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Title

Caregivers’ experiences of service transitions in adult mental health: An integrative qualitative synthesis

Abstract

Approximately 5% of the UK population live with serious mental health problems. Data show that informal caregivers of people with mental illness provide care for the highest number of hours compared to other illness and the economic cost of this care is highest in the UK when compared internationally. People living with serious mental health problems make transitions between different intensities of service as their needs fluctuate, including referral, admission, transfer or discharge. Although caregiving is associated with both stress and positive reward, service transitions are particularly associated with increased stress. This review aimed to investigate what is known about the experiences of informal caregivers during mental health service transitions.

An integrative qualitative synthesis was conducted following searches in six bibliographic databases and of the grey literature. Studies published in English between 2001 and 2017 were included if the study focus was on serious mental health problems, the experiences of caregivers and service transitions. Eleven studies were included, appraised using the Mixed Methods Appraisal Tool (MMAT) and synthesised, resulting in four themes: 1) Caregiver information 2) Caregiver involvement in decisions about care and treatment 3) Accessing services 4) Being a caregiver.

Caregivers’ experiences were similar during transitions to their usual caregiving role but they faced more challenges and their experiences were amplified. Concerns about confidentiality created barriers to information sharing. Continuity of professionals across transitions was helpful. Caregivers struggled to deal with their own conflicting emotions and with the behaviours of the person yet rarely received help. The review findings point to a need for continuity of professionals across service transitions, co-designed and delivered training for professionals and caregivers about information sharing, greater understanding of barriers to implementation of family interventions and interventions that address emotional needs of caregivers.

Keywords

Caregivers; mental health; psychiatry; transfer; discharge; referral

What is already known about this topic

- Informal caregivers are a critical part of mental health care delivery but often report feeling excluded and unsupported by professionals.
- Informal caregivers of people living with serious mental health problems may not identify with the term carer.
- Mental health policy and practice guidance identify additional stresses to informal caregivers in mental health during service transitions.

What this paper adds

- Caregivers' experiences are not substantially different during transitions to their broader experiences as caregivers but their role is more challenging and their experiences amplified.
- There are implementation gaps and training needs around information sharing between professionals and caregivers.
- Services need to provide interventions that provide continuity of professionals across service transitions that can flexibly meet the different needs of the person and their caregivers.

1. Introduction & background

Since the 1960s, the process of deinstitutionalisation has led to the vast majority of people with mental health problems residing in community settings rather than hospitals (World Health Organisation (WHO), 2013). For deinstitutionalisation to succeed, hospital closure needs to be balanced by increased community based services. In the UK this process was partly economically driven, and community provision was insufficient, which in turn pushed responsibility back onto families as providers of (unpaid) care and support (Parker & Clarke, 2002).

Approximately 5% of the UK population live with serious mental health conditions that cause significant disruption to the life of the person and their family, have a relapsing pattern for many people and are strongly linked with socioeconomic factors such as high rates of unemployment, unstable housing and social isolation (McManus et al., 2016). Although diagnostic criteria vary internationally, for the purpose of this review, serious mental health problems include people living with psychosis (including a diagnosis of schizophrenia) and serious mood disorders (including a diagnosis of bipolar disorder) (American Psychiatric Association, 2013;WHO, 1992).

A systematic review of approaches to economic valuation of informal care reported as having the highest average number of hours spent caring compared to other illnesses and the economic cost of this care was highest in the UK when compared internationally. The authors highlighted however the complexity in accurately calculating the financial cost of informal care (Oliva-Moreno et al., 2017). In the UK, informal caregivers of people with schizophrenia have been estimated to save health and social care services around £1.24 billion a year (The Schizophrenia Commission, 2012); making it crucial that they receive appropriate support. It is estimated that that there are around 1.5 million people providing informal (unpaid) care for somebody with a mental health problem in the UK; most are family members (Worthington et al., 2013). This review uses the term ‘caregiver’ to include any adult providing informal, unpaid care and support to a person living with a serious mental health problem; they may or may not be a family member.

Research has established that informal caregivers can experience high levels of stress, ill health (Ganguly et al., 2010), disrupted routines and financial difficulties (Goodwin & Happell, 2007; Awad & Voruganti, 2008). It is equally important, however, to acknowledge that many caregivers care deeply about the person, willingly provide care and have positive experiences of caregiving (Repper et al.,2008; Veltman et al., 2002).

Informal caregivers, in a mental health context, might not, however, identify as a caregiver and see themselves primarily as a spouse, parent or friend, making it harder to identify those who need support (Worthington et al., 2013). This may relate to an acknowledged difficulty defining the role of caregivers in mental health (Ridley et al., 2014), but also in part because caring for a person with a mental illness is different to caring for a person with a physical health problem by being more focused on supervision, befriending and coping with the behaviour of the person, (Department of Health, 2001). Caregivers have also describe reluctance to accept the label 'carer' as it is perceived as undermining the genuineness of the care they provide (Repper et al., 2008; Ridley et al., 2014).

Relationships between caregivers and mental health services are not always positive; caregivers often feel their concerns are not taken seriously (Shepherd et al., 1994), they do not get support during a perceived crisis (Albert & Simpson, 2015) and they are ignored by professionals (Askey et al., 2009; Lyons et al., 2009; Pinfold et al., 2003) who may not see supporting caregivers as part of their role (Kuipers et al., 2010).

The importance of providing recognition and support to informal caregivers is evident in UK legislation, primarily the Care Act (2014) which entitles caregivers to assessment and a right to have eligible needs met. NHS policy supporting caregivers (NHS England, 2014a; NHS England, 2014b) is based on seven principles including; facilitating assessment, providing a package of support for caregivers' physical and mental health, information sharing, respecting caregivers as experts, and providing support at key transition points. Guidance on implementation of caregiver-focused services in mental health was first published by the UK Department of Health in 2001, yet many of the problems caregivers describe with accessing information and support have continued to be reported. In recognition of this, The Triangle of Care (Worthington et al., 2013) is an initiative founded on six standards to achieve better collaboration with caregivers in the journey through mental health services. It draws particular attention to care transitions including hospital admission and discharge as being times caregivers may need more support.

