient's illness
Hansen (1975)	• A continuing relationship between a physician or health professional and a patient • Continuity of data information • The actual accomplishment of care itself
Shortell (1976)	The extent to which services are received as part of a coordinated and uninterrupted succession of events consistent with the medical care needs of patients. Underlying traits or characteristics are: • the extent to which the provider seen for the first visit is also seen in the next and subsequent visits • the extent to which broken appointment, whether due to provider or patient, are minimized • the extent to which duplication of test, examinations, history taking ,and procedures is minimised • the extent to which appropriate follow-up care, including patient compliance, is maximised • the extent to which medical care can be received in a single location
Test (1979)	• Cross-sectional care – at any given point in a chronically mentally ill person's treatment, the person must be involved in a system of are that is comprehensive (in meeting unmet needs) and integrated. • Longitudinal continuity – Care that is continuous and integrated over time

Starfield (1980)	• Longitudinality – the availability of a regular source of care (place or professional) and a decision, by the patient, to seek care from that source whenever care is needed • Continuity – the means by which the separate parts of an episode of illness are joined
Patten & Friberg (1980)	• Seeing the same physician over a period of time • Receiving care in the same location and having a single medical record • The number of physicians seen in a single spell of illness • The rate of complete immunisation, the number of hospitalisations supervised by the regular provider • The number of family members seeing the same physician
Roger & Curtis (1980)	• Chronological dimension – health services provided to both patients and family over time periods covering life cycle changes and life crises • Geographical dimension – the site at which care is given • Interdisciplinary dimension – the ability to provide holistic care • Relationship dimension – sense of continued responsibility towards the patient, the family and the community which transcends agreed commitments and working hours • Informational dimension – continuity given by care systems • Accessibility dimension – ease of access for the consumer • Stability dimension – the stability of the community within which care is provided and the stability and mobility of the provider.
Bachrach (1981)	A process involving the orderly, uninterrupted movement of patients among the diverse elements of the delivery system. Comprised of: • Longitudinal – care over time • Individual – care planned with and for the family • Comprehensiveness – care at any point in time according to needs • Flexibility – ability to move easily within the treatment system • Relationship – having associations with a person or persons who are interested in the patient and who respond to the patient on a personal level • Accessibility – able to reach the service system when needed • Communication – between the patient and service providers and between service providers

Nassif et al. (1982)	• Structural continuity – the site of the medical encounter • Process continuity – the coordinated delivery of care over a period of time or throughout and illness episode
Tessler (1986)	• discharge planning, having a discharge plan available before discharge from hospital • successful and rapid transfer between services, measured as the time between discharge and start of the new service • implementation of individualised service plans, which was the degree to which specific plans were carried through
Hjortdahl (1990)	• Chronological - involves the provision of patient care over time. • Comprehensiveness - involves taking care of the wide array of medical problems encountered in general practice • Personal - includes empathy and personal involvement with the patient, lasting over time, overlapping parts of the interpersonal dimension; • Responsibility - entails a longitudinal attitude and willingness to care for or coordinate the different medical needs of the patient.”
Brekke & Test (1992)	• Cross-sectional – the need at any one point in time for the client to be involved in a system of care that is comprehensive and integrated • Longitudinal – Care that is continuous and integrated over time
Freeman & Hjortdahl (1997)	• Longitudinality – care over time beyond individual bouts of illness • Continuity – the movement of information between contacts • Personal continuity – the ongoing quality of relationship between patient and practitioner
Freeman et al. (2000)	• The experience of a coordinated and smooth progression of care from the patient’s point of view (experienced continuity). To achieve this central element the service needs: • Excellent information transfer following the patient (continuity of information). • Effective communication between professionals and services and with patients (cross-boundary and team continuity). 4. To be flexible and adjust to the needs of the individual patient over time (flexible continuity). • Care from as few professionals as possible, consistent with other needs (longitudinal continuity).

	• To provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship (relational or personal continuity)."
Freeman et al. (2002)	The six attributes in Freeman et al. 2000, and: • Contextual continuity - care that improves a patient's social and personal relationships in the community and enhances their quality of life • Long-term continuity - providing care for a patient for as long as it is needed.
Reid et al. (2003)	Continuity of care relates to the care of an *individual patient.* It is the care of that individual patient *over time*. • Informational continuity means that information on prior events is used to give care that is appropriate to the patient's current circumstance. • Relational continuity recognizes the importance of knowledge of the patient as a person; an ongoing relationship between patients and providers is the undergirding that connects care over time and bridges discontinuous events. • Management continuity ensures that care received from different providers is connected in a coherent way. Management continuity is usually focused on specific, often chronic, health problems.
Saultz (2003)	Continuity is a hierarchy. • This begins as the basic information of a patient's case history (*informational continuity*) • leads to an ongoing relationship in which care occurs (*longitudinal continuity*) • and ends in an interpersonal relationship between a patient and their clinician (*interpersonal continuity*)
Burns (2007)	• Experience and relationships - High experienced continuity, good therapeutic relationship, a greater proportion of needs met and not having a user-rated break in care • Regularity - Being seen more frequently by staff from fewer different non-medical disciplines • Meeting needs - High level of need, high number of met needs and CPA copied to GP and user • Consolidation – Having contact with fewer agencies and no seeing primary care professionals • Managed transitions – having transitions managed • Care coordination - Having a designated care coordinator, having no psychiatrist or more than two and fewer needs met by informal carers • Supported Living - Living in supported accommodation, attending day care and having more letters copied to the user

Operational Definitions

More succinct and quantifiable conceptions of continuity of care emerged and were widely used in the 1980s and 1990s in an effort to measure and evaluate the delivery of health services (Reid et al., 2002; Uijen, Schers, Schellevis, & van den Bosch, 2012). Operational definitions took two forms, discontinuity-defined definitions and indices.

Discontinuity-defined definitions of continuity of care identify potential discontinuities in services and define continuity as the absence of these discontinuities. Examples of this approach are descriptions such as “extent to which a given individual’s total number of visits for an episode of illness of a specific time period are with a single or group of providers” (Bice & Boxerman, 1977, pg. 347), or “The extent to which paediatric care was given to a family by a single paediatrician” (Breslau & Haug, 1976, pg. 344). They address the discontinuity of not seeing the same doctor from one visit to the next, but do not refer to a broader conception of continuity. In discontinuity-defined definitions, the definition is derived from the measurement, rather than the measurement being operationalised from the definition.

Indices attempt to provide a single measure which describes multiple care patterns (such as the regularity of seeing the same doctor in comparison to other doctors). Two widely used indices were the Usual Provider of Continuity index (UPC, Breslau & Reeb, 1975), which measures the proportion of visits to a specified provider and the Continuity of Care index (COC, Shortell, 1976), which captures the distribution of visits to different providers. Indices were often used when evaluating continuity of care because the data required to calculate them was simple to collect and their results were easily interpretable. They are also useful in services where many professionals are involved in a patients care.

However, this conception of continuity of care is narrow, only linking the number of providers seen and number of contacts. It does not measure the many other dimensions that have been described in the conceptual definitions, such as the comprehensiveness or flexibility of care. Furthermore, operational definitions are often only applicable to the medical setting in which they were developed (Freeman et al., 2000). For instance, the proportion of patients transferred to another hospital during admission (Pugh & MacMahon, 1967) may be important in psychiatry or internal medicine but less so in general practice. Also, the multitude of operational definitions has increased the confusion surrounding the meaning of continuity of care (Starfield, 1980).

The reorganisation of health services towards the end of the 20th century due to specialisation, multidisciplinary working, technological advancements, and an increasing awareness of patient-centred care increased the interest in researching continuity of care (Freeman et al., 2000). In the United Kingdom, the NHS and Community Care Act (Leathard, 2000) made sweeping changes to the provision of health and community care. These changes were the result of health and social services recognising the need for continuity both between and within services. This required extensive collaboration between the service systems. It also had an impact on health authorities' attempts at intra-agency working.

By the end of the century the challenge of conceptualising continuity in a clinically useful and measureable manner was still apparent in the continued lack of consensus on a definition (Adair et al., 2003; Gulliford, Naithani, & Morgan, 2006; Johnson et al., 1997; Reid et al., 2002). Reid and colleagues identified 583 articles in a literature review which included the term continuity of care, of which less than a third explicitly defined the concept.

Current definitions of continuity of care

Two large research projects at the beginning of the 21st century greatly contributed to clarifying understanding of continuity of care. The first was the Canadian Health Services Research Foundation's (CHSRF) report on continuity of care (Reid et al., 2002) and the second the Scoping Exercise on Continuity of Care by the National Coordinating Centre for NHS Service Delivery and Organisation in the UK (Freeman et al., 2000).

Reid and colleagues' synthesis of the CHSRF review defined continuity as "how one patient experiences care over time as coherent and linked" (pg. i). They outlined three types of continuity that are needed to achieve this:

- *Informational continuity* - the accumulation and transfer of information over time in order to link care episodes.
- *Management continuity,* the maintenance of a clear and consistent plan of care for a health problem across services.
- *Relational continuity* - the continuous relationship between the patient and each of their care providers including both the quality and the length of these relationships.

Freeman and colleagues' scoping exercise did not define continuity but stated that care should be *experienced* as smooth and coordinated by the patient. The patient's experience of continuity was thus at the forefront of their conceptualisation. They suggested that five dimensions were required to achieve this experienced continuity.

- *Continuity of information* is the availability of high quality information about the patient wherever they go, not only between professionals but also to the patient.
- *Cross-boundary continuity* is an excellent level of communication between services.
- *Flexible continuity* is whether treatment suits the patient's current needs.
- *Longitudinal continuity* is being under the care of the same professional over time.

- *Relational continuity* is having a named professional with whom the patient has a good relationship.

A subsequent report by the same authors added *contextual continuity* and *long-term continuity* as additional elements in mental health care (Freeman, 2002). Contextual continuity is care that improves a patient's social and personal relationships in the community and enhances their quality of life. Long-term continuity involves providing care for a patient for as long as it is needed.

The information gained by these two projects was synthesised in a publication by Haggerty and colleagues (Haggerty et al., 2003). In it, continuity is defined as "the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context" (pg. 1221). The Haggerty synthesis identified two key features of continuity in both projects:

1. Continuity of care relates to the care of an *individual patient.*
2. It is the care of that individual patient *over time*.

The first key feature is that continuity of care is defined within the context of the care of an individual patient. It is this focus that distinguishes continuity of care from other characterisations of care such as integrated care and care coordination which focus on the organisation of teams and systems. Better integration of care can impact on an individual patient’s continuity of care but it does not guarantee continuity.

The second key feature is that this care takes place over time. Many previous conceptualisations refer to this as *longitudinal* or *chronological* continuity. Haggerty and colleagues argue that this longitudinality is present through all elements of continuity of care. Their three elements of continuity of care all require care over time. Relationship continuity, for example, is the relationship between the patient and the doctor (or care team) over time. They argue that care over time is what differentiates good interpersonal communication in one visit from good relationship continuity over the course of a healthcare episode. Informational continuity is using past information to inform current and future treatment, and management continuity is ensuring clear coordination of a health condition throughout the course of the illness and between periods of illness.

These two projects were the largest exercises in understanding the conceptual complexities of continuity of care. They contributed two major themes in continuity research, that it is a multidimensional construct, and that the patient experience is intrinsic in understanding it.

Revisions of the Freeman and Reid reports

Saultz (Saultz, 2003) reviewed the definition of continuity of care in general medical practice at the same time as the Freeman and Reid reports. He introduced the idea that elements of continuity form a hierarchy. This begins as the basic information of a patient's case history (*informational continuity*), leads to an ongoing relationship in which care occurs (*longitudinal continuity*), and ends in an interpersonal relationship between a patient and their clinician (*interpersonal continuity*). Saultz argues that each step in the hierarchy is required in order for the next level to be achieved and he positions interpersonal continuity at the top. He believes this hierarchical relationship should be the priority for research.

Another research strand puts both patient experience and service provision as equally important. Krogstad and colleagues (Krogstad, Hofoss, & Hjortdahl, 2002) draw heavily on the sociologist Erving Goffman's concepts of *frontstage* and *backstage* relationships in understanding and measuring both patient-level approaches to continuity and continuity from the perspective of professionals. Frontstage continuity is equivalent to Haggerty's relationship continuity. In this a patient sees the same doctor or nurse and has a good personal relationship with them. Backstage continuity is the organisational system required for patient care to be coordinated and is similar to a combination of informational and management continuity.

Krogstad and colleagues propose that patients are not generally aware of backstage continuity until it fails. Backstage continuity is reported by patients in terms of discontinuity rather than continuity. Examples are being asked to repeat information, having different doctors prescribe different medication, and missing drug charts. Patients' awareness of discontinuities is a common feature in the literature (Jones et al., 2009).

Gulliford and colleagues (Gulliford et al., 2006) furthered this concept by arguing that patients are not the best assessors of backstage continuity (which the authors call *seamless service*) as by definition it may not be visible to them. They identify that the *continuous caring relationship* (interpersonal continuity or relationship continuity) and the seamless service are both vital in providing continuity of care and relying only on the patient's experience of continuity does not fully elucidate all its important features.

In summary, modern definitions have emphasised that continuity of care is care experienced by an individual over time. It is multidimensional and these dimensions can interact with one another. Finally, it is also experienced differently by the patient and the healthcare provider.

The approach to continuity of care in this thesis

Based on the review of the theoretical literature, in this thesis continuity of care will be considered a process of care of an individual patient over time which is perceived by both the patient and providers of care as comprehensive, consistent, and connected. It comprises three dimensions, relationship continuity, information continuity and management continuity. Each of these dimensions is different for the patient and the provider of care, and each dimension contributes differently to the other dimensions. Figure 1.1 illustrates these interactions.

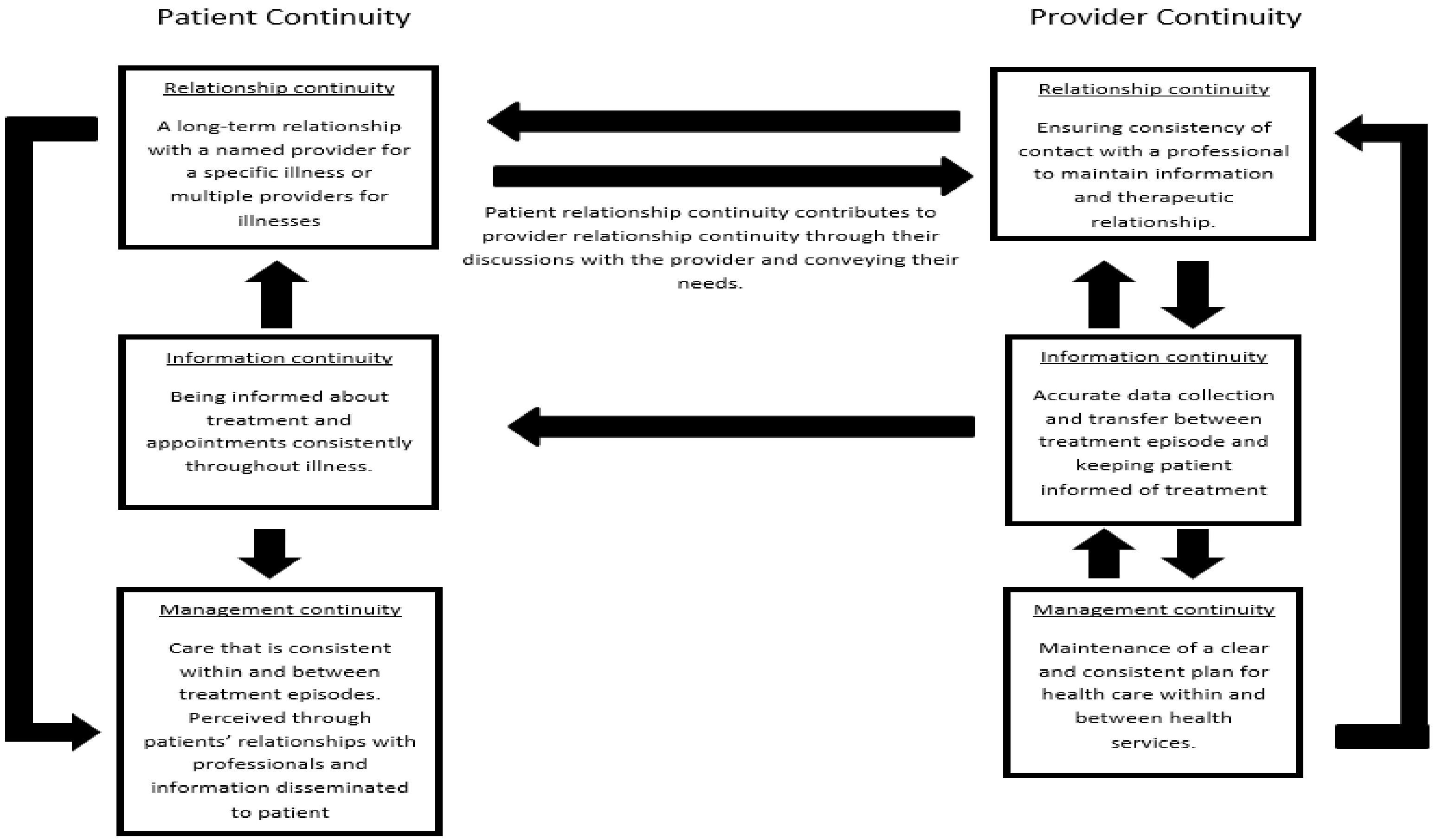
For the patient, continuity of care is achieved through having a long-term relationship with a healthcare professional who is identifiable by the patient as their primary source of care for a specific illness (and in some cases, across illnesses). The patient perceives that this clinician has good knowledge about their individual circumstances (*relationship continuity*). The patient contributes to this relationship continuity through their interactions with the provider of care and their communication of their current level of need. The patient must also feel informed about their treatment and the decisions made by the provider of care (*information continuity)*. Finally, the patient must experience the different aspects of their care (such as being referred to a different specialist or being given a different treatment) as linked (*management continuity*).

For providers of care, relationship continuity is ensuring that the patient-provider therapeutic relationship and the knowledge of the patient is maintained between the patient and the providers of care. This is achieved by both maintaining a regular professional as a point of contact and by ensuring any transitions between care providers is smooth. Provider information continuity has two functions. The first is always to have accurate information on the patient's health (in the form of medical records) available to the provider to use and to transfer relevant information between providers. This ensures there is a link between treatment episodes and healthcare providers.

The second function is to disseminate relevant information to a patient about their condition. The patient is likely to be aware of the information imparted to them but not the transfer of information between providers. The patient will experience the provider's ability to maintain information continuity through their relationship with the provider. For example, a patient being asked repeatedly to retell their story to different doctors reflects a lack of information continuity between providers, and would be experienced as disconnected by the patient in their communication with the provider.

Finally, management continuity for the provider is achieved when there is an utilisation of a coherent and structured approach (such as shared management plans or care plans) in the management of a patient's condition between services, and an approach that can adapt to changes in that condition over time.

Figure 1.1 Illustration of continuity of care dimension and their interactions



Distinguishing Continuity of Care from Related Concepts

The difficulty in defining continuity of care has led to problems distinguishing it from related concepts (Adair et al., 2003; Haggerty et al., 2003; Johnson et al., 1997). The terms continuity of care, coordination of care, and integrated care, all describe specific phenomena in how care is organised. Consequently, these concepts have some theoretical overlap and are often used synonymously. They are related yet there are important distinctions.

Coordination of care

When reporting on the delivery of care, *coordination of care* is often used interchangeably with continuity of care (Uijen, Schers, Schellevis, & van den Bosch, 2012). One definition of coordination of care is "a process of assessment, planning, implementation, evaluation, monitoring, support, and advocacy to facilitate timely access to services" (McAllister, Presler, & Cooley, 2007). It is affiliated with case-management and care coordination programs and is often described in terms of the case-manager's duties (Uijen, Schers, Schellevis, & van den Bosch, 2012).

Uijen and colleagues argue that the emerging theme of patient-centred views of care coordination in the late 1990s blurred the boundaries between coordination and continuity of care. The link with case management programs creates conceptual ambiguity as case managers provide services beyond coordinating care. Uijen and colleagues describe coordination of care as "the delivery of services by different care providers in a timely and complementary manner in order to achieve connected and consistent patient care" (pg. 266). The reviewers themselves are guilty of confusing the terminology as this quote comes from a paper by Haggerty and colleagues (Haggerty et al., 2008), where they describe 'coordination continuity', a subscale in the Primary Care Assessment Tool (PCAT, Cassady et al., 2000) rather than coordination of care. Such lack of precision often causes ambiguity between terms.

Many models of continuity of care include coordination of care as part of the model. Burns and colleagues included 'Care Coordination' as a factor in their multidimensional definition (Burns et al., 2009). Management continuity in Haggerty and colleagues' definition includes coordination of care as a vital component in achieving management continuity (Haggerty et al., 2003).

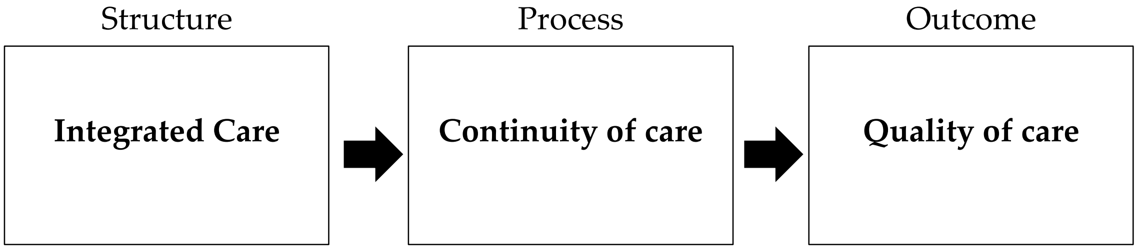
At a basic level, coordination of care is an attempt to coordinate services. In this sense, the meaning remains as in its dictionary definition, "The organization of the different elements of a complex body or activity so as to enable them to work together effectively" (Oxford Dictionaries), without a structured model of care coordination. When used in a patient-centred way, a model of intervention begins to form and one refers to 'care coordination', where a case management system is present. Case management is a structured programme of care planning for people with long term conditions which includes assessment and coordinating the medical and often social needs of the patient. In this conceptualisation, care coordination can be used as a structural tool within a team to accomplish continuity of care, but its presence does not guarantee continuity. Care coordination can however, contribute to continuity of care by identifying a named individual to improve relationship continuity over time, and the accumulation of information and processes to link services in order to promote informational continuity and management continuity.

Integrated care

Integrated care has been defined as "patient care that is coordinated across professionals, facilities, and support systems; continuous over time and between visits; tailored to the patients' needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health" (Singer et al., 2011, pg. 113,). It has six elements in its framework, *coordinated within care team, coordinated across care team, coordinated between care teams and community resources, continuity familiarity with patient over time, continuous proactive and responsive action between visits, patient centred, and shared responsibility*. This definition places integrated care conceptually close to continuity of care. Indeed, its framework includes continuity of care: *continuity familiarity with patient over time* is analogous to relationship continuity. In the attempt to make integrated care more patient-focussed Singer and colleagues blur the boundary by not stating explicitly that continuity of care is part of their model.

A different analysis of integrated care by Kodner (Kodner, 2009) acknowledges both continuity of care and coordination of care as discrete elements of care. He describes integrated care as "a means of optimizing system performance and attaining quality patient outcomes" (pg. 12). In this conceptual analysis, integrated care is placed in the domain of global organisational coordination. Integrated care is an overarching ideology from which to create effective care systems. Kodner considers care coordination and continuity of care mechanisms of a well-integrated system of care. Weirdsma and colleagues' conceptual analysis of a mental health service framework outlines a similar structure (Wierdsma, Mulder, de Vries, & Sytema, 2009). Fig 1.2 shows how integrated care, from that perspective, is a structure shaping the process of continuity of care, which then may affect the high quality of care.

Figure 1.2 Continuity of care in the context of related concepts in health services research (Weirdsma et al., 2009)



Continuity of Care in Mental Health Services

Continuity of care in mental health faces unique challenges. Like diabetes and heart disease, severe mental illness (SMI) can be a chronic disorder which requires long-term care. People with SMI can have complex needs and often require assistance with mental health, physical health, and social care. Freeman has identified three features of mental health care that make continuity of care of particular significance (Freeman, 2002). These are first, the deinstitutionalisation of psychiatric services, second, the clinical features of severe mental illness, and third, the difficulty of engaging with people who have SMI.

The deinstitutionalisation of psychiatric services

The last 50 years has seen a dramatic change in the nature of mental health services. Through the first half of the 20th century large psychiatric asylums were the primary sources of care for people with severe mental illness. Since then a process of deinstitutionalisation has taken place in the UK, Western Europe, and the US. This occurred for a number of reasons including the advent of chlorpromazine and other effective treatments for psychosis, changes in mental health legislation, the development of the welfare state, the prohibitive expense of large psychiatric hospitals, concerns about the quality of care and abuse of patients, and the movement towards patient-centred medicine (Fakhoury & Priebe, 2007; Turner, 2004).

The care that was provided by asylums was gradually replaced by community care. The majority of patients in the UK are now treated as outpatients. One outcome of deinstitutionalisation is that mental health care now needs to be coordinated across a variety of settings and services. Multidisciplinary community mental health teams (CMHTs), case management, and the care program approach (CPA) are approaches to improve coordination and subsequently continuity of care. However, there is little research investigating whether they do in fact improve it (Freeman, 2002). These approaches are described below.

The new structure of outpatient mental health services in the UK

The 1959 Mental Health Act in England and Wales introduced a requirement that psychiatric hospitals had to provide an outpatient service to discharged patients (Burns & Firn, 2002). This was the beginning of modernisation of mental health services to the current multidisciplinary CMHT structures. Before the 1980s outpatient care was traditionally supervised by a psychiatrist and community psychiatric nurses (CPNs) without any evidence-base for the structure of the service provided (Burns, 2014). Modern day CMHTs are multidisciplinary and can be composed of psychiatrists, CPNs, social workers, support workers, occupational therapists and clinical psychologists, all potentially contributing input into a patient's treatment. CMHTs are secondary care services and are usually for patients over the age of 18. Teams are sectorised, caring for patients over a set geographic area and there are usually specialist teams for specific patient groups within adult services:

- *Assertive Outreach Teams* – for patients who have complex needs and need more intensive support
- *Early Intervention Teams* – for patients experiencing a first episode of psychosis
- *Crises teams* – treat patients who are in need of short term intensive support such as when being discharged from hospital.

Most community mental health services operate a case management system. Case management is a programme of care for patients which includes assessment of needs, care planning, implementation of care, and regular reviews. Case management usually includes support for mental health, and social and welfare needs and is coordinated by a care coordinator (also known as a case manager or keyworker). The care coordinator is a named professional, usually a Community Psychiatric Nurse (CPN) or social worker, who is responsible for the overall management of the patient's care. Case management in the UK is delivered through a national framework called the Care Programme Approach, a structured guide of case management introduced in 1992 (Burns & Leibowitz, 1997).

The complex health and social needs of people with SMI

Deinstitutionalisation revealed that in order to live in the community, the needs of people with SMI go far beyond treatment for their mental illness. People with a psychiatric illness are at high risk of early mortality (Berren, Hill, Merikle, Gonzalez, & Santiago, 1994), homelessness (Folsom et al., 2005), unemployment (Mueser, Salyers, & Mueser, 2001), poverty (Saraceno & Barbui, 1997), and social exclusion (Huxley & Thornicroft, 2003). They also have high rates of comorbid alcohol and drug abuse (Regier et al., 1990) and poor physical health (Dixon et al., 1999). Consequently mental health services are required to coordinate and collaborate with many other medical disciplines, social services, and government departments.

Patient engagement with mental health services

Many people with psychotic illnesses have poor adherence to treatment, with estimates of between 11% to 80% non-adherence rates for medication (Corrigan, Liberman, & Engel, 1990). Reasons for non-adherence include greater symptom severity, lack of insight, substance abuse comorbidity, medication side-effects, lack of social support, and poor therapeutic alliance (Fenton, Blyler, & Heinssen, 1997). Services have to maintain contact and engage with patients who exercise their autonomy, may not believe they are ill, and may not want to engage with them. Patients who have poor treatment adherence and disengage from services are those most likely to have poor outcomes (Fenton et al., 1997) which makes continuity of care particularly important in this patient group.

