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## Mediated health campaigns: from information to social change

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## Chapter 13: Mediated health campaigns: from information to social change

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### Key words

**Health communication:** Forms of communication that empower people to take control over their health, through promoting one or more of the following: health-enhancing behaviour change, the appropriate accessing of health-related services and support, the development of health-enabling social capital, the facilitation of collective action to tackle obstacles to health and the development of health-related social policy (at the local, national and/or global levels of influence).

**Health communication strategies:** These include didactic health education campaigns which target vulnerable groups with information about health risks; community strengthening approaches which seek to promote health-enhancing social participation in vulnerable communities; and health advocacy approaches which target powerful decision makers who have the economic and/or political power to tackle and transform unhealthy social environments.

**Transformative social spaces:** Supportive social settings in which people are able to engage in critical dialogue with trusted peers – that ideally lead to the development of actionable understandings of obstacles to their health and well-being, and strategies for tackling these at the individual, community or macro-social levels.

**Collective action:** Forms of activism in which groups of people work together to ameliorate, challenge or resist the impacts of individual, community or wider social circumstances that place their health at risk.

**Mediated health campaigns:** Efforts to support healthy behaviours and healthy communities using communications media such as radio, television, print and the internet.

**Civic journalism** (also called public journalism and citizen journalism): a journalistic style in which news stories are produced through collaboration of journalists and members of the public.

**Edutainment:** the intentional placement of educational content into entertainment communicated through media including television, radio, music or theatre.

**Health-enabling community contexts:** Social environments which enable and support the likelihood that community members will behave in health-promoting ways.

**Dialogical critical thinking:** The process through which people engage in debate and discussion about the social roots of their individual life challenges and how these might best be challenged or resisted.

**Social capital:** Durable networks of socially advantageous inter-group relationships

**KAB (Knowledge + Attitudes = Behaviour) approach:** The implicit model of health behaviour that underpins many information-based health campaigns: namely the assumption that if a person has information about a health risk and a negative attitude to it, s/he will form an intention to behave in a way that reduces that risk, with behaviour change often following from behaviour-change intentions.

**Social identity:** Those aspects of a person's self-concept that arise from his or her membership of various social groups.

**Networked journalism: The construction of news stories through the** collaboration of professional journalists and lay people – made possible primarily through digital technology such as online opinion fora, blogs and video sharing websites.

**Journalism of information:** A journalistic style that conceives of reporting as the neutral and value-free presentation of objective facts. Health issues tend to be framed primarily as individual concerns, often within the context of biomedical understandings of health and disease.

**Journalism of conversation:** A journalistic style that conceives of reporting as the development of socially constructed interpretations of complex and multi-faceted situations. Ideally such constructions result from dialogue and collaboration amongst journalists and a wide range of concerned parties, including not only health professionals, leaders and policy makers, but also the voices of marginalised groups traditionally excluded the dominant public sphere in particular social settings. This approach is often associated with an emphasis on the social and political determinants of health.

**Introduction**

Health communication campaigns seek to promote healthy behaviours and to build healthy communities. What social psychological pathways are most likely to lead to healthy behaviours and healthy communities? What communication strategies are most likely to facilitate these social psychological processes? How can the media best be used to promote health-enhancing psycho-social changes in individuals, communities and the wider societies in which they are located, particularly in relation to the socially excluded groups who suffer the poorest health?

In this chapter health communication is understood to include any form of communication that seeks to empower people to take control over their health, through promoting one or more of the following: health-enhancing behaviour change, the appropriate accessing of health-related services and support, the development of health-enabling social capital, the facilitation of collective action to tackle obstacles to health and the development of health-related social policy (at the local, national and/or global levels of influence). A variety of strategies have been developed to tackle these goals. These include didactic health education campaigns which target vulnerable groups with information about health risks; community strengthening approaches which seek to promote health-enhancing social participation in vulnerable communities; and health advocacy approaches which target powerful decision makers who have the economic and/or political power to tackle and transform unhealthy social environments.

The first aim of this chapter is to map the evolution of health communication campaigns from their roots in information-based health education towards 'community strengthening' and 'social change' approaches. Information-based health communication targets individuals, seeking to persuade them to change their behaviour through providing them with factual information about health risks. Community strengthening approaches target communities, seeking to build 'health-enabling' social settings through facilitating health-enhancing dialogue and social participation by community members (Campbell and Murray, 2004; Stephens, 2008).

The second aim of the chapter is to examine the potential of various forms of mediated health communication - including edutainment, civic journalism and the internet - to facilitate the development of healthy community contexts. It is framed by the World Health Organisation's definition of health as a state of 'physical, mental and social well-being, and not merely the absence of disease or infirmity.' Particular attention is given to the potential for mediated communication to help people tackle various threats to health and well-being, including gender violence in the context of HIV/AIDS, child poverty, human rights abuses, supporting children with autism and breast cancer.

