

Can qualitative research play a role in answering ethical questions in intensive care?

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Abstract: Scientific and technological progress, as well as increased patient autonomy have profoundly changed the world of healthcare, giving rise to new situations that are increasingly complex and uncertain. Quantitative paradigms, of which the main bastion is evidence-based medicine (EBM), are beginning to reach their limits in daily routine practice of medicine, and new approaches are emerging that can provide novel heuristic perspectives. Qualitative research approaches can be useful for apprehending new areas of knowledge that are fundamental to recent and future developments in intensive care.

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Introduction

Scientific and technological progress, as well as increased patient autonomy have profoundly changed the world of healthcare, giving rise to new situations that are increasingly complex and uncertain. Quantitative paradigms, of which the main bastion is evidence-based medicine (EBM), are beginning to reach their limits in daily routine practice of medicine, and new approaches are emerging that can provide novel heuristic perspectives. Although based on positivist and biotechnological theories, the practice of intensive care medicine regularly raises a number of important questions and ethical dilemmas, some of which arise even before admission to the intensive care unit (ICU), and persist beyond discharge, be it among the patients, their families and relatives, or among healthcare workers (HCWs). Qualitative research approaches can be useful for apprehending new areas of knowledge that are fundamental to recent and future developments in intensive care.

Medical progress and EBM

The world of healthcare, and the professionals that shape it, has become a profoundly complex environment. Technical, scientific and biomedical advances, combined with hyper-specialisation of health professionals and the more recent drive to take into consideration the wishes of patients and their families, all concur to create complex situations and novel problems. Some authors have even gone so far as to call this change in the paradigm a “scientific revolution”, describing its main features as follows (1):

- (I) The model of certainty, reflecting the establishment, which was thought to be definitive, and of assured knowledge, has been replaced by a model founded on uncertainty and instability, reflecting a complex universe ruled by systemic causality;
- (II) The model of cumulating knowledge, in which the limits of the unknown are continually being pushed back to enable greater calculability in the world,

has been replaced by a more nuanced conception where the areas of non-knowledge move forward in parallel to advances in knowledge.

Accordingly, the complexity of these new situations means that HCW need to take uncertainty and areas of non-knowledge into account. The uncertainty arises from the inability to predict what is going to happen because of a large number of parameters. Faced with this situation, it is clear that EBM, with its systematic evaluations, continuous experimentation and algorithms, can, in some cases, be insufficient to allow decision-making (2). Daily practice nowadays brings to light a number of important differences between the reality of the facts, and the standards dictated by EBM that are not easily transferable (3,4). Figures are insufficient when attitudes, values and preferences affect the symptoms and outcomes of the disease, as well as treatment decisions and the appreciation of their efficacy (5). Accordingly, it can be seen how a heritage of positivist thinking from the 19th century, and triumphalist thinking from the advances of the 20th century have continually sought to render objective phenomena that are, in essence, subjective, simply because they are part of the human experience, i.e., the doctor-patient relationship. After all, fundamentally, medicine may indeed be, *de facto*, first among the human sciences.

Strengths and weaknesses of quantitative techniques: understanding the disease and understanding the patient

As stated by Malterud (3), the difficulty for medicine as a discipline may not be that this subjectivity is happening, but that the medical research tradition lacks strategies for the study of interpretive action, its dynamics and its consequences. The task is twofold for the clinician and for the researcher, in that they must understand both the disease and the patient at the same time. As a result, taking organisational and cultural aspects into account is a major challenge for health research (6). However, there is reason to believe that methodological procedures and investigative methods allowing analysis and understanding of these novel situations have poor visibility and legitimacy in the field of (bio)medical research. Among such methods, qualitative research remains little known in the medical work. Long considered the “poor cousin” of quantitative methods, and often erroneously presented as the antithesis to quantitative methods, qualitative research and techniques are none the less useful for investigating whole fields of research that cannot be accessed simply by measuring numbers and

statistics. In these new situations where traditional methods fail in the counting of occurrences of a phenomenon, or in measuring its extent, qualitative techniques can be applied to understand how and why such a phenomenon occurs.