Mental health care also differs in that patients who meet certain legal criteria may be treated without their consent. This can take the form an involuntarily admission to an inpatient hospital, or more recently, being subjected to compulsory treatment in the community in the form of a Community Treatment Order (CTO, also known as outpatient commitment). Some patients report experiencing 'informal coercion', non-statutory pressures such as persuasion or leveraging the offer of assistance, to adhere to their mental health treatment (Burns et al., 2011). Therefore patients may not only have difficulty engaging with mental health teams, they may feel forced to engage with a service they do not want.

The three features discussed above, deinstitutionalisation, the complex health and social needs of patients, and the difficulty in engaging patients with SMI have ensured that continuity of care has been a priority in mental health for a number of decades. It is considered a priority in the evaluation of service delivery in the UK (Freeman et al., 2000), is endorsed in NHS policy, and is a quality standard for service user experience for adult mental health in the National Institute for Health and Care Excellence (NICE) guidelines (NICE, 2011). Globally, continuity of care in mental health is considered a priority and is endorsed by the World Health Organisation (WHO) as an essential feature of good community care (WHO, 1996).

These unique challenges mean there is a need for continuity of care in mental health. Given the amount of theoretical work investigating continuity of care in mental health, there is surprisingly little empirical research (Adair et al., 2003). **Chapter two** will explore the link between continuity of care and outcomes in a systematic review of the literature. Due to the small number of studies which test the relationship between continuity of care and outcomes, there have been numerous calls to conduct more research within this field (Adair et al., 2003; Freeman et al., 2007; Reid et al., 2002). **Chapter three** will address one aspect of this lack of research in a longitudinal study which investigates the association between continuity of care and outcomes.

Legal Compulsion and Continuity of Care

The use of legal compulsion during treatment in psychiatry is common, with around 40% of all admissions to psychiatric hospitals in the UK currently being involuntary (Keown, Mercer, & Scott, 2008; HSCIC, 2015). Outpatient compulsion, also known as a Community Treatment Order (CTO), is legislated for in over 70 jurisdictions worldwide (Rugkåsa & Dawson, 2013). CTOs were introduced in England and Wales in 2008, making it a legal requirement for patients under a CTO to adhere to treatment.

Within medicine, the use of both inpatient and outpatient legal compulsion is almost unique to psychiatry. Critics have argued that over time, coercion may drive patients away from mental health services by fostering mistrust and poor relationships with the care team through the imbalance of power and the paternalistic nature of forced treatment (Hiday, 1992; Szasz, 1997). Critics of CTOs have argued that it may cause patients to disengage from mental health services, resulting in poor long-term continuity (O Reilly, 2004). This raises the possibility that outpatient compulsion may interfere with the continuity of care in patients with severe mental illness. Alternatively, supporters of such compulsion believe that it should lead to improved continuity of care. CTOs may foster continuity of care as patients are required to comply with their treatment including attending appointments with their outpatient team.

There are three published Randomised Controlled Trials (RCTs) of outpatient compulsion. None show any significant effect of outpatient compulsion reducing readmission rates (Burns et al., 2013; Steadman et al., 2001; Swartz et al., 1999). These studies did not measure the effect of legal compulsion on continuity of care. There is no published research investigating the effect of legal compulsion on continuity of care. **Chapter four** will attempt to address this by investigating the relationship between outpatient compulsion and continuity of care.

Summary

Health care has become more specialised and this stratification of services poses a challenge in both providing continuity of care, and in its conceptualisation and measurement. Whilst efforts have been made to measure continuity of care, there is little research into its association with specific outcomes in mental health, nor the impact of legal compulsion on it.

In this thesis I attempt to explore the association between continuity of care and outcomes in mental health care using a number of methods. Specifically I have four research questions.

1. **What is the definition of continuity of care?** In this chapter, **chapter one**, I critically reviewed the literature which attempts to define continuity of care. From this review, I produced a definition of continuity of care in mental health that will be used throughout this thesis.
2. **What is the current evidence for the association between continuity of care and outcomes in mental health?** In **chapter two** I present a systematic review which I conducted in order to summarise the current evidence of the association between continuity of care and outcomes in mental health.
3. **Is there an association between continuity of care and hospitalisation?** In **chapter 3** I conduct a prospective longitudinal study to investigate the association between continuity of care and hospital outcomes in patients with psychosis.
4. **Is there an association between outpatient compulsion and continuity of care?** In **chapter four** I describe an investigation of the association between outpatient legal compulsion and continuity of care.

Finally, in **chapter five** I summarise my findings, interpret them within the context of the changing mental health system, and suggest future challenges and directions of continuity of care research.

Chapter Two: Is continuity of care associated with patient outcomes in mental health? A systematic review of the literature

Introduction

Continuity of care is considered a cornerstone of modern health care provision and is included as an indicator of quality of care in national health policy both in the United Kingdom (Department of Health, 1999) and internationally (Reid et al., 2002). It is a concept that applies throughout the provision of healthcare. As I outlined in chapter one, continuity of care is a multidimensional construct which can broadly be defined as the long-term delivery of care that is coordinated within and between services and is appropriate to an individual patient's current needs. Haggerty and colleagues' summary of the definition outlined three types of continuity of care: relationship, informational, and management (Haggerty et al., 2003). Patients and professionals endorse the importance of continuity of care, and discontinuity of care is cited as a major source of patient dissatisfaction and disengagement (Jones et al., 2009; Waibel, Henao, Aller, Vargas, & Vázquez, 2012).

Continuity of care may be important as a quality measure of healthcare, but it has been argued that its value must depend on its potential impact on the outcomes of care (Gonnella & Herman, 1980). The study I conducted in this chapter is a systematic review of the literature that measures the association between continuity of care and outcomes in mental health, following the guidelines of the Centre for

Reviews and Dissemination guidance document for systematic reviews (Centre for Reviews and Dissemination, 2009)

Measuring Continuity of Care

There are a number of different published measures of continuity of care. Measures differ depending on the dimension of continuity that is being assessed (relationship, management, or information continuity). Measures can also be divided by whether they are collected from patient notes (which I will refer to as *service measures*), or patient-rated measures. This section will focus mainly on continuity of care measures used in mental health research, although many of the measures are used across specialties.

Service measures of continuity of care

Service measures of continuity of care can be divided into two categories, single-item measures and composite measures.

Single-item measures

Single-item measures only evaluate a single element of continuity of care. Most of these measures focus on relationship continuity, using prolonged contact between a patient and their team as an indication of good relationship continuity. Many of these have measured *contact intensity*, how often the patient is seen by mental health staff (Brekke, Ansel, Long, Slade, & Weinstein, 1999; Greenberg, Fontana, & Rosenheck, 2004), or *contact regularity*, which means being in contact with services over time. Others measure *breaks in care*, periods of time in which the patient had no contact with services (Bindman et al., 2000) and the *number of changes of keyworker* over a set period of time (Lehman, Postrado, Roth, McNary, & Goldman, 1994). Measures of management continuity tend to investigate transitions in care. In mental health studies, measures used also include *time to follow-up after discharge* from hospital (Greenberg & Rosenheck, 2005) and the *number of services used* by the patient (Huff, 2000). Information continuity measures investigate the flow of information between different services and the patient. Studies have used *number of referrals documented* or the *number of letters sent by the keyworker that a GP or service user is copied in to* (Burns et al., 2009).

Single-item measures focus on a single element of continuity of care so lack the scope to successfully account for its multidimensionality (Reid et al., 2002). Studies would need to analyse multiple single-item measures together in their investigations to achieve this, yet few have done so (Adair et al., 2003; Johnson et al., 1997).

Composite measures

Composite measures of continuity of care include multicomponent indices and observer-rated scales.

Multicomponent indices incorporate more than one measure of continuity to produce a single total score. The Usual Provider of Continuity (UPC) index measures contact density (the proportion of total contacts made to main provider,Breslau & Reeb, 1975) and the Continuity of Care (COC) index measures contact dispersion (the distribution of visits across providers, Shortell, 1976). The majority of multicomponent measures are variations of these two commonly used indices (Jee & Cabana, 2006), although the Sequential Continuity Index(SECON, Steinwachs, 1979), assesses consecutive visits to the same provider. Multicomponent measures are easy to apply and are widely used but they only report relationship continuity.

There is currently only one observer-rated scale of continuity of care in mental health care, the Alberta Continuity of Services Scale for Mental Health Observer(ACSS-MH-O, Adair et al., 2005). This is a 17-item set of stand-alone indicators of continuity of care that are each scored on a 3 or 4-point scale, giving a maximum possible score of 59. Data for this scale is collected through health records and address a number of different facets of continuity of care. The ACSS-MH-O has not been validated psychometrically and items can be used independently of one another.

Patient-rated instruments measuring continuity of care

Uijen and colleagues (Uijen, Heinst, et al., 2012) identified 21 patient-rated instruments developed for measuring continuity of care in a systematic review. Three of these were developed specifically for patients in mental health services, CONNECT (Ware, Tugenberg, & Dickey, 2003), the Alberta Continuity of Services

Scale – Mental Health User (ACSS-MH-U, Durbin, Goering, Streiner, & Pink, 2004), and Continuity of Care – User Measure (CONTINU-UM, Rose et al., 2009). Two further scales were identified that could be used for continuity of care in mental health, the Nijmegan Continuity Questionnaire (NCQ, Uijen, Schers, Schellevis, Mokkink, et al., 2012), designed for use across medical disciplines, and Gulliford and colleagues' continuity instrument for patients with any long-term illness (Gulliford, Cowie, & Morgan, 2011).

Uijen and colleagues rated the five identified mental health instruments on whether they covered all three dimensions of continuity of care, which they term *personal continuity*, *cross-boundary continuity*, and *team continuity* (similar to relationship, information, and management continuity). Only one instrument, CONNECT, did not cover all three domains (it addressed team and cross boundary continuity). The five instruments differed in content validity, reliability, and interpretability.

Patient-rated instruments are rarely used in mental health research and further evaluation of these instruments is needed. The NCQ has yet to be validated in English, the ACSS-MH-U has only been used in 2 separate studies (Adair et al., 2005; Fleury, Grenier, Bamvita, & Caron, 2010), whilst CONNECT and CONTINU-UM have not been used beyond the research studies they were developed for.

The validity of measurements of continuity of care

One limitation when measuring continuity of care is the lack of validation of measures against current definitions of continuity. The majority of measures used have not been validated. Validation through psychometrics and factorial analyses are difficult due to the lack of a 'gold standard' definition of continuity of care. Without a gold standard definition to validate measures against, measures often lack content validity or structural validity.

An example of poor content validity is the factorial analysis in ECHO. It identified a seven-factor structure of continuity of care (Table 1.1). However, many of the measures used in this factorial analysis would not be considered as conceptually independent from other closely related concepts (as described later in this thesis on page 92).

An example of poor structural validity is Durbin and colleagues' (2004) patient-rated instrument produced a three-factor structure, which they called *interpersonal aspects of care* , *system access*, and *team functioning*. These broadly fit relationship continuity (*interpersonal aspects of care)* and management continuity (*system access*, and *team functioning)*, two of the three dimensions of the definition used in this thesis. However, their factorial analysis only accounted for 36.6% of the common variance. Whilst outside the scope of this thesis, there is a clear need for psychometric validation and factorial analysis of measures in continuity of care.

Continuity of Care and outcomes in health care

Studies designed to test factors that improve continuity of care have been conducted in a number of primary and secondary care settings (Haggerty et al., 2003). In general medicine, there is evidence that continuity of care is associated with improved patient outcomes. In paediatric care, seeing the same paediatrician was associated with reduced emergency department visits (Brousseau, Meurer, Isenberg, Kuhn, & Gorelick, 2004; Christakis, Mell, Koepsell, Zimmerman, & Connell, 2001; Christakis, Wright, Koepsell, Emerson, & Connell, 1999). Seeing the same GP improved type-2 diabetic patient reported quality of life (Hänninen, Takala, & Keinänen-Kiukaanniemi, 2001), whilst in prenatal care, having a high proportion of visits with the same obstetrician is associated with greater maternal weight gains and greater foetal birth weights (Boss & Timbrook, 2001).

In internal medicine, better information continuity (measured as a GP having received a discharge summary) was associated with a lower risk of readmission after 3 months (Van Walraven, Seth, Austin, & Laupacis, 2002). Continuity of care has also been found to increase medication adherence in patients with diabetes (Chen, Tseng, & Cheng, 2013), and reduce rehospitalisation after heart failure (McAlister et al., 2013).

The association between continuity of care and outcomes in general medical care has been investigated in two systematic reviews. Cabana and Jee identified 18 studies in primary care settings (Cabana & Jee, 2004). They found associations between continuity of care and patient satisfaction, decreased hospitalisations and emergency department visits, and improved receipt of preventative services. None of the studies identified any negative effects of continuity of care.

Van Walraven and colleagues' review found 18 studies across medical fields which met their inclusion criteria (Van Walraven, Oake, Jennings, & Forster, 2010). Three of these studies were also identified in Cabana and Jee's review. 14 of the 18 studies in Val Walraven and colleagues' review found an association between continuity of care and an outcome.

Both reviews concluded that improved continuity of care is associated with better outcomes, however there was a lack of studies investigating informational and management continuity. Van Walraven and colleagues only identified two studies which measured information continuity, whilst neither review identified any studies which measured management continuity. Only one study, in the Van Walraven review, measured continuity of care in mental health.

In summary, the literature in general medicine suggests that good relationship continuity of care can lead to better patient outcomes, although further work is required in order to investigate informational and management continuity.

Continuity of care and outcomes in mental health care

Few studies have investigated the association between continuity of care and patient outcomes in mental health care. A conceptual review of continuity of care by Johnson and colleagues (Johnson et al., 1997) found three studies that reported on the association between continuity of care and patient outcomes. They concluded that these studies suffered from "substantial limitations," most notably that they focused only on one or two dimensions of continuity of care when the conceptual literature emphasizes its multidimensional quality. Studies also suffered from low response rates and short follow-up durations.

Adair and colleagues (Adair et al., 2003) conducted a systematic review and found only five studies between 1970 and 2002 that examined the association between continuity of care and patient outcomes in mental health care. They reported that the studies identified were inconsistent in both the way that they measured continuity of care and the patient outcomes that they investigated. They concluded that there is little evidence to suggest that patients have better outcomes with improved continuity of care but that this may be "primarily attributable to the underdevelopment of measures" (pg. 1351).

Aims

Given the renewed focus on continuity of care in modern mental health care over the past decade, in this systematic review I aimed to update the evidence on associations between continuity of care and outcomes.

Methods

Search Strategy

This systematic review follows the guidelines of the Centre for Reviews and Dissemination guidance document (Centre for Reviews and Dissemination, 2009). All relevant papers up to February 2014 were identified using MEDLINE and PsycINFO. The search strategy by Van Walraven and colleagues (Van Walraven et al., 2010) was used as a guide, including the search terms “continuity of care”, “continuity of patient care”, and related keyword phrases and keywords related to outcomes (Van Walraven et al., 2010). Their search strategy was modified by adding the Medical Subject Headings “Mental Disorders” and “Mental Health Services” in order to restrict the search to papers within the field of mental health.

Inclusion and exclusion criteria

Inclusion criteria for the review were:

1. The study should have at least one quantitative measure of continuity of care.

The study had to contain a specified measure of continuity. Examples of quantitative measures include “time from inpatient discharge to first outpatient contact with mental health services”, “the number of outpatient service contacts over a specified period of time”, “the number of changes in care coordinator”. Papers were excluded if they relied on a service structure (e.g. Assertive Outreach

Team) or specified model (e.g. the Continuation of Care' model) as a proxy for continuity of care rather than a distinct measure.

2. The study should investigate a continuity of care measure against a specified outcome.

Studies were excluded if they did not have a distinct measure of continuity of care, and a separate measure of outcome. Outcomes were clinical outcomes (e.g. hospitalisation, symptom reduction), functional outcomes (e.g. quality of life, employment, general community functioning), or patient service satisfaction and treatment adherence.

3. Only studies published in English were included.
4. Studies must investigate an adult sample (18 – 65yrs) with a primary diagnosis of mental illness.

Comorbidity for substance abuse was permitted but studies were excluded if subjects had substance misuse or a physical health problem as their primary diagnosis even with comorbidity of mental illness.

Study screening and selection

After identifying the screening criteria, two reviewers (S.P and A.F) practiced and agreed their application on a subset of the papers, before independently inspecting titles and abstracts against the inclusion criteria. Any disagreement was resolved through discussion. Subsequently, a single reviewer (S.P) inspected the full text of the remaining articles to assess eligibility. References and citations of the included articles were hand-searched for further relevant papers. This study only reports associations that were significant at the final stage of analysis either after Bonferroni corrections or multivariate analysis.

Quality assessment

There is no recommended instrument for quality assessment of non-randomised studies (Sanderson, Tatt, & Higgins, 2007). In their systematic review of continuity of care in health care, Walraven and colleagues used the Newcastle-Ottawa Scale (NOS) which has not been subject to psychometric evaluation or peer review (Van Walraven et al., 2010).

To select a quality assessment instrument for this systematic review, the NOS was compared against selected checklists described in Sanderson and colleagues' review of quality instruments (Sanderson et al., 2007). Sanderson and colleagues identified three types of instruments, simple checklists, checklists with additional summary judgements, and weighted scales. Only simple checklists were included in my review as Sanderson and colleagues advise against using weighted quality scales. Weighting component items and domains implies different levels of importance and Sanderson and colleagues found these weightings variable and inconsistent.

The final list was based on four criteria: i) the instrument was developed for future use, ii) the development was described in the paper, iii) the instrument was developed for use in systematic reviews, iv) the instrument was developed to assess cohort studies. Five quality assessment instruments fulfilled these criteria (Gyorkos et al., 1994; Khan, Riet, Popay, Nixon, & Kleijnen, 2001; Steinberg et al., 2000; Whiting, Rutjes, Reitsma, Bossuyt, & Kleijnen, 2003; Zaza et al., 2000). Two of these five assessments were excluded for not specifying scoring criteria (Gyorkos et al., 1994; Khan et al., 2001).One instrument was excluded as it measures diagnostic test accuracy, not study quality (Whiting et al., 2003). Zaza and colleagues' instrument was excluded after a pilot trial (Zaza et al., 2000) in which despite the instructions for completion, both reviewers (S.P and A.M) found several of the items difficult to interpret and too generic to answer confidently. For example, one item covered three separate questions of randomisation, matching, and allocation of participant. Therefore, only Steinburg and colleagues' (Steinberg et al., 2000) assessment instrument was compared to the NOS.

The NOS is a nine-item checklist divided into three subscales: Selection of the participants (4 items), Comparability of the study groups (2 items), and ascertainment of exposure/outcome (3 items). For the purpose of this study, articles were ranked on their total score ranging from 0 (lowest quality) to 9 (highest quality).

Steinburg and colleagues' checklist (the *Steinburg checklist*) contains 24-items, scored as 0, 0.5, or 1 depending on the extent to which they fulfil the required criteria. Not all items are relevant to all studies so not all are rated. A total score between 0 (lowest quality) and 1 (highest quality) is created by dividing the summed score of responses divided by the total number of rated questions. Papers with a score over 0.5 are considered of good quality.

Two reviewers (S.P and A.M) rated all papers included in the systematic review using both the NOS and the Steinburg checklist. Inter-rater reliability was chosen as the criterion to judge which quality instrument was to be used. Both reviewers also rated each paper using an overall judgement of quality as good, moderate, or poor based on five criteria: An adequate sample size, study design, whether the study controlled for extraneous variables either in design or statistically, the proportion of participant data collected (adequate participant follow up was considered to be ≥70%), and the absence of any obvious risks of bias. Studies were considered good quality if they were rated as good by both reviewers, or good by one reviewer and moderate by the other.

Results

The search strategy generated 984 studies (Figure 2.1). After duplicates were removed, abstracts of 688 studies were screened for relevance. Of these, 73 were identified as relating to continuity of care and after a full-text review, 59 were excluded. Reasons for exclusion were: 47 (80%) did not measure continuity of care, seven (12%) used continuity of care as an outcome measure, four (7%) were conceptual reviews of continuity of care, and one (1%) was not in English. A further four studies were included after hand-searching references and citations of the selected studies, resulting in 18 studies to be included in the analysis. These studies are presented in Table 2.1. All five studies from the Adair review (Adair et al., 2003) are included. Two studies that were published prior to, but not reported in, their review are also included in this review. Eleven included studies were published after the Adair review.

Design of included studies

There were no randomised control trials. The majority of studies used a retrospective cohort design (nine studies) or a prospective cohort design (seven studies). One study had a cross-sectional design and one had a quasi-experimental design. 17 of the 18 studies are longitudinal. The length of follow-up ranged from 30 days to 4 years (median = 12 months).

Measurement of continuity of care

There was little consistency in the measurement of continuity of care. Four studies (Chien, Steinwachs, Lehman, Fahey, & Skinner, 2000; Greenberg et al., 2004; Greenberg, Rosenheck, & Fontana, 2003; Hoertel, Limosin, & Leleu, 2014) used the Continuity of Care Index (COC), with two being from the same research team. Three studies used 'breaks in care' as a measure, although all defined a break in care differently (Bindman et al., 2000; Brekke et al., 1999; Sytema & Burgess, 1999). Five studies used the time from hospital discharge to first outpatient contact, again measured in a variety of ways (Greenberg & Rosenheck, 2005; Greenberg et al., 2003; Grinshpoon et al., 2011; Huff, 2000; Sytema & Burgess, 1999). Table 2.2

outlines the different continuity of care measures used in the studies. This inconsistency of measurement made meta-analysis impossible.

13 studies investigated continuity of care from the service provider's perspective. The majority of these studies used contact frequency and regularity, or changes in care provider as a measure of continuity. There are two exceptions to this. Adair and colleagues (Adair et al., 2005) created an observer-rated continuity instrument which measured various aspects of continuity of care, used in two studies (Adair et al., 2005; Mitton, Adair, McDougall, & Marcoux, 2005). Catty and colleagues' (Catty et al., 2013) combined multiple single-item measures into continuity factors through factorial analysis and measured those factors against outcomes.

Three studies measured continuity from a patient's perspective using specifically developed instruments (Adair et al., 2005; Catty et al., 2013; Sweeney et al., 2012)

Figure 2.1. Flow chart of study selection

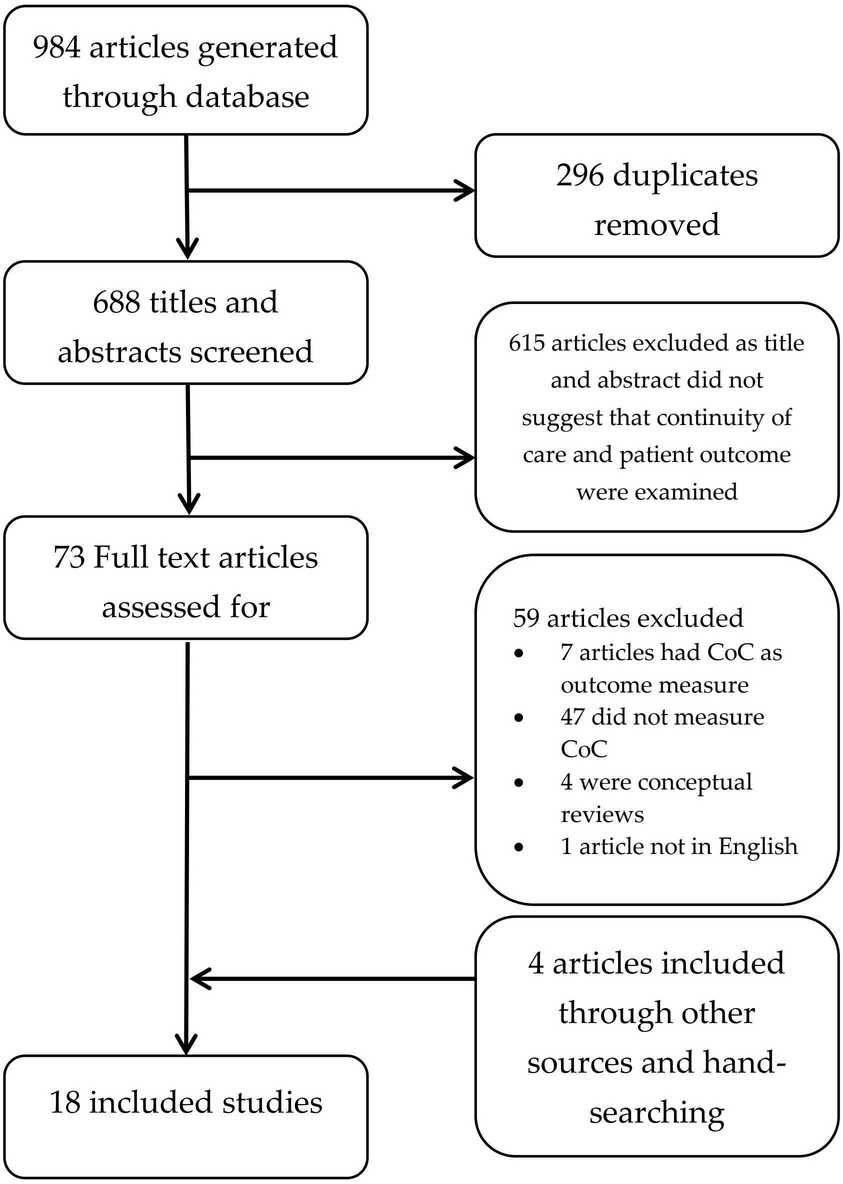


Table 2.1. Summary of studies measuring the association between Continuity of Care (CoC) and Outcomes

Author, Year, Country	Design	Follow-up	N	CoC Measures[1]	Outcomes Measured	Results Summary
Adair et al (2005), Canada[2]	Prospective cohort	17 months	411	B1, C1.	Symptom severity, functioning, service satisfaction, other: quality of life.	No association between CoC and symptom severity. CoC associated to better functioning, service satisfaction, and quality of life.
Bindman et al. (2000), UK	Prospective cohort	20 months	100	C3, F1, H1	Hospitalisation, symptom severity, functioning.	No significant associations between CoC and hospitalisation, symptom severity, or functioning.
Brekke et al. (1999), USA	Prospective cohort	12 months	41	D1, F2	Hospitalisation, symptom severity, functioning.	No association between CoC and hospitalisation. CoC associated with reduced symptom severity and improved functioning.
Catty (2013), UK	Prospective Cohort	24 Months	180	A5	Hospitalisation, symptom severity, functioning, Other: quality of life, therapeutic relationship, care needs met	*Consolidation* and *Care Coordination* factors associated with reduced odds of hospitalisation, whilst *Regularity* was associated with a higher risk of being hospitalised. *Meeting Needs* was associated with an increase in symptoms the previous year but a decrease the following year.
Chein (2000), USA	Retrospective cohort	12 months	351	A1, A2, A3	Other: Medicaid cost, life satisfaction; satisfaction with health.	Better CoC associated with reduced Medicaid costs. CoC not associated with life satisfaction or satisfaction with health.
Greenburg et al (2004), USA	Retrospective cohort	8 months	131	A1, A4, D2, E1	Symptom severity, functioning, Other: therapeutic alliance, life satisfaction, commitment to treatment, substance abuse, violence, employment.	No associations between CoC and outcomes.

