

**Title**

Parents' perceptions of the physical health outcomes of young people diagnosed with first episode psychosis

**ABSTRACT**

This study explores parents' perceptions of their son/daughter's physical health needs following a first episode psychosis diagnosis and commencement on antipsychotic medication. The research process was guided by grounded theory methodology and data were collected using semi-structure interviews with 16 parents. Four categories were identified. Participants described the importance, challenges and strategies for their son/ daughter to maintain their physical health, and the need to improve young people's health literacy, particularly in areas of physical health, diet and lifestyle. These findings will assist health professionals to provide parents with information to better support their son/daughter to maintain their physical health.

**Introduction**

Having a psychosis can be a debilitating and life-changing experience for young people, especially at the time of diagnosis (Gibb, Fergusson, & Horwood, 2010). Even though the prognosis of a full recovery is possible with evidence-based treatment, many young people continue to experience ongoing persistent psychotic symptoms (Reed, 2008). Moreover, the occurrence and treatment of first episode psychosis (FEP) can adversely affect the young person's physical health and general wellbeing (Curtis, Newall, & Samaras, 2012; Murphy et al., 2015). Longitudinal research reports that the majority of young people diagnosed with FEP experience poorer physical health than young people who do not have a psychosis (Mitchell et al., 2013). These physical health issues include obesity, diabetes and

cardiovascular disease (Curtis et al., 2012). The young person's use of alcohol and other drugs may further impact their mental and physical health (Carney, Cotter, Bradshaw, & Yung, 2017; McCloughen, Foster, Kerley, Delgado, & Turnell, 2016). Furthermore, taking antipsychotic medications makes them more likely to develop physical health problems earlier in life than young people in the general population (Correll et al., 2014; Curtis et al., 2011). Changes in weight and lipid parameters are also reported to be more significant in young people than in adults taking antipsychotic medications (Kryzhanovskaya et al. 2012).

Many young people diagnosed with FEP will have a lifelong psychotic disorder which may place a substantial caregiving burden on their parents and family (McCann, Lubman, & Clark, 2011). In Australia, it is estimated that 2.4 million people (15% of the population) provide care to people with mental illness (Bailey et al., 2018).

Parents are the most common caregivers (Poon, Curtis, Ward, Loneragan, & Lappin, 2018) providing functional, financial, social and emotional support to their son/daughter (Bailey et al., 2018). This support plays a significant role in their son/daughter's ability to manage their illness and on their recovery trajectory (Small et al., 2017). Cree et al. (2015) highlights that carers must be included as collaborative members in the care of their family members. Yet mental health policy in many countries place carers as central to many aspects of care (Happell, Wilson, Platania-Phung, & Stanton, 2017a ); several challenges remain when a person takes on a caregiving role (Bailey et al., 2018; Wynaden, 2007). Parents often feel unsupported in their caregiving role and as a result their own mental and physical health may be compromised (Poon et al., 2018; Wynaden, 2007).

Parents may be the first to notice changes in the physical and/or mental health of their son/daughter with FEP (Cree et al., 2015; Onwumere, Howes, Shiers, & Gaughran, 2018). Noticing emerging co-morbid physical health problems resulting from their son/daughter's illness, lifestyle choices and the effects of prescribed medications to treat the psychosis can

cause parents additional distress and further increase their anxiety and caregiving burden (Chang, Chiou, & Chen, 2010). How health professionals educate parents to assist their son/daughter to address emerging physical health problems is not well documented (Happell, Wilson, Platania-Phung, & Stanton, 2017b; McCann et al., 2011). This article documents the findings of research conducted with parents to obtain insights into their understanding of the physical health issues that their son/daughter may experience following a diagnosis of FEP. Qualitative research methodology was used as it is a methodology of choice when little is known about the issue being investigated. The findings of this work will assist health professionals involved in FEP programs to provide education to young people and to their parents/carers about the importance of maintaining physical health and making good lifestyle choices.

## **METHOD**

### **Design**

The grounded theory method was used in this research to describe parents' perceptions of the physical health of their son/daughter following diagnosis of a FEP. Data were collected using semi-structured interviews. The researchers did not set out to develop a substantive theory but used the grounded theory method as described by Glaser and Strauss (1967) to guide data collection and analysis. Purposeful and theoretical sampling techniques were used along with grounded theory coding techniques and the use of the constant comparative method of analysis. This allowed the emergence of categories that described participants' experiences. The Western Australian South Metropolitan Area Health Service Research Ethics Committee and the Curtin University Human Research Ethics Committee approved the research. Data were collected between July 2015 and June 2016.

