Towards culturally sensitive shared decision-making in oncology: a study protocol integrating bioethical qualitative research on shared decision-making among ethnic minorities with ethical reflection

Oueslati, R.; Reis, R.; Vries, M.C. de; Slager, M.T.; Sijp, J.R.M. van der; Stiggelbout, A.M.; Touwen, D.P.

Citation

Oueslati, R., Reis, R., Vries, M. C. de, Slager, M. T., Sijp, J. R. M. van der, Stiggelbout, A. M., & Touwen, D. P. (2022). Towards culturally sensitive shared decision-making in oncology: a study protocol integrating bioethical qualitative research on shared decision-making among ethnic minorities with ethical reflection. *International Journal Of Qualitative Methods*, *21*. doi:10.1177/16094069221086731

Qualitative Study Protocol

International Journal of Qualitative Methods
Volume 21: 1–12
© The Author(s) 2022
DOI: 10.1177/16094069221086731
journals.sagepub.com/home/ijq
SAGE

Towards Culturally Sensitive Shared Decision-Making in Oncology A Study Protocol Integrating Bioethical Qualitative Research on Shared Decision-Making Among Ethnic Minorities With Ethical Reflection

Roukayya Oueslati[1,2], Ria Reis[3,4], Martine C. de Vries[1], Meralda T. Slager[2], Joost R. M. van der Sijp[5], Anne M. Stiggelbout[6], and Dorothea P. Touwen[1]

Abstract

Background: Shared decision-making (SDM) is often considered the ideal for decision-making in oncology. Views of specific groups such as ethnic minorities have seldom been considered in its development.

Aim: In this study we seek to assess in oncology if there is a need for adaptation of the current SDM model to ethnic minorities and to formulate possible adjustments.

Design: This study is embedded in empirical bioethics, an interdisciplinary approach integrating empirical data with ethical reasoning to formulate normative conclusions regarding a practice. For the empirical social scientific part, a cross-sectional qualitative study will be conducted; for the ethical reflection the Reflective Equilibrium will be used to develop a coherent view on the application of SDM among ethnic minorities in oncology.

Method: Semi-structured interviews combined with visual methods (timelines and relational maps) will be held with healthcare professionals (HCPs), ethnic minority patients, and their relatives to identify values steering the behavior of these actors in SDM. In addition, focus groups (FGs) will be held with ethnic minority community members to identify value structures at the group level. Respondents will be recruited through organizations with access to ethnic minorities and collaborating hospitals. Data will be analyzed using a reflexive thematic analysis through the lens of Schwartz's value theory. The results of the empirical phase will be included in the RE to formulate possible adjustments of the SDM model, if needed.

Discussion: The integration of empirical data with ethical reflection is an innovative method in decision-making. This method enables a systematic and profound assessment of the need for adaptation of SDM and the formulation of theoretically and empirically based suggestions for adaptations of the model. Findings of this study may enrich the SDM model.

---

[1] Department of Medical Ethics and Health Law, Leiden University Medical Center, Leiden, the Netherlands
[2] Department of Nursing, The Hague University of Applied Sciences, The Hague, the Netherlands
[3] Amsterdam Institute for Social Science Research, University of Amsterdam, Amsterdam, the Netherlands
[4] Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, the Netherlands
[5] Research Group Oncological Care, The Hague University of Applied Sciences, The Hague, the Netherlands
[6] Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, the Netherlands

Corresponding Author:
Roukayya Oueslati, Department of Nursing, The Hague University of Applied Sciences, PO Box 13336, 2501 EH The Hague, the Netherlands.
Email: r.oueslati@hhs.nl

Keywords

shared decision-making, oncology, ethnic minorities, empirical bioethics, reflective equilibrium, culturally sensitive

Background and Study Justification

Shared decision-making (SDM) is increasingly advocated as the ideal model for preference sensitive decision-making (Charles et al., 1997; Stiggelbout et al., 2015), that is, when no clinically "best choice" exists (Wennberg et al., 2002) or patients' evaluations of benefits and harms strongly vary (Stiggelbout et al., 2012). In oncology, many preference sensitive decisions are made (Kane et al., 2014).

In SDM the healthcare professional (HCP) and patient collaborate to make treatment decisions for the patient based on medical evidence, the HCPs' expertise and the patient's preferences and context (Légaré & Witteman, 2013). While SDM is often considered the ideal for decision-making, barriers to implement SDM have been identified including system factors, physician factors, and patient factors (Covvey et al., 2019; Gillick, 2015; Gravel et al., 2006).

In European countries, ethnic minorities are expected to increasingly need oncological care due to their aging and the convergence of incidence rates towards the rates of the general population (Nijhuis et al., 2006; Smits et al., 2013; Stirbu et al., 2006). Ethnic minorities are defined as numerically smaller non-dominant groups distinguished by a shared "cultural heritage, including values, traditions and often language" (Phinney & Ong, 2007; p. 274; Yılmaz et al., 2019). Several studies from the USA show ethnic disparities in cancer treatments, which may result in lower survival rates among certain ethnic groups (Lathan et al., 2006; Morris et al., 2010; Revels et al., 2013; Shavers & Brown, 2002; Smith et al., 2011). Ethnic minorities in Europe, in contrast, generally have lower cancer mortality rates than the native population. For some types of cancer, however, excess mortality rates are higher among specific groups (breast cancer among Surinamese and premenopausal women), which is explained by inadequate access to care and treatment (Arnold et al., 2013; Spallek et al., 2012). In decision-making, ethnic minorities are more vulnerable for decision dissatisfaction and regret (Hawley & Morris, 2017; Lantz et al., 2005). This can be caused by insufficient information on treatment options due to language barriers, by a lack of alignment between patient's preferred and actual roles in decision-making (Gattellari et al., 2001) or by a display of less participatory behavior resulting in HCPs providing less information (Gordon et al., 2006). Peek et al. (2011) argue that ethnic minority patients may receive less information from their HCPs, despite their preference for an active role and their initiation of discussions with their HCP (Peek et al., 2011).

Several domains have been articulated that possibly challenge the application of SDM among ethnic minority populations, even apart from language barriers (Hawley & Morris, 2017; Suurmond & Seeleman, 2006).

The first domain concerns the different belief systems HCPs and patients may hold regarding health and illness. This can hamper communication as patients and HCPs are not discussing the same issue (Suurmond & Seeleman, 2006). Additionally, belief systems may influence preferences for treatment options (Killoran & Moyer, 2006; Margolis et al., 2003), care seeking behavior, and engagement in decision-making (Hawley & Morris, 2017). Another domain pertains to the division of roles implied by SDM. HCPs are supposed to provide patients with relevant information, create a comfortable environment, evaluate specific needs, and discuss patients' treatment preferences. Patients on the other hand are expected to share values, preferences, beliefs, and knowledge and to actively engage in the deliberation process (Charles et al., 1999). However, participation preferences for decision-making may vary between and within ethnic groups. While a strong desire for information on treatments exists, the preference for active or shared participation is more often seen among younger patients with higher levels of education and acculturation (Yılmaz et al., 2019). Furthermore, relatives and important others often play a significant role in decision-making (Coleman-Brueckheimer et al., 2009; Hawley & Morris, 2017; Mead et al., 2013), particularly among ethnic minorities, as relatives may function as interpreters for older patients (van Eechoud et al., 2017). The third domain concerns prejudice from both HCPs to patients and vice versa, which hinders the discussion of relevant issues (Suurmond & Seeleman, 2006). Also, patients' perceptions of discrimination result in less trust in HCPs (Boulware et al., 2003; Kaiser et al., 2011; Lin et al., 2014), while trust and feeling safe enable SDM (Groot et al., 2020; Jull et al., 2015).