Greenberg & Rosenheck (2005), USA	Retrospective cohort	3 - 6 months	181, 651	D3, E1 ,G1	Functioning	CoC associated with better functioning. Although intensity of contact (D3) associated with poorer functioning.
Greenburg et al (2003), USA	Prospective cohort	4 months	2357	A1, A4, E1, E2, G1	Symptom severity, Other: substance abuse, violent behaviour.	No significant associations between CoC and symptom severity or substance abuse. Better CoC reduced violent behaviour.
Grinshpoon (2011), Israel	Retrospective Cohort	6 months	908	G3	Hospitalisation.	Better CoC associated to lower risk of rehospitalisation.
Heffernan & Husni (2011), UK	Retrospective cohort	24 months	26	H2	Hospitalisation.	No association between CoC and number of days in hospital.
Hoertel et al. (2014), France	Retrospective cohort	36 months	14,515	A1	Other: Mortality rate	The likelihood of death was significantly lower in patients with better CoC.
Huff (2000), USA	Retrospective cohort	1 month	3755	G2, I	Hospitalisation.	Contact within 5 days of discharge (G2) related to a reduced risk of rehospitalisation. However, greater service utilisation (I) associated with increased risk of hospitalisation.
Lehman (1994), USA	Quasi-experimental	12 months	661	C4, H2, H3	Hospitalisation, symptom severity, functioning, other: life satisfaction.	CoC reduced symptom severity. No significant differences found in hospitalisation, functioning, or life satisfaction.
Mitton (2005)[2], Canada	Prospective cohort	17 Months	437	B1	Other: Health care costs	No association was found between total cost (although there was a trend p>.054), but better CoC was found to have lower hospital costs and higher community costs.

Olfson (1998), USA	Prospective cohort	3 months	208	J	Hospitalisation, symptom severity, functioning, other: employment, medication adherence.	CoC associated with reduced symptom severity. No association between CoC and hospitalisation, functioning, employment or medication adherence.
Sweeney et al. (2012), UK	Cross sectional	None	167	C2	Other: Therapeutic relationship, health and social needs.	CoC associated with better therapeutic relationships and more health and social needs met.
Sytema & Burgess (1999), Australia and The Netherlands	Retrospective cohort	48 months	2257	F3, F4, G3	Hospitalisation	No association between CoC and hospitalisation.
Vita et al (2008), Italy	Retrospective cohort	18 months	99	E1	Other: Medication adherence.	Regular CoC (1 visit a month) associated with better medication adherence. More intensity of contact (more than one visit a month) related to poorer medication compliance.

1. See Table 2.2 for continuity of care measures.
2. These two studies share the same sample.

Table 2.2. List of Continuity of Care (CoC) measures used by the studies arranged by type.

Type of measure	**No. of studies using measure**[1]
Multi-component CoC measures.	
Indices.	
A1. Continuity of Care Index (Chien et al., 2000; Greenberg et al., 2004; Greenberg et al., 2003; Hoertel et al., 2014)	4
A2. Usual Provider Continuity (Chien et al., 2000)	1
A3. Sequential Continuity (Chien et al., 2000)	1
A4. Modified Continuity Index (Greenberg et al., 2004; Greenberg et al., 2003)	2
A5. ECHO factors (Catty et al., 2013)	1
Observer-rated scales.	
B1. ACSS-MH observer (Adair et al., 2005; Mitton et al., 2005)	2
Patient-rated scales.	
C1. ACSS-MH patient (Adair et al., 2005)	1
C2. CONTINU-UM (Sweeney et al., 2012)	1
C3. Perceived accessibility score (Bindman et al., 2000)	1
C4. Met needs score (Lehman et al., 1994)	1
Single component CoC measures.	
Contact intensity.	
D1. Summed minutes of contact (Brekke et al., 1999)	1
D2. Number of days with at least one contact (Greenberg et al., 2004)	1
D3. Total number of contacts (Greenberg & Rosenheck, 2005)	1
Contact regularity.	
E1. Number of months with at least one contact (Greenberg et al., 2004; Greenberg & Rosenheck, 2005; Greenberg et al., 2003)	3
E2. Number of 2 months period with at least two contacts (Greenberg et al., 2003)	1
Breaks in care.	
F1. Number of days from missed contact to next contact (Bindman et al., 2000)	1
F2. Number of 30 day gaps without contact (Brekke et al., 1999)	1
F3. Number of 90 day gaps (Sytema & Burgess, 1999)	1
F4. Summed number of days of 90 day gaps (Sytema & Burgess, 1999)	1
Time-to-contact after inpatient discharge.	
G1 Visit within 30 days discharge (Greenberg & Rosenheck, 2005; Greenberg et al., 2003)	2
G2. Visit within 5 days of discharge (Huff, 2000)	1
G3. Number of days between discharge and first visit (Grinshpoon et al., 2011; Sytema & Burgess, 1999)	2
Changes in keyworker.	
H1. Total number of keyworkers (Bindman et al., 2000)	1
H2. Change in keyworker (Heffernan & Husni, 2009; Lehman et al., 1994)	2
H3. Keyworker allocated (Lehman et al., 1994)	1
Total number of services used (Huff, 2000)	1
Consultation between outpatient consultant before discharge (Olfson, Mechanic, Boyer, & Hansell, 1998)	1

1. Studies are counted for each continuity measure used.

Association between continuity of care and outcomes

Table 2.3 summarises the direction of the association between continuity of care and outcomes in all studies. There was little consistency in outcome measures across studies and some studies that did use the same outcome often measured it differently. For example, the six studies that used "duration of hospitalisation" as an outcome used three different measures of duration. These were, total number of days in hospital (Bindman et al., 2000; Catty et al., 2013; Heffernan & Husni, 2009; Systema, Burgess, & Tansella, 2002), average number of nights in hospital per month (Lehman et al., 1994), and hospitalisation measured with the Strauss Carpenter Outcome Scale, a broad scale of multiple outcomes including hospitalisation (Brekke et al., 1999). The relationship between continuity of care and specific outcomes are reported below.

Hospitalisation outcomes

Duration of hospitalisation

Six studies examined duration of hospitalisation (Bindman et al., 2000; Brekke et al., 1999; Heffernan & Husni, 2009; Lehman et al., 1994; Sytema & Burgess, 1999). Only one study found an association between continuity of care and duration of hospitalisation (Sytema & Burgess, 1999). They compared continuity of care between, Groningen in The Netherlands and Victoria, Australia and found that duration of hospitalisation was longer in the cohort with poor continuity of care

(Groningen) but there was no increase in the relative risk of readmission between the cohorts.

Relative risk of rehospitalisation

Four studies tested for associations between continuity of care and the relative risk of rehospitalisation (Bindman et al., 2000; Grinshpoon et al., 2011; Huff, 2000; Olfson et al., 1998). Using "time to first contact after discharge" as their measure of continuity of care both Grinshpoon and colleagues (Grinshpoon et al., 2011) and Huff (Huff, 2000) found it was associated with hospitalisation. Grinshpoon and colleagues found that patients who visited an outpatient clinic within 180 days of discharge from an inpatient hospital were less likely to be readmitted. Huff (2000) found a reduced risk of readmission over 30 days follow-up in patients who had an outpatient contact within 5 days of discharge from their index admission. However, the same study also found that increased service utilisation (more services contacted and a larger number of service contacts) was associated with an increased risk of readmission.

Number of days to readmission

Sytema and Burgess examined the association between continuity of care and the number of days to readmission and found no association (Sytema & Burgess, 1999).

Symptom severity

Eight studies investigated the association between continuity of care and symptom severity. Five used the Brief Psychiatric Rating Scale (BPRS, Adair et al., 2005; Bindman et al., 2000; Brekke et al., 1999; Catty et al., 2013; Olfson et al., 1998) to measure symptoms, two used specific rating scales for Post-Traumatic Stress Disorder (PTSD, Greenberg et al., 2004; Greenberg et al., 2003), and one used the Symptom Checklist-90 (SCL-90, Lehman et al., 1994).

Four of the eight studies found an association between continuity of care and symptom severity (Brekke et al., 1999; Catty et al., 2013; Lehman et al., 1994; Olfson et al., 1998). Brekke et al. (1999) found that greater intensity of contact and fewer gaps in care were associated with reduced BPRS scores 12 months after discharge from hospital. Olfson and colleagues found patients who had a pre-discharge contact with their outpatient clinician were significantly more likely to have lower BPRS scores after 3 months than those with no contact (Olfson et al., 1998). Conversely, Lehman and colleagues (1994) found that after a year symptom severity scores were worse in their intervention group compared to a control group. Catty and colleagues (2013) found that having a higher Experience and Relationship score or a higher Supported Living score were associated with increased symptom severity, whilst a higher Met Needs score (as determined by the Camberwell assessment of Needs, Phelan et al., 1995) was associated with decreased symptom severity as based on BPRS scores.

Neither of the two studies investigating the association between continuity of care and PTSD symptoms found any difference in symptom severity (Greenberg et al., 2004; Greenberg et al., 2003). None of the studies published since the Adair review have found an association between continuity of care and symptom severity.

Social Functioning

Eight of the eighteen studies investigated an association between continuity of care and social functioning. Three found an association between good continuity of care and improved functioning in the community. Greenburg and Rosenheck found that in a sample of 181,651 veterans on Medicaid (Greenberg & Rosenheck, 2005), Global Assessment of Functioning (GAF) scores increased over 6 months with improved regularity of care (the number of months with at least one visit) and provider consistency (COC index). Adair and colleagues found an increase in functioning, measured by the Multnomah Community Ability Scale (MCAS, Barron, McFarland, Bigelow, & Carnahan, 1994), over 17 months was associated with better continuity of care in 411 outpatients (Adair et al., 2005). Brekke and colleagues also found an association between increased regularity and intensity of contact and higher GAF scores (Brekke et al., 1999).

Table 2.3. Summary of the direction of outcomes in studies.

Outcomes are rated as a positive outcome (+), no difference (=), or a negative outcome (-). Multiple symbols represent findings in different directions.

Reference (sorted by date published)	Outcomes (compared to baseline or TAU)				
	Hospital Readmission[1]	Symptoms	Social Functioning	Service Satisfaction	Other
Lehman et al (1994)[2]	=	-	=	=	
Olfson et al (1998)	=	+	=	=	=
Brekke et al. (1999)	=	+	+		
Sytema & Burgess (1999)	=				
Bindman et al. (2000)	=	=	=		
Chein et al. (2000)[2]					=+
Huff (2000)	+				
Greenburg et al (2003)		=			+
Greenburg et al. (2004)		=	=		=
Adair et al (2005)[2]		=	+	+	+
Mitton et al (2005)					+-=
Greenburg & Rosenheck (2005)[2]			+		
Vita et al (2008)					+-
Heffernan & Husni (2009)	=				
Grinshpoon et al (2011)	+				
Sweeney et al (2012)[2]					+
Catty et al. (2013)	+-	+-	=		+-=
Hoertel et al (2014)[2]					+
Outcome score[3]	2	1	3	1	

1. A positive outcome (+) in hospital readmission means either fewer days in hospital, a reduced risk of readmission, or a longer duration until readmission.
2. Quality assessed as 'good' quality studies
3. The outcome score is a representation of the relative strength of agreement b created by summing results of each outcome category where + equals 1, = equals 0, and – equals -1. 'Other' category not scored as 'other' outcomes are too heterogeneous to compare.

Service Satisfaction

Three studies investigated the association between continuity of care and service satisfaction. Two of these found no association (Lehman et al., 1994; Olfson et al., 1998). Adair and colleagues found an association between Service Satisfaction Scale scores at 17 months and better reported and observed continuity of care (Adair et al., 2005).

Other outcomes

A range of other outcomes were measured. Ten of the 18 studies investigated 26 other outcomes, finding eight statistically significant associations in eight different studies. Three studies investigated quality of life (Adair et al., 2005; Catty et al., 2013; Greenberg et al., 2004). Adair reported a significant association between improved continuity of care and better quality of life (Adair et al., 2003) and the other two found no difference (Catty et al., 2013; Greenberg et al., 2004). All three studies used different measures for quality of life, had different follow-up durations, and targeted different patient populations (general psychiatric mental health and PTSD specific samples). Chien and colleagues found no association between continuity of care and satisfaction with health (Chien et al., 2000). Contradictory results were found with medication adherence (Olfson et al., 1998; Vita, Corsini, Bonomi, Sacchetti, & Cesana, 2008) and substance abuse reduction (Greenberg et al., 2004; Greenberg et al., 2003), finding both significant associations and no associations.

Three studies examined life satisfaction (Chien et al., 2000; Greenberg et al., 2004; Lehman et al., 1994), none finding any association. No association was found between continuity of care and employment (Greenberg et al., 2004; Greenberg et al., 2003; Olfson et al., 1998), violent behaviour (Greenberg et al., 2004; Greenberg et al., 2003), or levels of homelessness (Olfson et al., 1998). Three studies investigated the therapeutic relationship (Catty et al., 2013; Greenberg et al., 2004; Sweeney et al., 2012). Two found no associations (Catty et al., 2013; Greenberg et al., 2004). Sweeney and colleagues found that better self-reported continuity of care was related to a better patient-provider relationship (Sweeney et al., 2012). They also reported a significant association between self-reported continuity of care and a greater proportion of patient needs met as measured by the Camberwell Assessment of Needs (CAN). However, Catty and colleagues found no association between continuity of care and CAN (Catty et al., 2013).

Two studies investigated the association between continuity of care and health care costs. Chien and colleagues (2000) found an association between usual provider continuity (UPC) and decreased Medicaid costs which they attributed to less hospital usage, whilst Mitton and colleagues found a non-significant trend in reduced total costs with better continuity of care (Mitton et al., 2005). Finally, a large scale risk study by Hoertel and colleagues (2014) found an association between better continuity of care, as measured by the COC-index, and a reduced mortality rate.

Quality Assessment

The results of the quality assessments are shown in Table 2.4. The intraclass correlation coefficient (ICC) reliability between the two raters was .51 (95%CI 0.07 – 0.78) for the NOS and .58 (95%CI .17 – .82) for Steinburg. These are both considered at the lower bounds of "moderate" agreement according to Fleiss (Fleiss, 2011). Given the poor level of agreement and wide confidence intervals for both scales, neither quality instrument was used in evaluating study quality in this review. There was a "good" level of agreement for both researchers' 3-point rating scale, .67 (95%CI .30 - .86, see Table 2.4). Six studies were rated as good (either both raters rated the study as good, or one rater rated the study as good and the other as moderate), six as moderate, and six studies were rated as poor quality studies. The results reported here are restricted to the six studies rated as good by either of the two quality assessors.

All six studies rated as good quality reported significant associations between continuity of care and an outcome, with nine of the 15 outcomes tested found to be significantly associated with continuity of care. Of these six studies, only Lehman and colleagues did not find that good continuity of care was associated with at least one better outcome (Lehman et al., 1994).

Lehman and colleagues was the only study that investigated hospital readmission to find no association (Lehman et al., 1994). Two studies measured symptom severity; Adair and colleagues reported no association (Adair et al., 2005), whilst

Lehman and colleagues found an association between a lower proportion of a change in case manager and an increase in symptoms (Lehman et al., 1994). Three investigated the association between continuity of care and social functioning (Adair et al., 2005; Greenberg & Rosenheck, 2005; Lehman et al., 1994) with two finding an association between good continuity of care and an improvement in social functioning (Adair et al., 2005; Greenberg & Rosenheck, 2005). Adair and colleagues found an association between continuity of care and service satisfaction (Adair et al., 2005) whilst Lehman and colleagues found no association (Lehman et al., 1994). Other outcomes that were associated with continuity of care include mortality rate (Hoertel et al., 2014), therapeutic relationship (Sweeney et al., 2012), quality of life (Adair et al., 2005), number of needs met (Sweeney et al., 2012), and lower healthcare costs (Chien et al., 2000). There were no associations between continuity of care and life satisfaction (Chien et al., 2000; Lehman et al., 1994), and satisfaction with health (Chien et al., 2000).

Studies published since previous systematic review

Of the five studies described in the Adair review, only two found significant associations, one with symptom control and one with reduced costs. Of the two studies within the Adair review's study period but not reported, both found significant associations. The eleven subsequent studies were more likely to report significant associations, with nine finding an association between continuity of care and a variety of outcomes (hospitalisation, functioning, medication adherence, service satisfaction, quality of life, life satisfaction, violence reduction, health care costs, risk of mortality, and therapeutic relationships).

Table 2.4. Summary of rater scores and rankings for quality tools used to assess risk-of-bias.

	Newcastle-Ottawa1		Steinberg2		Rater's evaluation3	
Author	**SP (rank)**	**AM (rank)**	**SP (rank)**	**AM (rank)**	**SP**	**AM**
(Adair et al., 2005)[4]	**7 (2)**	**9 (1)**	**0.92 (4)**	**0.85 (3)**	**Good**	**Good**
(Bindman et al., 2000)	7 (2)	8 (2)	0.89 (6)	0.73 (6)	Moderate	Moderate
(Brekke et al., 1999)	5 (4)	5 (5)	0.77 (11)	0.67 (8)	Moderate	Moderate
(Catty et al., 2013)	7 (2)	6 (4)	0.85 (8)	0.77 (5)	Moderate	Moderate
(Chien et al., 2000)[4]	**5 (4)**	**6 (4)**	**0.92 (4)**	**0.83 (4)**	**Good**	**Good**
(Greenberg et al., 2004)	6 (3)	3 (7)	0.92 (4)	0.57 (11)	Poor	Poor
(Greenberg & Rosenheck, 2005)	5 (4)	4 (6)	0.89 (6)	0.62 (10)	Poor	Moderate
(Greenberg et al., 2003)[4]	**6 (3)**	**6 (4)**	**0.96 (3)**	**0.86 (2)**	**Moderate**	**Good**
(Grinshpoon et al., 2011)	6 (3)	6 (4)	0.79 (10)	0.83 (4)	Moderate	Moderate
(Heffernan & Husni, 2009)	6 (3)	6 (4)	0.86 (7)	0.86 (2)	Poor	Poor
(Hoertel et al., 2014)[4]	**8 (1)**	**8 (2)**	**1.00 (1)**	**0.92 (1)**	**Good**	**Good**
(Huff, 2000)	7 (2)	7 (3)	0.65 (13)	0.69 (7)	Moderate	Moderate
(Lehman et al., 1994)[4]	**6 (3)**	**9 (1)**	**0.90 (5)**	**0.63 (9)**	**Good**	**Moderate**
(Mitton et al., 2005)	8 (1)	7 (3)	0.81 (9)	0.69 (7)	Moderate	Moderate
(Olfson et al., 1998)	7 (2)	8 (2)	0.97 (2)	0.73 (6)	Moderate	Poor
Sweeney et al. (2012)[4]	**5 (4)**	**5 (5)**	**0.69 (12)**	**0.67 (8)**	**Moderate**	**Good**
(Sytema & Burgess, 1999)	7 (2)	6 (4)	0.53 (15)	0.57 (11)	Poor	Poor
(Vita et al., 2008)	6 (3)	7 (3)	0.58 (14)	0.54 (12)	Moderate	Poor

1. The Newcastle-Ottowa has a range between 0 – 9, with 9 having satisfied the most criteria.
2. Steinburg scores range between 0 – 1, with a score of one being the highest.
3. Rater's scored papers as good, moderate, or poor.
4. Papers in bold were papers rated as 'good' overall

Discussion

My aim for this study was to systematically review the association between continuity of care and outcomes in mental health. It updates and expands on the Adair review of a decade ago (Adair et al., 2003).

There has been a notable increase of interest in the study of the association between continuity of care and outcomes. Seven of the eighteen studies identified in this review were conducted in the 32 years between 1970 and the Adair review in 2002, whilst eleven have been conducted from 2002 to 2013. There have also been developments in measuring patient perceptions of continuity of care and its associations with outcomes, with two made-for-purpose patient rated scales utilised in three recent outcome studies (Adair et al., 2005; Catty et al., 2013; Sweeney et al., 2012). All three of these patient-rated continuity of care studies showed significant associations between continuity of care and an outcome. This move towards patient-rating follows the theoretical literature's shift towards a patient-focused understanding of continuity of care (Freeman, 2002; Johnson et al., 1997).

The increase in quantity of publications has, however, not brought increased consistency of measurement and there remains considerable variation in both measuring continuity of care and the choice of outcomes. As continuity of care is a multi-dimensional construct (Johnson et al., 1997), one would expect measures which addressed different components of continuity of care. However, most studies only examine the regularity of, or gaps in, provider contact, and the heterogeneity of measures is within this narrow conception of continuity of care. Whilst measuring continuity of care in a variety of different ways creates a comprehensive and rich understanding, progress in the field may have been slowed by this lack of consistency. To determine whether service-focused measures such as regularity of contact and changes in care coordinator are a meaningful construct when measuring continuity of care, replication of already existing measures and research may currently be more useful to the field.

This review found no clear association between continuity of care and outcomes. Whilst more than half the studies reported associations between continuity of care and an outcome, all the main outcomes investigated show conflicting results. Also, a number of the studies investigating the association between continuity of care and outcomes suffered from methodological limitations. These include small sample sizes (Brekke et al., 1999; Heffernan & Husni, 2009), short follow-up duration (Greenberg et al., 2003; Huff, 2000; Olfson et al., 1998), and poorly controlled cohorts (Sytema & Burgess, 1999). The impact of these biases in many of the studies is likely to influence their results.

The over-reliance on cohort designs makes it difficult to infer causality. For instance, Greenberg and colleagues' (Greenberg & Rosenheck, 2005) found that for their continuing outpatient group (those who were already outpatients in regular care), intensity of contact was associated with worse functioning. This finding may reflect an appropriate response to poorer functioning rather than greater contact intensity causing poorer functioning. Similarly, in Sweeney and colleagues' cross-sectional study, continuity of care was associated with the therapeutic relationship and number of patient needs met. In theory, the therapeutic relationship is a process that leads to better continuity of care, rather than an outcome of continuity of care.

Of the studies rated as good in the quality assessment, improved social functioning was the only outcome with a repeated association with good continuity of care (Adair et al., 2005; Greenberg & Rosenheck, 2005). Healthcare costs (Chien et al., 2000), risk of mortality (Hoertel et al., 2014), therapeutic relationship (Sweeney et al., 2012), and CAN number of needs met (Sweeney et al., 2012) also found significant associations between good continuity of care and better outcomes, however these are findings of individual studies without corroboration. Good continuity of care was found to be significantly associated with worse symptom severity in Lehman and colleagues' study (Lehman et al., 1994). Of these studies, only Lehman and colleagues measured the association between continuity of care and hospitalisation. It is surprising that only one of the good rated studies included hospitalisation as an outcome despite its frequent use as an outcome in mental health services research.

This review did, however, identify an emerging consensus of the outcomes that are important for measuring the effects of continuity of care. Hospital readmission, symptom severity, and social functioning were by far the most used outcomes.

There are a number of limitations to this review. First, continuity of care is a broad concept and authors use different terms such as coordination of care and care integration interchangeably to describe it (Uijen, Schers, Schellevis, & van den Bosch, 2012). The search strategy used was intentionally broad to find studies with different naming conventions but it is still possible that relevant articles were missed. Second, lack of conformity between designs, measures, and outcomes between studies means that a meta-analysis was not possible. Third, this study was restricted to adults of working age. It excluded papers with samples drawn from patients with a primary diagnosis of substance abuse with comorbid mental illness, children and adolescents, and older adults, possibly limiting its generalizability. Fourth, only one reviewer inspected the full-text articles for eligibility and therefore there were no inter-rater checks for this stage of the screening process.

Conclusions

Research into the relationship between continuity of care in mental health and outcomes has accelerated recently but there is still no clear evidence that continuity of care improves patient outcomes in mental health. These findings echo Adair and colleagues' (Adair et al., 2003) review of a decade ago. The eighteen identified studies found conflicting results on all main outcomes measured. Persisting variation in measuring both continuity of care and outcomes makes meaningful comparisons difficult. Studies that are poorly designed, use small samples, and only measure a single element of continuity of care are unlikely to add to our understanding of continuity. Future studies should incorporate experimental designs and focus on multi-dimensional measures of continuity of care. The more recent studies present modestly encouraging results, especially in relation to social functioning, but replications using better methodologies and measures are needed before evidence-based conclusions can be drawn.

Chapter Three: The association between continuity of care and the risk of rehospitalisation

Introduction

As discussed in chapter two, there is evidence that continuity of care improves outcomes in general medicine but similar evidence has not been produced for mental health care. This may be due to both a lack of consistency in research approaches and lack of consistency in the use of instruments to measure continuity of care.

The need for comparable research

Reproducibility of research (and results) is considered a core principle in science (Open Science Collaboration, 2015). When there are contradictory conclusions about a phenomenon, replication of existing studies can increase the positive predictive value of a research finding (Moonesinghe, Khoury, & Janssens, 2007).

There has been little replication of previously used methods in continuity of care research despite the contradictory evidence of whether improving continuity of care leads to better patient outcomes. There is also no established measure of continuity of care in community mental health research because of this lack of replication.

The lack of replication and lack of established measures account for the slow progress in identifying whether there is a relationship between continuity of care and outcomes. Therefore, the study described in this chapter attempted to replicate aspects of a continuity of care measure used in a previous study, the Experiences of Continuity of Care and Health and Social Outcomes study (ECHO, Burns, Catty, Clement, et al., 2007).

The ECHO study

The ECHO study was the mental health strand of a National Coordinating Centre for NHS Service Delivery and Organisation (NCCSDO's) Scoping Exercise into continuity of care. It used the multidimensional definition of continuity of care produced by Freeman to explore the experience of continuity of care from both patient and service perspectives (Freeman et al., 2000). In the development phase of the study, the ECHO team operationalised Freeman and colleagues' definition. The operationalisation included subjective and objective indicators and produced and psychometrically validated a user-developed questionnaire for patients, **CONTINU**ity of Care – **U**ser **M**easure (CONTINU-UM), and one assessing family carers' perspective of continuity of care (CONTINUES).

The main phase of the ECHO study explored these operationalisations empirically. Factorial analysis of the measures proposed by Freeman et al produced a 20 variable, seven-factor model of continuity of care that explained 62.5% percent of the total variance of continuity in their sample of 180 patients with a diagnosis of psychosis (Burns et al., 2009). The seven factors were *Experience and Relationships*, *Regularity*, *Meeting Needs*, *Consolidation*, *Managed Transitions*, *Care Coordination*, and *Supported Living*). Table 3.1 presents the definitions of each of these factors.

The ECHO team then tested for associations between the continuity factors and clinical and social outcomes (Catty et al., 2013). They found that a higher *Meeting Needs* score was associated with a decrease in symptomology, whilst a higher *Experience and Relationship* and a higher *Supported Living* score was associated with an increase in symptomology. Patients with a higher *Regularity* score were more likely to be hospitalised. The authors suggested that the relationship between continuity of care and outcomes was not unidirectional, but may be a dynamic process whereby continuity of care is adapted to patients' current needs.

The ECHO study had a number of limitations. First, it had a high refusal rate of eligible patients (64%) and dropouts during the study differed significantly in age, quality of life, symptomology, and *Supported Living* scores. This suggests that those who dropped out were the patients most likely to have fragmented care. Second, the continuity factors, whilst comprehensive, are complex and not intuitively meaningful nor likely to be used in a clinical context. The major strength of the ECHO study was that, unlike most previous studies which only focus on a single dimension of continuity, it attempted to operationalise all of Freeman and colleagues' continuity dimensions.

The ECHO study's seven-dimension conceptualisation of continuity of care is more inclusive than the three-dimension description of continuity of care in chapter one which consists of relationship, informational, and management continuity (the ECHO study began before Haggerty and colleagues' review of continuity was published). However, many of the ECHO measures can be interpreted within these three dimensions and these interpretations are described in the methods.

The OCTET study

The Oxford Community Treatment Order Evaluation Trial (OCTET) was a multi-centre randomised control trial (RCT) comparing the effect of community treatment under a Community Treatment Order (CTO) to voluntary treatment via a short term discharge on Section 17 leave (Burns et al., 2013). The OCTET trial recruited 336 patients diagnosed with a psychotic disorder due for discharge from psychiatric hospital after an involuntarily admission. The trial found no difference in readmission rates, time to readmission or total number of days in hospital between the two trial arms at a 12-month follow-up (Burns et al., 2013). An analysis of secondary outcomes showed no difference between the CTO and Non-CTO arms in symptom severity, functioning, insight to treatment, substance abuse, employment, therapeutic relationship with care coordinator, satisfaction with services, or experience of coercion (Rugkåsa et al., 2015). The only significant effect was that patients in the CTO arm reported an increase in the perceived effectiveness of treatment pressures (i.e. the patient's opinion of whether coercion was effective, not whether treatment was effective).

