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Exploring the Experiences of Parent Caregivers of Adult Children With Schizophrenia: A Systematic Review

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ABSTRACT

This is a qualitative evidence synthesis on the experiences of parents caring for their adult child with schizophrenia. The Joanna Briggs Methodology for systematic reviews guided the study and standard systematic review procedures were followed. Content analysis was used to synthesize findings from the five studies included into the following categories: '*Resources*,' '*Loss*,' '*Psychological Distress*,' '*Effects on Family*,' and '*Framing the Experience*.' Findings suggest that parent caregivers struggle to navigate services and need greater support to protect their mental and physical health. From a research perspective, factors influencing parents' abilities to stay engaged in caregiving warrant further exploration.

Background

The typical age of onset for schizophrenia is between late adolescence and early adulthood (Gogtay, Vyas, Testa, Wood, & Pantelis, 2011). At this time, individuals are transitioning through their senior years of high school or have recently graduated and are embarking on college, university, or joining the workforce. The symptoms of schizophrenia can have devastating effects on functionality during these life stages, through interrupted education, failure to attain and sustain work, and inability to live independently. The illness persists into adulthood and old age, and individuals with schizophrenia commonly depend on others for social support and housing. Less than 20% of persons with schizophrenia live alone in the community and almost half live with family members who support their health and well-being (Awad & Voruganti, 2008; Tsai, Stroup, & Rosenheck, 2011).

Outpatient mental health services, which provide the majority of psychiatric care, are focused on acute treatment and lack resources to address basic daily needs of persons with schizophrenia. As such, family members participate in the provision of ongoing physical, mental, social, and psychological care (Glynn, Cohen, Dixon, & Niv, 2006). Parents who live with adult children with schizophrenia (ACWS) facilitate day-to-day activities (cooking, cleaning, and housework), care planning and coordination, medication management, transportation, and making and attending appointments. Caregiving roles shift from providing medical care during acute illness, to sustaining social and psychological support during stable phases (Glynn et al., 2006; Janardhana, Raghunandan, Naidu, Saraswathi, & Seshan, 2015). Moreover, parents manage crisis situations and communicate with health and legal professionals (Small, Harrison, & Newell, 2010), and reconciling the competing priorities of ensuring psychiatric stability and being a parent is challenging (Chadda, 2014).

Researchers have explored aspects of family caregiving in schizophrenia. Investigations of family resilience (Bishop & Greeff, 2015), burden and coping (Caqueo-Urízar et al., 2014; Hsiao & Tsai, 2014), difficult symptoms involving family members (Onwumere, Learmonth, & Kuipers, 2016), role distress and quality of life (Quah, 2014), and navigation of the mental health care system exist (Jack-Ide, Uys, & Middleton, 2013; Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015). Findings suggest that family caregivers face many challenges affecting all aspects of their lives (Quah, 2014). They rarely seek care for their personal needs (Chadda, 2014), and their health and well-being suffer because of their caregiving responsibilities (Kate, Grover, Kulhara, & Nehra, 2014; Sapouna et al., 2013). Furthermore, parent caregivers are shown to have decreased overall quality of life related to less engagement in social outings and activities, more frequent disagreement and fighting in their households, increased rates of depression, economic difficulties, delays or cancellations of vacation plans, and declines in work or school performance (Awad & Wallace, 1999; Kate et al., 2014; Pshuk & Pshuk, 2015; Sapouna et al., 2013).

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Purpose

Qualitative studies exploring the experiences of parent caregivers for ACWS exist, which highlight the experiences of parent caregivers. However, findings have yet to be synthesized across studies. Synthesis studies aim to identify, evaluate, and summarize the findings of all relevant literature, thereby making the available evidence more accessible to decision makers, researchers, and other stakeholders. We have noted that authors tend to intermix parents with other forms of family caregivers or include various types of severe and persistent mental illness into their studies (Bauer, Koepke, Sterzinger, & Spiessl, 2012; Bishop & Greeff, 2015; Wainwright et al., 2015). While family caregivers may share common experiences, the nature of the parent-child relationship is different (e.g. parents are responsible for rearing and the relationship is expected to move from total dependence to independence of the child) and warrants investigation. A rigorous review is needed to shed light on the specific experiences of parents of ACWS to inform resources aimed at supporting this population. The purpose of this study was, therefore, to explore and synthesize the caregiving experiences of parents of ACWS. The specific research question was: Based on qualitative research literature, how do parents of adult children with schizophrenia (ACWS) experience and describe their caregiver role?

Methods

Design

This was a Qualitative Evidence Synthesis (Grant & Booth, 2009) modeled on the Joanna Briggs Methodology for Qualitative Systematic Reviews (JBI, 2014). Qualitative studies, by virtue of their design and philosophical underpinnings, give representation to the subjective nature of a phenomenon (Lincoln & Guba, 1985). Qualitative Evidence Synthesis (QES) integrates findings from qualitative studies and looks for themes or constructs that exist across individual qualitative studies (Grant & Booth, 2009). The JBI methodology allows researchers to answer a specific research question through reviewing the evidence in a systematic manner. The research team had expertise in schizophrenia, mental health, caregiving, qualitative research, and systematic review methodologies.

Selection criteria

We used the PICo (Population, phenomena of Interest, and Context) strategy (JBI, 2014; Murdoch University, 2018) to delineate eligibility criteria (Table 1), which included full-text and peer-reviewed qualitative and mixed-methods studies, published in English that explored parental caregiving experiences in schizophrenia or schizoaffective disorder. Unpublished or grey literature, abstracts, theses, dissertations, books, and conference summaries were excluded.

Table 2
Example search strategy.

