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Data Sharing in Nursing Research: Advantages and Challenges

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La documentation en sciences infirmières s'est peu attachée à divulguer l'information entre cliniciens-chercheurs. Le présent article relève la pertinence pour les chercheurs en sciences infirmières de faire connaître l'information et examine le genre d'information qui peut être divulgué. Les avantages, les inconvénients et les questions concernant le fait de faire circuler l'information sont abordés et des recommandations pour un plus grand partage de l'information entre les enquêteurs sont avancées. Les auteurs estiment qu'il est préférable de faire connaître les conclusions des recherches et que les chercheurs en sciences infirmières devraient viser à déposer dans des archives accessibles les résultats de projets de recherche en sciences infirmières financés par le public. Ils considèrent également que les chercheurs en sciences infirmières doivent intégrer des projets de partage des connaissances dans leurs programmes de recherche et demander les infrastructures nécessaires pour ce faire.

The sharing of data between investigators has received little attention in the nursing literature. Among other advantages, data sharing reinforces open scientific inquiry, encourages the development of multiple perspectives, and reduces respondent burden. However, ownership and control of the shared data, preservation of respondents' anonymity, and the costs of data sharing are among the issues that need to be addressed in agreements and contracts involving primary investigators, secondary investigators, and data repositories. The original researcher must spend time and energy to make data sharing possible. It is only when such efforts are acknowledged and rewarded that data sharing is likely to become a norm in the nursing profession. The authors argue that research data should be shared and nurse researchers should seek to have data from all publicly funded projects deposited in accessible data repositories. Nurse researchers need to incorporate plans for data sharing into their research programs and press for the infrastructures required to enable data sharing.

Data sharing as a topic of interest to nurse researchers has received little attention in the literature, with only a handful of papers available (Aaronson, 1990; Gleit & Graham, 1989; Jacobson, Hamilton & Galloway, 1993; McArt & McDougal, 1985). On the simplest level, the term data sharing means the sharing of data between investigators, however it is a complex concept. In an analysis of the literature Hilgartner and Brandt-Rauf (1994) describe at least four perspectives from which data sharing has been examined: the ethics of data sharing and ownership, scientific findings as communal property, intellectual property rights, and university-industry relations (p. 356). In the nursing literature, data sharing is generally addressed, if addressed at all, within the context of secondary analysis, which has also received scant attention. It has been suggested that this lack of attention to data sharing and secondary analysis reflects a norm within the profession in which greater value is assigned to primary data collection (Herron, 1989; McArt & McDougal, 1985; Thorne,

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1994). If this is indeed the case, it is not surprising that data sharing, on which secondary analyses are often predicated, has received little attention. We anticipate that in the future, secondary analysis will assume a higher profile in nursing research and that nursing will revise its norms and values to reflect the importance of both primary and secondary approaches to data analysis and the sharing of data between investigators.

Since the early 1960s, data sharing has been an issue in the social sciences (Hedrick, 1988) where there is a growing awareness of, and mandate for, the sharing of research data (Fienberg, Martin & Straf, 1985; Sieber, 1991b). In fact, some funding agencies such as the National Science Foundation (NSF) in the United States and the Social Sciences and Humanities Research Council (SSHRC) of Canada have established policies requiring investigators to deposit their data in a public archive within a designated time period after completion of their studies. Given the current social, political and economic climate, it is reasonable to expect that in the future, nurse researchers will also be required to make their databases broadly available to secondary investigators. Aaronson (1990) specifically addressed the need for data sharing and the development of a repository of nursing data. We contend that the data from all publicly funded nursing research projects should be in controlled and publicly accessible data repositories.

The purpose of the current paper is to explore the relevance of data sharing for nursing research and to examine courses of action that would facilitate data sharing within the discipline. More specifically, we discuss the kinds of data that ought to be shared and some of the advantages, issues, and challenges of data sharing. In the final section, we make recommendations to encourage more activity in this area. Without a clear understanding of the potential advantages and the issues related to data sharing, it is unlikely that nurse researchers will begin to integrate plans for it into their research programs or press for the infrastructure required to enable data sharing.

