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Joel Persson & Eva Wikström

To cite this article: Joel Persson & Eva Wikström (08 May 2025): Representing Illiteracy: Methodological Challenges and Ethical Ramifications in Research on Illiterate Refugees, Ethics and Social Welfare, DOI: [10.1080/17496535.2025.2495591](https://doi.org/10.1080/17496535.2025.2495591)

To link to this article: <https://doi.org/10.1080/17496535.2025.2495591>



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Published online: 08 May 2025.



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Representing Illiteracy: Methodological Challenges and Ethical Ramifications in Research on Illiterate Refugees

Joel Persson  and Eva Wikström 

Umeå universitet, Samhällsvetenskapliga fakulteten, Institutionen för socialt arbete, Umeå, Sweden

ABSTRACT

Researching vulnerable groups in social sciences is a balancing act of lifting their perspectives while protecting participants' integrity from thoughtless methods. Newly arrived refugees with limited literacy face challenges in making their voices heard in both society and research. Yet, the methodological and ethical difficulties of meeting such challenges may also deter researchers from studying these groups, resulting in their exclusion from collective knowledge. The aim of this literature review is to explore methodological challenges of representing newly arrived refugees with limited literacy in social science research, and the ethical ramifications that come from them. Initially, we made a mapping review of language education research relating to refugee illiteracy. Secondly, we conducted a critical review of social science literature on the subject. Lastly, we analysed how various methods make these groups visible and accurately represented. Our findings show a significant gap in research involving both refugeehood and illiteracy. Moreover, we find that the limited supply of existing studies seldom account for methods and ethical practices to make the target group substantively represented. We also highlight studies with well thought out methodological and ethical practices, pointing towards a possible ethics of engagement.

ARTICLE HISTORY



Received 20 December 2024
Accepted 14 April 2025

KEYWORDS

Refugee; illiteracy; social science; methodology; research ethics

Introduction

Studying groups of people referred to as 'vulnerable' will of necessity involve the basic question about inclusion: to weigh up whether the scientific and social benefits and values outweigh the potential risks of including respondents (ALLEA 2017; Brown 2022; Staunæss 2003; Wilkinson 2004). Any such inclusion of participants imposes a responsibility on the researchers to act in accordance with good research practice (ALLEA 2017; SFS 2019:504), and to represent them in an accurate way (Jacobsen and Landau 2003). When researching newly arrived refugees, certain challenges arise that are easily overlooked due to their being non-issues when studying other groups,

CONTACT Joel Persson  joel.persson@umu.se  Department of Social Work, Umeå University, SE-901 87, Umeå, Sweden

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often in terms of communication barriers and a number of ethical considerations (Block et al. 2013). Besides the time it generally takes for newly arrived people to acquire a second language (Benseman 2014), the heterogeneity of refugee immigrants' national origins and educational backgrounds will also give rise to a variety of levels of literacy (Block et al. 2013; Jacobsen and Landau 2003). The complexity of the methodological and ethical considerations that must be accounted for in the communication barriers between researchers and researched are likely to lead to hesitancy about framing research questions involving illiteracy. It is argued that much educational research has ignored marginalised groups by not addressing their concerns or regarded them as minorities who do not merit research (Parker and Lynn 2002). It is also often the case that research conducted with/on them uses inappropriate methods of investigation (Block et al. 2013). Many of the participants in social work studies have experienced marginality, poverty, discrimination, and oppression. Newly arrived refugees who have not yet mastered the language or the public sphere are often an invisible group in society at large (e.g. Herzog 2018). Although neither refugees nor illiterates are to be considered homogeneous groups, many share experiences of being newly arrived, fleeing oppression, disasters, or armed conflicts, while having marginalised citizenship – if any. Not to mention having limited ability to read or write. It is a position of complex vulnerability in relation to previous experiences and social participation (Brown 2022; Cohen, Manion, and Morrison 2011; Peled and Leichtentritt 2002). Including vulnerable groups in research places high demands on quality and requires that methodological barriers for their participation are actively addressed and removed. It is to counteract groups being made invisible, either by active exclusion, or passively by being taken for granted in their absence, that they become implicit dropouts or are represented by 'voices' other than their own.

The aim of this paper is to explore the methodological challenges of representing illiterate newly arrived refugees in social science research, and the ethical ramifications stemming from these challenges. This is achieved, firstly, by scanning the prevalence of social sciences research that addresses refugee illiteracy and discussing the ethical implications of various methodological approaches in research.

Secondly, we make a closer examination of the research that explicitly includes newly arrived refugees with illiteracy. We discuss how the various approaches correspond to sound methods for making visible and representing the group, without causing harm.

