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PARTICIPATION AND HEALTHCARE: A SURVEY INVESTIGATING CURRENT AND DESIRED LEVELS OF COLLABORATION BETWEEN PATIENT ORGANIZATIONS AND HOSPITALS

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ABSTRACT

Participation and healthcare: a survey investigating current and desired levels of collaboration between patient organizations and hospitals

Background: Patient participation is widely seen as a way of improving the quality of healthcare. It is encouraged by public health policies, but the systematic development and implementation of these policies in practice is still lacking.

Objective: To facilitate a structural approach to the involvement of patient organizations at the meso level, we conducted an explorative survey to gain an understanding of the current state of collaboration between patient associations and hospitals, and to gain an insight into the needs and wishes of these patient organizations.

Design: 111 patient organizations participated in our cross-sectional web-based survey. The results were analysed using a quantitative and qualitative approach.

Results: The majority of the patient organizations in the survey aspired to “advise” healthcare professionals regarding service development and evaluations. They wish to participate in hospital processes, produce brochures to inform their peers and provide support for peers. The aim of their collaboration with hospitals is fourfold: to offer complementary services to patients of the hospital, increase patient satisfaction, facilitate patient empowerment and increase the quality of care. In general, the organizations reported a need for increased support.

Discussion and conclusion: The ultimate ambition of patient organizations is to collaborate more closely with professionals and become an acknowledged partner in patient care networks. After all, successful collaboration can produce synergies and establish a complementary type of care and information for both patients and caregivers.

Key words

Belgium, survey, patient participation, patient associations, hospitals, experiential knowledge, health care

SAMENVATTING

Participatie en gezondheidszorg: een surveyonderzoek naar de huidige en gewenste samenwerking tussen patiëntenorganisaties en ziekenhuizen

Patiëntenparticipatie is één van de manieren om de kwaliteit van de gezondheidszorg te verbeteren. Het wordt dan ook gepromoot door verschillende beleidsinstanties, maar een systematische ontwikkeling en implementatie in de praktijk ontbreken voorlopig nog. Om een structurele aanpak van patiëntenparticipatie op mesoniveau uit te werken werd een exploratieve studie uitgevoerd om de huidige stand van zaken en de wenselijkheden op het vlak van samenwerking tussen patiëntenverenigingen en ziekenhuizen in kaart te brengen. In totaal namen 111 patiëntenorganisaties deel aan onze “cross-sectionele online enquête”. De resultaten werden geanalyseerd door middel van een kwantitatieve en kwalitatieve analyse. Uit de resultaten bleek dat de meerderheid van de patiëntenorganisaties ernaar streeft om ziekenhuizen en hun medewerkers te “adviseren”. Daarnaast willen patiëntenorganisaties samenwerken om brochures te ontwikkelen en hun lotgenoten te informeren en ondersteunen. Het doel van hun samenwerking is viervoudig: het aanbieden van aanvullende diensten aan patiënten in het ziekenhuis, het vergroten van de tevredenheid, het bevorderen van empowerment bij patiënten en het verbeteren van de zorgkwaliteit. In het algemeen signaleren de patiëntenorganisaties een behoefte aan meer ondersteuning tijdens participatieactiviteiten. De conclusie is dat de patiëntenorganisaties nauwer willen samenwerken met professionals om zo een erkende partner te worden in het zorgnetwerk van de patiënt. Succesvolle samenwerking tussen beide partijen kan immers leiden tot synergiën en een complementair type van zorg en informatie voor zowel patiënten als professionals.

Trefwoorden

België, survey, patiëntenparticipatie, patiëntenorganisaties, ziekenhuizen, ervaringskennis, gezondheidszorg

INTRODUCTION

Patient organizations (POs) are voluntary partnerships of people, which are structured to varying degrees, and which aim to enhance the care received by people with particular health conditions and the associated psychological or social problems that can affect them, either as patients or as

relatives of patients (Gielen, Godemont, Matthijs & Vandermeulen, 2010). In Belgium, POs have internal and external functions. Their internal function is to inform and advise fellow sufferers, facilitating their empowerment. Their external function is to participate in healthcare organizations and policies and defend the interests of their members. Participation in a PO usually includes: being informed and consulted about matters of concern; providing advice by serving on patient advisory councils or as members of quality improvement committees; and co-producing care by being involved in healthcare services to support peers. In this article we focus on the external functioning of POs, and in particular on their relations with hospitals (i.e. the organizational level).

