WHAT MENTAL HEALTH CARE EXPERIENCES AND OUTCOMES MATTER FOR PEOPLE WITH COMPLEX HEALTH AND SOCIAL NEEDS?

WHAT MENTAL HEALTH CARE EXPERIENCES AND OUTCOMES MATTER FOR PEOPLE WITH COMPLEX HEALTH AND SOCIAL NEEDS?

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Lay abstract

The phrase “complex health and social needs” is used to describe challenges that arise in providing healthcare for people who experience multiple physical and mental health concerns and social marginalization. Care for people with complex health and social needs is called “complex care.” Disagreement exists about the nature and goals of complex care; there is especially little evidence about the goals of complex care in relation to mental health. This dissertation aims to address these knowledge gaps by: 1) developing a new policy framework for complex care that is based on a clear definition of complex health and social needs as a policy problem; 2) exploring the mental health care outcomes that matter in complex care, from the perspective of leaders, including managers and clinicians as well as individuals with lived experience in advisory roles; and 3) exploring the mental health care experiences that matter to people with complex health and social needs.

Abstract

Individuals with complex health and social needs (ie. those experiencing physical and mental multimorbidity and social marginalization) are poorly served by health systems. “Complex care” programs have been developed to address these needs. However, scholarly debate surrounds the question of what problem complex care seeks to resolve, and how success can be measured. Within this debate, limited attention has been given to mental health.

This dissertation contributes to discussions of the objectives of complex care through three qualitative studies. First, a critical interpretive synthesis of literature is conducted to develop a novel framework for complex care policy. The framework integrates diverse academic and grey literature on complex care, while drawing on theoretical work on multi-level interventions. Second, a qualitative description study explores the perspectives of leaders (including operational and programmatic leaders, and individuals with lived experience in advisory roles) with respect to mental health outcomes that matter in complex care. Outcomes valued by participants include both individual-level objectives oriented along a dynamic continuum towards recovery, and system-level objectives. Finally, an interpretive description study unpacks the viewpoints of individuals with complex health and social needs on what constitutes a good experience in mental health care. Participants describe valuing mental health care that is founded on authentic relationships and that is tailored to the individual.

Taken together, these studies posit that complex care must be individualized, relationally-centred care, and situated within a flexible, multi-level system. This dissertation advances conversations on the aims of complex care and the conditions that might render these aims attainable.

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List of abbreviations

CIS: Critical interpretive synthesis
CCM: Chronic care model
IKT: Integrated knowledge translation
OPL: Operational or programmatic leader
PWLE: Person with lived experience

Declaration of academic achievement

This dissertation includes three chapters of original research (Chapters 2, 3, and 4), in addition to an introduction and conclusion (Chapters 1 and 5, respectively). I am the lead author of each of the three original research chapters. I conceptualized the overall dissertation including the focus and design of each original thesis chapter; designed data collection instruments and undertook data collection; conducted analysis; and prepared written manuscripts. My supervisor Dr. John Lavis and committee members Dr. Julia Abelson and Dr. Nick Kates provided input into study design, development of study materials, and analysis of data, and provided feedback on drafts. Alice Cavanagh was involved in screening articles and preliminary analysis in Chapter 2, and Jason Turi and Rebecca Sax contributed to study design and refinement in Chapter 3. Further details of the roles of each author are provided in the preface to each study.

Chapter 1: Introduction

Overview

People with complex health and social needs (ie. those facing concurrent mental and physical health challenges and social marginalization) may struggle to find appropriate healthcare. One symptom of this struggle is frequent health service use; while costly to healthy systems, this also represents a human cost of inadequately-addressed suffering.

"Complex care" policies and programs have been developed to address this challenge. However, complex care has proven challenging to evaluate. A lack of conceptual clarity surrounding the aims and nature of potential solutions contributes to the difficulty in determining whether and how complex care works. Moreover, while mental health concerns are a recognized component of complex needs, the domain of mental health has received scant attention in evaluations of complex care.

First, this thesis responds to the lack of conceptual clarity in the field by setting out a framework for complex care from a policy perspective. Moving beyond the predominant focus on service-level interventions evident in the literature, Chapter 2 sets out a definition of complex needs as a policy problem. This chapter argues that a central feature of complex care is its multi-level nature, spanning health and social system, service, provider, and client levels of intervention; and that these interactions each influence the others. Subsequent chapters narrow in to focus on a particular policy concern (quality), in relation to a particular facet of complex needs (mental health): Chapters 3 and 4 explore what good mental health care means for individuals with complex health and social needs, from the viewpoints of those in leadership roles and those receiving complex care respectively. In this introductory chapter, I provide background and set out the aims and approaches of the dissertation as a whole

Background

The field of complex care

The phrase "complex health and social needs" is a euphemism. The phenomenon it is used to describe–the inter-connected challenges of multimorbidity and social marginalization at an individual level–was identified through efforts to explain a system-level problem: in a number of high-income countries, a small number of patients account for an outsized proportion of costs. For instance in the United States, 5% of patients account for nearly half of all health care expenditures (Cohen and Yu, 2012), while in Ontario 5% of patients account for 65% of expenditures (Wodchis, Austin, & Henry, 2016). These findings point towards a potential "quick win" for healthcare cost control, suggesting an opportunity to drastically reduce costs through measures that are highly targeted rather than sweeping and systemic. But who are these expensive 5%?

Data analysis in the United States revealed a group of individuals facing a number of mutually compounding challenges. This group was characterized by multiple, concurrent chronic health issues; simultaneous mental health or substance use concerns; social marginalization; and difficulty carrying out activities of daily living (Long et al, 2017). Caring for individuals with complex health and social needs therefore requires coordination across multiple health and social services. In the absence of appropriate care, these individuals may experience "high-intensity, low-benefit service use," characterized by frequent hospitalizations and emergency service visits that do not result in improvements for their health and wellbeing (Thomas-Henkel et al, 2015).

Scholars have developed theoretical frameworks to explain complex needs. Some of these frameworks primarily enumerate factors contributing to complexity (eg. Safford et al, 2007). However, more dynamic approaches consider how complexity is generated, framing it as a site of disjuncture or a gap. In one framework, this gap falls between the "workload" required to manage an individual's health, and that individual's "capacity" to do so (Shippee et al, 2012). For example, workload may be increased by the intense self-management demands of multiple chronic illnesses, while capacity may be decreased by insufficient social support. Another framework highlights the contribution of systems themselves to the problem of complex needs: Grembowski and colleagues (2014) consider the gap to fall between individual needs, and system resources. They note that this gap between needs and resources occurs within a broader social ecology including population-level inequities, and health research and policy that tend to focus on single diseases.

If health systems contribute to generating complex needs as Grembowski and colleagues suggest, system redesign is required to redress these needs. The emerging field of complex care can be differentiated from the more familiar chronic care, as described in Wagner and colleague's enormously influential Chronic Care Model (Wagner et al, 1996) by complex care's intentional consideration of both multimorbidity and social marginalization; its foregrounding of integration of services; and its focus on care coordination to a greater degree than care provision. Complex care encompasses health services, systems, and policy. At a service level, specific programs may target individual users with complex health and social needs, offering interventions like comprehensive assessment and care planning. These services may be nested within broader inter-organizational efforts to integrate care across health and social services; meanwhile, these system redesign initiatives in turn are often carried out under the auspices of governmental policies. For instance, in Ontario, Canada a policy initiative called Health Links brought together voluntary networks of providers to implement individualized care plans. In the

United States, a provision in the Affordable Care Act introduced Health Homes which include integration across a continuum of services as well as care coordination.

Evaluating complex care

Definitive findings on outcomes of complex care have proven elusive (Kumpunen, 2020). Implementing complex care programs requires a holistic understanding of patients, continuity of care, trusting patient-provider relationships, and patient involvement in care (Czypionka et al, 2020). Common elements among programs that are considered successful include a single point of access, comprehensive assessment and care planning, care coordination, and a core group of providers with strong links to a broader network (Wodchis et al, 2015). However, in a hermeneutic review of literature on integrated care for patients with multimorbidity, Hughes and colleagues (2020) note difficulties in straightforward assessment of whether and how this care works. They attribute this to the multiplicity of meanings, objectives, and contexts for complex care, as well as the embeddedness of service users within broader societal structures.

Indeed, commentors have noted that perhaps we are expecting too much of complex care: given that individuals with complex health and social needs are exposed to adverse determinants of health across their life course, including profound material deprivation and often interpersonal trauma, it may be unreasonable to expect a short-term intervention to affect substantial change (Cantor, 2020; Cutts & Gunderson, 2020; Lantz, 2020). A further strand of commentary raises the question of whether we are in fact measuring the right outcomes at all. The bulk of studies take cost and utilization measures as outcomes; however, while complex care in many ways responds to the skewed distribution of healthcare utilization described above, some have argued that reducing cost and utilization are not–or should not be–the only goals of complex care (Cantor, 2020; Cutts & Gunderson, 2020).

Evaluation and values

The question of what to measure is a at least in part a question about values: what constitutes a good outcome? What sort of goals are both reasonable and important for complex care to achieve? The debate over outcomes in complex care highlights how values come to bear when generating and interpreting evidence in health services, system and policy.

While questions about values in measurement have bubbled to the surface in the field of complex care, these often are left implicit in discussions of health care quality improvement. This is perhaps surprising, given the normative nature of quality as a concept: undertaking a quality improvement initiative requires asking what counts as 'best possible' care in a particular context (Carter, 2018; Cribb, 2019). Choices are made about which dimensions of care matter, how they can be conceptualized, and how the importance of indicators across domains can be weighted (Cribb, 2020; 2021; Mitchell, 2019). However, while quality is generally understood to encompass multiple domains, the quality literature does not consistently offer justification for how to choose among potential dimensions of quality or navigate trade-offs and tensions among them (Cribb, 2020, 2021; Mitchell, 2019). Ethicists considering these challenges have suggested that tensions and disputes over values are inevitable, and should be surfaced and engaged with directly (Carter, 2018; Mitchell, 2019; Mitchell, 2021). As Mitchell (2021) points out, this will require clarity over the role of norms and values in setting directions, "rather than supposing that solutions can be read directly off available data."

While the emerging literature on the role of norms and values in health care quality improvement tends to draw on examples at an organizational level, similar arguments have been made in literature on evidence-based policy. While politics involves contestation over what sort of society we wish to build, policy concerns how to build it. As such, a policy cannot be inherently evidence-based, but rather may be evidence-based in relation to a particular, politically-established aim (Head, 2010; Khosrowi & Reiss, 2019; Sanderson, 2003; Sanderson, 2006). As one scholar states succinctly, "evidence of itself does not have and cannot provide a goal" (Allmark, 2015). While evidence-based policy holds the promise of more effectively achieving social goals, the goals themselves are derived from a much wider array of inputs and processes.

The field of complex care's dilemma over outcomes and objectives–at service, system, and policy levels–can be understood in light of the literature described above. Plainly, the field has paused to ask: *what is the point of complex care?* The initial identification of a cost problem would suggest that a primary goal of cost containment. However, the subsequent identification of high-cost users as a population of marginalized individuals who are poorly served by health systems shifts the problem definition, and implies other possible goals. Those who provide complex care are unlikely to see their jobs solely as making their clients less expensive to the system. Those seeking care are unlikely to do so in the hopes of costing less.

Values in the field of mental health

Mental health concerns (inclusive of substance use concerns) are a central component of complex health and social needs (Long et al, 2017). However, while the field of complex care is just broaching questions of aims and values, these issues have long been engaged in the fields of mental health and substance use.

Throughout the twentieth century, mental healthcare underwent a paradigm shift. Deinstitutionalization has been argued to result from the confluence of rights-based social movements and advances in medical treatment of mental illness, particularly psychosis. Service users organized and demanded rights, with some arguing for reforms to mental health care while others adopted a stance radically opposed to psychiatric services (Reaume, 2002; Morrison, 2005). Concurrent with this radical shift in the provision of mental healthcare was a re-envisioning of its aims. Dr. Patricia Deegan, a psychologist with lived experience of psychosis, set out the concept of recovery as a guiding light for mental health care. Her concept of recovery was oriented around individual self-actualization, independent of symptomatic remission. Recovery was described as a process not an endpoint, and personal meaning and connection were central themes. Deegan wrote:

> *The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human. The goal is not normalization. The goal is to become the unique, awesome, never to be repeated human being that we are called to be.* (1990)

This reconceptualization of the aims of mental health treatment soon found purchase in the mainstream. W.A. Anthony's widely cited 1993 paper framed recovery for a professional audience; recovery was adopted as a policy goal in the early 2000s in English-speaking countries including the United States, England, Australia, and Canada (Piat & Sabetti, 2009; Davidson, 2016). While the concept and discourse of recovery has wide uptake, the actual implementation of a recovery orientation in mental health services and policy has lagged (Morrison, 2005). Moreover, beyond struggles to actualize the vision of recovery within mental health systems, the current policy trend towards greater integration of physical and mental health services represents an additional challenge. The values and goals embedded in a recovery paradigm can run counter to norms in other areas of healthcare, and may be unfamiliar to providers outside of mental health (Au et al, 2019).

At the same time, deep paradigmatic tensions continue to beset the field of substance use care. Harm reduction and abstinence are frequently framed as opposing poles. Harm reduction in substance use is a philosophy that is driven by, and centers, people who use drugs. A harm reduction paradigm considers substance use to be both common and value-neutral, and seeks to pragmatically minimize harm that can arise from it at individual and social levels (Denis-Lalonde et al, 2019). Meanwhile abstinence-based approaches in substance use famously include Alcoholics Anonymous and other 'twelve-step programs.' These programs, which include a spiritual basis, frame total cessation of substance use as a prerequisite for a life of connection, service, and meaning (Greene, 2021). As such, these two ways of approaching substance use have fundamentally different goals that are difficult to reconcile (Dale-Perera, 2017).

At the intersection: values, mental health and complex care

Mental health dimensions of complex needs and complex care merit dedicated focus, for several reasons. First, despite efforts towards greater integration of mental and physical health care, siloing of mental healthcare persists. As noted above, this is produced in part by the challenge of bridging paradigms (Au et al, 2019). Mental health outcomes therefore may not be adequately accounted for in general health measures. Second, mental health needs may not be well-addressed in existing complex care programs. For instance, an older systematic review found that care coordination for multi-morbidity reduced emergency visits for physical but not mental health concerns (Tricco et al, 2014). More recently, a study of enrolled patients of a flagship American complex care program found high levels of unmet mental health and substance use needs, with just 10% of clients with substance use concerns and 17% of clients with mental health concerns receiving relevant treatment (Rentas et al, 2018).

Third, and more closely linked to the discussion of values above, ambiguity exists around the objectives of complex care vis-à-vis mental health. Shared objectives are critical in complex, multi-level integrated care interventions, to help provide coherence across activities and over time (Kaehne, 2019). However, aims and indicators relating to mental health in complex care require clarification. For instance, while complex care generally aims to decrease utilization, other literature suggests that appropriate coordination of mental health care may result in an increase rather than a decrease in total utilization due to the depth of unmet need (Au et al, 2019; Beil et al, 2019). Grey literature reports have also commented on a lack of mental health-specific quality indicators that are appropriate for individuals with complex needs (Niles & Olin, 2021). This suggests a need to explore the mental health-related objectives and experiences that are valued in complex care–in order to eventually inform work on whether and how these goals are (or can be) met.

However, the above proposition begs the question of 'valued *by whom?*' Health policies are animated by broad, top-down statements of objectives like the 'quadruple aim,' which specifies four goals: improving population health, patient experiences, and provider experiences while keeping per capita health care costs manageable (Bodenheimer, 2014). There are increasing efforts to involve service users in health system decision-making, in part to produce decisions that account for service user values and perspectives; however, involvement may not be accessible to users facing (multiple forms of) marginalization (Ocloo & Matthews, 2016). Moreover, health policy is ultimately implemented through interactions between individual service users and service providers, under the auspices of locally-managed organizations (Evans, 2016). Values embedded in policy may come into conflict with values in the contexts where those policies are implemented and the individuals involved in implementation (Hupe et al, 2014). After setting up an overarching conceptualization of complex care, this thesis will therefore focus on mental health care outcomes and experiences from the viewpoint of those in the "inner ring" of complex care: organizations, providers, and ultimately users.

Aims and approach of this thesis

Structure of this thesis

This thesis asks two broad overarching questions:

1) What does complex care entail in policy and practice, and to what problem does it respond? (Chapter 2)
2) What mental health care outcomes and experiences matter in care for people with complex health and social needs? (Chapters 3 and 4)

Specifically, this thesis includes the following chapters:

Chapter 2 presents a critical interpretive synthesis (CIS) of policy literature on complex care. CIS is a methodology for systematically sampling and critically interpreting a heterogenous body of literature, with the objective of developing a theoretical framework. This study begins with the question, "how do conceptualizations of complex health and social needs relate to policy responses?" The concept of multi-level interventions is invoked to organize elements of complex care policies, and to explain how dynamic interactions can occur across individual, health service, and health system levels of these policies. This study functions as a backdrop for the remaining chapters, by conceptualizing complex care as a policy problem that crosses levels of intervention.

Chapter 3 analyzes the mental health outcomes valued by stakeholders in complex care. This study draws on interviews conducted with leaders in American complex care organizations, including operational and programmatic leaders as well as individuals with lived experience who hold advisory roles. Qualitative description methodology is used to generate a descriptive account of the mental health outcomes that participants perceived as relevant and important in complex care. Following on the articulation in Chapter 2 of complex care as a multi-level intervention, this study considers the relationships among different objectives at individual, and health service and system levels.

Chapter 4 offers a "ground-level" view of a policy question, by asking about quality as understood by individuals affected by the confluence of personal and system factors that characterize complex health and social needs. Individuals accessing services for people with complex health and social needs in Hamilton, Ontario took part in semi-structured interviews about their perspectives on what makes for good mental health care experiences. An interpretive description approach is applied to explore participants' viewpoints. This study builds on Chapter 3 by considering the perspective of current service users; it also connects to the theme of multiple levels introduced in Chapter 2, which threads through the thesis as a whole.

***Overarching methodology*.**

As described above, this thesis applies three different qualitative analysis approaches. Chapter 2 uses critical interpretive synthesis to integrating diverse types of literature into a coherent, policy-relevant theory. This theoretical framework provides a backdrop for the subsequent two chapters, in particular through introducing the concept of complex care as a multi-level intervention. Chapter 3 uses qualitative description. In qualitative description, interview data is accepted to directly reflect participant views, and interpretation is "data-near" rather than transformative (Sandelowski, 2010). This approach was chosen because the study involved participants who are leaders in the field: given that the target audience also comprises leaders in the field, participants and audience already 'speak each other's language.' In contrast, Chapter 4 drew on interpretive description. Interpretive description brings existing, disciplinary knowledge to bear on data analysis, and involves deeper interpretation to generate a unified description of diverse experiences (Thorne, 2016). This enabled participant perspectives on their experiences in mental health care to be brought directly into conversation with concepts of quality. Thus, different qualitative approaches were used to allow Chapters 3 and 4 to more effectively 'speak to each other'–and to be nested within the theoretical concept of a multi-level intervention established in Chapter 2. The conclusion, Chapter 5, highlights commonalities in findings across these studies.

Anticipated contributions to the literature

This thesis aims to contribute to the emerging field of complex care theoretically, substantively, and methodologically.

Theoretically, Chapter 2 contributes a novel theoretical framework linking interventions to a policy-relevant conceptualization of complex health and social needs. Integrating theoretical concepts from literature on multi-level interventions offers a new perspective for exploring how and why complex care programs achieve (or do not achieve) intended outcomes. The resulting framework is in effect a hypothesis to be tested, about how the varying elements of complex care may be productively brought together into a functioning, multi-level policy package.

Substantively, Chapters 3 and 4 highlight the perspectives of different stakeholder groups, specifically in relation to mental health and complex care. In doing so, Chapter 3 brings the debate over outcomes in complex care into conversation with literature on recovery outcomes in mental health–a neglected intersection with potentially fruitful commonalities. Chapter 4, meanwhile, highlights preferences of current service users. This is a viewpoint that, while critically important, remains under-represented in literature on complex care.

Methodologically, this thesis makes iterative contributions to the application of critical interpretive synthesis, interpretive description, and integrated knowledge translation. Chapter 2 describes a decision to integrate prior theory on multi-level interventions on the basis of emerging findings during the conduct of a critical interpretive synthesis. This differs from published critical interpretive syntheses which typically either do not formally integrate existing theory, or involve an a priori choice to extend an existing theory. Meanwhile, interpretive description was developed in the field of nursing research and has been widely applied across health profession disciplines. Chapter 4 contributes an argument for why it is particularly suited to investigating lay perspectives on policy issues. Finally, integrated knowledge translation (IKT; Galgilardi et al, 2016) was used in Chapter 3. This chapter, which explores valued mental health outcomes in complex care, was a partnership with the Camden Coalition of Healthcare Providers' National Center for Complex Health and Social Needs in Camden, New Jersey. IKT is increasingly present in doctoral-level health policy and services research (Cassidy et al, 2021). This project included less-frequently employed elements including an international and fully-remote partnership, built 'from scratch' by the student investigator (ie. with no prior personal or institutional collaboration). The partnership is described in Chapter 3, adding to literature that describes the specific activities of partners involved in trainee-led IKT.

Positionality of the author

I am not a neutral observer of the phenomena under study in this thesis. My perspective is shaped by my professional work: I am an occupational therapist, and prior to my PhD I worked at a transition-aged youth mental health clinic where my role included a combination of occupational therapy, intake assessment, and care coordination. As a care coordinator, I often struggled to find appropriate and timely services for clients. It seemed that the magnitude, depth, and complexity of mental health need in the community vastly outweighed systemic capacity to respond–even in the comparatively well-resourced city in which I worked. I currently work in a private practice providing standard dialectical behavioural therapy; in this context, clients often have long histories of interpersonal trauma, as well as aversive, unhelpful interactions with health and mental health care. These professional experiences, among others, inform my viewpoint on what complex care is and could be, and what outcomes matter.

