

Original Article

Publication and Dissemination of Health Research Findings: Strengthening Post-Trial Benefit

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Abstract

There is a large discrepancy between the number of research studies being conducted in the Sudan and the number of scientific publications of research outcomes. This study explores the trends of Sudanese researchers toward publication and dissemination of research findings and post-trial benefit to the communities in which these research studies are conducted. We surveyed 95 researchers from different research and academic institutions and found that only 51% of researchers publish their research work in local and international professional journals. Approximately 20% of surveyed researchers provide feedback to the served communities and some of researchers (22.1%) make the tested interventions available to the communities. There is little structured support for dissemination of research findings in the Sudan, and research and academic institutions are generally left to create their own means of publication.

Key words: Publication, Dissemination, Research findings, Post-trial benefit, Sudan

Introduction

At the beginning of the twentieth century, health research in the Sudan was developed primarily as a function of colonial British Administration. In 1903, the Wellcome Research Laboratories (WRL) established the first health research laboratory in the country. There were no means for publications and dissemination of research findings at that time in Sudan⁽¹⁾.

It is a professional obligation in reputable institutes to publish the research findings in a recognizable journal to enable colleagues and other interested parties, including the community, to observe the research work⁽²⁾. Publications and dissemination of research findings are important to make knowledge gained through research publicly available and generalizable⁽³⁻⁵⁾. Publicly available data from evaluation and assessment studies can be used in evidence-based medicine and decision-making process⁽⁶⁻⁸⁾. Further, the risks or burdens that study subjects accept through participation is justified,

ethically, by the knowledge gained through research. If research is not published, however, knowledge cannot be gained and the entire premise of the research becomes ethically suspect. The Sudan Medical Association has recognized the importance of publishing research findings since its inception and, in 1953, launched the Sudan Medical Journal as an official means of scientific communication⁽¹⁾.

Health research has in recent years become a subject of increased policy attention in Sudan. In 1998 the Federal Ministry of Health (FMOH) established a research directorate within its structure and institutionalized a national health research system (HRS)⁽⁹⁾. Since then much progress has been achieved, including the establishment of a national health research policy, health research priorities setting, and other milestones^(10,11). In 2001 a new Ministry for Science and Technology was created within the country's political system to be responsible for

research, including health research in other institutions outside the FMOH. The upsurge in health research activities was not accompanied by an increase in the number of scientific journals and other periodicals published in the Sudan. This study was designed to measure the rate of publication and dissemination of research findings and also to identify factors contributing to why research is not published. The main objectives of this work are to explore the experiences and attitudes of Sudanese researchers regarding publication and dissemination, identify the obstacles and constraints of publication, and to determine to what extent communities get feedback and benefit from research.

Methods

This study recruited researchers both from local institutions lists and from the publicly available database of health researchers constructed by the Research Directorate, FMOH. We consider a person a researcher if he/she had conducted at least two health research studies in the last 5 years. Since its construction in 1999, the FMOH database has not been updated. We assumed that researchers who began employment after 1999 would not be included in database. We covered this gap by reviewing the employee list in each institution and adding names not included in the original database. We found that only 153 persons were eligible and fulfill the inclusion criteria. The selected 153 researchers were invited to participate in this study by telephone, e-mail and direct in-person contact. Study participants were asked to complete a self-administered, structured questionnaire. The questionnaire consisted of yes/no questions, multiple choice and open-ended questions. It was written in English, as these professionals are fluent. In order to ensure the quality of the instrument, it was pre-tested in a group of researchers other than the study participants. Data collectors received

training on the study protocol and data collection instrument.

Data were entered and analyzed using SPSS software program. Descriptive statistics were computed for all variables within each study variable, and frequencies were calculated for continuous and dichotomous variables, respectively. Open-ended questions were analyzed for recurrent themes using content analysis.

Ethical considerations

This study posed no physical risks to participants, though an interview of 30 minutes might have been inconvenient for some participants. It was an anonymous study, thus, neither the participant's name nor his institution is used in any of study materials. Personal identifiers were eliminated and each participant was assigned a unique identification number. Collected data were secured in a password protected computer to which only research team members had access. Consent was obtained from each participant prior to the commencement of the study. This study was funded by Fogarty International Center, and conducted in collaboration with Johns Hopkins, Bloomberg School of Public Health. It was initially approved by the Committee on Human Research at JHBSPH and by the Sudan National Ethical Review Committee at the Federal Ministry of Health.

Results

From the 153 who were eligible to participate in this study 37 initially refused to participate. One hundred sixteen researchers agreed to participate. We attempted to interview researchers in-person, though a self-administered technique was used if requested by respondents. 53 were interviewed by our interviewers and 63 requested to complete the questionnaire themselves. 21 did not return the questionnaire. Only 95 responded to the questionnaire with response rate of 81.9%. Both groups responded to all questions. 63(66.3%) were

males and 32(33.7%) were females working in 10 different research institutions, academic schools and teaching hospitals. 31(32.6%) were scientists, 29(30.5%) were physicians with various specialties, 11(11.6%) were dentists, 7(7.4%) were pharmacists, while other categories (nutritionists, lab technicians, etc...) totaled 17(17.9%). Respondents listed their job title as professor (12.6%), associate professor (21.1%), assistant professor (27.4%), and lecturer (12.6%). Many of them 38(40%) had spent more than ten years in the current job.

