



ORIGINAL ARTICLE

Needs, expectations and consequences for children growing up in a family where the parent has a mental illness

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ABSTRACT: *The lack of pan-European guidelines for empowering children of parents with mental illness 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 aim of this initial task in the project was to analyse needs, expectations and consequences for children with respect to living with a parent with mental illness from the perspective of professionals and family members. This qualitative research was conducted in England, Finland, Germany, Italy, Norway, Poland and Scotland with 96 professionals, parents with mental illness, adult children and partners of parents with mental illness. A framework analysis method was used. Results of the study highlighted that the main consequences described 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 described as emotional support, security and multidisciplinary help. Implications for practice are that professionals working with parents with mental illness should be aware of the specific consequences for the children and encourage parents in their parental role; multi-agency collaboration is necessary; schools should provide counselling and prevent stigma.*

KEY WORDS: *child development, family, mental illness, parenting, qualitative research.*

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INTRODUCTION

Parental mental illness is considered one of the strongest 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 UK live with a parent who has a mental illness (Royal College of Psychiatrists 2011); in Australia, up to one in five young people live in such families (Maybery *et al.* 2009); in Canada it is estimated that approximately 12% of all children under 12 have a parent with 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 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 multidisciplinary work. In addition, a greater emphasis needs to be placed on identifying emerging problems experienced by the children of parents with a mental illness (COPMI) (Lauritzen *et al.* 2014).

Mental illness in the family

Parents with a mental illness can struggle with parenting. These parenting difficulties are magnified by the stigma they frequently experience related to their mental illness (Jeffery *et al.* 2013). Some children growing up in families where there is a parent with mental illness might feel guilty, overburdened, and isolated, and take on responsibilities far beyond their years (Ahlström *et al.* 2011). Faced with these difficulties, children are often powerless and helpless, and might not know where to access support (Pitman & Matthey 2004; Trondsen 2012).

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

- 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 parent–child 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.* 2014), a parent-focused approach (Solantaus & Toikka 2006), online courses for parents with mental illness (van der Zanden *et al.* 2010), and psycho-educational interventions (Lucksted *et al.* 2012). Peer support groups are a method often used to improve the resilience of COPMI (Foster *et al.* 2014; Gladstone *et al.* 2014; Goodyear *et al.* 2009;

Hargreaves *et al.* 2008; Pitman & Matthey 2004). In a review of intervention programmes from Australia, Europe, and North America for COPMI, Reupert *et al.* (2012a) identified 12 peer-support programmes, seven family-intervention programmes (mostly targeting families of parents with depression and/or anxiety), two 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 health problems in COPMI have been shown to be effective (Siegenthaler *et al.* 2012; Solantaus *et al.* 2006, 2010). Siegenthaler *et al.* carried out a systematic review and meta-analysis of the effectiveness of family interventions to prevent mental illnesses or psychological symptoms in COPMI. They found that, in seven interventions, the risk of mental health problems in COPMI was reduced by 40%, and a further seven trials found lower symptom scores in COPMI receiving these interventions.

Need for pan-European guidelines

A review of the literature so far has led us to the conclusion that while certain interventions have been effective on a one-off basis, there needs to be a translation of these evidence-based interventions into clear guidelines and indicative training programmes for best generic core practice across adult and child care. Too often, adult and child services exist in isolation from each other. In several countries, there is an organizational gap between services focusing on either adult mental illness or child mental illness (e.g. Cooklin 2006; Maybery & Reupert 2009; Stallard *et al.* 2004). While some individual countries within Europe have developed good practice guidelines for child and adult services (e.g. 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 COPMI.

The organizational and policy gap between services focusing on either adult or child mental illness was the main driver that led to the European Union (EU) project CAMILLE. Its rationale was that there are few evidence-based training programmes for professionals working with children growing up in families where a parent is experiencing a severe, long-term mental illness (Hetherington *et al.* 2002; Ramchandani & Stein 2003; Reupert *et al.* 2011; Tchernegovski *et al.* 2015). Moreover, there are no pan-European guidelines for empowering COPMI.

