Community Mental Health Journal (2019) 55:271–278
https://doi.org/10.1007/s10597-018-0243-y

ORIGINAL PAPER

Volunteering to Care for People with Severe Mental Illness: A Qualitative Study of the Significance of Professional and Private Life Experience

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Received: 6 September 2017 / Accepted: 27 January 2018 / Published online: 6 February 2018

Abstract
Challenges in recruiting volunteers encountered by psychiatric services are barely elucidated despite a general societal increase in volunteering. The aim of the study was to explore the significance of professional and private life experiences in willingness to volunteer to care for people with severe mental illness. Focus group interviews with volunteers in the Community Family Programme was conducted, followed by thematic analysis. All interviewees had professional and/or private experience of SMI, which had a major influence on their initial willingness to volunteer. Volunteering was an opportunity to pass on their experiences and to care for SMI people in ways that were not possible in their professions. The interviewees did not distinguish between the influences of professional and/or private life experiences on their willingness to volunteer. The study demonstrates the importance of professional and/or private life experiences in initial considerations about volunteering for mental health care. The consequences for recruitment practices are discussed.

Keywords Severe mental illness · Community psychiatry · Social psychiatry · Volunteering · Community family programme · Qualitative research

Introduction

People with severe mental illness (SMI) frequently have problems in establishing and maintaining relationships, and consequently experience social isolation (e.g. Bengtsson-Tops and Hansson 2001; Boydell et al. 2002; Thompson et al. 2016). This problem is often addressed by psychosocial programmes that arrange friendships for people with SMI. Such programmes are known as 'befriending services' (Mitchell and Pistrang 2011; Thompson et al. 2016), 'compeer friends' (McCorkle et al. 2009), 'compeer volunteers' (Sacca and Ryan 2011), 'peer support' (Solomon 2004) or 'community families' (Jensen et al. 2017; Væggemose et al. 2017). The idea is to match a volunteer person or family and a person experiencing SMI to foster social relationships and reduce the negative effects of social isolation.

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Volunteer-based social programmes targeting individual difficulties reflect a general increase in volunteering in the Western world (Lauber et al. 2002; Smith and Greenwood 2014; Thompson et al. 2016; Wilson 2000). Despite the growing significance of volunteerism, empirical experiences from a Danish psychosocial programme, the Community Family Programme, indicate that psychiatric services have difficulties in recruiting volunteers. In one study, recruitment challenges in voluntary befriending services are mentioned (Dean and Goodlad 1998), but otherwise there seems to be a lack of literature addressing this issue.

Existing studies of volunteering in mental health care focus on the characteristics of volunteers or on their motivations and attitudes. Lauber et al. (2002) show that predictors of positive attitudes to volunteering in psychiatry are age, gender and a social profession. Sacca and Ryan (2011) find that compeer volunteers in general report low levels of stigma towards people with mental illnesses. Jensen et al. (2017) identify a wish to care for vulnerable people and to engage in a rewarding relationship as the main motivations for volunteering in a psychosocial programme. Moreover, work life seems to influence motivation to volunteer. Overgaard (2016) demonstrates that volunteers establish a link

between their paid and unpaid work to explain their unpaid work in terms of the trajectories of their working lives, while other studies show that mental health care volunteers are characterized by personal or professional experience with mental health (e.g. Dean and Goodlad 1998; Lauber et al. 2002; Solomon 2004).

Nevertheless, there is limited understanding of the impact of professional and private life experiences in people's initial considerations about volunteering in mental health care. Most studies do not distinguish between volunteers' considerations before their engagement—meaning the initial considerations and decisions about volunteering—and their later experiences as volunteers. To address recruitment challenges in mental health care volunteering, we need more detailed knowledge of the significance of professional and private life experiences in relation to willingness to volunteer in mental health care. Therefore, the aim of this paper is to explore the significance of these factors in willingness to volunteer for the care of people with SMI.

Methods

Because the aim of the study was to gain a deeper insight into a rather unexplored field, we chose a qualitative methodological approach, using focus group interviews with volunteers. The empirical focus of the study was a Danish psychosocial programme, the Community Family Programme.

Setting

The study was conducted in four municipalities where the Community Family Programme operated. The municipalities were located in the Central Denmark Region and included both rural areas and provincial towns. The aim of the Community Family Programme was to assist people with SMI in establishing on-going social relations with families outside the mental health services; these families engaged on a voluntary basis in arranged friendships with people with SMI. The programme was organized by municipal mental health workers, who recruited volunteers, matched people with SMI with volunteer families, and provided on-going support when needed. The concept of 'family' was broadly defined; it included couples with young and adult children, couples without children, and single people.

