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Title page

What are parents’ perspectives on psychological empowerment in the MMR vaccination decision?

A focus group study

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Abstract

Objectives: Most developed countries do not have compulsory immunization requirements, but issue recommendations. Parents are expected to make an informed, autonomous decision regarding their children's vaccinations. However, despite such a call for parents' empowerment, there is no evidence about how parents' interpret this call and the latitude of their decision-making. The goal of this study is to gain insights from parents residing in a low MMR uptake area on what constitutes feelings of empowerment in the decision they have to make on their child's MMR vaccination.

Design: A qualitative study employing focus group interviews.

Setting: Eleven vaccination centers and hospitals in the Province of Trento, Italy.

Participants: 24 mothers and 4 fathers of children for whom the MMR vaccination decision was still pending participated in six focus groups.

Results: Autonomy and competence were salient themes in relation to empowerment and were further connected with beliefs regarding legal responsibility and ethics of freedom concerning the decision, parents' relationship with the pediatrician, feelings of relevance of the decision and related stress, and seeking, avoidance, or fear of vaccination-related information. Competence was interpreted as medical knowledge and information-seeking skills, but it was also related to the extent parents perceived the pediatrician to be competent.

Conclusions: Since parents' interpretation of empowerment goes beyond mere perceptions of being informed and autonomous and differs across individuals, it is important that this construct be correctly interpreted and implemented by best practice, for instance by explicitly adopting a relational conception of autonomy. Knowing parents' preferences regarding their empowerment might help health professionals adapt their communication about immunization and promote parental perception of making an informed, autonomous decision.

Strengths and limitations of this study

- Provides insights into the significance parents attribute to empowerment in the MMR vaccination decision-making.
- Examines the perspectives of parents about empowerment in the MMR vaccination decision-making and highlights tensions of opinion.
- Explores the drivers of the MMR vaccination decision making of parents residing in a low MMR vaccination covered area in Italy.

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INTRODUCTION

The call for patient empowerment and patient-centered care that is pervading almost all health contexts has also involved parents as decision-makers on behalf of their children. The prominent principle of preserving and promoting individuals’ autonomous choices and actions has been translated, in the immunization context, into the principle of protecting and promoting parents’ ability to make and act upon free, informed decisions, resulting from “capable and un-influenced deliberation” [1]. With ethical attention being increasingly drawn to the vaccination decision, current vaccination programs in most developed countries have now called for parents’ willingness to make an intentional, informed, and autonomous decision. This is transferred, for practical purposes, both into the widespread use of informed consent forms disclosing the risks as well as the

benefits of the immunization [2] and the policy to make or keep vaccination non-compulsory [3,4]. Thus, public health authorities tacitly interpret empowerment as an ethically justified process that follows the acknowledgment of the official recommendations and eventually lead to a decision that is both free from controlling influences and not mandated by law. However, there is little concern with understanding how to practically recognize, safeguard, and promote empowerment in the vaccination decision, beyond the mere use of informed consent and non-mandatory immunizations [1]. How parents have interpreted and to what extent adopted the demands put on them when choosing whether to vaccinate their children or not is, at present, unknown. Furthermore, while several predictors are known [5], parents' perceptions about their empowerment in the vaccination decision have so far been neglected as possible drivers of their vaccination behavior.

Psychological empowerment

Although being recognized as a key element in the current shift towards a patient-centered healthcare, there is little agreement on what constitutes psychological empowerment [6]. Empowerment received increasing attention during the 1980s, when it was applied to the health context. Zimmerman [7] proposes a definition of psychological empowerment as a construct that consists of three interrelated dimensions: (a) an intrapersonal dimension consisting of cognitive appraisals of control, competence, motivation, and self-esteem, (b) an interactional dimension consisting of critical skills and knowledge, and (c) a behavioral dimension reflecting participatory, change-oriented behaviors in formal and informal contexts and organizations.

Spreitzer, on the other hand, sees psychological empowerment as an intrinsic motivational construct of the individual and separates Zimmerman's concept of intrapersonal empowerment into four dimensions or cognitions [8,9]: (a) meaningfulness (the extent to which what one does is perceived as being important), (b) competence (one's perceived competence to carry out an action), (c) impact (the perception of making a difference through a certain action) and (d) self-determination (the extent to which what we do is perceived as autonomous).

In the context of health, empowerment has been found to be related to positive health outcomes [10], more active decision making [11], increased knowledge [12], better self-management [13], and more satisfaction with one’s decision [11].

Aim of the study

Psychological empowerment may vary greatly across individuals and contexts, and fluctuate over time [14]. A single definition and measure cannot therefore be generalized to multiple settings [15]. The aim of the current study is to explore parents’ perspectives on empowerment in the context of the measles-mumps-rubella (MMR) vaccination decision, grounding in the conceptualization of psychological empowerment as a set of four sub-dimensions proposed by Spreitzer [8,9]: (a) meaningfulness, referring to the degree to which an individual thinks that making a vaccination decision regarding his or her child is an important issue; (b) competence, referring to the degree to which an individual feels able to make a sound vaccination decision; (c) impact, referring to the degree to which an individual feels that making a decision over the vaccination can generate a number of outcomes; (d) self-determination or autonomy, referring to the degree to which individuals think that their vaccination decision is free from controlling influences. For this purpose, we decided to conduct qualitative focus groups to maximize parents’ discussion, since we considered the vaccination decision as a socially constructed experience based upon interactions with other individuals [16].

METHODS

Recruitment

The study received ethical approval by the Ethical Committee for Clinical Trials of the Province of Trento (ID 54896583). We recruited our focus group participants through the 11 vaccination centers of the Province of Trento, Italy. MMR coverage in this area is 84.21% despite the 95% required threshold to achieve herd immunity [17], making it one of the seven regions in Italy where more

than 15% of children have not been vaccinated with the first dose of MMR by the age of 2 years. To be included in the study, parents had to have at least one child aged less than one year or for whom an MMR vaccination decision was still pending, and be resident in Italy.

Parents were handed an invitation to the study during their vaccination appointment for the first or second dose of the DTaP vaccination, administered when the child is 3 and 5 months, respectively. The invitation stated the objectives of the study, the interview process, and a guarantee of confidentiality. Parents filled out the invitation with their contact details and returned it in a box placed in the waiting room. Invitations were collected and we contacted each participant by either phone or e-mail to arrange the focus group meetings.

Data collection

Focus groups were held in a private setting within the local health authority buildings between March and May 2015. Each focus group lasted one hour and two facilitators and one recorder were present. Participants were asked to form an inner-circle in order to promote discussion. Before starting the interview, we obtained consent from the participants and informed them about the scope of the study, its duration, and the right to withdraw from the study at any point. After the interview, we asked parents to fill out a brief survey with questions on vaccination knowledge [18] and socio-demographic variables relative to both parents (origin, age, education, number and age of children) and gave them a skin care product for their child together with a debriefing letter.

A list of semi-structured questions aimed at probing parents on meanings and interpretations associated with empowerment in the MMR vaccination decision was developed by the research team on the basis of the literature (Appendix 1). Questions were open-ended and broad in order to understand both parents' decision processes and their experiences and feelings. We kept the grid as flexible as possible to allow a free-flowing discussion.

We recorded each interview using a digital voice recorder and transcribed them verbatim. We reached saturation of the data at six focus groups, when we decided that additional interviews would not yield new data, but only confirm what had already been found [19].

Data analysis

Two coders (MF and EG) independently performed an inductive thematic analysis [20] of the transcripts. The aim was to generate as many insights as possible, which would be merged or further distinguished at a later stage. We initially read the transcripts several times to become familiar with the content, and manually underlined meaningful quotes and gradually grouped them under a number of labels. Subsequently, we organized all labels hierarchically, and created links among labels to channel them into broader themes. The two coders then discussed the preliminary themes, labels and quotations, and interpretation discordances were resolved through discussion and by constantly referring to the transcripts. Both the transcription and the analysis of the interviews were conducted in the original language (Italian).

