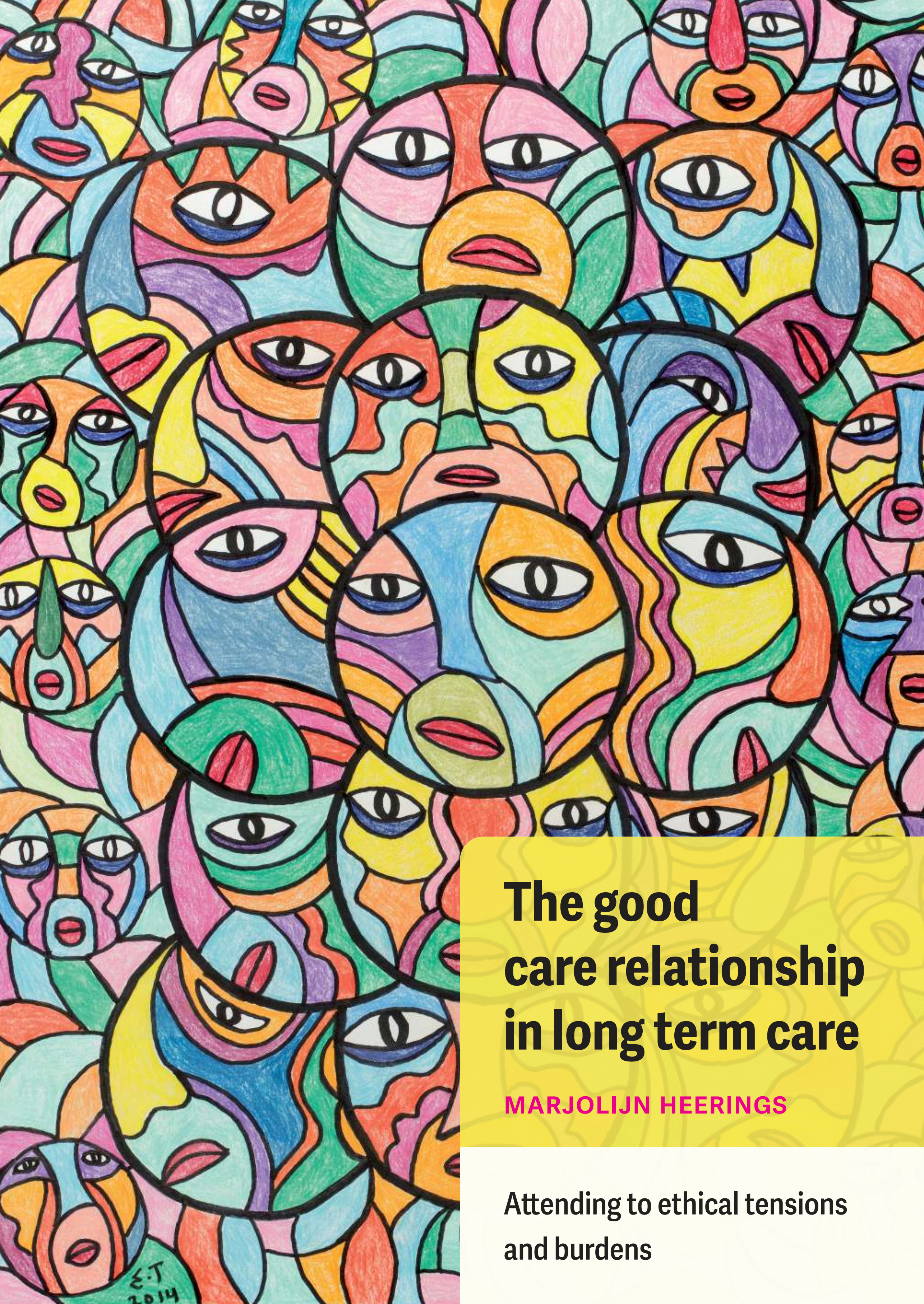

The good care relationship in long term care

MARJOLIJN HEERINGS

Attending to ethical tensions and burdens

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Colofon

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THE GOOD CARE RELATIONSHIP IN LONG TERM CARE
Ethical tensions and burdens

DE GOEDE ZORGRELATIE IN DE LANGDURIGE ZORG
Ethische spanningen en belemmeringen

Thesis

To obtain the degree of Doctor from the
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Table of contents

Chapter 1

Introduction: ethical tensions and burdens in supported independent living

Alone[1]

Client, supported independent living

when you're alone
that's when paradise is distant

people tell me you should want
to live independently
not having to share
everything at your own pace

But what's so joyful about having privacy?

I am bored to death
I do everything alone
cook alone
shower alone
eat alone

and why?
because it's the rule?
because it's cheaper?

just give me a group home
with a bit of arguing
that's what's fun
my roommates were my friends
we got by with each other

---

[1] The scripts placed as intermezzos in this thesis are based on ethnographic fieldwork in supported housing and home care services performed as part of this thesis. They are developed through a participatory process with clients, professionals next of kin, and policy makers in the participating care organizations and theatre Babel Rotterdam: in particular the theatre playwright Erik-Ward Geerlings, theatre director Paul Röttger (see chapter 6 for an elaboration on this process). Jonas Bal translated the Dutch scripts into English. These scripts are performed on camera by actors of Theater Babel Rotterdam. The total of 42 of these films can be viewed here (https://www.eur.nl/eshpm/onderzoek/als-je-het-ons-vraagt/videos).

and now I have to be grateful because I *could* leave?
No I had to!

a human isn’t made to be alone
not me

and now –?
people don’t just start talking to me
should I just start using dating apps then?

Risks

Professional, home care services

There are those who don't want to shower
for whatever reason
sometimes it's too early or too late, or they're t0o tired, or the water is too wet
there are those who don't want to be bandaged because they're going out
and there are those who want to do everything themselves
who don't want me to give them their medicine
even if that could harm them
Most of those people are very prone to memory loss.
what happens when they forget?
or drop their pills without noticing?

I always stay patient and civil,
and try to make them aware of the risks they're taking:
blemishes when someone doesn't shower
or a hypo when you don't eat properly
but that doesn't always sit right,
it asks a ton of patience
and a very strong sense of self-control
yet, sometimes I just make them a meal,
even though that's not my responsibility

It's not just about health
You want them to have some energy left for different things
so then you try to help
even if someone doesn't want that
Then, I try to make clear
that it's more important to see family, do enjoyable things
than making a point of showering themselves

My work isn’t always well-received
but I try my hardest
until one day it really can’t go on anymore
some people don’t leave their beds
are confused, drink and eat badly
and even then don’t want to go to a nursing home
yet I still continue to provide care…

INTRODUCTION

The care relationship in long term care is a vital part of good quality care [1-4]. Therefore, insight into the quality of this relationship and how it can be improved is important for improving quality of care. In the last decades, the values considered important in national and organizational policies in long term care have changed. Values related to autonomy and social inclusion have gained prominence [5-10]. The emphasis on these values raises numerous ethical tensions within the care relationship as illustrated in the scripts above. Following client choices may for instance involve health risks, and participation in the community can lead to risks of abuse [11-14]. Moreover, clients experience negative consequences from the way these values are practiced. Examples of such negative consequences include facing stigma and loneliness when the value of fostering independent living is implemented through motivating clients in group homes to move to independent settings, as also illustrated in the script above [15,16]. For gaining insight in the quality of the care relationship and how it can be improved, these ethical tensions need to be attended to.

In this thesis I explore the cases of supported independent living for people with serious mental illness (SMI) or an Intellectual disability (ID) and older persons receiving home care. These are interesting cases for developing insights into the ethical tensions and burdens in the care relationship as in these settings an emphasis is laid on de-institutionalization, which heightens the importance of autonomy related values and social inclusion [13,17,18]. These are thus places and practices in which ethical tensions are likely to be foregrounded.

Below, I first discuss the policy background to those ethical tensions and the lack of guidance that professionals are confronted with. Then I explore some theoretical perspectives that can be helpful in articulating ethical tensions in healthcare practices, before I move to introducing the research questions of and methods used for the research reported in this thesis.

Policy trends

Longterm care has changed significantly in the last century. Until quite recent, longterm care was provided in state institutions. Criticism on the quality of care in such institutions gave rise to a shift to community-oriented care [19,20]. For people with SMI or ID such de-institutionalization policy included a move to group homes and independent living with out-patient support [21]. For older people de-institutionalization includes a focus on aging in place: postponing nursing home care by providing care at older persons homes for as long as possible [17].

De-institutionalization policy is accompanied by other trends such as personalization of care [22-24], empowerment of clients [8,24-26] and a focus on social inclusion [7,27-30]. These trends change the values underlying the care relationship in supported independent living and home care services. Values such as self-determination, fostering an independent lifestyle and community participation have gained prominence as a result (an overview of the Dutch terms for these values and policy trends can be found in appendix 1). Recent policy reforms in the Netherlands have reinforced these values into care practices for people with serious mental illness, an intellectual disability, or older persons (see box 1 for an overview of these reforms).

Box 1. Recent policy reforms in the Netherlands

Recent policy reforms in the Netherlands have inscribed values at the level of individual care, which include: participation; self-determination; an independent lifestyle; living independently in the community as long as possible and more quality of life (SCP, 2018). As part of these policy reforms, the general law on exceptional medical expenses (AWBZ) was divided into three different laws: the Social Support Act (WMO), funded through the municipalities; the healthcare insurance act (Zvw), funded through health insurance companies; and the Long-term care act (Wlz), funded through regional health insurance offices. Supported independent living for people with SMI is generally funded through the WMO; long term care needs including people with ID is funded through the Wlz (which from 2021 is also applicable to people with SMI and long-term care needs) and home care services are generally funded through the Zvw. Besides values that are incorporated in these acts that impact the individual level, these transitions enact several values at the system level as well: more community participation and social inclusion, larger involvement of societal actors in people's care and financial sustainability [31].

Values underlying the care relationship

In the context of the above-mentioned policy trends, today dominant ideas on good care include attuning to clients' needs and goals for care. This makes self-determination an important value in the care relationship. Professionals foster self-determination by involving clients in decision making on their care planning, for instance through developing a personal care plan [32-36]. Furthermore, respecting clients' choices regarding 'small' aspects of daily live is important in promoting self-determination [37,38]. Integrating care of different providers such as supported living, treatment and support offered by other community organizations furthermore is expected to attune care better to client's needs [39].

Current ideas on good care also encompass care that builds on clients' strengths and limits dependence on professional services. Fostering an independent lifestyle is thus an important value in the care relationship. Professionals support clients with SMI or ID in developing an independent lifestyle by teaching practical skills, supportive conversation and providing space to practice. This support is directed at different aspects of daily life including cooking; grocery shopping; keeping personal hygiene; budgeting; doing administration; structuring daily activities and developing a vocation such as following an education or doing sheltered, volunteer, or paid work [40,41]. For older persons this support focuses on enabling older persons to do things themselves as much as possible and to continue living at home [42-44]. Older persons are also expected to continue or develop activities in the community such as seeing family and friends, doing their own shopping or visit community centers [45]. Nurses and aides support older persons with medical care such as wound care; changing colostomy bags; administering medications and personal care such as support with changing stockings; dressing and showering [46].

Professionals supporting people with SMI, ID or older persons are also expected to strengthen informal networks which can support clients and limit their dependence on professional support. Such networks are further important for social inclusion, as in these networks clients can develop or maintain valued social roles such as family member or neighbor [47-52]. Furthermore, professionals are expected to foster social inclusion by shaping the context clients live in (e.g. neighborhoods, places of work or spending leisure time) to better attune to clients' needs and capabilities and contribute to their flourishing and belonging [7,9,15,53].

Generally, values such as self-determination and an independent lifestyle are incorporated in current policies and quality instruments. For example, one can find them in government and stakeholder (e.g. patient and family) associations policy documents regarding people with SMI [54-57]; regarding people with ID [58-62] and regarding older persons [63]. Such descriptions of good care are further found in quality instruments that form the background to professional support such as professional competency profiles of social workers [64,65] and nurses [66,67], quality frameworks and quality standards [46,68-72] and descriptions of good practices such as regarding promoting self-determination [73], independence [74,75] and personalized care [76,77].

Cesspit

Mother of client receiving support with independent living

It’s not me that’s the problem
I always answer
I always give free advice
even if it’s the middle of the night
those care workers can always call me
they have my number

and when they call me they could also just ask
what it’s like for me

and I would also gladly hear from them about what’s going on
not just when there’s a problem

but most of the time care workers don’t even call me
and Ivo has to do it himself
just like last time, he had to go to the hospital
for an examination of his abdomen
and there he stood – all alone – in a labyrinth
that boy didn’t have a clue which way to go
then I had to direct him to the right department
but naturally I wasn’t prepared for anything like that at all
well of course he arrived too late
that could be arranged differently right?

and I do plenty
I take Ivo to the volleyball twice a week
practice, games – of course that’s really great for him
but when I see what’s growing on the wall behind his bed
and I see that all the food in his fridge is well past the shelf life
that’s when I really start to doubt all those care workers

I realize that they don’t have all the time
and that at most they’re doing the most necessary
it’s all a matter of cutting down everything
and it’s also becoming even less

but do I have to be their cesspit then?

Mostly
I just want to
sustain being his mommy too

Ethical tensions and burdens in supported independent living

As the scripts above illustrate, the emphasis on values such as self-determination, an independent lifestyle and community participation raises numerous ethical tensions within the care relationship. Moreover, clients experience burdens from the ways these values are practiced by professionals or inscribed in organizational structures. These ethical tensions and burdens are important to consider as they show the complexity of professional practice in the context of the policy trends described above. Explicating ethical tensions and burdens is a first step in improving the quality of care while responding to the complexity of the care relationship in long term care.

Ethical tensions

Ethical tensions emerge in different ways in care practices. Previous research has highlighted tensions between respecting autonomy and preventing harm, for instance when clients make choices that harm their health [78,79]. The potential risks – and thereby these ethical tensions – multiply as clients move to live independently or participate in the community [13,80,81].

Moreover, ethical tensions emerge as different stakeholders caring for the same client, including those clients themselves, differ in their views on good care [82-84]. Such tensions multiply in the context of recent policy trends emphasizing the participation of informal carers in care for people with SMI, ID or older persons and the integration of care offered by different care and community organizations: as more people are involved in care for the same clients and they are expected to collaborate. For example, as is illustrated in the script ‘Cesspit’, some parents experience negligence when a client’s household does not meet their standards of hygiene. However, for professionals not interfering may be a way to practice the value of self-determination as they respect how clients want to live.

Ethical tensions also emerge as a result of the values inscribed in organizational structures which may not align with what professionals, clients or family members consider good care [85,86]. This is specifically the case in the current Dutch policy context as a result of funding arrangements. For instance, care goals have to be developed early on in the care process to be accountable to municipalities. Organizations adhere to this by demanding from professionals to create personal care plans early in the care process. However, for professionals, good care sometimes requires building a relationship first through which clients develop a self-understanding and goals emerge in due time [87]. Their relational understanding of fostering self-determination is thus in tension with an organizational structure requiring them to act differently. These examples show ethical tensions are manifold in supported independent living and home care services.

Burdens

Next to ethical tensions experienced by professionals or informal carers, clients can experience burdens from the way care is practiced or organized in attempts to bring about the values central in this thesis. For instance, care aimed at independence may lead to overestimation and place demands on persons that are too high. This in turn might lead to emotional disturbances such as anger and aggression and even relapse in functioning [88]. For people with SMI, focusing on recovery in merely optimistic terms may responsibilize people when they are not able to live up to this ideal [89,90]. Similarly for older people emphasizing participation and active citizenship does not reflect the experiences of some frail older persons [91]. Regarding living independently, some people with ID and SMI and older persons experience loneliness and social isolation and receive limited support from staff in alleviating this [16,92-95]. These examples show clients not only experience benefits from care aimed at client empowerment or social inclusion, burdens are experienced as well. These need to be attended to in order to improve the quality of care.

Policy silence on ethical tensions and burdens

Ethical tensions and burdens with practicing values such as self-determination, an independent lifestyle or community participation do not figure much in policies that form the background to professionals' work. This can be understood as policy silence [96,97] as these tensions and burdens remain implicit.

Policy silence on ethical tensions and burdens is problematic for several reasons. First, it fosters a context in which the work of professionals focused on attending to these tensions remains invisible and by consequence without support [98]. For clients, the consequence of policy silence entails their complex needs are in danger of not being sufficiently addressed [99].

Policy silence of value tensions in policies

One way in which policy silence emerges is when external parties, such as insurers, municipalities and supervisory bodies, foreground some values in their policies and don't negotiate these well with other values important to clients, professionals or informal carers. Such a policy silence for instance is apparent between the value of fostering an independent lifestyle and social inclusion. This for instance is highlighted by the client association for people with ID. It notes how policies of municipalities often are phrased in the language of recovery, emphasizing a strength-based approach. This can overburden people with ID who benefit much more from developing places of belonging in the community [100].

Another example entails a tension regarding the value of participation and the role of family members. The policies of payers and supervisory bodies foreground fostering an independent lifestyle and fostering informal care over professional care. This is in tension with the need of professional services to prevent family members from becoming overburdened as they often already provide a lot of informal care. Moreover, family representative organizations put forward the value of fostering family relationships in their 'normal' role of parent, partner or sibling over the role of informal carer [101]. In the script 'Cesspit' above, this is illustrated by a mother who feels she is forced into the role of informal carer as her son is left too much to do independently, while she mostly values her role of just being a mum.

These examples highlight how value tensions accompanying the focus on self-determination and independent living are silenced by their one-sided emphasis in policy and regulation.

Policy silence in quality frameworks, guidelines, and competency profiles

Ethical tensions are often not acknowledged in quality instruments that are supposed to support professionals in bringing about good care in practice either.[2] For example, organizational complexities with fostering certain values remain unaddressed.

In the quality framework for home care services, it is stated that professionals need to support self-determination regarding the time clients would like to receive care in order to align care to the personal life-rhythm of the client [46]. This however does not attend to the organizational complexity nurses and aids face, as many older persons prefer to be showered and dressed early, making it very difficult to organize care in a way that attends to these preferences. As a consequence, professionals may feel that quality frameworks place unrealistic demands.

Some of the quality instruments do describe different, possibly conflicting, values such as self-determination and preventing harm. However, these tensions remain implicit nonetheless as these are discussed in separate paragraphs. For example, the quality framework for home care emphasizes the need to:

> "Care professionals need to have a strong orientation on quality of life and on what clients can do independently. They need to foster independence and self-determination by stimulating use of own abilities and those of the network." (Stuurgroep Kwaliteitskader Wijkverpleging, 2018, p. 10).

In a different chapter the framework also states safety needs to be addressed. This separation means possible conflicts between these values – which in fact often arise in practice – remain unaddressed.

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[2] I illustrate the ways in which tensions between values remain implicit in quality instruments by analyzing the quality frameworks for people with ID and home care services and -as no such national quality framework for supported living for people with SMI exists- the competency profiles and guidelines for professionals caring for people with SMI.

In other cases of policy silence tensions are taken up, however only in limited sections of the total document. For instance, in the quality framework for people with ID, the need to sometimes limit self-determination to prevent harm is explicated, as is illustrated in the following excerpt.

> "*Sometimes it is needed to, from a professional perspective, to limit self-determination to protect the health of the client or prevent harm to others"* (Stuurgroep kwaliteitskader gehandicaptenzorg, 2017, p. 10).

In the remainder of the quality framework, however, values such as self-determination, fostering an independent lifestyle and community participation are foregrounded without addressing their tensions.

Policy silence also occurs when limited guidance is given on how professionals should handle tensions, in the rare occasions these tensions are mentioned. This leaves room for professional discretion which can contribute to personalized and situated care [102]. However, no guidance is given on how professionals could use this professional discretion. The quality standard for support for people with SMI for instance states:

> *There needs to be attention to possible tensions. For instance, in situations where the professional perspective is in tension with the clients perspective […] this can emerge in situations with risk-taking (dignity of risk) […] Self-determination is an important priority in such situations. Self-determination entails the persons gives direction to their own lives and goals of care as much as possible, based on the client's own value system …* (Akwa, 2017b, p.26).

This leaves important questions unexplored: When should it be considered no longer possible for clients to have self-determination? What are acceptable limits of risk-taking and who determines those? Supporting professionals in attending to value complexity in the care relationship requires tensions to be explicated and guidance provided on how professionals can handle these.

In sum, ethical tensions and burdens are not well attended to in policy documents aimed at supporting professionals in providing good care. Tensions remain implicit as values are discussed separately; different values are brought together but without explicating their tensions or a single value is already foregrounded. Even when tensions between different values are mentioned, policy guidelines do not give procedural advice on how to handle them. Besides not attending well to the ethical tensions professionals face when promoting self-determination, and independent lifestyle and community participation, the burdens clients experience also are not responded to. These burdens, are almost only foregrounded by more critical scholars in the public domain e.g. [13,103]. These critiques however are not integrated in quality frameworks, competency profiles or guidelines. Current policy documents forming the background to professionals work thus do not support them sufficiently in attending to the value complexity in the care relationship. This begs the question how guidance can be given to professionals on how to use their discretionary space to handle ethical tensions and burdens.

Attending to ethical tensions and burdens in the care relationship

In the scientific and professional literature solutions for fostering a good care relationship proposed include the suggestion a good relationship comes about through 'determinants' such as listening, show interest and respect, have compassion and equality in the relationship [104,105]. Such suggestions also silence the value complexity in long-term care. Illustrative of this, a client representative stated: "If professionals would just listen to clients, these complexities would be resolved," in response to a journalistic article which delineated focus of this research project on ethical tensions and burdens [106]. Such emphasis on listening and putting clients' needs central stage is also present in care models that professionals can draw on to provide good care such as recovery-oriented care [107]; strength-based approaches [10]; person-centered care [22] or presence [108]. Listening and understanding clients' needs and wishes are surely important for good care. In fact, many clients, professionals, and family members alike have stated this as important for a good care relationship in my research. However, I do argue it is not enough for responding to the ethical tensions and burdens in care relationships as determinants like listening won't make the tensions and burdens mentioned above magically disappear. The literature does provide important theoretical concepts that can help to better understand and attend to these complexities. I will now turn to these.

Tronto's phases of good care

Scholars in the ethics of care, such as Joan Tronto, have offered useful insights in understanding the complexity of the care relationship and dealing with ethical tensions. In care ethics, the situatedness of what is good care is stressed as in each situation something different might be needed [109]. This sets it apart from ethical theories that take a more top-down approach by reasoning from principles for assessing good care [110]. For good care it thus becomes important to have good care relationships, as through such relationships the needs for care can be understood. Tronto's conceptualization of good care provides insight into how good care can come about in such situated relationships. Tronto has conceptualized good care as a process with several stages, each with its own moral qualities. Tronto's conceptualization of care and related good care relationships aligns with the focus of personalized care in listening to clients' needs. However, instead of putting the client central, Tronto's conceptualization puts the *care relationship* center stage [111]. This aligns with the focus of this thesis on both the professional experience, the informal carer experience, and the client experience.

The first stage Tronto describes is *caring about*, for which the moral quality attentiveness is vital. This stage is about recognizing and attending to the need for care. The second phase is *taking care of*, here the central moral quality is responsibility; that is, taking one's responsibility to act on the needs of the other is central. The third phase is *care-giving*, with the central moral quality of competence; the actual care giving has to be done in a competent manner. The last phase is *care-receiving* with as central moral quality responsiveness; this is about attending to the way a person in need of care has received the care offered. For instance, whether the care fitted the needs and other aspects of evaluating care [111].

In her more recent book *Caring Democracy*, Tronto helps to understand the complexities in the care relationship better by paying attention to the institutional context of this relationship. She argues how institutions incorporating neo-liberal values such as choice and individual responsibility do not foster caring relationships and leave people with the experience of not being able to trust their needs are responded to. Instead, institutions should foster the value of care. This she incorporates in her conceptualization of care by adding a fifth stage: caring with, for which the moral qualities solidarity and trust are important. This addition points to the importance of the organizational and policy context in bringing good care about [112]. This aligns with the focus of this thesis which also places the care relationship within the organizational and policy context.

'Tinkering': attending to the value complexities in the care relationship

The work of Tronto helps to recognize the complexity of the care relationship by pointing to the situatedness of what is good care and what is important in bringing about good care. Science and Technology Studies adds to this by unpacking this complexity further and helping to identify how professionals, clients and informal carers can provide good care by attending to these complexities by: 1) including a focus on material arrangements; 2) problematizing the focus on needs of clients and 3) explicating the experimental status of 'good' care practices [113,114].

Central to Mol et al.'s [113] account on good care is the notion of 'tinkering'. Tinkering is about experimenting with different care practices in which different values are brought together. These experiments need to be attentively followed and care practices adjusted accordingly to provide better care. As there is never a static solution because situations are ever in flux and bring new tensions to the fore, tinkering needs to be a continuous process.

Mol. et al.[113] deliberately use the notion of 'goods' instead of 'values' when talking about the tensions in care practices requiring tinkering.[3] This way they emphasize in situated practices many things come to the fore that are in tension and need to be assembled in a care practice, which transgresses the category of value alone. For instance, the material arrangements in which care takes place [115]. This can be illustrated by an example about care around eating in nursing homes. Here values such as having choice about what foods to eat, taste and coziness of eating at the same table with the pans in the middle need to be brought together. This includes all types of material arrangements, such as trolleys to dispense food and organizational structures such as the chain in which food is prepared in a separate kitchen and brought to the nursing home where it is heated up. To provide good food in the nursing home, professionals need to experiment with care practices in which the different values at stake are brought together [116]. This inclusion of material arrangements in the tinkering process thus makes this account suitable to address ethical tensions emerging from a mismatch with the organizational context.

Besides responding to the tensions of multiple values, Mol et al.'s account further contributes to Joan Tronto's stages of care by allowing for an understanding of clients' needs as complex. This is captured in the concept of 'multiple ontologies'. Ontology is about what things are. Multiple ontologies thus points to different orderings of reality existing at the same time. Mol develops the example of atherosclerosis, which in the hospital takes many different forms. For example, in some part of the hospital the veins of patients are inspected, enacting the disease in a particular way namely as a problem narrowing of veins. While in other parts walking takes central stage, which enacts the disease as a problem of loss of blood pressure [117]. While Mol mostly addresses multiple ontologies in terms of diseases and bodies, it can be inferred that different ontologies exist of 'who clients are' and relatedly what their needs are. This is also highlighted by Pols in her description of certain ways of washing clients, each way attending to different needs and foregrounding different values. For instance, focusing on choice making, independence or relatedness to others. This way the same client can be enacted differently through the practice of washing [118]. Tinkering is thus about bringing together different values and about bringing together their related ontologies of clients. Tinkering also emphasizes the experimental status of solutions and thereby the need for attentively following these and adjusting accordingly.

Mol et al.'s account of good care is thus specifically useful for attending to the ethical tensions as set out so far. However, it needs to be expanded in several ways. In supported living clients are often in multiple care relationships. They receive care from different professionals in the

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[3] While Mol et al. use the term 'goods' to broaden up the debate of what needs to be negotiated in practice to bring about good care, in valuation studies -another important part of my theoretical outlook- the term 'value' is foregrounded to address a broad spectrum of worth objects or practices can attain. Here the term value thus also stretches beyond merely ethical values. I will use the term 'value' in this same broad sense throughout this thesis.

same team, from different organizations and from informal carers too. How does tinkering work in such contexts? This is explored in chapter 3 and 5. Moreover, for responding to the ethical tensions and burdens of clients, a better understanding of these is needed. Which ethical tensions and burdens are experienced in the care relationship in long term care? These questions are explored in chapter 2 and 4.

Another question which remains is how the values put forward in the policy context influence tinkering. In the next section I will elaborate on the concept of valuation through which the dynamic relationship between tinkering and the policy context can be further understood.

Valuation: tinkering within a policy context

The ethical tensions and burdens in the care relationship take shape within the policy context in which different values regarding good care in supported independent living and home care services are foregrounded. Providing good care through tinkering is shaped by this context. The notion of 'valuation regime' as developed in valuation studies helps to better understand the dynamic relationship between values put forward at the policy level, the level of organizational structures and professional practice [119,120]. Combining the concepts of valuation regimes and tinkering highlights first how the tinkering process is at risk for leaving out values important to clients, professionals and informal carers. Second, it enables further understanding of how explicating tensions contributes to good care.

Regimes of valuation

Regimes of valuation shape what professionals, clients and informal carers value in the care relationship. Actors are being socialized into understanding entities, in this case care, as having certain types of worth through regimes of valuation. These regimes include the discursive, institutional, and material context in which values are produced and attributed [120].

Examples of discursive contexts in which professionals are socialized into understanding values such as self-determination and an independent lifestyle as important for good care include the courses they follow to develop their competencies or vision statements and other communications of the organizations they work for. Material contexts are also part of regimes of valuation. For instance, group homes and clients living independently in the neighborhood socialize professionals and clients alike in what is good in care: social inclusion as opposed to institutionalization.

These contexts on an organizational level are shaped by discursive and institutional contexts on the national level. Professional competency profiles, quality frameworks or outings from stakeholder organizations and professional associations delineate what can be considered good about care. They also further shape actors understanding of how they should organize or assess care. For instance, managers on the organizational level take notice of such policies and inscribe their related values in the organizational structures they help design, for example implementing a personal care plan. This shapes the daily practice of professionals as through this organizational structure they are obliged to align their support to the goals stated in the care plan. What the concept of valuation regimes highlights is how this also further socializes them into understanding values such as self-determination as important in the care relationship. This way the value of self-determination is also further consolidated as part of what is considered good in care relationships.

In valuation studies, valuation practices are also understood to be an important mechanism in bringing about certain values. Valuation practices include the ways in which entities are assessed such as rankings, audit procedures and the like [121]. In the example of the personal care plan, organizations providing care for people with ID and long-term care needs are assessed on whether each client has a personal care plan. This assessment is performative as it motivates organizations to increase efforts to have a personal care plan for each client and further fortifies the importance of self-determination for good care.

The values put forward by professionals, clients and informal carers when developing care practices are thus shaped by the values put forward in the policy context. This highlights certain risks within the tinkering process as values important to clients, professionals or informal carers not part of the dominant valuation regimes could be less likely to be assembled in a care practice. This begs the question on how such values can be attended to in order to bring about good care. This is addressed in chapter 5.

Ethical tensions as drivers for innovating care practices

Although actors are influenced by valuation regimes, they are not mere regime followers but have agency in shaping their practices as well. This also mitigates part of the risk of the tinkering process being colonized by regimes of valuation. Regimes of valuation are understood as dynamic. This recognizes actors' agency to creatively engage with these regimes and comply, resist, or negotiate and thereby change them [119,120]. Professionals may thus engage in care practices that enact these values differently from how they are expressed in these regimes of valuation. Such creative engagement is stimulated in a heterogenous context in which plural valuation regimes exist as opposed to the homogeneous contexts of single valuation regimes [122]. In supported independent living and home care services, the valuation regimes can be considered plural as they consist of different values that may be in tension. However, as I have argued, these tensions are often not explicated in policy documents and quality instruments.

Tinkering attends to how care practices can be improved by responding to tensions between values and experimenting with care practices in which these are assembled. Understanding tinkering in the context of valuation regimes thus highlights how tinkering is a continues process of innovation of care practices, driven by the tensions emerging in the context of heterogenous valuation regimes. Learning from tinkering practices in turn can be translated to these valuation regimes to make them more attuned to the value tensions and burdens experienced by professionals, clients and informal carers.

Improving the quality of the care relationship by attending to its value complexities

How good care can be improved by attending to its value complexities not only places demands on professionals. Organizations in supported living and homecare services need to make the time to reflect on ethical tensions and burdens. Moreover, they need tools to support such reflection and translate lessons learned into quality improvement. In this section, I identify the following leading principles for such a method: critical reflection, deliberation and co-design. Current quality improvement practices do not sufficiently incorporate these principles as I will show below. Therefore, I conclude, a novel method is needed which I developed as part of this thesis. The development of this method is elaborated on in chapter 6.

Principles for a quality improvement of the care relationship method

In order to support clients, professionals and informal carers in responding to the ethical tensions and burdens described above, tensions and burdens need to be explicated first. This can be supported through *critical reflection*. Critical reflection takes reflection beyond merely explicating tensions between values part of valuation regimes such as self-determination, independent lifestyle and safety. Through critical reflection, the meaning and ways of practicing such values can be questioned and different values important to clients, professionals and informal carers come to the fore [123]. Critical reflection furthermore heightens awareness of organizational structures influencing care practices [124]. Critical reflection is thus an important element for a method to improve the quality of the care relationship.

Second, the value complexity in long-term care includes a divergence between different professionals, clients and informal carers on what is good care. Therefore, a quality improvement method for the complex care relationship needs to incorporate a process through which these differences er explicated and mutual understanding on what is needed to provide good care is cultivated [112]. For this, *deliberation* between clients, informal carers and professionals is needed.

Last, deliberating different values is not enough to improve care; translating the results of this process to quality improvement is needed. This needs to be a *co-design process* including clients, informal carers and professionals in order to have different values assembled in the care practices designed [113]. Co-design can also address the ethical tensions emerging as organizational structures that incorporate values in ways that do not align with what professionals consider good care or that bring about burdens to clients. Regarding such challenges, co-design provides a practice-oriented approach through which such structures can be changed [125,126]. Integrating a process for co-design fosters quality improvements to materialize the different views of clients, professionals and informal carers to be assembled in care practices. Co-design should thus be incorporated in a method to improve the quality of the care relationship responding to its value complexities.

The need for a novel method for critical reflective co-design

A method incorporating critical reflection, deliberation and co-design aligns with current trends focusing on organizational learning in quality improvement and accountability in the Dutch context and elsewhere. Central in the quality frameworks of long-term care for people with ID and homecare is an emphasis on organizational learning[4] [46,68]. Organizational learning emphasizes reflection of professionals on their practice and empowering them to improve their practices. While organizational learning does imply more reflective spaces and involvement of professionals in quality improvement, current methods for enabling organizational learning do not suffice in attending to the ethical tensions and burdens.

Quantitative input and organizational learning on the complex care relationship

Currently, much quantified quality information is collected by care organizations in long term care. Collected quantitative quality information includes the client experience with services (PREM-measures) or the outcomes reported by clients (PROM-measures). In home care services for instance the 'PREM Wijkverpleging' questionnaires are an obligatory part of the quality framework for accounting for quality of care [46]. Similarly, for people with SMI the PREM messure CQI-beschermd wonen is advised to be used by the institute providing guidance to municipalities on how to organize accountability (VNG) next to Routine Outcome Monitoring (ROM) also promoted by the institute on quality of care in the mental health sector Akwa [128]. Also, in case of care for people with ID, client experiences need to be assessed although a range of different instruments is available for this (e.g. Personal Outcome Scale; Quality Cube and Ben ik tevreden?) [129]. This type of information however is in itself unfit for improving quality of care attending to the value complexities of the care relationship for several reasons.

First, as questions are pre-set, these instruments leave little room for clients to voice concerns that are not part of the questionnaire, such as their experienced burdens [130,131]. Moreover, such questionnaires are not sensitive to the tensions between values that make care relationships

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[4] For people with SMI with long-term care needs a quality framework is in the making which also is likely to include organizational learning as it is molded upon the quality framework of people with ID [127].

complex. As each question addresses a single subject, such questionnaires leave little room for voicing complexities related to value tensions [116,132]. Moreover, these questionnaires put clients' experiences central, but do not incorporate the experiences and perspectives of good care of professionals and informal carers. Questionnaires focusing on the experiences of these other actors are sometimes also administered. However, such data does not attend to the tensions between the different perspectives. Furthermore, the numerical values that are often the outcome of these questionnaires, provide limited insight into what needs to change to improve care [133-135]. Therefore, this type of quantified data provides limited input for organizational learning attending to the complexities in the care relationship.

Qualitative or narrative input for organizational learning on the complex care relationship

Partly in response to the limitations of quantative data, using qualitative or narrative information gains prominence in healthcare [136,137]. This includes clients' or professionals' stories or observations of care moments. These narratives allow for the expression of differing values, emerging tensions, and sense-making of different actors [130]. Thereby narrative information has more potential in showing the ethical tensions and burdens in the care relationship and fostering learning while responding to these complexities. Different methods have been developed that foster learning based on such qualitative information. However, existing methods do not incorporate all of the three key principles I described: critical reflection, deliberation and co-design nor include clients, professionals and informal carers equally in these activities.

Some methods focus on client's experiences at cost of professional or informal carers experiences. For instance, methods for client involvement such as the 'Partner benadering' [138] or 'Spiegelbijeenkomsten' [139] provide means for clients to narrate their experiences and being involved in improving services. In such methods professionals are involved as clients at one point also share these experiences with them. However, ethical tensions experienced by professionals themselves are not reflected on in these methods. Other narrative methods focus more on professionals' ideas on quality of care, such as methods available for team reflection. While some of these do incorporate client-experiences in some ways, most of them do not involve clients, professionals and informal carers equally (e.g. Beelden van Kwaliteit) [131]. Moreover, the process of quality improvement in many methods, if taken as a next step at all, is not co-designed. To conclude, available methods do not have a specific focus on improving the quality of the care relationship. Methods that do have such focus, such as those instruments part of the 'Horen, zien en Spreken'- toolbox, do not attend to the ethical tensions and burdens in the care relationship, do not foster a deliberative process between clients, professionals and informal carers nor involve them in co-design [140].

One quality improvement method does involve clients, professionals and informal carers in narrating their experiences and reflecting on them, deliberating their views on good care and involves them equally in co-design of improvements. This is Experience based co-design (EBCD) [126]. This method has been applied with people with SMI, ID and older persons [141-145]. However, EBCD currently does not focus on ethical tensions or burdens in the care relationship in long term care. To make this method suitable for quality improvement while responding to value complexities thus would require further development of this method. This is taken up in this thesis (chapter 6).