Today's hospitals, spurred on by societal developments such as socialization of care, increasing levels of education, changing patient expectations, budget constraints, and multimorbidity, are generally moving towards more patient participation (cf. the involvement of patients in their own care through shared decision-making, participatory medicine, peer support, the involvement of patients in care improvements, etc.) (Boivin, 2014; Tambuyzer, Pieters & Van Audenhove, 2014). This trend encourages POs to expand their external activities, since they are increasingly seen as an active partner in healthcare.

Patients' practice-based experience and knowledge are increasingly being viewed as highly valuable assets that can be used to increase patient satisfaction and achieve more accessible and higher quality care and better informed and more empowered patients (Baker, 2007; Crawford *et al.*, 2002; Longtin *et al.*, 2010; Sanders, Van Weeghel, Vogelaar, Verheul & Pieters, 2013). POs, as pools of practice-based experience and knowledge, have been able to contribute to care innovations and have become increasingly important healthcare partners (Kofahl, Trojan, Von dem Knesebeck & Nickel, 2014; Levin & Idler, 1981). By establishing peer-to-peer interaction, disseminating information, offering social support and advocating on behalf of their members, they are contributing to an overall trend towards more empowered users and more patient-centred care (Rabeharisoa, 2003). Collaboration between hospitals and POs appears to constitute an excellent strategy for hospitals to integrate patient participation into daily care practice and to achieve a higher level of patient-centred care.

The specific strength of POs is the competitive advantage of their representatives in building experiential expertise (Borkman, 1976; Rabeharisoa, 2003). As such, the representatives can contribute to improving the level of direct care for patients and improving the quality achieved in healthcare organizations (Carman *et al.*, 2013). At the level of direct care, members of patient groups and organizations help to disseminate interpersonal knowledge from peer to peer, which ultimately enhances the resilience of those affected by a disease. At the level of the healthcare

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organization, patient representatives can work together with healthcare professionals, on patient advisory councils for example. By using the collective experiential knowledge of POs for the benefit of others and combining it with professional knowledge, healthcare can become more patient-oriented (Kofahl *et al.*, 2014; Repper & Carter, 2011; World Health Organization, 2004).

POs are already participating in one way or another in hospitals in several countries. These initiatives suggest positive effects at the level of direct care (individual level) and the organizational level (collective level) (Gielen *et al.*, 2010). But although overall policy recommendations exist that promote patient participation through (membership of) POs in hospitals, structured cooperation remains limited in practice. Since active patient participation mainly occurs at the level of the hospital wards, this paper concerns social workers, nurses, as well as other hospital staff. In order to contribute to knowledge regarding the participation of POs in hospitals and to help hospital staff to overcome barriers, a survey was conducted among POs asking about how they currently participate in hospital processes, and their aspirations – how they would like to participate. To our knowledge, no systematic empirical research exists that addresses the needs and ambitions of POs regarding active patient participation in hospitals. The survey aimed to gain a better insight into the needs and ambitions of the associations in order to provide a strong foundation for continuing sustainable participation.

The two primary research questions were as follows:

- What is, from the perspective of patient organizations, their current state of collaboration with hospitals?
- What is, from the perspective of patient organizations, their ideal state of collaboration with hospitals?

POLITICAL BACKGROUND

International context

In the US and Canada, patient (and public) participation has been established by involving patient representatives (and citizens) in local/regional councils and in hospitals to achieve healthcare improvements (Agency for Healthcare Research and Quality, 2013; Health Canada, 2000). The EU has also developed policies to promote patient participation in hospital care. The inspiring concept of “selbsthilfefreundlichkeit” [self-help friendliness] was conceived in Germany and has successfully been implemented there, with formal agreements on collaboration between patient

associations and hospitals as the ultimate goal. Under this approach, hospitals collaborate with experiential experts in care (organizations) to establish more patient-oriented care policies (Nickel, Trojan & Kofahl, 2016). In the UK, patient participation is a key pillar of the National Health Service (NHS) (Barham, 2011). The NHS promotes the participation of patient groups in decisions relating to the planning, design and development of local health services with the aim of improving these services and patient outcomes. In French hospitals, patient associations are represented not only on a committee that deals with client relations and healthcare quality, but also on the board of directors. In the Netherlands, patient associations are the third party in health policy development alongside healthcare providers and insurance bodies (Denis & Teller, 2011). The system includes three levels of participation: information, advice and co-production. Patient associations are financially rewarded if they participate on all three levels.

The Belgian context

In general, several examples (Malfait, Eeckloo, Van Daele & Van Hecke, 2015; Malfait, Van Hecke, Hellings, De Bodt & Eeckloo, 2017) suggest a significant level of attention to patient participation in Belgian hospitals. However, until recently patient participation was implemented mainly by involving individual users at the level of overall hospital policy. It is only recently that the collective experiential knowledge and expertise of POs has been introduced to promote quality of care and patient-centred care.

