PART IV

DEVELOPING
PERSONAL HEALTH SKILLS
SELF-CARE IN HEALTH PROMOTION

Ilona Kickbusch

THE CONTEXT OF DISCOVERY

In their period of growth and development in the fifties and sixties (1), sociology of medicine and sociology in medicine had concentrated on matters related to the organized professional health care system: the organization of illness and its treatment with the corresponding patient-professional interactions. This reflected the rapid expansion of the medical system at the societal level. In much of this research the links to overall sociological theory and conceptualization were overshadowed by the fascination of the reference frame of medicine and the power of the medical model. The authority of the physician was rarely questioned, and patient behaviour was summed up in the issue of compliance. Meanwhile, in society the power relationships inherent in the patient-physician relationship were starting to be questioned. Medicalization became a popular notion, to which Ivan Illich’s work (2) gave overall expression and Michel Foucault’s (3) detailed studies supplied historical underpinnings. This was strengthened in the late seventies by a growing body of work within sociology of medicine, of a radical critique of the medical system with a political economic focus (4). These arguments were readily and rapidly taken up by the social movements concerned with issues of health and illness. For feminists, for example, the medicalization of birth and human reproduction was a key issue, and self-care in their terms expressed a wish for autonomy, self-determination and independence from male medical authorities. Our Bodies, Ourselves was the first of a wide range of texts teaching women self-care skills (5).

In the seventies self-care became known to a wider public (particularly in the United States of America) through the wellness and self-help movements. A major journal concerned with health promoting behaviour and positive health was published under the title of “medical self-care” for many years. It stressed to its readers that they could be important health actors, that they should gain confidence as health care consumers and that there were many options on the road to health and within medical treatment. The self-help movement in its many facets expanded so rapidly that some authors have termed these years “decade of self-help” (6). Self-help groups showed that coping with chronic illness and debilitating conditions can be approached through mutual learning and support rather than through medical regimes and that levels of independent living and self-esteem can be reached that many had not thought possible (7, 8). Self-help groups showed success in dealing with addiction.


1World Health Organization, European Regional Office, Health Education Program, Copenhagen, Denmark.
problems such as alcohol. They worked both as support and pressure groups, giving high visibility to what people can do for each other and how they can gain interest for their condition. This success of self-help paved the way for a more positive view of people’s own health activities and influenced the views on self-care (9).

Given this kind of starting point, the discovery of self-care was at first considered a fringe activity within academia. In many cases it was politically suspect, because the fact that people could do things for themselves and were doing things for themselves could lead to a cut in services for those that need them most and could imply blaming the victim—a notion, by the way, that came out of poverty research. In western and northern Europe the concept was often viewed as a conservative idea that could strengthen arguments for the dismantling of the welfare state. At the same time self-help and self-care were challenging medical dominance. In the mid-seventies a very active debate emerged around the differences between self-care and self-help, the latter often being considered more political than the former. Self-help was rapidly becoming attractive to political sociology and the sociology of social movements, raising the question whether self-help was to be considered a social movement, or even perhaps a new type of social movement. Questions were raised as to the political relevance of this upsurge in people’s own health actions, their refusal to submit to medical authority, their mutual organizational forms that aimed to avoid hierarchy (10). It was also of epistemiological concern whether such a challenge to professional knowledge, competence and authority should be the subject matter of serious academics. The challenge was one not just to medicine but to social science as a whole. Let us remember: one of the key books of the seventies was Thomas Kuhn’s discussion of paradigm shifts within science itself (11). Were we witnessing a paradigm shift from medicine to health, from cure to prevention, from medical care to self-care and self-help? Was this something much larger in terms of overall social change than we could see from close up? Could the lay insight of the world provide a knowledge not yet evident to science? This was reflected in the debates on women’s health care and the self-help movement (12). Thus self-care research was at its very start part of an important political and epistemiological debate in society and the social sciences.

SELF-CARE AS PART OF A LIFESTYLE
CONCEPT: W.H.O. AS A CATALYST

Given this context, it created quite an upheaval in the committees of the Regional Office for Europe of the World Health Organization when, in the early eighties, a new programme on Lay, community and alternative health care was introduced as part of an overall attempt to develop an approach to lifestyles and health. The first meeting organized by this programme was a workshop on “Self-Help and Health,” which for the first time in the Regional Office for Europe of WHO brought together representatives of self-help groups to debate the issue with health care professionals and researchers. To assist this work a WHO information centre on self-help and health was established in 1982 with the intention to network initiatives all over Europe. Several workshops followed the first and in 1983 an overview on self-help in Europe was published at WHO which proposed a terminology related to the lay health care system. This attempt used lay care as the lead category and related to it sub-categories such as: self-care, volunteer care, self-help (with another set of sub-categories) and alternative services. Self-care was defined as follows:

Self-care refers to unorganized health activities and health-related decision making by individuals, families, neighbours, friends, colleagues at work, etc.; it encompasses self-medication, self-treatment, social support in illness, first aid in a natural setting, i.e., the
normal context of people's everyday lives. Self-care is definitely the primary health resource in the health care system (8).