Aim and research questions

I have argued that the care relationship in supported living and home care services is complex as ethical tensions and burdens emerge with fostering self-determination, an independent lifestyle and community participation. This complexity is often not addressed in policies forming the background to care practices nor in practices for assessing or improving the quality of care. Narrative methods that include a process of critical reflection, deliberation and co-design are an interesting alternative. However existing methods need to be further developed.

The main research question of this thesis is:
How can the quality of the care relationship in long term care be improved, responding to its value complexities?

The aim of this thesis is fourfold and is aligned to four sub-research questions:

To gain insight into the complexity of the care relationship I ask:

1. *Which ethical tensions emerge in the care relationship in supported living and home care services against the backdrop of values such as self-determination, fostering an independent lifestyle and community participation?*

To gain insight into the burdens for clients and into positive consequences for clients of good care I answer the question:

2. *Which consequences, such as burdens for clients, emerge from the complex care relationship?*

To gain insight into how ethical tensions emerging in the context of valuation regimes can be attended to in the collective care relationship, I ask the question:

3. *How can good care, responding to ethical tensions, be practiced in collectives in the context of dominant valuation regimes?*

To conclude, to develop a quality improvement method that attends to the ethical tensions and burdens in the care relationship I answer the question:

4. *How can EBCD be adjusted to incorporate critical reflection, deliberation and co-design to supports clients, professionals and informal carers in responding to the value complexities in the care relationships?*

METHODS OF RESEARCH

Case selection

These questions were explored in an extensive participatory research in three care teams in two organizations in a large city in The Netherlands, covering the sectors supported independent living for people with ID, people with SMI and home care for older persons. The participatory research included two teams of a community housing organization (CCO): a team providing supported living to people with ID and a team providing such support to people with SMI. The third team was a home care team in an organization providing elderly care in the same city in the Netherlands (HO). These cases were selected as they offer a diversity of care practices in long term care. In all these cases de-institutionalization is taking place either in terms of moving to the community or living longer at home. The cases offer an interesting diversity, both because of their differences in client groups and in funding authorities (e.g. municipality; central government or health insurance).

Study design and data collection

The participatory design of the study allowed for exploration of complexities in actual care practices and making sense of these together with the people (clients, professionals, informal carers and managers) involved. This fits my theoretical focus of understanding good care in practice and with the people involved in these practices. Part of the participatory research was ethnographic work in the three participating teams. This included different research methods such as interviews, participant observation and shadowing. To look for ways to include the voice of clients with SMI and ID I also included photovoice workshops and involved experts-by-experience as co-ethnographers (for an overview see table 1). To sensitize the data collection to complexities in the care relationship the research started with a thematic synthesis of qualitative research on the care relationship.

In order to make sure the research design and the development of the method for quality improvement of the care relationship were sensitive to what is at stake in care practices in long term care, two project teams were involved, one in each organization. These project teams were involved in important decision making throughout the project (for an overview see table 2). Furthermore, clients, professionals and representatives of informal carers were involved in data validation sessions to ensure the emerging analysis of the complexities in the care relationship fitted their experiences and to involve them in the design of the quality improvement method.

Table 1 Overview of participants

	Team CCO Intellectual disabilities			***Team CCO serious mental illness***			***Team HO older persons***		
	Prof.	*Cl.*	*Carers*	*Prof.*	*Cl.*	*Carers*	*Prof.*	*Cl.*	*Carers*
Participant observation	12 visits, 65 hours total			12 visits, 19 hours total			-	-	-
Shadowing	-	-	-	-	-	-	10 visits, 60 hours total		
Interviews	12	12	4	8	8	3	9	13	5
Photovoice	-	6	-	-	1	-	-	-	-
*Interviews peer-support workers**	-	-	-	-	8	3	-	-	-
*Interviews policy makers and managers**	6						1		
Groep consultation on analysis (no. participants)	9	5	-	8	5	-	7	5	-

* part of multiple teams, not specific to a client group

Table 2 Overview of project teams

	Project group CCO	**Project group HO**
Participants	Two researchers; a member of a patient advocacy organization; four policy makers; one expert-by-experience; a professional of each of the two collaborating teams.	Two researchers; a member of a patient advocacy organization; two community nurses; a manager and a policy maker.
Involvement	1) selection of teams; 2) data collection protocol including informed consent and topic lists; 3) data analysis and 4) designing the instrument	1) selection of teams; 2) data collection protocol including informed consent; 3) data analysis
Number of meetings	Six meetings, 5 meetings of 90 minutes; one workshop of 4 hours focused on re-designing the group meetings in which two additional experts on client participation were involved.	Two meetings of 90 minutes.

Through a robust participatory process, a quality improvement method for the complex care relationship was developed. For this I involved the project group for each care organization and clients and professionals in each team in data validation sessions. The development of this method further involved a very fruitful artistic collaboration with the inclusive theatre company (including both actors with and without disabilities): Theater Babel Rotterdam. These were involved in translating the data gathered through the ethnographic research into engaging short films that spark critical reflection, deliberation and co-design. Some of the scripts of these films are presented in this chapter and as intermezzos between the following chapters.

OUTLINE OF THE THESIS

In chapter 2 I present a thematic synthesis of qualitative studies that show the ethical tensions of the care relationship in long term care for people with SMI. I show how values such as self-determination and fostering an independent lifestyle can be given different meaning in practice, can be in tension with each other and with other values such as preventing harm. Moreover, I show how professionals, clients and informal carers can have different views on what is good in the care relationship.

In chapter 3 I analyze how multiple values and ontologies put forward by different professionals, informal carers and clients with ID or SMI are tinkered with in order to bring about good care in the collective care relationship. Here I describe how tinkering is a collective process where also family members and professionals from other organizations need to be involved. Moreover, collective tinkering also is needed when organizing care practices for groups of clients.

In chapter 4 I look into the consequences of multiple values and ontologies in care for clients with SMI and ID. Here, I develop the concept of ‘burden of support’ to capture clients’ negative experiences with the way professionals enact values such as self-determination, fostering an independent lifestyle, personal recovery and community participation in the care relationship. This chapter further shows how organizational structures aimed at fostering these values can have the paradoxical effect of producing burdens instead. Understanding these burdens can support professionals and policy makers in being responsive to clients’ experiences with care and to better attend to their needs in providing care.

In chapter 5 I focus on the way professional assemble different values in the context of valuation regimes and valuation practices. I show how professionals differ in how they do so and the consequences for professionals when these differences are not attended to. I also show an important consequence for professionals of providing care within valuation regimes and valuation practices: work professionals engage in that brings about good care for clients remains invisible. I develop the concept of ‘invisible worth’ to attend to this valuable work. Attending to invisible worth furthermore is important as part of being responsive to how care is received.

In chapter 6 I describe the development of a quality improvement method – *Ask Us!* – for the care relationship in long term care, responding to its value complexity. This method brings together critical reflection, deliberation and co-design and is an adjustment of Experience-Based Co-design.

In Chapter 7 I conclude by developing a conceptualization of good care in collectives by responding to the value complexities in the care relationship, the burdens and invisible worth's. I furthermore discuss how the developed method of 'Ask Us!' can support professionals, clients and informal carers in bringing about good care responding to ethical tensions and burdens. Last, I discuss my findings in the light on the liberal-individualistic views on autonomy dominant in policy on long term care and show how a relational view on autonomy better fits good care.

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APPENDIX 1. OVERVIEW OF TRANSLATIONS USED FOR FREQUENTLY USED POLICY TERMS

Aid	Verzorgende
Aging in place	Langer thuis wonen (met of zonder professionele hulp zoals thuiszorg); niet of later naar een verpleegtehuis verhuizen
Beloning	Thuis voelen; erbij horen; ertoe doen; meetellen; sociale inclusie wanneer de nadruk ligt op ervaring van erbij horen
(care) provider; care organisation	Zorgaanbieder; zorgorganisatie; organisatie in maatschappelijke opvang of beschermd of begeleid wonen; organisatie in thuiszorg of wijkverpleging
Community participation	(Maatschappelijke) Participatie; meedoen
De-institutionalisation	De-institutionalisering; ambulantisering
Development	Ontwikkeling
District nurse	Wijkverpleegkundige
Home care (services)	Thuiszorg uitgevoerd door verpleegkundigen en verzorgenden zoals persoonlijke verzorging en medische zorg met uitzondering van huishoudelijke hulp.
Family	Naasten; familie; netwerk (inclusief vrienden en buren)
Fostering an independent lifestyle	Zelfredzaamheid; zelfredzaamheid stimuleren
House keeping	Schoonmaakwerkzaamheden in huis
Informal carers	Mantelzorgers; naasten; familie; netwerk in de rol van het ondersteunen van cliënten
Meaningfull life	Zinvol leven; zinvol bestaan; zinvol samenleven
Mental health counselor	GGZ-Agoog
Next-of-kin	Naasten; familie; netwerk
Out-patient care	Ambulante zorg
Person-centered care	De cliënt centraal; de patiënt centraal; persoonsgerichte zorg
People with SMI	Mensen met Ernstige Psychiatrische Aandoeningen (EPA); mensen met Schizofrenie; psychiatrie
People with ID	Mensen met een verstandelijke beperking
Personal care plan	Zorgplan; Zorg leef plan
Present; Presence	Presentie(-theorie); present zijn
Quality of life	Kwaliteit van leven; kwaliteit van bestaan
Recovery-oriented care	Herstel; herstelgerichte zorg
Rehabilitation	Rehabilitatie

Self-determination	Eigen regie in de betekenis van het zelf keuzes maken over je zorg en je leven.
Self-sufficiency	Eigen verantwoordelijkheid
Social Inclusion	Sociale inclusie
Strength based approach	Eigen kracht; eigen kracht benadering

Friends

Client, supported independent living

I just want to be friends
even though we aren't friends
we do have a relation
even if we aren't family
we keep being humans
even if that's not so ordinary
I just want to sit down
as a human
and have a conversation
etcetera etcetera

I don't want to keep starting over
to get to know each other

I keep having to explain everything
completely explaining it all over
what I can do and what I can't do
what I want and what I don't want
etcetera etcetera

a lot of things change all the time
care takers come and go
and I keep changing too
you have no clue about the chaos here
here in my head

there are so many crossroads in my head
so many sidetracks
or paths that nobody knows
where I'm all alone

at those moments, I want someone to be there
someone to keep an eye out
who knows where I am
and tells me what has priority

and I want to be able text him
if I can't find the way at night
or if I feel alone
and I do feel terribly alone
etcetera etcetera

LOVE

Brother of a client receiving supported independent living

I wish that I wouldn't worry as much
That I could trust, that my sister's taken seriously
That they see her as she is
That what she views as important is also seen as important
Basically, that they really listen to her

If you know her in the slightest, you already know
She can be a bit too fast in saying: I don't feel like it
If it's too difficult for her
You can't just say: be more self-reliant
That's really making it too difficult for her
But that doesn't mean she can't do anything

You shouldn't act too stern or too authoritative
Then she'll really lose interest
You should just be, kind, sweet and mostly just consistent

Investing in the relation simply takes time and effort
But you end up with so much more because of it

If the staff changes to often, then too much is lost
She really is sweet and not at all half-witted
But you should learn to speak her language
Just simply trying something different
Cycling, walking, shopping
not solely trying to achieve practical aims

you should just take her seriously
she deserves that, right?
That's what yields the most
Even things like self-reliance
She has a story, and once you know that
Then few things are problems for her

Of course, she has gone through a lot
Her own, well, disability –You could call it that –
That fire that one time, and that abuse incident
That’s why you should really try to build a connection with her
Develop trust
It really isn’t difficult to do something with her
It simply takes time
It’s all about love
She can feel that

When she's being loved

Professional. supported independent living

clients sometimes share things with me
probably because of my open personality
often, I know even more than their relatives do

there are always two sides
my professional side and human side
but sometimes the two of them combine

some of them I have on my private WhatsApp
that's discouraged generally
though, I think I should be able to be flexible like that

the fact that some have my phone number
makes life so much more pleasant for them

I never respond to a message right away though
So they don't expect me to always be available
I always take a moment and then give objective advice
because, you know, I leave my personal emotions out of it

that's not always easy
it doesn't always leave me unaffected
I mean, some of them can be very careless with their sexual partners
and then they'll tell me about it
when is intervening necessary?
there's a limit to my responsibilities

and that's tough
when I know things – about relatives for instance
things which are really unpleasant for a client
and would cause them instant stress
but I'm not supposed share that then

I can’t do this work without love
you want to protect them
but that’s not always an option

some of them cry on my shoulder
and yeah, it really hurts me when clients go through rough patches

but you must be realistic too
because, If I have another job, I won’t be there anymore
people simply get attached
there’s no way of preventing that

Chapter 2

Ethical dilemmas of participation of service users with serious mental illness: a thematic synthesis

This chapter is published as: Heerings, M., van de Bovenkamp, H., Cardol, M., & Bal, R. (2020).
Ethical Dilemmas of Participation of Service Users With Serious Mental Illness: A Thematic Synthesis.
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ABSTRACT

Mental health professionals are expected to stimulate the participation of service users with serious mental illness. This not only changes what is expected from service users and professionals, it also changes the values underlying their relationship. The value of autonomy becomes more important as a result. This raises potential ethical dilemmas. This paper reports the findings of a thematic synthesis of 28 papers on the views of service users, professionals and family members on the care relationship in inpatient, outpatient and community services for people with serious mental illness. It puts forward various perspectives on participation of service users, foregrounding differing values, which in turn can lead to ethical dilemmas for professionals. The key implications for mental health professionals and future research are discussed.

INTRODUCTION

Increasingly, mental health nurses and social workers are expected to stimulate user participation of patients with serious mental illness (SMI, including psychosis, bipolar disorder or mayor depression for over two years) [1,2]. Stimulating participation complicates the care relationship in inpatient clinics, outpatient clinics and community housing services in important ways as professionals face dilemmas. Stimulating user participation involves different activities including fostering self-determination and an independent lifestyle. Professionals face dilemmas as user participation changes the values underlying the relationship between service users and professionals. Increased participation means that the value of patient autonomy becomes more important. Autonomy is not a straightforward concept. It can be given different meanings resulting in dilemmas between different courses of action in stimulating user participation [3-5]. The value of autonomy is moreover not the only important value in the care relationship. Simultaneously, professionals have a responsibility for preventing or removing harm and promoting well-being. In some situations, preventing harm demands different actions of professionals than respecting patient autonomy, adding to the dilemmas professionals face [6-9]. The care relationship is complicated further by the fact that it involves several actors, including service users, professionals and family members who may all have other views on how to stimulate participation and deal with these dilemmas.

AIM

Current literature has identified the more active role for users and dilemmas possibly resulting from this participation trend. However, there is no in-depth understanding of how the varied nature of participation leads to different dilemmas. Moreover, studies often focus on only one of the actors involved in the care relationship (users or professionals or family members) thereby overlooking the complexities in this relationship resulting from different perspectives. To gain insight into the complexity of a care relationship that emphasizes participation, and how professionals can provide good care within this complexity, we conducted a literature review.

We conducted a thematic synthesis of qualitative studies on the perspectives of people with SMI, professionals and family members on the care relationship in the context of user participation. We asked three related questions. First, what does user participation mean for service users, professionals and family members? Second, what do professionals do to facilitate this type of user participation and which barriers are experienced? Third, what dilemmas arise from user participation?

METHODS

Design

The current review used a thematic synthesis approach which enabled combining a wide range of qualitative studies while constructing a novel heuristic framework [10,11].

Literature search strategy

For the purpose of study selection and appraisal, a list of relevant search terms was composed covering terms related to 1) service user participation, 2) healthcare workers, people with SMI and family carers, 3) healthcare setting (inpatient, outpatient and community care). An extensive search for peer-reviewed journal articles was conducted in Embase, MEDLINE OvidSP, Web of science and PsycINFO in May 2016 and updated in May 2017 (see Appendix 1 for search terms).

Articles on mental health care needed to meet all of the following criteria for inclusion (see Table 1).

Table 1 Criteria for inclusion

	Criteria for inclusion
Journal article	The care relationship between service users and professionals or the relationship between professionals and family carers providing informal care was a central theme.
	Based on empirical data on perspectives of healthcare professionals, service users with SMI or family carers.
	Articles were published in English.
	Articles were published after 2005 as our focus is on the care-relationship in the context of user participation and de-institutionalization.
Respondents	Service users were 18 years or older and diagnosed with a SMI. Substance dependence and abuse as a primary diagnosis were excluded as these place very specific demands on the care relationship.
	Professionals were nurses or social workers offering support in daily living. Professionals that provide treatment, such as psychiatrists, psychotherapists, general practitioners and medical residents were excluded.
Setting	The care was provided within an inpatient or outpatient mental healthcare setting providing services to assist in daily living to adults with SMI. Excluded were studies conducted on acute care wards as a deterioration of the state of people with SMI might ask for a specific care relationship with different ethical values and dilemmas. For similar reasons forensic and secure mental healthcare settings and coercive treatment were excluded.
	Care was provided within a Western country. This in order to limit cultural diversity in health systems and illness perceptions.

Two authors (author 1 and 2) individually screened titles and abstracts to exclude articles that did not meet the inclusion criteria. Author 1 screened all titles and abstracts, author 2 screened a random sample of 10% of all titles and abstracts. Differences between authors were discussed until consensus was reached. Author 1 screened the full text of the remaining articles for the perspectives of service users, family carers or professionals on user participation in the care relationship between professionals and service users. As two of the articles in this selection were review articles, [12,13] the references of these articles were scanned to identify relevant studies.

Search results

Figure 1 shows the number of studies included after each stage of the selection process. Eventually, 28 studies were included.

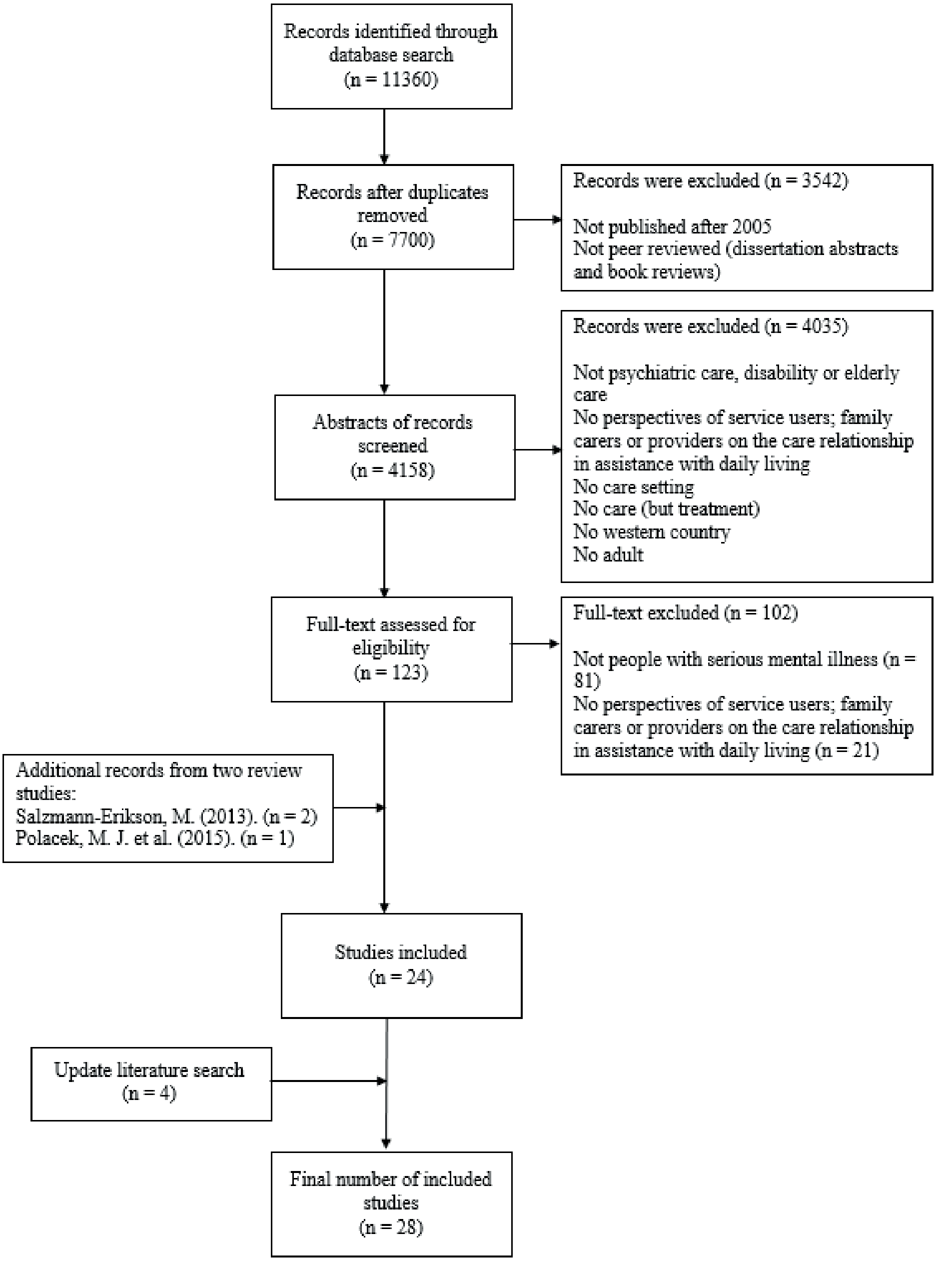

Figure 1 Studies included after each stage of the selection process

Features of the included studies

Included studies cover a comprehensive set of participants in terms of type of diagnosis for people with SMI, type of professional and family roles. The studies use diverse data collection methods and feature a wide range of care settings that assist in daily living: inpatient facilities, outpatient care and community care. The facilities were situated in Europe (Belgium, Denmark, Germany, Italy, the Netherlands, Norway, Spain, Sweden and the UK), Canada, the USA, Australia and New Zealand (see Table 2 for an overview of included studies).

Table 2 Studies included in the review

Reference and country of study	Study aim	Methods	Participants: service users (diagnosis), professionals (profession) or family members (role)	Relationship with: (not participants)	Setting
Bäck-Pettersson et al. (2014) Sweden	Describe patients' experiences of supportive conversation as long-term treatment in a psychiatric outpatient context.	Focus group	6 service users. Various diagnoses including: emotional unstable personality disorder, depression, dysthymia, general anxiety disorder, and bipolar disorder.	Contact person (often a qualified nurse specialist).	Out-patient
Blegen et al. (2016) USA	Understand the experience of being cared for in psychiatric care when being a patient and a parent.	Qualitative interview	10 service users. Various diagnoses including: depression, anxiety and bipolar disorder.	Professionals in psychiatric specialist health care contexts.	Out-patient
Coatsworth-Puspoky et al. (2006) Canada	Explore and describe nursing support relationships from the perspectives of recipients, within the mental health subculture.	Focused ethnography and qualitative interview	14 service users. Various diagnoses including: mood disorders, panic disorder, personality disorder and schizophrenia.	Nurses	In-patient and out-patient
Erdner et al. (2012) Sweden	Describe psychiatric caregivers' perceptions of self-esteem and activities for patients with long-term mental illness.	Qualitative interview	13 professionals. Mental health nurses and psychiatric nurses.	Service users not specified.	In-patient
Eriksen et al. (2012) Norway	Explore how users of community-based mental health services describe and make sense of their meetings with other people.	Qualitative interview	11 service users. Diagnoses not reported.	Psychiatric nurse or social worker.	Community services

Table 2 Studies included in the review (*continued*)

Reference and country of study	Study aim	Methods	Participants: service users (diagnosis), professionals (profession) or family members (role)	Relationship with: (not participants)	Setting
Gaillard et al. (2009) Australia	Examine mental health patients' experiences of being misunderstood.	Secondary analysis of qualitative interviews	20 service users. Various diagnosis including: depression, bipolar disorder, posttraumatic stress disorder, antisocial personality disorder, schizoaffective disorder, and schizophrenia.	Nurses, physicians, counselors, therapists, social workers and care coordinators.	In-patient and out-patient
Granheim et al. (2014) Sweden	Explore registered nurses' experiences of dialogues with inpatients in psychiatric care.	Focus group and qualitative interview	10 Professionals. All nurses without specialist training in mental health nursing.	Service users not specified.	In-patient
Happell (2008) Australia	Explore the relationship between service delivery and recovery from the perspective of mental health service consumers.	Focus group	16 service users. Diagnosis not specified.	Support staff, case manager.	Out-patient
Högberg et al. (2006) Sweden	Describe psychiatric nurses' experiences of different types of supported dwelling for persons with long-term mental illness, and their views on what they consider to be important principles to provide for in order to facilitate their social integration into the community.	Qualitative interview	9 professionals. All psychiatric nurses.	Service users not specified.	Community services
Jackson et al. (2014) Canada	Explore the experiences of Canadian registered psychiatric nurses.	Qualitative interview	10 professionals. All psychiatric nurses.	Family in a variety of clinical settings (diagnosis of relatives not specified).	In-patient
Jakobsen et al. (2006) Norway	Explore how parents of adult psychiatric patients experience collaboration with health professionals in the community healthcare services.	Qualitative interview	6 family members. All parents. Relatives' diagnosis not specified.	Professionals not specified.	Community services
Koslander et al. (2007) Sweden	Describe patients' conceptions of how the spiritual dimension is addressed in mental health care.	Qualitative interview	12 service users. Various diagnoses including: schizophrenia, depression and psychosis.	Nurses	In-patient

Table 2 Studies included in the review (*continued*)

Reference and country of study	Study aim	Methods	Participants: service users (diagnosis), professionals (profession) or family members (role)	Relationship with: (not participants)	Setting
Lakeman (2010) UK, New Zealand, Germany, Australia, USA	Identify a mental health recovery worker competency set through consensus by people with first hand personal experience of recovery.	Online delphi survey	31 service users; all self-identified as experts by experience in recovery. Various diagnoses including schizophrenia or schizoaffective disorder, bipolar affective disorder, depression, puerperal psychosis.	Professionals not specified.	Not specified.
Lilja et al. (2008) Sweden	Extend our understanding of inpatients' experience of psychiatric care by interviewing former psychiatric inpatients.	Qualitative interview	10 service users. Various diagnosis including: psychosis, schizophrenia, borderline personality disorder, mood disorder, obsessive compulsive disorder, eating disorder.	Registered nurses and enrolled nurses.	In-patient
Lindwall et al. (2012) Sweden	Describe how nurses experienced incidents relating to patients' dignity in a psychiatric nursing practice.	Participant observation.	16 professionals. All psychiatric nurses as co-researchers (conducting participant observation).	Service users not specified.	In-patient
Linz et al. (2016) USA	Explore the experience of workers on Assertive Community Treatment (ACT) teams surrounding their efforts to facilitate social integration for their clients.	Qualitative interview and focus group	24 professionals. All workers in the ACT team. Various professions including nurses, social workers.	Service users not specified.	Community services
Nicholls et al. (2009) New Zealand	Explore the relationship from both mental health professionals' and family caregivers' perspective	Qualitative interview	7 family members. Parents and sibling. Relatives diagnosed with Schizophrenia, Bipolar Disorder and Major Depression. 7 Professionals. Mental Health Nurses and social workers.	-	Out-patient
Oeye et al. (2009) Norway	Explore the challenges of implementing user participation in milieu-therapeutic work in a Norwegian psychiatric institution.	Participant observation and qualitative interview	22 professionals (not specified); 15 service users (not specified).	-	In-patient

Table 2 Studies included in the review (*continued*)

Reference and country of study	Study aim	Methods	Participants: service users (diagnosis), professionals (profession) or family members (role)	Relationship with: (not participants)	Setting
Pelto-Piri et al. (2013) Sweden	Describe and analyze statements describing real work situations and ethical reflections made by staff members in relation to three central perspectives in medical ethics; paternalism, autonomy and reciprocity.	Ethical considerations written in a diary by staff members	173 professionals handed in ethical diaries all are psychiatric staff members, doctors and other staff members.	Service users, not specified.	In-patient
Petersen et al. (2012) Denmark	Explore service user involvement in supported housing schemes as experienced by adults with mental illness in interplay with professionals during rehabilitation.	Participant observation, qualitative interview, focus group	12 service users. Various diagnoses including: schizophrenia, bipolar disorder, obsessive-compulsive disorder and depression.	Staff of supported housing facility.	Out-patient
Saavedra et al. (2012) Spain	Describe the functions of everyday life and daily routines in the recovery process.	Qualitative interview	10 professionals. Psychologists, social educators, professionals with non-health or social work related background.	Service users, not specified.	Out-patient
Schröder et al. (2006) Sweden	Describe how patients perceived the concept of quality of care in psychiatric care.	Qualitative interview	20 service users. Various diagnoses including: borderline, bipolar disorder, psychosis and depression.	Professionals not specified.	In-patient and out-patient
Schroeder (2013) USA	Give voice to the lived experiences of older adults with serious mental illness and their perceptions of the healthcare provider relationship.	Qualitative interview	8 service users. Various diagnoses including: schizophrenia, schizoaffective disorder, bipolar disorder, depression, obsessive-compulsive disorder and anxiety disorder.	Professionals not specified.	In-patient and out-patient
Secru et al. (2016) Belgium	Discusses the stigma experiences of service users in mental health care, within the debate on the role of the biomedical framework for mental health care and power relations in society.	Participant observation and qualitative interview	42 service users. Various diagnoses including: mood disorder; psychosis; dependency; acquired brain impairment. 43 professionals. Nurses, psychiatrist, psychologist and social workers.	Service users, not specified.	In-patient

Table 2 Studies included in the review (*continued*)

Reference and country of study	Study aim	Methods	Participants: service users (diagnosis), professionals (profession) or family members (role)	Relationship with: (not participants)	Setting
Shattel et al. (2006) USA	Examine what it means to individuals with mental illness to be understood.	Qualitative interview	20 service users. Same sample as Gaillard et al. (2009).	Nurses, physicians, counselors, therapists, social workers and care coordinators.	In-patient and out-patient
Skorpen et al. (2015) Norway	Explore the experience of patients and relatives regarding respect for dignity following admission to a psychiatric unit.	Qualitative interview	5 family members. All parents. 6 service users. Relatives all diagnosed with psychosis.	Professionals not specified.	In-patient
Topor et al. (2006) Italy, USA, Sweden and Norway	Examine the specific aspects that characterize other people's (healthcare workers', family members' or community members') actions when helping in the recovery process.	Qualitative interview	12 service users. Various diagnosis including schizophrenia, psychosis, major depression with psychotic features.	Professionals not specified.	In-patient and out-patient
Valentini et al. (2016) Germany	Investigate the experiences of relatives caring for severely mentally ill patients in an integrated care model.	Focus group and qualitative interview	24 family members. Spouses, parents, siblings and children. Relatives' diagnosis not specified.	Case manager	Out-patient
Van de Bovenkamp et al. (2010) Netherlands	Study the relationship between family members and mental health care workers to learn more about the support available to family members of mental health patients.	Qualitative interview and observation	18 family members. Parent, spouse, sibling, child. Relatives diagnosed with various diagnoses including: schizophrenia, schizoaffective disorder, bipolar disorder, psychosis. 7 professionals. Social workers, psychiatric nurses and the assistant of the family council. 2 service users. Diagnosis not specified.	-	In-patient and out-patient

Data analysis

The thematic synthesis was conducted in three steps[11]. First, descriptive themes were developed through line-by-line free coding of text reported under 'findings' or 'results' that was related to the care relationship. Second, codes were inductively organized into key descriptive themes using the constant comparative method. The final step involved generating analytic themes by organizing and interpreting the descriptive themes in order to answer the research questions [11].

Analytic themes represent different aspects of user participation; the activities professionals pursue to facilitate the participation type and the experienced barriers; the various dilemmas between different interpretations of autonomy in these aspects of user participation and between autonomy and preventing or removing harm and promoting well-being. These analytic themes were integrated in a heuristic framework of user participation and related dilemmas, combining the views of service users, professionals and family carers.

RESULTS

Four analytic themes emerged which represent different aspects of stimulating user participation: 1) 'user participation in decision-making', 2) 'fostering an independent lifestyle', 3) 'relationship-centred care' and 4) 'recovery-oriented care'. Four dilemmas were identified: 1) 'user participation in decision-making versus preventing harm', 2) 'fostering an independent lifestyle versus deciding on and pursuing own goals', 3) 'fostering an independent lifestyle versus preventing negligence' and 4) 'striving for an equal relationship versus keeping a professional distance.'.

User participation in decision-making

The first theme describes user participation in decision-making as a way to stimulate participation.

Service users' experiences with user-user participation in decision-making

In some studies the user's understanding of participation focused on having an influence on decisions on matters that affect them [14]. From the service user perspective this facilitated the trust they maintained with professionals [15]. It was also linked to feeling recognized as a valuable human being and feeling more involved in their own support, treatment and daily life [14]. Service users value participating in decisions, e.g. on goals to work towards in their care, in setting a care plan [14,16,17] and the frequency of meetings with the professional [18]. Likewise, service users value the possibility to choose their own contact person and have a say in recruiting new staff members [14,16]. Lastly, service users value having influence on decisions in everyday situations such as to do with food, social activities and their housing situation [14].

However, service users differ in how much influence they want to have on these decisions. Some want to decide for themselves (on some aspects), while others value being merely involved in the decision-making while not deciding on their own, or being involved in decision-making on specific aspects of support and not others. Service users describe negative experiences when professionals decided for them, or seemed not to trust their judgement which made them feel incapable [14]. On a different note, some service users value being informed and motivated by staff to do certain activities [14], and to be challenged to achieve personal goals beyond their own imagination [19]. This implies more engagement by professionals beyond asking for the service users' preferences and taking these into account. Furthermore, service users sometimes feel it necessary to have others decide for them because otherwise they risked hurting themselves [14]. They also report a retrospective desire for professionals to go against their wishes so that they can (still) receive the care they need [20]. Lastly, some service users say they are frustrated by being expected to be assertive, reflexive and express themselves while feeling that they lack the skills to do so [21].

Professionals' experiences with user-user participation in decision-making

Professionals describe striving to involve service users in the planning of their care[22,23] and to let service users choose their contact person [23]. Professionals advocate for service users' wishes in staff meetings [24]. They describe situations in which they forego their own suggestions and follow service users' wishes related to support and treatment[17] even when they disagree[25]. For example, professionals say that sometimes they agree with the service users' aim to stop medication, even if this could result in harmful situations. They claim to do so in order to build trust. In a trustful relationship, service users might accept more professional support than they are initially inclined, or at least not decline services altogether [26]. Alternatively, professionals negotiate a course of action that reflects a compromise between the user's wishes and the mental healthcare workers' recommendations [25].

Professionals state that sometimes they have difficulty involving service users in decisions due to the lack of time to engage in dialogue[27]. Professionals feel service users can be limited by their symptoms to engage in decision-making as sometimes the users do not respond to the provider's efforts to engage them in dialogue, or have unrealistic ideas about their own capacity [28]. In other cases, professionals lacked the resources to follow up on decisions, for instance, in assisting service users in activities they chose to engage in [23].

Sometimes professionals did not engage service users in decision-making on purpose, or they asked service users for their opinion but did not take them seriously and pursued their own agenda [28]. Staff sometimes deny service users their wishes in order to cater for their health and finances, for instance, restricting the number of cigarettes provided [29] or restricting the hours watching television to lessen passivity [28]. Respecting a service users' decision is sometimes not feasible because it would go against the house rules based on the service users' collective preferences [28] or result in harmful situations for other service users. For example, one service users' decision not to take medication to reduce aggressive behaviour could hinder the safe and calm environment for other service users [30]. Sometimes service users' wishes go against the personal values of professionals and are therefore restricted [23] and in some situations professionals take over when they consider the user unable to assume responsibility for their actions. In these situations professionals act in a way they believe is beneficial for service users [23].

Family carers' experiences with user-user participation in decision-making

Like professionals, family carers recognize the value of service users' involvement in decisions, for instance related to treatment planning [31,32]. However, family members sometimes feel their own participation in decision making regarding the care for their loved ones is unprecedentedly diminished when professionals claim to uphold service users' autonomy [33]. Several family carers were skeptical about the larger influence of service users on decisions as they feared it might result in negligence or harm [31]. Some family members ask professionals to promote healthy behaviour or prevent harmful behaviour, such as stop drinking alcohol when on medication. However, they report being dismissed with reference to the autonomy of the service user [31]. Professionals, in turn, report that family carers sometimes demand granting service users' decisions when professionals feel this would lead to harmful situations. For instance, letting a service user stop a pureed diet when professionals fear this might lead to another choking incident [30].

Fostering an independent lifestyle

A second emphasis of stimulating user participation is fostering an independent lifestyle.

Service users' experience of fostering an independent lifestyle

Service users wish that they could be like 'ordinary' people, able to work, able to finish their education and manage household tasks [34]. On a smaller scale, service users say they find it important to have structure in their day, to get up at a certain time and do meaningful activities [16]. At the same time, service users say they struggle to come to terms with a realistic version of themselves that fits with what their symptoms let them accomplish and the side effects of medication [34]. Service users value having a contact person who can teach them the skills related to managing life, such as learning to work towards goals, making life choices, solving daily problems and asking for help [15,35]. Furthermore, service users value having supportive professionals who teach them to cope with their illness, their inner experiences and manage their health [16,35,36]. They also want a professional to help them gain access to resources that can create new opportunities for education and sheltered, volunteer or paid work [17].