To mitigate these challenges, studies suggest the development of a more inclusive and culturally sensitive SDM (Charles et al., 2006; Hawley & Morris, 2017; Mead et al., 2013). Others plead for a relational approach to decision-making in general to embed it more profoundly in the context of patients (Mol, 2008; Olthuis et al., 2014; van Nistelrooij et al., 2017).

Therefore, the aim of this study is to assess if there is a need for adaptation of SDM to ethnic minorities and if so, to formulate possible adjustments. This will be achieved by gaining insight in the underlying values that structure both SDM and the behavior of actors involved, combined with an ethical reflection about the application of SDM in this intercultural clinical context. A theoretically and empirically informed and context-specific application of SDM will be developed by integrating empirical research with ethical reasoning (Ives & Draper, 2009). To our knowledge, the integration of these two methods have previously not been used

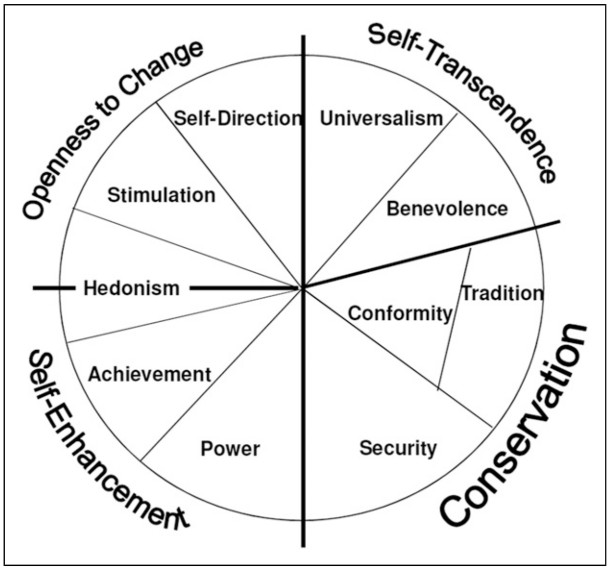

Figure 1. *Schwartz theory of basic human values* (Schwartz, 2012). The center consists of the 10 basic values that people recognize in different countries. The circular structure displays the relation between the values (e.g., compatibility and conflict). Values located next to each other express greater compatible motivational goals, while those located further from each other show greater conflict. The circular structure organizes the values along contrasting dimensions: "openness to change" to "conservation" values, and "self-enhancement" to the "self-transcendence" values (Schwartz, 2012) (Licensed under CC BY-NC-ND 3.0, https://creativecommons.org/licenses/by-nc-nd/3.0/).

for this purpose. We perform our research in oncology, since SDM is highly germane in this setting.

While the focus of this study is SDM among ethnic minorities, investigating groups based on their ethnic background bears several risks. It might suggest that values regarding SDM differ solely based on ethnicity, emphasize differences instead of similarities between ethnic groups, and blur the diversity within ethnic groups (Krebbekx et al., 2017). To mitigate these risks, we will remain sensitive to the existing diversity within ethnic groups. In addition, we will not solely explain agreements and differences between the value structures of SDM and the actors involved by ethnicity, but it may be an additional frame of reference to take into consideration (Hunter & Ammann, 2016). We will use our insights to enrich SDM by contributing to the development of a culturally sensitive approach, which can also benefit the population at large.

Theoretical Positioning and Methodological Approach

This study is embedded in empirical bioethics (EB), an interdisciplinary approach integrating empirical social scientific analysis with ethical reasoning to formulate normative conclusions regarding a practice (Ives et al., 2018).

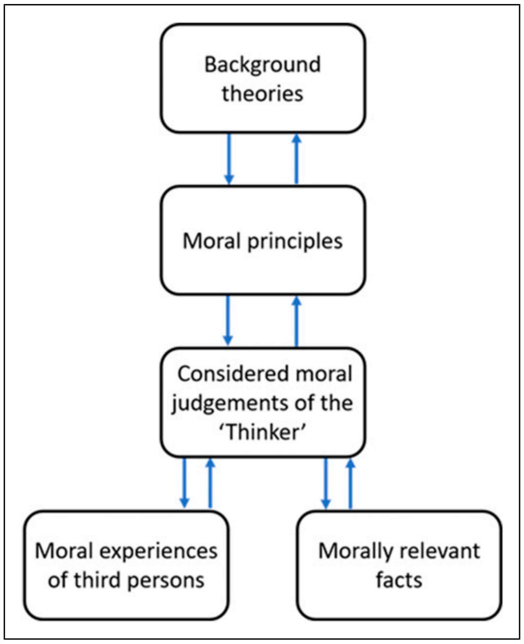

Figure 2. A model for the Reflective Equilibrium used by den Boer (2021) (den Boer, 2021) based on de Vries and van Leeuwen (2010) (de Vries & van Leeuwen, 2010) (published with permission).

Empirical Social Scientific Phase

In the empirical phase, we study both the values underlying published SDM models and the values of the actors involved in SDM. Values are central concepts for studying differences at the individual and group levels in the social sciences (Schwartz, 2012). In SDM, values and preferences are often used interchangeably. While preferences are object-focused and related to specific options in a decisional context (Brennan & Strombom, 1998; Grad et al., 2017; Llewellyn-Thomas & Crump, 2013; Pieterse & Stiggelbout, 2016), values are abstract trans-situational judgments about goals that guide the selection of behavior (Pieterse & Stiggelbout, 2016) and influence preferences about choices (Karimi-Dehkordi et al., 2019). Therefore, values play a key role in SDM (Makoul & Clayman, 2006). Whereas values are hierarchically organized (Schwartz, 2012) contextual factors (e.g., organization, social expectations, and culture), demographic factors (e.g., age and gender), and clinical characteristics (e.g., severity of a disease) influence value priorities (Karimi-Dehkordi, 2017).

Values play a dual role in SDM. First, they influence the decision-making *process,* through the role determination of every actor involved (Elwyn et al., 2012). Second, they influence the *treatment decisions* made, as HCPs preselect options before presenting these to patients, and frame information (Baldt, 2020; Beers et al., 2017; Ozdemir & Finkelstein, 2018), while patients choose treatment options in line with their values and life goals (Karimi-Dehkordi et al., 2019). The focus of this study is on the values influencing the decision-making process.

We will use Schwartz's theory of basic human values to study the values underlying SDM and of the actors involved in SDM. Schwartz's value theory has previously been used in studies on medical decision-making for both the investigation of patients' (Aavik et al., 2014; Karimi & Clark, 2016) and HCPs' values (Gschmeidler et al., 2016; Hermann et al., 2015; Moyo et al., 2016). The theory has been revised by Moyo et al. (2016) into more fitting personal and professional values for HCPs (Moyo et al., 2016). Schwartz defines values as *desirable goals motivating people's action* (Schwartz, 2012). He describes 10 broad values based on their motivational goal, in a circular structure (Figure 1). We will use Schwartz's value theory because it enables a cross-cultural comparison of values in SDM since the theory has been validated in different cultures (Sagiv et al., 2017; Schwartz, 1992). Also, the theory allows a comparison of values between the different actors involved in SDM and between the values of the actors and those underlying SDM within the same frame.

