

ETHICS IN HEALTH PROMOTION AND ITS EVALUATION

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ABSTRACT

It is widely accepted that all medical research should obtain an ethical approval. However, such ethical constraints are not equally considered in most health promotion activities and evaluation. As many health promotion programs either lack evidence of effectiveness or ensure risks-benefits balance, ethical issues may emerge in the process of planning, implementation and evaluation. In this context, health promotion should be regarded as "population health experiments" and health promotion should not be exempted from ethical constraints exclusively. Both government and health promotion workers have responsibility to assure that health promotion programs proposed achieve maximum benefits with minimum risks. To achieve this, a formal ethical assessment for a planned health promotion program and individuals' adequate knowledge and skills in dealing with the ethical issues are critical. Promoting existing guidelines and codes of ethical conduct, or summarising a specific document for health promotion, appear a practical strategy to improve health promotion professions' ethical knowledge and decision making.

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INTRODUCTION

Because risks and uncertainties in connection with medical research and intervention appear obviously, ethical consideration is often required for medical research. Unfortunately, this ethical consideration and requirement are not routinely addressed in health promotion.

The reasons may be that health promotion has been traditionally considered as a "good thing" and it seems no much risks and harms to individuals involved. Consequently, it seems no reason that health promotion and evaluation of health promotion programs should be as subject to ethical assessments.

Should health promotion be exempted from ethical constraints? Are we certain about the risks and harms in health promotion? Do we need worrying about "ethics" in health promotion practice? They are the key issues discussed in this paper.

The discussion is organised into five sections. After the introduction, the second section briefs some important development in health promotion, its theory, methodological and implementation issues merged in the past 20 years. The third section turns to explore some risks or harms that may raise "ethics" in the current health promotion and evaluation practice. Next, the options to deal with those "ethical concerns" in health promotion are discussed. Based on the above discussion, the last section provides a conclusion.

DEVELOPMENT AND PRACTICE OF HEALTH PROMOTION AND ITS EVALUATION

There has been enormous development in health promotion in the past 20 years. The development can be seen particularly in the following aspects.

Theories/assumptions

Health promotion theory is assumptions about how health promotion activities are expected to bring about desired changes in determinants of health (Chen, 1990, Weiss, 1997). The example representing the development in health promotion theory is the well known framework - PRECEDE-PROCEED model.

The PRECEDE model was firstly advocated in early 1980's by Lawrence Green and his colleagues and revised to PRECEDE-PROCEED model in 1991 (Green & Kreuter, 1991). The PRECEDE-PROCEED framework looks at broader factors that influence health and suggests a more comprehensive approach to health and program evaluation. Importantly, the updated model not only realises the factors influencing health, but also examines the relations between health, program factors and health outcomes to trace the causality of the program. The idea is conceptualised by Chen as "program theory" (1991). The

evaluation of a health promotion program is therefore not only interested in outcomes of the program, but also tends to test the theory hypothesised to answer how the program achieves its outcomes.

Technical and methodological consideration

Further development appeared in the field of technical and methodological requirement in designing and implementing health promotion and evaluation activities. In attempting to develop and test a proposed program theory, an evaluation design and methods are required to be logical and more rigorous. Together with the growing interest in evidence-based practice in medical and public health research, evaluations conducted as experiments or quasi-experiments have been advocated and grown rapidly in recent health promotion practice (Nyamwaya, 1997, Nutbeam, 1998). A qualitative approach such as focus group interview, individual interview and observation have been also used frequently in evaluating health promotion programs.

Data and reporting

More complicated and multiple levels of data are collected to test the program theory. Morbidity and mortality seem not be very useful in measuring the effectiveness of health promotion activities. Instead, individual knowledge, skills and demographic information of participants are often crucial for analysing the effectiveness of the program.

Multiple-disciplinary involvement of government, non-government organisations and community in health promotion results in sharing responsibility and ownership to the program. The finding of the evaluation, therefore, is not only interesting to health policy makers and evaluators. Government, academic bodies, community organisations, stakeholders even public have increased their interest in knowing how a health promotion program is implemented and what are the benefits.