Deliberating research on vulnerability

While including vulnerable people's perspectives in research could provide insights into their conditions and experiences, it may also carry significant risks of integrity violation. In accordance with European regulations (ALLEA 2017), and also Swedish law on ethical reviewing (2004, 460), research may only be approved if the risks it may pose to the health, safety, and personal integrity of research participants are counterbalanced by its scientific value. This is also known as the considerations of costs versus benefits of research (Brown 2022; Cohen, Manion, and Morrison 2011). Doubts about whether it is appropriate to research sensitive issues, or include vulnerable people, may seem both sound and reasonable, because thinking through research and its possible ethical implications must be part of every researcher's professional conduct (Wilkinson 2004).

Research may contribute to making visible a socially 'silent' group. However, opting for methods that only indirectly highlight their perspectives, or avoiding projects or research questions that include their experiences, may result in silencing of a group that is already marginalised. Admittedly, the use of the concept vulnerability should be handled with care. As pointed out by Virokannas, Liuski, and Kuronen (2018) it has been contested for lacking analytical clarity, and being stigmatising when referring to individuals or groups. The use of the concept has strengthened the impression of individuals as incapable, limited and deficient, especially when used to describe vulnerability for disabled and people with learning difficulties. Hence, there are methodological and ethical challenges for social work research; while making a vulnerable group visible, they may at the same time contribute to the reproduction of stigma and objectification. In this paper we do not view low literacy as an individual 'deficiency', but as a vulnerable *position* which is relational and situational (Virokannas, Liuski, and Kuronen 2018). In the Western context, difficulties to acquire a second language and limited literacy undoubtedly hinders social participation and the enjoyment of rights. Hence, research needs to focus on the social processes generating vulnerability and societies' efforts to reduce its risks and consequences. Moreover, to recognise the temporal, situational, relational and structural nature of vulnerability (Michaud, Fortier, and Amireault 2022). Individuals may have agency and strengths at the same time as they are in a vulnerable position. The latter fits well on refugee migrants who have escaped wars and violence, while leaving family and belongings behind, towards uncertain futures.

The benefits of language acquisition for refugees can be considered in both informal and formal terms. Informally, it provides autonomy and capability to participate in society on one's own terms. Formally, however, the completion of language education programmes determines access to labour market measures and employment, which is increasingly expected for privileges such as permanent residency, citizenship, and family reunification. Such demands are placed upon the educated and the uneducated alike. Needless to say, any social benefits that hinge on educational achievements will likely disadvantage the uneducated. With this in mind, there are strong motives for deliberating upon researchers' ethical conduct when producing new knowledge of societal interest (e.g. ALLEA 2017; Block et al. 2013). All research involving people's lives risk forcing them into ethical-analytical boxes in ways that objectify their bodies, experiences, and vulnerability (Fassin and d'Haluin 2005). Communicative barriers add to the complexity of research ethics and data-collection practices. The customary methods used to inform potential participants and ensure their voluntary participation may actively exclude individuals who have difficulties with reading and writing (Wikström 2021). At heart of the dilemma when researching vulnerable people and sensitive issues is the fact that the ethical, methodological, and analytical considerations are profoundly interwoven (Block et al. 2013). In the following, we address some of these key dilemmas, while referring to previous studies which have reflected upon issues of research ethics when involving vulnerable groups.

Methodological and ethical challenges of including vulnerable individuals in research

Research as language work

Research in the social sciences is a form of 'language work'; hence, language diversity poses ethical challenges and dilemmas at the individual, group, and societal levels (Hall

and Valdiviezo 2020). Such an understanding of social science research implies an approach to language that perceives it as an active social practice.

In many ways, the role of a social science researcher can be compared to that of social workers (Pösö 2014). The social worker needs to be prepared to meet clients at any given point, involving necessary language competences, but also the core competence of engaging diversity and difference in practice. This requires social workers to ‘recognize the extent to which a culture’s structures and values ... may oppress, marginalise, alienate, or create or enhance privilege and power’ (Pösö 2014, 7). Similar thoughts on research ethics have been articulated in feminist perspectives (Phillips 2012; Staunæss 2003). Thus, research ethics are always contextual and, therefore, the obligation of researchers are not only a matter of their obedience with code of ethics, but to employ situated strategies that are grounded on understanding the group and the local conditions (e.g. Block et al. 2013; Staunæss 2003). If so, researchers need to acknowledge linguistic challenges and the many layers of interpretation and translation that both research and social work practice implies (Pösö 2014).

