

HOW TO (QUALITATIVELY) INVOLVE OLDER PEOPLE WITH DEMENTIA AND THEIR INFORMAL CARERS WITH A MIGRATION BACKGROUND IN RESEARCH? INSIGHTS FROM A LONGITUDINAL PROJECT IN BRUSSELS

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Abstract

Representation of vulnerable groups and ethnic cultural minorities is inadequate in scientific studies. Aiming to include older people with dementia and a migration background in longitudinal research requires careful preparation to succeed. Based on this hypothesis we investigated what this good preparation means. What are do's and don'ts in the recruitment and retention of these older people and their carers? Based on insights acquired from the literature, interviews with ten experts with experience in involving older persons with migration roots and their close environment in their (research) projects we formulate six points of attention and possible success factors in involving the intended target group. Findings demonstrated 6 key-areas for consideration when developing a research design for older migrants with dementia: 1) investing in sustainable relationships with the respondents, beyond the traditional researcher-respondent relation; 2) collaborating with community key-figures for the recruitment of respondents; 3) focus on qualitative research methods; 4) investing in transparent communication techniques; 5) 'ethnic matching' by recruiting bicultural, bilingual researchers; 6) reflection on researchers own societal position. There's a need for specific, customized and flexible research design.

Keywords: ethnic minorities, older people, inclusion, methodological approach, qualitative research.

1 INTRODUCTION

In 2017 the Flemish governmental Research Centre estimated that in Flanders, the Dutch-speaking region of Belgium, 6% of all persons aged 65 and older had a migration background [1]. The number is much higher in those cities and regions that hosted the majority of migrants who came to Belgium during the nineteen-sixties and seventies [1],[2]. Moreover, this share of older persons of diverse ethnic background will continue to grow in the future: by 2020, nearly half of the older people living in Brussels will have a migration background [1].

In 2016 the Flanders Government estimated that 122 000 persons in the region had dementia. This prevalence of dementia is expected to increase by 25% by 2030 [3]. Given the difficulty of diagnosing dementia in ethnic minority seniors, it remains a challenge to accurately estimate the prevalence of dementia amongst such groups [4]. Recent research by Parlevliet et al. [5] in the Netherlands using culturally sensitive diagnostic tools shows a higher prevalence of dementia among non-European older people. The prevalence of dementia among older people with a Moroccan background in the Netherlands was fourfold than among native-born older people. In addition to differences in

prevalence, also the experiences might differ: researching how ethnic minorities in Belgium face dementia experience and manage the condition is important because (even when the clinical manifestations of dementia may be similar across different countries), migration and cultural background can influence the experience of the condition [6].

With the research project DiversElderlyCare – funded by European funding for regional development - we want to fill some of the research gaps and answer the following questions: how do migrant older persons and their informal and professional caregivers experience the dementia caring process and how can we work towards more suitable dementia care for these migrant older people in Brussels. This project runs over five years (2016-2021) giving the opportunity to follow participants over several years. Inclusion of participants with migration background, including the older persons with dementia, during this research project is essential to answer the research questions. However, research has shown that involving ethnic minority older people in studies comes with methodological challenges, explaining the underrepresentation of these specific older persons in scientific studies [7],[8]. Based on these insights, we can also expect methodological challenges in including older migrants with dementia and their family caregivers in our study. Careful preparation of the methodological approach is needed to guarantee an inclusion and retention of older migrants with dementia and their family caregivers. This article will therefore give an overview of the lessons learned during our search process of the do's and don'ts in including our target population and how we incorporated these insights into our methodological approach.

2 METHODS

This study aims to answer the question of how to include migrant older persons with dementia and their family caregivers in a qualitative (longitudinal) study. What is a successful methodological approach and which pitfalls should be avoided? The study is built upon two methodological steps: first a narrative review of the existing literature, followed by qualitative, individual interviews with ten acknowledged experts, who have experience in the inclusion of vulnerable groups.

To conduct the literature review we used Web of Science, Medline, Cinahl, Science Direct and Psycinfo as search databases. Combinations of the following search terms were used: ethnic minorities, migrants, elderly, family caregivers, informal caregivers, dementia, (longitudinal) qualitative research, inclusion, recruitment and retention. A selection of the articles was made based on the relevance for our research purpose.

