# Navigating in a Misty Landscape – Perceptions of Supporting a Relative Residing in Supported Housing for People with a Psychiatric Disability

A. Birgitta Gunnarsson, David Brunt, Carina Tjörnstrand, Elisabeth Argentzell, Ulrika Bejerholm & Mona Eklund

Published online: 30 Jun 2020.

Submit your article to this journal ⬚

Article views: 162

View related articles ⬚

View Crossmark data ⬚

Taylor & Francis
Taylor & Francis Group

# Navigating in a Misty Landscape – Perceptions of Supporting a Relative Residing in Supported Housing for People with a Psychiatric Disability

A. Birgitta Gunnarsson, PhD, OT reg[a,b] (iD), David Brunt, PhD, RN[c] (iD), Carina Tjörnstrand, PhD, OT reg[d] (iD), Elisabeth Argentzell, PhD, OT reg[d] (iD), Ulrika Bejerholm, PhD, OT reg[d] (iD), and Mona Eklund, PhD, OT reg[d] (iD)

[a]Department of Health and Rehabilitation, Institute of Neuroscience and Physiology, University of Gothenburg, Gothenburg, Sweden; [b]Department of Research and Development, Region Kronoberg, Växjö Sweden; [c]Faculty of Health and Life Sciences, Department of Health and Caring Sciences, Linnaeus University, Växjö, Sweden; [d]Department of Health Sciences, Lund University, Lund, Sweden

## ABSTRACT

The aim was to explore informal carers' perceptions of supporting the everyday life of a relative who has a psychiatric disability and resides in supported housing (SH). A qualitative study based on interviews with 12 informal carers was performed, and the data was analyzed with qualitative content analysis. The theme "Navigating in a misty landscape when striving to support a relative with a psychiatric disability" was identified, encompassing four categories pertaining to residents' needs, collaboration, environmental issues and the carer's situation. SH services can be enhanced by addressing informal carers' experiences and developing greater collaboration involving informal carers, residents and staff.

## Introduction

Those who are both family members of a relative with psychiatric disabilities, and also take care of this relative, have an important but difficult role. Many need to reevaluate their own life circumstances, and they struggle to balance relationships and convey both their relative's and their own needs (Stjernswärd & Östman, 2008). The situation of adult relatives has generally been described in three areas; perceived burden (Ghannam et al., 2017; Motlova, 2007), coping with the person with a psychiatric disability (Azman et al., 2017; Ebrahimi et al., 2018), and the support provided to family members that is not often offered but tends to enhance their coping ability and quality of life (Chien & Norman, 2009; Yesufu-Udechuku et al., 2015). Other research indicates that family members are seldom and insufficiently involved in the care (Östman et al., 2000).

The most severely mentally ill can also develop a psychiatric disability. This has been defined in Sweden as a lasting condition ($>2$ years) that, due to mental illness, prevents a person from leading an autonomous and satisfying everyday life (Swedish Government, 2006). A considerable minority in this group need the comprehensive support that is provided in congregate housing solutions, termed supported housing (SH) (Carlbom & Östman, 2007). The SH facilities constitute one of the two major types of housing solutions for people with a psychiatric disability in Sweden. The two types of housing provided by the municipalities are: independent living with flexible outreach support and congregate facilities. The latter generally have between five and 12 residents in self-contained apartments with on-site staff that can vary from daytime only to 24/7. This type of support may entail a relief for the family members (Brighton et al., 2016), whilst they continue to care about their relative. The roles and needs of family members in relation to SH are less well researched, and a literature search in Medline and CINAHL resulted in only few hits when combining 'supported housing' with mental illness/psychiatry and carers/caregivers/family members. This search showed that family members were often excluded from decision-making regarding housing for their relatives, but saw housing quality as an essential element for recovery from mental illness (Browne & Hemsley, 2010). Family members in that study also found stable outreach services and safety to be very important aspects of supported accommodation services. Piat and Seida (2018) found that family members of residents in SH credited the services with supporting residents in regaining control over important aspects in life, including development of social relationships and a positive self-identity. The families believed, however, that the SH support was focused on stability rather than great advancements toward personal recovery. Research focusing on how people with psychiatric disabilities use formal and informal support have revealed that family members were seen as essential and that a loss of such support entailed a risk for detrimental outcomes (Green et al., 2002). Another study found that residents saw

---

their families, rather than professionals and friends, as the ones who believed in them and their recovery (Piat et al., 2011).