RESULTS

Characteristics of the sample

Twenty-eight parents took part in six focus groups including four to six participants. Most participants were mothers (86%) and had Italian nationality (82%). As immigrants make 8% of the total population living in Italy (ISTAT, 2015), EU and non-EU participants were adequately represented in our sample. The average age was 36.5 years (SD = 5.5, range = 28-48), while in terms of education about half of the sample had completed University (46%), approximately half had completed secondary education (46%), and only two participants either had frequented a professional school or did not continue studying after obligatory school. Most parents (64%) had more than one child. Vaccination knowledge was found to be on average 6.15 (SD = 2.06; range = 0-9).

Table 1. Characteristics of the participants

(N = 28)	
Sex	
Women	<i>n</i> = 24 (86%)
Men	<i>n</i> = 4 (14%)
Age	M = 36.5; SD = 5.5; range = 28-48
Origin	
Italy	<i>n</i> = 23 (82%)
Other EU	<i>n</i> = 3 (11%)
Other non-EU	<i>n</i> = 2 (7%)
Education	
University	<i>n</i> = 13 (46%)
Professional school	<i>n</i> = 1 (4%)
Secondary school	<i>n</i> = 13 (46%)
Obligatory school	<i>n</i> = 1 (4%)
Number of children	
1 child	<i>n</i> = 10 (36%)
2-5 children	<i>n</i> = 18 (64%)
Vaccination knowledge	M = 6.15; SD = 2.06; range = 0-9

Issues of empowerment

In general, parents held varying views about empowerment in relation to the MMR vaccination decision, with most participants affirming that their views apply to all pediatric vaccinations and are not restricted to the MMR immunization. When asked about their reasons for participation, most parents reported that they hoped to find answers to their questions about childhood vaccinations, to understand why some parents do not want to vaccinate, to meet other parents to discuss the topic and know what they think, and because they considered providing information and helping research a civic duty.

Generally, about one quarter of the parents reported they felt uncomfortable in making the MMR vaccination decision, while the large majority reported to be confident with their choice. Autonomy was related to competence, which was interpreted as medical knowledge and information-seeking skills, but it was also related to the extent parents perceived the pediatrician to be competent and to the quality of their relationship with them. Parents held varying beliefs

regarding the legal responsibility and freedom of the decision, diverse feelings of relevance of the decision and related stress, as well as different orientations towards vaccination-related information.

Competence as a key to autonomy

The majority of the participants reported that, to feel autonomous in the MMR vaccination decision, it is crucial to possess adequate competence. Competence was interpreted as medical knowledge as well as a set of skills related to finding, objectively assessing, and finally understanding vaccination-related information

“[Autonomy means] gathering information, not letting myself being influenced by other mothers. I got information at the prenatal classes, where there was a pediatrician. Then I asked my own pediatrician. Then those from the vaccination center came in. [...] Autonomy in this sense, I documented myself.” (Mother, 32, Italian)

“You look at different websites, different forums, and different arguments. What really needs to be looked at. [...] Then you have to be objective, you have to step out of the thing, say, and try to analyze what you’ve just read. Rationally.” (Mother, 28, Italian)

Very few participants, however, stressed that it is impossible to reach complete autonomy because parents can never have the appropriate skills to make a decision by themselves, but always need to rely on medical professionals.

“I think it’s impossible to be autonomous for us, as parents, if we are not doctors. We do not have the skills to make such a decision. It’s far better to rely on someone who does that as a job, who can explain to you the pros and cons, the reasons... Then you, as a parent, can make your own decision, but then it’s your own personal decision which is not based on the scientific method.” (Mother, 48, Italian)

The large majority of parents reported to feel competent and, consequently, autonomous when they could also obtain vaccination-related information and guidance from an expert whom they could trust, e.g. the child's pediatrician.

"[I feel competent]...when I have a consultation with someone competent that I can trust." (Mother, 31, Italian)

"[To feel autonomous] I completely rely on the pediatrician. She is also the one who cared for me until I was 14, so I really trust her. If I notice that she is calm, I also get calmer." (Mother, 28, Italian)

In this context, about half of the participants reported that they tended to decide what the pediatrician suggested if they perceived there was affinity between them in terms of opinion.

"I'm afraid that... I would chose the opinion that is closer to mine, 'cause in the end one already has an opinion... I think I would go for... I would not be able to be completely objective 'cause in the end you feel fully in tune with someone if that idea appeals to you most." (Mother, 38, Italian)

Parents also listed a number of key skills that a pediatrician should have to be considered competent and trustworthy and to build a good relationship with him/her. Few participants complained that their pediatricians lacked these skills and, as a result, they had a poor relationship with them.

"When he dedicates me time, when I understand he is listening to me and is answering exactly what I am asking." (Mother, 30, Italy)

Autonomy as legal responsibility and freedom

When asked about their interpretation of autonomy in the MMR vaccination decision, the majority of the participants reported that having a free choice on their child’s immunization is equivalent to being asked to assume the responsibility for any potential positive or negative consequences that might result from vaccinating or not vaccinating their child. Parents differed in their views on this theme, with the majority reporting that they felt as being appointed a role not belonging to them. These participants considered that making the final decision on the vaccination is a matter of legal responsibility, which parents should not assume since they lack the medical skills needed to make an informed decision. Referring again at competence as vital to autonomy, they reported that their medical understanding was inadequate to enable an autonomous, responsible choice.

“For me autonomy means responsibility, and you are not always as informed or as prepared as a doctor would be, so... well, you can have the freedom to choose yes or not, but... I don’t always feel up to the situation.” (Mother, 38, Italian)

Only few participants reported that they were willing to assume full responsibility for the decision, even in case of negative consequences due to the vaccination or the disease.

“You cannot blame yourself for everything, but you have to take on your responsibilities.” (Mother, 40, Italian)

Almost all parents also reported that being autonomous in the vaccination decision is a matter of freedom. Parents had opposite views on this theme, with half of them seeing autonomy as a dangerous right that parents should not have. This group of participants includes those who were not willing to assume the legal responsibility of their MMR vaccination decision.

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3 *"I do not find this autonomy fair. I noticed that several diseases spreading around in the schools*
4 *could easily be prevented by vaccinating. In my opinion, those should be obligatory. After all, I*
5 *cannot decide by myself."* (Mother, 31, Italian)
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11 The other half of the parents, while stressing the ethical aspects of being free in the vaccination
12 decision, reported that it is morally important that all parents are free to make the final decision on
13 their child's MMR vaccination.
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20 *"The free choice on everything seems fair to me. It is reasonable to me that nothing is compulsory*
21 *any longer. However, if this free choice means that, out of 100 children, 60 to 70 vaccinate and 30*
22 *do not, then we should re-evaluate the situation."* (Mother, 48, Italy)
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28 *Information orientation*

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30 The majority of the parents reported that being autonomous in the MMR vaccination is a matter of
31 actively looking for information, expecting the information to be delivered by the pediatrician or the
32 health authorities, or simply avoiding any information. Half of the participants described themselves
33 as active information seekers who try to consult as many sources as possible, stating that it is up to
34 parents to look for information themselves.
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43 *"If one wants information, he or she should get out and find it."* (Mother, 46, Italy)
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48 About a quarter of the participants rather expected the health authorities, medical professionals, and
49 vaccination centers to provide them with easy and accessible information prior to their appointment
50 for the vaccination, stating that it is not up to parents to look for vaccination-related information.
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56 *"It's up to the pediatrician to start by providing information. They take it for granted that we know*
57 *all the things, but instead... this is not always the case."* (Mother, 30, Non EU)
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In this context, about a quarter of the participants reported that fear and lack of medical knowledge prevented them from looking for information on vaccinations and led them to avoid the information given by other parents.

“I tend to stay away from the websites ‘cause you read all sorts of things. It happened to me once, then I worried and started to do, to think much worse than it was, so I don’t even go and look at it!”
(Mother, 42, Italian)

Relevance of the decision and related stress

For the majority of the participants, confidence in the MMR vaccination decision-making was related to the relative importance of this decision. Almost all parents reported that the vaccination decision is something you just make, it is not among the priorities and does not cause stress.

