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TRUST OR DISTRUST TOWARD HEALTHCARE SERVICES: BREAST SCREENING IN THE NORTH AND SOUTH OF ITALY

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This article follows a previous study that has recently been published in *Narrare I Gruppi* and explored the reasons for the large numeric gap between the regions of the North and South of Italy, referring to the breast cancer screening program adherence rate sponsored by the Italian Healthcare System, that addresses all women living in Italy ranging in age between 48 and 69 years, and proposes a free mammogram every two years. The effectiveness of cancer early detections has been widely demonstrated by medical research; this kind of diagnosis is particularly important in the case of breast cancer. A diagnosis of this form of cancer at its early phases in 97% of cases allows women to survive at least five years after it. However, the different level of trust women feel for healthcare structures is the discriminating element between the North and South of Italy for their access to the screening program. This topic will be thoroughly analyzed by presenting the results of research aimed at evaluating the meaning given to the outcomes of a first exploratory study, this second study also offers the opportunity to share our results within the social context that has generated them. The outcomes of the present research have been presented to a group of “privileged witnesses” living in the South (Naples and its surroundings): 12 women aging from 49 to 65, and 5 healthcare workers (one doctor, 25 two nurses, and two Local Health Authority supervisors); they took part in three Focus Groups for an in-depth look of the theme in question. The analyses of the groups’ debates, carried out by means of a software for text analysis (T-LAB), confirmed the results of the previous research: the diffidence and lack of synergy between institutions and healthcare workers are the causes of southern women’s lack of participation to the breast cancer screening program. In particular, the comparison between women’s and workers’ viewpoints shows a different emotional connotation about the possibility to improve participation to the screening: the workers’ optimism countervails women’s distrust and pessimism.

KEYWORDS: *Cancer, early detection, healthcare Services, trust.*

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INTRODUCTION

This article follows a previous study that has recently been published on *Narrare I Gruppi* (Saita, Zuliani, Molgora, & Bonanno, 2014), where we have been trying to analyze and understand the reasons for the large numeric gap between the regions of the North and South of Italy pointed out by the *Osservatorio Nazionale Screening* [National Screening Observatory], referring to the adherence rate to the breast cancer screening program sponsored by the Italian healthcare system. Such an early detection program is highly important, because it offers a free mammogram every 2 years to all women living in Italy ranging in age between 48 and 69 years. The effectiveness of early cancer detection has been in fact widely demonstrated by medical research; this kind of diagnosis is particularly important in the cases of breast cancer. A diagnosis of this form of cancer at its early phases allows women to survive at least five years after it in 97% of cases.

Despite today's increasing knowledge about breast cancer and the development of technologies to operate and treat it, the most effective way to limit its consequences is a mammogram. The main reason for an in-depth analysis of breast cancer prevention psychological aspects is to understand how to increase primary prevention, always bearing in mind the most important goal: the reduction of morbidity and mortality rates of this pathology.

The conceptual framework of this article refers to the widely known definition of health given by the World Health Organization (WHO), according to which health has been defined as a complete state of physical, psychological, and social well-being. This definition clearly goes against medical reductionism and refers to the bio-psycho-social model (Engel, 1977), which expresses a way to conceive and approach the problem of health/disease overcoming the "boundaries" of the single individual. Even though a disease seeds itself into a physical body, such concepts like those of health and illness cannot be merely conceived as pertaining to one's body since all the significant relations – with one's partner, family, or community – in each individual's life revolve around his/her being well/ill. In this perspective, the physical body cannot be considered as the boundary of the individual (Saita, 2012) but rather as part of a broader relational system in constant exchange with its surroundings.

This conception brings us back to the theme of social cohabitation that has been an object of huge interest on the part of the various fields of the social sciences (psychology, sociology, pedagogy) over the last years; however, the more specific theme of living together within healthcare and promotion contexts, on the border between social and organizational–institutional levels, appears as less studied.