As such, I maintained reflexive awareness throughout the research process (Finley, 2002). While developing the protocols for each study I reflected on my motivations, my expectations for findings, and the paradigms and experiences that inform my beliefs. During data collection for the studies in Chapter 3 and 4, reflexivity included considering my positioning as a researcher in relation to participants, and how this might influence participant disclosure as well as my own emerging interpretations. During analysis, I looked for unexpected findings, and stepped carefully in situations where my interpretations aligned with my own beliefs and values (such as the importance of a trauma-informed approach in Chapter 2)–and where my interpretations challenged my values (such as the value placed by some participants on abstinence-based approaches in Chapter 3). In these instances, I took note of my reactions and my pull towards particular frames and returned to the data carefully, in consultation with my supervisory committee. While I cannot wipe the thumbprints of subjectivity from my work, I have done my best to avoid unduly fogging the lens.

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Chapter 2: A multi-level framework for complex care–a critical interpretive synthesis

Preface

There is a lack of conceptual clarity around both complex health and social needs, and complex care–particularly from a policy perspective. This chapter presents a critical interpretive synthesis of academic and grey literature addressing policy dimensions of complex care. In doing so, it provides a backdrop for the studies that follow by setting out a conceptualization of complex care as a multi-level intervention. It also provides a standalone theoretical contribution in the form of a novel theoretical framework for complex care.

I was responsible for conceiving the study objectives and design, analyzing data, and writing the manuscript. Dr. John Lavis, Dr. Nick Kates, and Dr. Julia Abelson provided input on study objectives and design. Alice Cavanagh and I screened articles for inclusion in the study, including a subset that were screened in duplicate. All co-authors provided feedback on preliminary analyses and manuscript drafts.

A multi-level framework for complex care: a critical interpretive synthesis

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Abstract

Background: Complex health and social needs–which span sectors, diagnoses, and traditional services–are a challenge to which health systems are poorly equipped to respond. This study considers how conceptualizations of complex health and social needs relate to policy responses, in order to put forward a framework for complex care.

Methods: This study used critical interpretive synthesis, a method for transparently searching and critically engaging with a large, heterogenous body of literature. CIS is a theory-generating methodology, where concepts and theories are developed using the body of literature as the object of inquiry.

Results: We included 73 results from a systematic search and eleven results from further purposive literature sampling. We suggest that complex health and social needs can be understood as a pattern of unmet needs occurring at the intersection of three issues: fragmented health systems and services, multimorbidity, and social marginalization. Drawing on conceptual literature on multi-level interventions, we propose a framework for complex care that accounts for each of these three issues and their intersections at the individual, service, and system level. We further identify five principles that have relevance at all levels in complex care.

Conclusion: Conceptualizing complex care as a multi-level intervention implies a need for collaboration across sectors and players in the health and social system. It also suggests that interventions may have unexpected and paradoxical effects, due to unanticipated interactions across levels. Further work is needed to test and refine this framework, and to contextualize it for particular populations and settings.

Background

A number of current trends in health systems converge around the issue of complex health and social needs. Descriptions of this phenomenon vary. Health economists point to a small percentage of individuals who use a large proportion of health resources: for instance in the United States, 5% of patients account for almost half of health care expenditures (Cohen and Yu, 2012), while in Ontario, Canada 5% of patients have been found to account for 65% of expenditures (Wodchis, Austin, & Henry, 2016). Meanwhile clinicians and clinical researchers have noted a rise in multimorbidity, as more patients present with multiple, discordant health conditions requiring coordinated care (Calderon-Larraña & Fratiglioni, 2019). A loose consensus suggests that complex health and social needs span sectors, diagnoses, and traditional services; impose barriers to accessing and benefitting from care; and are a challenge to which health systems are poorly equipped to respond.

In 2018, the US-based National Centre for Complex Health and Social Needs signalled their intent to organize a field around complex care with the publication of their *Blueprint for Complex Care.* The report comments, "Many interviewees noted that complex care has been struggling to articulate a common understanding around what complex care is, what problems it is trying to solve, and the populations it serves." A 2020 randomized control trial of the Camden Coalition's pioneering complex care program (Finkelstein et al, 2020)–which found null results–brought renewed focus to this question. Commentors queried whether short-term evaluations of cost and utilization are appropriate to the work of complex care, and the deeply rooted challenges that it seeks to address (Cantor, 2020; Cutts & Gunderson, 2020; Lantz, 2020). This paper starts from literature on current practice to address the former two questions noted in the *Blueprint* quotation above: specifically, what complex care entails, and what problem it seeks to solve.

Moreover, it begins with an assumption that these two questions are, or should be, related–the tools used in complex care (and the outcomes that are measured) should be linked to the problem at hand.

As such, this study begins with the question, how do conceptualizations of complex health and social needs relate to policy responses? It applies critical interpretive synthesis, a structured and systematic approach to critical analysis, in order to put forward a framework for addressing complex health and social needs.

Methods

This study uses critical interpretive synthesis to analyze the policy literature on complex care. Schick-Makeroff and colleagues (2016) describe critical interpretive synthesis (CIS) as one of a number of "emerging synthesis methods" that include both quantitative and qualitative studies, and that have distinct purposes beyond aggregation or interpretation of primary data. First described by Dixon-Woods and colleagues in 2004, CIS is a method for transparently searching and critically engaging with a large, heterogenous body of literature. It is particularly applicable to subjects for which clear, widely-accepted definitions do not exist (Dixon-Woods et al, 2004; Dixon-Woods et al, 2006). CIS is a theory-generating methodology, where concepts and theories are developed using the body of literature as the object of inquiry. As such, CIS provides a rigorous approach to tackle the loosely-bounded and methodologically-diverse literature on complex health and social needs.

Conducting a CIS begins with the identification of a question that acts as a tentative guide, rather than a firmly stated objective; it can be iteratively revised through engagement with the literature. A CIS search is broad and encompasses multiple information sources. Once a sample of literature is selected, quality appraisal typically is *not* applied: given the focus on critical interpretation, rather than critical appraisal, the methodological rigour of included articles may not relate to their relevance. For this reason, Dixon-Woods and colleagues advised excluding only "fatally flawed" studies and foregoing quality appraisal.

The analytical portion of a CIS employs the constant comparative method, drawn from grounded theory and described by Corbin and Strauss (1990), among others. Constant comparison is an iterative process whereby data points are analyzed in comparison to those previously analyzed, such that the set of identified concepts shifts as the study proceeds (Corbin & Strauss, 1990). In CIS, concepts identified in the body of literature under study may include constructs directly drawn from the literature, as well as synthetic constructs based on the researcher's analysis of the literature. These constructs are then organized into a theoretical framework which specifies relationships among constructs, called a synthesizing argument. The use of constant comparison to generate theory differentiates CIS from other qualitative synthesis methods.

Systematic search

A search was conducted of six databases (CinAHL, MedLine, Proquest Politics Collection, PsycInfo, Web of Science, and Health Systems Evidence). These databases were selected in order to capture a broad range of health services and policy research. Search terms were developed with the support of a research librarian, with strategies optimized for each database. The search strategy was developed to prioritize specificity, given the varied uses of the term "complex" in regards to health care. Search terms can be found in **Table 1.** Searches were carried out in July 2020. Results were entered into an EndNote database and duplicates were removed.

Table 1: Search terms

Concept	Terms
Complexity	Complex need* OR clinical complex* OR psychosocial complex* OR high cost us* OR super-utilizer OR hotspotting OR complex health and social needs
Policy and system-level responses	Policy OR governance OR regulat* OR fund* OR organiz* OR decision OR model

Inclusion and exclusion criteria were developed to guide article selection. Articles were included if they: included a definition of complex needs or clear statement of what complex needs entail; and pertained to policy at a governmental level or the level of an integrated delivery system. These inclusion criteria were developed to facilitate addressing the objective of linking conceptualization and policy. Articles were excluded if they: focused on a specific diagnosis or set of comorbidities (eg. services for people with comorbid diabetes and depression) rather than on multimorbidity as a more general problem; were not about health care (eg. articles solely about social services such as justice or housing); or were focused on children or infants, pre- and postnatal care, or transition-aged youth (as complex needs in children and youth often involve distinct systems including child welfare and education, and distinct principles of care including family-centred approaches). Articles were not restricted by year of publication, by type (eg. academic or grey literature) or by method (eg. review, quantitative, or qualitative studies).

Article selection

Screening of systematic search results. Screening of articles proceeded in stages. CE conducted an initial screening based on title, excluding those unrelated to the subject of the review or evidently meeting exclusion criteria. The remaining articles were then independently screened by CE and AC on the basis of title, abstract, and–when needed–full text. Disagreements were discussed to reach consensus. All articles deemed to meet the inclusion criteria were included in the critical interpretive synthesis.

Purposive sampling. The sample of articles was subsequently expanded through purposive sampling that occurred concurrently with analysis to fill out the theoretical framework. Purposive sampling took the form of targeted hand searches of academic databases and grey literature to identify high-impact or highly-relevant papers that addressed specific gaps in the emerging framework, in particular relating to principles of care.

Extraction. Data extraction was carried out for included articles. Extracted data included descriptive information (authors, title, year, location, methods) and verbatim quotations pertaining to the definition of complex needs, the policy under study, the policy rationale, and the study findings. The data extraction table was then uploaded to NVivo for analysis.

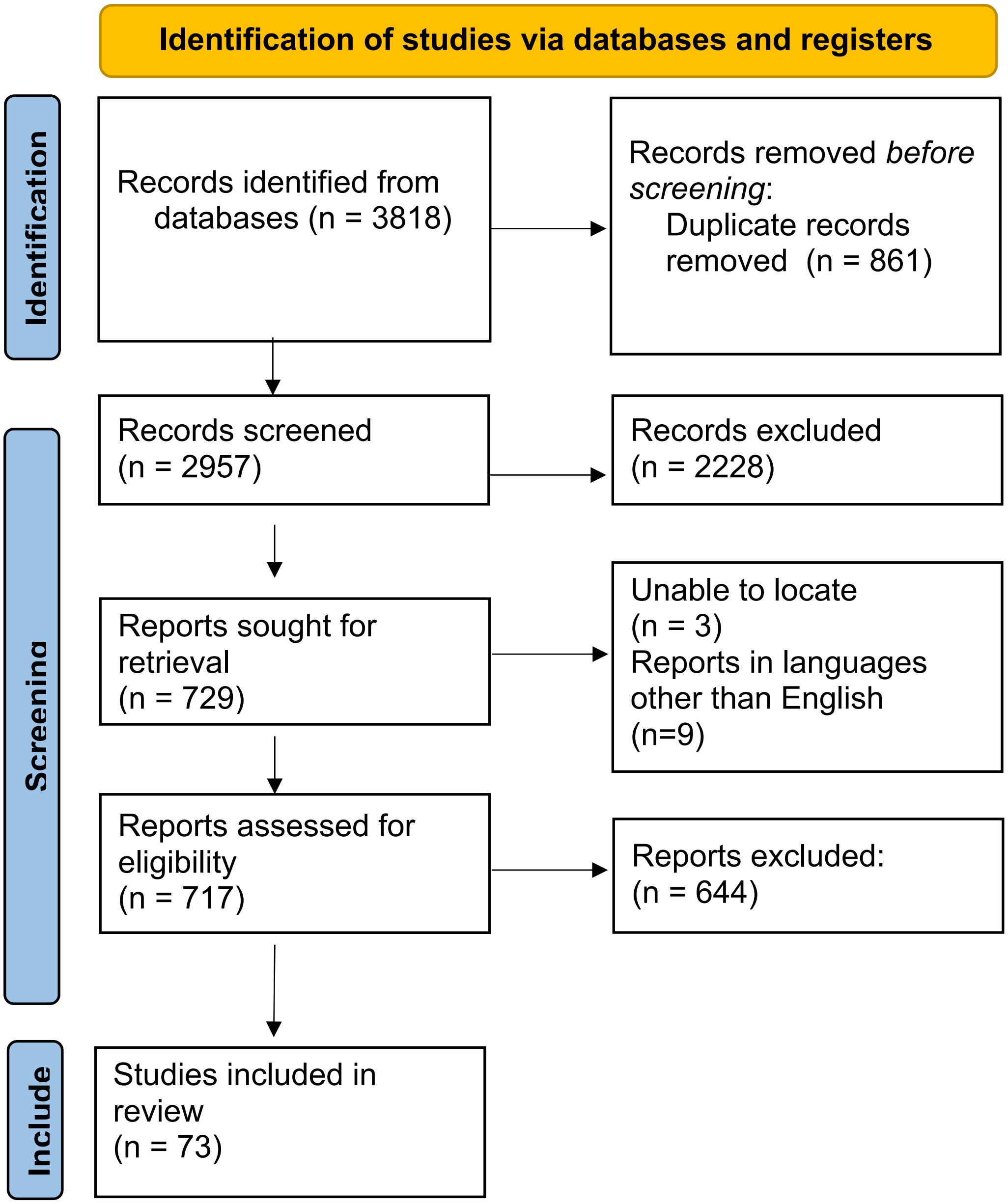
Analysis

Analysis was carried out iteratively. The first stage involved coding extracted data under the categories of definitions of complex needs, policy tools, and policy rationale. Within these categories, codes were developed through line-by-line coding of the extracted data. Initial codes were grouped based on conceptual similarities to identify broader commonalities. Iterative revisions to the groupings of codes was conducted in consultation with JL, JA, and NK to refine a categorical description of the literature. Analysis of relationships among various categories was used to organize these categories into a framework. The framework-in-development was iteratively revised through processes of sorting, checking against the literature, discussing, and re-organizing.

Results

3,816 records were retrieved for review from the database search. Following exclusion of duplicates, 2,950 records were screened and 73 were ultimately included in the critical interpretive synthesis. A summary of the systematic search results can be found in **Figure 1,** and information about the included studies can be found in **Table 2.**

Figure 1: Findings



Modified from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al.
The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71.
doi: 10.1136/bmj.n71
For more information, visit: http://www.prisma-statement.org/

Table 2: Attributes of included studies

Domain	Description	Number of documents
Date	2015-2020	48
	2000-2015	24
	Pre-2000	1
Geography	United States	26
	United Kingdom (or constituent countries)	12
	Canada	9
	Australia	5
	Sweden	3
	Norway	2
	International	11
	Other countries	5
Methods	Observational or quasi-experimental	24
	Qualitative	12
	Description of an initiative	12
	Non-systematic review	10
	Systematic review	9
	Commentaries	2
	Experimental	2
	Economic evaluation	2
Source	Academic	61
	Grey	12
Type of findings	Cost and utilization outcomes	20
	Factors affecting implementation	12
	Targeting interventions, segmenting populations, or defining case mix	9
	Provider experience	7
	Patient experiences	6
	Health outcomes	5
	Processes of care	5
	Uptake of approaches	5
	Components of complex care interventions	5
	*(*does not add to 80 as some papers reported multiple types of findings and some non-systematic reviews, case descriptions, or commentaries did not include findings)*	

All included articles from the systematic search except one were published after the year 2000 (with the exception being a 1979 article on case mix). Forty-eight were published in 2015 or later, reflecting a relatively recent expansion in interest. Seventy-two papers were from high-income countries, with the largest proportion (26 papers) from the United States. The sole paper from a low- or middle-income country was an article from China. The most common methods were observational or quasi-experimental (24 papers), followed by qualitative studies (12) and descriptions of specific initiative (12). Studies included a heterogenous set of objectives and findings, with the most common being cost and utilization outcomes (20 studies), factors affecting implementation (12 studies), and strategies for targeting interventions, segmenting populations, or defining case mix (nine studies). Sixty-one documents were from academic journals, and twelve documents were grey literature.

Following the database search, an additional eleven articles were identified through purposive searching. This includes three grey literature reports and eight academic articles, all published since 2000. The academic articles included four theoretical or conceptual articles, two empirical studies, and two systematic reviews.

Framing the Problem of Complex Health and Social Needs

Problem framing in the literature. The included literature predominantly framed complex health and social needs as a set of individual characteristics and resulting care needs. Multimorbidity was the most frequently mentioned individual characteristic, occurring in a majority of included papers. Individuals were also described as having experiences of social marginalization such as social isolation (eg. Carlton & Brissenden, 2011), homelessness (eg. Sorbero et al, 2019), or more general "social needs" (eg. Breton et al, 2017). These characteristics were described as giving rise to specific care needs: for instance multimorbidity was described as resulting in a need for multiple care providers (eg. Albreht et al, 2016), while social adversities were suggested to imply a need for social services (eg. Ferrante et al, 2010). The proliferation of required services was sometimes argued to create a need for coordinated care (eg. Peck et al, 2018).

A smaller subset of papers considered how services and systems contribute to complexity. For instance, some noted that coordination is required not only because of the nature of multimorbidity, but also because of the fragmented and siloed character of many health systems (eg. Hendry et al, 2016; McCarthy, Ryan, & Klein, 2015). Other papers noted the non-independence of health and social needs. For instance Miller and colleagues' (2019) ACT Complexity Quadrant Schema separated medically complex, socially complex, and medically *and* socially complex patients into separate strata and found that the latter had needs distinct from a simple cumulation of the first two categories. The finding of an interactive rather than an additive effect is echoed in papers noting that marginalization can both produce ill health, and decrease capacity for self-management (eg. Fleming et al, 2019; Rosati et al, 2014).

Synthesizing a dynamic framing of complex health and social needs. Taken together, the above constellation of elements suggests that complex health and social needs can be understood as a pattern of unmet needs occurring at the intersection of three issues: fragmented health systems and services, multimorbidity, and social marginalization. As described above, this problem is not one of simple co-occurrence. Instead, these factors influence each other within a dynamic system. Understanding complex needs in terms of fragmented health care, marginalization, and multimorbidity suggests that effective policy responses will need not only to account for each of these factors, but also the interactions among them.

A Multi-Level Framework for Complex Care

This description of complex health and social needs suggests that it is a problem that crosses multiple levels of analysis, from individual characteristics like multimorbidity to service and system challenges of fragmentation, along with the pervasive and cross-cutting issue of marginalization. Fittingly, policies have also been developed that tend to incorporate a range of tools and which often also occur across multiple levels: from individual treatment, to health service re-organization, to health system interventions. But these levels also exist within a dynamic context, and need to be brought into a coherent whole.

This critical interpretive synthesis develops a multi-level intervention framework for complex care policies, suggesting how the various interventions currently being deployed may be organized into a unified approach. Multi-level interventions, as the name suggests, are interventions that occur at multiple levels of analysis, which may include individual, team, organizational, community, and policy levels among others (Alegria et al, 2021). Multi-level interventions have been applied in fields including community psychology (Trickett & Beehler, 2013), public health (Scholmerich & Kawachi, 2016), and cancer care (Clauser, 2012). The theoretical roots of multi-level interventions include socio-ecological approaches, with Bronfenbrenner's hugely influential work on the ecology of human development underpinning the concept of "levels" (Scholmerich & Kawachi, 2016; Trickett & Beehler, 2013). Literature on multi-level interventions stresses the importance of interdependence across levels. Each level of a multi-level intervention has a distinct target for change, but effects at one level have implications for other levels (Alegria et al, 2021; Trickett & Beehler, 2013). These effects may be synergistic, but can also be contradictory: for instance, community-level decreases in risk may increase individual-level risk taking (Scholmerich & Kawachi, 2016). Proponents argue that multi-level interventions are appropriate to address social and health challenges that may defy more linear approaches (Alegria, 2021). These characteristics of multi-level interventions make it an appropriate conceptual scaffold for a framework for complex care.

During analysis of included papers, policy tools were observed to fall into three distinct levels: individual, service, and system interventions. Within these levels, policy tools also had varying targets that could be mapped onto the three intersecting components of complex needs described above (namely multimorbidity, marginalization, and system fragmentation). **Table 3** highlights the tools addressing each of these facets; while some strategies have relevance to multiple issues, they are categorized according to the area of greatest relevance. **Table 4** maps the facets of complexity and related policy tools across the systematic search results; as is evident in this table, despite the explicit focus on policy in the systematic search, findings focused predominantly on individual- and service-level interventions with sparser attention to the system level.

As argued above, the facets of complexity are not discrete entities but exist in dynamic interrelationship. Moreover, a key insight of the literature on multi-level models is that levels of an intervention are also dynamic and interact with each other. **Figure 2** organizes these policy interventions into a framework that includes relationships across and within levels of intervention, along with cross-cutting principles, to account for this enmeshment.

The framework in Figure 2 is described in further detail below. This section is organized as follows: for each level (individual, service, and system), interventions targeting each component of complexity are described as per Table 3, and mapped on Boxes 1-5 from Figure 2. Subsequently, the intersections among interventions within and across levels are addressed, with reference to arrows A-C in Figure 2.

Finally, after describing each level, principles that cut across all three levels (arrow D in Figure 2) are discussed.