“For me it’s among the last ones. Partly because I had health issues... and then because it was a decision that I had already made, in the sense that I knew I just had to do it, so that was not such a hard decision.” (Mother, 30, Other EU)

A small minority reported that making the decision is among the most important decisions, as it becomes a stressful task that consumes time and energy and creates tensions in the couple. These parents also reported to have a poor relationship with their child’s pediatrician.

“Deciding for MMR has really been a moment of tension between me and my husband... I remember. It was not like deciding whether to breastfeed or not. That was my decision. We really went through a period of tension.” (Mother, 38, Italy)

DISCUSSION

Main findings

The aim of this focus group study was to explore the construct of psychological empowerment in the MMR vaccination decision among a sample of parents residing in a low MMR coverage area in Italy. Issues of autonomy and competence largely dominate our results and appear to be strictly interrelated. Autonomy, interpreted as both responsibility and freedom, seems to largely depend on parents' competence and this, in turn, on their relationship with the child's healthcare provider, the relevance investing the decision, and their information-seeking behaviors.

First, the large majority of the participants reported they could feel competent and autonomous not only when having the appropriate knowledge and information-seeking skills but also when they could rely on a competent and trustworthy pediatrician. Parents also listed a number of characteristics the ideal pediatrician should have for a good relationship, namely availability, empathy, interest, and attentiveness. Few parents also stated they would rather listen to a pediatrician with similar vaccination opinions as theirs. These findings confirm a large set of literature on the importance of the child's provider on parents' vaccination decision [21–25] and on the tendency many parents have to choose a provider with similar vaccine beliefs as their own [26]. The results are also in line with the theory of relational or conscientious autonomy, which assumes that our sense of autonomy depends on other individuals' influence on our lives [27]. The theory stresses that “social interactions can affect autonomy not only by influencing individuals' health-related preferences and choices but also their self-identities, self-evaluations, and capabilities for autonomy” [27]. Our findings suggest that parents might be at the same time compliant with the pediatrician's recommendation, but claim the decision as their own anyway since it was guided by a trusted source with whom they have a good relationship [1]. The theory has also been confirmed by other studies [28], which found that patients felt they “owned” their decision when it was the one recommended by a trusted medical professional.

Second, the vast majority of the participants found that autonomy was related to issues of responsibility and freedom, thus reinforcing the idea that autonomy is connected to “morality, personhood, and agency” [1]. While only a small minority was willing to assume the legal responsibility derived from making an autonomous choice, participants were equally split in their opinion regarding the morality of having the freedom to make the final decision. Previous studies found that adolescents’ perspectives on their legal responsibility in relation to their vaccination might be a barrier to immunization adherence [29]. With respect to freedom of choice, studies also found that a small proportion of individuals are unlikely to vaccinate when immunizations are compulsory [30,31].

A third major finding was that parents reported about their preferences regarding their vaccination-related information when asked about their meaning of autonomy and competence in the MMR vaccination decision. Participants distinguished themselves as active seekers, passive recipients, or information avoiders. Research has previously found that those with more access to health-related information and better information-seeking skills are more likely to make informed medical decisions [32]. Moreover, information orientation (engagement vs. apprehension) has been found to predict one’s objective and perceived ability to use information technology for health [33].

A last finding relates to the empowerment sub-dimension of meaningfulness. When asked to compare the MMR vaccination decision to other decisions made for their child, the majority of the participants reported that it is something natural “you just do,” something that does not cause stress or require energy. A small minority, on the other hand, reported that deciding over MMR was a time-consuming, stressful task, which topped all other decisions. It is worth noting that these parents also lamented a poor relationship with the pediatrician. The idea that vaccination might be an obvious choice and that it might require more or less thinking on the basis of its relative relevance was also found in previous studies [25,34].

Strenghts and weaknesses of the study

This is the first study to shed light on parents' understanding of empowerment in their vaccination decision-making. The study is subject to a number of limitations. First, the self-selected nature of our sample might have resulted in focus group participants mainly being pro-vaccination parents willing to share their compliance with the official immunization recommendations. Second, recruiting through the vaccination centers might have prevented us from reaching those who are highly opposed against immunizations and even refuse the DTaP vaccination, which is mandatory in Italy (parents refusing it for their children may be subject to a fine). However, this could also be seen a strength of the study, as a large number of our participants were not completely decided on whether to vaccinate or not. Third, since we extracted our results from qualitative reports of a small sample of parents, our findings cannot be generalized to a bigger population.

Implications

The findings have a number of implications both for theory and for practice. First, the construct of empowerment appears to be perceived by parents in the context of the MMR vaccination decision as more nuanced than our initial conceptualization. While autonomy and competence are perceived as salient dimensions of the construct, they are strictly related to issues of freedom, responsibility, trust in the pediatrician, relevance of the decision and information orientation.

In terms of practice, it is worth noting that the large majority of the participants reported not to make distinctions between vaccinations. Thus, ambiguous or extreme interpretations of the empowerment principles (such as autonomy) need to be avoided for all vaccinations as they might result in contract-like relationships between parents and health professionals, isolate parents with their responsibility of the decision, or curtail other possible immunization solutions [35]. Also, it should be noted that not all parents wish to be empowered the same way. Some might need to be guided to feel in control of their decision, by simply conforming to the pediatrician's advice or the official recommendations and avoiding any information. Others might highly value active information seeking to feel competent and finally make an autonomous decision. In all instances, it

should be recognized that pediatricians are key in parents’ empowerment in the vaccination decision. Not only do they need to be perceived as competent professionals by parents, but they also have to build a trustworthy relationship with them. Furthermore, they should make an effort to understand whether parents do or do not wish to share the decision-making and recognize how their interactions and relationships with parents can either enable or impair parents’ empowerment.

Future research

Since a particular vaccination decision, the acceptance of the informed consent, or the attitude driving a given vaccination behavior may or may not be an expression of parental empowerment [1], future quantitative research has to clarify whether empowerment and its sub-dimensions can have an impact on the acceptance of vaccination recommendations. In this sense, developing appropriate measures of the empowerment construct in this particular context and testing its relationship with other key variables such as vaccination knowledge and risk perception would be a valuable step.

CONCLUSIONS

Parents’ empowerment in the vaccination decision should be encouraged to serve parents’ rather than institutional interests [36]. Misconceived assumptions about empowerment might be a contributing factor to vaccine hesitancy and to health professionals’ frustration about their potential to effectively cooperate with parents [35]. If parents are asked to be empowered in the vaccination decision, it is important that this be correctly interpreted and implemented by best practice. In this sense, by overtly employing relational autonomy as an crucial element of the vaccination decision, empowerment in parental immunization choice might become a more comprehensible and stronger principle, and could help pediatricians and other health professionals to genuinely promote and implement parents’ autonomy [35]. Health professionals can appeal to a principle of parent empowerment by facilitating parents’ ability to make an informed and autonomous decision and, at the same time, by promoting their relational autonomy [35]. This can be done by ensuring that

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3 parents are sufficiently informed, have the skills to find, assess and understand vaccination-related
4 information by other sources, and by building a trustworthy relationship with them. On the other
5 side, a view of empowerment that isolates parents in their decision-making would not be in line
6 with a patient/parent-centered model [35]. Furthermore, health authorities' risk communication
7 should include a description of the reasons for both restricting and expanding individual rights in a
8 way to maximize comprehension, since there is evidence that informed consent does not always
9 provide clear and useful information [37,38]. Trained staff should also be available in the
10 vaccination center to encourage parent's relational autonomy and answer questions [2].
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12 The advocated principle of parental empowerment in the vaccination decision in a context of
13 voluntary participation, while suggesting that parental autonomy is central, does not mean that it is
14 absolute [39].
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48 AUTHORS' CONTRIBUTION

49 MF and EG participated in the design and implementation of the study, the analysis of the data and
50 its interpretation. VC and PJS joined the design and implementation of the study. All authors
51 contributed to the drafting of the manuscript.
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DATA SHARING STATEMENT

Interview transcripts in the original language (Italian) are available from the corresponding author upon request.