People living with serious mental health problems make transitions between different intensities of service as their needs fluctuate, for example, admission to, transfer between or discharge from hospital. These times of transition are associated with increased stress and risk for both the person and their caregiver (Loch, 2012). One example is discharge from hospital; data show that the risk of suicide is increased and is highest on the second and third days post-discharge (Healthcare Quality Improvement Partnership, (HQIP) 2017). Current guidelines stipulate that every person should be followed up within three days after discharge from hospital (HQIP, 2017) although evidence has shown that this does not happen for one in ten people (Mind, 2017), leaving many caregivers unsupported.

The National Institute for Clinical Excellence (NICE) guidelines for psychosis and schizophrenia (NICE, 2014a) and bipolar disorder (NICE, 2014b) make recommendations for the involvement of families, parents and caregivers. In recognition of the specific stress people experience as they make a transition between inpatient mental health settings and community settings, NICE (2016) have also developed guidance to support service delivery at admission and discharge, including information sharing about all aspects of illness and treatment and personalised support (including other caring responsibilities, employment and wellbeing).

Although research details the risks associated with transitions and policy emphasises the importance of carer involvement at these points, what is unknown is how carers experience these service transitions. For example, rapid reviews of crisis services (Paton et al., 2016) and early discharge (Clibbens et al., 2018) found virtually no focus on caregivers and very limited evidence (quality and focus) for interventions. The purpose of this review was to investigate what is known about the experiences of caregivers of people with serious mental health problems during transitions between adult mental health services.

2. Methods

2.1. Design

The review type is an integrative qualitative synthesis (Sandalowski et al., 2007) which aimed to bring together different types of data sources (Booth et al., 2016) about caregivers' experiences during transitions between adult mental health services. The review is reported using the structure provided by the Preferred Reporting Items for Systematic review and Meta-Analysis (PRISMA) statement (Liberati et al., 2009). Integrative reviews require a comprehensive approach to the literature search in order to identify the maximum number of eligible primary sources (Whittmore & Knafl, 2005). This was achieved using three approaches, first by searching bibliographic databases, second by carrying out a focused grey literature search and third by searching the reference lists of included primary sources.

2.2. Search methods

The information sources and search terms used were identified by all authors of the review and agreed with a reference group made up of members from professional, academic and lived experience backgrounds. Six bibliographic databases were searched in March 2017 as follows: CINAHL (EBSCO interface), Cochrane Library (Wiley interface), EMBASE (NICE Healthcare Databases interface), Health Management Information Consortium (HMIC), (NICE Healthcare Databases interface), MEDLINE (EBSCO interface), PsycINFO (ProQuest interface). Other searches were conducted in ETHOS (The British Library), Open Grey (GreyNet International), NHS Evidence (NICE Healthcare Databases interface) and the National Institute for Health Research (NIHR) Portal using a truncated search strategy and all identified grey literature in July 2017.

The search comprised three facets with terms relating to: 1) carers, 2) mental health, and 3) care transitions. All terms were searched for in the title and abstract fields and controlled vocabulary terms were used where available. The Boolean operators AND and OR were used, alongside truncation. Where available, search limiters were applied to only retrieve studies published in English language since January 2001 onwards, following the first UK government guidance on implementation of services for caregivers of people with mental illness (Department of Health, 2001). The full search strategy, written up for MEDLINE is provided in Appendix 1.

2.3. Eligibility criteria

Studies eligible for inclusion in the review must have reported primary quantitative, qualitative, or mixed methods data, and have been published in English language between January 2001 and March 2017. Studies that reported participants aged 18 years or over, who were caring for a person who is an adult aged of 18 years or over with a primary diagnosis of a serious mental health problem were eligible for inclusion. Studies were excluded if the primary focus was on participants with: a physical health condition or a common mental health condition (unless comorbid to a serious mental health problem), palliative care, learning disabilities, substance use, dementia, or pharmaceutical interventions. The reported focus of the study must include; 1) the experience of caregivers, and 2) a transition between mental health services (including referral, admission, transfer and discharge).

2.4. Study selection

All papers were assessed for inclusion in the review based on their relevance using the eligibility criteria. The papers were independently screened by one reviewer (author 1) and to reduce bias, ten percent of papers were screened by a second reviewer (author 2). Screening for relevancy took place at title and abstract level, followed by a full-text reading of all remaining papers. Discrepancies were resolved by discussion.

2.5. Quality appraisal

The Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) was used to appraise and describe the quality of each of the included papers. It was chosen for its suitability to an integrative review because it comprises five sets of questions covering qualitative, quantitative and mixed method study designs. All of the included papers were appraised by one of the review authors (author 1) and three out of the eleven included studies were randomly selected to be appraised by a second reviewer (author 2). MMAT performance was not used to exclude studies from the review, the overall quality of each study is summarised and presented in Table 1.

2.6. Data abstraction and synthesis

Descriptive data were extracted from the studies and integrated into a matrix and included; author, year, country, study setting, study aims, sampling approach, study methods, study findings, and a quality appraisal summary (Table 1). A thematic synthesis was applied by two reviewers (authors 1&2). To achieve this, studies were divided into subgroups according to their study methodology: 1) qualitative studies, 2) quantitative studies and 3) mixed method studies, and were examined sequentially (Whittemore & Knafl, 2005). Quantitative studies were treated as a single subgroup because all included studies reported non-experimental designs.

Two reviewers (authors 1&2) independently analysed the qualitative studies to identify themes using an inductive process and followed by a shared comparison of themes to reach agreement

(Silva et al., 2013). A deductive process was then used to extract data from quantitative studies and one mixed method study using the identified themes as a framework (Grant & Graven, 2018).

3. Results

3.1. Study characteristics

The literature review screening process is summarised in Figure 1. The eleven included studies had all been conducted in high income countries (Table 1). Six studies reported qualitative designs (Gerson et al., 2009; Levine & Ligenza, 2002; Rose et al., 2007; Jankovic et al., 2011; Jones et al., 2009; Velligan et al., 2008), four non-experimental quantitative designs (Boye & Malt, 2002; Cleary et al., 2005; DelVecchio et al., 2015; Perreault et al., 2005) and one mixed methods (Gerson & Rose, 2012). Seven studies focused on both the caregiver and the person and included participants from both groups (Cleary et al., 2005; DelVecchio et al., 2015; Gerson & Rose, 2012; Rose et al.,2007; Jones et al., 2009; Perreault et al., 2005; Velligan et al., 2008). Four studies focused only on caregivers (Boye & Malt., 2002; Gerson et al., 2009; Levine & Ligenza, 2002; Jankovic et al., 2011).

