

APO^RRIA

LA REVUE EN SCIENCES INFIRMIÈRES • THE NURSING JOURNAL

Sommaire/Content

2013: Vol.5, Numéro 4/Vol.5, Issue 4

Éditorial/Editorial

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Le Protecteur du citoyen du Québec a récemment fait état des difficultés d'application de la Loi P-38 (Loi sur la protection des personnes dont l'état mental présente un danger pour elle-même ou pour autrui) par l'entremise d'un rapport publié en février 2011. Dans ce rapport, le Protecteur du citoyen souligne, en outre, des écarts importants entre les dispositions de la Loi et la manière dont elles sont mises en œuvre sur le terrain. Dans bien des cas, on note des situations dans lesquelles les droits des personnes mises sous garde (préventive, provisoire ou garde en établissement) ne sont pas respectés par les établissements de soins de santé et ses intervenants. Par conséquent, le Protecteur du citoyen a demandé au Ministère de la santé et des services sociaux d'élaborer des orientations afin d'assurer l'imputabilité des établissements en regard du respect des droits des personnes mises.

En tant que membre de la société civile, nous sommes portés à nous définir comme individus de droit. Nous estimons être des personnes dont la valeur et la dignité sont intimement liées à un sentiment d'appartenance et de respect collectifs; une appartenance et un respect qui définissent les balises de l'expérience citoyenne. Force est de constater que cette appartenance et ce respect s'avèrent incertains pour la personne aux prises avec un problème de santé mentale. Non seulement a-t-elle la responsabilité d'exprimer cette appartenance par le biais de comportements attendus (ex. retour au travail), mais elle est contrainte d'évoluer dans une société qui la construit comme une personne « à risque » (pour soi et pour les autres) (Perron et Holmes, 2010). Rares sont les conditions qui permettent de priver une personne de sa liberté et de ses droits. Toutefois, les questions relatives au risque et à la dangerosité associées aux problèmes de santé mentale font parties de ces conditions qui justifient une panoplie d'interventions (étatiques) préventives pour contrecarrer les dangers. L'expérience citoyenne, pour les personnes atteintes de troubles mentaux, se manifeste bien souvent comme une expérience en marge de la société. Alors qu'elles sont souvent recluses dans des institutions psychiatriques, leur expérience citoyenne représente bien souvent une lutte pour le droit à la reconnaissance et au respect.

Cette lutte à laquelle nous faisons référence est une lutte contre ces pratiques psychiatriques qui portent atteinte à la dignité humaine. Lorsqu'on ne reconnaît pas une personne comme un individu de droits, force est de constater qu'on ne lui reconnaît pas le même degré de

responsabilité au sein de la société. La privation de droit représente donc une atteinte à l'autonomie, mais aussi à l'estime de soi, où il devient difficile, dans ces circonstances, de s'envisager soi-même comme membre à part entière de la société (Honneth, 2000).

Ainsi, le processus d'exclusion, et les pratiques institutionnelles qui y sont rattachées, se traduisent chez la personne concernée, par une modification progressive des rapports à soi-même et à autrui. Au-delà des conceptions altruistes des soins psychiatriques, les rapports de sujétion entre le patient et le personnel prennent différents visages alors que le patient est contraint de se soumettre aux jugements de l'autorité en place. Ces rapports de force entre les personnes atteintes de problèmes psychiatriques et le personnel soignant sont bien connus et documentés. Pour la personne atteinte de troubles mentaux, ces rapports de forces donnent lieu à une nouvelle relation à soi-même, et d'autre part, une nouvelle relation avec les autres. Ce sont ces nouvelles relations, conséquences des atteintes au corps et à la dignité, qui se traduisent par une nouvelle identité citoyenne. Les pratiques psychiatriques en vigueur, celles que nous considérons routinières, naturelles et thérapeutiques doivent être problématisées. Il est temps de repenser à une citoyenneté inclusive, fondée sur une éthique de droits individuels et collectifs.

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Abstract

This is a case-control study about the relationship between the qualities of midwifery care, other factors, and the incidence of maternal mortality in the hospitals. Information collected were midwives placement, midwives working environment, and material support in the hospitals. Unmatched midwives placement leads to maternal mortality by 3.86 times compared to the matched midwives placement. Unmatched quality of midwifery care causes maternal mortality by 6.74 times compared to the matched quality midwifery care. Unmatched midwives working leads to maternal mortality by 1.11 times compared to the matched working environment. Also, unmatched support materials causes maternal mortality by 1.55 times compared to the matched support material. There is a relationship between midwives placement and maternal mortality with $p < 0.05$. There is also a significant relationship of quality of midwifery care to maternal mortality with $p < 0.001$ in the government-owned hospitals.

Key words materials support, maternal mortality, midwives placement, working environment

Maternal Mortality in West Sumatra Province: An Analysis of the Impact of Quality of Midwifery Care in the Hospital

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SISWANTO AGUS WILOPO, & OVA EMILIA***

Introduction

An estimated 529,000 women worldwide die from the complications of pregnancy and childbirth each year, but in developing countries, a woman is 46 times more at risk.[1] In West Sumatra Province, the maternal mortality rate (MMR) was 212 per 100,000 live births in 2011. The highest MMRs were in West Pasaman District, Padang Municipality, Padang

Pariaman District, Darmasraya, and Sawahlunto/Sijunjung District.[6,7] Quality assessment and improvement activities are relevant to the public health sector and community-based organizations in healthcare,[3] and thus, related stakeholders should be concerned because an improvement in performance by a pertinent institution can result in higher quality services.

Globally, a continuum of maternal and child health care is essential for the survival and well-being of mothers and newborns.[4] One of the recognized ways to prevent maternal death is to provide medical workers, including midwives, in sufficient quantities. Ideally, one midwife can serve 1000 childbearing women.[2] Throughout Indonesia, 751 midwifery institutions produce about 50,000 midwives per year. However, the practice fields are limited for midwifery students, making it difficult for them to achieve competency and ultimately affecting the quality of care.

In addition to complications of pregnancy that cannot be handled by untrained or unskilled midwives, maternal

mortality also results from various other factors. Women may face delays in reaching health centres because of the influence of social and cultural factors on decision making by families, or the lack of communication devices or physical access to these health services that makes referral difficult.[5] Once they reach hospital, they also face delays getting help.

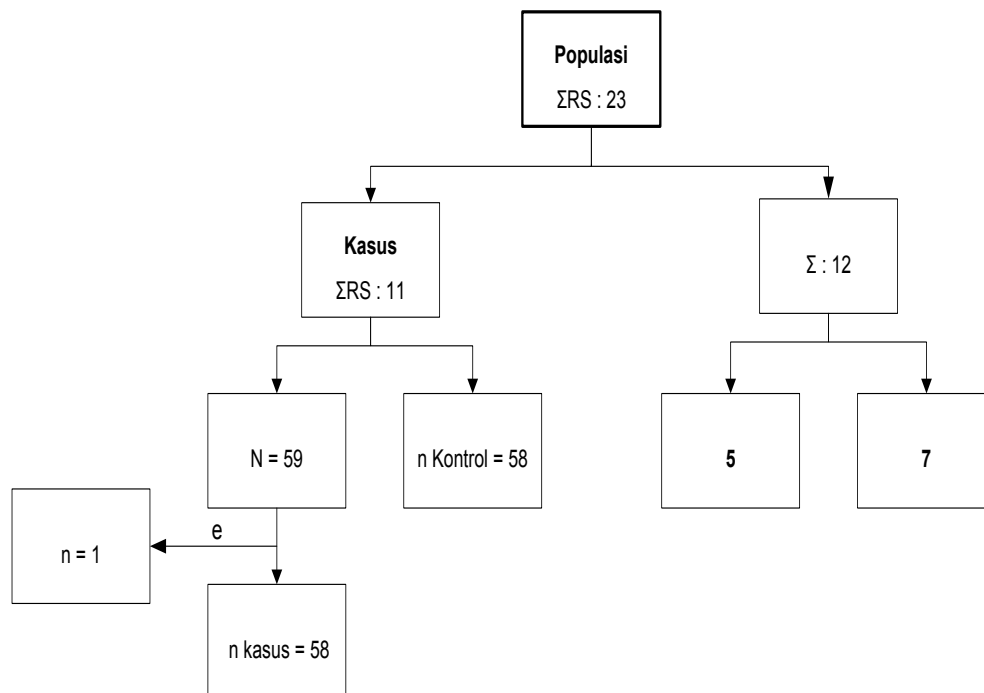
Other problems in hospital are administrative, in that the number of patients can sometimes exceed room capacity, and there is often a lack of material support or proper maintenance of equipment. Along with an unbalanced ratio in the number of health professionals and patients served, other problems include poor interpersonal relationships between health personnel and patients, and health workers sometimes lack motivation and have a poor work ethic. (8). In order to reduce the MMR, attention needs to be paid to the organizational factors of midwifery work, such as the placement of midwives and their practice environment. In general, there is a need to improve the quality of care by such efforts as improving the status of women, offering continuing education, developing midwife competency according to the standards of the International Confederation of Midwives (ICM) and, by improving the entire social context. Based on the above problems, the formulation of the research problem was: "Is there a relationship between the quality of midwifery care in hospitals and the number of maternal deaths in West Sumatra Province?" The objective of this study was to find ways to determine this relationship between the quality of midwifery care and other factors and the incidence of

maternal deaths in the government-owned hospitals in the West Sumatra province in the Republic of Indonesia.

Research method

This study used an unmatching case control design[9-11] with both quantitative and qualitative approaches. The quantitative approach identified clusters of cases and controls while the qualitative approach explored the deeper information needed to support or reinforce the results of the quantitative analysis. The qualitative approach was implemented with interviews with obstetricians as a function of collaboration in hospital. The study was conducted between March 1, 2012 and February 1, 2013, and West Sumatra Province was chosen as a location because of its high MMR. Eleven government-owned hospitals with maternal death cases were involved: M. Djamil General Hospital, Achmad Mochtar Local Hospital in Bukittinggi, Hanafi Batu Sangkar Local Hospital, Solok Local Hospital, Adnan Wd Local Hospital in Payakumbuh, Lubuk Sikaping Local Hospital, Pariaman Local Hospital, Sungai Dareh Local Hospital, Sijunjung Local Hospital, Pasaman Barat Local Hospital, and Pesisir Selatan Local Hospital. The study was carried out in stages: data collection of the midwives' placement and hospital-based maternal mortality data, observation of the midwives' working environment and the support material available, and assessment of the quality of midwifery care. Primary data was also collected directly through interviewing the respondents, by using a questionnaire based on the registers

Figure 1: Chartflow of research sample collection



or hospital reports. The questionnaires were taken by the Safe Motherhood Assessment Tool.[12]

Preliminary stages of the study included obtaining ethics approval, and assigning interviewers and training them to conduct interviews as well as with some obstetricians and gynecologists at the hospitals. Initially, the study population was all women giving birth at the 23 hospitals in West Sumatra Province, but the number was decreased to the 11 in which women had died in childbirth. The subjects were divided into two 2 groups: the case group consisting of mothers who died during pregnancy, in childbirth, or during the postpartum period, and the control group consisting of mothers who lived through their experience in these 11 hospitals.

This study used three kinds of variables: a) the dependent variable, which was the maternal deaths acquired in the Emergency Room, maternity room, Intensive Care Unit, maternity care unit, and operating theater in the 11 government-owned hospitals; b) the independent variable, which consisted of the individual level of placement of midwives (midwife ratios, qualifications, and positions) and the institutional hospital level, which consisted of the

organization and material support of the midwives' working environment; and c) the intervening variable, which was the process of midwifery care that included self-service, collaboration, referral, and continuing care.

The sample size used the 2008 PASS program with a comparison of case and control group of 1:1; thus, the number of respondents was 58 cases and 58 controls. The total number of samples in the study, therefore, amounted to 116 respondents.

Data analysis in this study includes univariable, bivariate, and qualitative analysis. In order to test the hypothesis, this study uses the χ^2 (Chi-Square) statistical test with a significance level (p value <0.05) or 95% confidence interval.

Results

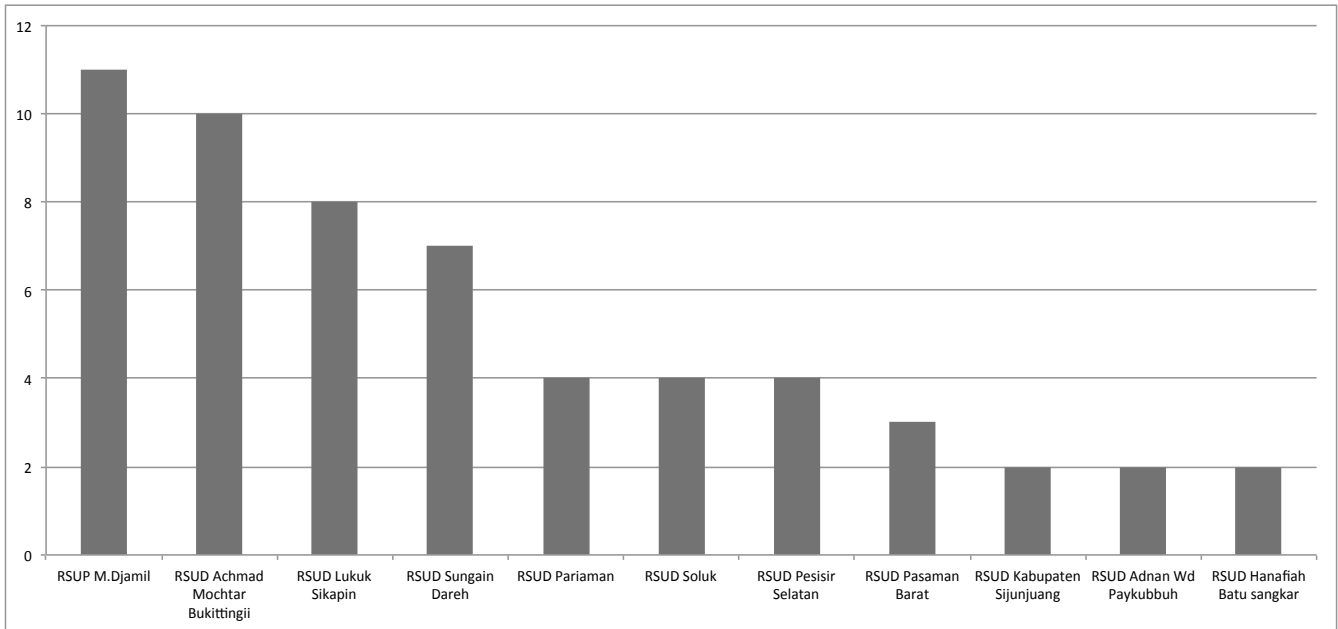
1. Descriptive data

Table 1 shows that 27 women (46.5%) obtained secondary education in the case group while 17 women (29.3%) did so in the control group. Twenty-nine (50%) of women in the case group were referral patients while 29 (50%) of women in the control group came alone (were not referred).

Table 1: Characteristics of case and control groups in government-owned hospitals in West Sumatra Province

Variable	Maternal deaths				p
	Dead		Live		
	n	%	n	%	
Gestational age					0.004
Trimester 2	8	13.8	0	0	
Trimester 3	48	82.8	58	100	
<i>Postpartum</i>	2	3.4	0	0	
Age					0.385
<20 years	1	1.7	1	1.7	
20-35 years	34	58.6	41	70.7	
>35 years	23	39.7	16	27.6	
Education					0.166
Primary	1	1.7	2	3.5	
Secondary	27	46.5	17	29.3	
High school	29	50.0	39	67.2	
Higher education	1	1.7	0	0	
Origin of patients					0.000
Referral	29	50.0	0		
Self-admission	29	50.0	58	0100	

Figure 2: Data on deaths found in 11 hospitals in West Sumatra Province



2. Outcome of data

The highest number of deaths (n=11) occurred in the Dr. M. Djamil hospital in Padang. This facility is the referral centre for the central region and is the leading public hospital for the Sumatra area.

Figure 3 demonstrates that the leading causes of death are hypertension, pre-eclampsia and eclampsia (44.8%), followed by hemorrhage (31%). According to Indonesian health profiles (2007), the leading cause of maternal deaths in that country is hemorrhage (28%) followed by eclampsia

(24%). Anemia and chronic energy deficiency (CED) in pregnancy are the major causes of bleeding and infection and factor heavily in maternal mortality. In many countries, at least a quarter of all maternal deaths are due to hemorrhage; the proportion ranges from less than 10% to nearly 60%.