Informed consent

Often, the language work of the research process has already started when collecting informed consent. Informed consent is often designed from the perspective of a researcher’s communication needs and does not sufficiently consider the participants’ information demands (Alby, Zucchermaglio, and Fatigante 2014). From an analysis of written consent forms, Alby et al. conclude that there is a tendency towards abstraction and generalisation rather than writing that is adapted to target groups and individual needs. Participants are assumed to be knowledgeable, yet this is not always the case. Alby et al. suggest that a researcher needs to consider what the individual participant understands about the project, decide how to adapt the information according to the level of literal and intellectual understanding, and reflect upon the consequences of it (Block et al. 2013). Ethical guidelines for informed consent are often based on the idea of generating equivalent and uniform ways of producing research information in writing, which takes for granted many of the research subjects’ circumstances and assumes that they are familiar with research contexts. For example, in the Swedish handling of research ethics permits, the guidelines provided by the Swedish Ethical Review Authority implicitly assume a standard procedure, where research information is provided in writing, and presume that people in general possess a basic knowledge of how to place research within a societal context (The Swedish Ethical Review Authority 2024). Hence, it presumes potential participants’ familiarity with a western institutional research context, where the research is linked to a state free from corruption, which does not control or regulate free speech, and where knowledge production has an independent position (see Görman 2021). There is also an expectation that research subjects can decide on participating by reading and understanding brief descriptions of research aims and have the ability to make an independent decision without further communication with the researcher. Both feminist and social work values direct us to go beyond a procedural and standardised approach to research ethics in our relationship with research participants, and to use the research as an opportunity to contribute to the empowerment of vulnerable and disenfranchised groups (Peled and Leichtentritt 2002). Peled and Leichtentritt underline the ethical conduct incumbent upon researchers involving vulnerable respondents,

to avoid the risk of exploiting them in the name of science. A key part of this process is to develop and understand ethical standards and procedures in the context of a relationship that takes place between the researcher(s) and the researched. The researcher needs to find creative solutions to provide participants with complete information about research goals and processes so that they can make a truly informed choice regarding participation, without feeling pressured to do so (Block et al. 2013). Transferred to refugees with illiteracy, we think that one of the key starting points is for the researcher to develop alternative ways to communicate apart from that of textual information, to explain the potential consequences of participation in research, adapted to the individuals' prior knowledge and worldview anchorage. Such an approach requires reflexivity in ethical considerations, which is constituent for developing an ethics of engagement (Pickering and Kara 2017)

Data collection as language work

When collecting information from newly arrived participants, both adherence to ethical standards and the quality of data depend on robust methods that account for language differences between the researcher and the participant. This is particularly important when working with illiterate individuals. Even when translated, letters, forms, and questionnaires are likely inaccessible to those who cannot read. Understanding of survey items can vary with cultural background (Michaud, Fortier, and Amireault 2022), potentially resulting in biases in coefficients and intercepts, misleading answers or even participant dropouts (Reichenberg and Berhanu 2019). Accepting dropouts or outliers on account of language difficulties can therefore be seen as systematic errors that further misrepresent potentially vulnerable individuals. The same applies to oral methods of data collection, where language differences may interfere with communication, mutual understanding, and the sharing of narratives (Hall and Valdiviezo 2020), all of which endangers the voices and perspectives of the participants (Block et al. 2013). Thus, to ensure reliable and ethically grounded data, researchers need to employ reflexive methods that are sensitive to both language and cultural barriers to a much greater degree than when researching other groups.

Theoretical framework on representation and visibilisation

Research as an invisibilisation practice

Limited access to language education may hinder an individual's social participation, cultural awareness, and knowledge of their rights. Intentionally or not, people can literally be prevented from being seen or heard due to their limited ability to read and write (Herzog 2018). This can be viewed as a 'social' silencing of the voices of non-hegemonic groups, even when they appear publicly. Drawing on Honneth (1995), Herzog argues that invisibilisation is a form of misrecognition and constitute a lack of attention towards specific groups' needs for cognitive respect and social esteem (Herzog 2018). The emancipatory potential of research postulates that how data collection is carried out, and how the 'writing-up' of results is performed, is decisive for whether research aids in giving vulnerable people a 'voice', where otherwise they would neither be heard, nor listened to. This is a task that so far has not been discussed frequently enough in the methodological literature, to actively consider measures for participants 'to tell their stories' and to give them a

'voice' using their own words and with minimal distortion by any third party speaking on their behalf.

Representation of participants in research

In social science research, presenting findings usually means representing research participants in certain ways, in terms of both how they actually participate in the research process and also how they are depicted in the text (Pickering and Kara 2017). Representation is associated with a whole range of meanings; here we anchor it in two classic notions, namely of political representation (Pitkin 1967) and cultural representation (Hall 1997). Normally used to investigate how public representatives speak for their constituents, we apply Pitkin's (1967) theory to examine how researchers represent their participants in our data. We use the concept of *substantive representation* as a framework to understand how refugees are voiced in research – in their own narratives and experiences, or by people who speak *for* them, such as researchers, teachers, interpreters, or the like. To substantively represent refugees is to move beyond them as a conceptual idea or political problem and rather attempt to clear any obstacles for them participating on their terms. Researchers may for example turn to their target groups merely as 'test persons', or *objects* necessary for accomplishing a comprehensive sampling of data. Hence, depending on the choice of method for data collection, we argue that participants may be *actively excluded* for not meeting the criteria for data inclusion, or *passively excluded* insofar as they are mistakenly assumed to be represented in the data collected.