The trial was funded for a further 24 months (totalling 36 months follow-up) to investigate the long-term effects of legal compulsion on disengagement and continuity of care. The study described in chapter four forms part of the OCTET programme. The study described in this chapter (chapter three) used the OCTET sample to investigate patterns of service utilization and continuity of care in a population of patients who were considered for a CTO because of their high likelihood of disengaging from services and risk of fragmented care.

Patterns of care in community services

Surprisingly little is known about the patterns of care provided by community mental health services. The constituent components of a modern CMHT, as described in chapter one, have been discussed in depth (Burns, 2014; Thornicroft & Tansella, 2004) and different models of community team such as Assertive Community Treatment (ACT) have been evaluated (Burns, 2010b). However few studies report on objective indicators of service provision such as the number of contacts with patients (an indicator of continuity), or staff turnover (an indicator of discontinuity (Adair et al., 2003; Haggerty et al., 2003). In this study I aimed to describe patterns of contact in UK community mental services.

Table 3.1. ECHO continuity of care factor structure and components

Factor	Factor Name	Component *(later omitted)*[1]	Description
1	Experience and relationships	• *CONTINU-UM*[2] • *STAR total score – any professional*[3] • *Proportion of needs met* • *Any user-rated breaks in care*	High experienced continuity, good therapeutic relationship, a greater proportion of needs met and not having a user-rated break in care.
2	Regularity	• Average gap between face-to-face contacts • Gaps of 2 months or more • Non-medical input spread	Being seen more frequently by staff from fewer different non-medical disciplines.
3	Meeting needs	• *CAN total level of needs*[4] • *CAN number of met needs*[4] • *CPA copied to GP and user*[5]	High level of need, high number of met needs and CPA copied to GP and user.
4	Consolidation	• *Number of agencies used in previous year* • *Contacts with primary care professionals*	Having contact with fewer different agencies and not seeing primary care professionals.
5	Managed transitions	• *Had a transition?* • Documented transition	1=no transition, 0=documented transition, -1=undocumented transition
6	Care Coordination	• Designated care coordinators • Designated psychiatrists • *CAN total level of needs met by informal carers*[4]	Having a designated care coordinator, having no psychiatrist or more than two and fewer needs met by informal carers.
7	Supported Living	• Supported accommodation • *Attendance at day centre or hospital* • Proportion of letters sent by CMHT or copied to user	Living in supported accommodation, attending day care and having more letters copied to the user.

[1] Items in italics were not collected in this DPhil project, for reasons given in text.
[2] CONTINU-UM is the Continuity of Care User Measure.
[3] STAR is the Scale to Assess Therapeutic Relationships in Community Mental Health Care.
[4] CAN is the Camberwell Assessment of Need.
[5] CPA is the Care Program Approach.

Continuity of care and readmission to hospital

In the study reported in this chapter, I aimed to test for associations between continuity of care and hospitalisation outcomes (rate of readmission to hospital, time to readmission to hospital, and number of days in hospital). There are three reasons why I chose hospital outcomes. First, hospitalisation outcomes such as rates of readmission are the most consistently used outcomes in mental health services research (Burns, 2007). Second, readmission is often used as a proxy for relapse of illness in patients with psychosis. It has been criticized for being a crude measure of relapse but it can be reliably collected, has face validity, and has direct utility for services in procedures such as bed-planning (Burns, 2007). Third, patient surveys also consistently show that staying out of hospital is important to patients (Schizophrenia Commission, 2012).

Time to readmission is commonly used in relapse prevention studies. Continuity of care is often presented as a key to relapse prevention and yet only one study of continuity of care has used time to readmission as an outcome. Sytema and Burgess found no association between time to readmission and continuity of care (Sytema & Burgess, 1999). However, that study used two cohorts that were treated in two different services in two different countries with not only a vastly different approach to community services, but very different levels of provision of inpatient services. Differences in time to readmission could thus be explained by differences in the availability of inpatient capacity as much as by continuity of care. It is therefore unknown whether good continuity of care is associated with reducing relapse rates.

Number of days in hospital is the most commonly used measure of hospitalisation in continuity of care studies (Puntis, Rugkasa, Forrest, Mitchell, & Burns, 2015). It is simple to compare between studies as it can be standardised to allow comparison of different follow-up lengths. Using number of days in hospital will allow comparison of the results of this study to those of previous studies.

Aims

- To investigate patterns of contact and continuity of care in community services.
- To test for associations between continuity of care and readmission to hospital, time to readmission, and number of days in hospital.

Methods

Design

In this study I used a prospective observational design. Participants were the 336 patients recruited to the OCTET trial (Burns et al., 2013). In OCTET, demographic data were collected via patient medical notes and an interview at baseline. For this study, I collected further data via medical notes at 36 months (three years) from patients' baseline measurement. Ethical approval was granted by the Staffordshire National Health Service (NHS) Research Ethics Committee (reference 08/H1204/131).

Sample

The 336 patients from the OCTET trial were recruited from 32 NHS mental health trusts across southern and central England. Recruitment of these patients took place between 10th November 2008 and 22 February 2011. Eligibility criteria were as follows:

- Between the ages of 18 to 65 years;
- A diagnosis of psychosis;
- Currently detained in an inpatient hospital under Section 3 or Section 37 of the Mental Health Act;
- Considered by their clinicians as a candidate for CTO;
- Able to give informed consent to take part in a research study

Three patients were excluded in the original OCTET trial after randomisation as they were found to be ineligible. The present study added one exclusion criterion: patients who remained as inpatients for the entire 36 months would be excluded as they would receive no community care and therefore continuity of care in community services could not be measured.

Data collection

I collected data from 1 April 2012 to 22 February 2014. Data were collected by accessing medical notes at the Mental Health Trust where the patient was being treated. Mental Health Trusts in the UK record medical notes in either paper or electronic formats, or a combination of both. Notes for each patient could exist in a number of locations, including hospitals, Community Mental Health Teams (CMHTs), and Trusts' Mental Health Act Offices (MHAOs). Inpatient and community services in some mental health trusts had separate medical notes and when these notes contradicted each other, further investigation with MHAOs was required. During the study, many Trusts changed from recording paper notes to electronic records. This often resulted in gaps in electronic notes whilst the migration from paper notes was underway. Collecting accurate data would then require requesting archived notes from remote storage facilities outside of the hospital or community team.

The data collected from medical notes included information on hospitalisation, changes in Mental Health Act status, tribunals and managers hearings, changes of care coordinator and responsible clinician, changes of community team and trust, any referrals made by the patient's community team to agencies both within the NHS (e.g. another community team, day hospitals, psychological services), and outside of the NHS (e.g. mental health charities, befriending services, social services), and all documents sent and received by the community team in connection with the patient, and all clinical face-to-face contacts between the community mental health services and patient. Information recorded for each contact included the date of the contact, the discipline of the mental health professional seen (e.g. community psychiatric nurse, consultant psychiatrist, social worker), whether that professional was the patient's care coordinator, and whether an attempted contact failed. Collecting a single patient's data took between half a day and two days depending on the volume of notes.

Selection of Measures

Baseline demographics

Baseline demographics were collected for OCTET by interview at the time of recruitment. Data were collected on age, gender, ethnicity, country of birth, years of education, marital status, diagnosis, duration of illness, number of past hospitalisations, and these data were confirmed using medical notes. Severity of symptoms was measured by the Brief Psychiatric Ratings Scale (BPRS, Overall & Gorham, 1962), and functioning was assessed using the Global Assessment of Functioning (Jones, Thornicroft, Coffey, & Dunn, 1995).

- *Brief Psychiatric Ratings Scale*: The BPRS is a 24-item scale which measures psychiatric symptoms (Overall & Gorham, 1962). Each item is marked on a seven-point Likert scale ranging from one to seven with one being 'not present' and seven being 'extremely severe'. Possible scores range from 24 to 168 with lower scores representing less severe symptoms.

- *Global Assessment of Functioning*: The GAF is a scale to assess psychological, social, and occupational functioning (Jones et al., 1995). It is rated on a 100-point scale with lower scores indicating poorer functioning.

Outcomes

There were three outcomes measured in this study:

*Readmitted to hospital***:** Recorded as whether a patient was readmitted to hospital at any point during the 36-month follow-up period. This was measured as a dichotomous yes or no answer and included both voluntary and involuntary hospitalisations.

Time to readmission: In this study, patients were recruited whilst an inpatient. Time to readmission was defined as the number of days between being discharged from this initial inpatient stay and being readmitted to hospital. In order to conduct a survival analysis, the number of days between a patient's initial hospitalisation discharge date and their 36-month follow-up time point was calculated for patients who were not readmitted. Time to readmission is a count variable and was expected to be highly skewed.

Number of days in hospital: This was calculated as the total number of days the patient spent in hospital from their first readmission to the end of the follow up. Patients who were not readmitted were recorded as spending no days in hospital and still included in the analysis.

During the OCTET trial patients in the non-CTO arm were discharged on Section 17 leave. Section 17 leave is a temporarily granted leave of absence from hospital for patients who are under involuntary detention. This leave can last between a few hours to a number of days (more rarely weeks or even months). During Section 17 leave the patient is still formally an inpatient. In order to calculate the number of days in hospital for patients on section 17 leave, patients were considered as being discharged after having seven days of continuous overnight leave. Once this was established, the period of discharge was backdated to the start of the seven days period of leave and number of days was calculated from the start of the admission to the start of that period of section 17 leave.

Continuity of care measures

There were three criteria for choosing a continuity of care measure to be used in this study. First, the measure or measures needed to assess more than one dimension of continuity of care. Second, the measure or measures needed to be intuitive to clinicians. The reason for the second criterion is that no measures of continuity of care have been adopted for use in clinical services. This may be due to most continuity measures being too complicated to calculate or collect. Continuity of care should primarily be a tool for service evaluation and therefore I decided any measure that was used in this study should be able to be collected (and used) in routine clinical services. Third, the measure or measures would have to be feasible to collect under the time constraints of a DPhil thesis. Therefore, measures had to be able to be found in routinely collected data (i.e. patient notes). None of the measures described in chapter two fulfilled all three criteria.

The ECHO measure is made up of seven factors comprised of 20 components (see Table 3.1). For this study, the factors were not retained because they did not fulfil the three criteria above. However, eight individual components that did fulfil all three criteria were used for this study.

The components excluded were excluded for the following reasons. The *Camberwell Assessment of Needs (CAN) number of met needs*, *CAN total level of needs met by informal carers*, and the *proportion of needs met* were excluded as they are better understood as outcomes of continuity of care rather than the process of continuity of care. *The Scale To Assess the therapeutic Relationship (STAR)* was excluded as the therapeutic relationship is a process that can lead to better continuity of care but is not a component of continuity of care (Adair, personal communication). Three components were excluded as they required patient interviews (*CONTINU-UM*, *CAN total level of needs*, *any user-rated breaks in care*). Four were excluded, after piloting the data collection process, as they could not be reliably ascertained from patient notes (*Contacts with primary care professionals*, *CPA copied to GP and user*, *number of agencies used in previous year*, *attendance at day centre or hospital*). *Had a transition* was excluded as all patients in this study had at least one transition as they were all discharged from hospital after being recruited. The eight remaining components used were:

- *Average gap between face-to-face contacts*: The mean number of days between each contact between a patient and member of their community team. This was calculated by summing the total number of days a patient spent in the community, and dividing it by the number of successful face-to-face contacts. It is reported as a continuous variable. This component was conceptualised by the ECHO team as a part of long-term continuity. This measure of the intensity of contact represents the regularity with which a patient is seen, and regular contact contributes to the long-term management of the patient's symptoms and a continuing relationship between patient and community team in this particular patient group (patients diagnosed with chronic severe mental illness).
- *Gaps of two months or more*: The number of instances when 60 days or more passed between a successful face-to-face contact of a patient and member of their community team and their next contact. The number of 60 day gaps is reported as a count variable. The ECHO team conceptualised these gaps as part of long-term continuity. Discontinuities in care, such as a break in treatment, are a measure of poor relationship continuity and may indicate a breakdown in the relationship between patient and team.
- *Non-medical input spread*: The total number of different non-medical professions seen (e.g. nurse, social worker, etc.) divided by the total number of contacts with

non-medical team members. The ECHO study used Non-medical input spread as a way of capturing relationship continuity, with the same profession or person being seen more often presumed to be better for continuity. Professional was used instead of individuals for pragmatic reasons as the ECHO team found it impossible to distinguish between individual staff in paper clinical notes (Catty, personal communication). This was simplified to the number of different non-medical professions the patient has been in contact with. Each profession was only counted once, and multiple members of the same profession could potentially see the same patient. It is reported as a count variable. Non-medical input spread is an operationalisation of Freeman and colleagues *longitudinal continuity*, 'having care from as few professionals as possible, consistent with needs'. This component has been reconceptualised as modern mental health services are more comprehensive and designed to address many more of a patient's needs. Greater numbers of professions seen represents more comprehensive care.

- *Number of designated care coordinators*: The total number of care coordinators (also known as keyworkers) the patient was assigned to during the follow-up period. A patient can only be assigned to one care coordinator's case load at a time and the sum of designated care coordinators is reported as a count variable. A change in care coordinator indicates a discontinuity of relationship continuity.
- *Number of designated psychiatrists*: The total number of consultant psychiatrists responsible for the patient's care during the follow-up period. A patient can only

be under the clinical care of one psychiatrist at a time and the sum of designated psychiatrists is reported as a count variable. A change in psychiatrist indicates a discontinuity of relationship continuity.

- *Supported living*: Whether the patient was discharged to supported accommodation from their index hospitalisation. Supported living is reported in this study as a dichotomous yes/no variable. It is an operationalisation of Freeman and colleagues' *contextual continuity*, the social context reflected in a patient's living situation and daily activities.
- *Documented transitions*: Has any referral to another agency been documented? Every recorded referral to a service from the community team was included. A documented transition is a referral which is supported by a referral letter or email with information about the patient, and recorded in patient notes. Relevant services were divided in to seven categories: Other mental health team (e.g. transfer to another community team, crisis team, home treatment team, or forensic service); psychological services; drug and alcohol services; social care (e.g. drop in centre, day centre; support group); individualised social support and advice (e.g. money management service; individual return-to-work advisor); specialist medical (e.g. cardiology department, neurologist); and other. Documented transitions were measured in the ECHO study as a binary yes or no variable. A *yes* answer would be recorded if the patient had one or more transitions and any of those were documented. A *no* answer would be if none of a patient's transitions were recorded or the patient had no transitions.

Documented transitions represent *continuity of information*, the information transfer which follows the user.

- *Proportion of letters sent by the CMHT copied to user*: The proportion of all letters containing information about the patient's care sent by the CMHT which are either addressed to the patient or that the patient has been copied in to. In ECHO, this proportion was transformed into a percentage and percentages were split into three categories. Having 0% of letters copied to the patient, having 1 – 50% of letters copied to the patient, or having 51% - 100% of all letters copied to the patient. This component is an operationalisation of continuity of information.

In the ECHO study these measures were transformed into categorical variables or z-scores. In this study measures were kept as continuous variables in order to make the results more clinically relevant. There were three exceptions to this. Supported Living and Documented transitions remained as dichotomous variables. Proportion of letters sent by the CMHT copied was also kept in the categories of 0%, 1 – 50%, and 51 - 100% as in the original ECHO study.

Changes in the organisation of psychiatric services in the UK

The structure of how psychiatric services were delivered in the UK changed dramatically during the course of the three year follow-up. Traditionally in the UK, psychiatric care was delivered *by the same* psychiatrist when a patient was in hospital and in the community. This is called an *integrated* system of mental health care. During the course of this study, most mental health trusts changed to a *functional* system of mental health care where consultant responsibility is divided between inpatient and community care. In a functional system the responsibility of care for a patient is transferred from an inpatient psychiatrist whilst the patient is in hospital to a community psychiatrist when the patient is in the community. These changes took place in all but two of the Mental Health Trusts that were used to recruit patients and complicated the interpretation of the number of changes in psychiatrist as a continuity of care measure in this study. Patients who were admitted to hospital would automatically have a change in psychiatrist and therefore the hospitalisation outcomes in this study would be highly correlated to the number of psychiatrists. Including it in the analysis with the full data set (including all readmissions) would produce a large effect in the statistical analysis but would not be clinically meaningful (increasing the likelihood of a type-II error). For this reason, the continuity measure 'Number of designated psychiatrists' was excluded from all analyses apart from the time-sensitive analyses.

Data management

All data were entered into a specially designed Microsoft Access (v. 2010) database. Data for the first 66 patients was first recorded on paper forms. These were double-entered into the electronic database and the double-entries were compared for accuracy and corrected. All other data were entered directly into the electronic database. Once all data was corrected the data was extracted to a

Microsoft Excel database to be cleaned. Data cleaning and quality evaluation included range checks and logical consistency checks. No further changes were made to the database once the analysis had begun.

Analysis

I created a detailed statistical analysis plan before any analysis of the data and I carried out all analyses using SPSS statistical software. Both predictor variables and outcome measures were examined using plots and graphs to check the distribution of data and identify any outliers. Pearson correlations were used to investigate associations between predictor variables. Continuity measures with a non-linear relationship to the outcome were transformed into categorical variables.

I conducted regression analyses to investigate univariate associations between the eight continuity measures and each of the three hospitalisation outcomes, adjusting for the baseline demographics of age (a continuous variable), gender (male/female), ethnicity (white/other) and BPRS score (a continuous variable). Trial arm was not included as a covariate as there was no significant difference between the two arms in the OCTET trial and there was an identical relative risk of admission RR = 1.00. Including trial arm as a covariate in the analysis would therefore not add any predictive power to the analysis whilst reducing overall power (Myers, Well, & Lorch, 2010) .I chose to use a level of significance of 0.05 in a 2-sided test.

Readmitted to hospital is a dichotomised outcome and logistic regression models were fitted between the predictor variables and outcome, adjusting for baseline variables. Results are reported as Odds Ratios (OR) with 95% confidence intervals (95% CIs).

Time to readmission is a time-to-event outcome and a proportional hazards model was fitted for each variable adjusting for baseline measures. Data were censored at the date of readmission, date of death or discharge from secondary services, or end of trial date (whichever occurred sooner). Results are reported as Hazard Ratios (HR) with 95% CIs. I conducted a sensitivity analysis using only the patients who were admitted to hospital during the trial to investigate if the differences observed in the main analysis were due to patients who were not readmitted.

Number of days in hospital is a count outcome and it was analysed using a negative-binomial model adjusting for each of the continuity of care measures and baseline variables. I chose a negative binomial regression because of the likelihood of many zero values. Results are reported as Incidence Rate Ratios (IRR) with 95% CIs. A sensitivity analysis was conducted which excluded patients who were not readmitted during the trial.

For all three outcomes, variables with a significance level equal to or below 0.05 were included in a multivariable model. I chose this approach to the analysis because of the high number of predictor variables. Retaining only the predictor variables which are significant in univariate analysis reduces complexity of the model and increases predictive power (Myers et al., 2010).

Results

Participants

Data for 323 of the 333 patients in OCTET were collected in this study. Five patients were excluded for being inpatients throughout the 36 month follow-up period, data for four patients could not be collected (two complete sets of notes were destroyed in a fire at a participating Trust's archive, the study team was denied access to one set of notes, and one set of notes was lost by an archive company delivering them to the community team). One patient withdrew consent during the follow-up.

There were 20 deaths during the 36-month follow-up period. These included 13 deaths from natural causes, six suicides, and one accidental death from a drug-overdose. 26 patients were discharged from secondary services during the follow-up period. Three of the 26 were discharged as they had moved abroad, and five of those discharged were later re-referred to community services. Data for deceased or discharged patients were censored at the relevant time point in the analysis.

Baseline socio-demographics and clinical characteristics

Table 3.2 presents the baseline socio-demographics and clinical characteristics of the included patients. The mean age of the 323 patients at baseline was 39.6 years (SD = 11.39) and 105 (33.5%) were female. The majority of patients were born in the United Kingdom (n = 246, 76.2%) and 196 (60.7%) were 'white'. Very few patients were married or cohabitating (n = 28, 8.7%), although 132 (41.1%)

had children. Only two patients (1%) were in regular employment. The majority of patients had a diagnosis of schizophrenia (n = 275, 85.1%). The mean number of previous hospitalisations was 6.7 (SD = 6), and time from onset of illness was a mean of 14.42 years (SD = 10.45).

Readmission and hospital

Almost two-thirds of patients were readmitted during the 36 months (n = 206, 63.8%, Table 3.3). Patients spent a mean of 192.4 days in hospital over the three year follow-up although this was highly variable (SD = 236.6, median = 107, IQR = 31, 261). The time between patients' index discharge and first readmission (or the end of the trial or censoring point) was also highly variable, with a mean of 586 days (SD = 413.0), and a median of 539 (IQR = 192, 1057). Including only those readmitted, the mean number of days between a patients' index discharge and first readmission was 325.3 (SD = 273.8, median = 249.5, IQR = 100.5, 489).

Table 3.2. Baseline socio-demographic and clinical characteristics of included participants.

	Total					
	Sample Size	Missing Data N(%)	N Mean	% (SD)	Median	IQR
Age, *years*	323	0	39.6	(11.4)	39	30, 47
Gender, male	323	0	218	67.5	--	--
General education, *years*	319	4 (1%)	11.9	(1.9)	11	11, 13
Ethnicity	323	0	--	--	--	--
White	--	--	196	60.7	--	--
Black	--	--	75	23.2	--	--
Asian	--	--	29	8.9	--	--
Mixed and other	--	--	23	7.1	--	--
Born in UK	322	1 (1%)	246	76.2	--	--
Married or cohabitating	321	2 (1%)	28	8.7	--	--
Children, *yes*	321	2 (1%)	132	41.1	--	--
Identified carer, *yes*	297	26 (8%)	111	34.4	--	--
Accommodation	309	14 (4%)	--	--	--	--
Independent	--	--	222	71.8	--	--
Supported	--	--	56	18.1	--	--
Homeless	--	--	31	10.0	--	--
Employment	322	1 (1%)	--	--	--	--
Unemployed	--	--	318	98	--	--
Voluntary/ protected/ sheltered	--	--	2	1	--	--
Regular employment	--	--	2	1	--	--
Duration of illness, *years*	313	10	14.4	(10.5)	12	6, 21
Number of past hospitalisations	302	21 (7%)	6.7	(6)	5	3, 8.3
BPRS total score	302	21 (7%)	38.7	(11.4)	36.5	32, 45
GAF total score	302	21 (7%)	38.7	(9.5)	39	30, 46.3

Service Utilisation

Table 3.4 presents descriptive data on service utilization during the 36-month follow-up. Patients had a median of 79.5 (range 1 – 490) face-to-face contacts over the 36-month follow-up. Patients had 2.3 (SD = 1.3) different care coordinators and 3.7 (SD = 2.8) consultant psychiatrists responsible for their care over 36 months. Patients had contact with 5.4 (SD = 1.7) different types of mental health professional, with most patients seeing a community psychiatric nurse (n=315, 97.5%) and consultant psychiatrist (n=309, 95.7%) during their time in the community. Other professions seen include social workers (n = 261, 80.8%), support workers (n = 235, 72.8%), staff-grade psychiatrists (n = 230, 71.2%), occupational therapists (n = 133, 41.2%) and clinical psychologists (n = 73, 22.6%).

Patients had a mean of 4.3 (SD = 3.2) referrals to other services and a mean of 18.9 (SD =11.5) documents sent by their community team to others involved in their care (this included letters to the patient themselves).

Descriptions of continuity of care measures

Table 3.5 presents descriptive data for each continuity of care variable. The median number of days between face-to-face contacts was 9.9 (IQR = 5.9; 15.2), and 181 (56.2%) patients did not have any 60-day periods without face-to-face contact. As detailed above, patients had a mean of 2.3 care coordinators responsible for their care and 3.7 separate *episodes of care* with psychiatrists. The mean number of *unique psychiatrists* was 2.9 (1.6) per patient. *Episodes of care* refers to each time a patient changed psychiatrists whilst *unique psychiatrists* refers to the number of different psychiatrists the patient was under the care of. Patients could have different episodes of care with the same psychiatrist (for instance, if the patient was admitted to hospital and cared for by an inpatient psychiatrist and then discharged to the same community psychiatrist).

There were 71 patients (22%) who were discharged to supported accommodation at the end of their index admission. Patients had just under two-thirds (mean = 0.6, SD = 0.4) of their referrals documented in their medical records and 42% of all documents about their care sent by the community team were copied to the patient.

Table 3.3. Patient hospitalisation outcomes at 36 month follow-up

	Total					
	Sample size	Missing	N Mean	% (SD)	Median	IQR
Readmitted, yes	323	0	206	63.8	--	--
Number of days to first readmission from index discharge	323	0	586.00	(413.02)	539	192, 1057
Of those readmitted	206	0	325.33	(273.85)	249.50	100.5, 489
Number of days in hospital from 1st readmission	323	0	140.37	(219.64)	51	0, 174
Of those readmitted	206	0	220.10	(241.124)	122	57.75, 285.75

Table 3.4. Pattern of care and documentation

	Sample Size	N Mean (SD)	% Median [IQR]
Number of successful community contacts	322	105.18 (89.00)	79.50 [46.75, 130.75]
Contacts per month		2.9 (2.47)	2.20 [1.29, 3.63]
Number of care coordinators, *per patient*	319	2.3 (1.26)	2 [1, 3]
1	--	109	34.2%
2 – 3	--	157	49.2%
4 or more	--	53	16.6%
Number of consultant psychiatrists, *per patient*	320	3.66 (2.78)	3 [2, 5]
1	--	74	23.2%
2 – 3	--	126	39.4%
4 or more	--	120	37.5%
Number of different mental health professions seen, *per patient*	323	5.42 (1.71)	5 [4, 7]
Number of referrals to other services	312	4.3 (3.2)	4 [2, 6]
Number of documents sent to other agencies about the patient	322	18.9 (11.5)	16.0 [11, 27]

Table 3.5. Description of continuity of care variables

	36 month follow-up		
	Sample Size	N Mean (SD)	% Median [IQR]
Average gap between face-to-face contacts	321	13.37 (15.36)	9.88 [5.95, 15.20]
Number of 60 day gaps without contact	322	0.93 (1.41)	
No gaps	--	181	56.2%
1 gap	--	68	21.1%
2 gaps	--	28	8.7%
3 gaps	--	19	5.9%
4 gaps	--	17	5.3%
5 or more	--	9	2.7%
Number of care coordinators, *per patient*	319	2.3 (1.26)	2 [1, 3]
1	--	109	34.2%
2 – 3	--	157	49.2%
4 or more	--	53	16.6%
Number of psychiatrists (episodes of care), *per patient*	320	3.66 (2.78)	3 [2, 5]
1	--	74	23.2%
2 – 3	--	126	39.4%
4 or more	--	120	37.5%
Number of unique psychiatrists (named individuals), *per patient*	320	2.85 (1.64)	3 [2, 4]
1	--	73	22.8%
2 – 3	--	164	51.3%
4 or more	--	83	25.9%
Number of different types of mental health professions seen, *per patient*	323	5.42 (1.71)	5 [4, 7]
Discharged from index admission to support accommodation, *yes*	322	71	22%
Proportion of referrals documented	295	0.64 (0.35)	0.67 [0.43, 1]
Proportion of documents copied to user	321	0.42 (0.26)	0.42 [0.23, 0.59]

Associations between continuity of care measures and outcomes

Readmitted to hospital

Table 3.6 presents the univariate associations between continuity of care measures and age, gender, ethnicity, and BPRS score with having been readmitted to hospital. Average gap between face-to-face contacts, number of care coordinators, and any referral documented were all significantly associated with readmission to hospital.

Multivariable analysis including only the measures that were significant in univariate analysis produced a significant model statistic n=311 $x^2 = 24.880$ $p>0.000$. Average gap between face-to-face contacts was significantly associated with readmission (OR=0.961, 95%CI = 0.938, 0.985, p=0.001), meaning that for every day increase in the average gap between face-to-face contacts the odds of being readmitted reduced 3.9%. Having no referrals documented was associated with a decrease in the odds of being readmitted (OR=0.569, 95%CI = 0.352, 0.922, p=0.022). Table 3.7 presents the results of the multivariate analysis.