SH includes support for the resident's everyday life activities, such as home maintenance and having something meaningful to do during the day (Brunt & Rask, 2018). What is seen as meaningful is a highly personal matter, and this is also true for meaningful activity. Research among people with psychiatric disabilities has shown, however, that any activity that results in feeling connected with others, feeling competent and accepted by society, having routines and projects, being creative and seeking knowledge, or taking care of body and mind to maintain health can be found meaningful (Argentzell et al., 2012; Leufstadius et al., 2008). Satisfying and meaningful everyday activities are important for the well-being of people with psychiatric disabilities in general (Eklund & Leufstadius, 2007; Höhl et al., 2017), as well as in the SH context (Eklund & Tjörnstrand, 2020). Meaningful activity is thus an important aspect of housing support, but there appears to have been no research that has addressed whether this constitutes a concern for family members. The family member has a specific perspective as someone who has a close and long-lasting relationship with the service user and knows about their previous preferences and habits and which activities they find meaningful. Family members' views on the opportunities for meaningful activity in the SH context could therefore be important for identifying possible limitations in this aspect of housing support and generating ideas as to how to improve the support. The perceptions of family members can be used to form a positive alliance between the family members and the staff, which may in turn benefit the residents (Weimand et al., 2018).

## Aim

The aim was to explore family members' perceptions of supporting a relative who has a psychiatric disability and resides in SH, with a specific focus on support for everyday activities.

## Methods

This qualitative interview study is part of a project focusing on everyday activities among people with psychiatric disabilities receiving housing support (Eklund et al., 2017). The study was approved by the Regional Ethical Review Board, Lund University, Sweden (Reg. Nos. 2013/456 and 2015/873).

## Participants

The project encompassed 17 municipalities located in four Swedish counties, representing both rural and urban areas. SH facilities in Sweden generally have 5–15 residents who have their own fully equipped or semi-equipped flat in a separate building or along a corridor in a block of flats. The staff, who provide support in activities such as cleaning,

shopping and appointments with professionals, are on hand up to 24 hours a day and have office space in the communal areas of this congregate setting.

The SH units included in the project (Eklund et al., 2017) were purposively selected for the present study. The SH managers for 15 SH units were asked whether they were willing to act as gatekeepers to identify family members of the residents. All the managers agreed and their first task was to ask residents who had family members whether they consented to the family member being contacted for an interview. Several residents did not consent to this, either due to not desiring a family member to become involved or them not thinking a family member who had sufficient insight into their situation at the SH. However, 13 of the residents agreed for contact to be taken with a family member by the research team. One of them declined to participate and the remaining 12 family members gave written informed consent to participate.

The participants consisted of 11 women and one man, all of whom were born in Sweden. Eight were parents of an adult resident, two had a sibling and two had a parent residing in SH for people with psychiatric disabilities.

## Data collection

The first author (ABG) and two project assistants performed the interviews. Three participants chose the interviewer's workplace as the site for the interview, while others chose to be interviewed in their relatives' SH unit or at a neutral place such as a café. Each interview lasted about one hour and was audio-recorded and transcribed verbatim. Data was collected from November 2015 to June 2016.

A semi-structured interview guide addressing the family members' thoughts around the following themes was devised: the residents' needs for support from staff and family members to cope with everyday life, the relative's possibilities for and limitations in taking part in activities at home as well as outside the SH, and the family member's view of the type of activity that would support the relative's health and well-being. The family members were encouraged to talk freely and the interviews developed into dialogs. This entailed that while all the interviews contained the same themes, each of the dialogs became unique with respect to specific questions asked and how each theme was emphasized and developed. Prompting questions were used when adequate, such as "Can you please describe that further?"

## Data analysis

The data were analyzed with qualitative content analysis (Graneheim & Lundman, 2004). The data were first read through several times, and then divided into meaning units and further condensed into codes. The various codes were sorted based on similarities and differences. Then, in an iterative process, the different sub-categories and categories were identified from the codes. The sub-categories and categories were discussed and modified between the first (ABG) and last author (ME), until the authors agreed that the

**Table 1.** Illustration of categories and sub-categories, covering the theme "Navigating in a misty landscape when striving to support a relative with a psychiatric disability".

| Categories | Meeting the needs of their relative | Collaborating to enable support | Reflecting on the SH environment and its surroundings | Dealing with personal needs and feelings of imperfection |
|---|---|---|---|---|
| Sub-categories | Enabling meaningful activities in everyday life | Interpreting signals concerning needs and capacities | Being able to cope with the apartment | Wanting to be there for their relative |
| | Being one of few loved ones | Collaborating at the managerial level | Mastering the common SH facilities | Being alone with responsibilities |
| | Enabling participation in activities in the community | Collaborating with the staff | Maintaining links with the community | Needing space to recover |

categories and sub-categories well represented the data. The next step was to formulate a theme that captured the latent meaning. Finally, in order to strengthen the trustworthiness, all the authors reflected on and discussed the sub-categories, categories and theme until consensus was reached. Furthermore, quotations were presented to illustrate the findings, these were edited by omitting humming sounds, stuttering and pauses.

## Results

The participants did not have direct insight into the everyday life of their relatives and seldom had contact with staff. However, many of the participants had a good comprehension of the SH services, the activities offered and what their relatives found meaningful to engage in, despite having a peripheral position. The activities they referred most frequently were: cooking, washing, cleaning and doing the laundry, and the residents could generally choose between eating alone or in a common dining area. Possibilities for social activities were also provided at hand, but usually not to the extent that the participants wanted when considering what was best for their relatives and what these would find meaningful. The provision of activities in the SH units included: participating in housing meetings, watching TV, making excursions, or celebrating birthdays and major holidays. The participants' peripheral view of what was happening at the SH units entailed the participants perceiving their relatives' everyday activities through a haze, through which they had to navigate and understand their relatives' everyday life. The theme "Navigating in a misty landscape when striving to support a relative with a psychiatric disability" was discerned.