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Appendix 1. Interview schedule

Interview topics	Key interview questions
1. General health-related decision-making	→ What do you usually do when you have to make a decision concerning your own health? → Why?
2. Child’s health-related decision-making	→ Now think about the last time you had to make a health-related decision for your child. What did you do? → Why?
3. MMR vaccination decision-making	→ How are you making a decision regarding your child’s MMR vaccination? → What are you taking into consideration? → How do you feel about making this decision? → Which experiences are helping or hindering you in making this decision?
4. Meaningfulness	→ What are the major decisions that you have made for your child so far? → How important is your choice about the MMR vaccination compared to other decisions made for your child so far? → Why is it more or less important than others are? → What makes it important?
5. Autonomy	→ In your opinion, what does it mean to be autonomous in making an MMR vaccination decision for your child? → Is it important to be autonomous?
6. Competence	→ What makes one able to make a sound decision about MMR? → Think of a competent parent who makes a sound MMR decision. Which skills does he or she have? → What skills would one need to have in order to feel able? → What does one need to know? → Can you mention three skills that one needs to have to be competent? → What is important for you to know right now?
7. Shared decision-making	→ Think of the meeting with the pediatrician when the topic of childhood vaccinations is discussed for the first time. How should it happen, in an ideal world? → How did it take place, in your case (if any)?
8. Gender roles	→ How do you and your partner share the MMR vaccination decision, if you do?
9. Reasons for participation	→ Why did you decide to participate in this study?

Qualitative research review guidelines – RATS

R Relevance of study question

- | | |
|--|---|
| 1. Is the research question interesting? | Research question explicitly stated (p. 1, p. 2, p. 5) |
| 2. Is the research question relevant to clinical practice, public health, or policy? | Research question justified and linked to the existing knowledge base (pp. 3-4) |

A Appropriateness of qualitative method

- | | |
|---|--|
| 3. Is qualitative methodology the best approach for the study aims? | Study design was described and usage of focus groups was justified (pp. 5-6) |
|---|--|

T Transparency of procedures*Sampling*

- | | |
|---|--|
| 4. Are the participants selected the most appropriate to provide access to the type of knowledge sought by the study? | Criteria for selecting the study sample justified and explained (pp. 5-6)

<i>purposive</i> : the objective was to interview participants from a low MMR coverage area |
| 5. Is the sampling strategy appropriate? | Appropriateness of the sampling strategy is described (pp. 5-6) |

Recruitment

- | | |
|---|---|
| 6. Was recruitment conducted using appropriate methods? | Details of how recruitment was conducted and by whom have been explained (p. 6) |
| 7. Is the sampling strategy appropriate? | Appropriateness of the sampling strategy is described (pp. 5-6) |

8. Could there be selection bias?	No details of who chose not to participate and why have been provided
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Data collection

9. Was collection of data systematic and comprehensive?	Data collection method(s) have been outlined and examples given (p. 6)
10. Are characteristics of the study group and setting clear?	Study group and setting are clearly described (p. 6)
11. Why and when was data collection stopped, and is this reasonable?	End of data collection justified and described (data saturation, p. 7)

Role of researchers

12. Is the researcher(s) appropriate? How might they bias (good and bad) the conduct of the study and results?	Researchers do not occupy dual roles. Researchers' biases are discussed (p. 7)
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Ethics

13. Was informed consent sought and granted?	Informed consent process explicitly and clearly detailed (p. 6)
14. Were participants' anonymity and confidentiality ensured?	Anonymity and confidentiality discussed (p. 6)
15. Was approval from an	Ethics approval cited (p. 5)

appropriate ethics
committee received?

S Soundness of interpretive approach

Analysis

16. Is the type of analysis appropriate for the type of study?
- thematic*: exploratory, descriptive, hypothesis generating
17. Are the interpretations clearly presented and adequately supported by the evidence?
18. Are quotes used and are these appropriate and effective?
19. Was trustworthiness/ reliability of the data and interpretations checked?

Analytic approach described in depth and justified (p. 7)

Indicators of quality: Description of how themes were derived from the data (inductive, p. 7)

Analysis and presentation of opinion tensions (pp. 7-13)

Rich and self-explanatory quotes were chosen (pp. 7-13)

Method of reliability check described and justified (two coders analyzed the data independently, p. 7)

Discussion and presentation

20. Are findings sufficiently grounded in a theoretical or conceptual framework? Is adequate account taken of previous knowledge and how the findings add?

Findings presented with reference to existing theoretical and empirical literature, and how they contribute (pp. 14-15)

21. Are the limitations

Strengths and limitations explicitly

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thoughtfully considered? described and discussed (p. 16)

22. Is the manuscript well written and accessible? Evidence of following guidelines (format, word count, p. 1)
Detail of interview questions contained in appendix
Written for a health sciences audience

23. Are red flags present? No
These are common features of ill-conceived or poorly executed qualitative studies, are a cause for concern, and must be viewed critically. They might be fatal flaws, or they may result from lack of detail or clarity.

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What are parents' perspectives on psychological empowerment in the MMR vaccination decision? A focus group study

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Title page

What are parents’ perspectives on psychological empowerment in the MMR vaccination decision?

A focus group study

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Abstract

Objectives: Most developed countries do not have compulsory immunization requirements, but issue recommendations. Although parents are expected to make an informed, autonomous (i.e. empowered) decision regarding their children's vaccinations, there is no evidence about how parents' interpret this demand and the latitude of their decision-making. The goal of this study is to gain insights from parents residing in a low MMR uptake area on what constitutes feelings of empowerment in the decision they have to make on their child's MMR vaccination.

Design: A qualitative study employing focus group interviews.

Setting: Eleven vaccination centers and hospitals in the Province of Trento, Italy.

Participants: 24 mothers and 4 fathers of children for whom the MMR vaccination decision was still pending participated in six focus groups.

Results: Autonomy and competence were salient themes in relation to empowerment and were further connected with beliefs regarding legal responsibility and ethics of freedom concerning the decision, parents' relationship with the pediatrician (trust), feelings of relevance of the decision and related stress, and seeking, avoidance, or fear of vaccination-related information. Competence was interpreted as medical knowledge and information-seeking skills, but it was also related to the extent parents perceived the pediatrician to be competent.

Conclusions: Since parents' interpretation of empowerment goes beyond mere perceptions of being informed and autonomous and differs across individuals, it is important that this construct be correctly interpreted and implemented by best practice, for instance by explicitly adopting a relational conception of autonomy. Knowing whether parents want to make an empowered decision and what their information and autonomy needs are might help health professionals adapt their communication about immunization and promote parental perception of making an informed, autonomous decision.

Strengths and limitations of this study

- Provides insights into the significance parents attribute to empowerment in the MMR vaccination decision-making.
- Examines the perspectives of parents about empowerment in the MMR vaccination decision-making and highlights tensions of opinion.
- Explores the drivers of the MMR vaccination decision making of parents residing in a low MMR vaccination covered area in Italy.
- The self-selected nature of our sample might have resulted in recruitment bias, as parents with favorable attitudes towards the MMR vaccination may be more likely to accept invitations to participate in a study and share their opinion.
- Our recruitment strategy, which targeted parents attending a number of vaccination centers to have their children's immunized against DTaP, might have prevented us from reaching those who are highly opposed against the MMR immunizations and other vaccinations such as DTaP.

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INTRODUCTION

The call for patient empowerment and patient-centered care that is pervading almost all health contexts has also involved parents as decision-makers on behalf of their children. The prominent principle of preserving and promoting individuals' autonomous choices and actions has been translated, in the immunization context, into the principle of protecting and promoting parents' ability to make and act upon free, informed decisions, resulting from "capable and un-influenced deliberation" [1]. With ethical attention being increasingly drawn to the vaccination decision, current vaccination programs in most developed countries have now called for parents' willingness

to make an intentional, informed, and autonomous decision. This is transferred, for practical purposes, both into the widespread use of informed consent forms disclosing the risks as well as the benefits of the immunization [2] and the policy to make or keep vaccination non-compulsory [3,4]. Thus, public health authorities tacitly interpret empowerment as an ethically justified process that follows the acknowledgment of the official recommendations and eventually leads to a decision that is both free from controlling influences and not mandated by law. However, there is little concern with understanding how to practically recognize, safeguard, and promote empowerment in the vaccination decision, beyond the mere use of informed consent and non-mandatory immunizations [1]. How parents have interpreted and to what extent adopted the demands put on them when choosing whether to vaccinate their children or not has only been explored marginally [5]. Furthermore, while several predictors are known [6], such as risk perception [7–11], beliefs and attitudes [12–16], safety concerns [17–19], trust [10, 20–25], and social norms [26], parents' perceptions about their empowerment in the vaccination decision have so far been almost exclusively neglected as possible drivers of their vaccination behavior, despite previous work suggesting the relevance of empowerment-related dimensions such as self-efficacy and self-determination in this health decision [5].

