

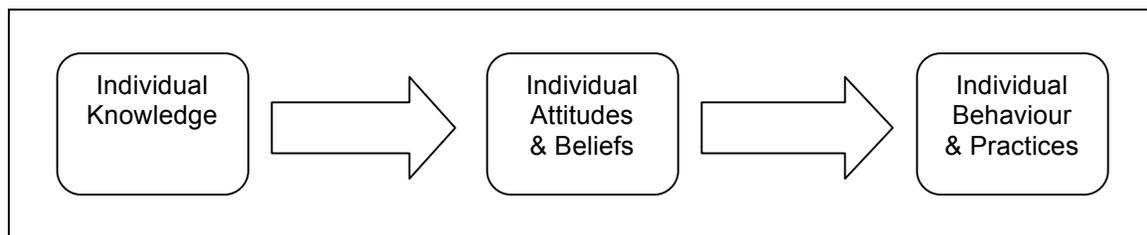
Putting the “Human” back into Human Immunodeficiency Virus research: A commentary on Helene Joffe’s (1996) article, “AIDS research and prevention: A social representational approach”

SARA K. BELTON
London School of Economics

It has been over 30 years since the world first heard of the disease which has come to be known as HIV/AIDS, with the health surveillance journal *Morbidity and Mortality Weekly Report* noting its occurrence in homosexual men in the United States (AVERT, 2011). At that time in 1981, HIV/AIDS didn’t even have an official name, yet still resulted in the significant suffering and death of those infected with it. Since then, HIV/AIDS has developed into a truly global pandemic, leaving no corner of the world or population untouched, with over 33 million lives affected and with efforts to fight it receiving, in the year 2009 alone, over 18 billion US dollars in funding for research, care, prevention and treatment (UNAIDS, 2010). Yet despite the monumental global effort in fighting the disease, a major reduction in infections and deaths from HIV/AIDS remains an elusive goal. Helene Joffe’s 1996 article, “AIDS research and prevention: A social representational approach”, provides the reader with a critical review of one of the more popular health and HIV/AIDS research methods, the KABP paradigm, suggesting that part of the problem in fighting HIV/AIDS may be exactly how we conduct research on it.

In this paper, which draws on her 1993 doctoral thesis work on the social representations of HIV/AIDS held by members of the public and HIV-affected and at-risk groups in the United Kingdom and South Africa, Joffe (1996) takes on the established research paradigm of the day and still of today, the KABP study paradigm. The KABP study, where KABP stands for knowledge-attitude-belief-practice, or knowledge-attitude-behaviour-practice, has its origins in North American reproductive health surveys of the 1950s, where questionnaires were used to survey large populations, in order to evaluate reproductive health needs and practices (Launiala, 2009). This research method is still popular in the health sciences and is often used in conjunction with more recent theoretical models, the “Health Belief Model”, and the “Theory of Reasoned Action” (ibid). Both hold as a main assumption that increased knowledge levels about health problems are directly linked to attitude changes in favour of healthier lifestyles and result in behaviour changes which prioritize healthy life choices (Joffe, 1996). In essence, they suggest that if you know more about good health, you’ll want to be healthier and therefore you’ll choose healthier behaviours, as in Figure 1.

Figure 1: A Basic KABP Paradigm Conceptualization (after Joffe, 1996; Launiala, 2009)