For the purposes of this paper, data sharing is broadly defined to include a broad range of sharing, from the willingness of a primary investigator to provide a copy of the data to another investigator, to the placement of data in formal repositories where they become part of the public domain. Although data sharing in its broadest conceptualization includes the sharing of institutional data such as those generated by health information systems and minimum data sets, the issues involved in sharing such data are somewhat different and have thus been excluded from our discussion. In addition, although the authors encourage the establishment and maintenance of data repositories for nursing research, we will not discuss their structures and functions here. For purposes of the current paper, the literature cited from January 1983 to December 1994 was reviewed using the CINHAL, SSCI and MEDLINE bibliographic databases. Search terms included *data sharing, secondary data analysis, data repositories,* and *data archives.* In addition, the reference lists of each of the retrieved articles were manually searched to ensure that important materials were not missed.

What Data Ought to be Shared?

When considering the kinds of data which ought to be shared, most often researchers think of survey data. This is probably a result of the considerable work done in the area of data sharing in the social sciences where surveys are used extensively. We contend that it is counterproductive for nursing to limit itself to this narrow notion of what constitutes shareable data. Nurse researchers need to consider sharing a wide range of data including field notes, interview data, audio/video tapes, photographs, and research diaries. Technology is rapidly making it possible to efficiently create, store, and retrieve various other forms of data and to handle the large text-form data sets that often characterize qualitative research (White, 1991; Wolfe, Gephart & Johnson, 1993). While little has been written about the preservation and sharing of data generated from qualitative nursing research White (1991), for example, has outlined some of the issues inherent in sharing qualitative anthropological data. The qualitative data sets generated by nurse researchers offer a rich source of data which need to be considered in determining the kinds of data that ought to be shared within the discipline.

Advantages of Data Sharing

The advantages of secondary analysis and data sharing have been enumerated by several authors, mostly in the non-nursing literature (Aaronson, 1990; Abel & Sherman, 1991; Card & Peterson, 1991; Fienberg, 1994; Fienberg, Martin & Straf, 1985; Gleit & Graham, 1989; Hedrick, 1985, 1988; Jacobson, Hamilton & Galloway, 1993; Lobo, 1986; McArt & McDougal, 1985; Sieber, 1989, 1991a, 1991b). These ideas are succinctly and accurately summarized by Hedrick (1985, 1988). The current paper focuses on the advantages identified by Hedrick (1988) that have the most relevance for nursing research: reinforcement of open scientific inquiry; verification, refutation, or refinement of original results; exploration of new questions; development of multiple perspectives; reduction of respondent burden; and development of knowledge about research and analytic techniques.

Reinforcement of open scientific inquiry. It is generally accepted that open scientific inquiry is an ethos in nursing. A climate of openness enables science to be self-correcting and cumulative and to benefit from multiple perspectives (Sieber, 1991a). Within nursing, data sharing permits extension of the work of primary nurse investigators as other nurse researchers use the available data in various ways in their projects. Data sharing allows gaps in theoretical knowledge, identified either by the primary or secondary investigator, to be addressed. It also affords opportunities for theory building and theory testing, which may not otherwise be available. However, in an environment where promotion, tenure, and publication are important motivating forces, nurse researchers may be reluctant, as are many social scientists (Ceci, 1988; Ceci & Walker, 1983; Sieber, 1991a), to share their data freely. Nevertheless, there is a growing recognition that individual research efforts are not as fruitful in developing nursing knowledge as the collaborative endeavours of several nurse researchers working in the same area of interest. The challenge for nursing is to demonstrate that such academic rewards as tenure and publication are better promoted through sharing rather than amassing and storing data.

Verification, refutation, or refinement of original results. In a climate of openness, data sharing enhances the honest reporting of findings. Scientific fraud has been rare in nursing research (Hawley & Jeffers, 1992). However, it is probably naive to think that the profession is not vulnerable to scientific misconduct similar to the recently reported misrepresentation of data in a breast cancer study or that described by Broad and Wade (1982) and addressed in recent issues of *Knowledge: Creation, Diffusion, Utilization* (LaFollet, 1992) and *Scholarly Publishing* (Carroll, Montagnes, & Shipton, 1993). Secondary analyses, which are made possible by data sharing, serve to improve the accuracy of findings, provide for the refinement and/or confirmation of results, and for the identification of problematic conclusions. Furthermore, different or additional findings may result when secondary investigators employ analytical and statistical techniques other than those used by or available to the original investigators.

