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Research in adolescent healthcare: the value of qualitative methods

Short title: Research in adolescent healthcare: the value of qualitative methods

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ABSTRACT

Background: The vast majority of publications about adolescent healthcare use a quantitative methodology that often involves long and expensive research protocols with results that do not always provide answers adequate to the complexity of the questions being asked. The qualitative method is sometimes a more effective alternative for exploring some of these. This method can be defined from its objective, which is to generate theoretical hypotheses, its mandatory consideration of the researcher's subjectivity, and the importance it ascribes to the context of the participants' experience. Among the many techniques of qualitative research, the use of phenomenological methods, in particular, interpretative phenomenological analysis (IPA), is highly developed in medical research.

Objectives: To define the qualitative method and describe the principal stages of a phenomenological qualitative study.

Results: The three stages of a qualitative study are data collection (population and sampling, data collection methods), data analysis, and writing up the results. Purposive sampling makes it possible to include participants who can describe in detail, and as experts, their experience during semistructured interviews. The analysis takes place in two stages, the first very descriptive, the second more interpretative. The results are written up in a narrative form, including both direct quotations from the interviews and the researchers' interpretation.

Discussion: The issues of health promotion and healthcare associated with the management of chronic symptoms or diseases in adolescents involve an extremely rich and complex context. Qualitative methods make it possible to approach these questions and to understand them better by generating hypotheses from a rigorous scientific procedure appropriate to the context and objectives. In addition to being used on their own, they can be used on an exploratory basis early in a quantitative study to help define it better, for explanatory purposes, to help understand complex quantitative results, or combined with a quantitative study. The qualitative and quantitative results will then be integrated.

Keywords: Adolescence, qualitative research, interpretative phenomenological analysis

1. INTRODUCTION

More than 2 million articles on adolescence have been listed in Medline/PubMed since 1966, with 60% written by groups of psychologists or psychiatrists. The rest involve, in equal proportions, preventive healthcare, surgery, and somatic medicine, often entwined. These numbers continue to rise, in France and internationally.

Medical research on adolescents covers three major themes: i) the physiology of their development (e.g., insulin resistance and puberty or cerebral maturation and its psychobehavioral implications [1]; ii) chronic diseases (from their pathophysiology to their clinical course, from their diagnosis to their treatment, and from their effects to adherence and transition [2]); and iii) healthcare and disease prevention (e.g., anti-HPV vaccination [3]).

Most studies published today are quantitative: they seek to validate the researchers' hypothesis by proving it statistically. Quantitative studies are essential for answering biological and medical questions. Their results have established the scientific foundations and underlie the recognition of medicine and the publication of numerous recommendations for management and guidelines for both therapeutic and preventive care [4]. The principle of quantitative methods is measurement : quantifying variables and demonstrating causal relations from a statistical model. Evidence-based medicine is based on the positivist paradigm in which the studies with the highest level of evidence are those based on quantitative research methods that are both objective and reproducible. The results are especially valued when they result from longitudinal research that measures quantitative traits in a large multicenter prospective cohort for a prolonged period of follow-up [5].

Increasingly more authors nonetheless underline the limitations of these types of studies [6]. The conditions for quantitative research are often expensive and difficult to put together. Due

to its cross-sectional nature, this is especially true for adolescent medicine. On the other hand, these studies, together with the meta-analyses that sometimes accompany them, while they collect numerous data and associations, are not always especially informative about the complex phenomena involved [7, 8]. The quantitative approach is limited in its ability to ask questions about and find solutions for problems related to healthcare. One example can be seen in the successful development of antitumor drugs by Eli Lilly, based on preliminary research about traditional texts and practices by indigenous physicians [9]: the first treatment was identified after 3 years of study of 40 species, while the US National Cancer Institute program (which randomly selected plants for testing) studied 35,000 plants and developed no treatments [10]. When health questions involve experience or interactions linked to the social environment, qualitative research is both invaluable and essential [6]. This type of study makes it possible to examine questions and themes that are not easily accessible to quantitative research. It is accordingly especially appropriate for the study of factors that are subjective or difficult to measure.

Medicine and healthcare specifically intended for adolescents is a recent, cross-sectional discipline at the intersection of somatic, psychological, behavioral, social, demographic, and cultural elements; in other words, it is complex. Qualitative methods are especially appropriate in this context [11]. Our team has been participating in the development and dissemination of qualitative methods in adolescent medicine and healthcare in France for several years [3,12–15].

We will briefly review the historic and theoretical context of qualitative studies and then describe the different stages of this type of study according to a phenomenological method: interpretative phenomenological analysis (IPA) [16].