Professionals' experience with fostering an independent lifestyle

Professionals try to help service users develop an independent lifestyle as this enhances the user's self-esteem and well-being [37] and leads to community participation [26]. Professionals try to foster independence by motivating service users to get up (on time) in the morning [29], go for walks, doing crossword puzzles [27,32,37] or engaging in structured activities such as following education, doing volunteer work or going on pre-employment programmes [26]. Professionals also motivate service users to become aware of social norms, to follow the norms and 'act normal' in order to be accepted by the community and form relationships with other community members [22,26]. This includes motivating service users to keep up their hygiene, by changing clothes and showering regularly [29,37]. Strikingly, service users did not mention hygiene as an important aspect of professional support. Besides motivating service users, professionals taught skills related to managing daily life and coping with illness by focusing on the user's healthy traits and encouraging them to apply their own abilities and capacity for self-care. Some professionals stress the importance of the relationship with the professional as the first step in learning skills, specifically social skills [26]. Contrary to this, professionals in some studies say that most conversations with service users are about practical issues and medication [27]. Lastly, professionals arrange activities such as community outings, organize peer-sharing groups on experiences or learning skills, and create educational and vocational opportunities for service users [26].

In some studies, professionals elaborated on barriers they experience in engaging service users to develop an independent lifestyle. Firstly, some service users withdraw from activities as they have poor self-esteem and low self-confidence and are hindered by their symptoms, which deplete their energy and level of commitment. Furthermore, some service users have insufficient knowledge of their illness to overcome symptoms [37]. For similar reasons, service users are perceived as being unable to form social relationships with neighbours [22] or keep up their personal hygiene. Professionals sometimes resort to more punitive actions to motivate service users to keep up their hygiene, for instance, setting a shower rota that is enforced by not allowing service users to eat in the community room if they do not comply [37]. Professionals wonder if some service users simply wish to stay in dependent relationships instead of 'getting a grip on their lives' and living as independently as possible [37]. For instance, professionals describe how some service users would rather remain in or return to an inpatient setting as this offers security and a social network [27]. At the same time, having professionals who believe in the user's capacity to do something meaningful in the community was stressed as crucial for success in engaging the user in education or finding and holding a job [26]. In other studies, professionals describe factors external to service users that create barriers to developing an independent lifestyle. These include lack of appropriate housing in safe communities [26,38] and stigma [22,26]. Lacking resources to provide attractive activities [27] or educational or vocational opportunities for service users [26] are also mentioned as preventing service users from becoming active.

Family carers' experience with fostering an independent lifestyle

Some relatives say that they recognize the value of making the patient responsible for their own life [31]. However, family carers also feel that fostering an independent lifestyle could lead to negligence. This leaves it to family carers to fill the gap professionals left behind. For instance, family members report having to provide necessary household items and help with grocery shopping to provide basic needs and protect their child (relative) from unnecessary stress after discharge [31]. On a different note, professionals describe some family caregivers as acting as paternalistic custodians towards their mentally ill family member, which they felt prevented the service user from living an independent lifestyle [38].

Relationship-centred care

The third theme emphasizes relationship-centred care to increase service user participation.

Service users' experience with relationship-centred care

Service users say that having open dialogues with professionals is important as it decreases their anxiety and creates a narrative that makes them more familiar with themselves [16,34,36]. Having this type of contact creates the sense of self-worth and being valued as a human being [15,16,34,39]. Open dialogue also helps service users to convey their preferences and concerns to professionals and that enables professionals to consider what matters to the users [20,35]. For service users, the important aspects of dialogue include professionals taking the time to listen and be responsive to their ideas, opinions and feelings [15-21,34-36,39]. Even when service users are incoherent or angry and reveal negative views of their treatment or professional relationships, they prefer professionals to stay calm, act respectfully, and take them seriously [15,16,24,39].

Being touched (e.g. a hug, hand holding or a pat on the shoulder) can be important. Some service users feel this is a powerful way to connect [15,16,24,26,39]. Service users expressing this view wanted professionals to strive for equality in the relationship, for instance treat them as an adult and not a child [15,16,18,35], be more like 'friends' and not just talk about problems but also about normal, fun things [15,17,34,35,39,40] or about spirituality [41]. Professionals who share something of themselves by disclosing their own experiences [34] including negative life events [39] made service users feel more on the same level. Professional behaviour that promotes the professional's control and authority over the service user leads to unsatisfactory relationships in the perception of service users. This includes situations in which service users are not being heard or talked down to [15,20,24,34,42] or defined by their diagnostic label [15,19,21,36,39,40,42].

Professionals' experience with relationship-centred care

Professionals in the analysed studies shared the ideal of open dialogue but were less keen on striving for a more equal relationship. Dialogue was perceived as important to alleviate suffering, empower service users and provide good care that fit their wishes [22-24,27,40]. Strikingly, only two studies reported striving for an equal relationship, for instance by being 'as friends' [26,28]. In studies where participant observation was part of the research methodology , professionals were observed stigmatizing service users, not engaging in open dialogue, talking condescendingly and abusing power [23,24,28].

Professionals note three barriers to open dialogue with service users. Firstly, they lack the time for proper conversations, and sometimes do not know whether they should prioritize relationships or tasks related to daily routines in care units [23,27]. Secondly, they can feel hindered by the service user's psychotic delusions, preconceptions and paranoia as these symptoms make it difficult to get through to the user [27]. Thirdly, professionals feel that they need distance at times in order to cope as they can feel burdened by the user's feelings and anxiety [27]. They say they need courage to meet the users' expressed needs to deal with their feelings, disappointment and sadness [24]. Dealing with suicidal people is especially demanding. Professionals differ in how they experience this barrier. Some say they find another person's suicidal thoughts a heavy burden and do not know how to respond, while others feel it is part of daily life on the units and are not personally affected [27]. All these barriers relate to keeping service users at a distance, either because of the lack of time or the need to prioritize other tasks, the service users' symptoms or having to deal with these symptoms.

Family carers' experience with relationship-centred care

Family members seldom discuss the importance of relationship-centred care in the analysed studies. Only one study described family members finding it important professionals talk to service users as equals and not 'from the top down' [20].

Recovery-oriented care

The fourth and last theme of user participation is recovery-oriented care. Recovery-oriented care is only put forward by service users.

Service users' experience with recovery-oriented care

Recovery encompasses a reconstruction of identity and decreasing self-stigmatization [25]. Service users say that the discourse on mental illness has negatively influenced how they see themselves; they feel the need to "unlearn the psychiatric interpretation imposed on oneself" [16,19,25].

The factors associated with recovery are fairly consistent, e.g. living well, finding or maintaining hope, optimism and meaning, taking personal responsibility or maintaining one's autonomy, engaging in meaningful activities, enjoying supportive relationships, having access to a range of services and participating fully in the community [25]. These are similar to the aim of theme two 'fostering an independent lifestyle'. At the same time, recovery is positioned as mainly an individual process in which patients decide what recovery means for them as opposed to the professional-directed aim of social integration. On the same note, self-acceptance and overcoming self-stigma is more key than fitting in with social norms for acceptance by the community.

Although recovery is described as a personal process, professionals and family carers can have a role in promoting or hindering it [17,18,25]. A Delphi study was conducted among experts-by-experience to assess recovery-oriented competencies for mental health workers[25]. The highest rated competencies related to respecting the unique expertise of people with SMI: recognizing and supporting the personal resourcefulness, reflecting the belief that recovery is possible, listening to what service users actually say and respecting their views, showing respect for the expertise and unique knowledge gained as a result of having experienced mental health problems and helping the person to develop self-belief, thereby promoting their ability to help themselves [25]. While the competency statements in this study all focus on professionals supporting the expertise of service users[25], service users in another study say that professionals can help them recover by applying professionals' expert knowledge, conveying information to the user and serving as an intermediary in various interventions involving money, activities, groups, housing, etc. Another example of professionals using expert knowledge deemed important to promote recovery is when they help users understand that what they experience is a hallucination [17].

Dilemmas

The four themes of user participation demonstrate that increased participation in mental healthcare is a complex, multifaceted issue. The themes have important consequences as they warrant different responses from users, professionals and family members. The above sections also point to dilemmas professionals face between the value of autonomy on the one hand and preventing or removing harm and promoting well-being on the other. Moreover, in the various forms of participation the value of autonomy is enacted differently. As a result, professionals can also face dilemmas when they try to stimulate different types of participation. This section deals with these dilemmas.

User participation in decision-making versus preventing harm.

The first dilemma relates to the theme of user participation in decision-making: service users make decisions that in the eyes of professionals or family members could be harmful, e.g. when users decide to stop their medication or decline other services that family members and professionals feel are needed. Other harms to be prevented were related to eating habits or using cigarettes and alcohol. In some cases, both family and professionals wondered if service users are not too inflicted by symptoms to be able to have a say on such decisions. Some service users also agree that professionals sometimes need to take over in order to prevent harm even if they at that moment say otherwise. Professionals and family carers sometimes have contrasting views on whether participation in decision-making should be stimulated or harm should be prevented, making the dilemma more poignant.

Fostering an independent lifestyle versus deciding on and pursuing own goals

A second dilemma arises between two different enactments of the value of autonomy in the themes user participation in decision-making and fostering an independent lifestyle. This becomes clear as service users might make decisions that hinder the road to community participation. For example, service users could prefer living in an inpatient setting where they have social bonds over living within a community where they are confronted with stigma and possible loneliness. Alternatively, this dilemma arises when service users choose not to keep up their hygiene or engage in other activities deemed important for living an independent lifestyle by professionals. Similarly, a dilemma could arise between autonomy as enacted in the theme fostering an independent lifestyle and recovery-oriented care. In the theme recovery-oriented care, pursuing recovery in a way that is important for the service user is central. This can conflict with fostering an independent lifestyle when service users pursue goals that are important to them but are not related or contradictory to community participation. Or, when service users focus on accepting themselves as they are if this conflicts with social norms held by the community.

Fostering and independent lifestyle versus preventing negligence

A third dilemma is found between enhancing service user participation by fostering an independent lifestyle and preventing the harm of negligence. Family members point out possible harm, e.g. letting service users buy their own groceries as a way to encourage them to do things for themselves but can lead to stress for the users or them not having necessary household items or food.

Striving for an equal relationship versus keeping professional distance

The last dilemma is between professional distance and equal relationship. In relationship-centred care, service autonomy is enacted by engaging in dialogue and striving for an equal relationship, both of which service users desire in their contact with professionals. Professionals seldom put forward the ideal of striving for a more equal relationship but instead emphasize needing to keep a distance from service users. This poses a dilemma between fostering professional distance and striving for an equal relationship. Similarly, in recovery-oriented care, professionals face a dilemma in how to balance their professional knowledge and the expertise of service users.

Discussion

This review has highlighted the complexity of the care relationship in the context of stimulating user participation. It shows the multifaceted nature of participation and the dilemmas associated with introducing these facets in the care relationship. Together these themes and dilemmas form a heuristic framework of the complex care relationship (see Figure 2).

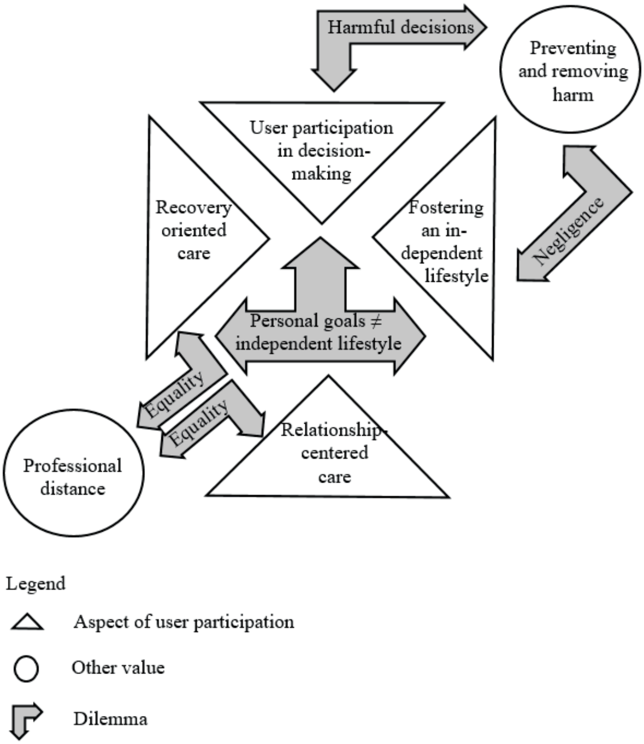

Figure 2 Dilemmas between values

Limitations

This study brings together the perspectives of 247 service users, 334 professionals and 59 family members in Western countries. However, a limitation of this study is that it does not differentiate the diagnoses of service users, the various educational backgrounds of professionals or between the care settings. Care relationships are bound to be characterized by different aspects of user participation in different contexts, with different service users and professionals. The advantage of our approach however, was that the variety of these studies provides an overarching view on user participation and dilemmas in the care relationship.

Implications for practice

The insight offered by the heuristic framework on aspects of user participation and dilemmas developed in this review can foster reflection on tensions within the care relationship and help people with SMI, their care professionals and their families to verbalize and deliberate on the tensions. This reflection need not be hindered by the lack of differentiation in the heuristic framework (diagnosis type, professional educational background or care setting) as seeing the similarities and differences between the proposed heuristic framework and the own care setting is an important aspect of this reflection. Reflection and deliberation on tensions associated with service user participation can improve the quality of the care relationship.

Implications for research

This review points to several avenues for future research. First, after analysing the complexity of the care relationship due to the increased attention for participation and its associated dilemmas, it is important to gain more knowledge on how professionals can deal with the dilemmas in practice. Several studies highlighting the importance of reflexively assembling different values in order to provide good care refer to this as 'tinkering' [9,43,44]. Given the complex situation of conflicting values, future studies could focus on 'tinkering' within the context of services aiming for enhanced user participation for people with SMI to increase our understanding of how good care can come about.

Second, qualitative studies including observations as a research method are important to gain insight into the experiences of service users, professionals and family members with services who aim to enhance user participation. This review has identified that many qualitative studies use interviews as the only research method. This can be considered an important limitation as focusing solely on interviews limits the diversity of included service users with SMI as service users who are more severely inflicted by their symptoms might not be willing or able to participate in an interview. The lack of ethnographic studies might explain the important differences between service users' and professionals' perspectives on stimulating user participation highlighted in this review. Throughout the four themes on enhancing user participation, service users preferred engaging in dialogue, either for being involved in decision-making, developing an independent lifestyle, engaging in an equal relationship or for forming a personal narrative. However, professionals indicated many barriers to engaging service users in such dialogue, e.g. service users who do not respond to attempts to start a dialogue or when users are hindered by their delusions and preconceptions as a result of their symptoms. The scarce observational studies did describe the problems with dialogues stated above without, however, analysing the service users' experience. Ethnographic studies are needed to do justice to the experiences of service users who are not able or inclined to be interviewed [45] and the experience of professionals providing care to these service users.

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APPENDIX 1 SEARCH TERMS IN EMBASE [5]

‘(doctor patient relation’/exp OR ‘nurse patient relationship’/exp OR ‘family relation’/exp OR (((professional* OR provider* OR doctor* OR therapist* OR physiotherapist* OR caregiver* OR care-giver* OR staff* OR geriatrician* OR aides OR worker OR counsellor OR assistant* OR institut* OR nurse*) NEAR/6 (patient* OR famil* OR client* OR resident* OR consumer* OR user* OR parent* OR next-of-kin OR sibling* OR sister* OR brother* OR spouse* OR partner OR partners OR neighbour* OR informal-caregiver* OR informal-care-giver*) NEAR/6 (relation* OR partnership* OR alliance* OR contact OR affinit* OR affiliation* OR coalition* OR communicat* OR liaison* OR tie OR ties OR social-competen* OR integrat* OR interaction* OR cooperat* OR responsib* OR conflict* OR conversation*)) OR (family NEAR/3 (relation* OR involve*))):ab,ti) AND (‘long term care’/de OR ‘institutional care’/exp OR ‘chronic patient’/de OR ‘intellectual impairment’/de OR ‘mental deficiency’/exp OR ‘nursing home’/de OR ‘nursing home patient’/de OR ‘residential care’/de OR ‘residential home’/de OR ‘mental hospital’/de OR ‘mental patient’/de OR (((‘long term’ OR ‘long stay’) NEXT/1 (care OR healthcare OR patient* OR hospital* OR facilit* OR institute*)) OR institutionalised OR institutionalized OR ((elderly OR geriatr* OR aged OR residential*) NEAR/3 (home OR homes OR housing OR house* OR facilit*)) OR nursing-home* OR care-home* OR ((intellectual* OR mental*) NEAR/3 (impair* OR deficien* OR retard* OR disabilit*)) OR ((psychiatr* OR mental*) NEAR/3 (hospital* OR institute* OR patient*))):ab,ti) AND (‘health care quality’/de OR ‘quality of nursing care’/de OR ‘patient attitude’/exp OR ‘empowerment’/de OR ‘self care’/exp OR ‘self monitoring’/exp OR ‘drug self administration’/exp OR ‘decision making’/exp OR ‘daily life activity’/exp OR ‘ADL disability’/exp OR ‘feeding’/de OR ‘food intake’/exp OR ‘personal hygiene’/exp OR ‘frail elderly’/de OR ‘independent living’/de OR ‘vulnerable population’/de OR ‘holistic care’/de OR ‘attention’/de OR ‘ethics’/de OR ‘coping behavior’/de OR ‘family attitude’/de OR ‘social support’/de OR ‘st ress’/de OR ‘family stress’/de OR ‘caregiver burden’/de OR ‘emotion’/de OR ‘independence’/de OR ‘adaptive behavior’/de OR ‘mental stress’/de OR ‘quality of life’/de OR ‘psychological well being’/de OR ‘wellbeing’/de OR ‘psychological wellbeing assessment’/de OR (qualit* OR ((patient OR client* OR famil*) NEAR/3 (attitude* OR satisf* OR participat*)) OR empowerment* OR ((shared OR assisted OR peer) NEAR/3 (care OR management)) OR (self NEXT/1 (care* OR management OR medication* OR monitoring OR administrat*)) OR (decision* NEAR/3 making) OR (daily NEAR/3 (life OR living) NEAR/3 activit*) OR adl OR iadl OR badl OR adls OR iadls OR badls OR ((life OR social) NEAR/3 skill*) OR feeding OR eating OR ‘getting dressed’ OR ((personal OR oral) NEAR/3 hygiene) OR frail* OR independen* OR dependent* OR dependenc* OR fragil* OR vulnerab* OR suffer* OR ((attentive OR holistic OR loving) NEAR/3 care) OR attention* OR responsiveness* OR presence OR ethic* OR coping OR cope OR support OR supportive OR dignity OR integrity OR adjust* OR comfort* OR experience* OR stress OR distress OR burden* OR emotion* OR adapt* OR resilien* OR need OR needs OR ((person OR patient OR client) NEXT/1 center*) OR moral OR dilemma* OR benefit* OR well-being* OR wellbeing):ab,ti) AND (‘qualitative analysis’/de OR ‘qualitative research’/de OR ‘unstructured interview’/de OR ‘semi structured interview’/de OR ‘grounded theory’/de OR ethnography/de OR phenomenology/de OR ‘life history’/de OR ‘participant observation’/de OR ‘thematic analysis’/de OR ‘content analysis’/de OR ‘constant comparative method’/de OR ‘field study’/de OR ‘audio recording’/de OR ‘anthropology’/exp OR ‘qualitative analysis’/exp OR ‘quantitative analysis’/exp OR ‘data collection method’/exp OR ‘observation’/de OR ‘assessment of humans’/exp OR ‘observational study’/exp OR ‘health survey’/de OR ‘health care survey’/de OR ‘open study’/de OR ‘review’/exp OR ‘systematic review’/exp OR ‘videorecording’/de OR ‘action research’/de OR (((observation*) NEAR/6 (stud* OR data OR research)) OR (health* NEAR/3 survey*) OR review* OR meta-analy* OR anthropolog* OR qualitative OR quantitative OR questionnaire* OR observation* OR assess* or qualitative OR multimethodolog* OR (mixed NEXT/1 method*) OR (compatibility NEXT/1 thesis) OR (pragmat* NEXT/1 paradigm*) OR ((unstructur* OR open OR ‘semi structured’) NEAR/3 interview*) OR (focus NEXT/1 group*) OR (grounded NEXT/1 theor*) OR ethnograph* OR etnograf* OR ethnograf* OR phenomenolog* OR hermeneutic* OR (life NEAR/3 (histor* OR stor*)) OR (participant* NEAR/3 observation*) OR ((thematic OR content) NEXT/1 analysis) OR (observation* NEAR/3 method*) OR (‘constant comparative’ NEXT/1 method*) OR (field NEXT/1 (note* OR stud*)) OR story OR stories OR (Abductiv* NEAR/3 analys*) OR (co NEXT/1 (creation OR design OR production)) OR videorecord* OR video-record* OR ‘action research’ OR shadowing OR mystery-guest* OR experience-base* OR mirror-meet*):ab,ti) NOT ([Conference Abstract]/lim OR [Letter]/lim OR [Note]/lim OR [Editorial]/lim) AND [english]/lim

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[5] As this search was part of a larger project, it includes search terms related to elderly and people with learning disabilities.

What I miss

Client, supported independent living

there are thoughts that go around my mind all day
things which I want to talk about
a conversation about the world
which is big
and I'm small

Only god knows how it ends
that's what I would like to discuss
about death
that's what I wonder the most

but when I talk about that
my care taker starts to discuss food and showers and
tidying
I don't think tidying is that interesting

I really miss a real conversation
about my way of living
and my way of thinking
what I can do or can't do
and what I desire

I really miss a girlfriend too
a real girlfriend
a relationship
an intimate relationship
someone whom you can touch
cuddle
and more
I mean sex
really cool sex
is that strange?

Kind of crazy

Father of a client receiving independent supported living

The supervisors came over to talk once
about our son
that he supposedly had sexual feelings
and that someone should come for him sometime

and we felt that:
in my opinion he wasn't occupied with such things at all
our son
I've never heard him say anything about it
even though we have a very, very strong bond
normally he shares everything that he's doing
he just turned 19
but he has a developmental delay of 15 years
though, his caretaker says nothing is wrong with his sexual development

that's why they want someone special to visit
who would sexually satisfy him
a professional you could say
that's not a small feat to talk about with your kid

though, I ended up doing that
I asked him whether he was thinking about those things
that wasn't an easy conversation
eventually, he told me that he would like that
but that it would have to be a man

I got startled by that
didn't know whether I had to laugh or cry
that he would be homosexual, that was something new for me

okey, I said, if that's what you want

the thing is that the money should come from the fund I manage for him
that's asking quite a lot from me, to organize that

and how does that even work?
his caretaker didn’t even know if there were homosexual sex workers
he would have to follow up on that
that’s what we’re waiting for now

I find It a bit strange
having to take care of that for my child
something like that should happen spontaneously, right?
I think that would be the first time for him
and with a guy then - -

Coming out

Professional, supported independent living

I find it difficult to talk about it
You don't just casually talk about something like that
I know that about myself
every person has their hobbies

this boy is 19
you could call that grown up
in his case that's not true
he has an intellectual disability, has an IQ of less than 70
he'll have to make do with just that

he has all these different dating apps on his telephone
and he gets messages from all these men

You see, I'd like to start a conversation about that
what do you need?
can't you do it another way?
what can I help you with?
but that's quite the conversation

I picture it like this
this boy can't say no to anything
doesn't draw the line anywhere
these men are all way older
and this boy just came out of the closet

I'm afraid he would tolerate anything
I'm not prudish
I want to protect him
cause forbidding is clearly not possible
should I just pretend not to know?

so, I thought I'm already complicit now
and I bought him condoms
you have to do something

he said he'd never … he told me that he'd never used one
so I just explained him how you can use them
but whether he'll actually do something with them?
I couldn't just go and practice with him

there are of course paid services
even for men nowadays
I've already inquired some
but that's sensitive with the family
they don't know he's attracted to men

Chapter 3

Tinkering as collective practice: a qualitative study on handling ethical tensions in supporting people with intellectual or psychiatric disabilities

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ABSTRACT

The values of patient autonomy and community participation have become central in healthcare. However, care practices involve a plurality of possibly conflicting values. These values often transgress the borders of the individual professional-client relationship as they involve family members, other professionals and community organizations. Good care should acknowledge this relational complexity, which requires a collective handling of the tensions between values. To better understand this process, we draw on Mol by developing the notion of collective tinkering. An ethnographic study was conducted in two teams in community housing services for people with Intellectual Disabilities and Severe Mental Illness. Collective tinkering is analyzed 1) within teams; 2) between professionals, family members and professionals from different organizations providing care for the same client; and 3) in organizing practices for a collective of clients. Collective tinkering involves assembling goods into a care practice, attentively experimenting with these care practices, and adjusting care accordingly within a collective of those involved in care for a particular client (group). When collective tinkering does not occur, the stakeholders excluded (e.g. clients or family members) may experience poor quality of care.

INTRODUCTION

The care relationship is an important part of the quality of social work [1-3]. While the determinants of the quality of the care relationship in long term care have been described, the ethical dimension of what constitutes a good care relationship is often overlooked [4,5]. It is important to study this dimension as different values play a role in the care relationship and need to be combined in care practices.

Addressing the ethical dimension is currently specifically prudent in relation to tensions with the value of autonomy. The value of autonomy has gained prominence and is promoted in care models such as recovery-oriented care, rehabilitation or person-centered care [6-9] Highlighted in these care models is the involvement of clients in care planning [7,10], the support of clients in managing activities of daily living and participating in the community [6,11,12] and the move from institutional settings to supported independent living [13-15]. This focus on autonomy has increased the complexity of the care relationship as is pointed out by care ethicists and shown in ethnographic research [16,17].

How individual professionals provide good care while handling this complexity has been conceptualized as tinkering, which is often described in the analysis of the relation between an individual client and a care professional [18,19]. However, care is often a collective practice, where teams, family members and professionals from different organizations collaborate [20,21]. Insight into how professionals handle complexity within these collectives is currently lacking. Our study develops a notion of tinkering as a collective practice through ethnographic fieldwork in community housing services for people with serious mental illness (SMI) or intellectual disability (ID). This way, we contribute to theories on the ethics of care that do justice to the complexity of care practice and provide directions for improving quality of care [18]. We do so by answering the following research question: *how do social care professionals tinker collectively to provide good care?*

This paper proceeds as follows: we conceptualize the complex care relationship; argue how this complexity multiplies when care is provided in collectives and lay out the tinkering approach to providing good care. In the results section we analyze tinkering in various collectives. We conclude by showing how the collective tinkering approach can help to improve quality of care and what it adds to other conceptualizations of ethics and social work.

The complexities of collective care

When complexity is discussed in social work it is often with reference to clients' multi-problems and the number of care-relationships clients are in [22,23]. However, in this paper we direct our gaze to another type of complexity; complexity in terms of how the care relationship is practiced. We do so by drawing on a specific strain of ethics of care which connects with Science & Technology Studies (STS) [18,24]. STS is a scientific field that studies science and technology as cultural artifacts that are constructed and become embedded in our social reality through networks of both humans and non-human actors. Adding to ethics of care this view highlights materiality as relationships stretch beyond humans to objects. Moreover, an STS approach highlights how bodies, objects and subjects come into being through practices (e.g. [25]).

To talk about care as a practice gives a specific focus on how we address the care relationship and its ethical dimensions. It means we do not talk about abstract values on how social care professionals ought to behave, or about what clients prefer social care professionals to do. Instead, we talk about what social care professionals and clients do together when care is practiced. Moreover, the care relationship is not about social care professionals and clients alone. It is also about family members or other important persons in clients' lives and various professionals from different organizations, like therapists providing treatment or policemen providing safety in the neighborhood where clients live [26]. Adding an STS approach points us moreover to the impact of materialities on the care relationship. For example, housing, electronic questionnaires and smartphones can impact this relationship [27-29]. So, when we talk about the care relationship in this paper, we talk about it as a practice between clients and social care professionals amid a collective of people and things.

When we say this care relationship is complex, we refer to two related complexities. First, how there are different ways of doing 'good' care, which may be in tension with each other. What is 'good' practice in a care relationship can vary and conflict. From the perspective of ethics of care, this is not about deliberating abstract principles, it is about considering good care in a specific situation. Good care in this view is about finding local solutions to specific problems. What good care is does not precede practice but is part of it [18]. What is 'good' and should be considered when evaluating or crafting a care practice is plural as it may include many different things beyond values [30,31]. Mol [31] gives the example of eating in a nursing home. Here self-determination matters as people are offered choices in what to eat. Taste matters as well, as does coziness of eating a meal together [32]. These may be in conflict as coziness may entail sitting together in a small group having food on the tables, while choice entails having many different foods available. This plurality of 'goods' at stake in practice makes the care relationship complex. Moreover, values can take on many different meanings and be put into practice in many ways. For example, autonomy as a core value of social work is defined by some as fostering service user's choice and minimizing dependence on others [33,34], while others see it as a relational concept and emphasize interdependence [35,36]. These different conceptions of autonomy give rise to various, sometimes conflicting, practices [37]. Moreover, organizational procedures also embed conceptions of autonomy which can conflict with professionals' perceptions of good care ([32,38]).

A second related complexity in the care relationship distinguished by Mol et al. [18] is about orderings of reality, or multiple ontologies [39]. These ontologies are important to consider as these also determine what is considered 'good'. In this paper we focus on the ontology of clients, on ideas about 'who clients are' and how these ideas shape and are shaped by care practices. We consider the ontology of clients as the dynamic interplay of clients' and professionals' individual understandings of clients' identity which shape what people can make themselves up to be [40]. Ontology is not merely discursive but is enacted in material practices [39]. That these different ontologies shape the notion of good care can be illustrated by an example from the work of Pols [41]. She shows how different practices of washing clients in mental health institutions for elderly enact clients either as patients who are repressed by being subjected to a regime of hygiene or as (becoming) citizens working towards being part of the community. Moreover, she shows how different washing styles enact clients as different citizen types, for instance focusing more on client's choice making, on learning to be independent or on relating to others. This example shows the 'same' client can be enacted differently through different practices. These multiple enactments may be in tension with each other which adds to the complexity of the care relationship.

Tensions aggravate when professionals, clients and family members have different views on what is good care or hold different ontologies of clients [37,42]. Moreover, clients often receive care from a multitude of health and social services including supported living, sheltered work and leisure activities. As providing integrated care is increasingly emphasized to be important, different conceptions of good care between professionals of these different organizations or different ontologies of clients may increasingly surface as well. It is therefore important to gain insight into how these differences are dealt with.

How to provide good care within the complex care relationship: collective tinkering

In light of the above, Mol et al.[18] conceptualized good care as: "Persistent tinkering in a world full of complex ambivalence and shifting tension" (p.14). Tinkering in this definition is about finding local practical solutions through attentive experimentation;—a reflective and experimental process of all involved, through which care practices are invented that bring together different goods and ontologies. The effects of these care practices need to be attentively followed as what is 'good' can only be established in practice. As clients and contexts are ever changing, different goods, ontologies and tensions are brought to the fore. Tinkering therefore is an ongoing process. As care practice is a collective of people and things, tinkering also relates to the material objects that are part of care practices. These need to be adapted to the situation and vice versa to create good care in a persistent process of tinkering [30]. Compared to person-centered theories and models, the tinkering approach emphasizes experimenting with practices over shared decision-making. Moreover, the tinkering approach is relationship-centered rather than person-centered as it focusses on how goods put forward by both clients and professionals are assembled in a practice [18,19]. The advantage of this 'tinkering approach' to good care is that it aligns with how social care professionals already 'do' good care amidst the complexities that they face, as this concept was developed through ethnographic studies on care practices. The added value lies in making visible and strengthening these practices [19,43].

While tinkering is posed as a relational concept that can be used to understand complex care practices, including all relations important to providing care, it is mostly used to analyze the micro-relationships between professional and client. Despite some exceptions [16,20,21,44] there is little focus on the wider network of care relations, including teams of professionals, informal caregivers and other health/social care providers [45]. As argued in the previous section, complexities and dynamics in such settings abound, as well as the need to handle tensions between different goods and ontologies. As care is increasingly a collective effort, handling tensions between goods and ontologies has become a collective process. Who is part of this collectivity is defined in practice as those involved in the care of a particular client. This may include family members and professionals from other organizations but also managers at the organizational level as their policies co-constitute care. This raises the question how tensions between different goods and ontologies are tinkered with within such collectives. Our study takes up the challenge of conceptualizing collective tinkering through conducting ethnographic fieldwork in community housing services for people with SMI or ID.

METHODS

Study design and setting

This ethnographic study took place in a Dutch community service organization that cares for people with SMI or ID. Autonomy-related values such as self-determination 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). This was a purposeful sample in which teams were selected to include diversity in terms of housing arrangements and service user population. Excluded were teams specializing in specific groups of service users, for instance with previous homelessness or addiction. 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, including goals for care that are negotiated between clients and professionals which are 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.

Participant observation

Participant observation was conducted by the first author and enabled observing care practices as they unfolded. The fieldwork took place over six months, three months in each team, 12 visits totaling 19 hours for the first team and 12 visits totaling 65 hours for the second in the period from autumn 2017 to spring 2018. The first author observed shift handover meetings when all clients were briefly discussed (team 2); bi-weekly team meetings (both teams); coffee moments for clients (both teams); meals (team 2); care moments (both teams); informal discussions between professionals in the office (both teams); and activities in the dayroom of the communal house (team 2). 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 clients and observe care practices. Instead, the researcher had to accompany professionals when they provided care, which meant clients had to agree with the researcher's presence before rapport could be established. Clients 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 clients 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. These are experts-by-experience that provide support to clients. As they worked in different teams, they could elaborate on complex situations they had witnessed, serving as co-ethnographers in situations that did not cater for the researcher's presence.

Interviews

In depth- interviews were conducted by the first author to gain insight into the complexities of fostering autonomy and community participation. Table 1 presents an overview of participants.

Professionals either were trained as social workers at a University of Applied Sciences or as support workers through post-secondary vocation education or on the job through a training institute by the community care provider.

Table 1 interviews

		Care team 1 SMI	Care team 2 ID
		N	*N*
Interviews	*Service users*	8	12
	Peer support workers	8*	
	Family members	3	4
	Family support workers	3**	
	Professionals	8	10
	Team coaches	2**	
	Team managers	1	1
	Managers on the organizational level	3 **	

* In multiple teams; ** not in a team

The topic list was similar for all respondents and opened with 'What do you find important in the care relationships you are involved in?' Each mentioned 'good' was prompted for narrative exploration of situations in which the value was easily practiced or proved complex when different goods were in tension. When autonomy related values such as self-determination and (community) participation were not named spontaneously, these were prompted by the researcher after spending elaborate time exploring the situations brought up by the interviewees. Prompts were formulated openly and enquired about both positive and negative experiences. For instance: "As you may know, self-determination is also something that is part of the mission statement of this organization. Which situations do you recall in which it was either easy or complex to foster self-determination with clients?" Interviews were audio-recorded and transcribed verbatim. Five clients and one professional did not want to record their interview. In these cases, extensive notes were taken during the interview which were elaborated on shortly after.

Data analysis

The various complexities described by respondents and observed during fieldwork were analyzed thematically by the first author and refined in deliberative sessions with the three other authors. The first round of inductive coding was guided by three questions: (1) which goods do different stakeholders find important for good care; (2) when goods are put into practice, which situations are complicated by tensions between different goods and ontologies; (3) how do stakeholders tinker with the tensions? This analysis was refined through discussions in data validation sessions.

After the first round, it struck the researchers that tinkering not only involved service users and professionals but was a collective process including individual service users, professionals, family members and other community organizations. This became the focus of a second round of coding, guided by three questions: 1) how do collectives tinker; 2) who is involved or excluded in tinkering; 3) how is collective tinkering shaped by the organizational context of the care team? Open coding guided by these questions was followed by a round of axial coding and selective coding. For this process of coding we used constant comparative method as described by Boeije [46]. Coding was done in Atlas-ti.

Data validation sessions

For purpose of member check and data enrichment, five data validation sessions with service users, professionals and family peer support workers (see Table 2) were held.

Table 2 Data validation sessions

	Care team 1 participants SMI	Care team 2 participants ID
Service users	5	5
Professionals	8	9
Family peer support	6 (both SMI and ID, not in a team)	

For these data validation sessions vignettes (five to eight per group) were developed by the first author through thematic analysis of the data (see first round of coding). Each vignette described complex situations containing tensions between different goods derived from participant observations and interviews [47]. Each vignette was read aloud by a facilitator (the first author and a member of a patient advocacy organization) or participant of the focus group. The facilitators then prompted reflection on these vignettes by questions such as: 'Is the situation in the vignette familiar to you, or not?'; 'What important experiences in the care relationships you are involved in are missing in these vignettes?' For service users and professionals all participants of the interviews were invited. As most interviewed family members had expressed their reluctance in joining a group discussion due to time restrains, this data validation session was organized with family peer support workers only during one of their monthly peer-to-peer coaching sessions.

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).

RESULTS

In this section we analyze tinkering as a collective practice, focusing on three types of collectives: (1) a care team including clients and family members; (2), a care team including clients, family members and other care/community organizations; and (3) a collective of clients for whom care arrangements are created. Each theme discusses tinkering in a complex situation that occurred in both teams, that various team members mentioned, and that participants in data validation sessions recognized as complex. The cases of three clients – John, Max and Jesse (all names are pseudonyms) – are highlighted as the data collected on these cases most clearly show the differences in the way the two teams included in the study managed or did not manage to tinker collectively.