The studies included caregivers from population samples of people living with psychosis or schizophrenia (Boye & Malt., 2002; DelVecchio et al., 2015; Gerson et al., 2009); people with unspecified ‘serious mental illness’ (Levine & Ligenza; 2002; Cleary et al., 2005) or specified as schizophrenia, bi-polar disorder and depression (Rose et al., 2007); a mixed sample of people with psychosis, mood disorders as well as people with non-psychotic disorders (including anxiety, depression and personality disorder) (Gerson and Rose, 2012; Jankovic et al., 2011; Perreault et al., 2005; Velligan et al., 2008) and a sample drawn from a larger study of people with a diagnosis of 1) psychosis and 2) non-psychotic mental illness (Jones et al., 2009).

The study settings included mental health; hospital services (Boye & Malt., 2002; Cleary et al., 2005; DelVecchio et al., 2015; Rose et al., 2007; Jankovic et al., 2011; Perreault et al., 2005; Boye & Malt., 2002), community services (Cleary et al., 2005), a transitional care community service (Velligan et al., 2008); and a community group (Levine & Ligenza, 2002).

3.2 Quality Appraisal

The qualitative studies reported small samples sizes; for example one study reported ten cases from the experiences of one nurse (Rose et al., 2007); were descriptive and did not outline (Levine & Ligenza, 2002; Velligan et al., 2008) or only party outlined (Gerson et al., 2009; Jankovic et al., 2011) a specific methodological approach. The process of analysis was clearly outlined in Levine & Ligenza, (2002) and the involvement of caregivers in the study design increased credibility and confirmability in the study by Jankovic et al., (2011). Recruitment of caregivers proved problematic in two of the studies; Gerson et al., (2009) were hampered by seeking to recruit caregivers and person receiving care living at the same address and Jankovic et al., (2011) only recruited caregivers with the consent of the person receiving care.

Four studies reported findings from descriptive quantitative study designs; none included a control (Boye & Malt, 2002; Cleary et al., 2005; DelVecchio et al., 2015; Perreault et al., 2005). The reported sample of caregivers was small in three of these studies and not clearly stated in Del Vecchio et al., (2015). Studies reported limitations in their findings due to high loss to follow up (Boye & Malt, 2002; Perreault et al., 2005) and recall bias (Cleary et al., 2005; DelVecchio et al., 2015; Levine & Ligenza, 2002; Jankovic et al., 2011; Jones et al., 2009). Reporting of the analysis was inconsistent with stated aim and method in two studies (Cleary et al., 2005; Perreault et al., 2005), was not fully outlined in DelVecchio et al., (2015) and was limited to descriptive percentages in Cleary et al., (2005). Two studies used non-standard measures that lacked content validity (Cleary et al., 2005; Perreault et al., 2005). Boye & Malt,

(2002) reported a more detailed method but reported high loss to follow up and low response rates for the acute care sample group. The mixed method study by Gerson & Rose (2012) was described as a pilot study with a small sample size, limiting the conclusions that can be drawn from the quantitative analysis, relying heavily on the qualitative data with no reported mixed method synthesis.

3.2. Results of the synthesis

The integrative qualitative synthesis resulted in four themes related to care transitions: 1) Caregiver information 2) Caregiver involvement in decisions about care and treatment 3) Accessing services 4) Being a caregiver.

Caregiver information

This theme focused on the exchange of information between services and caregivers, its content and timing. Transition points are a time of greatest need for information and yet caregivers described information as insufficient or non-existent (Levine & Ligenza, 2002). To ensure that caregivers are in possession of relevant information at transitions points, they needed information throughout their contact with mental health services (Gerson et al., 2009) and valued opportunities to discuss issues with the care provider (Velligan et al., 2008). Caregivers were frustrated when there were communication gaps between them and professionals but also when professionals did not communicate effectively with each other resulting in caregivers having to repeatedly provide up-to-date information (Jones et al., 2009). Caregivers understood the need for confidentiality but felt that it was unhelpful if practices to preserve confidentiality left them in the dark (Gerson et al., 2009; Jankovic et al., 2011). Equally, caregivers wanted to share information with professionals but had concerns about adverse effects on their family relationships (Jankovic et al., 2011).

At the onset of a crisis, families wanted more information about; how to manage the illness (Gerson et al., 2009); the diagnosis (Jankovic et al., 2011), and experienced frustration if there was no definitive diagnosis (Gerson et al., 2009). It was helpful when the information provided about prognosis reassured them that the person "can become well" (Gerson et al., 2009; p.5). Families asked for information that helped them understand the evolution of the person's health, how to prevent hospitalisation, and warning signs of relapse (Perreault et al., 2005).

At discharge, Cleary et al., (2005) reported that 75% of carers found discharge information unhelpful and that caregivers were given less information than the person. Families placed great importance on information sharing and this was sometimes hampered by services being unclear about the status of the caregivers in the care of the person (Jones et al., 2009). To provide optimal care and manage risk at home, family members needed to both receive information in ways they could understand (Jankovic et al., 2011; Velligan et al., 2008) and be listened to by professionals in order to avoid valuable information being lost (Jones et al., 2009).

Knowing the date of discharge and having information about follow-up care after discharge were more important to the caregiver than **to** the person (Perreault et al., 2005). One study found that caregivers were unable to describe follow-up care beyond the medication, suggesting that the information they had was incomplete (Gerson et al., 2012). When caregivers were asked what information they wanted at discharge, they asked for information about the discharge process (Jones et al., 2009); how to access a GP, training and employment opportunities, housing issues, information about physical health, advice about maintaining relationships with family and friends (Cleary et al., 2005); and services for relatives (Perreault et al., 2005). Psychoeducation groups were helpful in meeting some information needs (Levine & Ligenza, 2002) however information about medication, particularly about side effects and treatment options, was felt to be best provided by the doctor rather than the pharmacist (Velligan et al., 2008). Caregivers found the opportunity to attend information giving sessions about mental health alongside written information about discharge processes and community health services helpful (Cleary et al., 2005).