It can be seen clearly that this attempt at a definition was still heavily influenced by dichotomies between self-help and self-care and between the lay system and the medical system. But it was also influenced by the conceptual approach to lifestyles and health that the Regional Office had meanwhile adopted. The main argument on which this terminology was based implies that the starting point of the analysis of self-care is the social system with its enabling and constraining structures (i.e., the setting of people's everyday life), within which people are seen as active agents. Attitudes and behaviours related to health are understood as an integral part of the overall lifestyles of a society, a social group and an individual. This has been further elaborated in the materials on “Lifestyles and Health” produced by the World Health Organization, the framework of which was published in Social Science and Medicine in 1984 (23). Let me quote a key passage from this text, which was presented to the WHO Regional Committee's Technical Discussions in 1983:

For the purposes of analysis, lifestyle has to be defined in relation to collective and individual experiences and to conditions of life. The range of options open to an individual is confined to the area in which the two groups overlap.

Such a starting point allows us to understand health as a social project and within such an approach view self-care and self-help as social phenomena. This also allows for a linkage between the lifestyles debate and a more general debate on prerequisites for health. This was most clearly expressed by Nancy Milio in a seminal work on new types of health policy:

Lifestyles are patterns of (behavioural) choices made from the alternatives that are available to people according to their socio-economic circumstances and to the ease with which they are able to choose certain ones over others (14).

The approach chosen by WHO for its work on “Lifestyles Conducive to Health” (the title of a key section of the main policy document of the Regional Office Targets for Health for All [15]) was radically different from the one developed in the early seventies by behavioural epidemiology. Epidemiology in the seventies had moved the sphere of health action from hygiene (e.g., sanitation) and public health (e.g., immunization) to individual behaviour (e.g., smoking) and large-scale intervention projects (16). The notion of self-care used in this context is the adoption of a healthy lifestyle, which means individuals contribute towards their own health by avoiding risk factors, adopting more positive health behaviours and by self-monitoring. The approach focuses on modification of behaviour for reasons of health rather than on enabling healthier life patterns for reasons of well-being. This difference is crucial, as has been outlined in a recent article by Coreil et al. that reminds us of the origins of the concept of lifestyle (17). It outlines for epidemiological notions of lifestyle research what can be stated for functionalist notions of self-care research: the lack of linkages to overall sociological theory results in an oversimplified, non-scrutinized use of a sociological concept, which can in the end—as has happened to the term lifestyle—turn the term into its exact opposite. To quote Coreil et al.:

The failure of health promotion programs to adequately deal with the socioculture context of behaviour represents a major weakness of the lifestyle modification approach. What seems especially paradoxical is that the catchphrase for this atomistic perspective lifestyle—grew out of a scholarly tradition which gave primacy to context and meaning. Current discussions of lifestyle and health largely ignore systemic influences, and instead focus almost exclusively upon individual responsibility.
The lifestyle approach supported by WHO allows us to see self-care as something people do within a context. It constitutes part of the pattern that people establish for their behaviours, the meaning they attach to them; it is eased or made more difficult by cultural and structural elements and it will be influenced by overall cultures of health and illness and the role of medicine within a given group and society.

To study self-care today is therefore still a controversial undertaking, although the conflict is—at first glance—less of an overt political one. It is my view that a functionalist and medicalized focus has stood in the way of understanding self-care as active social behaviour and placing it firmly within a new public health perspective.