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Since modern health promotion has shared many medical research characteristics, it has therefore increased some concerns about likely "risks" and "ethics" in the practice.

Ethics in developing a program theory/assumption

Ethical issues may arise in the process of developing/choosing a program theory. A number of assumptions seem possible to explain how a health promotion program achieves its objectives. Figure 1 displays some possible theories for a health promotion program preventing elders from injury a diversity community. Option A shows that using mass media and social marketing campaign and providing to the elders with information about the importance of physical activity will increase their awareness and encourage their participation in physical activity. Mass media campaign may also advise the target group to attend an information seminar and/or walking group, thus resulting in an increased awareness and participation in the target group. The other two assumptions, B and C suggest that the target group can engage the intervention (seminar and walking groups) following recommendation from health professionals and from some community organisations such as senior citizen clubs.

From the implementation point of the view, both assumptions B and C seem simpler to implement. The project officer needs to contact or visit to health professionals and community organisations e.g., senior citizen clubs, to recruit the participants for

the program. As all participants are referred to the program by health professionals or through organisations, it is also easy for the program to follow up the participants to assess the effectiveness of the program.

Looking at option A, this path may require a wider range of involvement and considerable cooperation from the community including health and non-health sectors. Because the wider involvement, this approach may cost more to implement. Meanwhile, from the evaluation point of view, the effectiveness of the program (media and social marketing campaign) may not be clearly determined.

Hence, from both the economic and evaluation point of views, the program should be implemented and evaluated based on assumptions B and C. However, there are also some ethical concerns to implement the program based on assumptions B and C. It is likely both paths B and C may attract the groups who are well educated, who are from middle-higher socio-economic status, and who live near urban areas or people with a great motivation. Less advantaged individuals, e.g. people from Non English Speaking Background (NESB) may not be able to engage the program as they may not join or know any organisations, they may not have time or it is inconvenient for them to attend the seminar or the walking group. Clearly, human rights and an equal access to health information are the ethical issues if the program is designed and implemented following the program theories B and C in this specific community where the NESB group constitutes a large proportion of the population (WHO, 1986, Mann, 1996).

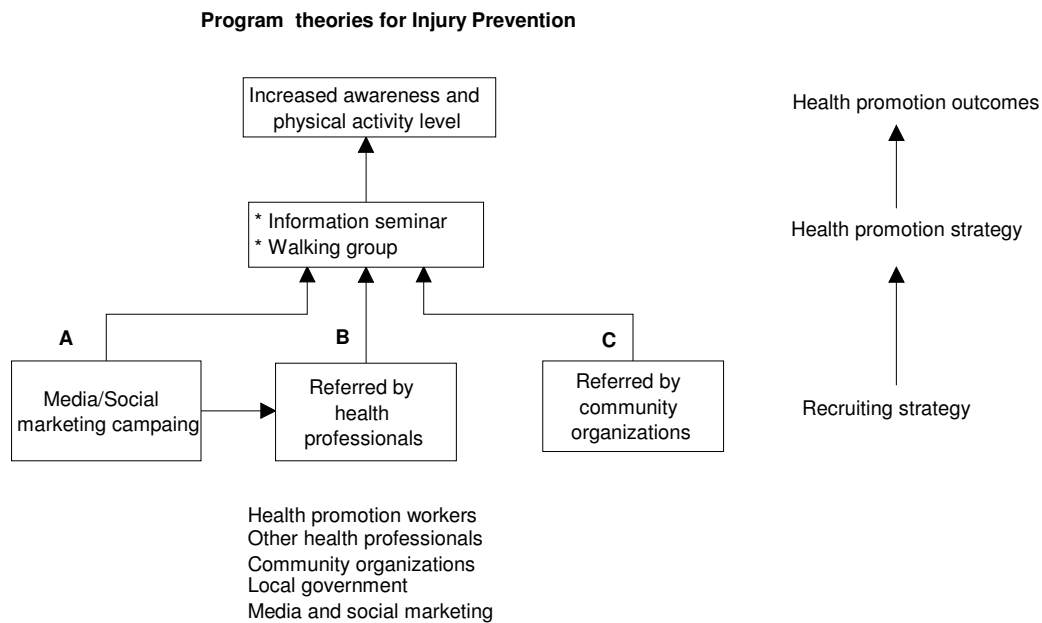


Figure 1 Program theories for a health promotion program preventing elders from injury

Ethics in designing and conducting an evaluation

Even a health promotion program is based on a desirable program theory, ethical dilemmas can still appear in designing and implementing the program and its evaluation. For example, when an evaluation is planned to test assumption A, how to design

the evaluation, what kind of information should be collected to test the assumption, and how to collect data still may contain some ethical concerns.

