

Coordinating mental health services for people with serious mental illness: A scoping review of transitions from psychiatric hospital to community

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The authors declare that they have no conflict of interest.

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Abstract

Effective coordination as people with serious mental illness (SMI) move between care settings is essential. We aimed to review challenges to care coordination for people with SMI and identify approaches for improving it. Sixteen articles were identified. Two main challenges emerged: people with SMI facing adjustment challenges during transitions and services struggling to provide continuity of care. Effective approaches addressed coordination challenges and resulted in better improvements in service utilization, social functioning and quality of life. Future interventions may benefit from shared decision-making, support for caregivers, and addressing the challenges associated with complicated medication regimes and accessing medications.

Key words: care coordination, continuity of care, care transitions, serious mental illness, scoping review

Introduction

The coordination of mental health services to meet a person's needs across service providers and sites of care is an essential feature of quality of care for people with serious mental illness (SMI) (Burns et al., 2009; Fontanella, Guada, Phillips, Ranbom, & Fortney, 2014; Jones et al., 2009). Coordination includes the organizing processes, measures and networks at the interfaces of the mental health hospital, primary care delivery and community health systems (Banfield et al., 2012). Coordination commonly occurs during and in response to care transitions as an individual's care needs change (e.g., across settings, within care teams, among care participants, between encounters or care episodes) (McDonald et al., 2014; Viggiano, Pincus, & Crystal, 2012). It involves bridging activities among health professionals; establishing shared accountability for patient care; communicating with stakeholders; exchanging information and transferring care responsibility; facilitating care transitions; performing clinical assessments of care needs and goals; monitoring care and responding to change; and supporting self-management and providing links to community resources (McDonald et al., 2014).

Coordination can be hampered by mental health systems that are fragmented and not integrated and/or difficulties that people with SMI have in obtaining mental health services. Either factor can lead to treatment nonadherence or service disengagement (Bao, Casalino, & Pincus, 2013; Bartels, 2003; Horvitz-Lennon, Kilbourne, & Pincus, 2006). People with SMI can be challenged by poor interpersonal communication skills, inadequate access to information about available mental and health care services, difficulties navigating the mental health care system, and a lack of opportunities to engage in shared decision-making (Morden, Mistler, Weeks, & Bartels, 2009). Organizational and structural barriers also exist, such as a

lack of resources, limited availability of inpatient beds, and a lack of continuity and community care follow-up services (Wright, Rowley, Chopra, Gregoriou, & Waring, 2016).

Two reviews on care transition models and interventions involving the transition from inpatient to outpatient care (Viggiano et al., 2012; Vigod et al., 2013) identified components that are relevant to the mental health setting and people with SMI. The components identified by Viggiano et al. (2012) can be divided into patient, provider, and system levels. Patient-level components include prospective modeling to identify individuals at risk of deteriorating health and patient and family engagement in treatment and transition planning. Provider-level components include guidelines and instructions for what to do and when and the provision of properly tailored information. Systems-level components include the use of quality metrics and feedback and the establishment of accountability mechanisms between providers to ensure shared responsibility for patient care. However, the ways in which these components are operationalized in the coordination of services in psychiatric hospital and community settings for people with SMI have not been extensively explored. Vigod et al. (2013) identified seven successful interventions that reduced hospital readmissions. Elements that contributed to the success of interventions included pre-discharge components (i.e., psychoeducation, structured needs assessments, medication reconciliation), post discharge components (i.e., telephone follow-ups, nurse home visits, timely follow-up with outpatient care providers, family education and communication, peer support), and bridging components (i.e., transition managers, timely inpatient-outpatient provider communication, and patient meetings with outpatient staff before discharge). However, the systematic review emphasized only the evaluation of the effectiveness of interventions and did not include descriptive studies that reported the experiences that people with SMI had with care transitions.

However, there is a need to investigate the perspectives of people with SMI toward the coordination of services. Because those with SMI, their families and caregivers are involved in care transitions, they may be highly relevant to the success or failure of coordination. The purposes of the present study are to map the research literature and provide an overview of the key challenges in coordinating services for people with SMI, their family members and caregivers and to identify approaches that can improve coordination and the ability of people with SMI to manage their lives in the community.

Methods

Scoping review design

A scoping review is an approach to gaining a comprehensive overview of the literature to map key concepts, identify knowledge gaps and convey the breadth and depth of the field (Arksey & O'Malley, 2005; Tricco et al., 2016). Our scoping review design followed Arksey and O'Malley's (2005) five-stage framework, as follows: stage 1) identify the research question; stage 2) identify relevant studies in a literature search; stage 3) select relevant studies; stage 4) chart the data; and finally, stage 5) collate and summarize the results, including the assessment of methodological quality.

Stage 1: Research questions:

This scoping review sought to answer two research questions:

- 1) What are the perceived challenges influencing coordination in care transitions from hospital to the community for people with SMI, including the challenges identified by people with SMI, their family members and caregivers?
- 2) What types of approaches can be identified in the research literature to improve the coordination of hospital-to-community transitions for people with SMI?

Step 2: Search strategy and identification of studies

To ensure that the literature and research questions were adequately illuminated, the authors (MS and YZI) collaborated with an experienced biomedical librarian to define and refine the search strategies, search terms and inclusion and exclusion criteria. The search was conducted by the librarian on May 30, 2017, and included studies published in English between 1990 and May 30, 2017. The following scientific electronic databases were systematically searched: CINAHL, Cochrane trials and Cochrane reviews, Medline, PsycInfo, Web of Science (WOS), and Google Scholar. The following search terms were included to represent care coordination in mental health (Medical Subject Headings (MeSH) terms used for searches in Medline are marked with an *): ‘continuity of patient care*’, ‘patient transfer*’, ‘care plan’, ‘patient discharge*’, ‘patient readmission*’, ‘care transition’, ‘continuity of care’, ‘care coordination’, ‘discharge planning’. The search terms were combined with ‘severe mental illness’ ‘severe mental disorder’, ‘depressive disorder*’, ‘major depression’, ‘schizophrenia*’, ‘schizophrenic psychology*’, ‘schizoaffective disorder’, ‘bipolar disorder*’, ‘stress disorder*’, ‘posttraumatic*’, ‘mental health services’.

