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To cite this article: Marjolijn Heerings, Hester van de Bovenkamp, Mieke Cardol & Roland Bal (2020) Ethical Dilemmas of Participation of Service Users with Serious Mental Illness: A Thematic Synthesis, *Issues in Mental Health Nursing*, 41:4, 283-295, DOI: [10.1080/01612840.2019.1667459](https://doi.org/10.1080/01612840.2019.1667459)

To link to this article: <https://doi.org/10.1080/01612840.2019.1667459>



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Published online: 28 Jan 2020.



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## Ethical Dilemmas of Participation of Service Users with Serious Mental Illness: A Thematic Synthesis

Marjolijn Heerings, PhD Student<sup>a</sup>, Hester van de Bovenkamp, PhD<sup>a</sup>, Mieke Cardol, PhD<sup>b</sup>, and Roland Bal, PhD<sup>a</sup>

<sup>a</sup>Erasmus School of Health Policy & Management, Erasmus University Rotterdam, Rotterdam, The Netherlands; <sup>b</sup>Research Centre Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, The Netherlands

### 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 major depression for over two years) (Leemeijer & Trappenburg, 2016; Parabiaghi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006). 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 (Atkins, 2006; Beauchamp & Childress, 2013; Mackenzie & Stoljar, 2000). 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 (Beauchamp & Childress, 2013; Broer, Nieboer, & Bal, 2014; Cardol, Rijken, & van Schroyen Lantman-de Valk, 2012; Dwarswaard & van de

Bovenkamp, 2015; Mol, Moser, & Pols, 2010; Pols, 2006; Pols, Althoff, & Bransen, 2017). 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?

**CONTACT** Marjolijn Heerings  [Heerings@eshpm.eur.nl](mailto:Heerings@eshpm.eur.nl)  Erasmus School of Health Policy & Management, Burgemeester Oudlaan 50, 3062 PA Rotterdam, The Netherlands

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**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.
Respondents	Articles were published after 2005 as our focus is on the care-relationship in the context of user participation and de-institutionalization. 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.

## 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 (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008).

### 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).

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, (Polacek et al., 2015; Salzman-Erikson, 2013) 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.

### 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).

### Data analysis

The thematic synthesis was conducted in three steps (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). 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 (Thomas & Harden, 2008).

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.'