3. Bivariable Analysis

Table 2 shows that 69% of the midwives' placement mismatch occurred in the case group compared to 43% in the control group. Analysis results obtained an OR value of 2.93 (95%

Figure 2: Data on deaths found in 11 hospitals in West Sumatra Province

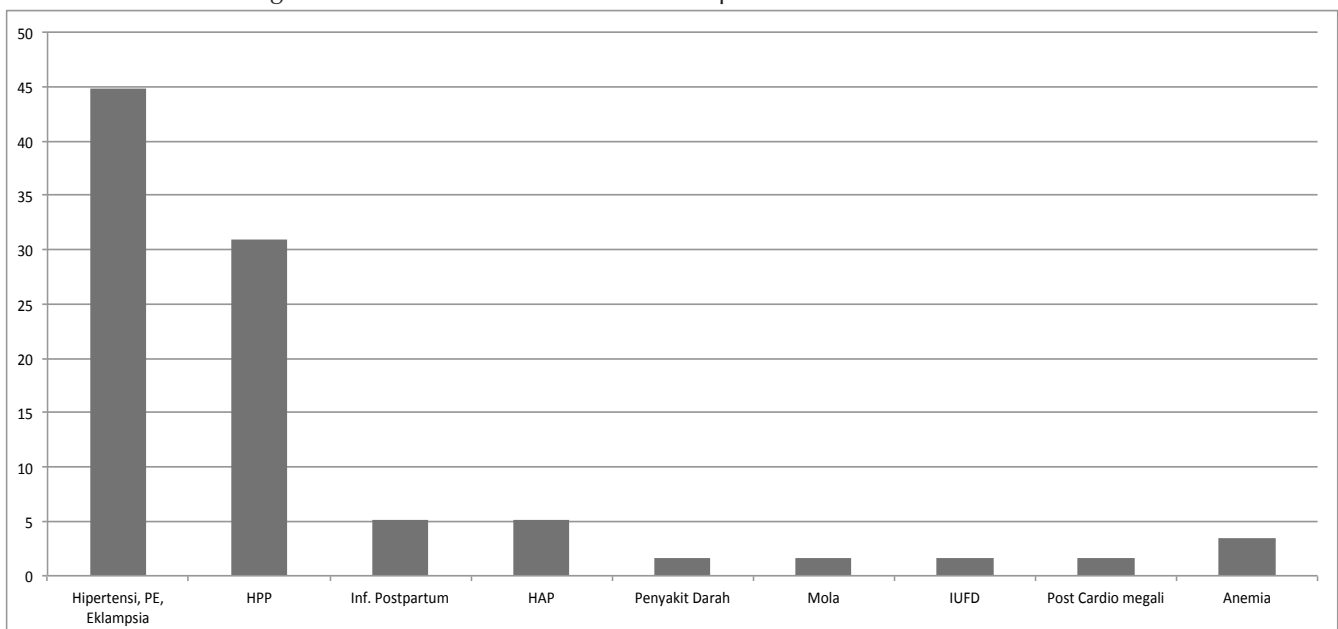


Table 2: Characteristics of case and control groups in government-owned hospitals in West Sumatra Province

Variable	Maternal deaths				p	95% CI
	Case		Control			
	n	%	n	%		
Midwives' placement						
Ratio						
Unmatched	33	56.9	17	29.3	3.18	1.38-7.39
Matched	25	43.1	41	70.7		
Qualification						
Unmatched	19	32.8	0	0.0	-	7.17-
Matched	39	67.2	58	100.0		
Position						
Unmatched	28	48.3	19	32.8	1.91	0.84-4.36
Matched	30	51.7	39	67.2		
Placement index						
Unmatched	40	69.0	25	43.0	2.93	1.28-6.75
Matched	18	31.0	33	57.0		
Quality of midwifery care						
Independent care						
Unmatched	42	72.4	22	37.9	4.29	1.83-10.16
Matched	16	27.6	36	62.1		
Collaboration						
Unmatched	33	56.9	19	32.8	2.70	1.19-6.19
Matched	25	43.1	39	67.2		
Referral care						
Unmatched	38	65.5	16	27.6	4.98	2.11-11.90
Matched	20	34.5	42	72.4		
Continuing care						
Unmatched	40	69.0	20	34.5	4.22	1.81-9.90
Matched	18	31.0	38	65.5		
Index of quality of midwifery care						
Unmatched	44	75.9	22	37.9	5.14	2.15-12.47
Matched	14	24.1	36	62.1		
Midwives working environment						
Unmatched	27	46.5	26	44.8	1.071	0.48-2.37
Matched	31	53.5	32	55.2		
Material Support						
Unmatched	21	36.2	20	34.5	1.078	0.46-2.47
Matched	37	63.8	38	65.5		

Table 3: Analysis of the relationship of midwives' placement, midwives' working environment, and material support to quality of midwifery care in government-owned hospitals in West Suma-

Variable	Quality of midwifery care				p
	NC		C		
	n	%	n	%	
Midwives placement					
Ratio					
Unmatched	29	58	21	42	0.835
Matched	37	56.1	29	43.9	
Qualification					
Unmatched	8	42.1	11	57.9	0.155
Matched	58	59.8	39	40.2	
Posisi bidan					
Unmatched	30	63.8	17	36.2	0.213
Matched	36	52.2	33	47.8	
Index of midwives placement					
Unmatched	43	66.2	22	33.8	0.023
Matched	23	45.1	28	54.9	
Midwives working environment					
Unmatched	39	73.6	14	26.4	0.001
Matched	27	42.9	36	57.1	
Material support					
Unmatched	32	78.1	9	21.9	0.001
Matched	34	45.3	41	54.7	

CI: 1.28 to 6.75). The unmatched midwives placement in the case group was 2.9 times more than in the control group. The mismatch in quality of midwifery care between the case and the control groups was 75.9% and 37.9%, respectively. Analysis results obtained an OR value of 5.14 (95% CI: 2.15 to 12.47). The unmatched quality of midwifery care in the case group was 5.1 times more than that in the control group.

The mismatch in the midwives' working environment in the case group was 46.5% compared to 44.8% in the control group. Analysis results obtained an OR value of 1.07 (95% CI: 0.48 to 2.37). The unmatched working environment in the case group was 1.07 times more than in the control group. The mismatch of material support between the case group and the control group was 36.2% and 34.5%, respectively. Analysis results obtained an OR value of 1.07 (95% CI: 0.46 to 2.47). The unmatched material support in the case group was 1.07 times more than that in the control group.

Table 3. Analysis of the relationship of midwives' placement, midwives' working environment, and material support to

quality of midwifery care in government-owned hospitals in West Sumatra Province

In Table 3, the mismatch of midwives' placement and quality of care obtained in the case and the control groups was 66.2% and 33.8%, respectively. The analysis showed a significant association between midwives' placement and quality of care ($p = 0.023$). The mismatch of working environment to quality of midwifery care in the case group was 73.6% compared to 26.4% in the control group. The analysis showed there was a significant correlation between working environment and quality of midwifery care ($p=0.001$). The mismatch of material support to quality of care in the case group was 78.1% and in the control group was 21.9%. The analysis showed there was a significant correlation between material support and quality of care ($p= 0.001$).

After considering hospital level, the unmatched midwives' placement would cause a maternal mortality 3.86 times greater when compared with the matched placement. The unmatched quality of midwifery services would cause a

Table 3: Analysis of the relationship of midwives' placement, midwives' working environment, and material support to quality of midwifery care in government-owned hospitals in West Suma-

Variable	Level 1	Level 2	Level 3	Level 4
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Midwives placement				
Unmatched	3.86 (1.60-9.31)			
Matched	1			
Midwife quality				
Unmatched		6.74 (2.73-16.61)		
Matched		1		
Working environment				
Unmatched			1.11 (0.44-2.81)	
Matched			1	
Material support				
Unmatched				1.15 (0.40-3.31)
Matched				1

maternal mortality 6.74 times greater when compared with the matched quality of midwifery services. The unmatched midwives' working environment would lead to a greater maternal mortality by 1.11 times compared with the matched midwives' working environment. Additionally, the matched material support would cause a greater maternal mortality by 1.15 times compared with the matched material support.

Discussion

1. Quality of midwifery care, which is better in hospitals with the matched midwives' placement compared with the unmatched midwives' placement

The dimension of midwives' placement consisted of midwife ratio, qualifications, and position. Table 2 shows the mismatch of 69 percent of midwives placement in the case group compared with 43% in the control group. The analysis results obtained an OR value of 2.93 (95% CI: 1.28 to 6.75). It was found that the mismatch midwives' placement was 2.9 times in the case group more than that in the control group.

In Table 3 concerning the analysis on the relationship of midwives' placement to quality of midwifery care, the mismatch in the case group and the control group was 66.2 percent and 33.8%, respectively. The analysis showed a significant association between the midwives' placement and quality of care ($p = 0.023$). Table 4 shows that, after

considering the level of hospital, there was the unmatched midwives' placement that caused maternal mortality of 3.86 times compared with the matched midwives' placement.

WHO and several other health organizations have identified midwives as key to reducing maternal and infant mortality and disability globally.[14] They play an important role in the lives of mothers and their babies,[13] boosting self-confidence in women and strengthening their commitment to parenthood. Results from the research and the interviews undertaken in this study found that the level of competence of Indonesian midwives has not yet reached international standards due to inadequate training and the number of midwifery institutions without proper practice fields for their students. Therefore, midwifery institutions must continue to develop curriculum and learning strategies in order to reach the expected competencies. Improved education and training of lecturers are needed to address these challenges.

A high quality of care depends on competent midwifery services and thus proper planning should be taken to meet these needs. Midwives, as professionals, are obliged to provide services to the public and must have core competencies to be able to carry out their function in providing quality midwifery services.[19] The assessment of quality services can be done by using ServQual dimensions, namely Responsiveness, Assurance, Tangible, Empathy, and

Reliability (RATER). Using RATER, healthcare providers can explore perceptions of patients/ care users about the quality of health services that they have received. Thus, a shared understanding related to the quality of services expected can be obtained between providers and users.[20] The quality of the interaction between the patient and the service provider, in this case the midwife, depends on several elements: quality of communication, ability of midwives to maintain patient confidence, and ability of midwives to provide services to patients with care, empathy, honesty, and sensitivity.[21] A high quality service, which is expected to maximize the well-being of patients, can thus be determined logically.[22] Its intended objective is a state of health, and a quality service is only obtained if a midwife can help her patients achieve appropriate levels of health to enjoy a healthier life.[22]

As healthcare providers, midwives have an important and strategic position in helping to reduce maternal and infant morbidity and mortality and in preparing the next generation. A sufficient number of midwives who have acquired competency through a standardized education is necessary to meet service needs throughout all healthcare facilities.

Midwives must meet standards of professional practice and abide by a code of ethics, but they also must be supported by adequate facilities and infrastructure. Adequate midwifery services will spearhead a reduction in the MMR,[15,16] According to the Minister of Health of the Republic of Indonesia,[17] healthcare excellence depends on a high quality of care, leading to satisfaction at both the level of the patient as well as the general population. Health care providers should be supported by sound knowledge and technical competence in order for them to engage willingly in productive work and harmonious working relationships. The application of professional standards of care that include a comfortable work environment and an adequate living wage will help to produce competent and motivated workers.[18]

2. Quality of midwifery care which is better in the matched midwives working environment compared with the unmatched midwives working environment

In Table 2 regarding the results of analysis on midwives working environment, the mismatch in the case and control groups was 46.5 percent compared to 44.8 percent, respectively. The analysis results obtained the OR value of 1.07 (95% CI: 0.48 to 2.37). It was found that unmatched working environment was 1.07 times more than matched working environment.

In Table 3 that shows the analysis on the relationship between midwives working environment and quality of

care, the mismatch of midwives working environment in the case group was 73.6% and in the control group was 26.4%. The analysis showed that there was a significant association between midwife working environment and quality of midwifery care ($p = 0.001$). Additionally, table 4 shows that, after considering the level of hospital, unmatched midwives working environment would lead to maternal mortality by 1.11 times compared with matched midwives working environment.

From the observations and interviews conducted for this study, there was little leadership for midwives, as suggested by irregular meetings. The process of recording and reporting was not timely and the feedback from the maternal audit was not maximized.

Research conducted by Franco-Santos, Kennerley, et al.[23] demonstrate that organizational culture and working conditions are determinants that affect employee motivation in public hospitals in Jordan. Sorrentino and Vielhauer[24], in their study conducted in a metropolitan hospital in Chicago, state that in situations where the head nurse assigns tasks to his or her subordinates in ambiguous language, subordinates were confused about what form the task took, the clarity of the task, and ultimately lost respect for their work. Effective leadership and supervision is important to ensure quality care to patients. The Path-Goal leadership model encourages leaders to motivate subordinates for effective performance in the workplace environment by implementing support training and providing awards.[24]

Individual characteristics have a positive and significant impact on work motivation. The results of this study found that midwives who were interested in midwifery from an early age, and who were interested in it not merely as a source of income but had a passion for helping others and for carrying out their duties in a professional manner, were more highly motivated. Research by Kuvaas and Dysvik[25] demonstrates that the basic elements of a good working atmosphere, congenial work relationships, a safe physical environment, and job security along with recognition for achievement and increased responsibilities motivated workers to perform better.

Suswati[26] suggests characteristics of an organization, including its policies, culture, and environment also affect the motivation of midwives. Wang and Noe[27] contend that rewards for employees for their achievements and constructive feedback on their work can also increase work motivation. Motivation increases when nurses are empowered, when they are able to undertake self-development autonomously and

have the opportunity to be innovative; these factors improve their competence and encourage them to perform their tasks professionally according to their skills.[28] Decisions are made by considering input from employees; in this case, information-sharing mechanisms can be delivered quickly by improving coordination between nurses and physicians. Interpersonal communication must be effective; if there are conflicts, they need to be resolved constructively.

The main motivating factor for health workers is appreciation by their leaders, colleagues, and others in their working environment. Low salaries and difficult working conditions, however, work to disadvantage this environment. Activities associated with rewarding still get less attention; thus, performance is not optimal. Therefore, ways to encourage employees that are not financial in nature should be taken into consideration for the development of human resources.[29] Supervisory systems and working conditions also require attention so that skilled workers can achieve their full potential. A research study in Vietnam shows that tightly controlled supervision does not help services. Findings from Zimbabwe, Benin, Vietnam, and Armenia all emphasized the importance of achievement and community recognition for health professionals.

3. Quality of midwifery care which is better with the matched material support compared with the unmatched material support

Table 2 shows the mismatch in material support that the mismatch in the case group was 36.2% compared with 34.5% of that in the control group. The analysis results obtained an OR value of 1.07 (95 % CI: 0.46 to 2.47). It was found that unmatched material support was 1.07 times more than the matched material support.

Table 3 shows the analysis of material support to quality of care. It obtained a mismatch value in the case group of 78.1% and in the control group of 21.9%. The analysis showed there was a significant correlation between material support and quality of midwifery care ($p = 0.001$). In Table 4, after considering the level of hospital, it obtained that the unmatched material support would cause maternal mortality by 1.15 times compared with the matched support material.

Material support in each hospital varied according to the type of hospital and the availability of funds. In general, hospitals had tools in accordance with SOP but they were not sufficient. In addition, the limited number of ambulances at hospitals and health centers often resulted in referral cases being overlooked. Blood supply problems were often caused by inadequate blood storage facilities.

Some hospitals had problems with infrastructure, leading to lower quality of service, less motivated health professionals, and infectious diseases in the community, all of which caused a lack of societal acceptance. Poor and rural communities often suffer the most because because health centres and hospitals often do not exist there.[30,31] Problems with infrastructure include (a) no buildings available or poor quality design and construction of those that do exist, (b) inadequate maintenance, and (c) lack of utilities such as water, electricity, fuel, or telephone.

It has been estimated that almost 40% of the medical equipment in developing countries is not in accordance with the needs of the services required.[32] Finding even the most basic items remains a problem. The availability of equipment has a very important function in providing care. International agencies from developed countries who donate equipment to developing countries have caused some difficulties since the operation and maintenance of some of the donated equipment is too sophisticated.[33] Using vacuum extractors in midwifery, for example, requires special care.[34] Medical supplies such as drugs, equipment, and other consumables are an important part of all curative and preventive services. Essential medicines and medical supplies that form the approved treatment protocol for maternity care should be available at all service points. Such supplies as magnesium sulfate (Langer et al) and special gloves for the treatment of high risk obstetric patients who have HIV and for those needing blood transfusions are essential.[35]

Similar to the need for better infrastructure and equipment, the functioning of the health system needs to be improved. Transport and communication must be available in all maternity care service facilities, from those in villages to a tertiary referral center in larger towns. Transport and communication are vital elements of the referral system; they are needed to support maternity care because of the complications that can occur in pregnant women and newborns (36). Three issues in developing countries that hamper referral systems are (a) delays in treatment decisions; (b) delays in reaching health facilities due to their distribution and location; and (c) delays in handling obstetric and neonatal cases due to limited transport, funding, and communication systems necessary to reach the facility. In most rural areas, health personnel are not available to the entire village, transport and communication are limited, and road conditions may hinder access.[37]

Personal or cultural barriers to access in poor communities increase the failure of women to reach a facility in a timely manner. However, pregnant women are routinely provided

education about childbirth and the early detection of the complications of pregnancy that commonly occur in the third trimester. Preparedness for complications is intended to increase the knowledge of danger signs and help the woman plan for who they want to provide delivery assistance, who will accompany them in childbirth, how they will reach the facility, and, and how they will pay for it.[38] This intervention is done to address the delay in decision making.