In Flanders, the Dutch-speaking part of Belgium, there are 431 active patient associations. They are supported by "a self-help clearing house" (Trefpunt Zelfhulp¹). A large number of these associations collaborate in the Flemish Patient Platform (Vlaams Patiëntenplatform²), an umbrella organization that defends the interests of chronic patients in several commissions and policy bodies at the macro level. Since 2016, Trefpunt Zelfhulp and the Flemish Patient Platform have been coordinating a regional support centre that focuses on the participation of POs at the meso level, facilitating their collaboration with professional organizations. The government funds these three organizations to provide support for POs (and self-help groups) and for their participation at the meso and macro levels. The patient associations finance their activities mainly from membership fees and fundraising activities.

THEORETICAL BACKGROUND

Patient participation can be defined as the contribution of patients or their representative organizations in influencing health and social care services by means of active involvement in a

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range of activities at the individual, organizational and policy level (Castro, Van Regenmortel, Vanhaecht, Sermeus & Van Hecke, 2016). The concept of patient participation is used at different levels: micro (individual care), meso (service development; planning, delivery and evaluation of care; education and training of healthcare providers) and macro (policy). Each level is associated with a range of types and activities (Vennik *et al.*, 2013; Vennik, Van de Bovenkamp, Putters & Grit, 2016). In this study, we focus on the meso or organizational level where (representatives of) POs support their peers and co-evaluate care. To develop a comprehensive survey that would provide an insight into the needs and ambitions of patients' associations concerning patient participation at the organizational level, we used several existing frameworks: the well-known participation ladder of Arnstein (1969), the five types of participation described by Tritter (2009), Tambuyzer's framework that includes determinants that enhance patient participation (Tambuyzer *et al.*, 2014), eight criteria for the "self-help friendly hospital" (Kofahl *et al.*, 2014) and the eight-phase model of Sarrami-Foroushani, Travaglia, Debono and Braithwaite (2014).³ Although the majority of these theoretical frameworks were developed for the participation of individual patients, we think they are generalizable to participation by the delegates of patients' associations.

METHOD

Questionnaire

The survey was conducted between 13 February and 27 February 2015, and was sent to all POs in Flanders, the Dutch-speaking part of Belgium (n=431). After sending two reminders, we received a total of 111 completed surveys.

The questionnaire was developed on the basis of an exploratory literature review and interviews with patient representatives and experienced self-help group supporters. A questionnaire of 13 questions was designed using a multi-stakeholders perspective. The first step was to consult three online databases (PubMed, Embase and Ystor) as well as grey literature. Various combinations of the following search terms were used: collaboration, participation, involvement, experts by experience, expertise by experts, self-help groups and hospital. The second phase involved collecting information through explorative interviews with five active members of different POs that have established successful partnerships with hospitals. Based on these two sources of information, a preliminary version of the questionnaire was drafted and critically evaluated in a peer review session. A revised version was later reviewed by three staff members and three researchers at the University of Leuven. To test face validity, a third version integrating

their remarks was sent to the full board of the Flemish Patient Platform, consisting of 12 PO representatives. Half of the individuals contacted completed the questionnaire and made a number of minor remarks, on the basis of which the final version of the survey was amended. The final questionnaire consisted of 13 closed questions (see Appendix A), eight of which included an open-ended answer option that allowed respondents to give “other” answers. Since this exploratory study does not aim to present a survey including an exhaustive list of answer categories, the respondents had the opportunity to give additional answers (if the presented answer categories did not cover their opinion).

Variables

Because of the exploratory nature of the research, we decided to focus on all possible dimensions of participation by POs. The global structure of the survey was modelled after the eight-phase model for implementation of consumer and community engagement (Sarrami-Foroushani *et al.*, 2014). Seven dimensions were therefore included in the survey:

1. Participation or non-participation in hospital processes
2. Assessment of current participation
3. Current and desired level of participation
4. Current and desired methods of participation
5. Goals of the participation process
6. Current and desired level of hospital support (conditions)
7. Desired competencies (knowledge, attitudes and skills) of delegates of the PO in order to participate in hospitals.

The variables surveyed are described in greater detail in appendix A. For the dimensions 3 to 7, it was possible to give multiple answers.

Data analysis

The survey data were analysed by generating frequency distributions for each variable using SPSS. The free text responses were analysed using a thematic analysis which helped us to gain a more in-depth understanding (Polit & Beck, 2012). After reading and rereading the comments, emerging (sub)themes were identified. Since the qualitative data was limited in scale, no software was used to support the coding process.