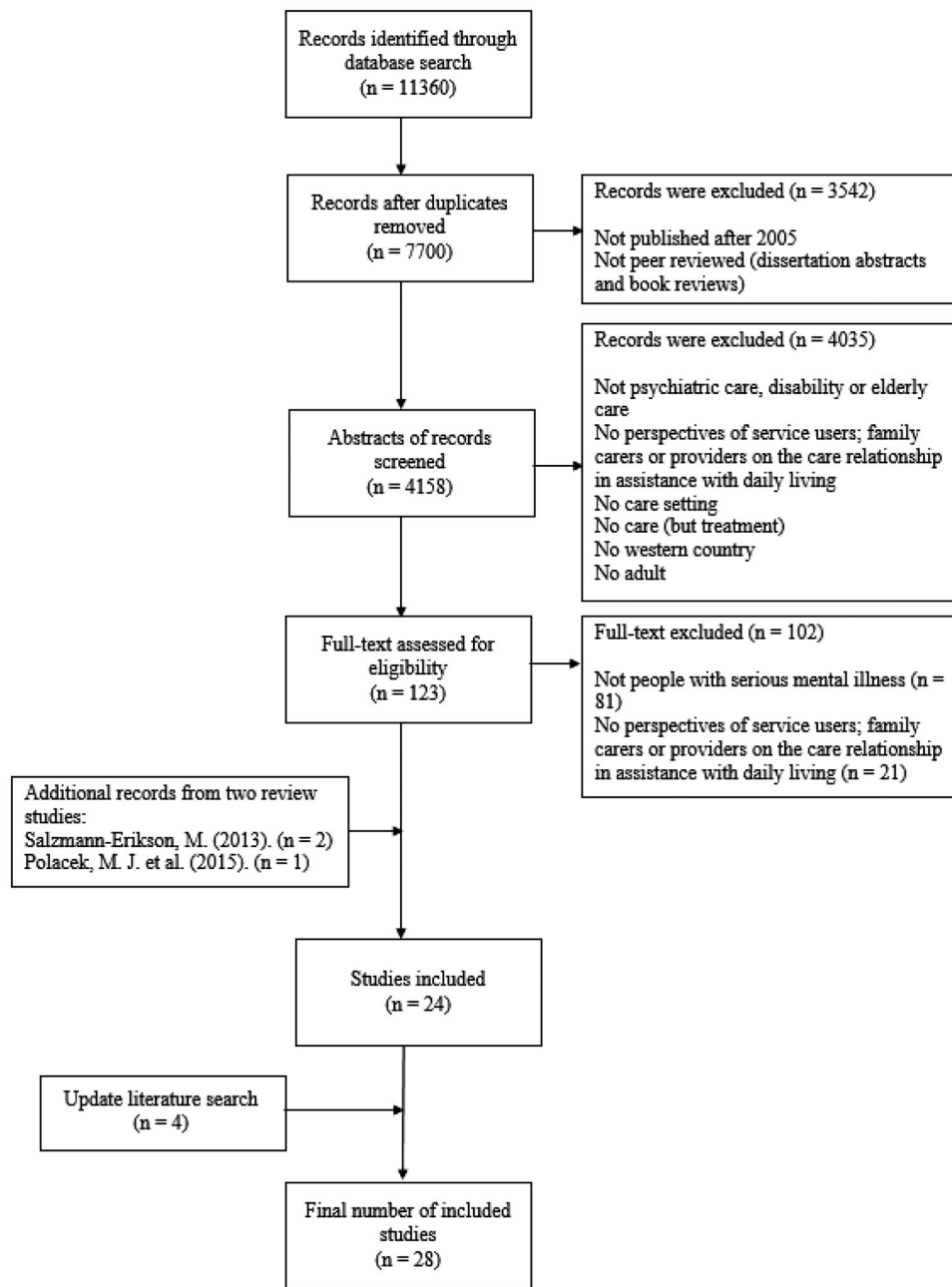


Figure 1. Studies included after each stage of the selection process.

### 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 (Petersen, Hounsgaard, Borg, & Nielsen, 2012). From the service user perspective this facilitated the trust they maintained with professionals (Coatsworth-Puspoky, Forchuk, & Ward-Griffin, 2006). It was also linked to feeling recognized as a valuable human being and feeling more involved in their own support, treatment and daily life

(Petersen et al., 2012). Service users value participating in decisions, e.g. on goals to work towards in their care, in setting a care plan (Petersen et al., 2012; Schröder, Ahlström, & Larsson, 2006; Topor et al., 2006) and the frequency of meetings with the professional (Happell, 2008). Likewise, service users value the possibility to choose their own contact person and have a say in recruiting new staff members (Petersen et al., 2012; Schröder et al., 2006). Lastly, service users value having influence on decisions in everyday situations such as to do with food, social activities and their housing situation (Petersen et al., 2012).

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

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 and Magnusson (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
Gaillard et al. (2009) USA	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
Graneheim 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 & Morrisette (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 and Severinsson (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 and Arvidsson (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
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,	Professionals not specified.	Not specified.

(continued)

Table 2. Continued.

Reference and country of study	Study aim	Methods	Participants: service users (diagnosis), professionals (profession) or family members (role)	Relationship with: (not participants)	Setting
Lilja & Hellzén (2008) Sweden	Extend our understanding of inpatients' experience of psychiatric care by interviewing former psychiatric inpatients.	Qualitative interview	10 service users. Various diagnosis including: depression, puerperal psychosis. 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 and Sturm (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 and Pernice (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
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
Sercu & Bracke (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

(continued)

Table 2. Continued.

Reference and country of study	Study aim	Methods	Participants: service users (diagnosis), professionals (profession) or family members (role)	Relationship with: (not participants)	Setting
Shattell 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 and Trappenburg (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

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 (Petersen et al., 2012). On a different note, some service users value being informed and motivated by staff to do certain activities (Petersen et al., 2012), and to be challenged to achieve personal goals beyond their own imagination (Schroeder, 2013). 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 (Petersen et al., 2012). They also report a retrospective desire for professionals to go against their wishes so that they can (still) receive the care they need (Skorpen, Rehnsfeldt, & Thorsen, 2015). 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 (Sercu & Bracke, 2016).

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

Professionals describe striving to involve service users in the planning of their care (Högberg, Magnusson, & Lutzen, 2006; Pelto-Piri, Engström, & Engström, 2013) and to let service users choose their contact person (Pelto-Piri et al., 2013). Professionals advocate for service users' wishes in staff

meetings (Lindwall, Boussaid, Kulzer, & Wigerblad, 2012). They describe situations in which they forgo their own suggestions and follow service users' wishes related to support and treatment (Topor et al., 2006) even when they disagree (Lakeman, 2010). 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 (Linz & Sturm, 2016). Alternatively, professionals negotiate a course of action that reflects a compromise between the user's wishes and the mental healthcare workers' recommendations (Lakeman, 2010).

Professionals state that sometimes they have difficulty involving service users in decisions due to the lack of time to engage in dialogue (Graneheim, Slotte, Säfsten, & Lindgren, 2014). 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 (Oeye, Bjelland, Skorpen, & Anderssen, 2009). 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 (Pelto-Piri et al., 2013).