## **Recruitment**

Initially purposeful sampling was used with parents of young people enrolled in FEP program at one mental health service in Western Australia. A total of 24 parents were invited to participate and they were given an information sheet outlining the research and what their voluntary participation would involve. Sixteen parents agreed to be interviewed. The principal researcher who conducted the interviews had no prior clinical involvement with either the young mental health consumers or their parents.

## **Procedure**

All participants provided written informed consent to participate before being interviewed. Semi-structured interviews were conducted at pre-arranged locations convenient to participants such as their home or at the health care facility. Interviews were digitally audio recorded. A semi-structured interview guide was used to provide structure and consistency for each interview. These questions not only guided the interview but also allowed the researcher flexibility to explore each participant's responses. Each interview lasted approximately 45 minutes. After the 10<sup>th</sup> interview, based on concurrent data collection and analysis, theoretical sampling was used to recruit participants who had different or expanded experiences to those recruited during initial purposeful sampling. These experiences included participants' pre- and post-engagement with their son/daughter's FEP clinicians and with the adult mental health service after their son/daughter completed the FEP program and care was transferred to adult service. Data collection continued until saturation was reached and no new information was being obtained. At this time, data were rich in descriptions and categories clearly defined.

## **Data analysis**

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As in keeping with grounded theory methodology, data collection and analysis occurred concurrently. The audio-recorded interviews were transcribed verbatim by the researcher along with field notes, and imported into a computer software, NVIVO 11, after each interview was completed. Participants' details were de-identified to ensure confidentiality. Each interview was then coded according to grounded theory coding families. The constant comparative method of analysis was used to analyze the individual interview and to compare each interview with others. As each transcript was read and re-read line by line for data familiarization, open coding was applied to break down, examine, compare, conceptualize and categorize the information provided by the parents. The data were then reconnected through formation of linkages between emerging categories and its subcategories. The process of linking data in axial coding determines the common features in the transcripts. The process continued with revision and creation of codes from the interviews to formulate the key characteristics of the data. Distinctive categories were mapped during the selective coding process.

### **Trustworthiness of data**

Trustworthiness of data during collection, analysis and identification of categories was ensured by adherence to grounded theory method (Foley & Timonen, 2015). The creation of an audit trail to link raw data and codes with categories and sub-categories increased the confirmability and dependability of the data. Furthermore, the principal researcher carried out the initial data analysis and another co-researcher reviewed the information independently. A semi-structured interview guide was used to ensure the interviews were conducted in a consistent manner to strengthened credibility. Participant quotes are presented to fully describe their experiences (Cooney, 2011; Foley & Timonen, 2015). Data were reported

according to the consolidated criteria for reporting qualitative research (COREQ) guideline (Tong, Sainsbury, & Craig, 2007).

## **RESULTS**

Of the 16 parents who participated, 14 (87.5%) were female. Participants' age ranged between 43 and 63 years (mean = 55.5, SD = 7.3). Ten parents (62.5%) reported that their son/daughter lived with them. The remaining six parents had either face-to-face meetings with their son/daughter or contacted them via phone calls on a weekly basis. Four categories emerged from the data that described participants' views about their son/daughter's physical health: (1) importance of physical health to overall health; (2) impact of taking antipsychotic medication; (3) lack of information about the need to stay healthy; and (4) strategies to improve physical health.

### **Category 1: importance of physical health to overall health**

Participants spoke of a healthy mind and body as two key factors that determined a person's quality of life and how young people can function more effectively when they are physically and mentally well. However, when their son/daughter was diagnosed with a FEP, it impacted on their son/daughter's physical health as one participant described:

I think mental illness and taking the medication [for the illness] is tied up with physical illness. If you don't feel like getting out of bed, you're not going to go for exercise and then if you don't do any exercise, you'll probably end up being obese. So that is a vicious circuit that sort of tie all up. If you're doing physical exercise I think it makes you feel better as the activity produces endorphins and you'll be physically well. (P8)

Parents spoke about the importance for young people with FEP remaining physically healthy to assist them to improve their mental health: "Your physical wellbeing affects

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mental and emotional wellbeing. If you don't feel well physically, you are not up to do things, and your thoughts aren't in tune" (P4). They explained that young people with FEP experience sleep dysfunction, loss of appetite, low energy levels and other physiological repercussions due to the constant disturbing presence of their psychotic symptoms. Having good physical health was viewed as a balancing factor as it increased their son/daughter's ability to manage the impact of their mental illness. Parents described numerous benefits of maintaining good physical health which included improved sleep pattern, increased energy level, enhanced self-esteem, and more positive mood and attitudes: "When you are physically fit and well, your mind works much better. When you exercise, you have better sleep at night because your energy is expended – definitely there is a relationship between physical and mental health" (P16).

