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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. These 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. 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.

Keywords: schizophrenia, mental health nurses, parents, adult children, professional-family relations.

‘Canaries in the Mine’. Parents of Adult Children with Schizophrenia: An Integrative Review of the Literature

Introduction

Schizophrenia has a worldwide prevalence estimated at twenty-one 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. Most health care providers now agree that there is little evidence to support this previously held hypothesis (Tuck, du Mont, Evans & Shupe 1997). Since the advent of deinstitutionalisation in the Western world, family members have found themselves adopting the roles previously held by health care professionals (Eassom, Giacco, Dirik & Priebe 2014). Parents have been impacted by their roles as informal carers, and family stress and burden have become widespread (Rose, Mallinson, & Walton-Moss 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. One such initiative is the National Standards for Mental Health Services (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 in-patient and community settings. Therefore, they are well positioned in the mental health system to also provide support for family members. Mental health nurses often 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).

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Substantive evidence has indicated that mental health nurses do not meet the needs of the consumers and their family members (Rydon 2005). At the same time, education directed at improving the capacity of mental health nurses to support carers has suggested that changes in practice can occur (Gall, Atkinson, Elliot & Johansen 2003). Improving the education of mental health nurses merits consideration, but there are other variables that may affect 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 sons and daughters' health care have been identified; including changes in the mental health organisation's philosophy and clinical practices, as well as the establishment of working routines that aid in family participation (Eassom, Giacco, Dirik & Priebe 2014). Nevertheless, although systemic changes in organisations and education may 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. Hence, an 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 synthesise available empirical reports 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?*

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Method

The method that was used to analyse and synthesise the literature was Whitemore and Knaf's (2005) integrative review methodology. There are five stages in Whitemore and Knaf's structure for data collection, analysis, and synthesis. The stages are 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: Cumulative Index to Nursing and Allied Health Literature (CINAHL); Medical Literature On-Line (MEDLINE); Psychological Information Database (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 2000-2015; written in English; research based; and focused on professional-family relations. The exclusion criteria were studies that focused on non-Western cultures; narrowly defined adult age groups and studies that focused on specific professional interventions.

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A total of eighty-two 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, thirty-three articles remained. An additional nineteen articles were excluded after full text screen. Fourteen records remained. The PRISMA flow diagram was used to illustrate the identification, screening, eligibility, and inclusion processes (see figure 1) (Moher, Liberati, Tetzlaff, Altman, and The PRISMA Group 2009).

**** insert Figure 1 ****

Data evaluation and analysis

The next phase was to perform an analysis of the data. According to Whitemore and Knafl (2005), there are four stages of data analysis: data reduction; data display; data comparison and finally conclusion drawing and verification. The fourteen articles were initially read in order to gain an overall view of their response to the research problem. Then, the papers were appraised using an adapted version of the Critical Appraisal Skills Programme (CASP) tools for qualitative research and for case control studies respectively (Critical Appraisal Skills Programme (CASP) 2016). Following quality appraisal, information about the primary sources was organized into a table of evidence (see Table 1). A further analysis of repeating topics within the texts resulted in the identification of five common themes (see Table 2).

As seen in table one, the participants in ten of the fourteen articles were exclusively parents. In McCann, Lubman and Clark's (2011) paper which discussed twenty participants' satisfaction with clinicians, there were seventeen mothers, one spouse, one grandparent and one aunt. Rudge and Morse's (2004) article included ten participants of which two were spouses and

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3 eight were parents. In Veltman, Cameron and Stewart's (2002) study, the twenty family
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5 members caring for relatives diagnosed with schizophrenia (13), schizoaffective disorder (3),
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7 bipolar disorder (3) and chronic major depression (1) included eleven mothers, four wives, two
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9 fathers, one daughter, one sister and one husband. Finally, Jungbauer and Angermeyer's (2002)
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11 study consisted of forty- two mothers, nine fathers and fifty- two spouses. Information was
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13 specific to the experience of parents was identifiable and accessible in all four of the above
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18 articles.