The second conception of representation is of cultural representation, originating from Stuart Hall (1997). This refers to the 'process by which members of a culture use language [...] to produce meaning' (225). It is the organisation of signs to understand and describe the world, into a wider set of values, forming ideologies. We use his framework of representation to illustrate how the target group of illiterate refugees are depicted in text. Researchers need to be especially careful when imposing particular findings or categories onto the participants or target group involved (Brown 2022). They might use categories or definitions that are theoretically informed, involving interpretations that may be reductionist or even loaded with stereotypical meanings. Such naming may result in positive or negative representations but may also result in *misrepresentations* of the individuals or group being depicted (e.g. Hall 1997). The risk of reproducing researched people's positions as 'subaltern', or even to produce new categories of inferiority, is inherent in research. Classifying and naming may be strongly connected to processes of stereotyping, which relate to questions of inclusion, exclusion, and domination (Pickering 2001).

Methodology

The study presented here is part of a doctoral project on understanding preconditions for language acquisition among refugees with limited previous education. We initially employed a *mapping review* approach (Grant and Booth 2009) to explore existing literature on language education among illiterate refugees for the sake of the thesis. In this context, 'illiteracy' and 'illiterate' are used as umbrella terms to include people with limited literacy as well as those with minimal education or no schooling whatsoever. While early search queries revealed a widespread use of the term in related research areas, such as 'health literacy' or 'computer literacy', we only employed a definition of

foundational literacy for time constraints and a manageable corpus. Data was systematically collected using the *Web of Science* search engine, using several expressions to encompass this variety (see Appendix A). Further inclusion criteria specified research on adults, that articles were published in peer-reviewed social science journals with relevance to the field, and in a language that the research team shared.

After finding numerous methodological and ethical issues when considering the corpus from the perspective of illiteracy, we decided to perform a second search using a *critical review framework* (Grant and Booth 2009). This involved narrower queries in order to systematically collect data that could undergo a thorough analysis of said perspectives (see Appendix B). While first including migrants in general to allow for the ambiguous terminology used in the field, it was now narrowed down to only look for research on refugees. Finally, for in-depth analysis, a selective sample was made of items that specifically addressed refugee illiteracy as part of their research question or participant characteristics. This was achieved largely by reading abstracts and methodology sections. Employing a qualitative analysis, we took an inductively inspired approach to the gathered material, coded it, and constructed themes following the research project's overarching aim. We then categorised the themes and predominant images (Marshall and Rossman 1999), and introduced silencing, visibilisation, and voicing as sensitising theoretical concepts (e.g. Blumer 1954; Bowen 2006). These were useful for seeing and organising the description of the articles' aims, methodological approaches, and ethical considerations. In the second round of analysis, theoretical perspectives were introduced in which several understandings of *representation* emerged as a guiding concept for a deeper comprehension of how research on illiteracy and illiterate refugees complies with ethical principles for conducting research on vulnerable people.

Results

In this section, we present our analysis of the literature, divided into two parts. The first part primarily focuses on the findings from our initial mapping review of language education research on *illiteracy and illiterates*. The second part addresses the findings from the *critical review* of social science literature and the selective sample of articles which explicitly addresses *refugee illiteracy*.

Scanning social sciences research focusing on illiteracy/illiterates

Throughout the review process, it was evident that matters of illiteracy create significant limitations for the range of existing education and refugee research. Initially, we searched over 74,000 articles on second-language acquisition, which were cross-referenced with various topics relating to illiteracy and migration (see Appendix A). This resulted in a final tally of 131 items with potential relevance for the study. Of these, 75 were of quantitative design and 48 qualitative. Seven used mixed methods and one was indeterminate. The articles were divided into two lists, those that explicitly addressed matters of *illiteracy* (n = 33) but with a broad spectrum of target groups involved, and those that did not (n = 98). A lesson to draw from this initial literature search was the blatant underrepresentation of people with illiteracy in the literature (cf. Phillips 2012), which not only reaffirms

previous reflections upon this understudied group (e.g. Michaud, Fortier, and Amireault 2022; Smyser and Alt 2018), but also raises questions about why illiteracy is largely excluded from researchers' interest.

A most noteworthy finding when analysing the list of 131 articles was that about a third ($n = 47$) used surveys as their single source of data, and of these, less than half ($n = 19$) employed measures to include illiterate participants. Many articles mentioned sending questionnaires to a large number of households without specifying if any measures had been taken to assist illiterate participants in answering them. Others used secondary data from large surveys, also without any such attention. Such passive exclusion serves to illustrate the need to substantively represent refugees with illiteracy, as distributing forms without considering respondents' abilities to participate will likely result in an underrepresentation of their voices, as methodological outliers (Phillips 2012; Pitkin 1967). Another important finding was the wide range of search queries needed to collect the list of 131 articles, indicating an inconsistent use of terminology in the field. Terms such as 'refugee', 'asylum seeker', and 'migrant' were often used interchangeably. Moreover, the migrant category was rarely differentiated, such as whether they had migrated for labour or partnership reasons; whether they were short-term or long-term migrants; or if they stayed on a temporary or permanent basis. All of these factors can have significant social consequences. At this point, we chose not to distinguish between legal statuses in order not to miss any potentially important articles. Moreover, it was common to see only brief discussions on methodology and ethics when researching illiterates.

