“Gendered” research: methodological aspects of a challenge

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Received 12 July 2016; accepted 23 December 2016

Summary. Gender or gender-specific medicine is an emerging clinical discipline that combines biomedical research with developmental psychosocial processes. It encompasses differences between males and females pertaining to both psychological and social aspects. In gender-specific studies, however, the risks for gender bias in measurement should be carefully evaluated, and several aspects are currently under reconsideration in biomedical research, including study samples, methodology, the sick role within the framework of social relations, and the inevitable stimuli imposed by societal changes. Most human science research relies on collection of self-reported data, which may be greatly affected by gender differences. We provide a couple of examples. The first regards the caregiver, typically a woman’s role. Women who fulfill the caregiving responsibilities often experience a high level of burden and psychological distress. Although there are several tools that measure strain related to care provision, none of them contributes to make caregiver burden a crucial political and societal issue of contemporary society. Newer tools and research avenues should be identified to achieve a more comprehensive assessment of caregiver burden. The second example regards depression. The statement that depression is female-specific seems quite unjustified on scientific grounds, and current detection scores or indices have been questioned. Available evidence shows that women are more likely than men to exhibit and report states of low mood, and they access services more frequently than men. Conventional social norms make men more likely than women to deny their symptoms of depression and to mask them with other behaviors, adopting a “wait-and-see” attitude. Many studies still support a gender-neutral approach, which suffers from a varying degree of gender bias influencing the design and interpretation of results. There is much left unexplored in gender-specific medical research.

Key words: gender research, gender medicine, transformative paradigm, gender bias, alexitimia, caregiver burden, depression, toughness, wait-and-see approach.

Per una ricerca “genere connotata”:
aspetti metodologici di una sfida


Key words: ricerca di genere, medicina di genere, paradigma trasformativo, gender bias, alessitimia, caregiver burden, depressione, toughness, wait-and-see approach.
Introduction

Numerous studies have shown that men and women are different from a biomedical point of view and in terms of anatomy, genetics and epigenetics, metabolism, the operation of receptors, enzymes and proteins, in the level of sex hormones and their effects, in the prevalence and symptomatology of different pathologies and in many other aspects related to sex differences. However, studies are also being conducted on differences between men and women in terms of: personal and social perception, adaptation skills and strategies with particular regard to illness and access to care, being more or less subject to non-medical factors (Oertelt-Prigione, Regitz-Zagrosek, 2012). On one hand, “gender” is over-represented (suffice it to think that typing the term in English returns 80 million hits) and has now achieved a certain level of awareness (Lindsey, 2016); on the other, at this juncture in time, gender is under-studied, also due to methodological issues which we will discuss below. We are still in the context of the broader issue of how to define and quantify the situation, as recently recalled by Marek Glezerman (2016), President of the International Society for Gender Medicine. We are confronted with the specific challenge of how to assess reality, measuring it in quantitative and qualitative terms as argued by Babbie (2010). This is the challenge of measuring the “burden” of gender.

Sex and gender. Two terms that should always be further explored

Sex and gender. These two terms often overlap and are misinterpreted by means of communication, as well as, surprisingly, by scientific literature. Therefore, it is necessary here to pinpoint the differences in their meaning because these lie at the base of this analysis. The word sex is referred to biological, morphological, functional, and other aspects that characterize being a man and woman and has been widespread for a long time now. Gender, instead, has a more recent history as a word and features a dual meaning.