Stage 3 Study selection and eligibility criteria/exclusion criteria

Stage 3 entails the study selection process and is illustrated in Figure 1 - The Prisma flow diagram (Moher, Liberati, Tetzlaff, Altman, & The, 2009). A total of 2479 records were identified by the librarian conducting the systematic literature search and were imported into reference management software. After the removal of 66 duplicate records, 2413 remaining titles were screened in three steps: (1) The titles were divided alphabetically into groups of 100 titles. Two authors (MS and YZI) reviewed the same first (in alphabetic order) 10 titles and 10 abstracts from each group. Disagreements regarding inclusion or exclusion were resolved through discussion. A total of 2205 records were excluded in this phase. (2) The two

authors reviewed the abstracts of the remaining 208 records independently and assessed eligibility, and 155 records were excluded based on their abstracts. (3) Four authors (MS, ECT, AMLH, and YZI) read the full text of the remaining 53 records and assessed their eligibility. The reference lists of the selected full-text articles were also screened. This phase led to the exclusion of 37 records and yielded the final sample of 16 articles to be included and analyzed in this review. The four authors conducted meetings to discuss their assessments of the abstracts and full-text articles and the inclusion and exclusion criteria to reach agreement on the studies to be included.

Inclusion and exclusion criteria:

To be eligible for inclusion, the study population needed to include individuals with SMI over age 18 years. Our definition of SMI corresponds to criteria identified by The Substance Abuse and Mental Health Administration (SAMHSA) (2016) and included mental disorders such as schizophrenia, schizoaffective disorder, psychotic disorders, major depressive disorders, bipolar disorders, and borderline personality disorder, along with persistent functional impairment. To meet the overall purpose of the scoping review, the included studies focused on transitions from psychiatric hospitals to the community. Eligible studies reporting on approaches to improve care coordination needed to include a description of a program or intervention that aimed to improve hospital-to-community transitions for people with SMI. We limited the search to 1990-2017 to allow a broad scoping search of the published research.

Titles, abstracts and full-text articles were excluded when there was no author and when the abstract could not be accessed. Additionally, we excluded editorials and discussion papers, research protocols, scale development and validation papers, systematic reviews/reviews/overviews, and articles that could not be accessed in full text in English. The exclusion criteria were tied to the study population (e.g., children, adolescents and youth

under age 18 years, older adults, immigrants, the homeless), patient diagnostic groups that were not in accordance with the SAMHSA (2016) SMI criteria (e.g., dementia, intellectual disability, eating disorders, posttraumatic stress disorder), comorbid mental and medical health condition, and study setting (e.g., prison and forensic settings, behavioral and primary care). Studies that focused on medication adherence and post discharge follow-up only (i.e., they included no intervention or program) and studies that did not evaluate hospital-to-community transitions were excluded. A complete overview of the inclusion and exclusion criteria is presented in Table 1.

Stage 4 Charting the data

We extracted and coded each included article according to the following descriptive data: authors, country of origin, aims, data collection and measurements, study sample and results. For the articles that presented approaches in terms of interventions or improvement programs, we extracted the intervention and program description. The extraction and charting of the data were conducted by MS with input from the coauthors (ECT, AMLH and YZI) (Table 2).

Stage 5 Collating and summarizing the results (including quality assessment)

To achieve a thematic presentation of the results and avoid bias, all the authors read and reviewed the included full-text articles. The results of each of the included articles were summarized in separate text description paragraphs by the lead author (MS). Four of the authors (MS, ECT, AMLH and YZI) read the text descriptions and suggested edits when necessary. These summaries were used to identify challenges and themes related to the coordination of transitions from psychiatric hospital settings to the community across the studies. For the intervention or program studies, the authors read the text summaries to identify how the challenges of coordination were addressed and the outcomes of the interventions or programs. The authors then discussed the interpretations of the study results and the challenges, themes and approaches identified.

We used the Critical Appraisal Skills Program (CASP) (2018) to assess the methodological quality of the qualitative studies. The tool contains 10 questions and assesses quality in three domains: validity, presentation and impact of study results. We used the Cochrane Collaboration Risk of Bias Tool (CCRB) (Higgins et al., 2011) to evaluate the methodological quality of the studies that included quantitative results. The CCRB is a 6-domain tool with a total of seven items that assess selection (2 items), performance (1 item), detection (1 item), attrition (1 item), reporting (1 item), and other sources of bias (1 item). The risk of bias was evaluated independently by all the authors who extracted the data (MS, ECT, AMLH and YZI); all discrepancies were resolved by discussions until a consensus was reached.

Results

Characteristics of the included studies

Sixteen articles were included in the review. There were six descriptive articles and ten articles that presented approaches for improving care coordination.

Six articles reported experiences with and perspectives on the coordination of services in care transitions. These articles were published in the period 2006-2016 and carried out in four countries: the USA (Gerson & Rose, 2012; Rose, Gerson, & Carbo, 2007; Velligan, Roberts, Sierra, Fredrick, & Roach, 2016), the UK (Jones et al., 2009), Japan (Niimura, Tanoue, & Nakanishi, 2016), and Canada (Perreault et al., 2005). Individuals with SMI and their family members or caregivers were the study participants in four articles, including two interview studies (Gerson & Rose, 2012; Jones et al., 2009), one focus group study (Velligan et al. 2016), and a cross-sectional survey study (Perreault et al., 2005). A study by Niimura et al. (2016) included interviews with individuals with SMI only. One study (Rose, Gerson & Carbo, 2007) used narrative logs written by nurses during home visits to document the home environment, functioning, and family situation. The studies are presented in Table 2.