**SELF-CARE AS SOCIAL BEHAVIOUR**

If we accept that self-care is basically about the actions people perform to improve their health and well-being within a context of everyday life, in which health is rarely the main frame of reference, then these actions must be related to the processes of structuration that they are subject to. Anthony Giddens names three key processes: meanings, norms and power (18). This implies that when studying human actions, we must relate the actions to the meanings people attach to them, the norms they are subject to and the power of decision making available. Let us take for example a day in the life of a 35-year-old middle class woman and state some of the health-related behaviours she goes through in her everyday life:

a. eat a fibre breakfast;
b. remind the children to brush their teeth and eat breakfast;
c. walk rather than drive to work;
d. make sure not to sit at the word processor too long;
e. discuss birth control with her physician;
f. read that article on pap smears again;
g. ask colleagues to cut down on their smoking in the joint office;
h. make sure children attach their seat belts on the way to music school;
i. jog;
j. call up a colleague who is ill in bed;
k. advise mother on treatment she should choose for her arthritis;
l. massage husband’s tired back and advise him to cut down on his drinking;
m. refrain from taking sleeping pills even though the jar is in her hands.

Some of these behaviours have become routine and habit (a, b, c); others involve conflict and negotiation skills (g, e); the health effects of others can hardly be influenced by the individual, such as the lead level in the street (c, i) or the deadlines the boss sets (d); some imply authority over others (b, h); some imply negotiation with authority and professionals (e, k); some imply self-control (i, m); others need empathy (j, k, l); others imply having or taking time (f, i, j, l).

The fact that I could also have chosen the much more complex example of a young, single, unemployed mother in Glasgow or a black HIV-positive drug user in New York raises yet another issue of self-care research that needs serious attention: its middle class bias, its lack of interest in social stratification, sexual stratification and inequities in health. But because of its simplicity and bias the example constructed above illustrates the point: it is near impossible to reach a clear distinction between self-care behaviour, caring for others, preventive behaviour, health promoting behaviour, self-treatment and medication, coping and providing social support. How then can we “understand” (verstehen as a method of understanding human behaviour as developed by Dilthey) the behaviour patterns in everyday life that help people to remain healthy or cope with certain conditions and how do these patterns relate to the life context and life chances of the respective individuals and groups? Do, for example, certain self-care practices re-
duce or widen inequities in health? What are the configurations that enable people to take actions that promote or improve their health and those of others? And out of which constellations of behaviour can we predict more (or less) health and well-being in specific social sub-groups?

Self-care research in the context of a lifestyles and health conceptual framework therefore becomes a complex undertaking (19). But prospects are not as bleak as they may seem if use is made of theoretical and methodological work done in other branches of sociology or other disciplines. For example:

- the work done on sociology of everyday life could provide conceptual approaches of how people understand and structure their day to day actions (20);
- various interpretative sociologies including ethnomethodology could deepen the understanding for meaning of actions and behaviours (21);
- various schools of anthropology could contribute particularly to the understanding of patterns (22);
- women's studies and feminist research could contribute to notions of body concepts and links between self-care practice and autonomy (23);
- grounded theory could heighten theoretical sensitivity and strengthen the explorative task of research (24).

This also means leaving the functionalist framework and adopting a frame of reference that accepts "some new rules of sociological method" as have been proposed by Giddens (18). Of the nine rules he develops I would particularly like to stress three in their relevance to self-care research:

- the production of society is a skilled performance, sustained and made to happen by human beings (this could lead self-care research to a focus on action rather than behaviour);
- the realm of human agency is subject to boundaries through structures that are not only constraining but can also be enabling (this could lead self-care research to enquire how structures for self-care are constituted through action and how self-care action is constituted structurally);
- sociological concepts obey a double hermeneutic: the frame of meaning established by the generalized theoretical scheme within social sciences (as outlined by Kuhn) and the frame of meaning by the social actors themselves. The primary task of sociological analysis is to relate the lay frame of meaning to the theoretical construct that has been selected (this could lead self-care research to develop a theoretical base of work).

My first plea is therefore to see self-care research as an integral part of lifestyles research based on context and meaning rather than on individual responsibility. This is a key point in relation to the policy consequences of self-care research, which I will take up in the last section of this article.

SELF-CARE—AN ECOLOGICAL APPROACH

The above holds if we wish to stay within the framework of sociology or specific academic disciplines. But inherent in both Giddens and Coreil’s arguments is a step towards a type of systemic thinking not yet categorized into an academic discipline—and not yet fully recognized by many social scientists. It could prove even more fruitful to follow these hints through and choose another frame of reference. The WHO lifestyle paper quoted above (13) ends with the following challenge:

A new perspective is needed on lifestyles and health promotion, one which places them firmly in the context of broad social trends and defines them as inherently social in ori-
gin and growth. This would reflect an ecological model of health, not a purely medical, behavioural, sociological, environmental or political one.

