‘Canaries in the mine’. Parents of adult children with schizophrenia: An integrative review of the literature

Debra Klages, Kim Usher and Debra Jackson

School of Health, University of New England, Armidale, New South Wales, Australia, and Faculty of Health & Life Sciences, Oxford Brookes University, Oxford, Oxfordshire, UK

ABSTRACT: The purpose of this integrative review was to evaluate the current state of knowledge of parents who have adult children diagnosed with schizophrenia and their relationship with mental health professionals. Findings indicated that parents (primarily mothers) believed they intuitively knew when their adult children were becoming unwell and that they doggedly pursued connections with mental health care providers. Five themes were evident in the literature: trusting your instincts, feeling dismissed and devalued, making connections and making concessions, living with distress and sorrow, and becoming your own health-care provider. The implications of the findings on mental health nursing practice indicate that professional family relationships were not ideal, and that parents wanted to improve these relationships. Parents wanted health-care professionals to respond to their requests for help for both their children and for themselves, and wanted to be able to help the mental health team to help their adult children.

KEY WORDS: adult children, mental health nurse, parent, professional–family relation, schizophrenia.

INTRODUCTION

Schizophrenia has a worldwide prevalence, estimated at 21 million according to the World Health Organization (2016). Originally, parents, especially mothers, were assumed to be responsible for the development of schizophrenia in their children; however, it is now generally agreed that there is little evidence to support this previously-held hypothesis (Tuck et al. 1997). Since the advent of deinstitutionalization in the Western world, family members have found themselves adopting the roles previously held by health-care professionals (Eassom et al. 2014). Parents have been impacted by their roles as informal carers, and family stress and burden have become widespread (Rose et al. 2004). In order to support consumers and their families, government agencies have endeavoured to provide guidance for health-care professionals working in mental health services. In Australia, one such initiative is the National Standards for Mental Health Services (Mental Health Standing Committee, 2010), which promotes the rights of carers ‘to be involved in the management of the consumer’s care with the consumer’s informed consent’ (p. 8). In the current health-care system, mental health nurses are experts in providing recovery-focused care for consumers living with schizophrenia, both in the inpatient and community settings. Therefore, they are well positioned in the mental health system to also provide support for family members. Mental health nurses are often the first point of contact with the consumers’ family members, and it
is at this juncture that the professional–family relationship begins. Nevertheless, difficulties can arise when the relationship begins, and it has been reported that a parent can feel excluded and devalued (Clarke 2006).

Rydon (2005) has asserted that substantive evidence suggests that mental health nurses do not meet the needs of the consumers and their family members. At the same time, education directed at improving the capacity of mental health nurses to support carers has suggested that changes in practice should occur (Gall et al. 2003). Improving the education of mental health nurses merits consideration; however, there are other factors influencing their ability to support family members. Factors that can aid or impede the ability of health-care professionals to support family members’ involvement in the care of their children’s health care have been identified, including changes in the mental health organization’s philosophy and clinical practices, as well as the establishment of working routines that aid in family participation (Eassom et al. 2014). Nevertheless, although systemic changes in organizations and education might be indicated, there are additional perspectives requiring consideration, such as the perspective of the mothers and fathers of adult children with a diagnosis of schizophrenia. Examination of the parents’ viewpoint merits attention and deliberation. Thus, we undertook an integrative review of the available literature on parental perspectives on their relationships with mental health professionals.

Aims

The purpose for conducting this integrative review was to identify, analyse, and synthesize available research on parents of adult children diagnosed with schizophrenia and their relationships with mental health professionals. The question that informed the review was: What is known about the professional relationship between the parents of an adult child with schizophrenia and the mental health system?

METHOD

The method that was used to analyse and synthesize the literature was Whittemore and Knaff’s (2005) integrative review methodology. There are five stages in Whittemore and Knaff’s structure for data collection, analysis, and synthesis. The stages begin with problem identification, literature search, data evaluation, data analysis, and presentation. The initial stage of the review was to identify the problem to be addressed. Problem identification requires variables of interest, including the idea, specific population, and the clinical concern. The stage of problem identification enables the decision-making process for data extraction. The problem to be addressed in this review is the impact of professional–family relationships on parents of adult children with schizophrenia. The subsequent four stages will be described in the next sections, beginning with the literature search.

Literature search

The literature search was performed by conducting searches of the following databases: CINAHL, MEDLINE, PsyINFO, and Google Scholar. The search terms which were used were schizophrenia AND nurse AND parent OR carer. The exact search term used for Google Scholar was ‘schizophrenia and adult child, nurse, parent’. To be included in this review, the papers had to be published between 2000 and 2015, in order to reflect contemporary issues; written in English; research based; and focussed on professional–family relations. The exclusion criteria were studies that focussed on non-Western cultures, narrowly-defined adult age groups, and studies that focussed on specific professional interventions.