Tinkering in teams including family members

A complex situation highlighted by many professionals is when clients neglect to do the grocery shopping they feel is required. One example of tinkering within a team is the case of John. John has an ID and has suffered psychotic episodes and is cared for by team 2. He lives in an apartment owned by a social housing company a few blocks away from the communal home and office of the care professionals. John has a weekly grocery allowance. Responsible for his own money and meals, John gains self-determination. Impulsively, however, he often buys expensive takeaways or flowers for his girlfriend, leaving him without money to buy food at the end of the week. This then puts professionals in a difficult situation as they also want to prevent the harm of John not eating properly.

John's contact moments are provided by the team members scheduled for that day. The team needs to work collectively to align their approach, for when he comes to the care unit to ask for food because he is out of money. John's sister is also involved as he asks if he can eat at her place. The sister doesn't mind having John over but wants him to learn how to take care of himself. This situation requires the team, with the sister, to arrange the value of self-determination while preventing the harm of not having food. Their collective tinkering involves chatting in the team on shift, at shift transition meetings as well as formal discussions of cases at bi-weekly team meetings. This structure fosters team communication *about* clients. It does not include clients or family members however. Family involvement depends on the efforts of individual professionals. One of John's professionals keeps in touch with the sister, frequently discussing his situation on the phone and asking for her input.

Needing to find a way to arrange these goods, the team experimented on doing the grocery shopping with John. The practice was then consolidated in John's care plan and the schedule that structures the professionals' daily tasks.

> "*We see him every week. Then he gets his grocery allowance, signs for it and we do the food shopping together, for the whole week. He's really good at it, always buys healthy products, and he's a super cook. In his case you present the organization's rules with sort of white lie. You tell him, we need to come along because we need your receipt for the bookkeeping. Every*

> *now and then it goes well, maybe twice in a row, and then we say, go on your own, but then it fails again and on Sunday he'll turn up at the care unit because he's run out of food and wants to eat with us or asks for bread. Well then, you take over again, make him go shopping with you but you only follow him, you needn't do a thing. Just the fact you're there limits him in his self-determination because he feels he has to do things right."*

Helping John with his shopping is not a one-time decision but an iterative process, evaluated and adjusted when necessary. Professionals experiment with what John can do by himself, attentively observing what happens and adjusting their actions accordingly. However, this arrangement creates tension with other goods, of being honest with John – why they go grocery shopping with him – and of helping him sustain the positive self-identity of a 'big man' capable of handling his own housekeeping. The ontology enacted about John is of someone capable of making healthy choices and cooking for himself but hindered by poor impulse control. The goods and ontology are then assembled in the care practice of presenting grocery shopping to John with a white lie: they tell him the care organization demands receipts from clients under curation.

In John's case different values and ontologies are assembled in one care practice. The case of Jesse (team 1), however, shows that collective tinkering does not always happen, which impacts the quality of care. In this case the client neglects his house. It is contrasted with the case of Max, cared for by team 2, who does the same but in his care collective tinkering within the team does happen.

Jesse receives support for independent living. He lives in a studio apartment with kitchen and bathroom in a building he shares with four other service users. Jesse used to study art and live in a student home but became homeless during a first episode of psychosis. His symptoms have diminished with the use of medication and Jesse is in a process of finding a vocation. Jesse likes to spend evenings reading and drawing, while having a glass of wine or a beer. His room is covered with paintbrushes, dirty laundry, dishes and cigarette buts. The problems for Max are much the same as Jesse's. He lives in a small room in the communal house, bordering the living room. His room is crowded as he moved in from a big apartment and brought along all his precious possessions. The only free walking space in the room, surrounding his bed, is full of dirty dishes and laundry, trash and cigarette ash.

In both cases, team members differ on how they work up the reality of who the client is, and which goods should be prioritized. In Max's case, some team members see his unhygienic living conditions as due to personal incompetence. Others see Max as someone able, but not willing. These different ontologies evoke different values in caring for Max. If Max is incompetent, good care involves helping him clean. If Max is competent but unwilling, helping him would hinder his goals to live independently. The team agrees that living in neglect will pose harm to Max. Something has to change. The team organizes his care collectively. Daily tasks, such as reminding Max to clean his room, are put on an agenda that the professionals who happen to work that shift execute. The team discusses Max's case at the twice daily handover meeting between shifts or at their bi-weekly meetings.

This is different for Jesse as team 1 has limited structures in place to discuss clients. Clients are cared for individually, with one or two caretakers making appointments with the client. This team has no meetings between shifts, where they discuss all clients, only monthly meetings where they discuss only those clients who the professionals have put on the agenda. In Jesse's case, some professionals in the team stress the value of self-determination, pointing out that Jesse might not share the norms of having a tidy house that other team members might have, and that the entire team should abide by how Jesse wants to live. Other team members emphasize the value of preventing harm from living in unhygienic conditions. Although the team discusses Jesse's case, they do not negotiate on the different values. The professionals favoring the value of self-determination simply convince the others that good care for Jesse means following his wishes. The team decides to stop helping him clean his room.

> *"So, I have this client who everyone finds really smelly and difficult. And they have a point, he is a bit stinky. When it comes to cleaning, he just lets things go. So, I try to tell the team that we're not talking about 'Mr. Stinky', we're talking about Jesse, who's just like… like… anyone else and a very smart guy. But Jesse says: 'I don't like things clean and tidy.' We have to know that, we have to understand how it works for him, and we shouldn't go there every Friday and make him feel uncomfortable by cleaning up his place."*

Instead Jesse's care professionals do sometimes nudge him to clean his room. For instance, by reminding him his laundry will start smelling bad if he doesn't launder it soon. This however seems to have limited effect in terms of the state of Jesse's house and thereby only limitedly attends to the tension between the value of self-determination and other values such as preventing harm from living in neglect. Not attending to this ongoing value tension stops the team from inventing experiments that would assemble the different goods and create 'better' care. Moreover, the team excludes the views of Jesse's mother from the conversation. She contacts the professionals several times, expressing her concern about the possible harm of living in neglect and feels that the approach chosen does not foster an independent lifestyle. While the professional holds an ontology of Jesse as someone capable of deciding for himself on his household, mother's ontology is different. She does not see him as fully capable. Instead, she pictures him as being too hindered by his symptoms to accept help in cleaning.

> *"At one point I thought, this room is filthy. The professionals kept pointing to his autonomy. I said, 'The situation is out of control and he was offered help, so will someone from [care organization] please help Jesse clean his room.' Well, Jesse didn't want that. Because you're touching his stuff, I get it. But they could have taken a structured approach. It would've benefited him, being able to do his own cleaning in due course. […] Of course, he'd say no. That's part of his schizophrenia, to say no to that sort of thing. It fits the diagnosis. Just say no […]. But you start thinking, it must go wrong sometime, he'll either get food poisoning or some other nasty disease."*

The team did not take the mother's view into account in their decision on how to care for Jesse. This not only limits their creativity in crafting care practices that arrange the differing goods, it leaves the mother feeling that Jesse is not receiving good care.

In contrast, team members realized that for Max, emphasizing the value of self-determination and leaving him in neglect simply does not work as it evokes ongoing tension with the value of preventing harm. This tension fosters a creative experimentation process to find ways to not interfere with Max's autonomy yet improve his hygiene. They follow these experiments closely and invent new ones when they do not work. Failed experiments include reminding Max to clean his room, telling him the consequences of not cleaning and to thoroughly cleaning his room themselves when he is on holiday. Some interventions disturbed Max, and none led to cleaner conditions in the long run. The team then decided to arrange for a professional to come help him every other week. This seemed to have a better effect and even Max was content. As he explained to me when we were eating a jelly pie he had made, he now feels he has more 'living space'.

Even though in Max's case it looks like collaborative tinkering created 'better care', this is not the end of the story. While team members agreed on the assemblage of goods in the experiment, they still held different ontologies on who Max is. Some felt that Max should get ongoing help as clearly he could not keep his room tidy on his own. Others felt that helping him clean risked keeping him lazy and would stop him from being able to do his own housekeeping in due time. For these team members the tension between the values of preventing harm and developing independence persist. This ongoing tension might motivate the team collective to invent new experiments negotiating these values in the future.

As in Johns' case, both Jesse and Max were left out of the team's collective tinkering process. Professionals often tried to engage clients in their own care, for instance through developing a personalized care plan in line with the value of self-determination put forward in care models such as recovery or rehabilitation. However, many decisions on client's care were taken in meetings between professionals. Here clients' needs were advocated by team members. While some ontologies and values put forward in team meetings likely have been influenced by conversations they had with clients, team members often did not engage in depth with clients to understand clients' needs fully on their own terms. Instead, team members decided on what represents value for clients and who they make themselves up to be, in ways that sometimes did not altogether align with clients' own views. Moreover, the teams barely considered material arrangements that co-constitute the tensions between values and ontologies.

Both these points are especially clear in Max's case. He points to the importance of material arrangements in constituting his situation. Interviewed, Max felt that his 'neglect' was caused by not having enough space to keep all his valuables because he had moved in from a larger apartment. As far as he was concerned, he is not lazy, because he does valuable work as a DJ on his own online radio station. He prefers the privacy of his room above sitting in the communal areas but due to the limited space he cannot work anywhere else than in bed. If the team had considered Max's goods, his definition of himself and the material arrangement, it might have fostered the development of care practices that better fit his needs. In other cases, professionals seemed to represent clients stated needs more adequately. For instance, in Jesse's case, where care is crafted on the single value of self-determination, his view on housekeeping seems dominant. In terms of collective tinkering, however, this is not 'good care' as Jesse was left out of the decision to exclude the goods of developing an independent lifestyle and preventing harm from his care practice.

In conclusion, tinkering collectively with both professional teams and family members brings together a multitude of goods and ontologies that creates tensions. When tensions are attuned to, teams and family members may invent care practices that assemble the various values and ontologies. Attentively following and adjusting the experiments may lead to providing good care. Collective tinkering requires a consideration of material arrangements and depends on structures that permit team members to discuss clients together. Both care teams 1 and 2 lack the structure to tinker collectively with family members, which makes family involvement highly dependent on the efforts of team members. Opposed to tinkering in professional – client relationships, clients are seldom involved in nor structured into collective tinkering.

Tinkering in teams including other care/community organizations

The second type of collective tinkering we analyzed takes place between team members and other care and community organizations.

A complex situation both teams encounter is when clients make friends with people who manipulate them into criminal activities. This then requires collective tinkering with a wide range of organizations, including other care organizations, local police and the municipality. Both teams had cases in which clients were manipulated into money laundering or growing marihuana in their homes. In care team 2 this situation involved John. John wanted friends and let a few 'cool men' befriend him. They often spent time in his home and one of the men even slept on his couch. John's sister found out about this and suspected possible harm. She questioned the good intentions of the men and wondered if John really desired this situation or if he was simply not capable of refusing the men. She contacted the care professional who took her concern seriously.

> *"He's looking for friends, of course, but they're not always the right friends. […] Once I wanted to come over and he said, 'No, you can't,' and he was so stressed. I found his response very strange. So, I went on asking about it and finally he said there were men in his house who didn't want to leave. So, I told the professional, who took it very seriously and looked into it straight away. And it turned out that there were indeed men staying in his house. So there too you have this question of self-determination. But how far do you let the situation go? […] Those men were just taking advantage. John didn't know how to solve the problem. And he didn't ask for help because he thinks of himself as, let's say, a 'big man' who should solve his own problems. I get that too, but naturally the solution is to ask for help. He finds that hard."*

The professional found out that John had given the men access to his bank account and they were money laundering, depositing criminally obtained money and withdrawing it in cash on John's bankcard. They also put several mobile telephone subscriptions on John's account. John collaborated in this as the men offered him a few Euros in return, making John feel he was one of the 'big men' which is what he wanted, according to this professional. Different goods were in tension here. John's bank account facilitated self-determination on spending some of his money and fostered an independent lifestyle because he could do some of his own shopping. After some deliberation, the care team and John's sister decided that the situation posed too great a risk for John and they crafted a care arrangement for his money to be kept under curation.

Later on, John wanted to fix up his house, but not having a lot of money he posted an add on Facebook asking who might want to help him. A few men replied. So far John's situation follows the autonomy-related value of community participation. One of the men didn't have anywhere to live and proposed living with John while he worked on his house. One of the team members learned of this and suspected potential harm. A professional with a good relationship with John tried to find out more about the situation and learned the names and home village of the men. He contacted a care professional he knew in that village to get information about the men. This care professional knew the men and suspected they wanted to use John's house to grow marihuana. This unfolding tension then required assembling the goods at stake: John's self-determination versus preventing John from the harm of complicity in criminal activity.

John's ontology of himself also needed to be part of the negotiation, or at least the professionals' representation of it. As John was perceived to see himself as 'a big man' he would not easily accept that these men were not his friends but were using him. The professionals from the different care organizations did not want to harm Johns' self-esteem by trying to convince him that he was being used. Thus, they crafted a care practice assembling the goods and ontologies. The care professional who knew the men would inform them that John's care organization had eyes on them, and the police would be called if they pursued criminal activities. The experiment worked: the men stopped seeing John and John had his house to himself again, which sadly was not fixed up but left rather decrepit.

This incident made another tension clear. As John lived a few blocks away from the care unit and rented his own house from the social housing company, his care workers had little oversight. This material arrangement contributed to the professionals being quite late in picking up the potential harmful situation and were limited in their interventions as they were not allowed to enter the house, change the lock or set rules about who could come in. These values were assembled in a new material arrangement by moving John closer to the care office into a unit owned by the care organization. This also required the involvement of a wider collective of stakeholders, such as the manager agreeing to the move and the care organization providing one of their houses. For John, having friends and being one of the 'big boys' was also an important value at stake, as was perceived by the professional which, however, this new care arrangement did not address so much.

In conclusion, as people move to community settings and participate more in the community, this enlarges the potential care network with other people and other organizations. Material arrangements also co-constitute care practice. This requires professionals to work collectively in networks and take the material arrangements into consideration. To provide good care, tinkering transgresses the borders of the assisted-housing service. However, daily care practices are not structured for this type of collective tinkering. Whether or not it happens, and who is involved, depends on the quality of the professionals' relationships with others in the care network and the personal efforts made by individual professionals.

Tinkering for a collective of clients

Collective tinkering not only happens in relation to individual clients. When creating care practices for a collective of clients, goods and ontologies also require negotiation. This may also involve other layers in the care organization beyond the team, such as managers working on an organizational level.

A complex situation both teams mentioned centers on clients' loneliness. One care practice addressing loneliness for a collective of clients involves organizing 'coffee moments'. Here again different goods and ontologies need to be negotiated. On the one hand, coffee moments are seen as potentially limiting community participation, as clients are then less inclined to seek social contact in the community. On the other hand, coffee moments are seen as providing a place for peer support in a safe space, where stigma is limited. Here the values of community participation and providing peer support are in tension. Meanwhile, multiple ontologies of clients are evoked: as clients capable of engaging in social relations in the community and as vulnerable clients needing a safe space to foster social contact. One professional in the first team voices these tensions:

> *"Some professionals believe in group stuff, while I believe in the individual approach. Group sessions are nice, having coffee once in a while [...] and catching up with others. Like on Sundays when the activity centers are closed. But don't have coffee moments for the sake of having them, every day a cup of coffee. They should go to an activity center, or a cafe. Then they'll meet new people and join the community. When they ended up in the healthcare system, they were cut off by society. And now they are allowed back in again. So, let them try, for God's sake. Don't arrange things in-house if it's not needed otherwise they'll never meet other people, be in the community."*

The two teams assembled these tensions differently, resulting in different arrangements for the coffee moments. Care team 1 organizes coffee moments on Sundays only, as this is when most community options for socializing are closed. This is reflected in the material aspects of this arrangement. The space where the coffee moments take place is not inviting. It looks like a conference room and is in fact the same space were team meetings take place. In care team 2, the value of offering peer support in a stigma-free environment resonates more with the team members, as is expressed by the following quote.

> *"It is important to facilitate [...] those coffee moments. You could call that inward-looking. But Ryan, with snot in his hair and Emma, who stinks, they're not going to be invited into people's homes. But they do come to these coffee moments. And so, you bring them together. Nobody here ever says, 'Did you notice how badly Emma smelled? Or how filthy Ryan is?'"*

Care team 2 arranges coffee moments twice a day in the communal living space of one of the houses where resident's live together. This material arrangement adds to the homely sphere. Clients who receive care from this team but live independently are welcome too. This way of organizing coffee moments was under threat as managers on the organizational level introduced a policy to arrange housing in such a way that every client has 'their own front door'. This policy was introduced to materialize the value of living an independent lifestyle. Due to this policy, care team 2 was in the middle of re-organizing the housing situation. Service users were moved one-by-one to their own apartment, each with their own kitchen and living space.

This rearrangement led to the demise of the coffee moments as this new set-up offered limited space for organizing communal moments. Social contact for service users was also reduced as clients could now more easily decide for themselves to stop socializing with their neighboring service users, as they no longer shared a house and occasional coffee moments were no longer in their own home. This example makes clear not only that professionals need to adapt care practice for a collective of clients but also that collective-client practices are enabled or limited by other layers in the care organization, such as managers.

The new context required inventing new experiments in assembling the values of promoting well-being through social contact, self-determination and independent living. The value of preventing harm was also part of this assemblage as professionals feared lonely clients would be more prone to engage with people who could take advantage of them (see the example of John). The team experimented with connecting service users to community organizations that arrange 'buddy contact'. Although the team felt this was not the best way to facilitate social contact, the corporate 'own-front-door' policy for service users limited their ability to provide the social contact they wanted, through regular, easily accessible coffee moments. Here, the team and organization managers undertook no collective tinkering, no experimenting with other material arrangements to assemble the values of providing social contact and fostering an independent lifestyle.

In sum, teams tinker collectively in creating care practices for the client collective. These arrangements need to handle the tensions between values and ontologies by assembling them differently and adjusting them to the ever-changing contexts. Here other stakeholders, such as managers may be implicated. Adding to previous points on the lack of structure for collective tinkering, this case shows that teams may have limited means in tinkering with organization-wide policies that impact care practices.

DISCUSSION

Community housing services are increasingly organized through individualistic practices such as the move from group homes to independent living arrangements. However, social care professionals often still have to collaborate, and in some cases even more so, with others to provide good care, such as team members, informal carers and professionals from other organizations providing care to the same clients. Practicing care in such collectives is complex as different goods and different ontologies of clients are in tension, especially as autonomy has gained prominence. Good care amidst these complexities is enacted through persistent collective tinkering: attentively experimenting with care practices in which different goods are assembled in collectives of people and things.

The complexity of providing care collectively in the light of ethical tensions is still barely studied in social work literature [48]. Some studies do describe ethical tensions related to teamwork and collaboration with service users and family members [49,50], inter-professional and multi-organizational collaboration [51,52] and between professional and organizational values [53]. We align with these studies by taking an empirical and situated approach to ethics [54] and promoting ethical pluralism [51]. However, our notion of collective tinkering, which is embedded in ethics of care and STS [18], expands these discussions of ethics in social work in several ways.

First, by expanding ethical pluralism beyond values to a plurality of 'goods' including different orderings of reality (ontologies) we were able to conceptualize how tensions are negotiated in situated practices (e.g. clients either as unwilling or unable to do household work independently, such as in the example of Max). Second, by including materiality in ethical negotiations (e.g. think about the communal rooms for coffee moments, or the small room of Max impacting care decisions of professionals) we were able to show how material arrangements and settings provide for specific affordances as to how 'good' care can be negotiated. Third, by focusing on how collectives bring together different goods within care practices we were able to shift attention to the 'doings' of good care. This focus on ontological politics, materiality and practice puts this approach apart *f*rom dialogue-based hermeneutic approaches to negotiating ethical tensions, as these accounts highlight merely the discursive practice of dialogue [55]. Other ethical concepts such as 'ethics work' do put practice central stage [50,56], however, the work of collective tinkering is not encompassed in current conceptualizations of ethics work. Collective tinkering adds a type of ethics work *focusing on how* social care professionals provide good care while assembling different goods in practice in collectives with clients and others that care. Here ontologies and materially come to matter too. Through developing the notion of collective tinkering, we not only enrich the understanding of ethics work, moreover – in line with the ethics of care agenda – we strengthen care practices in social work [56,57]. Here lies the added value of our approach to social care professionals, the notion of collective tinkering enables them to articulate their work in bringing about good care. At the same time the notion of collective tinkering sensitizes them to engage with other (human and non-human) actors and assemble different 'goods' together in practice.

Our notion of collective tinkering differs from 'individual' tinkering between professionals and clients in several ways. First, by including stakeholders involved with the client, collective tinkering adds goods and ontologies important in dealing with the situation which aids the creative process of inventing and experimenting with the care practices that assemble these goods. Different views on ontologies or values within a collective may continue even when a care practice is assembled. This creates tensions that might drive a collective to keep experimenting with other ways of caring, possibly inventing even 'better' care. When tinkering is not a collective process, for instance when team members are not engaged or family members are not involved, as is shown in the case of Jesse, these stakeholders might feel that the quality of the provided care is poor, given that their goods are not assembled in the care practice.

Second, collective tinkering needs organizational structures beyond direct professional-client contacts. Structures that provide the time and space for the wider collective involved in care to come together, reflect and shape care practices. Policy contexts, both on the national or organizational level partly bring such structures into being. In the UK context for instance, safeguarding policies would have provided a structure for interdisciplinary discussion of cases of abuse both by criminals such as in the example of John or from self-neglect in case of Jesse [51,58]. Also, on the organizational level there are differences between teams that have structures for discussing cases together, such as regular team meetings. However having structures in place for discussing cases does not suffice as tinkering requires professionals to feel safe enough to express doubts and dilemmas, actively deliberate on different goods and ontologies, assemble these in care practices and keep on evaluating and changing care practices to come to a better assemblage of values or to tune in to changing clients or contexts. Thus, even if there are spaces where professionals meet to discuss complex cases, collective tinkering need not occur. Moreover, in many contexts existing structures for discussing cases are insufficient for collaborative tinkering as stakeholders such as family members, other layers of the care organization or professionals working in other community organizations are not included. This makes this kind of collective tinkering dependent on the efforts and networks of individual professionals. As Rutz and de Bont [59] show in the case of youth inspectors, structures that permit collective deliberation to handle complexities improve the quality of compromises. It would thus seem that including the wider collective in tinkering would add to finding more robust goods.

This also includes the position of clients, which we found had no or a marginal role in collective tinkering, resulting in care that does not include their ontologies of themselves or the goods they prioritize. While clients and professionals may tinker in their personal care moments, clients are hardly present when teams of professionals, family members or other organizations assemble different goods and ontologies into care practices. This reflection of asymmetric power relationships demands critical examination [60]. Partly, the lack of client involvement in collective tinkering might be understandable in the context of community housing services. When situations become especially complex, clients often seem hindered by their competence or symptoms, at least in the eyes of family or professionals, and are thus deemed unable to maintain a coherent view of the potentially harmful consequences of their actions (e.g. John inviting criminally-minded men into his house). Research shows in other cases that clients are only minimally involved when their physical state hinders their ability to let themselves be heard [31] or when they are deemed limited in their competency to decide what is good for them [16]. Even in cases where clients have been assessed as lacking capacity in decision-making, involving clients with disabilities in tinkering is certainly not impossible, although it requires professionals to emphasize clients' experience-based expertise over their perceived incompetence [61]. A heuristic framework of how clients are negatively affected by care aimed at promoting autonomy might sensitize professionals to clients' concerns, thereby aiding professional in including client's perspectives in tinkering. For instance, how moving to an independent living arrangement can increase loneliness [62].

Moreover, for clients to voice an opinion of 'good care' in a group of professionals and be an equal partner in deliberating the different values might be quite demanding for clients with ID or SMI and for professionals too [50]. The challenge is to create space and means for negotiating different goods where such epistemic injustice is alleviated [63,64]. There have been calls to create deliberative spaces in which all involved in care, including professionals, clients, family members and managers negotiate complexities related to values together [65,66]. However, for collective tinkering, deliberation is not enough. In order to enable collective tinkering, reflective spaces also need to engage collectives in designing care practices that assemble different goods together. Promising in this regard are processes based on experience-based co-design which allow for collective tinkering on the basis of input from experiences with care practices [67].

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Macaroni

Client, supported independent living

I'm a great cook
I've done it so many times
first you need to boil the water
then you add the macaroni
and then - -

I know about macaroni
I like it a lot
but something should still be added

and you won't tell me what that is!

first, I should do groceries
and then I'll choose what I'm buying
I've done that so many times

I now where the store is
and that store is so large

but when I stand between all these things
I don't know what I was there for anymore

then it slips my mind
and I do know it anymore
that's when I go to bed
and leave it
no food in that case

I'll just go to bed then
and won't even shower
there's no use in it
completely no use

Astronaut

Client, supported independent living

and my coach says: is it cleaned?
and I say: yes
it's tidy
take a look
It's completely tidied

but my coach doesn't think so
I don't know what I could still tidy
here

my coach says:
"it's one of your goals
a clean room"
But it is cleaned!
I'm so tired of hearing:
"clean your room first"
I'm not a child, right!

but I did it
It is completely tidied
who says it isn't?
isn't it enough?

nobody ever asked me
whether I think is important
"It's a goal"
but It's not my goal
My goal is that it becomes cozy
and it's not cozy now
because it's such a problem

And I won't do it
I have better things to do

I want to become an astronaut
and I'll fly then
and I'll look at the earth from the moon
and see everything
even my room
and I'll take a picture
and you'll see
on that photograph my room is completely clean

Diagnosis

Client, supported independent living

when people know that I have autism
or borderline
or schizophrenia
they think I'm completely insane

but I'm not insane at all
I just have autism
or borderline
or schizophrenia

not all at the same time
that would be something right
but sometimes it is

kidding
I'm sensitive to having psychoses
I might have delusions sometimes, I guess
that's when I think there is another world
not just a light one
but a dark world as well
then I turn on the light in that dark world, otherwise
I don't see anything
and I go out with a cross of fire
It's a whole story
but you can just talk to me about that

and if I want to die
which I have sometimes
you can just talk to me about that too

talking is better then
better than jumping in front of a train

everything is because of my diagnoses
that was said to me once

my psychiatrist told me that
but he doesn’t know why
why I am like I am like I am

New neighborhood

Client, supported independent living

You need to participate in society
that's what everyone keeps telling me
the society
but I'm already part of society!?

there are all these rules for it
that may well be
I quite like rules
rules aren't bad
so long as they don't change all the time
that's what I find hard

I have a disability
you might not see it
but I'm never free from my mind
I have a hard time having to adapt
Again and again
to new situations
new habits
new people
It takes a long time to get used to things
otherwise, I panic

now I have to get out of my house
because my house is from the healthcare organization
and they want me to leave
from the neighborhood as well
because the other house
is in a completely different neighborhood

but I have no appetite for another neighborhood
there I would have to learn everything all over

people don't understand how difficult that is for me
and I don't have that many friends

to say who I am
I find that hard
and that must be done again and again

I don’t understand why

Chapter 4

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

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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 counternarrative 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 hours), 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.

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 vacation activities. This can be organized in various types of housing situations ranging from group homes to supported independent living [1]. 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 [2-4]. 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 [5-7], personal recovery through developing a self-identity free of self-stigma and developing a meaningful life [8,9], fostering an independent lifestyle, by developing skills for daily living [10,11] and community participation through vocation and leisure related activities and developing valued social roles [12-15].

Despite the aim of improving service users' empowerment and quality of life [1,16], 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 [17-19]. 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 [20-22]. 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 [23,24].

This paper aims to construct a framework of burdens of support in community housing services as a counter narrative [25,26] 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 and creates a ground for narrative resistance for service users and those who wish to advocate for them. 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 matter [27]. This paper aims to provide such a framework of 'burden of support', for which we build on burden of treatment theory [28-30].

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 [31,32]. Moreover, treatment burden includes emotional impact, such as feeling overwhelmed and hopeless from treatment and self-management related demands [33]. 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 [34]. 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 [35,36]. Moreover, aspects of organization of the healthcare system such as poor care coordination can also contribute to the burdens service users experience [37].

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 [38,39]. 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?*

METHODS

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 [25]. 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.

McKenzie-Mohr & Lafrance[40] state that for being able to tell and hear counter stories, interview questions need to be framed in ways that allow people to talk in new and potentially transgressive ways. Therefor the topic list for interviews with service users, started with the very open question: '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 minutes and 90 minutes. Five service users did not want to record their interview. 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 [41]. Moreover, through photovoice material aspects of burden become visible. 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 [42]. The researcher made notes of these conversations which were elaborated on shortly after. This method enriched themes already brought up in the interviews.

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 [26]. Secondly, participant observation allows the researcher to have informal conversations with service users and informal carers, which was important as Pols [43], points out the capabilities of service users in long term care sometimes restrain them in narrating their experiences in a formal interview setting. 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. Participant observation then also forms a means to capture the non-lingual enacted appreciations [43]. Participant observations took place over six months, three months in each team, 12 visits totaling 19 hours for the first team and 12 visits totaling 65 hours 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 photovoice workshop- was analyzed thematically by the first author. First all data was coded inductively for negative experiences with receiving 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'. Coding was done using Atlas-ti software. The codes developed through this combination of inductive and deductive coding were grouped in four burdens of support through axial coding [44], which will be presented in the results.

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 [45].

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. The experiences of the two service user groups—people with SMI and people with ID—largely overlap and are therefore discussed simultaneously. Differences between the three housing situations—supervised group home, satellite homes and houses where service users live independently in the community—are only discussed when they impact the burdens described.

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 users 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.

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.

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 or 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. When professionals don't put in the extra effort to maintain or develop the relationship this can aggravate the burden of re-placement as it results in signs of deterioration of a service user's (mental) health or signs of being abused by others going unnoticed.

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 [46-50]. 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 to which the burdens of support framework forms a counter narrative, are in themselves reactions to an institutionalized and paternalistic way of providing care for people with ID and SMI. We do not in any way want to argue for going back to this way 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 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 involvement 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 [49,51-53]. User involvement 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 [54,55], 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 [56]. 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 [57]. This 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' [58].

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 de-coupling can occur when professional practice is routinised in ways that no longer contribute to the original aim of the instrument [22,59]. Personalized care planning aims at fostering self-determination of service users. However, when professionals work to finalize the care plan early in de 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 professionals need to act as 'street level bureaucrats' or as 'rebels' in order to mitigate the adverse effects of these organizational procedures or organize re-coupling [60-62]. 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 [18,63-65]. 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. This requires professionals to not only act within the care relationship but also work on developing places of belonging in the community [66].

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 [67,68]. This should not only be a reflection-on-action but also a forward-looking reflection tinkering with care practices and procedures through which professionals can take responsibility for service users' needs, amidst the complexity of their practice [58,69]. 'Tinkering', in this sense should be a collective practice, incorporating the views of different team members, service users and others involved in support such as family members [57]. In order to make sure including service users' views does not remain tokenistic, spaces need to be opened up where service users' or their advocates', counter narratives of burden of support can be voiced and heard [25]. Besides changing professional practices, burdens also are alleviated by organisational procedures and arrangement of places of care. While some of the burden arising from this can be mitigated by professionals in their day-to-day work, engaging them in re-designing these may be more effective. Through co-design practices service users and others such as family members can be engaged in re-designing services in order to minimize burden [70,71].

This study delivers crucial input for the (critical) reflection, collective tinkering and co-design needed to minimize burden of support. These insights have been translated into a method for quality improvement in long term care: the 'Ask Us!' method. 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. Videotaped narratives or poetic representations of these can be an important tool in engaging both service users in reflection on their experiences with care, creating space for them to talk about this in different ways and voice negative experiences while at the same time convey service users experience to professionals in a powerful way [72-74]. The method further comprises of several dialogue sessions where these videos are used to foster service users, informal carers and professionals to critically reflect on their own experiences, deliberate about their different views on good care and design service improvement together.

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 [43].

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.

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Five additional minutes

Professional, homecare services

these people have all sorts of things
but the biggest pain is loneliness
and that's not indicated
a substantial deficit of contact
you could just send them to an arts and crafts hour
but most aren't interested in that
so they stay at home
then I simply make them a cup of coffee
not just cutting their story short and getting out
but a real conversation
look, when you have an eye for it, you see it every day
that people are hurting,
they're alone,
they crave for a moment of real attention
and I know: every minute counts
but I can't bear it to run away
so I just take a bit of extra time
and I help them with the dishes or throw the garbage out
and yes
sometimes I even take some small groceries along
and make a cozy atmosphere for them
even if it's not part of the care plan
and sometimes they'll share these things
whether they should get an operation, yes or no
they're really struggle with something then
because they're worried about recovery
and the costs of a care hotel
what happened recently: a woman had
a lump in her neck
which she had been carrying for far too long
she was so frightened to discuss it
So yes, that's when I talk to them briefly
to have a discussing about her fears of hospitals
and how to overcome them
in those five minutes

According to plan

Professional, homecare services

those colleagues that do extra jobs
make it difficult for me too
because people expect me to stay longer as well
to do dishes , to put the garbage out
and I refuse to do those things they get angry
you shouldn’t do those things
It’s not good for anybody

those extra things are for the relatives
and if the pharmacy is late
they can be angry with me,
but that’s really outside of my responsibilities

the care plan is there for a reason
those are always based on the needs
and if something extra has to happen
they should go to the case manager first

Of course we’ll bandage them
or give insulin on time
Look, I’m really professional in that respect
and really attentive
everyone can judge me on that

but as soon as you do things that aren’t indicated
well, then the horse gets loose from the wagon
or how do you say that,
the chicken escapes its coop
the beast is loose
Because that’s the way it is, people always ask for more
than they get

you should keep expectations clearly framed
and then people try to do more themselves
keeping yourself active increases pleasure
and lengthens your lifespan
that’s why I let people decide on what to wear as
much as possible
I enjoy seeing people doing more things by themselves
lead their own life

Vulnerability

Professional, homecare services

People are easily underestimated
they can do so much more than we think
but we do have to practice with them
I often sit next to them when they're ordering their medicine
or when they inject insulin
they often go a long way themselves
even to their own surprise
and when they succeed putting on their compression stockings
that's just beautiful
and then we can get rid of the care indication
I have one woman for example who I think could
replace her own ostomy
but when I start practicing it with her
she pretends to not grasp anything at all
because she doesn't want to lose contact with me
she's really frightened to lose her care indication
It's being underestimated, what we mean
to those people

and it also has its consequences for me
if these people really develop themselves
and need me less
holes will appear in my schedule
and I have to work more days, with shorter hours
and sometimes with teams I like less

But I don't want to complain
my first priority keeps being the vulnerability of
people
A lot of elderly are confused, instable, forgetful
If I stay away they miss the structure
or a point of contact
prevention
I do much more than putting on or taking
of those compression stockings

Chapter 5

Promoting autonomy in homecare services for older persons: an ethnographic study of different logics of the good care relationship

This chapter is under review at the journal Aging & Society

ABSTRACT

In homecare, professionals are expected to foster older persons' self-determination, independence and community participation. Such values are often in tension. Furthermore professionals put these values into practice in organisational contexts that are heavily influenced by accountability regimes, including time-and-task models that tend to undervalue the relational work that professionals undertake. By combining theoretical insights from 'valuation studies' and 'invisible work', we identify the different logics through which professionals negotiate these tensions and describe the work that remains invisible.

We conducted an ethnographic case study in a homecare team in the Netherlands in which we shadowed registered nurses (n=4), nurses in training (n=3) and aides (n=3) for one shift and conducted semi-structured interviews (n=9). Thematic analysis of the data resulted in three logics of the good care relationship: 'caring for dependent older persons'; 'sticking to the allocated tasks' and 'tinkering with self-determination and fostering an independent lifestyle'. We further identified three types of work and associated worth that remained invisible in these logics: providing psychosocial care, empowering care, and contexting. We develop the concept of 'invisible worth' to shift attention to deficiencies in the valuation of homecare services that render such work invisible. Understanding the logics and their invisible worth can help professionals, managers and policymakers to reflect critically on how to construct good care relationships and its valuation.

INTRODUCTION

The care relationship is an important aspect of quality of care in homecare services for older persons (Jose, 2020) and contributes to older persons' quality of life and health [1,2]. The care relationship should therefore be a key focus of attempts to improve quality of homecare services. For this it is important to gain insight into what a good care relationship entails. Morevover, as this relationship is influenced by valuation regimes, attention should be directed to the way the care relationship is assessed [3]. We contribute to this insight by taking a valuation approach in combination with a focus on invisible work[4].

Our approach highlights how different, possibly conflicting, values often play a role in healthcare practices. However, in assessment practices often only few of these values are brough to the fore, thus stimulating certain practices at the cost of others [5,6]. This raises questions about how the quality of the care relationship can be improved attending to different values and their tensions in the context of assessment practices. In this paper we shed light on this by delineating different logics professionals reason from to negotiate different values in practice and by analyzing the worths that remain invisible as a consequence.

The logics of professionals are informed by formalized processes of valuation. These provide the context in which professionals providing care in homecare services evaluate and enact the 'good' care relationship [7]. Valuation studies approaches the question of understanding what is good (in our case: the care relationship in homecare services) as something that cannot be objectively assessed, but as a social process through which an entity is shaped as having certain types of values. Professionals are socialized within regimes of valuation to understand the care relationship as having certain types of worth [8].

In case of district nursing this influence of valuation regimes can be illustrated by looking at dominant policy trends in homecare. Examples include aging in place (emphasizing values such as extending capacity for independent living, providing opportunities to participate in society and involving informal carers and volunteers [3], person-centered care (emphasizing values such as integrating care and self-determination [3] and new public management (emphasizing values such as efficiency, cost effectiveness and accountability [9]. These policy trends affect professional logics as they influence how they evaluate the care relationship and how they reflect on and make decisions about the care they provide [7,8].

