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Older Adults' Satisfaction with Medical Care Coordination: A Qualitative Approach

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This exploratory qualitative study aims to identify the dimensions of satisfaction with medical care and care coordination for older adults over age 70. Semi-structured interviews were conducted in spring 2015 with a sample of 18 people aged 72 to 90 years, living at home or in institution, as well as 4 informal carers looking after people suffering from cognitive problems.

All respondents (including informal carers), regardless of their type of accommodation, agree that the most important dimension in medical care is the quality of their relationship with health professionals. There seems to be a significant room for improvement in that relational quality and people's satisfaction which can be achieved often by means of simple gestures. Respondents evoke the importance of being well informed about their care process, having the opportunity to express themselves; and they stress the importance of communication and coordination between different healthcare professionals involved in their care.

In the context of an ageing population where the risk of chronic disease increases, improving care provision for older adults aged over 75, which accounts for nearly a quarter of healthcare expenditure, is identified as a major issue for the healthcare system (*Haut conseil pour l'avenir de l'assurance maladie*, HCAAM, 2011). The diversity of actors involved in care provision for this population makes it necessary to develop integrated approaches to care management, which are currently little developed in France. Ensuring quality care for the elderly people is complex because of the great diversity of situations and the num-

ber of health professionals and medical and social workers involved; but it is also due to patients' lack of understanding of the system as to the availability of care and services. In France, as in other countries, the number of initiatives to improve the overall care provision for frail elderly persons is increasing. However, the fee-for-service payment system in use which remunerates professionals for specific procedures and services rather than looking at patients' outcomes, does not foster an integrated approach. In this context, pilots "Seniors' health path" (*Parcours santé des aînés*, Paerpa), launched in 2014 in nine regions, aim to improve the over-

all care provision for older adults aged over 75 by financing a series of new interventions (Context page 5; Or, 2015).

Nevertheless, the knowledge about the quality of care for older patients, their expectations and satisfaction with their care, remains very limited in France. The notion of care quality, well developed internationally, covers the appropriateness, safety, and accessibility of care as well as patients' experiences (Kelly and Hurst, 2006). Patient experience, as a measure of care quality, is increasingly used and included in health information systems. A way to evaluate patients' sat-

isfaction is based on understanding their experiences of the care system. Patient experience does not simply reflect health outcomes or adherence to clinical recommendations but also includes more subjective dimensions - not easily measured. Thus, despite the development of increasingly varied measures, there is no consensus on the key dimensions for evaluating patient experience globally (LaVela and Gallan, 2014).

Therefore, this study aims to identify the major dimensions of quality of care process and satisfaction for older adults in French healthcare context, using a qualitative survey exploring the concrete experiences with the health system. It was conducted in 2015, using semi-structured interviews with 18 people aged 72-90 years, living at home or in institutions, and with 4 informal carers (Source and Method insert). The ultimate goal is to understand what the notion of satisfaction embraced as to care provision for older adults, in order to inform and accustom professionals and other stakeholders in the health system to the various dimensions of care quality. Identifying areas that are important for older patients and their informal carers is essential to improve their experience and satisfaction. This qualitative survey is the first step in the reflection about developing measurement tools such as questionnaires and indicators of satisfaction regarding care provision for older adults in France.

What does the literature say about patient satisfaction?

Studies in other countries and health systems tend to show that the level of patient satisfaction, and especially of the older people, is always higher when asked a general question rather than inquiring on more precise dimensions (Owens and Bachelor, 1996). Rather than direct questions on overall satisfaction, resorting on patients' experiences in concrete situations makes it easier to approach the notion of care quality and to identify areas for improvement (Berendsen *et al.*, 2009). In the literature, several dimensions have been identified as determinants of care quality and patient satisfaction (Figure

1). Krucien *et al.* (2014) show that people with multiple chronic diseases consider that regular information on their health status and treatments is essential for high quality care. Granting patients the opportunity to comment on the care and treatment provided by allowing them to involve in adjusting care to their needs and expectations effectively contributes to improving the responses by health and medico-social professionals (Donnet-Descartes and Dujardin, 2012). Studies show that the "patient-centered" approach (Bruus *et al.*, 2012) not only increases older persons' level of satisfaction but also promotes their recovery. This approach aims to take into account patients' needs and degree of autonomy, but also get them to participate in decision-making, in keeping with their values and preferences. Those who are informed and consulted about the treatments that will be provided perform better in terms of healing.

