Connecting visions and voices: Involving service users in realizing 'good mental health care'

van der Ham, A.J.

2013

document version
Publisher's PDF, also known as Version of record

SUMMARY

Introduction

During the last decades the scope of mental health and mental health care has broadened as more and more aspects of life are considered relevant for mental health care. In addition, an increasing number of stakeholders is taking up an active role in mental health care, including users of services themselves. These developments are stimulated by several major trends. First, there is an increased emphasis on community-based care instead of institutionalized care. Second, recovery, rehabilitation and related concepts and models are increasingly influential. Third, there is a growing emphasis on multidisciplinary, integrated approaches to care. A fourth major trend involves the shift from supply-based care to more demand-based and service user-centred care, in which care is increasingly shaped by needs and preferences of service users.

Despite past and current developments, the field of mental health still faces many challenges. An important challenge lies in the limited understanding of the aetiology of mental health problems. In addition, the global context of mental health is increasingly acknowledged, drawing attention to the enormous treatment gap in low and middle income countries (LMICs), which is difficult to close due to a lack of priority given to mental health care, limited availability of resources, differences between regions, and limited understanding of local notions and concepts of mental health and mental health care. Furthermore, defining what constitutes 'good mental health care' is a challenge which is of growing importance to mental health care as there is an increasing number of stakeholders, all with different knowledge, needs and visions regarding 'good care'. Therefore, more attention to communication and negotiation between practitioners, researchers and service users is necessary in order to be able to define and realize 'good care' jointly.

Service user involvement is central to the current developments and challenges in mental health care, especially in defining 'good care' in a multi-stakeholder setting. Although service user involvement is increasingly accepted in mental health care, this faces particular challenges and therefore requires extra attention. Moreover, significant changes in mental health care systems are needed to better acknowledge and integrate service user knowledge in mental health care. Little is yet known about the particular role of service user involvement in developing 'good care', and how changes regarding the role of service user involvement in mental health care systems can be brought about. Therefore, this thesis aims to:

gain insight into the contribution of service user involvement to realising good mental health care, by investigating the nature of service user knowledge and possible strategies for both its integration with other stakeholders' knowledge, as well as the embedding of service user involvement in mental health care systems.

Theoretical background

In the theoretical background, the main concepts and theories used in this thesis are introduced: knowledge integration, service user involvement in mental health care and a systems perspective to service user involvement.

Because stakeholders have different opinions, experiences and needs regarding mental health care, an exchange and integration of their perspectives and knowledge is needed in order to establish a shared understanding of what constitutes 'good mental health care'. As the scope of mental health care becomes broader and the number of stakeholders grows, the complexity of mental health care increases. As a result, the need for knowledge integration becomes more urgent, while at the same time the process of integrating knowledge from different stakeholders becomes more complex and challenging. The complexity of different mental health care settings varies as a function of the number of stakeholders that is involved and the scope of issues that are addressed. Based on these dynamics three types of knowledge integration can be distinguished: low complexity of knowledge integration (low number of stakeholders and a narrow scope), medium complexity of knowledge (low number of stakeholders and a wide scope, or a high number of stakeholders and a narrow scope) and high complexity of knowledge integration (a high number of stakeholders and a wide scope).

Service users can be involved in various aspects of mental health care, including individual treatment, service delivery and evaluation, research, education, and policy. Service user involvement can further be characterized by the extent to which service users are involved. Four degrees of involvement are distinguished: 1) information/explanation (the user is provided with information or an explanation but not included in the decision-making process); 2) consultation (professionals seek the views and opinions of the service user and decide whether or not these are considered in the decision-making process); 3) partnership (power is redistributed among service users and professionals so that decisions can be made jointly), and; 4) user-control (power is redistributed so that the user makes the decision). Furthermore, a typology can be made based on the level of care at which service user involvement takes place. At the micro-level, service users are involved in individual interactions with other service users or professionals. At the meso-level, service users engage in organization of local services. At the macro level, service users participate in the organization of overall services, often at the regional or national level in a policy context.

A systems perspective is applied in order to explore the role of service user involvement in mental health care systems and in system change. Transition Theory proposes that a transition within a system, in this case the embedding of service user involvement in mental health care systems, requires a fundamental change of structure (how people organize the things they do), culture (ways of thinking, mental models and perceptions) and practice (actual actions). The context of transitions can be explored using the *multi-level perspective* which describes three different levels in systems: landscapes (broader

societal context of transitions), regimes (dominant structure, culture and practices) and niche experiments (actors experimenting with innovations in the systems). In addition, the *multi-phase concept* describes the process of transitions as they develop in time, distinguishing the following four phases: pre-development (no significant change, status quo), take-off (change is slowly becoming visible), acceleration (change is accelerated and becomes clearly visible at regime level) and stabilization (the pace of change decreases and a new status quo is reached). Service user involvement as a system innovation appears to be around the take-off phase. New initiatives and experiments have emerged at the niche level and some experiments are being scaled up. However, service user involvement is not yet embedded in dominant structures, culture and practices. There are important differences between weak mental health care systems, mainly in LMICs, and stronger mental health care systems, usually in high-income countries. Whereas in weaker mental health care systems service user involvement is mainly in the pre-development phase and sometimes in an early take-off phase, involvement in stronger mental health care systems is often in the take-off phase and is in some cases heading towards acceleration.