Results

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24 The review of the literature exposed the challenges and complexities of professional-
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26 family relationships when parents have adult children diagnosed with schizophrenia. The
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28 findings revealed that the professional-family relations between parents with adult children
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30 diagnosed with schizophrenia were not ideal and that parents struggled to come to terms with
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32 and deal with their new life circumstances.
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37 The process of the parent's development revealed in the included studies was captured in
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39 five common themes. The themes were conceptualised as common threads that emerged from the
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41 parents' multifaceted experiences and these themes provided unifying ideas regarding their life
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43 events. The themes were: trusting your instincts; feeling dismissed and devalued; making
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45 connections and making concessions; living with distress and sorrow; and, becoming your own
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47 health care provider. These themes will be discussed in detail in the following paragraphs.
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Trusting your instincts

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55 Trusting your instincts can be seen as an unconscious decision making process. Trusting
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57 your instincts means relying on your gut feelings. Instincts may arise out of past experiences and
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knowledge. 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 focused specifically on the lived experience of fathers (Nystrom & Svensson 2004). Supporting evidence from McAuliffe, O’Connor, and Meagher (2014) indicated that parents were the first ones to know that their child was ill, 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, Stelling, Dietrich and Angermeyer (2004) 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, Lubman & Clark 2011).

Feeling dismissed and devalued

The socially proscribed goal for parents is to be relieved from their duties of active parenting, meaning that, as a young person becomes more responsible for their health and wellbeing, 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

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3 view their child's behaviour as a symptom of 'normal' adolescence and they gradually realised
4 that they needed to resume a more directive parenting approach (Milliken 2001). The parents
5 described their efforts to obtain help from health care professionals who failed to recognise
6 symptoms as indicative of a psychotic illness and dismissed the parental concerns until a crisis
7 occurred (Czuchta & McCay 2001).
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16 The mothers and fathers had known that all was not well with their child and they were
17 right. In Nystrom and Svensson's (2004) study, the fathers identified that they knew that their
18 children had a mental illness before well-trained professionals came to the same conclusion. It
19 was also recounted in Pejert's (2002) study that parents felt frustrated when the nurses'
20 expressed their opinions that they and not the family knew their sons and daughters better.
21 Mothers who provided essential care for their adult children with schizophrenia received little
22 acknowledgment of their expertise from the mental health team (Milliken & Northcott 2003;
23 Milliken, 2001). On a similar note, Rudge and Morse (2004) highlighted parental perceptions of
24 being excluded because their knowledge was seen to be less valuable than professionally
25 informed knowledge.
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41 The literature suggests that parents have a strong desire to maintain family bonds.
42 According to Veltman, Cameron and Stewart (2002) despite the family members feeling positive
43 about their ability to contribute in a meaningful manner to their loved ones' mental health needs,
44 they encountered barriers within the mental health system. The difficulties that parents
45 experienced when connecting with mental health professionals and the concessions which the
46 parents felt they needed to make will be discussed next.
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55 **Making connections and making concessions**
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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 or son began to develop a psychotic illness (Czuchta & McCay 2001; Milliken 2001; Milliken & Northcott 2004). Parents 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 specialised assessments for their children with a first episode of psychosis. According to Czuchta and McCay (2001); McCann, Lubman and Clark (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 son or daughter'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 authorised 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, Lubman & Clark 2011; Milliken 2000; Milliken & Northcott 2003). The literature suggested that there were difficulties when mental health clinicians attempted to implement various legislations and guidelines into practice whilst working with the consumer and their family members (McCann,