Such an issue also calls into question a broader reflection on the health care system functioning and, in particular, on the procedures adopted by service providers: they should address the population's needs rather than be focused on bureaucratic-computer or legal aspects and based on the idea of an abstract customer faced with a structure defined by mechanic-procedural rules (Cigoli, Saita, & Margola, 2006). Such a system may lead to denying and rejecting emotionally characterized mental dynamics and processes, as well as excluding some aspects concerning interpersonal relationships in favor of hypothetical efficiency. These considerations help

us understand the results of a first exploratory research (Saita et al., 2014), which allowed us to highlight the differences in the way breast cancer prevention is conceived according to the place of origin and context women have been growing and living in. To be more specific, differences between northern and southern Italy have to be led to the different levels of trust toward healthcare structures. Trust is a prerequisite to set a stable relationship between subjects and institutions, and, therefore, allowing for the chance of good cohabitation: it crucially determines women's accessing or rejecting the national screening program.

These outcomes have brought us to a new research question that aims at verifying the meaning given to results emerged in the first explorative study. At the same time it represents the chance to "share" these preliminary outcomes with the social context that generated them

The research project we are going to describe here actually shows a tension towards social change, a "change while exploring" (Di Maria & Di Nuovo, 1981, p. 68), which improves our research work and favors the transformation of the *healthcare system and policies*. Exploring psychological dynamics connected to breast cancer prevention is the first step to creating a stronger awareness on the theme among people who need "to receive treatments" for their health, as well as the workers who hand it out (doctors, nurses, etc.).

ACTIVATING A CHANGE PROCESS

As previously stated, our research project aims at thoroughly analyzing the theme of social coexistence through a participated research action (Kemmis & McTaggart, 1988; Lewin, 1951) ... in which the community is called to gain a greater awareness of the dynamics characterizing its functioning through an active involvement of all the social actors holding the local *knowledge* about breast cancer early detection in order to promote a more informed and adequate preventive behavior.

The results of a previous study (Saita et al., 2014) have pointed out a difference in the representations of breast cancer and breast cancer prevention between Northern and Southern Italy; these representations are connected to two treatment models, only one of which (in the North) seems "trustworthy"; namely, suitable to build a relationship between the subjects and their systems of belonging characterized by that trust which represents an essential condition of each social coexistence form (Carrera, 2006).

These results seem particularly interesting because they only partially confirm the theories present in the literature; for these reasons they were presented and discussed both with healthcare workers and women called to participate in the national breast cancer screening program living in Naples and surroundings, an area that can well—even if not exhaustively—represent the specificities of southern Italy.

PURPOSES

The present research aims at gaining information that is hard to access that may, however, influence a community's chances for development (Barr, Koppel,

Reeves, Hammick, & Freeth, 2005). In more specific terms, we aim at thoroughly analyzing the reasons for southern women's lack of participation to the national breast cancer prevention screening program. Within a participatory action-research framework (Kemmis & McTaggart, 1988; Lewin, 1951), the basic elements of the cognitive level stimulate actors to reflect upon the potentials and the limitations of a given situation and favor them to take a critical and self-critical stance encouraging transformative and developmental processes. In this view, our aim is to increase the knowledge and awareness on the topic of breast cancer prevention and early detection by setting up a dialogue with those who are directly involved in dealing with such issue: women living in the southern part of the country who, on the basis of their age, are at risk for developing breast cancer on one hand and healthcare professionals working in facilities located in the South of Italy who treat this pathology (e.g., Local Health Authority supervisors, doctors, nurses) on the other. Our basic assumption is that the culture and context these women live in influence both their representation and preventive action against cancer on the basis of different membership and confidence relations with institutions and people who deal with healthcare.

METHODOLOGY AND TOOLS

The underlying assumption of research-action is that it is not just a means to acquire information, but also an instrument to involve others; in other words, it is a way of relating to people that promotes an actual change in their real lives (Lewin, 1951). The rationale for this work is therefore supported by an active involvement of significant social actors, in order to favor southern women's larger participation in the national mammogram screening. On the basis of these considerations, the outcomes of a preliminary study have been turned into the following specific research topics:¹

1. Adhesion to the regional mammogram program (Women's and healthcare workers' reflections about southern women's lack of adhesion to the screening program),
2. "Coping" (Considerations on southern women's "delegating coping"),
3. Primary Prevention (Not very well known by southern women),
4. Possibility to improve women's adhesion to the regional mammogram program.