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The following section presents the main results of the study based on the seven dimensions of the survey where the current and desired situation is described for each dimension. Where applicable, the frequency and analysis of the free text responses are presented for each individual aspect.

RESULTS

Survey participants

We received a total of 111 completed surveys (26% response rate). Patient associations that participated in the survey can be categorized into three sub groups: problem category, degree of occurrence of the problem, and age of the group. Table 1 shows that the respondents were mainly representatives of organizations focusing on physical illnesses caused by common chronic diseases. The large majority of the organizations were established at least five years ago. The response analysis shows that distribution within the sample largely corresponds with the distribution across the whole of the PO.

Table 1: Division and sub groups of survey respondents (n=111)

Variable	Sample, %	Total of patients organisations, %
Problem category		
Physical illness	70	71
Surgery	16	11
Handicap	14	18
Problem occurrence		
Rare disease	12	22
Common disease	88	78
Age of group		
< 5 years	6	2
≥ 5 years	94	98

Collaboration with hospitals and rating of current collaboration

Of the 111 POs that completed the questionnaire, 67 or 60% were collaborating or had collaborated with one or more hospitals, and 44 or 40% had not (yet) collaborated with a hospital in any sense.

Eight POs (11%) gave a weak (10%) to very weak (1%) score for their current collaboration; 28 (42%) rated it as acceptable; 26 (39%) described it as very good; and 5 (7%) viewed their collaboration as excellent.

Other survey results

An overview of the frequencies and the qualitative data, is presented in Table 2.

Table 2: Frequency distributions of the “level of participation” dimension (multiple responses were possible)

Participation level	CS (n=67) ^a , %	DS (n=111) ^b , %
Being informed	26	43
Being consulted	15	53
Advise	12	49
Co-produce	9	31
Patient-driven	9	10

^aCurrent situation

^bDesired situation

Table 2 shows the frequencies concerning the level of participation. One in four POs reported that their collaboration currently consisted of being given information by hospital staff about developments that are relevant to their members and peers (26%). Almost 10% of the respondents participated at the co-production and patient-driven level. While the dissemination of information represented the most common level of collaboration, the majority of associations aspired to be two levels higher up on the participation ladder, i.e. advising. For half of the POs (49%), “advising” was the most desirable level of participation, followed by 43% who listed “being informed” as the most desirable level. One in ten organizations aspired to reach the patient-driven level.

Twenty-three respondents offered extra comments and discussion on the question about level of participation. Patient organizations expressed dissatisfaction with the lack of information provided on matters that affect their members directly. Respondents also reported inadequate collaboration: “the hospital does not ask for our opinion” (resp. 24); “we are often not involved – let alone informed – about issues that concern us” (resp. 47). They pointed to clear potential for increased consultation and advice. Participants also expressed their dissatisfaction with the gap between the agreements reached in theory (advisory role of the patient group) and everyday practice (opinion is in reality not asked).

Table 3: Frequency distributions of the “method of participation” dimension (multiple responses were possible)

Participation method	CS (n=67) ^a , %	DS (n=111) ^b , %
Focus groups	55	63
Patient panel or patient council	23	63
Satisfaction questionnaires	45	71
Working group or committee	18	55
Adhoc meetings	45	79
Interviews	39	61
Brainstorming sessions	48	63
Mirror conversations	28	59
Shadowing	19	35
Mystery guest	12	17
Patient diary	12	30
Inform and support individual peers	73	78
Inform and support peers in group	42	64
Collaborate with hospitals to produce leaflets and brochures informing peers	73	86
Collaborate with research organisations	54	54

^aCurrent situation

^bDesired situation

Table 3 shows the frequencies concerning methods of participation. The most common methods were “informing and supporting individual peers”, together with “the development of leaflets and information brochures”. Both these methods were used by 73% of the POs and thus clearly represent the most established methods. For other methods, no common practice could be identified. More than three-quarters of the POs described distributing leaflets and information brochures (86%) and individual peer support (78%) as desirable.

The open question yielded 44 additional answers, which were condensed and divided into the following four categories. First, POs want opportunities to communicate their experiential knowledge to both staff and patients. Education sessions organized for patients so they can become “expert patients” (i.e. “Experts Patients Programme”, Lorig, Ritter, Villa & Armas, 2010) were seen as a very useful method. Second, patients want to be represented in the management of the hospital. Third, patients aspire to act as expert patients in the training of professionals. Fourth, doctors or head nurses should invest more time in the collaboration, despite the existing demands on that time.