There were ten articles presenting interventions or programs that focused on improving care coordination and the care transition from the psychiatric hospital to community settings. The articles were published from 2000-2013. Half of the studies (n=5) took place in the USA (Batscha, McDevitt, Weiden, & Dancy, 2011; Bauer et al., 2006; Dixon et al., 2009; Price, 2007; Sledge et al., 2011). The rest of the studies took place in Belgium (Desplenter Laekeman, Moons, & Simoens, 2010), Canada (Forchuck, Martin, Chan & Jensen, 2005), Finland (Reynolds et al. 2004), Israel (Karniel-Lauer, Szor, Livn et al. 2000) and Iran (Khaleghparast et al. 2013).

Five studies employed a randomized control group design (Bauer et al. 2006; Dixon et al. 2009; Forchuk, Martin, Chan & Jensen, 2005; Reynolds et al. 2004; Sledge et al., 2011). The remaining five studies employed a variety of designs, including a one-group prospective interview study (Batscha et al., 2011), a descriptive analysis of the profiles of patients receiving discharge management (Desplenter, Laekeman, Moons, & Simoens, 2010), a longitudinal clinical trial (Khaleghparast et al., 2014), an intervention and control group design (Karniel-Lauer et al., 2000), and a posttest-only experimental design (Price, 2007). The measures included were attendance of the first outpatient visit (Batscha et al., 2011; Dixon et al., 2009; Price, 2007), rehospitalization and emergency room use (Dixon et al., 2009; Karniel-Lauer et al., 2000; Price, 2007; Reynolds et al., 2004; Sledge et al., 2011) and the utilization of health and social services (Dixon et al., 2009; Forchuk, Martin, Chan, & Jensen, 2005; Karniel-Lauer et al., 2000). Symptom ratings and social functioning (Bauer et al., 2006; Desplenter et al., 2010; Reynolds et al., 2004), quality of life (Bauer et al., 2006; Forchuk et al., 2005; Reynolds et al., 2004) and medication adherence (Bauer et al., 2006; Price, 2007) were also measured. Two studies included self-reports of knowledge of illness and social resources (Karniel-Lauer et al., 2000; Khaleghparast et al., 2014).

An overview of the characteristics of the programs and intervention studies, including the study aims, descriptions of the programs/interventions, methods for data collection and measurements and study results, is presented in Table 3.

Methodological quality of the included articles

The quality appraisal of the articles that employed qualitative methods indicated that three articles met nine out of the 10 criteria suggested by the CASP (Gerson & Rose, 2012; Jones et al., 2009; Niimura et al., 2016), and two articles met eight of the criteria (Rose et al., 2007; Velligan et al., 2016). The quality appraisal of the articles that included quantitative research methods indicated that all the studies had a high risk of bias in at least one measured domain. The “blinding of participants and personnel” item received the highest percentage of high-risk ratings, and the “incomplete outcome data” and “selective reporting” items received the lowest percentage of high-risk ratings. “Other bias” was noted in 25% of the articles for reasons that included implementation problems, contamination between conditions, and small sample size. The quality appraisal is presented as tables 4 and 5 in the Appendix.

Coordination challenges in hospital-to-community transitions for people with SMI

There were two major themes in the descriptive articles related to the challenges of coordinating the transition from hospital to community: 1) challenges influencing community adjustment and 2) challenges influencing continuity of care. Community adjustment challenges pertained to individuals’ reported difficulties with managing community life after hospital discharge, while continuity of care challenges referred specifically to difficulties with accessing and receiving consistent mental health treatment post discharge.

Coordination challenges influencing community adjustment

Symptoms and worries

The transition from an inpatient psychiatric setting to the community is a vulnerable phase for people with SMI (Gerson & Rose, 2012; Jones et al., 2009). Many of the study participants reported ongoing psychotic symptoms at the time of hospital discharge (e.g., hallucinations, paranoia, agitation and hearing voices); some had suicidal thoughts, and many experienced side effects of medications (fatigue, insomnia, weight gain, and akathisia (Gerson & Rose, 2012; Jones et al., 2009; Rose et al., 2007). These symptoms and issues may lead to hospital readmissions. People with SMI have reported that they were nervous about going home, concerned about not being able to manage their symptoms and family roles, felt helpless and isolated and feared not being able to integrate into the community (Gerson & Rose, 2012; Jones et al., 2009; Niimura et al., 2016; Rose et al., 2007).

Lack of daily activities

An absence of meaningful daily activities, a lack of places to go and unemployment were difficulties reported by people with SMI in several articles (Gerson & Rose, 2012; Jones et al., 2009; Niimura et al., 2016; Rose et al., 2007). The lack of social opportunities affected the study participants' ability to adhere to treatment and affected their quality of life. Individuals with SMI often did not leave the house, they were unable to handle a job, and they had impaired decision-making capacity and poor judgement. Several had unhealthy lifestyles (e.g., poor diets, excessive smoking) and disturbed sleep patterns (Rose et al., 2007), sometimes related to the side effects of medication (Niimura et al., 2016). Family members reported behaviors that negatively affected family relations (Gerson & Rose, 2012; Rose et al., 2007). People with SMI could be threatening, angry and loud toward their family members and caregivers.

Coordination challenges influencing continuity of care

Difficulties with information, decision-making and support

Family members wanted more advice and information about discharge (Gerson & Rose, 2012; Perreault et al., 2005; Velligan et al., 2016). They wanted information about the development of the person's health status, warning signs of deteriorating health, preventing rehospitalization, and the availability of services. Some individuals with SMI wanted to hear from peers about their experiences and to have a bigger say in treatment decisions during transitional care. Some were better able to cope, depending on the ability to incorporate the transition into their daily life (Jones et al., 2009). Individuals also talked about not being listened to or being considered in decision-making and not receiving enough information to participate in decision-making (Jones et al., 2009; Niimura et al., 2016; Perreault et al., 2005; Velligan et al., 2016). Although family conflicts were reported in some studies as negatively affecting the transition, family members were mostly a source of emotional support; they visited during hospitalization and served as someone to whom the person with SMI could talk about their illness (Gerson & Rose, 2012; Niimura et al., 2016; Rose et al., 2007).