Parents expressed that their son/daughter with FEP had a higher chance of leading a healthier, longer and more fulfilling life if they maintained a good level of physical health: "I think physical health is important because one can live to an old age. It is important for people around you too, if you are healthy, other people will also feel healthy as well" (P2). They believed that their son/daughter would enjoy a better quality of life because regular physical exercise released endorphins which produced the 'feel good factor' lifting a person's mood: "You have to be physically fit otherwise you'll feel grumpy or sad. I think going for a walk with the dog or exercise is the best thing. It improves fitness, your physical health affects mental health" (P12). However, they witnessed their son/daughter's efforts and setbacks to engage in physical activities: "It's a vicious cycle! When you get unmotivated, you look for vices – you look for drinks [alcohol], you eat too much ... it's definitely hard on the self-esteem and this pattern continues on, it's not good for anybody's physical health" (P12). Another participant explained that young people with FEP needed to be:

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Comfortable in their body and be able to do the things they want to do. They can go rock climbing if their weight is 20 kilos lesser, their quality of life is better. They don't want to get overweight, have high blood pressure or be unable to do things physically. (P14)

Participants recognized the importance of regular physical activity in preventing physical health problems and the need to provide their son/daughter with positive encouragement to maintain good physical health. They believed the emphasis on maintaining physical health should be an integral part of all FEP programs.

### **Category 2: impact of taking antipsychotic medication**

Parents expressed that the antipsychotic medication their son/daughter took for their psychosis was a catalyst for the development of physical health issues. When young people commenced taking the medications parents witnessed decreased levels in motivation in their son/daughter to engage in physical activities:

Well I don't nag at him [son], I don't tell him what he knows, what he should be doing you know, nobody likes that. I just like to encourage him – I go easy on him, it isn't easy for him to keep up his physical health. I think after being on medication for a while he doesn't feel motivated, he feels tired all the time, the medication makes a difference. (P4)

Parents believed that the effects of the medication led their son/daughter to lead a sedentary lifestyle which became difficult for them to change:

Well he's got to lose weight, I mean he put on so much weight so easily but losing weight is not easy. He doesn't feel like exercising all the time, that

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doesn't help he is unmotivated. He just doesn't have the energy to get up and exercise and do what need to be done to get back in shape. (P4)

Parents also spoke how antipsychotic medication decreased their son/daughter's level of motivation and overall capacity to function on a daily basis:

I've noticed that there is a link between the psychosis and his [son] physical health. Since he started taking the medication [antipsychotic] it destroys his self-motivation and kills his competitive attitude. He gains too much weight, he dips to the lowest, sloppy unhealthy denominator I have ever seen. The fight back from there is a difficult one. (P9)

Another participant provided a similar account:

Definitely no motivation, definitely the medication caused it, you know the once a month needle [Paliperidone, depot medication]. When he [son] has the injection all he does is sleep all day. He doesn't talk to anyone, no one can bother him for two weeks. After the second week, as the [medication] wears off, he starts to come good. He wants to go out and do things. Then he has another needle and he goes back to the same pattern. (P2)

### **Category 3: lack of information about the need to stay healthy**

Health literacy was viewed as important in order for parents to assist their son/daughter to make informed health care decisions. However, participants reported that they were not routinely provided with any education from the health professionals they had contact with: "Yeah, a lack of information can prevent people [son/daughter] from getting healthier" (P11). They wanted to be better informed so they could identify signs and symptoms of physical health deterioration:

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He [son] has been physically unhealthy for a very long time. I think it is lack of routine over time, but he has been in this state for a very, very long time [and] it didn't happen overnight. I didn't think there is anything wrong with him physically, I thought he was okay. What to do, I didn't see that [deterioration in his physical health] coming, I had no idea, no clue, no information, no support [in a frustrated tone]. (P3)

