

Middlesex University Research Repository

An open access repository of

Middlesex University research

<http://eprints.mdx.ac.uk>

Tabak, Izabella, Zabłocka-Żytka, Lidia, Ryan, Peter, Zanone Poma, Stefano, Joronen, Katja, Viganò, Giovanni, Simpson, Wendy, Paavilainen, Eija, Scherbaum, Norbert, Smith, Martin and Dawson, Ian (2016) Needs, expectations and consequences for the child growing up in a family with a parent with mental illness. *International Journal of Mental Health Nursing*, 25 (4) . pp. 319-329. ISSN 1445-8330 [Article] (doi:10.1111/inm.12194)

Final accepted version (with author's formatting)

This version is available at: <https://eprints.mdx.ac.uk/18098/>

Copyright:

Middlesex University Research Repository makes the University's research available electronically.

Copyright and moral rights to this work are retained by the author and/or other copyright owners unless otherwise stated. The work is supplied on the understanding that any use for commercial gain is strictly forbidden. A copy may be downloaded for personal, non-commercial, research or study without prior permission and without charge.

Works, including theses and research projects, may not be reproduced in any format or medium, or extensive quotations taken from them, or their content changed in any way, without first obtaining permission in writing from the copyright holder(s). They may not be sold or exploited commercially in any format or medium without the prior written permission of the copyright holder(s).

Full bibliographic details must be given when referring to, or quoting from full items including the author's name, the title of the work, publication details where relevant (place, publisher, date), pagination, and for theses or dissertations the awarding institution, the degree type awarded, and the date of the award.

If you believe that any material held in the repository infringes copyright law, please contact the Repository Team at Middlesex University via the following email address:

eprints@mdx.ac.uk

The item will be removed from the repository while any claim is being investigated.

See also repository copyright: re-use policy: <http://eprints.mdx.ac.uk/policies.html#copy>

Needs, Expectations and Consequences for the Child Growing up in a Family with a Parent with Mental Illness

Izabela Tabak¹, Lidia Zabłocka-Żytka¹, Peter Ryan², Stefano Zanone Poma³, Katja Joronen⁴, Giovanni Viganò⁵, Eija Paavilainen⁴, Wendy Simpson⁶, Norbert Scherbaum⁷, Martin Smith², Ian Dawson⁸

¹Academy of Special Education, Institute of Applied Psychology, Warsaw, Poland

²Middlesex University, London, England

³Centro di Salute Mentale (Mental Health Centre)-ULSS 18, Rovigo, Italy

⁴School of Health Sciences, University of Tampere, Finland

⁵Università L. Bocconi, Milan, Italy

⁶University of Dundee, Dundee, Scotland

⁷Department of Addiction Medicine and Addictive Behaviour, LVR-Hospital Essen, Hospital of the University of Duisburg-Essen, Germany

⁸Nordland Hospital Trust, Bodo, Norway

Authors' qualifications and contribution to the paper:

Izabela Tabak, PhD, Assistant professor - Study conception and design, Acquisition of data, Analysis and interpretation of data, Drafting of manuscript,

Lidia Zabłocka-Żytka, PhD, Assistant professor - Acquisition of data, Analysis and interpretation of data, Drafting of manuscript,

Peter Ryan, Professor of Mental Health - Acquisition of data, Analysis and interpretation of data, Drafting of manuscript,

Stefano Zanone Poma, MD-PhD, psychiatrist - Acquisition of data, Analysis and interpretation of data, Drafting of manuscript,

Katja Joronen, PhD, Adjunct professor - Acquisition of data, Analysis and interpretation of data, Drafting of manuscript:.,

Giovanni Viganò, Contract Professor in Quantitative Methods for Social Sciences - Analysis and interpretation of data, Drafting of manuscript:.,

Eija Paavilainen, PhD, Professor - Acquisition of data, Analysis and interpretation of data, Drafting of manuscript,

Wendy Simpson, PhD, Senior Researcher - Acquisition of data, Analysis and interpretation of data, Critical revision,

Norbert Scherbaum, Professor of Clinical Addiction Research, Head of the Department - Acquisition of data, Analysis and interpretation of data, Critical revision,

Martin Smith, Senior Lecturer - Acquisition of data, Analysis and interpretation of data, Critical revision,

Ian Dawson, Coordinator of services - Acquisition of data, Analysis and interpretation of data, Critical revision.

Corresponding Author:

Izabela Tabak, PhD, Academy of Special Education, Institute of Applied Psychology, Szczęśliwicka 40, 02-353 Warsaw, Poland

E-mail: itabak@aps.edu.pl

Abstract

Parental mental illness is considered one of the strongest risk-factors for development of offspring psychopathology. The lack of pan-European guidelines for empowering children of parents with mental illness led to EU project CAMILLE - *Empowerment of Children and Adolescents of Mentally Ill Parents through Training of Professionals working with children and adolescents*. The first task in this project, was to analyse needs, expectations and consequences for children, with respect to living with a parent with mental illness. The aim this paper is to report results of these analyses. The qualitative research was conducted in England, Finland, Germany, Italy, Norway, Poland and Scotland (N=96). There were 3 types of focus groups: (1) professionals (doctors, nurses, psychologists, social workers), (2) adult children and partners of a person with mental illness, (3) parents who have experienced mental illness during their parenthood. Framework analysis method was used. Results of the study highlighted that the main consequences for children of parental mental illness were role reversal, emotional and behavioural problems, lack of parent's attention and stigma. The main needs of these children were emotional support, security and multidisciplinary help. Implications for practice are: (1) professionals working with parents with mental illness should be aware of the specific consequences for the children; (2) to empower children they should focus on them, but not excluding parents from the parental roles; (3) the multi-agency collaboration is necessary; (4) schools should provide counselling and teach staff and students about mental health problems to reduce stigma.