Complicated medication regimens

Individuals with SMI and their family members were concerned about communication gaps that commonly occurred around hospital discharge, most often in relation to medication regimens (Gerson & Rose, 2012; Jones et al., 2009; Niimura et al., 2016; Perreault et al., 2005; Rose et al., 2007). They wanted to receive more and simpler information about medications, their side effects, and options (Jones et al., 2009; Velligan et al., 2016).

Individuals with SMI reported that trouble accessing medications at the pharmacy influenced medication adherence; there could be lengthy waiting times, and at times, the pharmacies did not carry the prescribed drugs (Gerson & Rose, 2012; Rose et al., 2007). Family members had concerns about medications; they assisted with filling prescriptions, and at times, they were

unsure about their role in medication administration (Jones et al., 2009). Several individuals with SMI seemed to consider the purpose of follow-up visits as medication management only (Gerson & Rose, 2012).

Poor access to services and instability of key workers

The importance of personalizing the transition and situating it within the daily life of the person transitioning were emphasized by Jones et al. (2009). Most individuals with SMI were able to make follow-up arrangements after hospital discharge but seemed unsure or unhappy about it. In several studies, the individual and family members called for more information and support regarding how to access the service system (Gerson & Rose, 2012; Jones et al., 2009; Niimura et al., 2016; Perreault et al., 2005; Rose et al., 2007; Velligan et al., 2016). Some reported problems with seeking outpatient care arose from long waiting times, and many individuals were unable to utilize available support resources in outpatient services (Gerson & Rose, 2012; Niimura et al., 2016; Rose et al., 2007). Individuals and family members talked about being unable to reach providers and centers and being turned away because of a lack of insurance, discontinuation of programs or non-acceptance of new clients (Velligan et al., 2016). There were difficulties with calling a nurse voluntarily as many individuals did not know the nurses; this complication emphasizes the need for continuity among key workers and the particular challenges arising from frequent physician changes (Niimura et al., 2016). Changing relationships sometimes led to the person feeling helpless and isolated as it took time to build relationships (Jones et al., 2009; Niimura et al., 2016).

Interventions and programs to improve care coordination

The interventions targeted several of the aforementioned challenges that are in play in hospital-to-community care transitions for people with SMI. One of the most commonly targeted challenges was difficulties with information, decision-making, and social support. Forchuk et al. (2005) evaluated a transitional discharge model in which inpatient staff

continued their relationships with individuals after discharge and peer support was available to the person for provide emotional support and community living skills training. Similarly, Reynolds et al. (2004) evaluated a transitional discharge model that included peer support and the overlap of inpatient and community staff. Sledge et al. (2011) tested an intervention that included support from peers and from a recovery mentor. Karniel-Lauer et al. (2000) tested the effectiveness of a re-entry group, which provided psychoeducation regarding mental illness and treatment.

Several interventions comprised multifaceted approaches that addressed more than one care coordination challenge. Batscha et al. (2011) addressed barriers to attending outpatient appointments, such as the instability of key workers and unfamiliarity with the treatment setting, by helping the individual to plan for the first postdischarge appointment, providing appointment reminders, and having a familiar clinician meet with the individual at the first appointment. Bauer et al. (2006) targeted information needs through group psychoeducation regarding illness management and access needs through the availability of a nurse care coordinator and psychiatrist during the hospital-to-community transition. Support for outpatient providers was also a focus of the intervention as the nurse care coordinator facilitated the flow of information among the outpatient team and provided education regarding evidence-based pharmacotherapy guidelines. Similarly, Price (2007) targeted access by providing individuals with SMI with prepaid cellular phones that were active for three months after hospitalization; additionally, the patients had 24/7 access to and home visits from a transitional nurse. The transitional nurse also communicated with the consumers' case managers to enhance continuity of care.

Other interventions also targeted the challenges that influenced community adjustment, such as symptoms, worries, and a lack of daily activities. Dixon et al. (2009) evaluated the effectiveness of a brief critical time intervention (B-CTI) model designed to enhance both

continuity of care and community adjustment. The intervention placed a heavy emphasis on personalized care planning and social support through routine contact between clients and familiar clinicians. Desplenter et al. (2010) utilized a discharge management program that emphasized care planning in accordance with individuals' social environment. An intervention evaluated by Khaleghparast et al. (2014) included patient training sessions that focused on daily living tasks, such as leisure activities, financial resources, independence, self-management of health and well-being, working, and daily living skills. A component of Reynolds and colleagues' (2004) transitional discharge model was peer support related to community integration, skills development, and recreational activities.

Some of the interventions and programs that aimed to improve coordination of care demonstrated improvements in service utilization, such as attendance of the first outpatient visit, reduced hospitalization, and improved medication and treatment adherence. They were also associated with improvements in the participants' social functioning, quality of life, treatment satisfaction and knowledge regarding the illness and available resources. Dixon et al. (2009) reported that B-CTI participants had significantly fewer days between hospital discharge and the first outpatient service visit, received more help with mental and medical appointments and with making family and community connections; furthermore, they received more information about medications than those in the comparison condition. Sledge et al. (2011) demonstrated that participants who were assigned a peer mentor had significantly fewer rehospitalizations and hospital days than controls. Bauer et al. (2006) demonstrated that the collaborative care intervention contributed to improvements in social functioning, quality of life and treatment satisfaction. Two articles also reported significant improvements in program participants' knowledge of their illness and the available social resources (Karniel-Lauer et al., 2000; Khaleghparast et al., 2014).

Discussion

This scoping review study mapped the research literature and identified 16 research articles that focused on care coordination for people with SMI in hospital-to-community transitions. The literature review identified symptoms, worries and lack of daily activities as coordination challenges influencing community adjustment. Difficulties with accessing information, lack of involvement in decision-making and support, complicated medication regimes, poor access to services and instability of key workers were coordination challenges influencing continuity of care. The approaches to improving care coordination were multifaceted programs or interventions that commonly addressed information, decision-making and support. Several interventions targeted several of the identified challenges to care coordination.