Table 3: Mapping policy tools onto levels and targets

Level	**Target**		
	Fragmentation	**Multimorbidity**	**Marginalization**
Individual	Care coordination	Individual care planning	Trusting relationships
Services	Coordination across health services	Multidisciplinary care High intensity	Low barrier access Coordination with social services
System	Information sharing Shared funding Local adaptation	Segmentation and data-driven planning	Integration with social services
Cross-cutting principles	Person-centred Co-designed	Person-centred	Anti-oppressive Trauma-informed Culturally-competent

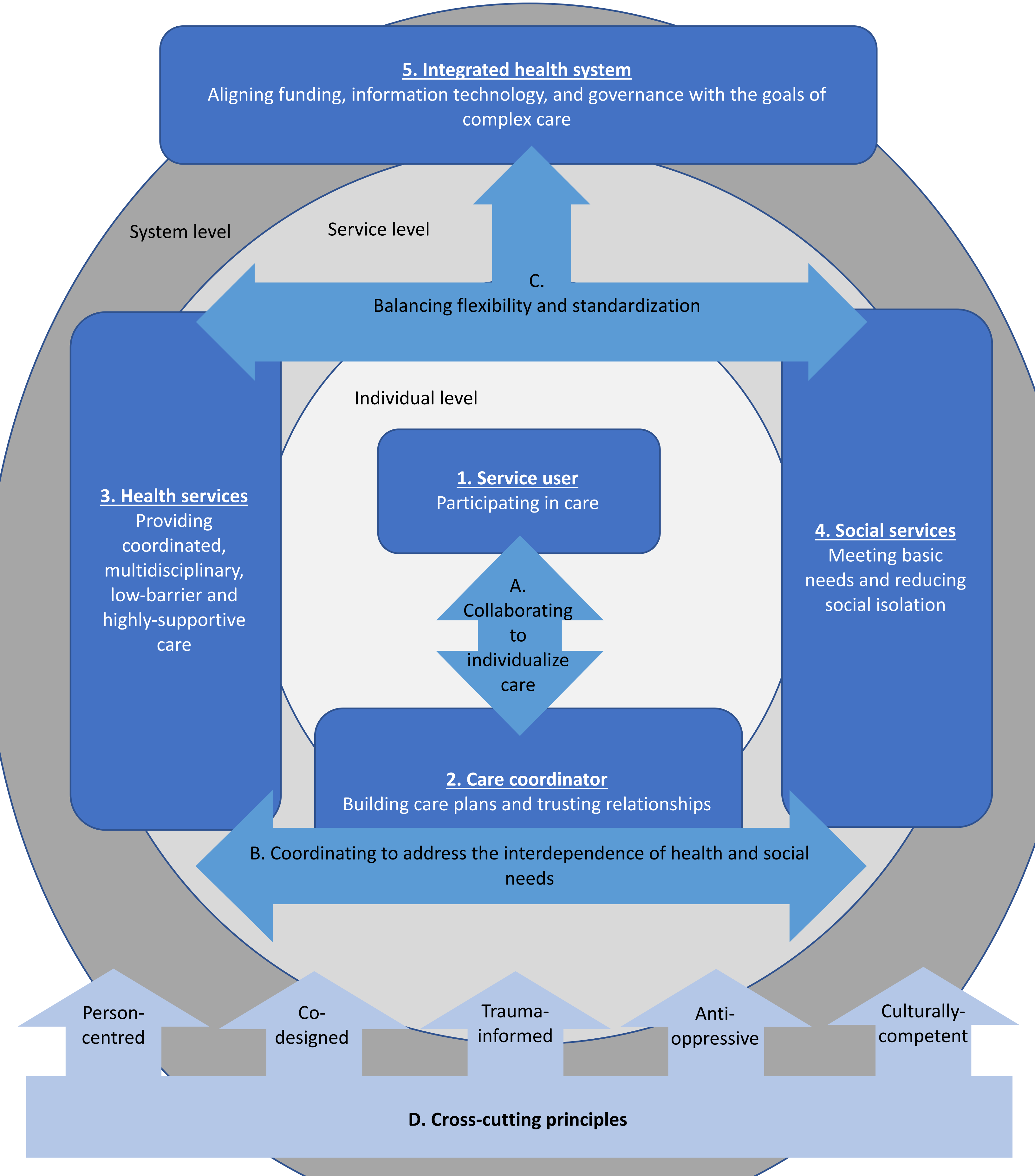
Table 4: Policy tools in systematic search results

	Problem			Individual level			Service level					System level				
Paper	Fragmentation	Multimorbidity	Marginalization	Care coordination	Individual care planning	Trusting relationships	Coordination across health services	Multidisciplinary care	Tailored intensity	Coordinating with social services	Flexible access	Information sharing	Shared funding	Segmentation & data-driven planning	Integrating social services	Local tailoring
Horn 1979														X		
Burti 2003					X	X										X
Chaudry 2003			X	X												
Ali 2004	X	X		X	X		X	X			X					
Guo 2006		X		X				X								
Wistow 2006	X		X				X									X
Sweeney 2007		X		X			X		X			X				
Greene 2008					X		X	X				X		X		
Huxley 2008	X	X			X					X						
Sutcliffe 2008		X						X								
Mrinska 2010	X												X			
Belling 2011						X		X				X				
Bjerkan 2011	X	X			X			X		X						
Rust 2011				X				X			X			X		

Turner-Stokes 2012														X		
Anonymous 2013				X												
Johnson 2013																X
Seddon 2013				X						X						
Angus 2014	X	X		X												X
Edes 2014		X			X	X		X			X					
Goldhar 2014		X		X	X		X	X	X		X	X				X
Hudon 2014	X	X	X	X						X					X	
Killaspy 2014									X		X					
Rosati 2014	X		X													
Vallaincourt 2014		X	X		X	X										
Jackson 2015	X													X		
Jingping 2015				X					X			X				
Mason 2015	X	X											X		X	
McCarthy 2015	X	X	X	X			X	X			X					
Alam 2016	X	X		X						X						
Albrecht 2016	X	X	X	X			X	X								
Daub 2016		X		X			X						X			X
Hendry 2016	X	X		X		X							X		X	
Melnick 2016			X				X	X			X					
Surbhi 2016	X						X				X					
Winters 2016	X						X			X					X	
Au 2017	X	X	X				X					X				X
Barbabella 2017		X										X		X		
Breton 2017	X	X	X				X	X							X	X
Damery 2017		X														
Jean-Baptiste 2017														X		
Larsson 2017	X	X			X										X	
Miao 2017																
Mondor 2017		X	X	X	X		X	X								X
Sendall 2017	X			X			X			X		X				
Smith 2017			X				X				X	X				
Banfield 2018				X	X	X				X					X	
Blumenthal 2018		X	X	X	X					X				X		
Burton 2018		X		X	X			X	X		X					
DuBard 2018		X	X	X	X					X						
Everink 2018		X		X	X		X					X				
Gentile 2018									X		X					
Hoyem 2018	X	X		X			X									
Johnson 2018	X	X	X	X			X	X		X	X					
Marino 2018		X		X	X			X		X						
Peck 2018	X	X	X				X							X		
Sevak 2018					X			X	X	X	X					
Shippee 2018			X													
Abdin 2019		X						X								

Bailey 2019		X		X		X		X	X		X					
Bartlett 2019		X	X				X									
Bernsten 2019		X		X	X			X				X		X		
Crossman 2019																
Enos 2019		X		X												
Fleming 2019		X	X										X		X	
Henderson 2019	X	X		X						X						
Larsson 2019		X			X		X									
Miller 2019		X	X	X				X	X		X			X		
Nurjono 2019		X		X	X		X	X	X							
Ouayogode 2019	X	X		X												
Sorbero 2019			X				X			X				X		
DuGoff 2020		X														
Kjellberg 2020		X					X						X			

Figure 2: A multi-level framework for complex care.



Individual level: Individualized care coordination. Care coordination was the single most common intervention in the literature reviewed. Care coordination mediates the individual-level relationship between the individual and the health system, and can enable individualization to address the interactions among elements of complex needs. Care coordination was most often carried out by an individual provider with responsibility for facilitating the development and implementation of a care plan.

Reducing fragmentation: Care coordination (Box 2 in Figure 2). Care coordination aims to address health system fragmentation by integrating care around the individual patient. To achieve this aim, care coordinators facilitate communication and collaboration in the development and implementation of complex care plans that involve multiple providers, services, and sectors. The scope of care coordination initiatives varied: care coordination was used to address transitions in care (eg. Everink et al, 2018; Kjellberg & Szucs, 2020), to enhance primary care (Breton et al, 2017; Ferrante, Cohen, & Crosson, 2010), and to span the continuum of care across ongoing, integrated or intersectoral treatment (eg. Goldhar et al, 2014; Seddon et al, 2013).

Managing multimorbidity: Individual care planning (Box 2 in Figure 2). For individuals with multimorbidity, each condition has implications for care as a whole (eg. Marino et al, 2018). As such, individualized care plans organized around personal needs and goals–rather than tightly standardized, disorder-specific treatment–may be more appropriate. Creating such a plan requires holistic assessment (eg. DuBard et al, 2018; Nurjono et al, 2019) and active participation of the service user (eg. Bjerkan et al, 2011; Everink et al, 2018). Given that some studies described complex needs in terms of difficulties engaging in health services (Killaspy et al, 2014), fostering this participation may require particular focus.

Addressing marginalization: Trusting relationships (Box 2 in Figure 2). The relationship between a client and a care coordinator is an important enabler in complex care (eg. Banfield & Forbes, 2018). While relationships are broadly important in health care, this may be especially critical for marginalized service users: Vaillancourt and colleagues' (2014) approach to developing "archetypes" of users with complex needs identified that experiences of discrimination and rejection in healthcare settings were common among this population. For these service users, care coordinators can act as an advocate and trusted navigator. However, the foundations of strong relationships between providers and marginalized service users were often left unexplored in the included literature.

Intersections (Arrow A in Figure 2). The care coordinator-client relationship therefore represents the "ground level" of complex care, where intersecting and overlapping needs are synthesized into a coherent, goal-driven plan in the context of a consistent and supportive relationship. The client brings the expertise of lived experience: the client's goals, preferences, and context animate the care plan. Meanwhile, the care coordinator bridges individual care and service levels of analysis by translating patient goals, needs, and strengths into a care plan, and facilitating access to the resources required to enact this plan.

Service level: Resource integration and appropriateness. The client/care coordinator relationship is nested within a set of local services, which broadly includes social services as well as health care. The care coordinator is tasked with coordinating services to address the interdependence of health and social needs. Care coordination is predicated on an assumption that appropriate care is available to coordinate.

Reducing fragmentation: Coordination across health services (Box 3 in Figure 2). Coordination across the care continuum at an organizational level is a tool for reducing system fragmentation. In some included articles, organizational partnerships were organized around specific patients with complex needs. This enabled representatives from multiple agencies to support care planning for individuals through case conferencing tables or other mechanisms (eg. Alam & Griffiths, 2016; Angus & Greenberg, 2014). In other articles, coordination across health sectors was developed through co-location, organizational mergers, or other approaches (eg. Au, Postman, & Verdier, 2017; Hudon et al, 2014), reducing the need for service users and providers to navigate organizational boundaries.

Managing multimorbidity: Multidisciplinary care; high-intensity (Box 3 in Figure 2). Multidisciplinary team-based care brings various healthcare professions–including social workers, nurses, pharmacists, and mental health care providers–together on a single team to address the plethora of medical and non-medical concerns that can accompany multimorbidity (eg. Belling et al, 2011; Rust et al, 2011). Managing multiple chronic conditions may also require a higher intensity of support, including frequent in-person contact (eg. Sevak et al, 2018).

Addressing marginalization: Low-barrier access; coordination with social services (Box 3 and 4 in Figure 2). Complex care services must be accessible to clients who face barriers to care. Primary (eg. Edes et al, 2014), acute (McCarthy, Ryan, & Klein, 2015), and post-acute care (Melnick, Green & Rich, 2016) have all been provided in home to reduce these access barriers. Other interventions included flexible approaches like mobile or outreach-based care (eg. Sevak et al, 2018) to reach clients in non-traditional settings.

Some papers highlighted that marginalized clients may have unmet basic needs that interfere with effective management of health concerns and achievement of an acceptable quality of life (eg. DuBard & Jackson, 2018, Marino et al, 2018). Other papers implied unmet basic needs through reference to resources addressing housing and food insecurity (eg. Sorbero et al, 2019). Reducing social isolation was also an explicit objective identified in some papers (eg. Goldhar et al, 2014; Johnson & Bascu, 2018). Partnering with social services gives healthcare providers an avenue to address unmet basic and social needs. In some initiatives, assessment of individual needs guides collaboration around the individual, as coordinators draw in appropriate services (eg. Mondor et al, 2017; Sendall et al, 2017). In other instances, intersectoral organizational partnerships are formed to create networks that enable complex care (eg. Alam et al, 2016; Hudon et al, 2014).

Intersections (Arrow B in Figure 2). Coordination among health and social services is therefore a key task at a service level. Multidisciplinary, highly-supportive, and low-barrier health services, working in partnership with social services to meet basic needs, may help to address the full range of client needs and goals. Meanwhile, the concurrency of health and social needs influences the presentation and management of each of these concerns. For example, lack of stable housing affects physical and mental health, while health-related functional impairment influences support needs with respect to housing. Collaboration across organizations and sectors may therefore enable joint working to address interdependencies among health and social needs.

System level: Creating the context for complex care. Health services are embedded in a broader health system, including financial, governance, and delivery arrangements. While often operating under separate policy frameworks, social services may also have formal roles within integrated health systems. System-level policy interventions can be leveraged to create a conducive context for complex care by aligning incentives, resources, data and communications infrastructure, and legislative and regulatory requirements with the goals of complex care.

Reducing fragmentation: Information sharing; shared funding; local adaptation (Box 5 in Figure 2). A range of systems strategies can support joint working across organizations and sectors. When care plans cross organizational boundaries, providers need access to the information required to support care plan implementation. Shared communications infrastructure was mentioned both as a policy intervention, and (when absent) as an implementation barrier (eg. Henderson et al, 2019; Sendall et al, 2017). Integrated funding across organizations was also a strategy employed in the literature (eg. Breton et al, 2017; Mason et al, 2015). This was sometimes justified as a form of "accountability" assumed to incentivize efficiency, although the actual pathway between integrated funding and more efficient decisions was not described.

A number of policies in included papers were developed at a jurisdictional level and implemented locally, with flexibility built in to enable use of local resources (eg. Angus & Greenberg, 2014, Banfield & Forbes, 2018): for instance, Goldhar and colleagues (2014) describe how care coordinators already in place from a previous policy initiative were redeployed to specific forms of primary care. However, while studies describe the use of local human and infrastructural resources, there was little specificity regarding how complex care programs have been adapted to local cultural, geographic, and social contexts.

Managing multimorbidity: Segmentation and data-driven planning (Box 5 in Figure 2). At a systems level, data-driven planning may be used to ensure that services are appropriately targeted and adequately resourced. For instance, data on clinical characteristics including multimorbidity was used to stratify populations by risk and segment according to need (eg. Jean-Baptiste, O'Malley, & Shah, 2017). Case mix strategies were also used to ensure that funding reflected the clinical complexity of patients (eg. Jackson et al, 2015; Turner-Stokes et al, 2012). In some instances, mechanisms for financial accountability were designed to enable whole-person rather than disease-specific approaches to care (eg. Jingping et al, 2015; Rust et al, 2011). However, while systems-level data may reflect multimorbidity it often does not capture patient-level factors contributing to complex needs, which were more often assessed by clinicians (eg. Burton et al, 2018).

Addressing marginalization: Integration with social services (Box 5 in Figure 2). This element of complexity was less clearly addressed at a system level in the existing literature. Integrating funding for health and social services was put forward in some papers as a cost-saving strategy, with the expectation (but not always the effect) of cost shifting away from costly acute intervention and towards cheaper social prevention (Mason et al, 2015, Mrinska, 2010). This entwining of social support and cost-saving objectives is directly addressed in a critical discourse analysis study by Fleming and colleagues (2019), who argue that complex care wraps neoliberal austerity objectives in a discourse of social assistance. Their argument suggests that health systems attend to social adversity insofar as doing so is germane to cost control objectives. As will be discussed in the section on principles below, systems-level strategies that respond intentionally to marginalization exist–but these have not been clearly engaged in the included literature on complex care policy.

Intersections (Arrow C in Figure 2). Shared communication and funding, and data-driven planning imply efforts towards standardization across the system. At the same time, the flexibility to use local resources and incorporate clinical input along with standard data point towards local approaches. This tension can be resolved within a multi-level model where the system provides an outer layer of context for complex care: an enabling context includes both standard elements to facilitate joint working, and the removal of barriers to enable local adaptation. Feedback across levels is required for a full understanding of population needs, including social needs. However, as noted above, systems-level elements that respond to the needs of marginalized users were not well-described in the literature reviewed, and merits further attention.

Principles: Approaches for complex care (Arrow D in Figure 2). Understanding the problem of complex needs as unmet needs at the intersection of fragmented care, multimorbidity, and marginalization provides groundwork for identifying relevant policy tools. Principles can add to questions of what to do by suggesting how and why (normatively) to do it.

In line with CIS methods, purposive searching was carried out to identify literature addressing gaps in the framework. Some principle-driven approaches are broadly present in the included literature, such as client-centredness; others, such as trauma-informed care, are addressed in grey literature but have not been widely acknowledged in academic writing on complex care. The included literature also tends to focus on the application of principles at the individual and service level.

Purposive searching was used for two reasons. First, it was used to expand on system-level implications of principles already present in the literature. Second, it was used to identify additional principles to address some of the gaps described above, including foundations for strong provider-service user relationships and system-level approaches to address marginalization.

Below, five suggested principle-driven approaches are described very briefly, with a focus on their relevance to dimensions of complex needs and examples of how they may be operationalized across levels. It is important to note that each of these sets of principles arises from very rich bodies of literature that cannot be fully represented or explored here.

Person- and family-centred. Person-centred care is referenced throughout the literature on policy responses to complex needs (eg. Albreht et al, 2016). Person-centred approaches have particular relevance to individuals with multimorbidity, for whom standard disease-specific care pathways and treatment approaches may not be appropriate (eg. Edes et al, 2014). A person-centred approach can also guide efforts to reduce system fragmentation by ensuring that care is designed to be seamless from the perspective of the service user (eg. Sendall et al, 2017; Vallaincourt et al, 2014). Individualized care planning at an individual level, co-located multidisciplinary care at a service level, and shared medical records at a system level are all examples of interventions that may reduce fragmentation as experienced by a service user.

Co-designed. Approaches to resolving health system fragmentation were often articulated at a policy level, but enacted and adapted locally (Angus & Greenberg, 2014, Banfield & Forbes, 2018). The nature of local adaptation was often left unexplored, although one older study described a community capacity development project wherein community stakeholders mapped and strengthened resources for individuals with complex needs (Wistow & Callaghan, 2006) and another described "enhanced citizenship in public services" through co-production and other strategies as a driver of health and social care integration (Mrinska, 2018). Experience-based co-design, while not explicitly mentioned in the reviewed studies, provides a framework for engaging local and lived knowledge in the development of complex care. In co-design, service users and providers are involved as equal partners in developing an understanding of a problem, and generating and evaluating solutions (Bate & Robert, 2006; Donetto et al, 2017). Co-design processes can be applied to any level within the health system, from individual care processes to organizational and systems-level approaches.

Trauma-informed. A high prevalence of trauma among service users was noted in some included papers (eg. Fleming et al, 2019), which is unsurprising given the association between adverse childhood experiences and multimorbidity (Sinott et al, 2015). Trauma-informed approaches involve recognizing the prevalence of psychological trauma and its profound impacts on behaviour, and implementing strategies to prevent re-traumatization of service users (SAMHSA, 2014). Trauma-informed approaches are largely absent in the included academic literature on policy responses to complex health and social needs, although they have been cited in grey literature, including the National Centre for Complex Health and Social Needs' *Blueprint for Complex Care* (Humowiecki et al, 2018). Providers can provide trauma-informed care by maintaining awareness of the prevalence and effects of trauma, and by enabling service user choice and empowerment (SAMHSA, 2014; Menscher & Maul, 2016). Trauma-informed principles can be adopted at a service level through strategies including revising organizational policies and supporting staff training (SAMHSA, 2014). Trauma-informed principles can also inform system-level changes: for example, a Centre for Healthcare Solutions report notes that information sharing (with protections for privacy and patient autonomy) can prevent the need for repeat trauma screening, thereby minimizing the number of times clients must revisit traumatic memories during assessment (Menscher & Maul, 2016).

Anti-oppressive. As described above, marginalization is a core component of the phenomenon of complex health and social needs, and as such anti-oppressive approaches offer guidance for providing care that is responsive to this reality. Anti-oppressive practice recognizes inequities in power and access to resources, and seeks to offset these inequities (Corneau & Stergiopoulos, 2012; Ramsundarsingh & Shier, 2017). Relevant strategies can include empowering service users to define their own needs and strengths (Corneau & Stergiopoulos, 2012) at an individual level, and enabling systems of mutual support among people affected by oppression (Corneau & Stergiopoulos, 2012; Ramsundarsingh & Shier, 2017), expanding the notion of local resources beyond formal services. At a system level, empirical studies have pointed to a need to consider power and resources when interpreting system-level. For instance a 2019 American study found that an algorithm widely used used to identify patients with complex needs systemically underestimated the needs of Black patients due to lower access to, and use of, healthcare (Obermeyer et al, 2019).

Culturally-competent. Only one article included in this review explicitly identified cultural considerations–in the context of a New Zealand program working with Maori populations (Breton et al, 2017). However, the ultimately local nature of complex care as described above suggests that adaptation to local cultural context may be a broadly applicable concern. Cultural competence refers to the capacity of a health service to work effectively across cultures (McCalman et al, 2017). In their widely-cited framework for culturally-competent health systems, Betancourt and colleagues (2003) call for attention to how cultural factors interact across levels of the health system including patient-provider interactions at an individual level, workforce and leadership characteristics at an organizational level, and processes of care at what they term a structural level.

Discussion

Key findings

The analysis above first aligns existing approaches to complex health and social needs with three targets that comprise this policy problem (Table 3); then brings these approaches together in a coherent multi-level intervention (Figure 2), describing interdependencies within and among levels and principles that cut across levels. Specifically, complex health and social needs are framed as a pattern of unmet needs arising through the interaction of three issues: fragmented health systems and services, multimorbidity, and social marginalization. At an individual level, interventions can target each of these three issues through individualizing and coordinating care. At a service level, interventions can ensure that appropriate health and social services are available and integrated to support individual-level coordination. At a system level, interventions create an enabling context through balancing standardization and flexibility. Five principles are suggested to guide work across and within levels: complex care policy is suggested to be person- and family-centred, co-designed, trauma-informed, anti-oppressive, and culturally competent.

Findings in relation to other studies

Dynamic models for the concept of complex needs exist in the literature. For instance, the cumulative model of complexity frames complex needs as a gap between the "workload" of an individual's needs, and that individual's capacities (Shippee et al, 2012). Meanwhile Grembowski and colleagues' (2014) conceptual model describes complexity as a gap between patient needs, and the capacity of healthcare services. They suggest this arises in a social context that includes economic, social and physical elements that in turn influence policy, research, and population health as well as health inequities; and that complex adaptive systems thinking can support effective responses. This latter model resonates with the present study's description of complex health and social needs as occurring at the intersection of fragmented health systems and services, multimorbidity, and social marginalization–and requiring a multi-level response.