A total of 82 records were retrieved. After removal of duplicates, there were 73 records. Following a screen of the title and abstract, an additional 40 records were excluded. After inclusion and exclusion criteria were applied, 33 articles remained. An additional 19 articles were excluded after full-text screen. Fourteen records remained. The preferred reporting

FIG. 1: PRISMA flowchart.
items for systematic reviews and meta-analyses flow diagram was used to illustrate the identification, screening, eligibility, and inclusion processes (Fig. 1) (Moher et al. 2009).

Data evaluation and analysis

The next phase was to perform an analysis of the data. According to Whittemore and Knafl (2005), there are four stages of data analysis: data reduction, data display, data comparison, and conclusion drawing and verification. The 14 articles were initially read in order to gain an overall view of their response to the research problem. The Critical Appraisal Skills Programme (Critical Appraisal Skills Programmed, 2016) tool for reviewing qualitative research and for case control studies was used to appraise methodological quality. Items, such as the study aim, design, and data collection, were scored with yes (1), no (0), or unclear (1/2), and studies scoring seven and over were included. Following quality appraisal, information about the primary sources was organized into a table of evidence (Table 1). A further analysis of repeating topics within the texts resulted in the identification of five common themes (Table 2).

As seen in Table 1, the participants in 10 of the 14 articles were exclusively parents. In McCann et al.’s (2012) paper, which discusses 20 participants’ satisfaction with clinicians, there were 17 mothers, one spouse, one grandparent, and one aunt. Rudge and Morse’s (2004) article included 10 participants, of which two were spouses and eight were parents. In Veltman et al.’s (2002) study, the 20 family members caring for relatives diagnosed with schizophrenia (n = 13), schizoaffective disorder (n = 3), bipolar disorder (n = 3), and long-term major depression (n = 1) included 11 mothers, four wives, two fathers, one daughter, one sister, and one husband. Finally, Jungbauer and Angermeyer’s (2002) study consisted of 42 mothers, nine fathers, and 52 spouses. Information specific to the experience of parents was identifiable and accessible in all four of the articles; therefore, all 14 articles were analysed.

RESULTS

The review of the literature exposed the challenges and complexities of professional–family relationships when parents have adult children diagnosed with schizophrenia. The findings revealed that the professional–family relations between parents with adult children diagnosed with schizophrenia were not ideal, and that parents struggled to come to terms with and deal with their new life circumstances.

The process of the parents’ development revealed in the included studies was captured in five common themes. The papers were read and reread numerous times until re-occurring topics became evident. Annotations were made in the papers throughout this iterative process. The themes were conceptualized as common threads that emerged from the parents’ multifaceted experiences, and these themes provided unifying ideas regarding their life events. The themes were trusting your instincts, feeling dismissed and devalued, making connections and making concessions, living with distress and sorrow, and becoming your own health-care provider.

Trusting your instincts

Trusting your instincts can be seen as an unconscious decision-making process. Trusting your instincts means relying on your gut feelings. The term a ‘mother’s instinct’ is widely used in the vernacular, and it became evident during the review of the included studies that many of the participants were mothers. There was, however, one exception, which focussed specifically on the lived experience of fathers (Nyström & Svensson 2004). Supporting evidence from McAuliffe et al. (2014) indicated that parents were the first ones to know that their child was unwell, only to have their concerns dismissed by health-care providers. Milliken and Northcott (2003) stated that mothers instinctively ‘know their child better than anyone else’, even better than psychiatrists do, and that they were dismayed when decisions were made to discharge them to their care without consultation.

Parents in the included studies believed that they had the capacity to accurately predict impending problems. In Jungbauer et al.’s (2004) study, it was proposed that parents were able to intuitively predict and proactively prevent relapses and crises. Furthermore, the parents in the studies contended that their innate understanding of their child’s condition and needs was just as valid as that of the mental health professionals who then independently made health-care decisions (McCann et al. (2012)).