Key words

child development, family, mental disorders, parenting, qualitative research

Introduction

Parental mental illness is considered one of the most potent risk-factors for the development of psychopathology in the general population (Reupert et al. 2012b). Recent data indicate that 10–15% of children in the United Kingdom live with a parent who has a mental disorder (Royal College of Psychiatrists 2011); in Australia, up to one in five young people live in such a families (Maybery et al. 2009); in Canada - it's estimated about 12.1% of all children under 12 which a parent has a mental illness (Bassani et al. 2009).

Even if the problem is acknowledged by all the professionals involved, much needs to be done in terms of everyday clinical practice. There is considerable evidence to suggest that neither adult nor child services work together on these issues very effectively (Cooklin 2010; Foster et al. 2012; Katz & Hetherington 2006). There is still a high priority for child and adult services to understand each other's philosophies and ways of working more accurately and to develop effective cross-agency and multi-disciplinary work. In addition, a greater emphasis needs to be placed on case identification in terms of emerging problems experienced by the children of parents with severe mental health problems (Lauritzen et al. 2014).

Mental illness and parenting

Parents with a mental illness can struggle with dealing with their problems in parenting. These difficulties are magnified as they frequently experience stigma related to their parental role (Jeffery et al. 2013). Some children growing up in families where there is a parent with mental illness may feel guilty, overburdened, isolated and take on responsibilities far beyond their years. Faced with these difficulties, children are often

powerless and helpless (Pitman & Matthey 2004; Trondsen 2012). As a result of this, they often find it difficult to express these difficulties and do not know where to turn to for help.

Recently published World Psychiatric Association (WPA) Guidelines on the protection and promotion of mental health of children of persons with severe mental illness (Brockington et al., 2013) found some common core pathways or routes through which a variety of severe diagnostic conditions in parents may impact upon their children:

- Parental preoccupation/emotional unavailability caused by their illness and its symptoms;
- Excessive, prolonged and inappropriate anger directed at the child resulting in severe problems of attachment, and undermining good parent-child communication;
- Disturbed behaviour (impulsivity, extreme mood swings, bizarre utterances or behaviour based on delusions, disturbing the interaction.

Previous interventions

Different types of intervention to address the issue of parental mental illness have been proposed including: support groups for children (van Santvoort et al. 2013); a parent-focused approach (Solantaus 2006); online courses for parents with mental illness (van der Zanden et al. 2010), and psycho-education interventions (Lucksted, et al. 2012). A lot of programs use peer support groups for improving resilience of children of parents with mental illness (Forster et al. 2014; Gladstone et al. (2014); Goodyear et al. 2009; Hargreaves et al. 2008; Pitman & Matthey 2004). Reupert et al.

(2012a) in a review of intervention programs from Australia, Europe and North America, for children whose parents have a mental illness, identified 12 peer-support programs, 7 family-intervention programs (most of them target families of parent with depression and/or anxiety), 2 online interventions (targeting older children and young adults) and bibliotherapy for children (especially useful for rural/remote populations and those on waiting lists).

A variety of evidence-based interventions aiming to prevent mental disorders and psychological symptoms in the children of parents with mental disorders have been shown to be effective (Siegenthaler et al. 2012, Solontaus et al., 2006, 2010). Siegenthaler and co-workers carried out a systematic review as well as a meta-analysis of the effectiveness of family interventions to prevent mental disorders or psychological symptoms in the children whose parents were suffering from severe mental illness. They found that in analysed seven interventions the incidence risk reduced by 40% and a further seven trials found lower symptom scores in the children of parents with mental illness receiving these interventions. They concluded that interventions to prevent mental disorders and psychological symptoms in the offspring of parents with mental disorders appear to be effective.

Need for pan-European guidelines

A review of the literature so far has led the current authors to the conclusion that whilst certain interventions have been effective on a one-off basis, there is still the problem of generalising the best research-based interventions to encompass generic core practice in the fields of adult and child care. Too often still, adult and child services exist in isolation from each other. Whilst individual countries within Europe have

certainly developed good practice guidelines for child and adult services (eg. Voksne for Barn in Norway, Effective Family Programme in Finland, Barnardo's Child and Family Support Service in Scotland), there is a lack of pan-European guidelines for empowering the children of parents with mental illness.

The organizational and policy gap between services focusing on either adult mental illness or child mental illness were the main drivers that led to the EU project *CAMILLE- Empowerment of Children and Adolescents of Mentally Ill Parents through Training of Professionals working with children and adolescents*. The rationale of CAMILLE was that there are few evidence based training programs for professionals working with children growing up in families where the parents are experiencing severe, long term mental illness (Hetherington et al. 2002; Ramchandani & Stein 2003; Reupert et al., 2011; Tchernegovski et al., 2015). At the European level, there are no pan-European guidelines for empowering the children of parents with mental illness. Furthermore, in several countries there is an organizational gap between services focusing on either adult mental illness or child mental illness (eg. Cooklin 2006; Maybery & Reupert, 2009; Stallard et al. 2004).

The focus of CAMILLE is to contribute to early prevention strategies and to promote the physical, psychosocial and mental health of these vulnerable children. CAMILLE therefore aims to facilitate trans-European multi-disciplinary collaboration with respect to promoting the inter-professional and cross-sectional efforts concerning supporting vulnerable children and adolescents growing up in families where the parents have experienced long term, severe mental illness. To that end the CAMILLE project is focusing on the development of a new pan-European training programme to improve the competencies and awareness of the professionals working with the families

of parents with mental illness. The first task in CAMILLE was to analyse the perceptions and needs of the key audiences concerned, namely professional staff working with children and families; children and relatives of patients with mental illness; and parents with mental illness themselves.

