Transforming clients into experts-by-experience: A pilot in client participation in Dutch long-term elderly care homes inspectorate supervision

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ABSTRACT

As experts-by-experience, clients are thought to give specific input for and legitimacy to regulatory work. In this paper we track a 2017 pilot by the Dutch Health and Youth Care Inspectorate that aimed to use experiential knowledge in risk regulation through engaging with clients of long-term elderly care homes. Through an ethnographic inquiry we evaluate the design of this pilot. We find how the pilot transforms selected clients into experts-by-experience through training and site visits. In this transformation, clients attempt, and fail, to bring to the fore their definitions of quality and safety, negating their potentially specific contributions. Paradoxically, in their attempts to expose valid new knowledge on the quality of care, the pilot constructs the experts-by-experience in such a way that this knowledge is unlikely to be opened up. Concurrently, we find that in their attempts to have their input seen as valid, experts-by-experience downplay the value of their experiential knowledge. Thus, we show how dominating, legitimated interpretations of (knowledge about) quality of care resonate in experimental regulatory practices that explicitly try to move beyond them, emphasizing the need for a pragmatic and reflexive engagement with clients in the supervision of long-term elderly care.

1. Introduction

Client participation in the supervision of quality and safety of care is not a new idea. For at least two decades, experts-by-experience, or lay-inspectors, have been identified as providing added value to the process of inspection - particularly the working of the team [1]. An expert-by-experience is perceived as a person who is in-between the 'life-world' of clients and that of the 'system' of professional inspectors and policymakers [2]. An expert-by-experience is thought to be able to bridge this in-between, liminal, space in order to enhance the quality and safety of care - either directly through participating in care practices or more indirectly through regulatory work. Experts-by-experience are trained in articulating practical experiences, through undergoing care themselves and through peer-contact, in their interactions with health care providers, experts and other clients [3]. Their added value to supervision has, similarly, been criticized [4,5]. The use of experts-by-experience can lead to confusion and distract from 'actually

empower[ing] the people using the services being inspected' ([6], p. 1901). Nonetheless, clients are exceedingly valued by inspectorates for their practical wisdom [7,8], and a significant proportion of (Dutch) clients appear to want to share their experiences with inspectorates ([9], p. 12).

In this paper, we focus on a natural experiment with experts-by-experience in healthcare supervision in the Netherlands that intended to open-up new perspectives on the quality and safety of long term elderly care delivery. We spent a year tracking a pilot by the Dutch Health and Youth Care Inspectorate (*Inspectie Gezondheidszorg en Jeugd:* IGJ) with the use of experts-by-experience in the risk regulation of long term elderly care homes. Our ethnographic evaluation focused on the information about quality of care and quality of life provided by experts-by-experiences in the experiment. For this paper, we broaden this scope and discuss how, and what kind of, knowledge is being produced and legitimated through the use of experts-by-experience as an experimental instrument of healthcare supervision. Thus, we focus on the (un)intended effects of the methodology that was used by the regulator in this particular natural experiment.

The IGJ has been inspired by projects in the UK (CQC) and motivated by societal and political attention to include patients, clients

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and citizens in its regulatory work [10–13]. The IGJ already has experiences in including citizens in institutional reviews [7] and is continuously experimenting with new formats of participation. Recent projects in long-term elderly care homes involve the use of 'mystery guests' that was helpful in raising a multiple perspective on elderly care, but the methods used in those projects raised particular ethical issues [14,15]. The pilot we study here has explicitly been set up as a follow up to these previous projects. Again, the aim is to discover a way to include citizens in order to better explicate and utilize clients' perspectives on quality of care in order to improve regulatory work, legitimate decision-making processes and enhance the public's image of, and trust in, the IGJ more generally ([7], p. 5).

