The perceived impact of public involvement in palliative care in a provincial palliative care network in the Netherlands: a qualitative study

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Abstract

Background and objective Public involvement in palliative care is challenging and difficult, because people in need of palliative care are often not capable of speaking up for themselves. Patient representatives advocate for their common interests. The aim of our study was to examine in depth the current practice of public involvement in palliative care.

Setting and sample The study was conducted in the province of Limburg in the Netherlands, with six palliative care networks. Study participants were 16 patient representatives and 12 professionals.

Method This study had a descriptive design using qualitative methods: 18 in-depth interviews and three focus groups were conducted. The critical incident technique was used. The data were analysed using an analytical framework based on Arnstein's involvement classification and the process of decision making. Impact categories as well as facilitators and barriers were analysed using content analysis.

Findings and conclusion The perceived impact of public involvement in palliative care in terms of citizen control and partnership is greatest with regard to quality of care, information development and dissemination, and in terms of policymaking with regard to the preparation and implementation phases of decision making. The main difference in perceived impact between patient representatives and professionals relates to the tension between operational and strategic involvement. Patient representatives experienced more impact regarding short-term solutions to practical problems, while professionals perceived great benefits in long-term, strategic processes. Improving public involvement in palliative care requires positive attitudes, open communication, sufficient resources and long-term support, to build a solid basis for pursuing meaningful involvement in the entire decision-making process.

Introduction

In recent decades, public involvement has increasingly become a part of policymaking, research and education in health care.[1–3] Public involvement in palliative care is challenging and difficult, because people in need of palliative care are often not capable of speaking up for themselves. Owing to this, their health condition makes them vulnerable.

The World Health Organization defines palliative care as '(. . .) an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (p. 94).[4] In the Netherlands, palliative care is a priority on the agenda of policymakers. The Ministry of Health, Welfare and Sport has institutionalized and is funding the so-called palliative care networks (PCNs), which cover the country in 65 PCN areas.[5] In these PCNs, the various providers of palliative care co-operate and aim to optimize the organization and provide high-quality palliative care within the specific context of each of the 65 PCN areas. Two of their main tasks are, first, to ensure that a variety of palliative services are available, so there is freedom of choice, and second to fine-tune palliative care services to the needs of people needing them and their family members. The ministry states that public involvement in the PCNs is compulsory.[6]

Public involvement in health care entails the involvement of lay people, community groups and patient representatives in various activities concerning health care, at both individual and collective level. Public involvement in this study meant the involvement of patient representatives at a collective level (sounding board groups). Patient representatives advocate for the common interests of people in need of palliative care, representing elderly people, patient associations and volunteer organizations. Public involvement is of major impor-

tance because, in a democratic approach, people should have a say in their own care, based on the principles of autonomy, inclusion and independence.[7] Ultimately, optimized public involvement will benefit tailored care and a dignified end-of-life process for people in need of palliative care.

The findings from the literature concerning the impact of public involvement can be summarized in three impact categories: planning and development of services; information development and dissemination; and the attitudes of both patients and professionals.[8–10]

With regard to the impact on decision making, Mockford *et al.*[10] reported 'little description about how much influence service users had' (p. 34). In cancer care, Attree *et al.*[9] described an impact on small and local, yet very essential, beginnings, although the aim was in fact quite the opposite, that is, to have an impact on strategic and long-term decision making.

As regards the facilitators and barriers for public involvement, previous studies distinguished three domains: structure and resources, politics and discourse, and the attitudes and culture of professionals.[9, 11] Some of the facilitators identified were leadership, support and facilitation, and perceiving one's own impact.[12]

The experiences of professionals with public involvement have been described as: ranging from rewarding to difficult;[8] unwilling at first, later on starting to feel comfortable;[10] or even that 'staff perceive patient and public demands as a potential source of stress.'[11] Professionals seem unable to find solutions outside their professional domain and rely completely on their professional perspective.[13]

In sum, much is known about the impact on, and decision making about public involvement and its facilitators and barriers. The literature provides valuable information in the context of advanced-stage chronic disease and cancer care, which is often closely related to, and may indeed be part of, palliative care. However, in palliative care situations where patients with an incurable health situation are in a vulnerable position and

patient representatives act as advocates, yet the impact of representatives in public involvement has barely been evaluated. In addition, little is known about the experiences of the professionals involved. This prompted the following questions. First, how do patient representatives and professionals in Dutch PCNs perceive the impact of public involvement in the PCNs? Second, what are the perceived facilitators and barriers associated with public involvement in PCNs, according to patient representatives and professionals? The aim of our study was to examine in depth the current practice of public involvement in palliative care.

