Research paper

Exploring representations and experiences of case-management users: towards difficulties and solutions to leading qualitative interviews with older people with complex living conditions

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ABSTRACT

Background By matching needs to resource services, case management could be a useful tool for improving the care of older people with complex living conditions. Collecting and analysing the users’ experiences represents a good way to evaluate the effectiveness and efficiency of a case-management service. However, in the literature, fieldwork is very rarely considered and the users included in qualitative research seem to be the most accessible.

Aim This study was undertaken to describe the challenges of conducting qualitative research with older people with complex living conditions in order to understand their experiences with case-management services.

Methods Reflective analysis was applied to describe the process of recruiting and interviewing older people with complex living conditions in private homes, describing the protocol with respect to fieldwork chronology. The practical difficulties inherent in this type of study are addressed, particularly in terms of defining a sample, the procedure for contacting the users and conducting the interview. The users are people who suffer from a loss of autonomy because of cognitive impairment, severe disease and/or psychiatric or social problems. Notably, most of them refuse care and assistance.

Results Reflective analysis of our protocol showed that the methodology and difficulties encountered constituted the first phase of data analysis.

Conclusion Understanding the experience of users of case management to analyse the outcomes of case-management services requires a clear methodology for the fieldwork.

Keywords: case management, elderly, fieldwork, interview, qualitative methods
Introduction

The elderly with complex long-term physical or social living conditions constitute a real challenge for professionals and the healthcare system in general. The Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA-France 2006–2010) was a pilot project involving case management to improve their care. The aim of PRISMA was to evaluate the benefits of case management using a qualitative approach based on comprehensive interviews, with researchers continuously analysing their data throughout the study. This type of research has been carried out previously. It implies that frail users of case management are willing and able to participate as key participants or informants.

The users of case-management services suffer from loss of autonomy for various reasons, e.g. cognitive impairment, severe disease and/or psychiatric or social problems. Most of them refused care and assistance. Interviewing them was challenging. Notably, we did not include those easiest to interview. For ethical and scientific reasons, we chose not to exclude the frailest or those suffering from dementia. Analysis of the sequential steps of the interview process provides a broad understanding of what this type of protocol implies, without ignoring its weaknesses and limits. Indeed, clear analysis of fieldwork constitutes the first phase of the research process. It gives weight to the subsequent analysis of the users’ representations and experiences with case-management services and prevents several biases.

How this fits with quality in primary care

What do we know?

There are many ways to evaluate the outcomes of a case-management service. The methodology of follow-up studies using validated tools and indexes has been extensively discussed. Some studies based on qualitative inquiry used interviews with patients. This methodological strategy obtained very informative results concerning the perceived role, function and skills of the case manager, and conclusions drawn about their function. However, details of fieldwork are lacking, perhaps constituting a bias concerning the results obtained. Very often, users of case-management services are frail individuals, who are difficult to meet and interview. This very rarely discussed, but critical point is almost neglected in the literature.

What does this paper add?

In the fieldwork described herein (2009–2010), the users of case management were older people with complex living conditions residing in Paris. Some of them suffered from loss of autonomy for various reasons, e.g. cognitive impairment, severe disease and/or psychiatric or social problems. Most of them refused care and assistance. Interviewing them was challenging. Notably, we did not include those easiest to interview. For ethical and scientific reasons, we chose not to exclude the frailest or those suffering from dementia. Analysis of the sequential steps of the interview process provides a broad understanding of what this type of protocol implies, without ignoring its weaknesses and limits. Indeed, clear analysis of fieldwork constitutes the first phase of the research process. It gives weight to the subsequent analysis of the users’ representations and experiences with case-management services and prevents several biases.

Conceptual framework

Interviewing old people, including those with dementia

Assessing the impact of a phenomenon (here, the implementation of a case-management service) on a population implies interviewing the population concerned. Our methodology took the view that the subject’s perspective constitutes a valid research input that can be used to take into account the effects of the project. We did not consider cognitive impairments a sufficient reason to exclude people. In agreement with Cotrell, we consider that ‘the absence of the patient’s perspective on dementia has led to a lack of representation of patient needs in the selection of care strategies’.

