Patient involvement in mental health care: one size does not fit all

Else Tambuyzer MSc Psychology MSc Public Health,* Guido Pieters MD PhD† and Chantal Van Audenhove PhD‡

*PhD student, LUCAS – Katholieke Universiteit Leuven, Leuven, †Senior Lecturer, University Psychiatric Centre at Kortenberg, Katholieke Universiteit Leuven, Leuven and ‡Professor, Dr in Psychology, Director, LUCAS – Katholieke Universiteit Leuven, Centre for Care Research and Consultancy, Leuven, Belgium

Abstract

Correspondence

Else Tambuyzer MSc Psychology MSc Public Health
PhD student
LUCAS – Katholieke Universiteit Leuven
Kapucijnenvoer 39 PB 5310
3000 Leuven
Belgium
E-mail: else.tambuyzer@med.kuleuven.be

Accepted for publication

23 September 2011

Keywords: empowerment, mental health care, patient involvement, patient participation

Background Involvement of mental health-care patients in the decision-making processes is considered to be an ethical requirement. Health-care systems worldwide are increasingly emphasizing the value of participatory approaches. There is, however, no consensus on the definition of patient involvement. The literature is particularly inconsistent and lacks clarity.

Objective The purpose of this article is to clarify the concept of patient involvement in mental health care (MHC), taking into account its multidimensional nature.

Search strategy We searched the literature in online databases from January 1998 until August 2010 using synonyms of ‘patient involvement’, combined with the terms ‘mental health(care)’.

Data synthesis Based on 45 different descriptions found in the literature, we constructed a definition of patient involvement and we drew up a model identifying its determinants and outcomes.

Results We propose a comprehensive model of patient involvement to be used in MHC. This model can serve as a guide for policy makers and field workers to shape policies to stimulate involvement.

Discussion and conclusions There are three main problems in the literature concerning patient involvement. First, there is a proliferation of conceptualizations of the topic, leading to conceptual vagueness. Furthermore, there is a lack of quantitative data, and some aspects of involvement remain underexposed, such as the involvement of specific target groups and practical ways to shape the involvement processes. Involvement processes should be tailored to the specific target group and context.

Introduction

Patient involvement is a trend in health-care systems worldwide. Patients and their families are increasingly asked to voice their opinion. Moreover, they take up an active role in their own care and on strategic levels such as in policy decisions. Even if not all countries proceed at the same pace in putting this trend into practice, at least the issue of involvement seems to be high on the agenda of governments and policy makers all over the world.

The current trend of patient involvement in mental health care (MHC) has had a number of contributing elements. A higher education rate paired with a higher literacy rate and the widespread availability of the Internet has led to greater information accessibility among the general population. A tendency to self-organization and self-determination has been another element, with a contiguous emphasis on empowerment, civil rights^{1,2} and autonomy. The user/survivor movement was an additional impetus.³ Several innovations in health-care practices further paved the way: patient-centeredness, deinstitutionalization and community-based care.⁴ Finally, the emergence of a market perspective in health care and a democratization tendency in the wider society⁵ also induced patient involvement. All these elements led to a greater openness and respect for the voice of patients.

Research objectives

This article aims to shed light on the complex nature of patient involvement, identifying the relevant topics and proposing to link them together in a model.

Method

Literature review

We searched the relevant literature from 1 January 1998 until 11 August 2010 using the following search terms: user involvement, user

participation, consumer involvement, consumer participation, patient involvement, patient participation, carer involvement, carer participation, family involvement and family participation. All search terms were combined with the terms 'mental health' and 'MHC'. We did not include related concepts such as recovery, shared decision making (SDM) and rehabilitation because these are outside the scope of the current study. We do consider them to be important as background concepts. Documents and articles were not retained when they dealt uniquely with learning disabilities, mental disability, ageing/elderly persons/dementia, poverty/homelessness and HIV/AIDS. Articles concerning involvement in general health care, forensic services and addiction services were retained when they discussed generic aspects of involvement. The online databases we searched were as follows: Academic Search Premier, CINAHL, Cochrane Library, Google scholar, JSTOR, PsycINFO, PubMed, Social Sciences Citation Index, Sociological Abstracts and Web of Science. Furthermore, some Dutch language journals (not included in the online databases) were searched manually. Lastly, we searched grey – mostly unpublished – literature, policy and legislation documents, the search engine Google, and we screened reference lists and citations of several articles, using the 'snow ball method'.

Definition development

As part of the literature study, we developed a comprehensive definition of what patient involvement in MHC means. Hereto, we scrutinized 45 definitions of involvement (a.o. derived from⁵⁻¹⁹). These descriptions were analysed using NVIVO 8, a content analysis program. We used a coding tree with the following 'key nodes': underlying values; decision making; patient involvement considered as an objective/as a means to obtain other outcomes; target group; expertise by experience; power notions; participatory manner (e.g. active/passive, paid/voluntarily); involvement

activities (e.g. planning, research, treatment, advocacy).

Use of terms

Throughout the literature, a plethora of terms is used to refer to the concept of patient involvement and its subjects. Each term has its own issues and tells something about the way the author views the person(s) involved. We use the term 'patient' to designate the person receiving MHC services. We use this term solely for reader-friendliness and want to emphasize that this does *not* imply that we view the patient as taking a passive role. The terms 'involvement' and 'participation' are used interchangeably throughout this article.