Recruitment of Interviewees

In the study, we included people who were active in the Community Family Programme. During the interviews, we focused strictly on their initial considerations before engaging in the programme. Because the focus of the study was to explore recruitment challenges, our intention was also to include people who were aware of the programme but did not wish to volunteer. However, very few such people agreed to participate, despite our attempts to use various methods and media to contact them, for example, by using invitations sent through the network of the community families or via a social media site of the programme and via municipal mental health workers.

The municipal mental health workers provided contact details to the families who were active volunteers at the time of data collection, and adult members of the families were invited by email or telephone. Of the 19 active families, two declined because of practical circumstances and 17 agreed to participate.

Data Collection

Focus group interviews were chosen as a method to encourage discussion and sharing of experiences by the interviewees (Halkier 2010). Three focus group interviews were conducted with four, four and nine interviewees each lasting 2–2½ h. Two interviews were conducted in two separate municipalities; the third group combined interviewees from two municipalities because of the low number of interviewees.

The interviews were conducted according to a semi-structured guide including open-ended questions and short tasks, for example, involving cards with statements about volunteering or about mental illnesses that the interviewees had to prioritize or discuss. The purpose of the tasks was to stimulate discussion. The interview guide was based on the research literature and preliminary interviews with municipal mental health workers. Themes included (1) initial considerations regarding volunteering to care for people with SMI, (2) perceptions of and attitudes towards people with SMI, (3) considerations of volunteering in general and specifically in mental health care, (4) reasons for involvement in the Community Family Programme, and (5) opinions on recruitment challenges. During the focus group interviews, the two interviewers strove to include the viewpoints of all interviewees and to encourage discussion in the groups. All interviews were audio-recorded and transcribed verbatim.

Analysis

Thematic analysis was conducted (Braun and Clarke 2006). The interviews were read by all authors and initial themes were generated. Following discussions among the authors, final themes were agreed. The interviews were coded thematically using NVivo 10.0 software. The two main themes analysed were: (A) the significance and influence of professional background (seven sub-themes), and (B) the significance and influence of personal background (nine sub-themes). The themes are shown in Table 1.

Table 1 Themes, subthemes and descriptions

Theme A Significance and influence of professional background		
	Sub-theme	Description
1	Professional background	Data about job situation and educational background
2	Get to know about the programme	Professional knowledge about mental illness means that one gets to know about the Community Family Programme
3	Not discouraged	Professional knowledge about mental illness means that one is not discouraged from engaging with people suffering from mental illness
4	Knowledge about making a difference	Professional knowledge about mental illness indicates a belief that it makes a difference to offer help to sufferers
5	Care	A desire to contribute an amount and type of care that cannot be offered in professional carer jobs
6	Use of professional knowledge	A desire to make use of professional knowledge as a volunteer
7	Professional development	A desire to develop professionally by learning and gaining experience with people suffering from mental illness
Theme B Significance and influence of personal background		
	Sub-theme	Description
1	Oneself	Current or previous personal experience of mental illness
2	Family members	Family members suffering from mental illness currently or previously
3	Gap	Missing something in life to engage in, a gap to be filled
4	Surplus of time and/or mental resources	Surplus of time and/or mental resources
5	Life events	Momentous life events/turning points prompted engagement in the Community Family Programme
6	Upbringing	Engagement in the Community Family Programme is compatible with values learned during upbringing
7	Self-understanding	Engagement in the programme is compatible with self-understanding
8	Learning	A desire for new perspectives on life, or that family members should have this
9	Volunteer work	Experiences with other kinds of volunteer work lead the person to engage in the Community Family Programme

Results

To provide an overview of the 17 interviewees in the study Table 2 presents the distribution of the relevant variables. The table shows that most interviewees were women over 50 years old, and half of them had left the labour market. Interestingly, all interviewees had some kind of professional and/or private life experience with SMI or related issues, and the table indicates the details and distribution of such experiences. We next explore this influence of their professional and private life experiences on their willingness to volunteer for the Community Family Programme.

The Meaning of Professional Experience

As noted, a number of interviewees had worked or engaged with SMI people in their current or former job, and thus had professional experience with SMI people. For instance, former prison officer Marianne had managed inmates with various forms of SMI; Sara, a trainee social worker, had undertaken her practical training in a psychiatric unit, and Annie had worked in municipal social care visiting SMI people in their homes to support them in their daily lives. Although not trained to deal with people with psychosocial problems, Tom often met SMI people in his job as an estate manager as they were commonly tenants in social housing estates. Most interviewees with no direct experiences with SMI people through their jobs had or have jobs in health or social care that they termed caring jobs, meaning that they were aware and took care of other people's physical and psychological needs.