MEDLINE		
1	Exp "schizophrenia spectrum and other psychotic disorders"/	150,346
2	schiz*.ti. or schiz*.ab.	139,483
3	psycho*.ti. or psycho*.ab.	555,205
4	1 or 2 or 3	691,074
5	Caregivers/	31,144
6	(caregiv* or carer* or "care giver*").ti. or (caregiv* or carer* or "care giver*").ab.	64,493
7	Parents/or fathers/or mothers/or single parent/	99,954
8	(parent* or mother* or father* or "single parent*").ti. or (parent* or mother* or father* or "single parent*").ab.	558,670
9	5 or 6 or 7 or 8	640,415
10	4 and 9	55,291
11	Limit 10 to (English language and full text and yr = "2006–2016")	4640
12	(qualitative* or interview* or "focus group*" or narrative*).ti. or (qualitative* or interview* or "focus group*" or narrative*).ab.	506,359
13	11 and 12	865

Search strategy

We designed a three-step strategy. First, within the MEDLINE, PsycINFO, and CINAHL databases, we searched with the keywords: schizophrenia, parents, and caregiving. This helped us to identify the following relevant MESH headings: schizophrenia, psychotic disorders, schizophrenia spectrum and other psychotic disorders, caregivers, parents, fathers, mothers, and single parent. Second, we tailored searches specifically for each database using these MESH headings and a predetermined set of keywords (See Table 2 for an example search strategy). Third, we reviewed the reference lists of all included articles, continued to look for new research published on the topic (i.e. handsearch), and included any relevant studies identified. The search strategy was developed with the assistance of two library scientists. One library scientist aided in clearly defining concepts and exploring potential search strategies. The other library scientist helped narrow concepts and identify keywords and MESH headings.

Study selection

After removing duplicate citations, studies were selected using a two-level screening process. Two reviewers conducted first-level screening (Authors 1 and 2) by title and abstract. During this initial screening, studies were excluded, kept, or marked as unsure based on their congruence with the eligibility criteria. The two reviewers independently screened all citations at this stage and a meeting was held

Table 1
Eligibility criteria.

Inclusion	Exclusion
Phenomena of interest – the caregiving experience	
Population – parents (mother, father, single parent, foster, grandparent, or adoptive parent – anyone acting in parental role) of an adult child (18+ yrs) with a diagnosis of schizophrenia or schizoaffective disorder.	Other caregivers, parents of youth or children, parents of an adult child with any other mental illness including substance induced psychosis, first episode psychosis, delusional disorder, or psychosis NOS.
	Persons with primary or secondary diagnosis of dementia
Qualitative or mixed method s studies with a standalone qualitative piece.	Quantitative studies only
Articles that include other caregivers but can distinguish a minimum of one parent quote supporting each theme or category	Articles without direct quotes
Articles published in English and within the last 10 years (2006 – November 2016).	Articles published in any other language and outside of the last 10 years or not available online.
Full-text peer-reviewed studies	Unpublished or grey literature, abstracts, theses, dissertations, books, and conference summaries.
Context – worldwide, any culture, race, or gender. Caregiving may occur in the community or while person is within hospital.	

Table 3
Joanna Briggs Institute – checklist for qualitative research.

Criteria	Huang et al. (2009)	Wiens and Daniluk (2009)	Yen et al. (2010)	McAuliffe et al. (2014)	Blomgren Mannerheim et al. (2016)
1. Is there congruity between the stated philosophical perspective and the research methodology?	Yes	Yes	Yes	Yes	Yes
2. Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes	Yes	Yes
3. Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	Yes	Yes	Yes
4. Is there congruity between the research methodology and the representation and analysis of data?	Yes	Yes	Yes	Yes	Yes
5. Is there congruity between the research methodology and the interpretation of results?	Yes	Yes	Yes	Yes	Yes
6. Is there a statement locating the researcher culturally or theoretically?	Unclear	Yes	Unclear	Yes	Yes
7. Is the influence of the researcher on the research, and vice-versa, addressed?	Yes	Yes	No	No	Yes
8. Are participants, and their voices, adequately represented?	Yes	Unclear	Unclear	Unclear	Unclear
9. Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	Yes	No	Yes	Yes	Unclear
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	Yes	Yes	Yes	Yes
Total	9	8	7	8	8

to resolve conflicts in selection. Second-level screening involved reading the full-texts for congruence with eligibility criteria. At this level, articles were only retained if they included direct quotes from parent caregivers of ACWS. Three reviewers (Authors 1, 2, and 5) completed this step and a second meeting was held to gain consensus on the included studies.

Data extraction

Author 1 extracted data from the chosen studies and created summary tables. Data included: a) study characteristics (i.e. author, year, title, country, purpose, design, data collection method, and data analysis method), b) parent caregiver characteristics (i.e. number of caregivers, age, sex, relationship with care recipient, marital status, education level, employment status, and years spent caregiving), c) ACWS characteristics (i.e. number of care recipients, age, sex, diagnosis, duration of illness, employment status, and housing type), and d) study findings (i.e. categories/themes and supporting quotes). These tables were reviewed and discussed in team meetings to ensure accuracy of the data extraction.

Data synthesis

Study, caregiver, and ACWS characteristics were summarized and reported descriptively. Data, including all thematic constructions, descriptions, and supporting quotes found in the original articles were aggregated and analyzed using the Conventional Content Analysis Approach (Hsieh & Shannon, 2005). Specifically, two reviewers (Author 1 and 2) read all quotes and made notes of first impressions and thoughts. Next, we highlighted text that captured key thoughts or concepts to derive initial codes (Morse & Field, 1995). Labels for these codes emerged from the text and were embedded into a preliminary coding scheme. We compared each label and code, and related codes were then aggregated into categories. Subcategories were used when appropriate. Finally, we embedded direct quotes from the original study participants into the synthesized findings. A quote was used to represent each category and subcategory. A third reviewer (Author 5) was consulted throughout the analysis process and aided in creating the final construction of the findings. The final findings were reviewed and agreed upon by all authors.

Rigour

This review is reported in accordance with the framework proposed by Tong, Flemming, McInnes, Oliver, and Craig (2012): Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong et al., 2012). The ENTREQ statement consists of 21 items grouped in the following five domains: introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings. Adhering to these items enhanced the transparency of our research process.

