Burden of support: a counter narrative of service users' experiences with community housing services

Marjolijn Heerings, Hester van de Bovenkamp, Mieke Cardol & Roland Bal

Published online: 22 Jun 2022.

Submit your article to this journal ↗

Article views: 201

View related articles ↗

View Crossmark data ↗

Routledge
Taylor & Francis Group

 OPEN ACCESS   Check for updates

Burden of support: a counter narrative of service users' experiences with community housing services

Marjolijn Heerings[a] , Hester van de Bovenkamp[a] , Mieke Cardol[b] and Roland Bal[a]

[a]Erasmus School of Health Policy & Management, Erasmus University Rotterdam, The Netherlands; [b]Research Centre Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, The Netherlands

ABSTRACT

Community housing services adopt care models such as rehabilitation, recovery-oriented care and person-centered planning to improve the quality of life of service users with an intellectual or psychiatric disability. However, the way these care models are implemented and practiced can negatively impact service users' experience with the service as their complex needs go unmet. In this paper, we conceptualize these experiences through developing the counter-narrative of burdens of support. For this we draw on burden of treatment theory. We conducted ethnographic fieldwork in a community service organization in the Netherlands. This included participant observation (84 h), interviews with service users ($n = 20$), experts-by-experience ($n = 8$), family members ($n = 10$) and photovoice workshops. Our analysis identifies four burdens of support: burden of self-determination; re-identification; responsibilisation and re-placement. The results show that burden of support is very much a relational concept: through their support, professionals can aggravate or alleviate burden.

Points of interest

- People with intellectual or psychiatric disabilities often receive support with living in the community. Good support fits people's needs (e.g. person-centered planning), builds on people's strengths and contributes to recovery and community participation.
- Even when support is practiced or organized with such aims, service users can have negative experiences. In this research we call this: 'burden of support'.
- Examples of burden of support identified include:

CONTACT Marjolijn Heerings Heerings@eshpm.eur.nl Erasmus School of Health Policy & Management, Burgemeester Oudlaan 50, Rotterdam, 3062 PA, The Netherlands.

- Clients' needs and wishes are sometimes not sufficiently attended too when working with a personal care plan.
- Too much responsibility is sometimes shifted to clients, which results in feelings of failing or abandonment.
- The focus on strengths and recovery sometimes leaves too little room for clients to voice support needs.
- Having to move to a different home or neighborhood as part of becoming more independent can result in many difficulties including loneliness.
- The research recommended that those who improve services should also alleviate these burdens.

Introduction

Social care professionals in community housing services support service users in activities of daily living. This includes supporting them in developing a daily structure and manage a household, personal hygiene, finances, and vocation activities. This can be organized in various types of housing situations ranging from group homes to supported independent living (de Heer-Wunderink et al. 2012). As a result of community housing services adopting care models such as rehabilitation, recovery-oriented care and person-centered care planning, the focus of this support is changing (Claes et al. 2010; Farkas and Anthony 2010; Macpherson, Shepherd, and Thyarappa 2012). Examples of changing support practices include enhancing service users' self-determination through engaging service users in decisions on daily life and the development of care plans (Di Maggio et al. 2020; Moran et al. 2017; Lachapelle et al. 2005), personal recovery through developing a self-identity free of self-stigma and developing a meaningful life (Leamy et al. 2011; Salzmann-Erikson 2013), fostering an independent lifestyle, by developing skills for daily living (Bäck-Pettersson, Sandersson, and Hermansson 2014; García Iriarte et al. 2016) and community participation through vocation and leisure related activities and developing valued social roles (Farone 2006; Millner et al. 2019; Race, Boxall, and Carson 2005; Webber et al. 2015).

In addition to improving service users' empowerment and quality of life (Cui et al. 2019; de Heer-Wunderink et al. 2012), the changes in professional support also have negative consequences for service users. Service users can experience burdens from the responsibilities and tasks that are shifted to them as part of these care models. For instance, moving to more independent living facilities poses burdens related to feeling lonely and developing belonging in a new community (McConkey et al. 2019; Strnadová, Johnson, and Walmsley 2018; Watson, Fossey, and Harvey 2019). These negative consequences often do not get (enough) attention in policy documents

on the national and organizational level, which form the background to professional work (Davies and Gray 2015; Karpetis 2020; Khoury and Rodriguez del Barrio 2015). Here the least impaired people are often used in the imagery to stand for all the others. As a result, the complex needs of many become underemphasized (Burton and Kagan 2006).

This paper aims to construct a framework of burdens of support in community housing services as a counter narrative (McKenzie-Mohr and Lafrance 2017; Bamberg and Wipff 2020) to the 'hurray terms' in which care models such as rehabilitation, recovery-oriented care and person-centered planning are often described in policy documents. A framework of burdens of support highlights some of the complexities of service users' needs and experiences with receiving support. This creates a ground for service users, and those who wish to advocate for them, to explicate such needs and have them taken up in quality improvement efforts. Moreover, such a framework could support professionals, managers and policy makers in providing good care by recognizing the needs of service users and taking responsibility for meeting these needs in a competent manner (Tronto 1993). Taking this focus of burden of support directs attention to the negative experiences of services users over their possibly numerous positive experiences with person-centered planning, rehabilitation and recovery-oriented approaches to support. Zooming in on these negative experiences is important as it potentially generates important lessons for improving services which adopted such care models. This way service models such as recovery-oriented care, can be practiced in ways that better meet their aim of empowering service users and improving their quality of life. This study thus does not aim to provide an overall assessment of current care practices, rather it aims at opening up reflection on improving quality of care by providing the framework of 'burden of support', for which we build on burden of treatment theory (May et al. 2014; Sav et al. 2013; Sav et al. 2015).

Burden of support

Burden of treatment theory argues that the work, such as lifestyle changes and taking medication accompanying treatment, can put burdens on patients which impact their daily lives in a negative way. Burden is conceptualized as both the work and the negative impact of this work. This includes treatment and self-management related work, such as self-measuring blood sugar levels in case of people with diabetes, which has impact on daily life (Tran et al. 2015; Llorca et al. 2017). Moreover, treatment burden includes emotional impact, such as feeling overwhelmed and hopeless from treatment and self-management related demands (Nordfonn et al. 2019). Burden of treatment lastly includes biographical impact. Patients not only have to come to terms with their illness identity, their sense of self and how others view

them is further impacted by the work related to treatment and self-management (Demain et al. 2015). For instance, adhering to dietary treatment regimens can impact how patients see themselves in relation to enjoying food. Literature on burden of treatment points to the quality of the professional patient relationship as important in limiting or enhancing burden (Ehrlich et al. 2018; Eton et al. 2017). Moreover, aspects of organization of the healthcare system such as poor care coordination can also contribute to the burdens service users experience (Ridgeway et al. 2014).

In this paper we take burden of treatment theory as an inspiration to develop a framework of burden of support in community housing services. Our analysis of burden of support is sensitized by the different aspects mentioned above: 1) the type of work service users engage in as part of receiving support in community housing services, 2) the impact of this work on daily life and the emotional and biographical impact of these tasks and responsibilities and 3) the role of professionals and organization of services. The latter may be specifically prudent as in community housing services, a service user's home is often part of the care organization and professionals play a significant role in the daily lives of service users (Linz and Sturm 2016; Shipton and Lashewicz 2017). We develop this framework through ethnographic fieldwork in a community housing service providing supported housing and supported independent living to people with an intellectual disability (ID) or with severe mental illness (SMI). We do so by answering the questions: 'what burdens of support are experienced by service users receiving support for daily living in community housing services and how can this support be delivered and organized to minimize these burdens?'

