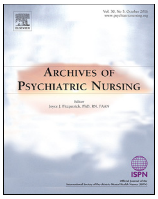
Archives of Psychiatric Nursing 33 (2019) 129–137

Contents lists available at ScienceDirect

Archives of Psychiatric Nursing

journal homepage: www.elsevier.com/locate/apnu



Parents of adult children with long-term mental disorder: Their experiences of the mental health professionals' approach and feelings of alienation – A cross sectional study

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ARTICLE INFO

Keywords:
Adult children
Alienation
Experience of approach
Long-term mental disorder
Parents

ABSTRACT

The aim was to describe how parents of adult children suffering from long-term mental disorder experience the mental health professionals' approach and any feelings of alienation regarding the provision of care. A further aim was to investigate any differences according to the parents' gender or the child's age. 93 mothers and 37 fathers participated. A majority experienced the mental health professionals' approach toward them as being negative and they felt alienated from the professional care. Regardless of the age of the children, parents have a considerable need for a positive approach from the professionals that can enable them to choose how they should act and what they should do, in order to help and support their adult child.

Introduction

This study focuses on the parents of adult children with a long-term mental disorder. Being a parent entails a moral responsibility for the wellbeing of one's child, with the ultimate aim of enabling the child to become independent. This includes encouraging independence, but also being aware of when the child needs continued support and when the parent must act on the child's behalf (Holm, 1993). Parenthood is significantly different if the adult child has a long-term mental disorder than if the child is healthy (Darmi, Bellali, Papazoglou, Karamitri, & Papadatou, 2017; Johansson, Anderzen-Carlsson, Ahlin, & Andershed, 2010; Johansson, Anderzen-Carlsson, Åhlin, & Andershed, 2012; McAuliffe, O'Connor, & Meagher, 2014). A doctoral dissertation by Johansson (2014) indicates that parents of adult children with long-term mental illness have no choice but to continue fighting and struggling for their child and that the process of caring can be regarded as endless. The family is often an important resource. Supporting a family-focused perspective requires knowledge, action and that the mental health professionals have the right pre-conditions in which to meet the needs and expectations of the family (Ferguson et al., 2018; Kertchok, 2014; Weimand, Sällstrom, Hall-Lord, & Hedelin, 2013; Wonders, Honey, & Hancock, 2018).

Background

Adult people suffering from mental disorder often have many difficulties in life, such as participating full time in school or work, and carrying out daily tasks. They can also involuntarily withdraw from relationships and thus have few social contacts other than their family members (Lindgren, Sundbaum, Eriksson, & Graneheim, 2014; McCann, Lubman, & Clark, 2012a). Young adults with mental disorders often need help from family members with emotional, economic, instrumental and/or practical problems (Andershed, Ewertzon, & Johansson, 2016; McCann, Lubman, & Clark, 2012c) and state that their family members help them to strengthen their resilience to cope through patience, tolerance, understanding and encouragement. McCann et al. (2012c) reported on the significance of an informed family who can recognize different symptoms and can provide timely, accessible and enduring support. Regarding family inclusion in mental health service planning, it is important from the consumers' perspective that the family members find the right balance in the support that they wish to provide (McCann et al., 2012c; Wonders et al., 2018). Lack of support has been reported to decrease the motivation of young adults to continue care and can also increase the risk of dropout (Lindgren, Söderberg, & Skär, 2015).

Family members emphasize the importance of cooperation and the

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https://doi.org/10.1016/j.apnu.2019.10.002
Received 22 March 2019; Received in revised form 9 September 2019; Accepted 18 October 2019

exchange of information with the mental health professionals (Gavois, Paulsson, & Fridlund, 2006; McCann, Lubman, & Clark, 2012b; Schröder, Wilde Larsson, & Ahlström, 2007; Sjöblom, Wiberg, Pejlert, & Asplund, 2008). If the mental health professionals explained the illness, its course and its consequences, the family members could become more secure and shame and guilt could be reduced (Schröder et al., 2007). Furthermore, the family members wished to be listened to, to be met respectfully and to be regarded as a resource (Johansson et al., 2012; Johansson, Andershed, & Anderzen-Carlsson, 2014; Weimand, Hedelin, Hall-Lord, & Sällström, 2011), as well as to be recognized and to participate in the professional care of the mental ill person (Wilkinson & McAndrew, 2008). Other aspects are the accessibility of the mental health professionals (Gavois et al., 2006) and that the professionals are encouraging, engaged and empathetic (Schröder et al., 2007).

