African Journal for Physical, Health Education, Recreation and Dance (AJPHERD)
Supplement 1 (September) 2013, pp. 117-129.

Health-related doctoral distance education programmes: A review of ethical scholarship considerations

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Abstract

Doctoral distance education programmes enable students to obtain their qualifications without leaving their homes, jobs or countries. There is an increasing demand for health-related distance education doctoral programmes. The objective of this paper is to consider ethical scholarship issues that might impact on the quality of these programmes, based on a literature review.Addressed ethical issues include the univeristy's admission procedures, the role and composition of institutional review boards for approving different types of health-related research, ethical aspects related to the research methodology, and to publications based on the research findings.The university's institutional review board members should ensure that doctoral research projects comply with ethical principles. Unless a university can guarantee the presence of a supervisor during research data collection and analysis, the authenticity of the findings might be questionable, as well as that of the doctoral degree awarded to the student.Health-related doctoral research might impact on the health and wellbeing of individuals and communities, and should thus comply with globally accepted ethical standards of such studies.Universities should encourage and support supervisors and students to publish research findings in academic journals and to present these at conferences. However, communities that participated in a research project are also entitled to this information.

Keywords: Distance education, doctoral programmes, ethics, scholarship.

***How to cite this article*:**
Ehlers, V.J. (2013). Health-related doctoral distance education programmes: A review of ethical scholarship considerations. *African Journal for Physical, Health Education, Recreation and Dance,* September (Supplement 1), 117-129.

Introduction

The University of Paris started awarding doctorates, mainly in the fields of theology, law and medicine, during the 12th century (Bourner, Bowden & Laing, 2001). Globally, doctoral degrees "license scholars to profess a discipline, to replenish communities of scholars within universities, and to advance disciplinary knowledge production" (Boud & Lee, 2009 cited in ASSAf, 2010). In South Africa, the Higher Education Qualifications Framework (HEQF) specifies that a doctoral graduate should "…demonstrate high level research capability and make a significant and original research contribution at the frontiers of a discipline or field … [and] must be able to supervise and evaluate the research of others in the area of specialisation concerned" (Department of Education, 2007 cited in ASSAf, 2010).

The term “research ethics”implies morally correct behaviour of persons (including students) conducting scientific investigations. In this document, postgraduate scholarship refers to the academic conduct and achievements of students conducting research to fulfil the requirements of doctoral programmes. Doctoral distance education programmes imply a geographical distance between the university campus offering the programme, and the student registered for his/her doctoral studies. Doctoral distance education programmes enable students to pursue part time studies without relocating from their homes, families, communities, jobs or countries to specific university campuses for the duration of their doctoral programme. Universities offering health-related doctoral distance education programmes might face ethical challenges exceeding those encountered by similar on-campus programmes, potentially impacting on students, supervisors, healthcare services, communities and countries. Unless universities examine the ethical scholarship issues pertaining to health-related doctoral distance education degrees, the ethics of offering such programmes, and awarding the doctoral degree, might be questionable and might impact on the health and wellbeing of persons in diverse communities and countries.

Burns and Grove (2001) state that conducting research, ethically start with the identification of the study topic and continue through the publication of the study. Based on this expectation, universities should be held accountable for ethical scholarship issues affecting all phases of each student’s research from registering a research topic till after the publication of the research results. Such accountability might be compounded by the geographic separation between doctoral distance education candidates and their academic supervisors, as indicated in this document, substantiated by a review of relevant literature.

Ethical scholarship issues of accepting doctoral distance education students’ registrations

All universities might encounter more challenges in accepting doctoral students in health-related fields than in other fields of study. However, distance education universities’ challenges might be exacerbated because of the potential geographic distances between the student and the supervisor. In addition to the usual admission criteria, ethical administrative criteria for registering distance education doctoral candidates should determine whether the candidate has access to the required resources such as laboratories. This could be problematic because no collaboration agreements might exist between the university and the healthcare services where the data should be collected, as would be the case for residential doctoral programmes. The student should be registered with a relevant health-related professional association (such as medical or nursing or health-professional associations/councils) and provide proof of his/her capability to express him/herself in English or in the language in which the thesis will be written.

If an appropriate joint supervisor and/or consultant cannot be appointed in the student's geographical area, then the university should consider sending a supervisor to the student's study area. Otherwise the ethical scholarship issues of leaving doctoral students totally on their own to collect data might become questionable. Supervisors might lack information about a specific country's legal, social, cultural and health-related issues, possibly resulting in unethical research being conducted by a doctoral student in a foreign country, and who should otherwise have been assisted locally by co-supervisors or consultants with the necessary expertise.