Method

Setting

This ethnographic study took place in a large community service organization in the Netherlands which supports people with ID or SMI. The selected organization was a good case to study the consequences of the changes in support we are interested in, as empowerment related values such as strengthening an independent lifestyle, self-determination, developing a positive identity and community participation are inscribed in the organizations' mission statement, policies, and practices.

Two care teams in a community housing service participated, one providing support to people with SMI (care team 1) and one providing support to people with ID (care team 2). Both teams consisted of social care professionals and a peer support worker (expert-by-experience). The teams provide support in three types of housing arrangements: a supervised group home with shared facilities and an office for professionals; single apartments in a

building with only service users, with each their own facilities and the professionals' office nearby and houses where service users live independently. Housing is organized as a stepped process where service users are moved from one setting into more independent settings. Each service user has a personal care plan with goals for care negotiated when services commence and evaluated each year. Goals include being able to keep up personal hygiene and a household, develop a vocation, organize finances etc. Professionals support service users in these goals through supportive conversations, teaching skills, giving practical assistance, and connecting service users to other services.

Recruitment of teams and respondents

We conducted our study in two teams. This was a purposeful sample in which teams were selected to include diversity in terms of housing arrangements and in terms of service user population. Excluded were teams specializing in specific groups of service users, for instance with previous homelessness or addiction.

All 36 respondents for the interviews were recruited using convenience sampling. In the second team, all twenty service users with ID or autism were invited to participate in an interview. In order to increase willingness to participate the interviewer acquainted service users first during daily informal coffee moments. Twelve service users agreed to an interview and eight declined. Reasons stated were not liking to talk to 'strangers'. In the first team recruiting service users with SMI for an interview proved demanding. The team had decided it would violate service users' privacy and diminish their care relationship if the researcher would approach service users directly. Therefore, professionals first asked service users if the researcher could contact them for an interview or if they researcher should tag along during a care meeting to make acquaintance first. Four service users were included through this recruitment strategy. Many service users however declined. Professionals stated that with some of their service users even posing the question had negatively affected their fragile care relationship, which made them reluctant in approaching more service users. As a second strategy for recruitment the researcher visited the weekly coffee meetings, acquainting the attending service users. Four of the regular attendees agreed to be interviewed. Three declined for reasons related to trust or being too busy with settling down after recently having moved. As these two recruitment strategies may have led to selection bias, selecting only those service users who were more social or less inflicted by symptoms to participate in the research, additional interviews were held with experts-by-experience. These worked as peer-support workers in teams providing supported housing or supported independent living for both teams caring for service users with

ID and SMI and could share care practices they had witnessed. This way experiences of service users for whom the interview was not accessible was included as they were shared and reflected on by the experts-by-experience. Family-members were interviewed as these can serve as proxies for service users and highlight burdens not identified by them. All included service users were asked permission to contact their relatives. Through this strategy seven family members were included. In order to enrich this data three family-support-workers were interviewed who provide support to family carers and have their own relative using the service.

Interviews

In depth interviews provided insight into service users' negative experiences with support including promoting self-determination, personal recovery, fostering an independent lifestyle and community participation which provided the building blocks construction of the counter narrative of burden of support framework (McKenzie-Mohr and Lafrance 2017). In total 36 interviews were conducted, with service users with SMI part of care team one ($n=8$), their family members ($n=4$), service users with ID part of care team two ($n=12$), their family members (n-=3), peer support workers ($n=8$) and family support workers ($n=3$), working in several teams.

The topic list for interviews with service users, started with the very open question which allowed service users to talk in potentially transgressive ways and counter narratives to emerge (McKenzie-Mohr and Lafrance 2017): 'What do you find important in the care relationships you are involved in within community services?'. Which was followed by open questioning prompting for narrative exploration of both situations in which this was experienced positively and negatively. Moreover, when self-determination, personal recovery, an independent lifestyle or community participation were not named spontaneously, these were prompted by the researcher after spending elaborate time exploring the situations brought up by the interviewees. This delivered many narratives about how respondents experience community housing services and provided rich data for exploring burden of support. Interviews were audio recorded and transcribed verbatim. Interviews lasted between 25 min and 90 min. Five service users did not want to record their interview, reasons included feeling pressure to express themselves 'the right way' or their hallucinated voices did not allow them to be recorded. In these cases, extensive notes were taken during the interview which were elaborated on shortly after. Interviews with experts by experience followed the same structure, eliciting situations involving service users of the teams where they worked as peer support workers and their reflections of the care experiences of service users in those situations. Interviews with family members and family support members also followed the same structure and focused both

on their own experiences as on their perspectives of how service users experience the support.

Photovoice

In order to gain a more in-depth understanding of the experiences with receiving support in community housing services we conducted a photovoice workshop in both teams. Photovoice offers additional means for exploring these experiences as it facilitates service users to share their experiences in a non-verbal way and in their own time (Golden 2020; Drew and Guillemin 2014). A total of six service users with ID participated in team two and one service user with SMI participated in team one. First a meeting was organized to acquaint participants with the digital camera and the assignment which was to take pictures of what participants like and don't like about living where they live in the coming two weeks. After this period an open interview was conducted in which all photos taken by the respondent were discussed in terms of content and relationship with the research question (Drew and Guillemin 2014). The researcher made notes of these conversations which were elaborated on shortly after.

Participant observation

Interviews and the photovoice workshop provided means for elicitation of narratives that served as building blocks for the counter narrative of burden of support. Additionally, participant observations allowed for observing 'small stories' that are told in daily interactions in community housing services (Bamberg and Wipff 2020). Secondly, participant observation allows the researcher to have informal conversations with service users and informal carers, which are more accessible ways for service users to express themselves compared to formal interviews. Lastly, the focus on narrative, privileges spoken word as unit for analysis. This ignores service users' experiences that aren't voiced. Service users however also enact their appreciations; through their actions they show their likes and dislikes about certain care practices which can be captured through participant observation (Pols 2005). Participant observations took place over six months, three months in each team, 12 visits totaling 19 h for the first team and 12 visits totaling 65 h for the second. Extensive field notes were made shortly after each observation. The difference of hours spent in each team and type of situations observed reflects a difference in the way care is organized in these two teams. The first team organized care in an individualized way. They had no frequently used communal spaces where the researcher could just 'hang out', establish rapport with service users and observe care practices. Instead, the researcher had to accompany professionals when they provided care, which meant

service users had to agree with the researcher's presence before rapport could be established. Service users often declined which resulted in limited opportunity for participant observation. This was strikingly different in the second team where the researcher had plenty of chances to meet service users informally and observe care moments in the communal day rooms, during many coffee moments and at communal meals. This challenge for data collection through participant observation in team 1 was partly resolved by interviewing peer support workers (experts-by-experience). As these people worked in different teams, they could elaborate on situations they had witnessed and reflect on service users' negative experiences, serving somewhat like co-ethnographists in situations that did not cater for the researcher's presence.

Data analysis

The data – transcripts from the interviews, notes from participant observations and notes from the interviews which were part of the photovoice workshop – was analyzed thematically by the first author. Our approach to thematic analysis was reflexive, guided by our research question and the theoretical concepts derived from burden of treatment theory (Braun and Clarke 2019). First all data was coded inductively, aligned with our reflexive approach to thematic analysis. This was guided by our research question therefor focusing on negative experiences with receiving services as related to those services. Secondly, the data was coded guided by central concepts in Burden of Treatment Theory: 'work related to receiving support; 'emotional impact'; 'biographical impact'; 'provider capacity' in combination with the aims of community housing services: 'self-determination'; 'living an independent lifestyle'; 'personal recovery' and 'community participation'. Themes describing different types of burden of support were developed from these inductive codes and theory-informed codes through a reflexive process of grouping, merging and splitting codes (Boeije 2002). Coding was done using Atlas-ti software.