Previous research has identified that parents of an adult child with mental disorder can experience themselves as being excluded and being taken for granted by the mental health professionals and as being alone in the support that they provide or wish to provide (Johansson et al., 2014; Lindgren, Aström, & Graneheim, 2010), and they often feel stigmatized (Clarke & Winsor, 2010). Frequently, the mental health professionals regarded the adult child as being an independent adult on the basis of their chronological age, even though they required continuing care and support from the mental health professionals as well as family support (Andershed et al., 2016). Parents wish to receive more support (Clarke & Winsor, 2010; Johansson et al., 2014; Lindgren, Söderberg, & Skär, 2016) and participating in the professional care can provide greater hope in their child's recovery (Lindgren et al., 2016).

The parents have been reported to shoulder a great responsibility and concern, which often negatively affects their life situation and quality of life (Johansson et al., 2015). The parents often live with considerable anxiety regarding the future and worry about who can take over the role of caregiver when they are no longer able to do so (Darmi et al., 2017; Johansson et al., 2010; Johansson et al., 2012; McAuliffe et al., 2014). Studies have shown that the mothers often had the main responsibility for their child's contacts with the health services, while the fathers wanted to be more involved in the care of their child than they were sometimes permitted to be. Both mothers and fathers felt themselves to be ignored by mental health professionals (Johansson et al., 2010; Johansson et al., 2012). The fathers believed that the mental health professionals took little interest in the fathers' caregiving role and left them as an unresolved resource (Johansson et al., 2012). The consequences of this responsibility have even been traced by bio physiological markers in the blood. Barker, Greenberg, Seltzer, and Almeida (2012), for example, found dysregulated diurnal cortisol patterns indicative of chronic stress experiences. If the parents do not feel well, this may impair their ability to provide a good support for the child (Johansson et al., 2010; McAuliffe et al., 2014).

In a study by Ewertzon, Lützén, Svensson, and Andershed (2010), a weak but significant relationship was found between the family members' experience of the health professionals' approach toward them and a feeling of alienation from the provision of care for their relative. A higher level of an approach characterized as respectful was associated with a lower level of a feeling of alienation. A respectful approach and good communication have also been described by family members as being of great importance in their being able to participate in the care in a meaningful manner (Goodwin & Happell, 2007).

Rationale for the study

Although there is existing knowledge concerning parents' experiences of having an adult child suffering from long-term mental disorder, less is known about their experiences of the mental health professionals' approach toward them and about any feelings of alienation that they may have regarding the provision of professional care for their son or daughter. There is especially little knowledge concerning differences in the experiences of mothers and fathers and differences relating to the age group of the adult children. Such knowledge is important in order to develop needs-adapted support for the parents, so that they can provide the best support for the adult child.

Aims and research questions

The overall aim of the study was to describe how the parents of adult children suffering from long-term mental disorder experience the mental health professionals' approach toward them, as well as any feelings of alienation regarding the provision of professional care. A further aim was to investigate any differences according to the parents' gender or the child's age.

Following research questions concern the entire group as well as differences between mothers and fathers, and between parents of adult children of different ages:

- How do the participants'experience the mental health professionals' approach toward them and how important do they consider the approach toward them to be?
- Do the participants´ experience any feeling of alienation from the provision of professional care?
- Is there any association between the participants´ actual experiences of the mental health professionals' approach toward them and any feelings of alienation regarding the provision of professional care?

Methods

This study was conducted with a cross-sectional design using a questionnaire.

Procedure and subject

The study took place in Sweden year 2013. It is part of a larger project that investigates, from different perspectives, the health-related quality of life of parents of adult children suffering from long-term mental disorders. Parents were recruited through newspaper advertisements in rural and urban areas of central and southern Sweden, on then by on-line advertisements on the websites of various Non-Governmental Organizations (NGO) for persons with mental disorders and their family members. The respondents were sent a set of self-report questionnaires. The eligibility criteria included being a parent of an adult child, aged over 18, with a history of more than two years of mental disorder. In addition, the parent should have had contact with the mental health services treating their child during the preceding 6 months. Full details of the sample and of the procedure are reported in a previous study within the project (Johansson et al., 2015). Of the 151 parents enrolled in the previous study, 130 parents met the inclusion criteria for this specific study. The reason for the reduced number was that 21 parents had not had contact with the health services or with the health professionals during the preceding six mounts.

Data collection/questionnaires

Data were collected using two questionnaires. The first was a project-specific questionnaire that collected information about the sociodemographic characteristics of the participants and of their adult child, such as their age, gender, civil status and place of residence. The second was The Family Involvement and Alienation Questionnaire (FIAQ). The FIAQ measures the family members' experiences of the healthcare professionals' approach and their feeling of alienation from the provision of professional care (Ewertzon, Lützén, Svensson, & Andershed, 2008). The questionnaire contains 28 items which are divided into two scales; (1) Experience of Approach, and (2) Feeling of Alienation.