Parents spoke of how health professionals did not collaborate with them or provide education in areas such as physical health and drug education and the negative influences this had on their son/daughter's physical health:

Well there was going to be a family meeting, but it never happened. There wasn't a lot of information about physical health given to me. He doesn't eat, doesn't do anything, I think he is going to die. I don't know what to do. I need help too. (P2)

One parent stated that her daughter's age was a factor in limiting the information provided to the family about her illness:

There was a lack of information, like in terms of medication – what sort of medication she [daughter] was taking? I felt that the doctors wouldn't really explaining much about the illness [psychosis] and other potential physical problems to her. Maybe because of her age, being sixteen she was a young adolescent when she first started seeing the psychiatrist. (P5)

Participants spoke of the need for physical health education to be an integral part of FEP programs as it was essential that their son/daughter acquired this information so they were informed about the need to maintain their physical health:

I think different people [son/daughter] need different information [and it] depends on where they are at in their life. For example, getting back to as close as what a person [with FEP] is doing before they get physically unwell – getting back to work, being able to function properly. It is a process; it all takes time, maybe longer for some. (P1)

#### **Category 4: strategies to improve physical health**

Role modeling was considered by parents to be an effective strategy to raise the importance of maintaining physical health for their son/daughter: "Role modeling, if I am healthy, eating and drinking healthy, people around me should follow my footsteps" (P2).

One parent explained:

I think there are a lot of challenges. In some people [who experience FEP], they're not well enough to take care of themselves properly so their physical health does deteriorate. They need lots of reassurance, encouragement to build them up. They just need that support, reassurance and I show them what and how to do it until they're a bit more stable. (P7)

Promoting a healthy diet was also a strategy used by parents to help their son/daughter to be more physically healthy. Parents understood that good dietary habits was an essential part of leading a healthy lifestyle and combining physical activity could help their son/daughter maintain a healthy weight, reduce their risk of chronic physical illnesses and promote their overall health: "He [son] is getting chubbier all the time and eating rubbish. So I cook for him and give him fruits and yogurt. I think he is starting to eat healthier and getting physically active" (P12). Other parents provided these perspectives:

I think it has a lot to do with his [son] motivation to keep an optimal physical health. He changed to drinking honey and healthy herbal tea and eating lots of nuts that is good for him. No fats, he eats eggs, lean meat, fish and all sort of proteins. He also has his mother's cooked meals and a good support structure from his two brothers. (P15)

When he [son] recovered mentally, I got him on a stable diet, I also got him a bike to get some exercise. He caught up with his sleep, and he did quick mathematical equation

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to exercise his mind. He would eat, exercise, sleep in a natural way and it becomes a habit. But he needs a mentor, someone or a group who can help him to go to the next level so that he can form a relationship with other people. (P3)

Although the level of physical activity and good diet seem to be critical for young people to maintain physical wellness, another strategy central to improving physical health identified by participants was support from family and friends. A parent shared: “We’re a good family, we stick together and love each other and help each other through the bad times” (P5); while another parent indicated: “Her [daughter’s] peer support worker was a motivating factor for her to exercise and to establish her daily routines. We [family members also] helped her and she had a lot of supportive friends” (P6). Parent also explained that young people should be empowered to make informed physical health decisions:

Well I guess it’s really important to have information and knowledge about physical health care – especially on self-care and medication [antipsychotic] side effects because it is empowering. I think people [with FEP] should write down their goals so that they have something to work toward. We [parents] can encourage them and reassure them, sometimes help them organize simple tasks as well as to set strategies just to get them through. It empowers them to be able to make the right choices. (P7)

## **DISCUSSION**

The findings of this research describe the distress that parents experience when their son/daughter is diagnosed with a FEP and their feelings of helplessness as their son/daughter’s physical health also begins to decline. While early and prompt treatment promises a good mental health outcome for young people with FEP (Mitchell et al., 2013), they remain a high risk group of developing physical health issues early in life (De Hert, Detraux, Van Winkel, Yu, & Correll, 2011). As a result, they have a reduced life expectancy

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when compared to young people in the general population. Although there is an increasing awareness of the physical co-morbidities occurring in adults diagnosed with a mental illness, emerging literature is now increasingly focused on the poor physical health outcomes in young people diagnosed with FEP (Hetrick et al., 2017). These poor health outcomes are often exacerbated by the early use of antipsychotic medications (De Hert et al., 2011; Murphy et al., 2015).