Another well-recognised determinant of satisfaction is the level of health workers' commitment, availability, empathy and humanity, as well as their personal qualities (Atherly *et al.*, 2004). This is especially important during a hospitalization episode, when patients feel particularly the need to be surrounded and reassured. Kindness and compassion from health professionals are also seen as a guarantee of care quality (Compagnon and Ghadi, 2009). The waiting times for an appointment and in the waiting room is also cited as a determining factor in choosing a health professional (Atherly *et al.*, 2004). Besides, the communication and transmission of information between GPs and specialists prove to be a central satisfaction element (Bentur *et al.*, 2004). In France,

F1

Dimensions of older people's satisfaction with their health and medico-social care, from the literature

In terms of organisation

- Ease in navigating in the health system
- Waiting time for obtaining an appointment
- Time spent in the waiting-room
- Time spent for obtaining care or in wards
- Discharge planning in case of hospitalization
- Information transmission among professionals

Concerning care experiences

- Quality of the relationship with health professionals
- Possibility to express one's views and be listened to
- Quality of the information received
- Participation in medical decisions
- Pain management

coordination among health professionals, but also among health, social and medico-social sectors, is identified as a challenge to improve the care quality for the frail elderly persons, which the system still struggles to meet (Bloch and Hénaut, 2014).

Consensus on important dimensions

The analysis of interviews shows that the elements mentioned as important for quality care and as determinant for satisfaction are the same for people living at home or in institutions as for their informal carers. The dimensions mentioned in the literature are found, and they can be grouped into two categories: the relational dimension and the organization of care (Figure 2). Informal carers agree that the system enables them to find some answers to their expectations but this is a time-consuming task that requires such investment and

F2

Relational and organizational dimensions of satisfaction for older adults, qualitative survey

Themes	Sub-themes
Relationship with health care professionals	Respect/dialogue: quality of listening by professionals and possibility to express views Involvement in decision-making
Organisation	Ease of access to the GP Waiting times for obtaining an appointment Waiting time in the waiting-room Excess payment borne by patients Articulation/communication between various health professionals; Place of family (informal caregivers)

Source: Qualitative survey IRDES, 2015. Score: 18 elderly people aged 70 years or more and living at home or in long-term nursing homes (Établissement d'hébergement pour personnes âgées dépendantes, EHPAD), plus 4 informal carers.

involvement that they sometimes feel in dismay. Finally, even though, overall, the stated elements are consensual, perceptions and priorities may, in turn, be sometimes different in the various groups surveyed.

The quality of the relation with health professionals: a crucial element for satisfaction

All the respondents consider that the relationship with health professionals is crucial to the quality of care and to their satisfaction. The trust they grant to health professionals builds up through the respect they are given, the feeling that they are listened and the possibility for them to express themselves and get involved in decisions that affect them. One of the respondents' highest expectations has to do with being treated with respect, particularly during interactions with health professionals and during treatment, which, it seems, is not always the case.

"They sometimes take us for old geezers; this gets on my nerves, it is really shocking, downright lack of respect".

Thérèse (88), lives at home

Small attentions and kindness are especially valued. A smile, a mere "Hello" or speaking directly to the person as well as gestures of respect are perceived as important qualities.

"She is so soothing, sweet, comforting and always has a smile. She can remember the last time I came to see her I was wearing a blue sweater; trifles like that, you know, it means I'm not just a number for her".

Monique (74), lives at home

The opportunity to interact with health-care professionals stands out as an important element of medical care satisfaction. During a consultation, the older adults come to seek comfort, besides care. They expect their doctors to have time for them and be able to speak freely with them.

"When I go see her to renew my prescription, she rushes through it, it's no use trying to ask something else, she won't even listen, I have to come back another time so I sometimes feel she makes short work of it".

Andrée (78), lives at home.

Family members or informal helpers confirm these remarks. It appears that, the way people are treated, especially when

they have cognitive limitations, may be of particular concern.