The first scale, Experience of Approach, consists of 15 items, which are divided into three sub-scales; openness, confirmation and

Please answer both A and B	(A) Experience				(B) Subjective importance			
My experience is that…	Completely agree	Partly agree	Partly disagree	Completely disagree	Of the very highest importance	Of great importance	Of little importance	Of no importance
..the health-care professionals give me with information regarding the condition of my family member	☐	☐	☐	☐	☐	☐	☐	☐

Fig. 1. Illustration of one statement and response categories in the part of "Experience of approach" in the FIAQ.

cooperation:

- Openness is characterized by the family members' experience of sincere information about the patient's state of health. They experience that the mental health professionals explain the situation in a way that enables them to deal with the situation.
- Confirmation is characterized by the family members' experience that the mental health professionals see and listen to them as important persons. They experience that the professionals welcome them and care about who they are.
- Cooperation is characterized by the family members' experience that the mental health professionals value them and their opinions as being important (Ewertzon et al., 2008, p. 441).

Each item in the Experience of Approach scale is evaluated in two ways; (A) by experience and (B) by subjective importance. The first of these (A) consists of the participants' actual experience of the professionals' approach toward them and the second (B) comprises the importance that they ascribe to this; see Fig. 1. The response categories regarding (A), experience, contain four alternatives that range from "Completely disagree" (1) to "Completely agree" (4). A high score indicates a positive response for the participants' actual experience of the healthcare professionals' approach toward them, whereas a low score indicates a negative response. The response categories regarding (B), subjective importance, also contain four alternatives that range from "Of no importance" (1) to "Of the very highest importance" (4). A high score indicates that the participants consider that the healthcare professionals' approach toward them is important, whereas a low score indicates that the approach toward them is of less importance or no importance.

The second scale, Feeling of Alienation, consists of 13 items that are divided into two sub-scales; powerlessness and social isolation:

- Powerlessness is characterized by the family member having a sense of low expectancy that his or her own behavior can control events in the care of the patient; there are others who decide. The family member has a sense that he or she does not have any influence over the care that the patient receives.
- Social isolation is characterized by the family member having a sense that he or she is excluded or rejected from the care of the patient (Ewertzon et al., 2008, p 441).

The response categories of the Feeling of Alienation scale also contain four alternatives, which range from "Completely disagree" (1) to "Completely agree" (4). A low score indicates a positive response; that the participants experience themselves as not being alienated form the professional care, whereas a high score indicates a negative response.

The reliability and validity of these scales and it's items have been evaluated in the context of the psychiatric care in Sweden (Ewertzon et al., 2008). In the first stage, content validity was assessed in seminars with experienced researchers who had a sound knowledge of the theoretical frameworks and concepts used in the generation of the items. The following criteria were evaluated; the items´ correspondence with the definitions of the concepts, missing items of importance, and the clarity of the items. In the second stage, the validity evaluation was conducted with family members to people with mental illness, the participants individually assessed if the items were understandable and gave information for their memory, then a group interview was conducted. The number of items decreased from 46 to 41. In the final stage, the evaluation of reliability was conducted within 1 week by test-retest ($n = 15$ family members). The test-retest was analyzed by a non-parametric statistical method. A lack of reliability was found in 13 items (further information see Ewertzon et al. (2008). Based on the evaluation process, the above scales and sub-scales in FIAQ were assessed to be useful in exploring the concepts of family members' experiences of the healthcare professionals' approach and their feeling of alienation from the provision of professional care in the context of psychiatric care.

The theoretical frameworks of the FIAQ

The development of the FIAQ was guided by two theoretical frameworks. The first theoretical framework was Involvement in the light and Involvement in the dark, in which the concept of the health-care professionals' approach is described as being crucial for the family members' ability to provide the best possible support to the ill person (Andershed, 1998; Andershed & Ternestedt, 2001). The metaphor of Involvement in the light is described from a positive understanding and is characterized by an open, confirming and cooperating approach that is based on trust and confidence between the family members and the health-care professionals. This approach can increase the opportunities for family members to understand what they need to know in order to support the ill person. It can also increase the opportunities for a meaningful involvement. The other metaphor, Involvement in the dark, is described from a negative understanding and is characterized as an isolated involvement, in which the health-care professionals' approach has deficiencies in communication and sincerity that lead to avoidance and inadequate cooperation. That can result in a feeling of being outside and the family members are therefore groping around in the dark when they try to support the ill person (Ewertzon et al., 2018).

The second of these theoretical frameworks was Seeman (1972) conceptualization of alienation. Seeman considered alienation to be a feeling that arises because of relations to other people and/or objects. Several varieties of alienation have been described, of which Powerlessness and Social isolation were found to be applicable in the psychiatric care context when the FIAQ was being constructed.

In accordance with these theoretical frameworks, previous studies in which the FIAQ was used indicate that a higher level of experience of being approached by openness, confirmation and cooperation is associated with a lower level of feelings of powerlessness and social isolation, and vice versa (Ewertzon et al., 2010; Weimand, Israel, & Ewertzon, 2017).