### ***Health communication: from social cognition to collective action***

Historically, health promotion has been driven by 'social cognition' models of behaviour, seeking to promote behaviour change by changing peoples' knowledge and attitudes. Such approaches assume that health-related behavioural intentions result from the decisions of rational individuals, on the basis of sound information

about health risks. These approaches are underpinned by varying elaborations of the KAB approach (Knowledge + Attitudes = Behaviour). This model holds that if a person has information about a health risk (such as lung cancer), and a negative attitude to it (e.g. lung cancer is a bad thing), s/he will form an intention to behave in a way that reduces that risk (e.g. avoiding cigarettes), with behaviour change often following from behaviour-change intentions.

Such approaches view human beings as rational individuals, capable of making sensible behavioural choices on the basis of sound information. A generation of health communicators have poured money into information-based awareness raising programmes, such as media campaigns, counselling and workshops to build health-related skills such as assertiveness in relation to refusing risky engagement with illegal drugs or unprotected sex. Whilst such approaches have had some successes in limited contexts, on the whole their results have been disappointing (Ogden, 2007). Few smokers, heavy drinkers or fast drivers are unaware of the potentially health-damaging impacts of their behaviour, for example.

Crossley (2000) points to three types of factors that undermine the assumption that people will necessarily make rational and well-informed decisions about their health: unconscious factors, socially constructed peer norms and power inequalities arising out of social relations such as gender and poverty (see Box 13.1). Against this background, there is growing recognition of the limitations of traditional health promotion in favour of community strengthening and social participation approaches, which focus not only on educating people about health risks, but also facilitating the types of social participation most likely to empower them to resist the impacts of unhealthy social influences. A growing body of evidence shows that participation – in community groups, voluntary associations and civic and political life, as well as informal networks of friends, neighbours or family – can be a powerful positive influence on health and well-being (Wallack, 2003). The individual behaviour change approach to health communication generally overlooks the health-enhancing benefits of participatory forms of communication. Against this background, a new generation of health communicators are seeking to understand the psycho-social pathways between participation and health, and how best to facilitate these.

In addition to providing the intrinsically health-enhancing benefits of social support (Berkman, 1984), social participation is health-enhancing because it links people into communication networks – which they can use to develop critical understandings of the social and psychological circumstances that place their well-being at risk. In this chapter such networks are said to provide ‘transformative social spaces’, namely supportive social settings in which people are able to engage in critical dialogue with trusted peers – that ideally lead to the development of actionable understandings of obstacles to their health and well-being, and strategies for tackling these at the individual, community or even macro-social levels. In ideal circumstances, such critical understandings inspire and empower people to collectively renegotiate the social norms that drive their behaviour and to engage in forms of personal or group activism that actively challenge the circumstances that place their health at risk.

## ***Social inequalities and health***

Various inter-locking social inequalities impact negatively on health. In many social settings it is those with the most limited access to economic and political power who are also the most unhealthy. Within this context, redistributive social policies – which increase peoples' access to economic resources and social and/or political recognition – are often seen as a necessary condition for narrowing the health gap between rich and poor, and in improving the health of groups who have limited access to social power in particular contexts, including women, children, the elderly and the disabled (WHO, 2008).

However, social elites seldom voluntarily give up economic or political power in the absence of assertive and vociferous demands from less powerful groups. Unfortunately, the very people who must provide this assertive and vociferous 'push from below' often have limited opportunities and resources to do so. Moreover, poverty and other forms of marginalisation often foster a sense of disempowerment and fatalism among the excluded. Before members of socially excluded groups are able to demand substantive changes in the unequal social relations that undermine their health, they need to come to see themselves as active agents capable of acting positively to improve their lives and to increase their control over their health and well-being (Gaventa and Cornwall, 2001). Against this background, this chapter examines how health communication might best facilitate the development of 'transformative social spaces' in which members of marginalised social groupings can participate in the types of communication, dialogue and action that facilitate the development of confident and empowered identities, which equip people to take better control of their lives and their health.

## **Theoretical framework**

To be human is to engage in dialogue with others in the on-going challenge of giving meaning to our lives. Through communication we construct the social identities that govern our behaviour and experience, and negotiate the 'recipes for living' that drive our actions and shape our health and well-being. The symbolic interactionist perspective (Mead, 1934) emphasises the role of social interaction and dialogue in constructing the social identities that influence the behavioural possibilities and constraints available to us. These are often associated with our membership of and position within hierarchical social groups. The assumption underlying the arguments made in this chapter is that health communication is effective to the extent that it provides opportunities for people to renegotiate these identities in health-enhancing and empowering ways. To improve their health, people need to engage in critical reflection and dialogue, develop new insights into the way unequal social relations limit their health and life chances, and brainstorm strategies through which they might begin to resist these negative impacts.