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3 Lubman & Clark 2011). Supporting evidence indicated that patient confidentiality may be the
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5 reason that health care practitioners did not consistently communicate with parents (Milliken &
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7 Northcott 2003; Pejler 2001; McCann, Lubman & Clark 2011). Making connections can be
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9 difficult and sometimes family members can draw inferences which needed to be interpreted
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11 with caution. One such example was reported in Pejler (2001) who described a situation where
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13 the nurses' use of confidentiality was interpreted by the parents as signifying a disinterest in
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15 sharing information or engaging in a collaborative relationship with them.
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21 The manner in which the medico-legal system applied the concept of adult autonomy
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23 may become a barrier to communication. In Reid, Lloyd & DeGroot (2005) it was asserted that
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25 health care teams did not include parents in treatment and care decision discussions because the
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27 consumer was an adult, despite the belief of parents that their children were too unwell to
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29 participate appropriately. Another related study revealed that parents of young people with a first
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31 episode of psychosis found that clinicians' positions on confidentiality and autonomy had
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33 negative impacts on their efforts to support their children during critical periods when a young
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35 person's mental health risks were extreme (McCann, Lubman & Clark 2011). One interviewee
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37 emphatically stated: "the parents are the ones who are going to be there, chasing them down the
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39 railway line in the middle of the night trying to get them home or get him into ...[hospital]"
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41 (McCann, Lubman & Clark 2011 pg. 228). Evidence from the studies indicated that barriers
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43 within the medico-legal system resulted in parents feeling distressed but that they persisted in
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45 their efforts to connect with health care professionals (Czuchta & McCay 2001; Veltman,
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47 Cameron & Stewart 2002). Parents understood that they needed to do whatever was necessary in
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49 order to get professional help for their sons and daughters.
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Fathers in the study by Nystrom and Svensson (2004) reported that they received 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 (McCann, Lubman & Clark 2011; McAuliffe, O'Connor & Meagher 2014). Similarly, Milliken (2000) reported that parents spoke of having good relationships with psychiatrists and health care workers. Nevertheless, a dialectical viewpoint was reported in Pejler (2001) wherein the parents reported that their son/daughter was 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 view point may require consideration in future discussions of professional-family relations.

It has been argued that over the long term, parents who have experienced a chronic state of tension may find themselves becoming increasingly emotionally sensitive (Jungbauer & Angermeyer 2002). Consequently, we may 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 bi-directional 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' (Nystrom & Svensson 2004).

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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, Wittman, Dietrich & Angermeyer 2003; Jungbauer & Angermeyer 2002). Correspondingly, it was proposed that chronic stress may have been a factor in declines in the parents' physical health (Foldemo, Gullberg, Ek, & Bogren 2005). Similarly, in Nystrom and Svensson's (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 that this also increased their level of distress (Foldemo, Gullberg, Ek & Bogren 2005). Not all parents were able to come to terms with their life-long challenges and some felt the need to dissociate from their sons and daughters due to concerns over the effect on their own physical and mental health (Jungbauer, Stelling, Dietrich & Angermeyer 2004).

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Grief reactions were common in most of the included studies. When their son or daughter was diagnosed with schizophrenia, the parents compared the experience to the death of the person who was their child (Reid, Lloyd & DeGroot 2005; Pejler 2001). Milliken and Northcott (2003) characterised the experience of the parents who have 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 sons and daughters that they had lost (McAuliffe, O'Connor & Meagher 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


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3 distress and grief (Milliken 2002; Milliken & Northcott 2003; Nystrom & Svensson 2004).

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5 Parents were able to identify the need to be comforted in their time of distress and sorrow and
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8 found their own health care provider.
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Becoming your own health care provider