Data analysis

The assessments in the FIAQ are subjective and the data consists of ordered categories (ordinal data). As in previous studies using the FIAQ (Ewertzon et al., 2010; Ewertzon, Andershed, Svensson, & Lützén, 2011; Johansson et al., 2015; Weimand et al., 2017), data were analyzed using rank-based, non-parametric statistical methods (Altman, 1991; Siegel & Castellan, 1988; Svensson, 2001b). The median level (Md) and quartiles (Q_1, Q_3) were used to describe the distributions of the response profiles (Svensson, 2001b). A global score for each scale and for its sub-scales was calculated by the median scoring technique for multi-items (Svensson, 2001a). When applicable, the Wilcoxon-Mann-Whitney test (W_x) (ordinal data with two-sample case) was used in the comparisons between sub-groups. Possible relationships between the scales and sub-scales were evaluated by the Spearman rank order correlation coefficient (r_s).

An overall *p*-value of 5% or less was regarded as significant. Data was analyzed using SPSS™ 22.1.0.0.

Ethical approval

The study was approved by the Regional Research Ethics Committee in Gothenburg, No 026-12.

Results

Socio-demographic characteristics

Table 1 shows the socio-demographic characteristics of the participants and the age of their adult child. A total of 93 mothers and 37 fathers were included in the study. Of the participating fathers, 43% were 65 years old or older. The fathers were married or cohabited to a greater extent than the mothers, and also cohabited with the child's mother more often than the mothers lived together with the child's father. The mothers were single, divorced or widowed to a greater extent than the fathers. The parents' place of residence was equally distributed between rural and urban areas and approximately 30% were members of a Non-Governmental Organization (NGO).

Table 1
The parent's and their adult child's socio-demographic characteristics ($n = 130$).

Variable	Mother	Father
	n (%)	n (%)
Gender	93 (71%)	37 (29%)
Age of the parents (years)		
40–49	18 (19%)	4 (11%)
50–64	50 (54%)	17 (46%)
65 +	25 (27%)	16 (43%)
Mean age (SD)	58 (9.3)	62 (9)
Age of the children (years)		
18–25 year	40 (43)	15 (41)
26–64 year	53 (57)	22 (59)
Civil status		
Married/cohabiting	68 (73%)	34 (92%)
Single/widow/widower/divorced	25 (27%)	3 (8%)
Living with the child's mother/father	46 (50%)	29 (78%)
Place of living		
City > 500,000 inhabitants	51 (55%)	20 (54%)
City < 500,000 inhabitants	23 (25%)	8 (22%)
Countryside	19 (20%)	9 (24%)
Frequencies in contact with the child		
Daily	23 (25%)	8 (22%)
Twice a week	37 (40%)	17 (46%)
Twice a month	16 (17%)	7 (19%)
More seldom	17 (18%)	5 (13%)
Member of non-governmental organization	29 (31%)	11 (30%)

The ages of the adult children ranged from 18 to 64 years, and 55 (42%) were young adults, aged from 18 to 25 years. Concerning the children's gender, 72 (55%) were female and 58 (45%) were male. The time since the first contact with the mental health services ranged from 2 to 33 years. Most of the children were diagnosed with depression and psychotic disorder, followed by anxiety and other mental disorders. Many parents reported comorbidity with one or two of the above diagnoses, most commonly with depression.

The distribution of the responses for the entire group

Experiences of the mental health professionals' approach and its importance

Fig. 2 shows the distribution of the responses regarding the parents' experiences of the mental health professionals' approach toward them. The median agreement level of the Experience of approach scale and of its sub-scales (Openness, Confirmation and Cooperation) was “Partly disagree (2)”, which indicates a response distribution that the parents experienced the mental health professionals' approach as being negative.

Fig. 3 presents the distribution of responses regarding the importance that the parents ascribed to the mental health professions' approach toward them. The median agreement level of the Experience of approach scale and of the Openness and Cooperation subscales was “Of the very highest importance (4)”, whereas that of the Confirmation sub-scale was lower, being “Of great importance (3)”. These indicate a response distribution that the parents considered the approach toward them as being of importance.

Feeling of alienation from the provision of professional care

Fig. 4 shows the distribution of responses regarding the parents' feeling of being alienated from the provision of professional care. The median agreement level of the Feeling of alienation scale and of its subscales, Powerlessness and Social isolation, was “Partly agree (3)”, which indicates a response distribution that the parents feel themselves to be alienated from the professional care.

The response profiles according to the parent's gender and the age of the child

The parent's gender

Table 2 presents the response differences in the scales and sub-scales of the FIAQ according to the parent's gender.

The values for the mothers were significantly greater than those for the fathers on the sub-scales for the importance of Openness and Cooperation. This indicates that mothers experienced an approach characterized by openness and cooperation as being more important than did the fathers. No other significant differences were found according to the parent's gender within the scales and sub-scales of the FIAQ.