Feeling dismissed and devalued

The socially-proscribed goal for parents is to be relieved from their duties of active parenting, meaning...
<table>
<thead>
<tr>
<th>No.</th>
<th>Title</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Purposes/results</th>
<th>Conclusions/nursing implications</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Help-seeking for parents of individuals experiencing a first episode of schizophrenia</td>
<td>Czuchta, D. M., and McCay, E. (2001)</td>
<td>20 parents of children 17 years and older with a first episode of schizophrenia</td>
<td>Triangulated design combining both qualitative and quantitative methods</td>
<td>Purpose: To examine the factors affecting the help seeking of parents whose child experienced a first episode of schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Results: Stigma increases the burden experienced by parents</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Education of parents results in decreased distress and burden</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Conclusions: Parents experience difficulties accessing mental health services due to dismissal of parents’ initial concerns</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>There is a lack of communication between service providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Nursing implications: Need to listen and respond to the needs of the families and facilitate streamlined easy access to mental health services</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Limitations: Canada Small sample size Mozambique well-educated females</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Sweden: Patient approval required Mozambique not be generalizable to adult children with schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Continued)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No.</td>
<td>Title</td>
<td>Author(s)</td>
<td>Sample</td>
<td>Methods</td>
<td>Purposes/results</td>
<td>Conclusions/nursing implications</td>
<td>Limitations</td>
</tr>
<tr>
<td>-----</td>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------</td>
<td>---------------------------------------</td>
<td>---------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>3</td>
<td>Living with a schizophrenic patient: A comparative study of burden as it affects parents and spouses</td>
<td>Jungbauer, J. and Angermeyer, M.C. (2002)</td>
<td>52 spouses: 42 mothers and 9 fathers</td>
<td>Qualitative Narrative interviews</td>
<td>Purpose: To compare the burden experienced by parents and spouses Results: The symptoms of schizophrenia, as well as the roles within the family, contribute to the burden on spouses and parents</td>
<td>Conclusions: Spouses perceive caregiver burden differently, but there are some similarities Nursing implications: Provision of support as early as possible when first episode occurs Regular conversations with physician and integration of family members in treatment planning</td>
<td>Germany: Selection effect: Patient’s consent required might have impacted the results</td>
</tr>
<tr>
<td>4</td>
<td>Schizophrenia: Problems of separation in families</td>
<td>Jungbauer, J., Stelling, K., Dietrich, S. and Angermeyer, M.C. (2004)</td>
<td>51 parents of adult children with schizophrenia</td>
<td>Qualitative Narrative interviews</td>
<td>Purpose: To explore problems of development and detachment in families with an adult child with schizophrenia Results: The onset of schizophrenia during adolescence has an effect on their individuation. Parents are challenged by their life-long roles as carers</td>
<td>Conclusions: Family-related support needs to account for the difficult detachment of patients from their parents Nursing implications: Need to involve parents of people with schizophrenia as equal partners Need to acknowledge the professional competence of parents</td>
<td>Germany: Selection effect: Patient’s consent was required, and this might also have an impact on the validity of the study</td>
</tr>
<tr>
<td>5</td>
<td>Subjective burden over 12 months in parents of patients with schizophrenia</td>
<td>Jungbauer, J., Wittmund, B., Dietrich, S. and Angermeyer, M.C. (2003)</td>
<td>51 parents of adult children with schizophrenia</td>
<td>Qualitative Narrative interviews</td>
<td>Purpose: Follow-up study of the subjective burden in parents during a 12-month period Results: Parents of continuously- and severely-affected patients experience excessive burdens related to caring tasks</td>
<td>Conclusions: An improvement in the mental state of the patient results in a decrease in the burden of care provided there are no additional burdening factors Nursing implications: Continuous psychological and pragmatic support related to everyday life problems needs to be provided</td>
<td>Germany: Selection effect: Many parents could not be interviewed because the patient refused to grant permission Sex: Most were women, and the findings might not be applicable to males</td>
</tr>
<tr>
<td>No.</td>
<td>Title</td>
<td>Author(s)</td>
<td>Sample</td>
<td>Methods</td>
<td>Purposes/results</td>
<td>Conclusions/nursing implications</td>
<td>Limitations</td>
</tr>
<tr>
<td>-----</td>
<td>-----------------------------------------------------------------------</td>
<td>--------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------</td>
<td>----------------------------------</td>
</tr>
</tbody>
</table>
| 6   | Primary caregivers’ satisfaction with clinicians’ response to them as informal carers of young people with first-episode psychosis: A qualitative study | McCann, T.V., Lubman, D.I. and Clark, E. (2011) | 20 primary caregivers of young people with a first episode of psychosis: 17 mothers, 1 spouse, 1 grandparent, 1 aunt | Qualitative Interpretive, phenomenological analysis | **Purpose**  
To explore first-time primary caregivers’ experience of the way mental health nurses and other mental health clinicians respond to them as carers of young people with first-episode psychosis  
**Results**  
Carers have both positive and negative experiences with mental health nurses and other clinicians | **Conclusions**  
The way caregivers are treated by mental health nurses and other clinicians has an impact on their experiences and their commitment to caring, and how they will engage with the health care team in the future  
**Nursing implications**  
Explore ways to demonstrate to the carers that their role is valued, include carers in clinical deliberations, take the concerns of the carers seriously, gain an awareness of the mental health regulation related to primary caregivers’ access to confidential information | Australia  
Small sample size  
Sex: Most were women, and the findings might not be applicable to males  
Setting: Highly-specialized setting with first-episode psychosis, clients which might not be generalizable  
Not exclusively parents |
| 7   | Parents’ experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: A qualitative study | McAuliffe, R., O’Connor, L. and Meagher, D. (2014) | 6 parents: 5 mothers, 1 father  
Carers of adult children diagnosed with schizophrenia | Qualitative Descriptive | **Purpose**  
To explore the experiences of parents living with and caring for their adult children with schizophrenia  
**Results**  
Parents experience severe psychological distress when their child is first diagnosed  
Mothers appear to be able to adjust to their new roles | **Conclusions**  
A flexible, family-centred approach is required to deal with the individual parents’ requirements  
**Nursing implications**  
Assessment and care planning should take into account the family as a unit  
Provide information and advice for family members in the community on how to handle specific situations | Ireland  
Small sample size  
Sex: Most were women, and the findings might not be applicable to males |
<table>
<thead>
<tr>
<th>No.</th>
<th>Title</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Purposes/results</th>
<th>Conclusions/nursing implications</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Disenfranchised mothers: Caring for an adult child with schizophrenia</td>
<td>Milliken, P.J. (2001)</td>
<td>29 parents</td>
<td>Qualitative</td>
<td>Purpose: To show how a mother’s parental identity might differ from that of a father, following the diagnosis of schizophrenia in an adult child. Results: Mothers feel the emotional strain more than fathers. The fathers agreed that the mothers are more affected.</td>
<td>Conclusions: Schizophrenia has a profound effect on family members. Moth...</td>
<td>Canada</td>
</tr>
<tr>
<td>9</td>
<td>Redefining parental identity: Caregiving and schizophrenia</td>
<td>Milliken, P.J. and Northcott, H.C. (2003)</td>
<td>29 parents of adult children diagnosed with schizophrenia</td>
<td>Qualitative</td>
<td>Purpose: To explore how parental identity is affected by their role as a caregiver for their child who has been diagnosed with schizophrenia. Results: Parents feel disenfranchised, because the mental health and legal system does not value their right to care for their child who has a mental illness.</td>
<td>Conclusions: Caregiving for someone lasts a long time. Parents feel marginalized by mental health providers. Nursing implications: Recognize the parents’ contributions. Provide care for parents, as well as education and practical advice on how to care for their family member.</td>
<td>Canada</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>No.</th>
<th>Title</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Purposes/results</th>
<th>Conclusions/nursing implications</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| 10  | Lived experience of being a father of an adult child with schizophrenia | Nystrom, M., and Svensson, H. (2004) | 7 fathers (63-78 years old) Carers of adult children diagnosed with schizophrenia | Qualitative Hermeneutic research | **Purpose** To analyse and describe lived experiences of being a father of an adult child with schizophrenia  
**Results** Fathers perceived that physicians did not believe them, professionals were uncaring, felt blamed for their child’s problems, felt objectified by standardized support | **Conclusions** The fathers experienced an existential crisis when their children became unwell.  
They struggled to regain control of their situation, but did so despite the lack of support from the mental health system  
**Nursing implications** Education of mental health nurses should include a caring ideology  
Need to be sensitive as to how much care family members can provide  
Refer parents to support groups | Sweden  
Small sample size  
Sex: Male only  
Age: Older males |
| 11  | Being a parent of an adult son or daughter with severe mental illness receiving professional care: Parents’ narratives | Pejlert, A. (2001) | 8 parents  
3 couples  
1 mother  
1 father  
Carers of adult children diagnosed with schizophrenia | Qualitative Phenomenological, hermeneutic approach | **Purpose** To explore the meaning of parental caregiving with reference to having an adult son or daughter with a severe mental illness living in a care setting  
**Results** Mental health professionals need to be aware of their own attitudes and treatment of families; improve their cooperation with, and support to families; and provide opportunities for family members to meet one another | **Conclusions** The family members experience grief and feel blamed by mental health services  
**Nursing implications** Confidentiality and patient autonomy should not result in the exclusion of family members | Sweden  
Small sample size  
Not exclusively parents |