The role of universities' institutional review boards

Any university's institutional review board (IRB), or research ethics committee, plays a key role to ensure that research activities cause no harm to research participants, and that the researcher adheres to ethical guidelines throughout the entire research process despite geographic distances.

From a global perspective, the mandatory approval of research projects by ethical committees came into being after hazardous studies, with harmful consequences for study participants, were reported in the public domain, as indicated by the following projects.

- For 12 years, from 1933 to 1945, the Nazi regime's prisoners of war were subjected to sterilisation, euthanasia and unethical medical experiments such as being subjected to "high altitudes, freezing temperatures, malaria, spotted fever (tyhus), and untested drugs and operations, frequently without any form of anesthesia… Subjects were frequently killed during or sustained permanent physical, mental, and social damage as a result of the experiments" (Steinfels & Levine, 1976 cited in Burns & Grove, 2001). These unethical research activities became known during the Nuremberg Tribunals, conducted after World War II.
- The United States Public Health Service conducted a study lasting 40years on untreated syphilis in 400 black men (experimental group) and compared these findings with those obtained from 200 men without syphilis (control group).The study commenced during 1932, and although penicillin became available during the 1940s to treat syphilis effectively, no treatment was offered to the experimental group. Since 1937 papers were published on the Tuskegee Syphilis Study every 4-6 years. Forty years after commencing the study, a report in the Washington Star sparked a public outrage and the ethical questionable study was discontinued in 1972 (Brandt, 1978; Rothman, 1982; Levine, 1986 cited in Burns & Grove, 2001).
- For almost 20 years, a study on hepatitis was conducted at the Willowbrook Institution for Mentally Retarded Children, on Staten Island

in New York. Only children whose parent's consented to their participation in the hepatitis study were admitted to the institution. The children were "deliberately infected with the hepatitis virus, early subjects were fed extracts of stool from infected individuals and later subjects received injections of more purified virus preparations" (Levine, 1986 in Burns & Grove, 2001). Several papers were published. Although this study was cited as an example of an unethical research project in the New England Journal of Medicine during 1966, it continued until the 1970s.

- In the 1960s, suspensions containing live human liver cancer cells were injected into 22 patients admitted to the Jewish Chronic Disease Hospital, in order to test whether or not they would reject these cancer cells (Hershey & Miller, 1976 in Burns & Grove, 2001). Patients were injected without providing informed consent, and without any institutional review board's approval. This study could "cause the human subjects injury, disability, and even death" (Burns & Grove, 2001).
- Also internal organs were removed from the bodies of dead children without the consent of their parents at the Royal Liverpool Hospital in the United Kingdom (Redfern et al. in Macduff, McKie, Martindale, Rennie, West &Wilcock, 2007).

The Nuremberg Code guides ethical research decisions by emphasising participants' voluntary consent and withdrawal from studies, and their protection "… from physical and mental suffering, injury, disability and death… and the balance of benefits and risks in a study" (Burns & Grove, 2001). The Declaration of Helsinki, applicable to clinical research, distinguishes between therapeutic (providing experimental treatments to subjects) and non-therapeutic research to obtain knowledge that might not affect the participants but possibly future patients (Burns & Grove, 2001). IRBs should consider the relevant country's health-related research guidelines in addition to the university's research-related ethical standpoints, and should at least consider research subjects' rights to privacy, autonomy, confidentiality, fair treatment, protection from discomfort and harm and informed voluntary consent. These rights cannot be side-stepped by performing clinical studies on animals as they should also be treated humanely, in venues complying with the relevant country's animal welfare policies and laws.

The composition of institutional review boards and approval of research proposals

Every university should ensure that its IRB members comply with the relevant requirements. This might necessitate the ad hoc appointment of knowledgeable consultants from the country where the research will be conducted.IRB members

should include legal experts and representatives from the communities where the study will be conducted.

Initially the major task of IRBs was to approve or challenge ethical aspects of proposals for all research studies conducted by a university's staff members and students, but IRBs' tasks continue to increase in number and complexity.IRB members from different institutions and countries complain that they spend too much time on methodological issues of research proposals (Macduff et al., 2007), not only on ethical issues, but these two aspects are interrelated and interdependent. Methodological decisions influence the reliability and validity of a study's findings. Invalid and/or unreliable findings amount to wasting scarce resources and might result in potentially hazardous recommendations, influencing future health-related decisions and treatments.