The theme encompassed four categories; "Meeting the needs of their relative", "Collaborating to enable support", "Reflecting on the SH environment and its surroundings", and "Dealing with personal needs and feelings of imperfection" (Table 1).

## Meeting the needs of their relative

The participants felt the obligation to be there to take care of the needs of the relatives, to support them to perform various activities in everyday life, to spend time with their family and friends, and to be someone from the world outside the SH unit.

### Enabling meaningful activities in everyday life

The participants perceived that their relatives generally received the support they needed, including opportunities to perform various activities and spend time with family and friends. Some indicated, however, that they had to intervene to make things work for their relative, such as teaching them how to cook. Others had observed that their relative was lonely and neglected by from the staff: "My mother was more active before she moved [to the SH]. Now she only cleans, does the laundry, showers, and does the dishes and/ …/and also goes out walking—but nothing more" (IT 12). Some relatives did not participate in any everyday activity, according to participants who perceived that there was nothing that suited their relatives' interests, or that the staff had not been able to catch the moment when the resident was motivated.

The participants had ideas about how the staff could develop and better align the activities in the SH units with the residents' needs and interests. These suggestions included; the staff using the municipality's cars more frequently, driving the residents to various activities in the community, and the staff spending more time with the residents, e.g., cooking together, walking together and going out on excursions that the residents ask for. Another suggestion was for the staff to make use of opportunities that naturally occur, such as seasonal changes in nature, events and happenings in the neighborhood or spontaneous ideas from the residents. The participants also suggested more scheduled activities to support engagement "Otherwise it won't work, if he [the son] sits down and starts thinking about what to do now … he just sits there" (IT1).

### Being one of few loved ones

Socializing with family and friends was important, according to the participants, because it provided an important source of meaningfulness and joy for the resident. There were also participants who received help from their relatives, for example, one informant frequently received help with cleaning and shopping from her son who lived in SH. It was also noticeable that family members were often the only social contacts the resident had. "My brother feels good when we meet—I'm the only one he has" (IT4). The family members perceived that the contact they had with their relatives were essential and meaningful for the latter and helped them maintain a sense of identity. Some met regularly, e.g. on a certain weekday to go for a walk or visit a café. There were,

however, also reports about conflicts, often triggered by the participants interfering in the relative's economy or how they looked after their flat.

### Enabling participation in activities in the community

The participants thought that the SH could provide a safe haven from which the residents could be able to take part in activities in the community. Some reported that that their relative received support for doing that from the staff, while others perceived that the staff were reluctant to accompany the residents outside the SH. The residents then became quite isolated in the SH unit and did not want to or were unable to make contacts. While some of the residents had good friends both within and outside the SH, others had acquaintances who were a burden on them "Begging for cigarettes and coffee early in the morning" (IT3). The residents were adults and were thus allowed to do as they pleased, but this could entail that they could not receive any help from staff in such difficult situations, which led to the participants feeling helpless. More positive examples were talked about where their relative still met former school friends or workmates, or could be supportive to others and help their friends with practical matters. Having links to the community could also entail them keeping abreast with what was happening in the world, e.g. watching documentaries on the TV, and as one informant said "Our son knows more than we can imagine" (IT10).

## Collaborating to enable support

Networking was seen as significant and as a challenge from the participants' point of view. They had to collaborate with several people in order to be able to support their relatives. These included the relatives themselves, the SH managers, and the housing unit staff.

### Interpreting signals concerning needs and capacities

Interpreting signals concerning the relatives' needs was one part of the collaboration and could include their relative's expressions of stress or need for a structure in their everyday life. One mother said: "My daughter gets stressed when she loses her routines, when there is too much noise" (IT9). The participants sometimes perceived that their relatives had difficulties expressing their needs and were not listened to during meetings with the staff. The participants then had to interpret what their relatives wanted, to get them involved, and to identify what meaningful activity they would like to do, and the participants emphasized the importance of "listening to what is not spoken about" (IT4). They were also careful to highlight the capacities of their loved ones, and tried to strengthen their self-esteem by giving them praising.

### Collaborating at the managerial level

Establishing a good relationship with the SH managers was seen as important. Some spoke of regular meetings, and contact afterwards when needed: "We met a manager twice a year—good meetings about mum's housing and activities—and the SH listened to us as relatives—and mum got to say what she wanted to" (IT8). Others had previously had negative expectations about the SH and these became positive experiences instead as they were received in a pleasant way and were given adequate information.