Results

As the concept of patient involvement gains momentum, involvement research and practices are appearing increasingly. There is, however, no consensus on the definition of patient involvement. A whole range of models of the concept exists and different stakeholder groups 'understand and practice user involvement in different ways according to individual ideologies, circumstances and needs'.²⁰ Apart from this conceptual vagueness, there is a lack of quantitative data on involvement.²¹ A few systematic reviews on the topic exist,^{6,21–23} mostly considering its effects. However, their results indicate that the majority of research are case reports⁶ or small-sample studies¹⁰ and have limited generalizability. Additionally, the literature on the effects of involvement is inconsistent and lacks clarity. For example, Crawford and colleagues⁶ found evidence for both positive and negative effects on patients who participate, and results regarding the effectiveness of peer delivered services remain equivocal.⁸ The fact that little is known about the process of involvement further contributes to the vagueness.^{7,24} This lack of consensus is of course not specific to the body of knowledge regarding involvement, as the same is true for the concepts like health literacy,²⁵ self-management²⁶ and SDM.²⁷

The whole picture: the model

To clarify the concept of involvement, we developed a model that captures the whole picture (Fig. 1). The different parts of the model are discussed below. We took a whole-systems approach and created a holistic model that takes into account several aspects of involvement. The model starts at the left with an overview of the *determinants of patient involvement*: the factors that enhance or obstruct meaningful involvement. These determinants are thought to influence the nature and significance of the involvement processes. They include the following: (i) the communication and information provision towards patients, (ii) the attitude of health-care professionals towards patient involvement, (iii) the financial resources and time available for patient involvement, (iv) the education and support of all stakeholders regarding patient involvement, (v) the availability of procedures for involvement, and (vi) the existence of a legal framework for involvement. These determinants are well described in the literature on patient involvement, so we will not elaborate on them further.

The model then goes into the essential part: *the concept of involvement*. When thinking about installing involvement processes or activities, the following elements should be borne in mind: the definition of patient involvement, the specificity of patient involvement in MHC, the reasons for involvement, the different perspectives on involvement, its organizational levels, the power dimension, the diversity issues, the participatory methods and three related concepts. While the process of involvement is important in itself, it is not an end goal. It is more like a means to attain positive outcomes. Consequently, the model presents the desired (short-term) *outcomes* of patient involvement. These entail patient empowerment, patient satisfaction, accessibility of health care, high quality of care and recovery of patients. The final part of the model is the desired long-term outcome of involvement: improved *quality of life*.

Figure 1 Comprehensive model of patient involvement. This model shows the processes of patient involvement. It gives an overview of the defining elements of patient involvement and its determinants and outcomes.

Definition of patient involvement

Based on our analysis of 45 definitions, we detected five key elements of patient involvement: (i) participation in decision making, (ii) the active character of involvement, (iii) involvement in a diverse range of activities, (iv) expertise by experience, and (v) collaboration with professionals. We describe each element, using illustrative citations.

Participation in decision making

Involvement implies participation in decisions, be it in one's own personal care or concerning higher level policy decisions.

Participation is the involvement of many people in decisions, giving them some feeling of control or responsibility.²⁸

Active involvement

Involvement is about taking up an active role, rather than merely being consulted or receiving information.

User involvement (...) is understood to mean active involvement.^{29–31}

Range of activities

According to Anthony and Crawford,³² patient involvement in MHC can imply several things, ranging from having a voice, having access to suitable information to sharing a set of basic values. In general, involvement can concern the following fields: planning, care delivery, evaluation, information provision, research, training and recruitment of personnel.

(...) the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and the wider public as potential patients.³³

Expertize by experience

Perhaps this is the single most important element: the person is an expert because of his own lived experience. This expertize can (and should) be considered as a new kind of knowledge. This type of knowledge should be distinguished from the academic knowledge created by the researchers without a lived mental health experience. Traditionally, this 'lay knowledge' has been criticized as (supposedly) being biased and being the weakest form of evidence in the hierarchy of evidence.³⁴ However, this expertize by experience is an equally valid form of knowledge; it is merely a *different* knowledge perspective.

The core of service user involvement lies in the expertise by experience of the clients.¹⁷

Collaboration with professionals

Involvement in MHC implies a partnership between the receiver of the services and professional caregivers or policy makers. If all decisional power lies with the individual or patient organization, we no longer consider it as a participatory initiative, but rather as a patient-controlled initiative.

(...) it is about being a partner in the clinical process rather than being merely compliant with the clinical decisions made by experts.¹⁴

Based on these elements, we propose a comprehensive definition:

Patient involvement in MHC means involvement in decision making and active participation in a range of activities (e.g. planning, evaluation, care, research, training, recruitment) starting from the expertise by experience of the person, in collaboration with and as equal partners of professionals.

Specificity of patient involvement in mental health care

MHC is not the only sector in which there is a tendency to promote patient involvement.

