Service user involvement and repositioning of healthcare professionals: A framework for examining implications of different forms of involvement

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ABSTRACT

Models or measures to strengthen the position of service users not only change the position of the users, they also alter the position of the professionals involved. However, different forms of involvement alter the position of professionals differently. The aim of this article is to present an analytical framework that allows for an examination of different, ideal types of involvement, and their implications for the positioning of professionals. Three basic forms of involvement are identified: involvement as a) self-determination and self-management, b) sharing of lived experience, and c) co-management and mediation of causes and concerns. Within each of these basic forms, different models or measures are classified according to the positions of patients and professionals respectively. The framework shows that professionals are repositioned as facilitators, not only therapists; as partners and co-workers, rather than sole experts; as learners, rather than experts and teachers; and as recipients rather than in the position of offering knowledge and skills. While detailed and long-term investigation is necessary to determine the impact of involvement in actual cases, the presence of models and measures to strengthen the position of the users in various ways transforms the context of professional work, as well as the classic meaning of professionalism.

Keywords

service-user involvement, health care, professionals, professionalism

The increasing prominence of service-user involvement has elevated the expertise of experience in European health care. A reconfiguration of the position of patients has taken place – from recipients of professional services to active and involved service users. This reconfiguration has not only taken place at the level of policy, but has also materialized in

legislation and in a variety of measures and organizational models within, outside, or beyond the individual encounters between professionals and users. Besides being individuals seeking professional services, service users voice user experiences as peer-providers and spokespersons. The concepts of "service-user involvement" and "service user" (rather than "patient") refer to such active and involved positions.

However, models or measures to strengthen the position of service users not only change the position of the users; they also alter the position of the professionals involved. In the classic sense (Evetts, 2013; Freidson, 2001; Noordegraaf, 2007), professionals are trained and skilled experts who apply specialized, complex, and esoteric knowledge to exercise discretionary judgements and take action in individual cases. They are granted occupational self-control premised on collegial self-regulation and codes of ethics. This classic or "pure" professionalism is challenged, altered or complemented as service user involvement introduces other kinds of professional positions.

It is important to note that different forms of involvement alter the position of professionals differently. To enable an elaboration of such differences, this article draws on existing studies of user involvement and presents a framework for the systematized examination and juxtaposition of different forms of involvement and their implications for the positioning of professionals.

In developing the framework, several previous contributions have been helpful (Brandsen & Pestoff, 2006; Dent & Pahor, 2015; Pollitt, 1998; Tritter, 2009; Vrangbaek, 2015). Compared to these contributions, this framework focuses on the positioning of the service users and professionals involved. In this framework, as well as in the contributions it draws on, fully market-based relationships, in which users are regular paying customers, are excluded. So are important questions about whether efforts made to strengthen the position of service users actually do influence service provision and the practice of professionals, and whether different groups of professionals are equally concerned. Hierarchies and inequalities exist among professional groups, and diversification and stratification appear to be expanding (Noordegraaf, 2013; Saks, 2015). Several of the contributions referred to in this article demonstrate difficulties in implementing user involvement. Such issues deserve analyses of their own. To assess the impact of involvement and of the claims, wishes, or requests that involved users raise, in-depth and long-term investigation of actual implementation processes is necessary, also taking into account the political or institutional context (Barnes & Cotterell, 2012; Barnes, Newman & Sullivan, 2007; Brooks, 2008; Martin, 2012; Tritter & McCallum, 2006; Truman & Raine, 2002). In this article, only implications resulting from the models or measures to ensure involvement are discussed.

Below, three main forms of involvement, including some distinctive models or measures and their subsequent repositioning of professionals, are presented as ideal types. In contrast to the blurred distinctions and mixes of models found in real-world settings, ideal types are analyst-constructed typologies aimed at identifying and making explicit patterns that appear to exist (Patton, 2002).

INVOLVEMENT AS SELF-DETERMINATION AND SELF-MANAGEMENT

Involvement as self-determination and self-management takes place at the level of individual service user–professional relationships, with the aim of bolstering the individual in his/

Idunn
Nordiske tidsskrifter på nett

her own case (Pollitt, 1998; Tritter, 2009). With measures aimed at strengthening the position of the individual user, the target group is the individuals, and the position of the users is as individual users. See Table 1.