Time to readmission

The univariate associations between the continuity measures and baseline demographics with time to readmission are presented in table 3.8. Average gap between face-to-face contacts, number of 60 day gaps without a contact, number of different mental health professionals seen, number of care coordinators, number of psychiatrists, and proportion of documents copied to user were all significantly associated with time to readmission. The symptom measure BPRS was also associated with time to readmission.

Table 3.6. Univariate associations between continuity measures and baseline characteristics with readmission

Measure	N (% missing)	OR	95%CI	Sig
Average gap between face-to-face contacts	321 (0.6%)	0.964	0.943, 0.986	0.001
Number of 60 day gaps without contact	322 (0.3%)	0.865	0.738, 1.013	0.073
Number of different mental health professions seen, *per patient*	323 (0%)	1.092	0.831, 1.435	0.526
Number of care coordinators, *per patient*	319 (1.2%)	1.229	1.014, 1.489	0.035
Discharged from index admission to support accommodation, *yes*	322 (0.3%)	1.302	0.759, 2.233	0.339
Any referral documented, *no*	314 (2.8%)	0.528	0.332, 0.841	0.007
Proportion of documents copied to user	321 (0.6%)	-	-	0.891
1 – 50%		0.929	0.443, 1.949	0.845
51 – 100%		0.867	0.401, 1.801	0.746
Age, *years*	323 (0%)	0.991	0.971, 1.011	0.366
Gender, *male*	323 (0%)	1.133	0.696, 1.845	0.615
Ethnicity, *white*	323 (0%)	1.397	0.880, 2.218	0.156
BPRS score	302 (6.5%)	1.017	0.996, 1.038	0.122

Table 3.7. Multivariate associations between continuity measures with readmission

Measure	**OR**	**95%CI**	**Sig**
Average gap between face-to-face contacts	0.961	0.938, 0.985	0.001
Number of care coordinators, *per patient*	1.175	0.962, 1.437	0.114
Any referral documented, no	0.569	0.352, 0.922	0.022

In the multivariable analysis (Table 3.9) an increase of one 60-day gap was associated with a 40% chance of having a later readmission to hospital (HR = 0.596, 95%CI = 0.480, 0.741, p = 0.000). For each extra mental health profession seen, there was an associated 14.3% increased chance of being admitted later than the median time to readmission HR = 0.857 (95%CI = 0.770, 0.953, p = 0.004). Each increasing change of care coordinator was associated with a 43.4% decrease in the risk of readmission earlier than the median readmission time HR = 0.566 (95%CI = 0.460, .695, p = 0.000). No documents copied to the patients was also significantly different from 1-50% (HR = 0.326, 95% = 0.230, 0.462, p < 0.000) of documents (HR = 0.326, 95%CI = 0.230, 0.462, p < 0.000) and 51-100% of documents (HR = 0.378, 95%CI = 0.259, 0.552, p < 0.000) copied. Having no documents copied to the patient was associated with a shorter time to readmission. The BPRS score was significantly associated with time to readmission, with each unit increase of total BPRS score associated with a 1% increased chance of being readmitted early HR=1.014 (95%CI = 1.001, 1.027, p=0.036).

A sensitivity analysis was conducted including only the readmitted patients. An increase in 60 day gaps was associated with a longer time to readmission (HR = 0.632, 95%CI = 0.497, 0.802m p > 0.000). A higher non-medical input spread (seeing more professions) was also associated with later readmission to hospital (HR = 0.884, 95%CI = 0.794, 0.983, p = 0.023) as was fewer changes in care coordinator (HR = 0.651, 95CI = 0.513, 0.827). Having no sent documents copied to the patient was associated with a shorter time to readmission in comparison to 1 – 50% of documents (HR = 0.371, 95%CI = 0.254, 0.541, p < 0.000) and 51% - 100% (HR = 0.378, 95%CI = 0.254, 0.562, p < 0.000) documents copied to the patient. The only difference between the full analysis and the sensitivity analysis was that BPRS was no longer associated with a shorter time to readmission (HR = 1.000, 95%CI = 0.988, 1.013, p = 0.992) in the sensitivity analysis.

Duration of readmissions

Table 3.10 presents the univariate associations between continuity of care measures and age, gender, ethnicity, and BPRS score with number of days in hospital. The variables significant in univariate analysis were average gap between face-to-face contacts, number of 60 day gaps without contact, number of care coordinators, documented referral, proportion of documents copied to user, and BPRS score.

In multivariable analysis a bigger average gap between face-to-face contacts was associated with duration of readmissions (IRR = 0.969, 95%= 0.959, 0.978, p=0.000, Table 3.11), meaning that for every day increase in gap between average contact patients had a 3.1% decrease in number days in hospital. Duration of hospitalisation was also associated with a higher number of 60 day gaps (IRR=0.876, 95%CI = 0.791, 0.970, p=0.011), with each extra 60 day gap associated with a 24% decrease in the number of days in hospital. Designated care coordinator numbers were associated with duration of hospitalisation (IRR=1.152, 95%CI = 1.052, 1.261, p=0.001), with each new care coordinator associated with a 15.2% increase in the number of days in hospital. Having a referral documented (IRR= 1.494, 95%CI=1.153, 1.937, p=0.002) was associated with a 49% higher rate in the number of days in hospital, and having a lower BPRS score (IRR=1.012, 95%CI = 1.001, 1.023, p=0.026) was significantly associated with fewer days in hospital so that each additional point increased the chance of having more days in hospital by 1%. Having 0% of documents copied to the patient was significantly different to both 1-50% IRR= 0.474 (95%CI= 0.317, 0.709, p=0.000) and 51-100% IRR=0.418 (95%CI=0.279, 0.627, p=0.000) of documents copied.

Table 3.8. Univariate associations between continuity measures and baseline characteristics with time to readmission

Measure	N (% missing)	HR	95%CI	Sig
Average gap between face-to-face contacts	322 (0.3%)	0.989	0.978, 1.000	0.042
Number of 60 day gaps without contact	322 (0.3%)	0.615	0.513, 0.737	0.000
Number of different mental health professions seen, *per patient*	323 (0%)	0.901	0.817, 0.994	0.037
Number of care coordinators, *per patient*	319 (1.2%)	0.515	0.426, 0.624	0.000
Number of psychiatrists, *per patient*	320 (0.9%)	0.699	0.599, 0.815	0.000
Discharged from index admission to support accommodation, *yes*	322 (0.3%)	1.097	.0784, 1.535	0.589
Any referral documented, *yes*	314 (2.8%)	1.143	0.865, 1.510	0.348
Proportion of documents copied to user	323 (0%)	-	-	0.000
1 – 50%		0.299	0.216, 0.414	0.000
51 – 100%		0.314	0.222, 0.444	0.000
Age, *years*	323 (0%)	0.958	0.988, 1.012	0.958
Gender, *male*	323 (0%)	1.077	0.807, 1.439	0.615
Ethnicity, *white*	323 (0%)	0.844	0.636, 1.121	0.242
BPRS score	302 (6.5%)	1.013	1.00, 1.025	0.044

Table 3.9. Multivariate associations with time to readmission

Measure	HR	95%CI	Sig
Average gap between face-to-face contacts	0.997	0.990, 1.004	0.361
Number of 60 day gaps without contact	0.596	0.480, 0.741	0.000
Number of different mental health professions seen, *per patient*	0.857	0.770, 0.953	0.004
Number of care coordinators, *per patient*	0.566	0.460, 0.695	0.000
Number of psychiatrists, *per patient*	0.929	0.783, 1.102	0.399
Proportion of documents copied to user		-	0.000
1 – 50%	0.326	0.230, 0.462	0.000
51 – 100%	0.378	0.259, 0.552	0.000
BPRS score	1.014	1.001, 1.027	0.036

A sensitivity analysis was conducted using only readmitted patients. Having more 60 day gaps was significantly associated with a fewer days in hospital (IRR = 0.876, 95%CI = 0.791, 0.970, p > 0.000) as was having fewer changes in designated care coordinator (IRR = 1.152, 95%CI = 1.052, 1.261, p = 0.001). Having no documents copied to the patient was associated with having more days in hospital than having 1 – 50% (IRR = 0.545, 95%CI = 0.339, 0.876, p = 0.012) and 51 – 100% (IRR = 0.440, 95CI% = 0.268, 0.722, p = 0.001) of documents copied. Three associations that were significant in the full analysis were not significant in the sensitivity analysis. These were the average gap between face-to face contacts (IRR = 0.985, 95%CI = 0.968, 1.002, p = 0.083), any referral documented (IRR = 1.171, 95%CI = 0.849, 1.615, p = 0.355) and BPRS score (IRR = 1.008, 95%CI = 0.995, 1.022, p = 0.227).

Table 3.10. Univariate associations between continuity measures and baseline characteristics with number of days in hospital

Measure	N (% missing)	IRR	95%CI	Sig
Average gap between face-to-face contacts	321 (0.6%)	0.959	0.951, 0.966	0.000
Number of 60 day gaps without contact	322 (0.3%)	0.759	0.703, 0.820	0.000
Number of different mental health professions seen, *per patient*	323 (0%)	0.888	0.779, 1.011	0.073
Number of care coordinators, *per patient*	319 (1.2%)	1.192	1.101, 1.290	0.000
Discharged from index admission to support accommodation, *yes*	322 (0.3%)	0.938	0.720, 1.221	0.663
Any referral documented, *no*	314 (2.8%)	0.656	0.524, 0.820	0.000
Proportion of documents copied to user (0%)	321 (0.6%)	-	-	-
1 – 50%		0.529	0.372, 0.752	0.000
51 – 100%		0.423	0.293, 0.612	0.000
Age, *years*	323 (0%)	0.998	0.988, 1.007	0.606
Gender, *male*	323 (0%)	0.903	0.714, 1.140	0.390
Ethnicity, *white*	323 (0%)	1.299	1.038, 1.625	0.022
BPRS score	302 (6.5%)	1.022	1.011, 1.033	0.000

Table 3.11. Multivariate associations with days in hospital

Measure	IRR	95%CI	Sig
Average gap between face-to-face contacts	0.969	0.959, 0.978	0.000
Number of 60 day gaps without contact	0.876	0.791, 0.970	0.011
Number of care coordinators, *per patient*	1.152	1.052, 1.261	0.001
Any referral documented, *yes*	1.494	1.153, 1.937	0.002
Proportion of documents copied to user	1	-	-
1 – 50%	0.474	0.317, 0.709	0.000
51 – 100%	0.418	0.279, 0.627	0.000
Ethnicity, *white*	0.927	0.714, 1.203	0.569
BPRS score	1.012	1.001, 1.023	0.026

Discussion

The aims of this study were to describe patterns of contact and continuity of care in a sample of patients with psychosis and to test for associations between continuity of care and hospitalisation outcomes.

Patterns of contact

Patients were seen by their community team with remarkable frequency, with a mean of 2.9 community contacts a month over a three year period. There appears to have been an increase in the amount of community contact with patients by mental health services in the UK in the last 25 years. At the beginning of the 1990s Burns and colleagues reported that a sample of general psychiatric patients in the community received a mean of 5.5 contacts *a year* (Burns, Raftery, Beadsmoore, McGuigan, & Dickson, 1993). In 2000 the UK700 trial reported that severe psychosis patients receiving standard community care from a CMHT received a mean of 1.46 contacts per month, which was considered good quality care at the time (Burns et al., 1999). Patients in this study received twice the amount of contacts as the patients in the UK700 trial.

Patients in this study were also seen consistently over the 36-month follow-up. More than half (n = 181, 56.2%) had no 60-day breaks in care and more than three-quarters (n = 249, 77.3%) had one break or less. Only 8% (n = 26) of patients were discharged from community services. This figure includes both those discharged due to disengagement and those well enough to no longer need community support. Reports in the literature of the prevalence of disengagement in patients with psychosis vary between 8% and 40% depending on the measurement of disengagement, follow-up duration, and country (O'Brien, Fahmy, & Singh, 2009). The data gathered from this study suggests that in the UK, patients with severe mental illness are seen frequently and are assertively kept engaged with services.

Patients changed care coordinator a mean of once every 15.5 months. Patients in this study had longer periods of care coordinator stability than in Bindman and colleagues' 2000 study (a change every 10 months, Bindman et al., 2000) and were comparable to Heffernan and Husni's 2009 study in three London-based community mental health teams (a change between 14 – 21 months, Heffernan & Husni, 2009). Turnover of care coordinators seems to have decreased in the last ten years, providing less fragmented care. However, in the context of long-term mental health treatment, changing care coordinator every 15.5 months is still fairly frequent given the mean duration of illness in this sample of 14.4 years.

Patients also had contact with many types of mental health professionals during the course of the study. Almost all patients had contact with a community psychiatrist and a community psychiatric nurse. Overall, patterns of contact suggest patients had frequent and continuous contact with the same professional care coordinator who was supported by a multidisciplinary team.

The association between regularity and outcomes

In this study, having more frequent face-to-face contacts was associated with increased odds of being readmitted and longer hospital stays. Having fewer 60-day gaps of contact was associated with an increased chance of being readmitted early and longer hospital stays. Continuity of care, measured as intensity and regularity of contact, was therefore associated with worse outcomes.

This finding is similar to the ECHO study which found that an increase in regularity (defined as being seen more frequently by staff from fewer non-medical disciplines) was associated with an increased likelihood of being hospitalised (Catty et al., 2013). Greenburg and Rosenheck found that intensity of contact was associated with poorer functioning (Greenberg & Rosenheck, 2005) and Vita and colleagues found greater intensity of contact was associated with a higher likelihood of treatment discontinuation (Vita et al., 2008).

This increase in contacts may represent an appropriate response to the needs of the patient. Readmissions may result from relapse which had been attended to by more frequent clinical follow-up. Frequent (and consistent) contact was considered by clinicians and researchers as vital to continuity of care at a time when many continuity measures were created. This reflected a widespread consensus that many patients needed more contact with community services. However, community patients at that time appear to have had far less contact with services than they do in current services. Most patients are now seen very regularly as part of standard clinical practice. Variations in the amount of contact a patient now receives appear to reflect the severity of a patient's illness. This suggests community teams operate flexibly by increasing contact with patients who need it. The benefit of this approach to coordinating care is that patients in the community are supported when ill but have more independence when doing better. How then does one measure this flexibility?

Measuring flexibility in continuity of care

In Haggerty and colleagues' continuity of care review they argue that in chronic conditions, consistency and flexibility are vital when managing care as patients' needs and circumstances change (Haggerty et al., 2003). Our data suggests that this flexibility is reflected in the services that teams provide. Measures of continuity of care that attempt to link accumulation of contacts, such as the average gap between contacts, to improved outcomes are not sensitive to services' clinical responsiveness and flexibility that are appropriate to patients' needs (referred to as flexible continuity from here on).

Two previous studies have attempted to measure flexible continuity, although both suffer from limitations. Adair and colleagues' Alberta Continuity of Services Scale for Mental Health (ACSS-MH) observer-rated scale has an item which measures flexibility. It asked the rater whether "frequency of appointments have changed in response to increase or decrease in need" (Adair et al., 2005). This required a subjective judgement to be made from patient notes. The ECHO study proposed two measures to indicate flexible continuity (neither was included in the ECHO final analysis). The first measured any increase in contacts in the three months prior to admission. Its limitation was that it could only measure deterioration that ended in admission. Deterioration that did not end in an admission, admissions averted by increased contact, or decreases in contact for a patient who was stable would not have been recorded. The second ECHO measure asked patients whether they had an increase in contacts in three months prior to deterioration in their health. It relied on patient report and it was only asked at the end of a twelve month period and therefore lacked the sensitivity to measure multiple changes in need through the course of the year.

The Adair and ECHO measures illustrate the challenge in measuring flexible continuity. One first needs to be able to record patient deterioration in order to ascertain whether changes in the frequency of patient contact are an appropriate reaction to deterioration (or improvement). Adair and colleagues achieved this by reading patient notes, whilst ECHO measured increased contact to being admitted to hospital or patient report of deterioration.

The association between changes in care coordinator and outcomes

In this study, more frequent changes in care coordinator were associated with a higher risk of longer hospital stays. Three previous studies found no association between changes in care coordinator and hospitalisation (Bindman et al., 2000; Heffernan & Husni, 2009; Lehman et al., 1994).

Conversely, patients with more changes in care coordinator also had a decreased risk of being readmitted earlier than the median time to readmission. This result may be misleading due to a time-dependant bias. Patients who took longer to be readmitted (or who were not readmitted) had more days in the community to experience a change in care coordinator than patients who were readmitted early. This bias exists in the opposite direction for the association with number of days in hospital. Patients who spent *more* days in hospital had fewer days in the community to accrue changes in care coordinator. Even with this bias, more changes in care coordinator were associated with more days in hospital. Therefore, if one were to control for the bias, having fewer changes in care coordinator could result in an even stronger association with fewer days in hospital.

The results from this study suggest that patients benefit from stability in their relationships with their community mental health team. Previously this stability was provided by a patient's psychiatrist, but today the relationship between a patient and their care coordinator is increasingly important. This is likely due to the relative infrequency a patient is seen by their psychiatrist in comparison to their care coordinator and because most patients in the UK now change psychiatrist each time they are readmitted due to a functional system of care, where inpatient and community clinical roles are divided.

The care coordinator looks after the patients' health and social needs and has frequent contact with them. Patients have reported that their relationship with the care coordinator takes time to develop, and that discontinuity in staff can leave users “helpless and isolated” (Jones et al., 2009). Some report that having to retell their history numerous times, and having to build new, trusting relationships with ever changing staff members is a distressing experience. This study’s result that a long-term stable relationship between patient and care coordinator is associated with a better outcome supports the qualitative findings. It also compliments Haggerty and colleagues’ description of relationship continuity, where staff consistency provides patients with “a sense of predictability and coherence” (Haggerty et al., 2003, pg. 1221). Once a relationship is established, there is some evidence that a more positive therapeutic relationship improves outcomes (Priebe, Richardson, Cooney, Adedeji, & McCabe, 2011a) and is stable over time (Martin, Garske, & Davis, 2000). It is this positive relationship over time which reflects a continuity of care that leads to better outcomes.

This may be because the care coordinators who have known patients for a long time are more aware of signs of deterioration and are able to respond quickly to it. This may result in earlier admissions, but shorter stays in hospital. Alternatively, this association may be due to the positive effect that a stable relationship has on patients *whilst they are in the community*. Patients with schizophrenia who have a positive relationship with their keyworker have been shown to have better medication adherence than those who do not, have fewer hospitalisations, and have improved symptom levels (McCabe et al., 2012; Priebe et al., 2011a). Regardless of the underlying mediator, the results in this study suggest every effort should be made to reduce the frequent changes in a patient's care coordinator.

The association between copying of correspondence and outcomes

Having a patient copied in to a higher proportion of letters sent about them was associated with a reduced likelihood of early readmission and fewer hospital days. Therefore having good information continuity, which includes keeping a patient informed of their treatment, is associated with better outcomes.

Haggerty and colleagues describe information continuity as "the thread linking care from one healthcare event to another" (Haggerty et al., 2003, pg. 1220). Copying letters to patients in GP surgeries is covered in Department of Health guidance and is considered good practice. A survey of 500 Ear, Nose, and Throat (ENT) outpatients found that 93% of patients said that copying them into the letter sent to their GP helped them understand their condition, whilst 95.5% expressed that it was a good thing to do (Pothier, Nakivell, & Hall, 2007). Similar results have been found in genetics (Cassini et al., 2011), orthopaedics (Pinder, Jefferys, & Loeffler, 2013), a general hospital outpatient department (Lepping, Paravastu, Turner, Billings, & Minchom, 2010), and with psychiatric patients (Nandhra, Murray, Hymas, & Hunt, 2004). In Lepping and colleagues' study, psychiatric patients were more likely to want letters copied than other medical and surgical patients. A feasibility study by Asch and colleagues found that giving new psychiatric outpatients a summary of their first consultation made them more satisfied with their consultations than those that did not receive a summary (Asch, Price, & Hawks, 1991).

Most patients wish to be more engaged with, and informed about, their treatment (Laine & Davidoff, 1996). Patients with psychiatric illness should not be excluded from this engagement and this study suggests that patients may benefit clinically by being included in the information shared about them. Including patients when disseminating information may improve continuity of care in two ways. First, patients may benefit directly through improving their understanding of their condition and the management of that condition. Second, keeping patients informed of their treatment across services may foster a trusting relationship between community team and patient. In a qualitative review of patients with depression and anxiety, patients receiving copies of letters reported having a better understanding of their care and feeling greater involvement. They also reported being satisfied that the psychiatrist had listened to their concerns when reading letters sent by their psychiatrist to their GP (Cape, Harvey, Johnson, & Linke, 2005). The benefits reported by Cape and colleagues may underlie the association found in this study.

The difficulty in measuring continuity of care

One of the aims of this study was to replicate the ECHO measures of continuity of care. However, during the design of this study a number of changes to the original ECHO methodology had to be made. The factorial structure was not retained and 12 of the 20 individual measures had to be excluded from data collection. Three of these were not collected because they required patient interview, five could not be collected reliably from patient notes and four were no longer considered to be true measures of continuity of care. This illustrates two key difficulties when measuring continuity of care. First, the information that services record changes over time. Therefore what may have been simple to collect in previous studies may not be possible in new studies and vice versa. Second, the difficulty in distinguishing continuity of care from other overlapping concepts, such as the therapeutic relationship, means that measures used in previous studies may no longer be relevant.

The variable used to indicate changes in psychiatrist was not used in two of the outcome analyses (risk of readmission and number of days in hospital) after it became clear that the nature of the relationship between measure and outcome had become directly influenced by the recent separation of inpatient and community roles. Having a different psychiatrist for inpatient and community treatment may still be considered a discontinuity of care, however the link between changes in psychiatrist and hospitalisation outcomes can no longer be measured in the way ECHO originally intended when a single psychiatrist treated a patient both as an inpatient and as an outpatient. In ECHO, the number of changes in psychiatrist represented the length and stability of a relationship between psychiatrist and patient. In this study, changes in psychiatrist happened each time that a patient was admitted and discharged and therefore is more of a reflection of mental health service structures than the stability of a relationship. Thus, changes in how services are arranged may also affect the applicability of previous measures. These three reasons meant that this study had to refine continuity of care measures used in the ECHO study.

Other limitations

In my analysis ethnicity was measured as a dichotomous variable; white or other. This analysis was chosen for simplicity. However, by using dichotomous rather than multiple categories, differences in continuity of care between ethnicities may not have been identified. For instance, previous research has shown that whilst both Black and Asian patients have a higher odds of detention than white patients, Black patients also have almost double the odds of detention than Asian patients (Singh et al., 2007). My analysis may have not identified such subtleties.

Another limitation is that the analysis did not control for the type of community team (i.e. ACT, CMHT, or Early Intervention Service) that the patient was assigned to. This study measured changes in community team and it became clear that the majority of patients changed teams so frequently, and the teams themselves changed so frequently, performing a cluster analysis by type of team was neither feasible nor would it reflect clinical practice. Examination of patients' records also seemed to show that contact frequency was related to severity of illness and team capacity rather than team type. It is possible that the frequency of contact may be different depending on the type of team a patient is assigned to but is unlikely given the surprisingly consistent high rates of contact identified in this study.

Conclusions

Two key conclusions can be drawn from this study. First, patient follow-up has improved considerably in the last three decades for patients with the most severe mental illnesses. Second, community mental health teams have shifted the focus of community contact from intensive services to flexible services and therefore using intensity of contact as a measure of continuity of care is of limited value.

The initial consensus when continuity of care theory in mental health was first debated was that more, and more consistent, patient contact would result in better outcomes. This echoed the approach of mental health services at the time. This approach to monitoring patients in the community has been turned on its head. Consistent and frequent levels of contact seem to reflect the severity of a patient's illness. This suggests that it is more important to measure continuity of care not by how often you have contact with a patient, but how often you *need* to have contact with a patient. Measuring flexible continuity may better represent the way that services are currently organised. Using a simple measure such as contact frequency as a measure of continuity of care may now be misleading and redundant.

A further finding was that a higher turnover of care coordinator was associated with poorer outcomes. Changes in care coordinator are likely to be independent of the severity of illness. Changes are probably due to staff turnover, because of service reorganisation, or less frequently, because patients leave the area.

Finally, this study found that copying in patients to the communications about them was associated with better outcomes. The involvement of patients in their own treatment is increasing throughout general medicine. The evidence from this study suggests that this simple contribution to increased involvement may be beneficial to this group of severely ill psychiatric patients and improve outcomes.

Chapter Four: The association between outpatient compulsion and continuity of care

Introduction

Chapter one described the process of deinstitutionalisation that has taken place in UK mental health services over the last 60 years. Many patients with severe mental health problems are now treated in the community and are only admitted to hospital when their illness becomes severe enough to warrant concern for the safety and wellbeing of themselves or others. The evolution from institutional care to community care is widely considered a success but treating patients in the community brings its own challenges. For many patients, the challenge is that their needs in the community go beyond the treatment of their illness, such as comorbid health problems and social needs. For community psychiatric services, the difficulties lie in how to provide mental health treatment, monitor patients, and ensure treatment adherence.

The effectiveness of treating patients in the community

As discussed in chapter one, there were ethical, political, economic, and medical drivers of deinstitutionalisation (Turner, 2004). It is generally accepted that there are clinical and social advantages to long-term treatment in the community compared to hospital treatment. Many patients who have been discharged after an extended period of institutional care gain independent living skills and report better quality of life, increases in social networks, and report a preference to living as outpatients (Creed et al., 1990; Hoult, Reynolds, Charbonneau-Powis, Weekes, & Briggs, 1983; Leff & Trieman, 2000; Stein & Test, 1980; Thornicroft, Bebbington, & Leff, 2005). Few of these patients become homeless, engage in criminal behaviour, or have to have long-term readmissions to hospital. Their mortality rates were no worse than those of psychiatric inpatients (Trieman, Leff, & Glover, 1999). Treating patients in the community was also shown to be less expensive although this has been disputed more recently (Smoyak, 2000).

There have been constant efforts to improve community care over the last 30-40 years and various alternate models have been proposed. Innovations such as Assertive Community Treatment (ACT), Early Intervention Teams, and Crisis Intervention Teams have initially been shown to be more effective than standard Community Mental Health Teams in reducing relapse and need for hospital care, although with accumulating research these effects have become less convincing (Burns, Catty, Dash, et al., 2007; Catty et al., 2002). Burns and colleagues identified that most of these programmes use the same kinds of mechanisms to support patients in the community. These include “regular outreach, predictable caseloads for case-managers, multidisciplinary team working, simultaneous attention to social care and the involvement of psychiatrists” (Burns, 2010b, pg. 339). The combination of these mechanisms in community treatment leads to most patients having better quality and more rewarding lives in the community in comparison to protracted inpatient care.

Despite these advances in community treatment, there has been an increase in the rate of involuntary admissions to hospitals (Priebe et al., 2005). This may be due to a reduction in inpatient beds causing patients to be discharged before they are well enough and a higher threshold of illness severity before admission meaning that involuntary patients are prioritised (Keown, Weich, Bhui, & Scott, 2011), increasingly risk-averse clinicians who readmit patients as soon as they deteriorate (Schizophrenia Commission, 2012), and social isolation of patients who need regular support (Vaughn & Leff, 1976). There also remains a group of patients who have frequent and persistent involuntary readmissions to hospital. These patients are often referred to as *revolving-door* patients (Joyce, Khan, & Jones, 1981). Risk factors for becoming a revolving-door patient include being diagnosed with schizophrenia, having poor medication adherence, being younger, and having comorbid substance abuse problems (Joyce et al., 1981; Kastrup, 1987).