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15 Witnessing your son or daughter's descent into a serious and persistent mental illness
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17 would be challenging for any parent. Nevertheless, in order to support their children, parents
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19 recognised that they needed to take care of their own mental health (McAuliffe, O'Connor &
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21 Meagher 2014). Similarly, Nystrom and Svensson 2004  speculated that regaining control over
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23 one's life situation, may have a positive impact on one's health.
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28 The parents gained expertise in adapting and developing the emotional fortitude to cope
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30 with their new family life as the illness progressed (Czuchta & McCay 2001; McCann, Lubman
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32 & Clark 2011; Veltman, Cameron & Stewart 2002). Correspondingly, in Nystrom and
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34 Svensson's 2004 study it was recounted that over time, the fathers were to able to deal with the
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36 ongoing challenges of living with their sons and daughters diagnosed with schizophrenia.
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38 Another study related that mothers experienced distress when they felt marginalised by the
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40 health care system but some were able become 'emancipated' from their status of victimhood
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42 through their own efforts (Milliken & Northcott 2003).
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47 The parents in the included studies had all experienced, endured and survived unusually
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49 stressful life changing events. In due course, many of the parents realised how amazingly strong
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51 their sons and daughters needed to be on a daily basis when living with the extraordinary
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53 challenges of schizophrenia (Veltman, Cameron & Stewart 2002). This admiration helped them
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3 come to terms with their ability to emotionally deal with their own losses (McAuliffe, O'Connor
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5 & Meagher 2014).
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9 Parents benefitted from their own self-care strategies and this became noticeable to
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11 others. For example, Rudge and Morse's (2004) study recounted how parents were able to
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13 calmly reflect on their own long term experiences of turmoil and distress. On a similar note,
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15 although McCann, Lubman and Clark (2011) described a parent's composed appearance as
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17 indicative of 'resignation', it could also be said that their demeanour might be viewed as a state
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19 of equanimity. In another study, Pejlert (2001) reported that maintaining an optimistic attitude,
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21 self care and maintaining hope were important coping strategies for parents. Correspondingly,
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23 fathers believed that they had developed an inner strength, which they felt that they never would
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25 have had if they hadn't experienced the difficulties with their children (Nystrom & Svensson
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27 2004).
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34 Even though the course of the illness was unpredictable, parents began to find ways to
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36 regain control over the aspects of their life they could control, altered their expectations and took
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38 comfort in the knowledge that they were never responsible for causing their child's illness
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40 (Milliken & Northcott 2003). Some parents made invaluable connections with support groups
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42 which helped them to learn how to survive and cope with the difficulties they encountered
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44 (Milliken 2002; Pejlert 2001; McAuliffe, O'Connor & Meagher 2014; Nystrom & Svensson
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46 2004; Rudge & Morse 2004; Reid, Lloyd & DeGroot 2005).
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51 Parents recognised that the developmental process for their sons and daughters had been
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53 disrupted and that they needed to make adjustments. A number of the studies recognised the
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55 existence of a  shifting of roles of parents towards that of life-long care givers (Jungbauer &
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3 Angermeyer 2002; Jungbauer, Stelling, Dietrich & Angermeyer 2004; McAuliffe, O'Connor &
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5 Meagher 2014; Milliken 2001; Milliken & Northcott 2003; Nystrom & Svensson 2004; Pejler
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7 2001; Reid, Lloyd & DeGroot 2005; Veltman, Cameron & Stewart 2002). The parents' role
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9 expanded further as they became de facto case managers for their children (Milliken & Northcott
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11 2003). In order to cope with their new identities, some parents developed and exploited their own
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13 inner resources and utilised self-care strategies such as "never giving up, hanging in there, and
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15 taking one day at a time" (Rudge 2004 pg.7).
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21 With their new-found knowledge, some parents sought acknowledgment as valued
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23 members of their sons' and daughter's mental health teams. (Milliken & Northcott 2003;
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25 McCann, Lubman & Clark 2011; Pejler 2001; Reid, Lloyd & DeGroot 2005). They remained
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27 dogged in their resolve to champion the rights of their sons and daughters to have a supportive
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29 family (Jungbauer & Angermeyer 2002; Jungbauer, Stelling, Dietrich & Angermeyer 2004;
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31 McCann, Lubman & Clark 2011; McAuliffe, O'Connor & Meagher 2014; Milliken 2003; Pejler
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33 2001; Rudge & Morse 2004; Veltman, Cameron & Stewart 2002).
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38 Although health care professionals provided parents with psycho-education on illness
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40 management, parents had other unmet needs (Reid, Lloyd & de Groot 2005). For example,
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42 Milliken and Northcott (2003) highlighted the importance of recognising the contribution that
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44 parents make and that health care professionals should be accountable for providing supportive
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46 care for the parents. On a similar note, the importance of providing professional support for
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48 parents was raised as an identified need for improvement in mental health service provision
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50 (Jungbauer, Wittmund, & Angermeyer 2003; Milliken 2001; Nystrom & Svensson 2004; Pejler
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52 2001; Reid, Lloyd, & de Groot 2005; Veltman, Cameron & Stewart 2002). In summary, although
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54 parents may have benefited from professional care as much as their adult children did, when the
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3 mental health system did not provide it, they had no choice but to develop their own self-care
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5 capacities and to seek supportive care from their peers.
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Discussion