The fact that POs offer complementary services to patients in the hospital (52%) increases patient satisfaction (50%), facilitates patient empowerment (48%) and increases quality of care (48%). These are all seen as goals that could motivate hospitals to collaborate more closely with POs. In the opinion of the respondents, the POs view all four of these goals as even more important than the hospitals do (between 88% and 95%). In addition, the results show that POs also see other goals relating to the level of participation in the hospital, such as improving internal functioning and facilitating the transition of patients to their home (see Table 4).

Table 4: Frequency distributions for the “goals of participation” dimension (multiple responses were possible)

Goals	HO (n=111) ^{a,c} , %	PO (n=111) ^{b,d} , %
Justify (policy) decisions	12	NA ^e
Outperform competitors	21	16
Match the offer with the demand	34	79
Improve own work	41	86
Improve own image	37	44
Offer complementary services	52	88
Offer patients more control (facilitating patient empowerment)	48	93
Come up with new ideas	35	77
Increase chance that new ideas will be successful	32	88
Test new ideas	36	79
Make economies	5	27
Offer good quality of care	48	92
Reduce workload	15	41
Increase patient satisfaction	50	95
Allow patient organisations to contribute to responsible management	20	58
Send patients home faster	11	26
Attract more people to the hospital	14	36
Meet the standards of a future-oriented hospital that values patient involvement	41	82
Facilitate transition to home situation	36	84

^aCurrent situation

^bDesired situation

^cGoals of patient organisations themselves

^dWhat patient organisations assume to be the goals of hospitals

^eNot asked

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The results in Table 5 show that the current state of collaboration varies significantly from the desired state of collaboration. Despite differences in the preconditions currently fulfilled, almost all forms of support were viewed as equally important by the majority of the POs (89% to 99%). Practical facilities such as free catering during participation activities represent an outlier and were seen as desirable by only 56% of the POs.

Patients were also asked an open question about how hospitals could support more successful participation by POs. One common response was good communication about organizational

Table 5: Frequency distributions of the “preconditions” dimension (multiple responses were possible)

Preconditions that hospitals should meet	CS (n=67) ^a , %	DS (n=108) ^b , %
Staff show respect for their organisation	88	98
Staff support change and innovation	72	97
Staff view the patient organisations as an equal conversation partner	60	93
Doctors have a positive care attitude towards the collaboration	81	99
Care providers have a positive care attitude towards the collaboration	88	99
Management has a positive attitude towards the collaboration	66	96
A written mission/vision on cooperation	25	90
Sufficient background information	60	97
Hospital staff communicate in a readily understandable language	78	98
Clear mutual expectations	58	97
Clearly defined goals	57	97
Availability of a permanent contact person	43	95
Regular feedback moment to discuss the collaboration	37	96
Regular feedback linked to action	31	95
Staff know how to collaborate	61	98
Meetings take place at accessible locations	49	94
Staff has sufficient time	37	97
PO can use infrastructure during participation activities free of charge	59	89
Free catering during participation activities	28	56
Clear guidelines provide framework for the collaboration	39	94

^aCurrent situation

^bDesired situation

changes in the hospital or new treatments and protocols (“There is a need for regular evaluation of – and feedback.” (resp. 20)). Second, facilities for expert patients and logistical support for the PO within the hospital were described as nice-to-have conditions but “it is extremely important to take into account the limitations of each PO.” (resp. 47). Third, the POs would like to see more collaboration at the level of continued care after patients are discharged from the hospital (“Doctors, especially, should mention the peer support options and encourage people to use them” (resp. 19)).

Education and support for patient representatives and healthcare providers were seen as crucial factors in establishing a successful participation process, since both groups need to have the right competencies (skills, knowledge and attitudes). The five most important competencies were

Table 6: Frequency distributions for the “required competencies” dimension (multiple responses were possible)

Required competencies (knowledge, attitudes and skills) of patient representatives	DS Peer support (n=111) ^b , %	DS QI (n=111) ^b , %
Background knowledge of the organisation of the health care system	77	76
Background knowledge of the hospital organisation	67	68
Background knowledge of group processes	65	64
Background knowledge of communication techniques	78	79
Background knowledge of legal and ethical issues	59	61
Background knowledge of relevant sources of information	84	74
Background knowledge of recovery-promoting and recovery-inhibiting factors	83	78
Distance him/herself from his/her experience	81	85
Empathise with experiences of peers	94	94
Actively listen	95	94
Give and receive feedback	96	94
Address conflicts	85	84
Speak in public	75	77
Adapt communication style to context	89	91
Write reports	58	63
Communicate viewpoints in a structured way	93	93
Working in an organised and structured way	87	88
Handle confidential information	94	94
Take initiative	89	87

^aCurrent situation

^bDesired situation

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the same for both peer support and quality improvements: handling confidential information (94%–94%), communicating viewpoints in a structured way (93%–93%), giving and receiving feedback (96%–94%), active listening (95%–94%) and empathizing with the experiences of peers (94%–94) (see Table 6).

