Expert views of children's knowledge needs regarding parental mental illness

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ABSTRACT

Children of parents with a mental illness are at significant risk of developing a mental illness. This risk may be reduced if appropriate interventions are provided that include information and knowledge about mental illness. While there are some interventions for children of parents with a mental illness, research is lacking about the type of mental health information children need and why they need that knowledge. This study presents the perspectives of a purposive sample of international research experts in the field of parental mental illness about the kind of mental health literacy information children with parents with a mental illness need. Twenty-three participants completed a self-constructed short answer questionnaire about the knowledge needs of children of parents with a mental illness. The qualitative data indicates that 'identifying information', 'making sense of parents' behaviour', 'coping better' and 'respecting safety' are key knowledge needs of children. Given the views presented, these findings suggest that health care professionals should advocate for policies that support individual-, peer-, and family-focused programs driven by strong evaluation and rigorous research. If this is done, children of parents with mental illness may experience 'myth busting' of incorrect information about mental illness.

1. Introduction

Children with a parent with a mental illness (COPMI) compose a large, at-risk group that receives little to no attention within mainstream mental health services. In a health care database study supported by the National Research Council and the Institute of Medicine of the National Academies (England & Sim, 2009), over 20 million American minor children were found to be living with a parent who had a singular diagnosis of major depressive disorder. An Australian national health care data base study identified that one in five children had a parent with a mental illness (Maybery, Reupert, Patrick, Goodyear, & Crase, 2009). Children reported living in a family with “good days and bad days” as parental symptom levels decreased (good days) and increased (bad days) for disorders such as anxiety, depression, bipolar disorder, schizophrenia, and borderline personality (Riebschleger, 2004). Despite their daily interface with parental mental health symptoms, COPMI tend to have low levels of mental health literacy. Mental health literacy is an individual's level of knowledge and attitudes about mental health conditions and the ability to prevent, recognize, and manage these conditions (Jorm, Christensen, & Griffiths, 2006; Jorm et al., 1997). Mental health literacy constructs also include an individual's knowledge of using coping skills to counter psychological distress. As children and adults, COPMI say they have insufficient access to accurate, non-stigmatized, information about mental health disorders and recovery (Bilsborrow et al., 2015; Mordoch, 2010).

This exploratory qualitative study offers new knowledge about COPMI specific mental health literacy content needs for school age children and the purposes of the information. Data are drawn from a survey sample of international experts who study the circumstances of children and families with a parent with mental health disorder. It is anticipated that the findings can help to inform resources, support, and intervention development for families that have a parent has mental health disorder.
2. Background literature

2.1. Risk

COPMI are a disadvantaged group with increased risks throughout their lives including a higher likelihood of the development of mental illness, reduced utilization of mental health services, increased stigma encounters, and an elevated risk of developing maladaptive coping skills (Beardslee, Versage, & Gladstone, 1998; Fraser & Pakenham, 2009; Rasic, Hajek, Alda, & Uher, 2014; Reupert & Maybery, 2010; Riebschleger, Tableman, Rudder, Onaga, & Whalen, 2009). These children and their families also face increased life stressors related to interactions with the legal system, family relational struggles, increased caregiving activities, and parent-child separations (Cooklin, 2006; van Santvoort, Hosman, van Doesum, & Janssens, 2014). COPMI have higher genetic and social environment risks for acquiring a mental health disorder when contrasted with children in the general population (Rasic et al., 2014). One of the most concerning COPMI risks is their likelihood of being diagnosed with their own mental illnesses, particularly as they develop into adolescents and adults. The risks of developing a mental illness increase if a parent's diagnosis includes a personality disorder and/or a co-occurring substance abuse or addiction disorder (Van Santvoort et al., 2014). The risk of a future diagnosis increases drastically if a parent is diagnosed with a more severe form of mental illness; then the risk of mental illness acquisition increases to 55% for any mental illness and 32% for severe mental illness (Rasic et al., 2014). Additionally, the risk of a future diagnosis and increased mental illness severity increases if both parents are diagnosed with mental illnesses (Rubovits, 1996). Parental mental illness also increases the risk that children will exhibit above average levels of internalizing and externalizing behaviours which may lead to the development of psychiatric disorders later in life (Van Loon, Van de Ven, Van Doesum, Witteman, & Hosman, 2014).

