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Perceptions, representations and logics of action of urinary incontinence in institutionalised elderly people: a concurrent mixed study protocol

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ABSTRACT

Introduction Urinary incontinence (UI) is a major public health problem. It affects many institutionalised elderly people. In the literature, the phenomenon is well defined. Its frequency, risk factors, individual and social costs, as well as the different therapeutic approaches, are described. However, there are few publications on its representations, both from the point of view of the patient and that of the carers. However, the literature shows that a better understanding of the social representations of this phenomenon could be a vector for improving care. We aim at understanding the perception of UI, to model its representations and to understand and characterise the logics of action in terms of protection.

Methods and analysis This will be a mixed-method concurrent study with a quantitative and a qualitative component. Data will be collected through 100 semistructured interviews, 8 focus groups and 10 000 surveys from 4 populations: institutionalised elderly people, caregivers, carers and individuals from the general population. The qualitative part will be analysed both manually and with ATLAS.Ti software, which will be used to centralise and organise all qualitative data collected. For the analysis of the quantitative part, a descriptive statistical analysis and a logistic regression type association will be carried out. These analyses will be enforced using R software. Then, an overlay and combination of quantitative and qualitative information for the triangulation analytical approach will be carried out. The study started in August 2021 and will continue until June 2022.

Ethics and dissemination The study protocol was approved by the Descartes ethics and research committee on 1 June 2021, with the IRB number 00012021-43. The findings will be published in peer-reviewed journals and presented at national and international conferences.

Trial registration number This protocol was registered with the Research Registry on 12 July 2021 and is numbered researchregistry6965.

Strengths and limitations of this study

► A large-scale study that focuses on the representations of urinary incontinence of four categories of individuals.
► A concurrent mixed methods that contributes to a more complete approach of the urinary incontinence phenomenon.
► Several challenges will have to be met: succeeding in recruiting the very large number of participants and avoiding bias.

INTRODUCTION

Urinary incontinence (UI) is defined as an involuntary and uncontrollable flow of urine through the urethra.[1] Depending on the mechanism of onset, there are three forms: stress UI, bladder overactivity incontinence and mixed UI. There are many risk factors. These include age, number of pregnancies, diabetes, obesity, a history of obstetric or bladder surgery, neurological diseases and intense sport activity.[2] UI is a major public health problem, affecting almost 9% of the world's population.[3] However, it is important to note that women are three times more affected than men and that its prevalence increases with age.[4] In fact, UI concerns more than 40% of women over the age of 70[4] and 60%–90% of residents in nursing homes.[5] Moreover, its consequences are multiple. The individuals concerned are obviously affected on a social level. Studies show that UI can be responsible for isolation, withdrawal, feelings of shame and low self-esteem, which can sometimes lead to depression.[6 7] UI is also associated with reduced quality of life, sleep disturbance and emotional distress. A randomised controlled trial[8] found UI to be a predictor of depression, along with mental and physical health. In addition to these consequences, several studies conclude that it is one of the primary causes of institutionalisation of elderly people.[9 10] Unfortunately, the literature shows us that once institutionalised, elderly people are hardly involved in the decision managing their UI. They are

dependent on the institutional structure and the carers' representation of UI.[11] The loss of physical control over bodily fluids puts the individual's identity and dignity at risk. The acquisition of knowledge is the basic assumption needed to improve UI management practices.

Social psychology explains that social representations play a major role in learning. Indeed, defined by Abric as 'an organised set of information, opinions, attitudes and beliefs about a given object', these can be an obstacle to the appropriation of knowledge. Therefore, the acquisition of knowledge and the modification of specific representations of UI could play a role in improving its management. But there are few publications on social representations of UI, both from the patient's point of view and that of the caregivers or the carers. However, a qualitative empirical survey[12] was carried out among 3300 carers to understand their representations of UI. A questionnaire was sent to doctors, nurses, midwives and care assistants. This study showed a link between better understanding of representations and improved management of this health problem. It shows that a better understanding of the social representations of this phenomenon could be a vector for improving care. Moreover, several authors have advocated a multimethod approach to the study of social representations.[13]

This study aims at investigating the social representations and logics of action that are put in place to improve the management of UI. To do this, it was chosen to explore the beliefs and opinions of four categories of people on UI: elderly people in nursing homes; their caregivers, who are often close to the elderly person, and who provide them with permanent or temporary help in their daily life[14]; their carers, nurses and care assistants, but also individuals from the general population. It will also look at the logics of action implemented in nursing homes in terms of protection, prevention of incontinence and preservation of continence. The main research questions are: what are the social representations of UI among institutionalised elderly people, their caregivers, their carers and also among individuals in the general population? What is the logics of action in terms of choice of means of protection? What is the logics of action in terms

of prevention of UI and preservation of continence? Answering these questions will make possible to adjust practices, develop patient empowerment and, depending on the results, propose innovative solutions for the management of urinary incontinent patients.