Ethical Analysis

The Reflective Equilibrium (RE) will be used for the formulation of normative conclusions regarding the application of SDM in an intercultural context by integrating empirical research with ethical reflection (de Vries & van Leeuwen, 2010). This method was first defined in the work of John Rawls (1921–2002) to facilitate ethical argumentation for moral questions arising in practical contexts (Rawls, 1971). We will use the RE version of de Vries and van Leeuwen (2010) which is derived from the "Network Model" of van Willigenburg and Heeger (1989) (Figure 2) (van Willigenburg & Heeger, 1989). Central to this version of the RE is the development of a coherent view by moving back and forth between background theories, moral principles, considered moral judgments of the primary researcher (the Thinker), morally relevant facts, and moral experiences of third persons. These components are given an equal status in the reflection process (de Vries & van Leeuwen, 2010).

Background theories form the normative background of the moral principles used in an RE (de Vries & van Leeuwen, 2010). In this context, background theories may consist of applied ethical theories (e.g., medical or care-ethical), SDM models, Schwartz's value theory, and theories about culturally sensitive care. Relevant moral principles may comprise the four principles of biomedical ethics (non-maleficence, beneficence, autonomy, and justice) and other fundamentals from health care, society and human rights thinking (Beauchamp & Childress, 2019).

Morally relevant facts can justifiably be appealed to in support of a certain moral judgment (van Willigenburg, 2014). In this study, morally relevant facts can consist of outcomes of SDM, guidelines on decision-making, or laws and regulations regarding medical treatment agreements between patients and HCPs. Finally, the moral experiences of third persons consist of the experiences of the actors involved in SDM. The inclusion of these experiences supports the notion that moral life is rooted and shaped in the lived context (de Vries & van Leeuwen, 2010).

The RE process starts with the formulation of a hypothetical equilibrium. This forms the deliberative starting point for the development of a readjusted equilibrium after the analysis of the moral experiences of the actors involved in SDM (de Vries & van Leeuwen, 2010). Departing from a baseline considered moral judgment (hypothetical equilibrium) on how SDM should be shaped in practice, moving back and forth between the various elements of the RE, including the moral experiences of the actors involved in SDM, will lead to a coherent view about the application of SDM among ethnic minorities.

Aims and Objectives

We aim to assess if there is a need in oncology for adaptation of SDM to ethnic minorities and if so, to formulate theoretically and empirically informed adjustments. To this aim, the following research questions are posed:

1. What are the values underlying the SDM models conceptualized by researchers?
2. What are the values of HCPs in SDM?
3. What are the values of ethnic minority patients and their relatives as well as members of their community regarding SDM?
4. How do the values of SDM models, HCPs, patients, and relatives from ethnic minorities as well as members of their community relate to each other?
5. What are possible adaptations of SDM based on the integration of ethical reflection and empirical research through the use of the RE?

Explanation and Justification of Method

Study Design. This bioethical study can be subdivided in five steps described in chronological order based on the research aims. A hypothetical equilibrium will be formulated resting on the underlying values of SDM, known facts, applicable principles and norms in practice (step 1) from which the qualitative study will be further developed. The qualitative study among the actors in SDM (steps 2–4) consists of a cross-sectional qualitative study embedded in an interpretative approach, in which the understanding of human interpretation of the world and their behavior takes a central place (Green & Thorogood, 2018). Ethical analysis will take place following the method of the RE (step 1, 5).

Methods

Step 1: the value system underlying SDM

During the first step we will investigate the values underlying SDM by including research papers in which SDM models have been conceptualized. We will make use of the SDM models recently analyzed by Bomhof-Roordink et al. (2019) when they identified key elements of SDM (Bomhof-Roordink et al., 2019).

The research papers will be analyzed using the reflexive thematic analysis (TA) which is a flexible approach to generate patterns of meaning (Braun & Clarke, 2006; Braun & Clarke, 2019; Braun & Clarke, 2020). Within the reflexive TA inductive analysis will be used allowing to investigate how values are constructed across SDM models (Braun & Clarke, 2019).

The six phases of analysis as distinguished by Braun and Clarke (2006, 2021b) will be followed using Atlas.ti 22 (Braun & Clarke, 2006, 2021b). As data analysis is a recursive and iterative process, the phases are not successive and might blend (Braun & Clarke, 2020).

First, the researcher will familiarize herself with the research papers through reading while making notes. During the second phase the research papers will be coded deductively through the lens of Schwartz's value theory (Schwartz, 2012). The research papers will be coded latently (implicit, underlying and "hidden" meaning), but we will also code the semantic (surface, obvious, overt) content (Braun & Clarke, 2020). In the third phase, the codes form the basis for the development of initial themes and sub-themes, which will be reviewed and refined in phase four and five. Ten research papers will be double coded and differences in coding will be discussed among the research team for the enhancement of reflexivity and interpretative depth (Braun & Clarke, 2021a). Also theme development will be discussed among the research team. In the sixth phase, we will write a report in which the value system underlying the SDM models will be described.

After this analysis, the primary researcher will formulate a hypothesis regarding SDM among ethnic minorities based on a theoretical deliberation about the value system underlying the SDM models and known facts, applicable principles and norms in practice and her own moral judgments. This hypothesis functions as a hypothetical equilibrium, from which the qualitative study among the actors involved in SDM will be further developed (de Vries & van Leeuwen, 2010).

Steps 2: and 3: the value systems of the actors involved in SDM

Semi-Structured Interviews

For the identification of individual values among the actors involved in SDM, semi-structured interviews will be held with three groups: HCPs, patients, and relatives.

The first group consists of HCPs. Their behavior is often steered by both personal and professional values (Baldt, 2020; Moyo et al., 2016). We will explore what HCPs consider important in SDM. Additionally, we will ask HCPs about their experience with SDM with ethnic minorities.

The second group consists of oncology patients from ethnic minorities; we will discuss their actual and preferred role in decision-making and the role of relatives and other involved actors.

Third, relatives of ethnic minority patients will be interviewed as they can influence patients' values (Karimi-Dehkordi et al., 2019). We will ask them about the treatment decisions the patient has made and how they perceive their role in this process. Furthermore, we will ask them about the different actors involved in decision-making.

The topic lists for the interviews will be developed using Schwartz's value theory (Schwartz, 2012).

Visual Methods: Timelines and Relational Maps

During the interviews with patients and relatives, visual methods (i.e., timelines and relational maps) will be employed. Combining visual methods with interviewing helps to surface tacit knowledge and enhances the identification of values that are often invisible and difficult to express (Austgard, 2007; Lim et al., 2016; Pieterse et al., 2008). Furthermore, using visual methods creates a more diverse image of respondents' experience with decision-making and improves the engagement of participants, especially if they have difficulties in expressing themselves verbally (Glegg, 2019; Marshall, 2019).

Patients and relatives will be asked to draw a timeline to create a visual representation of their treatment trajectory from the diagnosis to the present (Adriansen, 2012). This method helps respondents to reflect on and discuss the roles of actors during various treatment decisions (Marshall, 2019), but also provides an overview of the prioritized values and of possible changes in value priorities regarding decision-making during the treatment trajectory (Karimi & Clark, 2016).