Involvement in decisions about care and treatment

This theme describes caregivers' experiences of involvement and the responsibilities taken by caregivers during transitions in care. Caregivers required information before they could be meaningfully involved in treatment decisions and their involvement should occur throughout the person's care (Gerson et al., 2009; Rose et al., 2007; Velligan et al., 2008). Despite this, from a sample of 50 caregivers, 32% were involved in decisions about medication; 40% about decisions at discharge from hospital and 35% were not involved or contacted at all (Cleary et al., 2005). A lack of involvement was of greater concern to caregivers than to the person and as a result, caregiver satisfaction with services scored lowest where there had been no communication with them (Perreault et al., 2005). A lack of involvement left caregivers feeling abandoned by services until the next crisis (Jones et al., 2009) and they described being given too much responsibility for the care of the person at home, particularly where they had no involvement in treatment or discharge decisions (Jankovic et al., 2011).

Caregivers described disagreements with professionals, but most accepted professional decisions despite their reservations, and accepted an "unchanged situation with a tone of resignation, frustration and discouragement" (Gerson et al., 2012; p. 268). They also felt compelled to take on responsibility for providing care after discharge because their refusal could mean a more restrictive care option for the person (Jankovic et al., 2011). Caregivers believed that the person should have been admitted to hospital sooner and stayed in hospital longer; that at discharge the person was more unwell than professionals acknowledged; and that more support from services should be provided than was on offer (Jones et al., 2009).

Where continuity of care enabled relationships with professionals to be maintained through the transition, caregivers reported a greater sense of safety. They reported that transitions were most successful where professionals had "dovetailed" across the transition (Jones et al., 2009; p.636) and knew the person and their circumstances (Velligan et al., 2008). Conversely, a change of key worker at transition points was considered problematic (Jones et al., 2009) especially when this resulted in care being fragmented (Gerson et al., 2009). Family members described themselves as providing continuity when case managers "come and go" and effectively took on the role of "de facto case manager" (Levine & Ligenza, 2002; p. 349).

Involvement in discharge planning was important for caregivers to enable them to influence decisions and understand follow-up care (Velligan et al., 2008; Perreault et al., 2005) yet less than one third of caregivers were satisfied with discharge planning (Cleary et al., 2005). When asked about discharge planning, caregiver's placed higher importance than the person on the timing of the discharge, out-patient follow-up, management of medicines and the location of their discharge residence. The person placed the highest importance on services offered to support their caregivers (Perreault et al., 2005). The person was more confident than the caregiver that they were able to manage at home (Velligan et al., 2008) and caregivers were more confident than the person that they would be able to contact a service in response to changes in the person's mental health (Cleary et al., 2005). Medication changes at discharge were a source of conflict (Jones et al., 2009) and some caregivers felt that a lack of detailed medication information hampered their ability to contribute to decisions (Velligan et al., 2008).

Access to services

This theme describes caregivers' experiences of accessing mental health services. Transitions initiated by caregivers in these data were exclusively admissions to hospital; none were discharges. The responsibility for accessing health care for family members experiencing mental health problems often fell to family members. When family members sought help, they experienced frustration with the mental health system due to a number of barriers preventing access that is timely or appropriate to need (Gerson et al., 2009; Velligan et al 2008; Jankovic et al., 2011). Only two carers from a sample of 29 described a positive experience of accessing mental health services (Gerson et al., 2009).

Caregivers described needing most help early in the episode of mental ill health (Gerson et al., 2009) yet when seeking help carers described difficulties with knowing how to locate services, how to reach them (Velligan et al., 2011), arranging appointments and getting the person to attend them (Gerson et al., 2009). Furthermore when services were contacted, caregivers described being turned away because the person was too sick (Gerson et al., 2009) or conversely voluntary hospital admissions were delayed by professionals, leaving caregivers feeling that a later involuntary admission was inevitable (Jankovic et al., 2011). Economic pressures and insurance led health economies caused people to be turned away because of problems with their insurance, programmes going out of existence or the service taking no new referrals (Gerson et al., 2009). Some caregivers found that even when appointments were arranged, services did not keep the appointment or directed them from one service to another without clear guidance, leaving the caregiver unclear where to go for help (Jankovic et al., 2011).

Families described feeling invisible if the person was deemed to be well or stable by services and described services responding to crises rather than preventing them (Jones et al., 2009). Caregivers were dissatisfied with management of crisis situations and approaches used to prevent hospital admission (Perreault et al., 2005). When a hospital admission was arranged, family members found getting the person to hospital difficult (Gerson & Rose, 2012).

Being a caregiver

This theme describes caregivers' experiences of delivering care, coping with the burden of care and accessing caregiver support. Transitions were experienced as the most stressful time; measurement of psychological responses to hospital admission in relatives showed that admission with acute psychosis caused higher stress responses, levels of avoidance and intrusive thoughts than experienced by relatives of people with less acute psychosis (Boye & Malt, 2002).

Family members struggled with conflicting emotions linked to the relief they felt that the person had been admitted to hospital (Jankovic et al., 2011) and described hospital admission as their "cry for help too" (Gerson et al., 2009; p. 4). The process of diagnosis and hospitalisation caused traumatic feelings of guilt (Gerson et al., 2009: Jankovic et al., 2011) worry (Jankovic et al., 2011), fear the person would be hurt especially when the police were involved (Gerson et al., 2009), anger (Jankovic et al., 2011) confusion, sadness, helplessness, frustration, isolation and feeling overwhelmed by their responsibilities (Levine & Ligenza, 2002). Despite this, families reported few systematic efforts to provide them with support. Some caregivers experienced negative attitudes from professionals and this led to a perception that the family were part of the problem rather than the solution (Levine & Ligenza, 2002).