Besides the necessary competencies for representatives of POs listed in the survey, respondents cited a series of additional skills: willingness to collaborate, mutual respect, open communication, patience, time to listen to patients and regular feedback. Respondents also mentioned the following attitudes and types of knowledge: methods to successfully defend patients' interests and profound knowledge of illness and treatments. Finally, respondents called for more time and resources to be invested in collaboration: "There is not an endless supply of volunteers" (resp. 10).

To summarize, the open comments in the survey revealed tensions at the level of patient participation: (1) representatives do not feel sufficiently heard and do not feel that their views are taken into account, (2) representatives are not consulted about issues that affect them, (3) there is a gap between the agreements made and their implementation, and (4) the advisory role of representatives remains limited to the theoretic level. All these themes suggest that patients and their associations remain in a subordinate position.

DISCUSSION

60% of the patient associations surveyed participate in hospital processes in some way or another, while 40% do not. A frequently cited obstacle that impedes successful participation is the lack of interaction with the head of a specific hospital department, who is often a doctor or senior nurse. They seem to be crucial partners in facilitating collaboration and participation.

While disseminating information represents the most common level of collaboration, the majority of associations aspire to be two levels higher up on the participation ladder, i.e. playing an advisory role. For half the POs (49%), "advising" was the most desired level of participation, followed by 43% who cited "informing" as the most desirable level. Looking at the desired methods of participation, more than three-quarters of the POs described producing leaflets and information brochures (86%) and individual peer support (78%) as desirable. Bearing in mind that these two methods are situated at the "co-producing" level, the POs are more ambitious than their current situation might suggest. The results also demonstrate that, despite differences in the

conditions currently fulfilled, almost all forms of support (e.g. staff attitudes, formal procedures, communication and information) were viewed as equally important by the majority of the POs. Education and support for patients and healthcare providers are seen as crucial factors in establishing a successful participation process. The five most frequently cited competencies needed for this are: handling confidential information (94%–94%), communicating viewpoints in a structured way (93%–93%), giving and receiving feedback (96%–94%), active listening (95%–94%) and empathizing with the experiences of peers (94%–94).

The findings of this study add six new insights in the complex process of participation. First, when patients and their associations are able to establish collaboration with a hospital, the likelihood that this partnership will be satisfactory is high. Some 88% of the collaborating patient associations were fairly positive or very positive about their collaboration with hospitals. However, this high satisfaction rate still masks a degree of dissatisfaction among POs, as mentioned in the opening comments of the survey (see 5.3).

Second, POs appear to want to collaborate with hospitals more closely and intensely. “Advising” seems to be the level of participation that POs aspire to most frequently, while “informing” represents the most frequent level of current participation. “Advising” indicates that professionals explicitly ask for the opinions of POs, but are still free to pursue different proposals and ideas. Being asked for feedback on this was viewed as a sign of equality and of the involvement of POs being more than just a token gesture. The comments made in the survey show us that patient associations are aware of the requirements (e.g. accountability) that come with high levels of participation: the higher the level of participation, the more influence, responsibility and effort are needed. Our findings in this respect confirm the finding of previous research that the highest level of participation is not automatically the most appropriate: this depends on the aim of the participation process (Adams, Van de Bovenkamp & Robben, 2015).

Third, several respondents proposed actively exchanging, sharing and combining their experiential knowledge with the professionals’ clinical and scientific expertise. This clearly indicates that members of POs prefer direct interaction with social workers, nurses, other hospital staff and management through working groups and other face-to-face meetings, for instance.

Fourth, most of the associations expressed a desire to participate in the production of leaflets and brochures to inform their peers, in ad hoc meetings and in peer-support activities (to inform and support individual peers). This desire to exchange information was highlighted by the survey

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comments stating that, despite their limited capacity (time and manpower), patients and their organizations prefer methods that involve a considerable workload (e.g. questionnaires), or methods that match their experiential expertise (e.g. producing leaflets and brochures to inform peers and support individual peers). Furthermore, peer support and providing information are the core tasks for which patient associations were founded originally (Van de Bovenkamp & Trappenburg, 2011). The literature provides evidence that these two methods are effective (Nilsen, Myrhaug, Johansen, Oliver & Oxman, 2010; Repper & Carter, 2011).

Fifth, our qualitative analysis suggests that patients continue to be in a dependent position vis-à-vis hospitals, confirming Van de Bovenkamp's findings (Van De Bovenkamp, Trappenburg & Grit, 2010). To move beyond this subordinate position, POs wish to strengthen their competencies. They report that open collaborative attitudes are more desirable than having the right knowledge and skills, which underlines the importance of the careful selection of patient representatives, because it is harder to develop attitudes than it is to acquire skills or knowledge.