A university's IRB might grant approval for specific studies, based on academic merits, but should require subsequent proof of approval of the healthcare authorities in the countries and communities where the projects will be conducted. The duration of such approval must be stipulated on the IRB's ethical clearance certificate. Distance education doctoral students should be required to re-apply for revised ethical clearance and submit annual progress reports, endorsed by the supervisor and by the joint supervisor/consultant from the student's geographic area, to the IRB. This will enable the IRB to intervene in the best interest of the study participants, if appropriate, and to discontinue studies such as the Tuskegee Syphilis Study.

Institutional review board (IRB) approval for individuals versus communities

Although IRB members should protect the usual ethical rights of research participants, health-related doctoral research might necessitate valuing the current and future rights of communities as outweighing individual participants' rights. This is the case where individuals suffer from rare conditions, or where diseases unknown in specific geographic locations (malaria, cholera, yellow fever, Congo or Lassa fever) might begin to appear and/or might fail to respond to usual treatments. Unless this type of research had been done, many people and communities might have continued to suffer and die from multi-drug resistant tuberculosis (MDR and XMDR TB). "Individuals who reap the benefits of medical knowledge without contributing through research participation are not only acting unfairly toward others, but acting against their own self-interest… once the moral obligation exists, the burden of proof shifts: instead of individuals needing good reasons to sign up for research studies, they should participate in research unless they have good reasons not to" (Rennie, 2011).

Community engagement studies

Research involving community engagement "… raises ethical considerations that go beyond individual-level protections to include those at the community level" (Shore et al., 2011). In these cases, IRBs might be unable to protect the rights and welfare of communities and might need to collaborate with the community groups concerned through community-institutional-university partnerships, thus ensuring that communities benefit from the research activities and are not harmed thereby.Shore et al.'s (2011) community engagement report indicated that the "… primary process benefits included giving communities a voice in determining which studies were conducted and ensuring that studies were relevant and feasible and they build community capacity. The primary process challenges were the time and resources needed to support the process".

Public health service versus public health research

It might be difficult to determine whether public health practitioners' surveillance data (to prevent and control diseases and evaluate the impact of public health programmes) should be classified as service or research functions. Defining the boundary between public health research and practice remains a critical challenge within the evolving field of public health ethics (MacQueen & Buehler, 2004).

In cases where doctoral students envisage studying public health practices, they might regard the university's IRB approval as being irrelevant. Usually public health practice "… involves the implementation of standard or proven strategies and interventions to protect the health of the community, while research seeks to discover new strategies and interventions to protect the health of the community" (Taylor & Johnson, 2007). Consequently, in cases where doctoral theses, and possibly other subsequent publications are envisaged, this should be regarded as being research and IRBs of universities and service institutions should consider the proposal, even if available community health statistics will be used retrospectively. The same principles should be applied by IRBs to population-based studies which strive "… to promote social justice through testing unproven interventions that hopefully provide knowledge on how to improve the health status of populations with health disparities or other social, political, or economic disadvantages that result in poor health" (Taylor & Johnson, 2007).

Conducting ethical research in developing countries

Extra caution should be exercised about ethics of distance education doctoral studies conducted in developing countries, often in the absence of university representatives, pertaining to the"reasonable availability of interventions that are proven to be useful during the course of research trials… and the quality of

informed consent" (Emanuel, Wendler, Killen & Grady, 2004). According to Emmanuel et al. (2004) illiterate, poor people who have limited access to healthcare services might find it difficult to comprehend the nature of scientific health-related research, and thus the validity of informed consent might be questionable, especially if there are cultural and language differences between research participants and researchers. Hazardous consequences could result if research participants, who receive experimental injections to prevent influenza, might perceive these injections as providing immunity against HIV. Local consultants and/or joint supervisors should help to prevent similar misunderstandings during all phases of a research study.

Emanuel et al. (2004) maintain that the benchmarks of ethical research in developing countries should comprise eight principles, namely: minimising exploitation; collaborative partnerships; social value; scientific validity; fair subject selection; favourable risk-benefit ratio; independent review and informed consent.These eight issues should be considered by IRBs in registering a research topic until after the publication of research findings based on distance education doctoral students' theses.

Incentives for participants/respondents

IRBs should scrutinise the use of incentives to research participants. The aim of research incentives should be to ensure that recipients do not incur financial or other losses through their research participation. Offering research participants information pamphlets, bus or meal tickets or soft drinks need not cause ethical concerns. More controversial, are incentives for research participation: cash payments, prizes or other material benefits provided for the purpose of encouraging recipients to agree to participate in research (recruitment) or to continue their participation until the study is completed (retention) (London, Borasky, Bhan & Ethics Working Group of the HIV Prevention Trials Network, 2012). IRBs need to consider the pros and cons of paying large incentives to research participants within the context of the specific communities where the study will be conducted. "Whether paying people to engage in pro-health behaviors represents an effective, sustainable, and cost-effective tool for promoting individual and public health is an important research question" (London et al., 2012).