Results

The search strategy produced a total of 2321 citations. From these, we removed 750 duplicates and deemed 1549 irrelevant after first-level screening. A total of 22 citations were subjected to second-level screening at which point a further 18 studies were excluded. The reasons for exclusion were: 1) unable to identify a parental quote for each theme or subtheme (n = 9), 2) diagnosis incorrect or unclear (n = 7), and 3) Not about caregivers' experiences (e.g. ACWS's experiences) (n = 2). Four studies met eligibility criteria and were included into the review from the database search and one additional study was found through the hand-search. A final set of five studies were included into the review (Fig. 2).

Critical appraisal

To assess the quality of the included studies, two reviewers (Authors 1 and 2) applied the Joanna Briggs Institute's Checklist for Qualitative Research (JBI, 2016). This critical appraisal tool consists of 10 questions that address the possibility of flaws in design, conduct, or analysis (JBI, 2016). For each question, we allocated a rating of 'yes', 'no', 'unclear', or 'not applicable'. Once completed, the two reviewers met with a third reviewer (Author 5) to discuss ratings and come to agreement on discrepancies. One point was awarded for each 'yes' and a total score was obtained for each study. Scores ranged from 7 to 9, with three studies receiving a score of 8. When considering whether participants' voices were adequately represented, we made the decision to indicate "unclear" when the sources of quotes were vague (i.e. participant, parent, or informant). While quality assessment of included studies in Qualitative Evidence Syntheses is optional (Grant & Booth, 2009), we engaged in this step to comment on the state of science and make recommendations for future research on the topic (Table 3).

Study characteristics

The included studies were conducted in Taiwan (n = 2), Canada (n = 1), Ireland (n = 1), and Sweden (n = 1). The study sample sizes ranged from six to 20 participants. All studies were qualitative and guided by a recognized qualitative methodology. All studies were conducted in English or translated into English from Taiwanese, Mandarin, or Swedish by the original authors prior to publication. Study designs included grounded theory (n = 1), phenomenology (n = 2), and descriptive qualitative approaches (n = 2). Interviews were used to collect data in all cases and level of structure was described as either semi-structured (n = 4) or minimally structured (n = 1) (Table 4).

Caregiver characteristics

Four of the five studies (Blomgren Mannerheim, Hellström Muhli, & Siouta, 2016; Huang, Hung, Sun, Lin, & Chen, 2009; McAuliffe, O'Connor, & Meagher, 2014; Yen et al., 2010) included both male and female parent caregiver participants and one study (Wiens & Daniluk, 2009) included male participants only. Females represented 55% of the total sample (n = 26/47) and the ages of the participants ranged from 'late 40s' to 77 years. All participants identified as being either the mother or father of the ACWS. In three of the studies (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Yen et al., 2010), the authors reported on the number of years spent caregiving; this ranged from one to 25 years (Table 5).

ACWS characteristics

In total, there were 47 ACWS described and all studies included both male and female care recipients. Males represented 60% (n = 28) of the total sample. All ACWS had a diagnosis of schizophrenia, rather than schizoaffective disorder. The duration of illness was reported in two studies (Huang et al., 2009; Wiens & Daniluk, 2009) and length of diagnosis ranged from 3 to 26 years, with a mean duration of illness of 12 years. Age and type of housing was reported variably across studies (Table 6).

Themes and categories reported in studies

In three studies (Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009), the authors reported their results using themes and subthemes and in two studies (Blomgren Mannerheim et al., 2016; Yen et al., 2010) the authors reported categories and subcategories. In all cases, the presentation of the findings (i.e. themes vs. categories) was congruent with the methodologies and data analysis strategies chosen.

Table 4
Study characteristics.

Author (year)	Country	Title	Purpose	Design	Data collection method	Data analysis method
Huang et al. (2009)	Taiwan	The experiences of carers in Taiwanese culture who have long-term schizophrenia in their families: a phenomenological study	To explore the experiences of carers who live with someone with long-term schizophrenia, within the cultural context of Taiwan	Descriptive phenomenological approach	Semi-structured interviews	Colaizzi's (1978) seven-step method
Wiens and Daniluk (2009)	Canada	Love, loss, and learning: the experiences of fathers who have children diagnosed with schizophrenia	To give voice to fathers of young ACWS within the past 10 years	Phenomenological approach	Minimally structured data collection interview	Seven steps of phenomenological analysis outlined by Colaizzi (1978)
Yen et al. (2010)	Taiwan	A theory of meaning of caregiving for parents of mentally ill children in Taiwan, a qualitative study	To generate a theory of meaning of care-giving for parents of mentally ill children in Taiwan	Grounded theory	Semi-structured interviews	Constant comparative method
McAuliffe et al. (2014)	Ireland	Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study	To explore the experience of parents living with and caring for their a ACWS	Descriptive qualitative design	Semi-structured, interviews	Eclectic approach described by Creswell (2002)
Blomgren Mannerheim et al. (2016)	Sweden	Parents' experiences of caring responsibility for their adult child with schizophrenia	To systematically describe and analyze the experiences of parents' informal care responsibility	Descriptive qualitative	Semi-structured interviews	A mixed hermeneutic deductive and inductive method

Table 5
Caregiver characteristics.

Author (year)	N	Age	Relationship to adult child with schizophrenia	Marital status	Education level	Years spent caregiving
Huang et al. (2009)	7	67, 59, 75, 58, 62, 50, 66	4 Mothers 3 Fathers	5 Married 2 Widow	3 None 2 Primary 2 Junior	
Wiens and Daniluk (2009)	6	4 were in their late 40s and 50s, 1 in early 60s, 1 in early 70s.	6 Fathers			
Yen et al. (2010)	20	48–65 years	12 Mothers 8 Fathers		Ranged from primary to high school.	Range 1–12 yrs. Average: 1–3 yrs. (N = 11)
McAuliffe et al. (2014)	6	60–77 (mean not provided though, 69, 60, 77, 66, 76, 66)	5 Mothers 1 Father	3 Married 3 Widow		Range: 6–25 years. Average: 17 yrs. (25, 19, 23, 8, 22, 6).
Blomgren Mannerheim et al. (2016)	8	52–63 (58, 58, 56, 52, 57, 63, 59, 59)	5 Mothers 3 Fathers	Married (4) Single Parent (4)		5 years minimum

From the articles, we identified a total of 17 original themes and categories supported by 16 original subthemes and subcategories (n = 33 findings total).