These high hopes, and a concurrent sense of urgency, to include clients' perspectives in the regulation of care fit well with an age in which we can no longer take trust in institutions for granted [16,17]. Furthermore, it corresponds with an authoritarian form of populism that is gaining ground, which views the people as the 'true source of moral authority, and hence of legitimate political authority' ([18], p. 312). In this latter rationale of governing, legitimated knowledge is the 'knowledge that 'everyone knows' – that comes directly from the experience of the real people, undistorted, unmediated by experts' ([18], p. 314). Such notions of legitimate knowledge deviate from more traditional valuations of knowledge that rely on expertise and experts who are mostly professionals, a status acquired through specific, controlled and protected knowledge [19]. Lay people, citizens and clients were effectively excluded from this knowledge, thus maintaining that status. Despite clients co-producing care [20], and techniques such as shared decision making aimed at closing the power-differential, processes of in- and exclusion continue to emerge with many participatory methods [21,22]. Experts-by-experience are especially vulnerable to critiques on the particularity and validity of their knowledge ([6], p. 1893), as their expertise hinges on the articulation of particular subjective experiences of care to which their training is also directed [5]. For instance, inspectors might experience difficulties in working with experts-by-experience's input, as previous projects show inspectors to find such knowledge to be 'inconsistent, incomplete and/or incorrect' ([14], p. 827).

Hence, we analytically distinguish - crudely - two legitimated epistemologies on quality and safety of care here: one values the 'people', and in doing so foregrounds subjective and experiential ways of knowing while, generally, excluding differing values, histories and identities [18]; the other values the 'professional' rationalized expert and, in doing so, favors the objective and measurable aspects of knowing. In this paper, we trace the tensions between these two legitimated ways of knowing in a context in which an explicit effort is made to bring the 'people' into the more expert-centered practice of health care supervision.

2. Method

The pilot 'Experts by experience' of the IGJ ran from October 2016 to January 2018. During this time the IGJ worked to let seven experts by experience participate in twenty regular site visits to Dutch long-term elderly care homes, these visits happened in the summer of 2017. We were asked to conduct an evaluation study on this pilot. The research was done as an independent evaluation and our research commenced after the pilot had formally started. This means that prior to the start of our research, the IGJ already completed the planning and content of the pilot and the preparations for the selection and training of seven clients into experts-by-experience. In order to follow the pilot of the IGJ and discover the ways in which knowledge was produced, we have opted for a focused organizational ethnography [23] that includes participant

Table 1
Overview data.

Observations	52 hours of observation
Project meetings	23 (10x)
Training sessions	10 (2x)
Site visits	16 (4x)
Conversations clients/experts-by-experience	3 (8x)
Interviews	41 respondents
Experts-by-experiences	7 (2x)
Test-expert-by-experiences	2
Project team members	4
Inspectors	4
Clients	13
Board members care homes	5
Managers care homes	4
Other stakeholders	2
Documents	232 documents
Concept reports inspections	20
Final reports inspections	20
Notes experts-by-experiences	40
Test reports pilot	4
IGJ documents	120
Media (online, newspapers, television)	28

observations, semi-structured interviews and document analyses (See

We directly observed a total of 52 h of IGJ project meetings, training sessions and four site visits (4 out of the 20) to the homes for elderly care under review where experts-by-experience accompanied the inspectors of the IGJ. During the site visits we focused on the work of the experts-by-experience and observed them while they interviewed clients or tried to get an impression of the daily care practices. We conducted interviews with 41 respondents (see Table 1 for an overview) in order to understand participants' expectations and experiences of the pilot in order to fully grasp the flow of the pilot. The document analysis focused on the comparison of the content of notes of the experts-by-experiences and the formal reports that were written by the inspectors. Other documents served to contextualize the other sources of data.

During and after our observations, detailed notes were made digitally. Interviews were recorded and transcribed verbatim. Data was managed and analyzed using Atlas.ti software. The documents, formal reports and notes of the experts-by-experience, were intensively analyzed through an inductive coding of the material (final coding-scheme is available upon request) [24]. The notes of the observations and the interview transcripts were more selectively analyzed with a focus on the concrete practices through which knowledge was produced in this pilot [25,26].