On the other hand, there were also negative experiences with the participants talking of wanting to have meetings about how best to carry out their relative's care plans and sensing that the manager might feel as though he/she was controlled. Other participants spoke of difficulties in establishing a good relationship with the manager because of a high rate of turnover for those in that position. The participants felt that these had a negative influence on the residents' possibilities to lead an everyday life characterized by meaningful activity.

### Collaborating with the staff

Collaborating with the SH staff was seen as important by all the participants. Those with positive experiences described the staff as sympathetic and meant that their commitment was what made the SH work, one example of this was when the staff took care of pets if the resident was hospitalized. The participants spoke of the members of staff being able to understand the residents and devoting time to listening to them, and the participants felt that they could rely on these and tell them things they found important. This generated a sense of confidence in the staff functioning efficiently as key workers and providing good support to their relative.

There were also participants who had never, or just briefly, met the staff, and sometimes the staff had not communicated with each other about important matters and things the residents had told them, "It sometimes happens that the staff call when he [the son] is at home with us, and ask where he is" (IT6). The participants who had negative experiences of their collaboration with the SH perceived a lack of staff commitment and felt that the staff would prefer to relax and pursue their own interests rather than spending time with the residents.

The participants with negative experiences also perceived that the staff put too great a focus on daily routines/…/and there's no time for fun and doing things together" (IT11). Some participants also wondered about the level of the staff's skills in relation to mental illness and motivating the residents to lead an active and meaningful everyday life. Others thought that the staff should be more responsive to the residents' needs and previous interests and habits, and perceived that their relatives had difficulty asking for support when needed. However, the participants also noted that the staff "Always have an uphill struggle, the residents always say no first, and then

the staff have to motivate/…/to stimulate them to have more of a social life" (IT8).

## Reflecting on the SH environment and its surroundings

The participants perceived that being able to master the surrounding environment was important for the residents in coping with everyday life. They had observed the existence of both environmental limitations and resources for their relative in terms of being active and being stimulated to activity in their apartment, in the common areas of the SH, and in the community. They generally did not have an active role in this as family members, but had thought and reflected about these circumstances quite a lot.

### Being able to cope with the apartment

The participants noticed that coping with everyday life in their relative's apartment, such as cleaning and keeping the flat tidy, could be a challenge, both for the residents and the staff. Some talked of their relative wanting to be like other people and have an ordinary apartment, as in this description of a daughter who had tried to live in an apartment without support from staff: "And it all went wrong and there were disturbances and she had arguments… with the landlord and others" (IT3). Other perceived that their relatives were fond of their apartments and coped well with that environment. They wanted to be able to close the door, watch TV and potter about doing things they found meaningful. Other concerns were about the SH staff, for example, not pointing out the need to clean the apartment when a resident failed to do so. The apartment is the resident's own home, but the participants had noticed that the staff sometimes made changes in the apartment to facilitate for themselves, such as removing carpets, while at the same time making their relative's home more impersonal.

### Mastering the common SH facilities

Many of the participants reflected on the dual nature of the SH environment, which could provide both opportunities for having company and socializing in the common areas and possibilities to withdraw and have privacy in one's own apartment, and how their relatives could master that balance. Some participants perceived a pleasant atmosphere in the SH and good communication between their relative, other residents, and the staff; as though they belonged to a family. It was helpful and meaningful for some of the residents to have the company of others in the common areas, as one mother expressed; "She needs a lot of support and people around her" (IT9). Eating a meal together was important for many of the residents, particularly during the weekends and holidays, and it contributed to a sense of belonging, while others were better off by themselves.

Some residents were unable to be in the company of too many other people and had difficulty absorbing too many impressions at once, as expressed by one mother: "He participates in the house meetings in this larger SH now, and gets his food there, but eats in there [his apartment]" (IT10).

The participants knew about the house meetings, which were seen as a potentially important element of the common SH environment, but said that their relatives were not able to express their wishes and opinions there as they were not used to taking part in decision-making. Some said that these meetings were the only type of common activities. The participants who had negative experiences from the SH had expected that there would be both activities that were planned and opportunities for the training of household skills, such as baking, but this had not occurred. Some of the participants had experienced that there were activities that had been provided both inside the SH and also outside in the community, but then the residents had been difficult to motivate. On the other hand, saying "no" to proposed activities could indicate something positive: "I feel that he [the brother] says no because he has better self-confidence now" (IT4).

### Maintaining links with the community

The participants meant that their relatives had lost their previous social network and the new surroundings were unfamiliar to them when they moved to SH; they saw it as though their relatives had lost part of their identity. The residents were, however, able to maintain some of their links with the community, or develop new ones. The participants talked of some of the residents having interesting and meaningful activities that they performed outside the SH, such as genealogy, training dogs or going to the library. Some were able to take the bus on their own, while others needed support from the staff. One mother said: "Someone came with him sometimes, and other times not" (IT10), which led to her son having to give up his regular activity. The resident's need for company also depended on the nature of the activity; their relative might manage to do errands but could need support to go to a gym.