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 (Oeye et al., 2009). Staff sometimes deny service users their wishes in order to cater for their health and finances, for instance, restricting the number of cigarettes provided (Saavedra, Cubero, & Crawford, 2012) or restricting the hours watching television to lessen passivity (Oeye et al., 2009). Respecting a service users' decision is sometimes not feasible because it would go against the house rules based on the service users' collective preferences (Oeye et al., 2009) or result in harmful situations for other service users. For example, one service user's decision not to take medication to reduce aggressive behavior could hinder the safe and calm environment for other service users (Jackson & Morrissette, 2014). Sometimes service users' wishes go against the personal values of professionals and are therefore restricted (Pelto-Piri et al., 2013) 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 (Pelto-Piri et al., 2013).

#### ***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 (Jakobsen & Severinsson, 2006; Valentini et al., 2016). 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 (Van de Bovenkamp & Trappenburg, 2010). Several family carers were skeptical about the larger influence of service users on decisions as they feared it might result in negligence or harm (Jakobsen & Severinsson, 2006). Some family members ask professionals to promote healthy behavior or prevent harmful behavior, such as stop drinking alcohol when on medication. However, they report being dismissed with reference to the autonomy of the service user (Jakobsen & Severinsson, 2006). 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 (Jackson & Morrissette, 2014).

#### ***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 (Eriksen, Sundfor, Karlsson, Raholm, & Arman, 2012). 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 (Schröder et al., 2006). 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 (Eriksen et al., 2012). 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 (Bäck-Pettersson, Sandersson, & Hermansson, 2014; Coatsworth-Puspoky et al., 2006). Furthermore, service users value having supportive professionals who teach them to cope with their illness, their inner experiences and manage their health (Bäck-Pettersson et al., 2014; Blegen, Eriksson, & Bondas, 2016; Schröder et al., 2006). 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 (Topor et al., 2006).

#### ***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 (Erdner & Magnusson, 2012) and leads to community participation (Linz & Sturm, 2016). Professionals try to foster independence by motivating service users to get up (on time) in the morning (Saavedra et al., 2012), go for walks, doing crossword puzzles (Erdner & Magnusson, 2012; Graneheim et al., 2014; Valentini et al., 2016) or engaging in structured activities such as following education, doing volunteer work or going on pre-employment programs (Linz & Sturm, 2016). 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 (Högberg et al., 2006; Linz & Sturm, 2016). This includes motivating service users to keep up their hygiene, by changing clothes and showering regularly (Erdner & Magnusson, 2012; Saavedra et al., 2012). 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 (Linz & Sturm, 2016). Contrary to this, professionals in some studies say that most conversations with service users are about practical issues and medication (Graneheim et al., 2014). 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 (Linz & Sturm, 2016).

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 (Erdner & Magnusson, 2012). For similar reasons, service users are perceived as being unable to form social relationships with neighbors (Högberg et al., 2006) 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 (Erdner & Magnusson, 2012). 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 (Erdner & Magnusson, 2012). 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 (Graneheim et al., 2014). 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 (Linz & Sturm, 2016). 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 (Linz & Sturm, 2016; Nicholls & Pernice, 2009) and stigma (Högberg et al., 2006; Linz & Sturm, 2016). Lacking resources to provide attractive activities (Graneheim et al., 2014) or educational or vocational opportunities for service users (Linz & Sturm, 2016) 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 (Jakobsen & Severinsson, 2006). 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 (Jakobsen & Severinsson, 2006). 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 (Nicholls & Pernice, 2009).

#### ***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 (Blegen et al., 2016; Eriksen et al., 2012; Schröder et al., 2006). Having this type of contact creates the sense of self-worth and being valued as a human being (Coatsworth-Puspoky et al., 2006; Eriksen et al., 2012; Schröder et al., 2006; Shattell, McAllister, Hogan, & Thomas, 2006). 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 (Bäck-Pettersson et al., 2014; Skorpen et al., 2015). For service users, the important aspects of dialogue include professionals taking the time to listen and be responsive to their ideas, opinions and feelings (Bäck-Pettersson et al., 2014; Blegen et al., 2016; Coatsworth-Puspoky et al., 2006; Eriksen et al., 2012; Happell, 2008; Schröder et al., 2006; Schroeder, 2013; Sercu & Bracke, 2016; Shattell et al., 2006; Skorpen et al., 2015; Topor et al., 2006). 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 (Coatsworth-Puspoky et al., 2006; Lindwall et al., 2012; Schröder et al., 2006; Shattell et al., 2006).