In an effort to find more articles that addressed these matters, we broadened the scope of review from language acquisition to include topics of illiteracy in any relevant discipline within the social sciences (see Appendix B). In the search for literature at this point, legal status was limited only to refugees, to recognise their unique circumstances, such as: temporary residence permits, employment requirements to be permitted certain welfare rights, along with a well-founded mistrust of state representatives based on prior experiences while simultaneously being dependent upon them. This produced a new collection of 39 articles to review manually. Twenty-six of these were qualitative, eight were quantitative, and five used mixed methods. Qualitative interviews ($n = 16$) and mixed qualitative methods ($n = 10$) were the most common choices for data collection. Most of the articles, however, treated illiteracy as a secondary concern, e.g. in terms of general context, minor variables, or incidental findings. This implied that they had given little consideration beforehand to the potential issues that may arise when researching illiterate refugees. As such criteria were essential for assessing reliability and ethical conduct, only articles that had placed them front and centre of their research question or participant characteristics were retained for further analysis. This produced a final list of nine articles for in-depth review.

Visibilisation and representation of refugees' illiteracy in research

As the final collection and review of articles came from a selective sample that explicitly addressed refugee illiteracy in their research question or participant characteristics, it produced a list of nine items. As social work researchers, we had been curious about articles from our own discipline, and while some appeared initially, all had now been discarded

due to not meeting the inclusion criteria. Instead, the results came from educational sciences, linguistics, demography, and psychiatry. Nearly all of the research for these articles was conducted in an educational setting. Some studies evaluated tests and assessment methods where the refugees' experiences were not the main focus, while others aimed to address their circumstances directly. Most originated in Anglo-Saxon countries, with single studies from the Middle East and continental Europe. Many relied on one-to-one interviews or in small-group settings, while others used observations, quantitative tests, and surveys. Despite our selective sampling and the variety of the articles, many lacked in-depth discussions on the challenges of studying illiterate populations.

Representation in depicting research needs

While the researchers argued for carrying out their studies under discussion in the nine articles we analysed, all but two remarked on a palpable knowledge gap in the existing literature. The need for more attention in research mostly concerned this group's distinctive educational needs, illiterates as understudied learners, and the lack of effective educational strategies for them. As Hall (1997) argues, many of our assumptions can be perceived in the narratives we employ to make meaning of the world. The cultural representation of illiterate refugees must therefore be understood as a product of our own assumptions and values. Questions of such affect arose when considering arguments found in the data.

Another pressing issue in refugee education is that this population is significantly understudied and under-resourced. (Smyser and Alt 2018, 457)

Two main observations were made: SLIFE¹ are largely underrepresented in second language acquisition and teaching literature and, ethical and methodological issues are not thoroughly presented. (Michaud, Fortier, and Amireault 2022, 2)

A few other articles merely called for new perspectives on illiteracy. Furthermore, nearly all of them argued for language research for the benefit of the target group, while some were motivated by methodology development (Atkinson 2014; Purcell-Gates et al. 2012). Some articles had quite detailed arguments about researching learning methods that may bring empowerment, increase self-confidence, and enable illiterate participants to expand their 'voices' and be socially and culturally included (Kuschel et al. 2023; Michaud, Fortier, and Amireault 2022; Alhussain 2019; Benseman 2014).

This paper is based on research which points to the need to position the learning of literacy and numeracy in the ESL² context as a social and educational journey made meaningful by a learner's sense of (emerging) identity. (Atkinson 2014)

The method proposed here is an alternative that uniquely focuses on this group and adopts an empowerment approach to help them achieve self-reliance. (Alhussain 2019, 293)

While some articles made credible and caring arguments about the need to expand research studies 'for the sake' of illiterates (Alhussain 2019), illiteracy was mostly depicted as a barrier to labour-market inclusion and financial independence (e.g. Altherr Flores 2021; Ekblad 2020; Kuschel et al. 2023). Hence, in most of the articles, the need to increase research attention to illiterate refugees was presented in terms of solving a social problem, that of illiteracy. Such arguments are easily traced back to western labour-

market politics that seemingly equate education and language acquisition to employability (UNESCO 2021; Lindberg and Sandwall 2017). As only two of the studies (Benseman 2014; Michaud, Fortier, and Amireault 2022) made inquiries into how the participants valued their language learning themselves, this begs the question of whether this was an assumption made by the rest of the researchers, on behalf of the refugees. Somewhat pointedly, we argue that the desire for research to pay more attention to illiterate refugees may appear as a double-edged sword if their illiteracy is also represented as a societal problem that needs to be solved.