The parent's gender and the age of their child

Table 3 shows the response differences in the scales and sub-scales of the FIAQ according to the parent's gender and the age of their child.

The mothers of children aged 26–64 years old agreed to a significantly lesser extent with Experience of approach and its sub-scales, Openness, Confirmation and Cooperation, than did the mothers of children aged 18–25 years old. This indicates that the mothers of children aged 26–64 years old experienced a more negative approach from the professionals than did mothers of children aged 18–25 years old.

The mothers of children aged 26–64 years old also agreed to a significantly lesser extent with the sub-scale for the importance of Openness than did the mothers of children aged 18–25 years old. This indicates that the mothers of children aged 26–64 years old experienced an approach characterized by openness as being less important than did the mothers of children aged 18–25 years old.

No other significant differences were found according to the parent's gender and the age of their child within the scales and sub-scales of the

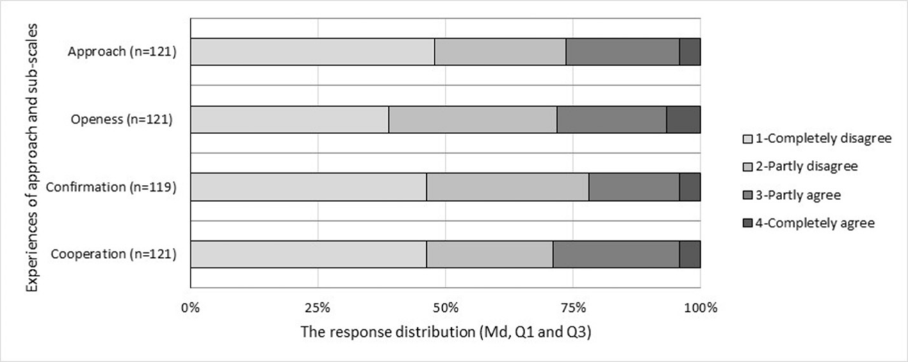

Fig. 2. The response distributions of Experience of approach and its sub-scales (Md, Q_1 and Q_3). The bars indicate the degree of experience, the darker the shading, the higher the degree of positive experience of approach.

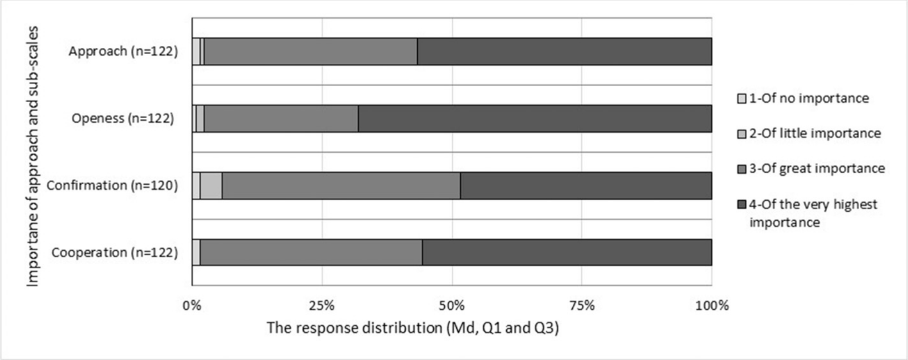

Fig. 3. The response distributions Importance of approach and its sub-scales (Md, Q_1 and Q_3). The bars indicate the degree of importance, the darker the shading, the higher degree of importance.

FIAQ.

Association between the scales and sub-scales of the FIAQ

Table 4 shows that the association between the parents' experiences of the mental health professionals' approach toward them and feelings of alienation were significantly correlated for the scales and sub-scales of the FIAQ. The Spearman rank order correlation coefficients (r_s) ranged from −0.62 to −0.74. The negative correlation coefficient between the parents' experiences of approach and feelings of alienation (−0.74) indicates that a lower level of an experience of being approached positively is associated with a higher level of feelings of alienation, and vice versa.

Discussion

Discussion of the results

The overall aim of this study was to describe how the parents of adult children suffering from long-term mental disorder experience the mental health professionals' approach toward them, as well as any feelings of alienation regarding the provision of professional care. Considered from the perspective of the theory of family members' "Involvement in the light and Involvement in the dark" (Andershed & Ternestedt, 1999, 2001), the results showed that the parents experienced a negative approach from the mental health professionals, and that they felt alienated from the professional care. This indicates that the parents' engagement could generally be characterized as "Involvement in the dark" (e.g. Andershed et al., 2016). Similar negative results

