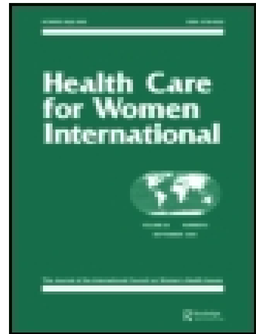

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Post-traumatic growth: Health professionals as mothers of adult children with schizophrenia

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ABSTRACT

Worldwide, mothers provide lifelong care for their ill children. Our aim in this paper was to describe the development of post-traumatic growth in an international group of mothers. Interviews with a feminist storytelling approach were conducted with 13 health professionals who were mothers of adult children with schizophrenia. Using thematic analysis, we found they had experienced a complex traumatic process complicated by gender and health care's dominant ruling relations. Over time, the women grew and became experts by experience due to their combined mothering and professional knowledges. Health professionals can play a central role and support their peers to care for family members with mental illnesses.

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There is a growing interest in the experiences of mothers caring for their adult children with schizophrenia (Wiens & Daniluk, 2017) internationally. Researchers have revealed that parenting an adult child with schizophrenia can have significant effects on the parents' physical and psychological well-being (Barker et al., 2012; Wiens & Daniluk, 2017), leading to their disenfranchisement and disempowerment (Milliken, 2001). Caring for an adult child with schizophrenia is fraught with challenges for any mother and the addition of a dual role as a health professional may further complicate their experiences of power and vulnerability.

In this paper, the authors discuss aspects of personal growth revealed in a recent international study of an interdisciplinary group of health professionals who have dual roles as mothers of adult children with schizophrenia. Drawn from a larger qualitative study (Klages et al., 2019) the authors of this paper aim to shed light on experiences of post-traumatic growth. We begin with a brief overview of post-traumatic growth theory and provide a definition of post-traumatic growth relevant to the women's unique

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social context and life experiences. Then we describe how the participants have reconstructed their perceptions of self and others from the primary and secondary trauma that they witnessed and endured. To avoid confirmation bias (Roulston & Shelton, 2015), wherever possible, quotes from the participants in the study are presented as intact as possible to accurately present their viewpoints rather than those of the researcher.

Background

For many young people diagnosed with schizophrenia, their first episode of psychosis is a distressing and traumatic life event (Berry et al., 2013; Jackson et al., 2004; Rodrigues & Anderson, 2017). Correspondingly, although the prevalence of post-traumatic stress disorder (PTSD) with people diagnosed with schizophrenia appears higher than in general population, researchers have posited that PTSD may actually be underdiagnosed and therefore an untreated comorbidity (Dallel et al., 2018).

As a result of their proximal nurturing relationships, mothers may experience trauma (Arnold et al., 2005) as they bear witness to behavioral disturbances known to be caused by the neurotoxic processes inherent in the pathophysiological changes in their children's brains (Kahn & Sommer, 2014) during episodes of untreated psychosis.

Literature: Post-traumatic growth

Existential theorists such as Frankl (2011) have focused on how people have been able to create meaning in the midst of traumatic experiences. The theory of post-traumatic growth is founded on the theoretical perspective offered by existential literature that people who have experienced adverse events often develop resilience (Tedeschi et al., 2018).

The interest in post-traumatic growth and resilience has been marked by recent debates about the validity of the research claiming that the majority of people who have experienced adverse life events remain unscathed or experience positive changes (Infurna & Jayawickreme, 2019). Others have argued that when life stressors are enduring, uncontrollable, and unpredictable, this stress can result in deleterious effects, yet at the same time result in the capacity to adapt to the ongoing disturbances (Masten & Cicchetti, 2016; Zimmer-Gembeck & Skinner, 2016) that threaten the health and welfare of individuals.

Methods

Drawn from a larger qualitative study, the researchers used a matricentric feminist perspective (O'Reilly, 2016), which provided a safe place where

participants described how they had created a delicate balancing act while mothering their adult children with schizophrenia. To obtain a deeper understanding of women's lived experiences, we chose a feminist narrative approach, as an egalitarian model of parallel communication between people who share common interests. This narrative approach was developed into a method to collect data in feminist qualitative research, as it gives access to the participants' lived experiences (Klages et al., 2019). The use of reflective thematic analysis (Braun & Clarke, 2019) made it possible for the researchers to visualize themes within the data corpus. By using this approach, we tentatively began to identify and examine underlying ideas and assumptions providing unanticipated insights (Braun & Clarke, 2006) into the complex experiences of mothers with dual roles as health professionals. This study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007).