Methods

Design

This study had a descriptive design using qualitative methods and was based on critical theory. We also sought to empower through action and dialogue.[14] In agreement with critical theory, we used Arnstein's framework to provide detailed insight into the different levels of involvement. This framework is based on a hierarchy with eight levels, ranging from manipulation (low) to citizen control (high) in decision making (Table 1).[15] We broke down the process of decision making into four steps: preparation, implementation, evaluation and adjustment, to be able to study the level of involvement in detail. We opted for this approach because we wanted to obtain comprehensive and rich findings regarding the impact of public involvement, based on a sound theoretical framework.

Setting

The study was conducted in the province of Limburg (1 123 000 residents) in the Netherlands, with six PCNs. All six consist of a PCN steering group, management team, working groups and a sounding board group (Figure 1), managed by a PCN coordinator. The sounding board groups have an average of five

Table 1 Arnstein's framework of involvement applied to the context of the PCNs

Level of involvement	Definition
Citizen control	The sounding board group has complete control in decision-making
Delegated power	The sounding board group is the dominant authority in decision-making
Partnership	The sounding board group and the management team share responsibilities in decision-making as equal partners
Placation	The management team selectively includes the sounding board group in decision-making. This may result in selectively adopting the advice of the sounding board group
Consultation	The management team requests the advice of the sounding board group, but holds decision power
Informing	The management team provides information to the sounding board group
Therapy	The management team actively aims to change the perspective of the sounding board group
Manipulation	The management team instructs the sounding board group on how things should be done

members and meet 4–8 times a year. Their function is to provide self-initiated advice and advice on request. They are supported by a PCN advisor from the House of Care, an umbrella patient organization in the province of Limburg.

Participants

Participants were patient representatives who were members of sounding board groups and professionals who were members of management teams. We included 14 patient representatives and 12 professionals and aimed for a mix of various backgrounds (Tables 2 and 3). We applied no exclusion criteria. We used purposive sampling[16] based on the participants' background and experience in PCNs, which could enable them to contribute rich information in terms of both relevance and depth.
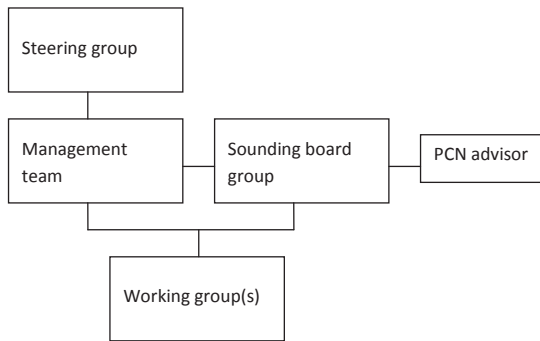
Figure 1 The structure of PCNs.

Approaching the participants

We used three ways to approach participants. First, we drafted an information letter about the study. The researcher (AH) was introduced by the PCN advisor at meetings of three of the six sounding board groups. Afterwards, the PCN advisor forwarded the contact information of those who agreed to be approached by the researcher. Second, organizational and time issues induced us to ask the PCN advisor for the three remaining sounding board groups to act as key person to inform the patient representatives and to forward the contact information. The professionals were approached by the researcher by attending a meeting of the PCN coordinators. The coordinators then asked other professionals to participate.

Ethics

Prior to the interviews and focus group sessions, participants received an information letter about the study, gave written informed consent and were assured that data would be treated confidentially. We secured the anonymity of the participants by code-numbering the interview and focus group transcriptions. The study was approved by the Atrium-Orbis-Zuyd ethics commission (11-N-95).