The focus of CAMILLE is to contribute to early prevention strategies and to promote the physical, psychosocial, and mental health of COPMI. Therefore, CAMILLE aims to facilitate a trans-European

multidisciplinary collaboration with respect to developing a core training programme designed to promote the inter-professional efforts concerning the support of these vulnerable children and adolescents. To that end, the CAMILLE project has focused on the development of a new pan-European training programme to improve the awareness and competencies of professionals working with COPMI. 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 partners of parents with a mental illness, and parents with a mental illness themselves. The present study provides the results of qualitative analyses that were used to inform the development of the new training programme. The research questions for this study were:

- 1 What are the perceptions of professionals and stakeholders experiencing mental illness in their family regarding the main consequences for children growing up in these families, the main needs of these children, and the main expectations of these children from professionals and school?
- 2 Are there any differences in these perceptions between different stakeholder groups and countries?

MATERIALS AND METHODS

The general methodology applied was the focus group, a well-known qualitative method (Mays & Pope 1996). However, individual interviews were also carried out. These research techniques allow the participants to express their ideas, feelings, and thoughts freely, in a non-judgmental context. The focus group method 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 qualitative research was conducted in seven European countries: England, Finland, Germany, Italy, Norway, Poland, and Scotland, between May and July 2013. Ethical approval was given in England and Poland. In other countries, the ethics committees were approached and decided that ethical approval was not required for this study.

In each country, one-to-four focus groups or individual interviews were conducted (18 groups with 2–11 participants; 2 individual interviews), each interviewed by one or two professionals (psychologists or registered nurses). Participants ($n = 96$) were recruited from health service centres, university-based education centres, social welfare centres, and non-statutory organizations. Participation in the study was voluntary; individuals 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 parents with a mental illness, and/or parents with a mental illness (whereby 2 countries did not carry out this component of the study and 2 other countries carried out individual interviews). There were higher numbers than would be ideal for the professionals' focus group in Italy ($n = 10$) and Scotland ($n = 11$). This was because more participants responded positively to the invitation than expected, and the facilitators did not want to turn professionals away when their input was relevant for the project's aims as a whole.

The research participants were drawn from three different populations:

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

Data presented in the present study were drawn from all three groups. The focus group/interview characteristics are presented in Table 1.

The focus groups and interviews were carried out in a flexible way to respond to particular group dynamics and/or time available, but using the same guidelines for all groups and countries. A topic guide was used to encourage discussion regarding specific problems for families of parents with mental illness and strengths and weaknesses of the existing services.

All participants were asked the following questions: (i) What are the main consequences for children of parents with mental illness (or what are your most significant experiences while living with someone with mental illness/ as a parent with mental illness)?; and (ii) What are the main needs and expectations of children?

Interviews took place in health service centres, social welfare centres, or at the university (Finland). Discussions were carried out in the national languages of the participants, recorded on a digital recorder, then transcribed verbatim. 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 wanted to speak more about their own experiences, in order to deal with people's feelings if painful memories were stimulated.

TABLE 1: *Composition of focus groups/individual interviews*

Country	Professionals		Children and partners		Parents with a mental illness
	Participants (n)	Type	Participants (n)	Type	Participants (n)
England	6	Psychologist, nurses, social workers	3	Adult children	3
Finland	3 + 2	School nurse, school curator, physician of healthcare 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

Data analyses

Framework analyses consisted of five stages (Lacey & Luff 2007; Pope *et al.* 2000; Richie & Spencer 1994):

- 1 Familiarization (transcription and reading of the data, in each country).
- 2 Identifying a thematic framework (by Polish researchers) (the initial coding framework was divided into needs, expectations, and consequences components).
- 3 Indexing (applying the thematic framework to the data, in each country).
- 4 Charting (using headings from the thematic framework to create charts of all data, in Poland).
- 5 Mapping and interpretation (searching for patterns, associations, concepts, and explanations in all the data by researchers from all partner countries).