Ethical issues

The ethical board of Erasmus Medical Centre judged the study as not in need of ethical approval under Dutch law (MEC-2017-122). Written consent was obtained using accessible information and consent forms. Emphasis was laid on voluntariness, possibility for withdrawal, purposes of data collection and pseudonymization (Frankena et al. 2015). To minimize impact and harm we recruited clients in close collaboration with support staff. We planned interviews at the location and time of the client's convenience. During interviews or informal conversation, we attended to signals of clients regarding negative emotions or fatigue and responded by aborting, re-scheduling or providing counseling (Digby, Lee, and Williams 2016).

Results

Four burdens of support in community housing services were identified. These are re-identification, self-determination, responsibilisation and replacement. These burdens will be described in this section as will the ways professionals can decrease or worsen them. These burdens were experienced both by people with SMI and people with ID.

Burden of self-determination

The first burden of support is the burden of self-determination. The enhancement of self-determination is an important focus of person-centered care planning (PCP). In PCP, service users are supported to formulate goals that are consolidated in care plans and evaluated periodically. This requires work from service users such as reflecting and vocalizing one's aims in life, support needs and progress. Negotiating with professionals is also part of this as professionals have their own take on what is desirable and feasible. This work can have a large emotional impact on service users, such as mourning over losses and lack of progress or feeling proud of oneself when goals have been attained.

> You fill it in for all kinds of life areas. Each time it is a confrontation with everything you don't have, you are not able to do (SMI_C_1).

Respondents reflect that professionals can decrease the burden of self-determination when they collaborate with service users in formulating goals and describe them in service users' everyday language. However, the way professionals structure discussions on PCP can aggravate the burden of self-determination when professionals interfere too much. For instance, by proposing goals related to independent living that are not service users own or labeling the service user's needs unrealistic instead of further exploring these together. One example is described by an expert-by-experience of a service user who declares he wants to become an astronaut, which was dismissed by the professional instead of exploring further the service user's interest in this topic. The organizational context can further aggravate the burden of self-determination when professionals must finalize a care plan early in the care process in order to account to funders. As a result, professionals aim to consolidate goals for care to be accountable instead of supporting and encouraging the service user to develop an understanding of their desires in life.

> Professionals often think in terms of those goals: 'That service user needs to shower that day, so we should remind him'. So, every day that service users get some professional telling him: 'did you shower yet?'. Of course, this could be important, but often this is not the goal of the service user. Or it is not his goal to shower every day but less frequent. Maybe that particular day something completely different

is on the service users' mind, he wants to talk about. But every day he only gets 'did you shower already?'. I see it in a lot of places where I work. I think a service user wants to be heard, to be understood. And that can become a very frustrating situation because the service user becomes oppositional as he only hears he must do things but is not being listened to (E_2).

As is illustrated in the quote above, the PCP further aggravates the burden of self-determination when the care plan limits self-determination in daily life. Experts-by-experience report that in some teams the care plan is quite rigidly translated into a daily agenda, structuring the daily work of professionals. Here a goal has become a task that a professional must accomplish during a shift. Service users may react to this by becoming resistant as they are told they must do something as it is scheduled for today (e.g. shower, or tidy-up the room) instead of engaging in conversation about what is on service users' mind. Contrarily, respondents describe situations in which professionals follow service users stated needs instead of the goals in the care plan. A family support worker discussed a case where a professional had an appointment with a service user with ID to help her study for her moped driver's license while the service users expressed, she would rather watch T.V. The professional stated he let the service user be as this is what self-determination entails. Experts-by-experience describe instances such as these in which they feel that the professional has not taken the right effort or communication capacities into motivating the service user, which they regard as neglect. Motivating, according to these experts-by-experience, involves developing an understanding of what matters to the service user and stimulate reflection on their choices. Such practices would alleviate the burden of self-determination.

Burden of re-identification

The second burden we identify is the burden of re-identification, which is related to personal recovery. Recovery oriented care includes developing a positive self-identity free from self-stigma, integrating vulnerabilities and capacities. The related identity work described by service users includes self-reflection on the positive parts of one's personality, a positive re-labeling of being different from the mainstream and developing a new narrative about oneself that provides a basis for self-direction and communication to others. This work obviously has biographical impacts as identity work is at its core. Emotional impacts reported by service users include a process of mourning as one comes to terms with the losses related to living with a disability and simultaneously positive emotional impacts such as feeling proud of oneself. The work of personal recovery is at stake for people with ID, however it fits more with support for people with SMI.

I try to develop a more positive view of myself or accept more that all these things are a part of who I am. It is a very complex process of mourning (SMI_C_1).

Experts-by-experience and service users state that professionals can support personal recovery work and alleviate its burden by being attentive to the positive aspects of people's personality and their capabilities to support themselves rather than aggravating self-stigma by viewing people through the lens of their diagnosis. Professionals further support the work of personal recovery by organizing opportunities in which people can develop their talents and positive roles (e.g. brother, friend, employee, etc.). However, as some respondents narrate, a sole focus on these positive aspects of identity can also aggravate the burden of re-identification. For instance, when professionals are not being honest in their positive appraisal, service users feel that they are not taken seriously.

> A fellow patient had put on make-up in a terrible way, her eyes were so blue, and lipstick going way past her mouth. A professional said to her: 'Oh you really made a pretty face!' and I thought to myself: 'I will never trust you again, you are lying' (E_3).

Similarly, when professionals attempt to surpass self-stigma by not using diagnostic related information in their contact with service users, this can leave service users feeling misunderstood, as is apparent in the next quote.

> In the beginning, I said to them: 'Maybe you should find some info about how to deal with my symptoms.'. But they said: 'No, we want to get to know you like a person'. But then you don't really understand what I need. It is rather important you know about my diagnosis when you support me. People who I just happen to know, like my friends or teachers or classmates, they can get to know me as a person. But as a professional, you need to go a bit deeper. On the one hand, I don't want to be dependent on my diagnoses, but I don't have them for no reason either (SMI_C_2).

Lastly, professionals and care organizations can unintentionally give the message that service users who are able to live independently are 'better' people compared to people with support needs. This may lead service users to adapt their self-understanding to this image and not be true to their own needs. The next example comes from participatory observation. It involves a man with an intellectual disability who is living in a group home with the same two people for over 10 years whom he refers to as his friends. They spend their evenings together, they watch tv and enjoy following the soccer league. They cook in turns which he enjoys as he is often tired after working all day at his sheltered job. An apartment for independent living will soon become available and he has expressed to the professionals in the team he would like to move there. When I speak to his sister-in-law, she tells me that when he lived alone before he moved here, he was quite lonely and had little energy to keep his household, cook or have social contact after work. She told me a couple of anecdotes for which the storyline is the same: he pretends he is better than he is as he doesn't want people to look down

upon him. She tells me she thinks he only wants to move as living independently means he will be seen as a better person, as this image of the independent service users is often portrayed as desirable. This I witnessed myself as well. For instance, in the kitchen of the group home a large poster is displayed which is part of a campaign by the community housing service. The poster shows a large photograph of a smiling service user covered by a large quote stating: 'doing things independently is wonderful'. This example illustrates how the empowerment rhetoric of the service organization can also aggravate the burden of re-identification. Alleviating the burden of re-identification thus requires professionals to be both attentive to service users' strengths and to their vulnerabilities and related support needs. Moreover, it is important professionals support service users in developing such an integrated understanding of themselves.