Role of patient representatives

Two patient representatives (MB, HvR) were involved in the research process from the very

Table 2 Characteristics patient representatives

Characteristics	N
Sex	
Female	12
Male	4
Age in years	
30–40	1
40–50	1
50–60	3
60–70	5
70–80	4
80 plus	1
Mean	62.6
Religion	
Catholic	10
Muslim	1
Other	4
Membership PCN	
1–2 years	4
2–5 years	7
5–10 years	2
10 years plus	2
Role in the sounding board group	
Chairperson	4
Member	12
Organization/target group representing	
Elderly people	5
Hospice	2
Voluntary palliative and terminal care	2
Mental health care	1
Ethnic minorities	1
Informal care support	1
The Toon Hermans House (Palliative care support for patients and family)	1
Client advisory body	1
No affiliation/personal interest	2
Personal experience with palliative care	
Yes	13
No	2

beginning, as members of the research project's own steering group and research team. They were involved in the writing of the research protocol, in approaching participants, preparing the study materials, analysing the data and writing this article. As regards the analysis, they reviewed several intermediate versions of the analytical matrices and provided feedback about the findings. They approved the final version. In the research project's own steering group meetings, they discussed the findings as

Table 3 Characteristics professionals

Characteristics	N
Sex	
Female	6
Male	6
Age in years	
30–40	1
40–50	3
50–60	8
Mean	50.4
Membership PCN	
0–5 years	3
5–10 years	8
10 years plus	1
Role in PCN	
PCN coordinator	5
Chairperson	1
Member	6
Organization representing	
Hospital	2
Home care	2
Hospice	1
Informal care support	1
Palliative care consultant	1
No affiliation/independent	5

representatives of all six sounding board groups. Their involvement was a dynamic and creative process in which mutual expectations were communicated. All participants considered this a suitable approach.

Data collection

Data collection lasted from December 2011 to May 2012. Twelve in-depth interviews with patient representatives were conducted. The participants were interviewed at a place of their choice, usually at home. Two focus group discussions were held, with four patient representatives participating in each. Four of these representatives had already been interviewed individually. This double participation occurred because some sounding board groups could not provide four participants, owing to the small size of the groups.

Six in-depth interviews were held with professionals, after which a focus group discussions took place with six different professionals. The interviews lasted approximately 45 min and the focus group discussions about 75 min.

Interview guide and procedure

The two different interview guides, one for patient representatives and one for professionals, consisted of open-ended questions that were loosely based on the literature.[17] We used the critical incident technique,[18] a method of obtaining data from participants by in-depth exploration of specific incidents and behaviours related to a topic under study. This technique was chosen because of its ability to identify people's experiences concerning public involvement, with the concrete experience of public participation serving as incident. Three aspects were addressed: a description of the situation leading to the incident, the actions and behaviour of the main character(s), and the outcome(s) of the actions and behaviour. We collected the critical incidents by asking about perceived involvement. For example: 'Can you give us an example of a substantial contribution made by the sounding board group to the PCN?' or 'Can you give an example when the sounding board group influenced the decision making of the PCN less strongly?' The researcher asked probing questions to get a full account of the critical incident, and of related facilitators and barriers. The interview guides were pre-tested by two participants, one patient representative and one professional. Minor adjustments were made, mostly involving re-phrasing sentences.

Two separate focus group guides were used for the focus groups discussions, one for patient representatives and one for professionals, each consisting of three fictional critical incidents (Box 1) that were designed based on the data analyses. The purpose of the fictional critical incidents was not to discuss a what-if situation, but to generate rich data by triggering accounts of new critical incidents and related facilitators and barriers. Interviews and focus group discussions were tape-recorded and transcribed verbatim. Field notes were taken during and after each interview and focus group discussion.

Box 1 Example fictional critical incident

About 3 years ago, we as a sounding board group advised the management team to set up palliative intensive care teams in our area. A palliative intensive care team advises caregivers who provide palliative care to patients in the home setting. A palliative intensive care team comes in when the patient situation becomes too complicated and too complex to be dealt with solely telephone consultations.

A member of the sounding board group had visited a national palliative care day and found out that they did this in other areas in the Netherlands as well. We also thought it would benefit the patient in more ways than one. For reassurance, we asked some of the people we represent in a member meeting. They gave us a number of well-grounded arguments, for instance: 'the care burden for family givers would be less.' That is why it seemed a good idea to us to introduce a palliative intensive care team in our area too, and why we advised the management team about this. The chairman of our sounding board group and the network coordinator has taken our advice to the management team.