At various treatment events on the timeline respondents are asked to draw a relational map to focus on the social context in which decisions are made. For instance, some decisions are made in the context of a clinical interaction with a HCP, others at home with one's partner (Griffioen et al., 2021). On this map, factors and people of influence in decision-making will be drawn as circles around the respondent (Bagnoli, 2009; Copeland & Agosto, 2012). For patients and relatives, these could consist of other relatives, important others in the community, and personal beliefs. Over the disease trajectory factors and people influencing decision-making may change (Epstein & Street, 2011).

Focus Groups

After the analysis of the individual interviews, we will hold focus groups (FGs) with community members of ethnic minorities to further explore and compare how value structures found at the individual level (interviews) relate to value priorities at group level (FGs) (Schwartz, 2012).

As decisions are shaped in collective collaboration between different actors (Epstein & Street, 2011; Sharma et al., 2009), community members can influence individual patient values (Epstein & Street, 2011; Mead et al., 2013). Through FG discussions, interactions between the respondents will illuminate the existing value priorities at group level and on how these values are negotiated (Green & Thorogood, 2018).

During the FGs we will use vignettes, short stories on a specific situation on which respondents are invited to react (Finch, 1987). This helps to explore respondents' values (Spalding & Phillips, 2007) and facilitates discussions when respondents have little experience with decision-making (Gray et al., 2017).

Study Sample

Through purposeful diversity sampling we will include various HCPs involved in decision-making in oncology (medical oncologists, surgeons, radiotherapists, nurse specialists, nurses) and experienced in providing care for ethnic minorities. In sampling, diverse characteristics (age, gender, profession, specialty, hospital) of HCPs will be considered (Green & Thorogood, 2018; Palinkas et al., 2015).

The study will be carried out around a large Academic Medical Center in South-Holland. The three largest minority groups in this area are people from Turkish, Moroccan and Surinamese Hindustani background (CBS, 2020; Oudhof et al., 2011). By a purposeful sampling strategy, patients and relatives from these ethnic groups will be included (Green & Thorogood, 2018): those who deal with different types of cancer, in various stages of their disease, and from different generations living in the Netherlands. Patients who are too ill to be interviewed or mentally incompetent will be excluded, as judged by HCPs.

For the appraisal of the sample size we use Malterud et al.'s (2016) concept of *information power* as guiding principle. The information richness of a sample in relation to the aims and requirements of the study determines how many participants will be included (Braun & Clarke, 2021b; Malterud et al., 2016). We estimate the inclusion of 12–18 HCPs, 12–18 patients, and 12–18 relatives. Appraisal of information power will continuously take place by comparing the results of our analysis with the aims of our study (Malterud et al., 2016).

Especially among first generation community members the FGs will be homogenously composed, based on ethnicity, generation and if preferred by gender. FGs with the second generation may be more heterogenous concerning these aspects. Two participating organizations in this research project with access to ethnic minorities will organize the FGs. Their involvement allows the FG to be culturally responsive, that is, in a familiar setting and in the presence of a person who is fluent in their native language (for the first generation) (Rodriguez et al., 2011).

Recruitment

Respondents will be recruited through our existing networks. HCPs in the participating and other hospitals will be contacted by e-mail and asked whether they are willing to be interviewed. Patients and relatives will be recruited through HCPs in the participating hospitals and the networks of the researchers involved in this research project. After patients and relatives consent to participate in this study, they will receive a call from the primary researcher providing them verbally with information after which also an information letter in Dutch and/or in their native language (Turkish, Arabic) will be sent to them. The participating organizations will recruit respondents for the FGs.

Data Analysis

Data collection and analysis will occur concurrently and will be an alternate process enabling the refinement of the topic lists in response to new insights from the analysis.

The interviews and FGs will be audiotaped and transcribed verbatim. Data will be analyzed by conducting a reflexive TA in the same way as the analysis of the SDM models discussed above, following the six phases of analysis as distinguished by Braun and Clarke (2006, 2021b) using Atlas.ti 22 (Braun & Clarke, 2006, 2021b), through the lens of Schwartz's value theory (Schwartz, 2012). Within the reflexive TA inductive analysis will be used allowing to see how values are constructed across the actors in SDM (Braun & Clarke, 2019).

For the enhancement of reflexivity and interpretative depth data will be double coded and discussed among the research team until the codes are refined (Braun & Clarke, 2021a). Also theme development will be discussed among the research team. After this analysis we have developed an overview of the value systems of the actors involved in SDM.

Step 4: Comparing the value systems

Now that we have developed an understanding of the value systems of the actors involved in SDM, we will investigate how these value systems relate to each other. Since we will analyze the values underlying the SDM models and those of the actors involved in SDM using Schwartz's theory, we can compare the value systems to each other. Divergent translations of values from Schwartz's theory may be found in the lived experiences of the different actors involved in SDM and in the SDM models. By comparing these value systems, locations of agreement and differences can be identified. These findings will be included in the deliberative process in the next step.

Step 5: Ethical reflection on possible adaptations

The hypothetical equilibrium (step 1) is the starting point for the formulation of a new equilibrium in which also the results of the empirical data from the practice are taken into consideration. By the establishment of a dialogue between information from practice (experiences from actors in SDM and morally relevant facts) and theory (principles and background theories, values from SDM models), a new empirical reflective equilibrium will be developed. The new equilibrium may differ substantially from the hypothetical equilibrium due to a “great shift in moral view” (conversion) of the researcher (de Vries & van Leeuwen, 2010; DePaul, 1993).

This ethical reflection will primarily be conducted by the primary researcher but will be openly discussed within the multidisciplinary research team (de Vries & van Leeuwen, 2010). The end product of this step may consist of the formulation of possible adaptations of the SDM model.

Ethics

To ascertain ethical clearance this study was submitted to the Medical Ethical Committee of the Leiden University Medical Centre (N20.195). Several ethical aspects will be taken into account during this study.

The first concerns the discussion of sensitive topics. A cancer diagnosis is a distressing experience for both patients and relatives (Holland & Alici, 2010). For some, talking about these experiences may be therapeutic (McIlfatrick et al., 2006), while it can be emotionally charged for others. The use of visual methods can intensify this experience (Adriansen, 2012). To mitigate these enhanced emotions, the researcher will be sensitive to the emotions the interview and FG can initiate, create a safe environment for respondents, end the interview and FG with a positive experience, and spend time afterward on reflection (Ashton, 2014). Possible reluctance of participants to discuss certain issues will be respected by the researcher.

The second concerns informed consent. Respondents can receive information letters and informed consent forms in their native language (Arabic, Turkish), which can also be verbally explained.

Rigor

The four criteria (credibility, transferability, dependability, and confirmability) for rigorous qualitative research formulated by Lincoln & Guba (1985) will be operationalized to ensure rigor (Lincoln & Guba, 1985). These will be enacted during the whole research process (Cypress, 2017).

Credibility, agreement between the respondents’ views and the researcher’s representation will be increased by prolonged, comprehensive, and thorough data engagement and familiarization with the depth and breadth of the data and by using multiple coders (Braun & Clarke, 2006; Nowell et al., 2017). Furthermore, a richer perspective on the data will be developed by peer debriefing, whereby the findings and progress of the study will be discussed with impartial researchers. This helps preventing the omission, and under or over representation of certain aspects (Janesick, 2015). Peer debriefing will also be applied during ethical reflection for the achievement of coherence between theory and practice (de Vries & van Leeuwen, 2010). Moreover, the use of visual in addition to verbal methods allows triangulation of data collection and enhances the researcher’s understanding of the respondents’ perspectives (Kolar et al., 2015).