(Continued)
<table>
<thead>
<tr>
<th>No.</th>
<th>Title</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Methods</th>
<th>Purposes/results</th>
<th>Conclusions/nursing implications</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>The psychoeducation needs of parents who have an adult son or daughter with a mental illness</td>
<td>Reid, J., Lloyd, C., and de Groot, L. (2005)</td>
<td>8 parents, 7 mothers, 1 father of adult children diagnosed with schizophrenia</td>
<td>Qualitative Phenomenological approach</td>
<td><strong>Purpose</strong> To explore the personal experience of families with psychoeducation programmes and other education on admission and in the long term, as well as establishing what parent needs and barriers exist. <strong>Results</strong> Family members had many other unmet needs, other than psychoeducation and other educational programmes.</td>
<td><strong>Conclusions</strong> More information about the illness and what to expect from mental health services when their adult child is admitted to the hospital. Education needs to be more flexible and individually tailored. Parents want to have a more collaborative role with mental health professionals. <strong>Nursing implications</strong> Include family members in decision-making processes.</td>
<td>Australia Small sample size Selection effect Participants were members of a schizophrenia support group.</td>
</tr>
<tr>
<td>13</td>
<td>Did anything change? Caregivers and schizophrenia after medication changes</td>
<td>Rudge, T., and Morse, K. (2004).</td>
<td>10 caregivers, 2 spouses, 8 parents of adult children diagnosed with schizophrenia</td>
<td>Qualitative Discourse analysis of semistructured interviews</td>
<td><strong>Purpose</strong> To explore the lived experiences of caregivers and how they perceive their roles. To explore caregiving as a socio-political event and the politics of care. <strong>Results</strong> Caregivers experience stigma personally and vicariously through their family members.</td>
<td><strong>Conclusions</strong> The mental health system’s power over the caregivers and family members contributes to their sense of powerlessness and stigmatization. Family and caregivers refuse to be completely excluded by the mental health system. <strong>Nursing implications</strong> Understand the importance of family bonds and the value of their expertise.</td>
<td>Australia Small sample size Not exclusively parents.</td>
</tr>
</tbody>
</table>
that, as a young person becomes more responsible for their health and well-being, parents can gradually disengage from their previously-held roles (Milliken & Northcott 2003). It was not uncommon for parents to experience some challenges in the individuation process, however, as it was also during this period that prodromal symptoms began to manifest (Czuchta & McCay 2001). In due course, the mothers and fathers could no longer view their child’s behaviour as a symptom of ‘normal’ adolescence, and they gradually realized that they needed to resume a more directive parenting approach (Milliken 2001). The parents described their efforts to obtain help from health-care professionals who failed to recognize symptoms as indicative of a psychotic illness and dismissed the parental concerns until a crisis occurred (Czuchta & McCay 2001).