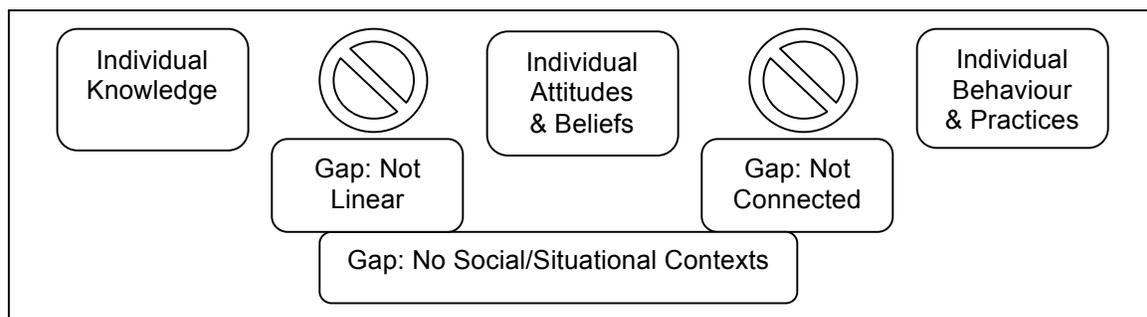
However, this underlying assumption of KABP studies fails in real life on two main points, which Joffe (1996) outlines well in her article. KABP studies assume that human behaviour is predictable and under conscious control of the individual (ibid). Sexual acts which have the potential to spread HIV/AIDS are essentially social acts, with shared negotiations between participants and are neither wholly individually-controlled nor predictable (ibid). Also, the KABP paradigm assumes that individuals will always make decisions in a reasoned way and that thoughts lead in a direct, linear way to actions (ibid). As these assumptions miss key aspects of human behavior and social circumstances, the research scope and findings produced are limited in their applicability to real-life social

situations. Joffe (1996) suggests that using a social representations approach would improve research findings, through a better understanding of the underlying social factors impacting on HIV/AIDS and outlines how that can be done.

IMPORTANCE OF THE ARTICLE FOR THE SOCIAL REPRESENTATIONS FIELD

Although there are many problems with the KABP model in terms of theory and procedure, Joffe focuses on key gaps for HIV/AIDS research in her article, shown in Figure 2. These gaps are the lack of situational and social contexts and the assumption that knowledge leads to attitude and behavior change in an individualistic, linear way. For researchers using social representations theory, the individual cannot and must not be divorced from the society in which he or she lives and this social milieu must always be examined in concert with individual views and interpretations of ideas (Jovchelovitch, 2007). Acknowledging the dynamic interplay between individuals and the social forces at work in the society in which they live, in order to integrate new or controversial knowledge and ideas, is the key component of social representations theory and the strongest asset of this approach (Joffe, 1996). It is precisely this strength of social representations theory that makes it ideal for researching HIV/AIDS and the social impact it has on communities and their health (ibid). Joffe's article remains a "call to arms" for more social representations health research and has interesting implications for the field, in the light of the continued popularity of the KABP model (Launiala, 2009).

Figure 2: An Outline of the KABP Gaps (based on Joffe, 1996)



Within the social representations community, health has been an area of research interest since Herzlich's (1973) original examination of the social representations of health and illness. However, it is Jodelet's (1991) study of the impact of social representations of mental illness on the daily practices of people who were hosting mentally ill people in their homes in a French village, that is perhaps the seminal work in illustrating how social representations both influence and underlie actions taken. More recently, Gervais & Jovchelovitch (1998) examined the social representations of Traditional Chinese Medicine and Western medicine held by Chinese immigrants to the UK and their impact on health care usage. Correspondingly, Flick et al. (2002) examined how the social representations held by health care workers impact on how they conceptualize and provide care to their clients. Such findings illustrate Wagner's (1994) assertion that it is actually social representations which underscore actions; given this, not examining the underlying social representations of a society means that researchers are missing key information and views which shape the way people perceive health and their health care options within a society.

Unfortunately, in terms of HIV/AIDS research globally, the trend has been to favor biomedical and clinical studies over socially-based studies, with the unintended consequence that health interventions and programming have often been not only ineffective, but directly at odds with the wider social context of the communities involved (Campbell, 2003). Such cultural clashes not only prevent effective research from being done, but can also damage community relations and prevent the uptake of provided services or programming altogether (Campbell & Cornish, 2010). Campbell's analysis of the Summertown project demonstrates how competing priorities and goals, as well as unacknowledged underlying sociocultural and political tensions, impacted negatively on the uptake and long-term viability of HIV/AIDS intervention projects in the community (2003, p. 151-165). Barnett & Whiteside devote a whole chapter in their book to country case studies which reflect how the cultural collision of international ideologies with local sociocultural realities, often result in mistrust, misunderstandings and missed opportunities for improved health research and program outcomes (2006, p. 110-138). Although such researchers make a strong case for the wider use of a social representations theoretical approach, the global HIV/AIDS research community has been

reluctant to respond, particularly given the new UNAIDS-led biomedical movement towards increased HIV/AIDS testing and drug interventions, called “Treatment as Prevention” (UNAIDS, 2010).