Both before and after hospital admission, caregivers described struggling to cope with the person's irrational and destructive behaviour (Levine & Ligenza, 2002). The behaviours caregivers found most challenging were; self harm; violence; a lack of insight, non-adherence to treatment; and the person's inability to manage independently (Levine & Ligenza, 2002; Rose et al., 2007). Several caregivers reported that they had been the target for aggressive language and behaviour (Rose et al., 2007). Caregivers described symptoms as "ongoing and unremitting" (Gerson et al., 2012; p.268), and the person's impaired decision making, poor judgement and impulsivity impacted on relationships between family members (Rose et al., 2007). Caregivers focused on keeping the person safe including from self harm (Jones et al., 2009) or from violence from others due to difficult behaviours outside the home (Rose et al., 2007).

Immediately following discharge from hospital, caregivers struggled to support the person to adjust from the routine of hospital to having no structure at home (Jones et al., 2009). At this time, caregivers supported the person with managing money (Gerson et al., 2012) and their prescriptions, although polypharmacy caused caregivers difficulties that they struggled to talk with the person about, especially when the person refused to take prescribed medicines (Gerson & Rose, 2012; Rose et al., 2007). Caregivers reported that the supported use of checklists and calendars to help structure behaviour at home (Velligan et al., 2008) and access to community based psychosocial support (Cleary et al., 2005) were helpful.

4. Discussion

This integrative review aimed to investigate what is known about the experiences of caregivers of people living with serious mental health problems during transitions between adult mental health services. Only tentative conclusions can be drawn about caregivers' experiences during service transitions due to the low overall quality of the evidence reviewed. This is reflective of the overall limited research into caregivers of people with serious mental health problems. This is the first review of caregivers' experiences of transitions between adult mental health care settings. The findings show that many of the issues faced by caregivers during care transitions have been described previously (Ganguly et al., 2010; Goodwin & Happell, 2007; Awad & Voruganti, 2008). The findings from the review confirm the importance of the policy emphasis on providing more support during service transitions (NHS England, 2014a; NHS England, 2014b; NICE, 2016) and suggest that caregivers' experiences are not substantially different during transitions to their broader experiences as caregivers but that their role is more challenging and their experiences amplified. This suggests that interventions designed to support caregivers during service transitions may not need to be substantially different but would need to be intensified and well timed as previously described (Slade et al., 2007; Olasoji et al., 2017). As well as an increase in support during service transitions the review has identified that caregivers' experiences of transitions are improved by more global improvements in engagement and information sharing throughout their contact with mental health services.

Caregivers' need for information is widely acknowledged in health policy and practice guidance. This review shows that specifically during transitions, caregivers describe a lack of information as a barrier to both their involvement in decisions and ability to provide care. Descriptions of caregivers trying to cope with the person's distressed behaviour leading up to an admission and after a discharge demonstrates a need for interventions to equip caregivers to manage self-harm and aggression, and maintain safety and family relationships.

Caregivers were able to articulate what information they wanted, for example about diagnosis, treatment (especially medication), caring for somebody experiencing distress, and how to access help, especially in a crisis. What remains unclear is at what point this information would be most useful for caregivers; in preparation for a transition, directly after a transition, or more generally. The timing of information sharing is of particular importance during service transitions because of the greater likelihood of changes in the person's health status, their treatment and care workers. The review identified that caregivers ask for information throughout the delivery of care, not only at transition points suggesting that information sharing needs to be both constant and focused on specific information needs at transition points, especially where there are changes in treatment or the care team. In recovery focused approaches to care, caregivers as well as the person, are engaged as full members of the care team and thereby, through a cooperative process, facilitate effective information sharing (Fox, 2017). In addition, previous research has identified group peer support as an important mechanism in improving knowledge acquisition amongst caregivers (Petrakis et al., 2012).

Concerns about confidentiality create a two-way barrier to information sharing between caregivers and professionals during service transitions and is evident throughout caregiver research (Albert & Simpson, 2015; Olasoji et al., 2017; Fox, 2017). On one hand, caregivers express concern that divulging information poses risks to relationships and may diminish trust. On the other hand, professionals describe a lack of confidence in sharing information with caregivers (Rapaport et al., 2006; Poon et al., 2018). This is despite the availability of a range of published guidance for both professionals and caregivers about ways to manage information without compromising regulations about confidentiality (Slade et al., 2007; Rethink Mental Illness, no date; Royal College of Psychiatrists, no date), suggesting incomplete implementation of guidelines into practice and may indicate a training need for both professionals and caregivers.

Ways to provide information and support to caregivers that do not infringe confidentiality could be supported by service protocols or advance statements that would allow the person accessing services to determine what level of information they want to be shared (Rethink Mental Illness, no date). Providing interventions that are focused on the caregivers' own needs may enable support during times when information sharing is limited by the decisions of the person; this may help to avoid feelings of abandonment that caregivers describe (Slade et al., 2007). In a crisis situation, caregivers who are informed and engaged in the plan of care could initiate the crisis plan, although there are gaps in understanding about caregivers experiences of crisis care and how best to involve them in joint crisis planning (e.g Farrelly et al., 2014).

The difficulties in securing the information caregivers perceived they needed also served as a barrier to involvement. Caregivers are often experts in the persons' past history and current symptoms and may have a valuable contribution to make to the planning and delivery of care. Despite this, many caregivers perceived professionals as dismissing or ignoring them, as found in previous research (Askey et al., 2009; Lyons et al., 2009; Katsikitis et al., 2017) and some perceived that they were even covertly blamed for the person's ill health (Repper et al., 2008). Clinical guidelines for psychosis and schizophrenia and recovery orientated practice (e.g NICE, 2014a; Australian Government Department of Health, 2014) already recommend the involvement of caregivers who are often the single point of contact other than the person themselves. Involvement of caregivers is especially important around times of transition as they provide continuity when the professionals involved may change. One of the factors that led to greater involvement of caregivers during transitions was continuity of professionals. The likelihood of changes to professionals involved was greater at transition points and meant that caregivers were constantly repeating information and nobody could develop supportive relationships. Partly as a result of necessity, caregivers often acted as de facto care managers as they provide the only continuity. If care systems continue to be unable to provide this continuity then it is all the more important that caregivers are better informed, involved and supported.