The earliest use of the word ‘gender’ dates to the fifties when the psychologist John Money and the sexologist Harry Benjamin introduced it to describe cases of people with sexual identities other than conventional ones. In this case, gender was used, as is still the case today, in one of its meanings, namely that of the personal and social categories of identity, femininity and masculinity, or other sexual and gender orientation, which, over time, have been followed by studies of specific interest in the field of psychology on the characteristics of perception, relationships, empathy, psychological and social skills, typical of males and females, self-assigned by subjects, as well as on the experiences that society associates with them. Society ‘expects’ that a man, as such, behaves in certain ways, and a woman, as such, in certain other ways (Ristvedt, 2014; Signani, 2013). ‘Gender’ has also been studied by sociology which, thanks also to the contribution of feminist movements, from the seventies onwards, has interpreted gender as a social role, an expected behaviour, associated with a status and conditioned by social norms that determine privileges and duties depending on the status of belonging. An attributed social status, in fact, assigns an individual a position within the social system which is organized in the stratifications created based on prejudice, stigma, discrimination, and overestimation of power. These stratifications are attributed greater or lesser social value1 and affect both men and women alike. Proof of this are, by way of paradigmatic example, preferences in politics2 and the attribution of social trust which is needed to obtain money loans3. In this regard, let us mention here the main terms of the theory of sexual and gender social roles, which we cannot dwell on, but that help to complete the conceptual framework: sexism (negative stereotypes linked to sex, usually negative for women); patriarchy (a social structure dominated by men) and androcentrism (when the point of reference of any social organization is linked to male-ness). These are all terms and concepts that are closely linked together (Lindsey, 2016). Going beyond the old classification limited to sex alone, gender was recognised by the Commission on Social Determinants of Health of the World Health Organization as a factor that determines health and disease only in 2008 and, quite surprisingly, the scientific community has been silent, perhaps because it has not fully understood its disruptive scope (Solar, Irwin, 2006).

Gender medicine: a transformational paradigm

Gender is mentioned in many different situations, but when it comes to health and illness, inter alia, one speaks of gender-based or gender-specific medicine (let’s not forget gender-related guidelines in psychology, nursing, etc.), which, when applied in the broadest sense, leads to the study and knowledge of the differences resulting from sex as well as from gender. Gender-based medicine is not only a new branch of clinical medicine, but also the application of a transformational paradigm (Mertens, 2007) that combines biomedical and psychosocial research to combat inequality and social injustices in ensuring a fair right to health. The strength of the transformational paradigm lies in combining quantitative and qualitative data and in combining the approach of the so-called life sciences with that of the human sciences in the name of that interdisciplinary approach that characterises the epistemological transition that
is currently in progress and which, through a new cultural mechanism and practices, can really help to improve society (Fitzgerald, 2013).

Gender in biomedical research

Annandale and Hunt (2000), in their analysis on how to remedy gender gaps in various fields of everyday life and particularly in health and disease, considered the important changes in the methods of biomedical research that are aimed at the progressive inclusion of gender. The authors identified a historical pathway: a traditional phase of research which we can place in the period when biomedicine considered the specificity of the female body almost solely in relation to the sexual and reproductive apparatus. This phase chronologically spans to the nineties when the scientific world considered gender differences only implicitly and, on issues of health and work, treated men and women as peers. This research was focused on the exclusion or inclusion of women and, almost by way of reparation, some clinical trials were carried out on women only (limited in number and on clearly marginal aspects).

The transitional phase of the research methods that we place in the twenty years at the turn of the century was characterized by a growing identification of cross-cutting gender inequalities, with an emphasis on different lines of inequality: for example, studies started to be carried out on stress related to role and social status associated with gender.

Now, we have come to a situation where there is an express attention to the gender dimension, understood as essential in biomedical research, as claimed by the two authors. It is an approach that is favouring a change of perspective in research on gender and health and involves several steps: from men-only or women-only research samples to research samples that compare the two sexes, considering also what impact gender characteristics have. Men and women are no longer regarded as isolated individuals, thus becoming part of a broader social structure that is made up of gender-based social relations. There is a transition from limited attention to the combination of sexual and gender roles (e.g., work-family balance) to an attention both to the complexity of roles and conditions and to the experience of an individual with respect to a given role. And finally, there is the transition from a season of errors in assessing the actual gender construct in various contexts, to the current emerging phase in which gender, rightly understood as something that is continuously built socially, is assessed in its implications for health, with eye on the characteristics of a constantly evolving society (Annandale, Hunt, 2000; Cherubini et al., 2011). Gender-based research also appears to be increasingly taking into account the fact that it can incur in gender bias, namely evaluation errors that occur when, even in the case of blatant differences, men and women have “egalitarian” behaviours, or when there are still negative stereotypes against, usually, women, so much so that men only are considered as the subject of reference in a more or less knowingly androcentric perspective (Risberg, 2009).