According to the interviewees, their professional experience made them aware of the challenges faced by people with SMI in establishing social relations outside the professional health care sector. As volunteers in the Community Family Programme, they were eager to assist with this. For instance, Annie commented:

> Through my work, I saw a need in many of our users to have a 'community friend'. I assumed that my knowledge of their problems could be beneficial…

Table 2 Relevant variables for characteristics of interviewees (N = 17)

Gender	
Female	12
Male	5
Age	
20–29	1
30–39	0
40–49	3
50–59	5
60–69	7
Not known	1
Labour market position	
Studying	1
Working	6
Unemployed	1
Retired, including early retirement, disability pension, employment and support allowance	8
Not known	1
Professional experience with mental illness (in current or former job)	
Working in health care (specifically working with SMI people)	8 (3)
Working in social care (specifically working with SMI people)	5 (3)
Meeting SMI people in other kinds of jobs	2
None/not mentioned	2
Private life experience with mental illness	
Personal experience with SMI	2
Family members with SMI	4
None/not mentioned	11

> and I thought, well, then it's here that I want to make an effort. That's how I started. (Annie)

This remark is an example of how professional background was the entry point to awareness and knowledge about the need of SMI people for social relations outside the health care sector. Such knowledge had a major influence on their initial volunteer engagement.

Some interviewees also indicated that their initial engagement was motivated by professional development and the opportunity to gain experience about this particular target group. Sara, the trainee social worker, said:

> It was actually mainly because of occupational experience, that I wanted to participate as a volunteer, so that I could write it on my CV. (Sara)

Importantly, many interviewees expressed the view that as professionals and in their professional jobs they were not in a position to remedy the problems of establishing and maintaining social relations among people with SMI. For instance, Katrine said:

> As a health care assistant, you work as a professional, whereas in this case, as a private individual volunteer, humanity and social relationships are in focus. (Katrine)

This comment illustrates the experience of voluntary engagement as opposed to that of the interviewees' professional jobs. Their motivation was to maintain an intentional distance from their respective professions. The interviewees felt that they had gained knowledge about the needs of people with SMI whom they would not accommodate in their professional jobs, but whom they were in a better position to meet as private individuals. Just as people with SMI had an identified need for care, the majority of volunteers also had an unsatisfied need to care and to be perceived as caring individuals, not only as professionals, but particularly in their own eyes. Interviewee Jane reported that she engaged as a volunteer because she hoped for "someone to understand that I was a human being, not just a 'municipality woman'". This constant frame of reference in relation to professional obligations seemed to clarify what the interviewees initially thought they could do as volunteers. Therefore, their initial voluntary engagement was based on a chance to care for people with SMI, to focus on what they described as human values instead of on a clinical diagnosis and therapeutic relationships; in that way, they were involved as private individuals with personal human values. These were all aspects that they contrasted with their professional experience.

In summary, many interviewees had professional experience from their current or former jobs within social and health care, and in some cases specifically with people with SMI. This made them aware of the needs of SMI people and made them eager to care for them in a way that they were unable to do in their professions.

The Meaning of Private Life Experience and Circumstances

As shown in Table 2, many interviewees had knowledge and experiences of SMI in contexts other than in their careers. Some had themselves suffered from stress, depression and/or other kinds of mental illness and challenges, and they wanted to use their personal experience to help other people with SMI. These interviewees, with personal experience of SMI, believed that community friends, for their part, felt more comfortable with someone who knew about their condition and could draw on personal experience and understanding of their problems. Allan, who had lived with SMI for many years, but had received good medical treatment, argued:

> I think it is easier for my community friend that I am ill myself. That is why she is so honest with me and has told me her life story. (Allan)

Moreover, the interviewees with personal experience of SMI were motivated by an intention to use their experiences and knowledge of mental illness to help other sufferers. Helle, who had suffered from stress and depression, said:

> As I got better, it realized that it's such a pity that all the experiences you get from living with this kind of disease are not used for anything. Then I saw an advertisement for the Community Family Programme, and I thought, 'well, that's it!'. (Helle)