Delays in the decision to seek treatment that occur at the household level concern the distance to reach care, its cost, and perceptions regarding the quality of available services. Institutional delays in the various aspects of care can be caused by lack of skill in dealing with obstetric emergencies, attitudes towards patients (soft skills), and lack of equipment and unavailability of medicines and blood supplies. Inadequate management structure at the tertiary level referral system can also cause bottlenecks in achieving appropriate level of care.[39-41]

The definition of adequate or inadequate geographical or physical access relates to the time required to transport women to the facility and takes into account the distance, road quality, climate, and type of transportation. Another definition determines that 5 km is the critical distance for the use of obstetrical services.[42-44] Estimated average time from the onset of postpartum hemorrhage, the leading cause of maternal mortality, to death is two hours, implying that it is not safe for women to be more than two hours away from emergency obstetric care.[45] For monitoring emergency obstetric care, no more than approximately two to three hours of travel time to the facility should be considered if life-saving treatment is to be implemented.[46] Also, according to research conducted in Kwale District, Kenya, antenatal service utilization decreases the farther away health services are; woman who live more than five kilometres from the service and treatment facility tend not to access antenatal care.[48] In Haiti, having a health center within 5 kilometers significantly improves acceptance of antenatal care.[49]

Travel time depends on whether it is the day or evening; this requires an organized transport system.[47] Ambulances and taxis are the most effective method to transport women who have been referred for treatment, but the problem is having an ambulance available at government-owned hospitals with many patients needing emergency care that is not due to pregnancy alone. Studies such as those in Sri Lanka suggest that the government provide each regional hospital with three to five ambulances in order to reduce delays in transport for pregnant women.[50]

Ambulance systems are expensive, limited to urban areas, and not practical everywhere. A motorcycle ambulance, however, is an effective and cheap option to transport patients in developing countries, especially in rural areas with little or no access to public transport. Using motorcycle ambulances is cost-saving compared to a car ambulance. One study that looked at how a village ambulance service was procured based on a village fund program demonstrated the effectiveness of motorcycles in transporting patients. In general, this kind of transportation is easily accepted by many people and is helping pregnant women in particular access services.[51-55] It is expected that the motorcycle ambulance service will be improved and health centers or government officials can guide managers of transportation services in the use of three-wheeled motorcycles, which would be particularly useful for maternity patients..

Local hospitals in this study received referrals from primary health facilities, such as health centers or other hospitals. The primary centres complained that phone calls were not answered or that patients who deserved attention were abandoned. The current ambulance facilities meant that perinatology cases could not be taken, both because of insufficient numbers and the lack of a special ambulance that could look after these cases. Although a health information system is available in hospitals, it was not optimal. Local governments should encourage villages and districts to utilize local resources to strengthen health care access. Existing community participation needs to be managed and organized better. Heads of health centers should provide more taxis for referral services primarily to areas in which transportation is difficult. More attention needs to be paid to training workers on how to maintain the security and safety of the patient during transport.

Community participation is part of the process of community empowerment; however, implementation is still not optimal and this is a challenge to the sustainability of health programs. Access to health care remains a problem for some people. Access can be defined as the dimensions that describe the potential and actual capabilities of a particular population group to reach health services. Improved access, better service utilization, and a higher quality of service are policy priorities.

Individuals who live far away from health facilities have the most difficulty with access, and research on this factor has claimed much attention. Some studies have been related to staffing in remote areas, the use of mobile nurses[56,57] and improving the availability of ambulances at health facilities. The program “desa siaga” or “alert village” is one program

utilizing a four-wheeled vehicle belonging to local citizens as a "village ambulance".[58] Community-based interventions aim at preventing maternal and child illness and infant mortality. Research has concluded that community-level intervention for perinatal care can reduce maternal mortality, thus, training for traditional birth attendants can improve health behaviours and pregnancy outcomes.[59]

Conclusions and recommendations

This study demonstrated a significant correlation between quality of care and both midwives' placement ($p = 0.023$) and midwives' working environment ($p = 0.001$). There was also a relationship of material support to quality of midwifery care ($p = 0.001$). Quality of midwifery care affected maternal mortality.

Based on these conclusions, recommendations can be made as follows: The competence of midwives need to be improved by: a) increasing the quality of midwifery graduates in cooperation with the Indonesian Midwives Association (IBI) and of the practice fields as a place to improve midwifery skills, b) holding training and basic or comprehensive emergency obstetric care (PONED/PONEK) or EMoC in accordance with recognized standards, c) providing rewards and health insurance for midwives. Other steps that should be taken into account include: bringing the organization of the environment under the supervision or control of the leadership to improve the quality of service; increasing respect for staff; clearly indicating the expectations for autonomy and the division of tasks between each profession, as well as for monitoring and evaluating through the PONEK program; and making available material support through standardized tools, maintaining equipment, instituting appropriate ratios for patient visits by physicians and other medical personnel, utilizing the correct capacity of rooms according to the number of patients, properly running health information systems, transportation, and communication links, and utilizing water, electricity, toilets, etc. as needed. Quality of service should be improved through (a) increasing ANC, facilitating pregnant women with the MCH book, integrating ANC services at health centers and implementing ANC classes for pregnant women; (b) implementing such programs as MCH, Maternal and Perinatal Audit; (c) strengthening the capacity of the midwives' coordinator to supervise the implementation of the facility; (d) increasing efforts for births assisted by skilled health professionals through a partnership program between midwives and traditional birth attendants, the development of homes for expectant mothers awaiting delivery, and the

implementation of successful delivery assurance programs; and (e) implementing a good referral system with community participation that will empower members and increase interest in the health of mother and child. Lastly, increase efforts at interprofessional collaboration to provide services to improve the quality of health services.

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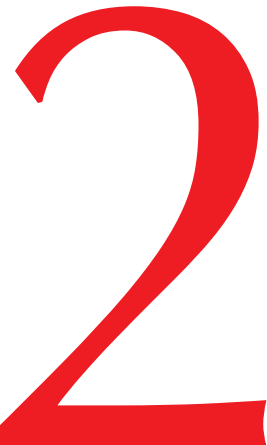
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Abstract

The painful accounts of people who experienced depression trace the contours of a test, both deeply personal and broadly social, that exceeds the usual categorizations enclosing it in a psychopathological entity, a medical diagnosis or a disease of the brain. This text is based on the sociological analysis of 60 interviews with individuals diagnosed with major depression. Through concrete experiences irreducibly singular, it highlights the societal grammars of depression, that is to say those that bite in both the “social body” and the “social spirit” of individuals who suffer and who attack their ordinary social individuality. Failure of action (not being able to) and motivation (not being able to want) that characterizes the test of depression cannot be understood without analyzing the societal tensions that define their conditions of possibility.

Key words depression, individuality, psychiatrization, psychologizing, social suffering

Depression as Trial of Ordinary Individuality: Being Unable and Being Unable to Want

MARCELO OTERO

Introduction

Pour le sujet, derrière la limite de son effort, il n’y a d’abord que ce qui est la victime de l’épuisement, c’est-à-dire lui-même – sur le mode de l’effondrement.[1]

For the subject, beyond the limits of his efforts, one finds first and foremost the victim of exhaustion, that is, himself – in collapse.[1]

The accounts, descriptions, and impressions of depression painfully retold by those who have experienced it depict a trial, both profoundly intimate and decidedly collective, that goes beyond the usual categorizations of psychopathological

entity, medical diagnosis, or brain disease.[2] The concept of trials, borrowed freely from Danilo Martuccelli, allows an analysis of specific individuals’ concrete experiences of depression in its constant fluctuation between, on the one hand, individual and private experiences and, on the other, the collective, public, and shared meanings codified by numerous authorities over which the individual has very little influence.[3]

Under this definition, trials are historically situated, socially produced, and inequitably distributed challenges to which individuals are subjected (and must face from differentiated social positions) and equipped with unequal resources. The particular case of the trial of depression constitutes a veritable sociological test of ordinary social individuality, thus revealing its principal characteristics, requirements, and promises. In this discussion, ordinary social individuality is, quite simply, despite there being nothing simple about it, the prevailing individuality at a given moment in a specific society to which one must, in some way or another, refer. It is the answers to the question “what is an individual today?”

However, referring to this individuality implies neither identifying with it nor bending to it, nor does it mean seeking to understand it with the goal of contesting or abolishing it through individual, collective, theoretical, or practical means.

Reference to an ordinary social individuality is a way to “know” who we are relative to others in a society of mass individualism and, less positively, to “know” that we are to some extent, somehow “flawed,” “out of sync,” and, less frequently, “at the margins” in comparison to what we are asked to be and do according to the different circumstances of our personal evolution: socioeconomic realities, socio-professional groups, age groups, gender groups, community groups, etc. This reference allows individuals to simultaneously establish an “understanding” of and a “distance” from the ordinary social individuality applicable to their social position; it forces them to distinguish themselves from a common reference necessarily “understood” by those who live in society. The individual cannot exist without reference to an ordinary social individuality. Furthermore, ordinary social individuality cannot exist without the individual, whose acts systematically create both “understanding” and “distance”. [4,5]

The societal discourses of depression launch unflinching assaults on both the individual’s “social body” and “social mind”; that is, they attack social individuality through one’s concrete and irreducibly personal experiences. As Martuccelli states, just as “the entirety of elements structuring individuation cannot be situated at the individual level” (3p24), the collection of ordinary individuality’s “flaws” specifically coded as mental disorders (clinically significant signs and symptoms associated with particular difficulties or dysfunctions) cannot be understood without considering the collective dynamics that unify, organize, and structure individual experience.

Consequently, a diachronic, sociological reading of a variety of individual trials of depression reveals the *common tensions* they share, the general characteristics that distinguish them, and the collective elements that connect them in specific ways to create a certain coherence. From data collected during several studies performed between 2005 and 2008, a corpus of 60 accounts of the complex effects of the trial of depression from people living in Montreal was compiled. Although this sample does not claim to be representative, much care was taken to reproduce, insofar as possible, the general socio-demographic characteristics of populations commonly affected by depression according to the parameters most often identified in epidemiological research:

age (adults between 20 and 60 years old), gender (twice as many women as men), and socioeconomic characteristics (low, low-middle, high-middle, and highest income). [6]

The goal of this text is to better understand, from a fundamentally sociological perspective, the *qualitative generalities* of the trial of depression. To do this, an analysis of specific and transversal similarities will be undertaken rather than focusing on characteristics related to inclusion in particular groups (age, sex, income, etc.). These similarities permit the concrete *reconciliation*, as it were, of the very gender, age, and socioeconomic divisions imposed by the general societal logic of the trial of depression. Analyzing the “common societal tensions” revealed by the trial of depression seems the best way to provide a sociological answer to the following question: what are depressed individuals “suffering” from? [6]

Initial approach to the trial of depression: inventories and images

They’re all at our disposal, yes, all ready to help us, but there’s nothing they can do about what’s happening to us right under our noses—because it’s going to happen, it must happen, and this radiant morning seems to be the perfect time for it to happen. [7]

The anthropological distinction between mind and body is epistemologically problematic, but it is not a classic for nothing. Despite the numerous, elegant, and sometimes convincing arguments against its logical, biological, and anthropological relevance, this dualism has persisted for centuries. [8,9] The fundamental mind-body distinction continues its systematic imposition as a necessary tool in the preliminary understanding of the complex dimensions of individuality involved in the trial of depression. Thus, the depressed person’s body, at once social machine and individual organism, is often described as “disturbed” due to difficulties with social functioning (inability to work, to perform ordinary tasks, etc.), lack of energy (fatigue, exhaustion, lethargy, etc.), and changes in basic functions (sleep, appetite, etc.). The depressed person’s mind, in both cognition and mood, is described as “disturbed” in terms of general disaffection (apathy, lack of interest, indolence, sullenness, detachment, disinterestedness, etc.), pronounced sadness (crying, discouragement, etc.), the presence of negative thoughts (about the future, the current situation, personal abilities, the relevance of living, etc.), and disorganized thinking (lack of concentration, loss of control, inability to make decisions, etc.). Describing a depressed individual’s difficulties as “disturbed” reveals that the social tensions of yesterday (neurosis) and today (anxiety/

depression) are founded more on “quantitative disharmony” than on “qualitative discontinuity”; disruptions are exposed without altering the essence of what has been disrupted. [10] One could say that the term “disturbed” rather than, for example, “altered,” refers to abnormal (i.e. statistically unusual) variations in the normal (i.e. common) elements of an inextricably organic, psychological, and social human existence.

The depressed individual’s tragic experience can be summarized in two very broad phrases: “being unable” (breakdowns in function, action, and energy) and “being unable to want” (breakdowns in motivation, desire, and interest). Those who have experienced depression use two general strategies to understand the essential features of a trial that at first appears incomprehensible: inventories and images. The first strategy, inventories of disabilities and descriptions of “what’s wrong” in order to define “what happened,” or even “what hit” them, focuses on the question of debilitating fatigue (“extreme,” “unbelievable,” etc.), followed by the issue of constant disinterest-sadness (“overwhelming,” “always,” “lots,” etc.), and lastly on problems related to disturbance of the body’s functions (sleep, appetite, etc.). The essence of the depressive experience is situated initially between two poles clearly dominated by “sad fatigue” and “overwhelming sadness,” respectively, their common and devastating effect being a breakdown in social functioning which, in certain cases, renders all activity impossible.

- *The fatigue is unbelievable, absolutely no way to do anything at all. You have no energy, no interest. No pleasure either. Making decisions is hellish, even trivial ones. Every day, it’s really hard. Despair, being sad all the time, wanting to cry.*

- *There’s an extreme fatigue, lots of tears, lots of pain, lots of sadness, and lots of longing, but a lot of physical symptoms too. A couple of times I lost a lot of weight, I had trouble sleeping. And, at the end, just before I started seeing a therapist, I had some pretty dark thoughts, very, very dark, and I was losing my coordination.*

- *There’s an extreme fatigue, exhaustion, I cried for nothing. And I didn’t understand anything anymore, people would talk to me and it was like they were speaking Chinese, I couldn’t understand a thing, I couldn’t remember anything anyone said. I couldn’t operate, function anymore, I had no energy, I couldn’t concentrate on anything;, even watching TV was difficult. I didn’t understand anything, really, everything was all mixed up.*

- *There’s a lot of physical pain. It’s everything, fear, anxiety, insomnia, the inability to concentrate, the inability to make*

a decision. The inability to act. Loss of energy, no energy whatsoever. That’s what it means to be depressed.

Almost as frequently as inventories of “what’s wrong,” individuals would call on images, metaphors, and analogies (abyss, machine, funnel, hourglass, etc.) to illustrate the dramatic nature of a trial that seizes at the heart of a person’s individuality. Five types of images, alone or in combination, were most common: “descent” (falling, going down, sliding, being sucked into something, sinking, etc.); the transformation of one’s “substance” (shapeless mass, disintegration, reduced to mush, heaviness, etc.); a mechanism wearing out or breaking (spring, gears, machine parts, etc.); an alien entity inside oneself (gnawing creature, machine of depression taking control, the sick “other” inside, etc.); and more classic images but much less frequent, of the soul being hunted, clouded/ or affected (dark, torn, unloved, profoundly unwell, etc.).

- *It’s like you’re falling into an abyss; you never quite know what’s happening and you never reach the bottom. You never know what’s going to happen but it gets worse and worse. It’s like a machine that you can’t stop on your own.*

- *It’s almost as though you’re made of sand. Slowly, you disappear into the funnel. You go, you don’t want to go toward the funnel but there’s something pulling you.*

- *It’s like some kind of creature that is going to feed off you, and put you through the worst time of your life.*

- *It’s a machine that’s been pushed past its limits, that’s used up. It’s not a coincidence that liquids no longer pass through our brains. We used them all up, it’s not complicated.*

- *It’s an unhappiness so deep that you’re not even able to find it.*

- *Your brain is reduced to mush. There’s nothing there. It’s a shapeless mass; you don’t control your life. It’s the machine of depression itself that guides you. It guides you downward, but it’s actually an anchor, an anchor that falls into the water, and you sink with it.*

- *It’s dark, it’s black, it’s like darkness, it’s isolation, confinement. All these images of isolation, sadness, lack of love for yourself too. Depression is exactly that.*

As with the inventories of dysfunctions, disabilities, and symptoms, the images and metaphors of depression both maintain and blur the mind-body divide. “Who” exactly falls into the abyss, slides through the tunnel, or disappears into the sand? “Who” carries the millstone or collapses through the floor? “Who” is the shapeless mass or the brain reduced

to mush--the bodiless mind? The same problem is true for depression inventories: "who" suffers from extreme fatigue? "Who" is overwhelmed with sadness? "Who" can't sleep--the mindless body? The mind-body distinction shows itself to be as awkward and inadequate as it is unavoidable and useful in outlining, in the first instance, what happens to depressed individuals and even "where" it happens. In fact, very often, it is the body that "cannot" while the mind "cannot want," or indeed, "does not want." However, in sociology, all too often, what usually counts is the "last instance" not the first. We will now take a closer look at this classic anthropological divide in its continued usefulness to describe "what's wrong" and "where it's wrong" among depressed individuals.