The aim of this article is to present the results of the CAMILLE project's qualitative analyses concerning perception of needs, expectations and consequences for children growing up in a family with a parent with mental illness, from the children's, parents' and professionals' point of view. These findings were subsequently fed back into the CAMILLE project, resulting in the development of its own training programme designed to address these issues. The research questions for this study were: What are the perceptions of professionals and stakeholders experiencing mental illness in their family of:

- the main consequences for children growing up in these families?
- the main needs of these children?
- the main expectations of these children from the professionals and school?

Materials and methods

The focus group method, a well-known qualitative methodology (Mays & Pope 1996), was applied. The technique of the focus group allows the participants to express their ideas, feelings and thoughts freely, in a non-judgmental context. The methodology of a focus group involves the formation of a group with the topic clearly defined to the group and discussed in a peer-to-peer interactive context (Krueger 1994). This focus group qualitative research was conducted in seven European countries: England, Finland, Germany, Italy, Norway, Poland and Scotland, in May - July 2013. Ethical

Approvals were achieved in England and Poland. In other countries, the Ethics Committees decided that no ethics approvals were needed for the CAMILLE project.

In each country, 1-4 focus groups or individual interviews were conducted (18 groups with 2-11 participants; 2 individual interviews), each interviewed by 1-2 professionals (psychologists,..... there was a need to establish clear structures and values for developing partnership working between generic and black and minority ethnic user/survivor organisations). Participants ($N = 96$) were recruited from health service centres, university-based education centres, social welfare centres or non-statutory organisations. Participation in the study was voluntary; subjects were invited to participate in the study by employees of these institutions. In some countries problems occurred with selecting groups of children and partners of parent with mental illness and/or parents with mental illness (whereby two countries didn't carry out this study, two others - did individual interviews). Problem with selecting groups of professionals relied on the fact that at the study invitation came forward more willing than expected.

There were 3 different constituencies for the focus groups:

1. Health and social care professionals (mixed group): doctors, nurses and psychologists, social workers, teachers, educators, voluntary agency workers, e.g. family support charities.
2. Children and partners of a person with mental illness (mixed group): adult children with the current or past experience of living with a parent with mental illness and current partners of a person with mental illness.
3. Parents who have experienced mental illness during their parenthood (but who are now recovered in terms of stabilized mood or other symptoms).

Data presented in this article were drawn from all three groups. Focus groups' characteristics are presented in Table 1.

<*Table 1*>

The focus groups were carried out in a flexible way to respond to particular group dynamics and/or time available, but using the focus group guidelines - the same for all groups and countries. The guidelines contained questions concerning specific problems for families of parents with mental illness and strengths and weaknesses of the existing services. After the interviews had ended and the audio recorder had been switched off, the facilitators remained at the disposal of any participants who needed support or further conversations about their own experiences, in order to deal with people's feelings if painful memories were stimulated.

All participants were asked the questions:

- *What are the main consequences for children of parents with mental illness (or your most significant experiences while living with someone with mental illness/ as a parent with mental illness)?*
- *What are the main needs and expectations of children?*

Interviews took place in health service centres, social welfare centres or at the University (Finland). The focus group discussions were carried out in national languages of participants, recorded on a digital recorder, then transcribed verbatim and presented in thematic frameworks.

Data analyses

Framework analyses consisted of 5 stages: Familiarisation (transcription and reading of the data – in each country), Identifying a thematic framework (the initial

coding framework divided into needs, expectations and consequences parts developed both from *a priori* issues and from emerging issues from the familiarisation stage – in Poland), Indexing (applying the thematic framework to the data – in each country), Charting (using headings from the thematic framework to create charts of all data – in Poland) and Mapping and Interpretation (searching for patterns, associations, concepts, and explanations in all data – researchers from all partner countries) (Lacey & Luff 2007; Pope et al 2000; Richie & Spencer 1994).

Thematic frameworks consisted of three parts:

- the main consequences for children who are experiencing mental illness in their family;
- the main needs of these children;
- expectations of these children from the professionals and school.

The research co-ordinator for the project (Poland) prepared the initial coding frameworks (Barbour 2007) on the basis of the stated research questions and an extensive literature review, and sent this to all partners. Each site (country) undertook its own preliminary data analysis according to criteria provided by the research lead site (in national language, then translated into English separately by two researchers), and then sent this data on to the research coordinator site in Poland for further synthesis and integration. Thematic coding was employed and themes were generated both inductively from the raw data and deductively employing the theoretical framework (Boyatzis 1998). Two researchers in each country coded all the transcripts separately; data were categorized into initial and higher codes and repeatedly searched for disconfirming cases as part of the coding refinement process.

Results

Consequences for children

The main consequences for children of mentally ill parents were comprised of five topics: (a) emotional problems, (b) lack of parental attention, (c) inadequate roles, (d) behavioural problems, and (e) stigma.

Emotional problems. Participants from all three types of focus groups in all countries described the situation of children in families with a parent with mental illness primarily as insecure. One of the professionals in Germany stated: “Unpredictability and insecurity. Parents who are this way now, that way tomorrow, and then different again”. Participants highlighted the anxiety and fear felt by children. Professionals, parents and children also described children’s feelings of guilt and shame, and the threat of physical and psychological violence.