I do not know what the result is, cannot answer that. Now that you ask me, I realize we have not heard anything back about this advice yet. But that's how it is in the network, ever since I joined the sounding board group. We bring certain issues to the table of the management group, but we do not actually get to see what they do. We do not get any information on how our advice is being handled.

Do you have a similar experience? Can you tell us your experience?

Data analysis

We performed an analysis at three levels: patient representatives vs. professionals; impact on the content vs. impact on decision making (In this study, the 'content' category included the nature of the work within the PCNs, such as quality of palliative care services or co-operation in palliative care provision. The 'decision-making' category involved the decision-making process (subdivided into decision-making steps) within the PCNs.); and facilitators vs. barriers. We began analysing while data collection was still in progress.

For the purpose of the analyses concerning patient representatives vs. professionals and impact on content vs. impact on decision mak-ing, we (AH and AM) first analysed the data deductively by matrix analysis.[19] We used an analytical matrix whose vertical columns related to the levels of involvement based on Arnstein's ladder[15] while the horizontal rows related to the decision-making steps. Next, we applied content analysis inductively by letting impact categories emerge by grouping and categorizing the data.[20] This resulted in two matrices, one with experiences of patient representatives and one with those of professionals.

Data concerning facilitators vs. barriers were coded using conventional, inductive content analysis.[20] First we broke up the text into smaller units, assigned descriptive code names and clustered the units together in a coding scheme, using categories and subcategories. This led to the identification of four facilitators and three barriers.

Frequent analytical sessions were held in which the coding was reviewed to find the best possible interpretation of the data. If there were two possible interpretations, we asked the patient representatives for advice. This happened in two cases.

Data saturation occurred after 18 interviews and one focus group discussion. The remaining focus group discussions were used to validate the findings.

Trustworthiness

Trustworthiness was assessed using four criteria: credibility, transferability, dependability and confirmability.[21] We used three strategies to ensure credibility. First, triangulation, in terms of sources (16 patient representatives, 12 professionals), methods (in-depth interviews and focus groups) and investigators (AH and AM). Second, peer debriefing: we informed the working group (MB, HvR, ES and AB) on a regular basis about organizational aspects of the research organization and analytical matters. Third, member checks were performed by providing summaries of the interviews and focus groups, which the participants could comment on. Participants gave feedback three times, which we incorporated in the transcripts.

Table 4 Perceived impact of public involvement by patient representatives (Vertically: levels of involvement; horizontally: decision-making steps)

	Preparation	Implementation	Evaluation	Adjustment

Citizen control	Quality of care
	  Accessibility
	  Continuity of care
	  Spiritual care
	Information
	  Dissemination
		Information
		  Development
		  Dissemination
		  Organization-specific issues		

Delegated power				

Partnership	Quality of care
	  Continuity of care
	Information
	  Development
	  Dissemination
		Quality of care
		  Continuity of care
		  Spiritual care
		Information
		  Development
		  Dissemination
		  Organization-specific issues		

Placation		Quality of care		
Consultation			Quality of care Continuity of care Policymaking	

Informing		Quality of care
		  Continuity of care
		Information
		  Dissemination		

Therapy	Information Dissemination			
Manipulation				

We secured transferability using thick description of setting, sample, inclusion criteria, interview guide and procedure. Dependability and confirmability were safeguarded by creating an audit trail, which is available on request (in Dutch).

Findings

We found four major impact categories: quality of care, information development and dissemination, policymaking, and organization-specific issues. For both professionals and patient representatives, the perceived impact of public involvement on the decision-making process was greatest in the preparation and implementation phases, the level of involvement being citizen control and partnership (Tables 4 and 5). For patient representatives, the perceived impact was smallest in the evaluation phase, the level of involvement being consultation, and there was no involvement at all in the adjustment phase. For professionals, the perceived impact was smallest in the evaluation and adjustment phases, the main levels of involvement being partnership and consultation. Patient representatives and professionals indicated four facilitators of public involvement, namely motivation, inter-relations, key persons and structural support, and three barriers: ambiguity in role expectation, attitudes and capacities, and lack of resources (Table 6).