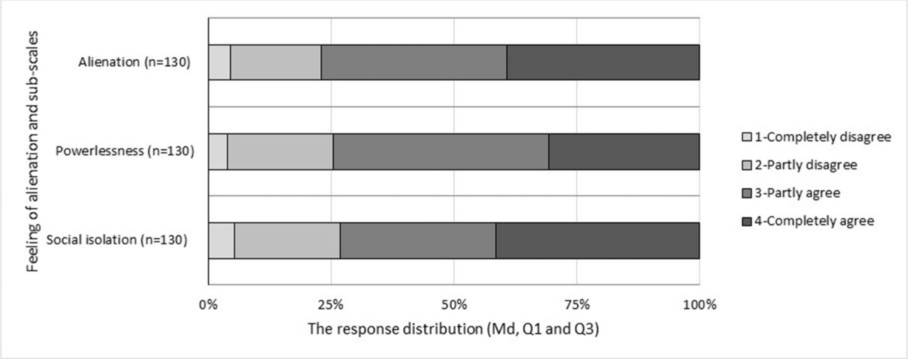

Fig. 4. The response distribution of Feeling of alienation and I sub-scales (Md, Q_1 and Q_3). The bars indicate the degree of alienation, the darker the shading, the higher degree of alienation.

Table 2
The response distributions of the scale and sub-scales in the FIAQ (Md, Q_1 and Q_3) according to the parent's gender.

Scales and sub-scales	Mother Md (Q_1, Q_3)	Father Md (Q_1, Q_3)	P-value of W_x[a]
	(*n* = 87)	(*n* = 34)	
Experiences of approach[b]	2 (1, 3)	2 (1, 3)	0.44
Openness	2 (1, 3)	2 (1, 3)	0.17
Confirmation	2 (1, 2)	2 (1, 2)	0.40
Cooperation	1 (1, 2)	2 (1, 3)	0.23
	(*n* = 87)	**(*n* = 35)**	
Importance of approach[c]	4 (3, 4)	3 (3, 4)	0.14
Openness	4 (3, 4)	3 (3, 4)	**0.02**
Confirmation	4 (3, 4)	3 (3, 4)	0.09
Cooperation	4 (3, 4)	3 (3, 4)	**0.05**
	***n* = 93**	***n* = 37**	
Feeling of alienation[b]	3 (3, 4)	3 (2, 4)	0.76
Powerlessness	3 (2, 4)	3 (3, 4)	0.65
Social isolation	3 (2, 4)	3 (2, 4)	0.35

Significant at the level 0.05 or less.

[a] The Wilcoxon-Mann-Whitney test.

[b] Response categories; 1 (completely disagree), 2 (partly disagree), 3 (partly agree) and 4 (completely agree).

[c] Response categories; 1 (of no importance), 2 (of little importance), 3 (of great importance) and 4 (of the very highest importance).

Table 3
The response distributions of the scale and sub-scales in the FIAQ (Md, Q_1 and Q_3) according to the parent's gender and age of the children.

Main and sub-scales	Mother (n = 93) Md (Q_1, Q_3)		P-value of W_x[a]	Father (*n* = 37) Md (Q_1, Q_3)		P-value of W_x[a]
	Age child 18–25	Age child 26–64		Age child 18–25	Age child 26–64	
	n = 38	*n* = 49		*n* = 15	*n* = 19	
Experiences of approach[b]	2 (1, 3)	1 (1, 2)	**0.01**	2 (1, 3)	2 (1, 2)	0.61
Openness	2 (1, 3)	1 (1, 2)	**0.01**	2 (1, 3)	2 (1, 3)	0.92
Confirmation	2 (1, 3)	1 (1, 2)	**0.02**	2 (1, 3)	2 (1, 2)	0.26
Cooperation	2 (1, 3)	1 (1, 2)	**0.00**	2 (1, 3)	2 (1, 3)	0.68
	***n* = 39**	***n* = 48**		***n* = 15**	***n* = 20**	
Importance of approach[c]	4 (3, 4)	4 (3, 4)	0.87	3 (3, 4)	3 (3, 4)	0.83
Openness	4 (4, 4)	4 (3, 4)	**0.05**	4 (3, 4)	3 (3, 4)	0.40
Confirmation	3 (3, 4)	4 (3, 4)	0.81	3 (3, 4)	3 (3, 4)	0.69
Cooperation	4 (3, 4)	4 (3, 4)	0.77	3 (3, 4)	3 (3, 4)	0.99
	***n* = 40**	***n* = 53**		***n* = 15**	***n* = 22**	
Feeling of alienation[b]	3 (2, 4)	3 (3, 4)	0.71	3 (2, 4)	3 (3, 4)	0.66
Powerlessness	3 (2, 4)	3 (2, 4)	0.88	3 (2, 4)	3 (3, 4)	0.26
Social isolation	3 (2, 4)	3 (3, 4)	0.83	3 (2, 4)	3 (2, 4)	0.75

Significant at the level 0.05 or less.

[a] The Wilcoxon-Mann-Whitney Test.

[b] Response categories; 1 (completely disagree), 2 (partly disagree), 3 (partly agree) and 4 (completely agree).