The user’s subjectivity as a data source

Qualitative interviews were used to discern informants’ mental representations and to understand ‘the meaning of respondents’ experiences and life worlds’. In this setting, the interviewer must be as non-directive as possible to avoid the risk of formatting the informant’s speech. We attempted here to determine the informant’s psychological state from interviews centred on his/her conceptions, reasoning and subjective logic.
Practical considerations

The researcher responsible for the interview, the major instrument of data collection, had prior experience in qualitative interviewing of older people. The researcher began by contacting case managers to access potential informants, contacted those individuals, conducted the interviews in their homes, and then transcribed and interpreted the data (Figure 1). The fieldwork in question was undertaken when the case-management service had just been implemented in Paris, in 2006–2010. Five case managers had a total caseload of 40 elderly service users.

Informants’ inclusions

The first step of the inquiry was to select key informants. It is imperative that the researcher’s work did not compromise the clinical relationships established. The objective was to select users who would not refuse the interaction and would be able to have meaningful interactions with the researcher. The researcher organised several meetings with the case managers to provide them with clear information on the objectives and methods of the study.

Making users informants was difficult. Among the 40 potential elderly informants, ten could not be included because they had begun using the case-management services too recently, five were temporarily or permanently not living in their homes (because of hospitalisation) and three had refused (at that time) a case manager’s assistance. Eight were excluded because of paranoid delirium or major and generalised anxiety. Three non-French speakers were excluded, as were two with cognitive disorders and one because of complete deafness. One user died just before the fieldwork started. This highlights the difficulty of the inclusion phase of this type of research. This crucial point illustrates how complex this kind of inquiry can be. Unfortunately, previous researchers did not expose how they selected and included their informants. The users included in the study are described in Table 1.

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**Figure 1** Flow chart of the entire meeting process from organising the first contact to the interview
First contact

Making contact: a phase fraught with obstacles

Making contact partially conditioned the continuation of the fieldwork process, as this was the time when informants formed their idea of the research and the interviewer. To avoid any misunderstanding of the researcher’s request and facilitate the intervention, case managers were asked to explain to users that they would be contacted soon by a researcher and to distribute a brochure describing the study’s objective and providing the researcher’s photo and telephone number. Immediately, two people stated they did not want to receive the researcher in their homes. The others were contacted directly by the researcher by phone. Each call turned out to be difficult, particularly because of hearing impairment. The researcher was transferred to a third party, present in three users’ homes at the time of the call. Through these intermediaries, a meeting could be scheduled. Two other people aware of the researcher’s upcoming call agreed to set up a visit. Another strategy for making contact, which yielded two visits, consisted of asking the case manager to set up a meeting with the person during a home visit.

Reaching the informants

To avoid the risk that informants would forget the meeting, the time between the phone call and the appointment date did not exceed three days. Despite that precaution, one informant forgot. She finally opened the door after the researcher patiently reminded her of the appointment.

The meeting took place in each elderly person’s home. It was difficult for the researcher to gain access to the homes of users with disabilities. Mrs D was confined to a wheelchair and could not reach the button that opened the door to her building, so the researcher had to ring neighbours’ bells until one of them consented to open the door. Mrs G no longer left her home and did not open the door to anyone except her caretaker and her son, so the researcher had to first speak with her caretaker to gain access to the informant.

Table 1 Elderly case-management users included in the first phase of fieldwork

<table>
<thead>
<tr>
<th>Name</th>
<th>Age (years)</th>
<th>Key elements of each informant’s profile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs D</td>
<td>82</td>
<td>Heart disease and Alzheimer’s disease</td>
</tr>
<tr>
<td>Mr G</td>
<td>80</td>
<td>Frail and confused</td>
</tr>
<tr>
<td>Mrs C</td>
<td>78</td>
<td>Husband in nursing home; frail; huge financial problems</td>
</tr>
<tr>
<td>Mrs G</td>
<td>88</td>
<td>Widow; frail and depressed</td>
</tr>
<tr>
<td>Ms H</td>
<td>84</td>
<td>Single woman; frail, bedridden</td>
</tr>
<tr>
<td>Mrs Z</td>
<td>90</td>
<td>Widow; frail, partially deaf and blind, refused care</td>
</tr>
<tr>
<td>Mr R</td>
<td>82</td>
<td>Married; stroke, hemiplegic and speechless</td>
</tr>
<tr>
<td>Mrs BC</td>
<td>78</td>
<td>Married; Alzheimer’s disease</td>
</tr>
<tr>
<td>Mrs B</td>
<td>86</td>
<td>Widow; isolated, Alzheimer’s disease, conflict with neighbourhood</td>
</tr>
<tr>
<td>Mrs GB</td>
<td>90</td>
<td>Widow; Alzheimer’s disease, frail, refused care</td>
</tr>
</tbody>
</table>