After aggregating and comparing the original findings for similarities and differences, we identified five distinct categories: '*Resources*', '*Grieving Losses*', '*Psychological Distress*', '*Effects on Family*', and '*Framing the Experience*'. These categories are presented below with supporting subcategories, and include illustrative quotes from the original studies (Fig. 1).

Resources

Problems with availability of and access to resources were identified in four articles (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009).

Missing resources

Parents predominantly spoke of deficits in resources available to meet their needs as caregivers for ACWS. Some parents reported a lack of overall support for family members: "But support for family members, nothing exists" (Blomgren Mannerheim et al., 2016), while others desired specific information, such as education and skills-based training to understand and manage symptoms of psychosis: "I appreciate the nurses who give us emotional support. But I need more help. For example, the skills to handle my daughter's auditory hallucinations…" (Huang et al., 2009).

Parents also described a lack of psychosocial interventions: "I felt there was no real care… I felt… they were pumping the drugs. There was no real counselling" (McAuliffe et al., 2014) and a lack of physical resources, such as hospital beds, when their child was in crisis:

> They let him out of the hospital and he became psychotic again. I tried to take him back in and they said, 'there are no beds.' I said, 'That's your problem. He's certified. You're supposed to have a bed for him… (Wiens & Daniluk, 2009)

Accessing available resources

Ease of access to resources was also cited as problematic (McAuliffe et al., 2014; Wiens & Daniluk, 2009). In particular, parent caregivers identified difficulties navigating the healthcare system:

> There was no easy way to access anything…You know, it's fine to say that resources are there, but there was nothing that allowed us to feel like it was part of – not a right, but something is good to do – part of what we should be doing (Wiens & Daniluk, 2009).

This extended to gaining appropriate access to health care professionals: "No one ever came to me to talk to me about it. I asked the nurses questions… make an appointment to see the doctor…" (McAuliffe et al., 2014).

Grieving losses

In all five studies, caregivers described experiencing a multitude of losses, which included loss related to self (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009) and their ACWS (Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010)

Grieving losses related to self

Losses related to self were described in four studies (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009), and related to being unable to pursue their own personal goals and aspirations (past, present, and future) because of the demands of caregiving activities. Parents grieved social losses and described deep disappointment about not being able to experience

Table 6
Care recipient characteristics.

Author (Year)	N	Age	Sex	Diagnosis	Duration of illness	Housing type/live with parent
Huang et al. (2009)	7	32, 31, 24, 38, 23, 38, 50	2 F 5 M	Schizophrenia	16, 6, 3, 18, 6, 19, 18	Inclusion criteria they had lived with the person for at least 1 year
Wiens and Daniluk (2009)	6	18–31 years	1 F 5 M	Schizophrenia	4 diagnosed approximately 4 yrs, 2 had been diagnosed 8 yrs	5 living semi-independently out of parental home; 1 living at home
Yen et al. (2010)	20	25.7 (SD 4.73).	12 F 8 M	Schizophrenia		
McAuliffe et al. (2014)	6	45, 36, 40, 27, 38, 37	2 F 4 M	Schizophrenia		Inclusion criteria all live with parents for at least two years
Blomgren Mannerheim et al. (2016)	8	22–31 (27, 25, 40, 23, 22, 31, 30, 27)	2 F 6 M	Schizophrenia	Minimum of 5 years as per parents informal caregiving provided minimum 5 years	

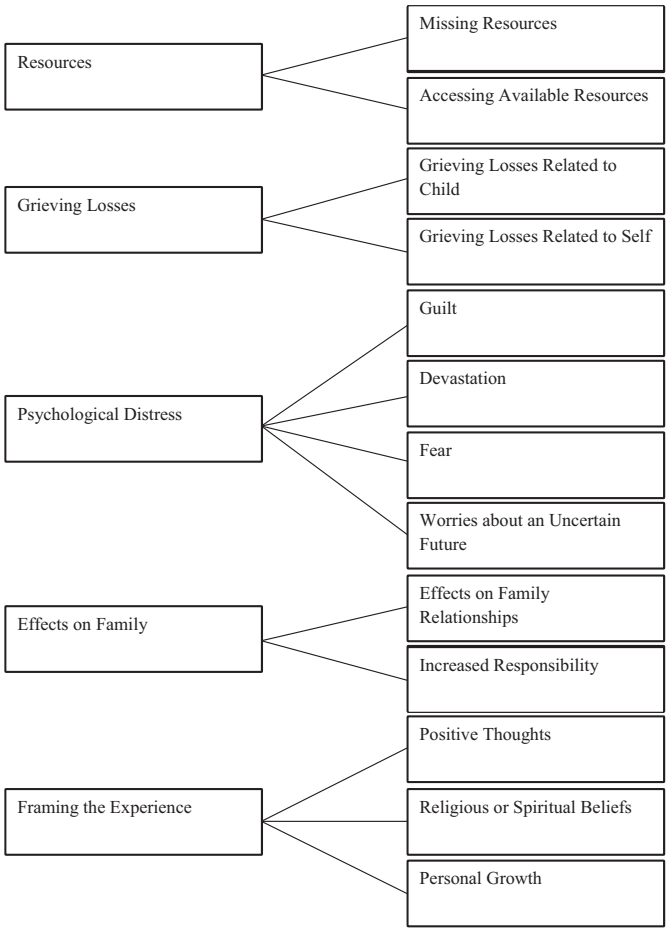

Fig. 1. Categories and subcategories.

the world as they anticipated: "My life was isolated. I feel sad about my life being like this…" (Huang et al., 2009). Another parent described personal losses in the following way:

> …lost a lot of my own life, things I'd like to do places I would like to go – I just can't do it… I'm 66 and not getting younger… I get upset about it at times… tormented. I get bitter about it in my own way (McAuliffe et al., 2014).