Psychiatric services have also had to address the public anxiety about severely mental ill patients living in the community. A number of high profile violent incidents in the UK in the 1990s highlighted the potential dangers of patients in the community who lose contact with services. The most influential was the case of Christopher Clunis, a man diagnosed with schizophrenia who killed Jonathan Zito in an unprovoked attacked (Killaspy, 2006). The Ritchie report, a public enquiry commissioned to investigate Christopher Clunis’ care, described the inability of community psychiatric services to adequately monitor patients and proposed a number of changes in policy. One of these recommendations was to introduce legislation to give clinicians the power to monitor patients in the community. This recommendation led to the inclusion of Supervised Discharge Orders (or a Section 25) in the 1995 amendment of the Mental Health Act. Supervised Discharge Orders were an early form (albeit quite different form) of compulsory outpatient supervision in the community.

Thus, despite the benefits of community treatment to most patients, increasing public concern and the inability to adequately treat revolving-door patients have both contributed to the introduction of involuntary treatment for patients in the community.

Involuntary Treatment of Patients in the Community

Psychiatry is the only medical speciality which can treat patients with capacity against their wishes. Most western countries have legislation which allows the involuntary hospitalisation of a patient with mental illness and compulsory treatment of that patient whilst an inpatient (Appelbaum, 1997). Legislation differs between countries but most require patients to be mentally ill and to be a risk to themselves or to others. The use of involuntary treatment used to be restricted to hospitals but has become more common in treatment of patients in the community and is now available in over 70 jurisdictions worldwide (Rugkåsa & Dawson, 2013).

Outpatient compulsion is an intervention aimed at treating revolving-door patients (Churchill, 2007). These are patients who have several hospital admissions separated by short, unstable periods in the community and they are characterised by poor adherence to treatment and disengagement from mental health services.

Patients who have been discharged from psychiatric hospital are usually discharged as voluntary patients and are under no legal obligation to accept treatment. The introduction of outpatient compulsion means that patients can now be required to accept treatment whilst in the community. The aim of this treatment is to establish a period of stability after leaving hospital by keeping the patient engaged with services and adherent to their medication. In England and Wales, outpatient compulsion was made possible by the 2007 Mental Health Act amendments titled Supervised Community Treatment but is commonly referred to as a Community Treatment Order (CTO, Department of Health, 2008b).

Community Treatment Orders in the UK

As part of the 2007 Mental Health Act amendments, on the 3rd of November 2008, outpatient compulsion was introduced in the England and Wales in the form of CTOs. According to the Department of Health, the primary aim of introducing CTOs in the MHA was:

"…to allow suitable patients to be safely treated in the community rather than under detention in hospital, and to provide a way to help prevent relapse and any harm…It is

intended to help patients to maintain stable mental health outside hospital and to promote recovery" (Department of Health, 2008a)

Patients can be made subject to a CTO on discharge from an involuntary hospital stay (Section 3 of the MHA). CTOs have two mandatory conditions. The first is that a patient must make him or herself available for examination by a second-opinion doctor and the second is that a patient must make him or herself available for an assessment for a possible renewal of the order. Further conditions can be set by the responsible clinicians and usually relate to having regular appointments with the community team, maintaining adherence to medication, and, less frequently, residing at a specific address (Lepping & Malik, 2013).

CTOs do not permit community teams to give a patient medication forcibly. If a patient does not comply with the CTO conditions and there is a risk of relapse they can be rapidly recalled to hospital and monitored or treated for up to 72 hours before either being discharged back to the community or having their CTO revoked. If a CTO is revoked the patient remains in hospital under a Section 3 involuntary hospitalisation. The recall can be enforced without a formal mental health assessment.

An initial CTO order is for up to six months, after which it is renewable for a further six months and then annually. A patient can be discharged from a CTO at any time by their responsible clinician or by the treating hospital or a Mental Health Review Tribunal at regular hearings.

Opposition to the introduction Community treatment Orders

The introduction of CTOs in England and Wales has been highly controversial. There had been strong arguments from both proponents and detractors for almost 15 years leading up to their introduction (Lawton-Smith, Dawson, & Burns, 2008; Pinfold & Bindman, 2001). Opinion as to whether CTOs should have been introduced differs both within and between staff, patients, and user organisations (Crawford, Gibbon, Ellis, & Waters, 2004; Manning, Molodynski, Rugkåsa, Dawson, & Burns, 2011). Opposition to CTOs is usually based on two grounds; that CTOs are unethical and that there is limited evidence for their effectiveness.

The ethics of compulsion in the community

Much of the opposition to CTOs is that legally compelling patients in the community to accept treatment could be considered unethical. Two key reasons that CTOs may be unethical have been highlighted. First, subjecting a patient to a CTO may permit the use of involuntary treatment for people who have the capacity to refuse it (Lawton-Smith et al., 2008). Involuntary treatment in hospital is often used as patients do not have the capacity to make decisions that are thought to be in their best interests (although there is evidence that the majority of inpatients do have this capacity, Okai et al., 2007). Being discharged from hospital can be taken as a sign that a patient has regained the capacity to live autonomously and CTOs are argued to contradict natural justice by removing this autonomy from patients in favour of psychiatric paternalism. Opponents to CTOs therefore claim that subjecting patients in the community to a CTO deprives them of their civil right to this freedom of self-determination (Allen & Smith, 2014; Moncrieff & Smyth, 1999). Lawton-Smith argues that people with mental health problems already face discrimination and curtailment of their civil liberties and CTOs would increase this discrimination.

The second key ethical argument against the use of CTOs is that introducing involuntary outpatient treatment dramatically increases the overall level of compulsion experienced by patients (Lawton-Smith et al., 2008; Munetz, Galon, & Frese, 2003). Patients on CTOs have been shown to have significantly longer periods of overall compulsion than non-CTO patients, and there is not a correspondingly significant reduction in inpatient compulsion (Burns et al., 2013; Steadman et al., 2001). When CTOs were first introduced in the UK, they were to be used with the most severe revolving-door patients. Recent data from the Health and Social Care Information Centre (HSCIC) recorded 5461 patients detained on CTOs in England and Wales on the 31st March 2015 (HSCIC, 2015). Since CTOs were introduced, 27940 orders have been made, with rates of CTOs rising sharply in the first five years, whilst in the two most recent years rates of CTOs have remained stable. Opponents of CTOs argue that this increase in compulsion moves the focus of mental health services from treatment and support to control.

Proponents of CTOs argue that a temporary restriction of liberties can be justified if there are overall benefits for patients, such as less time in hospital or improved long-term adherence and symptom stability. They also argue that it is always preferable to treat patients in the least restrictive environment, and that compulsory community treatment in that regard are preferable to involuntary hospital stays.

The evidence of the effectiveness of Community Treatment in reducing readmission

The second source of opposition to the introduction of CTOs is the lack of experimental evidence to show that they are effective in reducing readmissions. This criticism is addressed in of both non-randomised and randomised studies.

Non-randomised studies have mainly been conducted in the US, UK, Canada, Australia, and New Zealand. These are mostly controlled or uncontrolled before-and-after study designs. Non-randomised studies have reported mixed results with some showing reduced inpatient care, most showing no difference and others showing increased inpatient care. A narrative review by Swartz and colleagues in 2004 reported a moderate effect of CTOs on reducing hospitalisation whilst two more recent systematic reviews from Churchill and colleagues and Maughan and colleagues found no benefit of CTOs on patient readmission rates (Churchill, 2007; Maughan, Molodynski, Rugkåsa, & Burns, 2014; Swartz & Swanson, 2004). All three reviews described substantial methodological limitations in all non-randomised studies.

There have been three randomised control trials on the effectiveness of CTOs, two in the US (New York and North Carolina) and one in the UK (Burns et al., 2013;

Steadman et al., 2001; Swartz et al., 1999). All three used the proportion of patients readmitted as their primary outcome. The New York RCT had an eleven month follow-up whilst the other two had twelve-month follow-ups. Both US trials randomised patients to either outpatient compulsion or voluntary status whilst the UK trial, the Oxford Community Treatment Order Evaluation Trial (OCTET), randomised patients to either CTO or to voluntary care via short-term section 17 leave.

Section 17 leave is an established method for assessing the stability of a patient in the community for brief periods of time. Section 17 leave was the usual method of discharge for patients before CTOs were introduced and remains in the MHA. Randomisation through Section 17 leave (as opposed to direct to voluntary care) was chosen as the comparison arm after in-depth legal analysis (Dawson, Burns, & Rugkåsa, 2011). In practice, patients who were randomised to section 17 were only meant to spend about a week on section 17 leave before being discharged to voluntary care, enabling a similar comparison to the CTO vs voluntary care that the two US trials arm patients were allocated to.

None of the three trials found a difference in readmission rates between patients subjected to a CTO and patients in the comparison arm. All three trials had limitations, mostly due to the complexity of randomising patients to a legal condition (Kisely & Campbell, 2014). However, the results strongly suggest that CTOs do not reduce the rate of patients being readmitted to hospital.

In summary, randomised studies found no evidence for CTOs reducing rehospitalisation whilst the evidence in non-randomised studies was inconclusive.

The evidence of the effectiveness of CTOs in improving outcomes other than hospitalisation.

Reducing hospitalisation of patients is not the only aim of CTOs. Another objective was to create an environment for treatment which would produce long-term benefit to the patient. CTOs were envisaged as a tool to promote treatment adherence and engagement with services (O Reilly, 2004). It has been argued that this period of enforced stability would lead to eventual voluntary adherence and engagement.

A Cochrane review by Kisely and colleagues investigated the association of CTOs with outcomes other than hospitalisation and included secondary data from all three published RCTs (Kisely & Campbell, 2014). They found that CTOs did not increase contacts with services or improve social functioning, symptoms, or quality of life in comparison to usual care. A systematic review by Maughan and colleagues also included non-randomised studies and found examples of an increase, decrease, and no difference in contacts with services whilst on a CTO (Maughan et al., 2014). Both reviews suggest that CTOs do not improve contacts with services, social function, symptoms, or quality of life.

Long-term outcomes of CTOs

Swartz and colleagues' secondary analysis of the North Carolina RCT found that patients who were maintained on a CTO for six months or more and had three or more contacts a month had significantly fewer readmissions than the patients not subject to CTOs or those on CTOs for less than six months. These patients also had better adherence to treatment, fewer arrests, and better quality of life (Swartz et al., 1999). This result was interpreted to suggest that patients may only gain benefit from CTOs if they are maintained on one for six months or more. However, these analyses did not compare groups according to randomisation. Including only patients who were maintained on a CTO for six months introduces a selection bias. Being sufficiently stable to remain on a CTO for six months is an outcome itself and by including only those patients the study selected a group with better clinical trajectories. Swartz and colleagues' interpretation has been taken as evidence for a) the need for long-term follow up, and b) to investigate the association of longer periods of CTO use with outcomes.

As response to this, patients from the OCTET trial were followed up for a further 24 months (a total of 36 months after randomisation). The follow-up found no difference in readmission outcomes between patients randomised to CTO and those randomised to section 17 leave (Burns et al., 2015). It also found that in the whole sample, a longer of duration of CTO was associated with fewer inpatient days and a longer time to first readmission, although it was unclear whether this was a selection or treatment effect.

Community treatment Orders and Continuity of Care

Patients who are made subject to CTOs may be those for whom good continuity may be most difficult to achieve. Patients with psychosis, who have poor treatment adherence, multiple readmissions, and often have substance abuse disorders are more prone to disengage from services, have chaotic personal lives, and be vulnerable in the community (Joyce et al., 1981). Such patients often have discontinues in their care.

While CTOs may improve continuity of care, concerns have been raised by clinicians, academics, and patient advocacy groups that CTOs may drive patients away from services (Lawton-Smith et al., 2008; Manning et al., 2011; Moncrieff & Smyth, 1999; Romans, Dawson, Mullen, & Gibbs, 2004). Their concern is that increased coercion will undermine patient trust, resulting in them being suspicious of the intentions of community mental health services and that this would lead to them disengaging from services.

No study has investigated the effect of CTOs on continuity of care. In this study I aimed to investigate the association between CTOs and continuity of care by prospectively following patients recruited in the OCTET trial. I followed-up patients for 36 months in order to investigate long-term outcomes of CTO use. I also investigated the association between the length of time on a CTO and continuity of care in order to explore whether a longer duration of a CTO is associated with better continuity of care.

Aims

- To investigate the association between being made subject to a CTO and continuity of care.
- To investigate the relationship between the time subject to a CTO and continuity of care.

Methods

Design

I used a prospective observational design with a 36-month follow-up. Data were collected from patients recruited for the OCTET trial (Burns et al., 2013). I collected measures at 36 months via medical notes and Mental Health Acts Offices' records as described in chapter 3. Ethical approval was granted by the Staffordshire National Health Service (NHS) Research Ethics Committee (reference 08/H1204/131).

Sample

All 336 patients from 32 NHS mental health trusts who participated in OCTET were included in this sample. These patients were the same sample used in the study of the association between continuity of care and rehospitalisation described in chapter three and eligibility criteria were the same as described in chapter three,

Three patients were excluded during the OCTET trial as they were found to be ineligible subsequent to randomisation. The five patients (identified in chapter three) who remained in hospital for the entire follow-up could not be subject to a CTO nor could they have any outpatient contact and were therefore excluded from analysis in this study. I collected data between 1 April 2012 and 22 February 2014.

Measures

Baseline demographics

Baseline demographics were collected during OCTET baseline interviews. These include age, gender, ethnicity, country of birth, years of education, marital status, diagnosis, duration of illness, number of past hospitalisations, severity of symptoms as measured by the BPRS (Overall & Gorham, 1962), and an assessment of functioning using the GAF (Jones et al., 1995). Data about age, gender, diagnosis and past hospitalisations was confirmed using medical notes. Both the BPRS and the GAF have been described in chapter three.

Outcomes

The outcomes used in this study were the eight components of continuity of care described in chapter three. The components were: average gap between face-to-face contacts, gaps of two months or more, non-medical input spread, number of designated care coordinators, number of designated psychiatrists, supported living, documented transitions, and proportion of letters sent by the CMHT copied to user

Measures of outpatient compulsion

Outpatient compulsion in this study was measured in four different ways. The first measure was whether a patient had been randomised to the CTO condition in the original OCTET study (Burns et al., 2013). The aim of this analysis was to test for the association between the original trial arms and continuity of care.

The second measure of compulsion was whether a patient was subject to CTO at any point during the three-year follow-up, irrespective of randomisation. This was recorded as a yes or no dichotomous answer. This measure of compulsion was chosen as an alternative to the randomisation arm in order to account for crossovers. In OCTET, 166 patients were randomised to the CTO arm but of these only 124 were subject to a CTO in the first year. 167 were randomised to the non-CTO group of whom 45 were made subject to a CTO in the first year, 12 remained on a section 3, and 110 remained voluntary patients in the community. Beyond the first year of the study clinicians were not expected to maintain patients in the treatment arms and therefore many more patients may have been made subject to a CTO.

The third measure was the total number of days that a patient was subject to a CTO over the 36-month follow-up. This outcome measure gives an indication of whether there is an association between length of CTO use and continuity of care. If the patient was subject to multiple periods of CTO (for instance if the patient was hospitalised on a Section 3, and then discharged back on to a CTO), these were summed to yield the total number of days on a CTO. The period calculated did not include days that the patient was recalled to hospital. If a patient was not subject to a CTO throughout the follow-up, the number of days on a CTO would be recorded as zero. This allowed comparison between those who did and did not receive any outpatient compulsion.

The fourth measure of outpatient compulsion was the number of days of CTO as a proportion of the total number of days spent as an outpatient. This measure was used to counteract the potential bias in calculating only the total number of days on outpatient compulsion. The larger number of days that a patient is subject to a CTO over the follow-up, the more potential days they have to accrue continuity of care as they are not in hospital (and we are only measuring outpatient continuity). By measuring the proportion of CTO days out of the total number of outpatient days this risk of bias is reduced.

Analysis

I created a statistical analysis plan before analysing the data. SPSS 20 statistical software package was used to carry out the analysis. I checked all predictor and outcome variables using plots, graphs, measures of central tendency, and measures of spread.

I conducted regression analyses in order to investigate the association between the four different measures of CTO use and the continuity of care outcomes. All analyses included age, gender, ethnicity, and BPRS score as covariates. I conducted a sensitivity analysis to test the total number of days of outpatient compulsion and the proportion of CTO days including only patients subject to outpatient compulsion.

I fitted a linear regression model to test for associations between the four different measures of CTO use and the continuous outcome variable *average gap between face-to-face contacts*. Results for linear regression are reported in Beta values (B) with 95% confidence intervals (CIs).

I fitted separate Poisson regression models for each of *gaps of 2 months or more, non-medical input spread, designated care coordinators,* and *designated psychiatrists* as they are all count variables. If the outcome suffered from overdispersion (a greater than expected variability for a Poisson model), I used a negative binomial model instead. Each outcome is reported as an Incident Rate Ratio (IRR) with 95%CIs.

Supported living and *documented transitions* are binary outcomes and so I conducted logistic regression for both outcomes. Logistic regression outcomes are reported as Odds Ratios (ORs) with 95%CIs. I used multinomial regression models to test the association between the three CTO predictors and *proportion of letters sent by the CMHT copied to user*. Multinomial regression is reported as relative risk ratios (RRRs) with 95%CIs.

Results

Participants

Participants were the 333 patients from the OCTET trial. As described in chapter three, 10 patients were excluded. Five patients were inpatients throughout the follow-up period, data for four patients could not be collected, and one patient withdrew consent during the follow-up. No further patients were excluded. As reported in chapter three, there were 20 deaths during the 36-month follow-up period. There were six suicides, one accidental death from a drug-overdose, and 13 patients died from natural causes. There were 26 patients discharged from secondary services during the follow-up. Three of these moved abroad and five were later re-referred to outpatient services. Data for patients who died or were discharged were censored at the relevant time point in the analysis. For the five patients who were re-referred, collection of their data recommenced from the date of referral.

Baseline socio-demographic and clinical characteristics

The baseline characteristics of the sample were described in detail in chapter three (table 3.2). The mean age was 39.6 (SD = 11.39) and 66.5% were male. Most patients had been diagnosed with schizophrenia (n=275, 85.1%), and had first been diagnosed a mean of 14.42 years (SD = 10.45) previously. Table 4.1 presents demographic characteristics and clinical outcomes between patients made subject to a CTO and those who had not been made subject to a CTO regardless of randomisation.

Table 4.1. Demographic characteristics and clinical outcomes between patients made subject to a CTO and those who had not been made subject to a CTO at any time.

		CTO = 197		**Non-CTO = 126**	
	N	N Mean Median	% SD IQR	N Mean Median	% SD IQR
Mean age, *years* (SD)	323	39.59	11.24	39.48	11.68
Gender, male (%)	323	134	68%	84	66.8%
Ethnicity, *White* (%)	323	114	57.9%	82	65.1%
Mean duration of illness, *years* (SD)	313	14.41	10.01	14.42	11.17
Mean BPRS total score at baseline (SD)	302	38.62	10.87	38.92	12.15
Readmitted, *yes* (%)	323	131	66.5%	75	59.5%
Number of readmissions	323	1.63	1.83	1.17	1.55
Median number of days in hospital over 36 months[IQR]	323	116.00	34.50, 228	83.50	25.75, 300
Median number of days in hospital from 1st readmission [IQR]	323	74	0, 177.5	18.50	0, 139
Median number of days under compulsion [IQR]	323	605	342.50, 1088	120	38, 248

Number of days under CTO

Out of the 323 patients, 197 (61%) had been subject to a CTO during the 36-month follow-up with 145 (44.9%) patients on CTOs for more than 180 days. Patients who were made subject to CTO remained on it for a mean of 455.9 (SD = 326.1) days, with a range between 7 and 1088 days. The number of readmissions was significantly greater for those in the CTO group (n = 323, U = 2.45, p = 0.014). The total number of days under compulsion (defined as being on any MHA section) was significantly greater for those who were subject to a CTO (n = 323, U = 11.6, p = <0.000).

Of the 161 patients in this study who were randomised to the CTO condition in the OCTET study, 127 (78.9%) were subject to a CTO during the three-year follow-up. Of the 162 in the non-CTO arm, 70 (43.2%) were subject to a CTO during the three year follow-up. 43 (26.5%) of these were made subject to a CTO in the first 12 months, whilst 27 (16.7%) were made subject to a CTO between 12 and 36 months after randomisation. Figure 4.2 illustrates the experience of CTO in each of the trial arms.

Association between randomisation arm and continuity of care

Only the proportion of letters sent by the CMHT copied to user was significantly associated with randomisation arm. Being randomised to the CTO arm was significantly associated with an increased chance of having 1% - 50% (RRR = 1.809, 95%CI = 1.017, 3.218, p = 0.044) and 51% - 100% (RRR = 2.768, 95%CI = 1.490, 5.140, p = 0.001) of documents copied to the user.

The average gap between face-to-face contacts (B = -1.402, 95%CI = -4.981, 2.176, p = 0.441) was not associated with the randomisation arm as were the number of 60-day gaps (IRR = 0.919, 95%CI = 0.660, 1.280, p = 0.617), non-medical input spread (IRR = 1.002, 95%CI = 0.781, 1.281, p = 0.988), designated care coordinators (IRR = 1.069, 95%CI = 0.813, 1.404, p = 0.634), designated psychiatrists (IRR = 1.007, 95%CI = 0.780, 1.301, p = 0.956), supported living (OR = 0.93, 95%CI = 0.533, 1.621, p = 0.797), and documented transitions (OR = 1.063, 95%CI = 0.661, 1.707, p = 0.802).

Association between being subject to a CTO and continuity of care

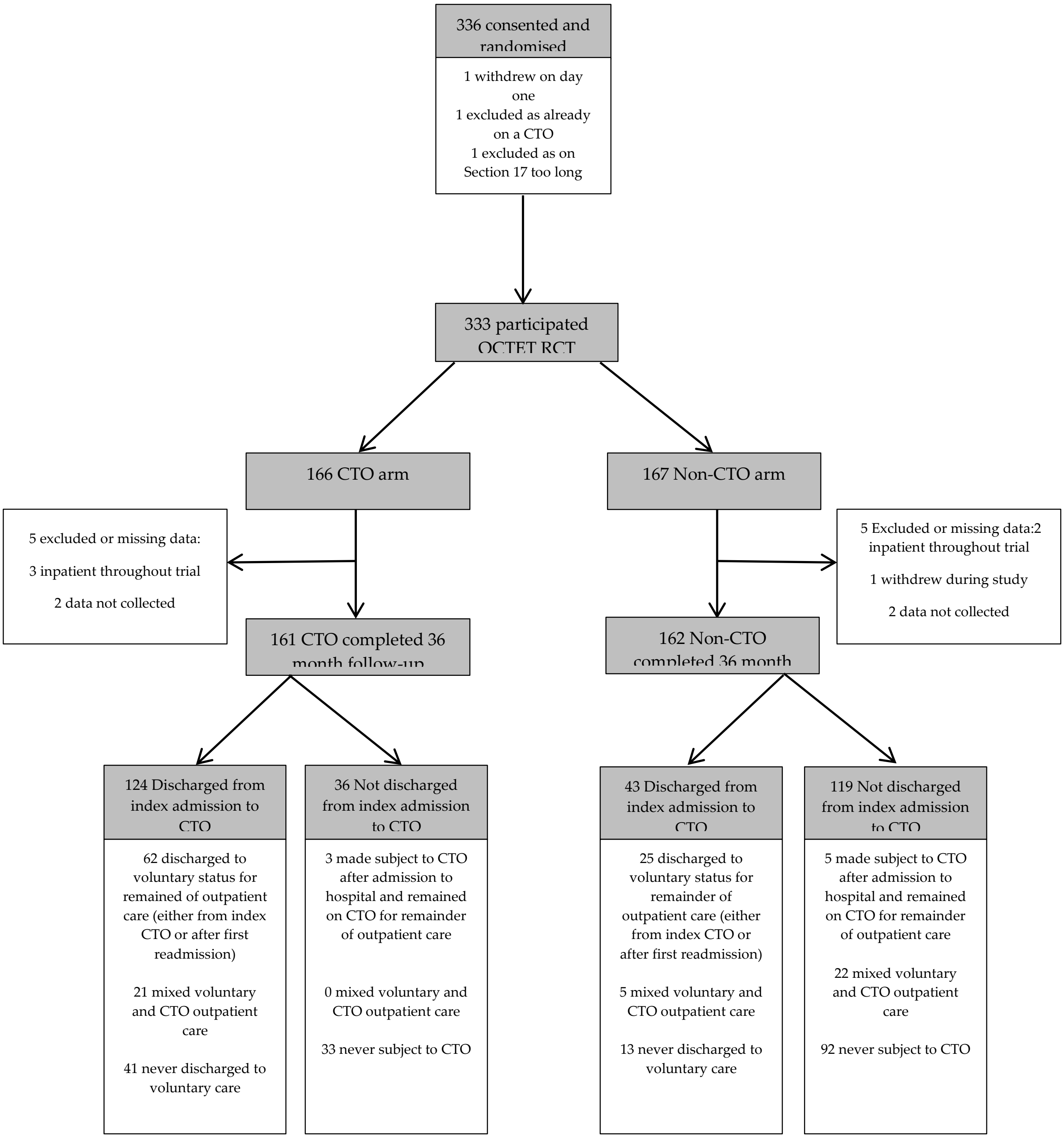
Having been subject to a CTO

Table 4.2 summarises the differences in continuity of care outcomes for patients who had been subject to a CTO against patients who were not. Table 4.3 presents the associations between being subject to a CTO or not and the eight continuity of care measures, controlling for age, gender, ethnicity, and BPRS score. Being on a CTO was associated with 5.09 fewer average days between face-to-face contacts (B = -5.090, 95%CI -8.17, -1.47, p = 0.006). Being on a CTO was also associated with a lower 0.62 incident rate of 60-day gaps compared to not being subject to a CTO (IRR = 0.62, 95%CI = 0.44, 0.86, p = 0.004). No other associations were significant. The model fit was poor and not significantly different to that of the null model (i.e. the explanatory power of a regression model without any predictor variables fitted) for the number of different mental health professionals seen, number of care coordinators, number of psychiatrist, and proportion of documents copied to user.

There were three patients who were identified as outliers by plotting the average gap between face to face contacts against patients' CTO status (see figure 4.1). Two had experience of CTO and one did not. A sensitivity analysis was conducted with these three patients excluded from the analysis. In this analysis, being subject to a CTO was significantly associated with average gap between face-to-face contacts

(B= -4.564, 95%CI = -6.978, -2.149, p < 0.000) and number of 60-day gaps (IRR = 0.582, 95%CI = 0.415, 0.816, p = 0.002).

Figure 4.2. Flowchart of participant experience of CTO in each of the OCTET trial arms at 36 months follow up.



Number of days on CTO

The number of days a patient was on a CTO was associated with the average gap between face-to-face contacts (B = -0.006, 95%CI = -0.011, 0.001, p = 0.020), and number of 60-day gaps (IRR = 0.999, 95%CI = 0.999, 1.000, p = 0.003). Each extra month of being subject to a CTO reduced the gap between face-to-face contacts by 0.19 days and reduced the incidence rate of the number of 60 day gaps by 2.4%. Number of days on a CTO was not associated with any other measure of continuity of care (Table 4.4).

Table 4.2. Differences in continuity of care between patients on a CTO and those not made subject to a CTO.