Finally, the importance of adequate support for the groups and their representatives, as well as for hospitals, is also stressed in previous research literature; support from all stakeholders (e.g. hospital management, decision makers at the policy level) enhances patient participation (Boivin, 2014; Castro *et al.*, 2016; Tambuyzer *et al.*, 2014). An independent intermediary organization such as a self-help clearing house or an umbrella organization could assume responsibility for organizing this kind of support. A large discrepancy, however, appears to exist between the current situation and the desired situation when it comes to clear guidelines and a written mission/vision, even though this aspect appears to be crucial. Clear guidelines (such as the guidelines for the German concept of the "self-help-friendly hospital" (Nickel *et al.*, 2016) create a framework for collaboration and have also been cited as an import determinant for successful collaboration in other studies (Tambuyzer *et al.*, 2014). Only one-third of the POs indicated that they received regular feedback from hospitals to discuss their involvement or meetings to monitor progress on action points that were identified through service improvement consultation. Other studies have shown that a lack of feedback can be demotivating and impede sustainable collaboration (Linhorst, Eckert & Hamilton, 2005).

Based on our findings, we would suggest some points for action and propose some recommendations. We conclude that engaging in a meaningful dialogue and building a mutually trusting relationship with hospital staff are important aspects in increasing interest in the role of POs and creating a successful partnership. Adjusting the modes of collaboration to both the abilities of – and the opportunities that are open to – POs and hospitals will be critical to further

improving collaboration between both (Vennik *et al.*, 2016). As such, a “co-design trajectory” before the start of the collaboration could be beneficial. Such a preliminary stage would enable both patient associations and hospital staff to reflect on certain aspects of their future collaboration (e.g. preconditions, tasks and roles, goals). In addition, there is a need for clear guidelines that outline what the parties concerned should expect from the collaboration. There is also a need for the recognition and appreciation of “informal” knowledge. This can be achieved by, among other things, motivating healthcare staff to systematically refer patients to patient associations. As a result, associations would have more members and, in turn, be able to do more. This might help them to achieve a (formal) place in the regular care system.

RESEARCH EVALUATION

This exploratory study aimed to provide insight into the current and desired state of collaboration between POs and hospitals. A web survey offered the best way to reach a large number of respondents quickly and inexpensively (Polit & Beck, 2012). Bearing in mind that web surveys yield an 11% lower response rate than other modes (Lozar Manfreda, Bosnjak, Berzelak, Haas & Vehovar, 2008), we applied a number of strategies to increase the response rate (Edwards *et al.*, 2009). However, the response rate of the survey was rather low compared to Shih and Fan's (2009) average response rate of 34%. Respondents may not have completed the survey due to the high number of questions asked. The potential bias caused by the relatively low response rate is, however, partly compensated by the fact that each respondent represents the view of the members of an entire organization active in a hospital setting, and by the similar distribution between the sample and total population. There is a likelihood of response bias to the open questions, but we would consider this fairly small. After all, the open questions focused mainly on the context or gave the respondents the opportunity to give answers that were not included in the range of answer options and to make extra comments on the subject.

Currently, the need for the participation of POs in the healthcare system is widely agreed upon. However, our findings cannot easily be transferred from one country to another. The key principles discussed can, however, have a place in various models of patient participation, either for collaboration between POs and hospitals, or for collaboration between non-organized patients and hospitals. Further research to explore the differences in participation activities between subgroups of patient associations (e.g. larger and smaller associations) would be useful. More descriptive variables on the nature of the association would need to be included in the survey for this purpose. Qualitative research is also necessary to a more in-depth understanding of the findings.

CONCLUSION

In this study, the current and desired state of participation of POs in hospitals is investigated. The survey provided useful baseline data. POs aspire to “advise” healthcare professionals and hospitals. They would prefer to participate through methods that are tailored to their capacities and resources, such as informing and supporting peers and professionals in different ways. In terms of the conditions for strong participation in hospital processes, there remains much room for improvement: two-way communication, sufficient support, guidelines, a clear mission and vision and a legal framework for patient participation are seen as critical success factors. Furthermore, the participation process must be a win-win venture for both the hospitals and the associations.

DECLARATION OF INTEREST

The authors report no declarations of interest.

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NOTES

1 See: <http://www.zelfhulp.be/>

2 See: <http://www.vlaamspatientenplatform.be/>

3 These frameworks have already been described in detail in the literature, so their description is outside the scope of this article.