The frame of reference for such a perspective is provided by Gregory Bateson in his work on Ecology of Mind (25, 26). Bateson’s starting point is the story. And because his stories are brilliant I will repeat one of them here:

A certain mother habitually rewards her small son with ice cream after he eats his spinach. What additional information would you need to be able to predict whether the child will: (a) come to love or hate spinach; (b) love or hate ice cream; or (c) love or hate mother?

At issue here is not the content of the story or the pedagogical approach of the mother but an approach to scientific enterprise. Bateson offers two key categories in answer to his question: context and meaning. These two phenomena he states define “a division between the hard sciences and the sort of science which I was trying to build.” Bateson’s notion of science is concerned with testing hypotheses derived from what he calls fundamentals of science and philosophy. Any particular piece of enquiry should be able to be connected to such fundamentals and as an ultimate goal increase fundamental knowledge. This is where a key theoretical issue emerges in relation to the discussion of health—which in turn influences the research done on health-related actions such as self-care. If health is seen along the lines of the man-machine notion of nineteenth century science, working with chains of cause and effect in relation to forces and impact, then a sociological approach based on functionalism may seem appropriate for health behaviour research. If health is seen as a process, i.e., as a living system, then form becomes essential. Or, in more sociological terms: if the production/reproduction of society is a skilled performance, sustained and made to happen by human beings, then the form that creates health becomes an essential matter of study. I have in another article proposed that one could start with defining health as a meta-pattern, a pattern that connects, and aim to analyse the interacting parts and processes in terms of context and meaning (27). Relationships then emerge as parts of the pattern, rather than as cause-effect correlations. To make a point: if lifestyle is interpreted as an individual behaviour and health promotion is defined as behaviour modification then self-care could easily be equated or subsumed under such a narrow term. If one follows the WHO concept of health promotion which is contextual, then self-care is an integral part of a wider concept. And since—according to Bateson—context defines relevance, this could lead to an important positioning of self-care within a new public health approach.

**SELF-CARE IN A HEALTH PROMOTION CONTEXT**

This argument becomes clearer when looking in detail at the definition of health promotion that has been put forward by the World Health Organization.

Health promotion is the process of enabling people to increase control over, and to improve their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities (Ottawa Charter) (28).

The notion of health and health action outlined in this quote is one that aims to move in the direction of pattern, context and meaning: people need to get through everyday life; their actions have rules and meanings in the context of this everyday life; their actions are linked to dreams and to reality, some are routine, some are deviant, some are imposed, etc. The question is: how to make health accessi-
ble in a form that implies not only health as an outcome, but increases control over one’s own life (29). This conceptualization could provide a lead into self-care research. Self-care could be understood as an integral part of health promotion, meaning all those actions an individual undertakes to take care of herself and of her immediate environment. These actions would then need to be analysed along the lines Giddens proposes as “processes of structuration” (meanings, norms and power) as outlined above. If, as a woman, I refrain from going to a pap smear regularly it is because:

I have not had the information;
I did not understand the information;
I did not believe the information;
I received controversial information and decided not to bother;
My culture does not permit me to go to a gynaecologist;
I am so afraid of cancer that I don’t want to know about it;
I have not been taught to take my own health seriously;
I have no relationship to my own body and dread to think of my genitals;
Or several of those reasons meshed together to give a pattern, etc.

Already inherent in such an example is of course the debate on the necessity and frequency of screening procedures in general and pap smears in particular, that I cannot enter into here. But it touches on the compliance issue, where self-care research shows a tendency to take the medial position of the day as the position people should accept and act upon. From the self-care research known to me I am not able to say whether an action like putting on a seat-belt and keeping to the speed limit is self-care or just the behaviour of a good citizen who does not want to get fined. Should we care as long as people do it? What makes the difference: the meaning or the motivation attached to the action, the context, the pattern? Is it the amount of power and control I have over the action? Is it important whether I undertake an action for health reasons or because I do not want a fine or because I always follow rules? Is buying and using condoms self-care? Does it make a difference if I use them for reasons of AIDS prevention or family spacing? Does accessibility make a difference? Or is self-care only related to those actions that are the usual subject matter of behavioural epidemiology and have more or less measurable consequences in terms of numbers of cigarettes smoked, glasses of alcohol drunk, doctors visited, lay referrals acted upon, hours slept, blood pressure monitored, etc.?

In its unreflected approach to human actions, self-care research has come too close to the precedent of the uncritical adoption of the term lifestyle in health education which has led to many shortsighted programmes for action. With this I do not mean that researchers on self-care should outline the programme steps for the health promoters and/or politicians. That is not their job. But they should be extremely practical and useful in the way Kurt Lewin stated: “there is nothing more practical than a good theory.”