Table 1: Involvement as self-determination and self-management: At the level of individual service-user–professional relationships

Model or measure	Target group	Aim	Position of the involved user	Position of the professional
Patient rights and entitlements	Individual patients/ users	Reduced power asymmetry	Target group: Holder of rights, consumer	Service provider
Patient education, professionally led	Individuals with chronic illnesses or disabilities	Strengthened self-efficacy Self-care and self-management	Target group: Manager/ care-taker of own illness	Trainer, adviser Teacher, educator
Reconfigured professionalism	Individuals with chronic illnesses or disabilities	Self-determination and participation in decisions about own treatment/ care	Target group: Active subject in one's own life	Supporter Guide
Restructured relationships through personal assistance	Individuals with severe disabilities	Self-determination	Target group: Subject in control of one's own life	Subordinated? Emerging new forms of professionalism?

Patient rights legislation and individual entitlements are widespread in Europe and involve strengthening the users' position and reducing user–provider asymmetry, e.g. by providing users with a legally founded right to information, a right to consent to or decline treatment, and options to make informed choices among forms of treatment. Such measures may, for example, enable the choice of a particular treatment procedure (Tritter, 2009), or participation in needs-assessment procedures and the development of care plans (Truman & Raine, 2002).

Some see such measures as "choice" strategies and "consumerism". Choice of providers, vouchers or client budgets aim to enhance the responsiveness of the services by giving users the power of "exit" (Dent & Pahor, 2015; Fotaki, 2011; Greener, 2008). The users are seen as consumers, in a position to make choices among different service providers based on information, for example, about service quality and patient satisfaction (Thomson & Dixon, 2006).

In contrast, concepts such as "patient-centred care", "empowerment", and "shared decision-making" demonstrate that ideas of user involvement have resonance in professional ideas and ideals about transferring knowledge and taking account of individual preferences (Charles, Gafni & Whelan, 1997, 1999), as well as helping individuals with chronic conditions or disabilities in mobilizing resources to achieve self-efficacy and a sense of control of their own lives (Anderson & Funnell, 2010; Pulvirenti, McMillan & Lawn, 2014; Tveiten & Knutsen, 2011). Although these concepts are sometimes poorly defined, are sometimes used interchangeably, and are politicized and contested (Bravo et al., 2015; Castro, Van Regenmortel, Vanhaecht, Sermeus & Van Hecke, 2016; Kreindler, 2015), they also signal that professionals may actively encourage a reconfigured professionalism that allows for greater self-determination by the users.

Idunn
Nordiske tidsskrifter på nett

Patient education is another measure to strengthen the individuals. The aim is not reduced asymmetry between service users and professionals, but rather the increased capacity of the individuals to manage long-term health conditions by providing them with better knowledge and skills to cope with their illness or impairment (Greenhalgh, 2009; Rogers, 2009). In some patient education programmes, education is provided by professionals, while in others, these programmes are lay-led by volunteers or experienced users who themselves live with the actual long-term health problems. (The latter form is presented in the next section, as it involves yet another position for the users.)

A more radical shift in the professional–service user relationship is suggested by arrangements for "personal assistants" for people with severe disabilities whereby the user is the manager of, and in some cases the employer of, the person who provides assistance in daily living. This is a model of care that some refuse to categorize as "care", and which other see as a shift of vulnerability from the service user onto the carer (the assistant), but which from the users' perspective has nonetheless profoundly enhanced their autonomy and self-determination (Askheim, 2005; Barnes, 2016; Glendinning, Halliwell, Jacobs, Rummery & Tyrer, 2000; Solvang, 2016).

The implications for the position of professionals vary. Patient rights and entitlements may have consequences through strengthening the user's position in encounters with professionals. Patient education adds the role of a trainer or teacher to the professional's treatment role. As a trainer or teacher, the professional shifts from instructing and deciding to guiding and advising (Greenhalgh, 2009). However, the professional expert position is retained if self-management means complying with treatment instructions (Greenhalgh, 2009; Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011; Lutfey, 2005; Rogers, 2009).

Still, patient education involves knowledge sharing, where professional knowledge is no longer utilized only by the professionals, but is also distributed to service users. Through the sharing of knowledge, a shift in the status of professional knowledge takes place, from esoteric knowledge to (more) transparent knowledge.