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APPENDIX

Appendix A Variables underpinning the questionnaire.

Name of the patient organisation

Collaboration or non-collaboration with hospitals

Assessment of current collaboration

Participation levels (Arnstein 1969)

Informing: 'Informing' means that the patient organisation is kept up to date and informed of issues that affect the lives of patients. There is no real commitment from hospital professions, who determine what happens. The organisation has a listener role and is not able to offer input.

Consulting: 'Consultation' means that professionals decide what happens, but nevertheless view the patient organisation as a serious partner. The professionals do not commit themselves to the results.

Advising: 'Advising' indicates that professionals decide what should happen, but the patient organisation may raise problems and formulate solutions. Professionals explicitly ask for the opinions of the organisation, but they can nonetheless pursue (reasoned) different proposals and ideas.

Co-producing: 'Co-producing' means that the patient organisations decide the course of action together with the professionals. The organisation is a partner and the professionals commit themselves to the outcomes of the collaboration.

Patient-driven: 'Patient-driven' means that the professionals adopt a counselling role and that the patient organisation takes the initiative to set goals and priorities.

Participation methods (Vennik et al. 2016; Vennik and Van De Bovenkamp 2013)

Focus groups: group discussions with six to 12 participants during which one topic is discussed

Patient panel or patient council: a group of patients or patient representatives that the hospital systematically calls together

Satisfaction questionnaires: questionnaires surveying patient experiences or patient satisfaction

Working group or committee: together with health care providers, patients take decisions that concern the care organisation

Ad hoc meetings: focused meetings to discuss particular bottlenecks and possible improvements

Interviews: conversations to obtain information about the delivered care with the aim of improving care

Brainstorming sessions: a methodology to develop new ideas and solutions aimed at improving care.

Mirror conversations: group discussions with other patients in which caregivers simply listen so as to obtain feedback about the care they provide.

Shadowing: a patient is followed during his complete trajectory at the hospital with the aim of improving care.

Mystery guest: a hospital is visited incognito and assessed on particular aspects so that the hospital staff can gain insight into the care and services they provide

Patient diary: through a diary, kept by a patient, caregivers gain insight into patients' experiences

Informing and supporting individual peers: informing individual peers about non-medical aspects of care (e.g. practical information) and providing psychosocial support if needed

Informing and supporting peers in group: informing peers in group about non-medical aspects of care (e.g. practical information) and providing psychosocial support if needed

Collaborate with hospitals to produce leaflets and brochures informing peers: patient organisations give feedback on the readability and appropriateness of patient documentation

Collaborate with research organisations: patient groups can offer research ideas, participate in research and offer feedback on ethical aspects

Goals

- Justify (policy) decisions
- Outperform competitors
- Match the offer with the demand
- Improve own work
- Improve own image
- Offer complementary services
- Offer patients more control (facilitate patient empowerment)
- Develop new ideas
- Increase chance that new ideas will be successful
- Test new ideas
- Make economies
- Offer good quality of care
- Reduce workload
- Increase patient satisfaction
- Allow patient organisation to contribute to responsible management
- Send patients home faster
- Attract more people to the hospital
- Meet the standards of a future-oriented hospital that values patient involvement
- Facilitate transition to patients' home situation
- Preconditions that hospitals should meet** (Tambuyzer et al. 2014)
- Staff show respect for their organisation
- Staff support change and innovation
- Staff view the patient organisation as an equal conversation partner
- Doctors have a positive care attitude towards the collaboration
- Care providers have a positive care attitude towards the collaboration
- Management has a positive attitude towards the collaboration
- A written mission / vision on cooperation
- Sufficient background information
- Hospital staff communicate using readily understandable language
- Clear mutual expectations
- Clearly defined goals
- Availability of a permanent contact person
- Regular feedback moments to discuss the collaboration
- Regular feedback linked to action
- Staff know how to collaborate
- Meetings take place at accessible locations
- Staff has sufficient time
- Patient organisation can use infrastructure for participation activities free of charge
- Free catering during participation activities
- Clear guidelines provide framework for the collaboration

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Required competencies (knowledge, attitudes and skills) of patient representatives

Background knowledge of organisation of the health care system

Background knowledge of hospital organisation

Background knowledge of group processes

Background knowledge of communication techniques

Background knowledge of legal and ethical issues

Background knowledge of relevant sources of information

Background knowledge of recovery-promoting and recovery-inhibiting factors

Distance him/herself from his/her experiences

Empathise with experiences of peers

Actively listen

Give and receive feedback

Address conflicts

Speak in public

Adapt communication style to particular context

Write reports

Communicate viewpoints in a structured way

Work in an organised and structured manner

Handle confidential information

Take initiative