Burden of responsibilisation

The third burden we identified is the burden or responsibilisation which is related to developing an independent lifestyle in community housing services. For service users, this involves a large array of work, which includes housekeeping, personal hygiene care, cooking, grocery shopping, budgeting, administration, developing social contacts, daily structure and vocation. Moreover, service users have to work on developing and maintaining a good relationship with professionals and organizing support from other organizations, peers or family members. Becoming more responsible for managing daily life has positive biographical impacts as this contributes to the service user's self-esteem. However, when the expectations professionals have of service users are set too high, service users report feeling overwhelmed and experience feelings of failure and abandonment. The next quote illustrates this feeling.

> I can't, like a normal person, do my school and cook every day. I also have to do dishes, and laundry and a lot of other things. And at the same time, I have to keep my head together. I would have liked someone who comes here and does the dishes together with me. Not for me, but together so I can also talk a bit about what is going on which helps me to keep sane. […] The other day, my support worker really insisted that I make a phone call to the social benefit organization on my own. And I told her I hadn't slept from having nightmares, but she insisted. And it totally didn't work which gave me extra stress and diminished my self-confidence (SMI_C_2).

The burden of responsibilisation is not only related to the way professionals provide support; burden may also arise from the material aspects of an independent living facility. One service user with ID for instance showed photo's he made of his garden as part of the photovoice workshop. His garden was covered in weeds standing over one meter tall. He explained

that keeping both his household and his garden in his new home was too much for him and gave him much stress, also as the neighbor had complained about the state of the garden.

Respondents reflect that professionals support the work of living an independent lifestyle by providing space for service users to experiment with doing things their own way and making mistakes and focusing on successes, not judging service users when they fail and complementing them when they succeed. However, when professionals give too limited acknowledgement of service users' vulnerabilities, professionals worsen the burden of responsibilisation. When the steps in which support is withdrawn are be too big service users report experiencing stress from being left to do things alone. In these instances, making mistakes is a demoralizing experience, not a learning one. Further adding to this burden, experts-by-experience narrate that professionals sometimes interpret service users being unable to do the work as being unmotivated and react by offering even less support.

> A service user gets 10 euro every day and then some professionals thought, because of fostering an independent lifestyle, I will give him his bank card. How he wants to spend his cash is his decision. And that service user went and emptied his entire account, and the next day he is without money and without cigarettes and he becomes aggressive. Doing that without taking small steps is simply asking too much of service users. You could also start building it up slowly, first giving the money for two days, then three etc. Build it up slowly to something he can trust himself with (E_5).

Developing an independent lifestyle often entails having less professional contact and more contact with the wider community. The burden of responsibilisation is increased when professionals do not realistically address the limits of inclusiveness in the community and overemphasize the service user's role in developing an independent lifestyle. For instance, an expert by experience addressed there are few paid jobs outside of care organizations where special needs and limited work experience are taken into account. Vocation trajectories offered to service users thus often did not result in employment, instead service users followed one trajectory after another while this problem remained unaddressed. When societal barriers are not realistically addressed, this resposibilises service users when goals are not attained and aggravates the burden of responsibilisation. Alleviating the burden of responsibilisation thus requires professionals to reflect on what type of support is still needed and how this can be arranged to enable service users to live in the community.

Burden of replacement

The final burden we identify is the burden of replacement. As care organizations follow policies of deinstitutionalization, service users are expected

to move to more independent housing facilities. This not only responsibilises them as discussed in the previous theme, it also creates specific burdens related to the work of moving and familiarizing yourself in a new environment and develop social contacts as peer contact is less readily available. The emotional impact and impact on daily life are very much interwoven with the housing facility and are therefore considered part of this burden.

> After so much time you have to move somewhere else to social housing. Chances are you have to move out of the neighborhood as well. And then you lose your sense of familiarity, people you know, surroundings and people often already feel down (E_7).

The different housing situations provide different burdens for service users. Living in a group home poses burdens such as only having a bedroom as a private space to seclude yourself or to have guests over. Burdens arise from having to live together with others such as people with different hygienic norms or different capabilities when it comes to chores, dealing with aggression or theft by peers. Lastly burdens arise as there is less space for self-determination. For instance, due to having to abide by house rules such as set dinner times. These burdens are alleviated when moving into a home with private facilities. Service users report positive impacts on daily life such as having a larger space, more privacy, having more self-determination and having more opportunities for learning skills related to maintaining a household. However, respondents also describe the negative emotional impacts of living independently. Loneliness increases as the easily available peer contact in the group home ceases and service users have difficulties getting to know others in the neighborhood and experience stigma.

> Only, being alone… I often found it too loud in the group home. But I also often like to have a chat with people. Here in your own home, you don't have that. Your neighbors are normal people so to speak. You want to act normal to those people. You have to be on your toes. When I go to [name community housing services], I feel comfortable, there people know what I am like (ID_C_1).

Other emotional impacts include moving out of a house and neighborhood service users feel at home and feeling unfamiliar in new surroundings. The burden of replacement is worsened when moving to a more independent housing situation is part of organizational policy and is not so much the service user's own decision or when service users have limited choice on what neighborhood they move into. Respondents reflected that professionals aggravate this burden when they do not acknowledge the difficulties regarding re-placement and offer limited support in developing social contact or in joining leisure activities.

> The professionals try things, like sending people to a community house. I think a support worker should really know the neighborhood well and have close contact

with the community center and go there with service users together. You can say to a service user: 'go visit the community center', but they might find it already very difficult to go and talk to someone. So, they stay indoors, get lonely, do not build a network nor develop competencies for building one (E_7).

Another aspect of the burden of replacement is the increased risk of abuse service users face when living independently in the community. Abuse reported or encountered during the participant observation includes being seduced to sell belongings for little money, having people taking advantage of the service user's house as a social meeting space, being seduced into criminal activities such as lending the bank account for money laundering purposes and lending the house to grow marijuana. As housing is scarce service users are often moved into low SES-neighborhoods which increases the burden of replacement. This burden is also increased as living in a more independent home diminishes contact between service users and professionals. Experts-by-experience describe living independently as a challenge for care professionals to develop a care relationship as there are less informal moments of interaction, and service users can decide to keep the door shut at their scheduled meetings with professionals. Professionals can alleviate this burden by putting in the extra effort to maintain or develop the relationship so signs of deterioration of a service user's (mental) health or signs of being abused by others do not remain unnoticed. Alleviating the burden of replacement furthermore requires professionals to recognize relocation as a significant life event for service users, which comes with specific support needs.

Discussion

This study developed a framework of four burdens of support which conceptualizes negative experiences of service users in community housing services aimed at fostering self-determination, personal recovery, an independent lifestyle and community participation. Previous studies have identified similar negative experiences in community housing services, which supports the relevance of our findings for an international audience (Fisher et al. 2016; Fullana, Pallisera, and Díaz-Garolera 2019; Hassan 2017; Krotofil, McPherson, and Killaspy 2018; Wilken et al. 2018). However, the negative experiences identified in these studies were never put together in a comprehensive framework of burdens of support.