Good practices in biomedical research

Many scholars have now stressed that the inclusion of gender in research goes beyond a mere sex stratification of data (Bekker, 2003); Nowatzki, Grant, 2011). Assessment tools gauged only on male samples (both in clinical medicine and in life sciences) may, in addition to constituting a gender bias per se, generate, in turn, gender bias in the measurement. An example of good practice is that of the Cochrane organization which between 2005 and 2012 set up a Sex/Gender Methods Group to evaluate the applicability and quality of a sex and gender-based approach in biomedical research and even drew up a guide to plan systematic sex and gender-based reviews.

Transformation and rethinking of research methods are the watchwords of another interesting good practice, the Gendered Innovations in Science, Health & Medicine, Engineering and Environment Project. It is the result of the collaboration between Europe and America, launched in 2016 and funded by the European Community, the US Science Foundation and the University of Stanford. It is directed by one of the most influential gender scholars, Londa Schiebinger, professor of the history of science, who coordinates international workshops using a sort of Delphi method for determining how research, in particular in biomedicine, can rethink concepts, theories, priorities, results, language and biomedical parameters of various pathologies by considering gender.

Gender skills in health and disease: research methods in the human sciences

The evaluation of the “burden” of gender involves the human sciences. Also within the scope of the human sciences, the application of a gender perspective to research is a process that is still unfolding. The fact of having treated the analysis of gender identity, sexuality, and the patriarchal structure of society for years has contributed to mistaking the topic with the method: analysing gender issues is one thing, identifying the characteristics of the research methods that are truly attentive to possible gender bias is another. The methods available to the human sciences range from action research, to descriptive, participatory, ex-
perimental and ethnographic research, through discourse analysis, to the study of documents and archival data, oral or written stories, life stories, and case studies, with tools such as interviews, questionnaires, tests and measurement scales (Dey, 1993; Cicognani, 2002; Dal-lago et al., 2004). These are tools that have not yet been modeled by taking gender into account: suffice it to think of the pending problem of developing research designs that can represent males and females equally and allow congruous comparisons or of the need to develop a methodology that reduces the influence of conditioning by the researcher and the instrument used (Metso, Le Feuvre, 2006; Marshall, Young, 2007). It should not be ignored that these methods, largely based on the “I-ask-you-you-answer-me or you-tell-me” approach, need a good deal of active collaboration of the person participating in the research sample.

The sample individual must therefore be available in general, which means specifically having time and being willing to establish a relationship (skill too is needed), to have trust and be truthful, and being able to self-report, i.e., describing one’s own thoughts, feelings, and opinions.

In the early seventies, a group of psychosomatists defined a set of personality traits highlighted in patients susceptible to psychosomatic manifestations, called “alexithymia”, from the Greek “a-” lack, “lexis” word, and “thymos” emotion (Nemiah et al., 1976). It means not having the words for emotions, not being able to speak of emotions to other people. It is a personality type that finds it difficult to identify and describe one’s own feelings and those of others and is oriented to the outside and rarely toward one’s own endopsychic processes. This is a trait that should not be overlooked when the ability to describe moods is required. There is a test, the Toronto Alexithymia Scale (TAS-20), which is validated also for Italy (Bressi et al., 1996) and which could lend itself to many more applications than it is actually used for. We will now dwell on one of the many possible examples of gendered research methodology that can make us surmise that there is also a “gender” alexithymia.