The depressed individual's disturbed body: being unable

I experience misfortune because I have a body. Without a body, what misfortune could fall upon me?[11]

Depression affects ordinary social individuality through two general and most often complementary injunctions: being unable and being unable to want. These expressions, although vague, reflect within inevitable limits the concrete problems faced by the depressed person. In what way is a depressed person's body disturbed? The major difficulty faced by these individuals is that their actions are reduced, slowed, blocked, hindered, stopped, and rendered impossible. The stoppage can sometimes be sudden, violent, spectacular, and irrevocable.

- *I was no longer functional, I couldn't do anything anymore; it was really awful. And it was by no means a psychological symptom.*
- *One day at work I completely lost it, I had a total breakdown at the office.*
- *A temporary paralysis, not very long, but for about three days it was as if I was nailed to my bed, I couldn't move.*
- *[It was] as if I had fallen in battle.*

On other occasions, the depressed person invokes a long process sometimes described as the slow wearing away of a particular internal mechanism or elastic that eventually gives out for once and for all.

- *You slowly lose all your resources.*
- *The elastic is stretched stretched stretched. At one point, if it can't stretch any more, it breaks. That's really how I felt.*
- *I just couldn't work at all anymore. I felt like my resilience*

was broken.

- *It started to have a serious impact on my regular functions, that I could no longer assume my responsibilities, because I was really losing it, losing any ability to do anything.*

That the body that sometimes likened to a "machine" stops functioning is often very important. All sustained activities must henceforth be suspended. The idea of the material body's role as a mechanical support system for a mind no longer able to give direction or impose its will is often evoked. Depressed individuals observe, much to their surprise, that they quite simply "cannot."

- *My body stopped listening to me.*
- *The entire machine stopped working.*
- *I couldn't do anything when I got up, that is, when I did get up.*
- *When you're depressed, nothing works.*
- *You can't do anything anymore; you're really in a vegetative state. You can't do anything at all at all.*
- *I was really non-functional. I'm someone who does a lot of sports, and I couldn't do anything. Zero.*
- *I wasn't able, was no longer able to drive, I couldn't leave my house.*
- *I can't function anymore.*

Although a complete breakdown in function, current or eventual, can be life-threatening, it is the inability to work that is most often mentioned and most extensively discussed. Being unable to work is highly symbolic; as the essential link to the "active" world, it is the veritable locus of social performance and productivity. Depression forces the interruption of this connection as it becomes physically unsustainable and sometimes even psychically intolerable. As will be discussed in more detail below, the complex relationships between work and depression, repeatedly discussed and problematized, play a key role in the paradoxical experience of the trial of depression.

- *I used to be happy to go to work, but now it's an absolute horror, and it's not the job, it's not work that's the problem.*
- *When just thinking about working makes you vomit, at some point, you have to stop.*
- *I wasn't really trying anymore. I was doing the minimum. I worked, I hated it. I came home, I had had enough.*
- *I knew that there was a connection between my work and*

depression, because I couldn't physically be there anymore, I was incapable of being at work.

The inability to function and, to a lesser extent, the deterioration of one's customary performance constitute a tragedy, the depressed person's foremost tragedy, in fact. It is also the tragedy of every "dysfunctional" person, regardless of the reasons for stoppage or diminishing performance. Depressed individuals use the word "function" in all of its forms throughout their narratives because, in the end, "to function" is to exist socially and individually. Even more than thinking or feeling, "functioning" is the most important thing. And the workplace is where, every day and more so than anywhere else, we demonstrate our ability to "function" and affirm our social and individual existence.

While we certainly exist "for others," those who watch, evaluate, and judge us, it is also "through others" that we exist "for ourselves," for we are "others" in another form. How can we be "others in another form" in a society of mass individualism--in our "average self," that is, our social particularity? It is important to remember that we refer here to "functioning-existing," not putting on great performances, leading a successful life, achieving a great career, being counted among the best, or pursuing unattainable goals. Rather, we refer to successfully "maintaining our position," to greater or lesser degrees of intensity (ups and downs) in the same manner we did until today. Put simply, this means being able to fade "daily" "into the crowd" by following the standard routine and demonstrating our "average self," our social singularity, our specific individuality. This is done not only for the benefit of those who are used to seeing us "function" in a particular way and with a specific intensity, but also for our own benefit as we pitilessly judge the "personal rhythm" of our existence. The depressed person's "average self" is seriously affected; its ability to function, indeed its very existence, is massively, essentially, and decidedly compromised. This depressed person describes it particularly well:

•Not only will I no longer be able to function and meet the expectations placed on me at work, but I won't be able to meet my own expectations either. Expectations that you'll pass incognito. Basically, that people say, "It's working for you." So you need all those elements in order to keep functioning, that's what I mean. In this way existing is functioning, to be able to function the way people are used to seeing you function and the way you think functioning and being OK are supposed to be.

If one's inextricably individual and social existence is

seriously threatened because the "machine-body," or the bodily machine, is somehow hindered, blocked, or broken, does the fault lie in the mechanism or the fuel? In psychology, the question of "energy" has a long tradition of debate ranging from classic organicism to new age humanism to the most orthodox psychoanalysis. [5]While the existence of a certain "energy" that plays a key role in the psychological life of human beings is a matter of consensus, there is little agreement on exactly what it is, where it comes from, where it resides, and, least of all, of what it is made. Freud once again no doubt hit the mark in stating that "psychological life implies a certain energy, but no information that would allow us to compare this energy to others is available".[10p27] As with the "mind-body" divide, the proposed existence of a particular form of "energy at play" in the psyche reveals itself to be simultaneously problematic and useful in the discussion of major difficulties in "functioning." Depressed individuals experience this energy, in a form altered, reduced, diminished, suddenly consumed, and eaten away by the dynamics of depression, as a fatigue as insidious, indefinable, and elusive as the mind-body divide and its hypothetical points of connection.[12] Each scenario, alone or in combination, is therefore possible: the body is tired, the mind is tired, the brain is tired, the mind and body are tired, etc.

•Mental fatigue is far more destructive than physical fatigue. With physical fatigue, you rest, you take a nice, hot bath and you'll probably be OK. With mental fatigue, whether you're alone or with lots of people, lying in bed or doing whatever, it's slowing eating away at you. So it's like my brain was tired.

•I was tired, no energy, I'd even say the fatigue was physical.

•It's hard to explain but a really, really powerful fatigue in the head. I've done a lot of sports, it's not the same thing, this is another kind of fatigue.

•Total physical and mental exhaustion.

•Because, in addition to suffering in our heads, we suffer in our bodies.

Although the difference between functional difficulties and breakdowns in action, on the one hand, and lack of energy, fatigue, and exhaustion, on the other, is far from clear-cut, it nonetheless exists in depressed individuals' narratives. The metaphors and images chosen to describe them illustrate this difference: the broken spring, the worn-out cord, and the snapped elastic versus the feeling of being emptied, flattened out, down, shapeless. Energy is a term all depressed individuals incorporate into their vocabulary.

- *No, I don't have any energy. That's what's so weird. No energy. Before, that word wasn't in my vocabulary.*
- *Depression? It means being really totally down, down, down.*
- *It's like being completely shapeless.*
- *There's no more energy, there's nothing, it's a freefall.*

Another difference between functional problems (machine) and lack of energy (fuel) is the context in which the difficulty is understood. Generally, the inability to function happens at work and the lack of energy happens, or is at least is most obvious, at home. The scene of the depressed person's "lack of energy" remains the privacy of the home, as though the painful spectacle of observing one's own functional inability, this form of social and individual inexistence, requires a maximum of discretion and a minimum of possible witnesses.

- *Having no energy means lying around the house.*
- *It means not even having enough energy to take a shower.*
- *I don't even have the energy to do the dishes.*
- *I couldn't do anything. Just getting up to go to the washroom was painful.*
- *I would get up, eat breakfast, take a shower, and go back to bed. It was hard to get up.*
- *Making a meal is impossible. Just thinking about getting cleaned up is like a terrible burden.*

Rather than being moderate or secondary, lack of energy is a radical and dramatic phenomenon. The metaphor of everything turning into a "mountain" is common, as are qualifiers that indicate the disquieting and immutable severity of the depressive experience.

- *Everything turns into a mountain.*
- *I really had no energy.*
- *There was an overall exhaustion.*
- *You're so tired you can't sleep.*
- *This extreme fatigue, you ask yourself how far you can go, you've reached the bottom, so you can't go any lower than that.*
- *Total lack of energy*
- *I couldn't do anything anymore.*

Generally speaking, the depressed body's two principal disturbances are "mechanical" (function) and "energetic" (exhaustion) and are most often situated (or manifest

themselves) at work and at home, respectively. At work, dysfunction happens primarily in view of others and at home, lack of energy is witnessed mostly by oneself. However, two other disturbances, both less "specific" or perhaps entirely unrelated to depression, pursue the depressed person along his or her harrowing journey: trouble sleeping and irregular appetite. For those who have already experienced depression, trouble sleeping becomes "an important barometer" and even the "warning sign" of what is to come. Sometimes insomnia dominates, sometimes hypersomnia, and certain individuals alternate between the two or experience irregular sleep patterns.

- *Sleep patterns are completely disturbed.*
- *I've always slept a lot, 12-hour nights, and then I was sleeping four hours a night.*
- *I was sleeping about two or three hours a night.*
- *You go to bed and you wait for sleep to come but then you don't sleep well, you have nightmares. You're in a sweat.*
- *I have a lot of insomnia, waking up in the middle of the night, having difficulty falling back to sleep, waking up early in the morning.*
- *I was sleeping 18 hours a day.*
- *I could sleep up to 20 hours a day.*

Irregular appetite and the resulting weight gain or loss are frequently mentioned but rarely considered warning signs of specific to depression. While sleep disturbances are almost always presented simply as facts or even as symptoms (not sleeping enough, sleeping too much, having trouble falling asleep, etc.), irregular appetite is often associated, closely or loosely, with primarily psychological factors (disinterest, somatization of emotions, self-abandonment, etc.), which calls into question its inclusion among the disturbances of the depressed body.

- *I didn't feel like eating anymore.*
- *What's the point of eating?*
- *I eat my emotions.*
- *I had absolutely no appetite, no desire.*

The inclusion of irregular eating habits in the list of potential elements of disturbance in the depressed body is indeed more difficult to justify. Sexuality (sexual energy, libido, sexual desire, etc.), more specifically the disturbance of desire and usually its inhibition, is almost entirely absent from the accounts of depressed individuals. The reason is simple

enough: sexuality is a minor issue compared to the myriad of other physical, psychological, and functional difficulties brought on by depression. It is not the embarrassment, taboo, or intimate details difficult to discuss in an interview that explain its absence, but its relative lack of importance in the economy of an individuality at odds with the trial of depression. The remarkable absence of sexuality as a critical etiological and symptomatic issue in the depressed person's universe is one of the most significant symbolic departures from traditional Freudian neuroses.

At times, the depressed body also experiences a variety of other symptoms (backache, fever, rapid heartbeat, abdominal pain, constipation, nausea, headache, colds, diarrhea, etc.) even before beginning psychopharmacological treatments that often cause such side effects. [2] These complaints, difficulties, or symptoms are somewhat "suspect" because they call other boundaries into question, specifically, those that separate psychopathological categories. Indeed, abdominal pains, a rapid heartbeat, and diarrhea, etc., represent the possible contamination of the realms of depression and anxiety by the body, as well as the current instability of the porous boundaries within the territory of social tensions.

The depressed body is therefore one that is "unable": unable to function at work in view of others and oneself; unable to function minimally at home, often even without the distressing presence of witnesses; unable to manage the body's essential functions; unable to find the smallest glimmer of motivation to continue existing as a social and individual being. A depressed person's body is at once a severely weakened social machine and an individual organism whose vital functions are profoundly altered. The disturbed body-machine and body-organism reveal the extent to which the depressed individual's "average self" is seriously compromised through massive, essential, and decisive difficulties in function and vitality, elements that together constitute a person's social, individual, and organic existence. But what of the "depressed mind"?

The depressed individual' disturbed mind: being unable to want

La subjectivité c'est cinétiquement l'effort-que-je-suis. Les limites de mon effort sont les limites de mon «tenir», les limites du tenir tête, du soutenir, du tenir ferme, de l'abstenir, de l'entretenir. Là où l'effort se termine, notre aptitude à nous tenir debout de nous mêmes parvient à sa limite, là commence «ce qui gît autrement».[1]

Subjectivity, kinetically, is the effort-that-is-me. The

limits of my efforts are the limits of my "stand", the limits of standing up to something, standing with someone, standing my ground, standing apart, standing watch. The ability to stand on our own reaches its limit where effort ends, and there begins "that which exists otherwise".[1]

In principle, the depressed person's disturbed mind falls under the category of "being unable to want" rather than "being unable." But how can this be known for certain? Depressed individuals would like to be "able to want," but they "are unable," "cannot," or "fail" to do so. Elements of the mind disturbed by depression are, in order of importance, disaffection (disconnection, apathy, disinterest, inertia, etc.), sadness (crying, longing, melancholy, etc.), pessimism (negative thoughts, hopeless future, etc.), self-deprecation (poor self-esteem, underestimating one's personal abilities, etc.), loss of autonomy and control over one's thoughts (lack of initiative, confusion, poor concentration), and, lastly, self-destruction (suicidal thoughts, significant neglect of one's person, etc.).

Disaffection and sadness are, without a doubt, the two principal features of the depressed person's disturbed mind, or would be if it were possible to define them in a satisfactory manner. What, exactly, is meant by disaffection or sadness? Are these terms appropriate? To what do they correspond, specifically? Depressed individuals draw from a wide, complex, imprecise, and sometimes contradictory semantic field to imbue these terms with meaning, and hybridization (sad disinterest, apathetic sadness, etc.) is common. Goethe, often cited by Freud to illustrate the existential paradoxes of happiness and sadness, states that in life anything can be tolerated except a succession of glorious days, so what can be said of a succession of drab, dull, and uninteresting days that must be endured, rather than lived?

- Every day was the same.
- I endured my life rather than living it.
- I was at a point where everything was boring.
- Life is no longer a pleasant thing.

However, when trying to understand and explain the factors leading to an intolerable succession of Goethean days without end, it is not the metaphor of existence as external climate that is evoked, but the metaphor of the more substantial internal climate of mood. Theoretically, the mind (force of will, motivation, desire, drive, interest, etc.) is responsible for the "external climate," not the opposite. Depressed individuals want nothing, desire nothing, crave nothing, are interested in nothing, and desire to do nothing.

And, they can do nothing to change this.

- *Complete disinterest in anything.*
- *You're not interested in anything.*
- *You have no interest in life, no stimulation.*
- *I wasn't interested in anything anymore.*
- *You don't want anything anymore.*
- *A deep lack of desire, of wanting something. I didn't want to do anything anymore.*
- *I don't think I even had a will of my own.*
- *I don't know what's happening, I don't have any motivation left.*

As in the case of the depressed body's lack of energy, the disaffected mind is usually situated in the private and very often solitary sphere of the home. The person lies in bed, collapses on the sofa in front of the television, and does nothing, or almost nothing.

- *I was always lying on the couch.*
- *I would get up and roam around the house. Why get up? I have nothing to do.*
- *I lay down on the sofa.*
- *All I did was rock myself and look at pointless magazines.*
- *You stay in bed for hours and hours. You have a lot of trouble leaving the house.*
- *I can spend 10 hours in front of the television.*
- *Often wanting to stay in bed and do nothing.*

Similar to the case of lacking energy, the powerful "desire to do nothing" rarely proceeds by half-measures as it establishes itself comfortably within the depressed person's mind. The detachment, disconnection, and apathy are often very severe, deep, and unsettling. One functions on "autopilot," lives "in a bubble," exists "in a fog."

- *I would shut myself away at home, all alone, and live in my bubble.*
- *You're not connected to anyone else anymore, you're in your own little bubble.*
- *I was functioning entirely on autopilot.*
- *It felt like I was living in some sort of fog.*
- *I really wanted to give up altogether.*

Certain accounts provide particularly eloquent illustrations

of depressed individuals' disconnection from all semblance of "active" life: a welfare recipient with nothing to expect from life, a senior living in an institution, a zombie, or even a vegetable. With nothing to do, they do nothing, want to do nothing, and no longer remember for what strange reasons they are being "kept alive" in these painful, unproductive conditions from which escape seems impossible.

- *It's almost as though I was on welfare, or a senior in a home.*
- *I was at home, I didn't do anything anymore, I was like a zombie. There was only emptiness.*
- *Imagine a zombie, someone who's not really alive and who's really just a body being kept alive for no good reason.*
- *A total vegetable.*
- *You're in another world. You really reach a vegetative state.*
- *I did nothing, I wasn't working, I wasn't going to school, nothing was happening in my life.*

Others talked about disconnecting from the world by retreating figuratively into oneself and literally into one's home leads, and in some cases, to neglect and abandonment of self, even unto letting oneself slowly die.