Young people with FEP are often supported by their parents who provide substantial hours of unpaid care to their son/daughter (Happell et al., 2017a). This caring role impacts on the parents' level of wellbeing and causes carer burden (Onwumere et al. 2018). While parents use strategies to assist their son/daughter to maintain their established lifestyle before to their diagnosis of FEP, parents often lack the support and partnership of health professionals in their caregiving journey. For example, Happell et al. (2017a) reported that health professionals did not listen to carers when they raised concerns about their family members' physical and mental health. This finding is counterproductive to mental health policy directions to involve carers collaboratively in care.

This current gap identified in practice devalues parents' role in their son/daughter's recovery and leaves them ill prepared to care effectively. It also ignores the integral role parents play in the provision of emotional support, advocacy and day-to-day care of their family member (Happell et al., 2017a; Onwumere et al. 2018; Wynaden, 2007). Furthermore, parents receive little education to improve their health literacy in the area of physical and mental health and are left to struggle to find effective ways to encourage, motivate and support their son/daughter to care for their physical health (Nilsen, Frich, Friis, & Rossberg, 2014).

Parents in this research reported the close links between mental and physical health problems and expressed concern about the impact of the medications used to treat their

son/daughter's mental illness on their physical health outcomes. Their concerns have been previously identified by other researchers (Happell et al., 2017b; McCann et al., 2011) and commonly relate to weight gain and problems with diet after commencing antipsychotic medication regimes. This is consistent with the literature that notes increased appetite and glucose tolerance which are known side effects of some prescribed medications (Onwumere et al, 2018).

The experiences of parents involved in this research suggest that parents and their son/daughter both require health education to increase their health literacy, particularly in relation to medication taken to treat FEP. This will assist parents to make informed decisions with their son/daughter to maintain their physical health at an optimum level (Cree et al., 2015; Happell et al., 2017a). This includes the need to participate in regular metabolic screening and monitoring procedures in line with recommended international guidelines to reduce the risk of weight gain and metabolic side effects associated with antipsychotic medications (O'Donoghue, Schäfer, Becker, Papageorgiou, & Amminger, 2014).

Early psychosis programs must include education on interventions that parents can initiate to improve their son/daughter's lifestyle and life skills such as increase exercise and healthy diet to reduce the risk of early weight gain and the development of metabolic syndromes (Curtis et al., 2016). Since parents know their son/daughter's interests and preferences, and behavior patterns and triggers, health professionals need to acknowledge that parents are active members of the treatment team, and that their views and concerns are important to overall care delivery (Eassom, Giacco, Dirik, & Priebe, 2014). Parents can provide the continuity of care to their son/daughter who is more likely to feel safe, comforted and secure in a familiar family environment. This may also lead to improved adherence with pharmacological and psychosocial interventions (Onwumere et al., 2018).

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Parents should also be linked with primary health care practitioners to promote improved physical health near to their homes after discharge from specialist mental health services. This enables them to remain integrated and active in their community (Funk, Saraceno, Drew, & Faydi, 2008). The pathway towards recovery for each young person experiencing FEP is challenging but this can be alleviated with the support from their parents. Parents must be actively engaged in care when the young person is enrolled in FEP program. They should be encouraged to attend appointments, ask questions and be involved in care planning. They should be viewed by health professionals as active members of the care team.

### **Limitations**

Several limitations to this research need to be considered. Data were collected at only one site which might impact on transferability of the findings. Although both fathers and mothers were invited to participate in this study, most participants were females (87.5%,  $n = 14$ ). While this indicates that most caregivers are mothers, it limits the findings to one gender. Fathers may have different caregiving experiences. Future research might benefit if the opinions of other family members and support persons are obtained.

### **Conclusion**

The benefits of integrating physical health care into mental health settings and removing everyday barriers to deliver integrated care to the young person with FEP is significant. Early interventions in physical health can reduce risk factors associated with the use of antipsychotic medication and improve an individual's quality of life. As importantly mental health professionals have to foster a positive collaborative culture with the young people's parents who are often the primary caregiver in the community. Parents need to feel respected and supported to be able to play an active and effective role in their son/daughter's mental

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health recovery. This is paramount towards helping young people maintain physical wellness while they recover from their mental illness.

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