Further, parents described loss as all-encompassing; like a trade-off of their former life for the role of parenting their ACWS:

> I really feel the responsibility to care for our son is mine. So I still give up everything to have the responsibility, but I'm quite upset about the fact that I'm getting older and I don't know, I just won't be able to do what I wanted to do (Wiens & Daniluk, 2009).

Changes to their day-to-day routines and the inability to engage as desired in activities were also described:

> His illness has also limited my daily freedom of action as well as weekends such as Saturday or Sunday, since half of the week xx and I eat dinner together. My social life is also limited because I get fewer free nights off to meet people (Blomgren Mannerheim et al., 2016).

Parents also spoke about future anticipated losses, especially related to loss of an enjoyable retirement. "It's not our idea of something as a retirement gift" (Wiens & Daniluk, 2009). Participants explained how a diagnosis of schizophrenia for their child was the greatest loss ever experienced: "The death of my father, the death of my mother, other deaths I've experienced – I've never felt like I did when my child was

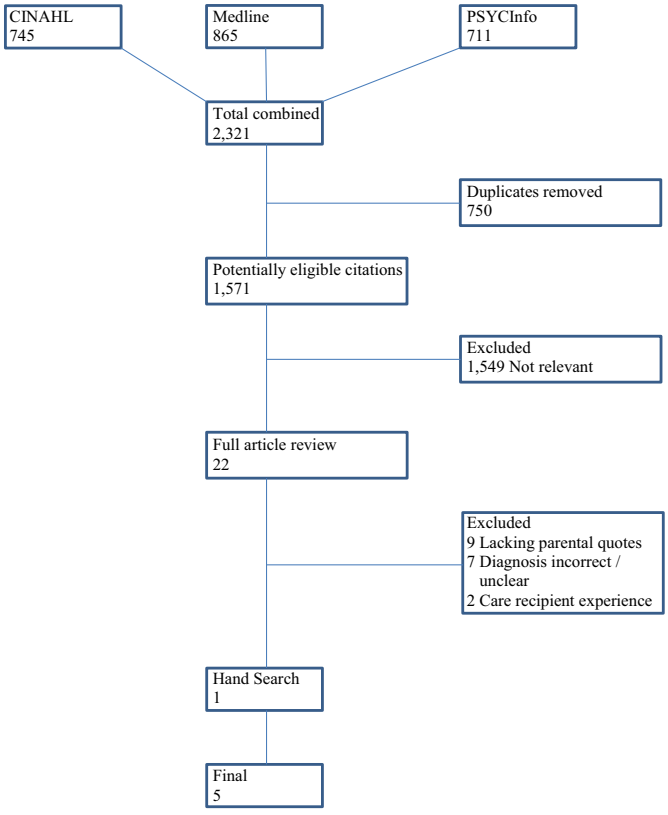

Fig. 2. Search tree diagram.

diagnosed with schizophrenia" (Wiens & Daniluk, 2009).

Grieving losses related to child

In four articles, caregivers explained their feelings of loss and grief. These losses were related to their child's cognitive abilities and academic achievements: "… every time, when I recall how smart he was compared with now… I really feel heartbroken…" (Yen et al., 2010), and affective changes to their former expression:

> He was a beautiful baby – there was nothing wrong with him… now he's a sick man – that's the difference…I've a sick man now and I had a beautiful baby… as you can see from his photograph – he was a real bubbly little fellow… I'd give a million pounds to somebody to change it – It's desperate… (McAuliffe et al., 2014).

Psychological distress

Psychological distress was evident in all five studies and was described as the psychological turmoil experienced by parent caregivers throughout their child's illness trajectory. Most often, this distress was described in terms of guilt about the past (Huang et al., 2009; Wiens & Daniluk, 2009; Yen et al., 2010), devastation regarding their child's illness and its effects (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010), fear (Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009), and worries about an uncertain future (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009).

Guilt

Parents expressed feeling guilty (Huang et al., 2009; Wiens & Daniluk, 2009; Yen et al., 2010) about their child developing schizophrenia: "I felt so guilty when my son asked me why I gave birth to him and why he got this illness. I always have a deep feeling of self-blame

about my son's illness" (Huang et al., 2009). This guilt was especially evident when parents spoke of the hereditary component of the illness:

> The doctor told me that genetics is one factor of mental illness. My husband and I kept asking, how come we have passed this bad gene? Are we the persons who should be blamed for our child's illness? The more I think, the more sorry I feel for him. Every time, when he goes into a temper, I tell myself… be patient…I gave birth to him (Yen et al., 2010).

Parents also blamed themselves for failing to recognize early signs and symptoms of the illness: "We always said we should have realized it sooner" (Wiens & Daniluk, 2009), and appeared to feel accountable for (not) recognizing the prodromal symptoms of schizophrenia:

> I should be responsible for her illness. I thought I was not a good mother because I did not take good care of her. If I had discovered her problem earlier, she might not have become mentally ill. Now, it's too late… all I can do was to do my best to provide good care (Yen et al., 2010).

Devastation

Devastation was evident in all five studies and was described across the illness trajectory in terms of overwhelming sadness (Huang et al., 2009; Wiens & Daniluk, 2009; Yen et al., 2010), and feelings of hopelessness (Wiens & Daniluk, 2009), powerlessness (Blomgren Mannerheim et al., 2016; Wiens & Daniluk, 2009), and desperation (McAuliffe et al., 2014). There was a temporal dimension to devastation: devastation with diagnosis, devastation with exacerbation of symptoms, and ongoing devastation.