Ethnography involves the need to strike a balance between in-depth observations and interviews and more distant analytics. In this research, such depth was reached in the initial phases of the research when we were granted the necessary access to the IGJ, her employees and documentation and were invited to all relevant meetings and visits. During the later stages of the research, more distance was maintained. We have strengthened the validity of our findings though informal member check ins with the pilot project-leader and formal member check ins with the pilot project group as a whole; furthermore, our findings were supported by a presentation of preliminary findings to a wider audience at the IGJ and, importantly, through an advisory committee existing of independent experts (of citizen participation and long term care, and the inspectorate), which assisted in substantive and methodological questions in three meetings.

3. Results

We discuss our results in the chronological order in which the pilot unfolded, beginning with the start of the pilot, followed by the site visits and the reports and accounts that were written. Throughout, we focus on the concrete practices that shaped the knowledge produced by these particular experts-by-experience.

3.1. Start of the pilot

The IGJ drafted the first plans for the pilot in 2015. The pilot was part of a broader project aimed at improving the supervision of elderly care. The project team was run by an experienced project leader and convened about two times each month. The team was responsible for the preparation and execution of the pilot, which ran in the summer of 2017; in particular, the selection and planning of the visits and the logistics of the pilot proved to take a significant amount of time. One of the first efforts of the team was to develop a clear profile for the clients to be selected as experts-by-experience, resulting in ten criteria, as shown in their documentation:

In the past two years of experience as client or first person of contact in care home;

Is able to travel independently to visit care homes;

Is vital enough to, next to travelling, also be able to maintain a conversation and write a report;

Is available for 5 visits in 4 months;

Is flexible;

Is able to have brief conversations with clients of elderly homes and write a brief report about these conversations;

Is able to observe well in a care home and write a brief report about these observations;

Can adequately and affably deal with possible resistance of clients and/or personnel;

Is prepared to work following current rules and regulations;

Is prepared to submit a formal statement proving proper behavior.

About 400 people responded to the call for participants to an existing panel of 23,000 patients and clients in the Netherlands (Zorgpanel Patientenfederatie Nederland). From these 400 people, seven clients were selected to be(come) the experts-by-experience in this pilot, including three women and four men. All were highly motivated:

'R: When the question was asked to participate, I was very enthusiastic, because the question intrigued me. The Inspectorate who admits to have limited reach with its work, and that they missed the social domain… Seeing that aspect is so very important, I just jumped in.'
[Expert-by-experience 3, Interview 1]

All experts-by-experience in this pilot shared this motivation to help improve the quality of life ('the social domain') in care homes. The selection-process ensured that all experts-by-experience are verbally strong, well-acquainted with the Dutch health care system and actively involved in this system either through informal care or patient organizations. Two experts-by-experience had direct personal experience in long-term elderly care homes, and the other five experts-by-experience provided informal care. Thus, the use of the ten criteria by the team excluded most (former) clients of elderly homes from participation. From our first interviews it emerges that existing experiences in care of the experts-by-experience proved

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Box 1: Themes as provided on the reporting form.
Living environment: Atmosphere, decor (room/apartment and common areas), facilities (e.g. internet, newspaper, television), facilities (e.g. bathroom, toilet, restaurant, sports), hygiene, level of privacy, etc.
Daily life: Activities/daytime activities (inside and outside the home), opportunities for mutual contacts and visits, level of freedom in daily routine/activities, house rules, etc.
Care: Coordination and fulfilling care appointments by health care providers, treatment by health care providers, feeling of safety, where to go for questions/problems, etc.

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extensive but also very much influenced by debates in Dutch media on the quality of elderly care. The selection process finished when the experts-by-experience took the oath as (unpaid) public officials, which gave the experts-by-experience a formal status.

The training for the experts-by-experience was prepared extensively. Over two days, they were introduced to the work of the inspectorate, the pilot, and the art of observing and interviewing clients by a professional trainer the IGJ hired for the purpose. The first day of training emphasized experts-by-experience's professional roles as public officials, such as their need for confidentiality, and forty-five minutes were spent on training them in observational skills, during which the importance of the neutral and objective observation of the situation in a home was stressed. The second day was more intensive and was primarily devoted to interview-skills training with an actor. Time was also spent on how to deal with a care home clients' emotions.