- *Personal hygiene? Not any more.*
- *I did no housework. It's quite an experience.*
- *Being clean? Not interested anymore. Shaving? Not interested anymore.*
- *The entire house was a disaster, I stopped washing myself, I was all alone, I didn't care.*
- *You don't even think about eating, washing yourself, getting dressed, none of that.*
- *I'm not there. I leave a burner on with a pot of water, I boil the water, I forget the pot.*
- *You feel useless, you ask yourself why you're alive. You want to let yourself die, literally.*

"Being unable to want," or sometimes "being unable," does not assume, require, or above all, automatically imply feeling sad. It is another aspect of "what" is experienced, rather than "what" is felt, even though the boundaries between the two are often unclear. Although contemporary depression bears little resemblance to the classic passion of sadness, many depressed people cry a great deal, often, and uncontrollably. Why do they cry, and why so much?

- *You wake up crying.*
- *I cried easily.*

- *I cried, I cried, I cried.*
- *I cry a lot.*
- *I cry all the time.*
- *I cry for nothing.*
- *Never-ending crying fits.*

What can be learned from phrases such as “crying over everything,” “crying for nothing,” “uncontrollable crying,” and “never-ending crying fits”? Are sadness and crying necessarily connected? Depressed individuals believe, with conviction, that the tears they shed have little to do with emotions they ordinarily experience and have even less to do with identifiable reasons or events that might justify them. Strangely, irregular eating habits are more clearly linked to psychological determinants than crying, weeping, or sobbing. This suggests that the disturbance is in the body rather than the mind: it is impossible not to cry and it is impossible to stop crying. This is just the way it is; it is a fact.

- *I could spend two or three days crying and I just couldn't stop.*
- *The worst thing is that you never stop crying.*
- *It's just not normal, always crying, all the time, every day.*
- *In my case, there was uncontrollable sobbing, I never stopped crying. The tiniest emotion, the smallest thing, everything made me cry, sob.*
- *I'm not saying I don't cry, but crying like that, being beat, tired, exhausted and not being able to see the light at the end of the tunnel, that's really the way I felt.*
- *I cry over everything.*

There are many reasons to cry: powerlessness, insecurity, uncertainty, irritation, rage, stress, even a Goethean succession of glorious days, but why, exactly, do depressed people cry? Most are unable to offer an explanation beyond the compulsion to do so, a state of irritation, emotional hypersensitivity, or profound, indefinable, and treacherous malaise. Is this the “sad mood” or “depressed mood” psychiatrists talk about? Is it really an objectless “emotion” more pronounced, distinctive, and compulsive than the simple “sadness” attributable to more-or-less identifiable reasons without, for all that, being “something else”? Or, is it actually a specific state of mind, without necessarily being an “emotion,” qualitatively distinct from sadness? Is this vivid, overwhelming, and sustained sensation nonetheless of the same order as “feeling down,” or is it a specific “depressive” sensibility? One thing is certain: crying “for nothing” or for

“almost nothing” is a constant.

- *You don't necessarily know why you're crying because so much has piled up that you can't tell anymore.*
- *When I cried, I was agitated, stressed, I wasn't crying because I was sad.*
- *I didn't know why I was crying, I just had to cry. And when I cried, it didn't seem to get any better, so I cried even more.*
- *I started to cry, I couldn't say why but I really felt a deep despair.*
- *When you're depressed you feel pretty down, all you want to do is cry and be at home, to collapse.*

Although not for many, for some the word “sadness” remains useful as a point of reference, however approximate, for their experiences and to help them discern and identify what feels different about crying. It is “like sadness,” but severe, deep, heavy, or persistent. It is “like sadness” but with effects that are clearly debilitating, incapacitating, paralyzing. It is “more or less” like sadness, but not quite.

- *Not sadness, it has to be lower than that. Because sadness-everybody is sad at times. When I'm sad, it's not a big deal for me. It's not serious.*
- *It was like a sadness, a heaviness.*
- *Spleen, melancholy, it's the same thing. But depression, I'd say it's even deeper.*
- *I was always, always, always depressed, I felt sad regardless of whether there was something good or bad happening in my life. I was sad, nothing was working, I cried every night.*
- *A sadness settles in, a sadness that practically puts me in a vegetative state, where I spend all day in bed. It's so deep it drains all my energy. It uses up all my energy. It's as though the sadness feeds off my energy. There's sadness in the subconscious.*

Turning now from the slippery slope of mood, if indeed mood is the appropriate term, to the more Cartesian realm of ideas, the existence of a depression-specific cognitive sphere is evident. Characterized by the presence, recurrence, and quite involuntary maintenance of “negative thoughts,” this “cognitive bias” sees only the “dark side” of everything or in everything, or paints everything with the same “dark” brush. As with “compulsive” crying, with nothing to be done and nothing to cause it, the persistence of “dark-negative” thoughts is described as “involuntary.” The mind is taken, invaded, clouded.

- Everything I saw was black, I saw nothing positive.
- My attitude: life is shit, there's nothing positive about it. I had a really depressed attitude.
- You see the dark side of everything. Everything changes colour. It's like you're wearing a different pair of glasses. It can't be controlled.
- You see things more and more negatively. And the more you see negative things, the less you're able to make an effort to change the things that bother you.
- I just couldn't see the positive side of things. I always saw the dark side of everything.
- I couldn't see anything positive. There was no light that I could see.
- You see life in a darker, blacker way.
- You build a negative bubble around yourself. Then you really enter into a negative world. Everything is negative.
- Black thoughts, it's black, black, black, black. Everything is black, everything is rotten, negative.

If everything is black, as it clearly is, it is also clear that for the depressed person there is no possible way out; for all intents and purposes, life is over. There is nothing to be done and no possible future. The only option is to endure the excruciating present or, at most, dwell on the past. Another thing is very clear: the future is most assuredly not of interest to the depressed mind. [13]

- You think that your life is over.
- I felt like my life was over. Like there was nothing ahead of me but I was always rehashing my memories, the past.
- I was at that stage, so much so that I couldn't see A-N-Y kind of future ahead of me, I had reached that point.
- You can't see any way out anymore.
- I didn't really believe that there was a way out.
- When I was depressed, I felt like a 70-year old person who sees their past and has nothing in from of them anymore. They only see their past.

When a person is convinced that there is no way out and no future, there comes a point when the issue is no longer disaffection, powerlessness, or disconnection from the "active world" but the brutal fact of remaining alive. Why continue living under these excruciating conditions? Without a doubt, suicidal thoughts are without a doubt the darkest of dark thoughts. At times vague, the result of these unspecific

and imprecise thoughts is the desire to simply die. Sufferers sometimes entertain specific scenarios and visualize their own deaths. Are "having suicidal thoughts" and "wanting to die" two distinct things? Can a clear distinction be made between "cognitive bias" and "mood"? Very often, the mind is seized, occupied, even obsessed, by the idea of dark suicidal thoughts.

- I had dark thoughts, I started having suicidal thoughts.
- I have very, very obsessive suicidal thoughts.
- Morbid, suicidal thoughts. I couldn't see myself living anymore.
- I even had dark thoughts; my life wasn't worth anything anymore.
- All of my thoughts were very, very black, very, very dark. I thought about suicide.
- I had suicidal thoughts quite often. It often came close. There wasn't much left to keep me going.
- Suicidal thoughts are a constant presence; I see the train, everything is empty, and I feel like throwing myself under the train.

References to wanting to die (or to no longer wanting to live), rather than to the specific presence of "suicidal thoughts," are less frequent.

- I wanted to die, and at that time it came very, very close.
- I didn't want to continue living at all. I didn't want to live anymore.
- All I wanted to do was to die. Sleep and die, that's all I wanted. I didn't want to live anymore at all at all.

The depressed person's mental, psychological, and social self-deprecation presents itself in many forms and in a variety of contexts, but is it of a cognitive nature or does it derive from mood (emotion, feelings, sensibilities, etc.)? The combination of feeling inferior, knowing that facing the most trivial challenge is impossible, and considering oneself morally weak or weakened, if not outright unworthy, constitutes: 1) a feeling painfully endured, 2) a persistent cognitive tendency to belittle oneself on every level, and 3) an interpretation of oneself and one's circumstances established at the very moment of feeling powerless in every aspect of existence. The simple fact of "falling into depression" is already believed to reveal a moral failing, tangible proof of psychological vulnerability, and a shameful breach in the ramparts of individuality that eventually exposes an existing social impairment. Indeed, many are convinced that only the

“weak” can suffer from depression.

- *When I thought that I might be depressed, I felt weak, only the weak are depressed.*
- *It was really hard to accept the diagnosis of depression.*
- *For me it was a sign of weakness, like I was an idiot.*
- *I considered it a real sign of weakness, of failure, that I wasn't worth much.*
- *You lose confidence in yourself, your self-esteem drops out of sight; it's not complicated, you think you're no good for anything, that's pretty much what depression is like.*

When depressed, individuals are often also convinced that nothing will ever be the same and that the experience of depression will weaken them rather than contribute to their growth. Those who have “fallen” into depression develop a new personal reality, a new “average self” whose abilities and performance are diminished and devalued.

- *I have doubts about myself, doubts about myself as a person.*
- *I really didn't have good self-esteem.*
- *Total disillusionment with myself.*
- *I'm hopeless, I'm hopeless, I'm hopeless!*

Thinking about the future means lowering expectations and social ambitions following the realization that certain activities are now out of reach and particular social tensions have become intolerable. The depressed person's social opportunities are unexpectedly and abruptly reduced. This is the very definition of social disability.

- *You'll never play in the big leagues again, you're going down to the minor leagues and then, you'll be good for what, exactly?*
- *The fact that I couldn't get there, just couldn't get there, made me sick, I compared myself to others and was unsatisfied. Maybe excessive ambition is the problem.*
- *I didn't have much self-esteem, I didn't think that I could succeed in doing anything productive or positive in my life.*
- *When you're depressed, you feel like you're not worth anything, that you're incapable of doing anything at all.*

We have seen that depressed individuals are neither able to stop crying nor stem the avalanche of negative thoughts, including those about themselves, that overwhelm them. However, another characteristic of the disturbed mind is the impossibility of using it correctly or even controlling its most basic functions. Difficulty concentrating is frequently

mentioned.

- *I have trouble concentrating.*
- *You aren't able to concentrate.*
- *Unable to concentrate.*
- *Zero concentration.*

Difficulties concentrating sometimes develop into a more complex and generalized cognitive incapacity characterized by confusion, disorientation, incoherent thinking, reduced memory, and the inability to communicate.

- *I couldn't read anymore. When I watched TV, I was confused. If I watched a movie, I couldn't remember who was who, who the good guy was, who the bad guy was. I mixed up the characters. I didn't do much of anything.*
- *I couldn't read an article, it was too complicated. Reading an article, understanding it and especially remembering it, it didn't work at all at all.*
- *My thoughts were very unstable.*
- *I would have had a lot of difficulty communicating like that, it would have been impossible.*
- *It's impossible to think correctly. You really lose all your points of reference.*

The inability to make decisions, the lack of initiative for even the simplest of things, is often identified as one of depression's distinctive characteristics; actions are blocked before they begin. However, unlike the dysfunctional body, blocked, tired, powerless, or lacking in energy, here the problem stems less from “energy” or “mechanics” than from “cognition.” The image of the muddled brain or the faltering mind illustrates this.

- *I have difficulty making simple decisions.*
- *And the inability to make decisions, even the most trivial.*
- *The brain is all muddled, incapable of making simple decisions.*
- *Should I leave now to buy a liter of milk or not? This turns into when would be the best time to go? Putting on some shoes and saying, “OK, now I'm going to the store.” And finally, saying “No, it's not the right time after all.”*

Finally, in some cases, the depressed person experiences a pronounced loss of control over their mind/brain, to the point that their autonomy is entirely compromised.

- *It's destabilizing, because you have no control over it. The lack of control, I think that's what scares people the most.*

Because it's frightening, it's unknown.

- *Being healthy means being in control of yourself, that no one is controlling your brain. That's what freedom is.*
- *Everything moves, you feel like nothing is under your control, you don't know what you're doing. You're at a loss.*
- *It was like everyone was trying to tell me what to do and depression, that's what it is, a feeling of helplessness.*

The depressed mind, disturbed in both mood and cognition, refuses to be assimilated into tired narratives of wholesale suffering and sadness. Rather, it requires contextualization within the critical issues of contemporary individuality: an active and permanent connection to the world, the recognition of intrinsically individualistic qualities (self-confidence, self-esteem, etc.), the recognition of one's own ability to change things (taking the initiative, making decisions, commitment to daily struggles, etc.), a future-oriented disposition (having projects, thinking positively), and autonomy (self-sufficiency, taking charge of oneself, etc.). Each of these key and widely socially instituted elements of individuality is sorely lacking in depressed individuals.

Conclusion

Depressed individuals face a major problem that threatens the very foundation of their social existence, that is, a disturbed body (being unable) and mind (being unable to want). In a world where social certainties are becoming rarer and their status increasingly unstable, the inability to act can mean immanent social death. Musil said that "it is so simple to find the strength to act and so difficult to find meaning in action" (14p108); however, this sentiment has aged too poorly to conceal that, today, it is finding the strength to act that poses the greater challenge. The trial of depression forces individuals to test both the "strength" of their bodies (being able to act) and the "strength" of their minds (wanting to act) in a context of unstable status and the constant need to readjust one's individual social possibilities. How can one not fail this test?

In societies of mass individualism such as ours, that depression is a solitary trial is sociologically consistent. It would seem that nothing can be done for the depressed person who always burns alone like a fuse symbolizing the ordinary tensions of liberal societies.[15] "Others" are often nothing more than mirrors in which individuals judge the disquieting fluctuations of their "average social self" within a context that values present performance over past or future actions. In a depressogenic society like ours, where depression is the

figurehead for mass psychological misery, the most common site of the myriad of individualistic tensions, indeed the site of one's very social existence, is without a doubt the workplace where individual limits can be perpetually tested and readjusted.[16-19] How far can people go? How fast can they go? How long can they hold out? This is another way of asking, under threat of permanent drops in status, "who" they are and "what social position" they are capable of holding.

If, as Miguel Benasayag states, that "freedom means using your own strength in each given situation," how can one avoid "suffering" from the radical impossibility of encountering conditions in which the "freedom to act" is possible?[20] Has this not become the ontological condition of social existence in contemporary liberal societies? Consequently, the trial of depression attacks not the metaphysics of freedom but the microphysics of action (acting and wanting to act). Therefore, the two sociological axes of being unable and being unable to want reveal the social substance of depressed individuals' "suffering."

Notes

a. The evolution of nosographic models of depression in successive manuals of the American Psychiatric Association, from the DSM I (1952) to the DSM-TR (2000), is analyzed in Otero M, Namian D[21]

b. The analyses presented in this text are based on a corpus of 60 qualitative interviews performed between 2005 and 2008. Participants consisted of 40 women and 20 men between the ages of 25 and 55 (approximately one third between 25 and 35, one third between 35 and 45, and one third between 45 and 55) who had received at least one formal diagnosis of major depression. Approximately 50% held a university diploma, 25% held a college degree, 20% had completed their secondary education, and 5% had not graduated from high school. Approximately 70% were employed full-time or part-time at the time they were interviewed. 15% were in or returning to school and another 15% were neither studying nor working at the time of the interview. During the previous year, the interviewees' "average household income," as defined by Statistics Canada, was as follows: 1) highest: 43%; 2) high-middle: 24%; low-middle: 12%; and low: 21%. Lastly, approximately 50% of interviewees had a spouse at the time of the interview. For more details, see Otero[6].

c. The different sociological dimensions of the trial of depression are discussed in detail in Otero[6].

d. Freud used this expression to show that neurotics were: 1) "almost ordinary," a mass of "nearly normal" people subjected

to the same unpleasant feelings, trials, and problems that “completely” ordinary (or normal) individuals handle rather well and 2) more “fragile,” we would say today, than other individuals due to certain hypothetical “quantitative disharmonies” (innate, acquired, circumstantial) that only reveal themselves later through the concrete manifestation of neurotic symptoms.[22]

e. See Chapter 4, «L’aggiornamento de l’humanisme thérapeutique», in Otero[23].

f. For more information on this subject, see Marc Lorient[24].

g. For a detailed analysis of individuals’ complex relationships to antidepressants, see Otero and Namian[21].

h. See Nicolas Moreau’s[25] analysis of the depressed person’s relationship to time.

i. For a detailed analysis of the experience of isolation in contemporary societies, see Doucet[26].

j. This well-known expression belongs, of course, to Freud, who used it for the first time in *Civilization and its Discontents*. Written in 1929, Freud shows the United States laying the groundwork not only for a deep economic crisis, but more quietly showing signs of a new phenomenon he brilliantly calls “mass psychological misery.” Much later it would be associated with the rise of mass individualism, which is, in a way, a sociological condition necessary to its existence.[27]

k. Despite numerous studies on the “end of work” produced since the last quarter of the twentieth century, the centrality of work as a contemporary form of social organization, of “living together,” as well as in individual life trajectories, has only become more apparent. For a systematic analysis of sociological discourses of catastrophe, see Castel[28]. For a sociological discussion of the centrality of work in contemporary societies, see Mercure and Vultur[29] and Kirouac[19].