All the residents could take part in staff-led excursions, which could give them a link to the society around them. A problem could, however, occur when a resident wanted to go on a specific type of excursion, which the staff were not interested in. Furthermore, not all the residents were always able to have the opportunity to come along because of limited transportation capacity, while at the same time there were also those who did not want to try new environments, as one mother said: "The SH rented a holiday cottage last summer but then she refused to come along" (IT11).

Some participants spoke of their relatives regularly participating in various types of activities outside the SH, such as going to day centers or doing voluntary work. All the participants said that activities performed outside the SH were important and meaningful because they brought positive spin-offs, such as meeting others, gaining new perspectives, and being useful to other people.

## Dealing with personal needs and feelings of imperfection

To get strength to support their relative, the participants had to take care of their own personal needs and wishes. They maintained that they had to, and wanted to be there for their relative. They often felt alone with their responsibility, however, and to manage this they needed to recover.

### Wanting to be there for their relative

The participants felt more at ease once their relative had moved to SH, but they were still concerned about them. "We worry about how he [the son] will manage when we're not around anymore—we're not young anymore, one day one of us might pass away" (IT10). Other worries could concern the relatives' mental and physical well-being, or how they would cope with situations that could occur. There were also indications that the participants' worries could be inhibitive for the relative; one daughter said "Our mother was always worried about him, that something might happen, but since she died he's become more independent" (IT7).

The participants still felt the need to engage in various practical matters, such as preparing meals for the coming week or paying the bills, despite the residents lived in SH. Their relative might also need support in what to do during the day, for example, to avoid staying in bed all day. Some of the participants who were parents meant, however, that they had the same role in relation to their child with a psychiatric disability as to their children who were well.

The participants sometimes had disputes with their relative, and there had been situations when they had been physically abused by them. They could also have to deal with situations where their relative had conflicts with other residents, which generally concerned money and cigarettes. They tried their best to cope with their relative's emotions, and to set limits for them. Furthermore, the participants who were parents tried not to burden their other children since they thought that these should be allowed to lead their lives as usual.

### Being alone with responsibilities

The participants often felt alone with the responsibility for their relatives. Some of them, especially those who were parents, had taken responsibility for their loved ones since they were children, while others had more recently taken on this responsibility since their relatives had previously led normal, active working lives.

The participants could feel the responsibility as pressure. In spite of the burden being reduced when their relative moved to the SH, the participants experienced that they had had to fight for their relatives, so that they would receive sufficient care and support, including meaningful everyday activities. The participants wanted just to be a relative, and not have to be the link between their relative and the care and support services. Their responsibilities could, however, sometimes be extended to determining whether their relative needed additional support and care. They thought that the authorities ought to take a greater responsibility for the collaboration, while acknowledging the family members as important persons in the residents' lives.

The participants perceived a need for support from the healthcare services, and also from the SH, in terms of what to do when a relative is mentally ill and in need of care and support. The participants had never been asked by the mental health services or the social services about their lives when living with a relative with a psychiatric disability. One son said: "When I think from the perspective of being a child—my mother was ill when I was little—I would have needed the healthcare professionals to ask how I felt" (IT8).

### Needing space to recover

The participants needed some breathing space, as they spent a great deal of time thinking about or caring for their loved ones, and one daughter told: "I wish there was something else that could give my mother quality of life—something that is not me" (IT12).

Being a family member and having the responsibility for a relative with a psychiatric disability who they might have seen as troublesome, but with whom they also had an emotional relationship, was difficult. The participants felt they were not always sufficiently strong, which made them feel the need to take a break in their contact with their relative. Even if this break was necessary, it gave them feelings of guilt.

The participants wanted contact with their relatives and were generally in touch at least every week in spite of the difficulties, although they sometimes felt frustration when their relatives constantly needed help and support. The participants emphasized that they could not build their entire lives around their loved one, they also needed to live their own lives, including taking care of other children, their households, their working lives, and their social lives, including leisure activities. For some of the participants, this meant that they had to set limits.

## Discussion

It has been shown that family members who have a caretaking role have an important supportive social role for their relatives with psychiatric disabilities (Pernice-Duca & Onaga, 2009). The perceptions of family members who have a relative residing in SH for people with psychiatric disabilities has received little attention in research, in particular in terms of the residents' needs for meaningful everyday activities. The findings of this study are thus important. "Navigating in a misty landscape when striving to support a relative with a psychiatric disability" summarized the participants' perceptions and concerned meeting the needs of the relative, collaborating with residents and staff, reflecting on the relative's SH environment and surroundings, and dealing with personal needs and feelings of imperfection. Motlova (2007) maintained that the whole family becomes involved

when a family member has severe mental illness, and the family's perspectives and issues of concern need to be taken into account in order for interventions to be successful. The current findings indicate that the family members took on an important role in being a bridge between the relative's previously more active life and former identity and his/her present social environment. They thus acted as ambassadors for their loved ones, which in line with previous research showing how important residents perceive their families (Green et al., 2002; Piat et al., 2011). Family members could supplement the staff's professional role, which was seen by the participants as more instrumental. The study also highlighted that the family members' roles and experiences of being there for their relative was accompanied by a limited insight into their situation and a lack of influence. They had several suggestions for how to remedy that situation, however, and the current findings can hopefully inspire to improve the support in SH.