At this stage, we can identify two ways in which the knowledge produced through the pilot was being structured. First, we see a strict selection of seven participants who, as a consequence of the selection criteria, have had limited personal experiences as clients - already limiting the role of client's experiential knowledge in an early phase. Second, we observe how the training focused on participants' abilities to provide unbiased, objective, observations of clients' everyday lives in the care homes.

3.2. Site-visits

The pilot focused on twenty visits to a selection of long-term elderly care homes throughout the Netherlands. These visits were standard planned institutional reviews. Each visit was done by two inspectors and two experts-by-experience. For experts-by-experience, the aim was to interview at least two clients, make observations, write a report on the spot and discuss findings during lunch with the inspectors.

The selection of clients to be interviewed was a recurring point of debate. The experts-by-experience needed help from employees to find clients who were willing (e.g. did not have visitors, were not tired) and able (clients of somatic wards can also have cognitive problems) to talk to them. This raised worries about bias, and during the pilot it was decided that the experts-by-experience would ask for those who were *unable* to talk to them in order to gain more control over the selection process of those who were. Another concern was the anonymity of clients, as employees were observed reporting to the management who the experts-by-experience talked to.

During the development of the pilot, the team decided the experts-by-experience had to perform semi-structured interviews. The topics were formulated without input from the experts-by-experience and were based on the main themes of the instrument used by the inspectors (see Box 1). Experts-by-experience were instructed to use a print-out on A3-size paper and write their findings from both the interviews and observations directly on that paper. For each main theme, a separate notes section was pro-

vided, and some descriptive information about the client (name, care home, date, indication of level of care) was required. Experts-by-experience were asked to provide direct quotes from clients, and a space was left to note observations. None of the interviews were recorded.

We observed experts-by-experience using the paper as topic list, whereas others told us they used it as a starting point for a conversation. The conversations we observed lasted between 15 and 30 min and generally took place in the rooms (apartments) of the clients. Experts-by-experience stressed that clients talked openly with them about their experiences in the care homes, and the clients we talked to afterwards were, except for one who noticed that this was not the expert-by-experience's everyday profession, positive about the course and intent of the interviews. The experts-by-experience thus appeared good at creating rapport with the clients. One proved, for instance, able to quickly create a comfortable atmosphere for a client to talk in by building on her existing experiences in making space for a wheelchair in a narrow room.

At this second stage, we can identify several additional ways in which the produced knowledge was being structured. First, the visits revolved around the experts-by-experience conversations with clients much more than their observations of the care homes, and much effort was made to select the 'proper' clients. Second, the experts-by-experience were not involved in the creation of the themes of the interview, and these themes appeared to largely structure how the interviews were conducted. The 'practical wisdom' of the experts-by-experience appears to manifest primarily in their relationship-building strategies with the clients.

3.3. Reports

The experts-by-experience wrote their reports by hand, and these were generally short and staccato. The experts-by-experience mostly noted information about how clients experienced quality of life. They wrote about the personal situation of the client, the aesthetics and atmosphere of a home and remarked on general policies and organization of the home as well as client participatory processes. This information was structured by the three given themes but was not determined by them. The experts-by-experience, for example, noted information about the feelings and emotions of clients or introduced their own topics. Process issues (e.g. about method) were written in the margins or mentioned afterwards. The experts-by-experience attempted to be as factual as possible in their reports and experienced the need to be objective:

'R: [. . .]. I also do not expect [the IGJ] to ask me [back] for a second pilot, because then I'll be screwed-up [verziekt].

I: . . . wasted, depleted. . .

R. Yes, you are probably already a bit screwed-up by then, eh.

I: I would not say that, but . . .

R: No, but, that you will already have gotten certain ideas. Then you're wrong, of course.'