Explorations of new questions. Data sharing allows questions to be posed and theories to be tested in new and different ways that otherwise would not be possible. As yet, nursing does not have a tradition of fully exploiting the data collected through research because of limitations in resources including time, money, personnel, expertise, and the constraints of individual research programs. This is particularly true of qualitative research, which often produces far more data than can be managed in any one study or by any one investigator. Furthermore, there may be several legitimate and supportable interpretations of the same textual data, which would be lost to the discipline if secondary analysis is not conducted by the primary investigator or another researcher. In both qualitative and quantitative analyses, nurse researchers need to debate the extent to which the assumptions underlying the secondary analysis must be consistent with those of the original study and the implications that inconsistencies may have for generating valid findings. Once the inherent scholarly, ethical, and technical issues related to data sharing have been reasonably addressed, it will likely be recognized that both qualitative and quantitative data sets are appropriate for sharing, and that such sharing generates new and different theoretical directions.

Encouragement of multiple perspectives. Data sharing enables the exploration of concepts from new perspectives, raising different questions and using different methods. It allows an exchange of data with other disciplines and permits each to explore similar concepts from their own perspective. Further, data sharing facilitates interdisciplinary research endeavours when the various perspectives and methods of several disciplines are brought to bear upon the same concept. It allows researchers to aggregate findings, pursue different aspects of a particular question, and develop more complete theories.

Reduction of respondent burden. The cumulative demands of time and physical and emotional energy that nurse researchers create for respondents have not received much attention in the nursing literature. Respondent burden is of particular importance in cases where there are few respondents exhibiting a particular phenomenon or where the health of the individual is such that repeated data collection is not feasible or ethical. By sharing data, nurse researchers make available data regarding how people, and in particular people comprising vulnerable populations, experience and manage their health. As a result, respondent burden is reduced and rare data sets are more completely utilized.

A related advantage of data sharing not addressed by Hedrick (1988) but highlighted by many authors is the *economy of resources* that can be realized in terms of people, time, money, and other assets. With research funding sources increasingly under pressure to downsize, researchers are likely to have increasing difficulty obtaining funds for major projects. Funding agencies can be expected to demand more efficiency and accountability in the use of databases that are expensive to collect and often result in considerable respondent burden.

Development of knowledge about research and analytic techniques. Nursing students are frequently exposed to research methods and statistics as separate subjects. The use of actual data sets, made possible by the sharing of data, is an effective way to encourage the integration of theory and knowledge of research methods and statistics, and needs to be encouraged by nurse educators. The use of shared data sets enables graduate students to participate in the research process without having to engage in costly and time intensive data collection (Abel and Sherman, 1991; Gooding, 1988). While data sets from other disciplines may serve the necessary educational purposes, the use of data sets generated by nurse researchers in response to the kinds of questions that nurses ask will enable nursing graduate students to learn in the tradition of their discipline. Sieber and Trumbo (1991) suggest that one of the advantages of using a data set generated by someone other than the teacher of the particular research course is that it facilitates learning without the constraints that might be imposed by the presence of the researcher, whose data are in all likelihood, imperfect in some way.

Issues and Challenges

Data sharing holds great promise for knowledge development within nursing. Despite this, numerous issues and challenges need to be addressed if nurse researchers are to be convinced of its merits and participate effectively in data sharing. Some of these include ownership and control of data, time frames for data sharing, costs, documentation, and ethical issues. As daunting as some of these may seem, they should not be deterrents to the sharing of nursing research data. Rather, they need to be explored so that thoughtful solutions can be formulated.

Ownership and control of data. Two common issues regarding data sharing are ownership and control of the original data set.[1] Resolution of these issues will vary depending upon the arrangements made for sharing. If the data are to be shared through a data repository, ownership and responsibility for maintenance and distribution of the data set generally rests with the repository. Unless specific limitations are established regarding who may access the data, the data become part of the public domain. If the data are to be shared on a more informal basis, such as between colleagues, the original investigator generally retains greater control and thus can determine who may access the data and for what purposes. This may include, but is not limited to, data obtained in participatory research with consumer groups. We recommend that in cases where data are to be shared in this way that an agreement or contract be established between the original and secondary investigators which clearly outlines the rights, responsibilities, and obligations of each. Such agreements should include, at minimum, a description of the data set and the supporting documentation, an estimation of the costs involved in the sharing of the data, and the responsibilities of each in covering such expenses. Further, it must be clearly established how appropriate reference citations and acknowledgements of the original researcher will be provided in subsequent publications and scholarly presentations.

Ownership and control of newly created data sets resulting from the combination of two or more previously existing data sets have not been clearly addressed in either the social sciences or nursing literature. Generally, if the original data sets were obtained from a data repository it would be

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[1] Ownership, within the context of research data, may be more appropriately viewed as stewardship. Ownership connotes exclusive control over and use of data (a connotation that nursing may be reticent to adopt), whereas stewardship implies that the data are held in trust rather than owned.

appropriate for the secondary investigator to ask whether the new data set should be deposited within the repository. In cases where the data were obtained from one or more original investigators, we recommend that an explicit agreement be established prior to data sharing. It should address the secondary investigator's responsibilities related to sharing the new database and its supporting documentation, and the timing of such sharing.