Introduction of the researcher

The first few face-to-face minutes determined whether the informant would agree, or not, to continue with the interview and its audio recording, and sign the informed consent form. Given the cognitive and memory problems of some older people, the researcher deemed it necessary to reintroduce himself. This phase of the inquiry was critical, because the informant’s perception of the researcher could strongly influence the interaction. Contrary to Johnson’s advice, the researcher did not use polite conversation icebreakers...
to avoid adding confusion to the situation and directly
focused on the reasons for his presence.\textsuperscript{14}

One informant said that she accepted the visit only
because she was interested in the research, flattered to
receive a researcher and pleased to have the company.
Most other informants assumed that the researcher
was a colleague or superior of the case manager who
had introduced to them.

Informed consent and audio recording

Eight informants did not want to read the informed
consent form or have the researcher read it to them,
but wanted to sign the form nonetheless, sometimes
after the researcher re-explained its content. One
informant signed the form before knowing what it
was about, and another only agreed to sign it at the end
of the interview, after having read it in detail and
asking questions for 20 minutes. One user said that he
greed to the interview but then refused to sign the
consent form; he could not be included in the re-
search. According to Warren (p. 89) ‘Some subjects
may not see written consent forms as at all protec-
tive’.\textsuperscript{10}

This formality provided insights into the inform-
ants’ profiles and their general attitudes concerning
visitors. Some informants thought that, by signing,
they were committing themselves to something further,
which proved they were at least partially aware of their
vulnerability and the risks they might incur by signing
a form. Although they claimed to understand what
they were signing, such comprehension could not be
verified. It is impossible to determine whether some-
one, with or without dementia, is 100% informed and
understands the content of the consent form. Nonethe-
less, they expressed their agreement and this should
be taken into account. The desire to participate in the
study and the agreement provided via the signed consent
form were also highly dependent on the circumstances
of the exchange, the informant’s emotional state at
that precise moment and his/her desire to please the
researcher.

All the informants gave their consent for the use of a
tape recorder. One user agreed to the recording, but
specified that he would sign the informed consent
form at the end of the interview, which he finally
refused to do, which led to his exclusion, as stated
above.

The first exchanges between the researcher and the
informants revealed some clues about the personality
and general attitude of the users towards caregivers.
For example, one person, who seemed very reluctant
to be interviewed, also appeared to have a general
attitude of refusing help. Some informants’ great
enthusiasm about the interview possibly revealed a
need for human exchanges and feelings of solitude or
abandonment. From the very first moments, when
consent to the interview was discussed, informants’
attitudes clearly revealed their sense of self-determined
identity. In addition, the refusals confirmed that the
case managers did not direct the researcher only to
users who agreed to participate.

The interview itself

Defining the level of interaction

Any inconvenience engendered by the interview had
to be limited as much as possible. This required
limiting the number of questions, thereby steering
the interview towards what might be perceived as a
teacher–pupil interaction. Thus, the interview began
with very general topics, such as, ‘To begin, since I
do not know you, I’d like you to tell me a bit about
yourself, whatever you feel is important, so that I can
get to know you’. Thereafter, the interview was oriented
towards the informants’ daily lives, asking questions
about their daily routines and then asking them to talk
about their needs and problems, and, if possible, on
how case management contributed to their situation.

Upon hearing the informants’ narratives about
their situations, the researcher felt mixed emotions,
somewhere between empathy and compassion for
them, and also a sort of guilty conscience described
by Izard.\textsuperscript{16} The researcher had the sensation of betray-
ing them, by listening to their difficulties and leaving
them without providing help.