Of course the field is not blank. Scientific support for people’s own contribution to health has come from other branches of health research: the literature on coping and social support that has been generated over the last 15 years clearly indicates that people can mutually reinforce their health, their convalescence and their rehabilitation. People’s forms of coping with everyday life are starting to be understood: for example, it took quite a while to realize that noncompliance could be a very rational and sound behaviour or that smoking could not only be viewed as a risk factor but could also be an integral part of an overall coping strategy. And of course the list could be prolonged. At WHO we have integrated self-care research as a part of an overall health promotion research network which includes research on health behaviours, on working conditions, on policies, on health potential, etc. Perhaps this
will bring us a step closer to understanding the pattern and the structures that create health and wellbeing. Only recently a new publication has outlined new trends in health behaviour research that point in the directions of WHO's approach (30).

If I state—and sometimes overstate—these questions then it is because I think there should be more in-depth theoretical and conceptual discussion of what self-care research is out to research and measure. And why. How much does this research really help us to know about people's willingness, opportunities and choices to take care of themselves and others? The current correlations do not answer the question of meaning and leave us without a frame of reference for the context of the actions.

Within WHO the concept of lifestyles and of health promotion has helped us to identify key entry points for action. In our view a definition of self-care is embedded in the following quote from the Ottawa Charter:

Health is created and lived by people in the setting of their everyday life, where they learn, work, play and love. Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members (28).

Of course we are far from achieving that, but maybe this could provide a useful framework for self-care research. The entry points proposed in the Charter are: build healthy public policy; create supportive environments; strengthen community action; develop personal skills; reorient health services. Self-care action and self-care research could be related to each of these areas: what public policies enable self-care; what supportive environments strengthen independence; what factors move self-care from an individualistic enterprise to a cultural pattern; what helps self-care skills develop; what factors in health services organization hinder self-care practice. And all these questions and their answers could help us not only in understanding self-care but in placing it within the framework of new public health action. As I have outlined in another paper (31) the idea of new public health is based on the understanding, that 150 years after the heroic phase of public health, we have a different understanding of what is health and what is public. Public participation in public health takes many forms, and self-care is one of them. But, since the new public health is based on the WHO principles of health for all, self-care in such a context is seen as empowering. It is seen as an important addition to human competence and skills (I refer back to Giddens' notion of people as skilled actors), not a delegation of health work nobody else wants to do or that societies cannot afford to have professionals do any more. This is essential particularly in its consequences for women, children and old people.

Thus the question that poses itself is a larger one that goes beyond the frame of this article and self-care research as such. Self-care actions do not take place in a political and societal vacuum. The movements for self-help, self-care and autonomy in health that were key to the seventies are not in the forefront of the health debate in the eighties. Of course, within pockets of the established health and medical care systems the interest in self-care, self-help, health promotion and non-medical solutions has grown and continues to grow, partly due to inherent problems of the systems themselves, partly as a consequence of financial and economic pressures. Self-care and self-help actions by people have made professionals and servicing systems more aware (but also more wary) of patient needs and patient rights.

But in times where new forms of the welfare mix are being heavily debated in political circles, where health systems all over the world are subject to severe cuts, and where self-care pleas by governments are often juxtaposed by restricting access to services, and
when people's participation in health is not top priority on the political agenda it is perhaps worth going back to the old debates around self-care in the seventies and comparing whether the questions posed then have been answered by the research done in the last 10 years. The key issue in the political debate was decision-making power in health, best expressed in the slogan from the women’s movement “the personal is political.” The key issue epistemologically was the relevance and soundness of lay knowledge and judgement. On both issues I believe self-care research still has far to go. Or in terms of Bateson: “the relevance of action constitutes itself through the context.” This applies also to the subject matter of sociological research. The new public health rather than behavioural epidemiology could provide a framework that enhances and strengthens self-care action and research and makes it part of a larger social project, as our societies face rapid changes in moving towards the end of the century.

Acknowledgements Special thanks to Judy Luce, who reminded me of my roots. Thanks also to Michel O’Neill, Jan Branckaerts, Ron Draper and Kathryn Dean for comments on preliminary drafts of this manuscript.

REFERENCES

Please note that in most cases the references given stand as examples for a wide range of literature on the subject.

15. Targets for Health for All, Section 4, pp. 53–74. WHO, Regional Office for Europe, Copenhagen, 1985.