Patient-centered professional approaches may suggest a different way of performing the professional role, in which the professional takes up roles as "supporter" (Greenhalgh, 2009), "guide", "catalyst", or "partner" (Alm Andreassen, 2009), or takes up tasks such as linking to relevant user groups or organizations, assisting users to interpret complex knowledge, providing emotional support, empathy, reassurance and affirmation (Kendall et al., 2011). A restructured relationship of service users and personal assistants might indicate a shift away from the classic professional–client relationship. Instead, the service users re-emerge as experts and in control in their own lives.

INVOLVEMENT AS SHARING OF LIVED EXPERIENCE

Involvement as the sharing of lived experience takes place at the level of individual recovery, in models such as self-help groups (lay-led or professionally led) or forms of formalized peer-support work (Greenhalgh, 2009). For conceptual clarification, see Solomon (2004).

Idunn
Nordiske tidsskrifter på nett

Table 2: Involvement as sharing of lived experience: At the level of individual recovery

Model or measure	Target group	Aim	Position of the involved user	Position of the professional
Self-help groups (lay-led or professionally led)	Individuals with chronic conditions or disabilities	Improved health and coping with illness and impairment through utilization of experiential knowledge of users	Peer supporter (fellow sufferers, equals)	None (in lay-led support) Facilitator (in professionally led groups)
Peer-support, "consumer- providers", "peer- delivered interventions"	Individuals with chronic conditions or disabilities	Improved health and coping with illness and impairment through utilization of the lived experience of experienced users	Co-service provider Educator, teacher (witness, role model, conveyer of coping experiences)	Colleague or co-worker (in collaborating teams)

Self-help groups and organizations offering mutual help and peer-to-peer support are widespread, sometimes supported by nationwide self-help support systems. An example is a self-help friendliness initiative in Germany aimed at implementing wider cooperation between self-help associations and health care providers (Nickel, Trojan & Kofahl, 2017). In a health-promotion perspective, self-help is considered a key element for coping or empowerment processes for people with long-lasting health problems (Aglen, Hedlund & Landstad, 2011). The participants are each other's equals or fellow sufferers.

In "peer-delivered interventions", users are engaged as volunteer or paid co-workers. Various terms are applied, such as "consumer-providers", "lived experience workers", "peer educators", and "peer-providers" (Repper & Carter, 2011). The aim is to utilize the lived experience to enhance the recovery and coping of others with similar conditions or in similar situations. The involved users take up roles as witnesses, role models, and conveyers of the experiences of coping (Greenhalgh, 2009).

An example is the 1999 Norwegian legislation that established patient education as a central hospital function, and the subsequent establishment of educational resource centres (Stokken, 2013; Strøm, Kvernbekk & Fagermoen, 2011). Here, patient education programmes were organized as a collaboration between professionals and peer-workers with the aim of rendering users' and professionals' knowledge equal in the planning, delivery and evaluation of the programmes.

In contrast to the measures in Table 1, where the target group and the position of the involved users are the same, in these measures, too, the target group is individuals with chronic conditions or disabilities, but the role of the involved users is a different one. The involved users enter positions that bear a resemblance to those of the professionals. They are to step out of the individual user position and apply their personal experiences, in a nurtured and detached form, as a resource for others.

Implications for professionals seem minor in lay-led services. Professionally led self-help groups might offer roles as facilitators, initiators and leaders. However, peer-support and consumer-providers imply that professional expertise is no longer the sole and ultimate expertise.

Teams in which professional expertise and the lived experience of peer-supporters both contribute to recovery processes entail professionals taking up new positions as partners, colleagues or co-workers (Martin & Finn, 2011; Stokken, 2013; Walker & Bryant, 2013). The situation is comparable to collaboration in inter-professional teams, except for the fact that some of the colleagues or team members are individuals whom the professionals would otherwise encounter as individuals in need of help and expertise.