## ***Communication and power***

Within unequal societies, there is an overwhelming tendency for unequal power relations to perpetuate themselves, with communicative possibilities and outcomes tending to reinforce the position of dominant social groups in the vast majority of social interactions (this is a theme present also in Habermas's critique of strategic as opposed to communicative action, see Chapter 6). One mechanism through which this happens is that marginalised social groupings become trapped in self-limiting understandings of their place in the world, and of their potential for action – forms of 'power-knowledge' (Foucault, 1980) that often lead to fatalism and passivity.

However, in principle, the exertion of power always goes hand in hand with the possibility of resistance (Foucault, 1980). Foucault speaks of the 'micro-capillarity' of power. Rather than being a monolithic force, power operates through a complex array of 'meticulous rituals' (Foucault, 1975). Since communication is a key medium through which the meticulous rituals of power are continually enacted and re-enacted, the possibility always exists that in ideal social circumstances, groups of marginalised actors may develop the insight, agency and confidence to refuse to engage in communicative styles and acts that undermine or disempower them. Key to this process of refusal is the process of reformulating their social identities and their associated sense of their place in the world in ways that challenge the negative social relations that compromise their dignity and well-being (see Chapter 7 for a discussion of the role of communication in shaping social identities). The task confronting health communicators concerned with challenging the social hierarchies that lead to health inequalities is to provide 'transformative social spaces' for the development of such resistance.

#### *From didactic to participatory communication*

A generation of programme evaluations suggest that information-based health promotion approaches, discussed above, have had remarkably limited impact on the behaviour of their audiences (Wallack, 2003). Information is often a very weak determinant of behaviour change, particularly amongst marginalised social groups whose freedom to control their behaviour may be limited by wider social conditions such as poverty or gender.

Furthermore, individuals are not 'empty vessels' that can be 'filled up' with new information. All human thinking takes the form of a process of dialogue – a communicative form, we might say – the process of debate or argument and counter-argument, conducted both internally and between individuals (Billig, 1996). In his account of 'the thinking society,' Billig argues that people are engaged, individually or collectively, in a constant process of weighing up different points of view. People constantly evaluate new sources of knowledge both in terms of pre-existing assumptions, habits, custom, ideology and tradition, and also in terms of the often contradictory motivations that influence their behaviour as they move from one social setting to the next.

Health-related behaviours are not simply the result of individual knowledge and skills imparted to passive audiences by active health communicators. They are nested within complex social structures in which people collectively appropriate and construct new meanings, identities and behavioural possibilities from one moment to the next in response to the challenges they face in their lives. For this reason, effective health communication needs to facilitate situations that constitute a microcosm of 'the thinking society' – through encouraging target audiences to participate in the processes of dialogue and debate through which identities and behavioural possibilities are created and recreated.

### *Building transformative social spaces*

How can the types of social spaces most conducive to empowering dialogue best be characterised? Fraser (1990) argues that in unequal societies, the public sphere tends to be dominated by men rather than women, and the wealthy rather than the poor, and to provide limited space for ethnic minorities to exert influence. Marginalised groups tend to lack the confidence, skills and social legitimacy to advance their needs and interests. For this reason, she posits the concept of 'counter-publics', which refers to safe separate spaces in which marginalised groups can retreat, to develop and 'rehearse' the types of critical arguments they will eventually take into the dominant public sphere as part of the project of challenging the power of dominant groupings, and demanding their share of symbolic and material social power.

What psycho-social processes need to take place within these 'counter-public' spaces, best equipping marginalised groups to make effective demands for social recognition? Paulo Freire (1973) answers this question with his concepts of dialogical critical thinking and praxis, through which people are able to reflect on and transform their existing understandings of themselves and their place in the world, and act to improve their life circumstances (see Chapter 2 for a more detailed account of Freire's work). It is through such reflection that excluded groups are able to deconstruct their existing self-limiting knowledge and develop understandings of how their taken-for-granted assumptions are shaped by oppressive power relations and by world views that support the interests of the dominant social classes.

Such reflection informs the development of new ways of making sense of the world, and more empowering understandings of the possibilities of alternative social relationships. Ideally participatory dialogue and reflection also lead to an enhanced sense of confidence in one's ability to change one's social circumstances, as well as the identification of existing individual and group strengths, skills and capacities to contribute to the fight for social change. Identification of strengths and skills is part and parcel of the collective formulation of feasible action plans to challenge limiting social relations. Finally, and ideally, effective dialogue leads to the identification of potential support networks that marginalised communities can draw on to enable them to put these action plans into practice.