The users’ ways of speaking gives
insight into their general attitudes
towards services: prolific informants

According to Wenger (p. 265), older people are
‘willing to help and really like the company’.\textsuperscript{15} Indeed,
the users in our study were, for the most part, relatively
isolated individuals (partially explaining why they
were case-management users) and the study provided
them with a unique opportunity to talk about them-
selves. For many, the researcher appeared to be the
only person to visit them simply to listen to them,
without formulating any particular request. For these
individuals, case managers co-ordinating users’ lives
with home caregivers or simply asking questions could
be experienced as a form of aggression. For some
informants, the researcher seemed to provide an oppor-
tunity to express themselves on subjects of importance
to them other than housekeeping and often forsaken
by their usual visitors.
Going with the flow and maintaining control of the interview

Most informants took advantage of an unrestrictive interlocutor’s presence to monopolise the conversation.

All informants tended to turn the conversation towards their life stories. This was highly informative because comprehension of the complex living situations was often related to past events in their lives. However, the informants’ pleasure had to be managed, because their stories did not always concern the research topics. Although frail, several informants exhibited remarkable abilities to control the interview and orient it towards the themes of their choice. Depending on the intellectual, emotional and behavioural characteristics at the moment of the interview, they used a variety of strategies to achieve that goal. One female informant was very directive, interrupting the researcher as soon as he attempted to redirect the conversation with phrases like, ‘Wait, I’m just finishing...’ or ‘No, but I haven’t talked about...’ So, her interview lasted nearly 1 hour and 45 minutes, during which she systematically ignored all the researcher’s questions or attempts to refocus the discussion.

Two other informants used a different strategy to retain their turn in the conversation by directing their comments/responses towards important affective events in their lives, such as the death of a spouse, that prevented the researcher from interrupting. Having rapidly understood the researcher’s obligation to listen to them, the informants, despite their frailty, were highly skilled in interacting. These people, whose power to act on their environments and others had considerably diminished, found the research interview to be a way of exercising a form of authority, obliging the researcher to either listen to them or accept their refusal to participate.

The informants’ role-playing

During an interview, as in all types of social interactions, part of the protagonist’s identity comes into play. A stage is set up between the speakers, in which both attempt to save face, preserve their image and gain recognition through their self-proclaimed identity. For these informants, the research interview provided an opportunity to project themselves as they would like others to perceive them.

Accessing users through case-management services was non-neutral. The users were targeted by the service because of their difficulties with everyday activities. So the informants strove to distance themselves from their situation of ‘aid receiver’ by strongly distinguishing between their current context and their identity. Therefore, they projected positive aspects of themselves throughout their narration. Their denial of difficulties and refusal of assistance could partially be explained by this claimed identity. Their reluctant recognition or belittling of the case manager’s work can be analysed in part by their self-projected image, which consisted of not attaching importance to this assistance or to their daily difficulties. By doing so, they frequently denied responsibility for their difficulties and placed the blame on a physician or caregiver they deemed to be incompetent. When they talked about the aid they received, they claimed it was not very helpful or saw it as unimportant.

Conclusion

Considering ethical and scientific perspectives, interviewing case-management users appeared to be a very useful way to evaluate the service’s performance. Nevertheless, old people with complex living conditions did not constitute an easy population to work with. The informants included had their own reasons to participate in the research that determined their behaviour and words during the interaction. Discussing their difficulties with them and understanding their representations of case management was extremely complicated, when they did not want to accept their needs or wanted to project themselves as being fully autonomous.

Paying attention to the informant’s subjective experience implies analysing their words in the light of the context in which the interview was conducted. From this perspective, the elderly with complex living conditions were able to dominate the interaction by using different strategies, like playing on the researcher’s compassion.

Finally, the most informative point in terms of methodological reflection is the manner in which the specificities and difficulties of a qualitative interview with this type of informant is, in itself, a source of data that can contribute to better understanding this population, questioning our own research methods and the issues targeted by our study.

Concerning the user’s mental representation of case management, a reflexive analysis of the methodology and the informants’ attitudes during the research interview re-established the subject’s position. Indeed, although the informants were first perceived as beneficiaries of an experimental service, they also proved to be major actors in that service, by refusing it and/or minimising the aid received. These findings can constitute an important line of research.
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REFERENCES


ETHICAL APPROVAL

The French Committee for the Protection of Human Research Subjects for Île-de-France approved this study. All the participants involved in this research read the information letter and signed the informed consent form.

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PEER REVIEW

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CONFLICTS OF INTEREST

None declared.

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