The individuals with SMI and their family members and caregivers in several of the included articles faced coordination challenges to community adjustment. These challenges influenced the consumer's quality of life, lifestyle behaviors, and the ability to live a meaningful life in the community (Davidson et al., 2005). The study results show that the transition from hospital to community is a vulnerable period, particularly when psychotic symptoms or suicidal thoughts are not sufficiently controlled. Research has documented that the period immediately following discharge is a high-risk period for suicide (Cutcliffe et al., 2012; Meehan et al., 2006), rehospitalization, homelessness and violent behavior (Viggiano et al., 2012). Needs assessments and systems for identifying people at risk of deteriorating health provide a way forward (Desplenter et al., 2010) by requiring that available measures and support are put in place across the hospital or community setting (Chung, Ryan, & Large, 2016; Viggiano et al., 2012).

Qualitative studies of care coordination challenges highlight the desires that individuals with SMI and their family members have for more information and involvement in decision-

making, the complicated medication regimens that affect adherence, numerous difficulties with accessing services, communication gaps and a lack of continuity in relationships with providers. These challenges reflect the current limitations in the ability of mental health service systems in many countries to coordinate and bridge across care settings, and measures of these challenges are needed at the patient, provider and system levels (Chung, Rotanski, Glassberg, & Pincus, 2016; Samal et al., 2016).

Our scoping review identified ten programs and intervention approaches that addressed the coordination challenges, including several recommended measures for successful care coordination and the integration of general medical and behavioral healthcare (Chung et al., 2016; McDonald et al., 2014; Vigod et al., 2013). However, the included care coordination interventions focused less on improving shared decision-making, medication-related difficulties, and lack of support for family members, which we have identified as challenges. Shared decision-making can be a particularly relevant tool to support the involvement of the consumer and family members in decision-making regarding medications and psychosocial matters, such as work, housing, psychotherapy and other services (Deegan & Drake, 2006; Deegan, Rapp, Holter, & Riefer, 2008). Shared decision-making can also help to provide information about the available services and programs in the community and help to enhance the knowledge of those with SMI and their caregivers regarding the transition process (Zisman-Ilani, Roe, Elwyn, Kupermintz, Patya, Peleg, et al. 2018). Through these means, shared decision-making may ease the individual's concerns before discharge from the psychiatric hospital about the unknown factors waiting for them in the community.

Health care professionals' competencies regarding the service system and the involved providers' complementary job tasks and functions are important for quality of care transitions and care coordination (Storm, 2017; Storm, Siemsen, Laugaland, Dyrstad, & Aase, 2014).

Provider competencies were not addressed as a coordination challenge in the included

qualitative studies, although two of the interventions focused on clinicians' and providers' capacity for and competencies regarding care coordination (Dixon et al., 2009; Reynolds et al., 2004). Future intervention studies to improve care coordination could benefit from addressing the provider competencies necessary for successful coordination and community adjustment for people with SMI.

The methodological characteristics of the included articles suggest a need for additional controlled studies of care coordination for people with SMI. Many of the intervention and program studies were characterized by small study samples, no randomization and a lack of control group, which increases the risk of bias and the ability to draw conclusions about outcomes (Higgins et al., 2011). Five of the studies employed a randomized control group design (Bauer et al., 2006; Dixon et al., 2009; Forchuk et al., 2005; Reynolds et al., 2004; Sledge et al., 2011). The randomized controlled trials examined interventions that included multiple components and demonstrated improvements in service utilization and the individuals' social functioning, quality of life and knowledge about their illness and available resources. These findings need to be replicated and extended in future studies to clarify precisely which approaches are associated with the greatest improvements in care coordination outcomes among people with SMI.

Our findings are subject to certain limitations. First, despite a comprehensive literature search of multiple databases that used broad search terms, the search may have missed relevant studies. We searched the reference lists of included articles and the full-text articles that were excluded with reason. However, these searches did not result in the inclusion of additional studies. Arksey and O'Malley (2005) recommend consulting experts in the field as a separate but optional stage in the search strategy. However, expert consultation was not feasible in this study. Second, discussions among the authors on the depth and breadth of the review during the study selection stage may have resulted in a reduction of the scope. For example, a

broader scope would have been to include studies that addressed the coordination of other types of transitions in the community setting. Third, assessments of the methodological quality of the studies is debated within the scoping review tradition (Pham et al., 2014). In the present review, the quality assessment was performed to identify the strength of the evidence base and was not used as a tool for the exclusion of studies. This resonates with the design and recommended use of the CASP checklist as a pedagogical tool.

Conclusion

Overcoming the challenges to coordinating community adjustment and continuity of care is essential for people with SMI. This scoping review identified several interventions with multiple components that address the identified coordination challenges. These interventions have demonstrated improvements in individuals' social functioning, quality of life and knowledge about their illness and the available resources. These findings need to be replicated in future studies to clarify which approaches are associated with the greatest improvements in care coordination outcomes among people with SMI. Future interventions or programs can also benefit from engaging individuals with SMI in shared decision-making, providing support for family members and caregivers, and addressing the challenges related to complicated medication regimes and accessing medications. Improving provider competencies regarding care coordination will also be important.