The mothers and fathers had known that all was not well with their child, and they were right. In Nyström and Svensson’s (2004) study, the fathers stated that they knew that their children had a mental illness before well-trained professionals came to the same conclusion. It was also recounted in Pejlert’s (2001) study, where parents felt frustrated when the nurses’ expressed their opinions that they and not the family knew their children better. Mothers who provided essential care for their adult children with schizophrenia received little acknowledgment of their expertise from the mental health team (Milliken 2001; Milliken & Northcott 2003). On a similar note, Rudge and Morse (2004) highlighted parental perceptions of being excluded because their knowledge was seen to be less valuable than professionally-informed knowledge.

The literature suggests that parents have a strong desire to maintain family bonds. According to Veltman et al. (2002), despite the family members feeling positive about their ability to contribute in a meaningful manner to their loved ones’ mental health needs, they encountered barriers within the mental health system. The difficulties that parents experienced when connecting with mental health professionals and the concessions that the parents felt they needed to make will be discussed next.

### Making connections and making concessions

Prior to their encounters with the mental health system, it would not be unusual for a family to have experienced a period of turmoil when their child began to develop a psychotic illness (Czuchta & McCay 2001; Milliken 2001; Milliken & Northcott 2003). Parents

© 2016 Australian College of Mental Health Nurses Inc.
gradually became aware that something was not quite right with their children and began to search for answers and advice. Unfortunately, making the first connection with a mental health professional was not always easy. Czuchta and McCay (2001) contended that disjointed communication processes between the mental health system and various health service providers presented a systems barrier for parents who struggled to obtain specialized assessments for their children with a first episode of psychosis. According to Czuchta and McCay (2001) and McCann, et al. (2004), making the connection and communicating with mental health clinicians was a concern, in particular, not being taken seriously or listened to during the first phases of the development of the young adult’s psychotic illness.

Once the connection had been made, parents wanted to be able to continue to communicate with the health-care team about their children’s circumstances. However, it was during this period that the parents learnt that, if or when their adult child became unwell and lost their right to self-determination, professional carers, and not the parents, were authorized to direct care (Milliken & Northcott 2003). According to many parents, there were two specific barriers that affected connections with family members, which were entrenched in the medico-legal system. The first barrier was the right of the individual to maintain their confidentiality, and the second was the right of adults to make autonomous decisions (McCann et al. 2012; Milliken & Northcott 2003). According to Czuchta and McCay (2001) and McCann, et al. (2004), making the connection and communicating with mental health clinicians was a concern, in particular, not being taken seriously or listened to during the first phases of the development of the young adult’s psychotic illness.