Measure	**N**	**CTO = 197** N(%) Mean (SD) Median [IQR]	**Non-CTO = 126** N(%) Mean (SD) Median [IQR]
Number of days between face-to face-contacts	321	8.86 [5.69, 14.11]	11.25 [6.53, 18.83]
Number of 60-day gaps,	321		
No gaps		117 (59.7%)	64 (50.8%)
1 - 2 gap		60 (30.6%)	36 (28.6%)
3 or more gaps		19 (9.7%)	26 (20.6%)
Number of different non-medical professional	319	5.76 (0.895)	5.38 (0.72)
Designated care coordinators	319	2.40 (1.28)	2.15 (1.23)
Designated psychiatrists	319	3.89 (3.04)	3.28 (2.289)
Discharged to supported accommodation, yes	321	47 (23.9%)	24 (19.2%)
Any referral documented, yes	314	110 (55.8%)	66 (54.1%)
Proportion of letter copied to user	323		
0%		53 (26.9%)	38 (30.2%)
1 – 50%		79 (40.1%)	53 (42.1%)
51 – 100%		65 (33%)	35 (27.8%)

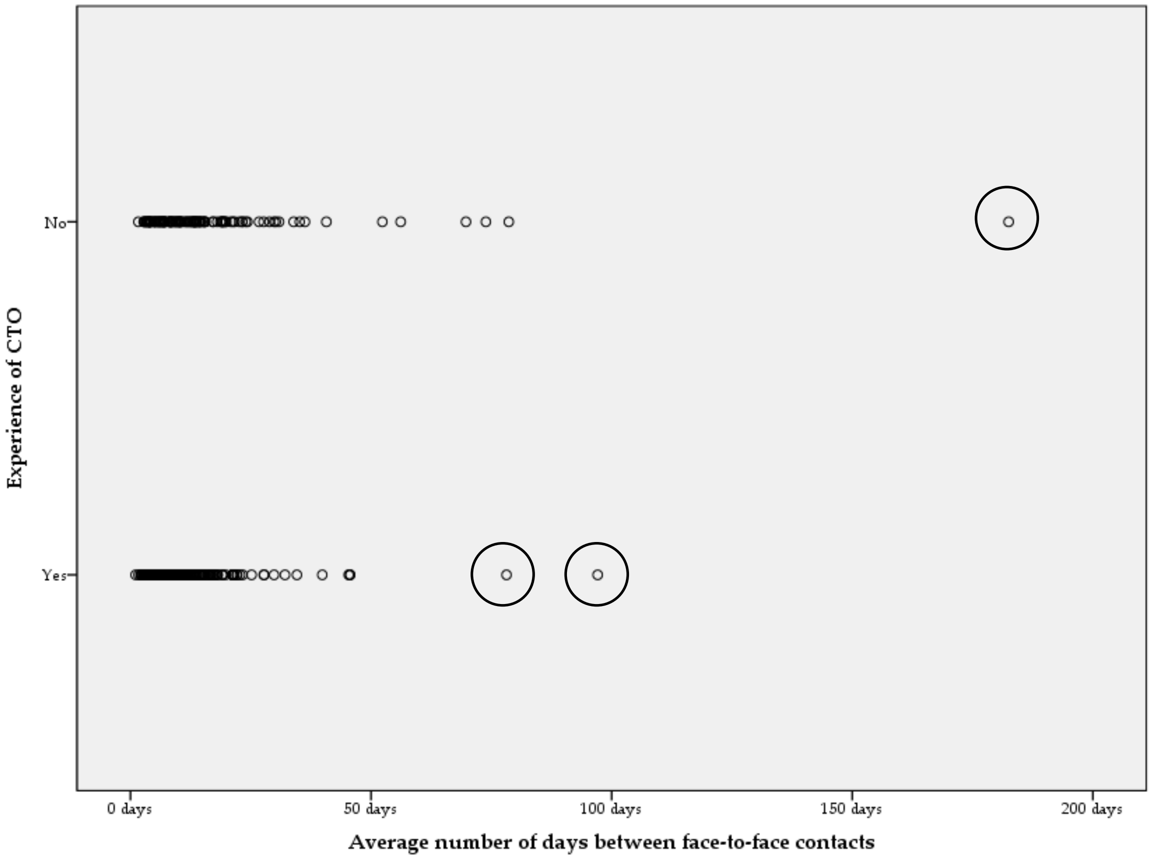
Table 4.3. Associations between being subject to a CTO and continuity of care measures, controlling for age, gender, ethnicity, and BPRS[1]

Measure	N	Beta/OR/IRR	95%CI	Sig
Average gap between face-to-face contacts	299	-5.090	-8.71, -1.47	0.006
Number of 60 day gaps without contact	301	0.615	0.440, 0.859	0.004
Number of different mental health professions seen, *per patient*[2]	302	1.075	0.836, 1.383	0.574
Number of care coordinators, *per patient*[2]	298	1.113	0.840, 1.474	0.456
Number of psychiatrists, *per patient*[2]	299	1.203	0.923, 1.567	0.171
Discharged from index admission to support accommodation, *yes*	301	1.361	0.759, 2.439	0.301
Any referral documented, *yes*	293	1.242	0.764, 2.019	0.383
Proportion of documents copied to user[2]	302			
1 – 50%		1.215	0.690, 2.140	0.500
51 – 100%		1.352	0.732, 2.496	0.355

[1] Brief Psychiatric Rating Scale – a measure of symptom severity

[2] Model was not significantly different to null model therefore all values should be interpreted with caution

Figure 4.1 Scatterplot of the average number of days between face-to-face contacts against CTO status (yes/no). Outliers are circled.



There were three patients who were identified as outliers by plotting the average gap between face-to-face contacts against patients' number of days under CTO compulsion. A sensitivity analysis was conducted with these three patients excluded from the analysis. Average gap between face-to-face contacts remained significant (B = -0.006, 95%CI -0.009, -0.002, p = 0.002) as did the number of 60-day gaps (IRR = 0.999, 95%CI = 0.998, 1.000, p = 0.001).

Proportion of CTO days to total outpatient days

The associations between the *proportion* of outpatient days subject to a CTO and the continuity of care measures are presented in table 4.5. Patients with higher proportions of outpatient time that was subject to a CTO had significantly fewer days between face-to-face contacts (B = -6.954, 95%CI = -11.839, -2.069, p=0.022). However, the overall model fit was poor (f = 1.942, p = 0.087) so this result should be interpreted with caution. Patients with a higher proportion of CTO days as an outpatient also had a reduced incidence of 60-day gaps (IRR = 0.423, 95CI = 0.257, 0.696, p = 0.001).

A sensitivity analysis was conducted excluding the three outliers. The effect size remained stable whilst the statistical significance improved for both average gap between face-to-face contact (B = -6.044, 95%CI = -9.315, -2.774, p < 0.000) and number of 60-day gaps (IRR = 0.371, 95%CI = 0.221, 0.623, p < 0.000). The overall regression model for average gap between face-to face contacts was also a better fit and statistically significant in this sensitivity analysis (f = 3.968, p = 0.002).

Table 4.4. Associations between *number* of days on CTO and continuity of care measures, controlling for age, gender, ethnicity, and BPRS[1]

Measure	**N**	**Beta/OR/IRR**	**95%CI**	**Sig**
Average gap between face-to-face contacts	299	-0.006	-0.011, -0.001	0.020
Number of 60 day gaps without contact	301	0.999	0.999, 1.000	0.003
Number of different mental health professions seen, *per patient*[2]	302	1.000	1, 1	0.596
Number of care coordinators, *per patient*[2]	298	1.000	1, 1	0.992
Number of psychiatrists, *per patient*[2]	299	1.000	1, 1	0.844
Discharged from index admission to support accommodation, *yes*	301	1.000	1.000, 1.001	0.920
Any referral documented, *yes*	293	1.000	0.999, 1.001	0.910
Proportion of documents copied to user[2]	300			
1 – 50%		1.000	0.999, 1.001	0.971
51 – 100%		1.000	0.999, 1.001	0.592

[1] Brief Psychiatric Rating Scale – a measure of symptom severity

[2] Model was not significantly different to null model therefore all values should be interpreted with caution

Table 4.5. Associations between *proportion* of outpatient days on a CTO and continuity of care measures, controlling for age, gender, ethnicity, and BPRS[1]

Measure	**N**	**Beta/OR/IRR**	**95%CI**	**Sig**
Average gap between face-to-face contacts[2]	299	-6.954	-11.839, -2.069	0.022
Number of 60 day gaps without contact	301	0.423	0.257, 0.696	0.001
Number of different mental health professions seen, *per patient*[2]	302	1.088	0.773, 1.531	0.630
Number of care coordinators, *per patient*[2]	298	1.076	0.738, 1.570	0.702
Number of psychiatrists, *per patient*[2]	299	1.203	0.842, 1.720	0.310
Discharged from index admission to support accommodation, *yes*	301	1.740	0.831, 3.644	0.142
Any referral documented, *yes*	293	1.123	0.580, 2.174	0.730
Proportion of documents copied to user[2]	300			
1 – 50%		1.036	0.359, 2.988	0.948
51 – 100%		1.232	0.412, 3.688	0.709

[1] Brief Psychiatric Rating Scale – a measure of symptom severity

[2] Model was not significantly different to null model therefore all values should be interpreted with caution

Sensitivity analysis using only patients who were subject to a CTO

Number of days on a CTO

The total number of days on a CTO for only participants who had been subject to a CTO was not significantly associated with any measure of continuity of care (table 4.6). None of the overall regression model statistics were significantly different to the null model.

Proportion of CTO days to total outpatient days

Only the number of 60 day gaps was associated with the proportion of CTO days for those patients who were on a CTO (IRR = 0.699, 95%CI 0.177, 2.76, p = 0.048). Patients who had a higher proportion of outpatient days subject to CTO had a lower incidence of 60 day gaps (Table 4.7).

Table 4.6. Associations between *number* of days on a CTO and continuity of care with only patients who had been made subject to a CTO included n = 197

Measure	N	Beta/OR/IRR	95%CI	Sig
Average gap between face-to-face contacts[2]	181	-0.940	-0.007, 0.003	0.349
Number of 60 day gaps without contact[2]	197	0.999	0.999, 1.000	0.163
Number of different mental health professions seen, *per patient*[2]	183	1.000	1.000, 1.001	0.825
Number of care coordinators, *per patient*[2]	182	1.000	0.999, 1.000	0.500
Number of psychiatrists, *per patient*[2]	182	1.000	0.999, 1.000	0.290
Discharged from index admission to support accommodation, *yes*	183	1.000	0.999, 1.001	0.889
Any referral documented, *yes*	178	1.000	0.999, 1.000	0.324
Proportion of documents copied to user[2]	181			
1 – 50%		1.000	0.999, 1.002	0.923
51 – 100%		1.000	0.998, 1.002	0.972

[1] Brief Psychiatric Rating Scale – a measure of symptom severity

[2] Model was not significantly different to null model therefore all values should be interpreted with caution

Table 4.7. Associations between *proportion* of outpatient days on a CTO and continuity of care with only patients who had been made subject to a CTO included n = 197

Measure	N	Beta/OR/IRR	95%CI	Sig
Average gap between face-to-face contacts[2]	181	-1.723	-9.31, 0.613	0.087
Number of 60 day gaps without contact	182	0.699	0.177, 2.764	0.048
Number of different mental health professions seen, *per patient*[2]	183	1.035	0.642, 1.670	0.887
Number of care coordinators, *per patient*[2]	182	0.950	0.566, 1.594	0.846
Number of psychiatrists, *per patient*[2]	182	0.991	0.603, 1.627	0.970
Discharged from index admission to support accommodation, *yes*	183	1.667	0.579, 4.815	0.343
Any referral documented, *yes*[2]	178	0.856	0.333, 2.201	0.747
Proportion of documents copied to user[2]	181			
1 – 50%		1.072	0.239, 4.817	0.927
51 – 100%		0.757	0.161, 3.566	0.725

[1] Brief Psychiatric Rating Scale – a measure of symptom severity

[2] Model was not significantly different to null model therefore all values should be interpreted with caution

Discussion

The aim of this study was to test for associations between outpatient compulsion and continuity of care over 36 months using four different measures of outpatient compulsion. The first used the original OCTET randomisation to test for differences in continuity of care between the trial arms. The second tested those subjected to a CTO at any point during the follow-up, irrespective of randomisation, against those not subjected to a CTO. The third tested the total number of days a patient was subject to CTO and its association with continuity of care. The fourth used the proportion of outpatient days that a patient had been subject to CTO.

CTO experience, whether measured by having been made subject to a CTO, a greater number of days on CTO, or a higher proportion of outpatient days on CTO, were all associated with more face-to-face contacts and also having fewer periods of disengagement, but no other measure of continuity of care. Patients randomised to the CTO arm had a higher proportion of letters copied to them and this was the only significant association between randomisation arm and continuity of care.

The association between outpatient compulsion and the frequency of community mental health team contact and disengagement

The evidence is mixed on whether CTOs increase the amount of contact and engagement patients have with their community team. Hunt and colleagues found that patients under outpatient compulsion in Toronto, Canada, were less likely to continue to engage with services after 12 months (Hunt, Silva, Lurie, & Goldbloom, 2007). Swartz and colleagues' RCT in the USA found that patients randomised to outpatient compulsion were rated as more engaged with services by their case managers (Swartz, Swanson, Wagner, Burns, & Hiday, 2001). Kisely and colleagues, in a controlled before and after study in Australia, found that patients on a CTO had 10.88 additional contacts with services per year (Kisely et al., 2013). A systematic review found that of ten studies reporting the association between contact frequency and CTO use, four reported increased contact for patients on a CTO, two reported decreased contacts, and four reported no statistically significant difference (Maughan et al., 2014).

Having at any time been subject to CTO and continuity of care

This study found no differences in contact frequency or in disengagement in patients who were randomised to the CTO arm of the OCTET study. Comparing those who were and were not on a CTO at any time during the 36-month follow-up found a median of five fewer days between the average gap between contacts and a 38% reduced risk of disengagement for patients who had experience of a CTO.

In this study, CTO experience improved continuity measures of contact and engagement with community services. Control and engagement are explicit ambitions for CTOs. Patients subject to a CTO in this study were legally required, as a condition of their CTO, to engage with their community team. This requirement may have led to patients having more appointments made, and kept, with their team. This explanation suggests that CTOs were achieving one of their stated purposes.

This difference was not however, found between the randomisation arms. Furthermore, patients who were made subject to a CTO were readmitted significantly more often than those who were not made subject to a CTO (many patients in the non-CTO arm of the trial were put on a CTO if they were readmitted). Therefore, an alternative interpretation to these differences is that patients on a CTO were seen more regularly in the community after having been readmitted to hospital. It has been shown that clinicians most often change treatment when patients are readmitted to hospital (Burns et al., 2006). Therefore, it is possible that the increase in contact could be attributed to a clinical decision to monitor a patient more closely after a readmission, rather than it being due to the CTO.

The length of time on CTO and continuity of care

Having both a greater number of outpatient days and a higher proportion of outpatient days subject to a CTO were significantly associated to having more contacts and a lower risk of disengagement. However, the effect sizes for both were very small. Each extra month of CTO use only reduced the time between contacts by 0.19 days and the risk of disengagement by 2.4%.

A sensitivity analysis which only included patients who were subject to a CTO (rather than all patients) did not find any association between length of time on a CTO and continuity of care. This means that the difference found in the previous analysis was due to the comparison between patients who had no CTO compulsion and those who did, rather than the difference between patients who had been on CTOs for different lengths of time. Keeping a patient who was already subject to a CTO on that CTO for longer did not result in the patient having more community contact.

Greatly increasing compulsory outpatient treatment for a small improvement in how often patients are seen by their community team may be criticised on two grounds. First, it can be criticised on the grounds of its restriction of patient's civil liberties. CTOs were proposed because their assumed benefits to patients was believed to outweigh its restriction. This argument cannot readily be justified when the benefits are small and may not be clinically meaningful. Second, the relationship between frequency of contact and good outcomes is not established. As was seen in chapter three, both more frequent contact and fewer breaks in care were associated with *worse* hospitalisation outcomes. The frequency of contact between a patient and community team is likely to be due to a number of factors including severity of illness, perceived need, and availability of resources. The increase in contacts for those on a CTO may reflect the clinical need in this group who were readmitted more frequently. My findings in chapter three that patients who were readmitted more often had more contact support this.

Limitations

There are a number of limitations to this study. Firstly, the study design cannot establish causality for the effects found, and the associations should be interpreted with caution. It was possible that patients could be made subject to the CTO at any point during the 36-month follow-up. Some patients may have had more intensive contact preceding or after the CTO, whilst others may have had it during the CTO. Averaging contact over 36 months cannot distinguish when the contact is made.

Second, this study only analysed successful contacts. Most CTOs include a condition that patients should attend appointments. While the number of failed contacts in this sample has been reported (an average of one in each two months, Burns et al., 2015) the differences in these analyses was not measured.

Third, as in chapter three, the continuity measures used in this study differed from the original ECHO study and only represents continuity from a service perspective. Patients' perception of their continuity of care when subject to a CTO may differ from the service measures.

Conclusions

The key finding from this study is that CTOs make little, if any, contribution to patients’ continuity of care. One of the key aims of introducing CTOs was to improve patients’ continuity of care and this aim appears not to be achieved with patients in this study. Patients on CTOs had slightly more contact with services but this increase was so small the overall effect is unlikely to have been noticeable by the patients or by the mental health practitioners.

A widely expressed concern of those opposed to CTOs is that they would drive patients away from services and cause a breakdown in relationships with clinicians. These concerns do not seem to have been realised either. Patients on CTOs had fewer breaks in care and did not have more changes in care coordinator or psychiatrist than those who did not experience.

One reason that CTOs appear not to be associated with continuity of care may reflect the patient and clinician understanding of their purpose. Qualitative interviews with patients, clinicians, and carers on their experiences of CTOs in OCTET found that all three groups considered their primary purpose to be the enforcement of medication adherence (Canvin, Rugkåsa, Sinclair, & Burns, 2014). This emphasis on medication adherence over social support or broader service provision in England and Wales is different to many other jurisdictions that use CTOs as a mechanism for getting a patient access to community services. For example, in New York, enhanced multidisciplinary community outreach services cannot be initiated without CTOs (Swanson et al., 2014). They are a gateway to better care.

A striking finding of this research is the persisting regularity of contact with this patient group, who are selected for being difficult to engage. Contact rates for our sample are comparable to what is considered assertive levels of contact in the UK and other countries (see chapter three). Patients in this study had regular and assertive care regardless of their legal status. The patients in both CTO and non-CTO groups were seen at least once a fortnight and had similar levels in most of the measures of continuity of care. We cannot, however, rule out that CTOs may have an impact in services which do not routinely offer assertive and intensive support.

In summary, community mental health teams were able to assertively and regularly keep contact with their patients and keep service discontinuities to a minimum for most patients regardless of their MHA status in the community.

Chapter summary

Being made subject to a CTO is associated with more frequent contact and fewer discontinuities with community services but no other measure of continuity. The length of time on a CTO is also associated with more frequent contact and fewer discontinuities. However, these effects are very small and may not, from an ethical viewpoint, outweigh the effects of restriction to patients' civil liberties. Furthermore, more intensive community contact may reflect a response to patient need rather a direct effect of the CTO. Previous research has repeatedly shown that

CTOs do not improve clinical outcomes when measured by hospitalisation. This exploratory research indicates that CTOs do not improve continuity of care sufficiently to argue for their use on the grounds that they will improve engagement.

Chapter Five: Summary and Conclusions

Origins of this Thesis

My aims in this thesis were to clarify the definition of continuity of care (in chapter one), to investigate associations between continuity of care and outcomes in mental health services both through a systematic review and my own empirical research (chapters two and three), and to test for associations between outpatient compulsion and continuity of care (chapter four). It has been explicit in research and policy for over 40 years that improving continuity of care is an important element in improving patient outcomes. This belief has endured despite a lack of any strong evidence to support it. Mental Health Services have changed substantially during this period, becoming more specialised and complex and it was unclear whether continuity of care has been affected by these changes.

There are three key reasons for this lack of evidence. First, the lack of a clear definition of continuity of care. Second, the conceptual complexity of continuity of care has made it difficult to conduct research. Third, few studies have been conducted to investigate the association between continuity of care and outcomes. In this thesis I set out to explore all three reasons in order to address my aims.

The lack of a clear definition

Continuity of care is “more often presumed than defined” (Reid et al., 2002, pg. ii). One reason for a lack of precision in how the term is understood and used is because continuity of care is most often considered from an overly narrow perspective, with research often devoted to a single identified discontinuity in a health system instead of investigating continuity as a multidimensional and complex construct. A second reason is that continuity of care is often confused with similar terms such as coordination of care and integrated care. Therefore, in chapter one I attempted to clarify this ambiguity by summarising and critically appraising the conceptual literature.

Two key themes emerged from my appraisal: continuity of care should relate to, one, the care of individual patients rather than the quality of the organisation of care systems, and two, the care of individual patients over time. Continuity can further be explained as the *process* of delivering care to individuals that is coordinated within and between services and which is experienced by both the individual and the service as coordinated. Relationship continuity, information continuity, and management continuity were three dimensions of this process that have been identified. These three dimensions are experienced differently by the patient and by the community team providing the service. This is because patients may not be aware of the work that is undertaken by services, behind the scenes as it were, in order to create care that is experienced as seamless or continuous by the patient.

My review of the theoretical and conceptual literature led me to consider three recommendations when measuring continuity of care. First, continuity must be measured at the level of the individual patient (e.g. the number of changes in care coordinator a patient has had rather than the rates of staff turnover in a team). Second, measurements of continuity must have a temporal aspect (i.e. must be a measurement or an aggregation of a measurement over a time period). Third, continuity of care is multidimensional and therefore research should assess more than one dimension.

The lack of research investigating associations between continuity of care and outcomes

Papers published on theory and models of continuity of care greatly outnumber empirical ones. In addition, the limited empirical literature is mostly devoted to improving continuity of care, rather than testing its effect on outcomes. A systematic review by Adair and colleagues in 2003 identified only five studies which investigated the association between continuity of care and outcomes (Adair et al., 2003). They concluded that there was little evidence that continuity of care was associated with outcomes although this was likely due to a lack of enough studies to assess it.

The systematic review I undertook in chapter two updated the Adair review. 18 studies were identified, five from the Adair review, two published before the Adair review but not included in it, and 11 new studies published between 2003 and 2014. A shift toward measuring patient perceptions of continuity of care was evident with three of the newly identified studies using patient-rated scales. Hospitalisation, symptom severity, social functioning, and service satisfaction were commonly used outcomes. However, both measures of continuity and outcomes varied enormously between studies.

My review found no clear association between continuity of care and outcomes. Although over half of the 18 studies reported significant associations between continuity of care and an outcome, the results were conflicting for all the main outcomes investigated. Most studies had methodological limitations such as small sample sizes, short follow-up durations, and poorly controlled cohorts. These limitations may have contributed to these inconclusive results. More importantly my systematic review also showed that no clear consensus has been reached on how to measure continuity of care. A wide range of measures were used which were often idiosyncratic to the study and the study setting, preventing useful comparisons between studies.

One possible reason for this failure of agreement is a lack of clarity in defining continuity. Many studies focused exclusively on patterns of contact, which is only one component of continuity of care. Only two studies, the ECHO study (which provided two papers, Burns, Catty, Clement, et al., 2007; Catty et al., 2013) and Adair and colleagues' study (Adair et al., 2005), investigated more than one dimension of continuity of care even though the conceptual literature clearly describes continuity as multidimensional.

My systematic review identified a clear need to replicate measures that use a multidimensional definition of continuity of care. Replicating some of these measures may help to establish an evidence base in order to determine whether currently used measures of continuity are useful. It would also enable studies to be compared.

A study of the association between continuity of care and outcomes

My empirical contribution to this thesis consisted of two studies. The study reported in chapter three was a prospective study which described patterns of community care and measured the association between continuity of care and outcomes in the community for patients with severe mental illness. I measured continuity of care over three years for 323 psychosis patients who had been recruited to OCTET. I chose both the continuity measures and outcomes according to recommendations from my systematic review. I attempted to replicate the measures used in the ECHO study, and used rehospitalisation (measured in three ways) as an outcome.

Results from it indicated that patients with severe mental illness are seen regularly by their community teams and have very few breaks in care. There was a strong association between more frequent contact and being readmitted to hospital, a shorter time to readmission, and longer stays in hospital. Fewer breaks in care were also associated with all three outcomes in the same direction. These results would suggest that better continuity of care (as it has previously been measured) is associated with worse outcomes, an unsettling finding. On the other hand, better continuity of care was associated with better outcomes using two other measures of continuity of care, changes in care coordinator and copying in patients to letters. These are measures which could be considered to be less directly influenced by fluctuations in the patient's clinical condition and more related to service ideology. Fewer changes in care coordinator were associated with shorter hospital stays and copying in patients more often to letters sent about their care was associated with not being readmitted to hospital, a longer time to readmission, and fewer days in hospital.

There are two striking findings from chapter three. First, that most patients with severe mental health problems are seen much more frequently by community mental health teams than is generally believed. Therefore, using frequency and consistency of contact as measures of continuity of care might be of limited value in such services when they already provide frequent contact to patients. Second, it appears that community mental health teams have shifted the focus of reviews of community contact from establishing a baseline frequency to responding flexibly to need. The drive to see patients frequently, which has been implicitly understood as the key feature and an often argued benefit of Assertive Outreach Teams, has been replaced by flexibly seeing the patient *when it is necessary* to support them. This study suggests that such an approach to patient contact is widespread. It appears that c*ontinuity of care theory may have been overtaken by practice.* Reid and colleagues hypothesised that frequency of contact may no longer be a useful indicator of continuity of care in modern mental health services (Reid et al., 2002). The study I conducted in chapter three is the first to lend support to this hypothesis empirically.

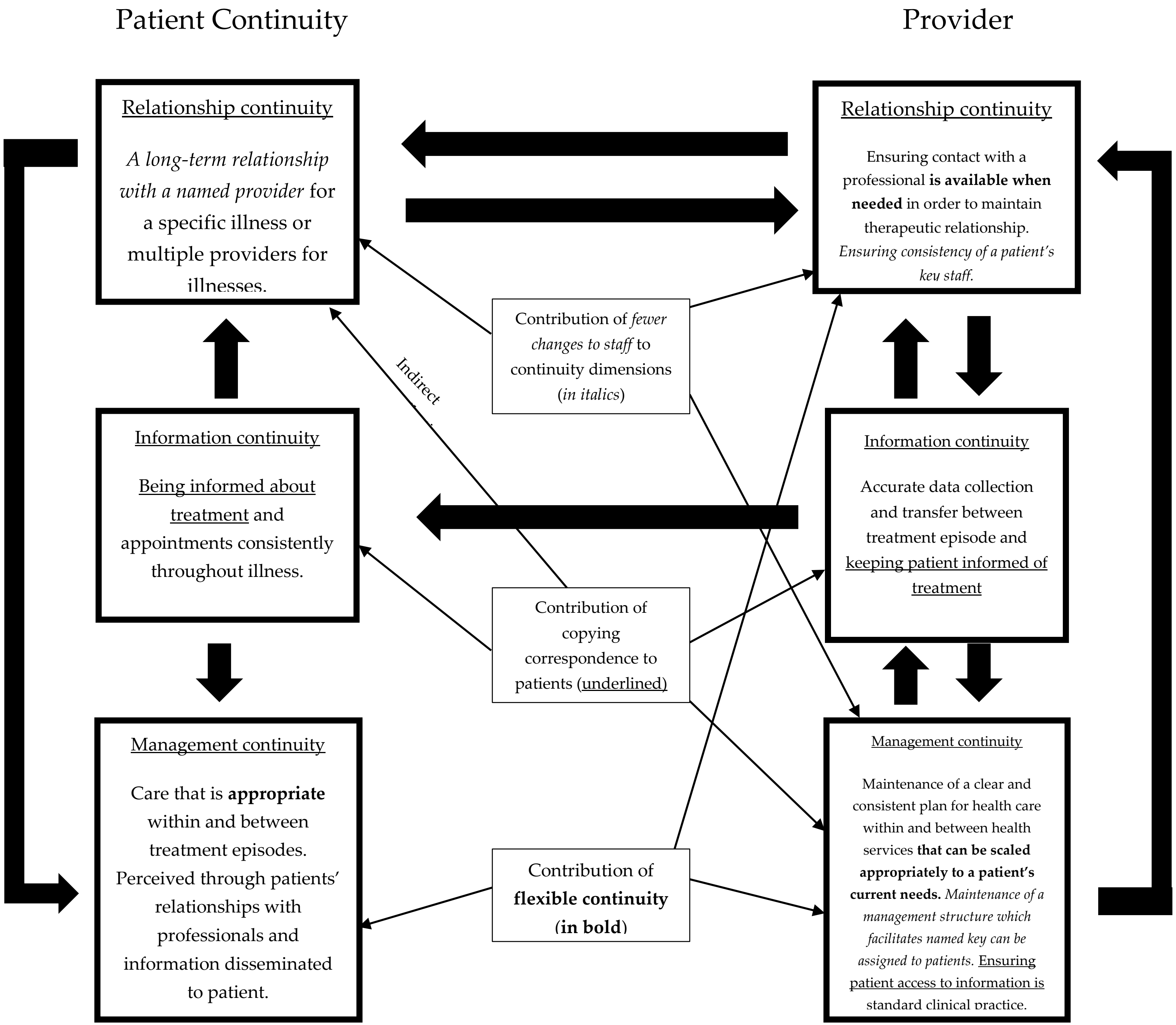
This flexibility may influence three aspects of continuity that was described in chapter one (Figure 1.1). First, relationship continuity from the perspective of the provider should be flexible rather than consistent. Second, it may also influence management continuity from the perspective of the provider. Thus, "Maintenance of a clear and consistent plan for health care within and between health services" (pg. 31) could now be considered the maintenance of a clear and consistent plan for health care within and between health services that can be scaled appropriately to the patient's current need. Third, it may influence the patient's perspective of management continuity: "care that is consistent within and between treatment episodes…" (pg. 31) may instead be viewed as care that is *appropriate* within and between treatment episodes. Figure 5.1 updates my original approach to continuity by including the evidence of flexible services.