General health care, social and welfare services and education systems are also developing involvement processes. To a large extent, these processes are similar across different types of services. For instance, psychiatric patients' desire for autonomy is probably similar to that of other patient groups.³⁵ Nevertheless, being a patient of MHC adds some specificities. Indeed, psychiatric disorders may influence some personal features in ways that are less likely to occur in other services. The presence of a psychiatric disorder may influence the process of a person's involvement in two main ways: it may affect the person's *ability* to be involved and his *motivation* or desire to be involved. The first aspect relates to the concept of 'mental capacity' and mainly has to do with the decision-making component of patient involvement at the micro-level. It is well-known that psychiatric disorders may impact a person's ability to make rational contributions,²⁴ and this ability may be further affected by the use of psychiatric medication. The body of literature regarding the decisional capacity of individuals with mental disorders has accrued extensively during the last decade.³⁶ The most common conceptual framework is the 'four abilities model',³⁷ which posits that capacity entails the ability to express a choice about treatment; the ability to understand relevant information; the ability to appreciate the significance of that treatment information for one's own situation; and the ability to reason with relevant information so as to engage in a logical process of weighing treatment options. It is obvious that the presence of a psychiatric disorder may affect each of these abilities.³⁸ The areas most likely to be affected include lack of insight and impaired neuropsychological functioning, thought disorder (e.g. delusions), and emotional disturbances.³⁹ A systematic review about mental capacity⁴⁰ showed that the main risk factors for incapacity are psychosis, illness severity, involuntary admission and treatment refusal. It has indeed been proven that individuals with e.g. schizophrenia³⁶ and depression³⁸ demonstrate deficits in understanding and are thus vulnerable to making poor decisions.

The second aspect that may be influenced by a psychiatric disorder is a person's motivation to become involved, be it in his own treatment or at collective levels such as in policy-making. Especially in the case of affective disorders, anhedonia and passivity are likely to affect the person's motivation to engage in participation processes. The impact of this aspect on involvement has been substantially less researched and needs further investigation.

While a person's involvement may be complicated by the presence of a psychiatric disorder, this does not mean that involvement of individuals with psychiatric disorders is infeasible. The majority⁴⁰ has sufficient decisional capacity and is ready to participate,⁴¹ and the abilities of those deemed incapable can be significantly enhanced through educational interventions.^{36,38} Furthermore, eliciting the patients' preferences⁴² and requests for care⁴³ may also enhance their involvement. Additionally, 'capacity to be involved' is not a binary, all-or-nothing story. We agree with Stein and colleagues⁴⁴ (in the context of disability care planning) that impairment of decisional capacity on one level does not imply total decisional impairment. Individuals may still have 'the capacity to make less complex decisions' or 'to appoint a trusted person as health care proxy'. We also concur with Elwyn and Miron-Schatz⁴⁵ that the process of deliberation and the act of decision determination need to be distinguished: although someone might not be capable of making autonomous decisions, it is still valuable to offer options and ask for opinions.

Reasons for involvement

Advocates of patient involvement quote different arguments, which can be divided in four main groups. The first (arguably most prevalent) set of arguments is *principle based*.⁴⁶ These arguments are mostly ethical and relate to ideas of democracy, citizenship and human rights.⁴⁷ The general idea is that patient involvement is 'the right thing to do' and that it is a fundamental citizen's right.⁴⁸ A second line of reasoning claims that patient involvement has a

therapeutic value.^{47,49,50} It is said to contribute to the empowerment,^{16,46,51–53} quality of life⁵⁴ and recovery of patients. Besides, it has a positive influence on their satisfaction and health.⁵⁵ A third set of arguments states that patient involvement enhances the *quality* MHC in several ways.^{14,49,54} It is argued that patient involvement renders MHC more responsive to the needs of the public.⁵⁰ Furthermore, it is believed to become more accessible as a consequence.⁵⁶ The last line of reasoning is actually a tokenistic one: here, patient involvement is implemented for *political* reasons.⁴⁷ Patient involvement is then advocated to meet governmental or funding requirements or because it is thought to increase the initiative's legitimacy.

Perspectives on involvement

Related to the arguments for involvement are the different perspectives on patient involvement in MHC. Throughout the years, a shift in perspective occurred, although the earlier perspectives are sometimes still endorsed. The *paternalistic perspective* was the predominant view until the eighties.⁵⁷ This perspective assumes patients to take a passive role, while doctors and other professionals are regarded as experts. Decisions are often made without consulting the patient, who also has no access to medical information.⁵⁸ The guiding principle in this perspective is 'the doctor knows best'. Patient involvement is consequently virtually non-existent. This perspective might, however, still be useful under certain circumstances (such as crisis situations) to be able to offer effective help.⁵⁹ Furthermore, not all patients want to be involved to the same extent.⁶⁰ Some are willing to discuss treatment options, but prefer the professional to decide for them. This attitude needs to be respected, but it should be checked that it does not result out of a lack of information or skill. A second widespread view on involvement is the *market perspective*,⁵ which consists of two lines of reasoning. The first line is the so-called *consumerism* that strives to increase the choices patients have while deciding upon a certain service. Empowerment is one of its core

concepts. The second line concerns *consumer solutions*, which are techniques derived from the commercial world aimed at improving the responsiveness of services to the needs of patients. In practice, the tenors are closely linked. While patients have freedom of choice in the market perspective, they are not able to decide upon the contents of the services, they only evaluate the output. This is the great difference with the *democratic perspective*, in which patients can decide upon the contents of the services.⁵ Within this perspective, citizens are involved in the decision making. Basic values include human rights, citizenship and empowerment and include a focus on the therapeutic value of involvement. As the millennium, a new model has gained importance: *the stakeholder perspective*, which is essentially an adaptation of the market perspective. It claims that MHC reaches its highest quality when the opinion of key figures and stakeholders (patients, professionals, the general public and the government) is actively sought and taken into account.⁶¹ The power imbalance between the different parties is accepted as a reality, contrasting the democratic perspective which questions this imbalance.