One interviewee emphatically stated: ‘The parents are the ones who are going to be there, chasing them down the railway line in the middle of the night trying to get them home or get him into (hospital)’ (McCann et al. 2012; p. 228). Evidence from the studies indicated that barriers within the medico-legal system resulted in parents feeling distressed, but that they

### TABLE 2: Themes

<table>
<thead>
<tr>
<th>Location</th>
<th>Study no.</th>
<th>Trusting your instincts</th>
<th>Feeling dismissed and devalued</th>
<th>Making connections and making concessions</th>
<th>Living with distress and sorrow</th>
<th>Becoming your own mental health-care provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>1</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>—</td>
</tr>
<tr>
<td>Sweden</td>
<td>2</td>
<td>—</td>
<td>—</td>
<td>x</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Germany</td>
<td>3</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Germany</td>
<td>4</td>
<td>x</td>
<td>—</td>
<td>x</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Germany</td>
<td>5</td>
<td>x</td>
<td>—</td>
<td>—</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Australia</td>
<td>6</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Ireland</td>
<td>7</td>
<td>x</td>
<td>—</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Canada</td>
<td>8</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Canada</td>
<td>9</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Sweden</td>
<td>10</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Sweden</td>
<td>11</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Australia</td>
<td>12</td>
<td>—</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>—</td>
</tr>
<tr>
<td>Australia</td>
<td>13</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>—</td>
</tr>
<tr>
<td>Canada</td>
<td>14</td>
<td>—</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>

Note: — = No theme within study.
persisted in their efforts to connect with health-care professionals (Czuchta & McCay 2001; Veltman et al. 2002). Parents understood that they needed to do whatever was necessary in order to get professional help for their children.

In Nyström and Svenssson (2004) study, fathers reported receiving disrespectful treatment from professionals, but that they made concessions and tolerated humiliation in order to ensure their children received the care they needed. In contrast, it was indicated that relations between the family members and the mental health nurses, as well as other mental health clinicians, were viewed by parents as supportive (McAuliffe et al. 2002). Similarly, Milliken (2001) reported that parents spoke of having good relationships with psychiatrists and health-care workers. Nevertheless, a dialectical viewpoint was reported in Pejlert’s (2001) study, where the parents reported that their children were being cared for by nurses who seemed to like them, but at the same time asserted that some staff were ‘lazy’ and even ‘incompetent’. This limited, subjective viewpoint might require consideration in future discussions of professional–family relations.

It has been argued that parents who have experienced a long-term state of tension might find themselves becoming increasingly emotionally sensitive (Jungbauer & Angermeyer 2002). Consequently, we might need to interpret their subjective experiences with both caution and respect. Nevertheless, the included studies reported that parents were frustrated and distressed with the professional–family relationships, especially when bidirectional open lines of communication between themselves and mental health professionals were not sustained.

**Living with distress and sorrow**

Themes of distress and sorrow were noticeable throughout the included studies. The early phases of their loved one’s illness was very difficult, and it was claimed that during the early years when his child was quite psychotic, one father’s level of distress was so acute that he felt that he had become a ‘broken man’ (Nyström & Svensson 2004).

The literature suggested that stress associated with caring for an adult child with a serious mental illness took a toll on the physical health of parents. For example, it was asserted that exacerbations of the adult child’s illness were directly correlated to levels of distress experienced by family members (Jungbauer & Angermeyer 2002; Jungbauer et al. 2003).

Correspondingly, it was proposed that long-term stress might have been a factor in declines in the parents’ physical health (Foldemo et al. 2005). Similarly, in Nyström and Svensson (2004) study, it was contended that the physical health of the fathers had been impacted due to extended exposure to psycho-social stressors related to their belief that mental health professionals blamed them for contributing to their children’s illness. Furthermore, it was reported that when the parents’ own health deteriorated and made it difficult for them to care for their loved ones, this also increased their level of distress (Foldemo et al. 2005). Not all parents were able to come to terms with their life-long challenges, and some felt the need to dissociate from their children due to concerns over the effect on their own physical and mental health (Jungbauer et al. 2004).