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Figure 1 - The Prisma flow diagram

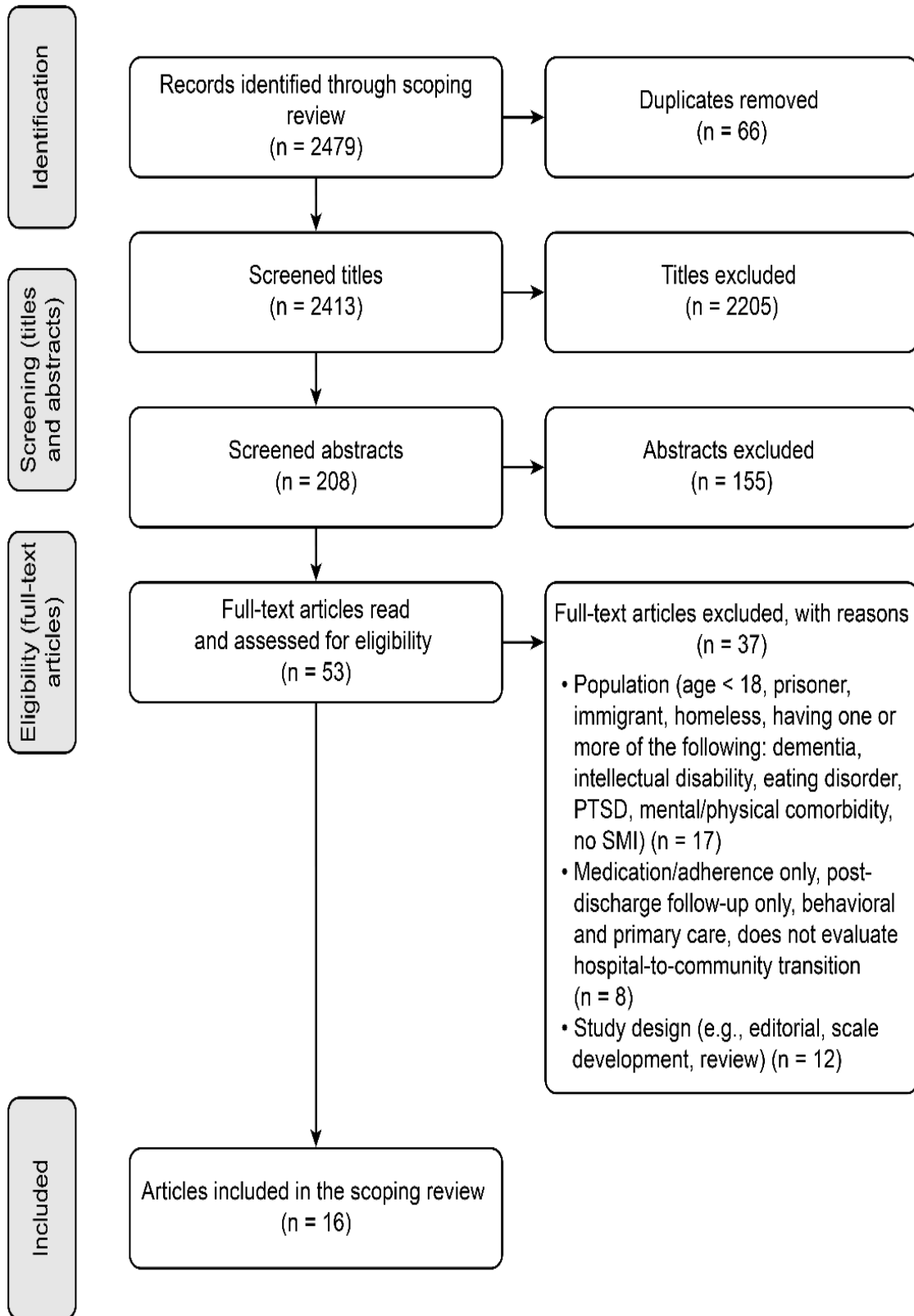


Table 1 Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Target group: Individual with serious mental illness >18 years old	Children, adolescent, youth under age 18, older adults over 75, prisoning, immigrants, homeless, not having SMI
	Patients with dementia, intellectual disability, eating disorders, post-traumatic stress syndrome, comorbid mental and medical condition
	Medication/adherence and post-discharge follow-up only, behavioral and primary care, psychiatric hospital to community transition not evaluated
Study design: All designs	Editorials/comments, systematic reviews/reviews/overviews, research protocols, scale development/validation papers
Published in peer-reviewed journals	Gray literature, no abstract, no author
Language: English	Non-English
	Dissertations
	Published before 1990

Table 2 Characteristics of descriptive studies

Authors and country of origin	Aims	Study design	Data collection and measurements	Study sample	Results
Gerson & Rose 2012 USA	To explore individual's and family members' perceptions of illness-related needs, functioning, coping and social support following transitioning to the community after in-hospital treatment	Descriptive interview study to follow up newly discharge patients with SMI	<p>Exploratory interviews with individuals and family members 48 Hours after hospital discharge and after four weeks.</p> <p>The interviews covered the mental illness, health concerns, and contact with providers and perceptions of functioning, support and coping.</p>	<p>Ten individuals with SMI were enrolled. Five had a psychotic disorder three bi-polar disorder and two major depressive disorder. Six men and four women. Age range 23-81. All were African American Number of times Hospitalized between 1-17</p> <p>Family members included six parents, one fried, three adult children</p>	<p>Study participants had residual symptoms and unmet care needs after hospital discharge interfering with functioning despite availability of follow-up services. Individuals were satisfied with care and the support they received from their families. Family members were concerned about the perceived lack of improvement in mental health. Both individuals and family members lacked a clear understanding of the goals for follow-up care</p>
Jones et al., 2009 UK	To capture the experiences and views of individuals and caregivers focusing on the meaning associated with dis-continuities	Descriptive study conducted as part of a large longitudinal study of continuity of care in mental health	Qualitative interviews to explore experiences of relationships with services, care continuity and transitions from the individuals' and	A sample of 20 individuals with psychotic disorder and 10 of their family members and caregivers, 11 males, mean age 42 (range 27-72). Carers were six mothers, three	Five key themes emerged from the data analysis: discontinuities in relationships, depersonalized transitions, invisibility and crisis, communicative gaps and social vulnerability.