Despite such challenges, there is a determined cohort of researchers working in HIV/AIDS from a social representations theoretical approach. In fact, even Serge Moscovici himself has stated that social representations theory is an excellent way to conduct research on HIV/AIDS, given its social impact and importance in our societies, interpersonal relations and world (Moscovici & Markova, 1998). Notable HIV/AIDS researchers using a social representations approach within sub-Saharan Africa includes Cathy Campbell and associates, in South Africa, Kenya and Zimbabwe, who have examined the impact of HIV/AIDS on communities, in terms of service uptake versus sociocultural norms, HIV stigma and orphanhood and the impact of masculinity norms on HIV service uptake (see Campbell, 2003; Campbell et al., 2010, Skovdal et al., 2011). Such research highlights how using a social representations framework allows one to uncover the impact of representations and social context on health choices. Joffe & Bettega (2003) examined the role of risk and identity amongst adolescents in Zambia, in terms of their risk perceptions of HIV/AIDS. Winskell et al. (2011) and Riley & Baah-Odoom (2010) have also used frameworks influenced by social representations to conduct health research related to HIV/AIDS in sub-Saharan Africa, although they express concerns in how interpretation and method selection impacted on their results.

Outside of the sub-Saharan African context, HIV/AIDS research using social representations theory has been conducted on HIV/AIDS and risk perceptions in the general UK population (Kitzinger in Marková & Farr, 1995) as well as in its prison populations (Marková et al., 1995). It is interesting to note that researchers using a social representations approach to examine the community impact of HIV/AIDS, as noted above, have generally focused their efforts exclusively on one particular geographical region or another. In contrast, Joffe’s article (1996) is the only one to compare and contrast both the sub-Saharan African context and the European context of HIV/AIDS, particularly in terms of risk perceptions, sociocultural context and the role of social identity in protecting the self by displacing stigma onto social out-groups. Not only is it key research in terms of risk, stigma and HIV/AIDS, but it also clearly outlines social

representations theory and applies it to a “real world” problem, making it very accessible to those new to the social representations field.

IMPLICATIONS OF THE ARTICLE, CONTROVERSIES AND FUTURE DIRECTIONS

Much of the author’s current area of research has been influenced by Joffe’s (1996) article and it raises lingering questions for the social representations community. Although it has been 16 years since the article was first published, in terms of HIV/AIDS research, positivistic, biomedical research and interventions remain the main mode of research, particularly now that UNAIDS is advocating for increased global access to antiretroviral drugs through its “Treatment as Prevention” campaign (2010). Although there is no doubt that drug intervention is important and life-saving with good biomedical research demonstrating that need, key personal and social aspects of the lived experience of chronic illness have not yet been studied in connection with the illness of HIV/AIDS (ibid). We simply do not know how the millions of people who would be the recipients of such drugs will see them, incorporate them into their daily lives and will, in effect, “live” with them and whether they will be successful in adhering to treatment or not. Given that HIV/AIDS is a highly stigmatized, socially complex illness, further research is needed, ideally from a social representations theoretical approach.

In this regard, Joffe’s study is crucial, as many of the issues she discussed in 1996 are still informative for these pressing areas of HIV/AIDS research. As the article discusses the social representations of HIV/AIDS as held by a dominant yet unaffected social in-group and compares them with the representations held by the minority affected out-group, it also examines the implications of such power dynamics within a society, in terms of social identity, and the concept of “spoiled identity” as linked to out-groups (Joffe, 1995, 1996, 1999; Howarth, 2002). Using examples from her research, Joffe (1995, 1996) outlines how the dominant social representations within a society can become the normative ones and can be internalized by minority members; this process may be further reinforced by power differentials and serve to prevent alternate social representations from being expressed within the society. As the advent of effective drug

interventions for HIV/AIDS is now a reality, the impact of drugs on the dominant social representations of HIV/AIDS in a society should be re-examined; such research is being conducted by the commentary author.