As different valuation regimes can co-exist at the same time [10], they can emphasize different values then can conflict with each other in practice[11]. For example, values part of the regimes of person-centered care and aging in place can clash when older person's self-determined choice is not to become less dependent on professional care [12]. Such value tensions can result in moral distress as what is good care is unclear in these complex situations or dissonance between professionals in a homecare team. However, in valuation studies this plurality of values and its clashes have also been described as something positive, as it can drive creative engagement of professionals with their practice and fosters innovation [10,11].

The logics professionals use to inform their actions are not only influenced by valuation regimes, but also by valuation practices in which such regimes are translated to the organizational level. Examples of valuation practices include quality indicators or audits [10,13]. An important valuation practice in home care services in many western welfare-states is a time and task model. In such a model homecare work is divided in specific tasks for which a set time is allocated [14]. This is shaped by a new public management valuation regime as a time and task model is understood to improve efficiency and cost-effectiveness. The type of tasks for which time is allocated is shaped through other valuation regimes, for instance shared decision making as part of the valuation regime of personalized care. However, also in this case tensions can occur.

From the above it becomes apparent that for gaining insight into what a good care relationship is it is important to identify which regimes of valuation inform actors' ideas on good care, how these are translated to valuation practices and how tensions resulting from these regimes and practices are dealt with in practice. However, it is also important to look at what is left out of these regimes and practices as this can also prove challenging for healthcare professionals in practice. This is the case because it can make certain types of work invisible and less valued [4]. For instance, time to have a supportive conversation can often not be allocated or accounted for [15]. Thus, if we want to learn more about the quality of the care relationship, we should direct our attention not only to what is included in valuation practices but also to what is left out. This is not only about the types of work for which time is not allocated, but also about the values which are expressed through such work.

The aim of this paper is to provide insight into the quality of the care relationship in homecare services and how it can be improved while attending to its value complexities. We do so by answering the following research questions: *Through which logics is the care relationship in homecare services evaluated by professionals and what worths remains invisible in the valuation practices and valuation regimes professionals are embedded in?* Answering this question can help professionals to critically reflect on their practices and attend to the breath of activities important in bringing about a good care relationship. Moreover, it can facilitate actors in homecare organizations in designing practices that bring about a better care relationship.

METHODS

Setting

This research was conducted in a large care organization providing personal care and nursing care, operating in a large city in the Netherlands. The home care team where this research was conducted covered a low-SES neighborhood. The team comprised of a community nurse who is responsible for allocating time to clients in co-ordination with older persons' general practitioner; registered nurses; nurses in training and aides. Aides provided personal care such as assisting older persons with showering, getting dressed and putting on compression stockings. Nurses provided both personal care and nursing care such as wound care, changing colostomy bags and administering medication. Nurses were further responsible for coordinating care with other providers such as rehabilitation services. Client care plans consisted of the care tasks which were connected to goals and allocated time. Goals could be described in terms of functional tasks such as showering regularly or healing a wound. Psychosocial care and household work are not allocated to homecare services; instead, these are taken up by other professional services when informal care does not suffice.

Recruitment

The data was collected by the first author using an ethnographic study design, combining both observations through shadowing and semi-structured interviews. All thirteen nurses and aides were asked permission for being shadowed by the community nurse. Four registered nurses, three nurses in training and three aides were shadowed for the course of one shift. Two aids declined for reasons of already experiencing too much work pressure. Another aid called in sick two times the researcher was supposed to shadow her, and a new appointment could not be made during the research period. Prior to the research all clients covered by the team were sent a letter asking permission for the researcher to tag along during care meetings. Fifteen older persons declined for reasons such as having shortage of breath due to COPD and not wanting to have extra stress, or not wanting to see too many strangers. Later, ten of these clients did accept as the nurse or aid explained more about the purpose of the research.

Data collection

Ten nurses or aides were shadowed during the course of one shift, seven during day shifts and three during evening shifts. Shifts generally lasted six hours. Shadowing provided insight into how the care relationship is enacted and the invisible work nurses engaged in. In-between care moments the researcher held informal interviews with the respondents. This allowed the researcher to gain more insight into logics of professionals on the care they provided. Two team meetings were observed which gave additional insights into the dynamics within the team. The data collection was conducted over a period of three months. Extensive notes were taken during and directly after the observations and elaborated shortly after.

Besides informal interviews and observations, a total of 9 face-to-face semi-structured interviews with nurses and aids were conducted and an additional interview with the community nurse. Prior to interviews consent was established. In case of shadowing during a day shift the interviews were held right after, in case of an evening shift a separate appointment was made. One of these nurses became ill for longer term and this interview could not be conducted within the research period. These interviews allowed for further elaboration on professional's evaluations of the care relationship. A topic list was used consisting of a general opening question asking what the respondents found important in the care relationship. Each named value was further explored for situations in which this was easily practiced and situations in which this had proved difficult. This allowed for exploring themes and tensions related to the care relationship important for professionals. After the values and related situations brought up by the professionals had been explored, the researcher asked respondents to further elaborate on tensions between values from the regimes of valuation: fostering self-determination (person-centered care), an independent lifestyle, participation and distribution of care work to informal carers (aging in place), and efficiency and accountability (new public management) and how they negotiated the valuation practice of the time and task model, in so far as these themes had not come up in the first half of the interview. For these questions the researcher prompted situations that took place during shadowing. Respondents were then further asked to elaborate on similar or different situations beyond these observed care moments. The interviews were audio recorded except for one as the respondent did not give permission, for this interview extensive notes were taken and elaborated shortly after.

Data analysis

Audiotaped interviews were transcribed verbatim. The data was coded using Atlas-TI software by the first author. Inductively the data was coded for evaluations of the care relationship and invisible work. This analysis was sensitized by the central concepts in the valuation regimes. As the different styles of evaluating and practicing the care relationship did not coincide with specific professionals or different roles (e.g. nurse or aide) the concept of 'logic' [16] seemed a good fit with the data and was used to describe the various patterns in which the care relationship was evaluated and enacted. The different types of invisible worth where also part of the work of both nurses and aides.

For purpose of member check we organized a validation session with the professionals of the team where the fieldwork was conducted in which seven professionals participated. For purpose of peer deliberation, we organized a validation session with the community nurse of the team in which data was collected, a community nurse from another team operating in the same area, a manager from both these and other teams, a member from a patient advocacy organization affiliated with the project and three researchers related to this project. In both the member check and peer deliberation session we shared our analysis in an accessible and meaningful way by reading out and discussing a one-page document for each logic. The document contained a compilation of anonymized quotes from the interviews and shadowing, edited into a single narrative addressing the main themes of that specific logic. The first validation session was audio recorded and transcribed verbatim, from the second validation session extensive notes were taken and elaborated shortly after. While in general our analysis was recognized by the participants in these validation sessions, some new themes came up which we included in our analysis in so far as they fitted our general research question.

RESULTS

In the results section we first analyze the valuation regimes and practices that play an important role in the context of the work of the professionals in home care central in our research, before we go into the logics that were present in the patterns in which the care relationship was evaluated and enacted by the professionals. In the final part we discuss work valued by professionals that remains invisible in the valuation practices and regimes.

Valuation practices in the context of professionals' work

In the Netherlands the 'quality framework of community nursing care' is an important policy document regarding the valuation regimes relevant to homecare services as this policy document describes what is to be considered good care [17]. The quality framework is the outcome of a negotiation process between stakeholders such as funders, provider-, professional- and client-representatives. The values elaborated in this document resonate both with the regimes of valuation of aging in place and person-centered care as put forward by the WHO, making them relevant to an international audience [3] The framework incorporates values such as providing integrated care, promoting self-determination and an independent lifestyle with the goal of improving quality of life. The care relationship is emphasized as a perquisite in bringing about these values. The quality framework emphasizes community nursing to have a 'broad view' and for instance include collaboration with numerous other parties in order to find solutions to older persons' daily problems and support them in living independently and improve quality of life. Furthermore, the framework emphasizes professional's role in stimulating clients to be cared for by informal carers and reducing formal care when the situation allows it [17]. The relation of the quality framework to the valuation regime of new public management and the valuation practice of the time and task model is a bit more complicated. The quality framework is positioned as a shift away from the previous focus on new public management with its emphasis on cost-reduction, and the valuation practice of time and task models. Instead, organizations need to become learning organizations, improving their processes through reflective practices informed by quality information such as client experience data. Moreover, accountability according to this policy document should be more outcome-based. Outcomes here include the level of independence, health and quality of life of the population. Which also resonate with international trends on commissioning and accounting in home care services [14]. While outcome-based accountability is the ambition, the document states this has of yet not been operationalized in instruments or procedures and is thus more described as an ambition to which stakeholders can guide their future developments [17]. However, generally in the Netherlands during time of fieldwork, accountability was still organized by commissioning certain tasks and related sets of time and goal-oriented care planning. In the care organization part of this fieldwork the time-and-task model was dominant in organizing care an accounting for it. This time and task model thus formed an important valuation practice through which some types of work were rendered as valuable while others remained invisible.

In the context of the plurality of the valuation regimes of aging in place, person-centered care and new public management, professionals evaluate the care relationship. This is further shaped through the valuation practice of the time and task model of organizing and accounting for care. From the way professionals negotiate this plurality in valuation we constructed three logics of the care relationship in home care services, each offering a different understanding of what a good care relationship entails. These logics differ on four dimensions: ontology of clients and their needs; The distribution of work between professionals and informal carers; Evaluation of self-determination; evaluation of fostering an independent lifestyle and participation. After describing these logics we take a closer look at the work that remains invisible in the context of the valuation regimes including personalized care and aging in place as expressed in the quality framework and the valuation practice of the time and task model of organizing care which is strongly shaped by the valuation regime of new public management.

Logic one: Caring for dependent older persons

In the first logic the *ontology of clients* is one of vulnerable people who, without homecare services, might not be able to self-manage medication or personal care. Moreover, clients are viewed to be limitedly able to manage other parts of their life that aren't allocated to the homecare services, such as keeping their household. Clients within this logic are also described as being lonely, having limited meaningful contact or activities outdoors.

For professionals in this logic *promoting self-determination* entails abiding to older persons' expressed needs, even when this work is not allocated. This includes doing dishes, taking away garbage and other household or personal care work. Besides meeting clients' expressed needs, self-determination is evaluated as abiding to clients' preferences related to time. For instance, the specific moment clients wanted to receive care in order to fit their daily structure or the pace in which care tasks are performed. Professionals stressed that having a close relationship is important for older persons in order to accept their care.

> *COPD clients, you can't tell them, you only have fifteen minutes. You have to abide to their pace and adjust to their needs. The trustful relationship you have with clients is important. They know how I work: not too hasty. Otherwise, they will refuse the care anyways (R12, RN).*

Some clients needed to be motivated to receive the care the professionals felt they needed. This was not experienced as in tension with fostering self-determination as clients often expressed being pleased afterwards and professionals described this care as necessary to prevent harm.

> *I pull out everything to get a client to take a shower, I make jokes, or I just put on my gloves and say, I didn't get out of bed for nothing! You get into a conflict because you push so hard for her to take that shower, but when you see her all fresh and cheerful after it's done, then you have reached your goal. She has blemished spots and is diabetic, so it is important. When the reports of colleagues say, she hasn't been showered in like, over a week, because she refused four times, I think that is just not right (R8, nurse in training).*

Professionals in this logic describe older persons as being in a phase in their lives in which they can just enjoy their old days and therefor need not be pushed to be more active. Moreover, professionals considered older persons' expressed needs for professionals to support them beyond the allocated care as genuine and stated older persons still have plenty of moments where they have to do things by themselves as professionals are not always around.

> *I find it important to make a cozy atmosphere for them. So, I make them coffee or tea. He is a sweet tooth, so I give him a cookie with it. I mean, they are 90 years old! When I leave, he surely fixes his own coffee again. (R6, aide).*

Professionals working from this logic, emphasize the potential harm when older persons are supported in learning to do allocated work independently. This harm includes older persons becoming socially isolated, loose their daily structure, neglect themselves and in the end would need more care to get back on their feet. The values of fostering independent lifestyle are thus evaluated as of limited importance in the care relationship within this logic.

Professionals stress the importance of taking up non-allocated tasks in this logic also because they perceive family members as too reluctant to take up work such as doing dishes or taking out garbage. Even when household work is allocated to other service providers, homecare professionals take up some of these tasks as they perceive this other support comes too infrequent or falls short due to poor quality.

> *We run into another professional of the team in the hallway of the apartment building where a few clients of the home care team live. She is carrying a garbage bag and says to R8, 'I just couldn't leave it there, you know. Also, I made them a nice cup of coffee, I mean, you just do these things for them. I did leave the dishes in the sink tough. It was quite difficult not to do them, but I left it for now.' Then she looks at me and at the garbage bag and says half-jokingly, half-serious: 'Don't tell anyone about this'. [Fieldnotes shadowing R8 a few days later]*

Moreover, professionals in this logic also do other small things for clients which enable clients to participate in the community. This includes for instance looking up things on the internet such as the phone number of a hairdresser to make an appointment or opening times of a market.

Besides taking up extra work including personal care, and housekeeping, psychosocial work is another need for which professionals take responsibility in the logic of caring for older persons. Professionals meet older persons' psychosocial needs by listening to their day-to-day experiences, listening to difficult life events or having a cheerful chat with them. Professionals also explained how they did something extra for clients in order to make clients feel better, such as bringing something special for them or making coffee. Professionals emphasized how older persons preferred the contact with them over community services offered by the municipality for alleviating loneliness. These services, according to these professionals, did not meet older persons' needs.

This type of contact offered by professionals is not only about preventing loneliness but also meets other needs of clients. Professionals for instance support clients to arrange things they need such as chatting about different options to heat the bathroom or what could be a next step in convincing the housing company to change the bathroom floor tiles that would prevent falling. Another example includes supporting clients in making decisions about other types of care as is described in the example below.

> *While taking care of the stocking R6 asks the client how he is doing. The client starts talking about a visit to a specialist. The specialist advised him to undergo surgery for his hip problem. However, he does not want the surgery as he worries about the rehabilitation process and the out-of-pocket cost of this. The specialist had even called him afterwards to convince him to undergo the surgery the client explains, but he decided not to do it. R6 starts quite an extensive conversation to the client about this. She says she understands it was quite a shock to him to get the news about the surgery and it is understandable he needs to think about it. Thereby she kind of opens up the decision process. She continues to talk to him about why he does not want the surgery and what could be solutions for his financial concerns. She asks*

> *him to consider the consequences of not having the surgery and weigh this with the negative consequences of taking the surgery. As the conversation continues, she checks who else could help the client to reflect on his decision and motivates him to talk about it further with other professionals this client has a good relationship with. When we get back in the car, she says to me: this client always says his hip doesn't hurt that much. But the other day a neighbor came up to me asking: what is the matter with this man? We often hear him scream in agony (fieldnotes, R6, aide).*

Sometimes professionals working from this logic provide psychosocial care other types of conversation during the allocated time for other tasks, for instance having a conversation during showering someone. Other times professionals spend their breaks with clients or stayed longer. This extra time is sometimes deducted from other clients where less time was needed that day. However, professionals working from this logic also report making longer hours than paid for in order to meet psychosocial needs of clients.

Logic two: sticking to the allocated tasks

From this view the ontology of clients is one of experts of their own life and being capable of making self-determined choices. This also or especially goes for situations where clients express, they do not want to receive the allocated care and there is no direct threat to safety.

> *These people are living in their own home. Their preferences are their preferences, I can hardly drag someone into the shower when they don't want to (R13, nurse in training).*

Clients however are perceived as not always fully taking up their expert roles and professionals need to foster self-determination in these instances. For example, professionals push clients to make choices, even when clients ask professionals to make these choices for them. Examples include making clients choose the type of food they want to have prepared or which clothes they want to wear. They also do not follow clients wishes when they ask homecare professionals to do non-allocated household work for them. Instead, good care demands professionals to be clear to clients about what is determined in the care plan and to teach them to stick to the allocated care and accept the various times on which care is offered. If changes are needed, they need to be discussed and formalized in the care plan first. In this logic, contrary to the first one, a close relationship is seen as a barrier to keeping to the allocated work.

> *I find it important to keep professional distance. Otherwise, clients start pushing you around: 'your colleague does this and that for me.' But it is important to remain matter-of-fact and always refer back to the care plan, which states the allocated care (Fieldnotes, shadowing R9, RN).*

Within this logic, fostering an independent lifestyle is evaluated as important within the care relationship and is understood as leaving non-allocated household work and personal care work for clients to do independently as this improves their health and self-confidence. Not abiding to clients' wishes for doing this work for them does not pose tensions with the value of self-determination in this logic as leaving these tasks for clients to do themselves promotes an independent lifestyle.

> *I find it important that you support them in doing things on their own. It does them well when they experience success in doing things independently. Other professionals in the team lack this type of insight. They tell clients: 'no let me take care of it, you stay seated'. While it is so important to get clients off their couches, so they don't stiffen or become dependent on others (R8, nurse in training).*

Fostering an independent lifestyle is further promoted by leaving clients to perform allocated care tasks as independently as possible. This is not something that is negotiated with older persons. Clients are simply taught to do care tasks themselves. Sometimes clients are even unaware they are engaged in a process of learning to do personal care independently as in the example below. Here not only the benefits of promoting participation for clients are stressed, also the benefits to professionals of saving time and limiting work that puts strain on professionals' bodies are emphasized.

> *The vision central to your work should always be: provide care with your hands on your back and leave clients as independently as possible. Like just now, I asked that client: 'how are your hands functioning?' He just started receiving care so I wanted to check how his capabilities were. Next week I will ask him to roll off his stockings to below his knees by himself. Because this he can do independently. We should also take responsibility for ourselves, because if you take of these high stockings by yourself, it takes a lot of strength and you have to kneel down each time. When the client does this part, you also save some time (R16, nurse in training).*

No or limited extra time is required for promoting self-determination or participation as promoting these is done merely by not doing extra work and leaving things for clients to do. This sometimes even allows professionals to finish care quicker than the allocated time, have extra breaks or leave early. Housekeeping, or other non-allocated work that older persons can't perform by themselves is left to family members or professionals of other service providers. Professionals in this logic only limitedly organize for these other parties to take up these tasks. When negligence is a possible outcome as these other parties are not taking up this work, the responsibility for this negligence is placed with those other parties.

> *With most people it is like, they try many things to cross borders. If you fall into that trap once, they keep on trying. Like this one time, an older lady was suspected to have a urine infection. And the informal carer had asked the community nurse if we could take the urine sample to the general practitioner to which she agreed. But this isn't in the care plan, it isn't our job. So, I told the daughter: I know it was confirmed we would do it, but we can't deliver on that promise. Because, it is the responsibility of the informal carer (R16, nurse in training).*

In this logic of sticking to allocated tasks the responsibility for care for clients with high care needs lies beyond the realm of homecare services, also when older persons much rather stay at home. For instance, when clients with dementia don't have a good daily structure anymore as they don't eat their dinners or don't go to bed at night, the necessary structure cannot be provided within the care that can be allocated to homecare services. When non-allocated tasks are performed for these clients their true vulnerability remains invisible and they do not receive the institutional care they need.

Logic three: tinkering self-determination and fostering an independent lifestyle

In this logic, clients are described as complex with multiple and sometimes conflicting needs. A good care relationship then requires having dialogues with clients in order to understand their different needs and find out what type of care fits these needs best. Different compared to logic one is that these needs are not merely followed, instead they are negotiated with what the homecare organization can offer. Different from logic two, this is not done by simply pointing to the allocated care and the care plan, instead clients' needs and restrains to what homecare services can offer are deliberated, with attentiveness to the needs of the older persons and arranging other care when these needs cannot be met by the homecare service.

> *The only care left is that we put a cream on his itchy back each night. It is not a medicinal cream, this is not something we should be doing as part of allocated care. However, it is quite difficult to get that conversation started. In the morning we used to do it as well, I already was able to stop that, which was quite difficult. And then with the evening, I noticed I went too fast. I told him, what about if we only come during the weekend? And all off a sudden he was again complaining a lot about how much burden he experienced from his back. And then we need to ask ourselves: why does he want to have someone come over each evening? Then you need to start thinking there is another question behind this. This could be about loneliness. And psychosocial care is arranged through other organizations, so you have to look into that. So, with changing these things, you really need to take small steps and investigate which needs are also at stake (R1, RN).*

In this logic, self-determination is enacted through engaging in dialogues. For instance, in situations where clients express they do not want to receive the allocated care, this is a starting point for conversation. These dialogues also are important for establishing a trustful relationship and lead to a care practice in which both the client's needs and the home care organizations restrains are assembled. In the following quote this becomes clear in the example of a client who does not want to shower.

> *One client only received care for her stockings, she was supposed to be showered as well, but each time we came she always said she already took a shower herself [which wasn't the case]. So, I started a conversation with her about what scared her about being showered. It was about standing naked in front of different people each time. So, I talked to her about just me coming over for a couple of weeks. This is difficult to arrange, but I did. And after a couple of weeks I showered her, I asked, would it be ok if now someone else came? But also, the same person each time? And it was ok. And now she is being showered by a small group of three colleges, while previously she always refused. It is about gaining trust with these clients, this is what I did (R17, RN).*

Professionals may experience tensions with practicing self-determination as clients expressed needs may not always be best for their health. These situations are then also deliberated with clients, which sometimes results in following their wishes and other times in motivating them to follow what professionals deem best for their health. When professionals perceive extensive deliberations are not possible with certain clients, they practice self-determination by being attentive to the different needs and wishes and how they can be assembled in a care practice.

> *On the bike to the next client R1 tells me this client has heart problems and probably only about a year to live. It is a lady with a lot of life energy who seems not to understand, or not wanting to know, she is in the final stages of her life. Each time she asks, 'what is the matter with me?', R1 stopped explaining it, she says. When we get there, the client says she will go to the Bingo later. R1 points to her legs to various small wounds that need care and a plaster. They talk about it and it is arranged the client will put on the plasters herself later, as for now she wants to take a shower by herself first. She also says she does not want to put on stockings today. R1 doesn't argue about this, finds the plasters and lays them out on the table for the client to put them on after her shower. When we are on the bike again, I ask her about not putting on the stockings. She explains this client needs the stockings because of her heart problems there is a lot of liquid in her legs which puts tension on her skin and causes wounds which might get infected. However, this client also finds it important to look good when she goes out. She wants to wear nice shoes when going to the Bingo and she can't wear those when she has her stockings on (fieldnotes shadowing R1, RN).*

Promoting an independent lifestyle in this logic is something that is done actively and step-by-step through learning someone to do care work on their own. This sometimes requires coordination with other services such as rehabilitation services. Moreover, within this logic promoting participation by doing care work independently can be in tension with promoting quality of life through being engaged in meaningful activities as doing things independently may cost clients too much energy. These tensions are then assembled in a care practice which in some cases entails motivating clients to accept the offered care so they have enough energy to engage in other meaningful activities. For instance, motivating clients with COPD to accept help with showering in order for them to have enough energy left to go to the playground with the grandkids. At other times this negotiation of different goods results in teaching clients to do care work independently.

> *Standing in the elevator R1 tells me this next client had COPD and she is investigating if he can be taught to put on his stockings by himself. She explains this would be nice for him as well as he likes to go out and then he doesn't have to wait at home twice a day for a professional to come for his stockings. I already e-mailed his occupational therapist if she can also assess if he can do it independently. She says: I say investigate as he also is quite short breathed, so maybe he is not capable of doing it himself. […] It is also about his quality of life, if he does it himself but it costs so much energy, he can't go out that day to do something he enjoys. This is quite a dilemma (Fieldnotes, shadowing R1, RN).*

In this logic, professionals take responsibility for the work that is not allocated to homecare services by being attentive to older persons' needs beyond the homecare service and organizing informal carers or other services take up the responsibility for meeting these needs. Some of this work in organizing extra care can be allocated through writing extra time with these clients under the generic category of non-direct client work. The work of psychosocial care is performed during the time allocated for other care tasks and therefor in most cases does not require extra time. While professionals perform the different tasks such as wound care or showering someone they listen to clients' stories and engage in conversation. When the need for psychosocial care structurally exceeds what can be offered during the allocated work this required professionals to organize this care also through other services. This however sometimes is complicated as available services do not match older persons' preferences.

> *During showering, I felt something on her, a knot in her breast. She said to me, I always had that. I said, I would go see a doctor if I were you. And she did and it was cancer. However, this lady, she never married, she is quite a difficult person, no contact with neighbors, she has nobody who visits her. But she has to go to the hospital for further diagnostics and checkups. So, I said to her, I mean we used to be able to go with such a client to the hospital, but this is no longer allocated care. So, I offered her, shall I call an organization, so a volunteer can*

> *come along to these hospital visits? And she agreed. So, they went along with her a couple of times. I mean she is 85, you get a lot of information at the hospital, maybe bad news. How are you going to process all that alone? (R17, RN).*

In this logic, tensions are experienced between different values such as self-determination, living an independent lifestyle, preventing harm and promoting quality of life. These are handled through having dialogues and designing care practices in which different values are assembled. Assembling different goods in a care practice asks from professionals to be creative and go beyond either motivating clients to accept the care offered or teaching them to do care work independently. Professionals experiment with different care practices and attentively following these, inventing new practices when others don't work well. This is also described as 'tinkering' [12,18]. Within this logic tensions also extend to informal carers as they prioritize different values in the relationship or hold different ontologies of clients and their needs. Professionals did express engaging in dialogues with family members however they rarely seemed to engage family members in tinkering, as the family members were not engaged in designing care practices together. This can also backfire when informal carers then don't support the care practices as their values were not assembled.

Invisible worth

Throughout these three logics in evaluating the care relationship in the context of the regimes of valuation such as person-centered care; aging in place; new public management and the practices of valuation such as the time and task model of organizing care, we can identify three categories of invisible worth. Invisible worth is akin to invisible work. But whereas the latter describes the activities undertaken to enable the flow of work, the former points at the underlying values and valuations that are thus expressed. The concept can thus sensitize to what is important in bringing about good care but is hardly explicated as it is not part of the regimes of valuation.

The first type of invisible worth we identify is providing psychosocial care. This worth is partly visible, as developing a trustful relationship with clients is important in providing person centered care. At the same time, the time and task model of organizing care does not identify maintaining a relationship as a separate task or allocates time for this, making this partly invisible. Moreover, according to the quality framework and in line with the valuation regime of aging in place, when more psychosocial care is needed, professionals are supposed to connect clients to informal carers or other services in order to provide this. For professionals following the logic of 'caring for dependent older persons', this does not suffice as they evaluate other community services as not aligning with older person's needs, and by consequence spend more time than is allocated to provide this care themselves. The practical work of chatting to clients is invisible as the worth of providing psychosocial care is (partly) categorized as part of the regimes of valuation, however it is not legitimized through the valuation practice of the time and task model.

A second type of invisible worth we distinguish is that of developmental/empowering care. During our observations we found that some homecare professionals supported older persons in making decisions regarding other domains of care or of their lives that were not part of the care offered by homecare services. As these homecare professionals have a close relationship with clients or see clients often, clients confide in them. In the conversations that follow professionals not merely provide psychosocial care – having a chat to prevent loneliness-, their dialogues with these clients foster their reflection on their needs and their decision making. This includes making decisions about other types of care as described in logic one. This work remains invisible as its related worth of relationally supporting clients' self-determination regarding important decisions in their lives not directly related to homecare services, is not articulated in the quality framework and not part of the valuation practice of the time and task model through which care in homecare services is allocated and accounted for.

The third type of invisible worth we identify is contexting. This type of worth is about organizing the context of older persons in order to enable their independence, community participation and living in a safe home. Part of the work related to the worth of contexting is described in logic three and entails connecting service users to informal carers or other services that can perform work that cannot be allocated to home care services. This fits with the valuation regime of aging in place and also partly with the valuation practice of the task and time model as time can be allocated through the generic category of non-direct client time. However, many other types of work related to the worth of contexting came to the fore which were less visible and mostly performed by professionals working from logic one. These include supportive conversations or looking things up on the internet to enable older persons to arrange things they need -for instance related to safety at home- or going out in the community. While this work may fit the regime of aging in place, time could not be allocated for it. Other types of work related to the worth of contexting where not part of any of the regimes of valuation, nor could time be allocated to it. These include when professionals provided care they felt no other services would fulfill these needs. This includes filling up the gaps others leave behind regarding household work. According to the valuation regime of aging in place professionals should organize this work is done by informal carers or other services. Family members however often did not do (parts of) the household work needed and other professionals' services also sometimes provided poor quality or came to infrequently for instance for older persons to have clean clothes, clean dishes and emptied trashcans. Professionals working in logic one, feel responsible for taking up this work when informal carers or designated professional services slacken. Bringing about a context for older persons to thrive in thus is an important value for a good care relationship in home care services. However, the related work is only partly legitimized as the worth of contexting is not fully part of valuation regimes.

These three types of invisible worth required time which was not or only partly allocated. Professionals evaluating the care relationship from the logic of 'sticking to the allocated tasks', do not engage in these types of invisible work. This also resulted in some professionals being done early with their rounds while other professionals seemed hardly able to fit their work in the allocated time and sometimes even worked longer hours unpaid. In sum, the three logics and the invisible worths is summarized in table 1.

Table 1 Overview of the three logics

	Logic one *Caring for dependent older persons*	*Logic two* *Sticking to the allocated tasks*	*Logic three* *Tinkering self-determination and participation regarding allocated care*
Ontology of clients and their needs	Dependent, vulnerable and in need for non-allocated care.	Self-reliant or ; manipulative when they express need for non-allocated care.	Complex with different and possibly conflicting needs.
Responsibility for non-allocated work (e.g. household work) and psychosocial care	Responsibility of the professional when work is not performed by others.	Harmful for promoting self-determination and participation.	Organizing others to take up this work
Evaluation of self-determination	Abiding to clients expressed needs regarding non-allocated care and time preferences.	As negotiated in the care plan; rejecting care is abided too. . .	Deliberating choices; developmental, tinkering
Evaluation of living an independent lifestyle and community participation	Promoting clients 'being in the world' through the relationship with the care professionals.	Leaving allocated care work for clients to do independently when possible.	Teaching clients to do care work independently when reasonable and possible while tinkering with other goods and being attentive to clients' needs/pace. Organizing collaboration with other services.
Overall quality of the relationship	Emphatic, personal, warm	Professional distance	Dialogical, empowering
Invisible worths	Psychosocial care; developmental/empowering care; contexting	-	Contexting; developmental/ empowering care

DISCUSSION

The three logics distinguished in this study give insight into the various ways in which professionals (nurses and aids) negotiate the plurality of values in valuation regimes such as person-centered care, aging in place and new public management (see table 1 for an overview). This shows professionals not merely reproduce these valuation regimes but creatively engage with them. It further shows this can in turn create tensions as professionals differ in how they assemble different values in different ways. This adds to the literature in which professionals in home care services are often depicted as speaking with 'one voice' in how they experience tensions between values related to New Public Management and person-centered care or aging in place [2].

These different logics are important to attend to for several reasons. First, they provide tensions within a team as professionals working from different logics evaluate each other's work as poor quality. This may impact team cohesion and job satisfaction[19]. Moreover, currently the tensions between the different values such as self-determination and an independent lifestyle are only explicitly attended to by professionals working from logic three as they tinkered by experimenting with bringing together different values in a care practices. When teams reflect together, they might learn from each other regarding such ways of handling value tensions. Second, as clients are seen by professionals operating from different logics, this may cause confusion and impact their and their informal carers' experience of quality of care. Moreover, when these ethical tensions are hardly reflected upon and deliberated within the team this hampers quality improvement.

The three types of invisible worth identified in the paper (see table 1) explicate the relational practices professionals are engaged in that bring about a good care. These are not fully acknowledged through dominant valuation regimes and valuation practices. This deficiency can be attributed to a lack in one of the subprocesses through which valuations emerge: categorization or legitimization [10]. A lack of categorization entails the type of worth has not been well articulated. In these cases, actors struggle to produce evaluative statements of (part of) their work as they cannot draw on existing categories of value within valuation regimes for sense making [20]. This might be the case in tinkering and empowering care as both these types of work were hardly articulated by professionals themselves. This results in important work not being supported or even dismissed by colleagues or managers as it is misunderstood. For instance, as the work of developmental/empowering care is not articulated this can be understood as simply providing social chats, for which no extra time should be allocated as it is not part of the formal tasks.

A lack in legitimization occurs when categories of value are not (fully) part of the valuation practices. For instance, the invisible work of spending extra time with clients for psychosocial care or doing household work, used to be part of allocated homecare services but is no longer. In these cases, actors' evaluations of their work can be considered 'old fashioned' by other actors and the invisible work of providing psychosocial care not part of professional conduct. Worths can also be only partly articulated and legitimized and partly remain invisible. For instance, in the case of the invisible work of contexting, some of this work is legitimized as the importance of coordinating care is part of both the regimes of person-centered care and aging in place and taken up in the quality framework. Some time can be allocated for this through a generic category. However, much of the work needed to make sure older persons can thrive in the neighborhood are not so well explicated nor can time be allocated for this work through the time and task model.

For quality improvement reflection is needed on these invisible worths and whether they need to be further fostered and the related work professionalized. If so, the different logics delineated in this research clarify the issue of invisible worth cannot be resolved by simply allocating more time to clients as some professionals conduct valuable but invisible work in this time, while professionals working from other logics simply finish sooner with their rounds. Instead, these worths need to be made part of the valuation regimes and the related work needs to be legitimized as part of the valuation practices. Simply categorizing invisible work by describing it as a certain task and then allocating time for it would not suffice as this leads to many detailed and elaborated categories and makes this work susceptible to rationalizing and surveillance agenda's [4,15,21]. This might be partly resolved by creating categories of worth, instead of categories of work, as categories of worth can be more abstract, leaving more discretionary room for professionals on how these worths are attainted. Next to categorization, attention needs to be paid to processes of legitimization [10]. Instead of the time and task model other types of valuation practices might be more prone to address the various types of invisible worth. These include valuation practices that are more flexible and locally tailorable [4] and/or practices that focus more on reflection and organisational learning [22]. When valuation practices attend to invisible worths this can improve quality of care as it motivates actors to perform this work more often, receive acknowledgement for it and this would motivate organizations to induce initiatives to professionalize this work [23].

On the team-level, improving quality of care would require teams to reflect on the ethical tensions between values part of the dominant valuation regimes. This would empower professionals to debate these valuation regimes, explicate the important worths not part of these regimes and thereby change them to better fit the work that brings about good care. To improve quality of care professionals should furthermore deliberate the different logics through which they assemble different values. Working through such tensions could drive them to innovate care practices that better assemble the different values part of different valuation regimes and alleviate some of the discrepancies in providing care for the same client by different professionals. The invisible worths and logics identified in this paper service as a framework for such reflections and deliberations. Reflection amongst professionals working in the same team often takes shape through informal learning processes such as ‘catching up’ [24] or during team meetings where cases are discussed [12]. However, more structured time and space is needed for such critical reflection and deliberation. This can be organized through methods of team reflection focusing on these issues. Involving clients and informal carers in these reflections might strengthen the quality of these practices (Heerings, van de Bovenkamp & Bal, forthcoming).

Limitations

While the three logics of the care relationship and the three categories of invisible work constructed in our analysis can facilitate other homecare teams to evaluate their own care practices, this study was conducted in one care team. Further research is required to finetune and complement these logics and categories of invisible work in order to improve their generalizability to other settings. Similarly, our theory on invisible worth should be further developed in other case studies. This study focused on how professionals in homecare services evaluated the care relationship. In this paper no attention was given to how clients and informal carers experience the various ways in which the care relationship is enacted and evaluate its worth. As they are the receivers of homecare services their experience matter in evaluating what a good care relationship entails. Future research could combine the framework of three logics and five categories of invisible work as set out in this paper with clients and informal carers experiences of the care relationship. Future research could provide insight into how teams, clients and family members can evaluate the care relationship using the framework as set out in this paper and reduce some of the frictions that arise from tensions between different logics and design practices that strengthen invisible work and its related worth. This is needed in order to bring this research further in the direction of practical application for improving homecare services.

CONCLUSION

Professionals in home care services evaluate and enact the good care relationship in various ways in the context of valuation regimes and practices. This study supports home care teams to critically reflect on their practices and managers and policy makers to re-design valuation regimes in order to strengthen the valuable visible and invisible work professionals engage in in bringing about a good care relationship.