Organizational levels of involvement

Involvement takes place at different organizational levels of care.¹⁹ First of all, involvement can occur on the micro- or individual level. This implies, for example, participation in decisions concerning a person's own care plan, choice of therapist or treatment choice. A second level of involvement is the meso- or health-care service level. An example of this is patient representation in the board of advisors of a care institution. Representation may be realized by individual patients or by delegates of patient associations. A third level is the macro- or policy level. Here, involvement means co-deciding upon MHC policy. An example of involvement in this context is implying patient associations when developing new policies or legislation. In addition to the micro-, meso- and macro-level, we propose a meta-level, including research and education concerning involvement. Indeed,

Figure 2 Organizational levels of patient involvement in mental healthcare. This figure illustrates the different levels at which patient involvement may occur and indicates the interplay between the levels.

patients and their families can have a valuable role in the education of, e.g., health professionals and in MHC research, because of their lived experience. Figure 2 gives an overview of the different levels and some examples for each one. In general, the dynamic interplay between the different levels is important to acknowledge: they are not isolated from each other, but rather they exert mutual influence.⁶² An example is that patient involvement in MHC policies (macro-level) may influence involvement possibilities at the micro-level.

The power dimension

At all levels, the degree of involvement can vary strongly, based on the decisional power of the person. Power is an important concept in theory-building around patient involvement and surely also in MHC. One of the key elements is after all participation in decision making, which is merely possible if one is able to exert influence and thus possesses a certain amount of power.⁵ The degree of decisional power for patients in MHC ranges from mere information and consultation to real decision-making power. This variation is often described by means of a 'participation ladder'. A crucial element of these ladders is the power position of all persons

implied. Several ladders of involvement exist, all more or less based on the basic model of Arnstein.⁶³ Her ladder starts with 'non-participation' and therapy, where the person has no decisive power whatsoever. Steps three to five are tokenistic forms of involvement. Here, the person is informed and listened to, but his opinion is not always taken into account. From stage six on, patients are able to negotiate along with the other parties involved. At the final stages, patients have the largest part or all of the decisive power. A whole range of adaptations to this original ladder exists, aimed at different target groups and with different accents. Common to all, the ladders is the underlying power notion and the stepwise evolution.

There are a number of criticisms of the ladders. A frequently named critique is that they do not do justice to the complexity of involvement.^{64,65} The ladders tend to ignore several aspects of involvement by simply focusing on the decisional power dimension, while involvement is a multidimensional concept. Furthermore, most ladders are only outcome-directed and do not take the involvement processes into account.⁶⁵ Such an approach ignores the different ways in which involvement can occur, as well as its success and impeding factors. As Radermacher and colleagues⁶² state, '*various models have been useful for understanding types of participation, but are less useful for understanding its processes*'. Finally, most models implicitly assume that involvement should always be aimed at the highest stage.⁶⁶ At the micro-level, an initiative is, however, not necessarily inferior because it only reaches the information or consultation level. Possibly, higher levels are not feasible or desirable. For example, a person may be acutely ill, very young or he/she may not desire to be implicated in the decision process. Patients also differ in their participation preferences.⁶⁶ Some patients wish to discuss treatment options, but choose to leave all decisional power to the health-care professional. Furthermore, a previous study⁶⁷ suggests that although many patients want to be involved in the decision making, they usually have no desire to take complete control over treatment decisions. In

general, it is suggested that offering more rather than less involvement possibilities is the best choice when no information about patients' preferences is available.⁶⁸ At the meso- and macro-level, however, systematic involvement should be an ethical choice of institutions and boards, aiming at real decisional power of patients and their representatives.

Diversity issues

Patients are not a homogenous group. Rather, several subgroups exist, which are important to take into account as the involvement differs according to the target group in question. First, patients as well as family carers can be involved. Dependent on the subject, different needs, perspectives and implications arise. It is often implicitly assumed that patients and carers have the same needs and can thus be reached through the same initiatives. Yet, this assumption is incorrect.^{69,70} In fact, they often have conflicting agendas and different needs⁷¹ and it is inherently difficult to empower both groups at the same time.⁷² Empowerment of one group frequently leads to disempowerment of the other group. Second, within the group of patients itself, large differences exist concerning ethnicity, age, pathology, decisional capacity and so forth. Involvement processes should thus be adapted to the specific target group.