Since the group is the place for participation, we have chosen the *Focus Group* (FG), a valuable tool to understanding unconscious aspects of motivation and behaviors concerning a specific theme (Krueger, 1994), useful to leading subjects to expressing ideas and emotions that would less easily show during an interview (Morgan, 1998; Oprandi, 2001; Stagi, 2000) and provide indications on how opinions and behaviors are built, their degree of stability, and the factors that can determine their change (Levy, 1979). In particular, we have chosen to carry out mini-groups (made up of 5–6 people), considered more suitable to investigate very sensible research themes. Such kind of groups guarantee a

greater privacy while allowing each participant more time to freely express their ideas and sharing personal life experiences (Zammuner, 2003). Three FGs were carried out in Naples. A moderator participated in all the groups. Their average duration was 95 minutes. Text data coming from FGs (recorded and fully transcribed discussions) were analyzed with the help of T-LAB, a software composed of a number of linguistic, statistical, and graphical tools for text analysis (Lancia, 2004). Three types of analysis were especially selected:

1. Thematic analyses of elementary contexts;
2. Specificity analyses; and
3. Factorial correspondence analyses.

Given that factorial correspondence analyses are more general and specificity analyses more focused on particular segments of the text, these techniques are complementary and often used together for textual analysis.

The thematic analysis of elementary contexts allows building and exploring the contents of the *corpus* through significant thematic clusters, each of which is composed of a number of simple contexts (sentences, paragraphs) characterized by the same key word patterns: each cluster allows reconstructing a specific theme in the overall discussion plot. Our hypothesis is that this analysis allows detection of not very aware attitudes connected to the theme of mammogram, consistently with what Ackerson and Preston (2009) had pointed out about the role played by emotions and mental processes underlying the preventive behavior.

The specificity analysis, based on the *chi square test* and thanks to word occurrence, allows finding out each group's typical (by shortcoming or excess) and exclusive words. The correspondence analysis extracts new summary variables, or dimensions (i.e., factors), which tell us about the relationships among units of text; in this regard, the statistical logic of correspondence analysis is that of traditional factor analysis, which tells us about the relationships among items in a scale: text units that are placed on opposite ends of the factor are mostly different from each other. Statistical tests are provided to differentiate the poles of each factor (test values ≥ 1.96 ; $p < .05$); the higher the value, the more important the text unit in defining the factor. We hypothesized that the research topics would produce differences in the language used by the subjects, with a different ability to disclose and explore emotions and feelings.

PARTICIPANTS

Seventeen subjects took part in the study: 12 women² aging from 49 to 65 years³ ($M = 56$, $DS = 37.3$) and 5 healthcare workers (2 ASL [Italian acronym for Local Health Authority] supervisors,⁴ a general practitioner, and 2 nurses; age $M = 55.2$, $DS = 8.2$).

Women were recruited by means of a *snowball sampling* (Baldry, 2005); all subjects accepted the invitation.

All subjects were born in Naples and its surrounding areas and live there.

RESULTS

The thematic analysis of elementary contexts applied to the entire text allowed the identification of four thematic clusters.

We will show clusters following the order given by the percentage of explained variance; their interpretation took place on the basis of words that mostly characterized elementary contexts.

Cluster 3 explains 35.03% of the variance, and therefore represents the most discussed thematic nucleus in FGs. This cluster is about the necessary *integration* of elements in order to let southern women adhere to the national mammogram program. Both women and workers agree when they think that on the basis of the lack of adhesion there is a lack of synergy between the parts, the most recurring words are “General Practitioner,” “ASL,” “Not Informed,” “Not Called” (words referred to women). A closer examination of the contents of the quotes associated to this cluster, shows the great relevance given to the general practitioner’s role of informing women on the importance of the national prevention program and convincing them to participate.⁵

Cluster 4, which explains 26.75% of the variance, refers to *primary prevention*, as it is considered and practiced in the South of Italy: the reference is exclusively to deeply rooted eating habits (food offered by their land is preferred, such as fish and fresh products), in this sense a balanced diet as preventive action is not a choice, but an integrating part of a person’s lifestyle.⁶ However, other primary prevention behaviors are poorly considered.