Perceived impact on content and decision making

The first major impact category that patient representatives and professionals reported was quality of care, such as accessibility to care for vulnerable groups such as ethnic minorities. Other quality-of-care issues were continuity of care involving communication (e.g. transfer from hospital to hospice and discharge from hospital to home), and spiritual care

Table 5 Perceived impact of public involvement by professionals (Vertically: levels of involvement; horizontally: decision-making steps)

	Preparation	Implementation	Evaluation	Adjustment

Citizen control	Information
	  Development
	  Dissemination
	Quality of care
	Accessibility
	Continuity of care
	Spiritual care
		Information
		  Dissemination
			Quality of care	

Delegated power				

Partnership	Policymaking
	  Organization-specific issues
		Quality of care
		  Accessibility
		  Continuity of care
		  Spiritual care
		Information
		  Development
		  Dissemination
		  Organization-specific issues
			Quality of care
			  Spiritual care
			  Policymaking
				Policymaking

Placation				

Consultation	Policymaking	Information
		  Development
			Information
			  Development
			  Policymaking
				Policymaking

Informing		Quality of care	Quality of care Continuity of care	
Therapy	Policymaking			
Manipulation		Quality of care Continuity of care		

(e.g. spiritual care plans and the availability of spiritual care providers). The impact that patient representatives had on decisions was experienced mainly in the preparation and implementation phases, the levels of involvement being citizen control and partnership.

> We're currently developing a social map for health care providers. We're not doing this as the sounding board group, but as the subproject group for palliative terminal care. Though I'm representing the sounding board group. (Patient representative A6)

The second major impact category was information development and dissemination, reported by both patient representatives and professionals. Patient representatives developed written patient information, such as a flyer about palliative care. Subsequently, they were involved in the dissemination of patient information, for example by presenting at activities in the context of World Hospice and Palliative Care Day, or to their fellow members. The impact that patient representatives had on decisions was experienced mainly in the

Table 6 Facilitators and barriers to public involvement

Facilitators to public involvement	Barriers to public involvement

Motivation
  Interested in topic
  Advocacy
	Ambiguity in role expectation
	  Lack of clarity in the statutes
	  Operational vs. strategic
	  One-way process

Inter-relations
  Sharing stories
  Exchanging ideas
	Attitudes and capacities
	  Volunteer vs. professional
	  Value of experiential knowledge

Key persons
  Chairperson
  PCN coordinator
	Lack of resources
	  Money
	  (New) members

Long-term support
  Organizational
  arrangements
  Professional expertise	

implementation phase, the levels of involvement being citizen control and partnership.

> (...) recently there was the *Pal voor u* magazine, which the management team isn't really keen on, as they're not sure it's necessary, but then the sounding board group made it very clear that we do think it's important, it's something care recipients like to see, like to read. So we'd like the network to get it going again. (...) So therefore they decided to do it anyway, though initially the management team wasn't too keen. (Professional C3)

The third major impact category reported by patient representatives and professionals was policymaking. Patient representatives were regularly faced with policy documents. These included organizational policy documents, such as the PCN's annual activity plan and internal regulations. Patient representatives and professionals also reported strategic health-care policy documents, such as a policy paper about the needs and preferences of patients concerning spiritual care and the resulting policy. The impact that patient representatives had was experienced mainly in the preparation and evaluation phases, the levels of involvement being partnership and consultation.

> The steering group, the management team and the sounding board group will all be in included the structure and procedure document. Of course this will be put to the sounding board group. (...) it's on the agenda for tomorrow. (Professional C4)

The fourth major impact category was organization-specific issues. These issues concerned approaching and including network partners and attendance rate at PCN activities, for example multidisciplinary meetings discussing a central theme and the PCN's start-up event. The impact that patient representatives had was experienced mainly in the preparation and implementation phases, the level of involvement being partnership.

> In any case, we managed to get one foundation to join the management team. Because as a sounding board group, we got the impression they were somewhat represented, but not fully informed about what was going on. So we

warned them, as in: you might want to pay attention to what's being decided for you. (Patient representative A2)

The above-mentioned four major impact categories were reported by both patient representatives and professionals, but the perceived impact differed. For both groups, quality of care was the main priority issue. However, patient representatives perceived information development and dissemination as the second and policymaking as the third most important impact category, while professionals assigned the opposite ranking to these two categories.