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In my pyjama

Client, homecare services

whether the sun is up or not
at half past five I'll stand next to my bed
by the time they'll come to shower me
I'll already be done with half of my day

I'm not saying it's always like that
I don't complain either
I don't have anything to complain about
they're really nice
that's not the problem

they can't do anything about it
at least that's what they tell me
sometimes I believe them,
and other times I don't

and it's different every day
they show up earlier,
and then later,
and I'm just waiting in my pajama's

meanwhile my legs start to swell
if they don't show up before 10
then they can't put on the stockings
and they know that
still, sometimes they show up at half past eleven

I'm not complaining
I'll pass the time in my pajama's

but the strange thing is
when I phone them up about it
because I have an early doctor's appointment
they're suddenly on time
I really can't tie a knot around that

Cooperation

Daughter of a client in homecare services

you can read online how he's doing
that's when I see how well they're looking out for him
whether he has small wounds
and how it's healing
and everything else they're doing with him
but I don't watch every day
Otherwise, it will keep me occupied

If something's wrong, then I get a text message
or my father calls himself
if nobody came
well, that happens sometimes
and then I have to go there myself
because those bandages have to come off
and often he's already missed his medication

when I call about that,
I never know exactly who it is on the line
a different person from the team every time
who has to pass it on to someone else
that's where you lose your grip
It would make a big difference if we had a regular contact

but yes, they're understaffed
or have too many,
or they're substitutes or flex workers,
I don't know either
But I do know
that often things don't go well

for diabetes, his blood values should be passed on
to the nurses,
every week,
but it hadn't been done for two months
It's that I found out
But is it my job to find out?
they're busy,
but they get paid to do so,
not me

Flexibility

Professional, homecare services

Medications and compression stockings are needed at
certain times, yes

but the rest- -?
Some people get really frustrated when I call that I'll
be later
it not nice of course when they have to wait
but we cannot be there at the same time every time
the morning lasts from seven till twelve
and we have keep a lot of different people
in consideration
that requires flexibility on our part
but also on the clients

That there're changes with the caretakers
has its pros and cons
people really want to have continuity,
someone they recognize
but we can see more, when we're with more
and we take a closer look at things that can improve

some women don't want to be showered by a
man,
not always with a reason
and some men particularly want a women
and that they have to be cleaned down there,
because they can't reach it supposedly

Some don't want woman with headscarves
or specifically do, It's all very sensitive
and we can't always consider everything
some react aggressively then
that's when it gets tough

because if it happens to often, then we want to cancel
the care
but that’s not always possible and I have to go there a couple more times, to start building a case file

Chapter 6

Ask Us!
A method for critical reflective co-design of the care relationship in supported living

This chapter has been published as Heerings, M, van de Bovenkamp, H, Cardol, M, Bal, R. (2022). 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*, doi:10.1111/hex.13436

ABSTRACT

Experience based co-design (EBCD) is a valuable tool for participatory quality improvement. However, the EBCD-process needs to be adjusted to make it suitable to long-term care. The focus of the improvement process needs to shift to the care relationship, as this is an important part of quality of care in these settings. Furthermore, the EBCD-process needs to be made more accessible to populations in a vulnerable position. Through a participatory research approach EBCD was adjusted to long-term care. The research was conducted in two care organizations: one supporting people with serious mental illness and intellectual disabilities in independent living and one providing homecare services for older persons. The participatory research resulted in the development of 'Ask us!' – a method for critical reflective co-design. The research furthermore provided valuable lessons for participatory projects with vulnerable clients. A common problem with participatory research in long-term care is ensuring involvement of clients and informal carers. We report on various strategies developed to include experiences of a diverse set of services users, such as combining interviews with participant observation, photo-voice and involving experts-by-experiences as co-ethnographers. In close collaboration with an inclusive theatre company, these experiences were translated into 42 short videos on complex situations in the care relationship from the perspective of clients, professionals, or informal carers. These videos instigate critical reflection and accelerate the participatory quality improvement process. Moreover, practical tools were developed to overcome barriers regarding involvement of people with disabilities. These include the use of photo-elicitation to enable participation of clients with disabilities in heterogeneous group discussions and involving experts-by-experience as proxies to share experiences of clients for whom participation in the 'Ask us' method remains inaccessible. The result of a robust participatory process, 'Ask us!' is a promising method for participatory quality improvement in long-term care. The research furthermore generated lessons for involving vulnerable populations in participatory research and co-design.

INTRODUCTION

Experience based co-design (EBCD) is a promising method for involving clients, professionals, and family members in improving the quality of care [1-5] (see box 1 for an overview of the EBCD process). Applying this method in long-term care settings however raises several design challenges.

First, a shift in focus of the improvement process to the quality of the care relationship is needed. EBCD often focusses on specific aspects or moments in service delivery that impacts the experiences of service users. However, in long-term care, the care relationship is central to quality of care [6-9]. The focus of EBCD in these settings should thus be on the care relationship. This care relationship is complex as it is often laden with value tensions [10,11]. Values that assign clients a more active role have become prominent in long-term care settings such as supported living for people with intellectual disabilities (ID), serious mental illness (SMI) or older persons. Values such as self-determination, independence and community participation have accompanied policy tends such as person-centred care,[12] recovery-oriented care,[13] active ageing[14] and rehabilitation.[15] Putting those values into practice is complex. For instance, how they should be enacted is not clear-cut because professionals also need to balance them against clients' vulnerabilities. Self-determination, for example, may mean respecting a client's decision to neglect standards of cleanliness or motivating them to clean their homes. Moreover, informal carers, clients and professionals can have different perspectives on these values, further complicating the care relationship.[10,16] In order to improve the quality of care in long term care, the EBCD process thus needs to shift focus to the ethical tensions in the care relationship.

Second, the EBCD process needs to be made more accessible to service users in long term care. Previous research has highlighted how the EBCD process can also produce vulnerabilities [17,18]. For instance, related to communication due to rapid information flows or service users having to express themselves in heterogeneous group deliberations [19]. Moreover, the length of the EBCD process also poses barriers to involvement as motivation declines or drop-out occurs for other rearons.[3] Previous adaptations of EBCD have accelerated the process by using existing films from a national archive to trigger responses in group sessions with clients, thus skipping the initial phase of interviews and observations. Using existing trigger films can have the advantage of making the process less threatening or challenging. A possible trade-off could be staff engagement is aversively impacted. However, such effect was not found in accelerated EBCD projects.[3,4,20,21]. A key design challenge is therefore to better enable clients to participate in the dialogue sessions and to accelerate the process while fostering engagement. However, even when engaging in relational strategies and offering creative means of participation such as photovoice to include services users well beyond 'the usual subjects' certain groups of service users still often are excluded from participation. This results in specific experiences not being taken up in the co-design process [17,19,22]. This raises the question how to ensure a diverge range of experiences is included to inform the quality improvement process.

In this paper we report on a participatory project adjusting EBCD to long term care settings. This resulted in the method 'Ask us!'. While a formal evaluation of 'Ask Us!' had not been conducted yet, the design process generated valuable lessons for participatory quality improvement with vulnerable populations which are further explicated in this paper.

Box 1. EBCD

EBCD (see figure 1) is a process in which clients and professionals reflect on the quality of care and co-design improvements together. Informal carers are sometimes included in this process.23 The method consists of several phases. The first phase is to collect care experiences through interviews and observations. Of the interviews conducted with professionals, informal carers and clients, those with clients are videotaped and edited into a trigger film showing the various 'touchpoints' where clients experienced the service in a way that impacted them emotionally. The trigger film also helps to create a level playing field in which client experiences receive enough attention and engage others towards change. Second, clients, professionals and sometimes informal carers reflect on their experiences in peer-homogenous focus groups and identify areas for improvement. These group dialogues are facilitated through emotional mapping and, in the client group, by the client trigger film. Having peer-homogenous groups gives the participants a safe space to share their experiences with peers and find common ground. Third, the separate groups come together to watch the client trigger film, deliberate the issues raised in their group dialogues and set common priorities for quality improvement. Smaller co-design groups representing all stakeholders are assembled for each priority and meet several times to develop organizational practices. The EBCD process concludes with a celebration that highlights the successes of the quality improvements.1,2,4

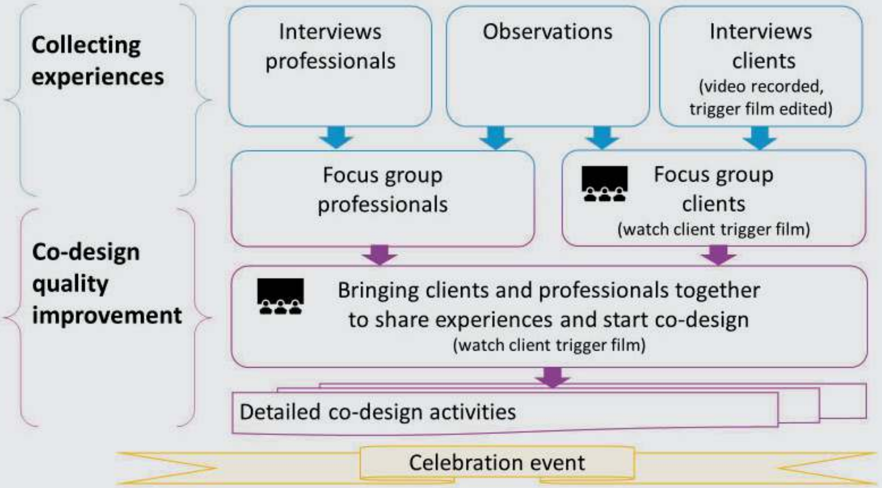

Figure 1 EBCD process

METHODS

Setting

We conducted participatory research in two care organizations situated in the same urban area in the Netherlands. The first was a community care organization (CCO) providing supported housing (group homes and supported independent living) to people with intellectual disabilities (ID) or serious mental illness (SMI). The second provided homecare and other services to older persons (HO).

Project group for designing the instrument and developing the trigger films

We set up project groups for both the CCO and HO organizations to co-produce the research and the instrument (see table 1 for an overview). The size of the two project groups and their level of involvement differed, with less meetings in HO and less involvement of policy makers. This reflected differences in the two organisations, with HO having a much smaller policy/management layer. The number of meetings in HO could be reduced as the data collection and analysis was less complex, covering only one client group (older persons) instead of two (people with ID or SMI). Moreover, the participatory research in HO was conducted after the CCO project had finished and several decisions, for instance regarding the production of the videos, were already set.

Table 1 Project groups

	Project group CCO	**Project group HO**
Participants	Two researchers; a member of a patient advocacy organization; four policymakers; one expert-by-experience; a professional from each of the two collaborating teams.	Two researchers; a member of a patient advocacy organization; a policymaker; two community nurses and a manager (one community nurse and the manager where off the collaborating team).
Involvement	1) selection of teams; 2) data collection protocol including informed consent and topic lists; 3) data analysis and 4) designing the instrument	1) selection of teams; 2) data collection protocol including informed consent; 3) data analysis
Number of meetings	Six meetings: five 90-minute meetings and one four-hour workshop focusing on re-designing the group meetings and involving two additional experts on client participation.	Two 90-minute meetings.

Engaging service users, professionals and informal carers

As part of the participatory quality improvement method, we collaborated on developing the trigger films of both client, professional and informal carers experiences with a care team for each client population (ID, SMI and older persons). Each team consisted of clients, professionals and informal carers, who acted as both informants and consultants. They provided input for the content of these films during in-depth interviews about their experiences with the care relationship and informal conversations during participant observation and shadowing. CCO clients also participated using the photovoice method. As consultants, clients and professionals from each team participated in data validation sessions, helping to analyse the input for the film scripts (see table 2 for an overview).

Table 2 Data collection

	Team CCO intellectual disabilities			***Team CCO serious mental illness***			***Team HO older persons***		
	Prof.	*Cl.*	*Carers*	*Prof.*	*Cl.*	*Carers*	*Prof.*	*Cl.*	*Carers*
Participant observation	12 visits, 65 hours total			12 visits, 19 hours total			-	-	-
Shadowing	-	-	-	-	-	-	10 visits, 60 hours total		
Interviews	12	12	4	8	8	3	9	13	5
Photovoice	-	6	-	-	1	-	-	-	-
*Interviews with peer-support workers**	-	-	-	-	8	3	-	-	-
Group consultation on analysis (no. of participants)	9	5	-	8	5	-	7	5	-

* part of multiple teams catering for both ID and SMI

All three CCO and HO teams included professionals whose experiences were collected through interviews, participant observation (CCO) and shadowing (HO). Professionals were further involved through group discussions on the analysis of the interviews and observations serving as content for the trigger films. CCO professionals consisted of social care workers, while HO professionals included a community nurse, registered nurses, nurses in training and aides. Reasons for declining included leaving the care team or being too busy.

Client recruitment proved more complex. Two things are specifically worth mentioning. First, it was difficult to recruit a diversity of clients with serious mental illness because the affliction itself prevented them from participating. For example, clients refused interviews because they did not want to talk to ‘strangers’ or said their ‘voices’ did not allow it. Moreover, professionals who asked clients about being interviewed reported negative responses; in some cases, their already fragile care relationship was impacted. In response, we developed relational strategies to involve clients, for example by getting acquainted with them during coffee moments where they socialised. [19,24] The clients who did participate were not, however, representative in terms of openness to contact. We therefore relied more on participant observation and informal conversation during these observations and developed further strategies to include the experiences of people unwilling or unable to be interviewed. This included interviewing experts-by-experience about situations they had witnessed during their peer-support work involving care relationships in the context of promoting self-determination, independence and community participation.

For HO, we excluded people with dementia from interviews because they had difficulty recalling experiences with care professionals. We were unfortunately unable to include a sufficient diversity of clients from minority backgrounds, resulting in underrepresentation of these groups. Partly these issues were resolved by including data from shadowing professionals.

It also proved difficult to interview informal carers in CCO. Service users acted as gatekeepers for contacting informal carers and their relationships were often complex.[19] Moreover, of the limited number of informal carers that we were able to contact, several declined for various reasons. We resolved this problem by conducting additional interviews with family support workers, who elaborated on their own experiences with the services and that of other family members they supported. It was less relevant in HO to include informal carers because the older persons often managed their own care (see table 2 for an overview).

Adjustments to the dialogue sessions

We organized a workshop to modify the method used to foster dialogue in both the peer-homogenous groups and the joint EBCD event. The aim was to mitigate vulnerabilities by making the method more inclusive for clients who have difficulty processing information and speaking up in deliberative sessions and to shift the focus to the complex care relationship (see table 1). The input for the workshop came from the researcher and the member of the patient advocacy organization, who suggested ways of adapting the various EBCD phases. Their suggestions were based on interviews (n=2) with EBCD project leaders involving people with SMI or ID, the literature on EBCD, and practical experience with other client engagement methods. During the workshop, participants suggested and discussed other adaptations and modifications to the dialogue sessions until reaching consensus.

RESULTS

This participatory research resulted in the 'Ask us!' method. It consists of the 42 trigger films and a process for the various group and co-design sessions (see figure 2). We first elaborate on the participatory process of developing the trigger films and reflect on lessons learned to include vulnerable groups in participatory research. We then describe the developed method for participatory co-design: 'Ask us' and explicate the lessons for participatory researchers aiming to involve vulnerable populations.

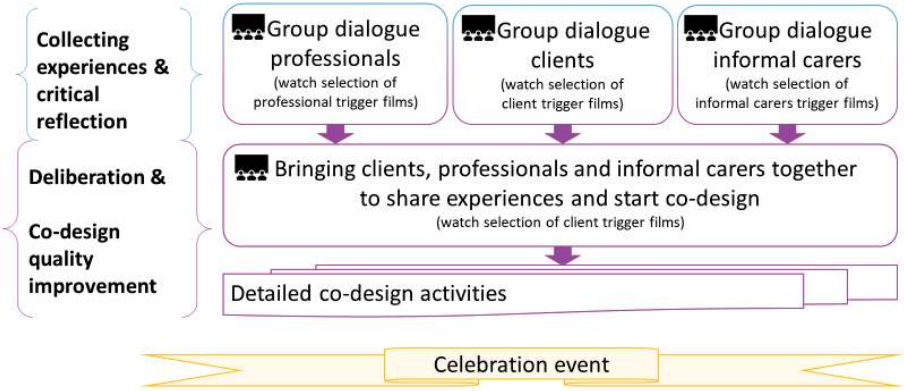

Figure 2 Adjusted EBCD process 'Ask us!"

Trigger films

The 42 trigger films are based on client, professional and informal carer experiences and are meant to accelerate the EBCD process and focus it on the complex long-term care relationship. The films length ranges between 1 and 3 minutes. The spoken language is Dutch, the films are made accessible to an international audience through English subtitling. For an overview we refer to supplementary table 1, which lists the main themes for each film; for the full content, please visit www.eur.nl/eshpm/onderzoek/als-je-het-ons-vraagt. The process we undertook to produce these trigger films differed from previous accelerated EBCD strategies.[20,21] Because many clients with SMI were unwilling to be interviewed on camera (similar to previous EBCD projects with this client group[22]), we collaborated with theatre artists and developed scripts based on different data collection methods. As this also fitted our aim to accelerate the method, this format was used to produce films reflecting experiences of services users with SMI or ID, older persons and experiences of professionals and informal carers as well.

After discussing various possible formats, including documentary, digital storytelling and animation, the project group decided to give the films a realistic feel. The CCO members suggested an inclusive theatre company as a possible partner, as many of its actors had disabilities and also received care from the CCO. They could contribute their own experiences to the creative process, making the films even more 'real'. The theatre company's director suggested a *mis-en-scene* of close-up monologues, to which the project team agreed. The format was therefore already set when we started the HO participatory process. The rest of the process ran similarly in CCO and HO.

Each film portrays complex situations in which values such as self-determination, an independent lifestyle or community participation conflict with other values, in which clients or informal carers may feel burdened by how care is enacted or organized, or in which clients, professionals or informal carers have different views on what constitutes good care. For example, one film considers the burden a client experiences when his personal care plan involves developing a personal hygiene routine and professionals are tasked with reminding him to shower on certain days. This practice leaves the client feeling misunderstood and restricted in his self-determination. Another film, from a provider's perspective, shows how she struggles with clients who neglect their personal hygiene. The professional wants to intervene to foster the client's social acceptance and community participation, but wonders whether doing so interferes with the client's self-determination. Yet another film shows the perspective of the client's mother, who has been told by professionals that her son's personal hygiene choices are up to him, which she perceives as professional neglect. These examples not only show a complex situation from every perspective but also possible differences between clients, informal carers and professionals and, consequently, the need for deliberation, which is part of 'Ask us!'.

The collaboration process involved translating the data of service users' experiences to the actual films in a series of steps.[25] Throughout, we adhered to both a qualitative research logic and an artistic logic to ensure that the trigger films were both grounded in empirical research and able to engage audiences in reflection on their own experiences. Below, we describe the participatory process and translations steps leading to the films.

The teams and the project group in each organization were involved in developing content for the trigger films. We followed the logic of qualitative research by using ethnographic methods to collect data on the complex care relationship (see table 2 for an overview). We used the same semi-structured interviews for clients, professionals and informal carers, opening with the question 'What is important to you in the care relationship you are involved in?'. Each named value prompted narrative exploration of situations in which this value was appropriately practised or proved difficult. When values such as self-determination, an independent lifestyle or community participation were not named, the researcher provided prompts in the second half of the interview. Interviews were audio-recorded and transcribed verbatim. The photovoice method included one session to explain how to operate the camera. Participants were then asked to take photos of what they did or didn't like about where they lived. After two weeks, the photos were examined in interviews for themes related to the complex care relationship,[26] with notes taken during the interviews being elaborated shortly after.

Different strategies were developed to include the experience of service users who were unwilling or unable to partake in interviews or photovoice [27] . A first strategy included participant observation in the group homes part of CCO or shadowing of professionals in HO. This allowed us to observe the ‘enacted appreciations’ of clients, or their reactions to care practices without them having to vocalize those [28]. Moreover, participant observation and shadowing allowed for many informal conversations with both clients and carers on care moments shortly after they unfolded. These informal conversations were often much more accessible to clients compared to formal interviews and proved very valuable in collecting their experiences with care.

The second strategy we engaged in to include the experiences of vulnerable clients in data collection was by conducting interviews with experts-by-experience in their role of peer support worker. In the CCO organization , experts-by-experience were part of care teams as peer support workers. As a result, they had witnessed many care moments and had many conversations with clients about their experiences with care. Similarly, the family-experts-by-experience could share many experiences of informal carers which complemented the interviews that where conducted. The interviews with these (family)-experts-by-experiences followed the same format as the other interviews although the focus was not on their own experiences but on those they had witnessed as part of their peer-support work. These strategies allowed for the experiences of clients who were unwilling or unable to partake in interviews or photovoice sessions to become part of the input for the trigger films. This is important as these clients seemed often more vulnerable and may have different experiences compared to clients who are willing and able to be interviewed.

In order to translate the different data of individual stories to common themes related to the complex care relationship, the first author conducted a thematic analysis. The analysis involved inductive coding of the data using Atlas-ti software, identifying similarities and differences, and using axial coding to develop the themes. To refine this analysis, the researcher edited quotes per subtheme into comprehensible narratives and discussed them in various sessions with the project group and with clients, professionals, and family support workers (see table 1 and table 2). The narratives were then adjusted based on these discussions.

The narratives developed in consultation with the project groups and the teams were shared with the theatre company to serve as text for the filmed monologues. The director found the narratives too lengthy and in lack of poetic use of language that would feel like ‘normal talk’ while moving and engaging audiences at the same time. A playwright was engaged to produce another translation based on an artistic logic. He re-wrote the narratives as monologues, changing most of the original phrasing. To prevent a loss of thematic content, the researcher had two sessions with the playwright to revise the text. Between these two sessions, the researcher also discussed the monologues with one of the CCO experts-by-experience (and theatre maker) and took her suggestions on board in the second meeting with the playwright. The project group checked and approved the final versions of the monologues, which the actors then rehearsed and recorded on camera. The rehearsal of the monologues by the actors proved a further check on the integrity of the monologues as actors were encouraged to use their own experiences as part of their interpretation of the monologues. Some of the actors had experience as a client of CCO or a similar organisation for supported independent living. Most of the other actors had experiences similar to those of professionals as the theatre company also served as community day-care and their formal role was those of support staff in this setting. Moreover, the interpretation of the actors also added a final layer of translation following an artistic logic, as the performances were based on different intentions (or emotions) to create a diverse pallet of films and to move their audience (see figure 3 for an image of the process).

Figure 3 Filming monologues

'Ask Us!' dialogue sessions

We now turn to the details of the participatory quality improvement method 'Ask us!' and explicate the lessons learned to a wider audience of participatory researchers aiming to involve vulnerable populations.

The first phase of the method focuses on collecting care relationship experiences and reflecting critically on the tensions between values associated with clients' playing an active role. In this phase, clients, professionals and informal carers engage in separate group dialogues in which they share experiences and reflect critically after viewing selected trigger films specific to each peer-homogenous group. One of the main issues for making the EBCD more accessible to vulnerable populations, which is also relevant in other participatory projects, was first to keep the input manageable and prevent information overload; second, to use visuals over textual information. For this purpose, we reduced the time of the trigger film to a selection of three to five films lasting no more than ten minutes rather than the usual 30-minute trigger film in EBCD. The selection is made in consultation with an expert-by-experience and professional familiar with the relevant team.

Figure 4 Worksheet after watching video's

After watching the selected videos, the participants reflect on their own experiences triggered by the films. We modified the EBCD emotional mapping method here to make it more accessible to a diverse group of clients and to focus on the complex care relationship. For this we developed various visual materials. Clients are asked whether watching the film evoked a memory of a recent experience in their care that still moves them emotionally or that they think about at times. They are asked to choose a worksheet belonging to one of the films that triggered this memory (see figure 4), or to choose a blank worksheet if this fits best, and to affix emoticon stickers to it or add drawings or words reflecting their experience. Each worksheet is then matched with the corresponding visual representation of the film and assigned the same colour code on the wall. Group facilitators initiate group dialogue by pointing out emotional responses on the wall and inviting people to share their story, highlighting aspects of the complex care relationship, instigating critical reflection and working towards common themes, which were made visual on the sheets by drawing or using pre-printed pictograms.

Next, the participants prioritize themes for quality improvement by placing three stickers with one or more of the themes. This way a theme is selected for deliberation at the joint event. Reducing the number of themes compared to the original EBCD set-up, not only makes the joint event more manageable but also promotes the in-depth deliberation that is at the core of this instrument and required in complex situations in which clients, professionals and informal carers may have differing perspectives.

Another key aspect of participatory research with vulnerable populations which emerged during the process of redesigning the various dialogue sessions is making sure their inputs are responded to in ways that encourage further participation even when their input is not further taken up in the research. This requires designing additional processes in which these concerns can be adressed. In EBCD this for instance is important in the process of selecting themes for quality improvement. This is a delicate process as it can be quite a big deal for some clients to voice a concern or area for improvement in the peer-homogenous group and they may feel hurt or demotivated if their concern is not selected. An additional procedure was therefore designed in which experts-by-experience coach clients to address these concerns in an appropriate setting, for instance in their individual care relationship, in the client council or in a team meeting of professionals. This procedure is in addition to more generic support for clients prior to, during and after the sessions.[22,29]

An important aspect of the design of participatory research is to reduce power imbalances to better enable clients to contribute to group discussions in heterogeneous settings. This requires development of additional tools to enable them to take a stand and to shift some of the responsibility for making their voices heard to other participants. For adjusting EBCD, this is especially relevant in the second EBCD phase, where clients, professionals and informal carers deliberate on the themes chosen by each peer-homogeneous group. One of the tools to foster a level playing field are the films shot from the clients' perspective on each theme watched at the beginning of this session. Smaller mixed subgroups then deliberate similarities and differences between the different groups' perspectives on each of the three themes. Participating in the deliberations with professionals and informal carers can be particularly challenging for clients. To address this, we developed a photo-elicitation method. Various cards with photographs relevant to the themes are laid on the table. Clients can take a card and hold it up to signal wanting to contribute to the conversation. This shifts the responsibility to the other participants to ask clients what they wish to contribute without clients having to verbalize this mentally before taking the floor. Between the deliberations on each theme, each group shares its main points with the whole group and the facilitator uses this information to construct a theme for quality improvement. At the end of the event, mixed groups are formed to co-design improvements for each theme. These smaller co-design sessions follow the blueprint developed by MH-ECO.[5] Managers from other organizational layers can be included in these sessions if the improvements involve their part of the service. A key point in facilitating these sessions is to inspire participants with best practices already invented in order to prevent re-inventing the wheel while also making sure participants remain ownership over the co-design process.

DISCUSSION

In this participatory research project, clients, professionals, informal carers, experts-by-experience, family support workers, researchers and policymakers collaborated on developing a method for participatory quality improvement of the complex care relationship in long-term care focusing on self-determination, an independent lifestyle and community participation.

EBCD was a valuable source because it involves a process whereby client, professional and informal carer engage in reflection, deliberation and co-design, but it needed to be re-designed for long-term care by:

1) accelerating the process and focusing on the complex care relationship: 42 short trigger films were developed addressing the dilemmas and burdens experienced by clients, informal carers and professionals in the care relationship in supported housing for people with intellectual disabilities or serious mental illness and homecare services for older persons.

2) reducing existing and preventing new vulnerabilities: the various group dialogues central to EBCD were modified to make the method more accessible for clients with serious mental illness or intellectual disability or for older persons.

The resulting method, 'Ask us!', brings together critical reflection, deliberation and co-design in a comprehensive process that has the potential to improve services.

'Ask us!' allows organizations to involve professionals in critical reflection, helping them to better handle complex situations, and to engage clients, professionals and informal carers in re-designing their services so as to empower service users. It should be noted, however, there has yet to be a formal evaluation, which will be an important next step in the refinement of this instrument. Collaborating care organizations and audiences at presentations and film viewings – including client representatives and professionals – however have responded positively to the method. Both clients and professionals expressed the content of the video's was recognisable to them and the videos could be useful in fostering conversation on quality of care [30].

The participatory process through which this method was developed yields several lessons to researchers aiming to involve vulnerable populations in participatory research. Previous research on involving vulnerable populations has highlighted how ensuring participation requires creating relationships with service users prior to engagement; including creative methods to enable them to share experiences and involving them in their own pace [17,19,22,31]. These strategies however proved insufficient in our research to ensure diversity in the experiences included in the quality improvement process. While it remains preferable both from a methodological and ethical standpoint to ensure direct involvement of vulnerable groups, alternative strategies might be needed. Specifically, when methods for direct involvement prove inaccessible thereby excluding the experiences of specific clients or informal carers. To overcome this barrier, interviews and more creative means of engagement such as photovoice can be supplemented with observations of enacted appreciations [28]; informal conversations during participant observations and involvement of (family) experts-by-experience as co-ethnographers.

Another important lesson is to develop a process through which the input of clients that is not part of the further co-design process is still taken up and responded to within the care organisation. This is an important addition to current research on involving vulnerable populations in co-design processes in which the need of having counselling available during and after sessions is often highlighted [22,31]. While this is an important part of caring for participants well-being, responding to their concerns regarding quality of care which were not selected in the design process is also needed.

Lastly, the traditional EBCD process already uses creative means to lift some of the power imbalances in mixed-group sessions: the trigger films showing client's experiences. We added a photo-elicitation method to further enable clients to take a stance and voice their concerns and professionals and informal carers to hear these.

These lessons emerged in our process of re-designing EBCD to fit long-term care settings. However, they are valuable to other researchers in involving vulnerable populations in participatory research or co-design projects.

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Supplementary table 1

	Clients	Professionals	Informal carers
Supported independent living for people with serious mental illness or intellectual disability	Develop a close relationship with professionals; provide support in a way that contributes to empowerment.	Build a close relationship while maintaining professional distance; use of social media; availability outside official hours.	Professionals invest in getting to know the client well; take the client seriously, engage in an equal relationship and have continuity in staffing.
	Not be stigmatized by a psychiatric diagnosis and be supported in limiting self-stigma; have professionals use their knowledge of mental health to deepen support; foster dialogues about the content of hallucinations, delusions, and about suicidal ideation.	Get to know the client beyond the disability-related identity; use professional knowledge to deepen contact.	
	Not let goals in personalized care plan limit choices in daily life, while also motivating clients to achieve these goals. Support personal goals even when these do not seem to contribute to developing an independent lifestyle or community participation.	Motivate clients to develop an independent lifestyle or community participation, or support clients in their self-determined goals even when these do not contribute to becoming independent.	Professionals motivate clients to work on goals that are important to clients or are important for developing a more independent lifestyle or community participation.
	Allow room to make mistakes (dignity of risk) while also relationally engaging in choice-making and sometimes limiting choices to support second-order desires.	Let client experience the consequences of self-determined actions as part of their learning process, or prevent harm.	Clients sometimes present themselves as more independent than they are, professionals should be wary of overestimating clients and make sure they provide sufficient support to prevent harm.
	Pay attention to (minor) strengths and progress and let clients do certain things themselves while also providing support where needed.	Intervene when clients do not keep up standards of (personal) hygiene to prevent stigmatization and promote social inclusion or accept this as personal preference/choice.	
	Engage in dialogue and provide support on ‘delicate’ subjects such as spirituality; existential questions and need for intimacy & sexuality.	Support clients in finding ways to meet their need for intimacy & sexuality or prevent abuse by others.	Difficulties when professionals feel client desires intimacy/sexuality while family members feel this is not the case.
	Not place taboos on wanting to stop taking psychotropic medications; know preferences on how to be approached in times of crisis.	How to deal with clients who are in crisis but refuse support.	
	Transition to living independently and facing stigma and loneliness.	Promote independent living or prevent loneliness and other risks; abuse and clients engaging in criminal activities.	Professionals should encourage clients to participate in the community to alleviate loneliness while also preventing risk of abuse.
	Acknowledge difficulties of moving to a new home/neighbourhood and provide support in community participation.	Stimulate clients to take part in community activities or organize social meetings for clients to get together.	
	Involve family members and support the improvement of relationships with family members while also guarding against overburdening family members with the role of professional carer; limit family members’ over-involvement and other negative influences on recovery or development.	Collaborate with family members on supporting client; prevent over-involvement of family members and deal with family members who fear negligence while the professionals’ aim is to support self-determination and an independent lifestyle.	Professionals provide information about how support is provided; professionals provide information on the client; use knowledge of family members to get to know clients; negligence by professionals leads to extra burden for informal carers; family members want to support client as family members, not as informal carers.

Supplementary table 1 (*continued*)

	Clients	Professionals	Informal carers
Home care services for older adults	Abide by preferences regarding care scheduling and whether care is provided by a man or a woman.	Not always being able to abide by preferences due to case load or other organizational complications.	Abide by the client's preferences; continuity in care. Inform informal carers on delivery of care.
	Abide by preferences regarding the client's home; smoking, pets, professionals taking off their coat; professionals ringing the doorbell instead of using a key.		
	Abide by preferences regarding how care is performed or when allocated care can be skipped on a given day.	Abide by client's preference not to receive scheduled care or motivate clients to undergo care to prevent harm (e.g. showering; stockings etc.).	Clients should be motivated to accept the allocated care they need to prevent harm.
	Don't rush, so clients can take the time they need to do things independently (e.g. dressing themselves after showering).	Support independence by not doing extra non-allocated work. Motivate clients to accept support so they have enough energy for other things important for their quality of life.	Negligence due to professionals leaving too much for clients to do by themselves and having no time for social contact.
	Support clients in (minor) needs even when these are not part of allocated care (including social contact).	Take extra time for social contact and be sensitive to clients' needs even when not part of allocated care or stick to allocated care and leave other tasks for older adults or their family members to do to foster active ageing.	Support needed for informal carer as well.

Chapter 7

Conclusions and implications: the complex care relationship

INTRODUCTION

This thesis started with the question how the quality of the care relationship in long term care can be improved, with attention to the value complexity thereof. The thesis concentrated on the cases of independent living for people with SMI or ID and home care for older persons. Here trends such as personalization of care, empowerment of clients and social inclusion have become dominant elements of the valuation regime. As part of these trends, self-determination, an independent lifestyle and community participation came to be important values in the care relationship. These values confront professionals with ethical tensions. Moreover, clients experience burdens from the way support is practiced and organized in these settings.

These ethical tensions and burdens are not sufficiently attended to in the policies that form the background to professional work. Such policy silence is problematic as the important work professionals engage in to negotiate these ethical tensions is insufficiently supported [1-3]. Furthermore, clients and informal carers are left with little discursive means to voice negative experiences accompanying the emphasis on these values. This limits their possibilities for impacting the improvement of quality of care. Moreover, current methods for quality improvement do not sufficiently attend to the value complexities in the care relationship. In order to improve the quality of the care relationship a method involving clients, professionals and informal carers in critical reflection, deliberation and co-design is needed and has been developed as part of this research.

In this chapter I will answer the research question and sub questions formulated in chapter 1:

How can the quality of the care relationship in long term care be improved, responding to its value complexities?

1. Which ethical tensions emerge in the care relationship in supported living and home care against the backdrop of values such as self-determination, fostering an independent lifestyle and community participation?
2. Which consequences, such as burdens for clients, emerge in the complex care relationship?
3. How can good care, responding to ethical tensions, be practiced in collectives in the context of dominant valuation regimes?
4. How can EBCD be adjusted to incorporate critical reflection, deliberation, and co-design to supports clients, professionals and informal carers in responding to the value complexities in the care relationships?

Ethical tensions in the care relationship

In answering question 1, I distinguish five grounds for ethical tensions in the care relationship. These are distilled from chapter 2, 3 and 5. Explicating these different ways in which ethical tensions come about helps to better recognize and respond to them.

Tensions between values

The first cause of ethical tensions is value conflict, for example between the value of respecting autonomy and preventing harm. The empirical chapters in this thesis show such tensions in practice, for example in supporting clients' choices to use internet dating and at the same time wanting to prevent risk of abuse. Or in case of home care services: supporting clients' choices, while these could harm their health, such as not wanting their legs to be bandaged in order to fit nice shoes when going out. The chapters also highlighted tensions between different autonomy related values, for instance when people's self-determined choice is not to want to live independently or develop ties in the community.

Tensions between different ways values are specified or practiced

Tensions not only emerge between values, but tensions also emerge as values such as self-determination, an independent lifestyle or community participation are specified and practiced in different ways. Fostering self-determination for instance may entail providing room to clients to make independent choices or relationally engaging with clients to help their process of exploring their wants and needs. These different enactments of a value relate to different care practices. For instance, leaving clients in their neglected households as they stated this is the way they prefer to live, may be a good way to foster self-determination when this is understood in terms of individual choice. Such an approach however would be considered abandonment from a relational point of view from which continued engagement would be required.

Multiple ontologies

Ethical tensions not only relate to different values or different interpretations of these values but also to different ontologies of clients. This notion of multiple ontologies I take from Mol [4] and Pols[5]. I apply the notion of multiple ontologies to the different ways in which clients and their needs are perceived. For example, as someone who is incapable of keeping their household themselves or as someone too lazy to clean up. These different ontologies result in different ideas on what good care is: organizing support with cleaning or refraining from doing so as this would hamper a client from developing an independent lifestyle.

Tensions between professionals, clients, and informal carers

Ethical tensions also emerge as different stakeholders caring for the same client – and those clients themselves – diverge in their views on good care, ontologies of clients and, relatedly, how care responsibilities should be distributed. Such a tension between clients, professionals or family members is illustrated in the script 'Cesspit' in the introduction, in which the professional feels leaving a client in their neglected household is good care as this way self-determination is respected while a mother feels harm is being done. Moreover, in such collectives, tensions also arise around distribution of responsibilities. This is about who is perceived to be responsible for certain care tasks. For instance, whether taking a urine sample to the doctor is a task of professionals in home care service or of family members. This is in line with other research showing tensions that emerge relating to the question who (e.g. professional or informal carers) takes up care tasks [6,7]. However, in this literature this is often not described as an e*thical tension* related to different views on responsibility.

Values inscribed in organizational structures

Last, ethical tensions emerge as organizational policies, including agreements between care organizations and external parties and other policies structuring care at the organizational level, may inscribe values in ways that do not match with the perception of good care of clients, professionals or informal carers. An example of such policy is described in chapter 3. Here – an everyone their own front door policy – was designed to provide clients with more independence and self-determination. This left professionals with the experience this could be harmful for clients as they would miss the readily available social contact in a group home.

The distinction between types of tensions helps to better understand the myriad ways in which professionals face ethical tensions in care relationships in long term care. By recognizing such tensions, professionals, clients, informal carers, managers and policy makers can identify areas where the quality of care can be improved. Tensions between the value of preventing harm and respecting autonomy are quite often described in the literature in supported independent living and in healthcare more broadly [8-10]. However, the other type of tensions delineated here are much less often described. For instance, ethical tensions emerging between professionals caring for the same client is a rather unexplored area [11], while explicating and negotiating such ethical tensions is important for improving quality of care.