Cluster 2 explains 21.66% of the variance and can be defined as *early prevention*. It actually refers to the habit to start undergoing mammograms before entering the age range considered by the screening program, especially for those women who have experienced cancer in their families and are afraid to be affected in their turn. It follows that, when they are called to participate to the program proposed by the National Healthcare Service, some women prefer to continue the prevention in the structures they already know and rely on.⁷

Finally, **cluster 1**, which explains 16.56% of the variance, is about the *perceived difference* between healthcare structures of the North and the South, not so much on a preventive level, but mostly as far as treatment is concerned. Words recurring the most for this cluster are: “structures,” “best,” “level,” “North,” “South,” and “abandoned.” Assessing in detail the elementary context selection, the firm belief emerges, especially on the women’s part, that when facing a serious health problem it is necessary to “run away” from their territory and go to the North, where doctors and hospitals are, according to them, better. This transfer is defined by them as the “journey of hope.”⁸

Let us consider the specificity analysis that allows us to underline differences among participants considering their role: women in an age at risk for suffering cancer and healthcare workers.

Taking a look at **Table 1**, we can observe that the words *hospital* and *I* characterize women’s conversations, while *woman*, *prevention*, *believing*, and *attention* distinguish workers’ discussions. Among less used words, instead, we find *woman*, *prevention*, *own* in women’s talks, and only the word *hospital* in workers’ conver-

Table 1
Specificity Analysis: typical words

WOMEN		HEALTHCARE WORKERS	
Over-used words	CHI2	Over-used words	CHI2
Hospital	4,71	Women	9,00
I	4,57	Prevention	8,60
		Believing	4,61
		Attention	4,29
Under-used words	CHI2	Under-used words	CHI2
Women	-9,00	Hospital	-4,71
Prevention	-8,60		
Own	-6,54		

sations. The analysis of the table concerning exclusive specificities (Table 2) helps us better point out the differences between the two groups.

The women's group shows exclusivity for the words *project*, *not called*, *no change*, *no medical report*, *not informed*, and *no hope*. Different is the perspective that distinguishes workers: *Mrs.*, *communication*, *general*, *favor*, *budget*, and *colleagues* are this group's exclusive words.⁹ Given the topic under discussion, its focus is, inevitably, the women who are alternatively connected to the places/services providing prevention (in their own discourses) or to some specific actions (in the discourses of the health care professionals).

Let us finally consider the factorial correspondence analysis applied to the variable QUESTIONS. Since there are five questions, four factors emerge; however, we only consider the first two factors, which, together, explain more than 60% of the variance (Fact-1 33.22%; Fact-2 29.94%); words and variables for each factor with their test values are reported in Table 3 and 4. Considering **factor 1** (Table 3) as a latent dimension that organizes the relationships among the five questions, it can be interpreted and defined as "prevention": this factor has shown a contrast between question 3 (about the action of prevention) and question 2

Table 2
Specificity Analysis: exclusive words

WOMEN		HEALTHCARE WORKERS	
Exclusive words	N.	Exclusive words	N.
Project	17	Mrs.	6
Not_called	10	Communication	4
No_change	8	General	3
No_medical_report	7	Favor	3
Not_informed	7	Budget	2
No_hope	5	Colleagues	2

Table 3
Factor 1: test values

POLE (–)	Test values	POLE (+)	Test values
VAR 3	– 16.7662	VAR 1	9.1647
LEM primary_prevention	– 8.3771	VAR 4	8.4160
LEM healthy	– 4.9486	LEM to call	2.9055
LEM to eat	– 4.5151	LEM family doctor	2.8729
VAR 2	– 3.4161	LEM screening	2.4518
LEM to follow	– 2.5796	LEM ASL	2.3286
LEM to put	– 2.4506	LEM not_called	2.2944
LEM cultural	– 2.4294		
LEM (feels) abandoned	– 2.3102		

(regarding the eventuality of cancer), on the negative pole, and another other two questions (question 1 regarding the low participation to the national program and question 4, about change) both on the positive pole. Overall, the language used answering question 3 and question 2 involved issues related to primary prevention: *healthy, to eat, life, to follow, to put, cultural, (feels) abandoned*; on the positive pole, we can notice a shift of the language from primary prevention (questions 3 and 2) to early detection (or secondary prevention): *to call, family doctor, screening, ASL, not called*.