Lack of parental attention. Participants of all groups stated that one of the main consequences of mental illness in the family was the lack of parental engagement. A professional in Scotland said: “Parents’ activity is affected in simple tasks, so that’s anything from getting the young person to go to school in the morning, if they can’t get up themselves... starts a pattern of non-school attendance”. The situation of children, but from the parent’s point of view, was described in England:

They want to have a parent that engages with them, and if a parent is already embroiled in their own mental illness, they can’t even engage with themselves, let alone their own children. And my children have said before, “There’s no fun with you, you’re not a fun dad, and you’re not a fun mum”.

Participants also described deprivation of the child’s needs. One of the parents in the English focus group recalled a situation with his own children:

I had depression, my wife had depression, and we couldn't talk to them, we couldn't play with them, and they felt a bit lost, because their friends were being played with by their parents, and I felt they were the ones who missed out.

One of the further consequences of lack of parent's attention can be foster care.

An adult child in Scotland shared with the group their own memories:

Unfortunately, my brothers were taken into care... because my dad was different and eccentric, they thought he couldn't look after us... My brothers were taken into a home – they suffered terrible physical abuse, so when I was 16 I married so I could provide a home for them.

Role reversal. Participants of professionals' and parents' focus groups pointed out the problem of the parenting role of the child - the reversal of parent-child roles, when the child begins to take care of a parent, and the child taking responsibility for a family. One of the professionals in Germany stated that: "You can sometimes observe a reversal of roles, so that a child is watchful e.g. over her mother and that she senses when the parent's condition worsens. And children are overstrained with that".

Behavioural problems. Consistently, participants of professionals' and parents' focus groups described school non-attendance as the main problem. "I think people stop going to school because they worry about leaving their parents back home – who is meant to help mum and dad when you're not there?" stated a professional from Scotland. They also highlighted anti-social behavior.

Stigma. Keeping the illness secret to avoid shame was noted, by children, parents and professionals, as a very important consequence of parental illness. From child's point of view it was pointed in Italy: "Often in addition of being frightened by what happens, we don't even have the possibility to ask for help because of stigma".

Professional in Poland stated that that further consequence of stigma is isolation at school: “There is no time to meet with peers, ashamed to invite them into home”.

Results of our study revealed also a few comments of professionals and children showing positive effects of growing up in family with parent with mental illness. One of English professionals said: “There are situations where the child may have picked up some good skills in managing the situation even before you, the specialist, come in... the children can actually be resentful of professionals coming in”. An adult child from Scotland stated:

It's not all negative – it's been the making of me – I didn't know what was wrong with my dad – I was just a kid, but what it did was, it galvanized me – to find out exactly what was happening, why they were the way they were – and I think that was quite difficult, but it enable me to look at all the different theories and policies with an open mind, instead of the accepted wisdom that was there when I was young.

Needs of children

Three main needs of children were described by the interviewees: (a) needs for emotional support, (b) needs for security and (c) needs for multidisciplinary and multi-agency care and help.

Needs for emotional support. Participants of professionals' and children's groups stated that children of parents with mental illness need to have someone who listens to them. A Scottish child said: “Could do with someone external that she could just say exactly what she's feeling”. Children also expressed a need to find ways to

manage tension in their relationships with their parents, and to be able to relieve stress and anxiety.

Needs for security. Professionals in all countries highlighted children's need for security. Professionals in Germany described also a need for the children to reduce their anxiety and excessive sense of responsibility for their parents:

...if you have... someone who knows the illness and is able to register when for example a mother starts to again lose contact to reality, and who also encourages the mother to seek medical help or to take her medication again, then this is a huge relief for the child who now can pass over responsibility...

Needs for multidisciplinary and multi-agency care and help. Professionals' and children's group participants stated that children from families with a parent with mental illness need care and support both from mental health service staff (trained in working with children) but also from other organisations which might offer help in solving 'daily hassle' problems. In England one of the professionals described the necessity for professionals' awareness of the needs of children:

From the point of view of the multidisciplinary team that is working with the person with a severe mental illness, the whole team need to have an awareness that the child will be affected... There are structures in the community which we do not take account of... consider liaising with these structures more when we are trying to provide support networks – because children are involved they need to get in contact with them whether they like it or not.

Children's group participants described the necessity for help in the everyday life of families with mental health problems.

Children's expectations (service responses required)

Three main expectations of children from the professionals and schools were (a) information on illness and services, (b) support from professionals and (c) support and assistance from school.

Information on illness and services. All focus group participants mentioned that children of parents with mental illness need more information about illness and its course (relapses). A professional from Poland stated: "Specific guidelines... Sometimes they need a "realignment", support in the acceptance of the disease, awareness that such relapses may be". Children and parents also suggested the need for knowledge about existing services and assisting organizations.

Support from professionals. Professionals from all countries stated that children of parents with mental illness need reinforcement and support in solving problems, more child focused interventions and removing the child's responsibility. A professional from Germany stated: "What children want is to pass over responsibility 'I do not want to watch out for my mother so that she doesn't kill herself'. The child wants to be a child". Children and partners pointed out mainly the need for patience and openness and suggested home based support instead of institutional support.

Support and assistance from school. Participants of professionals' focus groups perceived the role of schools in helping and supporting the child and in assisting in the reduction of stigma. Parents suggested the need to strengthen friendship networks at school so as to prevent isolation. Children and parents pointed out the need for a functional relationship between home and school to help in difficult situations. One Scottish parent with mental illness described children's needs as follows:

They could go to a particular person, like a guidance teacher or another teacher that they trusted, they could go and say, 'I'm having a really hard time at the moment...' if they were really stressed they could maybe have a card or something all the people knew so the guidance teacher, so they could email each other when there was an issue.