Existing reviews have enumerated promising practices in complex care (Commonwealth Fund International Experts Working Group on Patients with Complex Needs, 2018; David & Somers, 2018; Vrijhoef & Thorlby, 2016) but the relationships among these practices are not often described. Some literature has also called for or described multi-level approaches to target complex health and social needs. For instance the National Centre for Complex Health and Social Needs' *Blueprint for Complex Care* (Humowiecki et al, 2018) states that complex care "operates at the personal level by coordinating care for individuals. Complex care also works at the systemic level by creating complex care ecosystems, the local networks of organizations that collaborate to serve individuals with complex health and social needs" (p. 6). Again, however, the nature of relationships and interactions across levels are left unexplored.

The framework represented in Figure 2 therefore adds to the current literature on policy responses to complex needs in three ways. First, it makes explicit the embeddedness of complex care within a dynamic, interactional multi-level system. Drawing on conceptual work on multi-level interventions offers a tool for understanding unexpected effects (and null effects) observed in empirical studies, and provides grounding for designing future evaluations.

Second, this framework seeks to add nuance to the role of social services in complex care. While the role of social services in complex care is sometimes described in terms of attending to or addressing social determinants of health (eg. Sevak et al, 2018; Sorbero et al, 2019), the actual interventions may be described more specifically in terms of meeting basic needs and reducing social isolation. Social determinants operate across the lifespan, with long-lasting and often delayed effects; childhood exposures in particular often have lifelong ramifications (Sinnott et al, 2015; Solar & Irwin, 2010). Commentors have noted that it may be unrealistic to expect complex care, including social service referrals, to fully undue the effects of prolonged exposure to adversity, deprivation, and trauma (Lantz, 2020). Framing the role of social services in terms of basic needs may offer a more pragmatic guide to intervention and may also ground expectations around short-term impact. At the same time, avenues to move beyond survival to enable flourishing for complex care clients is an important area for further research.

Third, this analysis highlights ways that services can respond to social marginalization beyond incorporation of social services, through adopting principle-based approaches. This is critical because the structures that shape access to health-promoting resources are also embedded in health systems: for instance, while racism can affect individuals' physical and mental health and their social circumstances, it also affects experiences in health care and the appropriateness of care received (Castle et al, 2018; Stanley et al, 2019). While distinct from each other, each of the sets of principles included addresses the necessity of respecting clients' voices and strengths, and creating opportunities for empowerment. Anti-oppressive, trauma-informed, and culturally-competent approaches also require an understanding of the contextual factors shaping clients' lives, enabling more appropriate responses.

Strengths

Strengths of this study include a comprehensive and flexible search strategy, and use of theory-building analytic methods. The search strategy included an initial comprehensive search of multiple databases, enabling the capture of a broad range of academic and grey literature. Two authors reviewed inclusion of all studies in the systematic search. This systematic search was supplemented by purposive searching to address gaps–an approach that is appropriate both to the theory-building aims of this study and to the fuzzy nature of the concept of complex care. Using a constant comparative analytic approach brought elements of this literature into new conversations and configurations. Considering inter-relationships across concepts allowed this study to move beyond description to theory-building. Finally, the mid-range theory put forward in this critical interpretive synthesis is scaffolded on existing, empirically-tested theoretical insights about the working of multi-level interventions. This buttresses the arguments of the present study and suggests pathways for evaluation.

Limitations

This study has important limitations. First, the proposed framework is based on descriptions of current policies and practices, rather than evidence about whether these policies and practices achieve their intended effects. Existing approaches were categorized by target and by level; but the extent to which any of these approaches achieves change (alone or in concert with other approaches) was not addressed. Second, it is based on a generic conceptualization of complex health and social needs. The arguments above may not account for needs arising in specific contexts (eg. rural and remote areas) or populations (eg. individuals with polysubstance use and chronic illness). This study also almost solely identified literature from high-income countries and so does not address the nature of or responses to complex needs in low- and middle-income settings. Moreover, this study included only documents available in English. Nine studies were excluded on the basis of language, and non-English databases were not searched. As such this study does not represent the knowledge contained in academic and grey literature in other languages. It is also limited in its focus on articles that are framed around complex health and social needs explicitly, as will be discussed further below.

Implications for policy and practice

Conceptualizing complex care as a multi-level intervention implies a need for collaboration across sectors and players in the health and social system. It also suggests that interventions may have unexpected and paradoxical effects, due to unanticipated interactions across levels. Indeed, this has been observed empirically: a randomized controlled trial of the Camden Coalition's pioneering "hot spotting" program unexpectedly found that it did not reduce hospital readmissions relative to control conditions (Finkelstein et al, 2020); meanwhile an observational study of Ontario's Health Links program, which involved care coordination and planning for high-cost users, found enrollees in fact had lower reductions in utilization than matched comparators (Mondor et al, 2017). A multi-level framework can offer conceptual grounding for unpacking these disappointing findings, and for designing robust approaches to complex care.

Implications for future research

As noted above, the framework presented in Figure 2 represents a synthesis of current practices. It can be understood as a hypothesis in need of testing. Importantly, multi-level interventions require complex evaluations (Clauser, 2012). While observational and experimental designs have been applied to understand the effects of complex care interventions, a multi-level intervention implies a need to evaluate the contextual configurations of nested interventions that best support clients with complex needs. Multi-level interventions may also require longer time horizons to display effects (Paskett, 2016)–a challenge for researchers and funders. However, these complex and longer-term evaluations may be required to yield deeper insights into what works, for whom, and how, in complex care.

Conclusions

Complex health and social needs pose a persistent challenge for health systems–in addition to representing unalleviated suffering at an individual level. This study sets forward a policy-relevant conceptualization of complex health and social needs, and links this conceptualization to existing policy approaches through the framework of a multi-level intervention. Further work is needed to test and refine this framework, and to contextualize it for particular populations and settings.

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Chapter 3: Valued mental health outcomes in complex care

Preface

Evaluations of complex care have often focused on cost and utilization, a narrow subset of outcomes that do not reflect the full array of objectives of complex care programs. Moreover while mental health concerns are considered a component of complex health and social needs, few published studies address mental health outcomes within complex care–or articulate what outcomes might be relevant in this domain. This chapter takes a qualitative description approach to explore the mental health outcomes that are valued by stakeholders in complex care, including operational and programmatic leaders, and people with lived experience who hold advisory roles. Findings can help to inform and advance discussions of quality in complex care.

I developed the objectives of this study in collaboration with Jason Turi and Rebecca Sax, of the Camden Coalition of Healthcare Providers' National Center for Complex Health and Social Needs. I designed the study, conducted data collection, lead analysis, and wrote up findings. Dr. John Lavis provided input into study design and materials including data collection instruments. All study authors (Jason Turi, Rebecca Sax, Dr. Julia Abelson, Dr. Nick Kates, and Dr. John Lavis) provided feedback on analyses and drafts of this manuscript. Evelyne Kane of the Camden Coalition provided input into study materials and data collection tools for participants with lived experience.

A brief report and blog post based on this study can be found online at: https://www.nationalcomplex.care/research-policy/resources/publications-reports/valued-behavioral-health-outcomes-in-complex-care-2/.

Valued mental health outcomes in complex care

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Abstract

Objectives. While mental health concerns are a recognized component of complex health and social needs, few published studies report on mental health outcomes in complex care. This study explores the mental health outcomes valued by stakeholders in American complex care programs.

Methods. We adopted a qualitative descriptive methodology, which aims to generate a description of a phenomenon. Interviews were conducted with 25 stakeholders, including seven people with lived experience and 18 operational and programmatic leaders. Transcripts were analyzed using content analysis.

Results. At a patient level, valued mental health outcomes took the form of a continuum encompassing four inter-connected stages: initial contact, stabilization, treatment, and recovery. At a system level, valued outcomes included enablers of care and population-level outcomes. Current measurement practices do not fully align with valued mental health outcomes in complex care.

Conclusions. Understanding the value of complex care in the domain of mental health may require changes in measurement practice. Measurement choices can be aligned with both the potential for impact (ie. what a program can realistically change), and the value of impact (ie.

changes that matter to stakeholders). Mapping measurement tools onto valued outcome domains may identify gaps in the current repertoire of tools.

Background

Complex health and social needs have been described as arising at the intersection of physical and mental health multimorbidity and social adversity (Humowiecki et al, 2018; Long et al, 2017; Thomas-Henkel et al, 2018). Complex care programs, often focusing on care coordination, have been developed to support individuals with this constellation of needs. However while mental health concerns (including problematic substance use) are recognized as a key component of complex needs, little published literature addresses the mental health outcomes of complex care–or which mental health outcomes these programs seek to achieve.

The latter question is a question of values: identifying outcome measures requires identifying valued goals and objectives. This study seeks to explore the mental health outcomes that are valued by stakeholders in care for individuals with complex health and social needs.

Outcomes in complex care

Most evaluations of complex care have focused on costs and service utilization (Davis & Romm, 2017; Humowiecki et al, 2018). A high-profile randomized controlled trial of the Camden Coalition of Healthcare Providers' flagship program found null results for hospitalizations (Finkelstein et al, 2020), sparking debate over the aims and effects of complex care. Commentors noted that individuals with complex needs have often faced lifetimes of adversity, with cumulative health effects which are unlikely to be reversed quickly–and which may continue to be exacerbated by ongoing social exclusion and marginalization (Cantor, 2020; Cutts & Gunderson, 2020; Lantz, 2020). Moreover, indicators such as cost and hospitalization may not fully capture the breadth of effects of complex care (Cantor, 2020; Cutts & Gunderson, 2020).

In recognition of the unique characteristics of complex care, a recent report proposed a five-part framework for demonstrating value in complex care, which encompasses cross-sectoral costs, utilization, quality, equity, and provider and client experiences (Hardin et al, 2021). With respect to quality, Hardin and colleagues suggest measuring functional status and access to services. Another report identifies five overarching domains for quality measurement in complex care programs, including effectiveness and quality of services; equity; health and well-being; service delivery (including integration and coordination); and cost and utilization (Bossley and Imbeah, 2020). These reports do not specifically address mental health.

Outcomes in mental health

Like measurement in complex care, measurement of mental health outcomes poses unique challenges. In 2006, the IOM released a report addressing how the 2001 quality framework cited above could be tailored to address distinctive features of mental health and substance use care. These distinctive features include the siloed and fragmented nature of the sector, the pervasiveness of stigma, and the relative under-development of QI infrastructure (IOM, 2006). Over a decade later, Sunderji and colleagues (2017) found that measurement challenges in mental health persist. In a systematic review informing a quality framework for collaborative mental health care, few measures were identified relating to equity, accessibility, and timeliness. Sunderji and colleagues (2017) further critiqued patient-reported experience measures for a lack of transparency on how domains of experience were selected.

Mental health outcomes in complex care

As noted above, few published studies or evaluations have specifically addressed the mental health outcomes of complex care. An exception can be found in a policy brief summarizing states' efforts to integrate behavioral and physical health care for dually eligible

Medicaid-Medicare beneficiaries. The report identifies that states planned to use metrics such as evidence of individualized care plans and reduced service utilization to promote shared accountability (Soper & Ensslin, 2014). However, existing mental health measures and indicators may not be adequate for complex care. For instance, some authors have suggested that coordinating care may result in increased mental health service use and costs in the short term owing to the depth of unmet need. As such, measures of utilization should not be expected to show a straightforward pattern of reduction (Au, Postman, & Verdier, 2017; Beil et al, 2019). Beyond utilization measures, existing indicators may not be appropriate for assessing care of individuals with complex health and social needs (Au, Postman, & Verdier, 2017) and may not reflect service user perspectives (Nevola, 2020). These discussions point to the need to consider concepts specific to mental health in conversations about outcomes of complex care.

Study context

This study was conducted in partnership with the National Center for Complex Health and Social Needs ("the National Centre"). The National Centre is an initiative of the Camden Coalition of Healthcare Providers, an organization known for its data-driven "hot-spotting" approach to care management for individuals with complex health and social needs. The National Center was launched in 2016 with an aim of building the field of complex care. Through collaboration with stakeholders across the United States, the National Centre works to build the knowledge base, scale and spread effective models, and identify payment, policy, and community factors that support complex care.

This study considers mental health outcomes valued by stakeholders in the United States, drawing on the National Center's extensive network of partners. While limited to the US, the study will consider stakeholders within the field of complex care broadly rather than focusing on a specific city, state, regional or organizational context. This approach is congruent not only with the field-building work of the National Centre, but also a rich body of grey and academic literature that has sought to describe or define commonalities in complex care across contexts: reports from the National Academy of Medicine (Long et al, 2017), the King's Fund (Goodwin et al, 2013) and international research projects (eg. Bhattacharyya et al, 2020; Wodchis et al, 2018) have all taken an inter-jurisdictional (either international or inter-state) approach to understanding core elements of complex care.

Research objectives

This study explores the mental health outcomes valued by stakeholders in American complex care programs. Mental health outcomes here refer to program effects that relate directly to mental illness, mental health and/or problematic substance use. Complex care programs are initiatives that provide care for individuals who may be facing concurrent physical and mental health concerns; adverse social circumstances; and/or high-intensity and low-benefit service use. The focus of this study is on valued outcome domains, rather than on specific measurement tools.

Methodology

This study employs a qualitative description approach (Sandelowski, 2000; Sandelowski, 2010). Qualitative description is a methodology for generating a descriptive account of a phenomenon, grounded in what Sandelowski (2010) describes as a "factist" orientation towards data: participants' words and viewpoints are assumed to reflect reality, rather than to construct or perform a particular truth. As such, a qualitative description approach aims to describe and interpret the data in a manner that would be recognizable to, and agreed upon by, participants in the research (Sandelowski, 2000). The expected output of a qualitative description study is "a straight descriptive summary of the informational contents of the data" (Sandelowski, 2000, p. 339), in which data is organized into themes or categories that hew close to the original data and may even be labelled using participants' own words. A qualitative description approach is aligned with the aims of this study: it allows for presenting valued outcomes in a manner that resonates with stakeholders, in order to inform future practice.

Integrated knowledge translation

Integrated knowledge translation is an approach to research in which knowledge users are engaged in the research process, in order to enhance applicability of findings (Gagliardi et al, 2016). As noted above, this study was conducted as a partnership between a doctoral trainee (CE) and the Camden Coalition of Healthcare Providers' National Center for Complex Health and Social Needs. At the time of this partnership the National Center was actively working to support more holistic, standardized approaches to evaluation. The partnership was initiated by CE, who expressed an interest in focusing on value-laden dimensions of measurement and on mental health specifically. As knowledge user partners, staff of the National Centre (JT and RS) were involved in developing the research question, identifying key informants with rich knowledge of the field, reviewing preliminary analyses through a knowledge user lens, and supporting dissemination of findings through the National Centre's networks including through a webinar and blog post. These activities took place through remote meetings between CE, JT, and RS held biweekly to monthly, depending on the research stage. Separately, CE met with JA, NK and JNL who provided input and feedback at all stages of the project from an academic perspective.

Sampling and recruitment

Participants were drawn from two groups of leaders in complex care: 1) individuals who have lived experience of having complex health and social needs and mental health concerns, and who have taken on advisory roles within health service programs and organizations; 2) operational and programmatic leaders in complex care services, including clinical leaders as well as administrators and including payer organizations as well as delivery services.

A purposive sampling approach was used to maximize the richness of the data within the sample, including both criterion and intensity sampling. Criterion sampling involves applying inclusion and exclusion criteria to ensure that those sampled fall within the groups of interest (Palinkas et al, 2015). Intensity sampling identifies those with the greatest degree of involvement in the issue at hand (ibid). Criteria for each group are described below, followed by a description of how an intensity approach was applied.

1) People with lived experience (PWLE): Eligible individuals self-identify as having current or previous complex health and social needs including mental health concerns, and hold volunteer and/or paid advisory roles through which they contribute to a range of health system activities.

2) Operational and programmatic leaders (OPL): Eligible participants in this stakeholder group hold leadership roles within complex care organizations. Given that organizational size and structure may dictate the role of the individual most closely connected to complex care programming, individuals in this category may hold roles at any level program management, clinical leadership, and executive positions.

An intensity approach was used to sample participants meeting the criteria above, as well as having deep involvement in or knowledge of mental health outcomes in complex care. Factors indicative of deep involvement included their participation in field-building efforts in complex care; their involvement with mental health care specifically; and the duration of their involvement in this field. People with lived experience were sampled from the Camden Coalition's Consumer Advisory Council and from the Amplify Speakers' Bureau, an initiative of the National Center to develop leadership capacity among individuals with lived experiences of complex health and social needs. Operational and programmatic leaders were identified through the National Center's extensive network of partner organizations across the United States.

A snowball approach was also used, with participants asked to recommend additional individuals with deep involvement in mental health and complex care. This yielded two additional participants (who participated jointly in a single interview).

Participants with lived experience received a gift card in acknowledgment of their time. Operational and programmatic leaders, who were recruited on the basis of their employment and were participating during business hours, did not.

Data collection

Data were collected through semi-structured interviews. Almost all interviews were individual, with the exception of two interviews that included two participants each (by request of the interviewees). Interviews were conducted over WebEx, a secure videoconferencing platform, or by telephone according to participant preference. All operational and programmatic leaders chose WebEx, while the majority of participants with lived experience chose to participate over the phone. Interviews were semi-structured and lasted between 25 and 90 minutes. Interview questions asked about current practices relating to measuring mental health outcomes, beliefs about what outcomes are important in this field, and potential strategies and challenges for measuring these outcomes. A semi-structured approach enabled probing and exploration based on participants' unique experiences and responses. Interviews were conducted by the lead researcher for this study, who is a PhD candidate with experience interviewing health system decision-makers in the context of knowledge translation and evidence synthesis.

Interviews were audio-recorded. Recordings were transcribed using transcription software; the interviewer then checked and revised transcripts for accuracy and removed identifying information. Audio quality issues in some of the recordings of telephone-based interviews prevented full transcription. In these cases, memos and notes were used to supplement analysis.

Sample size

Sample size for this study took into account the principles of "information power" (Malterud et al, 2016). Information power reflects whether the data is adequate to answer the research question; considerations affecting sample size include the breadth of study aims, alignment of participant characteristics with study aims, richness of data, and use of theory, along with whether the study addresses variation or focuses on a single case. This approach is of particular relevance to exploratory research, as Malterud and colleagues note: "For an exploratory study, we do not head for a complete description of all aspects of the phenomenon we study. We are usually satisfied when a study offers new insights that contribute substantially to or challenge current understandings" (pg. 1759; see also Thorne, 2020). As such, information power is relevant to the present study, which seeks to extend current knowledge through exploring stakeholder perspectives–and which makes no claim to providing a definitive, comprehensive, or theorized account of potential mental health outcomes of complex care. This study included a total of 23 initial interviews (with 25 participants, including seven people with lived experience and 18 operational and programmatic leaders) and 15 member check interviews (with six of the original seven people with lived experience, and nine of the original 18 operational and programmatic leaders). Given the aims of the study and participants' deep experience with the subject area, this sample size was judged by the study authors to provide sufficient information power.

Analysis

Analysis proceeded in stages, using a modified conventional content analysis approach (Hsieh & Shannon, 2005). Categories were generated based on immersion in memos from initial interviews. These categories were summarized, and the summary was shared with participants during member check interviews. Morse (2015) argues against member checking as a strategy to increase validity of results, suggesting that participants need not agree with a researcher's interpretation in order for that interpretation to be valid. However, an explicit objective of qualitative description is to present a descriptive account that would be recognizable to study participants–a goal that is distinct from the aims of more interpretive qualitative methodologies (Sandelowski, 2000). In this study, the objective of member check interviews was not to confirm, but to deepen the emerging analysis. Participants were asked for their feedback on emerging concepts and categories, and this feedback was treated as additional data for analysis (Birt et al, 2016).

All interviews were subsequently transcribed and coded using NVivo 12.1, a qualitative data management software package. NVivo offers researchers the ability to label units of text with a code, and to create nested hierarchies of these codes. The summary presented to participants formed the scaffolding for an initial codebook, which was iteratively revised throughout the analysis. Subsequently, relationships among and across categories were considered, discussed among team members, and tested against the data to develop a final analysis.

Results

A summary of findings is included in Table 1, below. Valued outcomes were categorized into two levels. Some outcomes were relevant at a patient level, reflecting individual changes in engagement, health, and wellbeing. Other outcomes pertained to a health service or system level. These included changes to service characteristics and delivery, as well as changes to population health. Some objectives that participants identified may traditionally be viewed as process indicators rather than outcomes per se. However, all included objectives are viewed by participants as intrinsically valuable goals, and as such are described as "outcomes" in this report.

Table 1: Summary of valued mental health outcomes

	Patient level	**Service and system level**
Valued Outcomes	***Outcomes along a dynamic continuum*** • Initial contact: o Readiness for change o Trusting relationship with a provider • Stabilization: o Mental health stabilization (including medication management, safety planning) o Social stabilization (including housing, transportation) • Treatment o Symptom reduction o Functional improvement o Self-management o Insight into personal journey • Recovery o Meaningful life roles o Social relationships ***Longitudinal outcomes*** • Days of mental wellness/illness	***Outcomes as enablers of care*** • Access: o Availability of services o Equitable access o Manageable wait times • Appropriateness: o Alignment with evidence and patient preference o Community-based whenever possible • Principle-based approaches: o Trauma-informed o Culturally competent and anti-racist o Stigma-free • Provider and system capabilities: o Coordination across services o Provider sense of efficacy ***Population-level outcomes*** • Utilization outcomes**:** o Decreased use of avoidable emergency and inpatient mental health and substance use care o Decreased costs • Health outcomes:

	• Attainment of client-identified goals • Social support • Relationships with providers	• Equitable health outcomes for people with serious mental illness

Outcomes valued at the individual level

Participants suggested that different outcomes are relevant to patients at different stages in care. Valued outcomes were identified along a continuum from initial contact through stabilization and treatment to recovery. Participants noted that these stages are intertwined and nonlinear. Individuals may experience setbacks rather than a predictable course from contact to recovery. Moreover, some individuals may choose not to undertake particular tasks, such as seeking treatment for mental health concerns, or may take time to develop readiness for these tasks.