Methodological approaches of voicing

The use of interpreters as an aid in data collection was addressed in most of the nine articles. There were arguments addressing how interpreters may contribute to raising participants' voices at the same time as there were concerns about the risk of distorting or diminishing participants' narratives. Four articles stated that they had used interpreters to assist in gaining informed consent (Smyser and Alt 2018) and collecting data (Altherr Flores 2021; Ekblad 2020; Alhussain 2019), so that participants could speak freely. Others chose not to use them. Some instead sought help from bilingual teachers (Benseman 2014) and some stated that they had not used interpreters for fear of disturbing the group dynamics or causing trust issues among the participants (Michaud, Fortier, and Amireault 2022; Kuschel et al. 2023). One research team instead constructed easy-to-read interview questions and trained bilingual assistants to help participants answer them (Michaud, Fortier, and Amireault 2022).

While representation is a matter of enabling the inclusion of the researched and giving them a voice, it is also a question of *whose* voice one chooses to present. The nine articles were roughly equally divided between those using methods that only relied on participant narratives (Ekblad 2020; Michaud, Fortier, and Amireault 2022), methods that relied on standardised assessment tools or other people's perspectives on the target group – themselves or third-party experts (Alhussain 2019; Smyser and Alt 2018; Purcell-Gates et al. 2012), and articles that combined methods using both the participants' own accounts and external perspectives (Kuschel et al. 2023; Altherr Flores 2021; Atkinson 2014; Benseman 2014). It is safe to say that the research gap on vulnerable populations is not likely to be fully remedied without including narratives from the group themselves. This was well illustrated by the articles that presented results using direct quotes from the participants, alongside their own conclusions and assessments (Kuschel et al. 2023; Altherr Flores 2021; Ekblad 2020; Benseman 2014; Atkinson 2014). The others ranged from their own observations to statistical analyses.

Voicing in research ethics

Ethical considerations varied greatly across all of the studies. A surprising finding was the inconsistency of them, considering the recurring arguments that this group and issue need to be given more attention. While most reported having received approval from ethical review boards, they differed in the extent to which they described what further measures had been taken. Adequate measures for informed and voluntary consent without any undue influence is one of the hallmarks of research involving vulnerable groups that does not endanger participants' integrity (Block et al. 2013; Fassin and d'Haluin 2005). The articles ranged from omitting any discussion of ethical considerations

(Alhussain 2019), to thorough ethical analyses based on previous literature and personal experiences (Kuschel et al. 2023; Michaud, Fortier, and Amireault 2022; Ekblad 2020). However, most of the articles made brief remarks on the subject, especially relating to consent (Atkinson 2014; Benseman 2014; Purcell-Gates et al. 2012). Examples of this included brief statements that participants took part voluntary or joined on their own initiative, though further details were lacking (Altherr Flores 2021; Purcell-Gates et al. 2012). Since the practice of research information and consent needs to include adaptations to the research participants' abilities and contextual circumstances, using casual measures for consent, or none at all, is without doubt an example of the non-recognition or invisibilisation of the group of refugees with illiteracy specific circumstances and needs (e.g. Herzog 2018). Since the conditions faced by refugees with illiteracy appear to render them vulnerable in multidimensional ways, the issue of informed consent is not only a matter of communication and language barriers, but of ensuring 'no harm' and no exposure to the influence of power or pressure when deliberating upon whether or not to participate in research (Block et al. 2013; Fassin and d'Halluin 2005). In researchers' attempts to avoid research reproducing possible conditions of powerlessness, inferiority, and objectification, it is reasonable to expect them to not only practise ethical conduct, but also to describe how they have done so when publishing their results.

Forerunners to an ethics of engagement

Having presented findings that raised concerns of accurately representing target populations of illiterate refugees, we found several noteworthy examples where research methods were adapted and reflected upon to meet their demands.

Having individuals take part in research is not only a matter of representation in meeting certain criteria (Pitkin 1967) but also means employing appropriate methods that enable them to make substantial contributions to the production of knowledge without being overlooked or downgraded. Illiterate people are unlikely to independently read information letters, complete forms, or answer written questions. Collecting their perspectives therefore relies on methods that overcome literacy barriers, or that do not depend on them.

This may be the reason why qualitative methods were most commonly employed in the list of nine articles. There were variations of one-to-one interviews, group discussions, observations, and a few other methods (Michaud, Fortier, and Amireault 2022; Altherr Flores 2021; Alhussain 2019; Atkinson 2014; Benseman 2014). The studies using mixed methods also relied heavily on interviews and observations but complemented them with surveys and assessment tools (Kuschel et al. 2023; Ekblad 2020; Purcell-Gates et al. 2012).