[Expert-by-experience 2, Interview 1]

This expert-by-experience is serious in his assertion that it would be 'wrong' when he would acquire 'ideas' of his own. In this view a good expert-by-experience should not work with his own 'subjective' ideas nor get over-professionalized ('screwed-up'), but they should rather stick to the directly observable facts at hand. We found a similar emphasis on objectivity in the training of the experts-by-experience.

Inspectors and experts-by-experience often had lunch before the reports were fully written. Inspectors would ask direct questions to the experts-by-experience, taking care to also address the

needs and concerns of the experts-by-experience. This moment worked as the wrap-up for the visit. For the inspectors, information from the experts-by-experience served as part of the data collected during the day to judge the quality and safety of the care in a home. Inspectors wrote their own formal and public accounts, where they incorporated the information gathered by the experts-by-experience. Most often, inspectors used the information the experts-by-experience obtained about clients' everyday lives:

Expert-by-experience report:
'For meals often uses the living room or the recreation room (weekend). It is allowed to use the meal in the room if she wants to' [at living environments]
'If you've been away and you come back after dinner, they have even kept it for you. You can eat it later?' [quote at daily life]
[Expert-by-experience 2, Home 14-2]

Inspector's account:
"A client tells to an expert-by-experience that she eats in her room in the evening, she gets her own food in the restaurant, and when she comes home later, caregivers store her food and give it to her later."
[Account Home 14, p. 11]

Inspectors drew most on the direct quotes of clients provided by experts-by-experience and used these to illustrate other issues they were raising. It was difficult for the inspectors to process the information of the experts-by-experience. When inspectors could not compare the information from the experts-by-experience with other data, they would proclaim it 'N = 1' data: anecdotal evidence that has little place in their accounts. Inspectors noted how the experts-by-experience mostly followed the given themes and state: 'not to have written different accounts as a consequence of the pilot' ([27], p2). Another inspector 'does not know what the added value is here' [27]. To use the information of the experts-by-experience felt more like an 'obligation' [27], and not as valuable for safeguarding the 'bottom-line of quality' [27], which they argued is the core task of the IGJ.

In this third and final stage of the pilot, we can identify again how the knowledge in this pilot was produced. First, we see how the method used in the pilot structured both the information gained by the experts-by-experiences (e.g. written report) and the account written by the inspectors (formal, legally valid), which was structured by the instrument they used. The 'natural experiment' thus limited the inspectors to freely work with all of the information available. Second, we find how inspectors used the work and input of the experts-by-experience in their accounts, generally, as illustrations instead of relevant input upon which their formal judgments were based. As such, experts-by-experience were used to transfer information from clients, but their own perspectives on quality of care were less significant.

4. Discussion

In this pilot with experts-by-experience in the supervision of long-term elderly care homes, we might recognize what is called the 'emancipatory paradox' [5]. Whereas the enthusiasm for the empowering idea of client participation is clear, less attention is paid to the actual workings of the methodology used. This can lead to the repetition of pilots and programs without the integrative effort needed to judge their added value (cf [14,28]). It appears to be very labor intensive for the inspectorate to work with the experts-by-experience in this pilot, whilst the added value for information on individual care homes seems limited in this particular design. Our results show that throughout the different stages of the pilot a professional epistemology dominates the ways in which knowledge about quality of care is produced. Factual information

is repeatedly established as being more legitimate, ensuring that the experts-by-experience are unable, or feel compelled, to bring their own experiences in, except for when establishing contact and speaking with clients. We note a specific selection of active clients and informal caregivers and a focus on language (interviews, written reports), which are distinct from previous projects that focused on observations [14]. Moreover, this time we also note ethical issues (anonymity) and how legal and institutional responsibilities limit participants to explore possibilities. The dominance of the professional epistemology can, therefore, largely be understood from the design of the pilot, as it structures what is at stake and who can participate [22]. For instance, the lack of early involvement of clients in the development of the themes to use in their interviews appears to have made their involvement less worthwhile. Whereas this points to the need to involve clients early in efforts to work with experiential knowledge, this also underscores the need for different formats of participation to ensure diversity and representation of the most vulnerable and hard-to-reach groups of clients [21]. Such efforts generally seem to ask for an intensive and co-operative format, such as action research to include children's perspective [29]. Furthermore, the pilot casts doubt on the need for inspectorates to organize experts-by-experience to help supervise individual organizations, although a sectoral or thematic approach could have benefits. In fact, the experts-by-experience learned the most about the workings of the inspectorate itself. They appeared to value the inspectorate highly, illustrated by their pride in taking part in the pilot. Working with experts-by-experience might therefore open up new avenues for public accountability by inspectorates.