Devastation felt upon learning of their child's diagnosis was described as being especially difficult and life changing:

> When he said that our daughter has schizophrenia, I just felt like the bottom had fallen out of my world and I felt very sad for my daughter. I felt like it was a death sentence for her and I was mute. I have to say I felt hopeless at that time… the other word is powerless (Wiens & Daniluk, 2009).

During times of symptom exacerbation, parents described the devastation of having to bring their child to hospital against their will when they could no longer manage at home:

> We brought him back to the hospital – forced him back. It was just horrible – and he was crying and angry and it was devastating. It was another major, major blow to us… Then he didn't want to see us – was holding it against us (Wiens & Daniluk, 2009).

As parents navigated the trajectory of their child's illness, devastation continued to be a part of their existence: "I remember grabbing on to him and just saying, you know, that I love him and actually crying with him. And it was really weird because I don't do that… but I was just like – devastated" (Wiens & Daniluk, 2009).

Fear

Fear was described in three studies (Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009) and was expressed as generalized and ongoing. Parents feared unknown aspects of the illness: "When he wasn't well in the beginning – it was an awful worry that he could do anything… be afraid to watch him every single minute just in case" (McAuliffe et al., 2014). Parents also feared that their child might resist care when needed: "Sometimes when we went to the hospital we have spent up to five hours in emergency to get him hospitalized. And we're afraid our son will bolt on us" (Wiens & Daniluk, 2009). Finally, parents were afraid that their child might commit suicide because of the overwhelming nature of their symptoms: "I fear my daughter will commit suicide as hallucinatory voices often tell her to kill herself…" (Huang et al., 2009).

Worries about an uncertain future

Worry related to both the realization that schizophrenia is an unpredictable illness (Blomgren Mannerheim et al., 2016; Wiens & Daniluk, 2009), as well as worry about who will care for their child once they are no longer capable (Huang et al., 2009; McAuliffe et al., 2014): "I always worry about my son's future. Who will take care of him when I die? You know his illness can never be cured" (Huang et al., 2009). Some parents were concerned that their child would not function without them: "But I don't know can he look farther than just now and what would become of him, if I wasn't looking after him… He wouldn't be able to carry on, on his own" (McAuliffe et al., 2014), while others were more optimistic:

> He'd be thinking about the future himself – he'd like to get married – but sure he never will… he don't go anywhere like… I suppose I know he'd be on his own some fine day but then again as I said – they (siblings) are near him… He'd manage away (McAuliffe et al., 2014).

Effects on family

Caring for ACWS had significant effects on the families. This was described in terms of family relationships (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009) and increased responsibilities (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010).

Effects on family relationships

Family conflict occurred as a result of a lack of understanding of illness symptoms, such as beliefs that the person was lazy: "His brothers usually argue with him. Sometimes they fight with each other because he does not have a job and just sits around at home and gets looked after. They think he is a lazy, useless man" (Huang et al., 2009). If one parent experienced negative emotions and poor coping skills these appeared to have a ripple effect on other family members, creating greater conflict and tension:

> When (daughter) got ill, my husband became very hateful toward me and also put the hatred on my children. I've never felt so hated; it was like his aggressions went over to my daughter and she kind of threw darts at me. I've never felt so bad, it felt horrible and unfair (Blomgren Mannerheim et al., 2016).

The effects of caregiving on the marital relationship were mixed. From a positive perspective, some participants reported that their marriage was strengthened due to overcoming obstacles together: "I think, if anything, all of this experience strengthened our marriage – brought us closer together. We certainly have a common problem and we need to work together to deal with it" (Wiens & Daniluk, 2009). Others indicated that because of limited quality time spent together as spouses, their marriages suffered:

> It's very bad for a marriage – for a mother to have so much hardship so much worry because you have no time to spend with your husband – only that my husband is so understanding – all I go through – there's nothing I can do about it… under strain all the time – God almighty I couldn't sit down at night with my husband – we don't have time (McAuliffe et al., 2014).

Increased responsibility

Increased responsibility for caregiving and its effect on the family unit was described by parent caregivers in four studies (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010). This outcome was articulated as a value that was embedded in both family dynamics and cultural expectations. The sense of responsibility that caregivers described related to the belief that one should do all that they can to ensure a good life for their child:

"I would probably walk through a wall for him… that's just sort of the way I view how important he is in my life" (Wiens & Daniluk, 2009). The responsibility was embedded in parents' beliefs regarding parental obligation: "Our role is still to be the parent and do the best for him" (Wiens & Daniluk, 2009). Further, ensuring the best possible quality of life for their child, despite the limitations associated with schizophrenia, was paramount: "We have to make him have as good a life as possible… that's all we can do." (Wiens & Daniluk, 2009).

In one study, this sense of parental responsibility was strongly influenced by cultural beliefs and public perception of the family:

> He is my child, I have the responsibility to take care of him. We are family… that is what family should do… You know… We are Taiwanese… Taiwanese emphasise family ethics and values. If we give him up, the public will blame us and we cannot have peace of mind (Yen et al., 2010).

Furthermore, accepting added responsibility was related, in two studies, to religious or spiritual beliefs:

> Renming [accepting misfortunes as decreed by fate]… otherwise… what should I do? I am the person who believes in fate… It is my fate. Who would like to take care of him (son) for me? No one… I cannot abandon my son… and cannot change the reality… My life is destined. Accept the fate rather than hate my life (Yen et al., 2010).

Framing the experience

Participants described how appraising or "framing" their caregiving experiences in positive or meaningful ways helped them cope with their role. Framing the experience occurred through consciously choosing to focus on positive thoughts (subcategory: Positive Thoughts) (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009), believing and succumbing to a higher power (subcategory: Religious or Spiritual Beliefs) (Huang et al., 2009; McAuliffe et al., 2014; Yen et al., 2010), and engaging in personal growth (subcategory: Personal Growth) (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010).