Psychological empowerment

Although being recognized as a key element in the current shift towards a patient-centered healthcare, there is little agreement on what constitutes psychological empowerment [27]. Empowerment received increasing attention during the 1980s, when it was applied to the health context. Zimmerman [28] proposes a definition of psychological empowerment as a construct that consists of three interrelated dimensions: (a) an intrapersonal dimension consisting of cognitive appraisals of control, competence, motivation, and self-esteem, (b) an interactional dimension consisting of critical skills and knowledge, and (c) a behavioral dimension reflecting participatory, change-oriented behaviors in formal and informal contexts and organizations.

Spreitzer, on the other hand, sees psychological empowerment as an intrinsic motivational construct of the individual and separates Zimmerman’s concept of intrapersonal empowerment into four dimensions or cognitions [29,30]: (a) meaningfulness (the extent to which what one does is perceived as being important), (b) competence (one’s perceived competence to carry out an action), (c) impact (the perception of making a difference through a certain action) and (d) self-determination (the extent to which what we do is perceived as autonomous).

In the context of health, empowerment has been found to be related to positive health outcomes [31], more active decision making [32], increased knowledge [33], better self-management [34], and more satisfaction with one’s decision [32].

Aim of the study

Psychological empowerment may vary greatly across individuals and contexts, and fluctuate over time [35]. A single definition and measure cannot therefore be generalized to multiple settings [36]. The aim of the current study is to explore parents’ perspectives on empowerment in the context of the measles-mumps-rubella (MMR) vaccination decision in a low MMR covered area, building on similar previous work [5] and grounding in the conceptualization of psychological empowerment as a set of four sub-dimensions proposed by Spreitzer [29,30]: (a) meaningfulness, referring to the degree to which an individual thinks that making a vaccination decision regarding his or her child is an important issue; (b) competence, referring to the degree to which an individual feels able to make a sound vaccination decision; (c) impact, referring to the degree to which an individual feels that making a decision over the vaccination can generate a number of outcomes; (d) self-determination or autonomy, referring to the degree to which individuals think that their vaccination decision is free from controlling influences. For this purpose, we decided to conduct qualitative focus groups to maximize parents’ discussion, since we considered the vaccination decision as a socially constructed experience based upon interactions with other individuals [37]. The decision-making process focus of the present study is specific to the context of the MMR vaccination

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3 decision due to a number of features that make this vaccination unique compared to other childhood
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5 vaccinations. Not only is MMR at the center of the autism controversy [38] but also, since it is
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7 made of live attenuated viruses, administering this vaccine can be seen by parents as the closest
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9 thing to a natural infection [39]. Furthermore, MMR coverage is decreasing in several developed
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11 countries and postponing this vaccination may have serious consequences for future outbreaks [40].
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13 14 15 16 METHODS

17 18 Recruitment

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20 The study received ethical approval by the Ethical Committee for Clinical Trials of the Province of
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22 Trento (ID 54896583). We recruited our focus group participants through the 11 vaccination centers
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24 of the Province of Trento, Italy. MMR coverage in this area is 84.21% despite the 95% required
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26 threshold to achieve herd immunity [41], making it one of the seven regions in Italy where more
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28 than 15% of children have not been vaccinated with the first dose of MMR by the age of 2 years. To
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30 be included in the study, parents had to have at least one child aged less than one year or for whom
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32 an MMR vaccination decision was still pending, and be resident in Italy. Italy's MMR vaccination
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34 schedule envisages two doses which are given when the child is 12-15 months and 5-6 years-old
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36 respectively [42]. In the Province of Trento, childhood vaccinations are administered in the Public
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38 Health and Vaccination Centers located in each of the 11 local areas which the Province is divided
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40 in. Parents are invited to the vaccination through a written letter; in case of no-show for the
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42 scheduled appointment, parents are sent two more letters of solicitations. Vaccinations are usually
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44 administered by trained nurses and health professionals who are supervised by a preventive
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46 medicine doctor in the Vaccination Centers.
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52 Parents were handed an invitation to the study by the nurses during their vaccination
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54 appointment for the first or second dose of the DTaP vaccination, which are administered when the
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56 child is 3 and 5 months, respectively. Diphtheria and tetanus vaccinations are mandatory in Italy
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58 (parents refusing it for their children may be subject to a fine). The invitation stated the objectives
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of the study, the interview process, and a guarantee of confidentiality. Parents filled out the invitation with their contact details and returned it in a box placed in the waiting room. Invitations were collected and we contacted each participant by either phone or e-mail to arrange the focus group meetings.

Data collection

Focus groups were held in a private setting within the local health authority buildings between March and May 2015. Each focus group lasted one hour and one/two facilitators and one recorder were present. Participants sat in circle in order to promote discussion. Before starting the interview, we obtained consent from the participants and informed them about the scope of the study, its duration, the right to withdraw from the study at any point, and the reward that would be offered to them at the end of the focus group. After the interview, we asked parents to fill out a brief survey with questions on vaccination knowledge [43] and socio-demographic variables relative to both parents (origin, age, education, number and age of children) and gave them a skin care product for their child together with a debriefing letter.

A list of semi-structured questions aimed at probing parents on meanings and interpretations associated with empowerment in the MMR vaccination decision was developed by the research team on the basis of the literature on psychological empowerment, on Spreitzer’s empowerment model, and on previous health-related empowerment scales [8,9] (Appendix 1). Questions were open-ended and broad in order to understand both parents’ decision processes and their experiences and feelings. We kept the grid as flexible as possible to allow a free-flowing discussion.

We recorded each interview using a digital voice recorder and transcribed them verbatim. We reached saturation of the data at six focus groups, when we decided that additional interviews would not yield new data, but only confirm what had already been found [44].

Data analysis

To guarantee the quality of the findings and to generate as many insights as possible, which would be merged or further distinguished at a later stage, two coders (MF and EG) independently performed an inductive thematic analysis [45] of the transcripts. We proceeded according to the following stages: we initially read the transcripts several times to become familiar with the content, manually underlined meaningful quotes, gradually grouped them under a number of labels, organized all labels hierarchically, and created links among labels to channel them into broader themes. To validate the results, comparisons between the two coders took place in-between each of the above mentioned stages, so that the preliminary themes, labels and quotations were constantly discussed, and interpretation discordances resolved through dialogue and by constantly referring to the transcripts. All themes were then compared to Spreitzer's empowerment conceptualization into four sub-dimensions [29,30] to check for correspondences. Both the transcription and the analysis of the interviews were conducted in the original language (Italian).

RESULTS

Characteristics of the sample

We sent 1000 invitations to the 11 vaccination centers, distributing the number according to their size. Of the total amount of invitations that were sent, we received 128 invitation forms completed with the participant's details. Eligibility of the recruited parents was checked by the vaccination center nurses, therefore the invitation form was only handed to eligible participants. We contacted all 128 parents, of whom 67 were available to participate in the focus groups. Finally, 28 parents (dropout rate 58%) took part in six focus groups including four to six participants. All participants filled out a paper-and-pencil survey on vaccination knowledge and socio-demographic variables. Most participants were mothers (86%) and had Italian nationality (82%). The high a share of non-Italians (against 8,3% immigrants living in Italy) [46], ensured diversity in terms of origin in our sample. The average age was 36.5 years (SD = 5.5, range = 28-48), while in terms of education

about half of the sample had completed University (46%), approximately half had completed secondary education (46%), and only two participants either had frequented a professional school or did not continue studying after obligatory school. Most parents (64%) had more than one child, meaning that they had made an MMR vaccination decision for at least one older child. Vaccination knowledge was found to be on average 6.15 (SD = 2.06; range = 0-9), where 9 was the highest possible score. See Table 1 for an overview of participants' characteristics.