The greatest impact was reported by both groups in the preparation and implementation phases of decision making. However, only one example of involvement in all phases of decision making was reported. For professionals, involving patient representatives as partners in every decision-making phase is the ideal situation to strive for:

> And, well, since the sounding board group is consulted in the process so early, they rarely say no. Because it's not like they only get a say in it at the end of it, but they're there from the start, while ideas are being developed. (...) So in the end, the sounding board group rarely says 'no, you shouldn't do that'. So in that respect, they are full partners. (Professional C3)

The smallest impact was perceived in the evaluation and adjustment phases of decision making. Patient representatives reported little involvement in evaluation, only at the consultation level, and no involvement at all in the adjustment phase. Professionals reported little involvement in adjusting policies at the partnership and consultation levels, such as a document on regulations.

A few 'worst practice' experiences of public involvement were reported. These centred mainly on quality-of-care issues, such as case management, discharge and transfer from primary to secondary care. The experiences of patient representatives were reported across three decision-making phases with different levels of involvement, even citizen control. Those experienced by professionals related mainly to

the implementation phase, the levels of involvement being informing and manipulation.

> Well, it's not that good: proper discharge from hospital actually takes too long. Every ward has its own way. (…) It's been going on for a while. Yes, they'll have to get it done sometime and we need it to be clear whether what we ask is possible! We're no professionals, we're just saying there has to be a way to develop a hospital discharge procedure that applies to every ward. (Patient representative A11)

Facilitating factors

Motivation

The main drivers for patient representatives to get involved in a PCN sounding board group were personal interest in palliative care and defending interests of the very vulnerable and ethnic minorities:

> The sounding board group is the place where I can say what I have to (…) for migrants. This is why I wanted to get to know the sounding board group. (Patient representative A3)

Inter-relations

Doing volunteer work, sharing their life-experiences and stories concerning palliative care, and being involved with each other were perceived as important. Besides the relations between people within each sounding board group, the meetings and exchanges between all six sounding board groups were described as facilitating, in terms of meeting other patient representatives, exchanging ideas and learning from each other about activities.

Key persons

Patient representatives and professionals reported that having the 'right' person to chair the sounding board group was critically important. 'Right' means being able to communicate and present the issues of the sounding board group to the professionals in the management team and at the same time function as a linchpin in securing two-way involvement and information flow.

> Feedback from the network to the sounding board group through the chair. (…) And I have to say, our chair is good at that. The chair is very important in this, because they're the link between the network and the sounding board group. (Patient representative B1)

The other key person was the PCN coordinator. He/she is a professional who networks and connects organizations within the PCN. He/she was perceived as a decisive intermediary between patient representatives and professionals, in some cases even as the spokesperson on behalf of the patient representatives.

Long-term support

Both patient representatives and professionals reported long-term support as a prerequisite in terms of organizational arrangements, such as planning the meetings, drafting the agenda and taking minutes, and also in terms of professional expertise concerning the support of public involvement, for example, leadership qualities, having a large network, the right mentality to work with volunteers and making meaningful contributions to discussions about palliative care. This support was provided by a PCN advisor.

Barriers

Ambiguity in role expectation

Both patient representatives and professionals reported lack of clarity in the statutes. The role of sounding board groups was unclear, and patient representatives did not know exactly what was expected of them. They perceived the description of the aims and function of the sounding board group as vague and broad.

> Yes, regulations state there are contacts and there is a certain role for the sounding board in this. To observe, yes, and to bring this to the attention of their people. You can't put it in more general terms than that. (Professional D3)

Another aspect was the tension between operational and strategic involvement. Patient representatives experienced more impact regarding short-term solutions to practical problems. They

found it hard to commit to long-term, strategic processes and to read policy documents, while professionals perceived great benefits in the latter.

The third aspect, communication between professionals and patient representatives, was characterized as a one-way process by both patient representatives and professionals. Self-initiated advice by the sounding board groups dominated, and advice was seldom requested by the PCN.

> It's a two-way process, of course, but, looking back, I don't think we actually asked the sounding board group any specific questions. There's no interaction. (Professional C1)

The self-initiated advice given by sounding board groups had no follow-up. The patient representatives lacked information about the progress of their advice.