"Two men, and strong ones as well, came in to throw her in bed, well, it certainly wasn't the best thing to do. So, they didn't fuss over details. Then, they left her alone in her room, without feeding her [...] then finally the boss arrived and he said hello, which no one had cared to do so far".

Dominique, Léone's (94) informal carer.

In institutions, besides the relationship patients have with their health professionals, there is the issue of communicating with the nursing staff of the institution that assists patients in their daily lives.

"I have so much I would like to tell the nurse or even to the care assistant, but given my difficulty in talking, I'm so slow, they leave even before I get to the end of my sentence".

Pierre-Yves, 86, in a long term nursing home

Involvement in the care process emerges as a strong element of satisfaction for older patients. Most respondents stress the importance of explanations about their treatments as precisely and intelligibly as possible: how the care protocol is built, what are the different stages of treatment and the results of the required tests, etc.

"The surgeon explained very well everything, and that was important, he showed me the prosthesis he would place in my knee, I needed to know all about it".

Solange (82), lives at home.

When the frail elderly persons live in institutions, they are de facto assisted in a number of aspects in everyday life. Furthermore, their financial capital and personal assets are often managed by descendants. Consequently, they often feel dispossessed; besides, others get to deem what is good for them, sometimes without even consulting them, and order them about: it can feel very violent. As regards their health care, the situation is sometimes the same.

"One night, a male-nurse told me: 'Lie on the bed so I can put your diapers on'; it felt awful; when I need to go to the toilet, I usually ring and they help me go".

Marcelle (90), in a long-term nursing home.

When their cognitive status allows, respondents claim the right to have a look at their care scheme, they want to be informed of the care provided them and to know what drugs they are being administered.

"I never got any explanation; why am I never asked whether I need one? I was administered 5 or 6 medicines at the same time and I didn't know why I had to take them; once I was prescribed an antibiotic and it was discontinued overnight, without a word of explanation".

Colette (95), in a long-term nursing home.

When they live at home, the situation may be similar when patients are not able to understand what they are told. Sometimes, families also complain of a lack of feedback.

"The doctor gave my father a prescription for him to consult a specialist, but he [my father] was not able to explain why. He [the doctor] could at least have wrote a small note for us some kind of explanation, a sort of roadmap. Now, the prescription is there on the sideboard, and we don't even know what to do".

Frédérique, John's (88) informal carer.

The general practitioner's place is essential for overall satisfaction

The regular doctor's place, always a general practitioner in this sample, proves essential, regardless of how the older persons are accommodated. Either he acts as the coordinator: *"If you want, my GP is the one that centralizes it all"* - Sylvaine, 78, at home; or he may not do this, but according to respondents, he's the one who should play this role.

"Only the generalist, the GP can have the global picture and, most importantly, he is the only one to decide on prioritizing one sort of care over another".

Pierre-Yves (86), in a long-term nursing home.

In the three nursing homes (EHPAD, *Etablissement d'hébergement pour personnes âgées dépendantes*) that we visited, the organization was the same. Residents have the option of keeping their GP that they had when they lived at home or, if his/her practice is too far away, or if they think it would be more convenient, they have the option of being followed by a GP working with the structure. Retaining the GP who followed the person historically ensures care continuity but people also say it is reassuring because being admitted in the institution is already a great change and a source of considerable stress.

Thus, the interacting with a dedicated doctor, not of their own choosing, sometimes leads patients to feel distressed when

they see they do not have the ability to create a relationship with this doctor.

"She comes and visits five minutes and, presto, I never have time to explain my health issues properly".

Pierre-Yves, 86, in a long-term nursing home.

For people with one or more chronic disease(s) living at home, the referring doctor (GP) is consulted systematically when renewing prescriptions. Respondents in this situation are happy to point out that they have the possibility to see their doctor easily if they have an acute problem between two visits for prescription renewal and they are sensitive to the possibility that the GP can visit them in their home.

"At least, this is a doctor who drives to my home when I have a problem. He takes the trouble to".

Christiane (81), at home.

For the families, the place of the general practitioner is just as important for the older persons who are still able to manage the monitoring of their health condition.