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14 The findings indicated that a fragile relationship between health care professionals and
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16 family members began when the parents' instincts that their son or daughter was unwell led them
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18 to initiate contact. It is during this pre-psychotic or prodromal period, that studies have indicated
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20 that it is imperative that interventions occur in order to prevent the disabling effects of
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22 schizophrenia (McGorry et al., 2002). The parents' concerns were dismissed and devalued until
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24 it became clear that their children were in a state of crisis. The parents were aware of early
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26 warning signs which were harbingers of impending psychosis and deteriorations in their mental
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28 health. Metaphorically speaking, parents who have adult children with schizophrenia can be
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30 compared to 'Canaries in the Mine' because of their instinctive capacity to sense danger before
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32 anyone else can.
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39 When the parents were able to make the connections with mental health care providers,
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41 they encountered difficulties vis-à-vis being recognized for their contributions to their children's
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43 mental health care. Health care professionals have identified that the current system with
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45 inadequate staffing levels and the focus on crisis prevention means that interventions with
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47 families are not a priority (Rose, Mallinson & Walton-Moss 2004).
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51 The parents experienced distress and grief which may have been affected by their
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53 feelings of disempowerment and the effects of stigma. It can be argued that internalized stigma
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55 may result in parents feeling embarrassed that their family member has been diagnosed with
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3 schizophrenia. Recent research has indicated that family embarrassment may have a negative
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5 impact on the parents' ability to advocate for the requisite care for their loved ones diagnosed
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7 with schizophrenia (Ahmedani et al., 2013). Distress led to grief as parents became aware of the
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9 loss of their hopes and dreams for their own lives as well as for the lives of their children. Health
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11 care professionals have acknowledged that family members who are dealing with acute grief
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13 have difficulty absorbing any information provided to them, yet their priority was to provide
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15 information and not to help parents with their grief (Rose, Mallinson & Walton-Ross 2004). This
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17 factor had an impact of the professional-family relationship as well as on the ability of parents to
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19 provide support for their adult children.
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25 In the included studies, the parents were able to identify that they too needed support to
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27 cope with their mental health needs. The studies indicated that parents developed their own
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29 coping strategies and benefitted from attendance at support groups where they learned from their
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31 peers. The literature has concurred that mutual support groups reduce carer burden and help
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33 parents to cope with their daily stressors. Macleod, Elliot and Brown (2011) have recommended
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35 the need to differentiate between carer- focused and patient- focused interventions and to assess
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37 the economic impact of carer support interventions (Macleod, Elliot, & Brown 2011).
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43 Informal caregivers (which includes parents who care for their sons and daughters
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45 diagnosed with schizophrenia) are an invaluable resource. In Australia, the replacement value
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47 associated with the provision of unpaid care was estimated at \$ 60.3 billion (Deloitte Access
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49 Economics, 2015). Internationally the replacement costs of informal care were estimated at \$25-
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51 26 billion (Canada); \$450 billion (United States of America); £119 billion (United Kingdom);
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53 and \$10.8 billion (New Zealand) respectively (Deloitte Access Economics, 2015). Therefore, it
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55 can be argued that the provision of carer- focused interventions has potential to be a financially
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8 **Conclusion**

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11 The findings indicated that parents were supportive of their sons and daughters and felt
12 strongly that their contributions needed to be acknowledged by the mental health teams. For the
13 most part mothers participated in the research and the fact that fathers were in the minority was
14 raised as an issue by the researchers. The findings also revealed a need for mental health
15 professionals to generate more collaborative relationships with family members and that the
16 parents too needed individualized support.
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26 The review of the literature on parents of adult children diagnosed with schizophrenia
27 revealed fourteen studies which met the inclusion criteria and only ten referred to parents
28 exclusively. The gaps in the literature included 1) a paucity of research on the topic from 2000 –
29 2015, 2) few studies specifically targeted the professional family relationships and 3) gender
30 disparity (under- representation of fathers). The review has indicated that further research may be
31 required regarding effective strategies which address the parents' concerns of the lack of
32 acknowledgment by health care professionals of the valuable contributions the parents make in
33 nurturing and supporting their sons and daughters.
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47 **Relevance to clinical practice**