METHODS AND ANALYSIS
Study design
To meet the objectives, a two-part mixed-method study will be carried out (see figure 1). The qualitative part, with a descriptive and comprehensive aim, will be implemented using a phenomenological approach according to Hüsserl.[15] The quantitative part will be transversal. It will have a declarative cross-sectional aim. These data will be collected in private and public nursing homes, but also in the general population, throughout France and in part of Belgium. These data will be collected by researchers over a period of 6 months. The results will then be triangulated in order to compare them to determine their convergences, differences and possible combinations.[16]

Study setting
In this study, the population should naturally include elderly people in nursing homes, their caregivers, carers (nurses and care assistants) in private and public nursing homes, but also people of all ages from the general population. The multiplicity of the population is justified by the fact that each of these groups of individuals has a different relationship with UI. People in nursing homes may have been affected for several years, or may live with people who are affected. Relatives and caregivers may have dealt with the urinary problems of these elderly people and talk to them about this complex subject. Care assistants and nurses take care of urinary incontinent patients. The general population is more alien to the problem, but may know people who are affected or may be affected themselves. It will therefore be necessary to collect the opinions, beliefs and attitudes of several categories of individuals who have different relationships with the subject of representation. This choice is justified in the literature, where it is recommended to question a
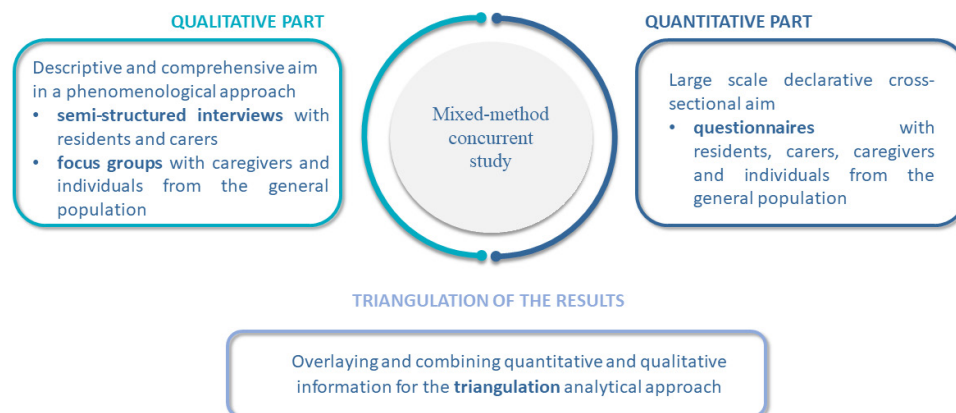
Figure 1 Study design.

large panel of individuals in order to achieve saturation of representations.[17] This heterogeneity will allow us to understand the existing representations of UI as precisely as possible. Recruitment will be on a voluntary basis. To participate in this study, respondents must be at least 18 years old and French or French-speaking Belgian. For institutionalised elderly people, they must be able to understand and answer questions.

Sample size

Semistructured interviews will be carried out with carers and elderly people in nursing homes. After a call of participation throughout France and part of Belgium, a list of volunteer nursing homes will be drawn up. In order to represent the population as accurately as possible, 12 private and 5 public nursing homes will be chosen at random. This number of institutions has been chosen to respect the increasing evolution that is currently taking place in France as well as in Belgium where the number of beds in private nursing homes tends to increase considerably, while the number of beds in public nursing homes has stagnated for several years. However, it is not the intention here to compare the responses of private versus public nursing homes. Within the 17 institutions, the sampling of interviewees will be non-random, cumulative and recruitment within these nursing homes may be carried out by the snowball method.[18] In total, at least 50 interviews will be carried out for carers and 50 for elderly people in nursing homes, that is, 3 interviews per institution and per type of population.