Table 1. Characteristics of the participants

(N = 28)	
Sex	
Women	<i>n</i> = 24 (86%)
Men	<i>n</i> = 4 (14%)
Age	M = 36.5; SD = 5.5; range = 28-48
Origin	
Italy	<i>n</i> = 23 (82%)
Other EU	<i>n</i> = 3 (11%)
Other non-EU	<i>n</i> = 2 (7%)
Education	
University	<i>n</i> = 13 (46%)
Professional school	<i>n</i> = 1 (4%)
Secondary school	<i>n</i> = 13 (46%)
Obligatory school	<i>n</i> = 1 (4%)
Number of children	
1 child	<i>n</i> = 10 (36%)
2-5 children	<i>n</i> = 18 (64%)
Children's age	
<6 months	<i>n</i> = 2 (7%)
<12 months	<i>n</i> = 25 (89%)
>2 years	<i>n</i> = 1 (4%)
Vaccination knowledge	M = 6.15; SD = 2.06; range = 0-9
Attitude towards the MMR vaccination	
Undecided	<i>n</i> = 9 (32%)
In favor	<i>n</i> = 19 (68%)

Issues of empowerment

In general, parents held varying views about empowerment in relation to the MMR vaccination decision, with most participants affirming that their views apply to all pediatric vaccinations and are not restricted to the MMR immunization. When asked about their reasons for participation, most parents reported that they hoped to find answers to their questions about childhood vaccinations, to understand why some parents do not want to vaccinate, to meet other parents to discuss the topic and know what they think, and because they considered providing information and helping research a civic duty. The majority of the participants found that vaccination was a public good, and thus deserves discussion and meetings.

Generally, about one quarter of the parents reported they felt uncomfortable in making the MMR vaccination decision due to safety concerns, uncertainty and low perceived competence, while the large majority reported to be confident with their choice. Autonomy was related to competence, which was interpreted as medical knowledge and information-seeking skills, but it was also related to the extent parents perceived the pediatrician to be competent and to the quality of their relationship with them. Parents held varying beliefs regarding the legal responsibility (the possibility to be held responsible in case of vaccination- or disease-related adverse events) and freedom of the decision, diverse feelings of relevance of the decision and related stress, as well as different orientations towards vaccination-related information.

Competence as a key to autonomy

The majority of the participants reported that, to feel autonomous in the MMR vaccination decision, it is crucial to possess adequate competence. Competence was interpreted as medical knowledge as well as a set of skills related to finding, objectively assessing, and finally understanding vaccination-related information

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3 “[Autonomy means] gathering information, not letting myself being influenced by other mothers. I
4 got information at the prenatal classes, where there was a pediatrician. Then I asked my own
5 pediatrician. Then those from the vaccination center came in. [...] Autonomy in this sense, I
6 documented myself.” (Mother, 32, Italian)
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13 “You look at different websites, different forums, and different arguments. What really needs to be
14 looked at. [...] Then you have to be objective, you have to step out of the thing, say, and try to
15 analyze what you’ve just read. Rationally.” (Mother, 28, Italian)
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21 Very few participants, however, stressed that it is impossible to reach complete autonomy because
22 parents can never have the appropriate skills to make a decision by themselves, but always need to
23 rely on medical professionals.
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30 “I think it’s impossible to be autonomous for us, as parents, if we are not doctors. We do not have
31 the skills to make such a decision. It’s far better to rely on someone who does that as a job, who can
32 explain to you the pros and cons, the reasons... Then you, as a parent, can make your own decision,
33 but then it’s your own personal decision which is not based on the scientific method.” (Mother, 48,
34 Italian)
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42 The large majority of parents reported to feel competent and, consequently, autonomous when they
43 could also obtain vaccination-related information and guidance from an expert whom they could
44 trust, e.g. the child’s pediatrician.
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51 “[I feel competent]...when I have a consultation with someone competent that I can trust.” (Mother,
52 31, Italian)
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3 “[To feel autonomous] *I completely rely on the pediatrician. She is also the one who cared for me*
4 *until I was 14, so I really trust her. If I notice that she is calm, I also get calmer.*” (Mother, 28,
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6 *Italian)*

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11 In this context, about half of the participants reported that they tended to decide what the
12
13 pediatrician suggested if they perceived there was affinity between them in terms of opinion.
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18 *“I’m afraid that... I would chose the opinion that is closer to mine, ‘cause in the end one already has*
19 *an opinion... I think I would go for... I would not be able to be completely objective ‘cause in the end*
20 *you feel fully in tune with someone if that idea appeals to you most.*” (Mother, 38, Italian)
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25 Parents also listed a number of characteristics the ideal pediatrician should have to be considered
26
27 competent and trustworthy and to establish a good relationship, namely availability, empathy,
28
29 interest, and attentiveness. Few participants complained that their pediatricians lacked these skills
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31 and, as a result, they had a poor relationship with them.
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37 *“When he dedicates me time, when I understand he is listening to me and is answering exactly what*
38 *I am asking.*” (Mother, 30, Italy)
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42 43 *Autonomy as legal responsibility and freedom*

44
45 When asked about their interpretation of autonomy in the MMR vaccination decision, the majority
46
47 of the participants reported that having a free choice on their child’s immunization was equivalent
48
49 to being asked to assume the responsibility for any potential positive or negative consequences that
50
51 might result from vaccinating or not vaccinating their child. Parents differed in their views on this
52
53 theme, with the majority reporting that they felt as being appointed a role not belonging to them.
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55 These participants considered that making the final decision on the vaccination was a matter of
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57 legal responsibility, which parents should not assume since they lack the medical skills needed to
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3 make an informed decision. Referring again at competence as vital to autonomy, they reported that
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5 their medical understanding was inadequate to enable an autonomous, responsible choice.
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10 *“For me autonomy means responsibility, and you are not always as informed or as prepared as a*
11 *doctor would be, so... well, you can have the freedom to choose yes or not, but... I don’t always feel*
12 *up to the situation.” (Mother, 38, Italian)*
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18 Only few participants reported that they were willing to assume full responsibility for the decision,
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20 even in case of negative consequences due to the vaccination or the disease.
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24 *“You cannot blame yourself for everything, but you have to take on your responsibilities.” (Mother,*
25 *40, Italian)*
26
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29
30 Almost all parents also reported that being autonomous in the vaccination decision is a matter of
31
32 freedom. Parents had opposite views on this theme, with half of them seeing autonomy as a
33
34 dangerous right that parents should not have. This group of participants includes those who were
35
36 not willing to assume the legal responsibility of their MMR vaccination decision.
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41 *“I do not find this autonomy fair. I noticed that several diseases spreading around in the schools*
42 *could easily be prevented by vaccinating. In my opinion, those should be obligatory. After all, I*
43 *cannot decide by myself.” (Mother, 31, Italian)*
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49 The other half of the parents, while stressing the ethical aspects of being free in the vaccination
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51 decision, reported that it is morally important that all parents are free to make the final decision on
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53 their child’s MMR vaccination.
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3 *"The free choice on everything seems fair to me. It is reasonable to me that nothing is compulsory*
4 *any longer. However, if this free choice means that, out of 100 children, 60 to 70 vaccinate and 30*
5 *do not, then we should re-evaluate the situation."* (Mother, 48, Italy)
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10 11 *Information orientation*