Other interviewees had personal experience of SMI in their family life, for example, from having children who suffered from various kinds of SMI, and as close relatives, they experienced a continuing struggle to deal with this. According to the interviewees, this made them aware of SMI people's need for help to establish and maintain social relations. They were accustomed to being with people suffering from SMI and were comfortable with this. In addition, they believed that they had important knowledge about how to deal with SMI that could be useful. For instance, Lisbet commented:

> We have a daughter who has been mentally ill for some years now. Therefore, we've gotten some knowledge of this area and we wanted to pass it on, for the benefit of others. (Lisbet)

In addition to personal experiences of SMI, some interviewees reported that they initially became involved in the programme because of personal needs and desires. Some interviewees mentioned that they had surplus time, often after leaving the labour market. They reported a desire to spend their spare time in a meaningful activity, and they perceived the Community Family Programme as one such opportunity. The interviewees referred to the personal values of helping others in need, and some mentioned that these values derived from their own upbringing. For instance, when Jane was a child, her family had foster children living in their home, and this made her always eager to help people in need.

However, the interviewees were not only motivated by a desire to support vulnerable people and the opportunity to contribute meaning to their lives. They also expected that being a volunteer in the Community Family Programme would offer meaning in their own lives. They assumed that they themselves would enjoy the company and might learn from being with another person who was different from them and the people with whom they normally socialized. For some interviewees, the opportunity to get to know a new person played an even more important role. Because of their life circumstances, they missed specific forms of social life that they hoped to gain from their community friend. For instance, after the tragic loss of her young daughter, Laura missed having someone to do girlish things with and was matched with a young woman, imagining they could go shopping and rollerblading together. Other interviewees also expressed an initial wish for a new friend, regardless of sex, age and areas of interest.

Overall, personal experience of SMI together with personal circumstances and values had a great influence on the interviewees' interest in joining the programme. Their own personal life experience, needs and desires as well as those of the SMI people were important, and in practice, these aspects were most often not distinguished. In the words of Marianne: "I did this for her [the community friend], but also for myself. It makes me happy!"

Merging Paths

Parallels appear across the two main themes: the influence of professional experience and the influence of personal life experience and circumstances. The interviewees' prior mental health experiences enabled them to feel confident and safe in the company of people with SMI, regardless of whether the experiences derived from their professional or private lives, or both. Their prior experiences were a kind of prerequisite for their voluntary engagement in the Community Family Programme. As Karen and Jane explained:

> If you haven't had the chance to know it [SMI], in one way or another, via personal experiences or among your acquaintances, it is still a taboo. And you don't quite know what you're getting into. (Karen)
> If you didn't know anything about it before, then I don't think that you would have the guts to intervene as a volunteer. (Jane)

Importantly, the participants' choice to engage as volunteers in mental health services was heavily influenced by the opportunity to distance themselves from their professional identity. They felt that as professionals they were not in a position to fully accommodate the needs of people with SMI. They experienced limited opportunities to act in a personal way and engage as a human being and scant possibilities to just being together. In other words, they missed 'caring about' instead of 'caring for'. Similar, the awareness of this need was also expressed by participants with personal experiences with SMI, so the voluntary engagement offered an attractive contrast to their occupational obligations, which enabled them to meet a mutual 'care need': the need for care and social relations identified in people with SMI and the need to be perceived as caring human beings, as distinct from professionals.

Thus, in the interviewees' narratives, the two influences frequently provided similar perspectives on volunteering in mental health care, and in practice, these influences often merged. The interviewees were conscious that their special experiences influenced their willingness to engage in volunteering in a new setting for the programme, but did not clearly distinguish whether this engagement was propelled by professional and/or private life experience.

Discussion

This study demonstrates that volunteers in the Community Family Programme used professional and private life experience with SMI and social work as a point of entrance and a frame of reference for voluntary engagement. The results are consistent with previous studies on volunteering in mental health care that also find that people who engage as volunteers in mental health services often have personal experience of mental health problems (McCorkle et al. 2009; Mitchell and Pistrang 2011; Solomon 2004), and that professional background (as well as age and gender) are important predictors (Hallett et al. 2012; Lauber et al. 2002). These studies describe the characteristics and motivations of volunteers, and do not specifically address the influence of professional and private life experience on the initial decision to volunteer. Our study contributes to the literature by demonstrating the significance of professional and/or private life experience of mental health care for initial considerations about volunteering and how such experiences are used in volunteering. Owing to their professional and private life experiences, the participants were knowledgeable about the challenges that people with mental health problems face in establishing and maintaining relationships. As professionals and/or users of the mental health care system, they were aware of the barriers within the system to engaging in important personal relationships rather than strictly professional and therapeutic ones. The study reveals that participants were strongly influenced by the opportunity to apply their professional and private life experience in a new setting.