[c] Response categories; 1 (of no importance), 2 (of little importance), 3 (of great importance) and 4 (of the very highest importance).

Table 4
Associations[a] between the scale and sub-scales in the FIAQ (*n* = 120).

Main and sub-scales	Feeling of Alienation	Powerlessness	Social isolation
Parents			
Experiences of approach	−0.74**	−0.62**	−0.67**
–Openness	−0.71**	−0.62**	−0.65**
–Confirmation	−0.71**	−0.64**	−0.64**
–Cooperation	−0.69**	−0.63**	−0.63**

[a] The Spearman rank-order correlations coefficient (r_s).

** Correlation is significant at the level 0.01 or less (2-tailed).

have also been found in studies conducted among target groups other than parents, such as among siblings and adult children (Ewertzon et al., 2010; Ewertzon, Cronqvist, Lützén, & Andershed, 2012). A study by Ewertzon et al. (2010) of family members of people with psychotic illness showed that the participants experienced openness from the professionals to a greater extent. Furthermore, the median agreement level for the statements of 'Feeling of alienation' was higher in this present study than in the study by Ewertzon et al. (2010). That is, the participants in the present study felt alienated from the professional care of their adult child to a greater extent than in the earlier study. This difference may be explained by the fact that all the participants in the study by Ewertzon et al. (2010) were members of a Non-Governmental Organization, while in the present study only a third of the participants were members of such an organization. It is possible that the exchange of experiences that takes place in an organization also affects the individual's sense of context and feeling of being less alienated from the professional care. Similarly, a study by Weimand, Hedelin, Sällström, and Hall-Lord (2010) found that family members who did not have anyone with whom to share the caregiving situation experienced a greater burden and poorer health in social functioning. In this context, it should be noted that the exclusion of family members has long been reported and several studies promote collaboration between the patient, family members and the mental health professionals (Johansson, 2014; Lindgren, Söderberg, & Skär, 2013; McCann et al., 2012c; Rusner, 2012; Sjöblom, Pejlert, & Asplund, 2005; Skundberg-Kletthagen, Wangensteen, Hall-Lord, & Hedelin, 2015; Weimand et al., 2011).

The parents in the present study wanted to be approached in a respectful way by the mental health professionals. This result is consistent with previous research in the context of mental health care that focused on what family members consider to be of the very greatest importance regarding the professionals' approach toward them (Ewertzon et al., 2010; Ewertzon et al., 2011; Weimand et al., 2017). It is also in line with the family members' perceptions of the quality of care in psychiatric settings found in the study by Schröder et al. (2007), and with the importance of the family members experiences of the mentally ill person being acknowledged by the mental health professionals (Skundberg-Kletthagen et al., 2015).

On the other hand, there are studies showing that family members had positive experiences. A study in Norway investigated the family members' experiences of Assertive Community Treatment (ACT), a care and treatment model in which multidisciplinary teams provide all the necessary services for people with severe mental illness. A higher level of being approached positively was significantly associated with a lower level of feeling alienated (Weimand et al., 2017). This result indicates that the participants' engagement could be characterized as "Involvement in the light" (e.g. Andershed et al., 2016). That is, the family members, the patients and the professionals had an open way of acting; a partnership with a family-focused perspective (Andershed & Ternestedt, 1999, 2001).

According to the FIAQ scales, the participants in the study by Weimand et al. (2017) agreed to a greater extent with items related to "Experiences of approach" and to a lower extent with items related to "Feelings of alienation" than in the present study. The study also shows the median agreement level for "Experiences of approach" was "Completely agree" (4) and for "Feelings of alienation" "Partly disagree" (2), whereas in the present study the median agreement levels were "Partly disagree" (2) and "Partly agree (3)", respectively.

A further aim of this present study was to investigate any differences according to the parents' gender and the age of the child. The results showed that the situation for the mother's and fathers' in both age groups could be characterized as mostly being "Involvement in the dark". Few significant differences were found between the mothers and fathers. The mothers experienced an approach characterized by openness and cooperation as being more important than did the fathers. Previous studies that examined the relationship of mothers and fathers to their adult children with long-term mental illness have shown that mothers usually carry the main responsibility for the child's provision of professional care (Johansson et al., 2010). It has also been previously found that fathers wanted to be more involved in their adult child's care than they are sometimes allowed to be. The fathers stated that it could be the child's mother, the child itself or the professionals who excluded them. Several fathers felt that the mental health professionals turned to the child's mother in the first place, without any agreement on this (Johansson et al., 2012). It is important to take into account that there may be different reasons for a feeling of alienation. In order to achieve a more equal care, mental health professionals need to consider whether there are any additional family members, such as fathers or other male relatives, with whom they can cooperate.