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Abstract

Our paper constitutes a theoretical analysis framed by fictitious, yet factually informed, case scenarios, constructed using a technique called 'critical fiction'. Based on our research experience in rural Newfoundland, these scenarios are used to illustrate how health subjectivities are enmeshed in social and economic conditions. While people perceive and make sense of health issues related to youth as signs of change in both community life and the way health is defined, more vulnerable youth are framed as 'at-risk' and efforts to address these issues are often institutionalised, medicalised, and relegated to a health domain. Consequently, we argue that by paying attention to the situated context of these issues, service providers and policy makers must look not only at the opportunities for preventing problems, but also at redefining what constitutes healthy environments for youth to thrive.

Key words culture of consumption, health subjectivities, socio-cultural environment, youth

The Culture of Consumption and the Construction of Youth At-Risk as a Health Issue in Rural Communities

MARTHA TRAVERSO-YEPEZ & JILL ALLISON

Introduction

As modern science and technology increasingly govern the task of caring for our health, there is a growing trend towards delegating full responsibility for disease and pathologies to a health care system and its teams of experts and service providers.[1] The dilemma is that modern medicine and technology have radically improved the outlook on debilitating illness and disease, but goals of fostering autonomy and participation within a broader concept of social health, citizenship, and agency remain largely underachieved. Moreover, concepts of health and healthy

behavior are increasingly shaped by the need to consume technologies. In this paper, we will argue that a culture of consumption not only dominates health care practices, but is present in other venues of life, including conceptions of youth's health and well-being. Consequently, it also influences new generations' socialisation in health related endeavors.

Our theoretical analysis will start with fictitious case scenarios based on our research experiences in rural Newfoundland (NL). Our fictional scenarios are constructed using a technique called 'critical fiction,' involving the use of recurring themes from real situations and framing them into fictionalised stories.[2,3] Although deliberately stereotypical, these cases are framed to illustrate our analysis about how the construction of youth at risk results from a dynamic that is present in the broader socio-cultural environment of rural communities, a construction that ends up reproducing itself. The NL contextual background is influenced by the consequences of the cod moratorium in 1992. Since then, out-migration in rural communities

in NL has been on the rise as people are challenged to look for working opportunities elsewhere. This has had an impact on a dwindling rural population and on the quality of life of these communities. Consequently, after the fictional scenarios, we will analyze issues exposed in the three scenarios presented as follows: (a) environmental influences on youth development and youth health in rural areas, (b) the complaint about youth boredom and 'addiction to technology', and (c) the construction of 'youth at-risk' and the concern about addictions. Our final considerations will critically discuss that greater attention is needed on the cultural conditions surrounding youth development, and on what constitutes healthy environments for youth to thrive.

The fictional scenarios

Case 1: Parent commuting to work away for weeks and single mothering

Fred is a trained welder working away in Fort McMurray, Alberta for the past decade, while his wife and four children live in a small rural town in NL. He is usually in town for two weeks for every four weeks he is away. While his job brings a fair income into the household, his intermittent absences contribute to inconsistent parenting and strain on his marital relationship. His wife takes care of the children, the household, and their seasonal vegetable garden. She also has to keep an eye on her aging retired parents, while also caring for Fred's ailing mother, sharing the task with Fred's two siblings in town. Jane is sometimes so busy that she is thankful that the children are able to entertain themselves with TV and computer games. Their four boys (two in high school and two in elementary school) are used to being 'fatherless' and, particularly the older ones, are not interested in doing the things that Fred enjoyed doing with his father when he was growing up, such as rabbit hunting during the winter or going fishing during the summer. As a child, Fred's extended family and friends would gather at the diamond in town to play soft-ball, preparing for the summer competitions with the neighbouring communities. The now abandoned softball diamond is a silent reminder of the once-popular sport. Jane blames Fred for the fact that, when not engaged in computers or videogames, the older children only seem to care about riding ski-doo's in the winter and motor bikes in the summer.

Case 2: 'Nothing to do' and boredom among teenagers

Mary, a divorced mother of two teenage girls, works as manager at the only supermarket in the area. Her former

husband was a commuter worker, until he met somebody else in Alberta and the marriage ended. She defends staying in the small town as she considers it 'a safe place for children to grow up.' She is also an active member at her church in the neighbouring community and on the 'Come Home Events' committee organised by the Town Hall every four years to welcome back the high number of residents who are now living and working in urban areas. Although she enjoys living in the community she grew up in, she also laments about how much things have changed from when she was a teenager. Most parents in her community are seasonal workers, living on Employment Insurance for most of the year. She believes that the parents who have chosen to remain at home are not necessarily the best role models to inspire the younger generation. Even when not working, most of them are not willing to engage in any kind of community commitment. The church membership has radically decreased because members do not regularly attend services anymore, unless is for a special occasion.

As a working mother she laments the lack of extra-curricular activities in her community. While growing up, she recalls youth always had something to do, either a hangout at somebody's house, a kitchen dance at a neighbour's place, or they would simply go outdoors to play, regardless of weather conditions. Mary complains that these days, her daughters and friends are not as active and usually complain of 'being bored', arguing that there is nothing to do. She asserts that her 15-year-old daughter is 'addicted' to her cell phone and the Internet and is unable to function without constant 'virtual' contact. She blames technology for these changes, but also talks about how the shrinking population has had a toll on the community. She claims that school premises are open only for an occasional party every two months and the only spaces available for youth to socialise in are the couple of fast-food outlets in the area, resulting in the increased consumption of unhealthy foods.

Case 3: Constructing youth at risk

Nancy, a low-income mother of two children, a teenage boy and a 4 year old daughter, also complains about the lack of activities for the youth in the neighborhood of the small town where she lives with a disabled husband, dependent on social assistance. Her main concern is the high number of 'youth at-risk' in town; as alcohol and hard drugs, such as cocaine, are easily obtainable. She is worried that her son may be into drugs because of the group of friends he is hanging with. As teenagers have nothing to do and are often exposed to drugs, it is easy for them to get hooked.

She noticed that when her son was nine years old he started smoking the butts that he collected from his father and her; she senses what little control they have as parents over their child's situation.

Nancy believes that there is need for more policing and services to deal with the high number of youth with addictions these days. She is glad that the local RCMP and health authorities are making efforts to raise awareness about the threats of drug addictions and have recently confirmed the arrival of a new addiction and outreach counsellor in the area. The counsellor is hired to connect with youth at the community level and to bring health promoting services as an early intervention strategy. However, feeling constrained by the structural conditions and lack of institutional collaborations, such as from the school system, he plans to address the addiction issues in youth through a harm reduction strategy approach.

Environmental influences on youth development and youth health in rural communities

Although existing research and plain common sense show that good living conditions in early life are pivotal for positive development, within a disease focused health system, scarce consideration is paid to the necessary social and physical environments for children and youth to thrive.[4-7] This is the case despite the fact that life-course epidemiology clearly shows the close relationship between quality of early experiences and health outcomes in adulthood.[8,9]

In rural areas, the situation is a complex one. Although people often argue about the positive aspects attached to living in rural communities with respect to social supports and pace of life, many organised occupational, cultural, recreational, and material resources that are common in urban areas are lacking in smaller communities. At the same time, youth are lured by the society's increasing consumerism and materialism within the media and Internet networks.[10,11] Commuting workers, represented in Case 1, often bring consumer goods into small communities that are simply unaffordable for people working and living in the local context. This adds to the disparity between households and the trend among youth to idealise urban areas and yearn for the chance to go elsewhere.

Lack of public transport and the predominance of a 'car culture' mentality only make things worse, especially for those who cannot afford to own a vehicle. In addition, the built environment commonly deters residents from gathering in any central place, as the few public places and commercial

areas are usually spread out among other neighboring rural communities. This arrangement discourages active lifestyles, as walking is not a feasible method of getting around. In the case of youth, the need for parents to have the time and a vehicle to take them to potential extracurricular activities, compounds the problem of a very limited offering of these types of activities. Consequently, for low-income youth, the opportunities are even more limited. The result is a greater dependence on technology, such as cell phones and the internet for social interaction. For those in more isolated rural areas the virtual world might be the only source of entertainment, exposing youth to and entrenching them more deeply in the increasingly normative materialism and consumerism promoted through the media.

Current trends in the health sciences also emphasise health care consumption within a model that mirrors business principles, in which people are constituted as 'consumers' or 'clients' of disease-focused services. Clients are conditioned not only to use the services, but to depend upon them, and are held accountable for health outcomes, neglecting the actual social conditions framing their health and health practices. This relationship fails to account for the fact that health-related practices are shaped by our subjectivities – the socio-culturally driven sense of who we are in relation to the world – and the complex circumstances for any kind of agency[12] In other words, how we perceive ourselves in relation to our life circumstances has a direct impact on how much power we feel we can exercise and what decisions we can make in a given situation.[13]

This business model of production and consumption in the health care system is deeply eroding the network of non-professional caregivers,[14,15] and even the sense of community itself.[16] This model reproduces itself through people's perceptions of it being logical, self-evident, or even natural in what Bourdieu calls 'a quasi-perfect correspondence between the objective order and the subjective principles of organisation'.[17] The resulting relations of power limit people's ability to perceive potential social change and stifle citizens' activism in relation to the production of healthy communities.[18]

On this path, health care has become a powerful currency, and its processes of objectification (health care as a subjectivity-free experience), commodification (health care as a marketable service), and standardisation (health care considered through a one-size-fits-all approach) are highly influential in the way the health-illness process is conceived and health and social services are provided.[19] The hegemony of the biomedical model and the high level

of consumption arising from a disease care system have also contributed toward a *medicalisation* trend in society.[20,21] This trend encourages people to think of social and cultural issues through an individualized pathology lens that creates illnesses for which professional services and biotechnology, offered as commercial commodities, are the solution.[22-24] The dominant biomedical discourse has become incredibly powerful, as it defines, sorts out, and regulates human bodies from birth to death, playing not only a clinical role, but also a moral role in the exercise of disciplinary power at the level of individuals and society.[25]

Consequently, although the quality of their socio-economic environment frames children's developmental health, defining lifestyles, trajectories, and health outcomes from the earliest stages, these lifestyles and behaviours are often decontextualised from broader structures that shape living conditions. Most health promotion and disease prevention efforts are focused on individuals and on modifying lifestyle choices and risky behaviors.[26-30] For example, despite the strong focus on childhood and adolescent obesity in recent years[31-33] and the increasing concern regarding the number of emotional and behavioural difficulties among teenagers,[34-36] little attention is paid to the cultural and economic issues surrounding these behaviours. An increasingly influential part of this social environment is the disease-focused culture in which institutional medicine and health services are seen as the most important piece of any health program.[37]

With the ongoing focus on pathologies, explanations for challenging youth behaviours tend to concentrate on isolated factors: escalating violence in TV consumption, single parenting and marriage breakdown, deficiencies in the school system, low-income and other forms of social exclusion, excessive consumerism, or the effects of technological or social change, all identified in the case scenarios. However, this attention to single issues does not take into account that all these factors are interrelated and deeply ingrained in contemporary culture with consequences on people's health.[25,38,39] It also forecloses any opportunity for agency in promoting changes in the broader social environment when all efforts are addressed to the singular individual behaviours or factor.

This problem-focus approach seems even more prominent among the less advantaged members of society, particularly those with low-income, youth, the elderly, or people with disabilities, whose voices are muted or absent from the political and institutional processes that seek to represent

them.[40,41] Disadvantaged individuals and populations are often medicalised in institutional discourses that draw attention to pathologies rather than to strengths and resources they also have, becoming increasingly dependent on health care workers and other service providers

'Nothing to do' and addiction to technology

While in rural areas there might be a lack of public spaces for social interaction and even less sporting and community activities, as evidenced in the case scenarios, there may also be a lack of enthusiasm and interest, reflecting a shift in cultural norms related to youth's activities and community life in general. The culture of ad hoc recreation with peers or self-directed participation in games or sports without formal structure and without the acknowledged achievement of something material or concrete (such as trophies, medals, or certificates) has been lost. Youth no longer seem to play because they like soccer or baseball or football, or because they enjoy this form of social interaction with peers, for example. Instead they play because there is a competitive and structured opportunity for personal gain, resulting in high-achieving families being the primary participants. The circumstances of participation are further stratified by economic resources, as many families cannot afford the cost of equipment, training and club fees associated with organized sports and other activities. Even among families who value participation, there is a feeling that the access to activities is limited.

However, parents' concerns tend to be focused on the lack of activities for consumption, rather than the lack of involvement and interest in communal activities, which were popular just a generation ago. The shift towards individualist social norms no longer supports imaginative and unstructured play and generalised physical activity as a part of healthy living. This trend is confirmed by other researchers. For example, research evidence on physical activity programs among youth showed that the most significant influence for adolescents' involvement in these programs is family support and reinforcing social norms,[42] as well as access within a school environment.[43] Using Bourdieu's social theory as framework,[17] Lee and Macdonald's research[42] shows that participation in physical activity is closely related to family's social, cultural, and economic capital. With regard to access to school facilities, in most rural communities in NL school space tends to be limited to academic activities, and school authorities are resistant to opening premises beyond regular hours, mainly because of potential liability issues and lack of volunteers to supervise the youth. Labour migration

patterns reduce the number of people available to provide the social framework for activities both in the household and in the community. In other words, the structures that should promote healthy activities for young people are disrupted on many fronts and both physical space and social networks to promote good health are diminishing in rural communities.

The social world for many young people in rural Newfoundland, like elsewhere in the world, is largely Internet and technology-based; the friendships and social connections are real but the space for interaction is a virtual one that fosters physical inactivity and emotional overload.[10] There is a widespread sentiment that youth *prefer* their virtual activities and although this kind of overconsumption is clearly defining sedentary lifestyles, and for parents working outside the home or isolated by distance and lack of transportation, there seems to be advantages to this. This is the point where we see an impasse in which socio-cultural conditions are discouraging physical and social activities, organised or otherwise, and yet people seem unable to envision alternative solutions.

The construction of ‘youth at risk’ and the concerns about addictions

In rural communities, youth are often constituted as a group-at-risk of developing social behaviours that will lead to poor health.[44] They are particularly at risk of becoming part of a cycle in which social conditions enable unhealthy behaviours, such as inactivity or poor diet. However, the most feared condition is substance abuse. In addition to the cultural shift towards increasing consumerist and materialist values, the affluence generated by commuting workers brings not only money, but an increasingly normative craving for fast relief to stressful lifestyles, both leading to an expanding drug dealing business.

The dissatisfaction generated by these values expresses a chronic emptiness in youth’s social lives, and the sense of disconnection is usually framed as ‘boredom’.[10,11] As youth participate in the same kind of consumer driven social world, if they cannot consume activities they look for alternatives to fill the void. Consuming alcohol and heavy drugs thus becomes not only a form of addiction, but also a form of resistance to the instituted system that holds few solutions to the lack of opportunities for a balanced life. In the meantime, the system medicalises the consequences and holds the youth accountable for the recklessness that this lack of opportunities generates.

It is beyond the aim of this paper to engage in a conceptual

discussion about the derogatory construction of youth at-risk, which sets up a distinction between a labeled ‘problematic’ minority versus a ‘normal’ majority.[45-47] However, we agree with Kelly,[46] that the construction of certain populations of youth in terms of deviance, delinquency, and deficit, provides grounds for forms of governance and control through expert systems. This kind of professionalization obscures the contextual issues and power relations complicit in producing the conditions for such risky behaviors in the first place.

Thus, while youth services are geared toward the production of a health risk identity, this systemic emphasis on intervention focused on targeting the addiction, remains reactive rather than proactive, as shown in the last case scenario. This perception is carried through from the institutional service domain to the general public. Despite their frustration, youth and parents tend to participate and conform to the ‘at-risk’ fixed identity that is imposed on them, since a system already exists in which they can participate as medicalised subjects. Usually there is a dual sense of hopelessness and blame among the consumers of this service and their parents. The paradox deepens as they recognize both the stigmatisation and inadequacy of the medical system, yet desire greater medical attention to the problem as a health concern.

Coincidentally, the perceived risk of substance addictions seems to be associated with the same social factors as those related to youth’s ‘addiction’ to technologies, such as computers and cell phones. However, rather than altering the social dynamic in which both the over-use of technology and substance abuse reside, a medicalised approach and consumption of professional services remains the focus.

