

Research Space

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Price, A.

Ann M. Price,

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Editorial

Ann M. Price

Ethics in Critical care research: scratching the surface

Introduction

Ethical practice is embedded into healthcare but application of principles including deontological (following moral obligations) or consequential (aim for good outcomes) is complex when faced with real life problems. Different views of ethics and intentions can be starker when considering research practice as both the researcher and ethical bodies try to balance what is 'good' or 'bad'. These broad terms are not particularly helpful as research can lead to unintended consequences, not only physical but psychological.

Various ethical theories are used in healthcare such as 'virtue ethics' which focus on moral evaluation; 'duty-based approaches' which focus on values and interests; and 'consequentialism' which recognises there is a consequence to our actions (Hester and Schonfeld 2012). Practitioners generally follow the key principles of ethical practice including autonomy, non-maleficence (do no harm), beneficence (do good), and justice but biomedical ethics has developed in complexity considering the importance of social value and scientific validity (Emanuel et al 2011). Hester and Schonfeld (2012) note that application of ethical principles is constantly evolving considering personal, professional, and organisational factors; this can be seen in critical care research as issues, such as age, gender, resource implications, clinical relevance, are highlighted. The distribution of healthcare and social justice is important when considering who receives care (Rhodes et al 2012) and was recently evident in the concern about lack of ventilators in the COVID-19 crisis (Thomas et al 2020).

Critical Care

Applying ethical principle to critical care research is a challenge. Patients may lack autonomy due to the illness; practitioners intend to be benevolent, and researchers may be trialling treatments that could cause harm, and ensuring any treatment is just and available to all is dependent on contextual economics. Critical care research involves people, whether patients, families, or staff, which adds a social and collaborative dimension as co-operation is needed to participate in the research (Emanuel et al 2011). The critical care setting is a stressful environment for patients and families with long term effects (Gawlytta et al 2020), therefore the benefits of undertaking research need to out-way the risks; however, what can be considered 'reasonable' may vary between different peoples' perception and values (Hester and Schonfeld 2012). Using staff as research subjects can appear more straightforward as they are autonomous, but the topic could be deeply personal, so researchers still need to consider the effects. There are already detailed ethical processes in different countries, including legal requirements and institutional processes, that must be completed before undertaking research – rather than becoming frustrated by these, critical care researchers need to embrace them.

Personal Data

Ethical issues currently influencing research include data protection and gender. The misuse of personal information has led to Europe strengthening data protection regulation (General Data Protection Regulation 2018). Personal data is described as any information relating to an individual person that could identify them, directly or indirectly, including name, but also characteristics such as age, gender, socio-economic, location, cultural, physical, or psychological. These are areas that

researchers generally collect under the title of 'demographics' within projects which are important considerations. For example, with COVID-19 the collection of this data has demonstrated that older people, those from ethnic minorities and with particular disease processes are more at risk of developing serious illness (Wang et al 2020). However, the challenge is to rationalise the reason for collecting this information so that personal data regulations are not infringed.

Critical care research routinely collects data on sex, i.e. male or female, but Heidari et al (2016) outlines the issue of gender which is more diverse and distinctive from sexual orientation. Sex, whether male or female, is decided by biological aspects (such as genitalia) but is recognised as more complex today (WHO 2020). Sex and gender are distinct but inter-related with gender being a complex sociocultural concept (Heidari et al 2016). Gender identities include a diverse range of descriptions with Facebook® recording more than 70 options. It may not be feasible to offer so many options in a research study but consideration whether sex (genetic), gender identity or sexual orientation is more relevant is needed. Where a person has/ or is transitioning genders there may be an overlap to consider. Deciding which is the most appropriate (or not) to the research question, and justifying its inclusion, needs careful consideration.

Another demographic that is often used is age related. Again, the focus is on biological age and for some research this is important, such as studies linking age to increased mortality (Wang et al 2020). However, is age always relevant to the research topic? Researchers in critical care should consider whether it is age or other aspects of experience (such as length of time working in critical care) that are more significant to the topic. Age can be used synonymously with other aspects of life which are not necessarily true. A person over 65 years of age may be assumed to be retired from work, younger people may be assumed to be more socially active, and the researcher needs to unpick these assumptions. There is a danger that age-related factors are clumped together assuming that all people within that bracket are acting in the same way; this can lead to a minority, who do not fit this, being marginalised. If researchers want to assess capacity to work or social engagement, then these need to be explicit questions within the research.

Conclusion

Researchers should always consider the limitations of their work and a deeper understanding of the assumptions within demographic data should be acknowledged where relevant. As a society we are becoming more aware and accepting of the diversity of persons, but this creates discord about how we record this in a manner that respects individuality but focuses on research aims. The issues of gender and age-related aspects is constantly changing as society develops and research needs to reflect the culture being explored. Research needs to be comparable across countries to make it internationally relevant and the use of guidelines (Heidari et al 2016) may enable a consistent and contemporary approach.

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