The research coordinator for the project (Poland) prepared the initial coding frameworks on the basis of the stated research questions, an extensive literature review, and other emerging issues the researchers encountered as they became more familiar with the material, and sent this to all partners (Barbour 2007). Each site undertook its own preliminary data analysis according to criteria provided by the research coordinator (in their 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). Thematic

frameworks consisted of three components: (i) the main consequences for children experiencing mental illness in their family; (ii) the main needs of these children; and (iii) children's service requirements. Two researchers in each country coded all the transcripts separately; the 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 COPMI were defined by five overall themes: (i) emotional problems; (ii) lack of parental attention; (iii) inadequate roles; (iv) behavioural problems; and (v) stigma.

Emotional problems

Participants from all three sample groups in all countries described the predominant experience of COPMI as being insecure, as expressed by one of the professionals in Germany:

Unpredictability and insecurity. Parents who are this way now, that way tomorrow, and then different again.

Participants also highlighted the anxiety and fear felt by the children. Moreover, all groups 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, as stated by a professional in Scotland:

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 child's experience, 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 focus group in England recalled a situation with his 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 the lack of parental attention can be placement in foster care. An adult child in Scotland shared her 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.

Inadequate roles

Participants of the professionals' and parents' sample groups highlighted the issue of the reversal of parent-child roles when the child takes care of a parent, and might take on greater responsibilities for the family than is age appropriate, as stated by one of the professionals in Germany:

You can sometimes observe a reversal of roles, so that a child is watchful; for example, over her mother, and that she senses when the parent's condition worsens, and children are overstrained with that.

Behavioural problems

Consistently, participants of the professionals' and parents' sample groups described school non-attendance as the main problem, as stated by a professional from Scotland:

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?

They also highlighted antisocial behaviour as a significant problem.

Stigma

Keeping the illness secret to avoid shame was noted by children, parents, and professionals as a very important consequence of parental illness. In Italy, it was pointed out by a professional from the child's point of view:

Often in addition to being frightened by what happens, we don't even have the possibility to ask for help because of stigma.

Professionals in Poland stated that that a further consequence of stigma is isolation at school:

There is no time to meet with peers, ashamed to invite them into home.

The data also revealed some positive effects of growing up in a family with a parent with mental illness. One of the professionals from England stated:

There are situations where the child may have picked up some good skills in managing the situation even before you, the specialist, comes 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 enabled 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

Two main needs of children were described by the interviewees: the need for (a) emotional support, (b) security.

Need for emotional support

Participants of the professionals' and children's groups stated that children of parents with mental illness need to have someone who listens to them. Children also expressed the need to find ways to manage tension in their relationships with their parents and to be able to relieve stress and anxiety.

Need for security

Professionals in all countries highlighted children's need for security. Professionals in Germany also described the need for a child to have someone to whom they can pass over their 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 with 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.

Children's service requirements

The three main service requirements of children derived from the data were: (i) information on illness and services; (ii) multidisciplinary and multi-agency care and help; and (iii) support and assistance from school.

Information on illness and services

All focus group participants mentioned that COPMI need more information about the mental illness and its prognosis, as stated by a professional from Poland:

Specific guidelines...sometimes they need a 'realignment', (children need) support in the acceptance of the disease and awareness that relapses can occur.

Children and parents also commented that they needed information about existing services and other assisting organizations.

Multidisciplinary and multi-agency care and help

Professionals' and children's group participants stated that COPMI need care and support from mental health service staff (trained in working with children), but also from other organizations that might offer help in coping with the problems of everyday life. One of the professionals in England described the need 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(s) 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.

Professionals from all countries stated that COPMI need more child-focused interventions, more support in coping with stress and solving problems, and to have unacceptable responsibility removed from them, as stated by a professional in Germany:

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 highlighted the need for professionals' patience and openness, and they suggested home-based instead of institutional support.

Support and assistance from school

Participants of the professionals' focus groups perceived the role of schools to support the child and assist in reducing stigma. Parents suggested that friendship networks at school should be strengthened 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 a mental illness described how communication could be improved between school and home:

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 that all the people knew so the guidance teacher (and people who knew)... could email each other when there was an issue.