The *transferability* of our study will be increased by using a purposeful sampling strategy. This will result in a rich, varied, and a broad scope of the data. This scope is further broadened by using information power as a guiding principle in the appraisal of the number of respondents to include (Cypress, 2017). In the end, whether our findings will be transferable and fitting to other contexts can only be judged by the readers and further studies (Koch, 2006; Nowell et al., 2017). Therefore, we will provide a detailed description of the research process and context (Koch, 2006).

Beside this detailed description, the *dependability*—the logical coherence—of our study will be demonstrated by auditing both the empirical and the ethical part of the research process and by the documentation of all the theoretical, methodological, and analytical choices made (de Vries & van Leeuwen, 2010; Koch, 2006; Lincoln & Guba, 1985; Sandelowski, 1986). During this process the primary researcher will be self-critical and reflect on impressions and interactions obtained before, during and after the data collection, and on how her own views influence the interpretation of the data and the ethical analysis (Braun & Clarke, 2019; Lincoln & Guba, 1985; Nowell et al., 2017; Sandelowski, 1986). Being reflexive authenticates *confirmability,* ensuring that the interpretations of the data are derived from the data and within the RE also from background theories, moral principles, and relevant facts (de Vries & van Leeuwen, 2010; Tobin & Begley, 2004).

Discussion

SDM poses several challenges in general and specific challenges in intercultural encounters with ethnic minorities. To develop a more inclusive and culturally sensitive variant of SDM, we aim to integrate empirical data with ethical reflection to assess the need for adaptations of the SDM model to ethnic minority populations and formulate possible adjustments of the model for its application in oncology in an intercultural context.

The integration of empirical data with ethical reflection is an innovative method in medical decision-making and enables both a systematic and profound assessment of the need for adaptation of the SDM model and the formulation of both theoretically and empirically based suggestions for adaptations.

The empirical social scientific part of this study has several limitations. The cross-sectional qualitative design provides only insight in the values respondents prioritize during the interview and the ones they have prioritized in previous treatment decision-making. In the course of their disease, however, their values may change (Karimi-Dehkordi, 2017; Karimi-Dehkordi et al., 2019). The timelines may provide information about possible changes in individual value priorities over time, while the inclusion of patients in several stages of their disease allows a comparison in value priorities between patients in different stages of their disease.

Another limitation is that the interviews with actors involved in SDM are conducted separately and that observations of interactions are not included. The image emerging during interactions may be more dynamic than our study will describe. The use of relational maps however allows for the identification of factors influencing decision-making in the perception of our respondents.

Lastly, while the use of empirical data in the RE ensures that ethical reflection is rooted in the clinical reality and applied in specific situations, it causes the normative conclusions to be time and context dependent and therefore less generalizable. Through transparency during the development and formulation of our equilibrium, readers will be enabled to judge whether our findings are also fitting to their context.

The results of this study will be disseminated through academic papers, training modules for HCPs, and by the formulation of possible suggestions for a tool that HCPs can use in daily practice.

Acknowledgments

We would like to thank the members of the Advisory Board for their input on our study design and plan of action. Furthermore, our gratitude goes to the staff members of the Walaeus Library (Leiden University Medical Center) for providing support in the literature research, especially Jan Schoones and José Plevier and of the library of The Hague University of Applied Sciences for providing technical support, especially Niloufar Soukhai. Lastly, we thank Randy Bax for his constructive feedback on the English language.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Author's note

Anne M. Stiggelbout is also affiliated with Erasmus School of Health Policy and Management, Erasmus University Rotterdam, Rotterdam, the Netherlands and Ria Reis is also affiliated with The Children's Institute, School of Child and Adolescent Health, University of Cape Town, Cape Town, South Africa.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of the article: This work was supported by ZonMw, Netherlands Organization for Health Research and Development [grant number 854011006]; and by The Hague University of Applied Sciences in the form of a PhD voucher.

ORCID iD

Roukayya Oueslati https://orcid.org/0000-0003-1617-4526

References

Aavik, T., Aavik, A., & Punab, M. (2014). Personal values that support and counteract utilization of a screening test for prostate cancer. *Behavioral Medicine*, *40*(1), 22–28. https://doi.org/10.1080/08964289.2013.831805

Adriansen, H. K. (2012). Timeline interviews: A tool for conducting life history research. *Qualitative Studies*, *3*(1), 40–55. https://doi.org/10.7146/qs.v3i1.6272

Arnold, M., Aarts, M. J., Siesling, S., van der Aa, M., Visser, O., & Coebergh, J. W. (2013). Diverging breast and stomach cancer incidence and survival in migrants in the Netherlands, 1996–2009. *Acta Oncologica*, *52*(6), 1195–1201. https://doi.org/10.3109/0284186X.2012.742962

Ashton, S. (2014). Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics. *Nurse Researcher*, *22*(1), 27–31. https://doi.org/10.7748/nr.22.1.27.e1255

Austgard, K. (2007). Language and the experience of patients' values in nursing care: A theoretical exploration. *Nurse Education Today*, *27*(2), 139–144. https://doi.org/10.1016/j.nedt.2006.04.005

Bagnoli, A. (2009). Beyond the standard interview: The use of graphic elicitation and arts-based methods. *Qualitative Research*, *9*(5), 547–570. https://doi.org/10.1177/1468794109343625

Baldt, B. (2020). The influence of values in shared (medical) decision making. *Ethik in Der Medizin*, *32*(1), 37–47. https://doi.org/10.1007/s00481-019-00549-y

Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics* (8th ed.). Oxford University Press.

Beers, E., Lee Nilsen, M., & Johnson, J. T. (2017). The role of patients: Shared decision-making. *Otolaryngologic Clinics of North America*, *50*(4), 689–708. https://doi.org/10.1016/j.otc.2017.03.006

Bomhof-Roordink, H., Gärtner, F. R., Stiggelbout, A. M., & Pieterse, A. H. (2019). Key components of shared decision making models: A systematic review. *BMJ Open*, *9*(12), Article e031763. https://doi.org/10.1136/bmjopen-2019-031763

Boulware, L. E., Cooper, L. A., Ratner, L. E., LaVeist, T. A., & Powe, N. R. (2003). Race and trust in the health care system. *Public Health Reports*, *118*(4), 358–365. https://doi.org/10.1093/phr/118.4.358

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Braun, V., & Clarke, V. (2021a). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*. https://doi.org/10.1037/qup0000196.

Braun, V., & Clarke, V. (2021b). *Thematic analysis: A practical guide*. Sage Publications.

Brennan, P. F., & Strombom, I. (1998). Improving health care by understanding patient preferences: The role of computer technology. *Journal of the American Medical Informatics Association: JAMIA*, *5*(3), 257–262. https://doi.org/10.1136/jamia.1998.0050257

Centraal bureau voor de Statistiek, Statistics Netherlands (2020). *Hoeveel mensen met een migratieachtergrond wonen in Nederland? [How many citizens with a migrant background live in the Netherlands?]* https://www.cbs.nl/nl-nl/dossier/dossier-asiel-migratie-en-integratie/hoeveel-mensen-met-een-migratieachtergrond-wonen-in-nederland- (accessed 4 December 2020).