Participatory methods

Several participatory methods have been developed over the years. Examples of this are participatory action research, patient panels, SDM and focus groups. These techniques can be classified as indirect (e.g. questionnaires, focus groups) or direct (e.g. SDM, representation in official bodies).⁷³ The first, indirect form of involvement is actually not considered to be real involvement,⁵⁸ but given the context and goal of the involvement, it can be an efficient way to obtain patients' views. Referring to the diversity issues discussed above, the chosen participatory method should fit the needs of the persons involved. For example, the involvement of

children with behavioural problems will require quite different methods than the involvement of adults with a bipolar disorder. Consequently, when thinking about installing involvement processes, the chosen techniques should be tailored to the target group as well as to the goal of the involvement activity.

Formality of involvement

A minor but still defining element of involvement is the formality of involvement processes. This can often be seen through its duration: is the involvement activity structurally organized, i.e., does it occur at regular intervals? Or is it rather a spontaneous, one-off event? This dimension co-determines the outcomes and forms involvement can take. It influences the resources and time invested and the perceived legitimacy of the initiative. Structural involvement may be promoted through three main channels. First of all, policy requirements such as patient representation in decisional bodies and the existence of patient councils may be an impetus. Protocols, guidelines and vision statements emphasising involvement are another way to formalize involvement. An example is the Dutch obligation that treatment guidelines should '*reflect patients' preferences*'.⁷⁴ and the consequence that patients are represented in the guideline development working parties. Furthermore, international treatment guidelines increasingly advocate patients' involvement in drug decisions.^{75,76} A third kind of involvement-promoting procedures pertain to the routine application of shared decision-making techniques, decision-aids and other participation-facilitating techniques.

Related concepts: empowerment, shared decision making and recovery

The concept of patient involvement is related to many other notions such as empowerment, recovery, SDM, autonomy, patient-centeredness and so on. We describe three concepts that are most relevant in the involvement context: empowerment, recovery and SDM. While these

concepts are closely related to the involvement concept, the four concepts ought to be distinguished.

Empowerment

WHO's⁷⁷ definition of empowerment is: '*Empowerment refers to the level of choice, influence and control that users (...) can exercise over events in their lives.*' The power notion is thus a defining characteristic of empowerment. In the literature, it is furthermore said that '*power, by its very nature, is gained or lost, not given. Power that is given is actually a subtle form of control (...)*'.⁷⁸ Consequently, patients cannot be empowered by professionals. Empowerment is a personal process and professionals can only enable environments wherein empowerment is more likely to occur. The concepts of empowerment and patient involvement are related in two ways. First, the power notion is a defining element of both concepts. Next, involvement has an empowering effect. Involvement is related to a strength-based approach on health-care delivery:⁷⁹ it appeals to the competences of patients rather than to their problems, as is the case for empowerment. The literature also shows that practically every kind of involvement is empowering.^{16,51-53} Consequently, we assume empowerment to be a possible outcome of involvement (see Fig. 1 above). Empowerment is an overarching concept that is broader than involvement. It can emerge through many other pathways than solely through that of involvement.

Shared decision making

A second related concept is SDM. This is an interactional process in which at least two parties are involved: minimally the health-care provider and the patient. Both parties are considered experts⁸⁰ and have '*different but equivalent contributions*'.⁸¹ The health-care provider brings medical and technical knowledge about the health problem, while the patient is an expert in his own experiences of the illness, as well as in his needs, values and preferences. Both parties engage in the decision-making process and negotiate a decision upon which they both agree.

It is important to note that SDM is particularly applicable in situations in which several equivalent choices are available. In some situations, there is only one good, medically sound treatment, or the patient himself is not ready or prepared to decide. In these situations, the patient is best helped by a health-care professional who cuts the knot. SDM is closely related to the notion of patient involvement in the sense that SDM is a participatory method that enables involvement at the micro (clinical)-level.

Recovery

'Being in recovery' is a concept developed by patient and family movements in MHC.⁸² A widely accepted definition by Anthony⁸³ is that it is '*a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness*'. Being involved in, for instance, decision making about one's own care might contribute to this person's recovery. As is the case for empowerment, we thus assume recovery to be a possible outcome of involvement.

Discussion

Our literature review shows that patient involvement is a complex, multi-layered and multi-dimensional concept. Three main problems exist in the literature about the concept. First, there is a *proliferation of conceptualizations* of the topic, leading to indistinctness and inconsistency. Apart from this conceptual vagueness, there is a *lack of quantitative data* on patient involvement. Although a few systematic reviews on the topic exist, the majority of research concerns case reports and has limited generalizability. A third problem relates to the lack of research concerning certain aspects of involvement. For instance, the involvement of *specific groups* of patients remains underexposed. Involvement of children, for example,

will run quite differently than involvement of adults. People from racial and ethnic minority communities are another specific target group, as are elderly persons and persons with mental and physical disabilities. Another underexposed matter concerns *practical ways* to shape involvement processes to obtain satisfactory, positive results and experiences for all involved parties. After all, truly positive involvement experiences remain quite scarce despite many efforts. A plethora of barriers hinders successful instances of patient involvement, e.g., tokenism, lack of information provision, medical jargon, representativeness issues. Given these barriers and in view of the frequent resistance towards the implication of patients into decision making, it seems that patient involvement remains a delicate topic. Future studies should focus at investigating practical ways to counter the barriers.