Participants of the children's groups in Italy suggested the need for a school counsellor who had everyday contact with the child.

DISCUSSION

The aim of the present study was to investigate the perceptions and experiences of different stakeholders regarding the consequences of living with a parent who has mental health issues. The results presented here indicate that the main issues for the child are reversal of the parenting role in the family, emotional and behavioural problems, stigma

surrounding mental health problems, 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; Weitzman *et al.* 2011). These studies have also highlighted parental emotional unavailability, the disturbed behaviour of children, and reversal of the roles in families where there is a parent with mental illness. Those authors have also found that children take an inappropriate amount of responsibility; are sometimes the main carer in the family; and could experience various emotional problems, such as insecurity, anxiety, fear, guilt, and shame (Somers 2007; Trondsen 2012). They also found that COPMI had more problems at school, experienced stigma, and believed that mental illness should be kept hidden in the family.

Our data indicate, primarily, the negative effects of growing up in a family with a parent who has a mental illness, with only a few statements showing that such experience can also bring positive outcomes. In contrast, in previous studies, Gladstone *et al.* (2006) pointed out that caring for a parent with a mental illness can be considered a 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 much is known about the consequences of growing up with parents who have a mental illness, findings from the CAMILLE project's initial research analyses presented in the present study can make an important contribution to existing knowledge. First, we have shown similarities between stakeholders from different countries. Problems of children from families with mental health issues were found to be similar in the wide range of European countries involved, which provides the rationale for implementing a pan-European solution. We also had the possibility of comparing different stakeholders' points of view.

In the present study, we revealed that perceptions of consequences for COPMI were similar among all stakeholders groups regarding emotional problems, lack of parental attention, and stigma. However, professionals and parents highlighted parent-child role reversal and behavioural problems, which were not discussed by the children and partners' group. Moreover, positive outcomes of living in families with mental health issues were described only by professionals and children, not by the parents themselves. The requirements for emotional support, as well as

multidisciplinary and multi-agency care and help, were perceived mostly by professionals and children, whereas the need for security was perceived by professionals only. All stakeholder groups mentioned that COPMI need more information about the illness and services, and that they require support and assistance from school. Support from school was described in different ways: professionals perceived the role of schools in supporting the child and in helping to reduce stigma, parents suggested the need to strengthen friendship networks at school so as to prevent isolation, and children and parents pointed out the need for better communication between home and school to help in difficult situations.

A previous study conducted by Maybery *et al.* (2005) also showed some similarities and differences between children's, parents', and mental health professionals' perspectives. Similar responses from the children and parents included problems with major episodes, issues regarding coping mechanisms, and the importance of sibling support. While parents considered it important for children to have a professional to talk to, the children themselves identified friends as being very important in their lives. Professionals identified support from different sources as more helpful than other key stakeholders. This finding was confirmed in the present study. Professionals might have identified supports as more helpful than other stakeholders because of their role in having to identify and employ appropriate support for families (Maybery *et al.* 2005).

In summary, according to our own and previous research results, it is clear that children growing up in families with a parent with a mental illness require input from a variety of different services. They need emotional support and security, and information about mental illness. They also require support and practical assistance from schools, both in difficult situations and in everyday life. 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, and difficulties encountered by these 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). Although some needs of these children are recognized, they are very often not receiving care or support (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 in addressing the needs of families where a parent has a mental illness have just

recently been just created (Goodyear *et al.* 2015). They are currently specific to Australia, but many of their suggestions, such as inclusion in treatment of all family members, offering psycho-education to all family members, and identifying any changes in parenting and offering support, are universally relevant.

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 COPMI, but family-related factors, such as families' fears and lack of time, hindered their work with children. Those authors concluded that knowledge of the risks faced by COPMI 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 might 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). This means that there is a need for new education programmes (e.g. CAMILLE) to provide knowledge about the needs of COPMI.