The care models of recovery-oriented care, rehabilitation and person-centered planning take shape in the context of policy trends towards personalization and independence. These are reactions to an institutionalized and paternalistic way of providing care for people with ID and SMI. By delineating the counter-narrative of burden of support, we do not in any way want to argue for going back to more institutionalized ways of providing care. However, we

do argue that care models aimed at empowering service users are sometimes framed in ways that do no justice to the complexity of service users' needs and the complexity of professional practice in providing support in community housing service. Improving quality of care then demands critical reflection on how these models are implemented and practiced. Our counter narrative of burdens of support provides a starting point for critical reflection on improving quality of care on four domains: service user involvement, professional conduct, the organization of care and the place of care.

First, related to service user self-determination our study shows how merely taking into account service users' stated needs does not suffice. Our study illustrates how service users expressed needs can be distorted by the image of the *empowered* service users. This is an addition to previous studies which highlight the impact of the *stigmatized* identity (Björnsdóttir, Stefánsdóttir, and Stefánsdóttir 2015; Dorozenko, Roberts, and Bishop 2015; Krotofil, McPherson, and Killaspy 2018; Tew et al. 2012). Providing good care thus requires professionals to engage in a relationship with service users through which service users can gain a sense of self and service users' needs can become known and taken into account (Ljungberg, Denhov, and Topor 2015; Ljungberg, Denhov, and Topor 2016), while mitigating both the impact of images on stigmatized and empowered service users in order to attend to their complex needs.

Our paper furthermore shows that when professionals foster service users' autonomy in a liberal-individualistic instead of a more relational way, service users face neglect, thus enhancing burden of support (Verkerk 2001). Think of the example of the moped driver's license or the abandonment service users experience when services are withdrawn in order to foster independence. As care work in community housing services is complex, value tensions between for instance fostering service users' self-determination and preventing harm, are bound to persist within the care relationship (Heerings et al. 2020, 2022). Good care requires professionals to bring together different values in care practices, carefully attend to the consequences of these practices and adjust accordingly. This has been described as a process of 'tinkering' (Mol, Moser, and Pols 2010; Heerings et al. 2022).

Third, our study shows burdens are impacted by the way care models such as recovery-oriented care and rehabilitation are implemented through organizational procedures and routines. The example of the personal care plan for instance shows how professional practice can be routinised in ways that no longer contribute to the original aim of the instrument (Bromley and Powell 2012; Khoury and Rodriguez del Barrio 2015). Personalized care planning aims at fostering self-determination of service users. However, when professionals work to finalize the care plan early in the care process in order to be accountable to funders instead of treating it as a living document which fosters deliberation with service users through which they can develop lifegoals this

aim is not attained. Here good care requires professionals to act as 'rebels' in order to mitigate the adverse effects of these organizational procedures or by addressing the changes required to these organizational policies (de Bree and Stoopendaal 2020; Matscheck, Ljungberg, and Topor 2020; Wallenburg, Weggelaar, and Bal 2019). Lastly, our identified burdens of support show the importance of attending to the 'places of care', both in terms of their physical and social set-up (Brolin et al. 2018; Townley 2015; Strnadová, Johnson, and Walmsley 2018; Ivanova, Wallenburg, and Bal 2016). The burden of re-placement illustrates how the set-up of these places and the moving between them creates burden for service users and enables or disables self-determination and belonging. Good care thus requires professionals to not only act within the care relationship but also work on developing places of belonging in the community (Williams, Almeida, and Knyahnytska 2015).

While the strategies identified above might alleviate some of the burden of support in individual client-professional relationships, alleviating these burdens furthermore requires work on the team and organizational level. First, social workers within teams need to critically reflect on the relationship between their care practices, the organization of care and the way these are backgrounded by care models such as recovery-oriented care (Fook and Askeland 2006; Brookfield 2009). This should not only be a reflection-on-action but also a forward-looking reflection in which teams also develop practices in order to minimize burdens (Keevers and Treleaven 2011; Mol, Moser, and Pols 2010). Developing such care practices can be done collectively incorporating not only the views of different team members, but also engaging service users and others involved in support such as family members (Heerings et al. 2022). Through co-design professionals, service users and family members can work together in making such changes (Palmer et al. 2019; Robert 2013). In order to make sure including service users' views does not remain tokenistic, such co-design processes need to include spaces where service users' or their advocates', counter-narratives of burden of support can be voiced and heard (McKenzie-Mohr and Lafrance 2017).

This study delivers crucial input for the (critical) reflection and co-design needed to minimize burden of support. These insights have been translated into a method for quality improvement in long term care (Heerings et al.). Part of this method are short video's where actors with a disability perform monologues in which the burdens identified in this paper are narrated (see: www.eur.nl/en/eshpm/research/ask-us/videos). These videos are an important tool in creating space for service users to voice negative experiences while and convey these experiences to professionals (Trevelyan, Crath, and Chambon 2014; Locock et al. 2014b, 2014a; Wulf-Andersen 2012). These videos are used in several dialogue sessions to trigger reflection on burdens by both service users, informal carers and professionals, to, deliberate about their different views on good care and design service improvement together (Heerings et al.).

Limitations

For developing a counter narrative of experiences of service users in community housing services it is important service users can participate in the research and their voices are heard. This proved quite a challenge. The first challenge was to engage service users in an interview. As care is organized more individually with limited use of communal spaces this limits possibility for establishing the rapport needed to engage service-users in interviews. In this study this is reflected in the differences between the two teams in recruitment of service users for interviews. Relatedly, our aim of developing a counter narrative focuses on language, while for some service users expressing themselves vocally is a challenge. These challenges were addressed by combining interviewing with participant observation, photovoice and engaging experts-by-experience as co-ethnographist having them describe and reflect on care moments that do not cater for the researchers' presence. These methods and their combination could be further developed as a research practice in social work when both working on narrative resistance and doing research with service users that are more prone to be unable or unwilling to participate in interviews (Pols 2005). This study focused on the burdens clients experience when services are organized around care models such as personalized care planning and recovery-oriented care. Such focus could be critiqued for being one-sided. Our focus has however not been on the assessment of the practices we studied. Our aim is to inform the discussion on how to provide good care by exploring the often-ignored counter-narrative of what the drive towards independence and personalization mean at a service level and what may be the negative unintended outcomes for service users as services push forward towards these well-meaning goals.

Conclusion

This study brings together negative experiences of service users in a comprehensive counter narrative of burden of support. This framework enables service users and their advocates to voice aspects of care aimed at fostering self-determination, personal recovery, independent lifestyles and community participation that negatively impacts their well-being. Moreover, professionals, managers and policymakers can take up the framework of burden of support to reflect on the complexity of service users' needs and deliver and organize community housing services in such a way that limits burden.

Ethical approval

The ethical board of Erasmus Medical Centre judged the study as not in need of ethical approval under Dutch law (MEC-2017-122).

ORCID

Marjolijn Heerings 🆔 http://orcid.org/0000-0002-8280-0305
Hester van de Bovenkamp 🆔 http://orcid.org/0000-0002-6412-2707
Roland Bal 🆔 http://orcid.org/0000-0001-7202-5053

Data availability statement

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to them containing information that could compromise research participant privacy and consent.

References

Bäck-Pettersson, Siv, Sofia Sandersson, and Evelyn Hermansson. 2014. "Patients' Experiences of Supportive Conversation as Long-Term Treatment in a Swedish Psychiatric Outpatient Care Context: A Phenomenological Study." *Issues in Mental Health Nursing* 35 (2): 127–133. doi:10.3109/01612840.2013.860646.

Bamberg, Michael, and Zachary Wipff. 2020. "Re-considering Counter Narratives." In *The Routledge Handbook of Counternarratives*, 60–72. London: Routledge.