Respondents were asked about their involvement with health research. 42(44.2%) have conducted, as principal investigator, more than 5 research studies in their career, and 33(34.7%) have been principal investigator in more than 5 research studies in the last 5 years. 76(80.8%) researchers conduct their research based on academic interest, 49(51.6%) said their academic interest falls within the national health priorities, 25(26.3%) are confined to their institutions' interest, and 32(33.7%) chose research topics based on available funding if it meets their academic interest.

Concerning publication and dissemination of research findings, 40(42.1%) respondents always publish their research works and 11(11.57%) have published some of their research. In total, 51(53.68%) respondents have published all or part of their research, and 44(46.32%) have never published their research. Among those who have published research findings, 5(9.80%) use solely the local journals, 14(27.45%) publish in international journals, and 32(62.7%) submit their research to both local and international journals. Among the surveyed males 36(57.1%) used to publish their research work, while 15(46.8%) of the females did so. The study revealed that 20(39.21%) of those who publish their work were scientists, followed by physicians 18(35.29%), dentists 6(11.76%), and pharmacists 2(3.92%) (Table 1). 12(100%) professors and 19(95%) associate professors publish their study findings. The study included 26 assistant professors, only half of whom claim to publish their works (Table 2).

The study revealed that 44(46.32%) respondents do not publish their work. They were asked to explain this behaviour in an open-ended question (Table 3).

Table 1: Publication trend according to profession

Profession	Publishing (total 51)		Do not publish (total 44)	
	Frequency	Percentage	Frequency	Percentage
Scientists	20	64.5%	11	35.5%
Physicians	18	66.7%	09	33.3%
Dentists	06	54.5%	05	45.5%
Pharmacists	02	28.6%	05	71.4%
Other	05	29.4%	12	70.6%
No response	0	0%	02	100%

Table 2: Publication trend according to academic title

Academic title	Publishing (total 51)		Do not publish (total 44)	
	Frequency	Percentage	Frequency	Percentage
Professor	12	100%	0	0%
Associate professor.	19	95%	01	5%
Assistant professor	13	50%	13	50%
Lecturer	05	35.7%	09	64.3%
Other	02	9.5%	19	90.5%
No response	0	0	02	100%
Total	51		44	

Table 3: Reasons for not publishing

Response	Frequency	Percent
We do not have enough budgets	9	21.42%
There are no referee scientific journals in the country	8	19.04%
We prefer verbal presentation	7	16.66%
We did not find help to write papers	7	16.66%
Have no time to write	6	14.2%
Poor outcome	4	9.52%
Sudanese are not good readers	1	2.38%
Total	42	100%

Only 15(15.79%) respondents state that they have access to the work of other Sudanese researchers. They have accessed these works in both local and international journals. We have found that 32(33.68%) respondents generally disseminate the research study findings to the community in which they conducted their studies, 15(15.79%) disseminate study findings sometimes, and 48(50.53%) never go back to the community. Only 21(22.11%) researchers or their institutions or sponsors make the tested material available to the community if it was proven to be effective.

Discussion

Approximately half of surveyed researchers did not attempt to publish their work. That such a small proportion of researchers actually publish their work is of significant concern. Publishing research findings is a critical part of the research process⁽¹²⁾. Indeed not publishing research findings at all will cause them to remain simply like a class exercise. Charging the authors some fees for publication is required by some international medical journals making them inaccessible for researchers from developing countries. An alternative may be free journals. They are highly demanded and receive a great number of requests for publication. Publication in such journals could be done after a long waiting time and may cause the data obsolete. Only 5(9.80%) of those who publish their work do this in a local scientific journals versus 47(92.16%) who use international journals. Some respondents were concerned about unavailability of referee

scientific journals in the country. As a matter of fact there are some scientific journals in the country. Unfortunately they are unstable and many rapidly die after the first volume^(13,14).

Publishing solely in international journals demonstrates that a significant amount of research work done in the country is published abroad. Eighty four percent of Sudanese researchers do not access the work done by their colleagues and consequently they do not benefit from them. It is of concern that so few Sudanese researchers report having access to published research.

More than two third of the surveyed researchers do not disseminate research findings to the communities in which they conducted their studies. Researchers and their institutions have responsibility to disseminate research findings to the community that was served in research. It is a core principle of community-based participatory research⁽²⁾. Only 22.1% of researchers or their institutions make the tested intervention available to the community if proven effective. This might be because most of research has been taken in academic institutions for academic purposes and did not address the health priorities. There is no link between researchers and academic institutions from one side and policy makers and decision-making process from the other side^(15,16). Researchers and their institutions behave like many other researchers in developing countries. They may inflict communities to the risk and harm of research studies without disseminating the knowledge and

without compensatory benefits⁽¹⁷⁾. The last behaviour could be explained by the paternalistic nature of health research and health services in general^(18,19). Research conducted in the Sudan depends heavily, if not entirely, on available funds. Funded research is directed by the sponsors, many of whom are international agencies. The continuation of both the paternalistic approach and adherence to research sponsors might increase the risk of exploitation of research participants if research doesn't meet the actual needs of the communities⁽²⁰⁾.