Involving caregivers has been reported in previous research to lead to better planned care (Cree et al., 2015; Coffey et al., 2017). The data showed that caregivers often disagreed with professional decision making and this might be as a result of not having the requisite information and not being meaningfully involved. Interventions to improve relations between professionals and caregivers would be of particular benefit in supporting both the sharing of information and promoting involvement. Caregivers having access to training about recovery has shown some promise in improving experiences of collaborating with professionals (Fox et al., 2015).

Family-based interventions, including family psychoeducation, are embedded in guidance and policy in the treatment of serious mental health problems (NICE, 2011, NICE, 2014a; NICE, 2014b), but they are poorly implemented (Kuipers, 2011; Bucci et al., 2016) and not embraced by professionals (Olasoji et al., 2017). Data has shown that family-based interventions reduce rates of relapse (Bucci et al., 2016) thereby reducing the likelihood of hospital admission (and therefore the number of service transitions), and have also been shown to reduce caregiver burden (Ma et al., 2017). Family approaches may also provide a way to support both caregivers and the person, who do not always have the same needs (Albert & Simpson, 2015; Coffey et al., 2017).

What remains unclear is if family-based interventions can be delivered across transition points, especially where the person has experienced deterioration in their mental health or a change of care workers. There may therefore, be value in research designed to explore tailored family-based interventions at times of service transition. Attention must however be paid to effective implementation of any such intervention to avoid the implementation gaps in family based interventions reported internationally for some time (Poon et al., 2018).

The support needed by caregivers for themselves during these transition periods was little discussed. The descriptions of the negative emotions that caregivers experienced shows the psychological impact of providing care for a person with serious mental health problems and there were scant reports of attempts to support them. For example, previous research has identified that professionals fail to acknowledge the sense of loss (non-death related) experienced by family caregivers (Rose et al., 2006) with professionals focusing on practical rather than emotional support (Lloyd & Carson, 2005). Recovery colleges have a role in supporting caregivers and evidence suggests that providing caregiver training and support with a hopeful recovery focus can reduce the distress caregivers experience (Fox et al., 2018) and may provide skills and knowledge that caregivers can draw upon during care transitions.

Caregiver involvement cannot be imposed on an unwilling person but must be negotiated so that the person can make an informed decision about the extent to which they would like their caregiver involved in decisions about their care. There may be legitimate reason for the person rejecting the involvement of a caregiver in cases of relationship breakdowns, including as a result of a breach of trust, or where there is abuse. However, it seems that often caregivers are not even identified and indeed do not self-identify (Worthington et al., 2013) so clarification of their presence and role as early in the contact with the person would go some way to avoiding their exclusion.

There was little information in the studies about the impact on caregivers' broader social and economic lives as have been reported elsewhere (e.g Awad & Voruganti, 2008; Lloyd & Carson, 2005). More specifically, the fluctuating nature of mental ill health is not discussed in these data, when a person is required to manage a crisis how they accommodate this in terms of employment and other family members and how they could be best supported with this, particularly over time.

Implications of the review

Whilst on one hand it is reassuring that the experiences are needs of caregivers during care transitions are mainly an amplification of experiences that are already known. On the other hand, it is concerning that despite our existing understanding; it seems that there is little improvement in the experience of caregivers evident in this literature. The identification of caregivers and their role at an early stage of engagement in services may help to improve the exchange of information and increase meaningful involvement at all stages of care. Providing information to family and friends about caregiving that is contextualised to mental health may support caregivers to identifying themselves as caregivers earlier, enabling more timely and effective identification of their needs.

Professionals and commissioners need to consider service designs that enable continuity of care workers or where this is not possible, provide dovetailing of care workers across transitions. Caregivers often provide continuity across transitions when services and care workers change, improved recognition of the importance of this role may enable the caregiver and the person to have improved experiences.

Given the existing availability of guidance about managing information sharing whilst managing concerns over confidentiality, there is a pressing need to understand barriers to implementation. The use of information sharing policy and guidance that is easily accessed in practice has been reported as helpful to professionals, especially when faced with dilemmas around ethical boundaries and professional responsibilities (Slade et al., 2007). Gaps in implementation of information sharing may be closed by delivering co-designed training for professionals, service users and caregivers as advocated by Grundy et al., (2017). Recovery colleges may provide a mechanism for the co-design and delivery of such training.

Caregivers do not always have the same needs as the person they care for, making it important to deliver care that ensures both are supported and their rights upheld. There is a need to understand the implementation gaps for family-based interventions and how these may improve experiences at transition points. There are gaps in understanding about the impact of transitions, as they are associated with periods of intense activity for caregivers, particularly around their social and economic life and the wellbeing of the caregiver themselves.

5. Strengths and limitations

The strength of this review is its specific focus on caregivers of people living with serious mental health problems during service transitions. This is an important area of focus because of the increased risks to the wellbeing of the person and caregiver already identified in health policy and practice guidance. The review has provided an overview of the experiences of caregivers during care transitions but conclusions drawn are tentative with regard to intervention and service design. The review has provided evidence of gaps in understanding of aspects of caregivers' experiences and the barriers to implementation of family based interventions. The review may not be fully comprehensive due to publication date and language limits being applied as well as studies being difficult to locate due to the limited evidence available focused specifically on transitions. The review may have been strengthened by including a wider literature focused on caregivers in adult mental health enabling extraction of data about care transitions from studies where this was not the sole or primary focus. There is also a need to establish more detailed understanding of issues for caregivers related to type of transition and the impact of the multiple transitions in care over time often associated with adult mental health services, not possible with these data; suggesting gaps in the published evidence.

Only a proportion of screening, appraisal and data extraction processes were carried out by two reviewers. The findings resonate with other reviews of caregivers experiences and many of the included studies struggled with recruitment of caregivers resulting in small sample sizes as noted in this field previously (e.g Fox, 2017).

6. Conclusion

Caregiver's of people living with serious mental health problems report increased levels of stress during service transitions. Their need for information and involvement in decisions is amplified as they may provide the only continuity during a time when professionals, services and treatments change. Concerns over confidentiality continue to be reported as a barrier to information sharing and involvement despite the availability of guidance suggesting a need for more effective training and a focus on implementation. There is a need for professionals to develop more consistent approaches to providing support, including a focus on emotional needs, alongside information for caregivers when the person has refused caregiver involvement, especially at care transitions. Despite evidence of their efficacy, family-based interventions have been inconsistently implemented and may need to be adapted for implementation across care transitions. Recovery orientated practice may provide a mechanism enabling caregivers to become integrated into the care team and peer group support may improve knowledge acquisition amongst caregivers although these have not been evaluated as part of transitional care. The review identified that little is known about the impact of care transitions on caregivers' themselves or how they manage the fluctuation in the person's mental health at times of transition.