One of the articles that we found applied an inclusive quantitative data-collection method, enabling a substantive representation of illiterate people. This was a project that used surveys and offered verbal assistance to answer them (Kuschel et al. 2023). They had also replaced their Likert scales with smileys for easy understanding. This enabled participants to express themselves even if they could not read, lending support to our previous decision to only include studies that explicitly address matters of illiteracy. Another article used experimental – and control-group tests within a classroom setting (Smyser and Alt 2018). While the research group had bilingual members who could help participants to understand their assignments, they also encouraged

them to translate for each other if needed. Such quantitative examples suggest that reflexive methods which allow participants to take part in research on their own terms are not limited to the qualitative domain.

Vulnerability is not an inherent trait of refugeehood, Michaud, Fortier, and Amireault (2022) argued, but contextual within settings of more or less familiarity. This may be useful to understand the varying and sometimes contradictory methods presented in our data. In some studies, interpreters were used to help participants partake on their own terms, while in others they were avoided for the same reasons. Some chose focus group discussions to provide participants with a safe environment for sharing their experiences (Ekblad 2020; Benseman 2014; Michaud, Fortier, and Amireault 2022), while there were occasions when that led to the loss of participants who were not comfortable sharing in group settings (Michaud, Fortier, and Amireault 2022). Vulnerability is *contextual* and thus methods need to be as well (Pickering and Kara 2017; Michaud, Fortier, and Amireault 2022).

Another recurring issue was protecting the identities of participants. Pseudonyms were often used for this purpose. One project that recorded video chose to only depict the hands of the participants to capture their emotions while keeping them anonymous (Altherr Flores 2021). Another switched from audio recordings to pen and paper when their participants were reluctant to be taped (Kuschel et al. 2023). Many of the researchers also employed trust-building methods, such as multiple visits beforehand to present themselves (Kuschel et al. 2023), setting ground-rules for focus group discussions (Ekblad 2020), and conducting pilot studies to try out their information letters and questionnaires beforehand (Michaud, Fortier, and Amireault 2022).

While the limited number of articles giving thorough accounts of ethical considerations complied with rules of conduct, they also brought attention to participants' circumstances (Herzog 2018). This was done both by actively addressing the fears and discomforts that may be part of their lives, and in many cases also by removing such obstacles and enabling them to take part and have a voice in a substantive sense (Pitkin 1967).

Discussion

One of the most striking findings of our study was that research addressing both refugees and illiteracy is severely lacking in the social sciences. This is not only important from the perspective of an academic interest in a notable research gap, but also from a pressing need to make visible a population of vulnerable people that is growing under societal demands of literacy. Furthermore, this limited supply of existing research has mostly addressed refugee illiteracy as a secondary characteristic in relation to other social phenomena. It has rarely given the attention needed to guarantee informed and autonomous participation by illiterates. If this group of informants is only present as a secondary finding or minor variable, it is unlikely that all the necessary measures will have been taken beforehand to ensure that their voices are heard. At best, it may draw attention to important topics for further research and some of the stakes involved when learning the language. Yet their scope and consequences cannot be fully understood without close attention being paid throughout the research process to the challenges faced by participants seeking to attend. In these times of increased refugee mobility (UNHCR 2024a), where schooling is a determining factor

for social inclusion (UNESCO 2021), these are individuals whom social scientists cannot afford to under – or mis-represent.

While it is difficult to assess the educational levels of adult refugees worldwide, it was estimated in 2018 that 75% of adolescent refugees were not attending secondary school and 35% of children were not in primary school (UNHCR 2024b). Needless to say, limited education and illiteracy is not a fringe phenomenon in these settings. Meanwhile, western politics has gradually transformed education from being an instrument of emancipation and self-actualisation towards becoming a threshold for societal inclusion through employment (UNESCO 2021; Lindberg and Sandwall 2017). Lack of formal school qualifications is now generally depicted as an integration problem in public debates, due to its impact on employability. This view was also represented in our data. Most of the nine articles in our in-depth analysis supported a contemporary idea of illiteracy as a hindrance to employment and financial independence. Participants were mostly depicted as recipients of services designed to improve their lives in accordance with western standards. Moreover, we conclude that the issues of low literacy and educational deficit are the main, or perhaps the only, points considered worthy of research attention in relation to this group. Not only is this a severely reductionist view of what we can learn from them and what other dimensions of everyday life research can pay attention to, it is also a stereotypical representation, and a definition of them as, first of all, bearers of a deficiency (Hall 1997; Pickering 2001). While our review joins them in an interest in addressing the societal consequences of illiteracy, it also draws attention to the need to move beyond a deficit perspective to a point where illiterate refugees are recognised as autonomous subjects in their own right, with their own qualities, dreams, and aspirations.

We have presented findings where researchers and other external parties talk about refugees and draw conclusions from their data without involving them. There are also examples where refugee narratives hold centre stage. One of the fundamental purposes of refugee research is to make vulnerable people's situations visible to the general public and policymakers in a sustainable manner (Jacobsen and Landau 2003; Block et al. 2013). Yet, without the involvement and personal accounts of the refugees themselves, we risk maintaining the very issues we address (Block et al. 2013).