Participants

Information about the study was disseminated through professionally oriented social media platforms as well as in professional journals and web pages. Recruitment was not limited to any specific geographic region. Inclusion criteria were as follows: mother of an adult child with schizophrenia and a health professional. The study was carried out by a researcher with insider experience of the research topic along with her colleagues who were experts in mothering research, feminism, and mental health nursing.

A sample of 13 women who were the biological mothers of adult children with schizophrenia were interviewed using Skype or in person. The participants from Australia, Canada, Scotland, and the United States included four mental health nurses, five registered general nurses, one social worker, one occupational therapist, one medical researcher, and 1 medical doctor.

Permission to undertake this study was granted by the relevant Human Research Ethics Committee. Prior to beginning the interviews, all of the participants signed a written consent form that explained the purpose of the study, and their rights as participants.

Procedure

Participants were deliberately recruited to gain access to women who shared common experiences. The research team of women included three nurses with PhDs and one nurse with a Master's in Advanced Nursing Practice (mental health). The interviews were scheduled with the women

who were interested in participating in the study after they had received written information about the study in which ethical considerations were also outlined. The participants and the interviewer mutually chose the settings in which they were to be interviewed. The interviews took place using Skype or in predesignated private locations. None of the participants had a preexisting relationship with any member of the research team.

Conversational interviews were used to facilitate the sharing of the participants' stories of negotiating care for their children who had been diagnosed with schizophrenia. The first author began the interview by disclosing her lived experience as both a mental health nurse and a mother and then asked the participants to tell their mothering stories starting from the onset of their child's psychotic illness. Good research ethics practice requires consideration as what the researchers give to their research participants and not just what they take. Self-disclosure through the reciprocal sharing of our mutual connection as mothers may have reduced any perceived power imbalances and improved communication.

In total, 13 interviews were conducted by the first author and they lasted approximately 1 hour. The interviews were conducted from November 2017 until July 2018. The interviews were audio recorded and then professionally transcribed. The first author validated the veracity of each transcription by listening to the recording while reading the written transcript.

The transcripts were analyzed according to Braun and Clarke's (2006) step-by-step guide to thematic analysis. The analysis was primarily carried out by the first author. During each phase of the process the nascent themes along with the positionality of the first author were discussed during regular meetings with the research team until there was a consensus. This strengthened the credibility of the research process and prevented researcher bias (Blythe et al., 2013). The analysis of the transcripts continued until saturation was reached and no new topics emerged in the interviews (Saunders et al., 2018).

Findings

As we analyzed the data within the interviews, it became clear that the first episode of psychosis was distressing. The mothers' distress was very present and continued after their child's subsequent diagnosis of schizophrenia. As they were able to come to terms with their new reality, their distress became a catalyst for post-traumatic growth. We were able to identify three themes that were associated with the women's post-traumatic growth processes. The first theme is "our hands were tied" and can be defined as the experience of disempowerment that accompanied the distressing events surrounding a first episode of psychosis. This was the seed of their

post-traumatic growth. The second theme is "accepting and adapting" and can be defined as a precursor of post-traumatic growth, which provided the environment that nurtured their ability to move forward as mothers and health professionals. The third theme is "I could make a difference" and can be defined as the actual growth of hope that, as experts by experience, they can help others care for their children who have been diagnosed with schizophrenia.

First experiences of trauma

Theme 1 "Our hands were tied"

Experiences during the first psychotic illness episodes were traumatic for these mothers. The trauma experienced by the mothers was exacerbated by the difficulties and delays in obtaining health care. As health professionals and as mothers, our participants knew that there was something wrong but struggled to gain access to support, particularly to early psychosis assessment and treatment.

One participant felt angry and distressed by what she perceived as the lack of an effective response from the mental health system to her concerns for her son's safety and the safety of others. She was aware of the warning signs that her son's mental health was deteriorating but was informed that they would only receive assistance after an impending mental health crisis had actually occurred and not before.

> There were numerous times when his behavior got, was getting worse and he was obviously getting paranoid, but because he wasn't threatening to commit suicide or threatening anybody else, there was absolutely nothing that anybody could do. And even when I clearly described what was going on there was absolutely no help … That's the bit that actually makes me angry because there must be so many people. (Nancy)

When participants were able to access mental health care for their children, this experience was not necessarily positive. One mother recalled the deeply disturbing experience of her 16-year-old child's admission to an adult inpatient mental health unit while overseas and stated: "It was an incredibly traumatic experience … it's like literally 'one flew over the cuckoo's nest' [Kesey, 1962] … people were tied to their beds" (Mary).