Participants of children's groups in Scotland and Italy suggested the need for a school counselor with everyday contact with the child.

Discussion

The aim of the paper was to present the perceptions and experiences of different stakeholders including what they see as being the consequences of living with a parent who has mental health issues. The results presented here indicate that main consequences for the child in growing up in a family with a parent with mental illness are reversal of the parenting role in the family, emotional and behavioural problems (insecurity, anxiety, not attending school, antisocial behaviour), stigma of being part of a 'mental health case' and lack of parental attention and engagement with the child.

Similar findings have been reported in the WPA Guidelines (Brockington et al., 2013), and in several previous studies (Agnafors et al. 2013; Cooklin 2009, 2013; Gladstone et al. 2006; Manning & Gregoire 2006; Maybery et al. 2005; Reupert et al. 2012b; Somers 2007; Trondsen 2012; Weizmal et al. 2011). These studies have also highlighted parental emotional unavailability, the disturbed behaviour of children and reversal of the roles in family with a parent with mental illness. The authors found that children took an inappropriate amount of responsibility, were sometimes the main carer in the family and could experience various emotional problems, such as insecurity,

anxiety, fear, guilt and shame. Children of parents with mental illness had more problems at school, experienced stigma and they believed that mental illness should be kept hidden in the family.

In our study, above all, we have shown negative effects of growing up in a family with parent with mental illness, but a few statements showed that such experience can bring also positive outcomes. In previous studies Gladstone et al. (2006) pointed that caring for an ill parent and a role reversal can be considered as protective factor that provides children with a constructive family role during times of stress. Aldridge and Becker (2003) found that in some cases helping in the care and support of parents can help to consolidate parent child relationships.

Although a lot is known about consequences of growing up with parents with mental health illness, findings from CAMILLE pre-analyses presented in this article can have an important contribution to existing knowledge. Firstly, we have shown similarities between stakeholders from different countries – problems of children from families with mental health issues are similar in Western/Eastern, North/South European countries, what gives rationale for implementing a pan-European solutions. We had also a possibility to compare different points of view – children's, parents' and professionals'.

In our study we revealed that perceptions of consequences for children living with parents with mental illness were similar in all stakeholders groups, regarding emotional problems, lack of parental attention and stigma. Professionals and parents perceived more parent-child roles reversal and behavioural problems. Positive outcomes of living in families with mental health issues found only professionals and children. Needs for emotional support as well as multidisciplinary and multi-agency care and

help were perceived mostly by professionals and children; needs for security – by professionals only. All focus group participants mentioned that children of parents with mental illness need more information about illness and services and support and assistance from school. Support from school was anyway understood in different way: professionals perceived the role of schools in helping and supporting the child and in assisting in the reduction of stigma; parents suggested the need to strengthen friendship networks at school so as to prevent isolation; children and parents pointed out the need for a functional relationship between home and school to help in difficult situations.

Previous studies conducted by Maybery et al. (2005) showed also some similarities, and differences between children's, parents' and mental professionals' perspectives. Similar responses from the children and parents included problems with major episodes, issues regarding coping mechanisms and the importance of sibling support. As regards the differences, while parents considered it important for children to have someone professional to talk to, the children themselves identified friends as being very important in their lives. Professionals identified supports as more helpful than other key stakeholders. This finding was confirmed in our study. Professionals might have identified supports as more helpful than other stakeholders, because of their role in having to identify and employ appropriate supports for families and having an interest in being able to provide various services (Maybery et al. 2005).

According to our own and previous research results, children growing up in families with a parent with mental illness need emotional support and security, and multidisciplinary care and help. They expect support and information about mental illness from professionals (psychologist, nurses, social workers, physicians). They also

hope to receive support and assistance from schools both in difficult situations and in every day assistance. Unfortunately, only very rarely does this seem to occur.

Rationale for CAMILLE training implementation

Despite the well-documented significant number of children at risk in the population accessing community mental health services, and difficulties encountered by the children, they are often ‘invisible’ to health providers whose focus of intervention is the adult with the mental illness (Ahern, 2003; Goodyear et al. 2015). It’s a strange situation where needs of these children are recognized, but nevertheless they are very often not in treatment (with the exception of formal child protection services that deal with children showing signs of abuse or neglect (Gladstone et al. 2006). Practice standards for the adult mental health workforce for addressing the needs of families where a parent has a mental illness are just created (Goodyear et al. 2015). They are specific to Australia, but many ideas like inclusion in treatment of all family members, offering psychoeducation to all family members, identifying any changes in parenting and offering support – are universal.

Many community mental health professionals are not sufficiently prepared to work both with children and their families. Korhonen et al. (2008, 2010) found that psychiatric nurses considered it important to support the children of parents with mental illness, but found many family-related factors, hindered their work with children. Authors concluded that knowledge of the risks faced by the children of parents with mental illness should be included in the basic core education of nurses. Puskar and Bernardo (2007) provide evidence that school nurses can be successfully involved in mental health screening, promotion and early intervention activities. However, many

authors indicate that there may be difficulties engaging school nurses in such work – not necessarily through a lack of willingness but through a lack of confidence or limited relevant training (Prymachuk et al. 2012; Wilson et al. 2008). It means that there is a great necessity to provide new education programs (like CAMILLE) providing knowledge about needs of children growing up in families with parent with mental illness.