Positive thoughts

Positive thoughts were described in four studies (Blomgren Mannerheim et al., 2016; Huang et al., 2009; McAuliffe et al., 2014; Wiens & Daniluk, 2009) and referred to parent caregivers consciously choosing a state of mind or gaining knowledge that shaped their perspective, which helped them to cope with their caregiver role. The participants indicated how adopting and maintaining a positive attitude was an essential ingredient for coping within their role: "I tried to keep thinking positively and resolve problems… I obtained knowledge from the doctor and the community nurse" (Huang et al., 2009). Parent caregivers also explained how being distracted or busy helped them to function day-to-day:

> Well you know – you live from day to day – I'm so busy in my life – I haven't time to sit down and cry… I'd get emotional maybe off and on and I'd say well – this is terrible – What can I do… You just have to move on… You get used to it (McAuliffe et al., 2014).

Making the conscious decision to prioritize balance helped caregivers maintain their role:

> I've got my own home that I can go to, and I can meet my friends at my place. I even try to have some fun stuff so I can get some balance. I have done this consciously to feel good and I work with it consciously (Blomgren Mannerheim et al., 2016).

and taking a break from their caregiving responsibilities for reflection, was helpful for gaining this balance and perspective: "… I said what I'll do is go away for a few days … come back with a fresh view… weigh the situation… which is what I did – I came to… the cottage – spent four days… thinking" (McAuliffe et al., 2014).

Religious or spiritual beliefs

Religious or spiritual beliefs were spoken about in three studies (Huang et al., 2009; McAuliffe et al., 2014; Yen et al., 2010). These beliefs and practices framed their experiences, both in terms of understanding why and how they came into this role, as well as providing strength and courage to continue. Some parent caregivers explained that they became parents of an ACWS because of karma or as punishment for behaviour in a past life:

> Why don't other people have to suffer the same thing (having a child with schizophrenia) as me. I always tell myself I must owe my son in my past life. So, I need to pay back in this life. When I repay my debt, then, my karma will disappear (Huang et al., 2009).

Similarly, other participants explained how their Gods aligned this role to foster their caring attributes or patience: "… it's a test and a practice of my life tasks… the gods might have some purpose to assign me to be a caregiver… I am not patient or caring enough… so the gods want to chasten my patience." (Yen et al., 2010). Religious ritual and the power of prayer, both within and outside of temples or churches, was also cited as being helpful to maintain one's role as caregiver: "I depend on him (God) for everything – he got me through all this… I am a believer… mass is very helpful because it was a nightmare you know" (McAuliffe et al., 2014).

Personal growth

Personal growth was identified in four studies (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009; Yen et al., 2010) and was described as both a motivating factor for caregiving and an outcome of caregiving. Personal growth involved the caregiver's evolution of character and their enhanced ability to cope with their caregiving experiences. Engaging in the role of caregiver led to strength of character and a greater ability to accept change, experience compassion, and be less judgemental:

> I have a history of difficult things happening in life; therefore, I feel proud that I have managed it – now I go and sing and make sure that I get out and away… dance and try to do the things that I'm good at and that's fun, to get some air under my wings. I've learned and I feel proud over this (Blomgren Mannerheim et al., 2016).

Furthermore:

> I think it's a real eye opener to me to see how I can change… What I do know is that I'm willing to do it. It's a fight between who I am and what I need to do for this child, right? (Wiens & Daniluk, 2009).

Discussion

This qualitative evidence synthesis highlights the caregiving experiences of parents of ACWS. Across the studies, findings revealed the psychological distress apparent in their lives, their experiences with loss, and the ways in which they framed their realities. This discussion will also address the influence of culture, sex, and gender on the transferability of the findings.

Psychological distress

Psychological distress was described in all of the included studies. This finding is consistent with quantitative studies reporting high levels of psychological distress experienced by caregivers of a family member with schizophrenia (Hanzawa et al., 2013; Ong, Ibrahim, & Wahab, 2016). Psychological distress is largely influenced by the subjective experience of burden and is shown to be mediated by severity of psychopathology of the care recipient, time spent in caregiving activities, and coping strategies used (Kate, Grover, Kulhara, & Nehra, 2013).

Unfortunately, parent caregivers for ACWS experience poor quality of life (Grover, Pradyumna, & S., 2015), receive inadequate support from psychiatric services (Shah, Sultan, Faisal, & Irfan, 2013), and are known to be at high risk for psychiatric comorbidities, such as anxiety, depression, or post-traumatic stress (Hanzawa et al., 2013; Schulz, Hebert, & Boerner, 2008). While support groups, education groups, counselling, and respite services are important approaches to supporting caregivers' psychological health and well-being (Dangdomyouth, Stern, Oumtanee, & Yunibhand, 2008), parents in the studies reviewed here described difficulties identifying and navigating the systems housing these resources (Blomgren Mannerheim et al., 2016; McAuliffe et al., 2014; Wiens & Daniluk, 2009).

Improving resource accessibility can effectively improve caregiver experience and reduce stress (Hanzawa et al., 2013). With appropriate training and knowledge of local resources, nurses can not only recommend support services, but also serve as system navigators for families. Furthermore, nurses can work with parents to help them use adaptive coping strategies to ease their distress, prevent further deterioration, and respond more positively to their environment (Ong et al., 2016; Tsai, 2003).

Loss

The parent caregivers in this review experienced a number of losses, including losses related to their child and personal losses. In some cases, the parents equated loss related to schizophrenia to death, with each loss including emotional turmoil and the need to make sense of things and create new meanings (Christ, Bonanno, Malkinson, & Rubin, 2003). Loss in the context of death is permanent, whereas parent caregivers experiencing loss in the context of schizophrenia have multiple unpredictable and non-linear losses, which occur throughout the illness trajectory. Parents described losing their child's 'normal life', academic achievements, vocational aspirations, and personhood because of cognitive, personality, and affective changes.