**Evaluating the burden of gender on caregivers**

A sick person is understood by contemporary medicine in the system of social relations in which s/he lives so as to also consider the person who delivers care. This perspective has helped to shed light on the importance of the role of the caregiver, the person who takes care of patients with chronic diseases and who is usually a woman, wife, companion, daughter, sister, or paid worker: that’s why we are discussing this figure in terms of gender. The degree to which this role can negatively affect the life of the caregiver is easily understandable, but it is neglected in political and social terms.

The considerations linked to the issue of the caregiver come from fields of knowledge other than medicine, but they can be useful for our analysis. Since the seventies, rethinking the way of working has introduced the concept that many of the resources that are needed to live are not produced by market activities, but by self-production, or better yet, by the welfare system, including families, which is not always connected to the market. This has contributed to bringing the issue of “care” to the fore (in families, as well as among public institutions, the third sector and the market), which until then had been an invisible issue. The research data show the disadvantageous situation of women engaged in daily care practices, in terms of time, worry and fatigue. Reflections on the work of delivering care have led to define both the phenomenon of “double” presence of women who are divided between work and family (Chiaretti, 1981) and the value of unpaid work traditionally attributed to women in our society as well. In 1974, Oakley published ‘The Sociology of Housework’ which stressed the consideration, already empirically clear, that the model of life of men and women is different, but even more importantly that work and social organizations segregate and have aspects that negatively and systematically affect women.

Studies on how people use time continue to show that women spend more time than men in unpaid activities, indicating that they have a longer working day, a substantial commitment to taking care of the house and family, with activities that are necessary and often forced by circumstances, and less time for rest, to the detriment of health.

The role of caregivers for sick people is now necessary due to the shortage, or absence, of public services in this field and to the concurrent increase in longevity and the consequent chronic pathologies present in the elderly population: it covers over 90% of home care needed by chronic adult patients (Adelman et al., 2014). The assess-ment of the burden of this clearly gendered role is still a matter of limited interest, perhaps because both the family members and paid workers engaged in the activity often have a clearly disadvantaged social status. Assessing the caregiver burden assumes undeniable importance if we consider that caregivers are increasingly becoming patients themselves due to the consequences on their health. There are in fact consequences in physical (suffice it to think of the bone and joint issues resulting from the management of patients who do not cooperate), mental, psychosocial, financial and health terms, with experiences of trapping, perception of over-load due to forced social isolation and, in the case of unpaid activities, to the pressures experienced in the context of paid work outside the home, which often does
not consider the difficulties in reconciling a "normal life" with the difficulties of family care. Family caregivers, connected to the family care network, moreover, can often be involved in real family conflicts, as a result of resentment, at times toward to the sick person, and at times toward other uncooperative family members (Costanzo et al., 2012).

To evaluate caregiver burden, some researchers have developed specific tools, suffice it to mention Zarit (1980), with his famous structured interview test, the Association Medical Association, with a self-assessment questionnaire, and the Caregiver Self-Assessment Questionnaire (Epstein-Lubow et al., 2010). Already in 1992, Braithwaite, who was among the first to address the issue of caregiver burden, had examined critically the concept of burden, stigmatising its lack of clear definition, the inconsistency between its conceptualization and operationalization, its inappropriate use within the stress paradigm, and in particular its marginal policy relevance. Adelman et al. (2014), in reaffirming that the role of caregiver is neglected, stressed that in the most recent version of the International Classification of Diseases (ICD 9) there is no provision for a classification of burden for those who perform this role. We are far from a social engagement on this issue/problem, which is relegated for now at a mere individual level. Targeted research on this topic is both necessary and urgent.