Time frames for data sharing. Investigators unfamiliar with data sharing may question within what time period data sets should be made available to others. Such questions often reflect concerns regarding being preempted in publications and other scholarly endeavours (Ceci, 1988; Ceci & Walker, 1983; Sieber, 1991a). Funding agencies may specify the time frame for data sharing or, as in the case of SSHRC, they may provide general guidelines such as "within a reasonable time period." It is generally recommended that original investigators make their data sets available after the initial data analysis and preparation of major publications have been completed.

Costs. Issues related to the costs associated with data sharing may become contentious if agreements between investigators regarding who will assume responsibility for specific costs are not carefully crafted. In the social sciences, it is generally accepted that the secondary investigator ought to bear the costs of obtaining the data. This may include, but is not necessarily limited to, costs of copying the data set in a machine-readable format; duplication of questionnaires, code books and other relevant documentation; postage; and in the case of qualitative data, duplication of field notes, video or audio tapes, photographs, and other available data. Funding agencies such as NSF and SSHRC who require that original investigators make their data available to repositories, encourage investigators to include data sharing costs in their proposal budgets. While this practice is not yet prevalent in nursing, nurse researchers need to begin to identify such costs in proposal budgets. In this way funding agencies will be made more aware of the logistics and associated costs of data sharing.

Documentation. One of the challenges in planning for data sharing is the preparation of the supporting documentation which provides crucial information regarding the data set (David, 1991). It is the responsibility of the original investigator to ensure that the data set is accurate and that the supporting documentation is adequate to allow the secondary investigators to decide whether or not the data set is appropriate for their purposes and, if so, to utilize the data effectively and efficiently. Normally this documentation exists as some form of the codebook, providing a legend for the study. The provison of a detailed codebook reduces the time spent by the original investigator answering routine questions regarding the data sets. The codebook may include information regarding the theoretical and conceptual basis of the study, underlying assumptions, sampling procedures, the original design for data collection and any deviations from that design. It should also include copies of instruments utilized, results of testing for reliability and validity, assumptions underlying particular questions or instruments, derived measures, and information regarding data transformations, aggregation procedures, and the creation of new variables. Decisions made regarding data coding and analysis also need to be recorded so that future investigators are not left to guess what was done and the original investigator is not left trying to recall such decisions some time later. In planning for the deposit of data in a repository, nurse researchers should ensure that they have met any additional requirements that data repositories may have.

If quantitative data sets are to be useful to other researchers they must be in a machine-readable format appropriate for use with one of the commonly available statistical packages. Similarly, qualitative data sets need to be compatible with software packages specifically developed for the analysis of qualitative data such as Ethnograph, NUDIST, and Hypertext (Richards & Richards, 1994; Tesch, 1990). Data should be stored on floppy diskettes, magnetic tape or optical disks, and subsequent researchers must ensure that they have appropriate and adequate computer resources to retrieve and analyze them. With advances in computer technology, data transfer is becoming, and will continue to become, less problematic for the secondary investigator.

Ethical issues. The ethics of secondary data analysis and the safeguarding of respondents' anonymity are issues that concern researchers in nursing and the social sciences (Baron, 1988; Ceci & Walker, 1983; McArt & McDougal, 1985). The current trend in nursing is to include provisions for secondary data analysis in consent forms which facilitates data sharing. However, data sharing is precluded if respondents' anonymity cannot be protected. While this is primarily the responsibility of the original investigator, data repositories also share some responsibility for ensuring that data sets accepted for deposit do not contain information which could be utilized to identify respondents. Of particular concern is the potential for cross-referencing when data sets are combined. For example, the identification of particular individuals may occur when some respondent characteristics are cross-referenced with specific geographical and occupational data. While ensuring anonymity may not be a problem when a data set involves a large survey sample, researchers may need to be more creative when the data set is comprised of a small sample and/or includes some forms of qualitative data sets. For example, in the case of qualitative data stored on video or audio tapes or in photographs, it may be necessary to employ electronic measures to disguise voices or facial features that identify the respondents. However, this may not be possible without destruction of the data. In such a situation, the original investigator must judge the appropriateness of sharing the data.