"He is looked after by a GP, who is God on earth for him, he is super-nice with him, he worships him, my father is thrilled and so are we".

Frédérique, John's (88) caregiver.

The time spent in the waiting-room for a consultation is a source of dissatisfaction, not so for waiting times for an appointment

Contrary to the results reported in some countries, in this corpus, the waiting time for an appointment with health professionals is not considered a source of dissatisfaction for the older persons. When monitoring chronic diseases, appointments with specialists are usually taken from one visit to the other and anticipated well in advance for the visit to the GP, often quarterly. In case of acute illness, patients living at home have quick access to their GP. However, the enactment of social aids for home assistance is sometimes considered too long, leaving people in uncomfortable everyday life situations. This is mainly the case of one-time assistance after a hospital

episode. It is often alleged that the lack of coordination between the medical sector and the social care results in delays.

"... On the other hand, the waiting period to get a cleaning lady was too long. She came two weeks after I had returned home, it was too late".

Solange (82), at home

Moreover, the time spent in waiting-room to consult the GP appears to be a source of dissatisfaction, especially when the GP only offers open consultations without possibility to make an appointment.

"If you wish to avoid having to wait, you've got to be there at quarter or even twenty to eight, otherwise, you might waste your whole morning there".

Andrée (78), at home.

During outpatients' visits at the hospital, the older persons often deem waiting times before consultations are excessive, all the more so if they are frail. According to informal carers of the oldest-old patients in frail condition, the episode of hospital-visit is a worrisome experience, a source

SOURCE AND METHOD

The semi-structured interview. The method of semi-structured interviews partly guide respondents' discourses around various themes that are previously defined and documented in an interview guide. This guide does not lock respondents' discourse in predefined questions; it leaves them the opportunity to develop and steer what they have to say; and the various themes are being addressed during all their statements (Quivy & Van Campenhoudt, 2011). Interviews are structured around the key dimensions identified in the literature (Figure1), while leaving the possibility to bring out new, respondent specific, elements. While it does not claim to be representative of the results, the qualitative analysis allows identifying the important dimensions of satisfaction from patients' and their informal carers' perspective, from specific cases.

T. Sample Description

	Hospitalisation (over the past 12 months)	Patient's mental health	Type of accommodation	Respondent	Number of usable interviews
Group 1	Yes	Without	At home	Patient	5
Group 2	Yes	With	At home	Informal carer	4
Group 3	Yes	Without	In nursing homes	Patient	6
Group 4	No	Without	At home	Patient	4
Group 5	No	Without	In nursing homes	Patient	3

Source: Qualitative survey, IRDES, 2015.

Score: 18 elderly people aged 70 years or more and living at home or in long-term nursing homes (Établissement d'hébergement pour personnes âgées dépendantes, EHPAD), plus 4 informal carers.

The sample reflects the diversity of older people's situations in terms of accommodation (at home or in long-term nursing homes, Établissement d'hébergement pour personnes âgées dépendantes (Ehpad)), state of health (physical and mental) and health care experiences (hospitalization during the last twelve months and existence of chronic disease). Hospitalization is indeed a typical situation in terms of organization and coordination, involving a large number of players caring for patients. Included in the survey are more or less fragile people living at home and long-term nursing homes (Table). By interviewing their informal carers we also tried to approach the quality issues that can be experienced by people with cognitive difficulties. Informal carers provide 80% of the aid received by the dependent elderly (Ghent S. et al., 2014). Since they are involved in the lives of people with loss of autonomy, these are able to distinguish crucial elements of medical care to the elderly. Several different groups are defined (table). In each of them, 3-6 individuals were interviewed. Respondents' are 72 to 90-year old (77 years old on average); the vast majority are women (18 in 22) and most live in Paris (50%) but also in more rural districts such as the Mayenne, Puy de Dome, the North and Picardy regions. Participants were

recruited on a voluntary basis through some acquaintances of investigators and professionals involved in the experiment, dubbed "Seniors' health path" (Parcours santé des aînés, Paerpa). The initial sample lost 9 individuals. Some interviews that had been conducted were excluded from the analysis because they proved unusable. This is especially the case of those carried out with Alzheimer elderly patients (2 individuals). Interviews conducted with individuals living in nursing homes, poorly informed beforehand about the conditions of implementation and on the subject of the investigation or whose expression, comprehension and concentration faculties were too limited to achieve quality exchanges (7 individuals) were also removed from the corpus.