The latter point is based on the insight that marginalised groupings are often not able to tackle the social settings that undermine their health without significant assistance from outsiders who have the economic and political power to assist them in achieving their goals. Bourdieu (1986) argues that limited access to social capital (which he defines as durable networks of socially advantageous inter-group relationships) is a key factor in perpetuating poverty and other forms of social disadvantage, hindering people from improving their life circumstances. Facilitating the development of ‘bridging social capital’ – linking health-vulnerable communities to actors and agencies outside of their community with the power to support them in improving their health, well-being and life chances – needs to be a key aspect of any health communication programme that seeks to strengthen the capacity of excluded groups to withstand or ameliorate the impact of harmful social relations on their lives. A key challenge currently facing health communicators is to develop better understandings of how communication strategies can facilitate links between marginalised communities and powerful and supportive outsiders (e.g. health or welfare professionals, political leaders and policy-makers, powerful economic actors, various local, national and global networks of support).

A growing research literature points to links between social capital and health. In addition to ‘bridging social capital’ discussed above, positive health has also been associated with ‘bonding social capital’, understood as norms and networks of solidarity and mutual support within marginalised communities. In view of evidence for links between both forms of social capital and health, Wallack (2003) argues that a key challenge facing health communicators is to develop ‘community strengthening’ communication strategies that go beyond the simple transmission of health-related information, seeking also to facilitate the development of bonding and bridging social capital in their target communities.

The remainder of this chapter discusses various forms of mediated communication in the light of their ability to facilitate the processes of health-enhancing critical dialogue, reflection and social capital construction outlined above.

### **Mainstream media**

There is no doubt that the mainstream media (commercial and public television, newspapers and radio designed to reach large audiences) play a key role in providing those who can access them with information about health risks, as well as providing advice about individual behaviour change strategies. However, as already argued, whilst information is a necessary condition for behaviour change, it is not a sufficient one. To what extent do these media facilitate transformative social spaces, in which people are able to engage in dialogue about their health and the social inequalities and/or pressures that enable or undermine it?

According to Hodgetts and Chamberlain (2006), the mainstream media tend to approach health from an individualistic and biomedical perspective. Health-related news stories and advertisements overwhelmingly frame health as a biomedical issue. They tend to place responsibility for change on the unhealthy individual, masking the

crucial role played by unequal social environments in shaping health, and in preventing many members of disadvantaged groupings from engaging in health-promoting behaviour. Furthermore, the media often favours sensationalising stories of diseases, focusing on the health problems of individual footballers' wives or pop stars, rather than locating the occurrence and distribution of health within the context of wider political and policy debates. In this way, the mainstream media reduce public understanding of and support for the need to tackle many health issues through redistributive social change.

Another limitation of traditional health communication stems from its expert-driven nature. Socially excluded groups, along with carrying the greatest burden of disease, also lack symbolic power or 'voice' – the power to contribute their views to the debates that shape public understandings of local realities and social challenges. In the mainstream media, journalists and health experts decide what counts as a health issue, and how marginalised groups will be presented to the public. Marginalised groups tend to be 'spoken of' by health professionals and members of government rather than having the opportunities to speak for themselves. They have little influence on the way they are represented in the media, generally situated as passive targets for advice and aid, often entrenching their own sense of disempowerment and fatalism. Excluding their perspectives from the creation of media messages can lead to incorrect, non-representative and biased coverage of issues. Moreover this exclusion often leads to health promotion messages that fail to resonate with the lived realities of the target group and are ultimately ineffective.

Examining how the media might play a more positive role in advancing the health interests of marginalised groups, Hodgetts and Chamberlain (2007) distinguish between a 'journalism of information' and a 'journalism of conversation', with the latter opening up greater possibilities for the facilitation of dialogue about health, the positioning of health as a social as well as an individual issue, and the inclusion of the voices of the marginalised in shaping representations of health and health-relevant social relations. A 'journalism of conversation' abandons the concept of journalist as detached and neutral observer holding an objective mirror to reality. Instead, it views the journalist as a collaborator who works with representatives of the lay public to produce stories that reflect a wider range of voices than those of the middle classes from which most journalists and newspaper readers are drawn. Such a 'journalism of conversation' opens up the possibility of more socially contextualised understandings of health, and positioning health issues as contested and socially constructed, rather than as the reflection of uncontroversial biomedical 'facts'. This form of journalism favours increased interactions between journalists, their traditional audiences and the social groups that form the topic of news stories or documentaries. Rather than simply viewing people as consumers of the media and of advertisements, the collaborative journalist views them as citizens with a stake in the key social, political and economic debates that shape the social relations in which they live.