Consequences of complex care

In this section I answer the second question about the consequences of the complexities of the care relationship for providing good care. For professionals such consequences entail the experienced ethical tensions as described above. For clients, an important consequence is the burden of support developed in chapter 4. Other consequences can be the experience of poor-quality care by clients, informal carers or professionals assessing the work of their colleagues (chapter 3 and 5).

Burdens of support

To capture the negative experiences of clients with the way values such as self-determination, an independent lifestyle and community participation are practiced or inscribed in organizational structures I have developed the concept burden of support. Burden of support is inspired by literature on burden of treatment. Adding to the literature on burden of disease, burden of treatment addresses how patients (including people with SMI) not only face negative consequences from their disease, they also experience burdens from their treatment such as having to take medication or following self-management regimes [12-15]. Burden of support adds to this literature by explicating the negative consequences clients face from being supported by independent living services. The burdens of support identified in this thesis are a consequence of values such as self-determination, an independent lifestyle and community participation not being negotiated with other values important in the care for clients. Connecting burden of support to the concept of 'counter narrative' [16,17] shows the added value to client involvement in service improvement and service design. Burdens of support constitute a counter-narrative to critically engage with the way autonomy-related values are practiced by professionals, discussed in (organizational) policy or inscribed in organizational structures. For good care attending to its complexity, it is important to be responsive to the burdens of support, as chapter 3 and 4 also highlight.

Experiences of poor quality of care

When ontologies, values or distributions of responsibility were not carefully negotiated or assembled in a care practice, those involved can be left with the experience of poor quality of care. This is obvious in the case of experienced burdens by clients and the ethical tensions professionals are confronted with. For informal carers, this consequence of experiencing poor quality care is described in chapter 3. In this chapter the example is given of Jesse's mother who complained about his neglected household. Whilst Jesse's mother expressed her concerns to the professionals, this was dismissed referring to Jesse's autonomy. Rather than using her reaction to discuss underlying values and ontologies, the discussion was cut short by referring to a dominant value held by the professionals. This left Jesse's mother with the experience of poor quality of care. Moreover, as chapter 5 shows, when differences between how professionals specify and assemble values is not deliberated, this leads to professionals assessing each other's work as of poor quality as well. This lack of deliberation might have further consequences for the care relationship as this could negatively impact the collaboration between clients, professionals and informal carers.

Practicing good care

By elaborating on the concept of collective tinkering developed in chapter 3 and invisible worth developed in chapter 5 I answer the third question: how good care can be practiced in collectives responding to ethical tensions, in the context of dominant valuation regimes. I conclude by bringing the concepts employed and developed in this thesis and the phases of care developed by Tronto[18] together in a conceptualization for good care.

Collective tinkering

In the introduction, I have argued how tinkering an important concept to understand good care [19]. This concept however needs to be expanded as in long term care, multiple professionals and informal carers are often involved in the care for clients. In chapter 3 and 5 I further conceptualized how tinkering can be practiced in such collectives. Collective tinkering entails: attentively experimenting with care practices in which values, ontologies, and distributions of responsibility of people and things involved in care are assembled.

Collective tinkering, like tinkering in individual care relationships, is both about experimenting with care practices to support a single client and about experimenting with care practices that structure care for a group of clients. However, collective tinkering includes several relevant stakeholders important in care in the tinkering process. Therefore, collective tinkering is a response to the ethical tensions emerging as people caring for the same client prioritize different values or enactments of these; hold different ontologies or different views on how responsibility should be distributed. Collective tinkering is also a response to ethical tensions emerging when values are inscribed in organizational structures in ways that do not match with what professionals (or others) find important for good care as collective tinkering also is about developing care practices for a group of clients. Finally, collective tinkering can be a way to decrease the burdens of support as experienced by clients.

Collective tinkering can lead to more robust care practices. An example includes a client with a neglected household discussed in chapter 3. Here different ontologies and values needed to be assembled including preventing harm and supporting an independent lifestyle. This was a collective process as multiple professionals were involved. In this case many experiments were performed, for instance informing the client about fire risks by a real firefighter or cleaning for him when he was away. These experiments were followed attentively but failed. They did not result in a more hygienic space and left this client feeling like his privacy was invaded. After some time, it was decided to have someone help him clean bi-weekly as a compromise between values. This led to a more hygienic space and also the client himself was happy as he now had more ‘life space’.

The example shows a few other important aspects of collective tinkering. Foremost, collective tinkering, like tinkering in individual care relationships, is a continuous and iterative process as the consequences of new experiments need to be reflected upon (e.g., does it decrease burdens experienced by clients). This is illustrated by the example of Max as some team members felt this solution could only be temporary as otherwise this client would not learn to keep up his household independently. This tension therefor would further drive the experimentation with the care practice.

Another important aspect specific to collective tinkering is, it requires time and space where people involved in care can deliberate and invent care practices together. Teams often have such moments for instance as part of team meetings. While these structures foster interaction, they need not support the specific activity of collective tinkering. Moreover, such pre-set structures often do not include all involved in care, such as clients themselves, informal carers or professionals from other care organizations. Collective tinkering would thus benefit from other methods that bring these collectives together.

The influence of valuation regimes on collective tinkering

Collective tinkering is influenced by the context of valuation regimes. A risk involved in collective tinkering is when certain values not part of these regimes, but important for good care, do not find their way easily into the tinkering process. To attend to these values, I developed the concept of invisible worth. For this I drew on notions of invisible work [20] and related this to the concepts of valuation regimes and valuation practices [21,22]. Invisible worth is akin to invisible work. But whereas the latter describes the activities undertaken to enable the flow of work, the former points at the underlying values and valuations that are thus expressed. The concept can sensitize us to what is important in bringing about good care. An important worth discussed in chapter 5 for instance, is empowering clients by relationally engaging with clients to foster their self-determination. This involves engaging in dialogue with clients about important life decisions to support their decision making. As the worth inherent in this work is not recognized, the work professionals engage in to bring about this worth is given another meaning: that of simply providing social chat.

The invisibility of certain values entails the important work professionals engage in is not discussed or even frowned upon as its worth is not understood by team members or managers. Thereby this important work is not supported but rather dismissed. Invisible worths are important to be responsive to as these can have positive consequences for clients. For good care these values need to be included in the tinkering process as part of the different values that need to be assembled in a care practice.

Conceptualization of good care

So far, I have elaborated on the insights applied and developed in chapters 2-5 regarding the value complexity of the care relationship. By relating these to the various phases of Tronto's[18] conceptualization of care I develop an approach to good care which attends to the complexities in the care relationship in the context of regimes of valuation. Providing good care while responding to the complexities in the care relationship requires an integration of Tronto's[18] conceptualization of good care and the concepts of multiple values, ontologies and tinkering as developed by Mol et al.[19] and Pols [5] and the concepts of collective tinkering, burden of support and invisible worth's as developed in this thesis.

Tronto's[18] first phase of care: caring about – that is: being attentive to the needs for care – is complex as professionals, clients and informal carers differ in how they perceive the client and relatedly their needs (e.g. their ontology). Tronto's [18] second phase of care: 'taking care of', which is about taking responsibility for care, is complex as clients, professionals and informal carers have different conceptions of the distribution of responsibility. In the third phase: 'caring about', which is about providing care with competence, tensions can emerge between what is considered good in specific situations (e.g. tensions between values or different ways in which values can be enacted). Other tensions include those related to the way values are inscribed in organizational policies, limiting professionals', clients' and informal carers' discretionary space to bring about care in the way they deem is good. Tinkering [19] is a process that attends to such complexities, which needs to be a collective process including both clients, professionals and informal carers. Tronto's [18] last phase is about being responsive to how care is received. In the collective care relationship this includes being responsive to the experiences of burden by clients and of poor quality of care by informal carers or of other professionals caring for the same client. Moreover, the invisible worths need to be responded to in order to strengthen care practices that bring about good care but remain unnoticed as they are not part of the dominant regimes of valuation.

From this analysis I develop a conceptualization of good care:

> *Good care involves a persistent collective process of tinkering which includes: attending to clients' needs by assembling multiple ontologies of who clients are and what they need; negotiating the multiple ways in which responsibilities can be distributed amongst clients, professionals and informal carers; providing care with competence by assembling the different values in a care practice; being responsive to how care is received by attending to values important to stakeholders not yet included in the tinkering process; and attending to burdens of support and invisible worths in the context of valuation regimes.*

In short, I will refer to this notion of good care as 'collective tinkering'. This notion supports clients, professionals, informal carers and policy makers in explicating good care and further fostering it. My conception of good care can be understood as a critique or alternative to dominant ways of understanding good care put forward in policies on long-term care including policies related to the transitions in long-term care, quality frameworks, and other reports addressing professionals on how to organize and practice good care.

Care models

My conception of good care can be understood as a critique to linear notions in which good care is conceptualized as an outcome of implementing certain care values such as self-determination [23] or care models such as personalized care [24,25] or recovery-oriented care [26]. I do not argue such care models cannot contribute to promoting good care. They can. However, these linear views do not do justice to the complexity of good care in practice described above. Promoting good care can take inspiration from such care models. However, bringing about good care requires the situated practice of collective tinkering with the values, ontologies and distributions of responsibility brought to the fore in these models; and being responsive to the burdens, experiences of poor quality of care and the invisible worth's emerging in this process.

Participation and integrated care

My conception of good care can moreover be understood as a critique to overly harmonious understandings of providing care in collectives of clients, informal carers and various professionals [27,28]. This critique is in line with that of other critical scholars emphasizing family members do not always want to take up the role of informal carers [29,30]. However, in addition I have shown how informal carers and professionals face ethical tensions as their views diverge on what is good care. My view on good care places the tensions often silenced in policy documents and quality instruments to the fore and further elaborates on what these demand for providing good care.

This view on complexity – inspired by discussions on multiplicity by Mol [4] and Pols [5] – should not be mistaken for *perspectivism* [4]. In perspectivism different perspectives are understood to all be parts of one single truth. Bringing together the different perspectives of clients, informal carers and professionals – in this view – would enable us to come closer to *the essence* of good care. This is not in line with my view on the complexity of collective care. In my view there is no single core to what good care entails which can be worked up to. Informal carers, professionals and clients are not understood to each have their own perspectives on good care together adding up to one single understanding of the truth about good care. Instead, informal carers, professionals and clients each may bring different ontologies, values, and distributions of responsibility to the table, creating tensions, which potentially are positive drivers for innovation of care practices. This is not to say there cannot be any guidance to this process of collective tinkering. The values put forward as part of valuation regimes (including care models such as recovery-oriented care or personalized care) can provide such guidance. However good care demands shifting attention from the abstract values put forward in these policies to the process of practicing these; specifically, to the tensions and burdens emerging in this process and the invisible worths' left out. Good care is what happens when relationships between clients, professionals and informal carers are strengthened in ways that enable them to experiment with care practices together. This process can be strengthened when such ethical tensions and burdens are already made somewhat explicit in such policies.

Autonomy

Last, my conception of good care can be understood as a critique on liberal-individual notions of autonomy and support of relational views on autonomy [31,32]. As other authors have also noted (e.g. [33]), in policies forming the background to professional work liberal-individual notions of autonomy are central. Such notions emphasize non-interfered choice-making and independence as important to autonomy. In more recent quality frameworks, the relationship is acknowledged as important for good quality of care. Even in such policy documents however at the same time autonomy is given an individual-liberal meaning as self-determination and independence are still often emphasized to be individual matters. Such notions do not align with the complexity of care in practice. First, an overemphasis on such notions leads to burdens for clients such as negligence (see chapter 4). Second, both clients and professionals' self-understandings and understandings of good care are shaped in the wider discursive, institutional, and material context (see chapter 4 and 5). This makes non-interference as part of fostering autonomy almost impossible. Instead, fostering autonomy demands relationships in which people are supported in critically reflecting on the contexts which shape their self-understandings, their choices and understandings of good care. Third, liberal-individual notions on autonomy render important relational work professionals engage in to enable clients to develop a self-understanding or flourish in the community invisible (see chapter 5). These findings support a more relational view on autonomy where care relationships are crucial in supporting clients' choice-making and flourishing, just as relationships are important for everyone else in these ways [31,32].

Competencies

A critique to my notion on good care could entail collective tinkering can be considered very challenging for professionals and therefore not a realistic demand. I would agree collective tinkering certainly requires skills such as reflexivity, being able to deliberate with multiple parties and creativity in developing care practices. However, professionals included in the studies part of this thesis also already engage in this type of work (see chapter 3 and 5). Moreover, one of the central points in this thesis is that the responsibility for bringing about good care this way should not only lay with professionals alone. This needs to be supported by managers and policy makers (see also implications for policy and practice). One of the ways to do so is by developing reflexive spaces [34,35] that focus on critical reflection, deliberation and co-design [36].

Such an intervention at team level can support professionals, clients and informal carers in developing the skills needed for collective tinkering and also help to adopt organizational structures and care practices to bring about better care. For this I developed the quality improvement method 'Ask Us!', which was based on EBCD [37]. I elaborate on this in chapter 6 and in the next section.

Designing a method for quality improvement of the complex care relationship

The development of the method 'Ask Us!' is my answer to the last question: 'How can EBCD be adjusted to incorporate critical reflection, deliberation and co-design to supports clients, professionals and informal carers in responding to the value complexities in care relationships?'. 'Ask Us!' was developed in response to this question. This method and the participatory process through which it was developed are discussed in chapter 6. Here I further explicate the relationship between 'Ask us!' and my conceptualization of good care. 'Ask us!' works to improve the quality of the care relationship as it: (1) fosters collectives to develop improvements of care together and (2) supports clients, professionals and informal carers in developing competencies required for collective tinkering.

Developing improvements

The method 'Ask us!' supports professionals, clients and informal carers to develop improvements in care practices. This is a process of several phases: (1) 'Ask Us!' engages clients, professionals and informal carers in critical reflection through which ethical tensions, invisible worths and burdens are explicated and the agenda for improvement is set; (2) deliberation through which the tensions between different values put forward by different stakeholders are explored and mutual understanding is fostered and (3) co-design through which care practices are improved. This may involve small improvements (e.g., the way client's coffee moments are organized, see chapter 3), it may also involve bigger changes (e.g. the way developing goals for the personalized care plan is organized, see chapter 4). Through the process of 'Ask Us!' care practices and policies can be developed in which: (1) values important to clients, professionals, and informal carers currently not part of care practices are incorporated; (2) burdens to clients are alleviated and (3) invisible worth's overlooked in dominant valuation regimes are explicated and strengthened.

Developing competence for collective tinkering

A second way in which 'Ask us!' improves the quality of the care relationship is through supporting clients, professionals and informal carers in developing the sensitivities and skills needed for collective tinkering in individual cases. This happens during the various group-, deliberation- and co-design sessions part of the process of 'Ask Us!'. In these sessions through critical reflection professionals are sensitized to the ethical tensions described in this thesis.

For clients, the groups sessions support developing skills to explicate experiences with care, both: (1) negative experiences which result from the way values such as self-determination, an independent lifestyle and community participation are practiced (e.g. burdens) and (2) positive experiences with care which they would like to see happening more often but which are not fostered as they are about other things than dominant values (e.g. invisible worths).

Similarly, for informal carers the group sessions support them to explicate: (1) how they see the client and their needs; (2) what they find important about who does what part of the care work; and (3) the values they consider to be important which are currently not part of care practices.

The films developed in this project (of which some of the scripts were presented throughout this thesis) play an important role in this. These films present engage clients, professionals and informal carers in critical reflection on their own experiences.

To further support the collective aspect of tinkering it is important professionals, clients and informal carers develop sensitivity toward the various perspectives on these complexities. Moreover, taking part in the deliberation part of 'Ask Us!' can further develop their skills to deliberate differences in case of collective tinkering for individual clients. As collective tinkering is not merely about deliberation but also about developing care practices; professionals, clients and informal carers need to be supported in developing the creative skills to assemble the various complexities in a care practice. The co-design sessions part of 'Ask Us!' thus not only aims to develop specific improvements but also to support clients, professionals and informal carers in developing the skills needed for collective tinkering.

Implications for policy and practice

This research has important implications for policy and practice. Here I discuss the implications of the central findings of this thesis.

Embedding 'Ask Us!' in care organizations

A major practical contribution of this research lies in the development of the method 'Ask Us!'. This method supports clients, professionals and informal carers in developing the skills and sensitivities needed for bringing about good care. Moreover, it supports them in developing improvements in the organization of care which further support bringing about the good care relationship. This method thus not only empowers clients to be involved in quality improvement, it also empowers professionals in changing services instead of merely offering resistance when these do not fit what they deem good care [38].

'Ask Us!' can contribute to the shift towards narrative and generative accountability as it fosters organizational learning and concrete quality improvement aligned with the narrative experiences of clients, professionals and informal carers and involving them throughout the improvement process [39,40]. When 'Ask Us!' is part of formal policy regarding assessment care, the complexity of the care relationship will be better acknowledged and attended to. ‘Ask Us!’ can be embedded in existing assessment structures as it brings together several requirements regarding accountability in long term care: client involvement (obligation under the Wet Medezeggeschap Cliënten in de Zorg) and team reflection (requirement in the quality framework for people with disabilities receiving long term care,).This is supported by our experiences with recruiting organizations for a follow-up project, some of which indeed recognize ‘Ask us!’ as way of organizing team reflection. Moreover, this understanding of ‘Ask us!’ as bringing together client involvement and team reflection was also recognized in an in interview by members of Zorginstituut Nederland, the dedicated body to govern quality of care in the Netherlands.

Reflection on ethical tensions and burdens

The concepts developed in this thesis and the films developed as part of the method ‘Ask Us!’, which illustrate these, provide means for different audiences to reflect on their experiences and engage in action to improve services. This includes clients, professionals and informal carers and their representatives. The ethical tensions, burdens and invisible worths and their translation into filmed monologues furthermore prove means for future professionals to attend to the complex needs of clients with ID, SMI and older persons and the ethical tensions emerging from differences between clients, professionals and informal carers. However, for this purpose these concepts need to be translated in Dutch and the everyday language use of professionals and clients. One way in which the findings were made accessible to clients, professionals and informal carers is by developing the 42 short films also part of the ‘Aks us!’ method. These films are productive in fostering reflection in a broad range of settings. This we experience for instance when we show them as part of presentations to many different audiences, including professionals, clients and policy makers. These films also prove valuable educational material for (future) professionals to reflect on ethical tensions and burdens. This was experienced by myself in education in Health Sciences but also by the collaborating member of the project team from the Rotterdam University of Applied Sciences who used these films as part of education in Nursing; Social Work and Occupational therapy.

For managers in care organizations and policy makers on various levels of government and in professional associations, the insights into the ethical tensions, burdens and invisible worths, provide means for attending to the complex needs of service users and the complexities in the work of professionals. Taking seriously these complexities would demand from policy makers to account better for them in organizational policies such as vision and mission statements and national policies such as quality frameworks and professional competency profiles. This would thus entail making complexity part of the regimes of valuation instead of leaving these complexities for professionals, clients and informal carers to work out in practice.

Suggestions for future research

Here I elaborate on the areas worth exploring in future research arising from this thesis.

Evaluation

An important area for future research is evaluation of the 'Ask Us!' method. The Covid-19 crisis started right at the moment I was about to evaluate the 'Ask Us!' method in two teams caring for people with SMI and ID and setting up the evaluation of the method with a team in home care services was in progress. For the two participating organizations it proved not to be feasible to start the evaluation process during these times. Moreover, care in times of Covid-19 differed much from care as usual, with the emergence of quite specific ethical tensions. This is another reason why the early times of the pandemic was not very suitable to evaluate the method. For these reasons the planned evaluation of 'Ask Us!' has of yet not taken place. While there were many positive reactions to the method during presentations for client-councils; patient organizations; professionals and other audiences, the merits of this method need to be further explored in a formal evaluation. Moreover, evaluation also needs to be done in other organizations to establish its generalizability.

Important questions for this evaluation include how the produced films engage audiences in critical reflection, voicing burdens and identify improvement for services. Moreover, regarding the use of film, it would be interesting to explore further what is gained (and lost) by using films produced in artistic collaboration as was done in this thesis, instead of using filmed client interviews from a national archive as is currently standard practice in accelerated EBCD projects [41,42]. Other areas worth exploring include how the adjusted dialogue sessions part of 'Ask Us!' are able to alleviate power differences and ensure participation of clients and how this can be further enhanced. Possible ways include involvement of experts-by-experience as co-facilitators of the method. Future research can also develop 'Ask Us!' for different contexts. This includes different client groups such as nursing home care; or different areas of support, such as spending leisure time instead of supported independent living.

Further advancement of main concepts

A second area for future research entails further advancement of the main concepts developed in this thesis including: burden of support; invisible worth and collective tinkering. As these concepts have potential in informing improvement of quality of care, further development of these concepts is fruitful. First, these concepts need to be extended to other cases in long term care, such as nursing home care to older persons and to other domains beyond supported living, for instance including sheltered work or support in spending leisure time. Second, as I did not elaborate each of these concepts for all cases involved in this study, this also requires future research. For instance, I have not developed the concept burden of support in the case of older persons in home care. The data collected in this research however suggests burdens are experienced by older persons receiving home care as well which may partly be different burdens from those distinguished so far. Moreover, the data collected in this research suggest informal carers such as family members experience burdens as well from the way values such as self-determination, fostering an independent lifestyle and community participation are practiced and inscribed in organizational structures. Similarly, I have not conceptualized the values that remain invisible in the cases regarding supported living for people with ID or SMI in this thesis. However, my data does suggest values important to bring about a good care relationship here also remain invisible. Expanding the scope of these concepts through future research supports in making client, professional and informal carers experiences more productive for quality improvement.

Policy silence

Another area for future research is related to the policy silence on the value complexity of the care relationship in long term care [1,2]. Such research could include conceptualization of the ways in which ethical tensions and burdens remain implicit in policy documents forming the background to professionals' work and develop understanding of how such policy silence comes about. In order to support policy makers in attending to value complexities such research should also address how value conflicts can be made part of policy documents in ways that both leave discretionary room to professionals and support them in attending to ethical tensions and burdens. This is important as such policy silence renders professionals with little support in handling these ethical tensions and clients with little means to voice their negative experiences. This thesis has shown such ethical tensions and burdens are manifold in long term care and are important to attend to for improving quality of care. While making the method 'Ask Us!' part of accountability structures is one way of supporting professionals, clients and informal carers with ethical tensions and burdens, attending to these complexities in policies could further support them.

The organizational context

A last area worth exploring relates to the organizational context in which the care relationship comes about. This includes developing understanding of how organizational structures bring about burdens or enable collective tinkering. This could further support improving the quality of the care relationship. This also relates to the normative organizational context (e.g. mission and vision statements; website; other communication towards clients; informal carers; professionals and payers; policies etc.). How do different normative contexts bring about ethical tensions, burdens and invisible worth's? Moreover, it would be fruitful to conceptualize how organizations differ in such communications and what could be legitimate ways of producing such normative contexts. Previous research for instance has shown some organizations portray client experiences in ways that brush away the complex needs of some of their clients. Similarly such organizations communicate about how they foster values such as self-determination in ways that brush away the complexities of providing good care [43]. How can organizational communication better account for the complexities in the care relationship, instead of reproducing 'hurray' policy terms? This is also important in further advancing narrative accountability as narrative accountability depends partly on how organizations communicate about their learning process. When such communication silences the complexity of care, this potentially poses threats to the feasibility and effectiveness of narrative accountability procedures as such accounts merely are about window dressing instead of showcasing developments in organizational learning.

Follow-up projects

I am in the fortunate position of having contributed to securing funding for two projects in which many of these suggestions for further research are taken up[6]. These research projects continue the partnerships developed in this research and involve new care organizations and research partners. Moreover, in these projects we will work on further disseminating the method 'Ask Us!' and develop educational activities for future professionals to reflect on the complex care relationship. As 'Ask Us!' fits a trend of developing novel ways of accounting that better attend to narrative experiences and foster learning, developing further understanding of how accounting can be improved in this way is also part of these projects [39].

Methodological reflections

This research involved participatory and ethnographic methods and artistic collaboration which were adjusted along the way in response to limitations encountered in the field. This provides valuable lessons for doing participatory research in supported living for people with SMI and ID and home care services for older persons.

Experts-by-experience as co-ethnographers

Involving experts-by-experience as co-ethnographers allowed for attending to experiences of service users that are unable or unwilling to be interviewed and that cannot be observed as these situations did not cater for the researchers' presence. In future research this role of experts-by-experience working as peer support workers could be further expanded. During this research I encountered the problem that care in supported housing facilities is organized in more individualized ways, especially in case of supported living to people with SMI. This is part of a larger trend of promoting an independent lifestyle. Providing individualized care

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[6] These projects are funded by NWO: 'Stories of adults diagnosed with psychotic spectrum disorders on social (re) integration: development of two experienced-based interventions' and ZonMw: 'Als je het ons vraagt: co-creatie van de zorgrelatie.'

(including in group homes) includes much less use of common spaces such as living rooms, and less common moments such as daily coffee moments and meals. This limits the possibility for researchers to establish rapport with clients or observe care moments. This also hampers possibilities for observing the enacted appreciations of service users which make up for the lack of people willing or able to engage in interviews [44].

In finding ways to resolve this issue, I included interviews with experts-by-experience. These worked as peer support workers in several care teams providing support for people with SMI and ID. Experts-by-experience were not interviewed so much on their own previous experiences with professional services. Instead, they were prompted to narrate complex situations they encountered in supported living and to reflect on the experiences of those involved. This way experts-by-experience were involved as co-ethnographists as their observations of care practices were collected. In combination with the observations, interviews and informal conversations that I was able to conduct myself this proved to be very valuable data on care moment that did not cater for the researcher's presence.

Critical client involvement in research

As clients are understood to be socialized in regimes of valuation it can be difficult for them to communicate negative experiences with the values put forward in these regimes. This hampers clients' critical involvement in research. In order to involve clients in a critical matter I elaborated on the method of developing counter narratives [16,17].

Client involvement is a rising priority in both service design and research. Discussions on client involvement in research often evolve around ways to organize optimal participation of clients in terms of being able to have an equal share in all steps of the research process, thereby acting as research partners [45]. Here it is often assumed that as long as clients can participate equally, critical issues arising from client experiences will be raised. Such a focus on involving clients in the research process however does not resolve the issue of epistemic injustice deriving from the dominant discursive context in which they discuss their experiences [46]. In this research, I organized the involvement process differently for clients' critical insights to emerge and be included: by developing counternarratives.

For clients' critical engagement through the development of counter narratives the researcher needed to be foregrounded at certain phases in the research. As elaborated on in chapter 4, I adopted the qualitative research methods interviewing, participant observation and photovoice to allow clients to express their experiences in ways that transgress the values part of valuation regimes and developed counter narratives from this. Developing counter narratives involves interpretative skills of the researcher to develop overarching themes and bringing these into dialogue with values enshrined in policy discourse. This requires careful balancing as to make sure the counter-narratives are grounded in service users experience and not appropriated for a researchers' critical agenda. Clients were involved in refining these counter narratives through data validation sessions as is discussed in chapter 4. The counter narratives produced through this process provide means for clients to critically reflect on their own experiences and for professionals, managers and policy makers to attend to clients' needs in practicing and organizing care and can thus be a way to limit epistemic injustice [46].

Translation as part of artistic collaboration

To engage a broader audience with the research findings I developed a process of artistic collaboration through articulating steps of translation from the ethnographic data to the filmed monologues. In chapter 6, I report on this collaboration process with a playwright and inclusive theatre company in developing the filmed monologues based on ethnographic research. In this artistic collaboration, films were developed that were both firmly grounded in research data and have an artistic quality in their ability to move and engage audiences. Developing films through artistic collaboration as opposed to filming interviews started as a response to a barrier encountered in the field as many clients were hesitant to share their experiences through interviews, let alone be recorded on camera. Through the artistic collaboration I could still represent their experiences and engage audiences in meaningful ways. Here a problem of representation arises as these films did not result unmediated from clients' interviews. Therefor questions could be raised to their representational value. This representation process can be made more transparent by explicating the translations made [47]. This explicates both the validity and value of these films. Moreover, this representation process can then can be seen as a way of representing voices of clients who otherwise are in danger of remaining unheard [48].

Personal reflections

I started out this research with a few experiences and values of my own in mind. I will elaborate on three of these as I think they were important in shaping this research.

The importance of narratives and co-design for quality improvement

I started my scientific education as a psychology student at the University of Amsterdam (2002). The psychology department of this university is known for its focus on experimental research. Qualitative methods thus were not part of my training. Moreover, I vividly recall a lecture part of a methods course in which the researcher elaborated on all the winners of the dubious award of worse research. He only recited examples from qualitative research while explaining how the 'observations' reported on there could never support the causal conclusions laid out in this research as these did not live-up to the standards he had previously laid out for quantitative (representational) research. He concluded by (jokingly) asking us to rip out the chapter on qualitative research from our books.

During my master's degree in clinical psychology, I did a yearlong internship that combined clinical and research work and lead up to my Master thesis (2008). My research internship was part of a larger study in which patient-reported outcome data was collected on regular intervals with the patients in therapy. These were analyzed to provide feedback on therapists and thereby improve quality of care. For my master thesis I compared two ways of modelling this data to see whether therapists differed in the effect they had on patient outcomes. Here I cruelly became aware of all the steps that were needed to be taken in reducing these data in order to make them fit to perform the analysis. For instance, for a multilevel analysis certain power (e.g. number of datapoints) is needed to perform the analysis. Where the factor of differences between case load of therapist (for instance diagnostical group, or level of symptoms at intake) would intuitively make much of a difference on therapist effect, especially as some therapists where specialized in more complex cases, this could hardly be controlled for as the units of analysis needed to be very large in order to have enough power. Moreover, in the literature there were various conflicting ways on how to model outcome: e.g. as the regression line between the starting point and the final outcome after finishing therapy; or as the gradual change in symptoms estimated by taking in all the data points from each session in the analysis. Such choices can't be made purely on rational arguments of what is a better model for outcome. However, they do matter for the results of the analysis. These and many other experiences I had (and discussed with my supervisors) made me quite skeptical about the whole endeavor of measuring quality of care through patient-reported outcomes and using these data for individual feedback to therapists or benchmarking quality of therapists or organizations.

Between my bachelor and master's degree in psychology I also did a master's degree in Medical Anthropology & Sociology. Here my whole world changed as I learned to critically reflect on the positivistic research tradition I was trained in and learned other outlooks on research, both in terms of philosophy of science as in terms of qualitative methodologies. Moreover, I learned many tools to critically reflect on the field of psychology in general including the practice of diagnostic labeling. This totally blew my mind, and I went on further exploring this by starting a pre-master's in philosophy of science.

My skepticism on the promises of mapping patient-reported outcome data and being able to compare quality of care providers was further expanded with experiences I had in various research context, which I was able to reflect on with the newfound outlook in medical anthropology. These include a side job where I supervised survey interviewers, data entry and coding of data where also quality data of care institutions was handled. Later on, I worked for a year (2011-2012) with the scientific department on a mental health care institute. There I shared many lunch breaks with the staff responsible for collecting various outcome data. I can vividly remember many of their stories which exemplified the major differences between peoples' lived experiences and what can be pinned down in a standardized questionnaire. One anecdote included a part of a questionnaire about aggressive behavior. A client was asked if he ever expressed any aggressive behavior towards humans or animals. The inquiry was interrupted as he yelled to his dog ‘be quiet or I give you a kicking you won’t recall’ and back to the interviewer responded with ‘no, never’ on her questioning on his aggressive behavior. Moreover, as part of this work I also administered questionnaires on depressive symptoms to older persons. Here many of their stories where so rich and felt totally lost in translation in the pre-set questions on depressive symptoms. For instance, a woman explaining how she could no longer perform her hobby of knitting as her hands hurt too much from rheumatism answered she lost interest in her hobbies and thereby scored high on a depression scale. Moreover, many rich stories of mourning and struggling to cope with losses part of growing older were simply reduced to a two-digit score indicating depression or not.

Later on (2012-2015) I worked at the Rathenau Institute (a thinktank supporting Dutch parliament) where I was involved in a project on opening up the debate on quality indicators to more narrative ways of improving quality of care. Here I extensively followed the political debate on this issue and felt the constant call for transparency was not much aligned with what I felt was possible from my previous experiences with outcome data. Here I experienced how ideologically driven this debate is. Part of this project was to collect stories of experiences with hospital care. I analyzed these stories thematically and compared the emerging themes with the questionnaire on patient experience data on quality of care (CQI). Again, I was struck by the richness and potential to learn from these stories in relation to how these experiences are reduced in response to such questionnaires. However, I also often struggled with the meaning of these stories as they could not be placed in the context of the experiences of the care providers or other specifics of the care setting. Another role I had in this project was to collect examples of good practices in which narratives were used for quality improvement. It was here I first came into contact with Experience Based Co-Design and felt it had great potential for quality improvement. This also resonated with previous experiences as a junior researcher part of a project on citizen initiatives in low-SES neighborhoods (2010-2011). As part of this project I coordinated interviews on experiences of citizens with initiating projects to enhance their neighborhoods and conducted some of these interviews myself as well. Here I saw the potential of citizen participation and co-creation. However, the experiences in this project also made me aware citizen participation and co-creation involves many tensions and does not necessarily lead to more social cohesion. This also makes me weary of uncritical accounts of client involvement and co-design.

These experiences have surely impacted this research. I can safely say I really care about, care for and want to take care of providing alternatives to reductionistic accounts of ‘quality’ from the unfortunately quite dominant positivistic outlook on what good research entails. This makes my endeavors to make a method like ‘Ask Us!’ work almost activistic. From a care ethics perspective this does not have to be problematic as it also makes me very motivated to produce something that actually will prove beneficial to practice. Moreover, while on the one hand I do not shy away from celebrating a success on the other hand I can be quite self-critical and do not easily consider something I did to be good. This I think will contribute to keeping me wanting to improve a method like 'Ask Us!' instead of too easily claim results that are not grounded in the experiences of participants. Moreover, the process of developing and evaluating Ask Us! is a participatory process. The various people involved, including the clients, professionals and policy makers of participating care organizations have strong stakes in ensuring the method lives up to its promise to improve the quality of the care relationship. Furthermore, various aspects of data collection and analysis is frequently deliberation with peers, such as colleagues and supervisors. These practices bring in important checks and balances.

Living in a group home as opposed to living independently in the community

I started out this research with somewhat of a preference for clients to live in a group home over living independently in the community. This derived from my two-year experience (2009-2011) working in intermural settings in mental healthcare as an aide. During this time, I was a bit lonely. I was single, no longer living in a student home with peers, but in my own appartement alone. I was no longer a full-time student, but also felt the rest of my life had not started yet. I followed courses at the philosophy department but wasn't really close to any of my peers in the working groups as I was not part of the fulltime study. Moreover, as my work as an aid was 'flexible' in the sense I often only knew a day before if I had to work or not, and often worked in the evenings and weekends, I had little possibilities to meet friends. My work as an aid was furthermore 'flexible' as I served over 30 teams in more than 15 locations part of two care institutions (this included forensic care; acute care; addiction care; psychiatric elderly care; long term care). In all of these places I worked so infrequently that hardly any of the regular staff remembered me or knew my name. During this timeframe I often felt as a 'ghost', a I was present in many places but not really connected to any of them.

My job as an aid was mainly to make sure the table was set and people were ready for meals and eat together; to go on walks with clients or accompany them in the fenced of garden depending on the amount of 'freedom' they had; or to do small social activities with people in the communal areas such as having a chat or playing a game. The times when I had meals with clients in the clinic actually often felt like good and warm experiences to me. There often where a few people in these settings I felt where really warm and open in their states of being somehow somewhat freed of the societal masks of daily life outside the clinic (although some of the acute wards were also in many ways quite horrific places I would not have liked to be in if I would come into a state of mental need). I think these experiences have warmed me up to the idea of clients living together in a group home and being supported by each other. During the research, however, my view on this also altered. I also really saw the downsides of living in a group home to some clients and heard their stories of (wanting to) live independently. This development I think is also reflected in my work for instance in chapter 4 on burden of support. I initially started my thinking with this analysis with merely reporting burdens, but gradually the analysis became more nuanced and more about specific ways care was practices or organized instead of with values such as fostering an independent lifestyle per se. To conclude, while in the beginning my view may have been a bit skewed to more communal ways of providing care, gradually this was shifted somewhat to integrating more the downsides of this as well. I think this led to a more nuanced story.

The care relationship

The last experiences I think are important to reflect upon are related to the care relationship. As having had diabetes type I since the age of 15 I am and have been in a few care relationships myself. In these relationships I have both experienced being patronized and not listened to as well as being neglected as my stated needs were taken at face value. From the beginning on I was never a compliant patient as I found it quite difficult to combine self-management with all the things I wanted to explore as a teen and young adult. At that time I was using an insulin pump but doing glucose monitoring by testing every so often. Since a couple of years now I am om the continues blood glucose monitoring and an insulin pump and doing much better. I realize now how immensely difficult it is to self-manage adequately with a bit of a flexible life and not being on continues glucose monitoring (and it is still hard, even when you have these tools). This I think is also why care burden literature resonates with me as to me this acknowledges part of the difficulties of doing self-management work.

At the time I was 18 I moved to my student town and lived alone for the first time. That time I also switched diabetes nurse as now I was receiving care in my new home city. Looking back I think this was a time I really needed a lot of care as my whole life changed and I also became responsible for doing my own groceries and cooking while at the same time having much less structure as part of the student lifestyle (going clubbing etc.). All these things make self-managing diabetes a much more difficult task. However, I was also fond of the newfound autonomy of my independent life. At the first meeting my new diabetes nurse asked me how I would like our care relationship to take shape. I answered I preferred to do things on my own. This she adhered to and hardly interfered as my blood glucose levels moved in every (wrong) direction. While she perfectly adhered to respecting my stated wishes, on hindsight I feel this can also be seen as neglect.