Many of the participants' concerns were related to the needs of the resident, and access to meaningful activities and social inclusion were particularly highlighted. This is in line with a study of what brought meaning in life to people residing in SH, showing that being with others and having something meaningful to do were prioritized (Eklund et al., 2012). Furthermore, our findings indicate that an awareness of the residents' needs could lead to the participants needing time and space to recover. The participants had to set limits in order to be able to cope with this, which is in line with research showing how family members maintained a balance between their own needs and those of their relatives (Stjernswärd & Östman, 2008).

Collaboration and communication formed another important focus. Increased communication between the residents, the staff and the family member could improve the situation for the residents, but also for the family members, which concurs with previous findings (Östman et al., 2000). The current findings showed that the family members and the residents did not have sufficient contact with the staff, and felt that their views were not always taken into consideration. Greater collaboration with the staff could be expected to lead to better support for a meaningful everyday life for the resident, and could preferably include education for the family members. This is in line with Yesufu-Udechuku et al. (2015), who found that psychoeducation and support groups for the family members enhanced their caring experience and reduced their psychological stress. Similarly, Ebrahimi et al. (2018) and the Swedish National Guidelines (2018) have recommended psychoeducation and support from the social services to informal caregivers who support and take care of relatives with psychiatric disabilities. Ebrahimi et al. (2018) showed that family members who lacked support from staff also lacked knowledge about how to care for their relatives. As well as receiving education, both the residents and the family members could be co-creators of the SH support, which is in agreement with Elg et al. (2012), who proposed co-creation and learning from the patient, and Grundy et al. (2017), who suggested the involvement of family members in the decision-making about care.

The surrounding environment was a recurring topic in the participants' accounts. It was seen as positive (friendship, good role models, good company etc.) and as negative (being used, bad company etc.), but several of the issues the participants highlighted appear to be clearly linked with essential aspects of recovery from mental illness. According to the CHIME framework (Connectedness, Hope, Identity, Meaning, Empowerment), connecting with others and mastering the social environment are important for recovery (Leamy et al., 2011). Mastering the environment also concerned the residents' physical environment, in terms of caring of one's own apartment. This type of activity together with other activities, which were perceived as meaningful, may be linked with building identity and feeling empowered (Bejerholm & Eklund, 2004; Bejerholm & Eklund, 2006). The participants thus intuitively focused on the constituents of the CHIME framework when they reflected on the needs and wishes of their relatives.

Dealing with personal needs and feelings of imperfection could potentially concern feeling burdened and exhausted as an informal caregiver, as shown in studies on family members who live together with their relative with mental illness (Ebrahimi et al., 2018; Östman et al., 2000). A major difference between those studies and the present one appears to be the experiences of burden on the family member. None of the participants conveyed such experiences in this study, while there are numerous reports of family members feeling burdened when they have a day-to-day responsibility (Ghannam et al., 2017). This may indicate that the relative's residency in SH may simplify life for the family members, which was also spoken about in the interviews. However, the relatives with psychiatric disabilities were constantly on the participants' minds and they felt a great responsibility for them.

The findings indicated the need for the participants to be able to recover, including participating in leisure activities, being with other family members and seeing friends. This may be seen as a coping strategy, and thus concur with the conclusions of Azman et al. (2017) that emotional coping, acceptance and engaging in leisure activities were among the coping strategies used by family members.

## Methodological considerations

Trustworthiness in research (Graneheim & Lundman, 2004) generally concerns pre-understanding, credibility, dependability and transferability. The researchers' pre-understandings stemmed from a broad area of experience within the health and caring sciences, psychology and occupational science, including qualitative research. The research group reflected on the findings in relation to their pre-understanding when analyzing data in an iterative process.

Credibility was strengthened by the iterative analysis process, first involving the first and last author. Consensus was then reached in the research group, agreeing that data were covered by the theme, categories and sub-categories.

Furthermore, credibility as well as dependability was strengthened by a detailed description of the data collection and analysis, exemplified by quotations. Three interviewers may be seen as a potential limitation, since the participants may have received different follow-up questions, but on the other hand this may also have strengthened the dependability and enriched the contents of the interviews.

Transferability is often left to the reader to assess, according to Graneheim and Lundman (2004), but the difficulties in the process of recruiting participants warrants some reflection. A few of the SH residents rejected the researchers request to approach tentative participants. This may have led to the participants who participated being the family members with closer and perhaps more positive contacts with their relative, which in turn may have influenced the findings and thus the transferability. It may be that the lack of reports of caregiver burden may be a result of selection bias. It is also not reasonable to transfer the findings to other ethnic groups. All the participants in the study were born in Sweden, which is regarded an individualistic society, and research has shown that the families of people with mental health problems have different roles in individualistic cultures in comparison with collectivistic cultures (Dwairy, 2006; Pooremamali et al., 2012).