This article is an attempt to bring order into the described conceptual vagueness in the literature concerning involvement. We propose a comprehensive, value-based definition that captures different dimensions of the concept. Additionally, this article makes a start with identifying the factors that contribute to successful involvement, structured by a comprehensive model. Many other models, such as the wide range of participation ladders, only take into account one or some of the important dimensions of involvement (e.g. degree of decision-making power). We consider all of them, including the determinants and outcomes. By being aware of all relevant aspects, one can also take into account all these factors while planning and developing involvement opportunities. It offers some kind of 'check list' with different targets to consider. The model is currently being tested in a study concerning involvement possibilities of patients in care networks for persons with serious and persistent mental illness. While not yet empirically tested, our model can serve as a mirror to reflect upon involvement practices. It helps to identify the enabling and constraining factors and – most importantly – it reminds us that each involvement activity should be adapted and tailored to the specific target

group and context. Patient involvement is strictly *not* a 'one-size-fits-all' case!

Conclusion

We presented an overview of the concept of patient involvement by taking into account its determining factors, defining factors and desired outcomes. This overview was structured through a comprehensive, value-based model and definition. The model can be a guide to mirror and optimize current and future involvement activities.

Source of funding

Belgian Federal Government Service of Public Health.

References

- Godfrey M, Wistow G. The user perspective on managing for health outcomes: the case of mental health. *Health and Social Care in the Community*, 1997; **5**: 325–332.
- Pilgrim D, Waldron L. User involvement in mental health service development: how far can it go? *Journal of Mental Health*, 1998; **7**: 95.
- Rose D. Madness strikes back. *Journal of Community and Applied Social Psychology*, 2008; **18**: 638–644.
- Liégeois A, Van Audenhove C. Ethical dilemmas in community mental health care. *Journal of Medical Ethics*, 2005; **31**: 452–456.
- Hickey G, Kipping CJ. Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing*, 1998; **7**: 83.
- Crawford MJ, Rutter D, Manley C *et al.* Systematic review of involving patients in the planning and development of health care. *British Medical Journal*, 2002; **325**: 1263.
- Koning Boudewijnsstichting. *Patiëntenparticipatie in het gezondheidszorgbeleid. Een literatuuroverzicht en verkenning van internationale en Belgische initiatieven*. Brussel: Koning Boudewijnsstichting, 2007.
- Kwaliteitsinstituut voor de gezondheidszorg CBO, Provinciaal Patiënten/Consumenten Platform Utrrecht, Nederlandse Patiënten Consumenten Federatie. *Patiënten betrekken bij de zorg in het ziekenhuis. Een handboek*. Available at: <http://www.cbo.nl/Downloads/83/pp%20handboek%20-%20versie%201.pdf> 2006, accessed 18 January 2009.
- Landelijke Cliëntenraad. *Cliëntenparticipatie*. Den Haag: Landelijke Cliëntenraad, 2003.
- Cahill J. Patient participation: a review of the literature. *Journal of Clinical Nursing*, 1998; **7**: 119–128.
- Davies J. Children's voices: a review of the literature pertinent to looked-after children's views of mental health services. *Child & Adolescent Mental Health*, 2008; **13**: 26.
- Day C. Children's and young people's involvement and participation in mental health care. *Child & Adolescent Mental Health*, 2008; **13**: 2.
- Kommers A. Cliëntenparticipatie: een kwestie van mogen, kunnen, willen en doen. *Passage*, 2007; **12**: 101–105.
- Lloyd C, King R. Consumer and carer participation in mental health services. *Australasian Psychiatry*, 2003; **11**: 180–184.
- Peck E, Gulliver P, Towel D. Information, consultation or control: user involvement in mental health services in England at the turn of the century. *Journal of Mental Health*, 2002; **11**: 441–451.
- Simpson EL, House A. User and carer involvement in mental health services: from rhetoric to science. *British Journal of Psychiatry*, 2003; **183**: 89–91.
- Truman C. The autonomy of professionals and the involvement of patients and families. *Current Opinion in Psychiatry*, 2005; **18**: 572–575.
- Wright C, Rowe N. Protecting professional identities: service user involvement and occupational therapy. *British Journal of Occupational Therapy*, 2005; **68**: 45–47.
- Beresford P, Croft S. Service users' knowledges and the social construction of social work. *Journal of Social Work*, 2001; **1**: 295–316.
- Fudge N, Wolfe C, McKeivitt C. Assessing the promise of user involvement in health service development: ethnographic study. *BMJ*, 2008; **336**: 313–317.
- The Center for Psychiatric Rehabilitation, National Institute on Disability and Rehabilitation Research. Systematic review of peer delivered services literature 1989–2009. Boston: *Disability Research Right to Know*, Available at: <http://www.bu.edu/drrk/research-syntheses/psychiatric-disabilities/peer-delivered-services/2010>, accessed 24 January 2011.
- Simpson EL, House A. Involving users in the delivery and evaluation of mental health services: systematic review. *BMJ*, 2002; **325**: 1265–1267.
- Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review). *The Cochrane Collaboration*, 2010; **3**, (doi: 10.1002/14651858.CD004563.pub2).
- Rutter D, Manley C, Weaver T, Crawford MJ, Fulop N. Patients or partners? Case studies of user