INVOLVEMENT AS CO-MANAGEMENT AND MEDIATION OF CAUSES AND CONCERNS

Involvement as co-management and mediation of causes and concerns takes place at the organizational level of service providers, or educational and research institutions, with the aim of improving professional and organizational policy and practice. Service users are involved in service development, evaluation of services, education and training, as well as research (Tritter, 2009; Vrangbaek, 2015). The target groups are the professionals, managers, researchers and policy-makers who construct the service provision, not the individuals with chronic conditions or disabilities as in the case of the sharing of lived experience. The users enter into positions as educators, teachers, lecturers, advisers or consultants. As spokespersons or members of user groups or organizations, they are carriers of users' perspectives, causes and concerns, or they serve as partners in co-governance and participate in the planning of public services (Brandsen & Pestoff, 2006).

Table 3: Involvement as co-management and mediation of causes and concerns: At the organizational level of service providers, education and research institutions

Model or measure	Target group	Aim	Position of the involved user	Position of the professional
Users-as-teachers: in education and training of professionals	Professionals, managers, policy-makers, researchers	Improved services through awareness of user perspectives	Educator, teacher, lecturer	Learner
Hearings, surveys of user experience or satisfaction	Professionals, managers, policy-makers, researchers	Improved services via information and opinions from users informing policy and practice	Carrier of user's causes or concerns, as spokesperson of user group	Recipient Interpreter Object of evaluation
Consultation: deliberative forums, advisory bodies	Professionals, managers, policy-makers, researchers	Improved services via collecting advice and discussing reform proposals	Partner in co-governance, on behalf of user groups, organizations or constituencies	Recipient Object of evaluation Facilitator of involvement processes
Collaboration: shared service provision or project	Dependent on the collaboration agenda	Enhanced services through the capacity of users and user organizations	Co-producer, volunteer or worker	Collaborator, co-worker, colleague
Delegated authority	Dependent on the collaboration agenda	Enhanced services through the capacity of users and user organizations	Producer: worker or manager (voluntarily or paid)	None? Controller, auditor

Idunn
Nordiske tidsskrifter på nett

Users-as-teachers represent forms of involvement that address the professionals directly through educative approaches. The aim is to enhance the professionals' awareness of the users' perspectives on the encounter with the service and their experiences of living with illness. Users participate in the teaching and training of professionals with illness stories or testimonials about their own experiences (Eriksson & Jacobson, 2016; Haeney, Moholkar, Taylor & Harrison, 2007; Wykurz & Kelly, 2002). They are witnesses and "experts-by-experience" and allow the professionals to see "the person behind the diagnosis" (Eriksson & Jacobson, 2016).

The implications for professionals are new positions added to the position of helper or therapist. Encountering users-as-teachers, they enter the position of a recipient or learner. Becoming the recipient may also imply becoming a knowledge interpreter who translates user perspectives into new forms of practice. In many forms of user involvement, the task of interpreting and implementing the consequences of user knowledge still resides with the professionals. Hearings and surveys of patient satisfaction typically entail information gathering from service users by health professionals and managerial staff (Tritter, 2009). They are a one-way transmission of users' views. Responses from the users take on the form of "raw data" to be interpreted by professionals and transformed into proposals for service improvement.

Consultation involves deliberative forums or advisory bodies, in the form of permanent forums and councils, or of a more ad hoc nature, such as involvement in planning processes or evaluation and improvement of service quality (Alm Andreassen, 2016; Newman, Barnes, Sullivan & Knops, 2004; Tritter, 2009; Vennik, van de Bovenkamp, Putters & Grit, 2015). Users may participate in determining which services are offered and how resources are used. Examples are a nurse-initiated patient council established in an acute hospital trust in England as part of the nursing managerial and governance structures (Brooks, 2008), and user councils in Norwegian hospitals who act as advisory bodies for the management group of the hospitals with which they are associated (Andersen, 2016). The degree to which such deliberative forums are – or are expected to be – responding to a pre-existing agenda (reactive), or are contributing to shaping the agenda (proactive), differ (Andersen, 2016; Brooks, 2008; Tritter, 2009).

Co-management refers to arrangements in which user organizations work in collaboration with public services or administrations (Brandsen & Pestoff, 2006), in this context referring not only to the shared producing of service, but also of plans, evaluations, research or development projects. Co-management in this context even includes delegated authority, such as when user groups or organizations run projects on their own.