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, *44*(5), 681–692. https://doi.org/10.1016/S0277-9536(96)00221-3

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine*, *49*(5), 651–661. https://doi.org/10.1016/S0277-9536(99)00145-8

Charles, C., Gafni, A., Whelan, T., & O'Brien, M. A. (2006). Cultural influences on the physician-patient encounter: The case of shared treatment decision-making. *Patient Education and Counseling*, *63*(3), 262–267. https://doi.org/10.1016/j.pec.2006.06.018

Coleman-Brueckheimer, K., Spitzer, J., & Koffman, J. (2009). Involvement of Rabbinic and communal authorities in decision-making by haredi Jews in the UK with breast cancer: An interpretative phenomenological analysis. *Social Science & Medicin*, *68*(2), 323–333. https://doi.org/10.1016/j.socscimed.2008.10.003

Copeland, A. J., & Agosto, D. E. (2012). Diagrams and relational maps: The use of graphic elicitation techniques with interviewing for data collection, analysis, and display. *International Journal of Qualitative Methods*, *11*(5), 513–533. https://doi.org/10.1177/160940691201100501

Covvey, J. R., Kamal, K. M., Gorse, E. E., Mehta, Z., Dhumal, T., Heidari, E., Rao, D., & Zacker, C. (2019). Barriers and facilitators to shared decision-making in oncology: A systematic review of the literature. *Supportive Care in Cancer*, *27*(5), 1613–1637. https://doi.org/10.1007/s00520-019-04675-7

Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, *36*(4), 253–263. https://doi.org/10.1097/DCC.0000000000000253

de Vries, M. C., & van Leeuwen, E. (2010). Reflective equilibrium and empirical data: Third person moral experiences in empirical medical ethics. *Bioethics*, *24*(9), 490–498, https://doi.org/10.1111/j.1467-8519.2009.01721.x

den Boer, M. C. (2021). *Improving neonatal resuscitation: Ethical aspects*. Dissertation/Thesis.

DePaul, M. R. (1993). *Balance and refinement: Beyond coherence methods of moral inquiry*. Routledge. https://doi.org/10.4324/9780203004180

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine*, *27*(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6

Epstein, R. M., & Street, R. L. (2011). Shared mind: Communication, decision making, and autonomy in serious illness. *Annals of Family Medicine*, *9*(5), 454–461. https://doi.org/10.1370/afm.1301

Finch, J. (1987). The vignette technique in survey research. *Sociology*, *21*(1), 105–114. https://doi.org/10.1177/0038038587021001008

Gattellari, M., Butow, P. N., & Tattersall, M. H. (2001). Sharing decisions in cancer care. *Social Science and Medicine*, *52*(12), 1865–1878. https://doi.org/10.1016/s0277-9536(00)00303-8

Gillick, M. R. (2015). Re-engineering shared decision-making. *Journal of Medical Ethics*, *41*(9), 785–788. https://doi.org/10.1136/medethics-2014-102618

Glegg, S. M. N. (2019). Facilitating interviews in qualitative research with visual tools: A typology. *Qualitative Health Research*, *29*(2), 301–310. https://doi.org/10.1177/1049732318786485

Gordon, H. S., Street, R. L. Jr., Sharf, B. F., & Souchek, J. (2006). Racial differences in doctors' information-giving and patients' participation. *Cancer*, *107*(6), 1313–1320. https://doi.org/10.1002/cncr.22122

Grad, R., Légaré, F., Bell, N. R., Dickinson, J. A., Singh, H., Moore, A. E., Kasperavicius, D., & Kretschmer, K. L. (2017). Shared decision making in preventive health care: What it is; what it is not. *Canadian Family Physician Medecin De Famille Canadien*, *63*(9), 682–684.

Gravel, K., Légaré, F., & Graham, I. D. (2006). Barriers and facilitators to implementing shared decision-making in clinical practice: A systematic review of health professionals' perceptions. *Implementation Science*, *1*(1, article 16), 16. https://doi.org/10.1186/1748-5908-1-16

Gray, D., Royall, B., & Malson, H. (2017). Hypothetically speaking: Using vignettes as a stand-alone qualitative method. In V. Braun, V. Clarke, & D. Gray (Eds.), *Collecting qualitative data: A practical guide to textual, media and virtual techniques* (pp. 45–70). Cambridge University Press. https://doi.org/10.1017/9781107295094.005

Green, J., & Thorogood, N. (2018). *Qualitative methods for health research* (4th ed.). SAGE.

Griffioen, I. P. M., Rietjens, J. A. C., Melles, M., Snelders, D., Homs, M. Y. V., van Eijck, C. H., & Stiggelbout, A. M. (2021). The bigger picture of shared decision making: A service design perspective using the care path of locally advanced pancreatic cancer as a case. *Cancer Medicine*, *10*(17), 5907–5916. https://doi.org/10.1002/cam4.4145

Groot, G., Waldron, T., Barreno, L., Cochran, D., & Carr, T. (2020). Trust and world view in shared decision making with indigenous patients: A realist synthesis. *Journal of Evaluation in Clinical Practice*, *26*(2), 503–514. https://doi.org/10.1111/jep.13307

Gschmeidler, B., Flatscher-Thöni, M., & Knitel-Grabher, E. (2016). Genetics in the medical and psychosocial practice: On the role of value hierarchies in counselling. *Journal of Public Health*, *24*(3), 253–261. https://doi.org/10.1007/s10389-016-0719-6

Hawley, S. T., & Morris, A. M. (2017). Cultural challenges to engaging patients in shared decision making. *Patient Education and Counseling*, *100*(1), 18–24. https://doi.org/10.1016/j.pec.2016.07.008

Hermann, H., Trachsel, M., & Biller-Andorno, N. (2015). Physicians' personal values in determining medical decision-making capacity: A survey study. *Journal of Medical Ethics*, *41*(9), 739–744. https://doi.org/10.1136/medethics-2014-102263

Holland, J. C., & Alici, Y. (2010). Management of distress in cancer patients. *The Journal of Supportive Oncology*, *8*(1), 4–12. http://europepmc.org/abstract/MED/20235417

Hunter, A., & Ammann, E. S. (2016). End-of-life care and rituals in contexts of post-migration diversity in Europe: An introduction. *Journal of Intercultural Studies*, *37*(2), 95–102. https://doi.org/10.1080/07256868.2016.1142052

Ives, J., & Draper, H. (2009). Appropriate methodologies for empirical bioethics: It's all relative. *Bioethics*, *23*(4), 249–258. https://doi.org/10.1111/j.1467-8519.2009.01715.x

Ives, J., Dunn, M., Molewijk, B., Schildmann, J., Bærøe, K., Frith, L., Huxtable, R., Landeweer, E., Mertz, M., Provoost, V., Rid, A., Salloch, S., Sheehan, M., Strech, D., de Vries, M., & Widdershoven, G. (2018). Standards of practice in empirical bioethics research: Towards a consensus. *BMC Medical Ethics*, *19*(1), 68. https://doi.org/10.1186/s12910-018-0304-3

Janesick, V. J. (2015). Peer debriefing. In G. Ritzer (Ed.), *The Blackwell Encyclopedia of Sociology*. https://doi.org/10.1002/9781405165518.wbeosp014.pub2

Jull, J., Giles, A., Boyer, Y., Lodge, M., & Stacey, D. (2015). Shared decision making with aboriginal women facing health decisions: A qualitative study identifying needs, supports, and barriers. *AlterNative: An International Journal of Indigenous Peoples*, *11*(4), 401–416. https://doi.org/10.1177/117718011501100407