Nevertheless, some of the articles described reflexive measures in recruitment and data collection. These examples demonstrate that representation *can* be made substantive (Pitkin 1967) by addressing potential obstacles. They are not only methodological concerns but may also lend a political voice to those who do not currently have one (Block et al. 2013). Representation is often depicted in research in terms of distribution and general descriptions of broad populations (Jacobsen and Landau 2003). While being crucial for understanding societal trends in general, such broad strokes may also fail to depict finer details, often leading to the continued underrepresentation of marginalised people. This is a dilemma of representation that needs attention and care whenever people in vulnerable positions are involved in research.

Notes

1. Students with Limited or Interrupted Formal Education (Michaud, Fortier, and Amireault 2022)
2. English as a Second Language

Acknowledgements

The authors would like to express their sincere gratitude to professor Mattias Strandh for his valuable counsel and insightful feedback throughout the process of writing this article. They are also grateful to the anonymous reviewers for their valuable comments throughout the review process.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Notes on contributors

Joel Persson is a doctoral student in Social Work, researching in the fields of migration, integration, and educational sciences. His doctoral work focuses on language education among refugees with limited previous education.

Eva Wikström is a researcher and teaching professor in Social Work within the field of ethnic relations and refugee integration. Her research involves issues around refugee integration, conditions for refugees' labour market integration, policy programmes for integration, and social and spatial conditions for inclusion.

ORCID

Joel Persson  <http://orcid.org/0009-0008-7815-0179>

Eva Wikström  <http://orcid.org/0000-0002-0365-0362>

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Appendices

Appendix A – Mapping review of language education research on illiteracy and illiterates

Web of Science search queries:

Query 1:

- Language NEAR training (Topic)
- Language NEAR education (Topic)
- Language NEAR acquisition (Topic)
- L2 NEAR training (Topic)
- L2 NEAR education (Topic)
- L2 NEAR acquisition (Topic)
- 'Swedish for immigrants' (Topic)

Filtered by Query 2:

- Refugee* (Topic)
- *Migrant* (Topic)
- *Migration* (Topic)
- Displace* (Topic)
- Asylum* (Topic)
- New* arriv* (Topic)

Filtered by Query 3:

- Illitera* (Topic)
- Litera* (Topic)
- Educated* (Topic)
- Educ* level* (Topic)
- Educ* Attainment (Topic)
- Schooling* (Topic)

Appendix B – Critical review of social science literature on illiteracy and illiterates

Web of Science search queries:

Query 1:

- Illiteracy (Topic)
- Low NEAR literacy (Topic)
- 'Low Literacy'
- Previous* NEAR/5 educ* (Topic)
- 'Pre-migr*' NEAR educ* (Topic)
- Limited NEAR educ* (Topic)
- SIFE (Topic) [Students with Interrupted education]
- SLIFE (Topic) [Students with Limited or Interrupted education]
- Uneduca* (Topic)
- Without NEAR/3 educ* (Topic)
- Little NEAR/3 educ* (Topic)
- Short NEAR/3 educ* (Topic)
- Interrupt* NEAR/3 educ* (Topic)

Filtered by: Refugee*

Appendix C – Table of articles for in-depth analysis

Author	Title	Methodology	Data source	Discipline	Country
<i>Kuschel et al. (2023)</i>	Combining Language Training and Work Experience for Refugees with Low-Literacy Levels	Mixed	Interviews Observations Surveys	Demography	Netherlands
Michaud, Fortier, and Amireault (2022)	Do I Have to Sign My Real Name?	Qualitative	Focus groups	Linguistics	Canada
<i>Altherr Flores (2021)</i>	The Interplay of Text and Image on the Meaning-Making Processes of Adult L2 Learners with Emerging Literacy	Qualitative	Interviews	Psychology / Linguistics	USA
<i>Ekblad (2020)</i>	To Increase Mental Health Literacy and Human Rights Among New-Coming, Low-Educated Mothers with Experience of War	Mixed	Focus groups Evaluation forms	Psychiatry	Sweden
<i>Alhussain (2019)</i>	An Empowerment Tool for Teaching English Effectively to Refugees	Qualitative	Observations	Linguistics	Saudi Arabia
Smyser and Alt (2018)		Quantitative	Standardised tests	Education / Psychology	USA

(Continued)

Continued.

Author	Title	Methodology	Data source	Discipline	Country
<i>Atkinson (2014)</i>	Developing mental orthographic representations in refugee spellers with low literacy	Qualitative	Focus groups	Education	Australia
<i>Benseman (2014)</i>	Reframing Literacy in Adult ESL Programmes	Qualitative	Observations Written narratives	Demography	New Zealand
<i>Purcell-Gates et al. (2012)</i>	Adult Refugee Learners with Limited Literacy	Mixed	Focus groups	Education / Psychology	Canada
	Measuring Situated Literacy Activity		Observations Standardised tests		