2. DEFINITION AND PRINCIPLES OF QUALITATIVE METHODS

While some authors consider that qualitative methods have always existed, protocols for their use were nonetheless first developed at the beginning of the twentieth century, first in sociology and anthropology, and then in the 1990s in health. Qualitative research made its first appearance as a MESH term (key word) in 2003. Glaser and Strauss (1967) defined qualitative methods as all types of research that produces data that do not result from statistical procedures or other means of quantification. We think that the best way to define a qualitative study is to consider it according to: i) its objective (to generate theoretical hypotheses), ii) its necessary consideration of the researcher's subjectivity, and finally iii) the importance given to the context of the participants' lived experience.

Generation of theoretical hypotheses: The classic questions presented in qualitative research are: why, how, what does that mean? Researchers seek to understand the processes at the origin of behaviors, symptoms, and disorders, to explore the meaning given to an event, or how a behavior or phenomenon occurs [17]. The objective is therefore to conceive and develop, based on the participants' personal experience and from their point of view, theories that help to understand social, medical, mixed, or other phenomena in their natural environment rather than under experimental conditions [18]. In adolescent health, qualitative methods can thus shed new light on the needs of adolescents, their families, and the professionals who care for them.

Consideration of the researcher's subjectivity: In qualitative methods, subjectivity is inherent in the research process. It is accepted and even used in interpreting the results, through the reflexivity that is a criterion of rigor in these methods. The researchers' points of view, together with those of the participants, enable the construction of more complex and more relevant theoretical hypotheses. The researchers' involvement enriches the results and

produces stronger, more complete hypotheses. This position contrasts with quantitative researchers' positions, considered exterior to their experimental system.

The importance of context: Qualitative research stresses in-depth analysis of the context by a small number of individuals involved within it [19]. The sampling of the study population is designed to promote a diversity of points of view and to enrich the data in this context specific to the research question. The contextual elements are essential to a detailed and deep understanding of the complex process. The generalization is theoretical and not statistical.

One of the first qualitative methods used in health sciences was grounded theory, that is, theory that is rooted or anchored, developed by Glaser and Strauss (1967) in the social sciences [20]. Their objective was to develop a method that would make it possible to propose a social theory applicable to a field site, based on data collected there, a theory that might then be generalizable to other situations. The method they developed used processes where both data collection and analysis take place continually. The research material is coded inductively and comparatively. The inductive approach enables the emergence of new theories that may be more or less associated with preexisting theories. Grounded theory is widely used in medical research today. It nonetheless required adaptation to the context of medical research (which is most often not field research); this adaptation involved more specific research questions and narrower objectives in terms of generalization.

The phenomenological methods focus on the experiences of participants, the meanings they give to these experiences. It is widely used in medical research, most especially the version known as interpretative phenomenological analysis (IPA) [16], used in psychiatry and increasingly in other medical disciplines. It is a process for conducting an in-depth study of a particular internal experience of an event or state, based on the person's individual

formulation of it. Phenomenology is a movement in philosophy that calls for the analysis of phenomena as they appear to the consciousness, of letting things appear as they are, in the subject's own words. The analysis of this narrative allows researchers to understand what meaning is given to the experience and how. Analysis according to IPA is described as interpretative because the researcher is personally involved in it [16]. Smith and Osborn thus describe a *double hermeneutic* (since Antiquity, hermeneutics has designated the art of interpreting): the participant undergoes an experience, or an event or a state, and gives it meaning. The researcher then analyses and interprets the participant's narrative [21]. IPA seeks to construct a model linked to a context. It moves from description to interpretation, from *idiographic* analysis (in-depth analysis to understand how a particular phenomenon is understood by the people who face it in a defined context) to the demonstration of a coherent set of *points of view* of a given group.

IPA is used in numerous situations: when the research question is complex, when the aim is to shed light on personal or private processes or questions [22], or when the subject is a new situation or the source of a dilemma [23]. It appears to be the reference method for answering numerous research questions about how patients and families experience chronic disease, psychological distress, cardiovascular diseases, or pain [24, 25]. It is increasingly used in adolescent medicine and healthcare [26].

The question of the scientific validity of qualitative studies has been raised repeatedly [6,17]. The criteria of credibility, reliability, transferability, and conformability (which correspond respectively to those of the validity, generalizability, and reproducibility of quantitative research) are increasingly accepted by the scientific community and requested by scientific journals [27]. In practice, it is essential to pay attention to: i) triangulation, which compares

the results of two or more different data collection methods or two or more data sources. From these the researcher looks for convergences to develop or corroborate a comprehensive interpretation; ii) validation by the respondent; iii) a clear description of the data collection process and of its analysis in a report written to enable the reader to understand what the researcher did; iv) the reflexivity of researchers, setting forth their background and preconceptions, so that the reader can understand how they reached their interpretation; and v) the equitable representativeness of the different points of view about the research topic [17].