Focus groups will be conducted with caregivers and individuals from the general population. Six of them will be carried out in voluntary private nursing homes and two in public nursing homes. These will be randomly selected from a list of volunteers. The sample of carers and individuals will be non-random and accidental.

For the quantitative part, surveys will be offered to all volunteer nursing homes. Elderly people, their caregivers and their carers will be asked to answer them. In total, 2000 questionnaires will be completed by population category within the nursing homes. For the general population, surveys will be offered in shopping malls. The data collection will be carried out on a non-random accidental sample. Age and gender parity must be respected, trying to interview men and women of all ages. This should ensure a heterogeneous panel of respondents. A total of 2000 surveys will be completed by the general population. The aim will be to obtain 10 000 surveys for the quantitative part. In order to determine the necessary and realistic number of respondents per population category, the following power calculation was performed. Five categories of respondents are included in this quantitative part of the study: elderly people in nursing homes, their caregivers, nurses, care assistants and individuals from the general population. The sample required for this study was calculated for each category. The last nursing homes prevalence study in 2016 estimated the number of institutionalised people in France to be approximately 600 000 and 7500 nursing homes. If we consider that only 5%

of this category could respond to the surveys and interviews, our pool of potential respondents is estimated at 30 000 institutionalised elderly people. Thus, in this cross-sectional study, we consider a sample pool estimated at 30 000 people and a 95% confidence level. Thus, we obtain a 2% margin of error for an expected sample of 2000 institutionalised elderly people. The same number of caregivers would be realistic if we considered at least one family member willing to participate in the study per elderly people interviewed. Thus, with an average of 3 nurses and 10 care assistants working in nursing homes, the sample pools for these two categories are respectively about 22 500 nurses (7500×3) and 75 000 caregivers (7500×10). Considering a margin of error of 2% and a CI of 95%, the sample size is 2000 participants for each of the two categories. For the general population, a number of 2000 people would be realistic with the same margin of error and confidence level.

Conceptual model

This study will be based on Abric's conceptual model and his theory of social representations.[19] More specifically, it will focus on the four main functions he describes, his theory of the central core and the silent zone.[20] The model puts forward the sociocognitive system 'with a specific organisation around and by a central core—consisting of a very limited number of elements—which gives its meaning and determines the relations between its constituent elements'. The surveys were therefore constructed in relation to the functions. The interviews and focus groups will make possible to identify the central core and constituent elements of the social representations of UI. However, this study will remain inductive.[21]

Data collection

The data collection tools (semistructured interviews, focus groups and surveys) were created on the basis of the literature[22] and a virtual brainstorming session with experts and members of our research team.

Qualitative part

The study will include semistructured interviews and focus groups. A minimum of 100 interviews will be conducted in private and public nursing homes: half with the institutionalised elderly people, and the other half with their carers. This method will be used to gather a great deal of information about people's representations of UI. Note-taking and voice recording will be used in these interviews.

Eight focus groups will also be carried out with caregivers and individuals from the general population, in order to bring out new ideas and clarify their representations. Three researchers trained beforehand in this data collection method will take part in the organisation of each focus group: a moderator, a secretary and an observer. At the beginning of the interview, the participants will be asked to create a network of associations.[23] Beginning with the administration of this tool will make possible to respect the 'projective nature of the technique'.[23] It is a cornerstone of the presented study because this gives the

possibility of different profiles (ages, socioprofessional categories etc) having various experiences with UI to share their perceptions and interact between each other .

For the semistructured interviews as well as for the focus groups, an interview grid was drawn up in order to collect a large amount of information in a structured framework, but allowing the interviewees to freely respond. Depending on the answers given, the interviewer may use verbal reminders to guide or refocus the interview.

Quantitative part

For the quantitative part, 10 000 surveys will be collected from 4 categories of population: residents, carers, caregivers and the general population. Each of these four categories will have its own survey. Carers in the nursing homes will distribute 2000 paper surveys to residents who are able to answer question. Another 2000 will be administered to their caregivers via their email address. Concerning carers in nursing homes, 2000 care assistants and 2000 nurses will also fill a survey thanks to an Internet link that will be sent to them by email. Finally, surveys for the general population will also gather 2000 responses, and will be administered by students from a junior company in shopping centres or supermarkets. All surveys will start with the respondent's presentation variables (age, gender, socioprofessional category, lifestyle and region). Each questionnaire will consist of open-ended questions, multiple choice questions, scaled questions and closed questions. The questions will expect verbal responses, but non-verbal attitudes will also be noted by the interviewers using a grid of facial microexpressions.[24] This will inform the research and understanding of the silent zone. In order to do so, students from the junior company will have been trained beforehand by the principal investigator of this study, both on the subject of UI, but also on how to ask the interviewees questions and to take into account their non-verbal expressions.