Precursors of post-traumatic growth

Theme 2 "accept and adapt"

For mothers of adult children with schizophrenia, their exposure to negative life events may have challenged their beliefs in their own capacity to exercise control within their world. The participants began to shoulder

the intense challenges involved in mothering an adult child with schizophrenia. They coped and adapted to their "changed worlds" by using their personal and professional strengths. One mother shared how she had nurtured her own tenuous sense of composure after she was able to accept and adapt to the reality that her son's future had been re-shaped by his diagnosis.

> He's not going to get back to where he was. I think I've pretty well resigned myself to the fact that he's not going to [be the same as before]. I think for me it's been a little easier, since I realized that I can't influence this… It doesn't do me any good to wish for stuff… I think all of this is even more for my own mental health and peace of mind. (Sheila)

For all of the mothers, their child's emergence from a teenager into a young adult had become a series of challenges due to exacerbations in their psychotic symptoms and frequent hospitalizations. One mother's son had behavioral disturbances in primary school and had been living with the effects of schizophrenia for several years. At the time of the interview, he was cycling between brief periods of wellness followed by crisis admissions to inpatient mental health units. Nancy had accepted her "changed world" and had become intimate with her discomfort while she navigated the uncertainties in their present and future lives:

> I don't know what part of him I'm going to get back. You know it becomes a new normal. So that's where we are. (Nancy)

After their children were discharged home from an inpatient mental health unit, the participants yearned to recover and resume their "normal" family lives. The mothers who may have previously fretted about common childhood illnesses now worried about caring for an adult child with a mental illness. Linda described how she struggled alone using her professional skills to care for her son after his diagnosis. Reflecting back upon her difficulties in adjusting to her new role, she admitted that her conceptualization of "normal" family life would likely have precluded her acceptance of "outside" professional help for her son.

> They [the mental health team] might have contacted him [my son] but we certainly weren't aware of it… We were totally in the dark in our understanding… You know, I think back then we were very much, "we'll just deal with this in our family," so there was an element of that, you know it was kind of okay because we didn't want their – we didn't really want them [the mental health team] in our family… I think we were keen to appear as normal as possible… I think we were oblivious; I think we were kind of fumbling around trying how to work out how to manage his behaviors and trying to take his medication. And I had done some narrative therapy stuff, so I was quite … I went into a little bit of counselling mode in terms of doing externalizing the problem. And, surprisingly, it worked really well. So, we're externalizing these voices which were external to him, but, you know, we can't see them of course. (Linda)

Relational growth: Experts by experience

Theme 3 "I could make a difference"

With the participants, any future goals for collective action as "agents for change" for improvements in mental health care were preceded by their individual process of relational growth. Their relational growth occurred as participants found meaning from their difficulties and experienced growth through their reciprocal sharing of their stories with others. One participant reflected upon how her own self-disclosure of her lived experiences had resulted in open discourses with her professional peers about their own experiences:

> So, once you say it, then more people tell you that they too have a partner or a child or a close relative who may even be living with them with a significant mental health problem. (Linda)

Their experiences as mothers with dual roles transformed them from being experts by profession into experts by experience. Opportunities arose that allowed them to share their newfound knowledge with others. One woman explained how she became empowered to use her combined knowledge to help others to navigate the isolating experiences involved in parenting children with mental illnesses.

> And I thought, I can't go back to nursing … It's funny, I just felt I couldn't, I don't know, I just couldn't take people's stuff on. I don't know. But I guess after a while I started thinking about peer work and about how lonely it is when you're going through this and, you know, I could make a difference. I could make a difference. (Mary)

Personal experiences of the negative effects of stigma while caring for their children prompted participants to make a commitment to engage at the mezzo (intergroup) level to reduce discriminatory practices and thus improve the treatment of people living with schizophrenia:

> Hopefully people like us are knocking down the stigma. That's my mission for the rest of my life is to reduce the stigma around mental illness and I guess schizophrenia in particular and psychosis. It's my thing that will take me to my last days, that's my mission. (Mary)

Definition of post-traumatic growth

Traumatic events can occur in a multitude of settings and the effect they have on particular individuals depends on any number of disparate factors. In the context of this research, we have defined post-traumatic growth as the growth that occurs as a result of the blending of knowledges (one knowledge coming from the professional/scientific knowledge held as health professionals, and the other knowledge coming through mothering a

child with schizophrenia). These two knowledges are fused into a single amalgam and both ways of knowing are strengthened as a result.