3. THE PRINCIPAL STAGES OF IPA

3.1. Data collection: population and sampling, collection methods

3.1.1. Population and sampling

In qualitative research, the inductive procedure requires the constitution of a theoretical, that is, purposive or intentional, sample. This sampling technique differs from those in randomized studies, where the aim is to obtain a representative sample of the population. Researchers conducting qualitative studies choose people they consider pertinent because of their characteristics (the depth of their opinions about and experience with the question) and their ability to contribute information that meets the study's objectives. They are thus key informants. The objective here is to generate data as rich and diversified as possible in order to construct new theoretical hypotheses. Because we are not seeking statistical proof, there is no point to randomized sampling; it might even be counterproductive.

The participants are recruited from a population assumed to be informative. In the domain of health, researchers most often interview patients, but they can also question patients' families, friends, and the professionals caring for them [3]. Researchers seek to represent the different points of view on the question. They therefore sometimes include people with extreme

positions, usually called extreme or *deviant cases*. These participants, who differ because of their particular experience or point of view, are often very useful for developing new hypotheses.

Qualitative studies generally include a modest number of subjects, ranging from single case studies to a few dozen (nine on average) [16]. The researcher must be able to maintain a global vision of the corpus of texts, which becomes increasingly difficult as it grows. If the sample is large, it loses homogeneity, and the analyses run the risk of underlining the diversity of the sample more than the diversity of their lived experiences.

3.1.2. Data collection methods

The data collection technique used for IPA is the interview, either individual or collective (in *focus groups*). The *semi-structured interview* (or in-depth interview) is the standard and generally preferred form of data collection [16]. Participants are queried in face-to-face interviews about their points of view, beliefs, and attitudes, with the questions framed to promote the recounting of individual experience, ideas, and feelings. The individual interviews enable participants to tell their stories, their situations, in their own words.

Studies can also be conducted with *focus groups*, either separately or combined with individual interviews. The focus group is a series of discussions in groups ranging from three to eight participants, led by a researcher. It is most often used for reasons of feasibility. It is especially useful when the interaction and exchanges of thoughts between the participants help to generate ideas leading to a more detailed examination of the study subject [28]. The groups can be homogeneous or heterogeneous: the homogenous groups are composed of people close in terms of their perspectives on the question, a closeness that promotes their expression in the absence of hierarchical constraints; in heterogeneous groups, debate is facilitated, but at the risk that conversations may be compromised [18,29].

Regardless of the mode of data collection:

- Researchers must stimulate the participants' reflexivity (consideration of their subjectivity) and support their efforts to explore and interpret their lived experiences.
- The interview is exploratory: the researcher seeks to discover the individual, personal points of view of the participants, who are considered experts on the study question, from their own experience.
- Researchers begin by specifying the context of the interview and the research. Next they intervene subtly to help the participants describe and share their experience more fully. The interview is a work of reflexivity shared between the participants and researchers.
- The interview begins with general questions and moves toward more specific, targeted questions. It is conducted from an interview guide of open questions, prepared in advance. The guide evolves, that is, it can be modified at any point throughout the study. Conducting the interview nondirectively promotes the most subjective expression possible.
- The interviews are generally recorded, with the subjects' consent; the recordings are fully transcribed and anonymized to enable them to be analyzed by one or several independent researchers [30].

3.2. Data analysis

The analytic process in IPA is inductive. The analysis of qualitative data, which is subjective by nature, is systematic, rigorous, and insofar as possible, not impeded by prior knowledge. The analysis deconstructs the data, to reorganize it into a hypothesis or an original theory [31]. It is not standardized and cannot be automated. Regardless of the technique, the common

point is rigor at each stage: from the method to the presentation of the results, via a complex analysis of the data.

In practice, the procedure moves through the following steps: the researcher analyses each corpus of text collected, in turn, and repeatedly, if possible starting with the first interview. The interviews are annotated with the comments, which are subsequently regrouped after coding and then organized into themes. The construction of connections between them enables a coherent thematic organization of the interview. Meta-connections are then drawn between interviews, to determine a set of meta-themes describing all of the narratives.

These meta-themes are explained in a written report. At each stage, the researcher verifies the coherence of the groups by continually going back and forth between the analysis and the source material. The coding work is performed manually in writing or can be assisted by software to help organize data (NVivo or Sonal). In this case, the software does not perform the analysis, but simply helps to organize the different analytic tasks. When enough data have been collected and their analysis makes it possible to generate sufficient hypotheses, the research ends, that is, the interviews stop [32]. Unlike in grounded theory [20], the end of the analysis is not linked to the principle of data saturation.

The coding is conducted simultaneously by two or three different researchers, who discuss the analyses at various stages and coordinate their codes. This technique, called triangulation, ensures richer results. It is one of the principles of rigor in qualitative research. The verification of the results by the interviewees and then peer revision are two further guarantees of the quality of the analysis. The internal validity (do the data collected represent the reality observed?) of a qualitative study can be increased by triangulating the types of data collection or its sources [18]; for example, both written and oral material may be collected, or both patients and their families interviewed.