The second step was interviewing ten experts using qualitative, individual interviews. The experts were researchers or health care- or social care workers in Belgium (n=3) or in Europe (n=7). They were selected, based upon their research publications or from their well-known experience in working with vulnerable and hard-to-reach groups (older people, older migrants, family carers). The interviews had a duration ranging from 60 to 180 minutes and were conducted by two researchers. Minutes were taken during the interview. Minutes of both researchers were put together afterwards and were the basis of a thematic analysis [9].

The last step was the translation of the insights from the first two steps into a research methodological approach suitable to our research goals. The team of three researchers discussed the insights from the first two steps, in three meetings and developed a research action plan that was presented and discussed with experts: a panel of four experts in successful collaborating with ethnic

minorities in Brussels and the steering committee (n= 8) of the research project consisting of experts in the field of ageing, dementia, care and migration.

3 RESULTS

This study's aim was to determine what could be a successful approach to include older migrants with dementia and their family caregivers into a longitudinal qualitative study. Neither literature, nor the experts examples could answer the research question to a full extend. This means that the results are based upon experiences with either older people or family carers from ethnic minorities, either older people with dementia and within other study designs than merely longitudinal research. Based on the insights gained from the literature review and interviews we made an overview of successful factors that will be elaborated in the next sections.

3.1 Insights from the literature review?

Longitudinal qualitative research has gained interest in the domain of the health sciences. Using such a research design is considered useful to better understand the nuances of experiencing a condition and providing care over time[10], [11]. Qualitative research provides - in general - different possible design approaches where the choice of approach is linked to the goals of the study[10], [11].

3.1.1 *Inclusion of (families from) older persons with dementia*

In general, including older people in a longitudinal study involves a number of challenges [12] . The first question that can be posed is which research method is best suited. In this case, Bond and Corner [13] advise the use of qualitative research in which the perspective of the older person with dementia is mapped. Methods such as participatory observation for example are relevant when the objective is to study the complex interaction of diverse factors during the experience of dementia together with the participants. This inductive approach aims at a first-line representation of the experience of the person with dementia in which general assumptions about these target groups and their experience are challenged. According to Bond & Corner [13], this approach is relevant if no theoretical framework is set beforehand.

Second, working with people with dementia also requires several points of attention in the execution of the research. For instance, considering the social desirability of the answers is important. Developing a good relationship with the older person is also an important point for attention here to pinpoint the social desirability [13]. This is also important in case of a conversation with a 'proxy'. Including proxies, such as (informal) carers, can even become a primary source of data during phases of dementia where the older person has lost their ability to communicate[13], [14].

Third, estimating the number of older people well before hand with strategies for the 'drop outs' are required. Integrating strategies in the research design that minimise the loss of the recruited participants throughout the research is important [15]. These strategies concern conscious actions to make it as easy as possible for older people to participate, such as flexibility in follow-up times, developing a good relationship with the older person and their environment, continuation of the same researchers and creating a pleasant environment. In this way, Personen, Remes and Isola [16] state that a combination interview of the older person with dementia together with his/her carer can give a better atmosphere of trust to the participants. In addition, it is also important to look at the effect of 'missing values'. Specifically, a lot of data is lost that could have influenced the results of the

research. The collection of the reasons why older people withdraw can help when processing the results [17].

3.1.2 Inclusion of older persons with a migration background

Several studies mention the difficulties of involving ethnic minorities in research. Arean and Gallagher-Thompson [18] already warned about the challenges connected with the recruitment and retention of older people with a migration background so that they are underrepresented in research. They argued for specific strategies to tackle these challenges. Based on the same motivation, Dreer et al. [19] argued for strategic planning in the recruitment and retention of older people with African American and by extension, with other roots. These strategies should take into account the multiple thresholds that hinder these older people and their environment from participating in studies: no trust in the researchers and health-related research, lack of cultural competencies and knowledge of native language in execution of the research, experience of racism, fear of being abused, lack of knowledge about the research process and fear or taboo around the research topic such as dementia [19], [20]. In addition, researchers can also be viewed as outsiders which causes a social disconnection [21], [22].

However, Zubair and Norris [23] warned for an essentialist research approach in studies including older persons in general and including ethnic minority older persons more specifically. Focusing on a single aspect of the older people like their poor health condition or their ethnic background is a problematic, one-dimensional approach [23]. This essentialist approach has a one-dimensional unrealistic image of a group of older people and expects them to fit into a classic research paradigm. According to Zubair and Norris [23], the current research criteria are not adjusted to the fieldwork reality. It is therefore necessary to question some assumptions and self-evidences within the research protocols and methods. It is a necessary step if we truly want to include ethnic minority older people on an equal way. They argue that lots of research protocols and methods, like the written informed consent, are based on a Western middleclass logic. Looking further to the informed consent as an example, also other authors like Mazaheri et al. [24] confirm the unsuitability of the written informed consent in a study involving older migrants, and use a recorded verbal consent instead. Their plea to broaden the more classic way of research with creative approaches as a way to include the underrepresented groups in research has also been supported by Swabrick [25].