Attitudes and capacities

Barriers perceived by the patient representatives included aspects of attitudes and capacities, that is, a lack of appreciation and acknowledgement. Professionals' recognition of experiential knowledge was very important to patient representatives, but they complained that they were not being taken seriously by the professionals of the PCNs. Several patient representatives talked in terms of volunteers vs. professionals, and how big a gap there can be between the two.

> I might be putting it too bluntly, but I just think the management team is an entirely different group. They're professionals; we can't compare ourselves to them. (Patient representative B5)

Professionals, in turn, assigned more value to capacities, such as analytical skills and being able to think on an abstract level, than to experiential knowledge. They expected patient representatives to subordinate their individual experiences to the 'big purpose' of the PCN.

> Members of the sounding board group have to be able to think analytically and to stand above their own processes or experiences. Otherwise you get people who've been through something

or heard something and who want to know if the management team is going to do something about it. I don't think anyone wants that (...). (Professional C6)

Lack of resources

Patient representatives, being volunteers, lacked sufficient financial resources. Major differences were reported between the sounding board groups in this respect. Some had a small budget only for travel expenses, while others had to prioritize which members had the greatest need for compensation, or did not receive any compensation at all. A few patient representatives also mentioned that they would like to go to symposia once in a while, but that the professionals were not able or willing to allow these activities to be funded from the PCN's budget.

Patient representatives and professionals perceived difficulties with recruiting new members for the sounding board groups, which was reported to impact negatively on 'true' patient representation. The reasons they mentioned were: little awareness among the public of sounding board groups and unfulfilled expectations of new sounding board members concerning their level of involvement. The latter resulted in dissatisfaction and frequent changes in membership.

Discussion

Impact of public involvement

We found four major impact categories on the content (nature of the work within the PCNs). The quality-of-care category relates to the planning and development of services,[8,10] which includes changes in services such as adjusting opening times, improving access for people with a disability and commissioning new services.[8] Information development and dissemination is a well-described impact category.[8–10] The policymaking category is a less frequently identified area of impact, with studies reporting minimal involvement in strategic processes.[8,9] Policymaking was not the most important category for our patient representatives. They seemed to value concrete and quick

results over long-term processes, and experienced greater impact at the operational than at the strategic level, while the professionals perceived equally strong impact at the operational and strategic levels. It seems that the patient representatives had greater impact than they actually perceived themselves. As regards the impact on organization-specific issues, the literature has remained silent to date. In the PCNs, the sounding board groups meet regularly, in close collaboration with the management team, giving the patient representatives the opportunity to stay informed and be involved in organizational matters as well. The impact on organization-specific issues was ranked lowest by both patient representatives and professionals. A possible explanation is that it does not occur to professionals to involve the public in organizational matters. Professionals mostly rely on their own perspective, finding it hard to find solutions outside their own domain.[13]

With regard to decision making, what is surprising is that few complete decision-making cycles could be found, and these were reported only by the professionals. In general, patient representatives were not fully involved in decision making: feedback and information about the follow-up to their advice were lacking. This reveals a contrast in the perceived impact between patient representatives and professionals and may be explained by different experiences regarding informing as the level of involvement. Patient representatives only reported positive experiences with regard to the informing level and would have liked to receive regular updates about the follow-up to their advice, while professionals described informing only in relation to the least favourable practical experiences, perceiving informing as of no real importance.

Facilitators and barriers

Four facilitators emerged from the interviews and focus group sessions: motivation, inter-relations, key persons and long-term support. Motivation and inter-relations have not previously been reported in the literature. Key persons partially fit in with the three types of

leadership described by Reed *et al.*,[12] and long-term support corresponds to what Reed *et al.*[12] call 'support and facilitation'.

Three barriers emerged, and almost all have also been reported in the literature in this field.[9–11] One facet of ambiguity in role expectations deserves more attention, viz. the 'one-way process' aspect of consultations, meaning the emphasis on self-initiated advice without follow-up, and a lack of requests for advice. Most of the representatives' self-initiated advice was not followed by regular updates from the professionals about the follow-up to their advice. This barrier seems to run counter to Arnstein's[15] ultimate goal, to arrive at the level of citizen control. After all, the patient representatives operate at the level of citizen control when they are providing self-initiated advices. Why then is the 'one-way process' in consultation perceived as a barrier? An explanation can be that Dutch culture is directed at partnership and reaching consensus (the so-called Polder Model).[22] Citizen control without any follow-up is perceived in this culture as 'pseudo' citizen control.