Another finding in this study was that there may be positive effects of long-term relationships between care coordinators and patients. As with regularity of contact, having fewer changes in clinician has been considered an indicator of good continuity of care (Hjortdahl & Laerum, 1992). Long-term patient-clinician relationships are believed to contribute to patient trust (Mainous III, Baker, Love, Gray, & Gill, 2001) and shared experience (Mainous III, Goodwin, & Stange, 2003), and provide a point of stability for patients (Jones et al., 2009). The results from this study suggest this relationship was provided by a care coordinator rather than a psychiatrist. This is different from other medical settings such as primary care where the doctor is considered the primary source of relationship continuity (Freeman et al., 2007). Unlike my findings with regularity of contact, the results of this study seem to support the traditional view of a long-term relationship (which is considered 'good' continuity) resulting in better outcomes. It also reinforces continuity theory which places importance on a lack of change and disruption to teams which may impact on patients' relationship with staff. This need to ensure not only a consistent named provider but also to minimize of disruption, *by limiting changes to a patient's key staff* , should be reflected in continuity theory. Figure 5.1 illustrates how ensuring consistency of key staff contributes to provider relationship and management continuity.

The final finding I reported in chapter three was the association between having more correspondence copied to a patient and better outcome. This finding suggests that information continuity is not only important between different services that have contact with the patient, but is also important between the different services and the patient. Copying correspondence to a patient could contribute to all three dimensions of continuity in my study. It can contribute indirectly to *relationship continuity* by improving the therapeutic relationship, contribute directly to *information continuity* by ensuring a record of information is circulated between all concerned parties, and contribute to *management continuity* via information continuity by ensuring copying patients into correspondence is part of standard practice. This is an illustration of how individual components of continuity can have an impact on more than one of its dimensions and that the dimensions themselves can overlap (Gulliford et al., 2006). Figure 5.1 updates my original approach to continuity by including the evidence of flexible services, the need to reduce staff turnover in order to maintain stable relationships with patients, and the contribution of copying correspondence to patients in promoting continuity of care.

It cannot, of course, be concluded that this association between copying letters and better outcomes is causal, nor indeed the association with fewer changes in care-coordinator. The relationship could be mediated either by more correspondence being copied to patients where there is a trusting relationship or it might be that services which are broadly more patient-centred are more likely to copy correspondence. The same considerations are also possible for the lowered rate of change of care coordinator.

Figure 5.1 Illustration of how findings contribute to continuity of care dimension and their interactions



Patient Continuity

Provider

Relationship continuity

A long-term relationship with a named provider for a specific illness or multiple providers for illnesses.

Information continuity

Being informed about treatment and appointments consistently throughout illness.

Management continuity

Care that is **appropriate** within and between treatment episodes. Perceived through patients' relationships with professionals and information disseminated to patient.

Relationship continuity

Ensuring contact with a professional **is available when needed** in order to maintain therapeutic relationship. *Ensuring consistency of a patient's key staff.*

Information continuity

Accurate data collection and transfer between treatment episode and keeping patient informed of treatment

Management continuity

Maintenance of a clear and consistent plan for health care within and between health services **that can be scaled appropriately to a patient's current needs.** *Maintenance of a management structure which facilitates named key can be assigned to patients.* Ensuring patient access to information is standard clinical practice.

Contribution of *fewer changes to staff* to continuity dimensions (*in italics*)

Contribution of copying correspondence to patients (underlined)

Contribution of **flexible continuity (in bold)**

The complexities of measuring continuity of care and how to address them.

The complexity of attempting to conduct a study to investigate the association between continuity of care and outcomes quickly became apparent.

There were two major challenges. The first was selecting which measures to use given the lack of clear descriptions of how measures represent the aspect of continuity of care they aim to operationalise. The second was attempting to recreate measures that were no longer measurable from patients' notes, because services had changed (i.e. the clinical reality that the concept was meant to describe had changed), or were no longer applicable because continuity of care theory had changed.

The first challenge can be addressed by authors being clearer in how they define and measure continuity of care. This appeal has been made repeatedly for over 35 years (Adair et al., 2003; Bachrach, 1981; Johnson et al., 1997; Starfield, 1980). Reid and colleagues' 2002 review of 583 papers found that only 187 (32%) explicitly defined continuity (Reid et al., 2002).

A consensus on the definition of continuity of care may be hard to reach. This reflects the conceptual complexity of continuity of care but also the priority given to different elements of continuity in different medical specialties (Haggerty et al., 2003). For example, a long term relationship between patient and clinician spanning months or years may be important in primary care or mental health, but less so in surgery. However, researchers can help future studies by being precise when describing *their* definition of continuity of care. They should also explain how the measures they have chosen relate to their definition, the population being studied, and services that are being measured.

The second challenge is more difficult to address. This study has shown that continuity of care may best be understood as a fluid construct, and because of this, its measurements and definitions change over time. For example, not all of the measurements used in the ECHO study were relevant or possible to measure because of changes to services. Three specific obstacles were faced because of these service changes. First, some measures could not be collected as the services no longer routinely collected them. Second, some were not applicable as they were no longer considered measures of continuity of care. Third, the measure of continuity derived from number of changes in consultant psychiatrist was no longer self-evidently meaningful. This was because most patients now have separate inpatient and community psychiatrists whereas during the ECHO study it was standard practice to have the same psychiatrist across the course of the illness. This means that in my studies change in psychiatrists would not represent the same discontinuity as the ECHO study assumed it to represent.

The finding that a higher frequency of contact is related to worse outcomes also illustrates that continuity of care is a fluid and context dependant construct. Baseline frequency of contact was considered central to continuity of care in mental health in the late 1990s and early 2000s. My study suggests that patients are now seen much more often, often enough that discontinuities of contact are rare. What was considered vital to improve continuity of care is now standard practice such that continuity of care theory needs to be updated to be in line with practice.

The operationalisation of continuity of care thus needs to change as services change. Changes to services, such as increased contact with patients, may bring continuity to an aspect of care that was previously far more fragmented. Conversely, other changes which are presently not understood, such as splitting inpatient and community services, may bring new fragmentation and discontinuities which need to be investigated.

Implications for further research

There is a clear interest in continuity of care yet its complexities contribute to the difficulty of designing and executing studies. The lack of research reflects this complexity. However, the study I conducted in chapter three illustrates that it may be possible to measure continuity of care despite this and it also provided a number of avenues for further research.

Replication and validation of continuity measures

A key finding from the systematic review in chapter two was the wide range of continuity measures used and the lack of agreement on which to use. One of the first challenges faced by researchers when designing a study examining continuity of care is whether to use an established instrument or to create a new one, tailored to their context. There is no well-established measure of continuity in mental health and this has probably contributed to the discrepant evidence on its association to outcomes. One of my aims in chapter three was to replicate previous measures. Some measures, such as measuring the changes in care coordinator were found to be both collectable and an adequate operationalisation of relationship continuity, whilst others, such as frequency of contact were shown not to be as useful.

Replication and validation of current measures, both service and patient-oriented, would help in moving towards a consensus on which measures to use. Using 'big data', large datasets such as the Clinical Record Interactive Search (CRIS) system or the Norwegian healthcare system's Core Health Record, could be the most time and cost effective way of conducting studies which replicate continuity of care measures. Modern large clinical datasets increasingly have access to a broader range of routinely collected data and can even search freeform text data from clinical notes. They also have large samples from which to investigate. These two features make the use of large datasets a pragmatic approach for the replication and validation of continuity measures.

Areas of future research highlighted by this thesis

The flexibility of care practiced by community teams and the splitting of inpatient and community services are two important areas of future research highlighted by the findings presented in chapter three.

The data from chapter three suggest that community teams were demonstrating flexible continuity by seeing patients who were more ill more often. However, I did not measure flexible continuity directly. Bachrach describes flexible continuity as "a flow in services (that) should correspond to changes in the patient's circumstances" (Bachrach, 1981, pg. 1451). Sytema and Burgess operationalised this definition as the number of days between discharge and follow-up, and the combination of inpatient, day patient, and community care (Sytema & Burgess, 1999). Unfortunately this operationalisation does not have much face validity and only addresses between-service flexibility rather than within-service flexibility.

As I discussed in chapter three, two later studies have also investigated within-service flexibility. Adair and colleagues' observer questionnaire contained an item that asked them to rate whether care had changed in accordance with need, whilst the ECHO group measured increases in contacts preceding an admission to hospital. Both suffer from significant limitations. The Adair measurement relied on a subjective judgement by a researcher, whilst the ECHO measure could only detect flexibility before admissions.

A more robust method would be to measure need and service provision concurrently. One possible method for measuring flexible continuity is by measuring symptoms and need at regular intervals (e.g. weekly) and matching this data to patterns of contact. Matching symptoms to contact frequency could show whether services have been flexible to patients' needs. A symptom self-monitoring system, which uses mobile phone technology to measures patient responses to questionnaires is one possible method for measuring patients experience at regular intervals (a similar approach has been used in mood monitoring in bipolor disorder, Bopp et al., 2010). Similar regular symptom monitoring is in use by many CBT therapists and is a feature of the UK's IAPT initiative. These are embedded in highly prescribed and inflexible regimes but there seems no reason why the same approach should not be tried with more individualised and responsive services.

The coordination of inpatient and community services is also an interesting area of research in continuity of care. The *integrated* system of care, means a patient's care is now transferred to a different psychiatrist each time they are admitted or discharged. This creates an automatic discontinuity in the relationship between a patient and their care team. There has been some debate as to whether these changes have led to fragmentation of care (Burns, 2010a; Lodge, 2012). Patients and clinicians cite the lack of continuity of care as one of their main concerns with the functional system of care (Dale & Milner, 2009) and patient satisfaction may also be lower (Laugharne & Pant, 2012). There is also a lack of evidence on whether either system of care leads to better outcomes (Omer, Priebe, & Giacco, 2015).

The Comparing Policy Framework, Structure, Effectiveness And Cost-effectiveness Of Functional And Integrated Systems Of Mental Health Care (COFI) study is a large, five country observational study currently being conducted into functional and integrated systems of care. COFI, will investigate the outcomes of patients from either functional or integrated systems in the UK, Belgium, Germany, Italy and Poland. It plans to recruit over 5000 patients and will measure clinical and social outcomes, patient quality of life, satisfaction with care, and cost effectiveness. It does not attempt to directly measure differences in continuity of care in any greater detail between these two systems (i.e. it is only investigating the impact of a discontinuity on outcomes, rather than investigating multidimensional continuity). This is surprising given clinician and patient concerns that functional systems of care will produce poorer continuity of care. This would be an important avenue of research for researchers to pursue.

Qualitative approaches in particular could contribute to explaining the differences in continuity between functional and integrated systems of care. In Jones and colleagues qualitative investigation of patients' experiences of continuity of care in two inner London CMHTs, two key themes that emerged were discontinuity of relationships caused by frequent changes in staff and poorly coordinated transitions (Jones et al., 2008). Both changes in staff and transitions are more likely in functional systems and a qualitative investigation of patients perspectives of how these discontinuities may be offset by the purported benefits of a functional system (quicker clinical decision making, fostering expertise in specific clinical settings, more intensive treatment in each setting) is currently absent from the literature. There is a lack of qualitative investigation of patient's perspectives of continuity of care in mental health, which may explain some of the lack of a clear phenomenological basis to many of the measures currently used in continuity of care research.

Community Treatment Orders and continuity of care

The potential benefit of CTOs had been heavily debated for 15 years before their introduction and has been heavily debated since (Dunn, 1991; Lawton-Smith et al., 2008). One of the arguments for their introduction was to improve continuity of care for patients in the community. However there was no evidence for any association between CTOs and continuity of care. Therefore, the second empirical objective of my thesis was to investigate the association between CTOs and continuity of care. This would be the first study of its kind.

A study of the association between CTO status and continuity of care

Chapter four described a prospective study of 323 patients with psychosis who were followed for 36 months and measured for both CTO status (i.e. whether they had been made subject to a CTO or not) and continuity of care. I collected data from health records for patients enrolled in OCTET, who had been randomised to either CTO or voluntary care via section 17 leave.

I measured CTO status using four different methods: the original OCTET randomisation arms, being made subject to a CTO at any time during the 36 months, the number of days subject to CTO, and the proportion of community days subject to CTO. I chose these methods in order to measure the potentially wide variation in CTO status of the patients.

Being made subject to a CTO, a higher number of days on CTO, and a higher proportion of community days subject to CTO were all significantly associated with having more community contact and fewer breaks in contact (60 day gaps). Patients randomised to the CTO arm also had a higher proportion of letters copied to them. No other measures of continuity of care were associated with any measure of CTO use.

A sensitivity analysis restricted to patients made subject to a CTO found that neither the length of time on a CTO nor the proportion of community days on a CTO was associated with a higher rate community contact. Having a higher proportion of community days on a CTO was, however, associated with fewer breaks in contact, although the 95%CIs were wide, which suggests caution when interpreting the result.

I drew two main conclusions from these results. First, CTO use is associated with a higher rate of community contact than voluntary community care. Second, the length of time a patient is subject to a CTO is not associated with contact frequency nor breaks in care.

The association between CTO status and community contact

There was a clear association between CTO use and an increase in contact in three of the four measures of CTO use. Only the measure of CTO randomisation from the original OCTET study was not associated with community contact. There are two competing explanations as to why CTO use in this study was associated with increased community contact.

It may be that being made subject to a CTO facilitates increased patient contact. This was an explicit aim in the introduction of CTOs. However, as discussed in chapter four, there are a number of confounders which may suggest another explanation. First, patients who were made subject to a CTO had a higher incidence of readmissions. Hospital admission is the most often used measure of relapse (Burns, 2007) and this suggests patients who were placed on CTOs over the 36 months were either more ill or more at risk of relapse. Patients who are readmitted to hospital also often have changes in their treatment regime (both medication and psycho-social). This may result in them having an increased frequency of contact as part of their discharge plan, which may be driving the association. Furthermore, in chapter three I argued that patients who were more ill (and likely to be readmitted and have longer hospital stays) had more community contact with services. Thus, the association between CTO status and an increase in community contact may be mediated by illness severity and relapse. Finally, patients who are more ill may be kept on CTO for the longest duration.

The association between the lengths of time a patient was on CTO and an increase in patient contact was very small, with each extra month of CTO reducing the time between two community contacts by 0.19 days. Thus nearly six months on CTO would be required to reduce the interval by one day. This association disappeared in a sensitivity analysis which analysed only patients who were made subject to a CTO. This would suggest that a longer time on a CTO does not increase the rate of contact with their community team.

Do CTOs improve continuity of care?

CTO use was associated with an improvement in two of the eight continuity of care components measured in this study, *average gap between face-to-face contacts*, and *number of 60 day gaps*. Both are measures of contact frequency which chapter three highlighted may be of limited value when measuring continuity of care, and both suffered from confounding factors such as illness severity. Therefore it can be argued that it remains unlikely that CTOs improve continuity of care.

The most likely process by which CTOs would improve continuity of care between patient and community team in the UK would be the legal requirement for engagement stipulated as conditions in most CTOs. As has been shown, most of the patients in my study were kept engaged with services regardless of their legal status in the community. It is questionable whether further engagement, compelled or not, would bring increased benefit. The concern of those who opposed CTOs was that they would drive patients away from services and create distrust between patient and community team (and consequently poorer continuity). This was not found in this study. It appears that CTOs have no effect, positive or negative, on a patient's continuity of care from a service perspective.

Despite the introduction of CTOs in England and Wales being expected to improve continuity of care there is no part of the Act which specifically targets continuity. There are only two mandatory conditions of a CTO. The first is to be assessed by the responsible clinician before the CTO expires and the second is to be assessed by a second opinion doctor. Neither of these mandatory conditions directly addresses improving continuity of care. A number of discretionary conditions, such as being required to keep appointments or to keep taking medication, can, and usually are added to the order. It is presumably believed that continuity of care will be improved indirectly by improved medication adherence making it easier for services to provide follow-up. However, the evidence is poor for CTOs in improving engagement or medication adherence (Maughan et al., 2014). It is improbable that CTOs could improve continuity of care if they do not improve those conditions assumed to indirectly influence it.

Some jurisdictions, such as New York, use CTOs in conjunction with enhanced community services (Swanson et al., 2014). For these jurisdictions it is possible that CTOs could improve continuity of care (although no studies have been published to support this) as they may represent a pathway to obtaining care in the first place. Community services in New York are considerably less intensive for most patients with mental health problems and because of this the increase in community support associated with the CTO could greatly improve continuity of care. In jurisdictions which do not add targeted community support, this would be an unlikely consequence of CTOs.

Implications for further research in the association between compulsion and continuity of care

In chapter four I explored continuity of care from a service provider's perspective and found no association between CTO use and continuity of care. It was limited in its scope in that it only measured objective outcomes of continuity of care.

Given that CTOs do not directly legislate for continuity of care, the influence of CTOs on continuity may be more nuanced and subtle. Quantifiable measures derived from medical notes, such as frequency of contact and changes in care coordinator, are not able to detect such subtleties. Investigations of the association between CTOs and continuity of care could therefore benefit from wider methodological approaches.

As highlighted in the systematic review, there has been a shift in the last ten years to investigating continuity of care from a patient perspective using validated questionnaires. The ACSS-MH patient questionnaire asks a number of questions about patients feeling involved in decisions of their treatment and long-term relationships with their care team (Adair et al., 2005). These aspects of continuity may be more promising in detecting differences between patients on CTOs and those in voluntary community care.

Final reflections on continuity of care and community mental health services in the UK

Is continuity of care a useful concept?

Continuity of care, or more often discontinuity of care, is easily recognisable to policy makers, clinicians, and patients. Despite the relative lack of research progress, it retains a justifiable hold on our clinical imaginations. Continuity of care has face validity. Many patients can relate to the experience of having to retell their medical history to different clinicians, of having constantly changing ward staff, or not being properly informed about the next stage of their treatment. Similarly, many clinicians can give ready accounts of lost notes and poorly coordinated transfers or discharges. The need for good continuity is intuitively understood by both patients and clinicians.

Illnesses are not cross-sectional events independent of context. They are longitudinal, sometimes lifelong, experiences. They are influenced by, and oblige the patient to interact with, the various elements of the health system. Because illnesses take a longitudinal course, continuity of care seems fundamental in its treatment. Having no information transmitted from one health visit to the next could be argued to be an inefficient use of resources and potentially dangerous. Evidence indicates that discontinuities in care are associated with adverse events, such as medication errors (Moore, Wisnivesky, Williams, & McGinn, 2003; Petersen, Brennan, O'Neil, Cook, & Lee, 1994).

Researchers have mostly been unable to successfully translate the face validity of continuity of care into measurement (i.e. construct validity). This may in part be because it is easy to identify a discontinuity but far harder to identify continuity. For instance, a medication prescribed to a patient on discharge that was not written on the discharge summary could be measured as a discontinuity of care, yet the inclusion of that medication on a discharge summary would not necessarily be considered continuity of care, it would more likely not be considered as anything notable.

Continuity of care is therefore more than the absence of discontinuity. There is an assumption that it is meaningful in its own right. Discontinuities are more easily noticed as they mostly are discrete events (and easily identified outcomes). Continuity of care may best be considered a *process*. For instance, ensuring a patient is seen by the same clinician over a number of visits or the collation and timely transfer of a patient's medical history during a transition between services will provide continuity of care. Thus, it may be realised that a medication was missed from the discharge summary (a discontinuity of care and an outcome) because the discharging clinician was not the clinician who had seen and had knowledge of the patient's medication (a continuity and a process). This discontinuity may then lead to a more clinically obvious and relevant outcome such as an adverse event. One reason for the failure to measure continuity of care may be due to the lack of precision when identifying process and its outcomes.

This failure to translate the concept of continuity of care to a measurable construct is especially noticeable in mental health where the landscape of care provision has changed so drastically. As services (and society) have changed, the standard and meaning of *good* care has changed and research into continuity of care has been unable to respond to the pace of these changes. This thesis investigated continuity of care using some measures that still accurately described continuity of care (such as changes in care coordinator) whilst others, on analysis, appear obsolete. This iterative process may be a useful way of prioritising measures of continuity of care that work in measuring current services.

Research into continuity of care in mental health probably requires a radical rethink to be useful to researchers, services, and patients. It has to predict, or at the very least keep pace with, societal and service changes to be of benefit to services and patients.

What are the new challenges to continuity of care in mental health?

A significant and time consuming amount of my DPhil was spent data collecting in community teams, hospitals, and other mental health services across the country. Both the process of data collection (reading through hundreds of case notes and struggling with access to sites and IT systems) and the analysis of the data (up-to-date data on patient's 'journeys' through mental health services) contributed to my understanding of the new challenges in improving continuity of care for patients in these services. Three challenges that were predominant throughout this process are discussed here:

The therapeutic relationship over time is important. Constant changes benefit no one.

Mental health services have changed drastically over time however there are some aspects of care which seem stable and fundamental to good continuity. My thesis found an association between long-term continuity of a care coordinator and good outcomes. A stable therapeutic relationship with a clinician who knows about the patient has been shown to be a benefit to both the patient and the clinician in many areas of medicine (Karver, Handelsman, Fields, & Bickman, 2006; Priebe, Richardson, Cooney, Adedeji, & McCabe, 2011b). Despite this evidence, services are becoming increasingly more specialised and fragmented. In mental health, inpatient and outpatient services are now run separately, and community mental health teams are continually reorganised (over the three years of this study, almost every community team involved in the study went through a name change and reorganisation of staff). Two examples of how patients are affected are given below.

Case examples of fragmented care due to service changes.

Example 1.

Patient A lived at the same address in Southampton throughout the study. During this time, his community team was reorganised twice. He was allocated a new psychiatrist once, and changed care coordinator twice as a results of these changes. Throughout patient A's notes there are references to the patients unhappiness at these changes followed by periods of disengagement.

Example 2.
Patient B lived in north London. North London has separate inpatient and outpatient consultants and the patient was readmitted to hospital twice in quick succession (resulting in three changes in psychiatrist and two different psychiatrists in four months). After the second admission, her accommodation was no longer available and she moved to north west London. This was outside the old Trust's area and she was assigned a new team and new psychiatrist. Following a short stay in the community the patient was readmitted again. Adding these changes up, over one year she was under the care of four different psychiatrists and had six changes in the psychiatrist who was responsible for her at any given time.

It is difficult to identify who these changes benefit. Both patients and staff value a long-term therapeutic relationship. Clinicians report that this relationship often makes the difference to whether patients respond positively to treatment decisions or not. When changes happen, patients often report feeling abandoned, vulnerable, and distressed. Staff report feeling undermined and devalued and staff morale has been reported as lower after reorganisations of mental health services. Clearly innovation is vital in mental health services. However without proper evaluation it risks creating worse outcomes for the people it was meant to benefit.

Transitions are an inevitable result of modern services and need to be improved

The specialisation of mental health services has created a system where transitions between services are frequent. Patients have transitions between CMHTs and inpatient units. They move from inpatient units to home treatment teams and then back to the CMHT. They move from child and adolescent services to adult services and from adult services to old age mental health services. If they are well they can be discharged to GPs, and if they are severely ill they can be transferred to assertive outreach teams, psychiatric intensive care units, and forensic units. When transitions occur, patients lose relationships. They change psychiatrist, care coordinator, and the multidisciplinary team that cares for them. Specialist services can benefit patients as they can provide a level of treatment that is appropriate to their needs. However, transitions between these services create discontinuity of care and probably need to be managed more carefully.

In this thesis I took a very simple approach to assessing transitions. I measured whether a referral to any service (not only different mental health teams) was documented in a patient's notes. I found only 64% of referrals were documented in patient notes. More robust analyses have shown similar results (Munoz-Solomando, Townley, & Williams, 2010; Singh, Paul, Ford, Kramer, & Weaver, 2008; Singh et al., 2010). For instance, the poor quality of transitions between adolescent and adult mental health services has been widely documented. Singh and colleagues found multiple different protocols and no clear strategy for transitions, poor information transfer, and many lost and disengaged patients during transfer to adult mental health services from adolescent services (Singh et al., 2008).

It seems that services have been slow to adapt to these transitions despite them regularly occurring which has an impact on patients' continuity of care and possibly their outcomes. This is one area of mental health services where continuity of care could be greatly improved.

Information continuity and patient health records

The separation of mental health services also increases the likelihood of failure in information continuity. Multiple professionals across multiple sites now all need access to a patient's medical records. One way of achieving this is through improved information technology (IT). IT has been absent from conversations about continuity of care in the UK and health services have been slow in utilising computer technologies for healthcare records.

During the data collection phase of my DPhil, the majority of patient healthcare records had to be accessed from the community team caring for them. Many of the mental health trusts had begun to use electronic healthcare records, but earlier information was often not transferred from paper to electronic records. This meant conferring between multiple different sets of data in order to find information. This is not only frustrating for researchers, but much more importantly will also have an impact on information continuity in clinical practice. Decisions about a patient's care are made more difficult when there is no single place to access all the information. For instance, an inpatient clinician could start a patient on medication without knowing that it had been found ineffectual previously as this was not available in the particular patient record that clinician had viewed. Time is then wasted during which a more effective treatment could have been given.

Electronic healthcare records have the potential to revolutionise information continuity in mental health, particularly in a system of care which is becoming more fragmented. Electronic records provide faster and more accurate information retrieval than paper records (Tsai & Bond, 2008), and can be accessed from any site with a computer. However, despite the potential benefits, the implementation of electronic records has been slow, and these have often had limited clinical function and poor compatibility with other electronic systems (Sheikh et al., 2011).

Collecting data from electronic notes during my DPhil was also beset with problems. There were eight different forms of electronic records software used in different Trusts, each requiring mandated training before use. The software (which was bought by the Trusts at considerable cost) was often poorly designed and lacked intuitive user interfaces, was slow and could often not be accessed due to maintenance. It included conflicting information, and was time consuming to input and retrieve information.

Better, more reliable IT systems could greatly improve information continuity in mental health. It could ensure that all patient data were immediately accessible to a clinician in any location. It could accurately keep track of prescribed medication, all patient contacts, recent transitions, referrals to other services, a patient's social and accommodation status, CPAs and other important elements of care. Despite the potential benefits, there seems to be no current published research into how better and more efficient IT systems may benefit continuity of care.

Summary

Continuity of care is useful as an indicator of the process of care. However for it to accurately describe what it purports to, and to be an effective research tool, there needs to be a considerable change in the way it is measured and the outcomes which it is measured against. This is because the context has changed and many measures of continuity of care no longer accurately describe the complexities of current mental health services. Today’s mental health services are characterised by separation and specialisation into different areas of care. The most useful measures of continuity of care will be the ones which successfully measure how it can be maintained (or fails to be maintained) between services. Three areas of continuity which are particularly affected by the separation of services are the longitudinal relationship between a patient and clinician, the transitions when a patient moves between services, and the methods by which information about the patient is transferred between staff involved in their care. Increased attention to describing and measuring these three areas could benefit both patients and future research into continuity of care.

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