Data collection was spread from April to June 2015. One on one individual interviews were conducted with every participant, and durations ranged from 6 to 60 minutes (26 minutes on average). The people living at home were interviewed at their homes. In long-term nursing homes, interviews were most often conducted in a drawing-room dedicated to meeting the family, in the coordinating doctor's office, or in residents' bedrooms. Informal carers were interviewed in an isolated corner of a café or in IRDES premises.

Results analysis. Studying the corpus of the fully transcribed interviews was based on a cross-thematic analysis. Returning to predefined assumptions and in view of emerging themes, an analysis grid of the main dimensions expressed in interviews has been built (Figure 2).

[†] For the sake of anonymity, interviewees' names have been changed.

Seniors' health path (*Parcours santé des aînés*, Paerpa) pilots, launched in 2014 by the *Direction de la Sécurité sociale* (Direction of Social security) in nine territories, aim to upgrade the care and living conditions of older people aged over 75 years old as well as their families. The evaluation of impact of the Paerpa pilots at the national level has been entrusted to the Institute for research and documentation in health economics, (*Institut de recherche et documentation en économie de la santé*, IRDES) followed by a committee headed by the *Direction de la recherche, des études, de l'évaluation et des statistiques* (DREES). This evaluation will assess likely effects of Paerpa projects, measuring their early outcomes observed by way of common indicators. This study which has been conducted outside the assessment aims to provide concrete elements to implement a satisfaction survey with older adults who are involved (or not) in the experimentation.

of fatigue and severe stress. Conditions during the waiting time are sometimes difficult and unsuitable, indeed.

"When someone has an appointment at 9, you might not be out before 13:30, if you're lucky! [...] And you have to stand in a corner, in dreadful conditions. I mean, I think this amounts to mistreating elderly people".

Carole, volunteer caregiver working in an association

Besides, for the older people, going to the emergency ward means also having to wait so long it is hardly bearable.

"Fire-fighters drove me to the emergency ward and it's sheer hell, there. We had to wait 6 hours, plus 2 more for the x-ray results".

Monique (74), at home.

The cost of care can also be a problem when the patient is on low income

When addressing the general matter of satisfaction with care management, the cost issue is sometimes raised. Even if the patient's healthcare is financially supported 100% for a number of diseases and is covered by a supplementary health coverage, upfront fees for a number of procedures, or the level of excess fees, is perceived as excessive financial efforts, given some people's low incomes.

"I told her: "Doctor, you can't ask me so much, if I pay you this, I won't have any money left to

tide me over the month, so alright, I'll pay you, but please, let me do it in three instalments".

Sylvaine (78), at home.

Lack of coordination among various stakeholders is a burden on families

For people with multiple pathologies, the matter of the relationship between various care actors seems to be very important. At the end of an hospital episode, some older persons report a feeling of abandonment; at this point, they often need support to go back their homes. The most frequently raised issue is helping the person cope with daily tasks.

"At the hospital, they only bother about what is strictly medical and when you are discharged, "Good luck to you, you're on your own!".

Yvonne, 72, at home

Informal carers also expressed the need to manage the schedule of nurses', physical therapists', referring doctors' and other caregivers' visits, since patients are often unable to coordinate each professional's interventions. This role often accrues to family members, who sometimes ask associations for help, to reduce their own involvement. When informal carers do not get any support from specialized structures and take on this task themselves, the investment required may be a heavy burden and a significant source of stress for them.

"The doctor and nurses do communicate with each other and they make sure they do not visit patients at the same time, and when a problem arises, it is easy to call them. Now, it is rather complicated with the physiotherapist. More than once, he has arrived at the same time as the nurse; they have bickered, and he had to wait. Eventually, they have asked me to make arrangements to manage their visits more rationally".

Dominique, Léone's (94) informal carer.

Moreover, patients have a very positive view of the coordination carried out by an association; they feel safe, accept the proposed organization of course, and they are aware that, without such coordination and assistance, maintaining home would not be possible.