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Table 1 Summary of included studies

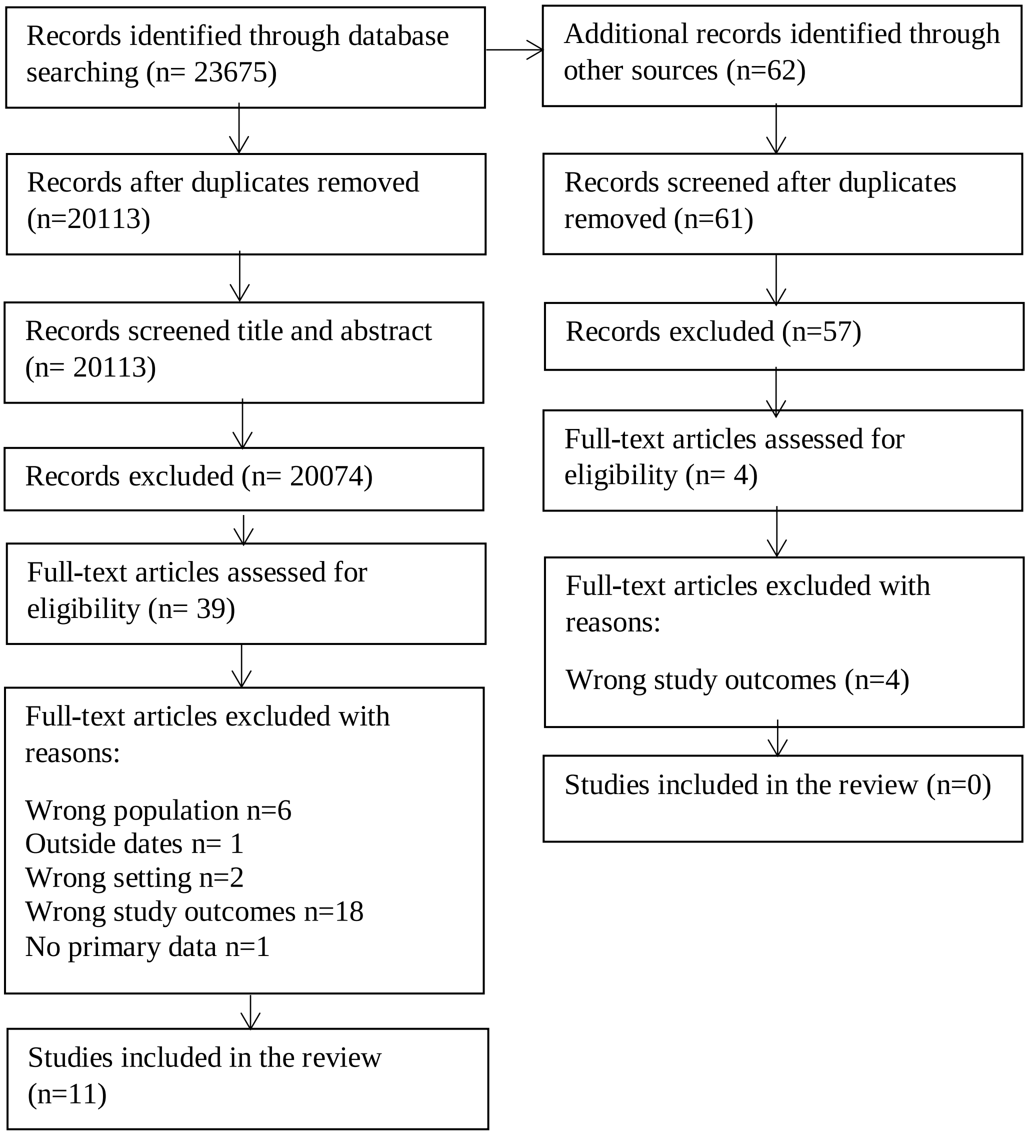
Author, Year, Location	**Study Purpose**	**Method/design**	**Findings**	**Quality Appraisal (MMAT)**
Qualitative Study Designs				
Gerson et al., (2009) USA	To understand from families of individuals with recent-onset psychosis, how services could be improved.	Population: Family members (n= 14); 4M , 10 F two psychiatric services in one city. Sample: Convenience Design: Qualitative interview with thematic analysis.	Family frustrations with the mental health system; traumatic experiences of diagnosis and hospitalisation; stigma of psychosis; family frustration after discharge; family need for information about managing crisis.	Methodology not fully outlined. The findings are not presented as themes.
Gerson et al., (2009) USA	To understand from families of individuals with recent-onset psychosis, how services could be improved.	Population: Family members (n= 14); 4M , 10 F two psychiatric services in one city. Sample: Convenience Design: Qualitative interview with thematic analysis.	Findings described in five areas: family frustrations with the mental health system; traumatic experiences of diagnosis and hospitalisation; stigma of psychosis; family frustration after discharge; family need for information about managing crisis.	Methodology not fully outlined. The findings are not presented as themes.
Jankovic et al., (2011) UK	To explore family caregivers experiences of involuntary admission and treatment	Population: Carers (n=29); 12Mand 19F, 12 psychiatric hospital sites in England. Sample: Purposive Design: Qualitative in-depth interviews.	Four themes: relief and conflicting emotions in response to the admission; frustration at delay getting help; being given the burden of care by services; difficulties with confidentiality.	Recall bias due to time between admission and research interview. Selection bias and recruitment issues. Involvement of carers contextualised the data.
Rees-Jones et al., (2009) UK	Experiences of service users and carers of meanings associated with (dis)continuities and transitional episodes over illness career.	Population: 14 carers (3M & 11F);7 community mental health teams. Sample: Purposively identified from study sample of 278 participants. Design: Qualitative interviews with thematic analysis	Five themes: relational (dis) continuity; depersonalised transitions; invisibility and crisis; communicative gaps; social vulnerability;	Study not solely focused on carers some findings cannot be clearly attributed to carer experiences.
Levine & Ligenza (2002) USA	Needs of caregivers of people with serious mental illness during times of transition and crisis.	Population: 55 caregivers (2:1 F) from two counties in one state. Sample: Purposive	Five themes: life before and after; something is wrong; ravaging effects of serious mental illness; toll mental illness	Limited focus on one support group in USA. Some conclusions not linked to the findings.