- There are some uncertainty of benefits and possible risks in health promotion programs as many program theories have not been tested and established. For instance, with no evidence of effectiveness of drug education, it is arguable whether school drug education may reduce drug use, or may create more drug use. Whether an informing consent should be provided to participants or parents, the decision made may raise some ethical concerns (Wallace & Staiger, 1998).
- Often when the evaluation is interested in testing a program theory, a control and active group design is desirable. Thus, a decision has to be made about how to equally allocate individuals to the different groups and whether an informing consent should be provided to the control group.

Ethics in data and reporting process

There are at least two issues here. The first is how to use the data and information collected, and the other is how to report the evaluation findings.

Regarding to the first issues, individual privacy and confidentiality are ethical issues in data collection and management (record and storage) as some information including personally identified information is likely to be collected in a written manner and kept for a period of time. Ethical issues may also arise in relation to the use of data and information collected. Particularly, when a follow-up is proposed and/or carried out by different evaluators or consultants, confidentiality verses disclosure of information collected previously (baseline) is a sensitive issue.

Regarding to reporting, too often an evaluation report is not fully available to stakeholders and public/participants, especially to the latter. There are two possible reasons. One is that, unlike medical research papers, most evaluation reports tend to cover complex issues relating to policy, implementation and some limitations. Some issues are therefore considered as "internal matters". The second possibility would be that the evaluation report is unlikely to be published if the program failed to achieve its objectives as publishing unsuccessful programs or exploring limitations of the evaluation may damage the image of health promotion.

It seems reasonable that the limitations of a program and unsuccessful programs should not be released to stakeholders and public/participants, in order to maintain public trust to government and health service. On the other hand, it is unfair that stakeholders and public are not informed or are not allowed to know the results, because of their involvement, contribution and ownership of the program and public resources.

In summary, as a result of the new developments in health promotion, there are growing potential "risks" and ethical concerns. Ethical conflicts may occur in most aspects of health promotion and, sometimes, beyond our anticipation and capacity to identify and to deal with. Because the real value, quality and effectiveness of any health promotion activities should be justified by many factors including the benefits and risks, ethical issues in health promotion should not be ignored.

WHAT CAN WE DO ABOUT THESE "ETHICS"?

Indeed, privacy and confidentiality in research might be considered legal issues in the legal context (Reynolds, 1998, Carter, 1998), but legal approach to these issues may not be applicable in practice. The possible arguments like:

- Health promotion is an activity directed towards enabling people to take action, not doing something to people (Netbeam, 1998). Thus, even the program fails its objectives, the program itself does not cause direct and serious delay or damage to individuals' health.
- Health promotion workers usually work in a team and their responsibility is to promote and influence people to do something for their health. They do not have "professional/legal obligation" in making a particular decision and suggestion on treatment and prevention options for a particular individual (like medical practitioners do). Even a health promotion program failed to achieve its objectives, it may be inappropriate to seek legal responsibility for any individuals in the working team.
- Because of a lack of evidence of effectiveness for most health promotion activities, it seems fair to argue that developing and testing a new theory should be considered as one task in health promotion. Hence, it should allow people to take part in this "adventure" with little legal concern.
- As health promotion is an unexclusive, it would not be possible to use the licensing process to restrict people to work in health promotion,

Considering the problems in using legal approach to these ethical issues in health promotion, what are the other alternative approaches? Two approaches to these issues could be considered. First, as there are some potential risks and uncertainties in health promotion, health promotion should be regarded as one kind of medical research. In this context, government (health service) or funding bodies should have responsibility to ensure that the planned health promotion activity has minimum risks and maximum benefits and must be implemented according to an ethical standard. This could be achieved through the mechanism of obtaining an ethical approval (like other medical research). Essentially, this process will ensure that the proposed program and practice must meet the minimum ethical standard of conducting research involving humans by examining the following key issues:

- If the program theory proposed is justified and balanced its benefits and risks;
- If the methodology planned considers issues of equity and autonomy;
- If the data required and management process respect individuals' privacy and confidentiality; and
- If health promotion workers have basic qualification and competence.