These losses cause tremendous distress and when preservation of family relationships is not prioritized, family support can wean over time, leaving ill persons isolated and alone (Avasthi, 2010). Very little research exists to explain this attrition of family support, yet research supports its occurrence (Glynn et al., 2006). Based on our practice experiences, we have similarly noted that the number of family members present and involved in care decreases over time, which from an anecdotal observation appears to be associated with exacerbations of illness symptoms. Clearly it is important to understand why this attrition in caregivers occurs, and research is needed to explore the associated factors.

For persons with schizophrenia, family support is imperative, and research shows that poor family support is a risk factor for exacerbation of symptoms and illness relapse, while adequate family support is a protective factor against illness (Glynn et al., 2006; Sariah, Outwater, & Malima, 2014). Currently, there are no specific guidelines or models to explain or predict loss, and we were unable to locate any interventions designed to support parents experiencing loss related to schizophrenia. Grief interventions for parents following death of a child (Endo, Yonemoto, & Yamada, 2015) might offer some insight into this phenomenon, though more research is needed to fully explore the ways in which loss is experienced in the context of schizophrenia. Our findings suggest that at minimum, nurses and other healthcare practitioners should engage in conversations, early in the illness trajectory, about recovery expectations and pre-planning for loss and relapse. Furthermore, formal structures are needed to support caregivers through their loss experiences.

Framing the experience

The findings of this review reveal how some parent caregivers frame their experiences of being the parent of an ACWS in adaptive ways. This is consistent with literature supporting the idea that cognitive appraisal plays a significant role in how individuals respond and adapt to situations (Lazarus & Folkman, 1984). Examining how caregivers adapt (or not) is important to stress in the context of schizophrenia (Avasthi, 2010; Awad & Voruganti, 2008; Bauer et al., 2012; Hsiao & Tsai, 2014), and evidence supports the use of coping processes that focus on positive psychological states when experiencing intense distress (Cohen, Colantonio, & Vernich, 2002; Folkman, 1997; Zarit, 2012). Unfortunately, there is a paucity of work in this area related specifically to schizophrenia. Counselling approaches, such as Cognitive Behavioural Therapy (CBT) (Beck, Rector, Stolar, & Grant, 2008), are often used with caregivers (generally) to help them frame their experiences more positively and ultimately cope better with their role (Alberti, 2016). While promising, there are symptoms inherent to schizophrenia that add complexity to the caregiving role (e.g. lack of insight, hallucinations, and paranoia) and more research is needed to examine the effectiveness of CBT and other therapeutic interventions in this context (Alberti, 2016).

Transferability of findings

It is important to recognize the influence of culture and sex and gender on the transferability of these findings. Two of the five studies included were conducted in Taiwan (Huang et al., 2009; Yen et al., 2010), where religion, spirituality, and karma perpetuated descriptions of these caregivers' realities. The belief that one's circumstances are determined by fate emphasizes a lack of control, which differs between Asian and North American or European Cultures. In Asian cultures, psychological and moral explanations of mental illness are common, whereas biological and genetic explanations of mental illness are more readily accepted by North American and European caregivers (Wu, 1992). In multicultural countries and countries that experience immigration, nurses provide care for people of vast cultural inheritance. Findings from this review provide some insight into the particularities of caregiver experiences across cultures, though the number of papers representing each are small. Further qualitative exploration of caregiver experiences within homogenous samples will better our understanding of cultural variations.

The influence of sex and gender on experience should also be considered when interpreting the findings of this synthesis. In the included studies, females represented only half (55%) of the total sample of parent caregivers. One study was specific to fathers' experiences (Wiens & Daniluk, 2009), and even when calculating proportions of males and females with the exclusion of this study, female participant representation was still far below estimated norms. In the United States, approximately 82% of family caregivers are female and 90% of schizophrenia caregivers are mothers of ACWS (Awad & Voruganti, 2008). Gendered research on caregiving highlights the differences between men and women in their enactment of this role, and differences in perceived needs may be rooted in gender. Researchers should consider exploring the differences in experiences between mothers and fathers as influenced by gender.

Limitations

There are three limitations to consider when interpreting the findings of this review. First, it is possible that the search strategy failed to identify all pertinent literature. To minimize this threat, we designed and conducted the search with the assistance of two library scientists with expertise in systematic review methodologies. Surprisingly, we found one study (Blomgren Mannerheim et al., 2016) by happenstance, which was not identified by our search strategy. In light of this discovery, an additional meeting with a library scientist revealed that the article did not have assigned MESH headings and was only available via an external link on PubMed Central, thus making it non-retrievable. It is possible that other pertinent studies with similar indexing issues were

also missed. Second, inclusion criteria specified that parent caregiver experiences needed to be supported by participant quotes, clearly reflective of only parent participants, and specific to ACWS. As such, studies with quotes that did not identify the source of the quotes or differentiate between mental disorders, were eliminated. It is possible that relevant experiences were embedded within these other study findings. Third, as with all meta-synthesis studies, there is a possibility for bias or misrepresentation of the original experiences because data are garnered from secondary sources (Sandelowski, Docherty, & Emden, 1997; Walsh & Downe, 2005). To minimize this, the research team, which had expertise in schizophrenia and family caregiving, discussed the synthesis process and interpretation of the findings.

Conclusion

The aim of this review was to synthesize qualitative literature that explored the experiences of parent caregivers for ACWS. Experiences of loss were prevalent and parent caregivers grieved losses related to their child and themselves. Parent caregivers appear to need help navigating available services and support for their own mental and physical health. Importantly, parent caregivers were able to frame their experiences in ways that were helpful for their coping and maintaining their caregiving role. In practice, there is a demand to improve accessibility and understanding of available resources in order to reduce psychological distress of parent caregivers. From a research perspective, the development of guidelines or models to explain and/or predict loss in schizophrenia is needed, as is the implementation and testing of parent caregiver support interventions like CBT. Family support is vital to the health and well-being of ACWS and it is therefore essential that appropriate strategies are implemented to address the needs of these families.

Conflicts of interest

The authors declare no conflicts of interested related to this study.

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