Complexity, uncertainty and new challenges in intensive care

ICUs owe their existence in large part to technological progress and scientific research. Since this discipline's first steps up to the present time, clinical activity in the ICUs has continually advanced in line with scientific progress, be it in terms of technology, biology, epidemiology or ethics. As underlined by Quenot *et al.* in their article in this issue about the profession of ICU physicians (7), critical care is aware of its proximity to technology and always keeps in mind the motivation that should be its guiding principle, namely humane reflection that gives meaning to the care dispensed in the ICU.

The positivist paradigm of EBM has long accompanied the development and transformation of ICU activities, but other methodologies are also used, and increasingly so in recent years. In particular, qualitative methods inspired by social science and theory of the 1950s as practised by the Chicago school, including leading sociologists like Everett Hughes and Anselm Strauss. In this way, faced with the “world” of modern and increasingly complex intensive care, ethical issues have become an integral part of the daily mission of healthcare teams in the ICU. First among these complex issues is the growing vulnerability of the patients admitted to the ICU, combined with the ever higher social expectations among the patients and their families. Medical decisions in the ICU, which can lead to a life being saved, or alternatively, to substantial handicap or death, are all the more complex because they not only call on medical judgement based on scientific evidence, but also on moral, ethical and judicial judgements (8). Consequently, in today's society, these issues must necessarily take into consideration factors that heretofore often went unmentioned, such as the impact of the patient's (and/or family's) experience and feelings on their relationship with caregivers and the healthcare environment. Or, what are the patient's preferences and desires in terms of therapeutic engagement? How far should healthcare go for a given patient?

However, all these questions that arise for healthcare professionals do not always have clear answers. Uncertainty about the diagnosis, the evaluation of prognosis, or the question of time and the future remain intractable problems

Table 1 Study of advanced directives (AD) writing: contribution of qualitative and quantitative methods to different research functions (12,17). Reproduced with permission from SAGE Publications

Functions of research	Qualitative methods to explore/understand	Quantitative methods to determine
Contextual	The nature of different forms of AD	The extent to which different forms of AD exists
	The experience/meaning of writing AD	The characteristics of people writing AD
Explanatory	The events leading to write AD/circumstances in which it occurs	Factors statistically associated with writing AD
	Why/how people start or continue to write AD	Characteristics/circumstances that correlate with different forms of AD
Evaluative	Appraisal of any interventions experienced	Extent to which different forms of AD writing services are used
	Formative factors in bringing periods to write AD	Extent to which interventions achieve required outcomes
Generative	Suggestions/strategies for supporting people to write AD	Prediction of future levels of AD writing
	Helping people to write AD	Levels of requirement for different forms of provision/intervention

that frequently prompt a need for ethical discussions bringing together caregivers, the patient and their family (1,7). The role of the HCWs' culture, and how they perceive (9) and perform (10) their activity are determinant elements in patient management, from admission (or not) to the ICU, along their healthcare pathway up to discharge from the ICU (11-14). The multidisciplinary that HCWs claim as their own is central to this daily reflection and is expressed through myriad exchanges and discussions. The large place accorded to other disciplines, such as social and human sciences, by ICU physicians, is a clear reflection of this. Quantitative methods, widely employed in medical research, are not suitable for investigating this new side to the practice of medicine in the ICU (15). Quantifying and counting is of no help in understanding the attitudes, beliefs or hopes guiding decisions to initiate, limit or withdraw treatment.

Qualitative research methods

Primarily used in human and social sciences, qualitative research methods are especially suited to the study of factors that are subjective and therefore, difficult to measure (16). Qualitative methods can be used to describe complex phenomena as they occur in their natural environment. They do not seek to quantify or measure, but rather, generally consist in collecting data (often verbal) to enable interpretation and comprehension. This approach is useful for constructing and developing new theories or new

conceptual frameworks, which can also sometimes generate further new hypotheses. Qualitative research methods are amenable to investigating behaviors, with a view to understanding (rather than measuring) the how and the why (*Table 1*). According to Corbin and Strauss (18), the term "qualitative research" means any type of research that produces findings not arrived at by statistical procedures or other means of quantification.