Discussion

In this paper, we have discussed the transformative process of growth arising from the blending of the professional and scientific knowledge with the experiential mothering knowledge. The process was challenging because from the beginning, the participants as health professionals and as mothers knew that there was something wrong but were unable to gain access to meaningful assessment and treatment.

Researchers have indicated that first episode psychosis treatment programs have been found to improve mental health outcomes by reducing the duration and severity of untreated psychosis (Galletly et al., 2016) and this access may have improved the lives of the participants' children. When families do access mental health care for their children with a first episode of psychosis, the first hospitalization can often be a frightening experience (Jackson et al., 2004; Large & Neilssen, 2011; McCann et al., 2011) as was the case for our participants.

Many people diagnosed with schizophrenia live at home and are cared for by their mothers (Tennakoon et al., 2000). For mothers of adult children with schizophrenia, exposure to the sequelae of the onset of an enduring mental illness may have challenged their beliefs in their own capacity to exercise control within their life and world. At the same time, there was the potential for post-traumatic growth to occur as a result of their ongoing struggles to endure these life-changing events as they continued to live in their "changed worlds" (Cann et al., 2010; Tedeschi et al., 2018; Zięba et al., 2019).

The participants shouldered the intensive and unique challenges involved in mothering an adult child with schizophrenia. They coped and adapted to their "changed worlds," by using their personal and professional strengths. At the micro level, empowered by their "internalized norms" as both mothers and health professionals (Gavrilets & Richerson, 2017; O'Reilly, 2016), they became informed providers of care for their children (Klages et al., 2019).

Due to the unpredictable and cyclical nature of schizophrenia, the intensity of their mothering practices fluctuated. By acknowledging the constraining effects in relation to their child's diagnosis, the mothers were not attached to an imaginary relationship with their current reality, which has been described by Berlant (2011) as "cruel optimism." Nevertheless, periods of recovery and resolution allowed them to recoup sufficiently to share their wisdom with others. Their unique life cycles enabled them to see the

mental health system from an "insider" perspective and they became empowered to use their voices to advocate for others. Research has indicated that self-disclosure and experiences of compassionate and accepting reactions can foster reciprocity between health professionals (Lindstrom et al., 2013) and aid in the future development of post-traumatic growth.

In collective action processes involving growth through social change, self-organization occurs under particular conditions within specific domains (Ostrom, 2000). Another facet of their burgeoning self-organized individual action was evident in their transformation into "professional expert companions" (Tedeschi et al., 2018) who, as have other health professionals, made a difference by providing support and guidance (Luthar et al., 2017) for their colleagues and peers.

The participants' capacity to cope and adjust to the changes within their family life resulted in clear, deep, and sudden insights into the importance of their individual contributions to compassionate conversations about mental ill-health. Thus, they were able to use their insider knowledge of living with schizophrenia as an impetus to challenge prejudice within their sphere of influence and promote empathic professional discourses.

The authors propose that contemporary theories about the love and laboring of mothering (Lynch, 2007; O'Reilly, 2016; Ruddick, 1995) may have been altered by the women who have shared their stories of mothering and caring as they struggled within the dominant ruling relations of mental health systems. Our findings suggest that theories of discrete mothering practices (Lynch, 2007) have been expanded and transmuted by the mothers' immersion in all aspects of the "love labor" required to maintain their primary relations with their children, along with their secondary or "general care" work, which subsequently began to include "solidarity work" in which they, as experts by experience and profession, began to engage.

We suggest that the women's distinct roles as mothers who perform "non-commodifiable" forms of caring (Lynch, 2007; Ruddick, 1995) have been blurred with their roles and forms of care provided as health professionals, as described by Giles and Williamson (2015) and that this has become a source of distress and strength for them. We also propose their difficult experiences during episodes of post-traumatic growth may have fortified them as mothers and as health professionals.

Summary

There is the potential for mothers who have survived similar traumatic events to experience positive changes, tenacity of spirit, and sometimes even a drive to help others in similar circumstances. Mental health professionals working with their colleagues, who have dual roles, can be sensitive

to the complex individual, familial, and institutional realities that inextricably involve processes of inclusion and exclusion from care and support for their adult children. We further argue that there is a need to support the wisdom of, and research around, health professionals who are mothers of adult children with schizophrenia.

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