Ethical consideration

In distance education programmes, supervisors and examiners might only have access to the contents of the thesis. Consequently, the presence of a joint supervisor/consultant during the data collection process could enhance the credibility and accuracy of the methodology adopted throughout the study.

Sampling

Obtaining a truly random sample, even if a sampling frame (census) is available, might be impossible in many studies. Research reports should provide honest accounts about factors that might have impacted on the randomness of the sample.Such factors should include the management of selected persons who refuse to participate and the implementation of inclusion and exclusion criteria during the data collection phase.In cases where vulnerable populations are studied, such as children, prisoners, hospitalised patients or mentally handicapped persons, knowledgeable gate keepers (rather than the students) might be requested to select the potential research participants, thereby safeguarding the best interest of the participants.

Data collection

Where research assistants are used to collect data, inter-rater reliability coefficients must be scrutinised and the completed research instruments (questionnaires) should be scrutinised by the student and at least one additional designated person, such as a co-supervisor/consultant throughout the data collection phase. To ensure that the recorded data reflect a specific participant's views, not those of the student nor the data collector(s), the co- supervisor and the student should check the recorded responses on a few completed instruments by asking random questions from a specific participant and cross-checking his/her answers against those recorded.

Locally recruited research assistants should be able to communicate fluently in the local language(s), facilitating data collection and recording.However, anonymity and confidentiality challenges might arise if locally recruited research assistants conduct interviews with persons known to them. If sensitive issues (like HIV/AIDS, sexually transmitted infections, practices of preventing mother-to-child transmission of HIV) are addressed, research assistants from different geographical areas should be employed.

Research assistants should be trained and supervised and should never be left to collect data without supervision. The doctoral student, and preferably the co-supervisor/consultant, should be available throughout the data collection process, not only to supervise the data collectors, but also to provide professional assistance to any participant who might need such assistance. This applies to clinical and non-clinical studies as well. Even if interviews are conducted about the home-based management of malaria, a research participant might become emotionally upset if one of her children died from malaria. Appropriate assistance and/or referrals should be provided by the student, and such events should be recorded and reported to the IRB, and verified by the co-supervisor/consultant.

Once data collection has been completed at a specific site, such as a hospital, school or clinic, the manager should be requested to sign a document indicating the duration of data collection and whether or not any research participant experienced any ill effects as a result of interactions with the data collectors and/or student. Such a document should be included as an annexure to the student's thesis. Unless a university can guarantee that the doctoral distance education student actually collected the data, as described in the thesis, the value of the degree could be questioned. Merely requiring a student to sign a declaration to this effect shifts the ethical responsibility from the university to the student, which is unacceptable because the university awards the doctoral degree, not the student. If the university's representative(s) cannot be present during data collection, then the university might award the degree, based on fictitious, manipulated, fabricated or inflated data, with potential harmful consequences for the student, university, communities and even countries concerned.

Universities cannot claim authenticity of doctoral distance education students' findings, based merely on signed declarations. Although prestigious professional journals require authors to sign declarations, articles have been published that were based on fraudulent findings, as indicated by the following reports:

- Dr Robert Slutsky, a heart specialist from the University of California, San Diego, published 161 articles over a period of six years, amounting to one article every ten days. He resigned in 1986 when 60 of his articles were judged by academic peers to be "questionable" and 18 other articles "… were found to be fraudulent and have retraction notices" (Friedmann, 1990; Henderson, 1990; cited in Burns & Grove, 2001).
- A psychologist from the University of Pittsburgh, Stephen Breuning, used $300 000 to conduct fraudulent research on mentally retarded children. In 1988, he was criminally charged with research fraud, pleaded guilty, was fined $20 000 and sentenced to up to 10 years in prison (Burns & Grove, 2001).
- Jan HendrikSchön, an award-winning physicist, published one paper almost every eight days during 2001. Investigations revealed that Schön had "fabricated data in 17 papers that he published between 1998 and 2001 in such journals as *Science*, *Nature*, and *Applied Physics Letters*" (Hudson-Jones, 2003:248).

Data storage, analysis and reporting

Anonymity and confidentiality of data storage must be ensured by keeping hard copies locked up and securing electronic data with passwords on computers to which only the student, data analyst and supervisor(s) can have access. Emerging

technology may help address threats by enhancing the privacy and security of data in transmission and storage (Myers, Frieden, Bherwani & Henning, 2008).