3.3. Writing up the results

The presentation of the results is thematic, descriptive, and narrative. Each theme is accompanied by verbatim extracts from the transcripts, attributed to each participant. The extracts chosen exemplify the themes. The discussion is more interpretative. It can compare the results with the existing data in the literature, proposing theoretical explanatory hypotheses of the results observed, constructed from the summation of the points of view of the participants, the researchers, and the literature. It can also lead to the proposal of practices for patient care or to theories.

Medical journals today demand increasingly often that researchers demonstrate the scientific rigor of their results, by imposing the use of guidelines, such as CONSORT or PRISMA [33]. Similar guidelines exist for qualitative studies. The most frequently used are the COnsolidated criteria for REporting Qualitative research (COREQ) [34] checklist of 32 items and the Standard for Reporting Qualitative Research (SRQR), a list of 21 items [35].

4. DISCUSSION

As qualitative methods are becoming an increasingly credible choice instead of or as a complement to quantitative studies, it is important to see how they are used today in adolescent medicine. Do they succeed in generating theoretical hypotheses or deepening or explaining the results of quantitative studies? Can they serve as prerequisites to begin the exploration of a clinical question that remains little known?

The exploration of adolescents' experience of their health helps to understand their behaviors better and provides useful information for prevention. Accordingly, Visram et al. (2017) explored the context and perceptions of energy drink consumption among pupils aged 10–14 years [36]. As the consumption of soda is decreasing in many countries, use of energy drinks

is progressing, especially among the young. The large quantities of sugar and caffeine they contain, consumed regularly or intensively by those younger than 18 years, are a health risk. The study shows that this consumption is associated with social activities (sports and video games, especially among boys), and appetency is associated with their taste, quality/price ratio, self-service availability, and marketing strategies, directed at young male consumers. Young participants want greater clarity about the composition and risks associated with consumption of these drinks, for example, by mandatory clear labeling.

Studying adolescents' experience of healthcare is useful for improving management. For example, in the UK, obesity intervention programs for adolescents recruit a very small percentage of the eligible population, and a substantial portion subsequently drop out and are lost to follow-up. Jones et al. (2019) [37] reviewed the qualitative studies of the experience of these adolescents with obesity. They found that these teens expected programs to be personalized to allow more involvement on their part; they also expected management of anxiety, greater support by professionals, family, and peers, and longer support over time.

Approaches to prevention can also benefit from qualitative results. One study, for example, explored the reasons for the failure of a systematic screening program for infection by *Chlamydia trachomatis*, although a randomized controlled trial had indicated in advance that it would be effective [38]. Interviews with staff at GPs' offices provided knowledge essential to improvement by showing the numerous practical limitations of the program as modified from the RCT (lack of access to continuing training, incentives, aid, support, and easily available testing kits).

The experience of healthcare professionals is useful for improving diagnostic and treatment processes. Accordingly, a qualitative study examined the issues related to transition programs and their timing for adolescents who had undergone kidney transplantations in childhood [39]. The transition to adult care is a known period of vulnerability in the management of

adolescents with chronic diseases: during this period patients with kidney grafts are at a higher risk of nonadherence and graft rejection. The difficulties of understanding and the alliance between the adolescents and their care providers echo the rigidity of the administrative procedures (e.g., age at transfer), which do not take the teens' individual issues into account.

The exploration of the experiences of adolescents and their families can provide a foundation of knowledge for the creation of specific care programs, such as patient education interventions [40], which can subsequently be validated quantitatively. In contrast, it could also follow statistical findings, to add texture to the results, that is, to give meaning to the results observed. Similarly, the study of the involvement of parents in the care of adolescents with obesity has produced useful results [12]. They show a major association between the functioning of family relationships and eating, which may endanger the treatment; they thus underline the importance of working on these relationships to enable more effective dietary management.

Finally, the combined use of qualitative and quantitative methods in a single protocol, known as mixed methods [41], can produce results that are simultaneously rich, complex, and statistically valid. Thus, the qualitative interviews by Al-Yateem et al. (2016) enabled the authors to develop a questionnaire assessing the factors related to the quality of care of adolescents and young adults with chronic diseases [42].

5. CONCLUSION

The issues of preventive and therapeutic healthcare associated with the management of symptoms or chronic diseases in adolescents involve an extremely rich and complex context.

The determinants of adolescents' development are linked to their individual transformation and to the necessary changes in their relationships with their family, social, and medical

environments. Qualitative methods make it possible to approach these questions and to understand them better by generating hypotheses through a rigorous scientific process adapted to the context and the objectives of the study.

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