What strategies might health communicators use to locate current representations of health as individual and biomedical issues within wider understandings of the

social structuring of health and illness? How might they draw marginalised social groupings into a more active engagement in shaping media representations of their lives? How might health communication encourage socially excluded groups to see themselves as experts in their own lives, as well as citizens and agents capable of acting in ways that increase their access to good health? The following sections focus on some examples of media strategies that have sought to tackle these challenges.

## **Edutainment**

Edutainment involves the intentional placement of educational content into entertainment communicated through television, radio, music or theatre (Singhal and Rogers, 2002). This approach to health communication constitutes a compromise between two extreme positions: those who believe the media should transmit accurate information about health free of commercial interests or distorting ideology, and those who argue that the mandate of the media is to make money and entertain viewers.

The South African television soap opera *Soul City* is an excellent case study of a programme with mass-based appeal – averaging up to 14 million listeners on prime time television. *Soul City* aims to increase critical public reflection and dialogue about HIV/AIDS, antiretroviral treatment and sexual health, in ways that serve as a springboard for the renegotiation of health-damaging sexual norms, as well as promoting development of a social environment that is supportive of health-enhancing behaviour change. Below, *Soul City 4* is taken up as the focus of discussion. *Soul City 4* sought to tackle gender-based violence, with survivors of violence being at particular risk of HIV/AIDS (Usdin *et al.*, 2002).

Pre-production research found that most South Africans regarded domestic violence as a private matter, in which outsiders should not intervene. The programme specifically sought to challenge this view, positioning violence as the result of socially structured gender inequalities, and providing audiences with ways in which they might respond and intervene. The programme worked hard to model behavioural opportunities for action. Thus, for example, one episode depicted people ignoring a man beating his wife. Later she stood up in a community meeting, accusing others of knowingly allowing the abuse to continue. Later, when her husband again tried to beat her, villagers surrounded the couple and banged pots, stopping the man. The rationale underlying this demonstration of community agency was to suggest that everyone had the capacity to challenge this practice, and to model ways in which they might do it.

A domestic violence hotline number was embedded in the programme, targeting both victims and concerned outsiders. The storyline also modelled various options for survivors: e.g. moving out of home, involving the police. It showed both these options working well and badly for women to promote a realistic sense of the possible consequences of action. For aggressors, the programme sought to develop critical thinking of violence as a choice made by men, rather than an inevitable response to angry feelings.

Some of the goals of the series were informed by ideals of health advocacy (see Box 13.2), and approach to health communication that seeks to target powerful economic and political actors and policy makers who have the power to create more health-enabling social environments. In this regard, the series was also used to raise public awareness of the South African government's slow progress to implement a Domestic Violence Act. Public marches were organised to coincide with the programme. Parallel workshops were held for journalists to improve the quality of their reporting of domestic violence, and training materials were developed for police called in to intervene in abuse cases.

Widespread firsthand audience participation in producing the programme was minimal compared with alternative media strategies such as civic journalism discussed below. However the latter necessarily operate on a much smaller scale in individual communities. Furthermore, whilst firsthand participation by audience members in designing programme messages is ideal, in reality, participatory health and development projects often find it difficult to involve the most marginalised community members, particularly women, who may be housebound due to domestic responsibilities, or other gender-based restrictions on their freedom of movement. Edutainment strategies of this nature offer a means of reaching such groups. Furthermore the entertainment format has the power to attract viewers (e.g. male abusers) who might otherwise resist explicit efforts to get them to think critically about their behaviour.

### **Civic journalism**

Various forms of civic journalism (also called public journalism and citizen journalism) involve the collaboration of journalists and members of the public in constructing media outputs. Like Soul City, this approach also seeks to generate critical reflection on the impact of social structures on health, as the first step towards political action to tackle health inequalities. Such awareness is seen to be necessary to counter the individualism of mainstream reporting in which the poor and the marginalised are unfairly stigmatised as suffering ill-health due to individual factors such as bad behaviour, general fecklessness or lack of motivation, masking the social circumstances that prevent them from being healthy. It also seeks to encourage members of excluded groups into dialogue about their health amongst themselves, as well as giving them a voice in public debates about how to tackle obstacles to their well-being, and involving them in efforts to challenge and renegotiate the way they are represented.

Many civic journalists collaborate with marginalised groups, not only in producing news stories, but also in promoting their involvement in social participation through public policy formation and democratic political processes. Aside from including community voices in the process of news production, they are also expected to be active in the community, convening public meetings, and working with citizens to think of the most effective ways to tackle community problems and advance community interests (Wallack, 2003).