		Design: Six qualitative focus groups with thematic analysis.	takes on the family; family perspectives on mental health system.	
Velligan et al., (2016) USA	Experiences of patients and caregivers of shared decision making during transitions in psychiatric care.	Population: 8 carers (2M & 6F) from a transitional care out-patient unit. Sample: Purposive Design: 2 focus groups. Constant comparative analysis.	Four themes: attitudes of providers toward patients; access to mental health treatment; decision making in mental health care; experiences with psychosocial treatment.	Study aims not clearly stated. Some issues related to insurance led health economy resulting in limited transferability.
Velligan et al., (2016) USA	Experiences of patients and caregivers of shared decision making during transitions in psychiatric care.	Population: 8 carers (2M & and 6F) from a transitional care out-patient unit. Sample: Purposive Design: 2 qualitative focus groups for carers constant comparative analysis.	Four themes: attitudes of providers toward patients; access to mental health treatment; decision making in mental health care; experiences with psychosocial treatment.	Study aims not clearly stated. Some issues related to insurance led health economy resulting in limited transferability.
Rose, Gerson & Carbo (2007) USA	To test the applicability and feasibility of transitional model of care (TMC) and the effects of TMC on patients' and family	Population: 10 female caregivers from one inpatient unit. Sample: Purposive Design: Qualitative case study design drawn from the caseload of one nurse. Documentary analysis to identify themes.	Four themes: caregiver concerns/health status; lack of structure and involvement in daily activities; structural and functional factors affecting adherence; presence of symptoms at discharge.	Results based on the reports of one nurse. One study site. Not clear that the study meets any of the stated aims in full. Qualitative research methods do not state a methodological approach or design.
Quantitative Study Designs				
Boye & Malt (2002) Norway	To compare relatives stress responses to hospital admission.	Population: Caregivers from acute and chronic mental health services (n=36) from a psychiatric hospital in one area. Sample: Prospective purposive Design: Cross sectional Measures: Postal survey; 4 psychometric questionnaires to measure stress and general health.	Relatives of acute psychosis at admission show high stress responses and high levels of avoidance and intrusive thoughts.	Small sample, high loss to follow-up. Recruitment approach may have been biased towards most impaired in acute sample creating artificially large differences between the two groups.
Cleary et al., (2005) Australia	To identify information and resources considered important by patient and carer at discharge.	Population: Caregivers from one inner city acute and community service (n=50). Sample: Random	Patients are willing to have carers involved Most carers not provided with mental health information and were less confident than the	Randomisation not described. Analysis is limited to percentage responses to Likert type scale. Psychometric

		Design: Cross sectional survey. Measures: Postal and face-to-face survey, descriptive analysis.	patients about managing in the community. More information needed about what to do when the person becomes unwell, medication and side effects, and community resources.	properties of bespoke measures unknown. Comparisons between groups lack statistical rigor. Recruitment problems and recall bias.
Del Vecchio et al., (2015) Italy	Relatives involvement in help seeking and family-related factors influencing delay in referral.	Population: 34 patients from one out-patient department. Sample: Purposive Design: Cross sectional Measures: Face-to-face questionnaire, clinical interview to confirm diagnosis followed by BPRS, Nottingham onset of symptoms and bespoke Pathways to Care form. Descriptive analysis.	Improved relatives understanding of psychosis Effect of psychoeducation relatively unstudied in early psychosis. Pathways to care may be improved by: information campaigns to improve the general population understanding of schizophrenia and provision of psychiatric consultations for young people.	Recall bias, small sample, single site, no comparator. Analysis is not fully outlined. Small sample of patients (n=34) and unstated number of relatives.. Although stated aim to explore the role of relatives, the data presented is focused on the patients.
Perreault et al., (2005) Canada	To evaluate contact between relatives and clinical staff, to document patient and family preferences regarding involvement and to examine satisfaction with family involvement in discharge planning.	Population: 40 relatives (54% female) from adult psychiatric services in one sector hospital and out-patient department in one city. Sample: Purposive Design: Prospective cross sectional. Measures: Face-to-face interview during short hospital admission and 2 months after discharge. Two bespoke questionnaires measuring preferences and satisfaction. Descriptive analysis using % and ranks.	Relatives lower satisfaction with discharge planning than patients. There are differences in in preferences between relatives and patients. Both groups expressed low levels of satisfaction in management of crises, hospital avoidance Increased involvement of relatives associated with higher satisfaction for patients and relatives.	Loss to follow -up large. New recruited relatives not identified as part of the analysis in second measure. Analysis is not clearly outlined and is limited to description. Consensus ranking is used in the analysis but was not outlined in the methods. Questionnaires were bespoke and had limited content validity.
Mixed Method Study Designs				
Gerson & Rose (2012) USA	To explore illness related needs, coping, satisfaction with care and social support of people with serious mental illness and their families in the first 4	Population: Family members (n=10) from one inpatient psychiatric unit Sample: Purposive Design: Pilot mixed method study. Open-ended interviews	Differences between patients and families. Patients satisfied with focus on medicines management but family wanted more. Families concerned that patients reverted	Small sample size. Participants represented a particularly challenging and treatment resistant group. Analysis of diary data is not

	weeks after inpatient treatment.	and quantitative measures of illness severity and coping. Measures: Baseline within 48 hours after discharge-BPRS, Families kept weekly diary of mental illness related concerns. Quantitative data analysed using descriptive statistics. Qualitative data thematically analysed and coded.	to pre-hospital inactivity and isolation. Families unaware of goals set by services. Patients felt supported by family members. Families were discouraged and burdened by caregiving role and lack of support from services.	outlined. No mixed method synthesis.

Figure 1 PRISMA Flow Diagram



(Liberati et al., 2009)