Qualitative versus quantitative approaches

Qualitative research differs from conventional quantitative techniques in several ways. Firstly, in qualitative research, the researcher is the primary data collector. This can be done in several ways, using various data collecting strategies, depending on the orientation or design of the research. For example, qualitative data can be obtained through individual interviews (which may be directive, semi-directive or non-directive), discussion or focus groups, memoirs, textual content analysis, documentaries, observation (participative or non-participative, also called *in situ* observation), or archive searches based on paper, digital, audio or video records.

In the case of semi-directive interviews, which is the technique most frequently used in qualitative studies in the field of healthcare, an interview guide is usually used. This interview guide comprises a list of points (non-exhaustive at the outset of data collection) that the researcher would like to address with the participants. It should be noted,

however, that this does not mean the researcher will ask the participant a direct question regarding each point on the list during the interview. On the contrary, such an approach would run the risk of falsely orienting the subject's discourse, or inducing certain subjects of conversation. On the contrary, the main aim is rather to present the topic with an open question, and then allow the participant to talk and spontaneously address whatever points they feel are important to that topic. If needs be, the researcher can re-direct the conversation towards the points listed on the interview guide if none of them is addressed by the participant, albeit taking care not to impose responses on the participant by "putting words into their mouth". As data collection proceeds, the interview guide may be modified as the interviews are performed, according to the data that emerges in the previous interviews. This inherent flexibility of qualitative research renders this methodology dynamic and amenable to being adapted to suit the natural environment in which the phenomenon under study is occurring.

A second major difference between qualitative and quantitative research resides in the analysis of data. In the context of qualitative research, several levels of analysis can be identified. The first level is familiarisation with the data in light of the research question. Second, coding of the data can be undertaken, either manually or using appropriate software to assist in the process (e.g., NVivo, ModaLisa, etc.). The major advantage of using computer software to assist with coding is that it helps to save a lot of time, by facilitating access to the whole corpus of text easily, with large capacities for storage and display. During the coding process, several theoretical standpoints can be adopted to apprehend the data. Thematic analysis (cross-sectional and longitudinal content analysis) is often used to identify major and minor themes present in a corpus of verbatim, in order to allow subsequent analysis. Systematic analysis of all the themes and categories that emerge through interpretation aims to give meaning to the information collected. In this type of scenario, the data (mainly text) are coded using an open and expandable coding system that is focused on the question at hand. Each interview transcript is read carefully, the text is broken up into smaller segments, and fragment by fragment, the text is re-organised into a list of categories that reveal major themes. This procedure can be repeated over and over again for each theme that emerges, to identify possible sub-themes or sub-categories. This type of analysis calls for repeated detailed reading of the text to identify all the themes and categories suggested by the textual elements, but also

by the behaviors and attitudes of the participants. Overall concepts then emerge, and the relationships between the different categories can be explored. Finally, a theory can be developed that explains all the behaviors and incidents observed (18). The constant comparison of incident to incident and category to category is necessary throughout the data collection process, to generate theoretical properties of the categories, round them out and give some indications of their range, conditions in which they occur, consequences and relations to other categories. All these methods are fundamentally opposed to the conventional quantitative, deductive approach, where the aim is to prove or disprove a set hypothesis, with analysis performed only after all the data have been collected (i.e., fixed in time).