Latin America has a rich tradition of citizen-professional collaboration in media projects, including radio, print, dance, murals, puppets, loudspeakers and theatre. These projects tend to be grounded in Freirian principles of democratic interaction, dignity and solidarity, in communities previously disabled by alienation, passivity or silence. Radio Estrella del Mar (REM), founded by Catholic Bishop Juan Luis Ysern, is a radio programme run on these principles through partnership between professional broadcasters and local community members (Rodriguez, 2003). REM is a network of six community radio stations in southern Chile, an isolated region which was of interest to the Pinochet government because of its rich natural resources. Ysern sought to build grassroots awareness of the value of these resources, as well as the capacity and confidence of local people to make self-benefiting decisions about which mining proposals to accept and which to reject. His starting assumption, present also in Freire, was that the aim of communication is the co-construction of meaning rather than the transmission of information. The station holds discussion fora on issues such as identity, culture, communication, empowerment and democracy. Emphasising process over product, it seeks to build cross-generational memory and community interactions to feed community reflections on the role they can play in taking control of their lives and futures.

Hodgetts and colleagues have conducted various studies seeking to carve out a role for civic journalism in New Zealand. They seek to promote public understandings of health as a political issue as well as a technical and biomedical one, and to give the poor a greater role in shaping how they are viewed in the wider society, as well as a greater voice in debates about how to tackle the social inequalities that undermine them (Hodgetts and Chamberlain, 2007). They challenge the media's tendency to construct a public of consumers rather than community oriented citizens interesting in sharing, caring and advancing the common good. One study (Barnett and Hodgetts, 2007) reports on the activities of the Child Poverty Action group which sought to challenge dominant negative representations of resource-poor parents. The group's work examined media reports on child poverty, highlighting the conceptual split between the working poor (represented as 'deserving'), and the unemployed poor (represented as 'undeserving'), which failed to take account of the cycle of poverty which trapped many families. It also challenged media stereotypes of poor people squandering their meagre resources on cigarettes and gambling rather than on their children. The group convened meetings with parents of children in poverty, who, given the opportunity were strong self-advocates, refuting claims that they were uncaring parents, and presenting themselves as morally worthy citizens battling with difficult circumstances.

### **Networked communication**

The internet is increasingly said to be a health communication tool that is sustainable, dialogical and inclusive of marginalised voices. It is said to provide unprecedented possibilities for lay people to participate in the construction of media representations of their worlds, to engage in dialogue about political and social issues of concern and to mobilise collective action to challenge social injustices.

Any such opportunities are obviously strictly limited to the relatively privileged two billion of the world's seven billion citizens who are currently online (Internet World Stats, 2009). Furthermore, certain levels of 'media literacy' are necessary for people to make optimal use of the internet's potential. However, what can it offer those who are fortunate enough to have the necessary access and literacy? Beckett (2008) is enthusiastic about the potential of the networked public sphere to act as a force for positive social change. He argues that the internet is pulling together a diverse and increasingly sophisticated audience, keen to participate in shaping their own representations, and their own lives. His research in western Europe suggests that young people and ethnic minorities are decreasingly interested in traditional television or newspaper communication styles, including their narrow interpretation of politics in terms of the activities and debates surrounding parliaments and traditional political parties. Such approaches are rejected for failing to reflect the diversity of voices that increasingly constitute the global public sphere. A growing number of people are more interested in finding out about the world through online news aggregates, friends and social networks than from television or newspapers. In abandoning traditional forms of public communication in favour of diverse satellite and digital media, they tend to be highly technically skilled in finding information that resonates best with their own social interests and cultural concerns.

Against this background, Beckett outlines a model of 'Networked Journalism', involving a high degree of interaction between the media and the public in the production of the news, an approach which provides a useful starting point for thinking about more collaborative ways of using the media to promote health-facilitating social participation. This approach regards news as the outcome of high levels of cooperation and engagement between journalist and reader. At the early stage of a news story it would be made up of publicly generated material in a fairly unprocessed form. However what started off as a report on an event (e.g. a factory fire), could evolve into another story (e.g. about unsafe working conditions), as a wider range of people (e.g. factory workers, union officials, industrial health consultants) got involved in constructing the story of the event. In this model the journalist acts as facilitator and mediator amongst participants in a story-building network, rather than simply as author representing the event in question. This model further illustrates Hodgetts' distinction between a 'journalism of information' and a 'journalism of conversation or collaboration'.