The second factor (Table 4) highlighted the linguistic specificities of question 5 (about the possibility to change) as compared to questions 1 and 3. In other words, when women and healthcare professionals were asked to speak about the possibility of change (question 5), the issue of negative emotions prevails (distrust and pessimism toward healthcare institutions in their territory) and contrasts more practical aspects also synthesized by the first factor.

DISCUSSION

The results of this research are extremely relevant because they let us better define and understand the cause of southern women's lacking participation in the mam-

Table 4
Factor 2: fact test values

POLE (–)	Test values	POLE (+)	Test values
>VAR 5	– 16.7304	VAR 1	7.1900
LEM no_change	– 6.1571	VAR 3	6.0576
LEM no_hope	– 5.6177	LEM primary_prevention	3.1881
LEM country	– 3.7749	LEM project	2.0720
LEM trust	– 3.2767	LEM to call	2.0644
LEM healthcare institutions	– 2.8174	LEM mammography	2.0592

mogram program. Such a goal is combined with that of increasing the knowledge and awareness on the topic by stimulating relevant actors to reflect on the possibility to promote a change towards the removal of the obstacles hindering a larger participation to the national screening program. The hypothesis that culture and context may influence both cancer representation and preventive action has been confirmed: women and healthcare workers confirm southern women's lacking participation to the national breast cancer screening program; however, this behavior is not to be blamed on women's lack of will or interest, but on a lack of communication and synergy; namely, integration among the figures involved in the screening program. It follows that primary prevention is only partially carried out, as for traditional eating habits that give value to what one's own territory can offer (fish, fresh products). In this sense, a balanced diet as preventive action is not a choice, but an integrating part of a person's lifestyle. Other primary prevention behaviors are, however, poorly considered. These elements thus confirm the theory proposed by Tversky and Kahneman (1981), who point out how an important variable of the decision-making process is also given by the formulation of the problem on the basis of norms and habits, the importance of which as far as healthy behaviors are concerned was also underlined by Dawes (1998). Primary prevention therefore ends up being simplified to those behaviors that imply no change, in an attitude of poor responsibility undertaken on behalf of women.

Such a lack of responsibility also characterizes the women's attitude towards mammograms: these examinations are performed early by some women (especially when led by fear), even before the age at risk, with doctors and in structures that do not belong to the national healthcare system, often encouraged by relatives and friends, people whose advice they rely on, while poor trust is given to public structures. Scarce information on primary prevention and a poor education on the benefits of a mammogram are therefore pointed out, and the latter is carried out following an emotional push and with imitating modalities.

Furthermore, results of more specific surveys (specificity analysis) show how women's conversations are characterized by helplessness experiences and lack of hope in change. On the other hand, healthcare workers seem to look for a defensive shelter in technical and administrative aspects of their job, hiding from the anxiety caused by the proposed theme and being obliged to recognize the inefficiency of the Italian healthcare system.

CONCLUSIONS

Early detection is the fundamental way to reduce breast cancer mortality rate because it increases successful treatment chances (WHO, 2013).¹⁰ Due to mammogram efficacy, the Italian Healthcare System has organized a breast cancer screening program for Italian women. Professionals belonging to medical, psychological, political, or social fields should aim at understanding how people conceive, comply with or ignore prevention in order to promote a better and more reliable dissemination strategy and to strengthen the weak points of prevention programs in order to reduce mortality rated through an increased primary and secondary prevention.