However, attempting to change the dominant social representations, or to alter them to better fit the wider social realities and experiences, is often extremely difficult, due to these inherent power differences between social groups (Joffe, 1996). Joffe cites the example of how, at the time, the British gay movement was instrumental in bringing about changes in the way HIV/AIDS was portrayed in society, via media and political engagement, and how this in turn began to alter the social representations of HIV/AIDS appearing in Britain (ibid). However, without the empowerment, mobilization and action of the most-affected minority groups, the existing social representations in a society may not change, or may even be reinforced, to protect the social status quo favoring the majority (ibid). In this regard, the question of “whose social representation is it?” is one researchers must always consider when conducting research.

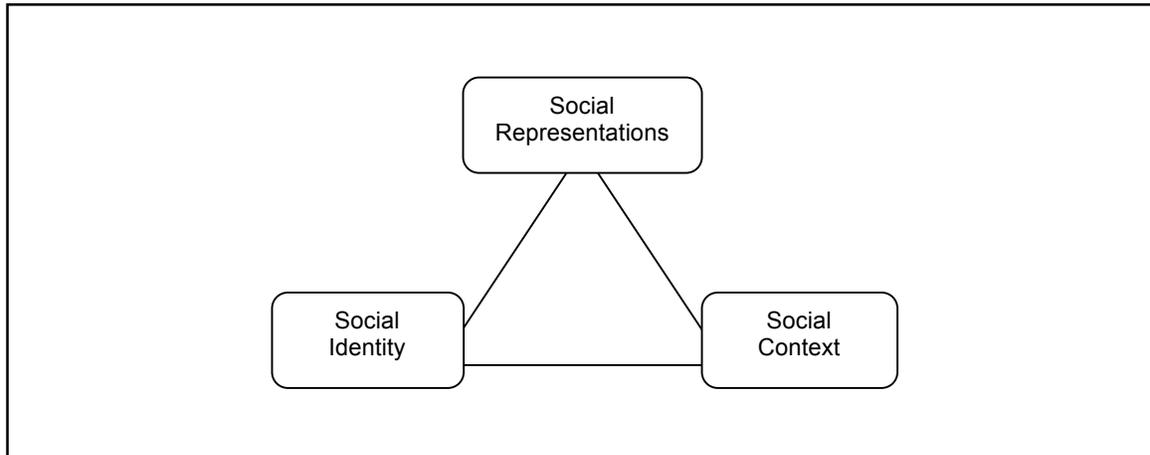
IMPORTANCE OF THE ARTICLE OUTSIDE THE SOCIAL REPRESENTATIONS FIELD

Although social representations theory is well-known in Europe, it is still not as well known in North America, particularly the United States, where most psychology and health research programmes have been developed based on behaviouristic and biomedical models, which favour the individual over society and take a positivistic approach (Launiala, 2009). Not only has this shaped the way such research is conceptualized, it also impacts on how it is conducted and what findings result, which often cause a mismatch between research outcomes and the social realities as lived by participants. Contrasting such results with those of Joffe (1996) and others, as has been done above, illustrates how crucial a role social representations research can play in expanding our understanding of health behaviours and the social and personal forces underlying health choices. Further expansion of social representations health research is an exciting area of growth and is clearly needed to improve health research and programming outcomes, by reconnecting findings on individuals and the social world.

The case for using a social representations theoretical approach in health care research can be furthered by linking it to wider, related theoretical considerations and models. In particular, social representations research can be combined with that on social identity to produce powerful findings, such as the work done by Howarth (2002) on the conflux of social identity, stigmatization and social representations in the Brixton community in London, England, in exploring questions of race, community and identity (see also Howarth, et al., 2004). The work by Campbell and Cornish (2010) has also emphasized the role of social context and representations in health research, examining how symbolic, relational and material social contexts impact on health programming design and service uptake by communities.

By including both personal and social aspects of the lived experience in health research, findings which are more relevant to the society which generated them result. The use of a conceptual research model which would help examine these aspects in a systematic way, could help introduce social representations to a wider audience and increase its use among researchers who are more comfortable working from a linear, positivistic framework such as KABP studies (Launiala, 2009). Such a model would provide a clearer conceptualization of social representations for researchers new to social representations theory and help make the transition to a different way of conducting health research easier for them. The author of this commentary has developed such a model for use in her PhD studies, drawing on her background in both psychology and the health sciences and uses it as a tool to help conceptualize three key areas of study in her research, as presented in Figure 3.