Even if data had been collected according to ethical standards, errors might occur during data entry, analysis and interpretation, especially if the doctoral distance education student engages in these activities without any inputs from the university or supervisor(s) concerned. Evidence should be provided that two persons entered quantitative data independently and that discrepancies were addressed. The practice of handing raw data to a statistician and transferring the statistician's data analyses and interpretations to the doctoral thesis should be questioned. Unless supervisor(s) have access to the student's raw data, electronic data records and analyses, and to the statistician, the validity and reliability of such data might be suspect.

Including independent coders' qualitative data analyses in a thesis, without active involvement of the student and supervisor(s), and without proof of following steps to ensure trustworthiness, might be regarded as being questionable research reporting. Unless the supervisor(s) became familiar with the raw data, the appropriateness of the data analyses cannot be evaluated.

The discussion of the research findings should be done honestly and contrasted with relevant literature reporting similar and different results. The conclusions of the study should be based on the actual research findings, including unexpected findings. Every recommendation should be based on a conclusion, and indicate ways in which healthcare issues could be addressed. Effective implementation of recommendations, based on relevant research findings, could help to make people and communities "more resilient to social and ecological factors impacting their health" (Stephen & Daibes 2010).

Ethical scholarship considerations pertaining to distance education health-related doctoral publications

The quality of adoctoral thesis determines whether the examiners will pass the thesis and the university will award the doctoral degree. Even well written theses, receiving academic accolades, might be fraudulent. A doctoral degree should be awarded only if a university can guarantee that the student actually collected the data, obtained the reported results and wrote the thesis (even if the student is from a foreign country). Efforts should be made to ensure that the student did not commit plagiarism, translate the thesis from another language, use a 'ghost author' to write the thesis, fabricate or falsify or modify research findings, or acted unethically in any manner whatsoever.

Doctoral theses are expected to make unique and original contributions to knowledge. Such unique contributions should be made accessible to the wider

scientific community, through articles published in academic journals and through conference presentations. The university and the supervisor(s) remain accountable for such publications and presentations, explaining why the supervisor(s) might be co-authors and co-presenters. However, supervisors should only be co-authors if they can defend and validate the study's findings. A creative process is required to rewrite and restructure the relevant contents of the thesis to form a new product which could get published in an accredited journal, ideally with 0% 'non original' contents, based on a 'turn-it-in' report.

Conference papers are essential to introduce the doctoral graduate to other researchers, opinion leaders and journal editors. The supervisor(s) should form a 'bridge' between the student and other academics at conferences and during negotiations with journal editors and reviewers.

Communities involved in the study are entitled to feedback but they might not read scientific journals. Feedback should be provided in the local newspapers, relevant magazines and/or radio broadcasts, after publication in an accredited journal with permission from the university, journal editor and authorities who granted permission to collect data.Recommendations should be made to relevant institutions and persons at community level, preferably during public meetings so that the feedback will be available to the study'sactual participants. Copies of a published article and summaries of the research report should be available during these sessions. Copies of the thesis should be supplied to the relevant healthcare authorities.The student's supervisor or co-supervisor/consultant should be present during these information sessions to support the student and to validate the distant university's research involvement in the project, and to emphasise that "… the process of translating research results into health improvements is complex, incremental, and haphazard" (Emanuel et al., 2004).

Recommendations

IRBs fulfil important gatekeeping functions to safeguard a university's reputation, the standard of research conducted by a university's staff members and students, and the wellbeing of research participants. These functions might be compounded or compromised in the case of doctoral distance education programmes. Consequently, universities offering such programmes should enable its current and future IRB members to develop their capacities to fulfil these demanding and time-consuming tasks effectively.

If a university cannot ensure a supervisor/consultant's presence during the data collection and analysis phases of a student's research project, then the student should rather register with another university, capable of validating the authenticity of these research processes.

Universities should encourage supervisors and students to publish reports based on doctoral theses in academic journals and at conferences. However, they should also share their findings with the relevant communities and healthcare authorities in order to meet the ethical scholarship expectations of doctoral distance education programmes.

Conclusion

Universities should address ethical scholarship issues of awarding doctoral degrees to distance education students. Unless universities can validate students' research findings, and the authenticity of the thesis, the ethics of awarding a doctoral degree might be questionable.

Ethical scholarship requires universities only to register doctoral distance education students if the university concerned can supply support and guidance to the student throughout his/her study, including the data collection and analysis phases and if the university's IRB can guarantee the safety and wellbeing of the research participants.

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