The study recognizes several challenges in publishing and disseminating research findings in our country. Some difficulties are due to the scarce number of professional journals. The already existing journals suffer very much from financial difficulties and irregularity. Poor skills in scientific writing, as mentioned by researchers themselves, add further constraints on the ability to publish. Finally, we think researchers do not exhibit sufficient responsibility towards the community. Failure to communicate post-trial knowledge and technology to local communities may raise ethical issues about using poor communities as simply as a supply ground for testing materials.

It is recommended that research institutions, universities and scientific associations and societies create their own publications. Activation of the already existing journals like Sudan Medical Journal, Juba Medical Journal and others will enrich the scientific publications and help researchers to find accessible local journals for their work. Availability of such journals in affordable price helps others (readers) who have no otherwise access to international publications. Capacity building and training in research methodology and scientific writing is also critical. Research institutions, universities and scientific associations and societies are encouraged to strengthen their link

with policy-makers in order to address, through their research, the real needs and health priorities of the local communities. Equal and transparent dissemination of knowledge and benefit to the communities will also improve the integrity of research conducted in Sudan.

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References

1. Bayoumi. *The History of Health Services in Sudan*. 1979. Nairobi.
2. Steven S. Coughlin, Tom L. Beauchamp. *Ethics and Epidemiology*, 1st ed. New York Oxford: Oxford University Press 1996.
3. WHO. *Investing in health research and development: report of the ad hoc Committee on Health Research Relating to Future Intervention Options*. Geneva, World Health Organization (unpublished document TDR/Gen/96.1) 1006.
4. Rona Hirschberg, John La Montagne and Anthony S. Fauci. Biomedical Research – An Integral Component of National Security. *N Engl J Med*. May 20, 2004. 350(21). 2119-2121.
5. Barry Bloom. *Enhancing Global Health Research*. Presentation to: International Conference on Health Research for Development; Bangkok, Thailand; 10-13 October 2000. Conference Report. P 114-23.
6. Don C. Des Jarlais, Cynthia Lyles, Nicole Crepaz, and the TREND Group. Improving the Reporting Quality of Nonrandomized

- Evaluations of Behavioral and Public Health Interventions: The TREND Statement. *American Journal of Public Health*; March 2004, 94(3); 361-366
7. Tikki Pang, Ritu Sadana, Steven Hanney, Zulfiqar A. Bhutta, Adnan A. Hyder, and Jonathon Simon. Knowledge for better health – a conceptual framework and foundation for health research systems. *Bulletin of the World Health Organization* 2003; 81 (11). 815-20.
 8. *Health research-essential link to equity in development*. Report of Commission of Health Research for Development. New York: Oxford University Press; 1990.
 9. WHO. *East Mediterranean Regional Office. Report 2000*. Available from: <http://www.who.int.net>. Accessed on 13 August 2006.
 10. Research Directorate. FMOH. *The National Health Research Policy*. Khartoum: July 1999.
 11. Research Directorate, Federal Ministry of Health. *National List of Health Research Priorities*: Khartoum; Sudan 2000.
 12. M Buxton, S Hanney. How can payback from health services research be assessed? *Journal of Health Services Research and Policy* 1996; 1: 25-43.
 13. Ahmed Mohamed Elhassan, Mohammed Ali Awad Alkareem, A/Kareem Mohammed Salih, Alrasheed M A/Alla, Iman A. Musatafa and Dya Eldin Mohammed Elsayed. *Situation Analysis of Health Research in Sudan*, 2004. Unpublished report.
 14. Awad Mohamed Ahmed. Sudanese Journal of Public Health: Comments on the First Issue. *Sudanese Journal of Public Health*. April 2006; Volume (1): 2. p 96.
 15. Dya Eldin Mohammed Elsayed. Strengthen Health Research: *The Research*, RD-FMOH: Issue No: 15, December 2003.
 16. Dya Eldin Mohammed Elsayed. Health Research Priorities: lessons learned and obstacles of implementation. *The Research*, RD-FMOH: Issue No: 14, September. 2003.
 17. Franklin G. Miller. Unnecessary Use of Placebo Controls: the Case of Asthma Clinical Trials. *Arch Intern Med*. Aug 12/26, 2002; Vol (162): 1673-1677.
 18. Doyal L. Informed consent – a response to resent correspondence. *BMJ*, 1998; (316): 1000-01.
 19. Warnock M. Informed consent-a publisher's duty. *BMJ*, 1998; (316): 1002-03.
 20. Ezekiel J. Emanuel, David Wendler, Jack Killen, and Christine Grady. What Makes Research in Developing Countries Ethical? The Benchmarks of Ethical Research. *Journal of Infectious Diseases*. 1 March 2004; (189). 930-937.