	and transitional episodes		caregivers' perspectives	wives and one community psychiatric nurse 11 user with a non-psychotic disorder, mean age 49 (range 29-59) and four of their carers (one mother, husband, partner and friend)	
Niimura, Tanoue & Nakanishi (2016) Japan	To elucidate the challenges faced by individuals after discharge from acute psychiatric inpatient treatment	Qualitative descriptive design	Qualitative interviews with individuals who had experienced involuntary admissions.	Eighteen individuals with a schizophrenia spectrum disorder eight male and ten female, median age 45.5 years, eight were married, 17 were living with family members.	Participants faces post hospital challenges related to problems with seeking outpatient care, lack of knowledge of their long waiting times, trouble to contact nurses in outpatient care, inability to coordinate matters required for their post-discharge life.
Rose, Gerson & Carbo (2007) USA	To assess the applicability and acceptability of a nurse-based in home transitional care intervention for people with serious mental illness.	Qualitative study presenting nurses' experiences with delivering the in-home transitional care intervention The intervention included; comprehensive discharge planning, home visits 48 hours	Narrative logs by nurses' during home visits documenting the person's home environment, functioning, family interaction, and the nurses' experiences with delivering the intervention and challenges encountered.	Ten persons with serious mental illness (schizophrenia, bipolar disorder, major depression) All were African American, five male and five female, age range 30-62. None were employed, two had more than 12 th grade education All received supplemental security income or disability insurance	Factors identified as important to community adjustment were; caregiver concerns and physical health status, structure /involvement of the individual's daily activities, structural and functional factors affecting adherence to medications and symptom presence at discharge.

		after hospital discharge, six additional home visits over a six week period and telephone contact			
Perreault et al. 2006 Canada	To assess the preferences and satisfaction of psychiatric inpatients and their relatives with family involvement in discharge planning	Prospective study quantitative study	Two interviews incl. a questionnaire with individuals and relatives during hospitalization and three months after	Ninety-eight individuals and forty of their relatives participated in the first interviews and completed a preference questionnaire. At the second interview, there were sixty-five individuals and thirty seven relatives Mean age 45, 52% women (n=51), 50% diagnosed with schizoaffective, 24.4% schizophrenia.	Preferences incl. information about health status, preventing hospitalization, services for relatives. More relatives that individuals with SMI reported that post discharge residence and activities were important areas to be involved. Most individuals were satisfied that their relatives were involved. 89% of individuals and 84% of relatives reported no communication between clinical staff and relatives regarding discharge, also reducing satisfaction.
Velligan et al., 2016 USA	To investigate views of individuals in transition from hospital to community service on their role in treatment decisions and the match with their desired role	Qualitative study	Focus group interviews with individuals with severe mental illness and family caregivers.	Ten individuals with severe mental illness, five male, five Hispanic, three non-Hispanic and two African—American, five had schizophrenia, five affective disorder. Eight caregivers participated in two	Individuals with SMI wanted longer visits and easier access to services and providers, to receive more and simple information about options, to hear from peers and their experience and a bigger say in treatment decisions in transitional care. Family members desired more involvement. Both individuals and

				separate focus group interviews (three mother, two siblings and three spouses).	family members were positive about available programs.
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Table 3 Characteristics of the programs and intervention studies

Authors and country of origin	Aims	Study design	Program/ intervention description	Data collection and measurements	Study sample	Results
Batscha et al. 2011 USA	To explore feasibility of a transition intervention on first post-discharge appointment attendance	One-group prospective interview study	Inpatient transition intervention	Interview study Attendance first out-patient visit	Fifteen individuals hospitalized with psychosis	Twelve participants attended the post-discharge appointment. Two were unable to attend because of readmission.
Bauer et al. 2006 USA	To examine improvement in outcomes for bipolar disorder from a collaborative chronic care model	RCT	Group psycho-education, medication-therapy and nurse care coordinator	Clinical variables Semi-structured interviews Weekly symptom rating for mania and depression, Social functioning/ adjustment scale, Quality of life, Treatment satisfaction Intensity of bipolar pharmacotherapy	Individuals with suspected bipolar disorder admitted to acute psychiatric wards	Significant reduction by 14% in weeks of affective episode, increased social functioning, mental quality of life and treatment satisfaction from receiving the intervention. No significant reduction in mental health symptoms
Desplenter et al. 2010	To present profiles of	Descriptive analysis	Governmental discharge	Family-, and living situation	Three-hundred and fifty-one	In general, individuals (54% were male), were about 45

Belgium	individuals receiving discharge management in ten Belgian psychiatric hospitals		program implemented in hospitals incl. systematic screening and discharge management for high-risk individuals	before and after hospitalization GAF-scores	hospitalized individuals in ten hospitals received discharge management.	<p>years old, had 55 days of length of hospital stay. 173 individuals (49.6%) were single, 62 (17.8%) had a primary care giver, and 69 (19.8%) had a professional aid. 131 (37.5%) lived in own home after discharge.</p> <p>92% of inpatients were screened, 50.8% had positive screening and discharge management were started for 57%. 20% of these individuals had a GAF score ranging 41-60, and 10.9% ranging 61-80. 13.5% of those that received discharge management were institutionalized.</p>
Dixon et al. 2009 USA	To test the effectiveness of a brief critical time intervention (B-CTI) for veterans with serious illness in outpatient care	RCT	Pre-discharge transition program rooted within community-based services and social support	Out-patient visits Hospitalizations Emergency room use Nature of help received	135 veterans diagnosed with a psychiatric disorder (N=64 intervention) & N= 71 control group) , living within 50 miles of an inpatient facility	B-CTI participants had shorter time between discharge and first outpatient visit, more total visits within 30-180 days post-discharge and greater continuity of care. No significant differences between groups in hospitalization and emergency room visits, and overall treatment satisfaction. Of Quality of life factors, satisfaction with legal and safety issues and social contact