Kaiser, K., Rauscher, G. H., Jacobs, E. A., Strenski, T. A., Ferrans, C. E., & Warnecke, R. B. (2011). The import of trust in regular providers to trust in cancer physicians among white, African American, and Hispanic breast cancer patients. *Journal of General Internal Medicine*, *26*(1), 51–57. https://doi.org/10.1007/s11606-010-1489-4

Kane, H. L., Halpern, M. T., Squiers, L. B., Treiman, K. A., & McCormack, L. A. (2014). Implementing and evaluating shared decision making in oncology practice. *CA: A Cancer Journal for Clinicians*, *64*(6), 377–388. https://doi-org.ezproxy.leidenuniv.nl/10.3322/caac.21245

Karimi-Dehkordi, M. (2017). The influence of heart failure patients' values on self-care decision-making *(Dissertation/Thesis)*. https://doi.org/10.13140/RG.2.2.24443.54569

Karimi-Dehkordi, M., Spiers, J., & Clark, A. M. (2019). An evolutionary concept analysis of "patients' values. *Nursing Outlook*, *67*(5), 523-539. https://doi.org/10.1016/j.outlook.2019.03.005.

Karimi, M., & Clark, A. M. (2016). How do patients' values influence heart failure self-care decision-making?: A mixed-methods systematic review. *International Journal of Nursing Studies*, *59*, 89-104. https://doi.org/10.1016/j.ijnurstu.2016.03.010.

Killoran, M., & Moyer, A. (2006). Surgical treatment preferences in Chinese-American women with early-stage breast cancer. *Psycho-Oncology*, *15*(11), 969–984. https://doi.org/10.1002/pon.1032

Koch, T. (2006). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, *53*(1), 91–100. https://doi.org/10.1111/j.1365-2648.2006.03681.x

Kolar, K., Ahmad, F., Chan, L., & Erickson, P. G. (2015). Timeline mapping in qualitative interviews: A study of resilience with marginalized groups. *International Journal of Qualitative Methods*, *14*(3), 13–32. https://doi.org/10.1177/160940691501400302

Krebbekx, W., Spronk, R., & M'charek, A. (2017). Ethnicizing sexuality: An analysis of research practices in the Netherlands. *Ethnic and Racial Studies*, *40*(4), 636–655. https://doi.org/10.1080/01419870.2016.1181771

Lantz, P. M., Janz, N. K., Fagerlin, A., Schwartz, K., Liu, L., Lakhani, I., Salem, B., & Katz, S. J. (2005). Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. *Health Services Research*, *40*(3), 745–767. https://doi.org/10.1111/j.1475-6773.2005.00383.x

Lathan, C. S., Neville, B. A., & Earle, C. C. (2006). The effect of race on invasive staging and surgery in non–small-cell lung cancer. *Journal of Clinical Oncology*, *24*(3), 413–418. https://doi.org/10.1200/JCO.2005.02.1758

Légaré, F., & Witteman, H. O. (2013). Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. *Health Affairs (Project Hope)*, *32*(2), 276–284. https://doi.org/10.1377/hlthaff.2012.1078

Lim, C., Berry, A. B. L., Hirsch, T., Hartzler, A. L., Wagner, E. H., Ludman, E., & Ralston, J. D. (2016). It just seems outside my health": How patients with chronic conditions perceive communication boundaries with providers (pp. 1172–1184). https://doi.org/10.1145/2901790.2901866.*DIS. Designing interactive systems (conference)*

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.

Lin, J. J., Mhango, G., Wall, M. M., Lurslurchachai, L., Bond, K. T., Nelson, J. E., Berman, A. R., Salazar-Schicchi, J., Powell, C., Keller, S. M., Halm, E. A., Leventhal, H., & Wisnivesky, J. P. (2014). Cultural factors associated with racial disparities in lung cancer care. *Annals of the American Thoracic Society*, *11*(4), 489–495. https://doi.org/10.1513/AnnalsATS.201402-055OC

Llewellyn-Thomas, H., & Crump, R. T. (2013). Decision support for patients: Values clarification and preference elicitation. *Medical Care Research and Review*, *70*(1), 50S–79S. https://doi.org/10.1177/1077558712461182

Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, *60*(3), 301–312. https://doi.org/10.1016/j.pec.2005.06.010

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Margolis, M. L., Christie, J. D., Silvestri, G. A., Kaiser, L., Santiago, S., & Hansen-Flaschen, J. (2003). Racial differences pertaining to a belief about lung cancer surgery: Results of a multicenter survey. *Annals of Internal Medicine*, *139*(7), 558–563. https://doi.org/10.7326/0003-4819-139-7-200310070-00007

Marshall, E. A. (2019). Timeline drawing methods. In P. Liamputtong (Ed.), *Handbook of research methods in health aocial sciences* (pp. 1183–1199). Springer Singapore. https://doi.org/10.1007/978-981-10-5251-4_10

McIlfatrick, S., Sullivan, K., & McKenna, H. (2006). Exploring the ethical issues of the research interview in the cancer context. *European Journal of Oncology Nursing*, *10*(1), 39–47. https://doi.org/10.1016/j.ejon.2005.04.002

Mead, E. L., Doorenbos, A. Z., Javid, S. H., Haozous, E. A., Alvord, L. A., Flum, D. R., & Morris, A. M. (2013). Shared decision-making for cancer care among racial and ethnic minorities: A systematic review. *American Journal of Public Health*, *103*(12), Article e15–29. https://doi.org/10.2105/AJPH.2013.301631

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge. https://doi.org/10.4324/9780203927076

Morris, A. M., Rhoads, K. F., Stain, S. C., & Birkmeyer, J. D. (2010). Understanding racial disparities in cancer treatment and outcomes. *Journal of the American College of Surgeons*, *211*(1), 105–113. http://doi.org/10.1016/j.jamcollsurg.2010.02.051

Moyo, M., Goodyear-Smith, F., Weller, J., Robb, G., & Shulruf, B. (2016). Healthcare practitioners' personal and professional values. *Advances in Health Sciences Education: Theory and Practice*, *21*(2), 257–286. https://doi.org/10.1007/s10459-015-9626-9

Nijhuis, H., Vlems, F., Belhaj, K., Devillé, W., Harmsen, H., Hoekman, K., & Koppenol-van Hooijdonk, M. (2006). *Allochtonen en kanker: Sociaal-culturele en epidemiologische aspecten [Immigrants and cancer: Socio-cultural and epidemiological aspects]*. KWF Kankerbestrijding. https://www.netwerkpalliatievezorg.nl/Portals/92/KWF%20folder%20Allochtonen%20en%20kanker.pdf

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 1609406917733847. https://doi.org/10.1177/1609406917733847

Olthuis, G., Leget, C., & Grypdonck, M. (2014). Why shared decision making is not good enough: Lessons from patients. *Journal of Medical Ethics*, *40*(7), 493–495. https://doi.org/10.1136/medethics-2012-101215

Oudhof, K., Harmsen, C., Loozen, S., & Choen, C. (2011). Omvang en spreiding van surinaamse bevolkingsgroepen in Nederland [spread and distribution of the surinamese population in the Netherlands]. *Bevolkingstrends, 2e Kwartaal*, 97-104.