Björnsdóttir, Kristín, Guðrún V. Stefánsdóttir, and Ástríður Stefánsdóttir. 2015. "'It's My Life': Autonomy and People with Intellectual Aisabilities." *Journal of Intellectual Disabilities: JOID* 19 (1): 5–21. doi:10.1177/1744629514564691.

Boeije, Hennie. 2002. "A Purposeful Approach to the Constant Comparative Method in the Analysis of Qualitative Interviews." *Quality and Quantity* 36 (4): 391–409. doi:10.1023/A:1020909529486.

Braun, Virginia, and Victoria Clarke. 2019. "Reflecting on Reflexive Thematic Analysis." *Qualitative Research in Sport, Exercise and Health* 11 (4): 589–597. doi:10.1080/2159676X.2019.1628806.

Brolin, Rosita, Susanne Syrén, Mikael Rask, Anna Sandgren, and David Brunt. 2018. "Residents' Perceptions of the Most Positive and Negative Aspects of the Housing Situation for People with Psychiatric Disabilities." *Scandinavian Journal of Caring Sciences* 32 (2): 603–611. doi:10.1111/scs.12485.

Bromley, Patricia, and Walter W. Powell. 2012. "From Smoke and Mirrors to Walking the Talk: Decoupling in the Contemporary World." *Academy of Management Annals* 6 (1): 483–530. doi:10.5465/19416520.2012.684462.

Brookfield, Stephen. 2009. "The Concept of Critical Reflection: Promises and Contradictions." *European Journal of Social Work* 12 (3): 293–304. doi:10.1080/13691450902945215.

Burton, Mark, and Carolyn Kagan. 2006. "Decoding Valuing People." *Disability & Society* 21 (4): 299–313. doi:10.1080/09687590600679899.

Claes, Claudia, Geert Van Hove, Stijn Vandevelde, Jos van Loon, and Robert L. Schalock. 2010. "Person-Centered Planning: Analysis of Research and Effectiveness." *Intellectual and Developmental Disabilities* 48 (6): 432–453. doi:10.1352/1934-9556-48.6.432.

Cui, Jialiang, Limin Mao, Grenville Rose, and Christy E. Newman. 2019. "Understanding Client Empowerment: An Online Survey of Social Workers Serving People with Mental Health Issues." *The British Journal of Social Work* 49 (2): 335–350. doi:10.1093/bjsw/bcy057.

Davies, Kate, and Mel Gray. 2015. "Mental Health Service Users' Aspirations for Recovery: Examining the Gaps between What Policy Promises and Practice Delivers." *British Journal of Social Work* 45 (suppl 1): i45–i61. doi:10.1093/bjsw/bcv089.

de Bree, Martin, and Annemiek Stoopendaal. 2020. "De-and Recoupling and Public Regulation." *Organization Studies* 41 (5): 599–620. doi:10.1177/0170840618800115.

de Heer-Wunderink, Charlotte, Ellen Visser, Annemarie Caro-Nienhuis, Sjoerd Sytema, and Durk Wiersma. 2012. "Supported Housing and Supported Independent Living in The Netherlands, with a Comparison with England." *Community Mental Health Journal* 48 (3): 321–327. doi:10.1007/s10597-011-9381-1.

Demain, Sara, Ana-Carolina Gonçalves, Carlos Areia, Rúben Oliveira, Ana Jorge Marcos, Alda Marques, Ranj Parmar, and Katherine Hunt. 2015. "Living with, Managing and Minimising Treatment Burden in Long Term Conditions: A Systematic Review of Qualitative Research." *PLoS One* 10 (5): e0125457. doi:10.1371/journal.pone.0125457.

Di Maggio, I., K. A. Shogren, M. L. Wehmeyer, and L. Nota. 2020. "Self-Determination and Future Goals in a Sample of Adults with Intellectual Disability." *Journal of Intellectual Disability Research : JIDR* 64 (1): 27–37. doi:10.1111/jir.12696.

Digby, Robin, Susan Lee, and Allison Williams. 2016. "Interviewing People with Dementia in Hospital: Recommendations for Researchers." *Journal of Clinical Nursing* 25 (7–8): 1156–1165. doi:10.1111/jocn.13141.

Dorozenko, K. P., L. D. Roberts, and B. Bishop. 2015. "The Identities and Social Roles of People with an Intellectual Disability: Challenging Dominant Cultural Worldviews, Values and Mythologies." *Disability & Society* 30 (9): 1345–1364. doi:10.1080/09687599.2015.1093461.

Drew, Sarah, and Marilys Guillemin. 2014. "From Photographs to Findings: Visual Meaning-Making and Interpretive Engagement in the Analysis of Participant-Generated Images." *Visual Studies* 29 (1): 54–67. doi:10.1080/1472586X.2014.862994.

Ehrlich, C., P. Chester, S. Kisely, D. Crompton, and E. Kendall. 2018. "Making Sense of Self-Care Practices at the Intersection of Severe Mental Illness and Physical health-An Australian Study." *Health and Social Care in the Community* 26 (1): e47–e55.

Eton, David, Jennifer Ridgeway, Mark Linzer, Deborah Boehm, Elizabeth A. Rogers, Kathleen Yost, Lila Finney Rutten, Jennifer St Sauver, Sara Poplau, and Roger Anderson. 2017. "Healthcare Provider Relational Quality is Associated with Better Self-Management and

Less Treatment Burden in People with Multiple Chronic Conditions." *Patient Preference and Adherence* ume 11: 1635–1646. doi:10.2147/PPA.S145942.

Farkas, Marianne, and William A. Anthony. 2010. "Psychiatric Rehabilitation Interventions: A Review." *International Review of Psychiatry (Abingdon, England)* 22 (2): 114–129. doi:10.3109/09540261003730372.

Farone, Diane Weis. 2006. "Schizophrenia, Community Integration, and Recovery: Implications for Social Work Practice." *Social Work in Mental Health* 4 (4): 21–36. doi:10.1300/J200v04n04_02.

Fisher, Marisa H., Jessie V. Baird, Andrew D. Currey, and Robert M. Hodapp. 2016. "Victimisation and Social Vulnerability of Adults with Intellectual Disability: A Review of Research Extending beyond Wilson and Brewer." *Australian Psychologist* 51 (2): 114–127. doi:10.1111/ap.12180.

Fook, Jan, and Gurid Aga Askeland. 2006. "The 'Critical'in Critical Reflection." *Critical Reflection in Health and Social Care* 2006: 40–53.

Frankena, Tessa Kim, Jenneken Naaldenberg, Mieke Cardol, Christine Linehan, and Henny van Schrojenstein Lantman-de Valk. 2015. "Active Involvement of People with Intellectual Disabilities in Health research – A Structured Literature Review." *Research in Developmental Disabilities* 45–46: 271–283. doi:10.1016/j.ridd.2015.08.004.

Fullana, Judit, Maria Pallisera, and Gemma Díaz-Garolera. 2019. "How Do People with Learning Disabilities Talk about Professionals and Organizations? Discourse on Support Practices for Independent Living." *Disability & Society* 34 (9–10): 1462–1480. doi:10.1080/09687599.2019.1594701.

García Iriarte, Edurne, Janine Stockdale, Roy McConkey, and Fiona Keogh. 2016. "The Role of Support Staff as People Move from Congregated Settings to Group Homes and Personalized Arrangements in Ireland." *Journal of Intellectual Disabilities: JOID* 20 (2): 152–164. doi:10.1177/1744629516633966.