						frequency showed a significant difference.
Forchuk, Martin, Chan & Jensen (2005) Canada	To assist hospitalized individuals with a severe mental illness in successful community living, and to determine the cost and effectiveness of a transitional care discharge model	RCT Clustered-randomized design	Transitional discharge model including overlap of in-patient and community staff and peer support for a minimum of one year	Quality of Life Utilization of Health & Social Services Six open ended questions about discharge and issues that hindered or facilitated the process	390 clients were enrolled. Intervention (n=201) Control (n=189) Female 87 Male 102 Mean age 39.5 Mean Age onset of illness 20.8 Length of admission (days) 333.5 Schizophrenia (n=98) Mood disorder (n= 64)	The intervention group did not have a significant improvement in quality of life compared to the controls. The intervention group consumed less hospital and emergency room visits than controls, but this was not significant (p=.009). Peer support was only done 22% of the time on intervention wards compared to 17% of the time on control wards. Participants in intervention ward were discharged 116 days earlier than controls
Karniel-Lauer, Szor, Livne, et al. (2000) Israel	To report the effectiveness of a short-term “re-entry group” compared to traditional discharge processes for individuals with severe mental illness	Intervention and control group	The “Re-entry Group” –a transitional therapeutic program carried out with hospitalized individuals with mental illness	Absorption of individuals into the clinic, Continued therapy, Compliance with treatment Re-hospitalization. Knowledge of Illness and	Seventy-five individuals with a severe mental illness (schizophrenia divided into an experimental group (n= 42) and control group (n=33).	Participants who continued treatment after three months were higher in the experimental group (85.7%) than in the control (51.5%) and continued after 1 year. There was a higher percentage of re-hospitalization in the control group A significant interaction effect was reported for: motivation for therapy (p<0.05) ,

				Resources Inventory		knowledge of the mental illness ($p < 0.01$), knowledge of medical treatment ($p < 0.05$) and knowledge of rehabilitation ($p < 0.05$)
Khaleghparast et al. 2013 Iran	To investigate the effectiveness of discharge planning on the knowledge, clinical symptoms and frequency of hospitalization of persons with schizophrenia	Longitudinal clinical trial	Program included an intervention during hospitalization and after discharge	Discharge list including 20 items measuring positive and negative symptoms, Knowledge measurement questionnaire including 19 items	46 hospitalized individuals randomized to intervention or control	The intervention group demonstrated improvement in clinical symptoms and greater knowledge at discharge and three months after discharge. Re-hospitalization were significantly lower in intervention group.
Price (2007) USA	To facilitate the transition of individuals with schizophrenia from inpatient to community care by implementing an evidence-based community care intervention	Post-test only experimental design	An advanced practiced psychiatric nurse interviewed hospitalized individuals, contacted outpatient clinics, communicated via phone with clients after discharge	Attending to outpatient appointment, Medication adherence Number of hospital re-admission days.	Thirteen English-speaking individuals with schizoaffective disorder, diagnosed within the last 60 months, scheduled for discharge to community. Seven received the intervention and 6 were in the control group.	No statistically significant results between the groups.

Reynolds et al. (2004) Finland	To test the discharge model designed to assist individuals discharged from acute psychiatric to community living	Pilot RCT	Transitional discharge model including peer support, and overlap of inpatient and community staff (transitional nurse)	Quality of life – brief version to measure the life experiences of people with mental illness Level of functioning and severity of illness and hospital readmissions	Twenty-five individuals from three admission wards assigned to experimental (n=11) and treatment as usual conditions (n=14)	Participants showed a general improvement, reported fewer symptoms, better functioning, better quality of life, and were less likely to be readmitted after participating in the intervention.
Sledge et al. 2011 USA	To examine the feasibility and effectiveness of using peer support to reduce recurrent psychiatric hospitalization	RCT with a follow-up nine months after discharge from a psychiatric hospital	The intervention included an adopted version of the peer companion model	Outcome measures were the number of hospitalizations and hospital days during the nine months study period	Seventy four individuals were recruited and randomly assigned to usual care (n=36) and peer-mentor and usual care (n=38)	Participants who had a peer mentor had significantly fewer re-hospitalizations and fewer hospital days. Sub-group analysis showed no significant association between number of mentor contacts and hospitalization outcomes.

Appendix Table 4 Quality assessment qualitative research designs

CASP Assessment questions *	1	2	3	4	5	6	7	8	9	10	SUM
Study											
Gerson & Rose 2012	yes	yes	yes	yes	yes	no	no	yes	yes	yes	8 yes
Jones et al. 2009	yes	yes	yes	yes	yes	can't tell	yes	yes	yes	yes	9 yes
Nimura et al. 2016	yes	yes	yes	yes	yes	can't tell	yes	yes	yes	yes	9 yes
Rose et al. 2007	yes	yes	yes	yes	yes	no	no	yes	yes	yes	8 yes
Velligan et al. 2016	yes	yes	yes	yes	yes	can't tell	no	yes	yes	yes	8 yes

Assessment questions: 1. Was there a clear statement of the research; 2. Is a qualitative methodology appropriate; 3. Was the research design appropriate to address the aims of the research; 4. Was the recruitment strategy appropriate to the aims of the research; 5. Was the data collected in a way that addressed the research issue; 6. Has the relationship between researcher and participants been adequately considered; 7. Have ethical issues been taken into consideration; 8. Was the data analysis sufficiently rigorous; 9. Is there a clear statement of findings; 10. How valuable is the research?

Yes: score of 1

No: score of 0

Can't tell: score of 0

Appendix Table 5. Quality assessment quantitative research designs

Assessment question*	1	2	3	4	5	6	7
Study							
Batscha et al. 2011	1	1	1	0	0	0	99
Bauer et al. 2006	0	0	1	0	0	0	99
Desplenter et al. 2010	1	1	1	1	0	0	99
Dixon et al. 2009	1	1	1	1	0	0	99
Forchuk et al. 2005	0	1	1	1	0	0	1
Karniel-Lauer et al. 2000	1	1	1	0	0	0	99
Khaleghparast et al. 2013	1	1	1	1	0	99	99
Price 2007	1	1	1	1	0	0	99
Reynolds et al. 2004	0	0	1	1	0	0	99
Sledge et al. 2011	0	0	0	0	0	0	1
Perreault et al. 2005	1	1	1	1	99	0	99

Assessment question*: 1. Random sequence generation; 2. Allocation concealment; 3. Blinding of participants and personnel; 4. Blinding of outcome assessment; 5. Incomplete outcome data; 6. Selective reporting; 7. Other bias.

0: Low risk of bias

1: High risk of bias

99: Unclear risk of bias

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