We find the tenaciousness of the professional epistemology remarkable in light of the enthusiasm espoused in starting and executing this pilot with experts-by-experience. An important part of its explanation lies in understanding the wider socio-political context of the inspectorate and the participants of the pilot. For one, historically, anecdotal experiential knowledge is valued less than knowledge claims for which validity can be ascertained through statistical means. The pilot itself has always had a political component for the inspectorate in response to explicit calls from Dutch government to take the client's perspective seriously [13]. More importantly, dominating ways of knowing are a cultural effect, not fixed but contingent, although dominating definitions in health risk policy appear to echo strongly in people's concerns about these risks [30,31]. Indeed, professionals' technocratic ways of knowing remain a measuring stick [5], and this measuring stick is upheld by way of the interactions between all participants in this pilot. Our results, therefore, underscore the strength of legitimated ways of knowing, as they persist in interactions aimed at challenging their dominion. Contrary to Rose's identification of the growing strength of authoritarian populism and its appreciation of the people as source of knowing, or advanced liberalism with an ethic of autonomy [18], here we identify the perhaps lasting strength of a rationality (or governmentality [32]) that maintains the highest regards for 'those who know what they are talking about' ([33], p. 195). Experts are, here, made responsible to define and value quality and safety of care and the practices through which these are appraised. Whereas this is might be valuable in its own right, when inviting clients, citizens or lay-people to the table without providing some form of control over what is at stake seems unlikely to be effective. In particular, this is because by 'disavowing division and foreclosing radical disagreement [such situations] will find itself confronted with [. . .] the reemergence of conflict' ([34], p. 1582). It is thus important to be 'bold and modest' [35] in addressing the tension between an epistemology of the 'people' and of the 'professional'; in particular, in new experiments with client participation it seems critical to leave room for expanding the notion of 'the people' to be involved so they are diverse in their experiences, histories, values and identities. One such effort might be patient-led

ethnographies that prove a rich source of information for improving healthcare [36]. We therefore call for further research on ways to engage clients in healthcare regulation that lead to truly valuing their own experiential knowledge.

5. Conclusion

In this paper, we have followed a natural experiment with the use of experts-by-experience in the supervision of long-term elderly care homes by the Dutch Health and Youth Care Inspectorate (IGJ). The pilot involved the institutional review visits of twenty homes for the elderly. Seven experts-by-experience were selected and trained by the IGJ to accompany inspectors on these visits. The experts-by-experience interviewed clients, made their own observations and reported their findings back to the inspectors who used these as part of their data to cast a judgement on the quality of care of the individual homes. However, whilst the experiment intended to open up valid new experiential knowledge of clients on the quality and safety of long-term care delivery to improve the regulation of long-term care, the methodology of the pilot structured the practices of experts-by-experience in such a way that this knowledge is unlikely to be opened up. Paradoxically, we find how a professional way of knowing is repeatedly valued more than the practical wisdom of clients in these experimental practices that are ostensibly aimed at valuing such experiential knowledge. We understand this in light of the broader socio-political context in which all participants of the pilot operate and see the tenaciousness of the professional way of knowing as a cultural effect. To deal with this cultural effect, we recommend that in future experiments clients might gain more control about what is at stake, that who is to be involved could be opened-up to include a more diverse range of experiences, and that the timing in which clients are involved seems crucial for their contribution to matter. We therefore call for further pragmatic and reflexive experimentation with, and research into, experiential knowledge in healthcare regulation.

Conflict of interest

None.

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