Further, all stages may not be relevant to all programs: for example, some short-term case management programs focus on connecting clients to formal systems of care, while outpatient treatment may begin once a client is connected and stable enough to engage. However, the concept of a continuum was already present in other programs. One participant described programming that was designed to move through three stages, including relationships with providers, self-management, and community connections (OPL5). Another described a continuum from “I [providers] do,” to “we do,” to “you [service users] do” with respect to level of responsibility for managing care (OPL6). While these continua informed engagement and treatment, they were not always tied to formal measurement.

Below we describe the stages that were identified across participants’ descriptions, and the outcomes relevant in each stage along with longitudinal outcomes.

Initial contact. Participants noted that initial contact can be fraught for individuals with complex needs, who often have long histories of interactions with health and social services in which their needs are not met. Against this backdrop, participants identified important outcomes including developing readiness for change, and building a trusting relationship with a service provider.

Readiness and trust were seen paradoxically as both built through the work of complex care, and required for that work. For some participants, readiness was seen as a prerequisite for reaching out for help–"If you're not ready for a change, none of the other stuff matters" (PWLE1)–while others participants spoke to readiness as something that could be built over time in the context of a provider-service user relationship. Like readiness, trust takes time: "if you're going to wait for trust to fully be there, then you're never going to have it" (OPL2). Participants with lived experience commented on the importance of service providers "being there" in the process of building trust; participants in operational and programmatic roles echoed these comments, noting that providers can earn trust over time by being consistent and following through on commitments.

Stabilization. Once contact was made, and the work of building relationships and trust was underway, the next set of outcomes related to stabilization. This encompassed both the stabilization of acute mental health concerns, and emergent social needs; these two tasks were perceived as interdependent.

Stabilization of acute mental health and substance use concerns included medication management where applicable, as well as safety planning to address suicidality, high-risk behaviours, and other urgent concerns. With respect to social stabilization, nearly all participants commented on the critical nature of housing. Other social concerns included access to hygiene, food, transportation, and income supports. Participants also commented on structural barriers to achieving this stability, including housing shortages and gaps in the social safety net.

The interdependence of psychiatric and social stabilization was noted by several participants:

> *I had no identification, none of that stuff. So you know, if they write me a script, I won't be able to get my medication anyway. But with housing, all of that, all of that became available to me. My medication, now I can take my medication. Now I can start the healing process. (PWLE4)*
>
> *For me if we're always going to wait for stabilization before we get the treatment, then that may not happen because some people need to actually have their treatment started while working on stabilization, because these meds take time. They also might not be capable of stabilizing their situation if they're if they're too acute with their behavioral health side. And so to me, these are worked on simultaneously. (OPL2)*

Social stability facilitated healing for the first participant above, while the second participant notes that highly acute mental health concerns can interfere with efforts at social stability. Like readiness, which participants framed as both a first step and a gradual achievement, stabilization was described as both a goal and a process.

Treatment. Treatment of mental health and substance use concerns was perceived as a step that could follow on stabilization, as described above. While participants agreed on some objectives, an important paradigmatic divide was evident with regards to substance use outcomes.

Participants broadly endorsed treatment goals including symptom reduction, functioning, self-management, and insight. Symptom reduction was most often discussed in relation to depression and anxiety symptoms. One participant cautioned that symptom reduction is important, “but it doesn't really show you wellness” (OPL5); functional improvement was suggested as a more holistic indicator. Another, related goal that participants identified was self-management. This included activities like taking medication as prescribed and attending appointments, as well as accepting and taking responsibility for one's own mental health and "knowing my limits" (PWLE5). Participants with lived experience also sometimes framed treatment goals in terms of insight into the roots and triggers of their distress. While this outcome was rarely raised by operational and programmatic leaders in initial interviews, all participants in member checking concurred with its inclusion.

However, divergent perspectives were evident with respect to appropriate treatment goals relating to substance use. Operational and programmatic leaders described adopting a harm reduction approach, focusing on supporting clients to achieve their own goals in a safe manner. This could include goals around reducing or stopping use, as well as goals relating to safer use. However, some participants with lived experience expressed staunch views in favour of abstinence-based approaches: "Substance abuse under control? You can't control it. It will control you… The only way to get it under control is to go into recovery." (PWLE6; for this participant, who endorses abstinence-based approaches, recovery necessarily includes abstaining from substance use). These disagreements reflect broader, entrenched divides within the field of substance use treatment, of which participants were aware.

Recovery. A number of participants identified valued outcomes that extended beyond treatment, functioning, and symptom reduction. These were goals relating to meaningful life roles and social connections.

One participant described the ultimate goal of mental health and substance use treatment as "feeling like you matter, and that you can be part of the world that matters to you" (OPL5). Another participant identified the phrase "a responsible and productive member of society" (PWLE6), from Alcoholics Anonymous, as a touchstone for her. Others described how mental health and substance use care can enable service users to take up meaningful life roles including working, parenting, and supporting fellow community members. Some participants noted that achieving these goals was not an endpoint, but rather part of the ongoing work of recovery– adopting valued roles was seen as an indicator of wellness but also a source of a routine and meaning that could help people stay well.

Similarly, social connections were considered an important outcome of engaging with mental health and substance use services. These social connections could include family, friends, faith communities, and community groups: “anything that involves reconnecting with other with other people outside of the of the medical setting” (OPL14). If the entry point to complex care is often marked by guardedness and mistrust as described above, social connections reflect the support and care at the other end of the continuum.

Longitudinal outcomes. Participants also identified mental health and substance use outcomes that are relevant at any stage in complex care. These included tracking quality of life or days of wellness and days of illness, with the objective of shifting to more well days over time; monitoring social support, again with the objective of building this as time goes on; and tracking relationships with care providers, as a strong relationship is essential throughout a service user’s tenure with formal systems of care. In addition to these specific items, several participants identified attainment of patient goals as an important outcome. Participants noted that while service users’ own goals are likely to shift over time, attainment of those goals is a relevant outcome at any point.

Service-level outcomes

In addition to outcomes that were relevant at the level of the individual service user, participants also identified valued outcomes that were relevant to, and which would be measured at, the level of a health service. These fell into two broad categories: service-level outcomes that would enable better care at an individual level; and population-level health outcomes that would indicate better care is in fact being provided. While the function of enabling care may align better with the concept of process measures rather than an outcome measures, participants framed the items in this category as intrinsically important objectives.

Outcomes as enablers. Four categories of outcomes could enable appropriate mental health and substance use care for people with complex needs: access, appropriateness, principle-based care, and provider and system capabilities.

Access. Participants described access as a multi-faceted concept. Accessibility of services included the actual availability of services appropriate to an individual's need. Another participant noted that services must not only be available, but available within the "magic window" (OPL15) when a participant is ready to change and actively seeking help. Others noted that access includes the visibility of those services to potential users, as well as the extent to which those services meet people "where they were at," for instance through outreach strategies. One participant, summing up these concerns, stated:

> *I think from a patient perspective, what people care about is can I get care when I need it, and can I get the kind of care that I need like, when I need it right? In the right amount of it. And so it's more about is it timely? Is it easy to access? Is it easy to navigate, is it a timely?* (OPL10)

The concept of access moreover included dimensions of equity, where services needed to be equally accessible to different population. For instance, a number of participants commented on specific access barriers for Black communities, including distrust of medical institutions due to both historical and current racism in health care.

Appropriateness. Appropriateness included alignment with both scientific evidence and patient preferences, as well as the appropriateness of settings of care (including providing care in the community wherever possible). Participants described matching evidence-based clinical treatments to patient needs and goals, and ensuring that individuals receive the right intensity and duration of support. One participant described their organization's approach to capturing appropriateness:

> *…an area that we're that we are in the process of defining is how are we identifying what the patient's priority areas are...whether that's the social service concern, medical follow up, mental health follow up, and then connecting them. Our success rate in connecting them to what their top priority is.* (OPL17)

This approach recognizes that service users have multiple, intertwined needs, as well as unique preferences. As such, a strictly algorithmic approach may not result in appropriate care.

Principle-based approaches. Participants also suggested that mental health services need to be responsive to the broader context of service users' lives. Participants specifically referenced cultural competence, anti-racism, and trauma-informed care as guiding principles to ensure this responsiveness. These principles were perceived to be central to the work of complex care, and under-valued:

> *I think meeting people as humans and seeing them as a full person in itself is a radical anti-racist act. And I don't think that gets enough credence and it certainly doesn't get funded.* (OPL34)

Participants suggested that service user experiences and provider competencies and behaviours could be measured to reflect the operationalization of these principles. Participants also spoke to the importance of fighting stigma around mental health, both within health care and within communities.

System and provider capabilities. Coordination across mental health services, and provider self-efficacy in managing mental health were both flagged as important objectives.

Coordination was discussed at multiple levels. One participant described the importance of "getting mental health and physical health to talk to each other" (OPL4), to avoid redundancies and incompatibilities in treatment plans. Several spoke to the importance of communication within the mental health sector, particularly around transitions in care such as discharges from hospitals or inpatient rehabilitation. Others called for coordination at the level of the sector as a whole. For instance, one participant described how agencies compete against each other for grant money rather than collaborating: “I think it looked like a circus. Everybody was pulling for this program and pulling for that program and pulling for that program…It shouldn’t be that way” (PWLE7).

Participants also spoke to the critical role of providers’ self-efficacy and sense of competence with regards to mental health. A lack of self-efficacy was seen as a critical contributor to stigma: providers who do not know how to recognize mental health concerns, or who feel ill-equipped to address them, may see service users as “an ornery human being, or a pain in the neck or a difficult patient” (OPL13). As such, several participants suggested that improving providers’ ability to recognize mental health concerns, address them within their scope, and support their clients to navigate the mental health care system were important goals.

Population-level outcomes. While the outcomes described above can support complex care, participants also described the end state to which better care may lead. This included changes to patterns of utilization as well as changes to population health.

Utilization outcomes. Participants noted that utilization and cost concerns are ubiquitous in complex care, and acknowledged the value of these outcomes. Utilization concerns were described as being linked to appropriateness of care: “I don't think that it's wrong to look at hospitalizations as a metric or especially repeat hospitalizations within 30, 60 days, because to me, that's a failure of outpatient to really connect with and engage a member” (OPL4). Participants described an objective of shifting care from unplanned hospitalizations, to longitudinal engagement with primary care and community services.

It was expected that this shift would eventually result in lower costs. However, participants noted that costs needed to be considered broadly: “the hospitals are saying we want to reduce utilization and the community mental health centers say oh, well, if you cost shifted the client totally over to us to provide uncompensated care then hey, good on you” (OPL9). This participant called attention to important costs that may be invisible to health plans and payers, and therefore missed in evaluation.

Health outcomes. Several operational and programmatic leaders referenced health inequities for people with serious mental illness, including inequities in mortality. One participant described reducing these discrepancies as “the true measurement of equity” (OPL11) and ultimate objective of complex care. However, in member check interviews, several participants with lived experience expressed doubt about the feasibility of this outcome. One participant attributed doubt to the role of health behaviours: “you have people who have mental illness, right, and they self-medicate themselves. They don't want to take their medications because the medications doesn't make them feel better.” (PWLE4). Another noted the role of social determinants of health, noting that people with serious mental illness often face adverse conditions such as homelessness that take an irreparable toll on health (PWLE2).

Tensions between values and practice in measurement

Some participants identified tension between valued outcomes, and current practices in mental health outcome measurement. Table 2, below, lists mental health measures that participants in programmatic and operational leadership roles reported in interviews. Participants in programmatic and operational leadership roles agreed that measurement practices are often shaped by funder requirements. Those in payer organizations in turn noted that their measurement practices are also often shaped by external requirements, including the Centers for

Medicare and Medicaid Services star rating system that provides public information on health care quality. Participants commented that externally imposed measures did not always reflect valued outcomes: “a lot of the current outcome measurements don't match what we treat or impact” (OPL). Moreover, the high volume of funder-required measurement precluded adopting additional measures to capture outcomes. One participant noted, “one of the biggest concerns that we hear is that any time you add something to the workflow there's typically not something that we can easily remove. And so, that is a huge challenge for us.” Other participants spoke to the trade-offs involved in measurement, which can take time and resources away from direct patient care. These dilemmas contribute to a disconnect between goals valued by providers and service users, and outcomes reflected in measurement.

Table 2: Measures identified in key informant interviews

Patient level measures	Service and system level measures
Measures of symptoms, including: • Patient Health Questionnaire (PHQ9) • Quick Inventory of Depressive Symptomatology (QUIDS) • General Anxiety Disorder 7 (GAD-7) • Hamilton Anxiety Rating Scale (HAM-A) • NIDA Drug Use Screening Scale ***Measures of functioning and self-management, including:*** • Global Appraisal of Functioning (GAF) • Patient/Clinician Global Improvement (PGI, CGI) • Self-Efficacy for Managing Chronic Disease 6 Item Scale ***Other measures:*** • Brief Addiction Recovery Capital-10 (BARC-10)	***Measures of access, including:*** • Percent of population accessing mental health care or mental health consultation • Time to follow-up after emergency department visits ***Measures of utilization, including:*** • Return visits to emergency services • Hospital readmissions • Return visits to outpatient and primary care services ***Other measures:*** • Comprehensive assessments required under state or federal regulations (eg. Adult Needs and Strengths Assessment–ANSA, Center for Substance Abuse Treatment Government Performance and Results

• Informal measures of goal attainment, social support, and social determinants of health • Internally-developed measures	Modernization Act tool–CSAT GRPA) • Patient satisfaction questionnaires

Discussion

Key findings

Participants described valued mental health outcomes in complex care as a trajectory towards a life of connection and meaning at the individual level, with service and system-level objectives contributing to and arising from that goal. Specifically, at an individual level, valued outcomes encompassed goals during initial contact, stabilization, treatment, and recovery. Interdependencies exist within and across stages, reflecting the complexity that gives complex care its name. At a service and system level, participants identified valued enablers of care and population-level outcomes. At both levels, there was a blurring between processes and outcomes, where many valued objectives were perceived to unfold over time or to contribute to the attainment of other goals.

Findings in relation to other studies

The outcomes valued by stakeholders in complex care reflect particular paradigms pertaining to the role of healthcare services, and the meaning of mental health and substance use. For example, all stakeholders interviewed referred explicitly or implicitly to the social determinants of health; many commented on the role of social justice in influencing health, and the role of health services in working towards a just society. Meanwhile the outcomes valued at an individual level align strongly with the recovery model in mental health. The recovery was first articulated in the 1980s by Dr. Patricia Deegan, a scholar with lived experience. It was subsequently adopted into clinical practice and policy in countries including New Zealand, England, Australia, and the United States (Davidson, 2016). Central concepts in the recovery model include the concept of recovery as a process rather than an endpoint, and the importance of meaning and relationships (Leamy et al, 2011). However, paradigm tensions also arise within mental health. In this study, the divide between harm reduction and abstinence-based approaches emerged as a point of contention. This is reflective of broader tensions in the field of mental health and substance use (Bartram, 2019).

Participants reported that decisions about mental health outcome measurement are shaped by influences external to the measurement context. This can result in a context where mental health outcome measurement does not fully reflect the work, or the values, of stakeholders in the field of complex care. This disconnect is reflected in the difference between current practices, and the valued domains. For instance, existing measurement practices do not routinely capture trajectories towards recovery, in particular missing the objectives of successful initial contact, social stabilization, insight, and engagement in life roles and belonging. Current practices also provide limited visibility into system-level enablers of care. This is particularly true in the valued domains of coordination, provider sense of efficacy (which participants viewed as both an outcome in itself and an important contributor to health outcomes and service user experiences) and the use of trauma-informed, culturally-competent, anti-racist and stigma-free approaches. This study does not comprehensively review current measurement practices; however, the misalignment between measurement practice and values in mental health care found in this study is consistent with other literature (Niles & Olin, 2021).

This study therefore contributes to ongoing conversations about evaluation within complex care. Findings reflect the viewpoints of experts with deep involvement in the field, across a range of system roles. By highlighting the mental health objectives and outcomes valued by stakeholders, this study points towards important domains for measurement. Moreover, while many of the objectives that participants valued are specific to mental health given the focus of this study, others have broader relevance. Indeed, a few participants working in mental health services noted that they hoped the field as a whole could learn from mental health, including the importance of service user goals, user-provider relationships, and trauma-informed care.

Strengths

A key strength of this study is the richness of data that informed analysis. Purposive sampling of key informants ensured that all participants had ongoing and intensive engagement with the field of complex care. As such, interview participants shared insights derived from their deep knowledge and experience. Participants were sampled from diverse categories of leaders, including people with lived experience, programmatic leaders including clinician leaders, and operational leaders. This permitted capture and cross-comparison of a range of perspectives, enabling a synthesis of patient level and service and system level outcomes as seen from various vantage points.

Moreover, a member check process was used to elicit participants' reflections on emerging findings, which added further data for analysis. This process highlighted areas of convergence (including operational and programmatic leaders' acceptance of personal insight as an objective) and, more rarely, divergence (including the rejection of harm reduction-based goals by some participants with lived experience). Participants in the member check process also highlighted the non-linear nature of recovery, a framing included in the findings above.

Limitations

This study has important limitations. First, while it included people with lived experience in current leadership and advocacy roles, it did not include current service users. The question of whether patient advisors are "representative" of patients in general–either politically or statistically–is complex and contested (Dukhanin et al, 2019; Glimmerveen, Nies & Ybema, 2019; Martin, 2008). In this study, the views of people with lived experience who hold advisory roles are not considered indicative of service user perspectives more broadly. Rather, participants were assumed to draw on a unique vantage point as both consumers of health services, and actors engaged in health service and system decision-making.

Second, the sampling approach leveraged a particular professional network through the National Center for Complex Health and Social Needs. As such, findings may not reflect values or practice beyond those engaged directly in field-building work in complex care. As well, some social and geographical contexts for complex care were not addressed by participants in this study. For instance, participants were predominantly from urban and suburban areas. Finally, the study is also limited by its focus on stakeholders in the United States. The American healthcare context has unique characteristics, including a multiplicity of payers and integrated service delivery systems. As a result, care must be taken when transferring findings to other contexts.

Implications for measurement practice and policy

Understanding the value of complex care in the domain of mental health may require changes in measurement practice. However, any changes would also have to be sensitive to frontline and administrative capacity requirements of additional measurement.

Measurement choices can be aligned with both the potential for impact (ie. measuring what a program can realistically change), and the value of impact (ie. measuring the changes that matter to stakeholders). Valued outcomes at the clinical level took the form of a continuum–and most services operate only at specific points along this continuum. For instance, shorter-term intensive care coordination may focus on initial contact and stabilization, while supportive housing may focus on recovery. Measurement choices can therefore be tailored to the stage of services provided by a particular organization or at a particular time. At a system level, the time required to achieve valued outcomes is an important consideration. For instance, provider sense of efficacy may be a shorter-term objective, while health equity for people with serious mental illness would likely take longer to achieve.

Implications for research

Mapping measurement tools onto valued mental health outcome domains within complex care may identify gaps in our current repertoire of tools (particularly for tools that are validated within populations experiencing complex health and social needs, and that are brief and easy to administer). Engagement of service users, caregivers, providers, and community partners can support the identification–and potentially the development–of mental health measurement tools that reflect values and meet needs within complex care. Moreover, as noted above, the present study does not include perspectives of current or prospective service users. Future research can explore the mental health outcomes valued by current or recent clients of complex care programs (as well as the outcomes valued by individuals with complex health and social needs who do not have access to complex care, or who decline care from these programs).

Finally, as participants noted, centering mental health raises values that may be relevant to the field of complex care more broadly. In particular, as noted above, the continuum of individual measures identified in this study align strongly with the recovery paradigm in mental health. A rich body of literature addresses how mental health recovery can be foregrounded in clinical practice (eg. van Weeghel et al, 2019; Winsper et al, 2020), health systems (eg. Slade et al, 2014; Frost et al, 2017), and measurement (eg. van Eck, 2017; Williams et al, 2012). In the field of substance use, the term “recovery” has a distinct meaning centering on abstinence;

however, shared elements including the importance of relationships, hope, and meaning have enabled some syntheses of the concept of recovery across substance use and mental health (Bartram, 2019; SAMHSA, no date cited). Researchers should consider potential for cross-pollination between literature and learning in recovery and complex care.

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Appendix 1: Informed consent guide–operational and programmatic leaders

LETTER OF INFORMATION / CONSENT

Valued behavioral health outcomes in complex care

Investigators:

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Dr. Nick Kates, McMaster University (Department of Psychiatry and Behavioural Neurosciences, McMaster University)
Rebecca Sax, Camden Coalition of Healthcare Providers' National Center for Complex Health and Social Needs
Jason Turi, Camden Coalition of Healthcare Providers' National Center for Complex Health and Social Needs

Purpose of the Study

You are invited to participate in a research study about the behavioral health outcomes valued by stakeholders in complex care. You are eligible to participate because of your work in the field of complex care.

Evaluations of care programs for individuals with complex health and social needs ("complex care") often measure whether these programs decrease hospitalizations or costs. However, the effects of complex care programs may be much broader that what is captured in these measurements. Moreover, while behavioral health concerns are a widely recognized component of complex health and social needs, little is known about the behavioral health outcomes that complex care programs seek to achieve. We hope to learn about the behavioral health outcomes that are valued by stakeholders in complex care.

Procedures involved in the Research

You will be invited take part in a remote interview that lasts between 45 and 60 minutes. Interviews are planned to take place between March and July, 2021. Interviews will be scheduled at your convenience and will take place over WebEx, a videoconferencing platform, or by telephone according to your preference. A link to the WebEx privacy policy is available here (LINK). While the Hamilton Integrated Research Ethics Board has approved using the platform to collect data for this study, there is a small risk of a privacy breach for data collected on external servers. If you are concerned about this, we would be happy to make alternative arrangements for you to participate via telephone.