Grief reactions were common in most of the included studies. When their children were diagnosed with schizophrenia, the parents compared the experience to the death of the person who was their child (Pejlert 2001; Reid et al. 2005). Milliken and Northcott (2003) characterized the experience of the parents who had a child diagnosed with schizophrenia who was still alive, but was not the child they had expected, as ‘disenfranchised grief’. The parents yearned for the children that they had lost (McAuliffe et al. 2014), but at the same time consoled themselves with the fact that life was unpredictable and that they were not the only ones who had difficult lives. In the included studies, parents reported that support groups were an invaluable resource during their experiences of distress and grief (Milliken 2001; Milliken & Northcott 2003; Nyström & Svensson 2004). Parents were able to identify the need to be comforted in their time of distress and sorrow, and found their own health-care provider.

**Becoming your own health-care provider**

Witnessing your child’s descent into a serious and persistent mental illness would be challenging for any parent. Nevertheless, in order to support their children, parents recognized that they needed to take care of their own mental health (McAuliffe et al. 2014). Similarly, Nyström and Svensson (2004) speculated that regaining control over one’s life situation could have a positive impact on one’s health.

The parents gained expertise in adapting and developing the emotional fortitude to cope with their new family life as the illness progressed (Czuchta & McCay 2001; McCann et al. 2012; Veltman et al. 2002).
Correspondingly, in Nyström and Svensson (2004) study, it was recounted that, over time, the fathers were able to deal with the ongoing challenges of living with their children diagnosed with schizophrenia. Another study related that mothers experienced distress when they felt marginalized by the health-care system, but some were able become ‘emancipated’ from their status of victimhood through their own efforts (Milliken & Northcott 2003).

The parents in the included studies had all experienced, endured, and survived unusually stressful life changing events. In due course, many of the parents realized how amazingly strong their children needed to be on a daily basis when living with the extraordinary challenges of schizophrenia (Veltman et al. 2002). This admiration helped them come to terms with their ability to emotionally deal with their own losses (McAuliffe et al. 2014).

Parents benefitted from their own self-care strategies, and this became noticeable to others. For example, Rudge and Morse’s (2004) study recounted how parents were able to calmly reflect on their own long-term experiences of turmoil and distress. On a similar note, although McCann et al. 2012 described a parent’s composed appearance as indicative of ‘resignation’, it could also be said that their demeanour might be viewed as a state of equanimity. In another study, Pejlert (2001) reported that maintaining an optimistic attitude, self-care, and maintaining hope were important coping strategies for parents. Correspondingly, fathers believed that they had developed an inner strength, which they felt that they never would have had if they had not experienced the difficulties they had with their children (Nyström & Svensson 2004).

Even though the course of the illness was unpredictable, parents began to find ways to regain control over the aspects of their life they could control, altered their expectations, and took comfort in the knowledge that they were never responsible for causing their child’s illness (Milliken & Northcott 2003). Some parents made invaluable connections with support groups, which helped them to learn how to survive and cope with the difficulties they encountered (Milliken 2001; McAuliffe et al. 2014; Nyström & Svensson 2004; Pejlert 2001; Rudge & Morse 2004; Reid et al. 2005).

Parents recognized that the developmental process for their children had been disrupted and that they needed to make adjustments. A number of the studies recognized the existence of shifting of roles of parents towards that of life-long caregivers (Jungbauer & Angermeyer 2002; Jungbauer et al. 2004; McAuliffe et al. 2014; Milliken 2001; Milliken & Northcott 2003; Nyström & Svensson 2004; Pejlert 2001; Reid et al. 2005; Veltman et al. 2002). The parents’ role expanded further as they became de facto case managers for their children (Milliken & Northcott 2003). In order to cope with their new identities, some parents developed and exploited their own inner resources and utilized self-care strategies, such as ‘never giving up, hanging in there, and taking one day at a time’ (Rudge & Morse 2004, p.7).

With their new-found knowledge, some parents sought acknowledgment as valued members of their children’s mental health teams. (McCann et al. 2012; Milliken & Northcott 2003; Pejlert 2001; Reid et al. 2005). They remained dogged in their resolve to champion the rights of their children to have a supportive family (Jungbauer & Angermeyer 2002; Jungbauer et al. 2004; McCann et al. 2012; McAuliffe et al. 2014; Milliken 2001; Pejlert 2001; Rudge & Morse 2004; Veltman et al. 2002).

Although health-care professionals provided parents with psycho-education on illness management, parents had other unmet needs (Reid et al. 2005). For example, Milliken and Northcott (2003) highlighted the importance of recognizing the contribution that parents make, and that health-care professionals should be accountable for providing supportive care for the parents. On a similar note, the importance of providing professional support for parents was raised as an identified need for improvement in mental health service provision (Jungbauer et al. 2003; Milliken 2001; Nyström & Svensson 2004; Pejlert 2001; Reid et al. 2005; Veltman et al. 2002). In summary, although parents might have benefited from professional care as much as their adult children did, when the mental health system did not provide it, they had no choice but to develop their own self-care capacities and to seek supportive care from their peers.