## Conclusions

The roles and perceptions of the family members of relatives residing in SH appear to differ from the findings from research focusing on family members who live with their relative with mental health problems, this study has thus contributed with unique knowledge that may be used to further develop SH services. Extended collaboration that involves all the parties and increased information and education for family members and SH residents are some of the proposed measures. It was also emphasized as important that staff could seize the moments when residents are open to participate in activities and want to have company. Furthermore, the findings show that family members are a poorly utilized resource as they have their relative constantly in mind, are already helping with practical things, and are willing to contribute with new ideas for how to improve the residents' everyday life. The family members can also convey important information about their relative's identity and preferences, and such knowledge can help staff motivate residents and make the support more personalized. The social and healthcare services should consider how to support family members through education, information and collaboration, so that they can feel some alleviation from their responsibilities and find some space for recovery. The findings from this study can also be utilized as a ground for new interventions in the SH context, aimed at supporting a more meaningful and active everyday life for the residents.

## Disclosure statement

The authors declare that there are no conflicts of interest.

## ORCID

A. Birgitta Gunnarsson (iD) 0000-0002-6976-5154
David Brunt (iD) 0000-0002-3164-8681
Carina Tjörnstrand (iD) 0000-0001-6018-0777
Elisabeth Argentzell (iD) 0000-0002-9405-4418
Ulrika Bejerholm (iD) 0000-0001-7505-6955
Mona Eklund (iD) 0000-0002-0136-3079

## References

Argentzell, E., Håkansson, C., & Eklund, M. (2012). Experience of meaning in everyday occupations among unemployed people with severe mental illness. *Scandinavian Journal of Occupational Therapy*, *19*(1), 49–58. https://doi.org/10.3109/11038128.2010.540038

Azman, A., Jamir Singh, P. S., & Sulaiman, J. (2017). Caregiver coping with the mentally ill: A qualitative study. *Journal of Mental Health*, *26*(2), 98–103. https://doi.org/10.3109/09638237.2015.1124395

Bejerholm, U., & Eklund, M. (2004). Time use and occupational performance among persons with schizophrenia. *Occupational Therapy in Mental Health*, *20*(1), 27–47. https://doi.org/10.1300/J004v20n01_02

Bejerholm, U., & Eklund, M. (2006). Engagement in occupations among men and women with schizophrenia. *Occupational Therapy International*, *13*(2), 100–121. https://doi.org/10.1002/oti.210

Brighton, R. M., Patterson, C., Taylor, E., Moxham, L., Perlman, D., Sumskis, S., & Heffernan, T. (2016). The effect of respite services on carers of individuals with severe mental illness. *Journal of Psychosocial Nursing and Mental Health Services*, *54*(12), 33–38. https://doi.org/10.3928/02793695-20161208-07

Browne, G., & Hemsley, M. (2010). Housing and living with a mental illness: Exploring carers' views. *International Journal of Mental Health Nursing*, *19*(1), 22–29. https://doi.org/10.1111/j.1447-0349.2009.00635.x

Brunt, D., & Rask, M. (2018). Resident and staff perceptions of the content of their relationship in supported housing facilities for people with psychiatric disabilities. *Journal of Multidisciplinary Healthcare*, *11*, 673–681. https://doi.org/10.2147/JMDH.S179322

Carlbom, A., & Östman, M. (2007). *Anhörigas uppfattningar om bostad med särskild service enligt LSS. Boendeprojektet. Delrapport 17 [The relatives' perceptions of supported housing. The Housing Project. Report no. 17]*. Linnaeus University. http://lnu.diva-portal.org/

Chien, W.-T., & Norman, I. (2009). The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: A literature review. *International Journal of Nursing Studies*, *46*(12), 1604–1623. https://doi.org/10.1016/j.ijnurstu.2009.04.003

Dwairy, M. (2006). *Counselling and psychotherapy with Arabs and Muslims - A culturally sensitive approach*. Teachers College, Colombia University.

Ebrahimi, H., Seyedfatemi, N., Namdar Areshtanab, H., Ranjbar, F., Thornicroft, G., Whitehead, B., & Rahmani, F. (2018). Barriers to family caregivers' coping with patients with severe mental illness in Iran. *Qualitative Health Research*, *28*(6), 987–1001. https://doi.org/10.1177/1049732318758644

Eklund, M., Argentzell, E., Bejerholm, U., Tjörnstrand, C., & Brunt, D. (2017). Wellbeing, activity and housing satisfaction - Comparing residents with psychiatric disabilities in supported housing and ordinary housing with support. *BMC Psychiatry*, *17*(1), 1–12. https://doi.org/10.1186/s12888-017-1472-2

Eklund, M., Hermansson, A., & Håkansson, C. (2012). Meaning in life for people with schizophrenia: Does it include occupation? *Journal*

*of Occupational Science, 19*(2), 93–105. https://doi.org/10.1080/14427591.2011.605833