Before distribution to the nursing homes, the surveys and interview grids will be tested with two individuals from each category of population concerned: residents, carers, caregivers and individuals from the general population. These tests will be carried out in two volunteer pilot nursing homes and will make it possible to judge the feasibility of the data collection tools.

Analysis
Qualitative analysis

The interviews and focus groups will be analysed both manually and with ATLAS.Ti V.9 software, which will be used to centralise and organise all qualitative data collected (field notes, interview transcripts). The next step will be to carry out a content analysis, by coding and categorising the units of meaning. This will highlight recurring significant phrases and words,[25] then coding them according to the strength of their occurrence. The codes will then be organised by taking into account the frequency within the corpora and the importance of these statements in the discourse of each participant. The units of meaning will be grouped progressively by proximity of meaning, then by classifying them by theme. Finally, the themes will be studied to note the associated concepts. The aim is to make the elements collected more readable and understandable and to identify the different themes, meanings, oppositions or associations of concepts.

Quantitative analysis

For the analysis of the surveys, a descriptive statistical analysis of the sociodemographic characteristics of the people participating in the study will be carried out first. Second, a logistic regression type association will be carried out between the dependent variables (perceptions, representations) and the independent variables (type of population, age, sex, sociodemographic situations, region, pre-existing relationship with urinary incontinent people). These analyses will be carried out using R software V.3.5.2. In addition, a similarity analysis according to Bouriche will be carried out with four different steps[26]: the creation and exploration of the similarity matrix, the visualisation of the maximum tree and threshold graphs, the visualisation of the maximum clique filter and the comparison of similarity matrices of different subpopulations. Finally, the search for the 'silent zone' will be carried out in order to obtain also the non-expressible elements of the interviewees.

The qualitative and quantitative results will then be triangulated to confirm, refute, corroborate or cross-validate.[27 28]

Potential limitation and bias

There are two main cognitive biases that affect perception. The Hawthorne effect of influence of the interviewer on the respondent, and the halo effect, also called the notoriety or contamination effect. Researchers will try to limit these biases by training interviewers.

Outcomes

The results of the qualitative analyses will be presented in the form of a dendrogram per cluster and then modelled. The results of the quantitative data will be presented in the form of a summary with profiles, simple sorting and cross-sorting by tables and graphs. Finally, the results of the triangulation will be presented in the form of comparative tables and diagrams.

Patient and public involvement statement

In this study, four categories of population will be interviewed: elderly people in nursing homes, their caregivers, their carers and individuals from the general population. In order to design this study, and especially the tools needed to collect the data, a presurvey was carried out with carers working in nursing homes.

Ethics and dissemination

This protocol was approved by the Descartes ethics and research committee on 1 June 2021, with the IRB number 00012021-43. The research will be conducted in accordance with international and French regulations on clinical research. Thus, the rules of confidentiality and

anonymity will be respected. All participants will receive an information letter and their informed consent will be collected verbally. During the interviews and focus groups, the participants' agreement will be requested for note-taking and recording. The ethics and research committee have approved this procedure.

The findings will be published in international peer-reviewed journals and will be presented at national and international conferences. The study started in August 2021 and is anticipated to continue until June 2022.

DISCUSSION

Improving the care of institutionalised elderly people affected by UI is a real challenge. This study will therefore have many perspectives. For elderly people affected by UI, this research will lead to an understanding of their feelings, but also to the development of their empowerment. Indeed, by understanding their needs in terms of protection mean choices, this research will help them becoming more autonomous and having greater control over their decisions. This process will also improve their self-esteem. For nurses and care assistants, this study will initially support their skills and understand their knowledge and attitudes towards this phenomenon. It will also allow them to adapt their professional behaviour according to the results of this research. In this way, their expertise will be enhanced and the management and quality of care will be improved. Finally, the results of this research will enable the development of innovations to prepare for the future on this complex subject.

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