Golden, Tasha. 2020. "Reframing Photovoice: Building on the Method to Develop More Equitable and Responsive Research Practices." *Qualitative Health Research* 30 (6): 960–972. doi:10.1177/1049732320905564.

Hassan, Nedim. 2017. "Putting Music on: Everyday Leisure Activities, Choice-Making and Person-Centred Planning in a Supported Living Scheme." *British Journal of Learning Disabilities* 45 (1): 73–80. doi:10.1111/bld.12178.

Heerings, Marjolijn, Hester van de Bovenkamp, Mieke Cardol, and Roland Bal. "Ask us! Adjusting Experience-Based Codesign to Be Responsive to People with Intellectual Disabilities, Serious Mental Illness or Older Persons Receiving Support with Independent Living." *Health Expectations* 23 (1): 5–18. doi:10.1111/hex.13436.

Heerings, Marjolijn, Hester van de Bovenkamp, Mieke Cardol, and Roland Bal. 2020. "Ethical Dilemmas of Participation of Service Users with Serious Mental Illness: A Thematic Synthesis." *Issues in Mental Health Nursing* 41 (4): 283–295. doi:10.1080/01612840.2019.1667459.

Heerings, Marjolijn, Hester van de Bovenkamp, Mieke Cardol, and Roland Bal. 2022. "Tinkering as Collective Practice: A Qualitative Study on Handling Ethical Tensions in Supporting People with Intellectual or Psychiatric Disabilities." *Ethics and Social Welfare* 16 (1): 36–53. doi:10.1080/17496535.2021.1954223.

Ivanova, Dara, Iris Wallenburg, and Roland Bal. 2016. "Care in Place: A Case Study of Assembling a Carescape." *Sociology of Health & Illness* 38 (8): 1336–1349. doi:10.1111/1467-9566.12477.

Karpetis, George. 2020. "How Experienced Social Workers Apply Recovery-Oriented Mental Health Policies in Everyday Practice." *European Journal of Social Work* 23 (1): 106–117. doi:10.1080/13691457.2018.1474855.

Keevers, Lynne, and Lesley Treleaven. 2011. "Organizing Practices of Reflection: A Practice-Based Study." *Management Learning* 42 (5): 505–520. doi:10.1177/1350507610391592.

Khoury, Emmanuelle, and Lourdes Rodriguez del Barrio. 2015. "Recovery-Oriented Mental Health Practice: A Social Work Perspective." *British Journal of Social Work* 45 (suppl 1): i27–i44. doi:10.1093/bjsw/bcv092.

Krotofil, J., P. McPherson, and H. Killaspy. 2018. "Service User Experiences of Specialist Mental Health Supported Accommodation: A Systematic Review of Qualitative Studies and Narrative Synthesis." *Health & Social Care in the Community* 26 (6): 787–800. doi:10.1111/hsc.12570.

Lachapelle, Y., M. L. Wehmeyer, M. C. Haelewyck, Y. Courbois, K. D. Keith, R. Schalock, M. A. Verdugo, and P. N. Walsh. 2005. "The Relationship between Quality of Life and Self-Determination: An International Study." *Journal of Intellectual Disability Research: JIDR* 49 (Pt 10): 740–744. doi:10.1111/j.1365-2788.2005.00743.x.

Leamy, M., V. Bird, C. Le. Boutillier, J. Williams, and M. Slade. 2011. "Conceptual Framework for Personal Recovery in Mental Health: Systematic Review and Narrative Synthesis." *The British Journal of Psychiatry : The Journal of Mental Science* 199 (6): 445–451.

Linz, Sheila J., and Bonnie A. Sturm. 2016. "Facilitating Social Integration for People with Severe Mental Illness Served by Assertive Community Treatment." *Archives of Psychiatric Nursing* 30 (6): 692–699. doi:10.1016/j.apnu.2016.05.006.

Ljungberg, A., A. Denhov, and A. Topor. 2015. "The Art of Helpful Relationships with Professionals: A Meta-Ethnography of the Perspective of Persons with Severe Mental Illness." *The Psychiatric Quarterly* 86 (4): 471–495. doi:10.1007/s11126-015-9347-5.

Ljungberg, Amanda, Anne Denhov, and Alain Topor. 2016. "Non-Helpful Relationships with Professionals: A Literature Review of the Perspective of Persons with Severe Mental Illness." Stockholms universitet, Institutionen för socialt arbete, Socialhögskolan.

Llorca, Pierre-Michel, Christophe Lançon, Ann Hartry, T. Michelle Brown, Dana B. DiBenedetti, Siddhesh A. Kamat, and Clément François. 2017. "Assessing the Burden of Treatment-Emergent Adverse Events Associated with Atypical Antipsychotic Medications." *BMC Psychiatry* 17 (1): 1–11. doi:10.1186/s12888-017-1213-6.

Locock, Louise, Glenn Robert, Annette Boaz, Sonia Vougioukalou, Caroline Shuldham, Jonathan Fielden, Sue Ziebland, Melanie Gager, Ruth Tollyfield, and John Pearcey. 2014a. "Testing Accelerated Experience-Based Co-Design: A Qualitative Study of Using a National Archive of Patient Experience Narrative Interviews to Promote Rapid Patient-Centred Service Improvement." *Health Services and Delivery Research* 2 (4): 1–122. doi:10.3310/hsdr02040.

Locock, Louise, Glenn Robert, Annette Boaz, Sonia Vougioukalou, Caroline Shuldham, Jonathan Fielden, Sue Ziebland, Melanie Gager, Ruth Tollyfield, and John Pearcey. 2014b. "Using a National Archive of Patient Experience Narratives to Promote Local Patient-Centered Quality Improvement: An Ethnographic Process Evaluation of 'Accelerated' Experience-Based co-Design." *Journal of Health Services Research & Policy* 19 (4): 200–207. doi:10.1177/1355819614531565.

Macpherson, Rob, Geoff Shepherd, and Praveen Thyarappa. 2012. "Supported Accommodation for People with Severe Mental Illness: An Update." *Advances in Psychiatric Treatment* 18 (5): 381–391. doi:10.1192/apt.bp.110.008714.

Matscheck, David, Amanda Ljungberg, and Alain Topor. 2020. "Beyond Formalized Plans: User Involvement in Support in Daily Living – Users' and Support Workers' Experiences." *The International Journal of Social Psychiatry* 66 (2): 156–162. doi:10.1177/0020764019894603.

May, Carl R., David T. Eton, Kasey Boehmer, Katie Gallacher, Katherine Hunt, Sara MacDonald, Frances S. Mair, et al. 2014. "Rethinking the Patient: Using Burden of Treatment Theory to Understand the Changing Dynamics of Illness." *BMC Health Services Research* 14 (1): 281. doi:10.1186/1472-6963-14-281.

McConkey, R., B. Bunting, F. Keogh, and E. Garcia Iriarte. 2019. "The Impact on Social Relationships of Moving from Congregated Settings to Personalized Accommodation." *Journal of Intellectual Disabilities : JOID* 23 (2): 149–159. doi:10.1177/1744629517716546.

McKenzie-Mohr, Suzanne, and Michelle N. Lafrance. 2017. "Narrative Resistance in Social Work Research and Practice: Counter-Storying in the Pursuit of Social Justice." *Qualitative Social Work* 16 (2): 189–205. doi:10.1177/1473325016657866.

Millner, U. C., T. Woods, K. Furlong-Norman, E. S. Rogers, D. Rice, and Z. Russinova. 2019. "Socially Valued Roles, Self-Determination, and Community Participation among Individuals Living with Serious Mental Illnesses." *American Journal of Community Psychology* 63 (1-2): 32–45. doi:10.1002/ajcp.12301.