**DISCUSSION**

The findings of the present study indicated that a fragile relationship between health-care professionals and family members began when the parents’ instincts that their son or daughter was unwell led them to initiate contact. It is during this prepsychotic or prodromal period that studies have indicated that it is imperative that interventions occur in order to prevent the disabling effects of schizophrenia (McGorry et al. 2002). The parents’ concerns were dismissed and devalued until it became clear that their children were in a state of crisis. The parents were aware of early warning
signs, which were harbingers of impending psychosis and deteriorations in their mental health. Metaphorically speaking, parents who have adult children with schizophrenia can be compared to ‘canaries in the mine’ because of their instinctive capacity to sense danger before anyone else can.

When the parents were able to make the connections with mental health-care providers, they encountered difficulties with regards to being recognized for their contributions to their children’s mental health care. Health-care professionals have stated that the current system with inadequate staffing levels and the focus on crisis prevention means that interventions with families are not a priority (Rose et al. 2004).

The parents experienced distress and grief, which might have been affected by their feelings of disempowerment and the effects of stigma. It can be argued that internalized stigma might result in parents feeling embarrassed that their family member has been diagnosed with schizophrenia. Recent research has indicated that family embarrassment might have a negative impact on the parents’ ability to advocate for the requisite care for their loved ones diagnosed with schizophrenia (Ahmedani et al. 2013). Distress led to grief as parents became aware of the loss of their hopes and dreams for their own lives, as well as for the lives of their children. Health-care professionals have acknowledged that family members who are dealing with acute grief have difficulty absorbing any information provided to them, yet their priority was to provide information and not to help parents with their grief (Rose et al. 2004). This factor had an impact of the professional–family relationship, as well as on the ability of parents to provide support for their adult children.

In the included studies, the parents were able to identify that they too needed support to cope with their mental health needs. The studies indicated that parents developed their own coping strategies, and benefitted from attendance at support groups where they learned from their peers. The literature has concurred that mutual support groups reduce carer burden and help parents to cope with their daily stressors. Macleod et al. (2011) recommended the need to differentiate between carer- and patient-focussed interventions, and to assess the economic impact of carer support interventions (Macleod et al. 2011).

Informal caregivers (which includes parents who care for their children diagnosed with schizophrenia) are an invaluable resource. In Australia, the replacement value associated with the provision of unpaid care was estimated at $A60.3 billion (Carers Australia, 2015). Internationally, the replacement costs of informal care were estimated at $CAD25-26 billion (Canada), $USD450 billion (USA), £119 billion (UK), and $NZD10.8 billion (New Zealand), respectively (Carers Australia, 2015). Therefore, it can be argued that the provision of carer-focussed interventions has the potential to be a financially-sound practice.

The limitations of the literature review were that it focussed on Western cultures, which might limit the generalizability of the results. However, given the paucity of information on this topic, the current literature review might be useful as an impetus for future research.

CONCLUSION

The findings indicated that parents were supportive of their children, and strongly felt that their contributions needed to be acknowledged by the mental health teams. For the most part, mothers participated in the research, and the fact that fathers were in the minority was raised as an issue by the researchers. The findings also revealed a need for mental health professionals to generate more collaborative relationships with family members and that the parents too needed individualized support.

The review of the literature on parents of adult children diagnosed with schizophrenia revealed 14 studies that met the inclusion criteria, and only 10 referred to parents exclusively. The gaps in the literature included: (i) a paucity of research on the topic from 2000–2015; (ii) few studies specifically targeted at professional–family relationships; and (iii) gender disparity (under-representation of fathers). The review has indicated that further research might be required regarding effective strategies that address parents’ concerns of the lack of acknowledgment by health-care professionals of the valuable contributions the parents make in nurturing and supporting their children.

Relevance to clinical practice

The current findings have implications for educational programmes for mental health nurses on the promotion of professional–family relations. Another intervention and solution to improving relationships would be a reformation of mental health systems towards a paradigm of family-centred care. Mental health nurses would then be able to collaboratively enhance the capabilities of parents who support their adult children diagnosed with schizophrenia. Ultimately, it is hoped that the material presented here can be used as a springboard towards improving professional–family relations.
REFERENCES


学霸图书馆
www.xuebalib.com

本文献由“学霸图书馆-文献云下载”收集自网络，仅供学习交流使用。

学霸图书馆（www.xuebalib.com）是一个“整合众多图书馆数据库资源，
提供一站式文献检索和下载服务”的24小时在线不限IP图书馆。
图书馆致力于便利、促进学习与科研，提供最强文献下载服务。

图书馆导航：
图书馆首页 文献云下载 图书馆入口 外文数据库大全 疑难文献辅助工具