Figure 3: The Social World Triad



This conceptual model, the Social World Triad, illustrates three key areas for health research, that of social representations, social identity and social context. These three aspects of social existence should be examined together, to provide a full picture of the social world in which research participants exist and act, in terms of health outcomes. By determining and evaluating these components together, as elucidated by the research participants themselves, the social world, or field, in which they exist and position themselves and their actions can be used to create interventions which are a better fit with how they perceive their reality to be.

As an example, the commentary author has used this model to help conceptualize data findings from fieldwork carried out on children's access to HIV/AIDS and health care in western Uganda, as a part of her PhD research. Data generated from qualitative research done with, in this example, health care workers, was analyzed using Attride-Stirling's (2001) Thematic Network Analysis method and this conceptual model. The author assigned the codes according to basic and organizing theme criteria as per Thematic Network Analysis (ibid). The organizing themes were then further discussed as per the Triad model, which illustrated the social representations held about HIV/AIDS, health care and children, the social identity of health care workers as it influences their work and the social context in which care is provided and the health care system operates. Whilst a more detailed discussion of the findings will be forthcoming in future articles,

this process allowed for a clear and systematic way of working with the data and a more succinct way of discussing the results, in terms of mapping out the social world in which the health care workers operated and how their interpretations and perceptions of their immediate reality impacted on their health care actions.

CONCLUSION AND POINTS TO PONDER

Even 16 years after the publication of Helene Joffe's article, its relevance and importance to both the field of social representations theory and health research remains clear: that a new research paradigm needs to be developed and put into use, to better understand the social aspects of health behaviour decisions. Using social representations theory as its base, this new paradigm could serve to assist researchers in finding new ways of conceptualizing and implementing health and HIV/AIDS programming, in ways that better reflect what people actually think, feel and do.

For too long, positivistic, biomedically-based health science research has separated the individual out from his or her social surroundings, under the false assumption that social context has no bearing on individual choice (Launiala, 2009). HIV/AIDS research, as well as health research in general, is slowly beginning to recognize that fallacy and recent research trends are beginning to rectify this misconception. As social representations theory has much to offer health research, it is hoped that it can be more widely adopted globally and that new conceptual models for research can be developed and used. Further advocacy for social representations theory outside of the discipline and introducing it into new geographic areas and interdisciplinary research, would provide new and exciting research opportunities and directions.

Despite the very thorough investigation of the social representations of HIV/AIDS undertaken in this article, there is one minor shortcoming (Joffe, 1996). One area of social representations theory not discussed in this article is that of cognitive polyphasia, although research on cognitive polyphasia and health choices has been conducted since then (see Gervais & Jovchelovitch, 1998; Provencher, 2011). Given how Joffe's (1996) article shows that the dominant social representations in a society will have an impact on

the way minority groups perceive themselves and their health, there is an impetus for social representations-based health research to consider any cognitive polyphasia which may occur in the society or social groups under investigation. Going back to Moscovici's original study and structuring research interventions in such a way, that the social representations held by varying social groups within a society can be examined in comparison to their specific sociocultural context, may be the best way of revealing competing representations regarding health behaviours and how they influence the health choices being made or rationalized (Moscovici, 2008; Provencher, 2007, 2011).

The author of this commentary hopes her research will contribute in this regard and encourages colleagues to also contribute to the continued development and use of social representations theory in health research. Revisiting Helene Joffe's research on HIV/AIDS and risk perceptions provides an excellent starting point for such research initiatives, in order to put the "human" back into Human Immunodeficiency Virus and health care research.

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SARA BELTON is a PhD student at the London School of Economics & Political Science, working with Professor Catherine Campbell at the Institute of Social Psychology. Her research focuses on improving access to HIV/AIDS and health services for children in western Uganda, using a Social Representations theoretical approach. A Registered Nurse originally from Canada, she is supported in her work by a Health Professionals Fellowship from the Canadian Institutes of Health Research. Email: s.k.belton@lse.ac.uk.