The reflections of the participants in their decision to volunteer in mental health care relate to humanistic values and ideas of reciprocity. On the one hand, the participants reported an altruistic interest in supporting fellow human beings in need. Marianne emphasized "…that you matter to others, offering friendship on their terms; where I do some of the things friends do because they need this, it appeals to me", thereby expressing a humanistic attitude underlying their willingness to engage as a volunteer for vulnerable people. Similar attitudes were found in a Canadian study of volunteer caregivers for people with SMI, who articulated the view that a humanistic–altruistic value system was powerful in their work (Piat et al. 2007). Additionally, the participants in our study hoped for reciprocity. Laura said: "Yes, I missed something to do; I missed someone to accompany me to cafés and the like". This is an expression of the anticipation of receiving something in return when volunteering to help people with SMI, which could overcome personal or emotional shortcomings in the volunteers' everyday lives or help them to acquire new skills. This idea of reciprocity underlying volunteering supports previous studies that find volunteers seek to meet other people through volunteer activities in general (Prouteau and Wolff 2008), and that motivating factors include personal goals (Yeung 2004; Jensen et al. 2017). Our study confirms that this is also the case in volunteering for mental health care. It demonstrates that people who consider volunteering in mental health care perceive the possibility of using their professional and private life experience of mental health to remedy shortcomings in the public system as well as in their private lives.

This link between type of volunteer work and personal experience and professional careers may be useful in addressing the recruitment challenges faced by psychosocial programmes in mental health services. However, the implications may differ depending on the ideas and values supporting the specific psychosocial programme. In an effort to increase the number of volunteers a possibility is to accept the group of people who so far have shown interest in volunteering, and as such acknowledge a social programme supporting a kind of 'peer to peer' support. An approach to meet the recruitment challenges might be to change recruitment practice from the current broad public-based system to purposeful recruitment. This would mean addressing communication and information directly to the specific group of people with experience and interest in SMI, for example to relevant study settings, workplaces and public and private sectors responsible for care of people with SMI. On the other hand, a significant value of a psychosocial programme could also be to support possibilities for social relations between people with SMI and 'the man in the street'. This is explicated for example in a recent study of users of a community family programme, where the opportunity for a relationship outside the mental health care system was one of the main benefits, mentioned as 'a haven outside psychiatry' (Væggemose et al. 2017). Related to the results from our study a suggestion could be to rethink communication strategies in order to expand the potential volunteering group. This could propose an approach to develop communication strategies in which known benefits of volunteering in mental health services attract a broader group of people.

Strengths and Limitations

A strength of the study is that all but two of the active volunteers at the time of data collection were included, which indicates representativeness. Also, taking the geographical

context—rural area and provincial towns—into consideration there are no indications that the interviewees constitute a distinctive subgroup compared to urban population. Furthermore, it is a methodological strength that focus group discussions rather than personal interviews were conducted, because this allowed interviewees to discuss and reflect on each other's opinions and considerations to provide solid data.

It is a limitation of the study that we did not manage to include part of the target group: people who are aware of the psychosocial programme, but who do not wish to volunteer. We attempted to minimise this shortcoming by strictly limiting the interview themes to the time around becoming a volunteer and by developing a short task targeting the interviewees' reflections about becoming a volunteer. Nevertheless, there is a risk of recall bias. Considering these limitations the study has scope for replication and expansion.

Acknowledgements The study is based on an implementation project conducted in co-operation between the public sector and civil society, funded by The National Board of Social Sciences, Denmark. The authors wish to thank the volunteer families for their willingness to share their experiences. We also acknowledge the municipal mental health workers for their assistance in providing contact to the interviewees. Finally, we thank Dr.Med.Sci. Jørgen Aagaard, Aarhus University Hospital, Denmark, for initiating research regarding "The Community Family Programme".

Compliance with Ethical Standards

Conflict of interest The authors declare no conflict of interest with respect to the research, authorship of the article, and funding.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The research project is registered with the Danish Data Protection Agency. Danish legislation requires no official ethical approval for studies not involving examination of human or biological material (National Committee on Health Research Ethics).

Human and Animal Rights and Informed Consent All interviewees were informed about the purpose of the study and use of the interviews, and provided written consent for participation prior to inclusion in the study. They received a gift voucher (value approx. €40) as appreciation for their participation. Interviewees have been anonymized.

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