**Evaluating the weight of gender in depression**

Now let us dwell on an issue mentioned earlier: mental distress. Let’s take a simple example to have an overview of the available investigation tools. One of the instruments for investigation on large numbers which has been adopted for population studies is the SF-12 (12-question Short Form Health Survey) which allows you to build two perceived health indices: one on your physical condition and the other on your psychological condition, so that, inter alia, data can allow determining "how depressed the population is". Let us focus on the latter aspect and bear in mind that it requires a personal point of view about one’s health, evaluating it using the scores of excellent, very good, good, fair or poor, and the self-assessment of one’s own psychological conditions using a questionnaire (paper, online or telephone interview). A person must then report if s/he has limitations because of bad health, for example, moving a table, playing golf, or climbing several flights of stairs. It then continues asking whether in the last four weeks the person has felt depressed or anxious, at work or in the family, if s/he has accomplished less than s/he would like, and so forth, and if this is considered by the person being interviewed to be the result of some emotional issue. This consideration, besides recalling the issue of alexithymia already discussed above, also poses the big question whether expressions of malaise can be gender-specific. In 2013, an important research study was published on *Jama Psychiatry*, a journal of the American Medical Association, which in addition to reporting that twice as many women as men are diagnosed with depression, confirmed that there are different manifestations of depression between men and women (a recent understanding), but also - an aspect to which we are paying attention - a different openness to reveal them. Women, for example, are more likely to manifest and tell about symptoms of stress, indecision, anxiety, sleep disorders, depressed mood, inability to adapt, while men are less willing to express their malaise and ask for help. The reported data present the characteristics consistent with gender social roles: introversion for women and extroversion for men (Martin et al., 2013). Having established that taking on a gender-specific role is a conditioning factor, tools like the *Conformity to Masculine Norms Inventory* that helps to evaluate what and how each man adheres to conventional gender norms are of particular interest (Mahalik et al., 2003). There is a recent interesting area of studies on how much influence conventional social norms linked to being a man have and, among these, how important toughness is. It is characterised by a desire to hide pain and be independent, associated also with the tendency not to manifest one’s own inner distress or even ask for help, but to wait and see if one can solve the situation without seeing a professional. This approach is defined as *wait-and-see*, (O’Loughlin et al., 2011) and suggests that - though data is still lacking - there is a consistent phenomenon of non-request for aid in general and non-access to services, in particular. Even though the belief that there are sex-related differences in psychiatric disorders is spreading and for some mental disorders this seems to be true (post-partum stress disorder is one example), equal attention is not paid to the influence that gender roles have on mental well-being/distress and on its social manifestation. Often in popular culture, but also in the scientific world, it is said that depression is a typical manifestation of women. Riecher-Roessler (2017), for example, stated that it is known (!) that women have a higher prevalence of mood and anxiety disorders in the course of life than men, while recognising a lack of research both on the etiological factors and on the pathogenetic mechanisms. In asking why depression is more common in women than in men, Kuehner (2017) hopes that future transdiagnostic research can contribute to better differentiate the specific susceptibility of males and females. Howard et al. (2017) argue that research on mental health, which has always been characterised per se and in a generalised way by a neutral approach in all research de-
Investigations into gender and suicide have provided evidence of the complexity of gender disparities in mental health, particularly in suicide rates. The male suicide rate is consistently higher than the female rate, with studies indicating that men account for almost 80% of deaths due to suicide, a ratio of three times more Italian men committing suicide than women (ISTAT, 2012). The gender disparity in suicide rates has been reported in many studies, suggesting a need to understand the socio-cultural factors influencing these patterns.

Evaluating the “burden” of gender, not only in health and disease, is truly a challenge that offers an interesting and exciting perspective in the world of research methodology and charts out a new field of gender research in health and diseases. An overall rethinking of instruments and methods, an articulated and detailed mapping of critical points and an interdisciplinary approach that is able to draw on knowledge from different disciplines are necessary to avert any gender bias inherent in the very structure of research designs that may affect the results which are often contaminated by negative stereotypes. It is a field that is still developing and requires great commitment. It should be consolidated with scientific and political support aimed at advancing knowledge and equity.

Conclusions

Evaluating the “burden” of gender, not only in health and disease, is truly a challenge that offers an interesting and exciting perspective in the world of research methodology and charts out a new field of gender research in health and diseases. An overall rethinking of instruments and methods, an articulated and detailed mapping of critical points and an interdisciplinary approach that is able to draw on knowledge from different disciplines are necessary to avert any gender bias inherent in the very structure of research designs that may affect the results which are often contaminated by negative stereotypes. It is a field that is still developing and requires great commitment. It should be consolidated with scientific and political support aimed at advancing knowledge and equity.