- involvement in the planning and delivery of adult mental health services in London. *Social Science and Medicine*, 2004; **58**: 1973–1984.
- 25 Chinn D. Critical health literacy: a review and critical analysis. *Social Science and Medicine*, 2011; **73**: 60–67.
 - 26 Kemp V. Use of 'chronic disease self-management strategies' in mental healthcare. *Curr Opin Psychiatr*, 2011; **24**: 144–148.
 - 27 Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions (review). *The Cochrane Library* 2010; **1**, (doi: 10.1002/14651858.CD007297.pub2).
 - 28 Holloway W. *Work Psychology and Organisational Behaviour: Managing the Individual at Work*. London: Sage Publications, 1993.
 - 29 Simpson EL, Barkham M, Gilbody S, House A. Involving service users as researchers for the evaluation of adult statutory mental health services (Protocol). *Cochrane Database of Systematic Reviews: Protocols*, 2003; **4**, (doi: 10.1002/14651858.CD004810).
 - 30 Simpson EL, Barkham M, Gilbody S, House A. Involving service users as service providers for adult statutory mental health services (Protocol). *Cochrane Database of Systematic Reviews: Protocols*, 2003; **4**, (Art. No. : CD004807 doi: 10.1002/14651858.CD004807).
 - 31 Simpson EL, Barkham M, Gilbody S, House A. Involving service users as trainers for professionals working in adult statutory mental health services (Protocol). *Cochrane Database of Systematic Reviews: Protocols*, 2003; **4**, (doi: 10.1002/14651858.CD004813).
 - 32 Anthony P, Crawford P. Service user involvement in care planning: the mental health nurse's perspective. *Journal of Psychiatric and Mental Health Nursing*, 2000; **7**: 425–434.
 - 33 Kelson M. *User Involvement: A Guide to Developing Effective User Involvement Strategies in the NHS*. London: College of Health, 1997.
 - 34 Callard F, Rose D. Mental health service user empowerment in research. Paper presented at the WHO Regional Office for Europe/EUFAMI 'Empowerment in mental health – Working towards leadership' conference, Leuven, BE, 2010.
 - 35 Hill S, Laugharne R. Decision making and information seeking preferences among psychiatric patients. *JMH*, 2006; **15**: 75–84.
 - 36 Misra S, Rosenstein D, Socherman R, Ganzini L. Bipolar mania and capacity to consent: recommendations for investigators and IRBs. *Ethics & Human Research*, 2010; **1**: 7–15.
 - 37 Grisso T, Appelbaum P. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. New York: Oxford University Press, 1998.
 - 38 Ghormley C, Basso M, Candlis P, Combs D. Neuropsychological impairment corresponds with poor understanding of informed consent disclosures in persons diagnosed with major depression. *Psychiatry Research*, 2011; **187**: 106–112.
 - 39 Owen G, Freyenhagen F, Richardson G, Hotopf M. Mental capacity and decisional autonomy: an interdisciplinary challenge. *Inquiry*, 2009; **52**: 79–107.
 - 40 Okai D, McGuire H, Singh S, Churchill R, Hotopf M. Mental capacity in psychiatric patients: systematic review. *The British Journal of Psychiatry*, 2007; **191**: 291–297.
 - 41 Mahone I. Shared decision making and serious mental illness. *Archives of Psychiatric Nursing*, 2008; **22**: 334–343.
 - 42 Van Audenhove C, Vertommen H. A negotiation approach to intake and treatment choice. *Journal of Psychotherapy Integration*, 2000; **10**: 287–299.
 - 43 Lazare A, Eisenthal S. A negotiated approach to the clinical encounter, in outpatient psychiatry. In: Lazare A (ed.) *Outpatient Psychiatry*. Baltimore: The Williams & Wilkinson Company, 1979: 141–156.
 - 44 Stein G, Kerwin J. Disability perspectives on health care planning and decision-making. *Journal of Palliative Medicine*, 2010; **13**: 1059–1064.
 - 45 Elwyn G, Miron-Schatz T. Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations*, 2009; **13**: 139–147.
 - 46 van de Bovenkamp HM, Trappenburg MJ. Reconsidering patient participation guideline development. *Health Care Analysis*, 2009; **17**: 198–216.
 - 47 Ward PR, Barber R, Armitage CJ, Boote JD, Cooper CL, Jones G. Critical perspectives on 'consumer involvement' in health research: epistemological dissonance and the know-do gap. *Journal of Sociology*, 2010; **46**: 63–82.
 - 48 Gordon S. The role of the consumer in the leadership and management of mental health services. *Australasian Psychiatry*, 2005; **13**: 362.
 - 49 Glasby J, Lester H, Briscoe J, Clark M, Rose S, England L. *User Involvement. Cases for Change*. Leeds: National Institute for Mental Health in England, 2003.
 - 50 McCann TV, Baird J, Clark E, Lu S. Mental health professionals' attitudes towards consumer participation in inpatient units. *Journal of Psychiatric and Mental Health Nursing*, 2008; **15**: 10–16.
 - 51 Felton A, Stickley T. Pedagogy, power and service user involvement. *Journal of Psychiatric and Mental Health Nursing*, 2004; **11**: 89.
 - 52 Frisby R. User involvement in mental health branch education: client review presentations. *Nurse Education Today*, 2001; **21**: 663–669.
 - 53 Masters H, Forrest S, Harley A, Hunter M, Brown N. Involving mental health service users and carers in