Final considerations

While perceptions of ‘youth at-risk’ are rooted in the assumption that youth must be organized in directed and supervised recreational activities in order to be safe, this discourages possibilities for unstructured play and sports and further perpetuates these conditions by refusing the legitimacy of alternative ways of being healthy and active. While such problems are part of the social environment, the ongoing efforts to address these behaviours have been institutionalised, medicalised, and relegated to a health domain. The pathology-focused approach also creates conditions for the exercise of power.[25] Thus, while people are identified by their problem, they are also conditioned to accept some form of institutional intervention that addresses the problem, even if the intervention does little to alter the social conditions in which the problem exists. The conditions

that perpetuate a model of consumer behaviour reside in this cleavage, somewhere between a lack of essential social structures that promote and produce health and the health structures that medicalise the resulting problems.[38]

The culture of consumption shapes individuals as consumers of health services and intervention programs. As such, they are conditioned to use the services and are held accountable for health outcomes, neglecting the actual social conditions framing their health and health practices in the first place. Illness prevention programs end up constituting the subjects they purport to be helping by creating persons 'in need'. [14] Health subjectivities are consequently shaped by these discursive practices. As power-laden, institutionalised ways of talking, these practices localise and normalise concepts of health as if intrinsic to personhood by virtue of being embodied and of the body.[12] People come to think of themselves as being the health concern, as opposed to *having* a health concern.

To conclude, our exploration of experiences and understandings about youth health sheds light on the role of the symbolic, cultural context emanating from socio-economic and political structures.[17] We highlight the dynamic relationship between health and the social, cultural, historical, and economic conditions in community life. From this perspective, the situated context, in addition to being the object of study, shows also the location of potential forms of action.[48]

People perceive particular health problems as signs of change in both community life and the meaning of health itself. The stories people share, the fears they raise, expectations they identify, and challenges they describe all reflect a general concern for a rapid change in the social fabric and a general sense that the new social reality is not conducive to 'healthy living.' However, the tendency is to emphasise personal responsibility, supported by the prevailing biomedical trends of disregarding broader social and cultural concerns. The systems of economic practices and cultural meanings that shape thinking, personal and collective experience, and lifestyles are overlooked in favour of scientific evidence-based practices limited to proximal causes of health issues.[12] Consequently, we argue that service providers and policy makers must pay greater attention to the social and cultural conditions that encourage healthy lives. It requires that we look not only at the opportunities for preventing problems, but rather at redefining what constitutes healthy environments for youth to thrive. At the conceptual level, we emphasise the need to reflect on the interactive dynamic of health subjectivities and potential for action, maintaining

discussion on how culture and social norms, as social determinants of health, permeate thoughts and actions of the whole population.

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Acknowledgements:

Martha Traverso-Yeppez acknowledges funding from the Industrial Research and Innovation Fund and Memorial University Faculty of Medicine Start-up Grant. Jill Allison acknowledges funding from the Atlantic Rural Centre and the Harris Centre at Memorial University.

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4

Résumé

Cet article adopte une approche historique pour interroger le rapport entre santé publique et politique, et explorer les positionnement actuel et positionnement possible du domaine de la santé dans l'espace public. L'argument porte sur deux types de données, statistiques et photographies de documentation, à partir desquelles un certain savoir sur la santé intervient dans l'espace public. L'utilisation de ces outils a le pouvoir de révéler le scandale des écarts de conditions de vie dans notre société. Santé publique, scandale et politique sont reliés ensemble pour conclure sur une approche agonistique de la démocratie plurielle.

Mots clés histoire de la santé, photographie, santé publique, statistiques

L'Affaire de la santé une question / occasion de scandale ?

ADRIENNE CHAM BON

Introduction

Mon travail porte sur la démythification des récits du passé qui traitent de « la question sociale » et sur la porosité des frontières entre les disciplines –les limites, les errements, mais aussi la contribution des domaines proches de la santé, du social, de l'économie, et de la culture, et les esthétiques de chacun de ces champs à l'aide d'un point de vue historique.[1,2]

Cet article comprend trois parties. J'aborderai en premier lieu le rapport entre santé publique et politique et le déplacement du domaine de la santé dans l'espace public. Je traiterai ensuite de types de données à partir desquelles un certain savoir sur la santé intervient dans l'espace public à

travers les statistiques et les documents visuels. J'introduirai alors l'idée de la mise au jour du scandale à partir de ces deux outils d'information. Je prends ici le contrepied d'une approche plus classique. Enfin, je relierai les notions de santé publique, de scandale et de politique et j'évoquerai, en conclusion, la théorie agonistique de la démocratie plurielle formulée par la politologue Chantal Mouffe afin d'éclairer notre propos sur la contribution que le domaine de la santé peut aujourd'hui apporter à une démocratie active et engagée.

Santé publique, savoir et politique

Je prends comme point de départ le propos de Michel Foucault dans son texte classique « La politique de la santé au 18ème siècle ».[3] A cette époque, la santé est venue remplacer les préoccupations sociales et religieuses autour de la charité, des indigents et leurs maux. La santé est devenue une question publique, administrative et politique. Elle a engendré tout un champ de paroles et d'enjeux qui se sont traduits par des visions et des injonctions autour de

dilemmes de société. Comment penser et que faire ?

Ma propre recherche porte sur le début du XX^{ème} siècle à Toronto qui fut une période de grands chantiers sociaux en réponse à l'urbanisation accélérée de la ville liée à son industrialisation intense qui s'accompagna d'une forte migration rurale et l'immigration de populations étrangères, autant de facteurs qui donnèrent lieu à d'immenses disparités au sein de la population dans les conditions de vie, en matière de salubrité, et de mortalité.

Pourquoi regarder en arrière ? Les développements à cette époque plutôt lointaine ne sont pas sans rappeler ce qui se passe aujourd'hui dans les grandes métropoles : migrations liées à l'économie globalisée qui s'accompagne d'écarts sociaux exacerbés ; recul du secteur public ; et retour d'une certaine philanthropie^[4] (néo-philanthropie) ; autant de points de raccord entre ce passé et le présent dans les grands centres urbains.^[5] Le développement de la ville de Montréal précède bien entendu celui de Toronto. Ces parallèles justifient une histoire du présent, pour reprendre un terme de Foucault. Le passé n'est pas révolu. Il a laissé des traces, et certaines de ses manifestations sont très fortes aujourd'hui. On ne peut que constater bien malheureusement qu'un tel rapprochement est davantage d'actualité de nos jours qu'il y a 50 ans.

La question sociale fin XIX-début XX^{ème} siècles remue des penseurs de tous horizons, théologiens et leaders des plus laïques autour de l'interrogation suivante : comment une société se disant 'moderne', rationaliste, progressive, éclairée^[6] peut-elle être en proie à de tels écarts dans les conditions de logement, de salubrité, de mortalité, de qualité de vie au sein de sa population ? C'est comme si une flottille de bateaux se trouvait dispersée en mer, à tous vents, en proie à un naufrage. Cela rappelle des tableaux de J. M. W. Turner (1775-1851), peintre romantique et peintre de la révolution industrielle en Angleterre. Deux tableaux aux noms évocateurs : *The Egremont Sea Piece*, circa 1806-7; *The Shipwreck (le Naufrage)* de 1805, tous deux au Tate Museum. Cela paraît difficile à croire, et même inadmissible. La question sociale agite donc les esprits.

Le champ du travail social devint alors un des champs d'explicitation, d'articulation de ces insatisfactions, et de démarrage de programmes sociaux à visée communautaire. De fait, le domaine de la santé se révèle être un des filtres les plus puissants de ce dilemme. Au-delà des propos envoûtants de vie et de mort, il se positionne comme le champion de la question sociale au début du XX^{ème} siècle. La santé cerne tout un chacun(e), et met en lumière les effets de distribution

du bien-être et du mal-être dans la population. Voilà son importance.

De nos jours, les frontières entre les professions du social et celles de la santé convergent à nouveau. Depuis quelques années déjà, on assiste à l'émergence (ou la réémergence) du champ de la santé ; ce dernier déplace le champ du social, ou plus exactement l'englobe. Dans une publication d'il y a plus de dix ans^[7], j'avais écrit :

les politiques de la santé publique et le développement des activités de 'promotion de la santé' déplacent les frontières de leurs savoirs et débordent activement sur les secteurs traditionnels du social, en incluant par exemple les 'déterminants sociaux de la santé', ces facteurs dits 'd'environnement social' qui comprennent indice de pauvreté, revenu, et conditions de logement. Ces nouveaux savoirs sont en passe de recouvrir les dimensions du social par le biais du médical, et en tout cas d'en redessiner les cartes.[p317-a8]

Un texte d'Anne Golse intitulé « De la médecine de la maladie à la médecine de la santé »^[8] adopte une position similaire. J'ajouterais aujourd'hui qu'il est préférable de distinguer le domaine médical de celui de la santé avec l'expansion de celle-ci.

A propos de résurgences, il est intéressant de noter que l'université de Toronto vient de rouvrir une École de santé publique, une entité qui avait été créée dans les années 1920 avec un financement de la Fondation Rockefeller. Cet institut fut éliminé plus tard avec l'avènement de l'état Providence. Le revoilà aujourd'hui. Un indice parmi d'autres. Le passé n'est pas entièrement passé, ou bien il revient au galop, pas exactement le même.

En cherchant à reconstituer les points d'ancrage d'une généalogie des moments de révélation, des cris d'alarme et des discours d'insatisfaction, on trouve également des expressions de compassion associées aux troubles moraux que suscitent de telles réalités. Car ces conditions humaines renvoient l'image d'une moralité trouble, 'in trouble' (à crise) qui n'a pas pu ou su trouver une voie d'issue.

Une exposition s'est ouverte fin octobre 2008 aux Archives de la Ville de Toronto. Intitulée « An Infectious Idea: 125 Years of Public Health in Toronto » (Une idée contagieuse : 125 ans de santé publique à Toronto), l'exposition retraçait l'histoire du département de la Santé de la ville depuis le début du XX^{ème} siècle. Elle révéla le rôle-clé qu'y joua Charles Hastings. Commissaire de la Santé de 1910 à 1929, Hastings est une des figures les plus remarquables de son temps.^[9]

Suite au décès de sa fille, emportée par la typhoïde qu'on a attribuée à la consommation de lait non-pasteurisé, Hastings abandonne sa pratique de médecin et se lance dans une vaste campagne de santé publique. Il entreprend de transformer la ville de fond en comble en s'attaquant aux problèmes aigus affectant la population. Ce lien entre santé et ville est des plus importants. A l'époque, Toronto était dépourvue de système d'égouts ; l'eau du lac n'était pas filtrée ni traitée au chlore.

Hastings part en croisade. Il mobilise une armée d'inspecteurs, ouvre un vaste chantier d'enquêtes et d'inspection et rend publiques les données qu'il fait réunir systématiquement. Il exige des mesures d'hygiène de la population : le nombre de personnes vivant sous un même toit, les conditions de logement (les taudis), les conditions d'insalubrité, les chiffres de morbidité et de mortalité. Il veut, en d'autres termes, prendre la mesure du désastre et mettre en place des contre-mesures. Hastings est responsable de la campagne de distribution de lait pasteurisé dans les écoles et les dispensaires. Il fonde un système infirmier de santé publique, des cliniques de quartiers, instaure l'immunisation pour les enfants, met en place des réserves d'eau potable pour la ville, et exige la fermeture des cabinets dans les cours des maisons. Les changements sont extraordinairement rapides. Dès 1922, Toronto atteint un des taux de mortalité les plus bas parmi les grandes villes d'Amérique du Nord, et est citée en exemple par la Ligue des Nations. Entre temps, Hastings est nommé Président de l'Association canadienne de santé publique (1916), puis Président de l'Association américaine de santé publique (1918).

« Mesures » radicales

Au vu des actions remarquables de Charles Hastings, il est bon de se pencher de plus près sur le terme de 'mesure,' qui en français, et également en anglais, porte des connotations multiples qui peuvent éclairer notre propos : (a) Mesure – registre scientifique : moyens de quantifier des données physiques ; (b) registre de la morale, spirituel, sens abstrait « prendre la mesure des choses », se pencher sur la signification, les ramifications, les conséquences d'un phénomène de société, appel à une compréhension plus vaste des enjeux humains ; (c) registre institutionnel « prendre des mesures », mesures prises par un gouvernement : mettre en place des dispositifs, une réglementation, des programmes, soit une politique sociale et une politique de la santé. Hastings accomplit tout cela à la fois. Son action touche à ces trois registres.

Hastings ne veut rien laisser au hasard et rien laisser dans l'ombre. Statistiques et images documentaires sont les deux armes de son combat. Pour bien asseoir son projet, il exige également une documentation photographique des chantiers qu'il inspecte et des programmes qu'il instaure[10]; cette nouvelle technologie de pointe, 'réaliste', étant mobilisée pour impressionner les esprits, modeler les points de vue du grand public et des autorités. Mises ensemble, ces traces circonscrivent un vaste champ qui articule la santé avec les domaines du politique et de l'esthétique.

Un des photographes les plus engagés dans ce travail fut Arthur Goss qui débuta son emploi à un très jeune âge. Membre du club de photographie de Toronto et fervent adepte de la nouvelle technologie, Goss occupe le premier poste de photographe de la ville. Infatigable, il accepte les commissions des divers départements municipaux : travaux publics, éducation, parcs et récréation, et surtout le département de la santé pour lequel il réalise des centaines de photographies documentaires sur la situation de l'habitat, les rues, les arrières cours insalubres, les logements d'immigrants. Il se penche sur les côtés visibles et cachés de la vie des habitants du centre-ville. Examinons maintenant ce qui sous-tend les données en santé publique, penchons-nous sur la portée des statistiques et sur l'impact que peuvent avoir des documents visuels.

Les données de la santé publique, textes et images

J'aborde maintenant le cœur de mon propos : le scandale qui peut survenir à propos de la question sociale captée sous l'angle de la santé, sur la base de chiffres rendus publics et par la communication d'images circonstanciées. Je prends les chiffres et les données visuelles comme autant de langages aux fonctions équivoques, et qui, cependant, se présentent comme distincts des pris à partis idéologiques et politiques. Cependant ces mêmes outils peuvent œuvrer de multiples façons. Mon argument ne se veut pas seulement 'critique.' Je cherche à suggérer, insuffler, proposer d'autres usages des données de santé publique. Les statistiques, tout comme les images photographiques, ne montrent pas que des résultats calmes et apaisants. Les statistiques comme les photos peuvent déclencher d'intenses questionnements, soulever des malaises profonds, indiquer des conditions de vie insupportables, pointer des causes de conflit éthique, d'une éthique publique, collective et solidaire. Que dire, que faire, que croire et que penser des chiffres (des statistiques) et des photographies (représentations visuelles) qui se donnent à voir pour susciter, soutenir, et orienter les politiques sociales?

Objet neutre ou objet de dispute – chiffres, politique et critique

Lorsque l'on se penche sur l'émergence historique de la probabilité et sur l'usage des chiffres, on découvre un champ d'études qui aujourd'hui porte le nom de « sociologie historique de la quantification ». La revue *Sociologie et Sociétés* a récemment traité de ce thème. Le responsable de ce numéro, Stéphane Moulin, met en relation les pratiques statistiques avec les politiques publiques. Dans son introduction, intitulée « La statistique en action, » il écrit ceci[11]:

Comme l'étymologie latine du mot l'indique, la statistique renvoie à l'État et aux formes de l'action publique [...] la naissance de la statistique est plutôt récente et contemporaine de la consolidation des appareils bureaucratiques d'État.

Moulin précise la portée multiple de ce nouvel outil (et pratique) de savoir :

la statistique comme produit de l'action de l'État et des discussions publiques ; la statistique comme ressource cognitive du pouvoir politique ; et enfin la statistique comme support de modèles différenciés de représentation du monde social.

Il ajoute :

Les histoires singulières [...] ont en commun de faire apparaître les quantifications comme l'objet d'enjeux sociaux, de négociations ou de luttes entre acteurs, et comme le résultat du jeu du rapport des forces en présence. L'analyse des instruments de quantifications est faite à partir de l'histoire des acteurs qui les produisent.[p11]

Moulin cite le philosophe Ian Hacking, fortement influencé par Foucault, qui a développé sa théorie sur l'émergence de la probabilité, et la construction de 'types humains' par le biais de la statistique.[12] Pour Hacking, la statistique en tant qu'outil de gestion de la population contribue à classer des groupes qui présentent des traits en communs. Ces 'types' de personnes (multiple personnalité, autiste) ainsi catégorisées sont perçues par les experts, et se perçoivent elles-mêmes en retour (*looping effect*) comme des sujets d'un certain type. Auparavant le sociologue de la deuxième École de Chicago, Everett Hughes, co-fondateur dans les années 1930 du département de sociologie de McGill (avec Carl Dawson), avait soulevé cette même question à partir d'observations apparemment anodines repérées dans des documents administratifs. Réfléchissant à des tableaux de statistiques nationales, il publie en 1955 un article dans la revue *The American Statistician* dans lequel il compare les logiques statistiques allemandes et américaines de l'époque.

[13] Il constate :

J'étais presque certain, ayant examiné les statistiques officielles allemandes que l'Allemand pré-Nazi avait eu une religion mais pas une race. L'Allemand statistique était le contraire de l'Américain statistique, qui lui avait une race mais pas de religion.