Notes

1 Suffice it to think of male footballers who earn up to 75 million euro a year (Lionel Messi and Cristiano Ronaldo, for example) in terms of their importance in the media and society and of their power compared to a maximum of 220,000 euro a year earned by a woman football player, Marta Vieira da Silva from Brazil, who has won the Golden Ball award 5 times and is regarded by many as the best female talent to have ever played. Sources: http://www.iltuosalario.it/main/stipendio/stipendiovippolitici/calcio; http://www.sportbusinessmanagement.it/2015/07/compensi-estipendi-delle-calciatrici.html

2 The women who hold positions of power, such as the president of a country, account for only 6% around the world. Source: http://www.tpi.it/mondo/italia/donne-potere-mondo

3 It was necessary to create the category of ‘female entrepreneurship’ to treat women like men and to facilitate the allocation of sums of money on loan for professional reasons.

4 The concept of gender bias was introduced for the first time in the Women and Health Research Report of the US National Institutes of Health, published in 1994, describing the potential distortions in the design and conduct of clinical trials which did not take the specific effects of sex and/or gender into due consideration. From then on, it has come to assume the broader meaning of “mistakes or bias” due to the failure to take gender into account (Signani, 2013).

5 The prestigious global network of researchers, professionals, patients, assistants and people (currently 37,000) involved in the management of health, independently and free from possible conflicts of interest, affiliated with the Campbell and Cochrane Equity Methods Group http://www.cochrane.org/about-us


7 The only legislative measure that we know of is that of the Emilia-Romagna Region (Resolution No. 87 of 25 March 2014 “Rules for the recognition and support of family caregiver/person who voluntarily delivers suitable care and assistance) which recognizes that family caregivers are an informal part of the care network of an individual.

8 Unpaid work includes work for subsistence (production of food and clothing; repair of clothing), housekeeping (shopping, cooking, laundry, ironing, cleaning, activities related to household organization and in the assignment of tasks, errands such as paying bills and much more), family care (care of sick relatives, children and the elderly) and community services or volunteer work (services offered to persons who do not belong to the family through religious or secular organisations).

9 The “Use of Time and Gender Studies” research of ISTAT (2012) confirmed unfortunately that Italy ranks first in time spent in housekeeping by women at all stages of life, even for the very high standards of cleanliness, the great importance attached to housekeeping and the acceptance of forms of traditional sociability which see men outside the home, even when they are not working, and women at home. This social situation is perhaps a consequence of the lack of alternative services for unpaid work. Italian women are engaged in housekeeping 12 hours a week when they live at home with parents and up to 51 hours a week if they live in a couple and have young children. Italian men are engaged at most 20 hours a week in family and housekeeping activities, even when they have young children, and are the least engaged at home compared to men in other European countries. About 58.3% of
Italian men do not cook, 73.5% do not set or clear the table, 98.6% do not wash or iron and 70.5% do not go shopping. Italian women spend 200% more time compared to their significant others in taking care of the house and family (OECD, 2015).


11 At the moment, the definition of depressive disorders is still arbitrary due to the absence of clear and uniform signs that can be detected by an observer (Piccinelli, Wilkinson, 2000). The term “depression” popularly indicates a depressed mood, loss of interest and pleasure, decreased appetite, insomnia and concentration problems, difficulties in completing tasks required to work and reduced interpersonal contacts. Depression is indicated in scientific language as “Disruptive Mood Dysregulation Disorder” and also takes into account a degree of “major” functional impairment (major depressive disorder) when episodes last at least two weeks. For this reason, even in population surveys, reference is made to this time period (DSMV, http://www.dsm5.org/Pages/Default.aspx).


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Conflicts of interest: The author declares the absence of conflicts of interest.

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