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50 The current findings have implications for educational programmes for mental health
51 nurses on the promotion of professional-family relations. Another intervention and solution to
52 improving relationships would be a reformation of mental health systems towards a paradigm of
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Parents of Adult Children Diagnosed with Schizophrenia

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3 family-centred care. Mental health nurses would then be able to collaboratively enhance the
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5 capabilities of parents who support their adult children diagnosed with schizophrenia. Ultimately,
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7 it is hoped that the material presented herein can be used as a springboard towards improving
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9 professional-family relations.
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Table 1 Table of evidence

#	Title	Author(s)	Sample	Methods	Purposes/Results	Conclusions/ Nursing Implications	Limitations
1	Help-seeking for parents of individuals experiencing a first episode of schizophrenia.	Czuchta, D. M., and McCay, E. (2001).	20 parents of children 17 years and older with first episode of schizophrenia.	Triangulated design combining both qualitative and quantitative methods.	<p>Purpose</p> <p>To examine the factors affecting the help-seeking of parents whose child experienced a first episode of schizophrenia.</p> <p>Results</p> <p>Stigma increases the burden experienced by parents.</p> <p>Education of parents results in decreased distress and burden.</p>	<p>Conclusions</p> <p>Parents experience difficulties accessing mental health services due to dismissal of parents initial concerns.</p> <p>There is a lack of communication between service providers.</p> <p>Nursing implications</p> <p>Need to listen and respond to the needs of the families and facilitate streamlined easy access to mental health services.</p>	<p>Canada</p> <p>Small sample size.</p> <p>Socio economic status: well educated females.</p> <p>First episode male patients average age of 23.9.</p> <p>May not be generalizable to older adult children with schizophrenia or to the Australian context.</p>
2	Quality of life and burden in patients of outpatients with	Foldemo, A., Gullberg, M., Ek, A., and Bogren,	44 parents of children 18 years and older with diagnosis	Quantitative Cross sectional	<p>Purpose</p> <p>To compare the quality of life of</p>	<p>Conclusions</p> <p>The overall quality of life was lower among</p>	<p>Sweden</p> <p>Selection effect: Patient</p>

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	schizophrenia.	L. (2005).	of schizophrenia.	study	parents of outpatients with schizophrenia with a randomly selected reference group and the relation between quality of life and burden on the parents. Results Parents were significantly dissatisfied with their overall quality of life. Care giving has an influence on the family situation.	parents of outpatients with schizophrenia than in the reference group. The heaviest burden is related to the lost hope for their child's future. Nursing implications An individualized approach for parental support rather than focusing on psycho-education is required.	approval required. May not be generalizable to adults with schizophrenia or to the Australian context.
3	Living with a schizophrenic patient: a comparative study of burden as it affects parents and spouses.	Jungbauer, J. and Angermeyer, M.C. (2002).	52 spouses 42 mothers and 9 fathers .	Qualitative Narrative interviews	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.	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	Germany Selection effect: Patients consent required may have impacted the results. May not be generalizable to the Australian

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						integration of family members in treatment planning.	context.
4	Schizophrenia: problems of separation in families.	Jungbauer, J., Stelling, K., Dietrich, S. and Angermeyer, M.C. (2004).	51 parents of adult children with schizophrenia.	Qualitative Narrative interviews	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.	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.	Germany Selection effect: patient's consent was required and this might also have an impact on the validity of the study. May not be generalizable to the Australian context.
5	Subjective burden over 12 months in parents of patients with schizophrenia	Jungbauer, J., Wittmund, B., Dietrich, S. and Angermeyer, M.C. (2003).	51 parents of adult children with schizophrenia.	Qualitative Narrative interviews	Purpose Follow up study of the subjective burden in parents during a 12- month period. Results	Conclusions An improvement in the mental state of the patient results in a decrease in the burden of care provided there are no additional	Germany Selection effect: Many parents could not be interviewed because the

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					Parents of continuously and severely affected patients experience excessive burdens related to caring tasks.	burdening factors. Nursing implications Continuous psychological and pragmatic support related to every day life problems needs to be provided.	patient refused to grant permission. Gender: most were women and the findings might not be applicable to males. May not be generalizable to to the Australian context.
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 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	Conclusions The way caregivers are treated by mental health nurses and other clinicians has an impact on their experiences and has an impact on their commitment to caring and how they will engage with the health care team in the future. Nursing implications Explore ways to	Australia Small sample size. Gender: most were women and the findings might not be applicable to males. Setting: Highly specialized