Data communication and confidentiality

As in quantitative research, data management and analysis must be kept strictly anonymous when using qualitative methods. The transcription of textual data (i.e., interviews) should take care to code and identify different participants (or other unit of analysis). Audio recordings should be transcribed in their entirety (word for word) to respect the exact expression of each participant, and also to ensure that no data are lost, and that any non-verbal indications are also taken into account (gestures, postures, attitudes). The source data arising from the data collection procedure (audio recordings, video files, transcripts, text files, etc.) as well as any backup files from analysis software should be stored in restricted-access computers with password protection. Only approved researchers and study investigators may have access to the data, after obtaining the necessary approvals from ethics committees and data protection agencies. Audio recordings of interviews should be transcribed as soon as possible after the interview, to allow in-depth reading of the text. This makes it possible to orient future interviews, and the interview guide, if necessary, as data collection advances, according to the concepts or themes that are emerging from the data.

Analysis of qualitative data: thematic analysis

We present here one method of analysing a body of qualitative text, namely thematic analysis. The principle is that of content analysis, namely to reveal in an objective fashion, the meaning contained in the text through reformulation and classification of everything the text contains (19). This type of analysis intends to identify,

then categorize different themes in a corpus longitudinally (i.e., the same theme recurring several times in a single interview) as well as cross-sectionally (themes that are common to several individuals, or units of analysis). A theme (or concept) is then considered as a meaningful unit in itself, independently of the discourse. After a first careful reading of the texts, the aim is to identify, for each participant, the different themes expressed during the interview, taking into account major themes (significant and meaningful, well developed by the participant), and secondary (minor) themes (complementary topics touched on lightly, less well developed). This preliminary work is first performed individually by each researcher, then group consensus meetings are organised (process of triangulation) to discuss, compare and agree on the meaningful units to be retained, and the definition of the major and minor themes that emerge from the data. The team can also then discuss possible merging of thematic categories, and any possible theoretical relationships that emerge.

Clearly, qualitative analysis is a fluid, dynamic, and continual process that starts with the first interview. The concurrent nature of the collection and analysis makes it possible to adapt the interview guide if necessary as the interviews proceed, but also to decide when saturation (see definition below) has been achieved, thus bringing data collection to an end.

Sampling and saturation

The question of the statistical representativeness of samples included in qualitative studies is moot, since there is no statistical determination of a required number of subjects based on quantitative measures, as in quantitative research designs. Indeed, in qualitative studies, the participants form a non-probability sample (also known as criterion-based sampling) where subjects are selected precisely to form as heterogeneous a group as possible, in order to bring out the diversity and specificities of each participant in the sample (20). While some stratification of criteria can be based on socio-demographic characteristics, for example, the overall aim is to have participants with singularly different experiences, attitudes, values, ideas, beliefs and roles, so that as wide a range of opinions and practices as possible can be covered.

Qualitative studies usually include quite limited numbers of participants, as compared to quantitative studies, but those included are studied in great depth, in their natural environment or life context. The qualitative study places

particular importance on the unique character of each participant, whether it be an individual, a household, a hospital ward, or other unit of analysis. The search for new ideas, and allowing the themes raised by participants to guide the researcher towards new participants from other contexts means that it is practically impossible to know in advance how many subjects will finally be included in a qualitative study. The “right” sample size is the number of participants needed to achieve theoretical saturation of the data. Saturation is generally defined as the point beyond which no new concepts or themes emerge that can further enrich the theory. Consequently, as stated above, the number of participants necessary to achieve this point cannot be known in advance. Although the general rule of thumb suggests that saturation is achieved after around 20 interviews, qualitative studies nonetheless aim to include a maximum of participants in order to ensure that as many opinions and practices as possible are taken into account. Usually, data collection can be stopped when the last few observations no longer reveal any new elements or themes. This principle is based on the idea that each supplementary piece of data provides slightly less new information than the previous one, up to the point where no new information emerges for additional data. This principle is observed empirically.

Conclusions

Recent transformations in the field of healthcare have prompted healthcare professionals to call on new techniques to obtain access to relatively new types of data related to contemporary medical practice. Critical care is a field of medicine that is particularly affected by this change in practice, and where innovative methods for research and interdisciplinary communication are necessary to deal with the transformations in the critical and intensive care environment. Qualitative research can partially respond to these new needs, through a comprehensive approach to the subjective human phenomena that underpin interpersonal interactions during the process of care.

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Footnote

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