Eklund, M., & Leufstadius, C. (2007). Relationships between occupational factors and health and well-being in individuals with persistent mental illness living in the community. *Canadian Journal of Occupational Therapy, 74*(4), 303–313. https://doi.org/10.1177/000841740707400403

Eklund, M., & Tjörnstrand, C. (2020). Associations between occupational and social interaction factors and well-being among people with psychiatric disabilities living in supported housing in Sweden. *Journal of Occupational Science, 27*(1), 54–68. https://doi.org/10.1080/14427591.2019.1620121

Elg, M., Engström, J., Witell, L., & Poksinska, B. (2012). Co-creation and learning in health-care service development. *Journal of Service Management, 23*(3), 328–343. https://doi.org/10.1108/09564231211248435

Ghannam, B. M., Hamdan-Mansour, A. M., & Al Abeiat, D. D. (2017). Psychological correlates of burden among Jordanian caregivers of patients with serious mental illness. *Perspectives in Psychiatric Care, 53*(4), 299–306. https://doi.org/10.1111/ppc.12179

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Green, C. A., Vuckovic, N. H., & Firemark, A. J. (2002). Adapting to psychiatric disability and needs for home- and community-based care. *Mental Health Services Research, 4*(1), 29–41.

Grundy, A. C., Walker, L., Meade, O., Fraser, C., Cree, L., Bee, P., Lovell, K., & Callaghan, P. (2017). Evaluation of a co-delivered training package for community mental health professionals on service user- and carer-involved care planning. *Journal of Psychiatric and Mental Health Nursing, 24*(6), 358–366. https://doi.org/10.1111/jpm.12378

Höhl, W., Moll, S., & Pfeiffer, A. (2017). Occupational therapy interventions in the treatment of people with severe mental illness. *Current Opinion in Psychiatry, 30*(4), 300–305. https://doi.org/10.1097/YCO.0000000000000339

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. *British Journal of Psychiatry, 199*(6), 445–452. https://doi.org/10.1192/bjp.bp.110.083733

Leufstadius, C., Erlandsson, L., Björkman, T., & Eklund, M. (2008). Meaningfulness in daily occupations among individuals with persistent mental illness. *Journal of Occupational Science, 15*(1), 27–35. https://doi.org/10.1080/14427591.2008.9686604

Motlova, L. (2007). Schizophrenia and family. *Neuro Endocrinology Letters, 28*(Suppl 1), 147.

Östman, M., Hansson, L., & Andersson, K. (2000). Family burden, participation in care and mental health - An 11-year comparison of the situation of relatives to compulsorily and voluntarily admitted patients. *International Journal of Social Psychiatry, 46*(3), 191–200. https://doi.org/10.1177/002076400004600305

Pernice-Duca, F., & Onaga, E. (2009). Examining the contribution of social network support to the recovery process among clubhouse members. *American Journal of Psychiatric Rehabilitation, 12*(1), 1–30. https://doi.org/10.1080/15487760802615566

Piat, M., Sabetti, J., Fleury, M. J., Boyer, R., & Lesage, A. (2011). Who believes most in me and in my recovery": The importance of families for persons with serious mental illness living in structured community housing. *Journal of Social Work in Disability & Rehabilitation, 10*(1), 49–65. https://doi.org/10.1080/1536710X.2011.546310

Piat, M., & Seida, K. (2018). Supported housing for persons with serious mental illness and personal recovery: What do families think?. *International Journal of Social Psychiatry, 64*(8), 707–714. https://doi.org/10.1177/0020764018806928

Pooremamali, P., Eklund, M., Östman, M., & Persson, D. (2012). Muslim Middle Eastern clients' reflections on their relationship with their occupational therapists in mental health care. *Scandinavian Journal of Occupational Therapy, 19*(4), 328–340. https://doi.org/10.3109/11038128.2011.600328

Socialstyrelsen. (2018). *Nationella riktlinjer för vård och stöd vid schizofreni och schizofreniliknande tillstånd [National guidelines for care and support for people with schizophrenia and related disorders].* Socialstyrelsen [The Swedish Board of Health and Welfare].

Stjernswärd, S., & Östman, M. (2008). Whose life am I living? Relatives living in the shadow of depression. *International Journal of Social Psychiatry, 54*(4), 358–369. https://doi.org/10.1177/0020764008090794

Swedish Government Official Report. (2006). *Vad är psykiskt funktionshinder? [What is a psychiatric disability?]. Rapport 2006:5 från Nationell psykiatrisamordning.* Socialstyrelsen [The Swedish Board of Health and Welfare].

Weimand, B., Israel, P., & Ewertzon, M. (2018). Families in assertive community treatment (ACT) teams in Norway: A cross-sectional study on relatives' experiences of involvement and alienation. *Community Mental Health Journal, 54*(5), 686–697. https://doi.org/10.1007/s10597-017-0207-7

Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., Kuipers, E., & Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: Systematic review and meta-analysis. *British Journal of Psychiatry, 206*(4), 268–274. https://doi.org/10.1192/bjp.bp.114.147561