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13 The majority of the parents reported that being autonomous in the MMR vaccination is a matter of
14 actively looking for information, expecting the information to be delivered by the pediatrician or the
15 health authorities, or simply avoiding any information. Half of the participants described themselves
16 as active information seekers who try to consult as many sources as possible, stating that it is up to
17 parents to look for information themselves.
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26 *"If one wants information, he or she should get out and find it."* (Mother, 46, Italy)
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31 About a quarter of the participants rather expected the health authorities, medical professionals, and
32 vaccination centers to provide them with easy and accessible information prior to their appointment
33 for the vaccination, stating that it is not up to parents to look for vaccination-related information.
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40 *"It's up to the pediatrician to start by providing information. They take it for granted that we know*
41 *all the things, but instead... this is not always the case."* (Mother, 30, Non EU)
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46 In this context, about a quarter of the participants reported that fear of the information that could be
47 found (possible side-effects of the MMR vaccination, including autism) and lack of medical
48 knowledge prevented them from looking for information on vaccinations and led them to avoid the
49 information given by other parents.
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3 *"I tend to stay away from the websites 'cause you read all sorts of things. It happened to me once,*
4 *then I worried and started to do, to think much worse than it was, so I don't even go and look at it!"*
5
6 *(Mother, 42, Italian)*
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11 *Relevance of the decision and related stress*
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13 For the majority of the participants, confidence in the MMR vaccination decision-making was
14 related to the relative importance of this decision. Almost all parents reported that the vaccination
15 decision is something you just make, it is not among the priorities and does not cause stress.
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22 *"For me it's among the last ones. Partly because I had health issues ... and then because it was a*
23 *decision that I had already made, in the sense that I knew I just had to do it, so that was not such a*
24 *hard decision."* (Mother, 30, Other EU)
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30 A small minority reported that making the decision is among the most important decisions, as it
31 becomes a stressful task that consumes time and energy and creates tensions in the couple. These
32 parents also reported to have a poor relationship with their child's pediatrician.
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39 *"Deciding for MMR has really been a moment of tension between me and my husband... I remember.*
40 *It was not like deciding whether to breastfeed or not. That was my decision. We really went through*
41 *a period of tension."* (Mother, 38, Italy)
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47 **DISCUSSION**
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49 **Main findings**
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51 The aim of this focus group study was to explore the construct of psychological empowerment in
52 the MMR vaccination decision among a sample of parents residing in a low MMR coverage area in
53 Italy. Issues of autonomy and competence largely dominate our results and appear to be strictly
54 interrelated. Autonomy, interpreted as both responsibility and freedom, seems to largely depend on
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3 parents' competence and this, in turn, on their relationship with the child's healthcare provider, the
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5 relevance investing the decision, and their information-seeking behaviors.
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8 First, the large majority of the participants reported they could feel competent and
9
10 autonomous not only when having the appropriate knowledge and information-seeking skills but
11
12 also when they could rely on a competent and trustworthy pediatrician. Other studies found that
13
14 trust in the pediatrician can be a relatively important factor influencing parents' vaccination
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16 decision [47-49] and, considering that according the Italian system children are administered the
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18 vaccine by a nurse in a vaccination center and not by their pediatrician, it should be further explored
19
20 whether trust in the vaccine provider as well could compensate for parents' perceived lack of
21
22 competence. Few parents also stated they would rather listen to a pediatrician with similar
23
24 vaccination opinions as theirs. These findings confirm a large set of literature on the importance of
25
26 the child's provider on parents' vaccination decision [50-54] and on the tendency many parents
27
28 have to choose a provider with similar vaccine beliefs as their own [55]. The results are also in line
29
30 with the theory of relational or conscientious autonomy, which assumes that our sense of autonomy
31
32 depends on other individuals' influence on our lives [56]. The theory stresses that "social
33
34 interactions can affect autonomy not only by influencing individuals' health-related preferences and
35
36 choices but also their self-identities, self-evaluations, and capabilities for autonomy" [56]. Our
37
38 findings suggest that parents might report that they can never be in a position to make decisions
39
40 autonomously because their health care provider will always know more than they do. However,
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42 they can be at the same time compliant with the pediatrician's recommendation, but claim the
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44 decision as their own anyway since it was guided by a trusted source with whom they have a good
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46 relationship [1]. The theory has also been confirmed by other studies [57], which found that patients
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48 felt they "owned" their decision when it was the one recommended by a trusted medical
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50 professional. Thus, to feel empowered does not necessarily mean that parents will always make
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52 decisions on their own. Having the ability to negotiate the extent to which one is involved in
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54 decision making is key; in some instance parents will be guided by health professionals entirely, in
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3 other situations it is a genuinely shared decision, and in others entirely the decision of the parent. It
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5 is an entirely context specific decision [48].
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8 Second, the vast majority of the participants found that autonomy was related to issues of
9
10 responsibility and freedom, thus reinforcing the idea that autonomy is connected to “morality,
11
12 personhood, and agency” [1]. While only a small, educated minority was willing to assume the legal
13
14 responsibility derived from making an autonomous choice, participants were equally split in their
15
16 opinion regarding the morality of having the freedom to make the final decision. Previous studies
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18 found that adolescents’ perspectives on their legal responsibility in relation to their vaccination
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20 might be a barrier to immunization adherence [58]. With respect to freedom of choice, studies also
21
22 found that a small proportion of individuals are unlikely to vaccinate when immunizations are
23
24 compulsory [59,60].
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28 A third major finding was that parents reported about their preferences regarding their
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30 vaccination-related information when asked about their meaning of autonomy and competence in
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32 the MMR vaccination decision. Participants distinguished themselves as active seekers, passive
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34 recipients, or information avoiders. It is worth noting that most information avoiders and passive
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36 seekers also had lower educational levels. Research has previously found that those with more
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38 access to health-related information and better information-seeking skills are more likely to make
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40 informed medical decisions [61] and that information-seeking preferences can affect one’s
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42 vaccination decision [49]. Moreover, information orientation (engagement vs. apprehension) has
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44 been found to predict one’s objective and perceived ability to use information technology for health
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46 [62].
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50 A last finding relates to the empowerment sub-dimension of meaningfulness. When asked to
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52 compare the MMR vaccination decision to other decisions made for their child, the majority of the
53
54 participants reported that it is something natural “you just do,” something that does not cause stress
55
56 or require energy. These parents also reported that their MMR vaccination decision could have an
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58 impact not only on the health of their child but also on their community’s health. A small minority,
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on the other hand, reported that deciding over MMR was a time-consuming, stressful task, which topped all other decisions. It is worth noting that these parents also lamented a poor relationship with the pediatrician. The idea that vaccination might be an obvious choice and a normal part of bringing up a child, and that it might require more or less thinking on the basis of its relative relevance was also found in previous studies [5,49,54].

Strengths and weaknesses of the study

This is the first study to shed light on parents' understanding of empowerment in their MMR vaccination decision-making in a low MMR coverage area. Previous work has explored the construct of psychological empowerment in the MMR vaccination decision [5], suggesting the relevance of parental self-efficacy and self-determination in such a decisional context. The study is subject to a number of limitations. First, the self-selected nature of our sample might have resulted in focus group participants mainly being pro-vaccination parents willing to share their compliance with the official immunization recommendations. Second, recruiting through the vaccination centers might have prevented us from reaching those who are highly opposed against immunizations and even refuse the DTaP vaccination. However, this could also be seen a strength of the study, as a large number of our participants were not completely decided on whether to vaccinate or not. Third, due to a high dropout rate, the focus groups conducted in this study included only 4 to 6 participants each. While groups of 6 participants is generally the minimal recommended number in focus groups, discussion among the participants was not prevented by the limited sample size thanks to participants' diversity in their opinion. Furthermore, the research team who participated in the focus group was limited to two members (one facilitator and one recorder) when the size of the focus group was below 6 participants. Finally, since we extracted our results from qualitative reports of a small sample of parents, our findings cannot be generalized to a bigger population.

Implications

The findings have a number of implications both for theory and for practice. First, the construct of empowerment appears to be perceived by parents in the context of the MMR vaccination decision as more nuanced than our initial conceptualization. While autonomy and competence are perceived as salient dimensions of the construct, they are strictly related to issues of freedom, responsibility, trust in the pediatrician, relevance of the decision and information orientation.