Strengths and limitations

The strength of this study is that we examined the experiences of both patient representatives and professionals, thus presenting rich data and a comprehensive picture of public involvement. We oversampled patient representatives because of their unequal power position and the dominance of the professionals' voice.[23, 24]

A limitation of our study may have been the self-selection aspect of our recruitment process which may have meant that it was particularly those who were highly motivated who participated. Persons with strong views and thoughts might thus have been overrepresented. The impact on the findings might have been that extreme views and thoughts dominated the data. On the other hand, the findings proved to be varied and presented a balanced picture. Intermediate versions of our analytical matrices as well as the findings were discussed with the patient representatives and the research team

in analytical sessions, and there were no direct signs in these meetings of a possible impact of patient self-selection on the findings. The strength of our study is the integration of two qualitative data collection methods: interviews and focus group discussions. The rationale was that we strove towards data completeness and confirmation. We used interviews to collect detailed accounts of participants' experiences.[16] We used the interactional nature of the focus group discussions to increase the depth of enquiry and reveal aspects that otherwise would be less accessible.[25] The minor overlap between the samples of participants used for the interviews and the focus groups appears to be a methodological weakness. However, qualitative research is real-world research and takes contextual particularities into account.[16] We wanted to do justice to the dialogical and empowering nature of the study design, so we ensured inclusion of all sounding boards in all phases of our study.

Using the matrix analysis, we established an analytical framework that was beneficial in providing detailed findings. However, the deductive character of the framework may disadvantage an inductive approach. We were careful not to lose sight of the impact as experienced by the participants.

Some levels of involvement in Arnstein's ladder (e.g. delegated power) did not appear in this study; this might relate either to the highly political character of Arnstein's framework or to the specific context and particularities of public involvement in this study. We do not perceive Arnstein's ladder as too broad and comprehensive; rather, we think that it is a useful framework and could be used to study the perceived impact of the many forms of public involvement in a variety of settings.

Implications for research and practice

This was a first attempt at researching the impact of public involvement by involving patient representatives in palliative care. It appears that evaluating the perceived impact requires more research than merely studying

the impact in each of the six sounding board groups, as we did not address the impact on the PCN as a whole – including the steering group and the relation to the Ministry of Health, Welfare and Sport. Further study is needed to obtain in-depth insights into the process, the perceived impact, and the facilitators and barriers of public involvement at different levels, for example project and organizational level.

With regard to implications for practice, three aspects demand attention, first, managing expectations, discussing in precise terms and prioritizing the nature of the work within the PCNs that patient representatives want to be involved in. We recommend that meaningful involvement, rather than maximal involvement, should be the aim of public involvement, tailored to specific situations. This means that patient representatives focus on specific areas and that citizen control, which is the highest level of involvement, is not always the ultimate goal. Second, we recommend ensuring the involvement of patient representatives at every step of the decision-making process. Involving patient representatives at an early stage in long-term strategic policymaking is a challenge, but when they receive regular updates and experience concrete results, this can be a rewarding experience for all parties. Finally, participants in this study included a great variety of patient representatives from various organizations, settings and professionals involved in the PCNs. PCNs focus mainly on the end-of-life care of terminally ill people. In our opinion, this focus justifies public involvement by patient representatives.

Conclusion

The perceived impact of public involvement in palliative care in terms of citizen control and partnership is greatest with regard to quality of care, information development and dissemination, and in terms of policymaking with regard to the preparation and implementation phases of decision making. The main difference in perceived impact between patient representatives

and professionals relates to the tension between operational and strategic involvement. Patient representatives experienced more impact regarding short-term solutions to practical problems, while professionals perceived great benefits in long-term, strategic processes. Findings suggest that improving public involvement in palliative care requires positive attitudes, open communication, sufficient resources and long-term support, to build a solid basis for pursuing meaningful involvement in the entire decision-making process.

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Conflict of interests

None.

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