3.1.3 Suggested successful approaches

A first important success factor is building up and maintain trust within the intended communities, in different phases. Researchers such as Dreer et al, Hinton et al. and Romero et al. [19], [20], [26] invested step-by-step in the development of the relationship with the recruiters, such as key figures or organisations which reach those communities, subsequently to develop a relationship with the older person and their environment, such as their children. Children after all appeared to be determining the participation of older people in the research [20]. When it comes to key figures, self-organisations, or other community leaders, it is important that the cooperation takes place respectfully and in (genuine) partnership [19]. This means also listening and formulating answers to the needs of these partners. This seems to increase the credibility of the researchers.

Second, several studies [19], [20], [26] also demonstrate the success of 'ethnic matching'. In this approach bi-cultural and bilingual researchers are members of the research team and are matched according to a shared ethnicity or language with the research participants. This approach however is challenged by Zubair and Norris [23]. Ethnic matching can become problematic when ethnicity of the researcher and the subjects is presumed the only way to avoid distance between a researcher and an ethnic group. The presumed proximity due to a shared ethnicity can be challenged by the distance

resulting from other factors, like the social class that researchers represent. Another distance creating factor, they argued, is the use of the classic, not adapted research protocols and methods.

Third, active 'face-to-face', respectful communication is needed [19], [20], [26]. This communication is supplemented with translated and image-recognisable flyers, posters, Being respectful means also being flexible as a researcher in collaboration with ethnic minority families. Adjusting to their reality is therefore a needed competence. In this approach, it is important that the older persons and their family understand the relevance and purpose of the research and can preferably also see a visible return in it. For example, in the study of Hinton et al. [20] families of the older person appreciated the information they acquired about dementia through the researchers which they would not otherwise have received. Dennis & Neese [21] also mention this 'reciprocity' as a success factor. The same study shows that ethnicity is not in itself a predictive factor. It is important for a researcher rather to know the historical and socio-economic context of the intended target group, the position of that group in society and what possible sensitivities must be taken into account. Furthermore, reflecting on the position of the researcher within this shared context is also necessary [21], [22].

3. 2 Insights from the expert interviews?

The experts interviewed were either researchers or practitioners working in Belgium or Europe. They were selected based on the expertise known through the literature or reputation in the field in involving the ethnic minority older persons and/or carers of family members with dementia.

These participants stressed first the importance of involving key figures and reliable networks or people in the recruitment of these older people and their environment. Key figures are people with a good reputation and an influence within particular communities. They also have broad networks and know from experience what does and does not work within those networks. In addition, it is important to work locally and to involve networks where the intended target groups may be in the recruitment and retention of participants. Being introduced as a researcher by these reliable people or key figures is important. This increases the chance that older people and carers agree to participate in the research.

Second, making the 'win-win' of their participation in the research clear to the intended target group appeared from the interview as important. In their opinion, the researcher must not only propose their 'win', namely finding respondents to answer his/her research question, but must also include, communicate and guarantee the 'win' for the participants in the research. Many ethnic communities have become distrustful of questioners (researchers and others). This is based on bad experiences in which the communities were often questioned without being informed of the result of that questioning or in which the results of the research were too little shown as an added value for themselves or for their own community. This results in a sense of 'being abused' which makes people reluctant to answer more questions. This 'win' for the community may only lead to access within the communities if it is sincere, visible and responds to a genuine need within the community.

Third, the respondents stressed that trust is a point of attention throughout the research. The carers and older people must trust the researcher concerned. Therefore, investing in a sincere relationship of trust in the execution of the research is important and that starts from contacting the key figures that lead you to the intended target group.

All of the above implies constant attention to the mode of communication, which is a forth key recommendation the experts discussed. Tailoring the communication to the person in front of you is important. This implies attention to both non-verbal elements, such as posture and verbal elements in communication. For instance, a respondent suggested it is important not exclusively to use biomedical names for disorders, such as dementia, but to search for names used by the intended group, such as 'forgetting'. This increases the recognisability of the subject which reduces the distance in communication.