Research design

The main research question that guides this thesis is:

What is the contribution of service user involvement to realising 'good mental health care', and how can service user knowledge be integrated effectively in mental health care?

Based on the main research question the following four research sub-questions are formulated:

1. What is 'good mental health' care according to service users?
2. How can service users be involved effectively in mental health care?
3. How can service user involvement be embedded in mental health care systems?
4. What is the potential of service user involvement in countries with weak mental health systems?

This thesis consists of two parts. *Part 1* includes three case studies about service user involvement in the field of mental health in the Netherlands, a country with a strong mental health care system. The first part addresses sub-questions 1, 2 and 3. Here a case study approach is used to study and gain insights into certain phenomena in a real-life setting. Three cases have been selected to answer the first three research sub- questions. There is diversity in the topics of the cases and the level of care at which participation takes place. The first case focuses on the effects of the crisis card, a specific type of a psychiatric advance directive which documents patients' preferences for care in advance of a potential psychiatric crisis (micro and meso level). The second case concerns an evaluation of a participatory video project and its effects on long-term mental health care (meso level). The third case assesses service user involvement in the development of multidisciplinary clinical practice guidelines in mental health care.

Part 2 addresses sub-question 4. It comprises one literature study and two exploratory studies relating to the potential of service user involvement in weak mental health care systems. The literature study explores the potential of service user involvement in developing 'good mental health care' in weak mental health care systems in LMICs from a transition perspective. The exploratory studies both focus on important aspects regarding the role of service user involvement in weak mental health care systems. One study explores perceptions of mental health and mental health care among community members, family members and health workers in urban Vietnam, while the other study focuses on the mental health and wellbeing of female migrant domestic workers from the Philippines.

Part 1: Case studies on service user involvement in mental health care in the Netherlands

Part 1 in the thesis presents the findings from the three case studies about service user involvement in the field of mental health in the Netherlands.

Chapter 4 and 5 focus on the crisis card, a tool to help people with psychiatric problems to determine how they want to be treated in a crisis situation. On the crisis cards service users document their treatment preferences in advance of a potential psychiatric crisis. The case study aims to provide insights into the potential of the crisis card, by documenting its perceived effects and implementation within a mental health care institution. Data were collected through interviews with fifteen participants from six stakeholder groups. Chapter 4 focuses on the perceived effects of the crisis card, indicating that experiences with the crisis card are positive. A number of effects are identified, including psychosocial effects, effects on crisis situations and effects on hospital admission. Psychosocial effects were most evident and entailed enhancing understanding and insights of different stakeholders regarding the crisis, stimulating a sense of security and safety among different stakeholders and reinforcing the empowerment and autonomy of service users. Chapter 5 investigates issues surrounding implementation of the crisis card. Identified implementation issues include: 1) the role of the crisis card counsellor; 2) lack of distribution and familiarity; 3) mental health care professionals' routines; and 4) service user readiness. The crisis card counsellor appears to play a key role in fostering benefits of the crisis card by supporting service users' perspectives. More structural integration of the crisis card in care processes may enhance the impact of the crisis card, but should be carefully explored.

Chapter 6 discusses a participatory video project carried out in a long-term care facility of a psychiatric hospital with the aim to improve long-term mental health care. Data were collected through interviews, a focus group and a dialogue session with providers, service users, managers and a family member. Four themes emerge from the data analysis: 1) the video elicits discussion by affecting viewers; 2) the video raises awareness and stimulates the discussion of service users' needs and desires; 3) the video and discussion give a voice to service users; and 4) the video and discussions draw attention to user-provider relations.

The study shows that video-mediated moral deliberation can be a useful tool for starting dialogue between service users and care providers. It can also contribute to changes in care provision by acting as a catalyst.

Chapter 7 and 8 focus on service user involvement in the development of multidisciplinary clinical practice guidelines in mental health. Chapter 7 comprises a desk study of twelve guidelines and case studies of service user involvement in five guidelines using document analysis, interviews and observations. Findings show that all multidisciplinary mental health guidelines have taken service user perspectives into account to some extent. Analysis of the five guideline case studies provides ten main themes and associated barriers and facilitators for service user involvement in clinical practice guideline development. Findings indicate that specific attention should be paid to integrating evidence obtained through service user involvement with evidence from scientific literature; proper selection and use of service user consultation methods; and the potential of service user involvement in enhancing the practical applicability of clinical practice guidelines. Chapter 8 discusses service user involvement in the development of the Multidisciplinary Guideline for Employment and Severe Mental Illness. To evaluate the quality of service user involvement a monitoring and evaluation framework was developed, including both process and outcome criteria. Data collection included observations, document analysis and semi-structured interviews. Service user involvement is evaluated as being of good quality. Aspects that contributed most to the quality of service user involvement include the use of different methods, reflection of service user input in the guideline text, a supportive attitude among professionals and attention for service user involvement throughout the process. The quality of service user involvement was lower with respect to representing the diversity of the target group, articulation of the service user perspective in the guideline development group, and clarity and transparency concerning methods of involvement. The monitoring and evaluation framework is considered useful for providing detailed insights into service user involvement in guideline development. The dialogue-based approach appears to be a promising method for obtaining integrated stakeholder input in a multidisciplinary setting.