### *Online patient communication*

Health websites and online discussion fora (message boards, journals, e-mailing lists and blogs) for those coping with disability or illness are growing steadily in popularity. Some research depicts these as a positive source of support, solidarity and activism, deeply empowering for parents of with autistic children, for example. Internet communication provides many parents with a vital opportunity to construct meaningful and constructive representations of the deeply complex and stigmatised condition of autism, often in the face of the failure of the health and educational

systems to offer their children the types of support and understanding they need. However other literature on the role of the internet paints a more complex picture. Orgad (2006) weighs up these complexities in her discussion of internet use by women with breast cancer.

Much has been written about the way in which biomedical treatments and approaches neglect the emotional and spiritual needs of cancer patients through an excessive focus on their physical tumours and complications, leaving many patients feeling alienated and unsupported with potentially very negative implications for their health (Crossley, 2000). Orgad's findings suggest that women with access to online communication often find it an invaluable tool in learning to cope with breast cancer and in generating vital support from similar others. Many women have used online communication to share experiences and to communicate with others in co-constructing life narratives in which they start to frame their experiences in ways that are meaningful to them. Through this process they are often able to regain a sense of control over their lives, a vital component of psychological healing.

However, Orgad argues that these positive possibilities are limited by the tensions and contradictions inherent in online communication as well as constraints from wider social structures. The 'disembodied anonymity' of online communication allows users to share personal stories with a high level of openness, but also creates relationships characterised by distance, which avoid the 'emotional price' extracted by conventional give-and-take interactions in the real world (Orgad, 2006: 20). The structure and form of online patient communication can increase a sense of closure and control, but can also constrain stories to a pre-determined and limiting formula. Orgad found that online postings tended to be constructed within unwritten rules, dictating that stories should focus on hope, optimism, success and survival, discouraging scripts that did not fit in, such as stories of hopelessness, anger, death and broader social discontent.

A further constraint of online communication, particularly relevant to the concerns of this chapter, is its contribution to what Orgad refers to as 'the privatisation of illness experiences' – the construction of illness as a predominantly intimate, individual and domestic drama. Through effectively containing patient voices within anonymous and disembodied internet spaces, online patient communication reduces the potential for patient experiences and issues to be heard offline, by policy makers, health professionals and others in the general public, where they could have broader social and political effects.

The much-heralded possibilities of networked communication for health and social change are limited in many ways. Whilst internet communication certainly opens up some possibilities for increasing the power of ordinary people to frame debates about their health and well-being, these opportunities are limited to those who have access to this form of communication. They may be shaped and constrained by powerful and limiting social representations about social reality, health and healing – which arise either from dominant forms of power-knowledge in the wider society, or from dominant groups within the internet site itself, as Orgad's case study shows.

There is also the worrying potential for the internet to fragment audiences. In the face of the sheer volume of material online, audiences may become segmented into groups that only access sites representing their particular interests, with not enough networking or engagement between different internet sites. Furthermore, the controversial rise of potentially health-damaging websites, such 'pro-ana' websites in which anorexic girls trade tips on how to evade parental or hospital surveillance of their diet and behaviour, raise a host of complex questions about what constitutes health-related empowerment, and about the role of the internet in this process.

## Conclusion

There is growing interest in the potential impacts for 'community strengthening' approaches to provide opportunities for people to develop a critical awareness of the social roots of many health threats, as well as bonding and bridging networks of health-enhancing solidarity and support - as the first step to working collectively towards health-enabling social change. This chapter has been framed by a conceptual framework which maps out some of the psycho-social pathways between social participation and health, drawing on Paulo Freire's (1973) argument that sustainable and long-term individual behaviour change is most likely to occur when people work collectively to understand and tackle the social circumstances that place their health at risk. Against this background various forms of mediated communication have been examined, highlighting their potential for providing 'transformative social spaces' for critical reflection, dialogue and social capital construction. In ideal circumstances, such reflection, dialogue and networking enables people to develop actionable insights into the links between social inequalities and ill-health, an increased sense of agency to challenge the negative impacts of social inequalities, and strong networks that might facilitate action at the individual, community and ideally even macro-social levels.

Ideally the development of such dialogue, agency and solidarity paves the way for the political and economic changes necessary to *challenge* the unequal social relations that place their health at risk. However large scale social change is often a long-term process whose outcome is by no means certain. A parallel interim measure may be that of health-vulnerable groups working together to develop practically feasible ways of *ameliorating* the impacts of negative social relations on health rather than changing them.