There are some examples of good practices in Australia, Europe and North America aimed at empowering children of parents with mental illness. Many of them are directly targeted at children and their families, in which professionals are involved in the delivery of the interventions. In these cases families play an active role in the implementation of the programme: this is the case of the Meriden Family Programme (Fadden & Heelis, 2011), run in Birmingham, UK, that adopts a psycho-educational approach (Behavioural Family Therapy) or the FAST programme (Kratowill et al. 2009), which specifically addresses the lack of engagement and communication skills of parents with younger children under the age of eleven. In other programmes the main targets are caregivers, who are trained to upgrade their skills and knowledge to support, assist and empower children of parents with mental illness. Training for professionals is, for instance, one the core aims of the Effective Family Programme initiated in Finland (Solantaus, 2006).

Strengths and Limitation of the Study

A focus group method, applied in presented analyses, provides a supportive environment designed to elicit optimal cooperation from the group's participants. This was the method primarily used in the present study, and enabled the CAMILLE project

to understand the problems, needs and expectations of children raised in families with a parent with mental illness from different points of view – children themselves, their parents and professionals who try to help them. Thanks to this method, the picture of the situation became more complete.

The limitation of the study was the relatively smaller number of focus groups conducted with adult children and partners of parents with mental illness, compared with professionals. This resulted from difficulties in accessing this group of respondents. Although this methodological assumption has made it difficult to collect research groups, due to the fact that the project CAMILLE involved 7 countries, the obtained data are very valuable.

The unique contribution of our research to knowledge is in highlighting the fact that the needs, consequences and expectations of children growing up in families with parents with mental illness are broadly similar in different European countries. It means, on the one hand, that the problem is common and difficult to solve, regardless of the wealth of the country or its specific cultural or political factors. On the other hand, we have highlighted the need to develop joint EU efforts, like this international training project.

Conclusions

There is a lack of pan-European guidelines with respect to empowering the children of parents with mental illness and insufficient knowledge and training of professionals working with children. This is an issue which the CAMILLE project is addressing. Training delivers both knowledge about mental illnesses, child development, and needs of families with mental issues, and guidance for working –

methods of supporting the family and recommendations regarding the development of institutions effectively working on the support of families with members with mental illness. Thanks to open access to the CAMILLE training (available after free registration on www.camilletraining.net) these materials can be used by professionals, policy makers and teachers providing trainings of professionals.

According to the data from the CAMILLE study reported here, professionals working with parents with mental illness should be aware of the specific consequences for the children experiencing the mental health problems within the family. To empower children, they should focus on them and at the same time on the other family members, so as not to exclude parents from the parental roles but to support and assist them in their parental responsibilities. Assisting the child is not enough. The whole family needs to be supported and the multi-agency collaboration necessary to achieve this is often sadly lacking. Schools should provide counselling, nurture peer relationships, cooperate with the whole family and teach staff and students about mental health problems to reduce stigma. The new pan-European CAMILLE training programme has been designed to address these specific recommendations.

Acknowledgments

We thank all coordinators of the study in particular countries (Maria Kaunonen, Ian Dawson, Norbert Scherbaum, Stefano Zanone Poma, Peter Ryan, Czesław Czabała, Alex Baldacchino) for permitting access to the international data and all country teams' members for their invaluable contributions to the study.

The authors disclosed receipt of the following financial support for the research: European Commission Daphne III project CAMILLE „Empowerment of Children and

Adolescents of Mentally Ill Parents through Training of Professionals working with children and adolescents”, JUST/2012/DAP/AG/3336.

References

- Agnafors, S., Sydsjö, G., deKeyser, L. & Svedin, C. G. (2013). Symptoms of depression postpartum and 12 years later-associations to child mental health at 12 years of age. *Maternal and Child Health Journal*, 17(3), 405-414. doi: 10.1007/s10995-012-0985-z.
- Ahern, K. (2003). At-risk children: A demographic analysis of the children of clients attending mental health community clinics. *International Journal of Mental Health Nursing*, 12, 223–228.
- Aldridge, J., & Becker, S. (2003). *Children caring for parents with mental illness: Perspectives of young carers, parents and professionals*. Bristol: The Policy Press.
- Barbour, R. (2007). *Doing focus groups*. Thousand Oaks, CA: Sage Publications.
- Bassani, D.G., Padoin, C.V., Phillip, D. & Veldhuizen, S. (2009). Estimating the number of children exposed to parental psychiatric disorders through a national health survey. *Child and Adolescent Psychiatry and Mental Health*, 3, 6. doi:10.1186/1753-2000-3-6
- Boyatzis, R. (1998). *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks, CA: Sage Publications.
- Brockington, I., Chandra, P., Dubowitz, H., Jones, D., Moussa, S., Nakku, J. & Quadros Ferre, I. (2013). WPA Guidance on the Protection and promotion of mental health of children of persons with severe mental illness. *World Psychiatry*, 10(2), 93-102.

- Cooklin, A. (2006). Children and parents with mental illness. In: L. Combrinck-Graham (Ed.). *Children in family contexts*. New York: Guildford Press.
- Cooklin, A. (2009). Children as carers [of parents with mental illness](#). *Psychiatry*, 8(1), 17–20.
- Cooklin, A. (2010). ‘Living upside down’: being a young carer of a parent with mental illness. *Advances in psychiatric treatment*, 16, 141–146. doi: 10.1192/apt.bp.108.006247
- Cooklin, A. (2013). Promoting children’s resilience to parental mental illness: engaging the child’s thinking. *BJPsych Advances*, 19 (3), 229-240. doi: <http://dx.doi.org/10.1192/apt.bp.111.009050>
- Fadden, G. & Heelis, R. (2011). The Meriden Family Programme: lessons learned over 10 years. *Journal of Mental Health*, 20(1), 79-88. doi: 10.3109/09638237.2010.492413
- Foster, K., Lewis, P., McCloughen, A. (2014). [Experiences of peer support for children and adolescents whose parents and siblings have mental illness](#). *Journal of Child and Adolescent Psychiatric Nursing* 27(2): 61-7. doi: 10.1111/jcap.12072
- Foster K., O’Brien, L., Korhonen, T. (2012). Developing resilient children and families when parents have mental illness: A family-focused approach. *International Journal of Mental Health Nursing* (2012) 21, 3–11. doi: 10.1111/j.1447-0349.2011.00754.x
- Gelkopf, M. & Roe, D. (2014). Evaluating outcome domains assessing caregivers of individuals with mental illness: A review. *Family Process*, 53(1), 150-174. doi: 10.1111/famp.12056