During the interview, you will be asked to provide a bit of background information about your role and the organization where you work. You will then be asked about current practices in measuring behavioral health outcomes, and what behavioral health outcomes you think are important in complex care. The interviewer will audio record interviews with your permission.

We may also follow up in July or August, 2021 with your permission to request your feedback on a draft of study findings.

It is expected that 25-30 people, from across the United States, will participate in this study. This number will include community advisors with lived experience of complex health and social needs; frontline providers; operational and programmatic leaders; and payers.

Costs to Participate

It will not cost you money to participate in this study.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. You may feel uncomfortable answering interview questions about valued behavioral health outcomes, for instance if there are current tensions or challenges in achieving those outcomes in your work or experience.
You do not need to answer questions that you do not want to answer. You can take a break at any time. You can also choose to withdraw from the study. We describe below the steps we are taking to protect your privacy.

Potential Benefits

There are no direct benefits to you. However, a report of findings will be shared with all participants. The findings of the study may also benefit decision-makers, leaders, providers, or service users in the future by suggesting domains that may be targeted in quality improvement and other initiatives in complex care.

Confidentiality

We will collect your name, organizational affiliation, and position/title, along with contact information (email or phone). Personal information will be kept confidential unless you opt in to being credited by name, organizational affiliation, and position/title in the acknowledgments of this study when findings are shared.

Study findings will not be attributed to specific participants. However, given that the field of complex care is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell us. Direct quotes may be used in final report. We will remove the names of organizations, individuals, and geographic locations mentioned in these quotes, if this information could be used to identify you. Quotes will not be attributed to you and will be described in relation to the rest of data, for example as an instance of a common or unusual response.

Your interviews will be audio-recorded, and transcribed using transcription software. We ask that you do not record the interview. The primary investigator will ensure that all files including recordings, transcripts, and the personal identifier key code are stored on a password-protected personal computer. This information will only be accessed by members of the research team. Once the study is complete, an archive of the data without identifying information will be stored for five years before being destroyed.

Participation and Withdrawal

You can withdraw for any reason. If you wish to end the interview early, you can indicate your choice to do so during the interview at any time. If you wish to withdraw following completion of the interview, you can contact the researcher indicating this choice. You can withdraw up until the point at which analysis of all interviews has begun. Audio recordings and transcripts from your interview will be deleted, and your information will be deleted from the study database.

Participating in this study does not preclude you from participation in any other studies.

Information about the Study Results

We plan to complete this study by September 2021. A report of findings will be sent directly to participants. Findings will also be shared in a webinar and published in a plain-language report that will be made available online.

Funding for this Study

This study is funded by a Fulbright Canada Special Foundation Fellow Award and an Ontario Graduate Scholarship to the student investigator.

Questions about the Study

If you have questions or need more information about the study itself, please contact Cara at: evanscn@mcmaster.ca, or (416) 550 5968.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

Person obtaining verbal consent: ___________________
Date and time: _________________________

Participant indicates:
They have read the preceding information thoroughly. They have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. They agree to participate in this study. They understand that they will receive a copy of this form.

____
Participant name Interviewer name Date

The participant consents to being contacted for a follow-up interview.

___ No
___ Yes

The participant wishes to be credited by name and organizational affiliation in reports of the findings of this study, including written reports, journal articles, and/or webinars. They understand that their specific responses will not be attributed.

___ No
___ Yes

If yes, list participant name and affiliation as they would like for it to appear:
____

Person obtaining consent:
I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

____
Name, Role in Study Signature Date

Appendix 2–Interview guide: operational and programmatic leaders

In this study we are interested in the behavioural health outcomes that are important to stakeholders in complex care. With respect to behavioural health, we are interested in mental health, substance use, and related concerns. Outcomes are measured effects of an intervention. Complex care supports individuals facing multiple physical and mental health concerns and social adversity, and who often have high-cost, avoidable service use. The following questions address the context of your work, current practices, and your perspective on what outcomes are important in this area.

- Context
    - Tell me a bit about your organization.
        - What are key features of the population that you serve?
        - What are key features of the context in which your organization is located?
        - What services are offered for patients/clients with complex health and social needs?
    - Tell me a bit about your role in the organization.
- Current practices
    - Does your organization measure complex care clients' attainment of behavioural health outcomes?
        - Which outcomes are measured? At what points? (Eg. immediately following treatment, at three months follow up.)
        - How and why were these outcomes chosen?
        - How are they measured? With what tools? How were specific tools chosen?
        - What challenges arise in measuring this?
    - Does your organization measure outcomes for people or groups other than individual clients? (Eg. caregivers/families.)
        - Which outcomes are measured? At what points? (Eg. immediately following treatment, at three months follow up.)
        - How and why were these outcomes chosen?
        - How are they measured? With what tools? How were specific tools chosen?
        - What challenges arise in measuring this?
    - How are issues of equity addressed in measurement of behavioural health outcomes?
- Valued outcomes
    - What behavioural health outcomes do you think are important in complex care?
        - What makes these outcomes important?
        - Are these outcomes currently measured? How?
        - If not, how could these outcomes be measured?
        - What challenges arise/might arise in measuring these outcomes?

Appendix 3–Informed consent guide: participants with lived experience

Valued behavioral health outcomes in complex care:
Verbal consent process

Title of study:

- Valued behavioral health outcomes in complex care

Invitation to participate in research:

- You are invited to participate in a research study. The study is about mental health and substance use outcomes, or goals, that matter to people involved in complex care.
- You are invited to participate because of your work with (Consumer Advisory Council/Amplify/other consumer group).
- It is completely up to you whether or not you want to participate. Choosing not to participate will not cause any problems for you or your work at (the Camden Coalition/other relevant organization).

Why is this study being done?

- Complex care programs can tell whether they are helping people with their mental health and substance use concerns by measuring outcomes, or goals. For example, programs might check if service users have fewer hospital visits after receiving care. Service users and care providers might keep track of whether goals are met, like finding stable housing.
- In this study, we are learning about the mental health and substance use outcomes that matter to people involved in complex care, including people with lived experience, care providers, leaders in complex care organizations, and insurers.
- We will share what we learn with you by sending you a description of what we found. We will also share this information with people who work in complex care.
- While the goal for our study is to learn more about the topic, we hope that people working in complex care can use this information to make services better. We cannot promise that feedback you provide will result in any changes.

Who is doing this study?

- The study is being led by a PhD student at McMaster University in Canada. Her name is Cara Evans. She is supervised by a professor at McMaster named Dr. John Lavis. Two other McMaster professors, Dr. Nick Kates and Dr. Julia Abelson, are also involved.
- Rebecca Sax and Jason Turi from the Camden Coalition of Healthcare Providers' National Center for Complex Health and Social Needs are also involved in this study.

How many participants will be in this study?

- We are hoping to talk to 6-8 people with lived experience.
- We are also going to talk to other people working in complex care, including: care providers, leaders in complex care organizations, and insurers. These people will be in a number of different states. We hope to talk to 25-30 people altogether.

What will happen to participants in this study?

- If you decide to participate in the study, we will schedule an interview.
- You can choose if you would like to do the interview over the phone or over videochat.
    - For videochat, we will use an application called WebEx. There is a small risk of a privacy breach when using this application. You can see the WebEx privacy policy online here. If this worries you, we can talk on the phone instead.
- Interviews will happen between March and July, 2021. Interviews will take 45 minutes to 1 hour.
- Interviews will be audio recorded, with your permission. Interviews will then be transcribed, meaning everything said on the tape will be written out. The researcher will use a software program for this. We ask that you do not record the interview.
- During the interview, we will ask questions like:
    - What mental health or substance use goals matter to people with complex needs?
    - How would we know if those goals were met?
- You can skip any questions you do not want to answer.
- After the first interview, you can decide if you would like to be part of a second interview.
    - The second interview would take place between June and August, 2021.
    - It will also take 45 minutes to 1 hour.
    - During the second interview, we will share what we learned from interviews with providers, leaders, and insurers. We will ask your opinion about what we found.
- You can choose to participate in other studies at the same time as this one.

Are there any risks?

- Talking about mental health and substance use services can be uncomfortable.
- When we write about what we learned in the research, we may share stories that you told us or quote things that you said. We will not say who told these stories or quotes, but people who know you might recognize stories that you tell. To help prevent this, we will remove the names of people, places, or organizations that you mention.

Are there any benefits?

- There aren't any direct benefits to you if you participate.
- We hope that people who work in complex care will use what we find to make services better.
- We will send you a description of what we learned in this study. We can send it by email or by mail.

Will I be paid to participate in this study?

- You will be paid $50 after completing the first interview.
- If you choose to complete a second interview, you will be paid another $50 after completing that interview.

Will there be any costs to me in this study?

- We do not expect that it will cost you any money to participate in this study.
- If your phone plan has limited minutes or if your internet plan has limited data, participating in the interview may use up minutes or data.

What will happen to my personal information?

- We will collect your name, phone number, and email. We will also collect your home address if you would like us to mail you the description of what we found.
- This information will be confidential. That means only we will see it.
- You can choose whether you would like to be thanked by name when the researchers share what we found. If you do not want to be thanked by name, only we will know that you participated in the study.
- We will keep your name and contact information on a password-protected computer.
- We will also include the recordings and the write-up of what was said during interviews on a password-protected computer. Your name will not be attached to these files, and the names of people, places, or organizations that you mention will be changed in the write-up.
- Information will be kept for five years after the study is completed. After that, it will all be deleted.

Can participation end early?

- You can leave the study at any time, including during your interview. If you decide you don't want to be involved any more, tell one of the researchers.
- If you decide you want to leave the study after starting your interview, you can decide whether or not you would like us to keep your answers. You will need to let us know before we start analyzing what we have heard from all the interviews.

If I have questions about this study, who should I call?

- If you have questions about this study, you can call, text, or email Cara: +1 416 550 5968, evanscn@mcmaster.ca
- A research ethics board is a committee that helps to make sure studies are fair and safe for people participating in them. The plans for this study were checked by a research ethics board in Hamilton, Ontario, Canada.
    - "This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the REB Chair, HiREB at 905.521.2100 x 42013."

Sponsor:

- This study is funded by two scholarships to the student involved: a Fulbright Canada Special Foundation Fellow Award, and an Ontario Graduate Scholarship.

Consent

Person obtaining consent:
I have discussed this study in detail with the participant, including all preceding information. The participant has had a chance to ask questions, and has indicated that all questions were answered to their satisfaction. I believe the participant understands what is involved in this study. The participant agrees to participate in the study.

Communication occurred via:
__ Phone
__ Videoconferencing

____
Name of participant Date

____
Name, role in study Signature Date

The participant consents to being contacted for a follow up interview.
__ No
__ Yes

The participant wishes to be credited by name and organizational affiliation in reports of the findings of this study, including written reports, journal articles, and/or webinars. They understand that their specific responses will not be attributed.

___ No
___ Yes

If yes, list participants' name and affiliation as they would like for it to appear:

The participant wishes to be emailed a copy of this form.

___ No
___ Yes. Email address: ___________________________

____

Appendix 4: Interview guide–participants with lived experience

Complex care helps people who have multiple physical health, mental health, and social challenges. We are doing this research study to learn about the mental health and substance use outcomes that are important to people involved in complex care. “Outcomes” are ways of measuring if a program is meeting its goals of helping people. We will ask about your experience as a member of [], your experiences with outcomes or goals in mental health or substance use, and the outcomes or goals that you think are important.

- Tell me a bit about what you do/did as a member of (CAC/National Consumer Scholars/etc).
    - What made you decide to get involved?
- Complex care programs can tell whether they are helping people with their mental health and substance use concerns by measuring outcomes, or goals. For example, programs might check if service users have fewer hospital visits or fewer depression symptoms after receiving care. In this study, we are learning about the mental health and substance use outcomes that matter to people involved in complex care, including people with lived experience.
    - Have you had experience with setting personal goals when accessing mental health or substance use services? If so, can you tell me about these experiences?
        - For each goal identified: What made these goals important?
        - For each goal identified: How did you know if those goals were met?
    - What goals related to mental health and substance use do you think are important for people with complex needs/people who have had similar experiences? [For example, goals relating to mental health symptoms, to coping, to daily life activities…]
        - For each goal identified: What makes these goals important?
        - For each goal identified: How would we know if those goals are met?
    - Have you had experience working with programs on evaluation, quality improvement, or outcome measurement in your role as a consumer advisor? If so, can you tell me about these experiences?
    - Are there communities that face injustice or inequity when trying to achieve mental health or substance use goals? [Eg. based on gender, race, disability…]
- Is there anything that I didn’t ask about that you would like to add?

Chapter 4: "With me and for me": what makes for good mental healthcare experiences from the perspective of service users with complex health and social needs?

Preface

This chapter continues the previous discussion of what good mental health care means for people with complex health and social needs, by exploring perspectives of current service users. Specifically, this chapter focuses on care experiences and involves participants with complex health and social needs including mental health concerns and homelessness. Interpretive description is applied to build an account of what "good care" meant to participants. This responds both to the need to clarify quality in the context of mental health care for people with complex needs, and the limited presence of service user voices in the literature on complex care.

I developed the study focus and design, conducted data collection, analysis, and drafted the manuscript. Dr. John Lavis, Dr. Nick Kates, and Dr. Julia Abelson all provided input into the study design and feedback on the analysis and manuscript. Dr. Nick Kates also provided as-needed clinical backup during the conduct of interviews.

At the time of writing, this study is under submission at *Community Mental Health Journal.*

"With me and for me": what makes for good mental healthcare experiences from the perspective of service users with complex health and social needs?

Authors: Cara Evans, Nick Kates, Julia Abelson, John N. Lavis

Keywords: mental health, care experiences, complex needs

Word count: 5,413 (main text); 6,710 (inclusive of abstract and references)

Abstract

Objectives. Individuals facing multimorbidity and social marginalization are considered to have "complex health and social needs." Mental health concerns are recognized as a component of complex health and social needs. Efforts are underway to improve quality in both complex care and mental health care, making it important to understand the perspectives of individuals with complex needs on what constitutes good care. This study seeks to address the following question: What mental health care experiences are valued by individuals with complex health and social needs?

Methods. 14 interviews were conducted with individuals experiencing complex health and social needs, including homelessness. Interview data was analyzed using an interpretive description approach.

Results. Participants valued services and providers who cared *with them and for them. Care with* service users demanded genuine, collaborative interpersonal interactions. *Care for* service users with complex needs required flexible processes and individualized care planning and treatment. These elements were evident across stages in an episode of care.

Conclusions. These findings have implications for the implementation of evidence-based and person-centred care, and highlight particular barriers to operationalizing these concepts in mental health care for people with complex health and social needs.

Background

The phrase “complex health and social needs” refers to individuals who experience both multimorbidity and social marginalization (Humowiecki et al, 2018; Long et al, 2017; Thomas-Henkel et al, 2015). Mental health concerns, including substance use disorders, have been identified as a cross-cutting facet of complex health and social needs (ibid). Health service quality and health system performance are areas of increasing focus in both complex care (ie. care programs targeted at individuals with complex health and social needs), and mental health care. This study situates itself at the confluence of these issues, asking: What makes for good experiences in mental health care, from the perspective of service users with complex health and social needs?

Improved service user experiences comprise one arm of the Quadruple Aim framework for health system performance. The remaining three aims are improved population health, improved the work life of providers, and controlled costs (Bodenheimer, 2014). While user experiences in complex care are rarely addressed in the literature (Rijken et al, 2019), the available evidence does suggest that strong relationships with care providers are highly valued by service users with complex needs (Mautner et al, 2013; Webster et al, 2015). However, measurement in the field of complex care has historically focused heavily on the latter domain of cost.

In light of unique features of mental health and mental health care, Kerman and Kidd (2020) call for a field-specific, “recovery-oriented Triple Aim” that embeds recovery considerations into each domain of the Triple Aim framework (they do not address the more recently-added fourth aim of provider experiences). Kerman and Kidd suggest that care experiences relevant to a recovery orientation include the alliance between consumers and providers, perceived stigma, and service user choice and control in treatment, among other concepts. These experienced are reflected in research demonstrating that relationships are a high priority for service users in mental health, along with ease of access and personalized treatment plans with a choice of treatment options (Biringer et al, 2017; Powell & Rowen, 2022).

Improving mental health care for people with complex health and social needs requires an understanding of what constitutes good care from the view of members of this unique population. In this study, the term mental health will be used to refer to the broad array of mental illness and mental health concerns, inclusive of substance use disorders and problematic substance use. Similarly, the term mental health care will be used to describe all treatments for mental health concerns, including substance use treatment.

Study context. This study was carried out in Hamilton, a mid-sized city in the province of Ontario, Canada. Compared to provincial averages, residents of Hamilton experience higher rates of selected chronic diseases, opioid overdoses, and poverty, and poorer self-rated mental health (Hamilton Community Foundation, 2018). Hamilton hosts a broad range of health and social services, including academic hospitals, interdisciplinary primary care, community agencies, and user-led initiatives. It is also home to a number of programs specifically addressing the needs of residents experiencing poor health and social marginalization. Two such organizations participated in this study. One is a health care team that provides medical care, midwifery, and peer support through street outreach and drop-in clinics (referred to as the "drop-in clinic" in the rest of this paper). The other is a drop-in centre that offers a safe indoor space and service navigation support during evening hours (referred to as "the evening drop-in").

Research objectives. This study seeks to address the following question: What mental health care experiences are valued by individuals with complex health and social needs?

Methodology

This study uses interpretive description (Thorne et al, 2004; Thorne, 2016). Interpretive description originated within nursing research as a naturalistic and pragmatic approach to applied health research questions. The expected output of interpretive description moves beyond a surface-level description of the features of the data, but stop short of theorizing. The goal instead is to provide a coherent way of conceptualizing a phenomenon, that accounts for and is accommodating of inevitable individual variation (Thorne, 2016).

One unique feature of interpretive description is its treatment of prior knowledge. While interpretive description adopts an inductive approach to data analysis, the researcher enters the study with both theoretical and practical knowledge. This knowledge provides a "scaffold" (Thorne, 2016) which influences but does not fully determine analysis. In this study, existing mental health care quality frameworks provided a scaffold that informed the research question and sensitized the researcher to particular concepts during analysis. These frameworks included Kerman and Kidd's recovery-oriented Triple Aim as described above, along with the Quality Mental Health Care Framework (Follwell, 2021) and the Behavioral Health Quality Framework (Niles & Olin, 2021). However, these frameworks were not used to drive analysis (in contrast to qualitative studies that are explicitly designed to test or enhance theory), nor did the scaffolding circumscribe potential findings.

Sampling and recruitment

Population. This study focuses on adults whose complex needs include homelessness or housing insecurity, in addition to self-reported mental health concerns. As noted above, the health services and policy literature uses the phrase “complex health and social needs” to describe individuals facing marginalization, chronic illnesses, and mental health concerns. Homelessness or housing insecurity is often given as an example of the social aspect of complex health and social needs (eg. Humowiecki et al, 2018; Thomas-Henkel et al, 2015). Individuals experiencing homelessness face unique issues when seeking and receiving health care in Canadian cities similar to the study setting (Duhoux et al, 2017; Macdonald et al, 2020; Purkey & MacKenzie, 2018; Ramsay et al, 2019).

Sampling. Programs were approached regarding participation in this study if they serve clients with complex health and social needs, with a focus on those who are homeless or underhoused. A snowball approach was further used to identify programs with the deepest engagement in this area: leaders from approached programs suggested other programs and initiatives to approach, based on their knowledge of services in the area. Two programs agreed to participate in the study, as described above.

Sampling of individual participants drew on the following inclusion criteria: individuals were eligible to participate if they were a current client of a participating program (and as such presumed to have complex health and social needs); over the age of 18; capable of communicating verbally in English; self-identified as having past or current experiences of mental health and/or substance use concerns as an adult; and were capable of providing informed consent to participate in the research study. Capacity to consent requires the individual to understand and appreciate the consequences of choosing to participate. The consent process before the interview included a modified version of the University of California, San Diego Brief Assessment of Capacity to Consent screening tool, a brief tool to screen capacity to consent for research participants (Biros, 2018; Jeste et al, 2007).

Exclusion criteria included: signs of active psychosis including responding to internal stimuli or unusual beliefs; signs of current intoxication; reporting or appearing to be in current high distress; or disclosure of active suicidal ideation.

Within the above criteria, a convenience approach to sampling was adopted. Program staff were oriented to inclusion and exclusion criteria. Potentially eligible clients of participating programs were then invited to participate by program staff as they were encountered, with further screening of interested individuals conducted by the interviewer.

Recruitment. Recruitment strategies were developed in collaboration with participating agencies to maximize the accessibility of participation. Recruitment occurred within the evening drop-in and drop-in clinic, with screening, consent, and interviews then conducted on the spot. This strategy meant that participants did not need to have a phone or other means of being contacted. It also avoided the need for participants to attend a scheduled interview, as attending scheduled appointments can be difficult for participants facing barriers relating to transportation, cognition, or other concerns.

Data collection

Data collection took the form of individual, semi-structured interviews. These interviews were primarily conducted in a private room in the evening drop-in or drop-in clinic. In some instances when private space was unavailable in the evening drop-in, interviews took place in a quieter area within the main space, with participant consent. The interview guide asked participants to describe good and bad experiences within mental health care. A semi-structured approach enabled probing and follow-up questions tailored to each participant's unique experiences as well as communication styles. Interviews were conducted by the lead researcher, an occupational therapist with 6 years' experience in mental health care. All interviews were audio-recorded and hand-transcribed by the lead researcher.

Sample size. Sample size was guided by the concept of "information power," or the sufficiency of data to answer the research question (Malterud et al, 2016). This approach suggests the adequacy of a sample is influenced by five factors: 1) the breadth of the study aims; 2) the extent to which participants' traits reflect the study aims; 3) the use of theory to guide the study; 4) the richness of the interview data; and 5) the focus on a single case or on variation (Malterud et al, 2016). Information power is a good fit for interpretive description, which takes a pragmatic approach to generating useful knowledge and which acknowledges the inevitability of individual variation. Interpretive description therefore rests on data that is rich and deep enough to generate a coherent, meaningful description–and which does not require theoretical saturation of relationships among concepts, or data saturation such that all possible variation has been observed.