Few of the strategies outlined above have been formally evaluated, and this chapter has sought to map out the psycho-social mechanisms underlying their potential impacts rather than to engage with the programme evaluation literature. It is particularly difficult to evaluate such programmes, given the two kinds of challenges that face health communicators who see their role as more than simply transmitting information, seeking also to facilitate the forms of dialogue, empowerment and social capital construction that are believed to impact on health. The first outstanding challenge is that of developing more detailed and fine-grained insights into the complex and multi-layered pathways between communication strategies and processes of individual and social change. The second challenge is that of

developing research tools and research designs that are able to identify and track the types of complex and multi-layered individual and social processes that we have discussed in this chapter. These are often unpredictable, and may unfold over longer periods of time than those available to the average programme evaluator, as well as taking complex and indirect forms and routes to health-enabling change, that are not immediately evident. Furthermore, the pathways between communication and health may take different forms in different local settings. In such a context, Auerbach *et al.* (2009) argue that complex health communication programmes will often of necessity often have to be guided by frameworks and models that have 'sociological plausibility', rather than being backed up by quantifiable evidence of the kind that would be preferred in the more linear, cause-effect, input-output models of behaviour change underpinning traditional public health evaluation research for example.

Notwithstanding the outstanding difficulties of providing an evidence base for community strengthening and social change approaches to health, the evidence for the links between social inequalities and ill-health is undeniable. Furthermore, within the international 'social determinants of health' field there is widespread acknowledgement that tackling health inequalities is likely to be an infinitely complex and long-term process, and involve careful and concerted action on many fronts, from the micro-local to the global levels (WHO, 2008). It is in this context that the concept of 'transformative social spaces' has much to offer those seeking to advance community strengthening approaches to health. On their own, one-off health communication campaigns are unlikely to constitute a 'magic bullet' capable of tackling the complex interface of unconscious factors, peer norms and social inequalities discussed in Box A. However, the patient and sustained efforts of activist health communicators – with careful targeting of efforts at both marginalised communities and the powerful actors whose decisions impact on their lives – constitute one important level of influence in a long-term multi-level process of social change to reduce health inequalities.

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### **Box 13.1**

#### **WHY DO PEOPLE KNOWINGLY ENGAGE IN HEALTH-DAMAGING BEHAVIOUR?**

Three sets of factors lead people to engage in unhealthy behaviours, even when they are in possession of accurate factual information about health risks and how to avoid

them. The first are *unconscious factors* – outside of the individual’s rational and conscious awareness – that nevertheless exert a profound influence on their behaviour. Research has found that socially isolated gay men in Norway are more likely to engage in unprotected sex than their more socially connected peers, with skin-to-skin contact symbolising unmet needs for intimacy. Over-eating may sometimes be driven by unmet needs for love and nurturing. Some young women use the strategy of under-eating to increase their sense of control over their lives. The second factors relate to *socially negotiated peer norms*. Whilst levels of cigarette smoking are falling amongst many groups in the UK, they are rising amongst teenage girls in Scotland, where smoking is often a key criterion for membership of particular friendship circles. Peer influence often drives abuse of illegal drugs and alcohol. Finally *socially structured power relations* undermine the likelihood that people will engage in health-enabling behaviours. Gender, poverty and social isolation make smoking a compelling behavioural option for many lone mothers in England, battling to cope with the overwhelming demands of their daily lives. The social construction of masculinity often leads men to ignore early signs of health problems, and to delay accessing vital health services when illness threatens. A combination of poverty and economic dependence on men leads many African women to engage in unprotected sex, despite sound knowledge of HIV/AIDS and a keen desire to avoid infection. See Crossley (2000) and the references therein for an account of this research.

### **Box 13.2**

#### **HEALTH ADVOCACY: TARGETING 'THE POWER GAP'**

Health advocacy is an approach that regards ill-health as the result of a 'power gap' rather than an 'information gap' (Wallack, 1994). Strategies seek to persuade powerful people to promote health-enabling social environments through campaigns:

- to pressurise politicians to develop policies and budgets that promote access to health care by marginalised groups; and reduce discrimination against women, the elderly and the disabled;
- to encourage pharmaceutical companies to lower the costs of life-saving drugs in poor countries;
- to 'name and shame' industries associated with polluting factories, unsafe working conditions or employment practices that discriminate against women;
- to challenge commercial companies that target young people through cigarette and alcohol advertisements.

Health advocacy is often implemented as part of a comprehensive toolkit of strategies to facilitate change, and efforts to target leaders often go hand in hand with grassroots activism. A frequently cited US example is the 'Million Mom March', which sought to promote public awareness of the dangers of guns that kill thousands of children every year. This campaign combined a public event involving the mass mobilisation of 'ordinary citizens' and the very successful mobilisation of media publicity. Starting with one mother's outrage at watching a high school massacre on television, the campaign ended up involving thousands of mothers in a march on Capitol Hill in Washington DC. This was a highly publicised event seeking to use the symbolic power of motherhood as a way of lobbying politicians to work towards stricter gun control to protect their children.