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 (Coatsworth-Puspoky et al., 2006; Lindwall et al., 2012; Linz & Sturm, 2016; Schröder et al., 2006; Shattell et al., 2006). 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 (Bäck-Pettersson et al., 2014; Happell, 2008; Schröder et al., 2006), be more like 'friends' and not just talk about problems but also about normal, fun things (Bäck-Pettersson et al., 2014; Coatsworth-Puspoky et al., 2006; Eriksen et al., 2012; Lilja & Hellzén, 2008; Shattell et al., 2006; Topor et al., 2006) or about spirituality (Koslander & Arvidsson, 2007). Professionals who share something of themselves by disclosing their own experiences (Eriksen et al., 2012) including negative life events (Shattell et al., 2006) made service users feel more on the same level. Professional behavior 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 (Coatsworth-Puspoky et al., 2006; Eriksen et al., 2012; Gaillard, Shattell, & Thomas, 2009; Lindwall et al., 2012; Skorpen et al., 2015) or defined by their diagnostic label (Blegen et al., 2016; Coatsworth-Puspoky et al., 2006; Gaillard et al., 2009; Lilja & Hellzén, 2008; Schroeder, 2013; Sercu & Bracke, 2016; Shattell et al., 2006).

#### ***Professionals' experience with relationship-centred care***

Professionals in the analyzed 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 (Graneheim et al., 2014; Högberg et al., 2006; Lilja & Hellzén, 2008; Lindwall et al., 2012; Pelto-Piri et al., 2013). Strikingly, only two studies reported

striving for an equal relationship, for instance by being ‘as friends’ (Linz & Sturm, 2016; Oeye et al., 2009). 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 (Lindwall et al., 2012; Oeye et al., 2009; Pelto-Piri et al., 2013).

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 (Graneheim et al., 2014; Pelto-Piri et al., 2013). 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 (Graneheim et al., 2014). 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 (Graneheim et al., 2014). They say they need courage to meet the users’ expressed needs to deal with their feelings, disappointment and sadness (Lindwall et al., 2012). 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 (Graneheim et al., 2014). 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 analyzed studies. Only one study described family members finding it important professionals talk to service users as equals and not ‘from the top down’ (Skorpen et al., 2015).

#### **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 (Lakeman, 2010). 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” (Lakeman, 2010; Schröder et al., 2006; Schroeder, 2013).

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 (Lakeman, 2010). 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 (Happell, 2008; Lakeman, 2010; Topor et al., 2006). Lakeman (2010) conducted a Delphi study among experts-by-experience to assess recovery-oriented competencies for mental health workers. 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 (Lakeman, 2010). While Lakeman’s competency statements all focus on professionals supporting the expertise of service users, 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 (Topor et al., 2006).

#### **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 afflicted 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 an 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.

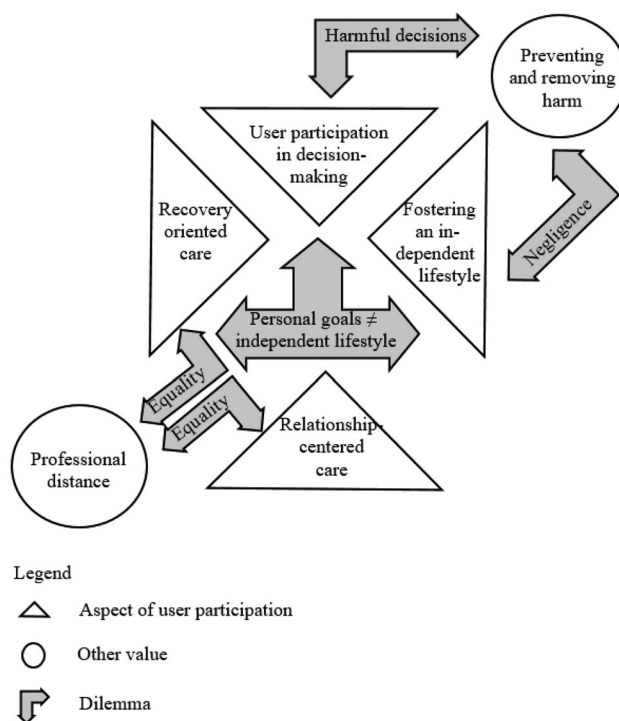


Figure 2. Heuristic framework of dilemmas in the care relationship.

## 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).

## 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 their 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 analyzing 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’ (Mol, 2008; Mol, Moser, & Pols, 2010; Pols et al., 2017). 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 afflicted 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, analyzing 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 (Pols, 2005) and the experience of professionals providing care to these service users.

### Acknowledgements

An earlier draft of this paper was presented at a Healthcare Governance seminar of the Erasmus School of Health Policy and Management. We thank the audience for their comments. We thank

information specialist Wichor Bramer for his help in composing the list of search terms.

### Disclosure statement

The authors report no conflicts of interest.

### Funding

The authors are grateful to the Netherlands Organization for Health Research and Development for funding this research (grant no. 80-83900-98-202).

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## Appendix 1 Search terms in Embase\*

'(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 Counselor 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

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

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 'stress'/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