Ozdemir, S., & Finkelstein, E. A. (2018). Cognitive bias: The downside of shared decision making. *JCO Clinical Cancer Informatics*, *2*(2), 1–10. https://doi.org/10.1200/CCI.18.00011

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Peek, M. E., Tang, H., Cargill, A., & Chin, M. H. (2011). Are there racial differences in patients' shared decision-making preferences and behaviors among patients with diabetes? *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, *31*(3), 422–431. https://doi.org/10.1177/0272989X10384739

Phinney, J. S., & Ong, A. D. (2007). Conceptualization and measurement of ethnic identity: Current status and future directions. *Journal of Counseling Psychology*, *54*(3), 271–281. https://doi.org/10.1037/0022-0167.54.3.271

Pieterse, A. H., Baas-Thijssen, M., Marijnen, C. A. M., & Stiggelbout, A. M. (2008). Clinician and cancer patient views on patient participation in treatment decision-making: A quantitative and qualitative exploration. *British Journal of Cancer*, *99*(6), 875–882. https://doi.org/10.1038/sj.bjc.6604611

Pieterse, A. H., & Stiggelbout, A. M. (2016). What are values, utilities, and preferences? A clarification in the context of decision making in health care, and an exploration of measurement issues. In M. A. Diefenbach, S. Miller-Halegoua, & J. B. Deborah (Eds), *Handbook of health decision science* (pp. 3–13). Springer. https://doi.org/10.1007/978-1-4939-3486-7_1

Rawls, J. (1971). *A theory of justice* (22nd pr. ed.). Belknap Press of Harvard University Press.

Revels, S. L., Morris, A. M., Reddy, R. M., Akateh, C., Wong, S. L., Reddy, R., Akateh, C., Akateh, C., Wong, S., & Wong, S. (2013). Racial disparities in esophageal cancer outcomes. *Annals of Surgical Oncology*, *20*(4), 1136–1141. https://doi.org/10.1245/s10434-012-2807-3

Rodriguez, K. L., Schwartz, J. L., Lahman, M. K. E., & Geist, M. R. (2011). Culturally responsive focus groups: Reframing the research experience to focus on participants. *International Journal of Qualitative Methods*, *10*(4), 400–417. https://doi.org/10.1177/160940691101000407

Sagiv, L., Roccas, S., Cieciuch, J., & Schwartz, S. H. (2017). Personal values in human life. *Nature Human Behaviour*, *1*(9), 630–639. https://doi.org/10.1038/s41562-017-0185-3

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, *8*(3), 27–37. https://doi.org/10.1097/00012272-198604000-00005

Schwartz, S. H. (1992). Universals in the content and structure of values: Theoretical advances and empirical tests in 20 countries. *Advances in experimental social psychology* (pp. 1–65). Elsevier Science & Technology. https://doi.org/10.1016/S0065-2601(08)60281-6

Schwartz, S. H. (2012). An overview of the schwartz theory of basic values. *Online Readings in Psychology and Culture*, *2*(1). https://doi.org/10.9707/2307-0919.1116.

Sharma, R. A., Shah, K., & Glatstein, E. (2009). Multidisciplinary team meetings: What does the future hold for the flies raised in Wittgenstein's bottle? *The Lancet Oncology*, *10*(2), 98–99. https://doi.org/10.1016/S1470-2045(09)70006-3

Shavers, V. L., & Brown, M. L. (2002). Racial and ethnic disparities in the receipt of cancer treatment. *Journal of the National Cancer Institute*, *94*(5), 334–357. https://doi.org/10.1093/jnci/94.5.334

Smith, C. B., Bonomi, M., Packer, S., & Wisnivesky, J. P. (2011). Disparities in lung cancer stage, treatment and survival among American Indians and Alaskan natives. *Lung Cancer*, *72*(2), 160–164. https://doi.org/10.1016/j.lungcan.2010.08.015

Smits, C. H. M., van den Beld, H. K., Aartsen, M. J., & Schroots, J. J. F. (2013). Aging in the Netherlands: State of the art and science. *The Gerontologist*, *54*(3), 335–343. https://doi.org/10.1093/geront/gnt096

Spalding, N. J., & Phillips, T. (2007). Exploring the use of vignettes: From validity to trustworthiness. *Qualitative Health Research*, *17*(7), 954–962. https://doi.org/10.1177/1049732307306187

Spallek, J., Arnold, M., Razum, O., Juel, K., Rey, G., Deboosere, P., Mackenbach, J. P., & Kunst, A. E. (2012). Cancer mortality patterns among Turkish immigrants in four European countries and in Turkey. *European Journal of Epidemiology*, *27*(12), 915–921. https://doi.org/10.1007/s10654-012-9746-y

Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. J. M. (2015). Shared decision making: Concepts, evidence, and practice. *Patient Education and Counseling*, *98*(10), 1172–1179. https://doi.org/10.1016/j.pec.2015.06.022

Stiggelbout, A. M., Weijden, T. V., Wit, M P T D., Frosch, D., Légaré, F., Montori, V. M., Trevena, L., & Elwyn, G. (2012). Shared decision making: Really putting patients at the centre of healthcare. *Bmj*, *344*(1), Article e256. http://dx.doi.org/10.1136/bmj.e256

Stirbu, I., Kunst, A. E., Vlems, F. A., Visser, O., Bos, V., Deville, W., Nijhuis, H. G. J., & Coebergh, J. W. (2006). Cancer mortality rates among first and second generation migrants in the Netherlands: convergence toward the rates of the native dutch population. *International Journal of Cancer*, *119*(11), 2665–2672. https://doi.org/10.1002/ijc.22200

Suurmond, J., & Seeleman, C. (2006). Shared decision-making in an intercultural context. Barriers in the interaction between physicians and immigrant patients. *Patient Education and Counseling*, *60*(2), 253–259. https://doi.org/10.1016/j.pec.2005.01.012

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388–396. https://doi.org/10.1111/j.1365-2648.2004.03207.x

van Eechoud, I., Grypdonck, M., Leman, J., Van Den Noortgate, N., Deveugele, M., & Verhaeghe, S. (2017). Balancing truth-telling: Relatives acting as translators for older adult cancer patients of Turkish or northwest African origin in Belgium. *European Journal of Cancer Care*, *26*(5), Article e12498. https://doi.org/10.1111/ecc.12498

van Nistelrooij, I., Visse, M., Spekkink, A., & de Lange, J. (2017). How shared is shared decision-making? A care-ethical view on the role of partner and family. *Journal of Medical Ethics*, *43*(9), 637-644. https://doi.org/10.1136/medethics-2016-103791.

van Willigenburg, T. (2014). Morally relevant facts: Particularism and intuitionist rationality. In G. A. den Hartogh, W. van der Burg, & T. van Willigenburg (Eds.), *Reflective equilibrium: Essays in honour of Robert Heeger* (pp. 41–54). Springer Netherlands.

van Willigenburg, T., & Heeger, F. R. (1989). Justification of moral judgements: A network model. *Societas Ethica Jahresbericht*, 53-61.

Wennberg, J. E., Fisher, E. S., & Skinner, J. S. (2002). Geography and the debate over medicare reform *Health affairs (project hope)*, *20*(1), 96–114. https://doi.org/10.1377/hlthaff.w2.96

Yılmaz, N. G., Schouten, B. C., Schinkel, S., & van Weert, J. C. M. (2019). Information and participation preferences and needs of non-Western ethnic minority cancer patients and survivors: A systematic review of the literature. *Patient Education and Counseling*, *102*(4), 631–650. https://doi.org/10.1016/j.pec.2018.11.018