- Gladstone, B., Boydell, K. & McKeever P. (2006). [Recasting research into children's experiences of parental mental illness: Beyond risk and resilience](#). *Social Science & Medicine*, 62(10), 2540–2550.
- Gladstone, B., McKeever, P., Seeman, M. & Boydell, K. (2014). Analysis of a support group for children of parents with mental illnesses managing stressful situations. *Qualitative Health Research*, 24(9): 1171-82. doi: 10.1177/1049732314528068
- Goodyear, M., Cuff, R., Maybery, D., & Reupert, A. (2009). CHAMPS: A peer support program for children of parents with a mental illness. *Australian e-Journal for the Advancement of Mental Health*, 8(3), 296-304. doi: 10.5172/jamh.8.3.296
- Goodyear, M., Hill, T-L., Allchin, B., McCormick, F., Hine, R., Cuff, R. & O'Hanlon, B. (2015). Standards of practice for the adult mental health workforce: Meeting the needs of families where a parent has a mental illness. *International Journal of Mental Health Nursing*, 24(2), 169-80. doi: 10.1111/inm.12120
- Hargreaves, J., Bond, L., O'Brien, M., Forer, D., & Davies, L. (2008). The PATS peer support program: Prevention / early intervention for adolescents who have a parent with mental illness. *Youth Studies Australia*, 27, 43-51.
- Hetherington, R., Baistow, K., Katz, I., Mesie, J. & Trowell, J. (2002). *The Welfare of children with mentally ill parents: learning from inter-country comparisons*. New York: John Wiley & Sons.
- Jeffery, D., Clement, S., Corker, E., Howard, L. M., Murray, J. & Thornicroft, G. (2013). Discrimination in relation to parenthood reported by community psychiatric service users in the UK: a framework analysis. *BMC Psychiatry*, 13, 120. doi: 10.1186/1471-244X-13-120.

- Katz, I. & Hetherington, R. (2006). Co-operating and communicating: a European perspective on integrating services for children. *Child Abuse Review*, 15, 429–439. doi: 10.1002/car.965
- Korhonen, T., Vehviläinen-Julkunen, K. & Pietilä, A. M. (2008). Implementing child-focused family nursing into routine adult psychiatric practice: hindering factors evaluated by nurses. *Journal of Clinical Nursing*, 17, 499-508. doi: 10.1111/j.1365-2702.2007.02008.x
- Korhonen T., Pietilä, A-M. & Vehviläinen-Julkunen, K. (2010). Are the children of the clients visible or invisible for nurses in adult psychiatry? – a questionnaire survey. *Scandinavian Journal of Caring Sciences*, 24, 65-74. doi: 10.1111/j.1471-6712.2009.00686.x
- Kratochwill, T. R., McDonald, L., Levin, J.R., Scalia, P. A. & Coover, G. (2009). Families and Schools Together: an experimental study of multi-family support groups for children at risk. *Journal of School Psychology*, 47(4), 245-65. doi: 10.1016/j.jsp.2009.03.001
- Krueger, R.A. (1994). *Focus groups. A practical guide for applied research*. London/Beverly Hills: Sage.
- Lacey, A. & Luff, D. (2007). *Qualitative research analysis*. The NIHR RDS for the East Midlands / Yorkshire & the Humber.
- Lauritzen, C., Reedtz, C., Van Doesum, K. T. & Martinussen, M. (2014). Implementing new routines in adult mental health care to identify and support children of mentally ill parents. *BMC Health Services Research*, 7, 14:58. doi: 10.1186/1472-6963-14-58.

- Lucksted, A., McFarlane, W., Downing, D. & Dixon, L. (2012). Recent developments in family psychoeducation as an evidence-based practice. *Journal of Marital & Family Therapy*, 38, 101-21. doi: 10.1111/j.1752-0606.2011.00256.x
- Manning, C. & Gregoire, A. (2006). [Effects of parental mental illness on children](#). *Psychiatry*, 5(1), 10–12.
- Mays, N. & Pope, C. (1996). *Qualitative research in health care*. London: British Medical Journal Publishing Group.
- Maybery, J. D., Ling, L., Szakacs, E. & Reupert, A. E. (2005). Children of a parent with a mental illness: perspectives on need. *Australian e-Journal for the Advancement of Mental Health*, 4(2), 1-11.
- Maybery, D. & Reupert, A. (2009). Parental mental illness: A review of barriers and issues for working with families and children. *Journal of Psychiatric and Mental Health Nursing*, 16, 784–791.
- Maybery, D., Reupert, A., Patrick, K., Goodyear, M., & Crase, L. (2009). Prevalence of children whose parents have a mental illness. *Psychiatric Bulletin*, 33, 22-26. doi:10.1192/pb.bp.107.018861
- Pitman, E. & Matthey, S. (2004). The SMILES program: A group program for children with mentally ill parents or siblings. *American Journal of Orthopsychiatry*, 74, 383–388.
- Pope, C., Ziebland, S. & Mays, N. (2000). Analysing qualitative data. *BMJ*, 320(7227), 114–116. doi: <http://dx.doi.org/10.1136/bmj.320.7227.114>
- Prymachuk, S., Graham, T., Haddad, M. & Tylee, A. (2012). School nurses' perspectives on managing mental health problems in children and young people. *Journal of Clinical Nursing*, 21, 850–859, doi: 10.1111/j.1365-2702.2011.03838.x