There are some examples of good practices in Australia, Europe, and North America aimed at empowering COPMI. 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 for the Meriden Family Programme (Fadden & Heelis 2011) in Birmingham, UK, that adopts a psycho-educational approach (behavioural family therapy) or the Families and School Together (FAST) programme (Kratochwill *et al.* 2009), which specifically addresses the lack of engagement and communication skills of parents with younger children under the age of 11 years. In other programmes, the main targets are caregivers, who are trained to upgrade their skills and knowledge to support, assist, and empower COPMI. Training for professionals is one of the core aims of the Effective Family Programme initiated in Finland (Solantaus & Toikka 2006).

Strengths and limitation of the study

The focus group method 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 group to understand the problems, needs, and service requirements of children raised in families with a parent who has a mental illness from different points of view –

children themselves, their parents, and professionals who try to help them. This method has enabled a better understanding of the situation.

The limitation of the present 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 all countries accessing this group of respondents. Nevertheless, due to the fact that the CAMILLE project involved the combined data of seven European countries, the obtained data are valuable.

There is paucity of information in the field of epidemiology, interventions, and experience of COPMI. However, in practice, the professional support of children and parents is often not as good as it could be, considering what is known. The answers of the professionals taking part in our study are therefore of high interest, because they simultaneously formulate the needs of children and professionals for a training programme.

The unique contribution of this research 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. The consistent study design across seven countries is a unique methodology and the results are coherent. 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 programme.

CONCLUSIONS

There is a lack of pan-European guidelines with respect to empowering COPMI and insufficient knowledge and training of professionals working with children. This is an issue that the CAMILLE project is addressing. The new training programme will deliver three main themes: knowledge about mental illnesses, child development, and needs of families with mental issues; guidance for working – methods of supporting the family; and recommendations regarding the development of effective institutions. Because of open access to the CAMILLE training (available after free registration on www.camilletraining.net), these materials can be used by training providers and trainees.

According to the data from the CAMILLE study reported here, professionals working with parents who have a mental illness should be made aware of the specific consequences for the children experiencing the mental health problems within the family. To empower children,

they should focus on them, but assisting the child is not enough. The whole family needs to be supported. In particular, parents need to be supported with their parental role, but the multi-agency collaboration necessary to achieve this is often sadly lacking. Schools are well placed to help families, and 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.

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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), 405–14. 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, 223–8.
- Ahlström, B. H., Skärsäter, I. & Danielson, E. (2011). Children's view of a major depression affecting a parent in the family. *Issues in Mental Health Nursing*, 2, 560–7.
- 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: Combrinck-Graham, L (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, 141–6. DOI:10.1192/apt.bp.108.006247.
- Cooklin, A. (2013). Promoting children's resilience to parental mental illness: engaging the child's thinking. *British Journal of Psychiatry Advances*, 19(3), 229–40. DOI: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*, 21, 3–11. DOI:10.1111/j.1447-0349.2011.00754.x.
- 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), 2540–50.
- 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., et al. (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, 429–39. 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*, 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), 10–2.
- 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, 784–91.
- Maybery, D., Reupert, A., Patrick, K., Goodyear, M. & Crase, L. (2009). Prevalence of children whose parents have a mental illness. *Psychiatric Bulletin*, 33, 22–6. 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, 383–8.
- Pope, C., Ziebland, S. & Mays, N. (2000). Analysing qualitative data. *BMJ*, 320(7227), 114–6. DOI:10.1136/bmj.320.7227.114.
- Pryjmachuk, 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, 215–23. 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), 242–3. 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, RG (Eds). *Analysing qualitative data*. (pp 173–94) London: Routledge.
- Royal College of Psychiatrists. (2011). *Parents as Patients: Supporting the Needs of Patients who are Parents and Their Children*. (College Report CRI64). 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), 1319–34. 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), 174–88. 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*, 473–84. 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), 1126–34. DOI:10.1542/peds.2010-3034.
- Wilson, P., Furnivall, J., Barbour, R. S., et al. (2008). The work of health visitors and school nurses with children with psychological and behavioural problems. *Journal of Advanced Nursing*, *61*, 445–55. DOI:10.1111/j.1365-2648.2007.04505.x.