2.2. Children’s experiences of living with a parent with a mental illness

Adolescent caregiving for a parent struggling with mental illness is one of the major experiences facing COPMI within their family system (Cooklin, 2010; Gladstone, Boydell, Seeman, & McKeever, 2011; Trondsen, 2012). COPMI adolescents sometimes become caretakers and managers of their households. Adolescence is typically a time in which the developing individual acquires independence from their family systems and strengthens peer relationships (Collins & Steinberg, 2006). However, COPMI adolescent caregivers are often isolated from others and sometimes face increased risk of abuse and neglect (Campbell et al., 2012; Sheehan, 2004). They are rarely acknowledged for their difficult role and they may not completely grasp their complex contributions to the functioning of their family system (Cooklin, 2010). Some are described as “young carers”; this means that they are often responsible for maintaining their homes, preparing meals, as well as helping their parents to take their medications and adhere to treatment regimens. COPMI report feeling that they must increase the amount of caregiving on “bad days” when parental mental health disorder symptoms increase (Riebschleger, 2004).

In addition to their responsibilities as young caregivers, many COPMI also encounter feelings of blame, stigma, and embarrassment associated with parental mental illness (Gladstone, Boydell, & McKeever, 2006; Gladstone et al., 2011; Reupert, Cuff, & Maybery, 2015; Reupert & Maybery, 2010). Many COPMI adolescents reported hiding their experiences from others in their social spheres and the community. Some report feeling embarrassed about their family and say that they keep the family's struggles with mental illness a secret; these secretive behaviours may lead to an increase in social isolation and a lack of peer support (Mordoch, 2010). Social isolation is a recurring theme in the challenges faced by adolescent COPMI (Campbell et al., 2012; Foster, McPhee, Fethney, & McCloughen, 2014; Mordoch, 2010). This isolation may be rooted in multiple factors including caregiving responsibility and feelings of shame and embarrassment.

2.3. Resilience

Exposure to developmental risks, such as parental mental illness, does not mean a child will always develop psychopathology. Most COPMI do not acquire diagnosable mental health disorders (Rasic et al., 2014). The presence of resilience, and resiliency-promoting factors, may reduce the likelihood that children that are exposed to psychosocial risks will experience maladaptive psychological development (Rutter, 1993). These factors include the presence of supportive relationships, coping skills, positive relationships between parents, and higher socio-economic status. Additionally, resiliency comes from learning how to handle risk with appropriate support or coping skills; it is a process of positive adaption in the face of adversity. Children exposed to some developmental risk may become better adjusted to dealing with future adversity (Rutter, 1993). However, when risk levels are overwhelming and enduring, children may be unable to build resistance. They may face increased mental health and behavioral difficulties. COPMI resiliency for overcoming adversity is associated with higher levels of coping, self-esteem, mental health knowledge, and inoculative exposure to tolerable levels of risk (Rutter, 1993; Zimmerman, 2013).

Rutter (1987, 1993) uses a challenge model, in which early encounters with risk in smaller doses prepare the developing person to overcome larger difficulties later in life. Additional resiliency theorists identify protective models as a way that children learn to navigate adversity because of the presence of mediating factors that increase individual coping skills (Zimmerman, 2013). These mediating factors include “compensatory factors” and “protective factors” (Zimmerman, 2013, p. 2–4). Compensatory factors are a form of resiliency that help children counteract the negative effects of the encountered risk and adversity. Protective factors, such as increased mental health literacy, improved coping, and positive adult relationships can provide the skills to help children avoid symptoms of mental illness. These stressors must be challenging enough that children build necessary coping skills to overcome future adversity. However, the scenario must not be so difficult that it overwhelms the children’s coping strategies and leaves them traumatized (Zimmerman, 2013).

For example, while COPMI face increased stressors in relationship to the responsibility of caring for their ill parent(s), they have also reported perceptions of developing an earlier emotional maturation and a stronger sense of empathy from their time caring for their parents (Fraser & Pakenham, 2009). In caregiving roles COPMI contribute to their family functioning and need access to knowledge about parental mental illness and personal coping to assist in navigating this complex role (Day, 2008). Accurate, nonstigmatizing information about mental health and recovery may serve as a developmental protective factor for COPMI (Day, 2008).

2.4. Children of parents with a mental illness and mental health knowledge

Despite the fact that many COPMI deal with parental mental health issues regularly within a family setting, they may not have much information about mental illness or recovery (Mendenhall, Frauenholtz, & Conrad-Hieber, 2014). Riebschleger, Onaga, Tableman, and Bybee (2014) asked parents about their children's mental health knowledge; parents noted that their children had very little mental health knowledge other than that gleaned from the media. Much of what COPMI know can be incorrect, such as assuming people with mental illness look physically aberrant, have low cognitive abilities, and/or are dangerous people to be avoided; COPMI may report that they have not talked about their parent's illness within the family and/or with others (Riebschleger et al., 2009).
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