- Puskar, K. R. & Bernardo, L. M. (2007). Mental health and academic achievement: role of school nurses. *Journal for Specialists in Pediatric Nursing*, 12, 215–223. doi: 10.1111/j.1744-6155.2007.00117.x
- Ramchandani, P. & Stein, A. (2003). The impact of parental psychiatric disorder on children. *BMJ*, 327(7409), 242-243. doi: 10.1136/bmj.327.7409.242
- Reupert, A., Cuff, R., Drost, L., Foster, K., van Doesum, K. & van Santvoort, F. (2012a). Intervention programs for children whose parents have a mental illness: a review. *MJA Open*, 1(Suppl 1), 18-22. doi: 10.5694/mjao11.11145
- Reupert, A., Foster, K., Maybery, D., Eddy, K. & Fudge, E. (2011). “Keeping Families and Children in Mind”: An evaluation of a web based workforce resource. *Child & Family Social Work*, 16(2), 192-200.
- Reupert, A., Maybery, D. & Kowalenko, N. (2012b). Children whose parents have a mental illness: prevalence, need and treatment. *MJA Open*, 1(Suppl 1), 7-9. doi: 10.5694/mjao11.11200
- Richie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research. In: Bryman, A. & Burgess, R. G., eds., *Analysing qualitative data*, London: Routledge, 173-194.
- Royal College of Psychiatrists. (2011). *Parents as Patients: Supporting the Needs of Patients who are Parents and Their Children*. (College Report CR164). London: Royal College of Psychiatrists.
- Siegenthaler, E., Munder, T. & Egger, M. (2012). Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. *Journal of American Academy of Child and Adolescent Psychiatry*, 51, 8-17. doi: 10.1016/j.jaac.2011.10.018

- Solantaus, T., Paavonen, E.J., Toikka, S. & Punamaki, R. J. (2010). Preventive interventions in families with parental depression: Children's psychosocial symptoms and prosocial behaviour. *European Child and Adolescent Psychiatry*, *19*(2), 883-892. doi: 10.1007/s00787-010-0135-3
- Solantaus, T. Y. & Toikka, S. (2006). The Effective Family Programme: Preventative services for the children of mentally ill parents in Finland. *International Journal of Mental Health Promotion*, *8*(3), 37-44. doi: 10.1080/14623730.2006.9721744
- Somers, V. (2007). Schizophrenia: The impact of parental illness on children. *The British Journal of Social Work*, *37* (8), 1319-1334. doi: 10.1093/bjsw/bcl083
- Stallard, P., Norman, P., Huline-Dickens, S., Salter, E & Cribb, J. (2004). The effects of parental mental illness upon children: A descriptive study of the views of parents and children. *Clinical Child Psychology & Psychiatry*, *9*, 39-52. doi: 10.1177/1359104504039767
- Tchernegovski, P., Reupert, A. & Maybery, D. (2015). "Let's Talk about Children": An evaluation of an e-learning resource for mental health clinicians. *Clinical Psychologist*, *19*, 49–58. doi: 10.1111/cp.12050
- Trondsen, M.V. (2012). Living with a mentally ill parent: exploring adolescents' experiences and perspectives. *Qualitative Health Research*, *22*(2), 174-188. doi: 10.1177/1049732311420736
- van der Zanden, R. A., Speetjens, P. A , Arntz, K. S. & Onrust, S. A. (2010). Online group course for parents with mental illness: development and pilot study. *Journal of Medical Internet Research*, *12*(5), e50. doi: 10.2196/jmir.1394.
- van Santvoort, F., Hosman, C. M., van Doesum, K.T. & Janssens, J. M. (2014). Effectiveness of preventive support groups for children of mentally ill or addicted

parents: a randomized controlled trial. *European Child and Adolescent Psychiatry*, 23, 473-484. doi: 10.1007/s00787-013-0476-9

Weitzman, M., Rosenthal, D. G. & Liu, Y. H. (2011). Paternal depressive symptoms and child behavioral or emotional problems in the United States. *Pediatrics*, 128(6), 1126-1134. doi: 10.1542/peds.2010-3034

Wilson, P., Furnivall, J., Barbour, R. S., Connelly, G., Bryce, G., Phin, L. & Stallard, A. (2008). The work of health visitors and school nurses with children with psychological and behavioural problems. *Journal of Advanced Nursing*, 61, 445-455. doi: 10.1111/j.1365-2648.2007.04505.x

Table 1. Composition of focus groups / individual interviews

Country	Professionals		Children and partners		Mentally ill parents
	number	type	number	type	number
England	6	psychologist, nurses, social workers	3	adult children	3
Finland	3 + 2	school nurse, school curator, physician of health care centre, director of psychiatric nursing, teacher of day-care centre.	3	adult children and 1 husband	5
Germany	7	social workers and social pedagogues	-		-
Italy	10	social workers, psychologists, neuropsychiatrists	6	adult children	7
Norway	4	psychologist, midwife, social workers	-		1
Poland	7	psychiatrists, psychologists, a nurse and a social worker	1	wife	4
Scotland	11	nurse therapists, family therapist, consultant psychiatrist, family and community support team manager, early years support charity manager, educational home visitors, clinical psychologist, senior health promotion officer, carers support charity worker	2	adult child and sister	6 + 5