- curriculum development: moving beyond 'classroom' involvement. *Journal of Psychiatric and Mental Health Nursing*, 2002; **9**: 309.
- 54 Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews: Protocols* 2006; **3**, (doi: 10.1002/14651858.CD004563.pub2).
 - 55 Stringer B, Van Meijel B, De Vree W, Van der Bijl J. User involvement in mental health care: the role of nurses. a literature review. *Journal of Psychiatric and Mental Health Nursing*, 2008; **15**: 678–683.
 - 56 Pagett J. Listening to user views: an out patient user panel in Llanelli and Dinefwr NHS Trust. *The Bulletin of the Community Consultation and User Feedback Unit*, 1994; **4**: 9.
 - 57 Charles C. Decision making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science and Medicine*, 1999; **49**: 651.
 - 58 Coulter A. Paternalism or partnership? *BMJ*, 1999; **7212**: 719–720.
 - 59 Breeze J. Can paternalism be justified in mental health care? *Journal of Advanced Nursing*, 1998; **28**: 260–265.
 - 60 Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. *Journal of General Internal Medicine*, 2005; **20**: 531.
 - 61 Rush B. Mental health service user involvement in England: lessons from history. *Journal of Psychiatric and Mental Health Nursing*, 2004; **11**: 313–318.
 - 62 Radermacher H, Sonn C, Keys C, Duckett P. Disability and participation: it's about us still without us!. *Journal of Community and Applied Social Psychology*, 2010; **20**: 333–346.
 - 63 Arnstein S. A ladder of public participation. *The Journal of American Institute of Planners*, 1969; **35**: 216–224.
 - 64 Kelly L, Caldwell K, Henshaw BL. Involving users in service planning: a focus group approach. *European Journal of Oncology Nursing*, 2006; **10**: 283–293.
 - 65 Tritter JQ. Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations*, 2009; **12**: 275–287.
 - 66 Treseder P. *Empowering Children and Young People: Training Manual*. London: Save the Children and Children's Rights Office, 1997.
 - 67 Hamann J, Neuner B, Kasper J *et al.* Participation preferences of patients with acute and chronic conditions. *Health Expectations*, 2007; **10**: 358–363.
 - 68 Gattellari M, Butow PN, Tattersall MH. Sharing decisions in cancer care. *Social Science and Medicine*, 2001; **52**: 1865–1878.
 - 69 Goodwin V, Happell B. Conflicting agendas between consumers and carers: the perspectives of carers and nurses. *International Journal of Mental Health Nursing*, 2006; **15**: 135–143.
 - 70 Noble LM, Douglas BC. What users and relatives want from mental health. *Current Opinion in Psychiatry*, 2004; **17**: 289–296.
 - 71 Van Weeghel J, Van Audenhove C, Colucci M *et al.* The components of good community care for people with severe mental illnesses: views of stakeholders in five European countries. *Psychiatric Rehabilitation Journal*, 2005; **28**: 274–281.
 - 72 Lammers J, Happell B. Research involving mental health consumers and carers: a reference group approach. *International Journal of Mental Health Nursing*, 2004; **13**: 262–266.
 - 73 Crawford M, Rutter D. Are the views of members of mental health user groups representative of those of 'ordinary' patients? A cross-sectional survey of service users and providers. *Journal of Mental Health*, 2004; **13**: 561.
 - 74 Gezondheidsraad. *Van Implementeren Naar Leren. [From Implementation Towards Learning]*. Den Haag: Gezondheidsraad, 2000.
 - 75 American Psychiatric Association. *Practice Guideline for the Treatment of Patients with Schizophrenia*. Arlington: American Psychiatric Association, 2004.
 - 76 National institute for clinical excellence. *Schizophrenia. Core Interventions in the Treatment and Management of Schizophrenia in Primary and Secondary Care. Clinical Guideline*. London: NICE, 2002.
 - 77 WHO Regional Office for Europe, European Commission. *User Empowerment in Mental Health*. Copenhagen: World Health Organization, 2010.
 - 78 Macaulay AC, Commanda LE, Freeman WL *et al.* *Responsible Research with Communities: Participatory Research in Primary Health Care. A Policy Statement*. Kansas City: North American Primary Care Research Group, 1998.
 - 79 Van Regenmortel T. *Empowerment en Maatzorg. Een Krachtgerichte Psychologische Kijk op Armoede*. Leuven: Acco, 2002.
 - 80 Drake RE, Deegan PE, Rapp C. The promise of shared decision making in mental health. *Psychiatric Rehabilitation Journal*, 2010; **34**: 7–13.
 - 81 Van Audenhove C, Vertommen H. A negotiation approach to intake and treatment choice. *Journal of Psychotherapy Integration*, 2000; **10**: 287–299.
 - 82 Davidson L, Drake RE, Schmutte T, Dinzeo T, Andres-Hyman R. Oil and water or oil and vinegar? Evidence-based medicine meets recovery. *Community Mental Health Journal*, 2009; **45**: 323–332.
 - 83 Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychiatric Rehabilitation Journal*, 1993; **16**: 11–23.