Il poursuit :

L'incident qui a consisté pour ma part à remarquer un changement de catégories (avec l'introduction en 1938 d'une classification raciale des mariages dans le recensement allemand) m'entraîna à me poser la question suivante : Quelles sortes de modifications ont dû être introduites par le statisticien du IIIème Reich avec l'avènement du gouvernement national socialiste ? Une question plus profonde est alors mise en évidence qui concerne les statisticiens en général : peut-on continuer de considérer leur travail comme étant neutre ? Dans quelle mesure, les catégories à l'aide desquelles ils/elles rendent compte de leurs données sont-elles sujettes à des attentes/exigences politiques ?[p8, ma traduction]

Tout récemment, la revue *Medical Anthropology* consacrait un numéro à la quantification « Enumeration, identity and health ». [14] Les deux anthropologues des sciences qui l'ont dirigé, Thurka Sangaramoorthy et Adia Benton, abordent dans leur introduction les conséquences inattendues de la construction de 'sujets' – propos qui rappelle fortement l'argument de 'gouvernementalité' (autre concept Foucauldien). Ils formulent leur question ainsi :

« How are people made to count ? – in other words, who and what is made visible (and invisible) in the process of counting ?[p288]

En traduction : « Qui doit compter ? » i.e., être comptabilisé, répertorié, et identifié. Soit : « qui et quoi sont rendus visibles (et en parallèle invisibles) dans tout processus de quantification ? » Ils ajoutent (ma traduction) :

Les données regroupées au nom de la protection de la santé ont souvent une/des histoire(s) ; elles reflètent les changements dans les exigences et les usages des informations relevant de la santé à partir d'une diversité de projets d'ordre institutionnel et personnel.[p289]

Un exemple extrême est la décision prise en 2010 par le gouvernement de Stephen Harper au Canada de supprimer le questionnaire détaillé du recensement de la population qui permettait le suivi des statistiques nationales et les comparaisons des conditions sociales d'un recensement à l'autre. Cet outil était essentiel pour toute étude longitudinale de la population. En y substituant un questionnaire simplifié à usage volontaire, sans obligation citoyenne, le gouvernement se prive et prive les membres de la société canadienne et internationale de l'accès aux données de base.

Par conséquent, nous ne serons plus à même de débattre des conditions de société en l'absence de données adéquates. Cette décision politique d'affaiblissement de la démocratie a suscité de fortes oppositions tant de la part de chercheurs que de politiciens[15], mais hélas sans effet.

Le pouvoir de nommer ne comporte pas seulement un volet réducteur voire répressif ; il permet tout autant, dans l'esprit des écrits de Foucault, de nommer les phénomènes de façon productive et cette fois progressiste. Ce pouvoir comprend l'option d'une démarche de réflexivité, de mise en garde, d'indexation autre, tout aussi « productive » mais s'exerçant à d'autres fins, pour soutenir d'autres projets. Les exemples cités ci-dessus montrent tous à quel point les enjeux politiques (statistiques) sont l'objet de passions, d'émotions fortes, et d'attachements. Il n'est pas uniquement question de réflexion à froid.

Il me semble ainsi que le débat sur les déterminants sociaux de la santé peut prendre une direction significative. La publication de Juha Mikkonen et de Dennis Raphael en 2010[16] qui attribue les inégalités en matière de santé au Canada à des catégories statistiques telles que le revenu, le sous-emploi, l'éducation, le logement, l'insécurité alimentaire, et l'exclusion sociale renvoie à des catégories fortes. Dans cet ouvrage, celles-ci sont mises en œuvre pour soutenir un projet de société juste et équitable. L'engouement pour les déterminants sociaux de la santé exprime un retour à la question sociale ; la revue *Social Science & Medecine* comprend ainsi de nombreuses contributions à ce sujet.

La Déclaration de Rio de Janeiro faite en octobre 2011 par la Commission des Déterminants sociaux de la Santé de l'OMS (organisation mondiale de la santé) est un autre exemple d'importance. La résolution WHA62.14, intitulée « *Réduire les inégalités en matière de santé par une action sur les déterminants sociaux de la santé* » comprend en effet trois recommandations majeures: "améliorer les conditions de vie quotidiennes, lutter contre les inégalités dans la répartition du pouvoir, de l'argent et des ressources et mesurer le problème, l'analyser et évaluer l'efficacité de l'action" et plus précisément pour en citer des extraits :

[6] Les inégalités en matière de santé sont le fruit des déterminants sociaux de la santé, c'est-à-dire des conditions sociétales dans lesquelles les individus naissent, grandissent, vivent, travaillent et vieillissent. Ces déterminants englobent les expériences vécues dans les premières années de la vie, l'éducation, le statut économique, l'emploi, le travail décent, le logement et l'environnement, et l'efficacité des systèmes de prévention et de traitement des maladies. Nous sommes convaincus qu'il est essentiel d'agir sur ces déterminants, pour les groupes vulnérables

et pour l'ensemble de la population, afin de créer des sociétés soucieuses de n'exclure personne, équitables, économiquement productives et en bonne santé. Considérer la santé et le bien-être comme des caractéristiques parmi les plus importantes d'une société prospère, juste et qui n'exclut personne, au XXI^e siècle, va dans le sens de notre engagement en faveur des droits de l'homme aux niveaux national et international.

[7] [...] En tant que buts communs, la santé et le bien-être de tous doivent être considérés comme absolument prioritaires aux niveaux local, national, régional et international.

[8] [...] Sur la base des expériences échangées lors de cette Conférence, nous exprimons notre volonté politique de faire de l'équité en santé un but national, régional et mondial et de relever les défis actuels, par exemple éliminer la faim et la pauvreté, assurer la sécurité alimentaire et nutritionnelle, l'accès à une eau de boisson sans risque pour la santé et à des moyens d'assainissement, l'emploi, le travail décent et la protection sociale, protéger l'environnement et assurer une croissance économique équitable, en agissant résolument sur les déterminants sociaux de la santé dans tous les secteurs et à tous les niveaux.

Il s'agit désormais de suivre dans quelle mesure et par quels moyens cette déclaration sera concrétisée et mise en œuvre dans un avenir proche. Une déclaration ne suffit pas, mais une déclaration compte.

Je me tourne rapidement maintenant sur un autre type de données, visuelles cette fois qui accompagnent souvent les arguments statistiques. Ces images s'adressent davantage aujourd'hui à un grand public et au public des électeurs.

Photographies à l'appui, le scandale des images

La photographie fait scandale. Savoir qu'il y a des conditions de logement insalubres c'est une chose, en voir une image avec tous les détails, y voir des personnes vivant leur vie ordinaire dans le manque et l'inconfort, voir des enfants vaquer à leurs affaires ou qui regardent la caméra, tout cela devient vite insupportable. L'emprise des photos crée le choc d'une rencontre avec des conditions d'existence lointaines de ce que les lecteurs connaissent dans leur vie quotidienne. L'action des images est ainsi de double portée : La photo montre « ceux-là », et suggère par là-même l'écart entre eux et nous, nous et les autres.

Un photographe expérimenté et sensible comme Goss laisse entrer les jeux d'ombre et de lumière autour des personnes,[17] leur accorde le respect, ne force pas sur la note. Ce qu'il nous donne à voir ne peut pas se replier sur une forme de stéréotype, ce que Susan Sontag[18] dénonçait comme une forme de spectacle de l'autre, qui à l'inverse

nous éloigne de tout engagement. À travers les photos de Goss, nous sommes mis face à face avec des personnes qui, si elles ne nous voient pas, demandent à être vues.[19]

On a tendance à partir du sens commun de séparer comme étant irréconciliables deux types d'images photographiques : (a) les images passionnelles que nous donnent à voir les quotidiens à scandale, et (b) les images dites de précision et de réalisme documentaires. Certes ces deux types d'images diffèrent l'un de l'autre, mais les fonctions de l'image diffèrent bien moins que l'on ne pourrait croire.

Weegee (Arthur Fellig) fut le photographe célèbre des menus scandales quotidiens qui firent la 'une' des journaux New Yorkais dans les années 1930 et 1940. Ses reportages de photographies prises sur le vif constituèrent une chronique urbaine des accidents et des meurtres ordinaires. Par ailleurs, comme l'a décrit l'historien d'art John Tagg[20] les photographies de médecine et de psychiatrie décrivaient des états pathologiques d'exception par le biais du portrait de spécimens, faisant la révélation de leur monstruosité qui suscitait de puissantes réactions de rejet de la part du spectateur.

À la même époque, le photographe Lewis Hine faisait des portraits d'enfants, de femmes et d'hommes travaillant dans les usines. Ses images contribuèrent à la forte pression qui fut exercée sur le gouvernement américain pour instaurer des lois de protection des enfants et des femmes au travail. [21] Par la suite, le photographe Stieglitz et son équipe ont soutenu les politiques de New Deal de Roosevelt. Ainsi la photographie comme le cinéma peuvent être pensés comme des *arts d'intervention*; je reprends le terme d'« interventions visuelles » à l'anthropologue Sarah Pink[22]; des arts de combat, comme disait Bourdieu pour la sociologie.

Le pouvoir des images est une notion importante. Je fais appel ici au très beau texte de l'historien d'art George Didi-Huberman[23] sur « l'expérience des images » et plus précisément, le surgissement de l'image :

Enchantement, ravissement, oui cela peut arriver devant une image. Mais aussi l'inquiétude ou la terreur, cela dépend. [...]. L'apparition d'une image, pour autant qu'elle soit « puissante », efficace, nous « saisit » donc nous déssaisit. C'est tout notre langage qui est alors, non pas supprimé par la dimension visuelle de l'image, mais remis en question, interloqué, suspendu. Il faut ensuite de la pensée, et même du savoir – beaucoup de savoir –, pour que cette remise en question devienne remise en jeu : pour que, devant l'étrangeté de l'image, notre langage s'enrichisse de nouvelles combinaisons, et notre pensée de nouvelles catégories.[p83]

On pourrait ainsi parler en parallèle du rugissement des chiffres et du surgissement de l'image.

Ce par quoi le scandale arrive. La santé met à jour le scandale

Qu'est-ce qui est scandale ? Et qu'est-ce qui fait scandale ? Définitions des dictionnaires (Larousse, Petit Robert) : Fait qui heurte la conscience, le bon sens, la morale, suscite l'émotion, la révolte ; le scandale de la faim dans le monde; le scandale du gaspillage alimentaire ; grave affaire qui émeut l'opinion. Indignation que causent les actions, les situations inacceptables pour la morale. Faire tapage.

Le registre du scandale est en premier lieu d'ordre religieux. Non plus le mystère de la pauvreté, de l'indigence, mais son infamie. Le scandale touche l'ordre public. Le scandale se nourrit d'air, ne peut rester dans les caveaux des oubliettes. Le scandale se révèle au grand jour. Le scandale révèle le dépassement d'une limite (explicite ou vertueuse et implicite), la non-assimilation d'une certaine réalité (sociale) qui ne peut pas se raccorder avec les principes revendiqués d'une meilleure société. Le scandale montre du doigt des lacunes, des failles, des erreurs dans l'armure et dans le décor. Ce furent là le socle et la substance du mouvement d'hygiène sociale entrevu comme une croisade pour parer au pire, pour divertir de l'échec. Le scandale révèle un désordre profond qui risque de faire tâche ; et le désarroi d'un non-savoir. Le scandale entraîne le risque de déconfitures, de mise à mal de personnes, le risque profond de défaire le tricot maille à maille.

Le scandale est rempli du feu des émotions, c'est comme un incendie qui ne peut pas s'éteindre, qui embrase l'horizon. Il va effrayer et défrayer la chronique. Le scandale est une mise à l'effroi (le cri de la chouette; la tête de la Méduse). L'horreur, la honte. Fait immoral et révoltant. Le scandale suscite la juste révolte, le 'plus jamais ça.' Il peut entraîner une révolte plus profonde de toute une société, c'est l'esclandre qu'on ne peut plus éviter, et qui a un effet de ralliement.

La question sociale peut être comprise comme une question de pauvreté, de danger de contamination que représentent certaines classes, les classes dangereuses. Question qui pointe la vulnérabilité de certains individus et de certains groupes, mais qui mine aussi le corps social dans son entier. Formes extrêmes de destitution, formes qui instaurent un regard diffamatoire d'exclusion, et qui révèlent l'impuissance des puissants à se débarrasser de ce problème. Scandale économique, scandale social, et scandale culturel. Le scandale est le résultat et l'expression de violences. Doit-

on 'étouffer le scandale' ou 'souffrir le scandale' ou bien répondre à l'indignation et à la fureur qu'il soulève ? Le scandale invite à l'action.

La santé n'est pas le pur lieu de l'apaisement – même Florence Nightingale battait les campagnes pour faire prévaloir ses idées. La santé ne renvoie pas seulement à une expertise assurée, pacifiée, planificatrice et lénifiante. Soporifique comme on dit 'sanitaire.' Le cinéaste italien, Pasolini, avait cette phrase bien connue: 'ne vivre que de scandales'. On a davantage l'habitude de penser le scandale par le biais de la littérature, de la fiction. Mais le scandale s'obtient tout autant par les chiffres, le détachement des chiffres et la monstruosité de ce que les chiffres peuvent montrer. On a tendance à oublier cet effet qu'exercent l'objectivité et la distanciation. Une densité inouïe de l'habitat ? Le chiffre tout comme l'image peut émouvoir, déplacer notre perception et modifier notre compréhension, agir sur nos usages.

Scandale, politique et démocratie

Si j'ai pris la figure du scandale comme propos c'est dans un double esprit : (1) de responsabilité individuelle, la *parrhesia*, le risque à prendre par tout citoyen au nom de la chose publique. [24] (2) Simultanément, en référence à un concept non édulcoré de débat de société, à ce qui s'est appelé une '*disputatio*' au sens fort. La démocratie, nous rappelle la politologue Chantal Mouffe, n'est pas affaire de consensus. Elle est affaire d'affrontement entre des intérêts opposés autour de projets distincts de société. Le politique se joue à partir de passions et de positions. Dans une communication qu'elle a faite au Collège international de philosophie à Paris et publiée en 2004 dans la revue du Collège, *Rue Descartes* (2004/3), Mouffe développe sa pensée dans un texte intitulé « Le Politique et la dynamique des passions ». [25] Elle pose les choses en ces termes :

Je me penche depuis un certain temps [...] sur l'incapacité croissante de nos sociétés à poser les problèmes auxquels elles sont confrontées en termes politiques. Les solutions à ces problèmes ne peuvent en effet être de nature technique, mais exigent de véritables décisions politiques. Cela suppose qu'existent différentes manières légitimes de concevoir la vie en commun, lesquelles doivent alimenter un conflit dans les sociétés. [p1]

L'interrogation ne peut pas se limiter à une question d'ordre moral, elle est éminemment politique. Les deux grands modèles en vigueur, dit-elle, celui de l'agrégation des intérêts individuels d'une part, et de l'autre, le modèle fondé sur la délibération (d'Habermas) ne tiennent pas compte des réalités sociales ; le premier évite le domaine

du collectif, le deuxième évite les rapports de force, comme si un consensus pouvait s'obtenir en dehors du champ de forces qui s'exercent. Le pluralisme démocratique, pour Mouffe, implique conflit ouvert de société dans lequel une confrontation véritable (qu'elle nomme *agonistique*) a lieu dans l'espace public autour de projets radicalement divergents. [26] Les passions qu'engendre le politique ne sont pas évacuées mais « amadouées ». Il ne s'agit pas d'une lutte à mort, mais d'un combat pour aboutir à des décisions avec lesquelles tous peuvent vivre, étant donné qu'il y a des gagnants et des perdants mais que le jeu permet les renversements de visions, et non pas un état d'hégémonie continue comme il semble être le cas (avec la Troisième Voie qui ne diverge pas fondamentalement de la voie dominante).

Il me semble que les données statistiques en tant que pratiques de quantification, tout comme les documents visuels dits 'réalistes' sont des moyens apparemment techniques mis en œuvre dans l'arène publique du débat de société sur les questions de la santé, du bien-être et du mal-être de tout un chacun, mais assurément de certains plus que d'autres.

Conclusion

Pour conclure, nous nous retrouvons devant la question du savant et du politique. La science soit-elle chiffrée ou de démonstration visuelle ne peut se contenter de se montrer sous l'angle de la compétence technique. Les différentes voix sur lesquelles je me suis appuyée pour construire mon propos convergent autour d'une idée simple. Le savoir et sa communication sont l'objet de pratiques et de représentations. Les percevoir comme étant neutres, et s'en servir de cette manière, constitue autant d'évitements avec une confrontation sur les écarts profonds des enjeux de société, sur les vastes différences (comme autant de planètes) entre le bien être et le mal être de certains groupes face à d'autres. Nous avons à notre disposition des données qui font scandale (scandale économique, scandale social, scandale culturel). Il serait bon que l'on s'en serve pour promouvoir un débat profond de société.

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Remerciements :

Je tiens à remercier le Conseil de la recherche en sciences humaines et sociales du Canada pour le financement de cette recherche.

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