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					Carers experience both positive and negative experiences with mental health nurses and other clinicians.	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	setting with first episode psychosis clients which may 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. Gender: most were women and the findings might not be applicable to males. May not be generalizable to the Australian context

Parents of Adult Children Diagnosed with Schizophrenia

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	8	Disenfranchised mothers: caring for an adult child with schizophrenia.	Milliken, P.J. (2001).	29 parents 16 mothers 13 fathers Carers of adult children diagnosed with schizophrenia.	Qualitative Exploratory grounded theory	Purpose To show how a mother's parental identity may 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.	Conclusions Schizophrenia has a profound effect on family members. Mothers assume the major responsibility for providing care and are most affected family member. Nursing implications Recognize the contributions that family members. Accept professional responsibility to provide care for family caregivers especially mothers. Become aware of stigmatizing behaviours.	Canada Small sample size. May not be generalizable to to the Australian context
32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49	9	Redefining parental identity: caregiving and schizophrenia.	Milliken, P.J. and Northcott, H.C. (2003).	29 parents of adult children diagnosed with schizophrenia.	Qualitative Exploratory grounded theory	Purpose To explore how parental identity is affected by their role as a caregiver for their child who has been diagnosed with schizophrenia.	Conclusions Caregiving for someone lasts a long time. Parents feel marginalised by mental health providers. Nursing implications	Canada Small sample size. May not be generalizable to to the Australian

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					<p>Results</p> <p>Parents feel disenfranchised because the mental health and legal system does not value their right to care for their mentally ill adult child.</p>	<p>Recognize the parents' contributions.</p> <p>Provide care for parents, as well as education and practical advice on how to care for their family member.</p>	<p>context.</p>
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	<p>Purpose</p> <p>To analyse and describe lived experiences of being a father of an adult child with schizophrenia.</p> <p>Results</p> <p>Fathers perceived that physicians did not believe them; professionals were uncaring; felt blamed for their child's problems; felt objectified by standardised support.</p>	<p>Conclusions</p> <p>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.</p> <p>Nursing implications</p> <p>Education of mental health nurses should include a caring ideology.</p> <p>Need to be sensitive how much care family members can provide.</p>	<p>Sweden</p> <p>Small sample size.</p> <p>Gender: male only.</p> <p>Age: older males.</p> <p>May not be generalizable to to the Australian context</p>

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						Refer parents to support groups.	
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 care-giving 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 on 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. May not be generalizable to to the Australian context.
12	The psycho education needs of parent who have an adult son or daughter	Reid, J., Lloyd, C., and de Groot, L.	8 parents 7 mothers 1 father of	Qualitative Phenomenological approach	Purpose To explore the personal experience of families with	Conclusions More information about the illness and what to expect from mental	Australia Small sample size.

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1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	with a mental illness.	(2005).	adult children diagnosed with schizophrenia.		psychoeducation programmes and other education on admission and in the long term as well as establishing what parent needs and barriers exist. Results Family members had many other unmet needs other than psychoeducation and other educational programmes.	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. Nursing implications Include family members in decision making processes.	Selection effect: Participants were members of a schizophrenia support group.
24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49	13 Did anything change? Caregivers and schizophrenia after medication changes.	Rudge, T., and Morse, K. (2004).	10 caregivers 2 spouses. 8 parents of adult children diagnosed with schizophrenia	Qualitative Discourse analysis of semi structured interviews	Purpose 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. Results Caregivers experience stigma personally and vicariously through	Conclusions The mental health system's power over the caregivers and family members contributes to their sense of powerlessness and stigmatisation. Family and caregivers refuse to be completely excluded by the mental health system. Nursing implications	Australia Small sample Not exclusively parents.