Despite these benefits, getting this process carried out in practice inclusively can be neither necessary (e.g. education/smoking campaign) nor comprehension in some occasions. These are some possibilities:

- Due to a lack of evidence of effectiveness for many health promotion programs, ethical committees may be uncertain about what strategy may raise ethical concerns and which may not. Consequently, some ethical issues may not be clearly determined in the process. For example, should an informing consent be provided to participants if the benefit of the program is uncertain or if there are some possible harms relating to the program? (e.g., school drug education).
- It may also not be easy for some ethical committees to explore all the ethical issues and related risks when the program theory and strategies are complex and require a multi-disciplinary approach.

Another alternative approach and/or supplementary approach to the ethical issues in health promotion should be considered. It would be ideal that health promotion professionals have sound knowledge and skills in dealing with some ethical issues in their practice (like medical practitioners and researchers). However as health promotion is an inclusive field and anybody could join, it seems unrealistic to expect that everybody working in this field should have sound understanding and competence to deal with these issues sufficiently. To help health promotion workers increase sufficient knowledge and skills in dealing with "ethics", establishing and promoting some guidelines, statements and codes of ethical conduct appear useful.

There is a plenty of guidelines, statements and codes of ethical conduct developed by governments, funding bodies and professional associations nationally and internationally. For example:

- In Australia, as many countries, a number statements and guidelines in relation to ethical matters in medical research have been produced and reviewed by the National Medical Research Council (NMHRC, 1993, 1995, 1997). Although a set of ethical standard for epidemiological research was particularly suggested in the current guidelines, it is still very much medical experimental research focused (NMHRC, 1998). Some ethical dilemmas in public health such as health promotion, early disease intervention and detection are not discussed specifically.
- Looking at outside medical/health fields, the Australian Evaluation Society has endorsed the Guidelines for the Ethical Conduct of Evaluation as one of the peer group publications on ethical matters in the international evaluation society (AES, 1998). Overall, the document provides a more direct and systematic mechanism dealing with ethical issues to people involved in evaluation of any kinds.
- A multiple approach to ethical issues in research involving humans has also been proposed internationally. In late 1998, a final report - Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans was released by three Canadian federal research funding Councils - the Medical Research Council (MRC), the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC) (1998). This document is built upon an ethical framework and covers a range of major ethical issues in research involving humans.

It can be seen from the review, lots of common ethical issues in research involving humans are captured by the existing sources, and some of them could be applicable to health promotion. Theoretically, there is no need to develop any new/specific documents or codes of ethical conduct for health promotion and evaluation. However, as health promotion professions may have different background and qualification, it may be practical and useful that a specific statement and code of ethical conduct for health promotion is synthesised based on the existing sources.

CONCLUSION

As health promotion may contain some uncertainties of benefits and risks, it should be regarded as one type of medical experiments so called - "population health experiments"(Skrabanek, 1990, Gillon 1990). In this context, health promotion professions and evaluators may face a number of ethical dilemmas in their practice and health promotion should not be exempted from ethical approval exclusively.

Both government and health promotion professionals have responsibility to ensure that the health promotion programs proposed and implemented respect human rights and "Ethical Principles". To achieve this, formal ethical review mechanisms, together with adequate individual knowledge and skills in dealing with ethical issues, are important. For the latter, promoting existing principles or codes of ethical conduct or synthesising a specific document for health promotion would be beneficial.

In addition to ethical approaches to these "risks" and ethical concerns in health promotion, it is also significant that health promotion professions should develop soundly professional knowledge and skills in identifying and designing a health promotion program which contains less risks and ethical constraints. (e.g., using new theories, advanced methodology - waiting list control, effective sampling strategies - community/organisational level data). This could be achieved through professional training and education.

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