In terms of practice, it is worth noting that the large majority of the participants reported not to make distinctions between vaccinations, therefore our findings could be applied to multiple vaccinations. Because empowerment was viewed in different ways by our participants, ambiguous or extreme interpretations of the empowerment principles (such as autonomy) need to be avoided for all vaccinations as they might result in contract-like relationships between parents and health professionals, isolate parents with their responsibility of the decision, or curtail other possible immunization solutions [63]. Also, it should be noted that not all parents wish to be empowered the same way. Some might need to be guided by the child’s pediatrician to feel in control of their decision, by simply conforming to his/her advice or the official recommendations and avoiding any other information sources. Others might highly value active information seeking to feel competent and finally make an autonomous decision. In all instances, as other studies found [48,49,64], it should be recognized that pediatricians are key in parents’ empowerment in the vaccination decision. Not only do they need to be perceived as competent professionals by parents, but they also have to build a trustworthy relationship with them [49]. Furthermore, they should be willing to address parents’ questions and concerns, make an effort to understand whether parents do or do not wish to share the decision-making, recognize how their interactions and relationships with parents can either enable or impair parents’ empowerment, and finally adapt their communication style accordingly [48,49,64].

Future research

Since a particular vaccination decision, the acceptance of the informed consent, or the attitude driving a given vaccination behavior may or may not be an expression of parental empowerment [1], future quantitative research has to clarify whether empowerment and its sub-dimensions can have an impact on the acceptance of vaccination recommendations. In this sense, developing appropriate measures of the empowerment construct in this particular context and testing its relationship with other key variables such as vaccination knowledge and risk perception would be a valuable step.

CONCLUSIONS

Parents' empowerment in the vaccination decision should be encouraged to serve parents' rather than institutional interests [65]. Misconceived assumptions about empowerment might be a contributing factor to vaccine hesitancy and to health professionals' frustration about their potential to effectively cooperate with parents [63]. If parents are asked to be empowered in the vaccination decision, it is important that this be correctly interpreted and implemented by best practice. In this sense, by overtly employing relational autonomy as a crucial element of the vaccination decision, empowerment in parental immunization choice might become a more comprehensible and stronger principle, and could help pediatricians and other health professionals to genuinely promote and implement parents' autonomy [63]. Health professionals can appeal to a principle of parent empowerment by facilitating parents' ability to make an informed and autonomous decision and, at the same time, by promoting their relational autonomy [63]. This can be done by ensuring that parents are sufficiently informed, have the skills to find, assess and understand vaccination-related information by other sources, and by building a trustworthy relationship with them. On the other side, a view of empowerment that isolates parents in their decision-making would not be in line with a patient/parent-centered model [63]. Furthermore, health authorities' risk communication should include a description of the reasons for both restricting and expanding individual rights in a way to maximize comprehension, since there is evidence that informed consent does not always

provide clear and useful information [66,67]. Trained staff (preventive medicine experts, vaccination nurses) should also be available in the vaccination center to encourage parent’s relational autonomy and answer questions [2].

The advocated principle of parental empowerment in the vaccination decision in a context of voluntary participation, while suggesting that parental autonomy is central, does not mean that it is absolute [68].

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AUTHORS’ CONTRIBUTION

MF and EG participated in the design and implementation of the study, the analysis of the data and its interpretation. VC and PJS joined the design and implementation of the study. All authors contributed to the drafting of the manuscript.

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DATA SHARING STATEMENT

No additional data available.

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For peer review only

Appendix 1. Interview schedule

Interview topics	Key interview questions
1. General health-related decision-making	→ What do you usually do when you have to make a decision concerning your own health? → Why?
2. Child's health-related decision-making	→ Now think about the last time you had to make a health-related decision for your child. What did you do? → Why?
3. MMR vaccination decision-making	→ How are you making a decision regarding your child's MMR vaccination? → What are you taking into consideration? → How do you feel about making this decision? → Which experiences are helping or hindering you in making this decision?
4. Meaningfulness	→ What are the major decisions that you have made for your child so far? → How important is your choice about the MMR vaccination compared to other decisions made for your child so far? → Why is it more or less important than others are? → What makes it important?
5. Autonomy	→ In your opinion, what does it mean to be autonomous in making an MMR vaccination decision for your child? → Is it important to be autonomous?
6. Competence	→ What makes one able to make a sound decision about MMR? → Think of a competent parent who makes a sound MMR decision. Which skills does he or she have? → What skills would one need to have in order to feel able? → What does one need to know? → Can you mention three skills that one needs to have to be competent? → What is important for you to know right now?
7. Shared decision-making	→ Think of the meeting with the pediatrician when the topic of childhood vaccinations is discussed for the first time. How should it happen, in an ideal world? → How did it take place, in your case (if any)?
8. Gender roles	→ How do you and your partner share the MMR vaccination decision if you do?
9. Reasons for participation	→ Why did you decide to participate in this study?

Qualitative research review guidelines – RATS

R Relevance of study question

- | | |
|--|---|
| 1. Is the research question interesting? | Research question explicitly stated (p. 1, p. 2, p. 5) |
| 2. Is the research question relevant to clinical practice, public health, or policy? | Research question justified and linked to the existing knowledge base (pp. 3-4) |

A Appropriateness of qualitative method

- | | |
|---|--|
| 3. Is qualitative methodology the best approach for the study aims? | Study design was described and usage of focus groups was justified (pp. 5-6) |
|---|--|

T Transparency of procedures

Sampling

- | | |
|---|--|
| 4. Are the participants selected the most appropriate to provide access to the type of knowledge sought by the study? | Criteria for selecting the study sample justified and explained (pp. 5-6)

<i>purposive</i> : the objective was to interview participants from a low MMR coverage area |
| 5. Is the sampling strategy appropriate? | Appropriateness of the sampling strategy is described (pp. 5-6) |

Recruitment

- | | |
|---|---|
| 6. Was recruitment conducted using appropriate methods? | Details of how recruitment was conducted and by whom have been explained (p. 6) |
| 7. Is the sampling strategy appropriate? | Appropriateness of the sampling strategy is described (pp. 5-6) |

8. Could there be selection bias?

No details of who chose not to participate and why have been provided

Data collection

9. Was collection of data systematic and comprehensive?

Data collection method(s) have been outlined and examples given (p. 6)

10. Are characteristics of the study group and setting clear?

Study group and setting are clearly described (p. 6)

11. Why and when was data collection stopped, and is this reasonable?

End of data collection justified and described (data saturation, p. 7)

Role of researchers

12. Is the researcher(s) appropriate? How might they bias (good and bad) the conduct of the study and results?

Researchers do not occupy dual roles. Researchers' biases are discussed (p. 7)

Ethics

13. Was informed consent sought and granted?

Informed consent process explicitly and clearly detailed (p. 6)

14. Were participants' anonymity and confidentiality ensured?

Anonymity and confidentiality discussed (p. 6)

15. Was approval from an

Ethics approval cited (p. 5)

appropriate ethics
committee received?

S Soundness of interpretive approach

Analysis

16. Is the type of analysis appropriate for the type of study?	Analytic approach described in depth and justified (p. 7)
<i>thematic</i> : exploratory, descriptive, hypothesis generating	<i>Indicators of quality</i> : Description of how themes were derived from the data (inductive, p. 7)
17. Are the interpretations clearly presented and adequately supported by the evidence?	Analysis and presentation of opinion tensions (pp. 7-13)
18. Are quotes used and are these appropriate and effective?	Rich and self-explanatory quotes were chosen (pp. 7-13)
19. Was trustworthiness/ reliability of the data and interpretations checked?	Method of reliability check described and justified (two coders analyzed the data independently, p. 7)

Discussion and presentation

20. Are findings sufficiently grounded in a theoretical or conceptual framework? Is adequate account taken of previous knowledge and how the findings add?	Findings presented with reference to existing theoretical and empirical literature, and how they contribute (pp. 14-15)
21. Are the limitations	Strengths and limitations explicitly

thoughtfully considered?

described and discussed (p. 16)

22. Is the manuscript well
written and accessible?

Evidence of following guidelines
(format, word count, p. 1)
Detail of interview questions
contained in appendix
Written for a health sciences
audience

23. Are red flags present?

No

These are common features
of ill-conceived or poorly
executed qualitative studies,
are a cause for concern,
and must be viewed
critically. They might be fatal
flaws, or they may result
from lack of detail or clarity.

review only