However, women living in southern Italy show very low participation rates in the national screening program. In this respect, the present study aimed at outlining the prevention strategies carried out by these women while understanding the rationale for their failure to participate in the screening program.

In conclusion, our data support the idea that women living in the South of Italy adopt rather unruly prevention strategies, characterized by a great degree of freedom and autonomy, that, however, do not seem to be particularly effective. The context in which these prevention strategies take place appears in jeopardy while a lack of connection between women and the National Health Care system has to be acknowledged. Doctors are experienced as “anonymous specialists,” bureaucrats who prescribe examinations to impersonal users considered as cut off from their belonging context. Outlined figures are weak: doctors appear unable to inform and guide women in their prevention path, women take on a “passive” role with respect to cancer prevention: their actions are informed by long-acquired habits and carried out within a family-like system of care in which affective relations are of the utmost importance (Carli, 2000).

When faced with a disease, these women turn their hopes elsewhere and, more specifically, towards the North of the country, where physicians are assimilated to redeeming-miraculous figures. As a consequence, women perceive a sense of loneliness: they feel abandoned, lack the necessary trust in the professional figures operating on the territory while a generalized pessimism towards the possibility of future change seems to prevail. According to the classification proposed by Gozzoli (2016), a *chaotic-paralyzing* cohabitation system seems to emerge from the outcomes of this study. Subjects (women who have to undergo a mammogram in our case) are not acknowledged by the system that should take care of them and, feeling rejected, they assume a rather distant approach or even escape towards other facilities that give them more hope.

In short, these are outcomes that point out how the lack of trust, as well as the discouragement concerning the possibility to change jeopardize good life together, people’s well-being, and the “productivity” of healthcare organizations. These latter can favor southern women’s access to the national screening program only through an innovative process based on new relationship modalities.

A first step could be represented by forms of cooperation and “dialogue” between healthcare workers and women, because one of the most important predictors of women’s participation in the mammogram program is represented by doctors’ recommendations (Lubetkin, Santana, Tso, & Jia, 2008; Rauscher, Hawley, & Earp, 2005).

NOTES

1. The four research topics are investigated by means of five questions proposed as a discussion outline: (1) Data highlight southern women’s lack of adhesion to screening programs proposed by the National Healthcare System, what do you think about it? (2) Data suggest that in the South the idea of cancer is connected to the urgent need to find out the “right doctor,” possibly living in the North, who can solve the problem. What do you think about it? (3) When the discussion topic is prevention, people from the South immediately think of medical examinations, less importance is given to a healthy lifestyle, what do you think about it? (4) According to you, what must be

- changed to favor the adhesion to the national screening program? (5) Do you think this change is possible? In what way?
2. Three of them had already taken part in the previous research.
 3. Women's age range was chosen on the basis of the risk of a breast cancer onset and reflects the one determining the inclusion in the Italian Healthcare System prevention program described in the introduction.
 4. ASL is the Italian acronym for *Azienda Sanitaria Locale*, Local Health Authority, which is the organization guaranteeing prevention activity on the territory.
 5. Shown below are some quotation examples concerning this theme: "According to me, a general practitioner should inform and insist on the importance to participate to the project ..."; "... how to involve the patient to convince her to undergo a mammogram ... information should be provided by general practitioners, it's their job, but except for the younger ones, the other are disheartened ..."
 6. As an example we report here a fragment taken from analyzed discussions: "Yes, of course, and yet we have absorbed it as part of our lifestyle, we don't think it as prevention, but we make it ... therefore, when they talk about prevention, women directly go to diagnostics, a higher level ..."
 7. We report below a fragment of the analyzed text: "Women do it privately because they do it earlier, they don't wait until they're 50."
 8. As an example we report here a fragment taken from analyzed discussions: "My father left, he was operated, it's true there were a lot of problems, he left and came back in three months, but they had saved him ... he died years later for a completely different issue ... for the hospital in Naples he would have immediately died ... this is South and that is North ..."
 9. Typical and exclusive words, defined by the proportion of relevant occurrences (i.e., their over/under use), are detected through the calculation of the CHI2.
 10. Cf. website: <http://www.who.int/en/>

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