Recommendations

It is clear that data sharing, despite its challenges, has considerable potential for facilitating knowledge development in nursing. However, for this to occur nurse researchers must be convinced of its merits and be willing to support data sharing as a worthwhile endeavour. Toward this end, we make the following recommendations.

First, nurse researchers and scholars need to engage in ongoing debate regarding the advantages and disadvantages of data sharing to develop common understandings and guidelines. In particular, they must carefully consider the ethical issues that are likely embedded in the practice of data sharing. We need to establish guidelines that are appropriate to the assumptions underlying particular research traditions. We need to develop standards regarding the quality of data sets and the accompanying documentation which are to be shared. Input should be sought from such sources as nurse (and other) investigators, educators, professional associations, journal editors, consortia for data archiving, and funding agencies (Fienberg, Martin & Straf, 1985).

Second, in terms of professional rewards, criteria for promotion and tenure need to acknowledge not only primary research, but also the efforts required to prepare data sets for sharing, and the endeavours of secondary investigators. Secondary investigators need to consistently cite the original data set and, where appropriate, the data repository in which the data are located (Fienberg, Martin & Straf, 1985). It has been suggested that in the social sciences some journal editors have held a bias toward publishing primary as opposed to secondary research (Fienberg, Martin & Straf, 1985). Nursing has the opportunity to circumvent this concern if journal editors continue to ensure that sound research based on shared data is given equal opportunity for publication.

Third, nurse researchers need to plan for data sharing during the initial phases of proposal development and ensure that the supporting documentation is developed as the research progresses (Fienberg, Martin & Straf, 1985; Sieber, 1991b). Otherwise, important information pertinent to the study and subsequent analysis of the shared data may be lost to secondary investigators. One strategy for achieving this is to include a data archivist as an integral member of the research team from the beginning of the project. Funding agencies need to encourage data sharing by providing the resources required for the preparation of data, including the supporting documentation, for deposit in a data repository. In fact, Sieber (1991b) suggests that research proposals that include plans for data sharing should be given priority for funding. Funding also needs to be made available for the development and ongoing maintenance of data repositories. Nursing may not need to develop its own repositories but could, as Aaronson (1990) suggests, establish specialty nursing archives within existing data repositories. In so doing, the costs of developing such an infrastructure would be reduced and the data made available not only to other nurse researchers, but to investigators from other disciplines as well.

Fourth, to facilitate the retrieval of shared data, nurse researchers need to work toward developing and maintaining a current directory of data sources that nurse researchers can access, similar to those developed by Jacobson, Hamilton and Galloway (1993), Kiecolt and Nathan (1985), McArt and McDougal (1985), and Saba, Oatway and Rieder (1989). However, unless the resources are available and a concerted effort is made to add new sources and ensure that the entries are correct, such directories will quickly become outdated. To facilitate retrieval, a classification system that enables users to determine the quality of the data set and accompanying documentation would be useful. Such a system was developed by the Inter-University Consortium of Political and Social Research (ICPSR). Retrieval would also be enhanced if data sets housed in repositories were indexed in bibliographic databases in the same manner as books and periodicals (Kiecolt & Nathan, 1985).

Conclusions

Data sharing is, at present, an ideal rather than a norm in nursing. However, as Clubb, Austin, Geda and Traugott (1985) note, norms of data sharing cannot be established and accomplished by fiat. Rather, a climate in which data sharing is accepted as a norm can only be achieved through discussion and demonstration of the value of data sharing. Unless nurse scholars and researchers are committed to the concept, data sharing is likely to be sporadic and fragmented. Weil and Hollander (1991) effectively summarized some of the normative issues related to data sharing:

> Data sharing cannot be looked at in the abstract but must be viewed as a set of social practices within specific research communities. The practices are governed or constituted by conventions, and the conventions evolve. They respond to internal requirements and opportunities, many rooted in the subject matter. They also accommodate external demands, such as those of business, government, and other social organizations, public opinion, and cultural change ....Each of these constituencies can play a role that preserves disciplinary autonomy and helps to make a discipline accountable within itself as well as to outsiders (p. 152).

A decade ago Ceci and Walker (1983) charged that federally funded research was intended to benefit the health and welfare of the public, not to advance individual careers. With this in mind, we have argued for increased awareness of data sharing among nurse researchers and for the establishment of professional standards to facilitate the incorporation of plans for data sharing into research proposals and programs. We urge Canadian nurse researchers to increase their efforts to collaborate with each other and to provide the leadership and mentorship that will be required to engage in a meaningful debate about the advantages, issues, and challenges of data sharing.

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