This study had a tightly focused aim, and involved participants with traits closely connected to this objective. Data varied in the level of detail, as participants differed in the extent of their engagement with services, and their comfort and facility in describing their perspective. Data collection was stopped when study authors believed the emerging analysis was adequately supported for the purposes of developing a novel description that extends existing knowledge.

Analysis

Analysis in interpretive description is iterative, inductive, and informed (but not constrained) by prior knowledge. It occurs concurrently with data collection (Thorne, 2011). Thomson Burdine, Thorne, & Sandhu (2020) suggest that analysis in interpretive description can make use of a process of constant comparison that draws on template analysis. This process, used in the present study, began with data immersion through conducting and transcribing interviews and reading transcripts in full. Initial impressions of broad themes within the data, along with the "scaffolding" of prior knowledge, were used to form an initial coding template. This template was then applied, revised, and synthesized as both analysis and data collection proceeded. Once all data was coded, analysis proceeded through exploration of tensions and relationships among categories in the template, and variation within categories.

Results

Fourteen interviews were conducted, involving fifteen participants (as one couple requested to participate in an interview together). Interviews lasted between ten and forty-five minutes. Four participants were recruited from the drop-in clinic and the remaining eleven were from the evening drop-in, which runs more frequently and serves a higher volume of clients at any given time.

Participants' ages ranged from 19 to 67 years. Eight participants were men, six were women, and one was a nonbinary person. Seven participants were white, four were multi-racial (including three who were Indigenous and white, and one who was South and East Asian), two were Indigenous, and one was Black. One person did not disclose their race.

All participants reported that they had accessed some form of mental health care, and many had accessed multiple types of care. Types of services that participants reported accessing included psychiatric assessment (six participants); mental health or substance use peer support (5 participants); residential substance use care (4 participants); psychotherapy or mental health counselling (4 participants); outpatient or community substance use care (3 participants); and inpatient mental health care (3 participants), among other types of services. These examples are illustrative and not a comprehensive list of services accessed by participants in this study.

Participants valued experiences of care that were collaborative and individualized–as described by one participant's phrase, "with me and for me" (HS03). Care *with users* required authentic relationships that created a foundation for shared understanding and user-led planning. Care *for users* required flexible processes and treatments that are responsive to the idiosyncratic contexts of individual lives. Below, the concept of care *with users and for users* is discussed across steps in an episode of care, from intake through assessment and treatment planning, treatment, and discharge and transitions in care.

Intake. While relationships are built over time, participants valued when providers signalled openness to engaging in *care with* service users from the start. Participants often experienced initial interactions with services as dismissive or even adversarial. For instance, one participant felt a service was "kinda shrugging me off" (HH08) by providing a crisis line number with no further navigation to services that could meet his needs. Another described his experience in hospital: "I felt like I was misunderstood by the professionals. Maybe I got off to the wrong foot with them…I was made out to be the bad guy when I was just trying to get by" (HH01). He presented to hospital voluntarily and was shortly afterwards placed in restraints, which he interpreted as punishment for being "the bad guy." Some participants framed the alternative to these adverse interactions simply as providers who appeared "there to assist" (HH04) or "willing to help" (HH03). However, beyond mere willingness, *caring with* service users at intake could be facilitated by a warm welcome. One participant described this as a sense of being "with people that know me" (HH07). Feeling known in a new place required providers to take a nonjudgmental stance, informed both by competence in this participant's areas of concern and openness to learning about her particular story.

Participants also valued adaptable intake processes, reflecting the value of *care for* them. This was critical because existing, standard processes could pose near-insurmountable barriers to access. For instance, one participant described the intake process for a specialized outpatient program. She needed to download three separate apps, submit several symptom questionnaires, and attend a remote orientation session before being placed on a two-year wait list (HH11). For this participant, who slept in encampments and frequently moved from one city to another, each of those steps–from downloading apps, to finding private space to attend a remote appointment, to maintaining stable contact information over the course of two years–were incompatible with the realities of her daily life. However, some participants had experiences where services were proactive in outreach:

> *I'm also very unreliable when it comes to remembering to take my meds or even remembering I have an appointment. It's one of the biggest struggles for me accessing mental health. And it doesn't even seem like he [healthcare provider] notices. Like it's just business as usual the next day. Um. He's even called me back like a week after if I've missed my appointment two times to see if I'm still kicking…it's not about his practice, it's about the fact that I'm trying to receive help.* (HH14)

This outreach diverges sharply from the rigid requirements for access described above. Stating "it's not about his practice," this participant describes the experience of *care for* him*,* oriented around his own unique needs.

Assessment and treatment planning. During assessment, providers needed to engage in *care with* participants to reach an understanding of their concerns. This collaborative interpretation did not always take place. For instance, one participant expressed confusion that her reaction to experiencing intimate partner violence was treated as a mental health concern: "Maybe they thought I was in a crisis, which I was, you know…I guess because I never had any mental health problems in that sense, that I–I don't know. I guess I couldn't relate, really" (HS04). Another participant related her extensive trauma history then said, "Now when I…told my whole life story to this counsellor or whatever he was, psychiatrist or psychologist, he told me that the reason why I was the way that I was, was due to [my] alcohol and drug abuse" (HS03). These participants felt that their own interpretations of the causes of their distress were ignored, and subsequently that the treatment recommendations they received were not relevant. Instead, participants expressed a desire for dialogue to reach a shared understanding: "he [psychiatrist] kept telling me like oh I don't think you have this or I don't think you have that and I'm like, you know, that's fair, but like can you listen to my reasons why I think that?" (HH12). This participant wanted to work with the provider to develop a formulation that included her own knowledge of her life experiences.

This shared understanding was necessary to drive individualized treatment planning. While participants wanted responsiveness and collaboration in assessment, they often felt assessment processes skated over complexity. This reflects a failure to offer *care for* needs that exceed the bounds of specific diagnoses and predetermined treatment pathways. As one participant lamented, "I've never felt that [compassion] from any doctor, even most psychologists or mental assessments. It's very textbook like, are you feeling x, than y" (HH14). Another participant used the phrase "blanket solutions" (HH09), describing how he felt that treatment planning ignored the specificity of his needs and circumstances. Rather than "textbook" assessment and treatment planning and "blanket solutions," participants wanted to be understood in the context of their lives.

Treatment. Participants valued treatment relationships founded on shared respect and understanding. For some, this meant exclusively seeking peer-led treatment. One participant stated that in peer-led settings, he feels "that I'm not alone. That there's other people that go through what I go through, the anguish and the anxiety" (HH08). Others found a sense of equality in relationships with professionals. Authenticity was crucial in these relationships, as described by a participant who appreciated when providers:

> *…talk to you like a real person, like they're real people. They aren't afraid to be a little bit personal. There's still that level of okay, they're not going to go too deep into it, because they have to keep that professional, but they'll meet you halfway* (HH15).

Another described the mutual process of resolving disagreements and relationship ruptures with his counsellor: "And then she forgived me and I said I forgive you so we worked out that way" (HH06). These participants highlighted the importance of authentic connection based on shared humanity. *Caring with* service users required the willingness of peers or providers to enter into the emotional reality of service users–not "too deep into it," as the participant above cautions, but enough to engage genuinely and with humility.

However, consistent with the challenges encountered during assessment, participants often struggled to find *care for* their complex concerns. For instance. a participant reflected on a positive experience with trauma treatment, noting that the specific focus on sexual assault trauma was still a limitation: "I was a little sad because I have a lot of different types of trauma, so I felt like if I wanted to talk about something else it was kind of a little out of place." (HH11) Another participant stated that he needed intensive supports to stay housed, and felt that most housing-focused interventions did not meet this need:

> *Like you know what, what you don't understand is the reason why I'm homeless is because the entrenchment. Why am I so entrenched? Because of the trauma. Why am I traumatized? Because of sexual abuse and the physical abuse I sustained in the hands of fucking people that were like, in charge and older than I was. So it's like you need to address that first. But also like you know, addressing addiction issues, and when we can address that eventually then I'll be able to address the entrenchment issues and once I'm not so entrenched and you know have some exposure therapy about actually getting my own place right? Actually being able to stay and sit with it? Then I can actually be housed.* (HH09)

Reflecting the concerns about "textbook treatment" described above, these participants were facing multiple, entangled concerns that they felt were not accounted for in interventions focusing on a single issue. In particular, several participants highlighted complex trauma as a foundational issue not fully addressed in the interventions they encountered.

Discharges and transitions in care. When transitioning between services (including transitions between mental health and broader social services), participants often experienced failures of providers to provide *care with* them through that process. One participant described being discharged from inpatient mental health treatment to shelter with minimal support: "here's a taxi chit, figure out where to go, what to do, where you're going" (HH01). He felt lost and unsure of how to navigate the services he needed. While this hands-off approach represented one type of failure to collaborate with service users, others experienced tightly controlled or even coerced transitions. A participant who overdosed in a shelter was given the unappealing choice of either being sent to hospital where she had previously felt unsafe, or discharged to the street. She acknowledged the shelter's concerns about liability if she stayed, but remarked, "the person being discharged just feels like they've gotten tic-tac-toe'd" (HH07). Her phrase suggests an experience of being shifted around a 'game board' at the whims of service providers, without a meaningful say in her own transitions in care. In contrast, one participant spoke to his personal value of autonomy, and described how navigation supports enabled this: "They gave me direction. They gave me drive too." (HH04). Providers were partners in *care with* him, helping him to move in the direction of his own goals and supporting him through complex and interlocking systems of care.

Participants described how discharges from services could better reflect *care for* individual needs, but were more often defined by timelines, rules, and the capacity limits of services. For example one participant felt she was discharged from hospital because "they [the hospital] wanted an empty bed" (HH11), and not because the life situation that precipitated her crisis had stabilized. Another noted, "I wasn't able to stay at the detox until my place at the rehab was open…I relapsed between there so it wasn't really a flawless transition" (HS01). For these participants, treatment timelines appeared to be dictated by the needs of services rather than clients. As an alternative, participants envisaged discharge processes that were adaptable to their distinct needs. One queried:

> *But like, who says you have to discharge? People always think you have to because oh, the program's over… I think that if you're doing a mental health thing, it would be better to not close it down for a certain amount of time before you make a decision (HS03).*

Another participant, when asked about positive experiences with discharge, valued services "keeping tabs" on him through occasional check-ins (HH03). These viewpoints suggest a more fluid relationship to services, with varying levels of support being provided according to the individual's needs, and a smoother transition between treatment and discharge. This fluidity mirrors the fluctuating nature of participants' mental health concerns symptoms.

Discussion

Key findings. Participants valued services and providers that cared *with them and for them. Caring with* service users demanded authentic, collaborative interpersonal interactions. *Caring for* service users with complex needs required flexible processes and individualized care planning and treatment. These elements were evident across stages in an episode of care. For instance, *caring with* users included a warm welcome, assessment driven by shared interpretations, authentic treatment relationships, and collaborative transition planning. Strategies for *caring for* participants included proactive outreach, personalized assessment and treatment, and adaptable timelines for discharge.

Moreover, *caring for* service users and *caring with* service users were inextricably linked. Processes and treatment plans cannot be tailored to individual needs (*caring for*) without building a shared understanding of the context, causes, and potential responses to individual experience (*caring with*). Meanwhile, collaborative relationships (*caring with*) cannot be built without flexible structures and processes that make engagement in care possible in the face of adverse life circumstances (*caring for*). For instance, relationships can only be developed if service users can in fact access services; a co-constructed treatment plan can only be implemented if the resources for doing so exist.

Findings in relation to other studies. This study finds that service users with complex health and social needs place value on relational authenticity (*care with me*) and individualization (*care for me*) in mental health care. Our findings about the importance of *care with me* resonate with and extend current knowledge on experiences in mental health care. Meanwhile, our findings relating to *care for me* highlight particular barriers to operationalizing evidence-based mental health care for people with complex health and social needs.

The importance ascribed to *care with* service users was unsurprising: relationships are well-known to be important in mental health care (Norcross and Lambert, 2018). Participants in this study highly valued relationships in which peers or providers engage authentically from a standpoint of common experiences or common humanity. This aligns with existing knowledge: for instance, a meta-ethnography found that service users with serious mental illness valued therapeutic relationships that are "mutual and equal, and allow for professionals and individuals…to meet as two complex persons" (Ljungberg et al., 2015). The current study adds to this literature by focusing on a specific subset of mental health service users with complex health and social needs, and considering relationships with various actors within the system beyond clinicians such as peer workers.

Caring for participants, meanwhile, entailed individualization; participants' distaste for "textbook" treatment has implications for the implementation of evidence-based care. Evidence-based practice is a worthy goal in health systems, but synthesized evidence may not exist for any given constellation of diagnoses affecting an individual with complex health and social needs, and linear solutions are not always effective when dealing with complex problems. This can result in "stacking" care regimens for multiple conditions, resulting in care plans that are unmanageably burdensome for patients (du Vaure et al., 2016; Ong et al., 2020). While interventions have been developed that specifically address complex mental health needs (such as Flexible Assertive Community Treatment), these are not widely available. Moreover such services may quickly reach capacity in settings in which they are implemented (Stergiopoulos et al., 2018). As a result, individuals with complex needs may be expected or required to seek care from services designed for a more general population. Participants' desire for individualized care may therefore reflect a mismatch between standard, evidence-based treatments and the convoluted realities of their lives.

Of course, evidence-based practice is fully compatible with–and even demands–flexibility: an oft-cited definition of evidence-based medicine highlights the integration of "the best" research evidence with clinical expertise and patient preferences and values (Sackett et al., 1996). However, much of the literature on evidence-based medicine has focused more narrowly on ensuring that health care practice aligns with the findings of synthesized research findings (Kelly et al., 2015). Moreover, participants in this study wanted more than preferences and values to be taken into account: they also wanted care that took seriously their explanations for and interpretations of their distress.

However, participants often reported experiences in which their interpretations were dismissed. Recent scholarship applying the concept of epistemic justice in health care can help to contextualize these experiences (eg. Bogaert, 2021; Grim et al., 2019). Epistemic injustice, originally described by philosopher Miranda Fricker, occurs when individuals are unintentionally but unfairly treated as incapable of knowing or understanding (Bogaert, 2021). While epistemic injustice is enmeshed with marginalization and stigma, the limits of the existing evidence base to address complex needs are also relevant here. One facet of epistemic injustice, hermeneutic injustice, occurs when the experiences of a particular group are rendered invisible by a lack of broader, shared meaning about those experiences (Bogaert, 2021). Within an evidence-based paradigm oriented around synthesized, relatively decontextualized evidence, providers may lack an interpretive framework to effectively engage in *care with* service users with complex needs (Grim et al, 2019), making it difficult to appropriately plan and organize *care for* these clients.

Strengths and limitations. An interpretive description approach enabled participant perspectives, based in experience, to be brought into conversation with concepts of quality existing in the literature. Results were considered in relation to existing disciplinary knowledge, maximizing applicability while also creating opportunity for unexpected findings; for instance, the hesitation towards “textbook treatment” presents a particular challenge to some traditional measures of quality including implementation of evidence-based practice.

This study also employed recruitment practices that minimized barriers to participation. By recruiting from drop-in programs and engaging in on-the-spot interviews, we were able to include individuals with barriers both to research participation, and to seeking care. Moreover, by recruiting outside of a mental health setting, we were able to connect with participants who may have disengaged from mental health care. These are important voices to capture in mental health services research.

However, as part of the commitment to accessibility, many interviews were relatively short. This entailed a trade-off between access, and detail. Mental health and substance use services were also considered broadly, without distinction between settings (such as emergency, acute, outpatient, residential, community, or user-led settings) or types of treatment (such as therapy, crisis care, medication management, withdrawal management, harm reduction services, or case management). While this enabled the analysis of broadly valued experiences, further research studies can consider variation across setting, treatment, and other factors.

Implications for policy and practice. Our findings reflected a frequent mismatch between participant needs, and the structure and content of available services. As such, interventions specific to complex needs should implemented, scaled and resourced to enable sufficient capacity and stability to meet population needs. It is important to note that interventions addressing complex needs are necessarily intensive. This is reflected in participants' comments, for instance around flexible discharge: currently, resource limitations would create a challenge in enacting this. Existing evidence also points to the importance o service intensity. For instance, systematic review of case management interventions for people experiencing homelessness found that while assertive community treatment improves mental health, intensive case management (which offers a lower level of support) has mixed effects and standard case management had null or even adverse effects (Ponka et al, 2020). Meeting complex needs is therefore an inherently resource-intensive endeavour.

Providers need to be equipped with skills and knowledge to *care with* clients. Participants in this study valued the times when their current realities and past adversities were taken into account. A deeper engagement with concepts of social determinants of mental health (Alegria et al, 2018) and trauma-informed principles (Sweeney & Taggart, 2018) may help providers to foster more collaborative meaning-making and authentic understanding during assessment and treatment.

Moreover, while providing intensive services appropriate to complex needs is critical, many interactions of service users with complex health and social needs will continue occur outside of targeted services. In order to build the capacity of general services to *care for* service users with complex needs, these services can consider embedding flexibility into processes, including at intake and discharge, to address complex needs as they are encountered. Ensuring a full complement of services will also require attention to social services (Stergiopoulos et al, 2018) and, as highlighted by some participants in this study, inclusion of peer-led initiatives.

Implications for future research. Participants in this study highly value providers and peers who engage in *care with* users by taking a genuine and collaborative stance. While abundant literature focuses on characteristics of effective provider-service user relationships in mental health, particularly in psychotherapy (Norcross & Lambert, 2018), less is known about the role of health services and systems in enabling these relationships. Future research can explore how service and system-level conditions and resources can facilitate authentic, collaborative relationships in mental health services for people with complex health and social needs.

Future research can develop and evaluate models of mental health care that offer individualized *care for* clients by focusing on goals and context rather than diagnosis-specific protocols. The concept of "minimally disruptive medicine" may provide a useful framework. Developed to address multimorbidity, minimally disruptive medicine considers the patient "work" required for each element of a treatment plan and the capacity of the client for that work. It also focuses on interventions that are feasible and in line with patient goals (Boehmer, 2021; May, 2009). Future research can explore the outcomes and experiences engendered through taking a minimally disruptive approach in mental health services for clients with complex needs, and the barriers and facilitators to doing so.

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Appendix 1: Informed consent guide

Service user perspectives: quality in mental health care for people with complex health and social needs

Verbal consent process

Title of study:
Service user perspectives: quality in mental health care for people with complex health and social needs

Invitation to participate in research:

- You are invited to participate in a research study. The study is about the mental health care experiences and goals that matter to people who are living with difficult life and health circumstances, including mental health concerns and homelessness.
- You are invited to participate because you access services at [organization]
- It is completely up to you whether or not you want to participate. Choosing not to participate will not cause any problems for you or affect your services at [organization]

Why is this study being done?

- Mental health care services measure different things to see if they are providing good quality care.
- But people who access services might have different perspectives on what counts as good quality.
- In this study, we are learning about the mental health care experiences and goals that matter to people who are living with difficult life and health circumstances.
- While the goal for our study is to learn more about the topic, we hope that people working in mental health care can use this information to make services better. We cannot promise that feedback you provide will result in any changes.

Who is doing this study?

- The study is being led by a PhD student at McMaster University. Her name is Cara Evans. She is supervised by a professor at McMaster named Dr. John Lavis. Two other McMaster professors, Dr. Nick Kates and Dr. Julia Abelson, are also involved.

How many participants will be in this study?

- We are hoping to talk to 12-15 people

What will happen to participants in this study?

- Participants will take part in an interview
- The interview will take between 30 minutes and one hour.
- Interviews will be audio recorded, with your permission. Interviews will then be transcribed, meaning everything said on the tape will be written out. The researcher will use a software program for this. We ask that you do not record the interview.
- During the interview, we will ask questions like:
  - What makes for a good experience in mental health care?

  - What goals did you set/would you set when seeking mental health care?
  - What helped or didn't help you achieve those goals?
- You can skip any questions you do not want to answer.
- You can choose to participate in other studies at the same time as this one.
- By participating in this study you do not give up any rights to which you may be entitled under the law.

Are there any risks?

- Talking about mental health and substance use services can bring up bad memories or difficult emotions.
- When we write about what we learned in the research, we may share stories that you told us or quote things that you said. We will not say who told these stories or quotes, but people who know you might recognize stories that you tell. To help prevent this, we will remove the names of people, places, or organizations that you mention.

Are there any benefits?

- There aren't any direct benefits to you if you participate.
- We hope that people who work in mental health care will use what we find to make services better.

Will I be paid to participate in this study?

- You will receive a $15 Tim Hortons gift card in recognition of your time.

Will there be any costs to me in this study?

- It will not cost you any money to participate in this study.

What will happen to my personal information?

- We will collect your name and the name of the organization where we connected with you. This information will be stored in a password-protected file that will only be accessed by members of the research team.
- We will keep the recordings and the write-up of what was said during interviews on a password-protected computer. Your name will not be attached to these files. The names of people, places, or organizations that you mention will be changed in the write-up. This information will only be accessed by members of the research team.
- Information will be kept for five years after the study is completed. After that, it will all be deleted.
- If you disclose during the interview that you are at risk of harm to yourself or someone else, staff at [organization] and/or emergency services may be notified.

Can participation end early?

- Yes. If you would like to stop the interview, please tell the interviewer.
- If you decide you want to leave the study after starting your interview, you can decide whether or not you would like us to keep the answers that you already gave.

If I have questions about this study, who should I call?

- If you have questions about this study, you can call, text, or email Cara: 289-318-0308, evanscn@mcmaster.ca
- A research ethics board is a committee that helps to make sure studies are fair and safe for people participating in them. The plans for this study were checked by a research ethics board in Hamilton, Ontario, Canada.
    - "This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the REB Chair, HiREB at 905.521.2100 x 42013."