Part 2: Exploring service user involvement in mental health care in a global context

Part 2 of the thesis presents the findings from a literature study and two exploratory studies investigating the potential of service user involvement in weak mental health care systems in LMICs.

Chapter 9 explores the potential of service user involvement in developing 'good' mental healthcare in LMICs through a literature study. Transition Theory is used as a conceptual framework, by outlining barriers and opportunities in terms of the dominant structure, culture and practice of a mental healthcare system and how they relate to integration of

service user knowledge. Current situations are described thereby providing insight into regime factors that hamper knowledge integration. Some important hampering factors include: the lack of mental health policy, legislation and resources, stigma, and power differences between professionals and service users. In addition, the envisioned changes are elaborated upon and facilitators and possible opportunities for change at the niche and landscape level are identified. Opportunities for integration of service user knowledge might be found in adopting rights-based, wellbeing-oriented approaches thereby connecting to broader societal trends. In addition, adopting strategies of deepening, broadening and scaling-up of current initiatives at the niche level might enhance shift towards integration of service user knowledge.

Chapter 10 focuses on perceptions of mental health and help-seeking behaviour among adults in Vietnam. Research methods included questionnaires and focus group discussions. Findings show that respondents were often unable to name specific mental illnesses. Frequently mentioned symptoms of mental illness were talking nonsense, talking/ laughing alone and wandering. Pressure/ stress and studying/ thinking too much were often identified causes. Most respondents appear to have a preference for medical treatment options, often in combination with family care. The results show that perceptions of mental health and help-seeking behaviour are influenced by a lack of knowledge and a mix of traditional and modern views.

Chapter 11 and 12 assess stress and wellbeing of female migrant domestic workers from the Philippines. Data were collected among returned domestic workers residing in the Philippines using questionnaires. Validation of findings took place in a work shop and two focus groups. Chapter 11 focuses on the perceived stress levels and coping strategies of domestic workers in different phases of the migration process: prior to migration, in the country of destination and upon return to the Philippines. Findings indicate that perceived stress levels of women were significantly higher abroad than in the Philippines. Stress and coping in the Philippines appears mostly related to financial issues, while stress and coping abroad relate more to loneliness, working conditions and employers. Chapter 12 investigates factors that potentially contribute to the resilience of female domestic workers from the Philippines, and explores their relation to stress and wellbeing. Results show that participants perceive their wellbeing abroad as relatively good, while they also experience high levels of stress. Workers use a variety of resources in dealing with stress. Connectedness to others and spirituality seem to play an important role as personal resources. Characteristics of employers and social networks strongly determine social resources and are more often related to stress and wellbeing than personal resources.

Conclusions and discussion

This thesis provides an overview of the role of service user involvement at different levels (micro-, meso- and macro-level) and degrees (consultation, partnership, control). The different research questions address service user involvement through different lenses, with

a widening scope: 1) the perspective of service users themselves; 2) the role of service user involvement in specific initiatives; 3) the role of service user involvement in health care systems; 4) the role of service user involvement at the global scale. This heterogeneity of the studies and the lenses by which they are assessed allows for a broad exploration of the dynamics and complexity of service user involvement in mental health care.

Although no simple answers or golden standard can be provided in response to the main question, several overarching conclusions and lessons are formulated. First, this thesis shows that the perspectives and needs of service users regarding mental health care reflect the different roles and ambitions users have in society as well as their individual strengths and weaknesses. These findings connect to more general trends in mental health care that promote a broader, holistic approach to mental health care. The views of service users differ from those of other stakeholders such as health care professionals because they take a broader approach to mental health, in which mental illness and related symptoms are merely one aspect of service users' lives. Second, the findings show that service users involved in the different case studies were able to participate and provide relevant input. However, fundamental challenges include the integration and utilization of service user knowledge and the establishment of partnerships. Although service user involvement is most likely to become embedded in mental health care if it occurs in a partnership, the power imbalance between service users and professionals and the lack of recognition of experiential knowledge often prevent true collaboration. Third, although service user involvement is gaining momentum, limited changes are yet visible in dominant structures, cultures and practices in mental health care systems. Our findings suggest that existing initiatives tend to focus either on structures or on cultures, while changes to both of these structuring aspects are necessary to have an impact on practice. Finally, integration of service user knowledge can be a powerful instrument for strengthening weak mental healthcare systems from a needs based perspective. Currently, service user initiatives in LMICs with weak mental health care systems still scarce and often occur on a small scale. The absence of a well-functioning mental healthcare system could be seen as an opportunity for innovation at the niche level because there are fewer structures in place to block transition and change. Embedding service user involvement within broader community involvement initiatives through participatory methods might be a strategy for connecting to local contexts, thereby enhancing knowledge integration.