My self-management improved some as I grew older and my life became a bit more structured and at some point, I also switched to another nurse who was a bit more involved. However, my blood glucose levels only got within acceptable range after another period. During my pregnancy I was monitored very extensively by a diabetes team to ensure health of the fetus. This included two weekly meetings at the clinic and sometimes even contact in between. While I also have some experiences in this period (mostly with professionals that were not my regular care givers) where I absolutely felt patronized, for the most this intense period of care has fostered my self-management in ways I still benefit from. It was during this time I re-read Mol's account of the logic of care and it really resonated with me. At one point I even wanted to send it to one of the nurses. I had spent months working with my regular nurse to get the settings on my insulin pump to make them work for me. Some of these settings were not what is considered standard in the protocol. One time my regular nurse was on holiday and a stand in nurse read-out my data from my pump. She e-mailed me in a very demeaning tone my settings on my insulin pump were all wrong and I had to change them to the regular settings (without even asking me why they had been this way, as she was not familiar with my case). These and many other similar experiences have shaped my view on the care relationship. On the one hand I can really emphasize with the call for more patient-centered care and patient empowerment. On the other hand, I have also experienced how neglect can be a result when your statements as a client are taken at face value without exploring these further as part of a care relationship. Or how you can feel objectified as a patient when you notice a professional is merely following some protocol he learned in some course (this could also be a patient-centered course or one on shared-decision making or motivational interviewing or the like). This I think has sensitized me also to situations in which values related to patient centered care or self-determinations are practiced in ways that do not bring about good care. Moreover, my experiences managing diabetes have sensitized me to the complexity of adopting care to ever changing situations and thereby the need for tinkering and moreover how this can be supported by good professionals, other people important in your life and it requires these different people to align the values they deem important in good care.

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Summary

In supported living services for people with intellectual disability, serious mental illness or older persons, values such as self-directedness, independence, personal recovery, and community participation have become prominent. This thesis analyses practicing such values as complex. Complexity arises from values being in tension, or clients experiencing them as a burden. Attending to these normative complexities is important for improving quality of care. This thesis provides both the insights necessary to recognize and reflect on these normative complexities as well as the means to improve quality of care taking these normative complexities into account.

The thesis is indebted and contributes to debates in care ethics, Science and Technology Studies (STS), valuation studies, medical anthropology and -sociology. The overall research goal of the thesis is twofold.

First, to develop a better understanding of the complexity of practicing values such as self-directedness, independence, personal recovery and community participation in supported independent living. For this purpose, the book relies on three case studies. Two case studies were conducted at a community care organization: in a combined group and ambulant care setting for people with intellectual disabilities and a combined group and ambulant care setting for people with serious mental illness. The third case study was conducted at an organization providing nursing home care and home care services. This case study focused on one homecare team. The cases were explored using ethnographic methods such as participant observation, shadowing, interviews, photovoice and focus groups. To include the experiences of people for whom these methods were not accessible we asked experts-by-experience to reflect on experiences they witnessed as peer support workers in supported living.

The second goal of this research was to develop a method to support clients, professionals, and family members to voice their experiences with care; reflect and deliberate on normative tensions and co-design practices that better attend to these tensions. Through a participatory research project, various stakeholders were involved in adjusting the Experience-Based Co-Design method to fit this purpose. These stakeholders include researchers, clients, professionals, family members, managers of the involved organizations for supported independent living; Zorgbelang Inclusief and theatre company Babel Rotterdam. The result of this participatory process is the ‘Ask Us!’ method for participatory quality improvement (or in Dutch: ‘Als je het ons vraagt’, see: https://www.eur.nl/eshpm/onderzoek/als-je-het-ons-vraagt).

Chapter 1 introduces the policy trends in long term care and the values underlying the care relationship implicit in these trends. The chapter highlights how these values can be in tension and how ways of enacting these values can pose burdens on clients. Moreover, I show how these tensions are silenced in policies forming the background to professional practice, such as quality frameworks and competency profiles. In this chapter I introduce and integrate the theoretical notions that allow me to focus on the relationality of care while attending to its value complexities within the broader organizational and national context. The chapter continues with a critical review of current practices and methods for improving quality of care and argues why a novel method is needed. The chapter ends with the research questions and the research methods central in this book.

Chapter 2 introduces ethical tensions between values in long term care for people diagnosed with serious mental illness. Based on a thematic synthesis of qualitative studies, the chapter shows how values such as self-determination and independence can be in conflict. For instance, when clients do not want to move from a group home to an ambulant care setting. Moreover, the chapter shows how clients, family members and professionals can prioritize different values. Family members for example might perceive a household as neglected, whereas professionals see their non-interference as a form of fostering self-determination of clients.

Chapter 3 further elaborates on the value complexity of the care relationship by introducing the theoretical notions ‘multiple ontology’ and ‘tinkering’ (as developed by Mol, Moser & Pols). Through the empirical cases of supported independent living for people with an intellectual disability or serious mental illness, this chapter shows how value tensions need to be handled in a collective of clients, professionals, and family members. To capture these practices of good care, the chapter develops the theoretical notion of collective tinkering. Collective tinkering entails attentively experimenting with care practices in which different goods are assembled in collectives of people and things. From this notion it follows that quality improvement requires to move beyond reflection amongst professionals to include deliberation between clients, professionals and family members and co-design of practices in which different values are assembled.

Chapter 4 focusses on the experiences of clients with care aimed at promoting self-determination, independence, personal recovery and community participation. The chapter shows how clients can experience negative consequences from the way such values are practiced by professionals or inscribed in organizational structures. For example, the personal care plan, in which clients formulate their goals for care, is an organizational structure aimed at promoting the value of self-determination. However, in practice this structure can paradoxically limit self-determination, for instance when the goals are translated into tasks professionals need to tick off each shift. The theoretical notion: ‘burden of support’ is developed in this chapter to capture the negative consequences experienced by clients. Burden of support forms a counternarrative aimed at empowering service users and their advocates to voice such negative consequences. This way services are supported to improve the quality of care.

Chapter 5 elaborates on a case study in homecare services for older persons. It introduces insights from valuation studies to show how professionals' understanding of good care is shaped by the organizational and national context. Within this context, professionals differ in the way they understand and practice good care, leading to ethical tensions within the team. The chapter further shows how institutionalized values push other ways of providing good care to the background. This chapter develops the theoretical notion of 'invisible worth' to capture these values. For improving quality of care, it is important that such invisible worths are attended to.

Chapter 6 elaborates on the development of the quality improvement method 'Ask Us!'. This method is an adjustment of the Experience Based Co-design method and aims at improving quality of care while attending to value complexities. The method is designed to enable professionals, clients, and family members to reflect on their own experiences with ethical tensions, burdens of support and invisible worth's; to identify areas for improvement and deliberate their different perspectives on these. These deliberations are supported by filmed theatrical monologues, which are translations of the ethnographic work of the three case studies. These films were developed in collaboration with an inclusive theatre company: Theater Babel Rotterdam. The method 'Ask Us!' furthermore includes a process of co-design to improve care practices. This way the method provides a structure for collective tinkering in organizations in supported independent living.

Chapter 7 ties together the insights from the different chapters. First, the chapter provides an overview of the type of ethical tensions in the care relationship that emerge with a focus on values such as self-determination, independence, and community participation. Second, I go into the consequences of when this normative complexity is not sufficiently attended to. This includes the burdens of support and experiences of poor quality of care. For good care it is important that clients, professionals, and informal carers tinker collectively. Within collective tinkering it is important to also attend to the values that contribute to good care but are often rendered invisible. The chapter continues to discuss how the method developed as part of this research: 'Ask us!' supports good care.

The chapter ends with methodological reflections and implications for policy and practice. Methodological reflections include the involvement of experts-by-experience as co-ethnographers to include a wider variety of experiences and to overcome the limitations of interviews, focus groups or participant observation. Other methodological reflections include how critical client involvement through the development of counternarratives requires to move beyond the rhetoric of equal client participation in research, as developing counternarratives requires significant efforts of the researcher. Lastly, the use of translations as part of the development of the filmed monologues is reflected upon. For policy and practice the book highlights the importance of reflection, deliberation and co-design of normative complexities in healthcare and the way the ‘Ask Us!’ method can contribute to this.

Samenvatting

Waarden zoals eigen regie, zelfredzaamheid, persoonlijk herstel en participatie worden steeds belangrijker in begeleid- en beschermd wonen voor mensen met een verstandelijke beperking of een ernstige psychiatrische aandoening. Ook in de thuiszorg voor ouderen zijn deze waarden in opkomst. Dit proefschrift gaat over de ingewikkeldheden die gepaard gaan met het in de praktijk brengen van deze waarden. Professionals ervaren bijvoorbeeld dilemma's en cliënten kunnen last hebben van hoe de zorg is georganiseerd. Dit proefschrift geeft inzicht in deze normatieve complexiteit, zodat professionals, naasten, cliënten, managers en beleidsmakers deze normatieve complexiteit beter kunnen herkennen en erop kunnen reflecteren. Het proefschrift biedt ook handvatten om beter om te gaan met deze normatieve complexiteit en zo de kwaliteit van zorg te verbeteren.

Het proefschrift is geïnspireerd door en draagt bij aan discussies binnen de zorgethiek, wetenschaps- en technologie studies, valuation studies, medische antropologie en medische sociologie. Het onderzoek heeft twee doelen:

Het eerste doel van dit onderzoek is om inzicht te krijgen in normatieve complexiteit. Wat voor ingewikkeldheden komen professionals tegen als ze waarden als eigen regie, zelfredzaamheid, persoonlijk herstel en participatie in de praktijk te brengen? Hoe ervaren naasten en cliënten dit? Hiervoor zijn drie casus studies uitgevoerd: een woonlocatie waar cliënten met een verstandelijke beperking in een groepswoning wonen of ambulante woonzorg krijgen; een vergelijkbare woonlocatie voor mensen met psychiatrische problematiek en een thuiszorgteam in de ouderenzorg. Deze cases zijn onderzocht met etnografische methoden zoals participatieve observatie, schaduwen, interviews, photovoice en focusgroepen. Deze methoden waren niet voor elke client toegankelijk. Daarom hebben we ook ervaringsdeskundigen gevraagd om te reflecteren op wat zij zagen en meemaakten bij hun werk in de woonvoorzieningen.

Het tweede doel van dit onderzoek is om een methode te ontwikkelen om cliënten, professionals en naasten te ondersteunen om hun ervaringen te delen; gezamenlijk te reflecteren op normatieve complexiteit en om samen verbeteringen te ontwikkelen (co-design). De bestaande 'Experience Based Co-Design' methode vormde hiervoor het uitgangspunt. Via een participatief proces is deze methode aangepast. Hierbij waren naast de onderzoekers van de Erasmus School of Health Policy & Management en Kenniscentrum Zorginnovatie ook cliënten, naasten, professionals en managers van de twee deelnemende organisaties betrokken. Ook Zorgbelang Inclusief en Theater Babel Rotterdam namen hieraan deel. Het resultaat van dit participatieve proces is de 'Als je het ons vraagt' methode (zie ook https://www.eur.nl/eshpm/onderzoek/als-je-het-ons-vraagt).

Hoofstuk 1 introduceert de beleidstrends in de langdurige zorg en de waarden onderliggend aan de zorgrelatie in deze trends. Het hoofdstuk laat zien waar deze waarden met elkaar kunnen botsen en hoe cliënten last kunnen hebben van de manier waarop professionals en zorgaanbieders deze waarden in de praktijk brengen. Ook laat ik zien hoe deze ethische spanningen te weinig aan de orde komen in de beleidsdocumenten die het werk van professionals ondersteunen, zoals competentieprofielen en kwaliteitskaders. Verder introduceer ik in dit hoofdstuk de theoretische concepten die me in staat stellen om naar de zorgrelatie te kijken, waarbij aandacht is voor normatieve complexiteit binnen de bredere context van de zorgorganisatie en beleid op nationaal niveau. Vervolgens geef ik een kritische analyse van de bestaande methoden om kwaliteit te verbeteren en beargumenteer ik waarom er een nieuwe methode nodig is. Het hoofdstuk eindigt met de onderzoeksvraag en de onderzoeksmethoden die centraal staan in dit proefschrift.

Hoofdstuk twee introduceert ethische dilemma's in de langdurige zorg voor mensen met een ernstige psychiatrische aandoening. Dit hoofdstuk is gebaseerd op een thematische synthese van kwalitatieve studies. Het hoofdstuk laat zien hoe waarden zoals eigen regie en zelfredzaamheid kunnen botsen. Bijvoorbeeld wanneer cliënten niet willen verhuizen van een groepswoning naar een meer zelfstandige woning. Het hoofdstuk laat ook zien hoe cliënten, naasten en professionals verschillende waarden belangrijk kunnen vinden. Naasten kunnen bijvoorbeeld vinden dat een client verwaarloosd wordt omdat zijn huis niet is opgeruimd, terwijl professionals juist niet ingrijpen omdat zij het belangrijk vinden op deze manier de eigen regie van de client te ondersteunen.

Hoofdstuk drie gaat verder in op de normatieve complexiteit in de zorgrelatie door de theoretische noties 'meervoudige ontologie' en 'knutselen/uitvogelen' (tinkering) te introduceren (ontwikkeld door Mol, Moser & Pols). Dit hoofdstuk is gebaseerd op etnografisch onderzoek in de woonzorg voor mensen met een verstandelijke beperking of met een ernstige psychiatrische aandoening. In het hoofdstuk laat ik zien dat het belangrijk is dat cliënten, naasten en professionals gezamenlijk met de ethische spanningen om gaan, juist ook omdat ze soms andere waarden belangrijk vinden. Er zijn mooie voorbeelden waarin zorgverleners, naasten en cliënten samen proberen uit te vogelen hoe ze verschillende waarden samen kunnen brengen in een zorgpraktijk. Bijvoorbeeld om zowel de eigen regie te ondersteunen als ook te zorgen dat cliënten niet in een verwaarloosde omgeving leven. Om deze goede ondersteuningspraktijken zichtbaar te maken ontwikkel ik in dit hoofdstuk het concept 'collective tinkering' (gezamenlijk uitvogelen). Dit houdt in dat cliënten, naasten en professionals gezamenlijk experimenteren met zorgpraktijken waarin zij verschillende waarden samenbrengen; aandacht hebben voor hoe dit uitpakt en wanneer dat nodig is iets nieuws gaan uitproberen. Hieruit volgt dat kwaliteitsverbetering een gezamenlijk proces is van cliënten, naasten en professionals waarbij het belangrijk dat zij niet alleen samen reflecteren maar juist ook praktisch aan de slag gaan.

Hoofdstuk vier richt zich op de ervaringen van cliënten met ondersteuning gericht op zelfredzaamheid, eigen regie, persoonlijk herstel en participatie. Het hoofdstuk laat zien dat cliënten hier ook negatieve gevolgen van kunnen ondervinden. Een voorbeeld is het zorgleefplan. Dit is bedoeld om cliënten te ondersteunen om doelen te formuleren voor de ondersteuning en zo de eigen regie te vergroten. In de praktijk kan het zorgleefplan echter ook de eigen regie beperken, bijvoorbeeld wanneer professionals de doelen in het zorgleefplan vertalen naar een takenlijstje wat ze afwerken. Om deze negatieve gevolgen te expliciteren ontwikkel ik in dit hoofdstuk het theoretische concept 'last van ondersteuning' (burden of support). Het uitwerken van de manieren waarop cliënten last hebben van de ondersteuning kan cliënten, professionals, naasten en clientvertegenwoordigers helpen om deze ervaringen te herkennen en bespreekbaar te maken. Zo kunnen deze ervaringen ook gebruikt worden om de zorg te verbeteren.

Hoofdstuk vijf bespreekt het etnografisch onderzoek in de thuiszorg voor ouderen. Het introduceert inzichten vanuit 'valuation studies' om inzichtelijk te maken dat wat professionals als goede zorg zien, mede gevormd wordt door de context waarin zij werken. Het hoofdstuk laat ook zien dat professionals binnen hetzelfde team verschillen in wat zij als goede zorg zien, waardoor er ook ethische spanningen binnen teams ontstaan. Het hoofdstuk laat verder zien hoe sommige waarden meer op de achtergrond komen te staan omdat andere waarden meer geïnstitutionaliseerd zijn. Een voorbeeld is dat de werkprocessen in de thuiszorg zo zijn ingericht dat goede zorg door sommige professional wordt gezien al het uitvoeren van de taken die zijn geïndiceerd. Dit duwt andere waarden voor het leveren van goede thuiszorg, zoals het in gesprek gaan met cliënten om hen te helpen bij het nemen van beslissingen over hun leven, meer naar de achtergrond. Om dit soort waarden te kunnen herkennen en bespreekbaar te maken ontwikkel ik in dit hoofdstuk het concept 'onzichtbare waarde'. Voor het verbeteren van kwaliteit van zorg is het belangrijk ook aandacht te hebben voor zulke onzichtbare waarden.

Hoofdstuk zes geeft het proces weer waarbinnen het kwaliteitsinstrument 'Als je het ons vraagt' is ontwikkeld. Deze methode is een aangepaste versie van de 'Experience Based Co-Design' methode. Het doel van de 'Als je het ons vraagt' methode is om beter om te gaan met normatieve complexiteit en zo de kwaliteit van zorg te verbeteren. De methode ondersteunt professionals, cliënten en naasten om te reflecteren op hun eigen ervaringen met ethische spanningen, lasten of onzichtbare waarden; om over hun verschillende perspectieven hierop in gesprek te gaan en om gezamenlijk verbeterthema's te formuleren. Deze gesprekken worden ondersteund door gefilmde theatrale monologen, die gebaseerd zijn op de drie casusstudies van dit proefschrift. Deze films zijn ontwikkeld in samenwerking met een inclusief theatergezelschap: Theater Babel Rotterdam. De methode bestaat verder uit een proces van co-design om ook gezamenlijk verbeteringen uit te werken. Op deze manier biedt de methode een structuur om 'gezamenlijk uitvogelen' (collective tinkering) vorm te geven in organisaties die begeleid- en beschermt wonen of die thuiszorg aanbieden.

Hoofdstuk 7 brengt de inzichten uit de verschillende hoofdstukken samen. Het hoofdstuk geeft als eerste een overzicht van de ethische spanningen in de zorgrelatie in de ondersteuning gericht op eigen regie, zelfredzaamheid, persoonlijk herstel en participatie. Het hoofdstuk laat vervolgens zien wat de consequenties zijn wanneer deze normatieve complexiteit geen aandacht krijgt. Hierdoor kunnen cliënten juist last hebben van de manier waarop professionals hen ondersteunen of van de manier waarop de zorg georganiseerd is. Om beter om te gaan met normatieve complexiteit is het belangrijk dat cliënten, professionals en naasten gezamenlijk experimenteren met zorgpraktijken waarin verschillende waarden samengebracht worden; dit aandachtig te blijven volgen en iets nieuws te proberen wanneer dat nodig is. Hierbij is het belangrijk dat zij ook aandacht hebben voor de onzichtbare waarden. Het hoofdstuk bespreekt verder hoe de methode die in dit proefschrift is ontwikkeld: de 'Als je het ons vraagt' methode, goede zorg ondersteund.

Het hoofdstuk eindigt met methodologische reflecties en implicaties voor beleid en praktijk. Zo reflecteer ik op het interviewen van ervaringsdeskundigen over wat zij zien in de woonvoorzieningen waar zij werken. Hoe helpt dit om ook de ervaringen van cliënten mee te nemen in het onderzoek voor wie andere onderzoeksmethoden zoals interviews, focusgroepen of participatieve observatie niet toegankelijk zijn? Ook reflecteer ik op hoe je zichtbaar kan maken waar cliënten last van hebben, ook als dit tegen de gangbare manieren van denken over goede zorg in gaat. Het construeren van zo'n tegengeluid vraagt een actieve rol van de onderzoeker. Tot slot reflecteer ik op het ontwikkelen van de gefilmde theatrale monologen. Het proefschrift is relevant voor beleid en praktijk omdat het laat zien dat aandacht hebben voor normatieve complexiteit door reflectie, deliberatie en co-design belangrijk zijn in de zorg- en ondersteuning om kwaliteit te verbeteren. Ook laat het proefschrift zien hoe de 'Als je het ons' methode daaraan kan bijdragen.

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Nienke, al sinds het begin van onze studie Psychologie bewandelen wij dit academische pad samen. Eerst met de overstap naar Medische Antropologie en Sociologie, en nu met onze gezamenlijke interesse in het onderzoek naar ervaringsverhalen en nu met het Kwalitatief Onderzoeks Collectief GGZ. Ook als wandelmaatje in de bergen hebben we elkaar gevonden. Hopelijk zullen er nog vele wandelvakanties volgen! Ik ben ontzettend dankbaar voor jouw vriendschap en voor jou als paranymf.

Francisca jij was nooit te beroerd om met mij over STS te brainstormen. Niet tijdens corona wandelingen in Amsterdam Noord, noch op de rand van het zwembad bij een wildpark in Zambia, waarvoor veel dank! Jurjen en Mirehmet jullie hebben ieder op jullie eigen manier mijn blik verruimt en plaatsen mijn eigen werk en leven geregeld in het juiste perspectief. Anne en Carolien, onze Duitsland-Zweden connectie heeft mij ook ontzettend veel inzicht gegeven in hoe cultuurverschillen doorwerken, bijvoorbeeld in ons moederschap. Hopelijk kunnen we elkaar na al deze Corona perikelen weer meer zien! Marjon, jij hebt altijd een luisterend oor of een kaartje op de belangrijke momenten! Hiske, ik vind het ontzettend leuk dat wij elkaar weer hebben gevonden, jij gaat altijd een laagje dieper en weet mij zo tot nieuwe inzichten te brengen zowel op persoonlijk als op werkvlak. Anne door onze toevallige ontmoeting in Amsterdam Noord, mag ik nu ook weer van jouw lieve oprechte betrokkenheid genieten. Koen, zo fijn dat de Kennemerduinen ook jouw favoriete plek zijn! Basisschool vriendinnen Mallika, Sarah-lee, Pytrik, Kyara en Rianne, zo leuk dat wij elkaar de afgelopen tien jaar weer regelmatig treffen. Ook wil ik mijn medebestuursleden van het Kwalitatief Onderzoeks Collectief GGZ (KOC-GGZ) bedanken. Femke, Nienke, Arjen, Lisa en Annemarie, wellicht zonder dat jullie het doorhebben zijn jullie voor mij heel belangrijk in het opnieuw verbinden met een identiteit die ik dacht achter me te hebben gelaten. Hopelijk geven we samen kwalitatief onderzoek een prominente plaats in de psychologie! Koen, Maaike, Bette, Gillian, Joost, Diana, Jesse, Antoinette, Janneke, Edwin, Kathelijne, Inge, Tom, Liselotte, Max, Jan en Roelie jullie zijn eigenlijk tegelijkertijd met dit PHD-traject in mijn leven gekomen (maar dat is een toevallige samenhang). Heel veel dank voor jullie interesse en gezelligheid de afgelopen jaren!

Tijdens het schrijven heb ik veel zorg gekregen van veel mensen, wat me in staat stelde dit proefschrift af te ronden. Zo hielden eerst Cisca en later Esther ons huis schoon en leefbaar. Dankzij Nienke en de andere lieve juffen van de Banjerberen was Morris altijd in goede handen en maakte ik me nooit zorgen als ik hem naar de opvang bracht. Ook wil ik mijn lieve ouders Berry en Gerrie bedanken. Jullie staan altijd voor mij klaar en zijn een nooit aflatende bron van steun. Dankzij de heerlijke dag die Morris met oma (en soms opa) heeft kan ik met een gerust hart de deur van mijn werkkamer dichtdoen. Simon, jij weet altijd op de juiste momenten een droge grap te maken waaruit blijkt dat wij, zonder veel woorden, van elkaar goed begrijpen waar we vandaan komen. Heel bijzonder ook om onze kindjes zo dicht op elkaar te zien opgroeien als neeftje en nichtje. Ben, jou ben ik enorm dankbaar dat je steeds met me bent meegegaan in de gedachte dat het over twee weken echt rustiger zou worden op mijn werk, ook al geloofde je het op het laatst niet echt meer. Jij hebt in het laatste jaar van het proefschrift (en daarna) mij vele avonden en weekenden de ruimte gegeven om te werken. Nu werk ik aan meer ruimte maken voor ons gezin. Morris en jij zijn mijn grootste schatten.

Curriculum Vitae

COURSES

WTMC (Netherlands Graduate Research School of Science, Technology and Modern Culture)

2013 Participation and the Politics of Difference (summers school)
2017 STS and art
2017 (Re)inventing responsibility & innovation
2017 Ethnography, digital objects & STS (summer school)
2018 Doing comparison
2019 Post-colonial
2019 Experimenting, or trying to change the world with STS (summer school)
2019 WTMC writeshop (2x)

Erasmus Graduate School of Social Sciences and the Humanities (EGSH)

2016 Project management for PhDs
2017 Qualitative data analysis
2017 Working with Atlas.ti
2017 Academic English writing
2017 Ethnography and its varieties - autoethnography
2017 Analytical storytelling
2018 How to get your article published
2018 Philosophy of the social sciences and humanities
2019 Great Thinkers of the 20th Century
2019 Participatory action research

Open Studio

2017 Camera and montage
2017 Sound (camerajournalism)

Crea

2017 Making a documentary
2018 Scenario for documentary

RISBO

2017 Basic didactics
2017 Group dynamics

Other

2016 Scientific integrity (ESHPM)
2017 Experience Based Co-design (Point of care)
2018 Skillshare writing workshop (Maastricht University)

PRESENTATIONS

2016 *Participatieve kwaliteitsverbetering in de langdurige zorg*
Pameijer, Rotterdam
2017 *Dilemma's with service user involvement in long term care (poster presentation)*
International Society for Quality Improvement in Health Care (ISQUA), London
2017 *Teamreflectie in co-creatie*
Pameijer Rotterdam
2017 *From burden of treatment to burden of care*
Reconfiguring care infrastructures workshop, University of Sussex, Brighton
2017 *Participatory quality improvement in complex care relationships in long term care*
International disability studies conference: 'The art of belonging', Amsterdam
2018 *Assisted living services: fostering self-determination and an independent lifestyle*
Pecha Kucha PhD contest (winner of first price), ESHPM, Rotterdam
2018 *Developing a participatory quality improvement method for assisted living services*
European Health Management Association (EHMA), Budapest
2018 *Experience based co-design over de complexe zorgrelatie in de langdurige zorg*
Langdurige zorg projecten, Zorginstituut Nederland en ZonMw, Utrecht
2018 *EBCD: sharing experiences and co-designing new applications (organizer and speaker)*
Invitational conference, ESHPM, Rotterdam
2019 *Experience based co-design over de complexe zorgrelatie in de langdurige zorg*
Symposium Cliënt aan zet: kwaliteitsverbetering voor en door cliënten in de langdurige zorg, Den Bosch
2019 *Vijf sterren inspraak*
Landelijke dag cliëntenraden RIBW, Rotterdam
2020 *Reflecties op het meerjarenprogramma: 'zinvol meedoen' (op uitnodiging)*
Sociaal Cultureel Planbureau (SCP), online event
2020 *Participation dilemma's (invited talk)*
Changing the world through STS, panel WTMC annual day, Amsterdam
2021 *Als je het ons vraagt… (invited talk)*
Lapré lezing, Erasmus Centrum Voor Zorgbestuur, Rotterdam
2021 *De waarde van verhalen voor onderzoek*
Webinar patiëntwetenschappen ESHPM, Rotterdam

2021 *Als je het ons vraagt… (invited talk)*
Klik Kenniscentrum verstandelijk gehandicaptenzorg jubileumcongres, Amersfoort

PEER REVIEWED PUBLICATIONS PART OF THIS PHD

Heerings, M., van de Bovenkamp, H., Cardol, M., & Bal, R. (2020). Ethical Dilemmas of Participation of Service Users with Serious Mental Illness: A Thematic Synthesis. *Issues in Mental Health Nursing, 41*(4), 283-295.

Heerings, M., van de Bovenkamp, H., Cardol, M., & Bal, R. (2021). 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.

Heerings, M, van de Bovenkamp, H, Cardol, M, Bal, R. (2022). 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*. Advance online publication.

Heerings, M, van de Bovenkamp, H, Cardol, M, Bal, R. (2022). Burden of support: a counter narrative of service users' experiences with community housing services, *Disability & Society*. Advance online publication.

Heerings, M, van de Bovenkamp, H, Cardol, M, Bal, R. Promoting autonomy in homecare services for older persons: an ethnographic study of different logics of the good care relationship, *Under review at Aging & Society.*

PEER REVIEWED PUBLICATIONS PRIOR TO THIS PHD

Bröer, C. and Heerings, M. (2013). Neurobiology in public and private discourse: the case of adults with ADHD. *Sociology of Health & Illness*, (35), 49-65.

Van Beljouw, I. M., Van Exel, E., De Jong Gierveld, J., Comijs, H., Heerings, M., Stek, M., & Van Marwijk, H. (2014). "Being all alone makes me sad": Loneliness in older adults with depressive symptoms. *International Psychogeriatrics*, *26*(9), 1541-1551.

van Beljouw, I. M., Laurant, M. G., Heerings, M., Stek, M. L., van Marwijk, H. W., & van Exel, E. (2014). Implementing an outreaching, preference-led stepped care intervention programme to reduce late life depressive symptoms: results of a mixed-methods study. *Implementation science*, *IS*(9) 107.

van Beljouw, I. M., Heerings, M., Abma, T. A., Laurant, M. G. H., van ‘t Veer-Tazelaar, P. J., Bauer, V. E., Stek, M. L., van Marwijk, H. W., & van Exel, E. (2015). Pulling out all the stops: what motivates 65+ year olds with depressive symptoms to participate in an outreaching preference-led intervention programme?, *Aging & Mental Health*, *19*(5), 453-463.

Van Egmond, S. & Heerings, M. (2014). Leren van patiëntverhalen voor een goede zorgsector. *Tijdschrift voor klachtenrecht*, 12-14.

OTHER PUBLICATIONS PRIOR TO THIS PHD

Van Egmond, S., Heerings, M. & Munnichs, G. (2014). *Sterke verhalen uit het ziekenhuis. Leren van patiëntenverhalen voor goede zorg*. Den Haag: Rathenau Instituut.

Van Egmond, S., Heerings, M. & Munnichs, G. (2014). *Bericht aan het parlement: gebruik patiëntverhalen voor betere ziekenhuiszorg.* Den Haag: Rathenau Insituut.

Van Egmond, S. & Heerings, M. (2014). *Laat cijfers los, gebruik patiëntverhalen*. Medicalfacts.nl

Geesink, I. & Heerings, M. (2015) Assisted Reproductive Technology. In: Geesink, I. et al. (Eds.), *Economic landscapes of human tissues and cells for clinical application in the EU*. (pp. 159-242). Brussel: DGSANTE.

Geesink, I., Heerings, M. & van Egmond, S. (2016). *De meetbare mens. Het digitaal meten van het zieke en gezonde lichaam.* Den Haag: Rathenau Instituut.

Geesink, I. & Heerings, M. (2016). *Bericht aan het parlement: bescherm de digitale patiënt.* Den Haag: Rathenau Instituut.

Heerings, M. (2016). De genetwerkte patiënt. Data delen zonder zorg? In: Geesink, I., Heerings, M. & Egmond, S. van. (Eds.), *De meetbare Mens*. Den Haag: Rathenau Instituut.

Heerings, M., Egmond, S. van & Sools, A. (2013). What TA can learn from patient narratives. Using narrative methodology to assess the role of patients in Dutch hospitals. In Michalek, T. et al. (Eds.), *Technology Assessment and Policy Areas of Great Transitions*, (pp. 171-178). Prague: Informatorium.

Munnichs, G & Heerings, M. (2015). *Startnotitie cliëntenrechten en stand van zaken zorginfrastructuur. Deskundigenbijeenkomst Eerste Kamer 13 april 2015*. Den Haag: Rathenau Instituut.

TEACHING ACTIVITIES

Bachelor Health Sciences, Erasmus University Rotterdam

2016-2018 Workgroups: "Philosophy of Science"
2019-2021 Workgroups: "Qualitative research methods"
2019 – 2021 Workgroups and lectures: "Choices and Dilemma's for healthcare managers and policy makers" (since 2021 coordinator of this course)

Pre-master Zorgmanagement

2016-2018 Workgroups: "Kwalitatief leeronderzoek"

Master Healthcare Management

2017-2018 Workgroups: "Quality & Safety"
2019-present Thesis supervision

Guest lectures

2018	*Patiënten betrekken bij kwaliteitsverbetering*, Kritische studies van management en innovatie, ESHPM
2018	*Patient centered care and quality improvement*, Minor Health Sciences, ESHPM
2019	*Patient involvement in quality improvement*, Health Services Management & Organization, ESHPM
2019	*Translations from findings to film*. Visuele antropologie, Universiteit Utrecht

AWARDS

2021 Best societal impact 2020, Graduate School Award for PhD Excellence, graduate School of Social Science and Humanities, Rotterdam.

About the Author

Photograph by Dara Ivanova

Marjolijn Heerings was born on January 17th, 1984, in Eindhoven and moved to Amsterdam to study psychology. She completed a bachelor's degree in Psychology at the University of Amsterdam during which she went on exchange to Otago University Dunedin, New Zealand. Here she followed courses in Philosophy and Medical Anthropology. During her study Marjolijn worked at Desan Research Solutions where she supervised and trained survey interviewers and data entry. She continued following a master's program in Medical Anthropology and Sociology where she analyzed the meaning of ADHD in the life stories of people who received this diagnosis in adulthood. Partly simultaneously she conducted a master's degree in Clinical Psychology (With Distinction). During her master's she conducted a combined research and clinical internship at GGZ Noord Holland Noord. Here she assisted in a research project developing an outcome monitoring feedback system for outpatient mental health care. For her master thesis she compared different ways of modeling outcome data to establish therapist effect.

After finishing her two master's degrees, Marjolijn followed several courses in philosophy of science at both the bachelor and master level at the UvA (contract education). During this time, she worked with Christian Bröer on a Q-study following-up on her master's thesis. Here she analyzed the types of public discourses used by people who are diagnosed with ADHD to give meaning to their experience. Furthermore, she worked as an aide at the flex pools of both ARKIN and GGZinGeest, serving various intramural mental healthcare facilities ranging from crisis care to long term care. In this period, she volunteered for the telephone line and chat function of 113 Zelfmoordpreventie (suicide prevention) and followed post-academic education on Solution Focused Therapy (RINO) and Cognitive Behavioral Therapy (VGCt).

While pursuing a career as a clinical psychologist, Marjolijn kept being hired as a researcher. She worked as a junior researcher at the Sociology department of the UvA on a project on community participation. At GGZinGeest she conducted qualitative research as part of a process evaluation of a stepped depression prevention intervention for older persons. During these times she also continued working as an aide for the flex pool of GGZinGeest.

Marjolijn went on to work at the Rathenau Institute for four years where she assisted in projects aiming to inform the Dutch Parliament. These included a project on the potential of using patient stories in assessing quality in hospital care and a project on the social, ethical and legal aspects of quantified health, for which she also investigated her own experiences with diabetes self-management. For the European Commission she assisted in a project on the political aspects of economization of tissues and cells for donation within the European Union.

At age 32 Marjolijn started her PhD at the Healthcare Governance Group of the Erasmus School of Health Policy & Management (ESHPM). This project focused on ethical tensions in long term care and participatory quality improvement. During her PhD she completed the WTMC graduate program of the Netherlands Graduate Research School of Science, Technology and Modern Culture and the Erasmus Graduate School of Social Sciences and the Humanities. Marjolijn also taught several courses on the bachelor and master level, including philosophy of science, qualitative research methods, Quality & Safety and Healthcare Ethics. She also supervised seven master students with their thesis on written patient experiences (books) of people who experienced psychosis and of family members' experiences of nursing home care.

Marjolijn is currently working as an assistant professor at ESHPM. Her research interests include normative complexity; public administration ethics; narrative quality improvement in long term care; narrative analysis of patient stories and mental health recovery. She currently works on further developing the 'Ask US!' method together with Zorgbelang Inclusief, Theater Babel Rotterdam and Kenniscentrum Zorginnovatie, Hogeschool Rotterdam. Together with UMCG she is also developing a DIPEx module about the experiences of psychosis (www.pratenovergezondheid.nl). Marjolijn is co-founder and board member of 'Kwalitatief Onderzoeks Collectief GGZ' which aims to anchor qualitative research within mental healthcare research and education and to bring together qualitative researchers working in this field.

Marjolijn enjoys theatre and loves hiking. She lives with Ben and their son Morris in Santpoort-Noord.

In supported living services for people with intellectual disability, serious mental illness or older persons, values such as self-directedness, independence, personal recovery, and community participation have become prominent. This thesis analyses practicing such values as complex. Complexity arises from values being in tension, or clients experiencing them as a burden. Attending to these normative complexities is important for improving quality of care. This thesis provides both the insights necessary to recognize and reflect on these normative complexities as well as the means to improve quality of care taking these normative complexities into account.

For gaining insight into normative complexities in supported living services, an ethnographic approach was used. Three case studies were conducted: one in a supported independent living setting for people with intellectual disabilities, one for people with serious mental illness and one in homecare services for older persons. The insights from this ethnographic study were translated into 40 filmed theatrical monologues. Through a participatory process the Experience Based Co-design method was adopted to enable clients, professionals, and family members to reflect on and deliberate about their experiences with care and co-design improvements together: the Ask Us! Method.