Examples are co-managed patient education programmes (Stokken, 2013; Strøm et al., 2011), user participation in a management team for a quality improvement process (Vennik et al., 2015), and the collection of systematic feedback from service users through group interviews chaired by workers who themselves have been service users (Alm Andreassen, 2009).

In contrast to involvement as the sharing of lived experience, in which users provide services to other users, the target groups of collaborative efforts or efforts undertaken by users via delegated authority may be professionals and managers in charge of service provision, health care staff or researchers, and, only in a more indirect sense, the actual users.

Idunn
Nordiske tidsskrifter på nett

There are several implications for the professionals. As members of service-providing organisations, professionals are not only recipients, interpreters and translators of feedback from users into service improvement. Through the same measures, they become objects of evaluation and are held accountable to audiences of service users. Moreover, these measures introduce new tasks and positions – sometimes occupations, as facilitators of involvement processes, intermediaries and translators between the worlds of service users and the systems of health care deliverers (Eriksson & Jacobson, 2016; Newman, 2016; Newman et al., 2004).

Involvement as co-management provides professionals with positions as collaborators, co-workers or colleagues, similar to that given by involvement through peer-delivered interventions, but at the level of management rather than the level of front-line service delivery. The position for professionals in delegated activities is limited, but if the activities are funded via public budgets, they might achieve a position as controller or auditor with the task of checking that funds are used correctly.

DISCUSSION AND CONCLUSION

Service user involvement belongs among the many changing service realities that call for what Noordegraaf (2007, 2013) describes as a "reconfigured" and "hybrid" professionalism, in contrast to a classic or "pure" professionalism. This professionalism means that professionals take up tasks and competences outside their core activities, and professional work becomes "connective", due, among other things, to the need for coordinated services and inter-professional collaboration. It also means that professional fields become more divided, with more diversification among the professionals, and more fluid boundaries with the outside word.

Measures and models of service-user involvement have enabled service users to be present in health care organizations in new positions. They are reconfigured from individuals "in need" of expert knowledge to "possessors" of knowledge and competencies that are of value both to individual professionals and to the achievement of the broader professional goal of contributing to individual health and well-being.

A repositioning of professionals follows the repositioning of the service users. Professional expertise is distributed and shared with the users, and thus becomes less of an esoteric form of knowledge. It is also more clearly demarcated and, in processes of recovery, supplemented by the "expertise" of experience.

Professionals develop other kinds of connections with people otherwise placed in positions as individual users. As users appear as stakeholders and spokespersons in deliberative forums, occupational self-control is supplemented with transparency and accountability towards audiences other than the professional community. Professionals enter positions as partners and co-workers rather than sole experts; as learners, not only experts and teachers; and as recipients of experiential knowledge rather than in the position of offering knowledge and skills.

Organizing tasks and positions are added to the core activities of professionals. A relocation of professional work takes place, to include work outside of the clinical work settings. A diversification of professional tasks appears as some professionals take up organiz-

Idunn
Nordiske tidsskrifter på nett

ing tasks (facilitating involvement, improving service quality based on feedback from users). As facilitators, professionals shape agendas, enable discussions, and ensure the transmission of issues from health care providers, and feedback, opinions and ideas from user groups and organizations. As translators of users' experiences and agendas into service improvement, professionals take on tasks of quality improvement at an organizational level of health care.

To conclude, in-depth investigation is necessary to determine whether the prerequisites are present for making user involvement valuable for both the agencies and the user groups, and to trace whether the claims or wishes voiced by the users have real impact on service provision. User involvement does not inevitably transform the professionals' sense of holding exclusive knowledge and legitimate authority, or an inclination to incorporate involvement efforts into institutionalised professional practices (Larsen, 2016; Newman & Vidler, 2006; Slomic, Christiansen, Soberg & Sveen, 2016). This may involve lengthy implementation processes to develop a shared understanding of what user involvement means, or to overcome scepticism, professional defensiveness, or fear of criticism (Brooks, 2008; Vennik et al., 2015).

Nonetheless, European health care organizations increasingly encompass a diversity of models and measures that involve volunteers or workers whose qualifications are primarily derived from a background as service users. This, in itself and in a variety of ways, transforms the context of professional work, as well as the meaning of professionalism. It is to be hoped that an awareness of how the various models and measures contribute to such transformation will support a sound discussion of the impact of service-user involvement.

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