On the other hand, to make sure patients' overall care is guaranteed, it's important for them that all stakeholders share information on their condition. As it turns out, this continuity is not always warranted, for

example when transferring from one hospital to another, or from one ward to another.

"One of the problems with hospitals is that they don't share information. Had they had my medical file on my heart condition when I arrived there, they would have avoided doing the tests all over again, three times as well, especially when you think the costs [for social health insurance], too.

Maryvonne (83), in long-term nursing home

Especially as patients think that having access to their medical dossier is an important step: its content is the best way for patients to get all the information they need on their own health state and on the treatments provided; it asserts the work has been performed.

"I was very well taken care of, I was discharged on time, and they gave me two copies of my dossier with information about which doctor performed which protocol".

Yvonne (72), at home.

For people living in long term nursing homes, the file is transmitted less frequently. And when it is, it often bypasses the patient and is sent directly to the nursing home. Besides great frustration, patients feel great dissatisfaction.

"When I was discharged, I took my dossier along, but when I arrived here, they took it, I hadn't had the time to look at the results, so I asked the care assistants and they told me I would have to ask the GP, because it's up to him to communicate results".

Marcelle (90), in long-term nursing home.

Apparently, when a patient is admitted to hospital, errors occur that could have been avoided if the hospital team had had the patient's medical record at their disposal.

"What I realized is that once the GP has sent the patient to hospital, he stops dealing with the dossier altogether. The relationship is de facto discontinued. He was given a medicine that was totally contraindicated with his usual treatment at the hospital. He would stick his spoon at the top of his head and was unable to stand".

Frédérique, John's (88) informal carer.

* * *

This qualitative survey, conducted with a small sample of people, identified some key elements of satisfaction with health care provision from the point of view of older persons and their informal carers, and brought up new elements. Recall, however, that the sample is not representative of the general population and, among other

issues, women and white collar professions are overrepresented. Moreover, some specific elements of care quality, in hospitals especially, such as pain management, safety, etc., were not discussed during the interviews. The objective was to understand the diversity of factors contributing to the satisfaction with overall care provision. Despite limitations and in the context of French care, this exploratory survey confirms the main dimensions of care quality and satisfaction, already identified in the literature. It is worth noting that both elderly people living at home or in institutions and their families agree that caring gestures of health professionals can greatly improve the quality of the relationship and therefore the experience of older patients as well as their informal carers. In many cases, courtesy, an attentive listening or a clear explanation from health professionals address the need for respect the older adults feel, and help to improve their satisfaction. Moreover, respondents of this survey clearly claim their right to information about their health and treatments as they are keen on being involved in decisions affecting them.

Yet, different from what some English studies showed, waiting time for an appointment does not seem to be a source of dissatisfaction here. The treatments of chronic diseases are planned in advance, so appointments with the GP or specialists are all the more easily anticipated as the older adults generally have a more flexible schedule. On the contrary, waiting times and conditions in doctors' offices or in hospitals are significant sources of stress and dissatisfaction. Interviews have also pointed to some new dimensions. The out-of-pocket payments for some treatments are said to be too high compared to some respondents' income and is cited as problematic. Moreover, both for people living at home and for those in institutions, coordination of their care by the general practitioner is a means to improve their experience of the care system.

Considering the continuous rise in life expectancy and health needs of our ageing society, it is necessary to adjust the health system to improve the care of older patients, who often have multiple chronic

conditions. Collecting and integrating information on older patients' experiences and preferences about their care is crucial for several reasons. The point is not only to improve the quality of their medical care and care pathways but also to strengthen their position in the health system as active and independent people. Studies in social sciences can support this approach (Balard *et al.*, 2013; Le Galès and Bungener, 2015) but, to date, there is no specific investigation in France that compares older adults' experience and their satisfaction with their care.

While this qualitative survey provides some useful lessons on key dimensions of satisfaction for older adults, the next step would be to conduct a broader survey to quantify these elements in order to obtain representative results in different areas/regions. Asking seniors about their experience of health care services would give the possibility to monitor the level of perceived quality of care but also to identify the problem areas and find solutions ♦

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