Mol, Annemarie, Ingunn Moser, and J. Pols. 2010. *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Bielefeld: Transcript.

Moran, Galia S., Kinneret Westman, Esther Weissberg, and Samuel Melamed. 2017. "Perceived Assistance in Pursuing Personal Goals and Personal Recovery among Mental Health Consumers across Housing Services." *Psychiatry Research* 249: 94–101. doi:10.1016/j.psychres.2017.01.013.

Nordfonn, Oda Karin, Ingvild Margreta Morken, Lars Edvin Bru, and Anne Marie Lunde Husebø. 2019. "Patients' Experience with Heart Failure Treatment and Self-care—A Qualitative Study Exploring the Burden of Treatment." *Journal of Clinical Nursing* 28 (9–10): 1782–1793. doi:10.1111/jocn.14799.

Palmer, Victoria Jane, Wayne Weavell, Rosemary Callander, Donella Piper, Lauralie Richard, Lynne Maher, Hilary Boyd, et al. 2019. "The Participatory Zeitgeist: An Explanatory Theoretical Model of Change in an Era of Coproduction and Codesign in Healthcare Improvement." *Medical Humanities* 45 (3): 247–257. doi:10.1136/medhum-2017-011398.

Pols, J. 2005. "Enacting Appreciations: Beyond the Patient Perspective." *Health Care Analysis: HCA* 13 (3): 203–221. doi:10.1007/s10728-005-6448-6.

Race, David, Kathy Boxall, and Iain Carson. 2005. "Towards a Dialogue for Practice: Reconciling Social Role Valorization and the Social Model of Disability." *Disability & Society* 20 (5): 507–521. doi:10.1080/09687590500156196.

Ridgeway, Jennifer L., Jason S. Egginton, Kristina Tiedje, Mark Linzer, Deborah Boehm, Sara Poplau, Djenane Ramalho de Oliveira, Laura Odell, Victor M. Montori, and David T. Eton. 2014. "Factors That Lessen the Burden of Treatment in Complex Patients with Chronic Conditions: A Qualitative Study." *Patient Preference and Adherence* 8: 339–351. doi:10.2147/PPA.S58014.

Robert, Glenn. 2013. "Participatory Action Research: Using Experience-Based co-Design to Improve the Quality of Healthcare Services." In *Understanding and Using Health Experiences–Improving Patient Care*, 138–149. Oxford: Oxford University Press.

Salzmann-Erikson, Martin. 2013. "An Integrative Review of What Contributes to Personal Recovery in Psychiatric Disabilities." *Issues in Mental Health Nursing* 34 (3): 185–191. doi:10.3109/01612840.2012.737892.

Sav, Adem, Elizabeth Kendall, Sara S. McMillan, Fiona Kelly, Jennifer A. Whitty, Michelle A. King, and Amanda J. Wheeler. 2013. "'You Say Treatment, I Say Hard Work': Treatment Burden Among People with Chronic Illness and Their Carers in Australia." *Health & Social Care in the Community* 21 (6): 665–674. doi:10.1111/hsc.12052.

Sav, Adem, Michelle A. King, Jennifer A. Whitty, Elizabeth Kendall, Sara S. McMillan, Fiona Kelly, Beth Hunter, and Amanda J. Wheeler. 2015. "Burden of Treatment for Chronic

Illness: A Concept Analysis and Review of the Literature." *Health Expectations* 18 (3): 312–324. doi:10.1111/hex.12046.

Shipton, Leah, and Bonnie M. Lashewicz. 2017. "Quality Group Home Care for Adults with Developmental Disabilities and/or Mental Health Disorders: Yearning for Understanding, Security and Freedom." *Journal of Applied Research in Intellectual Disabilities: JARID* 30 (5): 946–957. doi:10.1111/jar.12289.

Strnadová, Iva, Kelley Johnson, and Jan Walmsley. 2018. "… but If You're Afraid of Things, How Are You Meant to Belong?" What Belonging Means to People with Intellectual Disabilities?" *Journal of Applied Research in Intellectual Disabilities: JARID* 31 (6): 1091–1102.

Tew, J., S. Ramon, M. Slade, V. Bird, J. Melton, and C. Le Boutillier. 2012. "Social Factors and Recovery from Mental Health Difficulties: A Review of the Evidence." *British Journal of Social Work* 42 (3): 443–460. doi:10.1093/bjsw/bcr076.

Townley, Greg. 2015. "It Helps You Not Feel so Bad—Feel like You Again": the Importance of Community for Individuals with Psychiatric Disabilities." *Journal of Psychosocial Rehabilitation and Mental Health* 2 (2): 113–124. doi:10.1007/s40737-015-0036-3.

Tran, Viet-Thi, Caroline Barnes, Victor M. Montori, Bruno Falissard, and Philippe Ravaud. 2015. "Taxonomy of the Burden of Treatment: A Multi-Country Web-Based Qualitative Study of Patients with Chronic Conditions." *BMC Medicine* 13 (1): 1–15. doi:10.1186/s12916-015-0356-x.

Trevelyan, Christopher, Rory Crath, and Adrienne Chambon. 2014. "Promoting Critical Reflexivity through Arts-Based Media: A Case Study." *British Journal of Social Work* 44 (1): 7–26. doi:10.1093/bjsw/bcs090.

Tronto, Joan C. 1993. *Moral Boundaries: A Political Argument for an Ethic of Care*. London: Routledge.

Verkerk, Marian A. 2001. "The Care Perspective and Autonomy." *Medicine, Health Care and Philosophy* 4 (3): 289–294. doi:10.1023/A:1012048907443.

Wallenburg, Iris, Anne Marie Weggelaar, and Roland Bal. 2019. "Walking the Tightrope: How Rebels "Do" Quality of Care in Healthcare Organizations." *Journal of Health Organization and Management* 33 (7/8): 869–883. doi:10.1108/JHOM-10-2018-0305.

Watson, Jasmin, Ellie Fossey, and Carol Harvey. 2019. "A Home but How to Connect with Others? A Qualitative Meta-Synthesis of Experiences of People with Mental Illness Living in Supported Housing." *Health & Social Care in the Community* 27 (3): 546–564. doi:10.1111/hsc.12615.

Webber, Martin, Hannah Reidy, David Ansari, Martin Stevens, and David Morris. 2015. "Enhancing Social Networks: A Qualitative Study of Health and Social Care Practice in UK Mental Health Services." *Health & Social Care in the Community* 23 (2): 180–189. doi:10.1111/hsc.12135.

Wilken, Jean Pierre, Zsolt Bugarszki, Karin Hanga, Dagmar Narusson, Koidu Saia, and Marju Medar. 2018. "Community Orientation of Services for Persons with a Psychiatric Disability. Comparison between Estonia, Hungary and The Netherlands." *European Journal of Social Work* 21 (4): 509–520. doi:10.1080/13691457.2017.1289896.

Williams, Charmaine C., Marlene Almeida, and Yuliya Knyahnytska. 2015. "Towards a Biopsychosociopolitical Frame for Recovery in the Context of Mental Illness." *British Journal of Social Work* 45 (suppl 1): i9–i26. doi:10.1093/bjsw/bcv100.

Wulf-Andersen, Trine. 2012. "Poetic Representation: Working with Dilemmas of Involvement in Participative Social Work Research." *European Journal of Social Work* 15 (4): 563–580. doi:10.1080/13691457.2012.705261.