Furthermore, for experiences of approach, the mothers of children aged 26–64 years old agreed to a significantly lesser extent with the sub-scales of experience of openness, confirmation and cooperation than did the mothers of children aged 18–25 years old. This indicates that the mothers of older children experienced a worse approach than did those who had children in the younger age group. It is important that elder mothers also receive a good approach and support, as it has been found in a study by Dunkle, Ingersoll-Dayton, and Chadiha (2015) that elder mothers gave considerable support to their adult child with mental illness. The mothers of children aged 26–64 years old also experienced an approach characterized by openness as being less important than did the mothers of children aged 18–25 years old. Andershed et al. (2016) also reported that the parents of young adults, aged 18–25, described an isolated involvement in which they were not informed, seen or acknowledged by the mental health professionals. Regardless of the age of the mentally ill person, family members have a considerable need for the knowledge that can enable them to choose how they should act and what they should do, so that they can help and support the mentally ill person.

In the present study, nothing was known about how the care and treatment model were designed, which may affect the results in relation to those of other studies, such as that by Weimand et al. (2017). Few studies have examined the importance of different care and treatment models for family members. In the study by Weimand et al. (2017), 75% of the participants felt that the approach that they received from the mental health professionals of the ACT team was better than that which they had previously experienced. With the ACT team, half of the participants also experienced a lower level of alienation from the professionals than had been the case in the previous care of the mentally ill person. Similarly, a study by Lakeman (2008) also revealed the importance of a care and treatment model with which the collaboration and involvement of family members clearly appeared. In that study, most of the participants were satisfied with the extent to which they were involved in the professional care. Kertchok (2014) described collaboration in caring for people with schizophrenia as a basic social process that coordinates the behaviors of both the mental health professionals and family members. The first step in this process is to establish trust in each other, before engaging their concern and needs. This entails believing each other, feeling free to relate information to each other and feeling comfortable with one another (Kertchok, 2014; Radcliffe, Adeshokan, Thompson, & Bakowski, 2012). This is in line with Person-Centered Care (PCC). Collaboration between health professionals, patients and family members has been shown to improve health outcomes and increase patient satisfaction. Research has shown the importance of establishing routines that initiate, integrate and safeguard PCC in daily clinical practice, in order to ensure that PCC is systematically and consistently practiced (Ekman et al., 2011). The results of these studies indicate the need for continued research in which different care and treatment models also evaluated from the family members' perspective.

Methodological considerations and limitations

Several methodological considerations within this study should be taken into account. It is unavoidable that studies with the present design are to some extent limited and that they are not based on a representative sample of parents of adult children with a long-term mental disorder.

With regards to the recruitment methods and their possible influence on the results, it should be considered whether parents whose children suffer from severe mental disorders and who have negative experiences from the mental health services are more likely to participate in studies such as the present one. The particular socio-demographic characteristics of the participants may also influence the result; a majority were females, middle-aged or older. For example, among the participating fathers, 43% were 65 years old or older and most lived with the adult child's mother. The mothers were more often single/divorced or widowed than were the fathers, and thus less often lived with the child's biological father. In addition, fewer fathers than mothers agreed to participate in this study. Similar patterns have been reported in several studies e.g. (Clarke & Winsor, 2010). Thus, caution should be exercised in generalizing the findings.

The study investigated a group of parents in Sweden across a broad geographical area, including both urban areas and sparsely populated districts. This offers a larger generalization than would a study that was restricted to a particular psychiatric unit or clinic. The decision to investigate such a broad geographical area was made in awareness of the limitations of the design and of the possibilities that the approach entailed.

The questionnaire used in this study, the FIAQ, was developed and evaluated in Sweden, among a target group that was similar to the participants in the present study, that is, family members of persons with long term mental illness. This supports the suitability of the instruments used in this study.

Conclusion

Important for mental health professionals to be aware of in their encounter with parents of adult children with long-term mental disorder, is that both mothers and fathers may experience a negative approach as well as that they may feel themselves as being alienated from the professional care. Regardless of the age of the mentally ill person, family members have a considerable need for positive approach from the professionals as well and to be involved in the professional care, that could enable them to choose how they should act and what they should do, in order to help and support the mentally ill person.

Relevance to clinical practice

To achieve a common family-focused approach, it is important to invite family members into the planning of professional care and to make use of each other's knowledge in a partnership.

There are few studies that have examined care and treatment models from a family-focused perspective. This indicates the need for continued research in which different care and treatment models are evaluated from the family members' perspective.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Author contributions

Study design: AJ, ME, AAC, data collection: AJ, data analysis: AJ, ME and manuscript preparation AJ, ME, AAC.

Declaration of interest

No conflict of interest had been declared by the author.

Acknowledgment

The authors would like to express their gratitude to all the mothers and fathers who participated in this study for sharing their experiences. We would also like to thank the Research and Development Centre at Skaraborg Hospital and Ersta Sköndal Bräcke university college for supporting this study.

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