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					their family members.	Understand the importance of family bonds and the value of their expertise.	
14	The experience of providing care to relatives with chronic mental illness.	Veltman, A., Cameron, J. I. and Stewart, D. E. (2002).	20 family care givers 11 mothers; 2 fathers; 4 wives; 1 daughter; 1 sister; 1 husband family members diagnosed with schizophrenia (13), schizoaffective disorder (3), bipolar disorder (3) chronic major depression (1)	Qualitative research using interviews.	Purpose To gain a better knowledge of the meaning that caregivers derive from their situation, including the positive aspects of caregiving. Results Stigma: participants believed that stigma is related to mental illness and does not affect carers of patients with physical illnesses. Conflict with mental health system: family members felt unsupported.	Conclusions Family members reported positive and negative impacts of providing care for their sons and daughters. Nursing implications Need to be sensitive about the needs of both the patients and their family members. Family members need to be supported in making choices about their roles as carers.	Canada Small sample size. Self selection may have biased the results. Not exclusively parents. Gender imbalance: 17 out of 20 participants were females. May not be generalizable to the Australian context.

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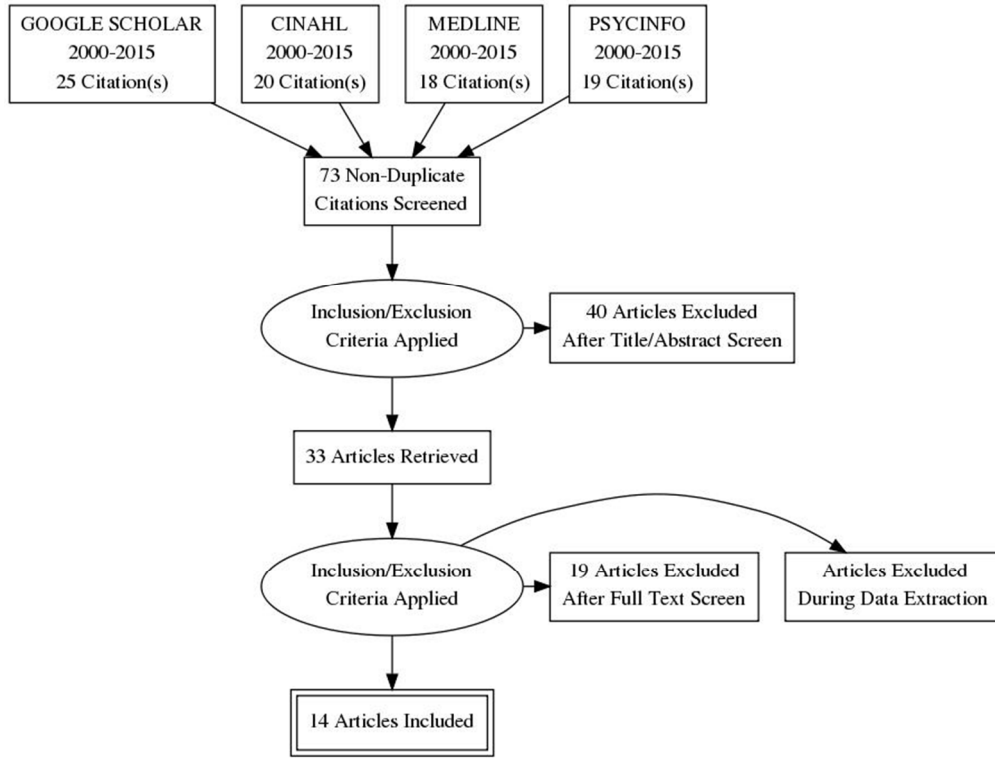
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Table 2 Themes

Location	Study #	Trusting your instincts	Feeling dismissed and devalued	Making connections and making concessions	Living with distress and sorrow	Becoming your own mental health care provider
Canada	1	x	x	x	x	
Sweden	2			x	x	
Germany	3	x	x	x	x	x
Germany	4	x		x	x	
Germany	5	x			x	x
Australia	6	x	x	x		
Ireland	7	x		x	x	x
Canada	8	x	x	x	x	
Canada	9	x	x	x	x	x
Sweden	10	x	x	x	x	x
Sweden	11	x	x	x	x	x
Australia	12		x	x	x	
Australia	13	x	x	x	x	
Canada	14		x	x	x	x

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For Review Only



Flow Chart
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