Consent

Participant:
I have reviewed the information above. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a copy of this form.

Name of participant	Signature (if participant wishes)	Date

Person obtaining consent:
I have discussed this study in detail with the participant, including all preceding information. The participant has had a chance to ask questions, and has indicated that all questions were answered to their satisfaction. I believe the participant understands what is involved in this study. The participant agrees to participate in the study.

Name, role in study	Signature	Date

Appendix 2: Interview guide

We are doing this study to learn about the goals and experiences that service users think matter in mental health and substance use. We are especially interested in hearing from service users who are dealing with difficult life and health circumstances, including people who are homeless.

As a reminder, you can skip any questions that you don't want to answer, and you can stop the interview at any time.

Participant information

- Have you accessed mental health and/or substance use care before? If so, what services did you receive?
- Do you have a primary care provider (doctor or nurse practitioner)?
- Do you have a case manager or care coordinator?
- What is your age?
- What is your gender?
- What is your race?
- Are you an Indigenous person?

Experiences

I will now ask questions about experiences with mental health or substance use care that were good, and experiences with mental health and substance use care that weren't good. Which would you like to start with?
[proceed according to participant choice]

- Have you ever had a good experience with mental health care? If so, can you tell me about it?
    - What made it good?
        - When first connecting to care?
        - When receiving care?
        - When being discharged?
    - What was important about [topic discussed above]?
- Have you ever had an experience with mental health care or substance use that wasn't a good experience? If so, can you tell me about it?
    - Why wasn't it a good experience?
        - When first connecting to care?
        - When receiving care?
        - When being discharged?
    - What was important about [topic discussed above]?
    - What would have made the experience better?

Outcomes

Now I have some questions about goals that you set in mental health or substance use care.

- If you have previously accessed mental health or substance use care, was this care helpful to you?
    - Why or why not?
- What goals did you set (or would you set) when seeking mental health or substance use care?
- What helped or didn't help you achieve those goals?
- What would getting better look like for you?

Chapter 5: Conclusions

This dissertation encompasses three studies, which address two issues. First, I set out a multi-level framework for approaching health system design to enable care for people with complex health and social needs. Second, I explore stakeholder perspectives on quality in mental health care for people with complex health and social needs, including operational and programmatic leaders, individuals with lived experience who hold advisory roles, and current service users.

In this concluding chapter I summarize key findings from each study, and from the dissertation as a whole; highlight the substantive, theoretical, and methodological contributions of this dissertation; address strengths and limitations; and suggest implications for research and policy.

Principal findings

Chapter 2: A multi-level framework for complex care–a critical interpretive synthesis.

This study puts forwards a framework for complex care policy, based on analysis of a systematically-obtained sample of academic and grey literature. The framework begins with a definition of complex health and social needs as a pattern of unmet need occurring at the intersection of fragmented health systems, multimorbidity, and marginalization. Components of policy interventions described in the literature are organized into a multi-level intervention addressing these three issues, animated by cross-cutting principles. The framework places a collaborative, client-care coordinator relationship at the centre of complex care. This is nested within health services that provide low-barrier, high-intensity, and interdisciplinary support, and social services that meet basic needs and reduce isolation. These service-level elements are in turn enabled by a health system with aligned funding, technology, and governance structures.

Cross-cutting principles of person-centred, co-designed, trauma-informed, anti-oppressive, and culturally-competent care provide further direction to the framework. Within this dissertation, Chapter 2 offers a backdrop for the subsequent two studies.

Chapter 3: Valued mental health outcomes in complex care. Chapter 3 is a qualitative description study that explores the mental health and substance use outcomes valued by organizational leaders and individuals with lived experience who hold advisory roles in the field of complex care. It was conducted in partnership with the National Center for Complex Health and Social Needs in Camden, New Jersey. This study found that participants valued outcomes at two levels: at an individual level, and at a service and system level. Individual-level outcomes follow a continuum from initial contact through stabilization and treatment to recovery. Goals at initial contact include building trust and readiness; stabilization encompasses both mental health and social stabilization; treatment objectives include symptom reduction, self-management, and personal insight; and recovery involves building meaningful life roles and relationships. This continuum is nonlinear, with relapse and setbacks described as an expected part of care. Meanwhile service and system level outcomes include enablers of care like access, appropriateness, implementation of trauma-informed and anti-racist approaches, as well as population-level outcomes like changed patterns of utilization and health equity for people with serious mental illness. While many of the goals that participants identified may be more typically considered as process indicators rather than outcomes, participants believed these objectives had intrinsic value.

Chapter 4: "With me and for me"–what makes for good mental healthcare experiences from the perspective of service users with complex health and social needs? Chapter 4 took an interpretive description approach to understand the mental health care experiences valued by individuals with complex health and social needs, including homelessness. Findings were summarized by one participant's phrase, *with me and for me.* Care *with me* required a collaborative, genuine relationship built on mutual respect. Care *for me* required flexible processes and treatments that could be tailored to the individual. At intake, participants valued flexibility to enable access, and warmth and sincerity from the first staff or providers encountered. During assessment, participants wanted to move beyond algorithmic approaches and to work with assessors to build a shared understanding. Treatment needed the context of an authentic relationship, and content that addressed participants' intersecting and overlapping concerns (including, notably, trauma). Discharge and transitions were envisioned as flexible, steered by service user needs and goals.

Overarching findings. Taken together, these studies suggest that complex care must centre relationships, allow for individual variation, and take place within a flexible, multi-level system.

The included studies all suggest that relationships are at the heart of complex care in general, and mental health care for people with complex health and social needs in particular. In Chapter 2, the relationship between clients and care coordinators is placed at the centre of a multi-level framework. The rest of the framework was built outwards from this central element. Chapter 3 suggests building a trusting relationship is an intrinsically important goal in complex care. This goal was framed by study participants both as a necessary first step in care, and as an ongoing process. Finally, Chapter 4 provides insight into what a strong provider-user relationship in complex care may entail. Service users stated that they valued authentic relationships, built on shared understanding.

This dissertation also finds that complex care needs to be tailored to the needs of each individual. In Chapter 2, care coordinators are described as working with service users to create individualized treatment plans. In Chapter 3, outcomes were described along an individual's trajectory towards recovery–where recovery involves the actualization of individual goals and values. Moreover, in this chapter "appropriateness of care" was a systems-level goal encompassing both the use of evidence, and alignment with service user preferences and values. The concept of "appropriateness" is furthered by findings in Chapter 4. Participants in this study wanted to move beyond "textbook treatment" and "blanket solutions," in order to receive care that meaningfully addressed the conditions of their daily lives, the origins of their distress, and the intricacies of their mental health concerns.

These studies further suggest contextual elements that can facilitate relationally-sound, individually-tailored care. First, this care requires attention to multiple levels of intervention. The multi-level nature of complex care is most clearly articulated in Chapter 2, which explores the nesting of levels in complex care. For instance, care coordination is suggested not as a stand-alone intervention. Rather, it is dependent upon other system components such as adequately resourced health and social services, and linkages among these components. The layered nature of complex care also comes across in the remaining chapters. In Chapter 3, participants suggested service- and system-level objectives that they perceived as enablers of care at an individual level. This is echoed in Chapter 4, where participants spoke about experiences related both to the care they received, and to service-level processes such as those relating to intake and discharge. Second, complex care not only requires multiple, interlocking levels: these levels also must interface in ways that permit flexibility. This is most clearly highlighted in Chapter 4, where *working for* service users by tailoring treatment is a key concept. Participants spoke to the importance of services that adapt to their individual needs–rather than expecting users to adapt to services' rigid processes. Flexibility is implicit in the framework put forward in Chapter 2, which calls for high-intensity, low-barrier health services–attributes that not all services currently have the flexibility to offer. Meanwhile in Chapter 3, the concept of a dynamic continuum of individual-level outcomes driven by service user goals suggests a need for flexibility to accommodate individual variation.

Contributions

This dissertation contributes theoretically, substantively, and methodologically to the emerging field of complex care. These contributions are described below and summarized in Table 1.

Theoretical contributions. The theoretical contribution of this dissertation is found in Chapter 2, which proposes a theoretical framework for complex care policy. This framework departs from existing literature in important ways. While it shares similarities with the influential Chronic Care Model (Wagner et al, 1996), the framework in Chapter 2 is specific to complex needs (while the chronic care model was not developed to address complexity or multimorbidity). The difference in the population of focus accounts for several major differences from the CCM, including: a reduced emphasis on self-management, given that complex needs may have implications for self-management capacity; an explicit inclusion of care coordination as an intervention, since multiple sectors and services are likely to be involved; and specification of attributes of health and social services (such as high intensity and multi-disciplinarity) to address the challenges of multimorbidity and marginalization. The proposed framework can also be compared with "minimally disruptive medicine," which has been proposed as a theoretically-coherent clinical approach to multimorbidity (Boehmer et al, 2021; May et al, 2009). Some system-level considerations for implementation of minimally disruptive medicine have been described, including the challenges posed by existing quality metrics and practices like defensive medicine (Shippee et al, 2015). However, an account of an enabling system for minimally disruptive medicine has not been described. As such, this dissertation makes a novel contribution by theorizing the components of a health system that can deliver complex care, and highlighting the importance of concordance of objectives at every level.

Substantive contributions. The key substantive contributions of this study are an account of the mental health outcomes and experiences that are important for service users with complex health and social needs.

Chapter 3 addresses valued mental health outcomes in complex care. The values underpinning quality measurement, including outcome measurement, are often left implicit (Carter, 2018; Mitchell, 2019). In mental health research and services, the extensive literature on recovery-oriented outcomes has allowed values to be brought into conversation with questions of measurement (van Weeghel et al, 2019; Williams et al, 2012). However, the field of complex care is much younger, and accordingly is only beginning to broach field-specific conceptualizations of quality (Bossley & Imbeah, 2020; Hardin et al, 2021). Chapter 3 contributes to this conversation by considering perspectives of leaders, including lived experience advisors, on the mental health outcomes that matter in complex care.

Chapter 4 addresses valued experiences in mental health care for people with complex health and social needs. Service user perspectives have been notably under-represented in publications addressing issues of quality in complex care; indeed, user perspectives are under-represented in literature on complex care in general (Rijken et al, 2019). Care experiences valued by mental health service users have been explored in the literature, including values of individuals with serious mental illness (Ljungberg et al, 2015) and those experiencing homelessness (Carver et al, 2010; Kerman et al, 2019). However, I am not aware of similar work framed around complex needs. This study also included recruitment strategies designed to increase accessibility of participation (see Strengths, below). This deepened the contribution by enabling findings to reflect viewpoints of individuals whose “structural precarity” (Ellis, 2021) may result in unintended exclusion from some research. As such Chapter 4 contributes both to the more substantial existing literature on user perspectives in mental health, and to the nascent literature on user perspectives in complex care.

Methodological contributions. Each chapter includes incremental development or novel application of a particular method or methodology.

Chapter 2 uses critical interpretive synthesis (CIS). CIS is not new, having first been described in 2004 by Dixon-Woods and colleagues. However, it continues to be described as an “emerging synthesis method” (Schick-Makeroff et al, 2016). CIS is a theory-generating methodology, and published CIS studies vary in their engagement with prior theory and frameworks. For instance, Bullock and colleagues (2021) used an existing taxonomy to structure data extraction during analysis. Others are more straightforwardly inductive, building a framework “from scratch” (eg. Moat et al, 2013). Chapter 2 does not begin with existing theories or disciplinary viewpoints on complex care. However, prior literature on multi-level interventions was adopted as scaffolding during analysis, to further explore the implications of the observation that policies crossed levels. This purposive adoption of an existing framework represents another possible use of prior theory within critical interpretive synthesis, and is based on a mixed inductive-deductive approach that is consistent with the iterative nature of theory development in CIS.

Chapter 3 draws on integrated knowledge translation (IKT), which is increasingly popular in trainee-led health services research (Cassidy et al, 2021). This study was carried out in partnership with the National Center for Complex Health and Social Needs in Camden, New Jersey, an organization that "connects complex care practitioners with each other and supports the field with tools and resources that move complex care forward" (National Centre for Complex Health and Social Needs, 2020). While most trainee IKT studies are conducted in settings in which the trainee is an "insider" (Cassidy et al, 2021), this study was conducted through a novel, international partnership. Owing to pandemic-related constraints, this partnership was fully remote. Moreover while IKT often involves clinicians and policy-makers (Gagliardi et al, 2015; Lawrence et al, 2019), the National Centre may be described as a health system intermediary: an organization that bridges elements of the health system to support work towards a common goal (Bullock & Lavis, 2019). Knowledge needs were therefore identified at the level of the field of complex care, rather than a particular care delivery organization or policy unit, as may be more typical in IKT.

Finally, Chapter 4 uses the methodology of interpretive description. Interpretive description, developed by nurse researcher Sally Thorne (Thorne et al, 2004; Thorne, 2016), has been widely used to explore patient, caregiver, and/or provider perspectives on issues at a clinical or health service level. In contrast to these applications, Chapter 4 uses interpretive description to explore user perspectives in relation to a policy problem (ie. quality measurement in complex care). A similar approach is found some recent papers, for instance in Jones and colleagues (2022) study of patient perspectives towards data sharing, and Bryam and colleagues' (2021) mixed-methods inquiry including public preferences for advance directives in medical assistance in dying. Chapter 4 contributes to this emerging use of interpretive description, by focusing on how interpretive description's treatment of prior knowledge facilitates applied policy research with lay participants. Specifically, "scaffolding" but not constraining analysis on the basis of disciplinary knowledge enabled us to interpret user experiences through and into discourses of quality. The ability to bring applied knowledge to bear on analysis makes interpretive description a promising approach for exploring the ground-level view of policy concerns.

Table 1: Contributions to the literature

	Chapter 2	**Chapter 3**	**Chapter 4**
Theoretical contributions	A novel framework for complex care policy	-	-
Substantive contributions	-	Mental health outcomes valued by leaders, including operational and programmatic leaders and individuals with lived experience who hold advisory roles, in complex care	Mental health care experiences valued by service users with complex health and social needs
Methodological contributions	Novel treatment of prior theory in CIS	Description of IKT methods and roles in a trainee-led project	Justifying use of interpretive description to explore ground-level perspectives on a policy problem

Strengths

Strengths of this dissertation include: drawing on multiple perspectives and data sources; using an integrated knowledge translation approach (in Chapter 3); and drawing on and extending from existing frameworks and theories.

Several strategies were embedded in data collection to ensure a breadth of data sources. Critical interpretive synthesis, in Chapter 2, enables sampling of grey literature–an important information source in an applied health service domain. Purposive sampling was also used to intentionally broaden the sample of literature, capturing principles implicit or left out of existing sources. In Chapter 3, inclusion of individuals with lived experience who hold advisory roles along with other health system leaders captured multiple forms of expert opinion. Finally, recruitment strategies in Chapter 4 were designed to facilitate participation of those with substantial barriers to participation in health services and in research. By completing variable-length, on-the-spot interviews in drop-in settings, we ensured that participants did not need contact information, access to transportation, the ability to schedule and attend planned appointments, or the stamina to take part in a prolonged conversation. As such we were able to reach a diverse sample of individuals.

Chapter 3 in particular also drew on an integrated knowledge translation approach. This enabled tailoring of the study to address timely applied concerns–in particular, around the question of outcome measurement. Study findings were shared through a report and webinar hosted by the National Center, allowing a rapid cycle between developing and disseminating knowledge.

Finally, this study is strengthened by its engagement with existing theories and frameworks. Work on multi-level interventions underpins the framework in Chapter 2. This suggests mechanisms of action for complex care policy, and can be leveraged to implement and evaluate the proposed framework. In Chapter 3, some findings were framed in terms of recovery. This is a concept with a rich theoretical heritage, that offers conceptual grounding for understanding the idiosyncratic goals and trajectories that may be relevant to service users in complex care (within and beyond mental health). Meanwhile, the use of existing quality frameworks to “scaffold” analysis in Chapters 4 brought findings into conversation with existing literature, while leaving the door open for departures and unexpected findings outside of these frameworks. This is reflected in findings which underscore some familiar dimensions of quality, such as coordinated transitions–while querying others, such as adherence to standardized pathways of care.

Limitations

There are important limitations in this dissertation, including the limitations of the framing of "complex health and social needs," and inconsistencies in context.

This dissertation focused on literature and services explicitly oriented around "complex health and social needs." This runs the risk of excluding services and system initiatives addressing similar concerns under different labels. For instance, in the field of mental health, a number of models of care address serious mental illness. Many clients of these programs could also be considered to have complex health and social needs, given the marginalization of people with serious mental illness and the high incidence of physical comorbidity (Firth et al, 2019). Similarly, social services addressing homelessness are likely to encounter individuals who could be described as having complex health and social needs, as physical and mental health concerns are common in this marginalized population (Aldridge et al, 2018). Findings may therefore be missing lessons that can be derived from approaches developed outside of the emerging field of complex care.

This dissertation also spanned a range of health system and policy contexts. Chapter 2 drew on literature globally, Chapter 3 involved stakeholders across the United States, and Chapter 4 involved service users in a single mid-sized Canadian city. This presents an issue for synthesizing findings across this dissertation–particularly since Chapter 2 establishes health systems themselves as a contributor to the issue of complex needs. In an example of this, concerns arising from the labyrinthine network of payers in the United States, as described in Chapter 3, are unique to that country. Meanwhile, participants in Chapter 4 are embedded in the specific community context and service ecosystem of a single city. Their viewpoints are shaped by this context. However, the broad literature included in Chapter 2 suggest that many high-income countries encounter several similar challenges in addressing complex health and social needs. These challenges include fragmented care systems, disjunctures between health and social services, and deeply embedded social injustices. As such, core findings of each study may be transferable with appropriate consideration of the specificities of context.

Implications for future research

A number of implications for future research arise from this dissertation. First, Chapter 2 points towards a need to develop and test explicitly multi-level models of complex care policy. Developing these interventions will require engagement of stakeholders across levels, from service users and providers to organizational leaders and policymakers. Evaluations should take into account recommendations for studying multi-level interventions, such as longer time horizons and attention to mechanisms of action (Clauser et al, 2012; Paskett, 2016).

Future research can also identify–and if needed, develop–quality measurement tools to capture valued domains of mental health outcomes and experiences in complex care. Appropriate measurement tools are important for identifying whether complex care fulfills its promise in the eyes of users, providers, and leaders. These may include measures of valued outcomes like recovery, processes of care including individualization and relational authenticity, systemic concerns like coordination, and implementation of principles such as trauma-informed and anti-oppressive care. Measures also need to be fit-for-purpose, taking into account considerations such as ease of administration and cross-cultural validity. These measures should be developed with input from service users.

Finally, it will be important to identify how mental health services can best contribute to valued outcomes like recovery, and experiences like relationally-centred and individualized care. This may involve complex evaluation methods to explore relationships between service and system design elements, and service user experiences and outcomes. Case studies of high-performing programs can also play a role in building the evidence base for addressing mental health concerns of individuals with complex needs in a manner that aligns with stakeholder values.

Implications for policy

The key findings noted above–relationally-oriented and individualized care, within a flexible and multi-level system–can guide policy efforts to provide mental health care for people with complex health and social needs.

While healthcare relationships may traditionally be viewed as a clinical concern, health system decisionmakers can consider how mental healthcare structures and processes can make strong relationships possible. Providers need to be equipped with skills, knowledge, and resources to enable authentic engagement with service users. Shortages of health human resources that have emerged or deepened in Canada and other countries during the COVID-19 pandemic (Denis et al, 2021) pose an obvious barrier: the value placed on relationships found throughout this dissertation suggests that improving quality in complex care cannot be accomplished by reducing human contact.

While mental health systems continue to advance towards implementation of guidelines and standards, there is also a need to consider how systems can enable individualized responses to complex needs. Of course, this does not entail abandoning scientific knowledge about "what works"–but rather integrating that knowledge with individual values, preferences, capacities, and beliefs, as intended in the initial articulation of evidence-based medicine (Sackett et al, 1996). The focus on individualization also dovetails with concepts of recovery. Policymakers can draw on literature on recovery-oriented systems of care to guide development of complex care policies, and literature on recovery outcomes to inform measurement in complex care (eg. van Weeghel et al, 2019; Williams et al, 2012).

Moreover, as described above, relationally-centred and individualized care is facilitated by a flexible and multi-level approach. Policymakers can develop multi-level complex care policies by starting from an individual-level view and building outwards. This may help to create an enabling context for effective clinical care and care coordination for people with complex health and social needs. Flexibility is a challenge for large systems, and needs to be balanced with accountability to shared objectives and indicators.

Finally, efforts to improve mental health care for people with complex health and social needs should be informed by the viewpoints of those affected. This will require creative and proactive efforts to engage individuals with complex health and social needs in policymaking processes. Lessons may be drawn from initiatives like Canada's At Home/Chez Soi project, a large-scale, national randomized controlled trial of Housing First initiatives for people experiencing homelessness and mental health concerns. The study involved people with lived experience, and lessons learned in that process–including strategies for building trust and collaboration in the face of steep power differentials–have been documented (Nelson et al, 2015).

Conclusions

Across three studies, this dissertation suggests that care for people with complex health and social needs (including mental health care) should be individualized, relationally-oriented, and provided within a flexible and multi-level health system. These findings dovetail with existing knowledge on valued outcomes and experiences in mental health care, and broaden current conversations on quality in complex care.

Indeed, the field of complex care is moving forward from treating cost and utilization as standalone features of complex needs and care quality; and leaders in organizations are striving to reconcile broader institutional imperatives with values of users and providers. However, service users too often continue to experience adversarial, disempowering health care encounters. In the study that forms the basis of Chapter 3, one participant with lived experience described his vision for addressing mental health needs in complex care:

> *A village mindset. Take care of everybody. Addictions and mental health, everything. A village should be able to take care of itself. And we should find some way to do it. So if we all had the village concept in our mind, taking care, then we would sit down and have a conversation.*

Complex care fundamentally must be about *taking care*; care *with and for* service users, in the service of their recovery, and in the context of a system redesigned for this vital purpose.

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