It also requires dealing with communication tools consciously and in a targeted way. Experts recommend using different types of tools simultaneously, each time with a different objective. For instance, leaving behind an official folder will legitimize your research and make you seem more reliable to the participants, but the information about it should preferably be given verbally.

4 DISCUSSION

This study is attempt to formulate an answer to the following question: how to include migrant older persons with dementia and their family caregivers in an qualitative (longitudinal) study. We did not find any research that could respond to this question to a full extend, but researchers' experiences in preforming dementia research on the one hand and research including ethnic minorities on the other hand provides valuable insights. Their experiences confirm that research including underrepresented target groups demands a careful preparation and execution. These suggested success factors will be included in our research. A phased action plan, in which flexibility is central and where evaluation of our methodological approach is included. These planned evaluations in the action plan gives us the opportunity to analyse our methodological approach and to adjust it to the experienced needs of that moment.

First, in terms of research design, we opt for a qualitative approach rather than a quantitative approach. In addition, based on the suggestions of the literature review we will supplement classical data collection methods such as interviews with an alternative creative approach such as participatory observations and collecting intermediate calls/texts/emails. In addition some aspects of standard research methodology are not included in our approach or will be adapted to the reality of the field. An example of this is the inclusion of an oral consent by the older person with dementia as a substitute for written informed consent.

It is also clear from both the literature as the interviews with experts that the communication approach in the study should be conducted in a thoughtful way. Good communication starts with a reflective, modest and open attitude [6], [22], [27]. Every researcher involved in our research project reflects on how his background, approach, ... can come across to the respondents and this during every step of the research. We also aim for a sincere and honest communication with the older migrants and their family caregivers about the research and the goal of the study. The researchers are clear about their role and what they can or cannot expect from them. Building a relationship of trust is therefore sincere and not something instrumental. We also aim to communicate sincerely about the win-win for the community, and to explicitly search for a win for the older person and his carers. The respondents are not seen merely as subjects in our research but they should experience short and long term benefits of our study and therefore should be seen as a partner in the research. Possible ideas are organizing information group sessions about dementia to the targeted community, or training social and health care professionals who work with our target group. In addition, this research should contribute to the improvement of care for the older people with a diverse background. This is a long term sincere goal of our research project. To realize this, we actively communicate about our, and valorize recommendations and examples of good practices to policy makers and the care sector.

The results indicate as well that in our communication strategy we have to pay explicit attention to the choice of verbal and non-verbal communication tools accessible information, where the different target groups could identify themselves in. Language bridging is also a point of attention [27] which is why we opt for multilingual researchers and communication tools. 'Ethnic matching' is a success factor that we carefully and critically approach. The research team is ethnically diverse but socio-economically homogeneous. Moreover we are also very keen on not to approach ourselves as a researcher from a particular ethnic background, and to approach the migrant older persons and their family caregivers in a one-dimensional way. We are aware of several, intersectional nuances [28] and take these into the reflections and the team discussions.

Final, collaboration with key figures within the various communities is also appeared to be essential. They open the door to the different communities. We could benefit from the trust that the families have in such key figures. Recommendation of a key figure makes us a trustworthy person to initiate a contact with. We want to further collaborate with the key figures during all phases of the study. Their critical feedback, from different perspectives, about our approach is an important added value for the research. This reflective and step-by-step approach will unlikely lead to the use of other (above-mentioned) methodological success factors. Because it is clear that in addition to traditional research skills, specific actions and skills are also required to conduct a research thriving to give a underrepresented group like the ethnic minorities a voice [29].

5 CONCLUSION

Both the experts interviewed as the literature emphasise that the involvement of older people with dementia of different origin and their environment requires a well-considered approach. Traditional research methods are inadequate to involve this population and to make their voice visible in the field of research. The results demonstrate a number of specific elements which research on older people with dementia, and with a migration background has to take into account: flexibility from the researchers and good listening abilities to listen carefully to those involved in our approach; investing in the trust and relationship with these target groups; building a relationship with the ethnic minority elders means also building a relationship with their gatekeepers: key figures and children of the older person with dementia. A relationship in trust is only sustainable when there is a transparent communication and partnership based on equal and a balanced 'win-win' on both sides. To achieve all these requirements researchers should have the time and resources to do so. To conclude, if we truly want to include underrepresented target groups into scientific research we should integrate tailored actions and move away from the 'one-size-fits-all' research approach.

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